



HOUSE OF LORDS

Select Committee on the Assisted Dying for the
Terminally Ill Bill

Assisted Dying for the Terminally Ill Bill [HL]

Volume II: Evidence

Ordered to be printed 3 March 2005 and published 4 April 2005

Published by the Authority of the House of Lords

London : The Stationery Office Limited

£48.00

HL Paper 86-II

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NOTE:

The Report of the Committee is published in Volume I, HL Paper No 86-I.
The Evidence of the Committee is published in Volume II,
HL Paper No 86-II.

Minutes of Evidence

TAKEN BEFORE THE SELECT COMMITTEE ON THE ASSISTED DYING
FOR THE TERMINALLY ILL BILL [HL]

THURSDAY 9 SEPTEMBER 2004

Present	Arran, E	Mackay of Clashfern, L
	Finlay of Llandaff, B	(Chairman)
	Hayman, B	Patel, L
	Jay of Paddington, B	Taverne, L
	Joffe, L	Thomas of Walliswood, B
	McColl of Dulwich, L	Turnberg, L

Memorandum by the Voluntary Euthanasia Society

1. INTRODUCTION

1.1 The Voluntary Euthanasia Society (VES) was founded in 1935 by a group of eminent doctors, theologians and lawyers. VES believes the patient should be the decision maker at the end of life irrespective of whether he wishes to prolong his life, or ask for medical help to die if terminally ill. It is for this reason that VES is committed to securing a change in the law so that a terminally ill person who is suffering unbearably may ask for and receive medical help to die.

1.2 VES has around 55,000 members and supporters. It is the foremost independent research organisation in the United Kingdom on legal and human rights issues relating to end-of-life decision making. VES regularly advises NHS Trusts, doctors and lawyers on end-of-life decision making and advised the European Court of Human Rights in the Dianne Pretty case on the comparative legal position on assisted dying throughout Europe.

1.3 Currently in the UK many terminally ill people die painful and distressing deaths. This is best understood with reference to neurological illnesses such as Motor Neurone Disease (“MND”) and was noted by Lord Steyn in the Dianne Pretty case:

“She is paralysed from the neck downwards. She has virtually no decipherable speech. Her life expectancy is low. She has only months to live. Yet her intellect and capacity to make decisions is unimpaired. She wishes to be spared the suffering and loss of dignity which is all that is left of her life for her. She wishes to control when and how she dies.”

1.4 The vast majority of people in the UK (over 80 per cent) wish to see a change in the law so that a dying person who is suffering unbearably can ask for and receive medical help to die. The law at present prevents this choice. We recognise that a small minority of our society is opposed to assisted dying—their opposition in many instances being based on their religious beliefs. While respecting their views in relation to their own lives and deaths, we believe it would be undemocratic to allow this minority to impose their beliefs on the majority of our society who do not share their beliefs.

1.5 We share the view expressed by the General Medical Council that it is for society as a whole, through the democratic process, to determine whether, and on what basis, assisted dying should be made lawful¹. This view is shared by the BMA who state: “although the medical profession has an important voice in the debate, ultimately these decisions are for society as a whole, not just doctors”².

1.6 We welcome the House of Lords’ decision to consider Lord Joffe’s Bill in detail. VES believes that regulating the wishes of terminally ill patients by the law of murder and the Suicide Act of 1961 is ineffective, out-dated and inhumane and the Bill puts forward a considered alternative approach to this important issue. The Bill gives terminally ill patients who are suffering unbearably the option of medical help to die. It will also better protect vulnerable people and provide guidance to medical professionals who might otherwise have been criminalised for their compassionate acts.

2. KEY DEVELOPMENTS SINCE 1994

Since the House of Lords last considered end-of-life decision-making (including medically assisted dying) 10 years ago, there have been many significant developments including the following:

2.1 Assisted dying has been decriminalised and underpinned by rigorous legislation in Oregon (1997), the Netherlands (2002) and Belgium (2002).

2.2 There is a wealth of data on assisted dying, particularly from Oregon and the Netherlands (referred to throughout this submission). This evidence demonstrates that it is far better to provide for medically assisted dying within a properly regulated system.

2.3 Surveys show that the majority of the UK public, inclusive of elderly and disabled populations, support medically assisted dying³. A recent NOP survey (August 2004) found 82 per cent of respondents support a change in the law. This included 81 per cent of Protestant and Catholic respondents⁴.

2.4 Many terminally ill patients support medically assisted dying (73 per cent in a study by Wilson, 2000; 80 per cent in a study by Sullivan, 1997)⁵.

2.5 Many UK doctors and nurses now also support a change in the law⁶. A Medix-UK survey (2004) found that when asked to choose between criminal prohibition and legislation to permit medically assisted dying, 56 per cent of doctors chose legislation⁷. A 2003 *Nursing Times*' survey found that two out of three nurses supported a change in the law⁸.

2.6 Patient choice is central to NHS policy and patients increasingly wish to make their own medical treatment decisions at the end of life⁹, as seen in the legal cases of Dianne Pretty, Miss B and most recently, Leslie Burke.

2.7 Surveys, such as those by the *Nursing Times* (2003), McLean (1996) and *Doctor Magazine* (1995) show that doctors and nurses are being asked by their patients for help to die¹⁰.

2.8 Surveys, such as those by *The Sunday Times* (1998), McLean (1996) and *Ward and Tate* (1994) also show that in the UK, doctors are already assisting their patients to die¹¹.

2.9 Three of the House of Lords Select Committee members who were unable to support assisted dying legislation in 1994 now support the Bill¹².

2.10 The Law Commission has recently raised concerns in connection with the Homicide Act 1957 and its application to mercy killing¹³.

3. THE IMPACT OF THE CURRENT LAW ON PATIENTS, THEIR FAMILIES AND HEALTHCARE PROFESSIONALS

3.1 At the request of the Home Secretary, the Law Commission considered the Homicide Act 1957 in its report published on 6 August 2004. Currently, a person who ends the life of a dying person who has asked for help to die, can be charged with murder and if convicted receive a life sentence. This applies even when the dying person is helped to die by a doctor acting out of compassion. The Law Commission noted that: "at present, in such cases, a conviction for murder, with consequent mandatory life sentence, can only be avoided by a 'benign conspiracy' between psychiatrists, defence, prosecution and the court, to bring them within diminished responsibility". They further stated: "it is however a blight on our law that such an outcome has to be connived at rather than arising openly and directly from the law"¹⁴.

3.2 The Suicide Act of 1961, which governs England and Wales, is no better. This Act provides that any person who assists in the suicide of another even if they are dying, shall be liable to imprisonment for up to 14 years. However its application is erratic and arbitrary¹⁵. This is despite the House of Lords finding in the Dianne Pretty case, that the Director of Public Prosecution could publish guidelines making clear the types of cases he would not prosecute¹⁶. This Act is also the harshest of its kind in Europe. Assisting a suicide is not a crime in countries as diverse as Sweden, Finland, Switzerland, Germany and France, and in the Netherlands and Belgium, where medical help to die is underpinned by rigorous legislation¹⁷.

3.3 Evidence clearly shows that despite it being a criminal offence, doctors assist their patients to die¹⁸. A Medix-UK survey (2004) found that 45 per cent of doctors believed their colleagues actively help patients to die (a further 44 per cent were unsure; 4 per cent "would rather not say")¹⁹.

3.4 Doctors who are asked by a terminally ill patient for help to die can do one of two things: they can ignore the request and risk undermining their relationship with the patient and their patient consequently feeling abandoned²⁰. Alternatively, they can explore the request. If the patient still wants help to die and the doctor gives that assistance, he risks criminal prosecution.

3.5 In some instances, a terminally ill patient may ask a loved one for help to die. Relatives can feel compelled to help even though they may be prosecuted. The psychological and emotional impact of helping a loved one to die in secret can be immense. Perhaps even worse, when that help has not been successful, the patient can be left in even greater distress and in a worse physical condition²¹.

3.6 To end their suffering, dying patients may take their own life, in some cases violently²². Seven per cent of doctors in a Medix-UK survey (2004) reported that at least one of their terminally ill patients had committed or attempted to commit suicide in the last two years²³.

3.7 Others like Reg Crew and John Close, both of whom suffered from MND, may, as a last resort, travel to Dignitas for help to die—an organisation in Switzerland without proper regulation or safeguards²⁴.

3.8 The use of the Suicide Act 1961 and the law of murder to regulate a terminally ill person's wishes at the end of life is deeply inhumane. Further it:

- Does not stop assisted dying. It simply drives it underground where it takes place without transparency or accountability (Meier 2003; Magnusson, 2002; Emanuel 1998; Kohwles 2001; Ward and Tate 1994)²⁵;
- Prevents an open discussion between a doctor and a terminally ill patient about the end of that patient's life, causing further anguish (Ryan 1998; Bascom and Tolle 2002)²⁶;
- Denies terminally ill patients the choice of medical help to die thereby causing great distress; (Quill and Cassel 2003; Quill 1996)²⁷;
- Compassionate doctors who, at the request of a patient, help him to die, have to do so secretly for fear of prosecution. This adds to the doctor's burden and criminalises his compassionate behaviour (Kohwles 2001; Back 2002)²⁸;
- The lack of transparency puts vulnerable people at risk (Lee 2003; Emanuel 2002; Brock 2000)²⁹.

3.9 A law which is not respected, even at great risk to those who break it, is a law that needs changing.

4. PALLIATIVE CARE AND MEDICALLY ASSISTED DYING

4.1 VES is committed to the improvement of all palliative care, both in terms of resources and access, and supports the recent House of Commons Health Select Committee's recommendations³⁰.

4.2 Palliative care should be standard care for all terminally ill patients. However, medically assisted dying should not be seen in opposition to palliative care. Rather, we should adopt a patient centred approach, which provides all options to dying patients, including access to excellent palliative care and a medically assisted death as a last resort³¹.

4.3 Some commentators have argued that legalisation would undermine palliative care service provision and its future development³². However the evidence from both Oregon³³ and the Netherlands³⁴ demonstrates that palliative care can successfully work alongside the option of help to die. The vast majority of patients who choose assisted dying under the Oregon Death with Dignity Act 1997 (ODDA) are enrolled in hospice programmes³⁵. Oregon hospices continue to care for those who are considering this option³⁶. In the Netherlands, better palliative care has been a core goal of medical policy since the mid 1990's and has improved substantially since that time³⁷.

4.4 In Belgium, legislation providing all patients with the right to palliative care was passed in parallel with assisted dying legislation³⁸.

4.5 Research from both the UK (Seale and Addington-Hall) and abroad shows that even with good palliative care, some dying patients still suffer unbearably and want help to die³⁹. The BMA⁴⁰ the National Council for Hospice and Specialist Palliative Care Services⁴¹ and Macmillan Cancer Relief⁴², have all recognised that good quality palliative care will not meet every patient's needs.

4.6 No amount of palliative care can address some patients' concerns regarding their loss of autonomy, loss of control of bodily functions and loss of dignity. An inability to meet these needs arises not because of a failure of palliative care, but because these are person-centred issues. These issues most frequently lie at the heart of a request for help to die⁴³.

5. CORE PRINCIPLES OF THE BILL

5.1 The Bill would permit a terminally ill person who is suffering unbearably to ask for and receive medical help to die. Such assistance should be viewed as a “last resort” option, alongside other “last resort” palliative care options (eg sedation at the end of life, withholding and withdrawal of treatment, aggressive pain relief)⁴⁴.

5.2 The Bill is very similar to the ODDA but it is not a simple copy. Careful consideration has been given to the experiences of patients, carers, doctors and nurses, as well as vulnerable populations.

5.3 Autonomy and competence are key principles at the core of virtually all medical treatment decisions. Patients can, without safeguards, refuse to give consent to treatment even if this will lead to their death. At the heart of this decision-making process is a presumption of capacity and respect for the person’s autonomy⁴⁵.

Munby J reiterated this point in the recent case of *Burke versus the General Medical Council* on 30 July 2004⁴⁶.

He noted:

“... Personal autonomy—the right of self-determination—and dignity are fundamental rights, recognised by the common law and protected by Articles 3 and 8 of the Convention [European Convention of Human Rights]. The personal autonomy which is protected by Article 8 embraces such matters as how one chooses to pass the closing days and moments of one’s life and how one manages one’s death”.

He further stated:

“Important as the sanctity of life is, it has to take second place to personal autonomy; and it may have to take second place to human dignity”.

5.4 While autonomy is an important principle in the Bill, it is not unfettered autonomy. The principle of autonomy is counterbalanced by an array of safeguards.

5.5 Only competent adults, domiciled in England and Wales, suffering unbearably from a terminal illness, can make a request to a doctor for assistance to die. Only the patient, not the doctor, can initiate the process. Before the patient can proceed with his request, he must be seen by two doctors one of whom must be a consulting physician who is a specialist in the patient’s condition. The prognosis must be confirmed, and all other alternatives to assisted dying including palliative care must be explored. Should competency be in question, the patient will be referred for a psychiatric assessment. If the patient cannot fulfil all the criteria, his request will fail⁴⁷.

5.6 The importance of the patient acting voluntarily is stressed throughout the Bill with a range of safeguards that include a written declaration, which must be independently witnessed by two adults one of whom shall be a practising solicitor⁴⁸. At any stage the patient can revoke his request⁴⁹.

5.7 The Bill provides that a specialist in palliative care, who can be a doctor or a nurse, is required to attend any patient who requests help to die, in order to see if their needs can be met in an alternative way⁵⁰.

5.8 The option of having a medically assisted death can act as “an insurance policy”, giving terminally ill patients reassurance that, should their suffering become unbearable, they can request and receive assistance to die. This can help people live with less fear of the future, regardless of whether they ever use this option⁵¹. As Jim Rooney, a Motor Neurone Disease sufferer who received a prescription under the ODDA but died naturally from his disease noted, “Just knowing that this law is an available option is very liberating for a person with my condition”⁵².

5.9 In response to the fact that some doctors are uncomfortable with being directly involved in a patient’s death, the Bill only permits patient self-administration of medication to hasten death unless the terminally ill patient is physically incapable of ending his own life. This provision will predominantly relate to people suffering from neurological illnesses such as MND. Its key objective is to prolong life—no longer will such patients make the decision to end their life just because they are physically still able to do so. Instead, this provision will enable them to continue to live and give them the reassurance of an assisted death should their suffering become unbearable, even though they are physically incapable of self administration.

5.10 No healthcare professional (such as a doctor, nurse or pharmacist) with a conscientious objection, is required to take part in assisting a patient to die⁵³.

5.11 Section 15 of the Bill creates the right of a patient to request and receive such medication as may be necessary to keep him free, as far as possible, from pain and distress. It is a safeguard against pain being a motivating factor behind a request for help to die. In a Medix-UK survey 97 per cent of doctors supported this right⁵⁴. This is an important clause for three reasons. Firstly, a proportion of patients (3–30 per cent) still suffer from poorly controlled pain at the end-of-life⁵⁵. For example, a survey published by Cancer BACUP (2001) found that 77 per cent of cancer patients reported they suffered pain, 54 per cent were not involved in making decisions about their pain control and 63 per cent had not discussed the different types of medication

available with their doctor⁵⁶. Secondly, as noted by Rogers and Todd in *Palliative Medicine*, clinicians can underestimate terminally ill patients' distress and pain⁵⁷. Thirdly, Home Office proposals to reform the Coroner and Death Certification Service are likely to create further problems around pain relief at the end-of-life. Dame Janet Smith, Chair of the Shipman enquiry, has suggested that investigators should be trained to "think dirty" when looking into causes of death⁵⁸. In the aforementioned survey, 74 per cent of doctors said they would now be more nervous about prescribing pain relief as a result of these proposed changes⁵⁹.

6. RESPONSE TO CONCERNS EXPRESSED ABOUT MEDICALLY ASSISTED DYING

6.1 It is important to test the validity of concerns in connection with medically assisted dying against the experience and empirical data of countries and states which permit medically assisted dying, most notably, the Netherlands and Oregon. The Select Committee may therefore find it helpful to visit Oregon and the Netherlands or invite relevant professionals from these places to address the Committee.

6.2 In assessing this data, we think it helpful to proceed on the basis that the humanity, integrity and skills of doctors in both England and Wales and doctors in the Netherlands and Oregon will not be significantly different.

6.3 *Slippery slope*

- We acknowledge that concerns have been raised in connection with a "slippery slope". The concern is that assisted dying legislation for competent terminally ill adults will lead to a devaluing of human life and that vulnerable people will become "victims" of this legislation⁶⁰. We have found no evidence to support these allegations⁶¹. We agree with researchers such as Emanuel, Lee and Brock who have concluded that assisted dying legislation would help ensure doctors adhere to strict safeguards and thus protect vulnerable people⁶².
- Evidence from the Netherlands and Oregon suggests that legislation will not lead to an "avalanche" of assisted deaths. There has been no such increase in Oregon or the Netherlands. Evidence from the Netherlands shows that year on year roughly the same number of patients are assisted to die⁶³.
- Further, the Bill has been very tightly drafted and it would require new legislation to extend its scope.

6.4 *Reasons for assisted dying*

- In Oregon, research often led by Dr Linda Ganzini has found that the primary reasons terminally ill patients receive help to die are: loss of autonomy and dignity; being less able to engage in activities; being ready for death; having a poor quality of life; seeing life as existentially pointless; avoiding dependence; and wanting control over the manner and timing of death⁶⁴. Pain is not a primary concern⁶⁵.
- This research has also found that such patients are more likely to be from a higher socio-economic group, be more educated⁶⁶, have strong personalities and are forceful and persistent in their request⁶⁷.

6.5 *Competence*

- Mental health professionals in the USA have observed through their work that the thought processes underlying the decision by terminally ill patients to ask for and receive medical help to die are similar to the thought processes of patients when deciding to refuse life-sustaining treatment⁶⁸. People who have a terminal illness can and do make rational and reasoned decisions to ask for help to die (see for example, Fenn and Ganzini 1999; Werth and Cobia 1995)⁶⁹.
- Dr Ganzini and others have concluded from looking at all the evidence that depression does not play a role in terminally ill patients in Oregon who receive assistance to die⁷⁰.

6.6 *Burden*

- Evidence suggests that when patients who receive assistance to die feel "a burden", this is related to their frustration at being dependent on others during their dying process, and is linked to losing autonomy⁷¹.

6.7 *The effect on the medical profession*

- There is no evidence that medically assisted dying legislation has an adverse effect on the medical profession.
- In Oregon, an unexpected benefit of the legislation has been that it has helped to improve doctors' knowledge and skills in connection with dying patients⁷².
- Professor Back and others have found that based on their research and experience, the best outcome for patients and their families is when the doctor is able to discuss all the patient's concerns and requests, including any request for help to die. If the doctor cannot be open to such a discussion, the patient can feel abandoned and suffer further distress⁷².
- A six country European study found that the best communication between doctors and their patients and families concerning end-of-life decisions, occurred in the Netherlands⁷⁴
- Out of eleven European countries surveyed (including the UK), the Dutch have the highest regard and trust for their doctors⁷⁵.
- We have found no research to show that people would distrust their doctors if medically assisted dying was legalised⁷⁶.
- Surveys show that where assisted dying is permitted, society remains supportive of the legislation. In a survey conducted in Oregon in August 2004, 74 per cent of those surveyed have become more supportive since the ODDA took effect (4 per cent less supportive)⁷⁷. In the Netherlands, 81 per cent supported assisted dying (a further 7 per cent were neutral)⁷⁸.

6.8 *The "1,000" patient deaths in the Netherlands*

- The "1,000" cases of patient deaths due to life ending acts in the Netherlands without explicit request are often cited as evidence of abuse of assisted dying legislation⁷⁹.
- We note that this is a concern. However, according to the most recent Government research from the Netherlands, Onwuteaka-Philipsen has found no increase in these types of cases over the last 10 years⁸⁰. Further, it is incorrect to say that these cases prove "abuse". The authors of the 1991 Rummelink study that identified these "1,000" cases noted: "In more than half of these cases the decision has been discussed with the patient or the patient had in a previous phase of his or her illness expressed a wish for euthanasia should suffering become unbearable . . . The decision to hasten death was then nearly always taken after consultation with the family, nurses, or one or more colleagues. In most cases the amount of time by which, according to the physician, life had been shortened was a few hours or days only"⁸¹.
- Professor Luc Deliens and others have argued that one of the benefits of assisted dying legislation may be that doctors approach end of life decision making with greater care⁸². In some countries which lack a properly regulated and transparent system for medically assisted dying, doctors are up to five times more likely to end their patients' lives without their explicit request⁸³. Where there is no transparency or regulation concerning end of life practices (such as in the UK), it is possible that vulnerable people are at greater risk⁸⁴.

6.9 *Reporting in the Netherlands*

- The percentage of Dutch doctors reporting assisted deaths continues to increase from 18 per cent in 1991 to 54 per cent in 2001⁸⁵.
- There is no evidence to indicate that the failure to report reflects abuse or an increase of assisted deaths⁸⁶.
- Dutch doctors who fail to report are not protected by their legal system. They are in the same position as doctors in England and Wales who fail to comply with the law on assisted dying, namely they are subject to criminal prosecution.
- The Dutch have recently developed a package of Government measures designed to improve reporting⁸⁷.
- Irrespective of what the criminal law provides in England and Wales, we know from countless surveys that assisted dying does take place but, unlike Oregon and the Netherlands, reporting remains at zero.

6.10 *Safeguards in the Bill*

- The Parliamentary Joint Committee on Human Rights found the Bill’s safeguards adequately protect the rights of vulnerable patients⁸⁸.
- The safeguards in the Bill are more stringent than those in Oregon, the Netherlands and Belgium.
- These safeguards, when viewed in the context of other end-of-life medical decisions where there is no legislative framework or nationally agreed safeguards, are carefully considered and comprehensive. These other end-of-life medical decisions include decisions to withhold or withdraw treatment, and to provide sedation at the end of life or aggressive pain relief where consciousness levels/competency will be impaired.

6.11 *The absence of similar safeguards in other end-of-life decisions*

- Researchers have noted that abuse is more likely to occur in end of life decisions other than medically assisted dying (eg sedation at the end of life, withholding and withdrawal of treatment). This is because in such cases, the patient may not be the decision maker⁸⁹. These practices are not underpinned by a legislative framework or even nationally agreed safeguards, thereby exposing vulnerable populations to possible inappropriate end-of-life decisions.
- Frequently, withholding and withdrawal of treatment decisions lead to the ending of that patient’s life. Patients such as Mr Burke are concerned that when they can no longer communicate, the decision could be made by medical practitioners to withhold and withdraw treatment which could end his life. This concern has been echoed by the Disability Rights Commission⁹⁰.
- We endorse their concern and contend that it is only when the patient is the principal decision maker, as in the Bill, that vulnerable people can be adequately protected.

7. CONCLUSION

- Currently many people in the UK suffer distressing and painful deaths. Many of these terminally ill people would like medical help to die, but under the current law, such help is a criminal offence;
- The wish of a dying person like Dianne Pretty to receive medical help to die should not be regulated by the Suicide Act and the law of murder. As recently recognised by the Law Commission, “this is a blight on our law”;
- Irrespective of what the law may say, health professionals break it on a repeated basis out of compassion and respect for the wishes of their terminally ill patients;
- Currently, terminally ill people whose suffering is unbearable may with or without the help of a loved one, attempt to end their own lives sometimes with deeply distressing consequences, not just for the patient but also the relative. In an NOP survey conducted in August 2004, 50 per cent of those surveyed were willing to break the law in such circumstances⁹¹;
- A law which is not respected, even at such very real risk to those who break it, is a law which needs changing;
- The general public, in repeated opinion polls, have made it clear they wish to see the law changed;
- Evidence from Oregon and the Netherlands shows that it is far better to provide for medically assisted dying within a properly regulated system;
- Lord Joffe’s Bill draws on the experience of Oregon in particular. The Bill would not only deliver greater patient choice to terminally ill people who are suffering unbearably, but also provide clear guidance to the medical profession in these circumstances and better protect the more vulnerable groups within our community;
- The Bill will give patients better end of life care. For the first time terminally ill patients who need pain relief will have the legal right to request and receive it. Further, for the first time, patients who are terminally ill and ask for medical assistance to die, will have a guaranteed right to be attended by a palliative care specialist;
- The Bill gives terminally ill people “an insurance policy” of an assisted death, thereby enabling them to continue to live without so much fear and anxiety about their future. They know that if their suffering becomes too much they can have help to die;
- At the most critical time in a patient’s life, the Bill will enable open and honest discussion between doctor and patient of all the dying patient’s desires and concerns;

- The Bill will relieve a considerable burden from the shoulders of many medical professionals. They will no longer have to act in secret out of a fear of prosecution;
- Finally, as noted by commentators such as Professor Griffiths and Roger Magnusson, the choice before the Select Committee is not between permitting or preventing medically assisted dying. The choice is between making medically assisted dying visible and regulated, or allowing it to continue “underground”, without any safeguards, transparency or accountability.

August 2004

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Examination of Witnesses

Witnesses: PROFESSOR JOHN HARRIS, University of Manchester, PROFESSOR SHEILA McLEAN, Glasgow university, DR EVAN HARRIS, a Member of the House of Commons, MISS DEBORAH ANNETTS, Chief Executive, Voluntary Euthanasia Society, and MR TL BARCLAY, examined.

Q1 Chairman: Thank you all for coming. This is a public session of the Select Committee on the Assisted Dying for the Terminally Ill Bill. It is our purpose to hear the oral representations from the Voluntary Euthanasia Society. I would like the Chief Executive Officer of the Voluntary Euthanasia Society to introduce herself, and then the individual members of the team to introduce themselves. Then it is over to you as to exactly how you wish to conduct the proceedings: you may either make a single opening statement, or you may decide to have opening statements from each witness. The point obviously is that the more time that is taken up by that, the less time there is for questioning; and it is for your judgment as to which bit of the proceedings is more important from your point of view. The evidence is recorded, and therefore it is clear that it would be a great help if you can be so kind as to articulate as carefully and clearly as you can, without of course unduly delaying the time of the presentation that you want to make. The evidence will be submitted in draft to the witnesses with an opportunity to point out any corrections that are required to be made on the transcript. With that introduction, Miss Annetts, would you like to proceed?

Miss Annetts: We welcome the decision of the House of Lords to give time to this very important issue, and I would also like to thank the Committee for asking the Voluntary Euthanasia Society to give evidence in connection with Lord Joffe's bill. I would like to introduce you to the witnesses who are here today. We have asked them to attend because of their expertise in their individual fields. They are not representatives of VES; they are here because of their particular levels of experience. I would now like to hand you over to Sheila, who will briefly introduce herself and outline her background.

Professor McLean: Chairman, my name is Sheila McLean. I am Professor of Law and Ethics in Medicine at the University of Glasgow and, as Deborah said, not associated with the Voluntary Euthanasia Society.

Professor Harris: I am John Harris, bio-ethicist and philosopher at the University of Manchester, and I am also not a member of the Voluntary Euthanasia Society nor otherwise associated with it.

Mr Barclay: My name is Tom Barclay, and I am here because the Voluntary Euthanasia Society asked me to come in view of the fact that I have an incurable complaint.

Dr Harris: My name is Evan Harris. I am a Liberal Democrat MP for Oxford West and Abingdon, and formerly a doctor, and a member, like Sheila and John, of the British Medical Association Medical Ethics Committee, though we do not speak for either the BMA or indeed the Medical Ethics Committee. We are here in a personal capacity. I was involved in a successful attempt to steer—through open debate—a policy around doctor-assisted dying through my own party conference just last spring.

Miss Annetts: There have been a number of very significant changes over the last 10 years, which we have set out in the VES submission. I would like to highlight four of the most significant changes. There has been much speculation as to what would happen if medically-assisted dying were permitted. We no longer need to speculate. Medically-assisted dying is now permitted under the law in Oregon. The Netherlands and Belgium. Decriminalisation has made it possible for independent researchers to examine all aspects of medically-assisted dying, particularly in Oregon, where many academics, in conjunction with the Oregon Hospice Association, have undertaken comprehensive research. The second important point is that since 1996 there have been repeated opinion polls, not least the British Social Attitudes Survey from 1996, which have found that 82 per cent of the public support medically-assisted dying. Many UK doctors and nurses also support a change in the law. We concur with the GMC and the BMA, which have said that this is a matter for society. There is a clear consensus amongst the majority of the public, who want to see the law changed; and Lord Joffe's bill meets these wishes with great clarity. The third point I wish to address is palliative care. VES supports palliative care, and we would like to see increased provision to meet the needs of patients who want it; and we welcome the growing political commitment to realise this aim. However, many have argued, including the BMA and Macmillan Cancer Relief, that palliative care cannot meet the needs of all dying patients, and this has been

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reinforced by research carried out over the last 10 years. Lastly, we now have clear evidence that, irrespective of what the law may say, doctors, nurses and relatives are being asked by terminally ill people for help to die. We also have evidence that doctors and relatives are breaking the law and giving this help. Indeed, a recent UK survey found that 47 per cent of people would be prepared to break the law to help a terminally ill loved one to die. The law is clearly not working. It is not humane or effective. Indeed, the Law Commission has found that the current legal position is a blight on our law. Evidence from around the world has shown that it is far better to regulate medical help to die than to allow it to go unchecked and unregulated as an underground medical practice. Many safeguards have been built in to Lord Joffe's bill to protect the vulnerable, something that the current law simply does not do, whilst at the same time providing choice to dying patients and giving clear guidance to the medical profession when faced with a request from a dying patient for that help. I would now like to ask Mr Barclay to say a few words.

Mr Barclay: Thank you for allowing me the opportunity to address you. I have been asked to tell you about my personal circumstances. I was a consultant plastic surgeon for 30 years, before retiring in 1989, and have been responsible for the treatment of many patients with big head and neck malignancies, both the resection and the reconstruction; and I am very familiar with the situation in which I have to tell a patient that there is nothing that I can do for them. I have been a member of the Voluntary Euthanasia Society for 17 years. Two years ago, I developed fasciculation of the muscles to my legs and arms, which are characteristic of Motor Neurone Disease, which is bad news, invariably fatal, and there is no cure—and I well knew that. In January of this year, because of wasting of my hand muscles, I consulted my neurological colleague, and he confirmed the diagnosis with EMG tests. Since then, my muscular wasting has steadily progressed, giving me some degree of disability. This process will continue. The next thing that will happen to me is that I shall get a dropped foot and have to use a wheelchair. After that, I shall become too weak in my arms to move the wheelchair, and I shall have to be carried about. The end stage of Motor Neurone Disease is called bulbar palsy, in which I shall be unable to swallow, and my speech will become unintelligible. Finally, after several years, I shall die of pneumonia caused by inhalation of saliva. This is all going to happen. If, in the end stage of my illness, I wish to commit suicide, I shall be physically unable to do so. I shall not be able to hang or drown myself and I will not be able to swallow the necessary pills if they are available. We all have to die. I have been very

fortunate in having had a worthwhile career, good health, and a marvellous wife. I am not complaining about anything except that anyone who assists me in my project, as the law now stands, will be prosecuted. For the disease I have, no palliation is possible. The sensory nerves are not involved; there is no pain, only motor weakness. Nevertheless, I shall have what my medical textbook calls “intolerable suffering for the patient and his family caused by this terrible illness”. My life expectancy is still of several years' duration, of which at least the last two are very likely to be end-stage helplessness, dysphagia and anarthria. I do not believe that under all these circumstances being medically helped to die at my instigation and with my full understanding and approval would in any way undermine the basis of modern caring medicine.

Professor Harris: I would like to make two points in this very brief time that I have. The first concerns autonomy. Respect for persons, something we all wish to show, requires us to acknowledge the dignity and value of others and to treat them as ends in themselves, not merely instrumentally. This means respecting their autonomy. Autonomy is the ability to choose and the freedom to choose between competing conceptions of how to live. It is only by the exercise of autonomy that our lives become in any real sense our own. The ending of our lives often determines life's final shape and meaning, both for ourselves and in the eyes of others. When we are denied control at the end of our lives, we are denied autonomy. As Ronald Dworkin memorably put it, “making someone die in a way others approve, but he believes a horrifying contradiction of his life, is a devastating, odious form of tyranny”. Autonomy is the underlying rationale of laws that, I hope we all accept, allow patients to refuse life-sustaining medication. To permit this and to deny medically-assisted death is, I believe, radically inconsistent. Next, I want to turn to vulnerability. Many objectors to medically-assisted death emphasise their concern to protect the vulnerable. There are two groups of vulnerable people to whom we owe concern, respect and protection. One consists of those who might be pressured into requesting death. The others consist of those, like Dianne Pretty, who are cruelly denied the death they seek. We are surely not entitled to abandon one group of vulnerable people in favour of another group of vulnerable people: we have somehow to protect both. Those seeking medically-assisted death are the more vulnerable because it is they who are truly coerced at the moment, absolutely prevented from obtaining the remedy they seek. Those who might be encouraged to die are free to refuse. They are not victims unless we permit them to be, or unless they make themselves victims. Those who seek and are denied death are the ones currently who are genuinely coerced, and who are at the

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moment, I believe, victims of tyranny. Concern for the vulnerable does not, as so many falsely believe, tell us that we should forbid medically-assisted dying: on the contrary, it tells us that we should permit it, with the safeguards such as those in Lord Joffe's bill. In this way, we can protect both of the groups of vulnerable people whom we owe our concern, our respect and our protection. Thank you.

Professor McLean: If I may, I would like to approach the question from a slightly different perspective, given that my background is in law. It is not overstating things to say that citizens can expect their laws to be cogent, clear and consistent. I would suggest to you that for the moment the law in respect of end-of-life decisions offers none of these characteristics. I am happy to expand on this in questions if anyone would like me to. I think, secondly, we should recognise that this is an issue about human rights, not just those rights that are laid down in the Convention of Human Rights or in the Human Rights Act, but fundamental human rights. It is not a question of medical practice pure and simple, as both the GMC and the BMA have recommended, but our current legal regime relies on sophistry to allow assistance in dying in a number of circumstances, but paradoxically precludes this only where a competent individual contemporaneously requests it, a situation which Lord Mustill in this House described as the law being "intellectually misshapen" in the case of *Airedale NHS Trust v. Bland*. I would also like to pick up Professor Harris's point on the question of autonomy. There are many principles that people use in the argument against legalising assisted dying, the prime amongst which is the concept of the sanctity of life. This is undoubtedly a principle to which we would all subscribe, and one which clearly protects people who wish to have their lives protected. However, in most of the cases in respect of end-of-life decisions, the courts, up to the most senior courts, have indicated that the principle of autonomy to which Professor Harris referred, predominates over the principle of the sanctity of life where an individual person is competent in making a decision, as would be the case were Lord Joffe's bill to become law. Finally, from a legal perspective, I am confident that the protections that are placed in Lord Joffe's bill are sufficient and appropriate to ensure both competence of decisions that are made, the informed quality of decision-making, which is so essential to the exercise of autonomy, including the need for provision of information about alternatives to assisted dying. In fact, it may be another paradox of the current legal situation that Lord Joffe's bill would offer to those seeking assistance in this way many more safeguards than are currently available for those who at present can lawfully choose to die.

Dr Harris: It is my first time on this side of the table, and I see a different perspective than usual, and I rely on your Lordships' reputation of politeness to rescue

me from what I might have inflicted from that side! I have looked at this from the public policy point of view in terms of seeking to have this debate in public, and it seems to be from that, albeit short, experience that the public requires that Parliament debates this matter to a conclusion. In my short time in the elected house, we have debated most ethical matters at the beginning of life and around personal sexual morality, but this is one thing where there has barely been any debate or consideration; and it is a mystery to me why the political establishment, by which I mean those in all parties who determine business in Parliament, particularly in the House of Commons, should wish not to even debate this and show no sign of being willing to. The parliamentarians should not be let off the hook, and it is timely therefore that this bill comes forward. Even if it were rejected, I think many people would feel happy that at least Parliament had done its duty and fully debated the matter, preferably in both Houses, obviously. The letters I get, having clearly taken a relatively high-profile role, come from both sides, but I do get more from older people who are very worried that they will end up in the position of Dianne Pretty, or indeed her husband. They are as moving letters as one gets in other areas. I do not believe that in this sense this matter is any different from some of the contentious issues, like cloning and issues of sexual morality, that we have debated. For a number of years now, since my medical student days, I have been a participant and observer of the medical politics of this, and it is true that the British Medical Association has failed to support the change in the law at its annual representative meeting and, most recently in 2000. I have asked myself the question: "Why do doctors' leaders appear to be against this?" I think that they find it politically one of the more difficult issues, partly because they do not wish to be seen to be pressing for this change; but in my view, having spoken to many who have publicly stated that they do not wish to see a change, they would not actually mind if society did decide, and they would certainly go along with it unless they were conscientious objectors. Of course, there is that provision within this bill. The doctor/patient relationship has evolved, and often it has not been easy for doctors—more autonomy and choice for patients, and patients requiring and demanding more openness on difficult subjects with doctors. This is one of those areas that is the next to see an evolution in the doctor/patient relationship. Even if doctors' leaders are not yet calling for it, I believe that patients are, and those that represent patients ought to be.

Chairman: That completes the presentations and it is now my privilege to invite members of the Committee to ask questions to any or all of those who have spoken.

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Q2 Lord Taverne: I should like to ask two questions, the first of Deborah Annetts. There is a lot of evidence, you say, now from Oregon and The Netherlands. What does this show in relation to the argument deployed against the change, namely that there is a danger of the slippery slope? The second question is one I should like to put to Professor Harris. One of the most fundamental moral dilemmas involved in this seems to me to be illustrated by the so-called policeman's dilemma, which you refer to in your written evidence. Would you expand on that particular aspect?

Miss Annetts: Thank you for asking that question. It is a very important question because it has been raised—concerns about the slippery slope. We now have very clear data from Oregon and from The Netherlands that this simply is not happening. If anything, commentators have said that perhaps regulation is the best way to stop a decline into the slippery slope¹. That is an important point. The research from The Netherlands has been led by Professor van der Wal, a very key researcher in The Netherlands, and he has conclusively found no slippery slope in terms of either an increase of people wanting to have assisted dying or people from perhaps vulnerable groups making access of these particular provisions under the law in The Netherlands. Exactly the same has been found in work carried out by Linda Ganzini in Oregon: there is no evidence whatsoever of the slippery slope.

Professor Harris: I will be as brief as I can, but I think I should state what the so-called policeman's dilemma is. This was a case first brought into the literature by Herbert Hart, Professor of Jurisprudence at Oxford, supposedly a real case in America in which there was a motor accident—a lorry driver was trapped in the cab of his burning lorry. The policeman was on the scene and it was quite clear that the lorry driver would be burnt alive before he could be extracted from the vehicle, and he pleaded with the policeman, who, as American policeman are, was armed, to shoot him in the head rather than allow him to be burnt alive. Everybody would agree that the policeman did the morally correct thing in shooting him in the head. This case shows that there is no principled objection to euthanasia; the rest is an argument about safeguards. I have not met a single person who could look me in the eye and say that that policeman did a wicked thing and did something that he should not have done. If we concede this case, then we concede the principle of assisting death in cases of extreme distress where the condition, as the lorry driver's was, is clearly a terminal one—the very conditions envisaged in Lord Joffe's bill.

¹ *Note by witness:* Lee, DE "Physician Assisted Suicide": a conservative critique of intervention, The Hastings Center Report 2003: 33 (1): 17.

Q3 Lord Patel: We have seen, in paragraph 2.8 on Page 4, evidence that doctors are already assisting their patients to die. We have one of the authors here, Lord Chairman, and I would like further expansion of that.

Professor McLean: The evidence to which you refer was the result of a survey conducted as part of a study into voluntary euthanasia and assisted suicide in 1996. We distributed some 2,000 questionnaires to doctors and also to some pharmacists—given that, where assisted death had been regulated by way of physician-assisted suicide, then they clearly would be implicated in the final decision. We had a 50 per cent response rate, so we had about 1,000 responses to our questionnaire. Fifty-four per cent of the respondents indicated that they would welcome a change in the law to permit assistance in dying. At the same time, I coerced BBC Scotland into conducting an opinion poll of the Scottish public, and they surveyed some 1,000 people of whom 72 per cent agreed that there should be a change in the law to permit assistance in dying. Of the professionals who responded to us, something like 4 per cent said they had helped a patient to die, which is, interestingly, significantly lower than similar work done in the United States, but 11 per cent knew a man who had, so it was obviously not entirely lacking in being fairly widespread. Is that the evidence you were referring to?

Lord Patel: Yes.

Q4 Earl of Arran: If palliative care were available for all the terminally ill, do you still see a need for this Bill?

Miss Annetts: A lot of professional organisations, like the BMA and Macmillan Cancer Relief, have said that palliative care cannot meet the needs of all patients, and I think that is backed up by the evidence from Oregon, which has shown that 93 per cent of people are in receipt of palliative care who actually ask for and receive help to die. They are actually in a hospice when they are making the request, and then have that request accepted by their attending physician in Oregon. That clearly demonstrates that palliative care, for those particular people, has not met all of their needs. Palliative care is obviously something that is central to the dying process, and we absolutely endorse that view. That is why we are very pleased that Lord Joffe has included in Section 3 of his bill something called the "palliative care filter"; that, if somebody asks for medical help to die, then a palliative care specialist is required to attend that patient to explore whether palliative care can meet their needs better. We are absolutely behind that particular provision.

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Professor McLean: One other piece of research that might be of interest is that there is a certain amount of evidence now, certainly from the United States, that patients who are receiving good palliative care are more rather than less likely to ask for control at the end of their life; the very fact that they are adequately informed about the alternatives, and that they are palliated to the stage at which they are competent to ask these questions, they are more likely than less to ask for control at the end of their lives.

Q5 Baroness Finlay of Llandaff: Can I thank you, Mr Barclay particularly, for having come to speak to us and explaining what is clearly a very difficult situation to be in. I am not certain from the evidence that you have submitted why you feel that it must be doctors that do this, given that we have had evidence from doctors who have said that they would not want to be involved in any way in a process of ending patients' lives—"killing patients" is the phrase they use—and why you have not proposed some kind of Scientology service that would be separate and outside, in terms of bringing about the same end for the patient but without impinging on the conscientious ability of a doctor to take a decision—because in the bill there is also provision that, whilst someone may object, they have a duty to refer, and therefore they have to be part of the process however deep their personal objections may be.

Miss Annetts: Lord Joffe has noted concerns around Section 7 and may well be putting in an amendment to Section 7 in relation to the obligation to refer on to another medical practitioner. However, if you look at the evidence from Oregon and from the general public in the UK, they see the medical practitioners as the person they want to help them at this critical time, and that marries up with the evidence from Timothy Quill, who is a palliative care consultant in the States. He said it is very important for the medical profession, for the doctor, not to abandon the patient at the end of life. There is a concern that, if the doctor almost sub-contracts this role, and if that were the provision in the bill, then the patient might feel a sense of real abandonment. Notwithstanding that, of course, the conscientious objection clause is absolutely vital.

Dr Harris: To add to that, the problem you cite is not a new dilemma for doctors—for example, the abortion procedures they are faced with, having to refer to someone else if they have a conscientious objection. There will always be areas of practice where doctors need to refer because they are opposed to participating in the process. If the process is lawful, then I think we have a right to expect doctors to make the onward referral, even if, as this bill does, it provides a conscientious objection, which is well recognised as something that is reasonable to do. My

understanding is that this has not been a major problem in other jurisdictions where this has been made possible. The other point I would make is that it is always useful to make the comparison with the more passive situation where a patient refuses treatment that is life-saving, and they do not need even to be suffering from unbearable suffering, however that is defined, or even have a terminal illness, because if they have the capacity they are entitled to make that decision. Some doctors, I am sure, would find that even more distressing because they know there is a life-saving or ameliorating treatment that a patient, for whatever reason, is rejecting. Again, that is not a new dilemma, and I suspect, based on my own career, that all doctors have seen situations that they are not entirely happy with but they recognise that, when it is a question of patient autonomy, that has to override their unwillingness and unhappiness about referring this case, or participating if they are not a conscientious objector.

Mr Barclay: Speaking personally, if my request for suicide help were medically approved by people whom I knew, that would satisfy me perfectly well. I would not want my own practitioner necessarily to do the final injection.

Q6 Chairman: Mr Barclay, it is rather a delicate question, but have you any idea from the point of view of your own condition how much time of life would be stopped if you were able to ask for medical help to have suicide in your situation?

Mr Barclay: According to my reading and the people I have asked, the process can last a very long time or not a very long time. My medical textbook, on which I rely, suggests that a terminal period of two to four years in a helpless state is to be expected, but it may be less. It is very unlikely to be more. That is what one would have to anticipate when one were making the request. I believe that, when I get to the stage when I cannot swallow, I shall ask for it then.

Q7 Baroness Hayman: I wonder if I could explore with our witnesses the issue about the evidence of who it is who most supports or asks for assisted dying in the experience that we have from abroad. You mentioned that it was those who had perhaps best experience of palliative care who still wished to be in control, and I read in the evidence from Oregon that there seemed to be a bias in terms of educational standards and perhaps social class of those who asked for assisted dying. Do you have any comment on that phenomenon, and how do you explain it? Do you have any thoughts or concerns about that? Would that be an issue for you were it to be replicated, in the terms that we address other issues of equality of access? Is that something that your

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organisation would consider was a concern; or would you simply say it was reflective of—?

Miss Annetts: Again, on the Oregon statement, the Department of Human Services and Linda Ganzini have been researching into the types of people who access this particular provision. They have found that people who pursue the request through and have help to die are people who have a particular need for control and autonomy but who also may be suffering from quite a high level of existential suffering—loss of dignity, loss of bodily functions, *et cetera*. There is a combination here of what their suffering is, and what their suffering means to them personally. Interestingly, a much higher percentage of people actually request a prescription but do not use it, and we think that is because they are using it like an insurance policy—“if it gets too bad, I have control, but I will not use it until I get to that point”. In the words of some of the Motor Neurone Disease sufferers from Oregon, they have said, “this has enabled me to live a better life because I do not have to worry about the future”. There seem to be two different things going on there, one the insurance policy aspect and the other the illness combined with the personality type. In terms of access—and I can only express a personal view—it comes back to personal autonomy and who this person is. It is clear from Oregon that people from a higher socio-economic group seem to be using this particular provision, although interestingly people who make the request may come from a lower socio-economic group; so there may be a whole variety of things going on there. I am not sure we would want to start advocating on the basis of access actually. I think it is very much a personal thing; it is how you want your death to be at the end of your life, and I do not think VES should be involved in that.

Q8 Baroness Jay of Paddington: I would like to follow up more specifically one of the general points that Lord Taverne asked about in relation to the argument of the slippery slope. One of the issues that is often raised—and it has come up in some of the responses made to questions that have already been posed—is that there is a particular difficulty for the medical profession in terms of the potential loss of trust. We are all familiar in this country where that has been a specific problem. Have you done any work on that, or has anybody for example in The Netherlands and Oregon—I saw it referred to briefly in your written evidence, but is there something you can expand there on the potential loss of trust?

Miss Annetts: Again, we have to go to Oregon and The Netherlands to see what the evidence is there. There have been a number of pieces of research done which are either on the point or adjacent to it. Firstly, there is a piece of research by Graber in the States

who looked at this issue and found that there had been no reduction in trust whatsoever. Secondly, there was a piece of research conducted in 2002 which found that the Dutch trusted their doctors more than any other nation, including doctors in the UK, which is a very interesting finding. That may relate to the fact that, again, the six-country European study from 2003 found that there was the highest level of discussion between doctor and patient in The Netherlands around end-of-life decisions, so trust seems to have something to do with that whole discussion process between doctor and patient, which is very important.

Professor Harris: I have no empirical evidence, but intuitively it would seem to me that this would be a trust-promoting measure. The patients will know that they can trust doctors to do precisely what the patient believes is in their best interests, and is necessary to protect them. Knowing that the doctors are able and willing to do that would promote trust rather than reduce it.

Q9 Baroness Jay of Paddington: Do I understand that the VES position is not that there is what one might jargonistically call competition with palliative care in this whole area—because sometimes the argument is expressed that it is palliative care versus assisted dying? That is not your position?

Miss Annetts: Absolutely not, no. The two work hand-in-hand. Indeed, the Oregon Hospice Association has come up with a very useful leaflet, which it delivers to everybody who has been diagnosed with a terminal illness, which goes through all the different options: refusal of treatment, withdrawal of treatment, palliative care, pain relief, also medical assistance to die. The whole thing is a package from which the patient can take what they want.

Dr Harris: Baroness Jay, I happen to agree with Professor Harris that it would be a healthier and more trusting relationship if the patients were aware that their autonomy would be respected and be paramount. But even if you do not accept that argument—and some people do not—I would say that it is not a particularly healthy relationship, and it is rather old-fashioned, for patients to be in a position to say, “whatever you say, doctor; I trust you explicitly; I do not even have to think about this; I am going to go with whatever you say”. I think the relationship has evolved, and it is a good thing that it has become more equal. It has a long way to go in my opinion. With respect to the palliative care point, clearly at the end some people do argue that, if everyone had the maximum amount of palliative care, they would not want this assistance. However, we do know of cases; there is no question that Dianne Pretty had access to palliative care, and that many

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other people often will have—and I am sure that Mr Barclay would have access to that; but I do not think it is proper palliative care for people involved in palliative care to say, “you are wrong about your wishes at the end of life because here we are giving you palliative care; how dare you then request help to die because of dignity and things that are personal to you”. Palliative care in some cases does meet some people’s every need but in some cases it clearly will not, and it has to be a subjective matter.

Q10 Baroness Thomas of Walliswood: Dr Evan Harris spoke of the benefit of discussing the subject even if they are not successful or it still never comes to anything. Like many people, I take the argument in favour of autonomy as a very strong argument, but many of the people who have written to us have associated this Bill and what they know of it with a fear that they will be, to put it vulgarly, bumped off by somebody else. They do not see the Bill, perhaps because they do not understand it, as an effort to give autonomy, and they see it in quite the reverse, as a threat to what could happen to disabled people or people with mental difficulties and so on. I would like you to comment on that and how that relates to what has been drawn to my attention—that “do not resuscitate” messages can be put on a file without the patient being aware of it. That might give people, as it were, reason to suppose that we are moving towards a state, not of increasing autonomy, but decreasing autonomy?

Dr Harris: The “do not attempt resuscitation” notice, as it should be properly known, is an example of what the present poor practice is, where the matter has not been discussed. Patients with capacity ought to have that discussed, and there should be a duty on doctors to discuss that situation in appropriate cases. One instinctively says that it is terrible to discuss that sort of thing with patients as they enter hospital, but there is a real risk that patients, many of whom do die in hospital, run the risk of having resuscitation attempted inappropriately. So the danger you cite, where people feel that they might be bumped off, is something we must be vigilant around now, and in the future, whatever the state of play of the law. I am certainly aware from my own practice of patients who have had heavy strokes, for example, being put on sedation, diamorphine pumps; and for no good reason, because they had such a dense stroke that they were not in pain, but it was just the way that their end of life was seen off. I think that is inappropriate and in other jurisdictions this sort of legislation has been brought in in a climate of regulation in an attempt to tackle the abuses that are occurring in order to reduce them. I have been able to persuade people who have contacted me, maybe because I have taken a public position, that they will be in an

environment where there would be more safeguards against non-voluntary acts if the law were changed.

Professor Harris: This is clearly a real issue, but if the fear that people will be bumped off, as you put it, is ill-founded and can be met with clear safeguards, then one of the answers to this is education. But an important point is that we, you, Parliament, we the society, should not condemn others to a terrible death because of the ill-founded fears of another group. All we have to do with those fears is show that they are ill-founded and make sure that the safeguards are in place so that people can clearly see that they are ill-founded; and I believe that that is what Lord Joffe’s bill does.

Professor McLean: A longer version of what I am about to say here is in the written evidence that I submitted to the Committee, but which you may not yet have seen. I support what Dr Harris was saying. One of the difficulties in the current legal regime is that there is scope for fear because people are not actively engaged in the kinds of decisions that are being taken about the end of their lives. One of the benefits of Lord Joffe’s bill is that it introduces safeguards for a person in this situation that do not exist in any other areas. It is possible for clinicians to make decisions on behalf of incompetent people about the moment that their lives should be ended. To come back to the earlier question about doctors not wanting to be involved in this, I think it was a mistake to suggest that merely because the doctor’s involvement is characterised by withdrawing or withholding treatment, for example from a patient in a permanent vegetative state, it is a mistake to suggest that they are not involved in the death of that particular patient. Clinicians already are involved. One of the problems is that they tend to be involved in circumstances where the individual concerned is not in a position to make a request. What Lord Joffe is doing in a sense is putting people who require active assistance on a par with those who have a treatment that they could otherwise refuse. If I happen to have a condition that has a life-saving treatment, I am legally entitled to refuse that treatment, and my clinician cannot interfere. The only group of people where that decision cannot be made are those who are competently saying the same thing with the same intention, seeking the same outcome, but who require active rather than passive assistance. In my view, the distinction between acts and omissions, and active and passive, certainly within the context of a doctor/patient relationship, where there is a duty of care, is a distinction without a difference.

Q11 Lord Taverne: Mr Chairman, can I follow up the question of the fear of being “bumped off”? It is sometimes said that people have a lot of fears that their relatives will put a lot of pressure on them to

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give their consent because it causes a lot of inconvenience to the relatives, and they may be forced, as it were, by moral pressure, into giving their consent, which otherwise they would not give. That is a fairly widespread fear from the correspondence we have had. Can you deal with that?

Miss Annetts: We have not seen any research to that effect. We have undertaken a huge search of literature in relation to all these issues which relate to end-of-life decision-making. However, what we have found from Oregon is that there is some research to the effect that sometimes a patient will hold off going through the final act of having help to die for a few days as a result of their relatives putting pressure on them not to do so; so it is the other way round.

Professor Harris: To follow Sheila McLean's point, as far as we know there is no evidence that people are refusing treatment in droves because of the pressure put on them by their relatives, but if that was a real fear you would expect it to apply as much to refusals of treatment as it would to positive assistance.

Q12 *Earl of Arran:* If, as would seem to be the case at the moment, assisted-patient-dying is gaining force or credibility, call it what you will, in western Europe, are there signs in Oregon that the neighbouring states are beginning to take some interest?

Miss Annetts: There has been some interest in other states. What is interesting about Oregon is that the legislation came into being as a result of a citizens' initiative, so it was a push from society at a very grass roots level that brought about the Oregon Death With Dignity Act. I cannot assist any more.

Q13 *Baroness Finlay of Llandaff:* In relation to the boundaries that you have proposed—and you talk about the need for open discussion with patients about what is happening, with which I completely concur—this debate has been healthy for people who are ill in empowering them to talk. However, the evidence that I see from Holland suggests that approximately one in five patients' lives are being ended using euthanasia, without their explicit consent, despite the law having been changed there for some time. I wonder why you therefore feel that the safeguards that you propose would be law, because 20 per cent without consent seems to be quite a high number.

Miss Annetts: The law came into being formally in The Netherlands in 2002, so the statistics you are referring to are pre the legislation coming into effect, and during that time doctors were working on the basis of guidelines coming out from the case law rather than actual statute. Having said that, the research in other countries, Belgium and Australia—and those are the only other two places where we have specific percentages of assistance or of end of life

decisions without the explicit request of the patient—shows much higher levels. In The Netherlands it is 0.7 per cent, in Belgium it is 3.2 per cent and in Australia it is 3.5 per cent. Going back to that 0.7 per cent, yes, that is a concern and the Dutch absolutely recognise it and they have been working very hard to try and put in better provisions—if you like, better medical practices—have in order to deal with that issue. What is noticeable, though, looking at the 900 deaths which occurred, without explicit request, is that most of those patients will have made a request to the doctor; they may not have gone through the formal process but they will have gone through an informal discussion². The latest figures from The Netherlands show that in virtually all those cases there will have been a discussion, if not with the patient themselves then with the relative or a colleague. But, of course, in the UK we have no statistics whatsoever; we do not know the extent to which this particular medical practice goes on within our own hospitals.

Q14 *Baroness Finlay of Llandaff:* I want to ask Professor McLean whether you have done any research, looking at the case notes, where doctors had said that they had done something to suddenly end a patient's life? Looking as to whether it was that they had not understood the action of opiates or whether this had been a cessation of futile—if I can use that word loosely—treatment or whether in fact it had been an administering of a lethal dose of something like barbiturates and kurari, which is what we have been talking about?

Professor McLean: I do not, in fact, have that information; I have not done research on that. But I can tell you that, of the doctors who responded to my survey, the question was quite specifically about active assistance on request from patients, so it would be precisely the situation that you envisaged. In that survey, as I say, it was only something like 4 per cent, with another 11 or 12 per cent who were able to say that they knew that this was happening with colleagues.

Miss Annetts: To go back on the Dutch experience, I suspect that Professor Van der Wal, who has done most of the research in this area and sponsored by the government, would be able to assist the Committee much further in relation to looking at those cases and the approach which the Dutch government would take in relation to regulating end of life decision making, with reference to those medical practices. There is also a piece which appeared in *The Lancet* in 1993, which we could certainly let you have, which

² Note by witness: Van der Maas *et al*, 1991 (The first Dutch Government report).

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goes into those deaths in more detail, and perhaps can provide you with the information that you seek³.

Q15 Lord McColl of Dulwich: You said that Dutch doctors were more trusted than British. What is the basis for that research? As somebody who works with Dutch doctors and Dutch nurses, communication is sometimes a little difficult, and I wondered how the comparison was made?

Miss Annetts: I suspect the best thing to do is to let you have a copy of the entirety of that research; I think it did cover most European countries⁴.

Dr Harris: I do not know the specific research, and some of these qualitative studies, I think we both recognise, are limited. I think it is a point to make that there does not appear to have been detected a problem, even despite the climate and legislation in The Netherlands, of loss of trust. Indeed, if anything, we should expect empirically, in my view, that doctors who are prepared to overcome the British reticence to talk about death, which pervades all parts of society, may well engender more trust these days from their patients because they are putting everything on the table. That is a personal and empirical view but I have not seen any evidence against it.

Q16 Lord Turnberg: I have found your presentations enormously helpful and valuable, and I am very grateful to you for coming to talk to us. As you are probably aware, we have been getting enormous amounts of letters and submissions, not all of which say the same thing as you do. There are a number of fears that come up, and we need your responses to them. One relates to Professor McLean's comment regarding the relationship between sanctity of life and autonomy—which has precedence, which is secondary to which and whether they are of equal weight, and so on. The other relates to John Harris's comments about, once we have got through the ethical view, we are then into how to determine the safeguards, and I think that is where most fears have been coming through—to me at least. How do we ensure that there are sufficient safeguards to satisfy us and the public that dangers will not ensue? I think that is an extraordinarily difficult area, and you may pass that over, but I wondered what your comments were?

Professor Harris: Can I start with that last point? As far as I know, in no realm of human life is it possible to have absolute safety, an absolute guarantee that

there will be no errors or nothing will go wrong. But against the possibility of a safeguard failure we have to set the fact that without assisted dying many people are going to terrible deaths, which they need not go to and from which assisted dying would save them. So we are not entitled to expose that group to certain danger because we can never be sure that there are absolutely foolproof safeguards in any human endeavour. We have to take a balanced view, it seems to me, but that balanced view should not be at the expense of one group always in order to offer absolute protection to another group.

Professor McLean: Can I add to that that? There was an editorial in the *New England Journal of Medicine* a number of years ago—and it was in fact written by the editor, I think—in which it was noted that the fastest growing group of suicides in the United States at that time were amongst the elderly. The reason given for that was that they feared being inappropriately kept alive in circumstances where they would have preferred not to be. So there is another side to that particular issue. On the question of the law's approach to autonomy and sanctity of life, I think, from reading any of the judgments, perhaps in the last 15 or 20 years, from the House of Lords down, that the attitude of the courts has been to adopt a sanctity of life principle which is, if I can describe it this way, a secular sanctity of life principle; in other words, the presumption is that people's lives must be safeguarded by the State. Indeed, as you know, there are requirements under the Human Rights Act that that is done. But the secular nature of it is that it is not taken to be an obligation to live, which is entirely in line with removing the prohibition or the criminality of suicide, for example. So what the courts have said, very senior Judges have said, is that, when there is a tension between the State's underpinning commitment to preserving the sanctity of life and the autonomous decision of a competent person that they no longer wish to have their life protected by the State, the function of autonomy or the value of autonomy is more significant than any adherence to sanctity of life. That has been the judgment in any number of cases in all sorts of different arenas, covering cases in which people have actually had a diagnosed mental illness to pregnant women making decisions about whether or not they should undergo Caesarean sections to deliver a healthy foetus. So it is now very much ingrained in the way in which the law approaches these issues.

Miss Annetts: May I come back on one final point in relation to safeguards? There is plenty of evidence to show, I think, both in the UK and overseas, that medical assistance to die is happening; it is happening now, irrespective of what the law may say, and it is happening without any safeguards, without any stringent tests, without a waiting period, without

³ Note by witness: Pijnenberg, L; van der Maas, PJ; van Delden, JJ; and Looman, CW. "Life termination acts without explicit request of patient", *Lancet* 1993; 341: 1196–1199.

⁴ Note by witness: Graber, MA; Levy, BI; Weir, RF; Opplinger, RA "Patients' views about physician participation in assisted suicide and euthanasia", *J Gen Int Med* 1996; 11: 71–76, also Kmietowicz, Z "R.E.S.P.E.C.T"—why doctors are still getting enough of it", *BMJ* 2002; 324 (7328): 11–14.

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checking on the patient's competence, without an exploration of palliative care. That is what is happening. There is an underground of medical assistance to die, which has been documented, for example, in the work of Professor Magnusson and Professor Emanuel. So it is not a question of prohibition or not prohibition; it is a question of coming up with the best regulation.

Dr Harris: On the question of sanctity of life, may I say I feel very strongly that the comparison needs to be made with decisions to refuse treatment. If sanctity of life as a priority were any basis for regulation, then we would seek to prevent competent patients from refusing life-saving medical treatment. We do not. I do not even believe it is controversial that we allow competent patients, even who are not suffering from a terminal illness, even who are not suffering unbearably, both of which are safeguards for the active case in Lord Joffe's Bill, from refusing life-saving treatment, despite the view that the sanctity of life is an issue. So for those patients who require help I cannot see ethically, as John Harris has said, that there is any difference, except in this Bill there are additional safeguards requiring there to be a terminal illness and requiring there to be unbearable suffering in the context of that. So it is an even more rational decision, and the autonomy is in fact bounded by those requirements.

Q17 Baroness Jay of Paddington: You said at the beginning, Deborah Annetts, that you felt that things had changed in the last decade, and obviously you have cited changes in the law of the countries that we have talked about this afternoon, and Professor McLean has just spoken about the change because of the Human Rights Act and encapsulating in law matters like autonomy and so on, which were not, at least in British law, extant before that. We have also had in your written evidence the necessary reference to the Law Commission's Report on the Homicide Act, talking about the issues which have just been raised, about driving this kind of procedure underground. Do you think that there has been a cultural change in which all of these issues are embraced, which makes you feel that there has been much greater openness, perhaps much greater public support, as you have measured it, for matters of this kind? What exactly is it, do you feel, that is happening in our society which makes this something that is more readily addressed? We have mentioned the factors of the law; we have mentioned changing the legal framework from the statutory point of view, and perhaps the more cultural one. Can you in any sense draw these threads together? Or do you think that these are things which have just happened, not necessarily in parallel but just at the same time?

Miss Annetts: I think it is a very interesting question to try to work out what is going on. I think they may all be impacting on one another. I think there is something very organic going on from the grass roots up, if you like; that most people will have experienced personally a bad death in their family. They know what the law is and they also know that they cannot ask a doctor for help to die without getting the doctor into trouble. So there are discussions amongst family members—"What do we do?" I think what the case of Dianne Pretty did was to give people the opportunity to start to talk publicly and really voice their concerns, and of course that is also underscored by the rise in the principle of autonomy, which of course is a thread going through the Human Rights legislation.

Professor McLean: I have only limited reasons for saying this, but I have a large Masters programme in the University, which is primarily addressed to doctors and other healthcare professionals, and in the last 10 years—perhaps five—something like 50 per cent to 60 per cent of those clinicians choose to write their dissertation on end of life issues, and 99.8 per cent of them—that is probably an accurate figure—are now arguing in favour of legalisation of assisted suicide or voluntary euthanasia. The reason I mention this is that one of the other things that has been happening is that people have become better educated about the issues that surround it and a new generation in particular of hospital doctors and other doctors and nurses are increasingly seeing the relationship between healthcare providers and patients as a more balanced relationship, which leads to more openness, which allows people to learn more about the sensations that people on both sides are feeling. Certainly my experience is that with a certain amount of openness people's minds do change very easily, and I think the new emphasis in medicine—if I can call it new, Lord McColl might disagree with me—on sharing and what Harvey Teff called a therapeutic alliance means that there is also the incentive within that for people to respect other people's views more.

Q18 Baroness Finlay of Llandaff: Can I go for a moment to the research that has come out on the reasons that people ask for death? Amongst those there is a fear of the future being worse than it is today, and a fear of what might happen. One of the reasons commonly cited is a fear of being a burden. I wondered how you felt patients will respond in the current climate where we now have less general practitioners available out of hours, often no district nursing at night available at home, and the family are increasingly having to pay for care and to provide that care themselves. I wondered what you felt about this increasing load that is being put on the individual

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and on their family in terms of that background to the request that has occurred, when people talk about their fears of the future?

Miss Annetts: Can I start by answering that question with reference to the Oregon research, which comes out year on year and, as you rightly point out, has been plotting the reasons why people have been asking for help to die? As you have explained, one of those reasons which has been coming up is burden but, in fact, burden is quite a long way down the list and comes after losing autonomy, being less able to engage in activities making life enjoyable, loss of dignity and loss of bodily functions. So it does come some way down the list. Secondly, burden has been found to be quite complex and is often linked to a sense of hopelessness or indeed a feeling of loss of autonomy. So in Oregon “burden” is not burden to care givers. It is not what this is about⁵. The research from The Netherlands shows that, if somebody has made a request for that reason, being a burden to care givers, it is most likely that that request will be turned down. So, again, we have to unwrap what “burden” may mean and be quite careful in looking at that. Obviously I take your point in relation to burden and that is why Section 3 of the Bill is so important.

Dr Harris: I draw a comparison with the refusal of treatment. If there is a problem with potential coercion, whether it be active or just a feeling of burden, then that is likely to apply in cases of refusal of treatment, which are common now and lawful at present. The safeguards in this Bill, which require effectively two doctors and a solicitor with a duty to explore issues of whether those are feelings or whether there indeed has been coercion, will, in my view, because of the way this Bill has been constructed and the safeguards in it, act to deal with that problem, if it is a problem, unlike those cases where it is a question of refusal of treatment. And obviously people who are terminally ill often go through phases where they require treatment to stay alive during their terminal phase—treatment of infection, for example. So if that is a concern, the safeguards in this Bill provide additional safeguards compared to the refusal of treatment situation.

Q19 Baroness Finlay of Llandaff: I was not thinking about treatment so much as about social care issues, which are a huge problem for people. As you know, with people who have a disability and are at home, their physical care can actually be extremely difficult for the family.

Dr Harris: I did understand the point you are making. Let me try to explain what I meant, because I do not think I made my position clear. Someone who has a terminal illness and is cared for at home

and the care is provided largely by the family, as you said, they may get an infection and at the moment they are perfectly entitled to reject treatment for that infection, and it may well be, if your concerns are correct, that it may be because they feel a burden. In contrast, the safeguards around this Bill, for circumstances which may run simultaneously with those episodes where they require life prolonging treatment, actually enable those issues to be explored, with the consulting physician, in the Bill and, of course, if it reaches that stage, with the solicitor.

Q20 Lord McColl of Dulwich: I was interested to hear that there was a proposal to modify Lord Joffe’s Bill as far as protecting doctors and nurses who may not wish to be involved in this process. I was also interested to read that that part of his Bill is exactly the same, word for word, as in the Abortion Act 1967. Bearing in mind that at least two Professors of Obstetrics in the UK had their lives made a living hell simply because they insisted on doing abortions “within the law”—that was their only crime—not to mention hundreds of midwives and budding obstetricians, who had to emigrate for the same reason, how confident are you that the same thing will not occur with this Bill?

Miss Annetts: If I may start by answering that and perhaps then pass it on to my colleagues? That certainly has not been the case in The Netherlands or in Oregon, where the doctors may decide, for conscientious objection reasons, not to assist the patient. So, again, drawing on that evidence, I would hope that that would not happen in the UK. The crux of this is about finding that partnership between the patient and the doctor, finding the balance in relation to autonomy between these two parties. I think it is very important that, in the same way that we are asking for respect for the wishes of somebody who is dying, who is suffering unbearably, that respect goes the other way, from the patient to the doctor, for example, if the doctor feels that they cannot assist for conscientious objection reasons.

Professor Harris: The issue of how we protect our citizens who act in good faith out of conscience is an important one—it arises in animal experimentation, it arises on the other side of the abortion debate as well—and of course we have a responsibility to protect people in the appropriate exercise of their conscience, and we should see that that is done.

Lord McColl of Dulwich: My point is that the wording in the two Bills is identical. It did not work with the Abortion Bill, whatever one may feel about abortion, and I am asking what is the basis of your confidence that it is going to work for this Bill?

⁵ *Note by witness:* Third Oregon Report by Department of Human Services, February 2001.

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Lord Joffe: May I intercede there, my Lord Chairman, because it is my intention to amend the Bill so that it is not obligatory for a doctor who, on conscientious grounds, refuses to assist the patient to die. The Bill will be changed. The reason for this is that the Human Rights sub-committee, when they considered this particular provision, came to the conclusion that it was probably contrary to the European Convention of Human Rights to place that obligation on doctors. So I was intending formally to bring this to the Committee's attention when I presented the Bill to the Committee next week.

Q21 Chairman: I would like to ask about the research that you referred to, Miss Annetts, into the attitudes and the problems associated with the provisions of this Bill. Would you be able to give us in documentary form the results of that analysis? It must be quite extensive and I think it might save us from having to do some of the work. Obviously we would want to look at it in a certain amount of detail.
Miss Annetts: Absolutely, yes.

Q22 Chairman: The second point I wanted to ask you about, you mentioned the situation in The Netherlands in which a person in a terminal illness situation was afraid that matters would get worse and therefore wanted something akin to an insurance: in other words, to have the necessary prescription at hand, not to use immediately but to use if their fears were realised, that matters had got worse. Is that a situation for which you think provision ought to be made?

Miss Annetts: I think it is one of the unforeseen benefits of the legislation. I think this particular piece of research comes from Oregon. When the Bill was passed, one of the guiding factors was autonomy and giving terminally ill people the right to an assisted death if that is what they wanted. But an unforeseen benefit of that has been that terminally ill people have found it a tremendous reassurance to them during the last few months of their life. So that the take-up rate for prescriptions is higher than the number of people who use this particular option at the end. Again, research from Oregon has found that patients find it very reassuring that, if things get too bad, they have a way out, and that is particularly apparent in some of the Motor Neurone Disease cases that my colleagues have been looking at.

Q23 Chairman: As far as that aspect is concerned, you were asked earlier about why a physician needs to be involved and the possibility of it being opened more widely than that. I think you indicated that the link with the physician was very important. Is there any particular reason why that kind of request could not be made to a pharmacist and then the insurance

policy, as it were, was at hand, assuming the patient was able, himself or herself, to make use of the prescription once it was there? One envisages that there may be difficulties in that situation. One could see, for example, in Mr Barclay's evidence, a development in which that became no longer possible. Is that not an area in which some question might arise about who should be involved in this?

Miss Annetts: I do not think that there is a clear-cut answer in terms of this issue, and certainly Switzerland has taken a slightly different approach. However, it is fair to say that over 50 per cent of doctors in the UK believe that in certain circumstances a terminally ill person should be allowed medical help to die. I think that is an important point. Not all doctors are against this. Secondly, one of my concerns would be regulation, and this Bill is about regulation, it is about regulating a current medical practice. I think that is one of the important reasons why the doctor needs to be involved to the extent that they have been in the Bill. I am not sure that we would feel comfortable with passing this across to a pharmacist, particularly since Professor McLean has talked about the therapeutic relationship between doctor and patient at the end of life, which is very, very important to the dying patient.

Dr Harris: I agree. I see no good reason why the medical profession should be allowed to opt out of this entirely, because respect for patient autonomy around end of life decisions including, as I have said many times, a refusal of treatment is in fact probably one of the most essential parts of the doctor/patient relationship, and it would seem to me to be artificial to take this and transplant it out of the doctor/patient relationship, and there would have to be very good reasons to do that. I cannot see those reasons and, as I say, I cannot agree with doctors' leaders who claim that patient autonomy is not really the main issue here, because there are other duties that the doctors have. Respect for patient autonomy has always been, in my view, and is increasingly being seen, as central to the duty of the doctor, and that is why it is such a critical part. Of course the death of the patient is a key part of their illness, sadly, and inevitably, and therefore I do not understand why doctors should seek to be removed from it.

Q24 Chairman: I want to follow that up a little. If this Bill became law in its present form, would there be protection for a pharmacist who knowingly provided a prescription that would lead to the suicide effectively of the patient?

Miss Annetts: There are provisions to that effect, provided that all the other safeguards have been followed through, with the involvement of the physician.

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Baroness Hayman: My Lord Chairman, apologies for not coming in earlier, but may I follow up one remark that Miss Annetts made?

Chairman: Yes, please.

Q25 Baroness Hayman: Could you tell me a little more about this evidence about how the unexpected benefit came about and was assessed, because one could also envisage unexpected dis-benefits in this situation? In this country we have stopped allowing people to buy large quantities of Paracetamol because of opportunistic suicide bids and, as I understand, that has been very beneficial in terms of teenagers who shot their livers to pieces. There is the possibility (and certainly echoed in some of the evidence that we have had) of personal experience of people who talk about being in despair and then, at a certain point in the terminal illness, receiving the appropriate care and having what is called a “good death” at the end of it, which could be an option taken away if people cash in their insurance policy too early. It is very difficult to evaluate that one, but do you have any sense or response about that?

Miss Annetts: There have been a number of investigations carried out by Oregon Health Sciences University and Oregon Department of Human Services, often led by Dr Linda Ganzini, who is herself a psychiatrist, and takes no position in relation to the Oregon legislation, and it was she who started to uncover this unseen benefit of the insurance policy⁶. But I think there are other aspects as well which need to be considered, which again come from Oregon. Largely, that once the prohibition of medical assistance to die has been removed there can be a fuller and more meaningful discussion between the physician and the doctor at the end of life. The patient can raise all of their concerns, nothing is off limits; all of those concerns can then be addressed and the best solution found for that particular patient. In many circumstances that would be palliative care. At the moment we have a prohibition, which means that, if a patient actually starts talking about medical assistance to die, then that immediately triggers concerns and difficulties for the medical team and the nursing team as well, and I have heard that from talking to many professional people working in this field. What do they do with that request, because they are immediately edging into the Suicide Act? Once you put in place Lord Joffe’s Bill, it is much easier to have that full discussion and to put the patient perhaps in the right area for their needs to be met fully, and many of those patients will be feeling despair and despondency. Again, once you have a system of regulation, you can take the patient

through the prognosis, the diagnosis and palliative care. The palliative care specialist will be required to attend and to talk to the patient about all these different aspects and how they can be best helped. So I suspect you would see better end of life care and, again, that is something coming through from Oregon and The Netherlands. Once you regulate in this area, doctors start considering end of life care in a slightly different way, which means that everybody ends up with a better standard of care at the end of life⁷.

Q26 Lord McColl of Dulwich: Can I go back to this business that the doctor should be expected to take part in this as part of his job? Your thinking, of course, is from the point of view of the patient. There is another side, which is illustrated by the man who witnessed his mother having euthanasia, and it was done by an anaesthetist who came in and said to the lady, “I am going to put a little needle into your arm, it will not hurt, it will be quite painless and you will go off to sleep and everything will be fine.” A month later the man was involved in a serious accident, was taken to the hospital and had to have an emergency operation. You can imagine his horror when the same anaesthetist came into the room and said to him, “I am going to put a little needle into your arm, it will not hurt, it will be quite painless and you will go off to sleep and everything will be fine.” So there is another side to this too.

Dr Harris: For that anecdote there are presumably also other alternative anecdotes out there of people who see a doctor who is actually helpful to their loved one in easing their suffering at their request and respecting their view and, indeed, therefore, that would make that family have more faith in that general practitioner or that consultant, whereas at the moment there is the despair. There is the case of Dianne Pretty, for example, and her family, that the doctors could not help. So there are two sides to those experiences which will be personal.

Professor McLean: You did not actually mention in the example whether or not the lady in question had asked for assistance in dying.

Q27 Lord McColl of Dulwich: Yes, of course she had. That is not the point I am making. I am saying that there is a question of confidence among the general population.

Professor McLean: I appreciate that, but my point is that I am unclear why the young man in question, or the middle-aged man in question, would have been so concerned if in fact his mother asked the anaesthetist to do that and he understood that the anaesthetist

⁶ Note by witness: The view that the Oregon Death with Dignity Act can act as an “insurance policy” has been noted by commentators such as Dr Timothy Quill and Professor Margaret Battin.

⁷ Note by witness: Bascom and Tolle (2002), Goye *et al* (2003) and Dobscha *et al* (2004).

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only did that on the basis of a competent autonomous request.

Lord McColl of Dulwich: *But we are all human and the man was just very worried, and I am saying that there are a number of other people who might be worried under similar circumstances.*

Chairman: I think that we have managed to finish this session with everyone having had the opportunity they wished to ask questions. Thank you all very

much indeed for coming and giving us your evidence. As I said at the outset, a draft statement of what you have said will be circulated for you to get a chance to see whether they are as good as you thought they were, without of course altering the substance, only to correct anything that appears to be a mistake in the transcription. Thank you all very much and I look forward to receiving the account of the researches that you mentioned earlier into the attitudes of people in relation to the problems that we have faced in this Bill.

TUESDAY 14 SEPTEMBER 2004

Present	Arran, E	McColl of Dulwich, L
	Finlay of Llandaff, B	Patel, L
	Hayman, B	St Albans, Bp
	Joffe, L	Thomas of Walliswood, B
	Mackay of Clashfern, L	Turnberg, L
	(Chairman)	

Memorandum by the Centre of Medical Law and Ethics, King's College London

The issues raised by the Bill divide into those concerning fundamental moral principles and those about possible risks and dangers if the Bill is passed and how they compare to the possible risks and dangers of the status quo.

1. FUNDAMENTAL MORAL PRINCIPLES

Supporters and opponents of the Bill tend to appeal to different basic moral principles. Those who support the Bill usually give great emphasis to *Autonomy* and to *Preventing Avoidable Suffering*. Those who oppose the Bill usually give great emphasis to the *Sanctity of Life*. People on both sides appeal to *Respect for Dignity*. There are questions to ask about the principles invoked.

(a) *Autonomy*

This part of the case for the Bill is that it respects the autonomy of the terminally ill person. (This line of thought was encapsulated in the title of the play and film *Whose Life is it Anyway?*) This was part of the case for removing the legal prohibition against suicide, and the present Bill can be seen as an extension of this. People able to commit suicide are legally allowed to do so, and the Bill would extend the same control over their life and death to those not able to commit suicide without assistance.

Critics of the appeal to autonomy make the point that respecting someone's autonomy is most often a matter of not preventing them from doing something. For society to respect autonomy in matters of religion is to allow people to build churches, synagogues and mosques as they please and to allow them to practice their religion unimpeded. It does not require society or anyone else to assist them in worship or to provide them with facilities. On the other hand, providing facilities such as wheelchair access is often seen as required by respect for the autonomy of people with disabilities. There is controversy over the line to be drawn between what kinds of positive assistance are or are not required if someone's autonomy is to be respected.

(b) *Preventing Avoidable Suffering*

This part of the case for the Bill appeals to the humanitarian thought that, if someone is suffering, it is desirable to stop their suffering if it is possible to do so. Here "suffering" can mean physical pain or other, psychological, distress. Few would dissent from the principle as stated, but critics say that sometimes there are other, less drastic, ways of avoiding suffering. (How often this is so is a disputed issue of fact.) Critics also point out that the humanitarian thought has a suppressed "other things equal" clause. A lot depends on what means are needed to eliminate suffering, and what are the costs (not in any limited financial sense) of those means. The central disagreement is whether it is acceptable to end someone's suffering by ending their life. The humanitarian principle may come into direct conflict with the principle of the sanctity of life.

(c) *The Sanctity of Life*

The sanctity of life is not normally interpreted to mean that any life ought to be preserved at all costs. It is normally restricted to human life (though supporters of animal rights query this). And it is normally interpreted to prohibit absolutely the intentional killing of innocent human beings. ("Innocent" allows the possibility of killing, for instance, in a just war. Someone who is part of an army committing an unjustified act of aggression is not in this sense "innocent".) The phrase "intentional killing" allows for two other possibilities. Allowing someone to die is distinguished from killing. And some doses of pain relieving drugs

have the foreseen consequence of accelerating death, but if the intention is only to relieve pain, this is not intentional killing.

Critics of the sanctity of life say that “sanctity” suggests a religious prohibition and that in a society with a plurality of religious and non-religious views, particular religious prohibitions have no place in the law. Others question whether the distinction between killing and letting die is a clear one and whether it is a distinction that really has moral importance. Critics also claim that the contrast between consequences that are intended and those that are foreseen but unintended is a distinction without a difference.

(d) *Respect for Dignity*

Some of those who request assisted suicide do so less because they wish to avoid suffering than because they wish to avoid the indignities of incontinence and of other forms of loss of control.

Opponents of assisted suicide sometimes say that respect for human dignity requires absolute respect for innocent human life.

It is clear that different conceptions of what human dignity is are in play in the debate.

2. RISKS AND DANGERS

Supporters and opponents of assisted suicide also disagree about the relative risks and dangers of enacting the Bill as against the status quo.

Supporters cite the danger of the law being made to look an ass, or at least out of touch, when there is a wave of public sympathy for someone in a distressing state and yet the law does not allow their request to be helped to die. This may lead to doctors furtively doing things to get round the law, which may not enhance the standing either of the law or of the medical profession. It may lead people to go to other countries to obtain the assistance that is illegal here.

Opponents cite the danger of a slippery slope. Will legalizing assisted suicide or voluntary euthanasia lead on to legalizing euthanasia without the request of the person whose life it is? There is the memory that the Nazis murdered 70,000 psychiatric patients in the name of “euthanasia”. On the other hand, there is a question of how we tell which slopes really are slippery. (There are factual disputes about whether the experience of the Netherlands tells for or against the slippery slope argument.)

Opponents also cite the danger of medical professionals feeling obliged to act against their own religious and/or moral convictions. And they cite the dangers of people being pressured by family members to request assisted suicide. It is clear that family members could have motives for this: either financial motives or the desire to be rid of a burdensome relation. We will make some brief comments on whether the Bill contains adequate safeguards to meet these concerns and make some comments on the experience in other jurisdictions.

Supplementary memorandum by the Centre of Medical Law and Ethics, King’s College, London

CRITERIA BASED ON TYPE OF SUFFERING—AN OVERVIEW

<i>Type of Suffering</i>	<i>Bill</i>	<i>Netherlands¹</i>	<i>Belgium²</i>	<i>Oregon³</i>
	Cl. 2 (c), (d) patient must have a terminal illness and be “suffering unbearably as a result of that terminal illness”	s.2(1)(b) “attending physician . . . must have been satisfied that the patient’s suffering was unbearable, and that there was no prospect of improvement”	s 3 para 1 “patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident”	patient must be suffering from terminal disease (para 2.01); no additional suffering requirement
terminal illness	✓ Cl. 1 “inevitably progressive, the effects of which cannot be reversed by treatment . . . and which will be likely to result in the patient’s death within a few months at most.”	✓	✓	✓ para 1.01(12) “an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months”

somatic but non-terminal illness	no	✓	✓ there are additional requirements if the patient “is clearly not expected to die in the near future”: s 3 para 3 (second consultation with either psychiatrist or relevant specialist; waiting period of at least one month)	no
non-somatic suffering from psychiatric disorder	no	✓ <i>Chabor</i> ⁴ assisted suicide is almost always preferred over euthanasia in such cases; the conditions will not be satisfied if a meaningful treatment option exists, even if the patient has rejected it; there is some suggestion that two independent consulting physicians must be involved (with one a psychiatrist) ⁵	✓ there are additional requirements if the illness is not terminal: s 3 para 3 (second consultation with either psychiatrist or relevant specialist; waiting period of at least one month); there is some disagreement as to whether a psychiatric patient could meet the condition of voluntariness ⁶	no
existential suffering (non-somatic; no psychiatric disorder; “tired of life”)	no	no: <i>Sutorius</i> ⁷	no: s 3 para 1 requires a “serious and incurable disorder”	no

THE REQUEST

Competence

Belgium: the patient must be “legally competent” (s3 para 1).

Netherlands: the request must be “carefully considered” (s2(1)(a)). Commentators note that “the problem of competence of patients suffering from a somatic disorder has received relatively little attention.”⁸

Oregon: the patient must be capable, which is defined as having “the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient’s manner of communicating if those persons are available.” (para 1.01(3))

Bill: competent is defined as “having the capacity to make an informed decision” (Cl 1(2)) and will presumably rely on the new definition of capacity in the Mental Capacity Bill, June 2004, Cl 3. Concerns have been raised regarding the assessment of capacity in terminally ill patients.⁹ See below, discussion of longstanding or pre-existing physician-patient relationship as one factor in improving competence assessments.

Voluntariness

Belgium: the Belgian law states that the request must be both “completely voluntary” (s3 para 2(1)) and “not the result of any external pressure” (s3 para 1).

Netherlands: the Dutch law only requires that the request be voluntary (s2(1)(a)) but this has been interpreted by caselaw and the requirements of careful practice as meaning “not the result of undue external influence.”¹⁰

Oregon: the witnesses must attest that the patient is acting voluntarily and is not being coerced to sign the request (para 2.02). Concerns have been raised about the quality of voluntariness assessments in Oregon.¹¹

Bill: while the Bill requires that a request be made voluntarily (Cl. 2(2)(f)), there is no mention of pressure/influence—perhaps this would be superfluous? The mandatory palliative care consultation in the Bill (Cl. 3) may assist in ensuring that the patient is aware of all of his options. See also below, discussion of longstanding or pre-existing physician-patient relationship as one factor in improving voluntariness assessments.

Suffering

Netherlands: the “attending physician . . . must have been satisfied that the patient’s suffering was unbearable, and that there was no prospect of improvement” (s2(1)(b)). The attending physician must “have come to the conclusion, together with the patient, that there is no reasonable alternative in light of the patient’s situation” (s2(1)(d)).

Belgium: the patient must be “in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident” (s3 para 1).

Oregon: there is no additional “suffering” requirement beyond the requirement that the patient be suffering from a terminal illness.

Bill: Cl. 2 (c), (d) patient must have a terminal illness and be “suffering unbearably as a result of that terminal illness”. The Dutch jurisprudence has clearly established that in cases of somatic illness, the patient may reject alternative treatments and still be eligible for euthanasia, provided he is aware of the alternatives available. The Bill seems to envisage a similar situation (Cl. 2(3)(e), Cl. 3) but perhaps this could be made clearer? For example, terminal sedation might be offered to a patient who might reject it.

SAFEGUARDS

Longstanding or pre-existing physician-patient relationship

Netherlands: The Dutch caselaw and requirements of careful practice require a close doctor-patient relationship (where the doctor has treated the patient for some time) as the doctor must know the patient well enough to be able to assess whether his request is both voluntary and well-considered, and whether his suffering is unbearable and without prospect of improvement.¹²

Belgium: Adams and Nys suggest that the requirement of a longstanding or pre-existing physician-patient relationship could possibly be derived from s3 para 2(2) of the Belgian Act which requires that the physician has “several conversations with the patient spread out over a reasonable period of time” in order to be certain that the patient’s suffering is constant and that his request is a durable one. The Dutch argument (that in order to assess whether the requirements of the statute are met, the doctor must have some familiarity with the patient) might also be used. However, Adams and Nys note that the legislative history makes clear that the patient should be able to completely exclude his attending physician if so desired—from which one might infer that there is no requirement for a pre-existing physician-patient relationship.¹³

Oregon: the attending physician is defined as “the physician who has primary responsibility for the care of the patient and treatment of the patient’s terminal disease” (para 1.01(2)). The evidence suggests that many patients who sought PAS had to ask more than one physician before finding one who was willing to provide a prescription. Unfortunately the Oregon Dept of Human Services appears to have stopped collecting data on this point, as such data is only found in the first three (of six) annual reports. Over the first three years, only 41 per cent of patients received their prescription from the first physician asked.¹⁴ This suggests that in many cases there will have been no longstanding or pre-existing physician-patient relationship.¹⁵ The median duration of the physician-patient relationship in Oregon over the six years of operation is 13 weeks. The range is between 0 and 851 weeks.¹⁶ Commentators opposed to the Oregon law have raised the possibility that a patient refused PAS by one physician on the grounds of failing to meet one of the statutory criteria may simply seek the prescription from another physician.¹⁷

Bill: the attending physician is defined as “the physician who has primary responsibility for the care of the patient and treatment of the patient’s illness”. Both the Oregon and Bill definitions (which are almost identical) would seem to allow for the possibility that there is no longstanding or pre-existing relationship between the physician and patient. Requiring such a relationship might improve the quality of the competence¹⁸ and voluntariness¹⁹ assessments, which are notoriously difficult to make.

Psychiatric Referral

Netherlands: Dutch guidelines (Dutch Association for Psychiatry) require psychiatric consultation if the attending physician suspects the patient is incompetent “or suffering from psychiatric (co)morbidity.”²⁰ The Dutch also use psychiatric consultation to check regarding transference and counter-transference issues,²¹ and to check voluntariness and whether there has been undue pressure from others.²² However, one Dutch researcher has concluded that the “benefits of [mandatory psychiatric] consultation should be balanced against the disadvantages of pushing the psychiatrist to the fore as the final gatekeeper.”²³

Belgium: if the patient’s illness is not terminal, then a second consulting physician’s opinion must be obtained. This second consulting physician can be either a psychiatrist or a relevant specialist (s3 para 3).

Oregon: a counselling referral must be made if the attending or consulting physician suspect that the patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment. PAS is not available unless the counsellor determines that the patient is not suffering from a psychiatric or

psychological disorder or depression causing impaired judgment (para 3.03). The Guidebook recommends that all requesting patients be referred for counselling.²⁴

Bill: only requires a psychiatric referral if the patient “may not be competent” (Clause 8(1)). A psychiatrist must determine that the patient “is not suffering from a psychiatric or psychological disorder causing impaired judgement, and that the patient is competent” (Clause 8(2)). Perhaps psychiatric referral should be triggered by suspicion either that patient “may not be competent” or that the patient is “suffering from a psychiatric or psychological disorder causing impaired judgement”. Voluntariness, undue pressure and transference/counter-transference could also be considered during a psychiatric referral, and suspicions about these could trigger such a referral.

Discussion with nursing team

Belgium: s3 para 2(4) requires discussion of the patient’s request with nursing team that has regular contact with the patient (if one exists).

Netherlands: Dutch requirements of careful practice impose a similar requirement.²⁵

Bill: contains no such requirement—would such a requirement simply be in line with good medical practice?

Role of next of kin

Oregon: para 3.05 requires the attending physician to recommend to the patient that he notify his next of kin of his request. “A patient who declines or is unable to notify next of kin shall not have his or her request denied for that reason.”

Belgium: s3 para 2(5) requires that the doctor discuss the request with relatives designated by the patient (if the patient so wishes).

Netherlands: Dutch requirements of careful practice impose a similar requirement “unless the patient does not want this or there are other good reasons for not doing so”.²⁶

Bill: Cl. 9 requires the attending physician to recommend to the patient that he notify his next of kin of his request (following the Oregon model). Should the doctor be required to discuss the request with relatives if the patient wishes? Should there be an explicit statement in the Bill that declining to notify next of kin will not affect the request?

Waiting period

Netherlands: there is no waiting period.

Belgium: there is a waiting period of one month only in cases when the patient is “clearly not expected to die in the near future” (s3 para 3(2)).

Oregon: oral and written requests must be made, the oral request must be reiterated no less than 15 days after the initial oral request (para 3.06).

Bill: 14 days (Cl. 1(2)). There is a difficult balance to be struck between allowing sufficient time to undertake competence and voluntariness assessments (which are preferably done over a period of time)²⁷ and possibly a psychiatric referral, and ensuring that the option of assisted death is a meaningful one (that is, that the waiting period does not in effect disentitle patients who are near the end of their lives). If the waiting period is longer, there may be an incentive for patients to request assisted death earlier in their illness, for fear of “running out of time.”

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- ¹⁰ Griffiths et al, *Euthanasia and Law in the Netherlands* (1998) 100 and n30.
- ¹¹ Martyn et al, “Now is the Moment to Reflect: Two Years of Experience with Oregon’s Physician-Assisted Suicide Law” (2000) 8 Elder L J 1 at 23–30.
- ¹² Griffiths et al, *Euthanasia and Law in the Netherlands* (1998) 103 and n41; Netherlands Ministry of Foreign Affairs, *A Guide to the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act* (2001) para 15.
- ¹³ Adams and Nys, “Comparative Reflections on the Belgian Euthanasia Act 2002” (2003) 11 Med L Rev 353 at 359.
- ¹⁴ Oregon Dept. of Human Services, *Oregon’s Death with Dignity Act: Three Years of Legalized Physician-Assisted Suicide*, 2001, Table 3.
- ¹⁵ See Ganzini et al, “Physicians’ Experiences with the Oregon Death with Dignity Act” (2000) 342:8 NEJM 557 at 559-561 (27 per cent of respondent physicians had known the patient for less than one month at the time of the request).
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Examination of Witnesses

Witnesses: PROFESSOR JONATHAN GLOVER, PROFESSOR IRENE HIGGINSON and Ms PENNEY LEWIS, examined.

Q28 Chairman: Good afternoon, we would like to extend a welcome to our witnesses for today. Professor Glover, you will be in charge of the distribution as it were, and we have about an hour and a half to devote to the hearing of the evidence you would like to put before us. The evidence is taken down and you will get an opportunity of considering whether any typographical corrections and so on are required. We would invite you to arrange for a short statement, either from one or from each of you, as you see fit, and then the Committee would wish to ask you some questions. It is possible that during the time we are hearing evidence there may be a call for a division in the House; in which case you will understand if we suspend the sitting for a time sufficiently long to enable to members who wish to do so to vote and to return. Would you like to make your introductions?

Professor Glover: Thank you. I am Jonathan Glover, I teach ethics at the Centre of Medical Law and Ethics at King's College. My background is in philosophy, in particular moral philosophy. This is Irene Higginson, who is a physician who specialises in epidemiology and especially palliative care, who has worked in St Joseph's Hospice in Hackney and is now Professor of Palliative Care and Policy at King's College. This is Penney Lewis, who teaches medical law at the Centre of Medical Law and Ethics at King's College. She has done a wide range of research in a number of areas of medical law, but one of her particular specialities is end-of-life issues, and she has spent some time in France looking at the legal position there. I am going to start by saying that the Centre of Medical Law and Ethics as such has no view. You have heard from, no doubt, Pro-Life groups, the Voluntary Euthanasia Society and so on; we as a Centre have no view, but that is not to say that as individuals we do not have views, but we are not here representing a particular viewpoint. Our aim is to try to contribute to clarifying the underlying moral issues, but also some of the practical issues that arise in this debate. We are going to present in three parts: I am going to talk a bit about some of the underlying moral questions that are at stake on both sides of the debate, and some of the practical issues that arise in their implementation. Irene is going to link my abstract principles with the real world of medical practice—she is going to be discussing such issues as what we do and do not know about the stability of the preferences of people who maybe come within the scope of this Bill, and she is also going to discuss something about how widely available palliative care actually is. After that, Penney is going to look at different jurisdictions and what lessons we can learn from different approaches taken elsewhere to these matters, but also she is going to raise the question of

how adequate the safeguards in the Bill are and make some comments on that, safeguards against some of the possible abuses. I will start, if I may, with, some of the fundamental principles. I want to suggest that the debate on this Bill, and the debate on assisted suicide and voluntary euthanasia generally, always seems to me to take place at two rather different levels. At the one level there are really quite deep clashes—the fundamental world view, fundamental moral principles, which really people deeply disagree about, sometimes because of differences of religion, sometimes for other reasons. Then there are also practical debates about how can we really know what a person wants, how can we be sure that it is a deeply-rooted preference: Is there not a danger of a slippery slope towards things which we would not like to see? There are questions about whether there are dangers of family pressures being put on people to ask for assisted dying, and what we can do about that? I want to start by talking about some of the underlying moral principles at a deep level of the debate. As I understand it, the arguments for the Bill really centre around two types of claim: one is the claim about the value of autonomy—the value that was brought out very clearly in that play and film *Whose Life is it Anyway?* Should the person in question have autonomy over decisions about life and death? And, second, the appeal to what one might call the humanitarian principle, the principle that when other things are equal it is desirable to prevent avoidable suffering if you can. The central argument against the Bill at the level of moral principle does seem to me to be the sanctity of life, sometimes defended on religious grounds but also sometimes supported for quite secular reasons. Then there is another principle that comes into the debate which, interestingly, is appealed to by both sides, and that is respect for the individual, respect for the individual's dignity. I will not say much about that, I will simply say here, as an aside, that I think it is fairly clear that there are two rather different perceptions of dignity which are in play in the debate. On the one hand, there are the people who use dignity as an argument for the Bill and have in mind the indignities of incontinence and other forms of loss of control, and say that it is desirable that, if people want to be spared those indignities, they should be so spared. On the other hand, the principle of people's dignity is also sometimes invoked on the other side, where people say that you cannot have the proper amount of respect for human dignity unless you have absolute respect for the principle of the sanctity of the individual human person's life. I am going to talk a little bit about autonomy and a little bit about the humanitarian principle, and then talk a bit about the principle of the sanctity of life. The argument from

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autonomy in favour of passing this Bill, or one like it, is really a concern related to the fact that in the 1961 Suicide Act we removed the legal prohibition against committing suicide. That was done for a number of reasons, but one of them was the idea that, whether we think suicide is morally somebody's right or whether we think it is morally unacceptable, people ought to be able to decide that sort of thing for themselves. Supporters of the Bill very often appeal to the idea that the Bill is an extension of that, giving people the right to decide for themselves about their own death, and as an extension of that to people who are not able in practice to kill themselves. This raises a number of issues. One is that there is a question of what respect for someone's autonomy requires. People who favour the Bill say that it requires assisted suicide if the person requests it and is not able to carry out suicide himself or herself. But other people say that respecting someone's autonomy does not necessarily have to involve providing positive help. For instance, I may respect other people's religious autonomy, and that simply means that I do not obstruct them, I do not harass them, I do not try and interfere or prevent them practising their freedom of worship; I am not obliged to build churches, mosques or synagogues in order to respect their autonomy. So there is a difference between respecting autonomy requiring not interfering with what someone does and providing positive assistance. That is one part of the debate. There is also an absolutely key practical issue about interpreting autonomy, and that is that there is obviously a question about the genuineness of the request. This raises a number of issues: one is how do we decide whether or not a person is making a competent decision—something Penney will talk a bit about later; another is whether there is freedom from external pressures by other family members. It is not clear at all if someone's request to die counts as an autonomous request if they are doing so under that kind of pressure. Then there is the issue that we all know people's moods change enormously—people get depressed and think quite differently about their lives from how they think at other times. How do we know that this is a stable request, because respecting autonomy seems to require not just acting on any whim that someone may have at any moment, but being sure that this reflects what they most deeply think when they are reflective. And that is something which Irene will be talking about—how we can know about the stability or otherwise of their desires, how we do know about that. I now turn to the second principle used in favour of the Bill, the humanitarian principle that we should prevent avoidable suffering where we are able to do so. I have a couple of points to make about this. One is that suffering, of course, does not have to be just physical pain, but clearly

psychological distress, for instance of suffering indignity or not having your autonomy respected. One issue is— are there less drastic alternatives? We all know that there are great disputes of fact at stake here about whether, for instance, palliative care is sufficiently adequately available, whether it is always possible to eliminate pain. Sometimes people on one side of the case say euthanasia is never necessary because good medical practice will always eliminate pain. That is a disputed claim and one which I as a philosopher have rather little, I am afraid, to say about, but Irene is going to talk a bit about that. As I see it, the main issue at stake here is that the two principles I have mentioned, autonomy and respect for autonomy and the humanitarian principle, the prevention of avoidable suffering, may well come into conflict with the principle of the sanctity of life, so it is to that that I now turn, the central principle on the other side of the debate. Firstly, there is a question of interpretation. I interpret the sanctity of human life, as I think most people who believe in it do, as suggesting that there is an absolute prohibition on the intentional killing of innocent human beings. I have worded that rather carefully because it is not just a prohibition on killing; the word “innocent” for instance allows the possibility of defending the killing of people in a just war, because people who are part of a threat in a war no longer count as innocent. They may be morally innocent, it may not be their fault they are fighting on the wrong side, but innocent is used in a slightly technical sense here. Then, again, intentional killing is the thrust if we are allowing someone to die, and the cases which come under the moral theology principle known as the “doctrine of double effect” being those cases where death can be the foreseen but unintended outcome of, for instance, stepping up doses of medicine intended to relieve pain. Some issues about the sanctity of life principle. One issue is that the phrase “sanctity of life” suggests a religious prohibition and one criticism has been that it is hard to see how something which is purely a religious prohibition could be an adequate justification for law in a pluralist society, where people have many different religions and some have none. I do not believe that only religious people support the doctrine of sanctity of life: I think there is a secular version too. Another set of criticisms are of the moral relevance of the distinction between killing and letting die and of the distinction between unintended and foreseen consequences. The second one is sometimes described by its opponents as a distinction without a difference. I would just mention some of the risks and dangers, and in doing so, of course, one has to compare risks and dangers on both sides. There may be risks and dangers in passing the Bill, there may also be risks and dangers in the status quo. I will start with the risks and dangers of the

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status quo and then go on to the risks and dangers of allowing assisted dying. One of the risks and dangers of the status quo is that the law may get out of touch with public opinion. When there is a particularly distressing case which might reinforce it, there may be a wave of sympathy for the person and a widespread sense of indignation that the law does not allow the person to exercise his or her desire to die. Then, again, there is a danger that doctors may secretly be assisting suicide behind the scenes, without it being legalised, and there may be all sorts of dangers in that; danger and risks to the people concerned because there may not be adequate safeguards, and there may also be the risk of bringing the law into dispute; I cannot also think that it is necessarily in the interests of the medical profession to have to act furtively in that sort of manner. Then, again, there may be people who go abroad—a recent case comes to mind—for assisted suicide, not available here. One wonders whether that could really be a rational defence of the state of affairs. I think the biggest risk of danger, looking at it on the side of the status quo, is that people in favour of the Bill say that it is more than a risk, it is an actuality—that people have their autonomy overridden and sometimes die in indignity and distress which could have been avoided if the Bill had been passed. On the other hand, the risks and dangers of allowing assisted dying. One question is—are there adequate conscience safeguards to prevent the medical profession from being pressured into acting against their conscience? And are there adequate safeguards to prevent requests resulting from family pressure? I have to say that in my reading of the Bill I got the impression that the Bill was rather stronger on protecting the medical profession from doctors having to act against their conscience than it was on the family thing. But I am not the expert on that: the other two speakers on my either side you should listen to rather than me about that. Another issue is the slippery slope argument. Any debate on euthanasia has to be a little bit at least in the shadow of the terrible fact that the Nazis murdered 70,000 psychiatric patients in the name of what they called euthanasia. But, of course, what they were practising was not voluntary euthanasia: they were not motivated by compassion for the individual people concerned, they were not motivated by a desire to respect the autonomy of individual people, they were trying to tidy up the gene pool in a way that most of us would find revolting. There is the question, if we allow this Bill—is there a slippery slope that might lead us in that direction? My belief is that it is very difficult to evaluate slippery-slope arguments. We all know that there are some slippery slopes that, as individuals, we do fall down and others we do not—it is possible to have a glass of wine without going all

the way down the slope to being an alcoholic. It seems to be a very difficult empirical question where one needs evidence before one too readily says either there is or is not a serious danger of going down a slippery slope. I think I have talked too long; I will stop there and hand over to Irene.

Professor Higginson: Good afternoon. My evidence takes a somewhat different tack in that I am looking at some of the evidence in terms of research and in terms of what we know in two fields, really: the first is understanding the trajectory of desire for death or wish for euthanasia or, conversely, the will to live; the second area of evidence I want to look at is that of access to palliative care services. Our understanding of what people want towards the end of life, or the wishes of those who are suffering a terminal illness, from reasonable research studies or from any kind of systematic selection of data is extremely poor indeed in most countries, and it seems that it would be important to recognise that the views of people who are actually at the end of life may be different to the views of people at earlier stages of their illness. We know from the Disability debate that it is not possible to project views; so I, as a healthy , now might say what I want when I reach a terminal illness, but by the time I reach a terminal illness my view may actually be quite different. That change in perception—which is known as a Response Shift, when people recalibrate and reframe what is important to them—is not well understood, but it seems to me that we should be looking where we can at the evidence from people who are actually reaching the end of life in trying to make those decisions. In Canada Chochinov and a group of colleagues have done some work interviewing people with advanced illness about their will to live and also about desire for death and euthanasia. In particular, in one study, by Tarbalan and Chochinov, they interviewed 168 patients with cancer who were admitted to a terminal care unit, and they asked about will to live measured using a simple self-report scale, which they measured every day. During the period of time in the palliative care unit in Canada, just over half the patients, that is 58 per cent, displayed a high will to live over the time of care, including during their illness progression. A further 11 per cent sustained a fairly unchanged moderate will to live. However, for just over a quarter of people (28 per cent) the will to live fluctuated over time, it was not stable, and it increased for some and reduced for others. A minority of patients (around 3 per cent) sustained fairly constantly a low will to live. While it is not clear from this study to what extent a moderate or low will to live translated into a wish for assisted dying under the terms of this Bill, the study does certainly suggest that a wish to die or a lack of will to live, and therefore any request to do so, is likely to fluctuate

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over time in most people who may make such a request. Understanding what influences this wish to die is also quite complicated. Studies, primarily from the States and from some other countries, suggest that will to live or, conversely, the move towards life-terminating measures, is influenced by a whole host of factors. But ones that have been highlighted in particular include depression, pain, feeling a burden to others, loss of a sense of purpose, loss of meaning or hope, and loss of dignity. Some of these concepts are really quite poorly understood, although in some countries—in particular, the work of Chochinov—people are trying to develop interventions to improve, for example, a feeling of hope or ways to improve feelings of dignity. Similarly, the concept referred to in this Bill as “unbearable suffering” has not yet been clearly defined in the literature. It is not something that is easy to measure and it is really open to quite wide and varied interpretation. It too, like will to live, may be prone to fluctuations over time. However, the studies that I have quoted you are small in number. The Chochinov work is from a single unit in Winnipeg in Canada which includes fairly highly selected people who were entering the palliative care service at the time of the study and therefore were fully aware of their diagnosis and may also have been well aware of their prognosis and so would be a selected group of people. We do not know what would be found if a study of this kind were replicated in this country. Indeed, research in the UK into ways to understand patients’ wishes about, or to find ways to improve, care at the end of life has been relatively neglected. Analysis by the National Cancer Research Institute, which has recently been established in this country, shows that in the UK, of all the research money spent on cancer research by the main research organisations—which would include Cancer Research UK, Macmillan Cancer Relief, Marie Curie Cancer Care, the Medical Research Council, the Department of Health and a number of other smaller charities—0.18 per cent of it was spent on end-of-life and palliative care issues. So a very significant minority of work that goes on in research in the medical field is not directed towards the field of palliative care. One of the issues is that this dearth of knowledge and the absence of support for research into understanding what people want towards the end of life, how this changes and ways to improve care, need to be addressed. The second area I wanted to highlight is the variation in access to care. There is a fairly wide variation in the UK in the dissemination and availability of and access to palliative care services. There are certain under-privileged communities which have lower access to palliative care services, and in particular these include those who are living in rural areas, those from ethnic minorities and those in the older age group, who all

have a lower chance of receiving expert palliative care and pain relief. Work that we have done in the south London area has shown a mixed experience in advanced cancer, for example, among the local black Caribbean community; and reports from family and friends of people from the black Caribbean community revealed quite a mixed experience, but fairly significant unmet need, with poorer access to specialist palliative care services, a trend towards a greater number of unmet needs and also reports of less satisfactory care across a range of different measures when their reports were compared to a local white UK-born population. The second point to consider is that much of the palliative care available, particularly that in in-patient hospices, is concentrated on patients who have cancer. Although a few patients with Motor Neurone Disease and far-advanced AIDS have received hospice care, in general few patients with non-malignant conditions receive in-patient hospice and in some instances home palliative care. For example, analysis in the UK has shown that less than 5 per cent of new referrals to many in-patient and community palliative care services have conditions other than cancer. It is slightly different for some hospital palliative care services, but then that only addresses care whilst patients are in hospital. I have provided to the Clerk to the Committee some figures which demonstrate the disparity in services and systems experienced within the London region.

Ms Lewis: Good afternoon. Given the time, I am just going to briefly outline some areas in which the experience of other jurisdictions which have already legalised either euthanasia and assisted suicide or assisted dying might be of assistance, and then I think I will leave it to members of the Committee to pick me up on those areas later. There are two ways in which we derive assistance from the experience of other jurisdictions. The jurisdictions that I am most familiar with are The Netherlands—which, I am sure you will know, has recently codified the existing legal situation, so there has not been a really dramatic change in the law as a result of their legislation (there were many years of case law and prosecutorial practices which had effectively legalised euthanasia for some time); Belgium, which I think can be contrasted with The Netherlands because they have recently legalised euthanasia without having any kind of experience of effective legalisation through judicial decisions; and finally Oregon, which has an even more unusual experience, I suppose, in the sense that they legalised assisted suicide through a referendum seven years ago. There are two ways in which we can use this experience. One is to look at ways in which euthanasia and assisted suicide are regulated in those jurisdictions and how those regulatory frameworks develop, and then we can

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maybe look at the regulatory framework proposed in the Bill and see if we can learn anything from other such frameworks and how they developed. The second way is to look at the evidence that exists in those jurisdictions, and possibly other jurisdictions, about the effectiveness of the regulation that is in place, in particular in The Netherlands (because they have the most data, but there is also quite a lot of data from Oregon as well), in terms of how effective their regulation has been and who, for example, is using the provisions of their statute. There are four aspects which might warrant the scrutiny of this Committee. The first is the kind of criteria that one might choose for accessing assistance with dying. Generally one thinks of criteria—and these are the criteria that appear in the Bill—relating to suffering and to possibly some kind of terminal disease. Interestingly, we might compare the position in Oregon and the position in the Bill—which both require there to be a terminal disease—with the situation in The Netherlands and Belgium, neither of which require there to be a terminal disease. So these criteria are not necessarily the only ones one might contemplate. The second aspect relates to regulation of the request for assistance, so issues around the competence of the patient, the voluntariness of the request, what kind of information is being provided to the patient before the request is acted upon, etc. The third aspect is one which Jonathan already referred to, which is in relation to the safeguards that might be put in place. I think in particular what I would really like to highlight—and I am happy to talk about this later—is something which is very important when considering The Netherlands's experience, which is the nature of the physician/patient relationship. I think there is a danger in thinking about The Netherlands without realising that the nature of the physician/patient relationship in The Netherlands is very different, for example, from that in Oregon. Most acts of euthanasia in The Netherlands are carried out by general practitioners who have known their patients for many, many years, and the reason why this is significant is because issues like competence and voluntariness are very difficult to assess on the basis of one meeting. If there is an existing and long-standing relationship between the patient and the doctor, I think that that does change the dynamic of evaluating whether or not this is a competent and/or voluntary request. If you look at the data from Oregon you will see that often there is a very, very short-term relationship between physician and patient. Other safeguards which I think are worth considering and maybe learning from how other jurisdictions have regulated them are: consultation with another physician, psychiatric consultation and psychiatric referral and when that should take place—should it be mandatory in all

cases? Or should it just be triggered in certain cases? And, if so, what should be the triggering circumstances? Also what should the psychiatric referral be doing? What should it be looking for? Is it a competence assessment or is it looking for something more? Is it trying to diagnose depression etc? What role should the next of kin have? The Bill adopts the Oregon model of saying that the doctor should recommend to the patient that the next of kin be told. The Netherlands and Belgium have adopted a model where the doctor is obliged, if the patient wants, to discuss with the next of kin the situation. Also, what role should the nursing staff have and also other healthcare professionals who may be involved, particularly in terms of multidisciplinary palliative care teams? The final safeguard that, I think, is worth looking at is that of a waiting period: how long should it be? What are the advantages and disadvantages of having a longer waiting period or a shorter waiting period? Or, indeed, as in The Netherlands, no waiting period at all? Finally, and this goes back to something Jonathan alluded to as well, what does the evidence from other jurisdictions tell us about how malleable these criteria are and how effective these kind of safeguards are? In particular, I think it is worth looking at the debate around the evidence which relates to the slippery slope. How is the evidence in The Netherlands interpreted? How does it compare with evidence from other jurisdictions, both jurisdictions which have legalised euthanasia and jurisdictions which have not? What kind of comparisons can we make? What kind of evidence is there of a causal link between evidence of non-voluntary euthanasia and legalisation, for example? Those are the four aspects which I think might warrant scrutiny, and I am happy to deal with them.

Chairman: Thank you very much. It is now open to members of the Committee. Lord Turnberg, would you begin?

Q29 Lord Turnberg: Thank you very much, I found that extremely valuable and helpful. I was very interested in Professor Higginson's report of the Canadian study of patients who were in this end-of-life state who were suffering from cancer, the vast majority of whom were not particularly interested in assisted suicide, but there were some who might have been if that had been on offer. It is important to have the views of patients who are likely to be in this position, and you pointed to large groups of individuals. But in Oregon and in The Netherlands they have had a lot of experience. Have there been any studies of this type?

Professor Higginson: Not that I am aware of. I have looked in Oregon and The Netherlands and we do see evidence of people who take up the request,

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obviously, for euthanasia and then do or do not use it, but how that relates to whether people have thought about it or the will to live or depression or changes in views over time, I am not aware of studies that have looked at that.

Q30 Lord Patel: Can I pursue that study a bit further? I accept what you say about it being a small study of 168, but did I understand you correctly to say that, of those 168, 3 per cent had shown a consistent will not to live?

Professor Higginson: Yes, that is correct. Of that group, which was a group of people entering the hospice, 3 per cent had a consistent view, which really did not fluctuate very much, of a will not to live. As I said, that was reported as a low will to live on the scale that they used, but that is as much as you can take from that. You do not know whether that would have translated or not into a wish for euthanasia, but that group reported a low will to live.

Q31 Lord Patel: Then there were 25 per cent?

Professor Higginson: 28 per cent of people fluctuated; some increased and became more interested in living and some people reduced and some people moved back and to.

Q32 Lord Patel: Was there further stratification or further information on these two groups as to whether they were different kinds of patients in any way?

Professor Higginson: If you read the papers, they did attempt to look at factors which made people more or less likely to change their mind, in the fluctuating group in particular. And factors which Chochinov developed from that that seemed to make people change their mind or fluctuate were related to elements such as depression, feeling a burden or not to others, feeling that their life was uninteresting or hopeless or not and, to some extent, pain, although pain was not a huge feature in his study. When Chochinov has talked informally about his work in presentations and so on, which is not written in papers and is hypothesised, is whether some of the issues in the small percentage who remained unchanged are not so much related to external views but issues of a wish to feel in control. He has put forward that hypothesis, but it is only a hypothesis and it was not measured as far as I can see.

Q33 Lord Patel: It was not that with these patients the palliative care, the symptom relief care, was failing?

Professor Higginson: It is difficult to judge from the data he has presented. There certainly was some fluctuation in relation to depression and in relation to feeling a burden on others. He did not have a measure

of failing, so I am not sure whether your question could be answered.

Q34 Lord Patel: I pursue this, because one of the things that comes out in several of the submissions of evidence that we have had is the need to have good quality palliative care and that, if we had, then the number of people seeking such recourse to voluntary euthanasia would diminish.

Professor Higginson: There is evidence of that from the Oregon experience, and the experience in Oregon of the legalised position of assisted suicide shows that nearly half the people requesting it changed their mind after substantive palliative care interventions had been provided. That you can see in papers from the Oregon experience.

Q35 Lord Patel: Half did not change their mind?

Professor Higginson: Half did and half did not, so there is some change, yes. There is evidence in other literature that there is some change.

Q36 Lord Joffe: You mentioned this research in Canada and you, of, are familiar with the research in Oregon and, presumably, with Professor Ganzini's, which suggests that people who continue with the wish for assistance to die tend to be powerful people, people who are used to controlling their lives, and once they make up their mind they continue with that course; and they are different perhaps from the rest of the population who express a mild wish to die but they do not actually carry on with the request.

Professor Higginson: There is not really comparable work of that kind in this country, and the study you are quoting is not one I have before me. But it would be consistent with the findings from the Chochinov work. Studies of that kind are not available in this country, are they?

Q37 Lord Joffe: You mean in relation to this population?

Professor Higginson: Yes.

Q38 Lord Joffe: In all the authorities and all the papers I have seen on both sides there is extensive reference to what happens in other parts of the world, in Oregon and in The Netherlands, and presumably that is so because it is thought to be relevant to what will be the likely position over here, although obviously there can be differences of culture. Would you agree with that?

Professor Higginson: I never like to agree with a really long sentence.

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Q39 Lord Joffe: I will pose it more simply. Would you agree that the evidence of what happens with assisted dying in Oregon and The Netherlands is relevant to this Bill?

Professor Higginson: I think evidence anywhere across the world is relevant to this Bill, and I point to the fact that there is a lack of evidence in many countries. Translating from the United States to the UK brings with it some challenges: the organisation of healthcare is different, the population in Oregon is different from the UK population in terms of its educational level, its knowledge and so on, from what I understand. So there are issues and dangers always when you extrapolate from one healthcare system or one country to another, which was exactly the reason why I placed some caution on quoting from the Chochinov study, and I would place the same caution on quoting the work of Oregon and The Netherlands or wherever.

Q40 Lord Joffe: Even within a country there can be difference of views and different interpretations, would you agree?

Professor Higginson: Yes.

Q41 Baroness Finlay of Llandaff: My questions are really for Professor Glover, and possibly a bit for the other two presenters. When you were talking about autonomy and sanctity of life and respect for dignity, you spoke about the sanctity of life and fear of the physical. But you did not talk about issues around self-worth and your perceptions of self-worth and dignity coming from the way that you are behaved towards and treated, and I wonder if you had any comment on Kissane's work on demoralisation and demoralisation syndrome that occurs with people, depending on how they are treated by those who are providing care for them and around them?

Professor Glover: I have not read that work, but I can well believe that how people think of themselves and value their lives is highly likely to be influenced by how they are treated, yes, I would accept that.

Q42 Baroness Finlay of Llandaff: The other thing that came out in the paper you presented, and I think you alluded to, was this concept which—you did not use the term “double effect” but I think it has been termed “double effect”—about unforeseen consequences and the argument that there may not be a great difference. I just wanted to pursue that a little bit in terms of how often and how much evidence we have that that double effect, in the setting where somebody is dying of their disease, does actually occur, and whether that is different to the predictable but unwanted effects that you may see, for example, in someone with end-stage renal failure with an infection, where you will give them an

antibiotic which is known to be toxic; you know that that is a risk, you hope that they will not go into end-stage renal failure because they have an infection, but some do and some will die. Do you feel philosophically and morally that there is a difference between that and the perceptions of using analgesics that you allude to in your presentation? Some might say that the misuse of analgesics is the thing that will result in life-shortening, but the evidence is that actually, when those drugs are used well, they may even be life-prolonging.

Professor Glover: My comments were not really comments of fact about what the situation is or what the actual consequences of one medical policy or another are, because I am not an expert on that and I think you should ask Professor Higginson if that is what you want to know. My comments were really about whether the intent to reduce suffering, with the foreseen consequence that someone will die, is a principle that is morally acceptable, whereas it is not acceptable to intend to put someone out of suffering by means of death. I was really just reflecting the debate in ethics about this: some people think that that is a really important distinction, some people think it is not. I was really raising the question—is that really an important distinction, and if so why? I believe that part of the deep malaise of this debate is that people tend to divide into people who focus centrally on the consequences for the patient and say what really matters is—is the patient suffering? Is the patient alive or dead? people who might be called consequentialists; and the people on the other side, who say what really matters is what we do and what we intend to do, people who might be called deontologists. My belief is that one reason why these debates are so extraordinarily difficult, and perhaps one reason why they are often so passionate, is that actually most of us have some consequentialist inclinations and some deontological inclinations. Most of us both want best outcome for the patient and think that ought to be central, but also think it matters what sort of intentional actions we commit, and there is a tension between those two. I am sorry, I am not able to answer your factual questions about what actually happens; as I said, Professor Higginson is better qualified than I am.

Q43 Baroness Finlay of Llandaff: Could I just pursue this a little further because you did not address issues of scope in terms of the effect of a decision on others, either on the rest of the family—particularly children in a family as relatives—or the impact of having what we might term an arbitrary barrier of an 18 year old, 18 years being the age limit as defined within the Bill, when we have got strong evidence coming from the medical literature that teenagers can actually be particularly difficult to achieve symptom control in,

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and that may be the physiology of the teenage changing state.

Professor Glover: Yes. You raise two separate issues really. One is the effect of allowing or not allowing assisted dying on other members of the family, and again that is a factual question which feel I am the least qualified to answer. I assume that there are likely to be effects, either from having the knowledge that your parent, say, is slowly dying in agony and wishes that he or she was not, wishes to be dead and has that view overridden; or, alternatively, knowledge that someone has decided, in the family perhaps or the doctors, that it is acceptable to kill them. I can imagine either of those might have a traumatic effect on a child, for instance, but not being aware of the relevant psychological research I am not sure which of those is likely to be greater. The thing on the age thing—and I am very interested in what you say that there may be differences in control of symptoms, for instance, in teenagers—I would have thought that that is highly relevant. My own belief is that I am always slightly inclined to think that these lines that are drawn, say at 18 or wherever, seem to be a bit like the speed limit. There is no magic moment when you become an adult who is rationally competent to vote: we all know of some young teenagers who are much brighter at talking about politics than some people who are my contemporaries, and I am in my 60s. What we are trying to do is to ask, as it were, roughly where should the line be drawn, and for legal purposes it has to be sharp, so one takes an age limit. But I actually do agree that it may not always be exactly right in the individual case.

Q44 Baroness Finlay of Llandaff: Might I ask Professor Higginson, do you know of any research that has been done into the effects on families?

Professor Higginson: I am sorry, unfortunately I cannot think of anything at the moment, but there may be some I do not know.

Q45 Lord McColl of Dulwich: Could I stay on the same theme about the question of relieving suffering by giving increasing doses of sedative? That was the situation in the old days, but it is not the situation now. So, when you talk about unintended but foreseen things going on, that was the situation 20, 30, 40 years ago, when in fact you only gave them morphine when they had the pain. There have been great advances in palliative care, and Dame Cicely Saunders found that, if you gave them a steady dose and kept the blood level up at an appropriate level, kept them out of pain, they required less and they were much more wide awake. I speak with some experience because I was associated with setting up the first hospice for people of dying of AIDS in

Europe, in fact, so I am not unfamiliar with the subject. The fascinating thing was that, when a patient comes into the hospice, you may take a day or so to sort out what doses they need of the various drugs. But, when you have settled on a dose, by and large it tends to stay at that dose until they die. So this question of some doctors being described as hypocrites, because they are relieving pain but they know very well that they are going to kill the patient, does not obtain.

Professor Glover: I am glad to hear it. What happens to people who are kept on the stable dose and are still dissatisfied with being alive and request to die? What happens to them?

Q46 Lord McColl of Dulwich: Your colleagues will probably be in a better position to answer, but I am amazed how many people who do ask for euthanasia, once their symptoms are relieved, no longer do. I am also fascinated by the fact that some of those who ask for euthanasia—I remember one particular man coming into the hospice and he said “I want to die”—he had cancer in his bones—and they said “I am sorry, we do not do that.” He asked the next day and the doctor suddenly remembered that his serum calcium—the level of calcium in his blood—was kept down to a safe level by him taking tablets. The doctor said “If you stop taking the tablets, you will be dead in 24 hours”. He never stopped taking the tablets until he died.

Professor Glover: I think that brings out very interestingly this point that there is a real question about how genuine, how deeply felt the euthanasia request is. I think one of the problems is that anecdotes like that influence us very powerfully. There may be many cases like that; there may also be some cases on the other side of the debate—Mrs Pretty’s case for instance—which influence people very powerfully too. Much of the difficulty of this debate is that one needs to bring the advocates on both sides into connection with each other and see, as it were, if there is any way of doing justice to the response we have to these kinds of individual cases.

Q47 Bishop of St Albans: I am very grateful, Professor Glover, for your fundamental moral principles. It seemed to me that lurking within them was something about the nature of the good, but at no point did you define what you thought the good was, either in terms of individuals or in terms of what might be called the common good. I am wondering whether that was a deliberate decision to omit it, or whether it is actually in any case unanswerable?

Professor Glover: I was brought up in the Oxford philosophy of the early 1960s, in which almost the whole of our philosophy was about the meanings of words like good, right, ought, duty. I like to think

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that one of the contributions that my generation of philosophers tried to make is to shift discussion towards practical issues of the kind we are discussing today. That is not intended, please, as a put-down of the question you have asked, because obviously there are real questions about what is a good life for a person, what makes life worthwhile; and it would take a very long time for you and I to debate those issues. My inclination is to feel that in practice what one has to do is take the view that it takes all sorts to make a world and all sorts have all sorts of different perceptions of what a good life is, so what we need to do, with any individual patient, whether they are medical or cancer and so on, is try to elicit what that person's deepest values are. They may not be the same as yours and they may not be the same as mine, but really respecting other people seems to me to be a matter to trying to implement for them—so long as it does not conflict with other people's interests—what their perception of the good life is. You also mentioned the good of society, and one dimension of the debate is, if we are doing the right thing for this person, if the slippery slope argument turns out to be right we may be causing worse things down the line, so one needs to take both of those into account. I have not even begun to answer your question but I think I have gestured at some points.

Bishop of St Albans: I would like to go on, but there are other members.

Chairman: Earl of Arran.

Q48 Earl of Arran: Whilst the arguments, the passion and the persuasion sway to and fro amongst the professionals, do you agree that at the end of the day it is for society as a whole to make up its mind on this—whether the law should be changed or not?

Professor Glover: We live in a democracy and so, ultimately, there is a sense in which all decisions—even as to whether to go to war in Iraq—ought to be in some sense democratic decisions, but as we know we do not take a referendum on every issue. What I feel I am doing in casting my vote for a Member of Parliament is voting for someone who, I hope, has judgement that I can trust. Of course public opinion is a dimension to consider, but I think I would be worried if the implication of your question was that perhaps the whole thing should be decided, either by referendum or focus groups.

Q49 Earl of Arran: It is in no way an answer of course to create august bodies of professional advisers. But at the end of the day, if there is no agreement amongst professionals, which normally there is not, probably in particular on this Bill, society should as a whole be included in the decision.
Professor Glover: What does that mean—society should be included in the decision?

Q50 Earl of Arran: The general public as a whole—the wish of the public as an entirety in itself—obviously accepting professional advice at the same time.

Professor Glover: How does one measure the wish of the public?

Q51 Earl of Arran: It is very difficult to know, it is probably for the government of the day to decide upon that.

Professor Glover: I suppose that, while I am a democrat in spirit, I am also someone who is very glad that capital punishment was abolished, despite the fact that at that time there was a strong majority in favour of it. I do not think I am a majoritarian who thinks that whatever the majority opinion is must be right. For instance, if we lived in a society where there was a racist majority, we might nonetheless be likely to have to have legislators who would not reflect that particular aspect of opinion.

Q52 Baroness Thomas of Walliswood: I wonder if you, Professor Glover, have had any thought about the differences, from a moral or ethical point of view, between the fact that a patient may refuse treatment and the fact that patients may be unresuscitated without being told that, and the fact that now we are thinking about allowing a patient to request to have her/his own life ended. What are the moral differences between all those things? They seem to be very close together in that they are different approaches to things that are actually quite similar. I am asking the question because I think we have all been approached on the subject of the slippery slope, and what I, I suppose, want you to tell me—you are not going to, I know that—is, if we pull that last thread, the thread that is representing this Bill, are we going to suddenly find a whole decoupage of things collapsing because we have taken that one step which is essentially different from the other steps we take in approach to the end of life?

Professor Glover: I will not discuss that after such a brief acquaintance. You have sussed me out so well as to know that I am not going to tell you the answer. I suppose what I want to say is that there are two different types of issues here; one is, is there a logical distinction that can be brought between these different kinds of actions or failures to act; and the other is, whether or not there is logical distinction, will introducing one kind of thing lead causally to another? I defer to Penney on the factual question, which is one reason why I am not going to answer this question, because she has studied the effects in different places of bringing in legislation of one kind or another and I have not; so I am not going to pontificate on the factual side. I simply say that I think one can draw logical distinctions, but I take it

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that the central distinction is between acts of euthanasia that result from respecting the person's autonomy—and that involves thoroughly investigating what their deep wishes are and not some immediate fleeting request—and those that are taken by someone else in what are taken to be the person's interests. I think that is a distinction which in logic can be maintained; it seems to me a socially very important one to maintain, but whether there actually is going to be an empirical side is a matter for Penney rather than me.

Q53 Baroness Hayman: Can I follow that up and ask you whether you feel there is an ethical divide? One of the issues that troubles me most is between the would-be suicide patient who has the physical capacity to end their own life and is able so to do and some of the most difficult and troubling cases which, as we have heard, do not often receive the palliative care that they need—palliative care is not always available and palliative care is very difficult to tailor—particularly in cases of degenerative disease. Do you feel that ethically as a society there is an issue about allowing the situation to continue where autonomy is available to one group and not to the other, simply by virtue of disability or the nature of their terminal disease?

Professor Glover: I have a couple of things to say about that. One is that it seems to me discriminatory and objectionable that somebody who is capable of committing suicide is able to do that, but somebody who happens to lack the physical capacity to do that is denied it. That seems to me a case of those who have the physical ability having more rights than people who do not, and I think that is harsh and unjust. On the other hand, the question of degenerative diseases seems to me an extremely difficult one, because part of the problem with something like Dementia is that as, you get into the position where you might rationally prefer to be dead, you may at the same time become not competent to make the request. That seems to me to be a very, very difficult area.

Q54 Baroness Hayman: Motor Neurone Disease is perhaps an easier example than Dementia to deal with in that area.

Professor Glover: Yes.

Q55 Baroness Hayman: One other philosophical question. You said you were not a majoritarian. Can I ask you about minorities and the protection of minority rights here. Do you think there is a philosophical issue or do you think perhaps that in legal terms it is important for us to understand—even if this is a desire or popular with a very small minority of those who will be actually affected,

should that sway our judgment as legislators? Even if the 3 per cent who do not have the will to live come down to 1 per cent and actually wish to avail themselves, is it important that it is 1 per cent or 10 per cent or 20 per cent? What weight should we give to that?

Professor Glover: It seems to me not hugely important because under this proposed Bill or legislation broadly of this type no one who does not want to have access to assisted dying is going to be made to do so, so the question of respecting the rights—if that is the correct terminology—of the minority—whether it is three per cent, one per cent or whatever—who do feel that they want this control over their lives, do want to be able to make this request and have some chance of it being acted on, is covered; and even if it is a small minority that still does not seem to me to matter. If I may again use the analogy of capital punishment, one of the arguments against capital punishment is the fact that sometimes innocent people might have been executed and, whereas you could make some sort of redress if someone is wrongly convicted and sent to prison you cannot do anything if you have already executed a person. I am still worried about that, even if it is only one person; and, if there is one person who desperately wants to avoid incontinence and misery and is denied that, that seems to me serious and much more serious than the fact that other people may not agree that they should have the right.

Q56 Baroness Hayman: How would we ever know if there was one person who availed themselves of the right to assisted dying who would have changed their mind about it the next day?

Professor Glover: You are absolutely right—there are risks in both things. In the status quo there is the risk that people who really do have a long-term desire, for serious reasons, reflecting their deepest values, who want to die are denied that; on the other hand, if we bring in the Bill, on the other side of course there is the risk that people are going to take a decision which they think is serious, and we are going to sometimes fail probably to pick up the fact that it is a temporary mood of depression. There are risks both ways.

Q57 Lord Patel: I have a question for Dr Lewis. I think in your presentation, if I understood it correctly, you put particular emphasis on the need for there to be a doctor/patient relationship to exist in society for there to be such legislation. Can you enlarge on that?

Ms Lewis: I think that is one of the big distinctions between The Netherlands and other jurisdictions, in particular Oregon, and I think that is one of the reasons why the Dutch have sometimes said that you should be careful about translating their experience,

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for example, into the US context, partly because they have a very different healthcare system where everyone is entitled to healthcare, unlike the US, but also they do have a system where people tend to have very long-standing relationships with their general practitioners, and it tends to be the general practitioner who would provide euthanasia. I think both in terms of generally knowing their patients and knowing what kind of person they are, having a long-standing relationship helps with that, particularly when you look at the criteria for the request—that it has to be competent and it has to be voluntary and well-informed. I think as a professional—and the evidence bears this out—it is much easier to assess competence if you can do it over a series of visits. One of the concerns that has been raised in the literature on Oregon is that often there are very, very short relationships and people are being asked to evaluate competence in half an hour, and even if there is a referral it is still only one meeting. Those issues about whether we are getting it right that Jonathan was just speaking about—the dangers of missing a depression diagnosis etc—are more serious if you are in a situation where there is not a longstanding physician/patient relationship. Particularly, I think, if you look at Oregon, there is quite a lot of evidence—interestingly, halfway through the Oregon period they stopped collecting some of this evidence, which I found worrying—that more than half of the people who obtained a prescription did not get it from the first doctor they asked, which makes it even more likely that they are getting it from someone that they have never met before or that they have only met very, very briefly. If you look at the evidence that they are still collecting, which is on how long was their doctor/patient relationship, the median over the last six years has been 13 weeks. There is not directly comparable data in The Netherlands, but there certainly is a lot of data that suggests that the GP relationship is the one that most often produces a euthanasia discussion and sometimes an act of euthanasia, but that tends to be many years in length. I think that that is a concern, both in terms of evaluating the translatability of evidence from one jurisdiction to another but also, I would say, it is something that we might want to consider when deciding what kind of doctor should be able to participate in this, whether we would want some sort of requirement that it be evaluated by someone who has at least known me for some period of time, whether that person be a GP or, if there has been a diagnosis of illness that has gone on for some time, that person could be a consultant specialist. What we might want to avoid is the situation in Oregon where, to put it in quite blunt language, I think there is some evidence of doctor-shopping—in other words, you ask one doctor and, if that doctor says no, maybe

because that doctor has some concern about your competence and your voluntariness or the durability of your request etc, you go and find another doctor. I think our healthcare system would probably prevent that for the most part, but there is not an explicit safeguard about that in the Bill and it is something that is worth considering, because it is what distinguishes The Netherlands from other jurisdictions.

Q58 Lord Patel: If we take the example of The Netherlands, at the time when they were at the same stage as we are—of discussing the issue whether to legislate or not, we have heard the same issue turned the other way round—that it is the very relationship that the general practitioner may have with the patient's family that would make them an unlikely candidate to assist. This is something that was different.

Ms Lewis: You mean a general feeling that, in this country, general practitioners would be reluctant to assist?

Q59 Lord Patel: Yes.

Ms Lewis: I do not think you can say when The Netherlands were in the same position as we are, because they never were. There was never a big conversation in The Netherlands 25 years ago saying “Should we have a law?” They developed their law through a series of judicial decisions and eventually a set of prosecutorial guidelines, which were incorporated in a regulatory manner. So they did have a big discussion but it was not the same kind of discussion; it was not a discussion about “Here is a law”. Eventually they had some discussions about passing draft laws, but it was many years after euthanasia had become very well established in The Netherlands. Your question is interesting about why is it that GPs in The Netherlands seem to be willing to do this but maybe some GPs over here would not be. And I do not think that there is any evidence that really explains that, except that there are some discussions in the Dutch literature about the Dutch character generally and why it makes sense, given the Dutch character and Dutch history etc, that this has developed in The Netherlands. But that discussion in the literature is not really at all specific as to why Dutch GPs are more favourable than GPs in this country. They certainly do not in any way force doctors to participate in euthanasia in The Netherlands and there are many doctors who do not, but they are actually quite a small proportion in comparison with what I would expect would be the case here. One of the concerns about doctor-shopping is that, if you end up in a situation where only a small number of doctors are willing to perform euthanasia, you do of course have a higher risk that

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the doctor who performs it does not know the patient very well, because if those doctors who do know the patient very well are not willing to participate—and I think that may be what is happening in Oregon—then people in the community, your patients, will talk and they will find out who is going to be willing to write a prescription, then they go and see that person.

Q60 Lord Joffe: Dr Lewis, I found the chart that you prepared comparing the legislation in the various countries very helpful. We are keen, from the point of view of those supporting the Bill, to make sure that it is as foolproof as we can, recognising that nothing can ever be totally foolproof. I was wondering, based on your experience and your comparisons, if you have any suggestion as to whether there are any gaps which could be closed, accepting of course your basic premise that the doctor/patient relationship is terribly important.

Ms Lewis: I think it would be difficult to legislate for that. It has been developed as one of the requirements for careful practice in The Netherlands that it must be a doctor who knows the patient, because otherwise the doctor cannot assess whether or not the request is voluntary and well-considered, which is where they do their competence assessment, and also whether the suffering is unbearable. So it is a requirement; and I think, if you were a Dutch doctor and you did not really know the patient, you could get into some trouble. One of the concerns that I have about the Bill, which I think is in my paper, is about the criteria that trigger a psychiatric referral, and it seems to me that there are two points. One is that there is only one criterion which triggers a psychiatric referral in the Bill, which is a concern about competence, yet there are two issues which the psychiatric referral is supposed to deal with, the competence issue and whether or not the patient suffers from a psychiatric or psychological disorder causing impaired judgment. It seems strange to me that you would only trigger the referral through a concern about competence, but then you would go on and look at two issues. So it might be worth thinking about what should be the trigger for a psychiatric referral and whether both of those possibilities should trigger it. I have then raised a couple of other issues that one might consider for triggering a psychiatric referral or being evaluated or both, and they both come from evidence on what they use psychiatric referrals for in The Netherlands—and they do not use them uniformly. One is to look at voluntariness, and I think one could be concerned about voluntariness without being concerned about the risk of a psychiatric or psychological disorder. So one might just want someone else to evaluate the voluntariness, although the evidence seems to be quite a difficult thing to evaluate, so I am just raising it as a

possibility. The other issue which comes out of the Netherlands literature is that they are concerned about transference and counter-transference. I wonder whether it might be worth the Committee hearing from psychiatrists about whether they think that is a real problem and whether it is something which should be looked at in some cases or in all cases. I am not a psychiatrist, so it is not my area of expertise, but it is something that comes up in the Dutch literature as one of the things which psychiatric referrals can be used to look at more closely. There is quite a lot of material suggesting that psychiatrists in some of these jurisdictions are not particularly happy with the idea that they become the final gatekeeper. So I think it is worth not just saying we will add even more and more safeguards and we will scrutinise more and more using psychiatrists, but there is a danger that the psychiatrists are put in quite difficult positions. So there is a balance to be struck there, but I do think that having at least one more trigger would make more sense.

Bishop of St Albans: I would like to go back, if I may, to the 1960s and the view of Professor Glover. I suspect you may not be too happy with a hierarchy of values kind of language, but nevertheless in several places you referred to people's deepest values; not quite life or death but we are talking of something in that field. Would you be willing to say what you think to be either the highest or the lowest moral value of an individual human being and/or of society?

Q61 Chairman: I wonder if we could leave you to think that over and we will come back as soon as we can.

Professor Glover: Saved by the bell.

The Committee suspended from 4.22 pm to 4.35 pm for a Division in the House.

Q62 Chairman: You have had an opportunity to consider your answer. I hope we have not forgotten the question?

Professor Glover: I remember the question; alas, turning it over in my mind has not made me more confident of my answer, but I will give it all the same. I think that there probably is a central core of human values that perhaps not everybody but the great majority of people across different cultures might well subscribe to. It is a highly controversial question and it is an incredibly difficult empirical question, whether there is such a central core of human values that we all share. But in teaching in a number of different countries, but mainly in this country, I spend a lot of time asking students about their values and exploring them, probing and questioning. I am surprised how often it seems to me that they refer to certain basic, central values, and among them are, for instance, a desire for one's life to add up to

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something, to mean something, which is not as it were easily encompassed within, for instance, a crude utilitarian answer that says that all that matters is pleasure and the absence of pain. You asked me an extremely difficult question—is there a hierarchy such that one is the key one? And I think here I am inclined to say that my own opinion is No, there are a number of things. Isaiah Berlin spent a lot of his life talking about the plurality of different values and how there may be certain integral values that we are deeply committed to that are not bedded down easily with each other, and there may be no right answer to the question—what is the calculus which says liberty is more important than equality or the other way round. We all know those sorts of debates, say about education: equality of opportunity may require that everybody has the same sort of schooling and liberty may require that parents are free to choose different sorts of schooling. But I know of no way of saying that one of these obviously trumps the other. I would be prepared to say Yes, there is probably a central core of human values, but I do not actually think that I am at all confident that whatever happens to be my key value is going to be that of anyone else.

Bishop of St Albans: Thank you very much.

Q63 Chairman: I would like to ask you why you are glad, in relation to the capital punishment question, to live in a country that was not ruled by public opinion, which is what I think you said?

Professor Glover: Yes. I did not say that I wanted a country in which public opinion is taken no notice of. I believe in democracy, roughly of the sort we have—although I am not always sure how well it works. I believe that ultimately governments and legislators ought to be answerable to the people in some form or other. But I do not believe that on every issue legislators should say the right answer to the question, what sort of Bill we should have on this matter, is to be found by asking what most people in the country believe. In the case of capital punishment what I want to say—and here I am displaying some of my own values, which certainly are not universally shared and may not even be shared by everyone in this room—I believe that capital punishment is something barbaric, I think it is something which runs the risks of a quite appalling injustice: it is hard to imagine anything much worse than knowing you are going to be executed for a crime that you know you did not commit. That seems to me a degree of injustice which is monstrous. I believe the evidence that it reduces the murder rate is extraordinarily poor, so for those sorts of reasons I think it is a wonderful thing that, in the now-much-derided Sixties, of which I am a product, we got rid of that particular mode of punishment. I know that at the time that Parliament voted to remove capital

punishment a majority of people, then and certainly for some years afterwards, actually supported capital punishment, and I am not even sure what the current position is. In answer to your question there are powerful moral arguments against capital punishment, and I think they trump the idea that we ought to always do what most people believe is right.

Q64 Chairman: You mentioned that the sanctity of life is a principle that comes into this debate, and that it comes in, not only in what I might call faith communities, but also is a principle that is subscribed to by others?

Professor Glover: Yes.

Q65 Chairman: Could you please say what you understand by that principle as understood by those who are not a faith community?

Professor Glover: I should put my cards on the table. I am not a religious believer. I am actually not a typical subscriber to the principle of sanctity of life either, but I think that it is one value that I very well understand the pull of without it being a matter of it being commanded by God. What I understand the secular version to be is identical to what I understand the religious version to be—namely, that there is an absolute barrier, an absolute ban, not derived from a religious source, on the intentional taking of innocent human life. It is the same principle, and if it seems a puzzle why someone who does not believe it is God who says “Thou shalt not kill” should take that view, perhaps I could mention George Orwell—and this links back to capital punishment. George Orwell describes how, when he was in the colonial service, somewhere in the Far East—I forget exactly where but possibly Burma—he was once part of a group of men who were present at an execution. He describes walking towards the place of the execution, the group of the guards, the officials and so on, and in the middle was the man who was to be executed. As they walked along the path there was a puddle and everybody, including the man who was about to be executed, swerved to avoid the puddle. At that moment George Orwell suddenly had this very powerful intuitive response. He said that here we were, a group of men, walking along together, and all of our bodies were toiling away as they usually do—hearts were working, brains were working, it was all working—but in a few moments there would be one of these people less—“One life less, one world less”, he said. “At that moment it came to me”, as he put it, “the unspeakable wrongness of cutting off a life in full tide.” I can imagine walking along in that group, and I am not a religious believer, but I can certainly imagine having that overwhelming feeling about the awfulness, the seriousness, of what was about to be done. Because I have thought a lot about the sanctity

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of life I am both pulled towards the George Orwell response, but also want to make lots of qualifications about respecting people's wishes not to go on living, qualifications about how it could be justifiable to kill someone in pursuit of a just war. And for that reason I think there is something to be said for the formulation I gave, which actually allows for that possibility. I think there is a powerful pull, which possibly could be explained in terms of evolutionary programming but possibly would not have to be, and most human beings think that the issue of taking someone's life is a deeply serious issue and one that requires a great deal of justification. I do not think one needs religious authority to take a view like that.

Q66 Chairman: Can you help me on a slightly related matter—and it may be that you would want to ask one or other of your colleagues to assist in this—that, in relation to suicide, at the present moment if people are in prison there is often thought to be a risk that they may commit suicide, and precautions have to be taken by the prison authorities to obviate that risk so far as possible. How do you see the basis of that particular practice?

Professor Glover: I take it that it is a bit similar to the practice that I believe prevails in hospitals when someone comes in having attempted suicide. Because the act of suicide is such a serious one and so irrevocable if successful, if somebody comes into hospital unconscious, having attempted suicide, there is a strong moral case for reviving them, unless you have masses of documentation showing that this was a very serious thing which has been discussed and planned and so on. In the normal case where someone comes in, there is not any evidence one way or the other, but it seems to me that there is far less moral risk in reviving someone—who will after all have another chance to commit suicide if that is their deep and serious intention—than there is in letting someone die in those circumstances, when it might be the product of temporary depression and not reflect their deep values. There is a case where you do not know, and have not gone through all the types of procedure that this bill envisages, there is a case for taking very seriously the idea that suicide is something to be prevented if possible. But that is a temporary thing, and in prison my worry is it might be that someone, say, serving a life sentence might have a very serious wish to die, but one of the ways in which prison may be an abrogation of that person's life is that they may not be allowed to do that. My colleagues might have something to add—does either of my colleagues want to contribute?

Ms Lewis: I think there is some authority for the legal proposition that a competent prisoner, even though some of his civil rights may have been suspended by the fact that he is a prisoner, can make decisions

which will result in his death. There have been a couple of cases recently, one involving a hunger strike and one involving a prisoner who was self-harming in a way that was going to be fatal if he did not accept medical treatment, which he was refusing to do. So there is some authority for the idea that, if the person is not competent, he could then go ahead and either refuse food or refuse treatment which would be life-saving, and from that one might infer that a competent prisoner could decide to commit suicide. The kind of prisoners who are placed on suicide watch are prisoners where there is some concern that actually they may be suffering from a mental illness or a mental disorder which prevents them from making a competent decision. And I know there is a debate in the literature, which spills over sometimes into the euthanasia literature, about whether or not it is possible rationally choose to kill yourself. I suppose one scenario where one might argue that it would be rational to commit suicide would be a case of a life sentence, but I do think that Jonathan is right that the concern in those cases where prisoners are placed on suicide watch is because we are not sure if they are competent or if they have a treatable mental disorder which, if treated, might make them change their mind.

Q67 Chairman: That brings me to ask about the situation of a person who is not thought to be competent but suffering from mental illness, who is obviously also suffering very severely from physical illness. What is the position that differentiates that from the person who is competent who wants to request assistance to die?

Professor Glover: It seems to me to make a difference to your question whether we envisage that the person who is now incompetent did or did not give an advance directive.

Q68 Chairman: I am assuming for the moment that he or she did not give an advance directive. They are mentally affected but obviously to the doctors who are looking at the matter they are suffering very severe pain, which I am assuming, for the sake of example, cannot be alleviated.

Professor Glover: My colleagues may have different views on this, but I will simply express mine. To me it is so important to keep the barriers of euthanasia or assisted dying by request from any other sort for slippery slope reasons. Although it might be very cruel to leave a person alive when they are not competent, if they are not competent to ask I believe that we should not kill them, because if you do that you are moving over what seems to me to be a very fundamental moral barrier. You are moving away from respecting the autonomy by reason of a particular request to taking a decision from outside

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on their behalf; that is something which, I think, we should be extraordinarily reluctant to do, but my colleagues may differ on this.

Professor Higginson: My comment would be that you seem to be describing a context where an individual might be, for example, profoundly depressed and be requesting euthanasia but might have previously said they would want euthanasia. And I suppose that the issue is that we know that, when people are depressed or in states of mental distress, they are more likely to wish to die than not; but, if one reverses that mental distress, then they are less likely to want to die. That we know. There is concern, for example, that people in prison sometimes have a recognised health problem and sometimes they have ended up in prison because of health difficulties which have led them into crime or whatever. It seems to me that in those instances there is a requirement to attempt to treat the problem that someone has, and drawing the fine

line between depression and a sustained wish to die in that instance and in many instances is extremely difficult.

Q69 Chairman: Thank you. We are going to have to break again. I am just wondering if we necessarily want to come back. Perhaps you could consider yourselves free, thank you very much indeed.

Professor Glover: Could I just say one more thing, which is that I have been passed a note. Somebody has passed me a note saying— could someone remind the Committee of the story of Sodom and Gomorrah and the small number who need to repent. I think this has to do with your question, Baroness Hayman— does it matter what percentage it is? I make no comment.

Chairman: Thank you very much indeed. I am sorry to leave you with slightly less deliberation than I normally would, but thank you.

THURSDAY 16 SEPTEMBER 2004

Present	Arran, E	Patel, L
	Carlile of Berriew, L	St Albans, Bp
	Finlay of Llandaff, B	Taverne, L
	Jay of Paddington, B	Thomas of Walliswood, B
	Mackay of Clashfern, L	
	(Chairman)	

Examination of Witness

Witness: THE LORD JOFFE, a Member of the House, examined.

Q70 Chairman: The purpose of this public session is to enable Lord Joffe, as the proposer of the Bill, to briefly explain its terms and then to give the members of the committee a chance to explore these terms in such detail as they think necessary. The precise terms of the Bill will be what ultimately become law, assuming the Bill was passed into law without any further amendment. Therefore, it is extremely important to know exactly how it would work and what the different provisions of the Bill are intended to achieve. Evidence will be taken, a record of the evidence will be available and it will be, as usual, subject to correction by the witness in so far as the transcript does not appear to represent exactly what he thought he had said.

Lord Joffe: Thank you, Lord Chairman. I appreciate the opportunity to give evidence in relation to the Bill which I introduced. I will begin by outlining the background to the Bill in its present form and its purpose, and then go on to deal with the detailed provisions. My starting point is to draw attention to the recommendation of the Select Committee on Medical Ethics in 1993–94. That was part of a much wider consideration of end-of-life decisions and, amongst other issues, it advised against a change to the law criminalising voluntary euthanasia. Since then, as the Liaison Committee has pointed out, and I quote, “other countries have introduced legislation and public opinion in the United Kingdom has become more engaged in the issue”. In addition to the legislation in The Netherlands, in Belgium and Oregon, motions proposing a change in the law are awaiting debate in the French Assembly, and the new Spanish Government included a commitment to change their law in their 2004 electoral programme. It is now widely recognised that palliative care, of which the Bill is totally supportive, is not the answer for a number of terminally ill patients who, suffering terribly, wish to bring their suffering to an end by being assisted to die with dignity at a time of their choosing. The purpose of the Bill is to change the law in order to allow such patients to have this option alongside—and I emphasise alongside—all the other lawfully available end-of-life options. The Bill is based on the principle of personal autonomy and

patient choice, the right of each individual to decide for themselves how best he or she should lead their lives. The Bill recognises that in the exercise of personal autonomy vulnerable people should not be put at risk, and accordingly it contains an array of safeguards to protect people who could be vulnerable.

I now briefly touch upon how the Bill reached its present form. It started last year as the Patient (Assisted Dying) Bill, which I will henceforth refer to as “the previous Bill”, which was introduced on 20 February 2003 and which had its Second Reading on Friday 6 June of last year. At that reading, which was attended by approximately 100 peers—on a Friday, I might add—39 peers took part in the debate and roughly equal numbers spoke in favour for and against the Bill. In accordance with the usual convention, the Second Reading was not opposed. However, following upon a proposal by Baroness Jay, the House agreed to the appointment of a Select Committee to consider the Bill and the Bill itself lapsed in November last year at the end of the session. On 8 January of this year, the current Bill, which is entitled the Assisted Dying for the Terminally Ill Bill, and which I will henceforth refer to as “the Bill”, was introduced. It contained three substantive changes from the previous Bill in response to concerns expressed at its Second Reading. Firstly, whereas the previous Bill applied to all competent adults who are suffering from a terminal or a serious and progressive physical illness, the Bill is now limited to terminally ill patients only. Secondly, responding to the reluctance of some physicians to directly bring an end to their patient’s life, the attending physician may only provide the patient with the means to end the patient’s life, the obligation being, or rather the option being, for the patient to decide whether to take these drugs or not as he or she chooses. The only exception to this is where the patient is physically unable to take the medication, in which event, as in the case of Diane Pretty who suffered from Motor Neurone Disease, the physician can actively end the patient’s life. Thirdly, in response to concerns about patients not being fully informed about the benefit of palliative care, there is now a requirement for a

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palliative care specialist to see the patient. This provision illustrates the importance the Bill attaches to palliative care. We would think that palliative care is the first option and assisted dying would normally be the last resort option. The Bill had its Second Reading on 10 March of this year and, with a view to avoiding repeating the speeches made at the Second Reading of the previous Bill last year, it was agreed by opponents of the Bill that they would not oppose the Second Reading on the clear understanding that their decision was made solely for the convenience of the House and it was in no way to be considered as an endorsement of the Bill. The Bill was then read a second time and committed to this Select Committee. Since then, two further important amendments are proposed to the Bill, as will appear from the Notice of Amendment to be moved in committee, which you will find in the plastic folder in front of you. There are a number of amendments but only two of real significance. The amendments are endorsed on the copy of the Bill in the plastic folder. I do recognise that some members of the Committee may have marked up their existing copy of the Bill but I do not think in practice this will cause any real problems because the amendments are very limited. The first amendment is the deletion of Scotland from the Bill. I have been advised that the issues contained in the Bill are devolved to the Scottish Parliament and I understand that a motion for debate in that Parliament to consider changing their law was moved last week. The second amendment removed the obligation upon physicians who had a conscientious objection to the Bill to refer patients who ask for assistance to die to a physician who is willing to provide this assistance. This amendment is necessary because the Joint Select Committee on Human Rights in its Twelfth Report this year was of the opinion that while, and I quote, “the safeguards in the current Bill would be adequate to protect the interests and rights of vulnerable patients”, the existing requirement on conscientious objectors contravenes the provisions of the European Convention on Human Rights. In addition, there are a number of consequential amendments, such as replacing the words “Great Britain” with “England and Wales” and introducing a greater consistency in the terms used in the Bill.

Before I turn to the Bill itself, I would like to underline the following. The Bill is based on the principle of personal autonomy, and central to it are the following. It applies only to terminally ill, competent adults who are suffering unbearably; it does not apply to children and it does not apply to patients who are mentally incompetent. It is very limited generally in its application. Secondly, it is the patient who must initiate the request for assistance to die, not the physician, and no physician or other member of the medical team is entitled to assist the

patient to die without the patient having initiated the request and all the safeguards contained in the Bill having been complied with. I emphasise this to the members of the Committee because, among the large number of letters that I have received opposing the Bill, there is total confusion as to what the Bill really provides. Many of my letter-writers also think that the Bill is the same as the Mental Capacity Bill, which has been introduced in the House and has gone to another place. Thirdly, it is the patient who must make an informed decision to die, which he can revoke at any time. The role of the physician is limited to ensuring that the safeguards and processes set in the Bill are complied with; it is not for the physician to decide whether the patient has made a wise or unwise decision nor to decide on the patient's best interests or quality of life. Again, there is a considerable misapprehension in the letters I have received, whose writers think that the physician can unilaterally kill the patient. It is nothing of the sort. In drafting the Bill, careful attention has been given to the legislation and experience in Oregon in particular and The Netherlands and Belgium. The result is that the Bill is considerably more restrictive and has more safeguards than any such legislation. It also contains many more safeguards than other end-of-life practices which hasten death in the United Kingdom, such as the withholding and withdrawal of life-prolonging treatment.

I now turn to the detailed provisions of the Bill. Could I start on page 1 of the Bill, without looking at the first page? The preamble sets out what I think I have mentioned. Again, it enables a competent adult who is suffering unbearably as a result of terminal illness to request medical assistance to die at his own considered and persistent request. Then there is a further important issue raised in the Bill and that is to make provision for a person suffering from a terminal illness to receive pain relief medication. It has been suggested that there is no connection between these two issues: assisted dying and pain relief medication. I will submit that they are related and it is natural to include them in the same Bill. If we then go to section 1(1), that empowers the physician to assist a patient who has made a declaration that he wishes to die, provided that all the safeguards have been complied with. When we get to the definition section I want to draw attention to a number of issues that might possibly be missed. “Assisted dying” is clear as is “attending physician” as well as competent. But then, when you get to “consulting physician”, we say it means a consulting physician practising in the National Health Service. We have deliberately included that because we do not want a private practice to build up in relation to assisted dying, where one or other consultant actually makes this the main service that they offer patients. As one of the many safeguards in the Bill, we have included the

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requirement for the consultant to practise in the National Health Service. There is another point in the same definition which again is a further safeguard; we require the consulting physician to be independent of the attending physician. That is in the last line of this definition. Again, this is because we do not want partnerships to be developed in terms of which the attending physician has an ongoing relationship with the particular consultant to whom all patients are passed. The declaration is clear and must be witnessed.

Then I come to what is really the key, the informed decision. Here we repeat in the Bill all the factors which have to be taken into account by both the doctor and the patient before proceeding. We will come to these subsequently in the rest of the Bill but the important point is that these all are defined as part of the informed decision which the patient is required to make. Moving down from what are self-evident definitions, we get to the “qualifying patient” and that means a patient who has reached the age of majority—which I have mentioned before—and we add “who has been resident in England and Wales for not less than 12 months as at the date of the declaration”. Again, this is to stop tourists coming to the United Kingdom to avail themselves of this facility. We then define “terminal illness”, which has been very carefully defined and which effectively is that the opinion of the consulting physician is that the patient’s death is likely, not certain but likely, to take place within a few months at most. We then move on to “unbearable suffering”. Firstly, that means “suffering whether by reason of pain or otherwise”. We think, and much of the evidence elsewhere suggests, that existential suffering is actually a far greater issue than pain control. If the physician attending the patient is competent, that can normally be controlled, although not always. We make this definition. It is not an objective test. It is not a test of what the average of all people would consider to be unbearable suffering. It is very clearly defined as a subjective test, and so the wording is “which the patient finds so severe as to be unacceptable”. That is actually the key to this test. It is not what a doctor might say is the norm; it is that particular patient’s suffering which is the subject matter of his decision. Then we have a “waiting period”. There has been some confusion, and I will clear that up in relation to the waiting period. It is 14 days from the time when the patient first informed the attending physician that the patient wishes to be assisted to die. It is not 14 days from the date on which the declaration is made. We thought very carefully about this provision. We are concerned that, if there were so many steps, and we have already included a surprising number of safeguards, the patients will all have died before we get through them.

I next refer to the qualifying conditions, which are key to the whole administration and implementation of the Bill. The attending physician must have examined the patient and the patient’s medical records, and that is sub-section (b). That reference to the patient’s medical records is very important because there will be a lot of information there which it is important for the attending physician to consider. He has to make a determination that the patient has a terminal illness at (c) and at (d) that the patient is suffering unbearably as a result of that terminal illness. Then we have to go on to a number of issues which must be raised with the patient. He has to inform him of the diagnosis, the prognosis, the process of being assisted to die and of the alternatives, including, but not limited to, palliative care, care in a hospice and the control of pain—all of these and any others. It is only then, if a patient persists with his request, that he or she is referred to the consulting physician. The consulting physician has to go through the same process as the attending physician all over again. This provision is somewhat unusual in the NHS and in most areas of end of life decisions, but we require a “consulting physician” as well. Then, at the end of that process, if he is satisfied that the patient has complied, that the patient has thought about everything and he is able to make an informed decision, he asks him if he would like to complete a written declaration. He tells the patient that it can be revoked at any time. Then we get to clause 3, which is this offer of palliative care, which is unique when compared to the countries in which assisted dying is permitted. It was, in fact, recommended in Belgium but not accepted by the legislators. Under this offer, the attending physician has to ensure that a specialist in palliative care, who could either be a physician or a nurse, has attended the patient to discuss the option of palliative care. We then move on to the declaration. The declaration is described in 4(1) and it can only be completed after all these other processes—two consultations, an offer of palliative care and, as I will touch on later, if there is any doubt about competence—that the patient is referred to a psychiatrist. After all this has happened, a written declaration can be made in the form set out in the annex to the Bill. This declaration has to be witnessed by a solicitor to whom it must appear that the patient is of sound mind and that he has made the declaration voluntarily and the solicitor has, in subclause 2 (3)(c), to satisfy himself that the patient understands the effect of the declaration. An independent witness is referred to in (4), and it must also appear to him that the patient is of sound mind and has made the declaration voluntarily. They should have to sign this document, this declaration, in the presence of each other. Then there are exclusions, again as part of the precautions and safeguards, of individuals who are not allowed to

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sign as witnesses, including anyone who has a financial interest in it or who can benefit from it. Then, after all this, under clause 5, the attending physician comes to the stage where he or she has to attend the patient for the purpose of ending their life. In all cases the physician, after informing the patient of his right to revoke the declaration and verifying that the declaration is in force and that it has not been revoked by the patient, will ask the patient immediately before assisting him whether he wishes to revoke the declaration. If the answer is "no", the attending physician will produce the prescription which will prescribe the drugs which the patient will ultimately take, and this will be taken to the pharmacist and the pharmacist in due course will produce the drugs, which will be provided to the patient to be taken or not to be taken at his or her option. The timing is very important. The timing, if the patient decides to go ahead, will be at the patient's option and it will be his decision as to when and who will be there. In the case of someone like Diane Pretty who suffered from Motor Neurone Disease, the doctor will be allowed directly to administer the appropriate drugs to assist that patient to die. Clause 6 just deals with the revocation of the declaration and ensures that a note is made recording its recommendation, that the declaration is removed from the patient's medical file and destroyed. There is then the question, under clause 7, of conscientious objection. As it now reads, or will read if the amendments which I have proposed actually are passed, it will state specifically that any member of the medical care team and any of the physicians involved can distance themselves from the process if they have a conscientious objection to it. There is no requirement on them any longer to refer the patient to another physician who might be willing to assist. This deals with what I think was a constant concern of many commentators about the Bill, and I think it is right that if a physician has a conscientious objection, he or she should be entitled to withdraw completely. This, of course, applies not only to the physician but to the whole medical team, including the nurses and social workers and everybody involved. Clause 8 deals with the position of psychiatric referrals, to which I have referred. If any of the physicians have any doubts about the patient's mental competence, those doubts must be referred to a psychiatrist who will have to satisfy himself that the patient is competent in order for the process to continue. Clause 9 deals with the notification of next of kin. It says that the attending physician shall recommend to the patient that he or she notifies their next of kin of the request for assistance to die, but it does not require the patient to do this. That again is a considered decision and comes directly from the key principle underpinning the Bill of personal autonomy. It is the patient always who must decide

what is in his best interests, not his family, although I am sure that the great majority of patients would wish to consult their family. Certainly, the evidence that we have received suggests that their families, far from encouraging them to be assisted to die, will try to get them to prolong their lives for as long as possible. Clause 10 deals with the protection of physicians and other medical personnel. In addition to protecting them from the consequences of the existing law, it also provides, under (3), that they will be deemed not to be in breach of any professional oath or affirmation. Sub-Clause (4) is yet a further safeguard. It disqualifies the physician or any member of the medical care team from taking any part in assisting the patient to die if they have grounds for believing that they will benefit financially or in any other way as a result of the death of the patient. Again, that is a safeguard to make sure that no physician or member of the team has any inducement at all to assist in the process. Clause 11 deals with the offences. Sub-Clause (1) is where some person wilfully falsifies or forges a declaration with the intent or effect of causing the patient's death. This seems to be equivalent to murder, or homicide, and the provision is that the person would be guilty of an offence under this subsection and liable on conviction on indictment to imprisonment for life or whatever shorter term the court provides. In the further three subsections, which deal with a range of possible offences, which I do not think it would be particularly helpful for me to comment upon, the person committing the offence is liable on conviction to up to five years' imprisonment. We then move on to section 10, which is insurance. In order to ensure that no policy of insurance is invalidated which has been in force for 12 months, we have put in this provision that the insurance will remain in place after it has been in force for 12 months. Clause 13 deals with all the documentation, which has to be very carefully provided and retained so that the attending physician can send a full copy of the file to the monitoring commission within seven days of the patient having been assisted to die. The monitoring commission is set up under clause 14 and consists of a registered medical practitioner, a legal practitioner and a lay person having first-hand knowledge or experience in caring for a person with a terminal illness. The intention of the lay person is that such a person would have an understanding of how patients react on a day-to-day, hour-to-hour, even minute-to-minute basis. If the monitoring commission is of the view that the necessary safeguards and processes have not been followed, it will refer the matter to the district coroner. If it is in order and they are satisfied that all the conditions have been complied with, they will advise the attending physician of that fact. I now move on to section 15, which needs a little clarification. It relates to the administration of drugs

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to patients suffering severe distress and provides that a patient suffering from a terminal illness shall be entitled to request and receive such medication as may be necessary to keep him free, as far as possible, from pain and distress. I have been surprised at the opposition by much of the medical profession to this particular clause. The reason for its insertion and inclusion is that there is clear evidence that many patients do not get sufficient pain relief perhaps for any one of a number of reasons. Research published by CancerBACUP this year¹ demonstrates that a large number of patients are not even consulted about their pain relief. Research from the Nuffield Trust last year found that a considerable number of patients actually suffered unnecessary pain which could have been prevented. There is a range of other research elsewhere which supports this. Of course anecdotal evidence from any number of people with whom I and others have spoken always refers to the terrible death of somebody they have known or who was close to them who suffered terribly. Finally, in relation to this clause, there is the view of a very well-known antagonist of assisting the dying by the name of John Keown, who has written extensively on the subject. His concern is that the case of *Rex v Woollin* has undermined the double-effect principle, which is so key to palliative care, and that doctors will feel at risk, if the principle of palliative care has been adversely affected by this particular judgment of the Appeal Court. There is a further factor which is also very relevant to this clause and that is that it is clear that there are a number of doctors who are concerned about using the double-effect principle in order to ease the pain of their patients because they are frightened that they may be prosecuted; there might also be a question of religious belief. The principle of course, as is known to the Committee, is that if a doctor prescribes medication which he believes could hasten the patient's death, this is not in any way an offence if his intention was to relieve pain. One of the further issues which concerns many medical practitioners, and which was the subject of a doctors' survey, is that new legislation is being proposed in relation to the role of the coroner. As the presiding chair of I think it was the Shipman Inquiry said, coroners must start to "think dirty", and that means to be suspicious of all the cases where somebody has died if in any way it could be suggested that their death had been foreseen. We move on to Clause 16, to the usual power of the Secretary of State to make orders or regulations. There we have replaced the wording which we originally had in the Bill, which I do not feel was appropriate, with what we believe to be the standard rights of the Secretary of State. The Bill then provides for the schedule which incorporates all the safeguards which I have mentioned and which has to be signed by the patient

when he has finally made his decision to ask for assistance to die, even if he subsequently withdraws that request. In addition to the Bill, there will naturally be regulations by the Secretary of State. Additionally, it is good practice for the BMA and/or the General Medical Council to prepare detailed guidelines along the lines of those they prepared in relation to the withholding and withdrawing of life-prolonging treatments. I believe that this Bill is a deeply humane piece of legislation which will protect patients as well as their physicians and families and, for the first time, will regulate assisted dying which already takes place in England and Wales. As I reflect on the suffering of these patients and their families, which is so graphically described in the three typical letters included in your plastic folder which has not yet been distributed by the Clerk to the Committee, it is my belief that in our caring society we can no longer ignore the suffering of vulnerable people like Diane Pretty and brush away their pleas to end their suffering with the uncaring message that they must simply continue to suffer in order to protect others. Thank you,

Chairman: Thank you, Lord Joffe.

Q71 Lord Carlile of Berriew: Lord Joffe, I am sure everyone would agree that you have given us a very valuable outline of the Bill. Might I start at the beginning? What you set out in the Bill seems to me to be an evidential process followed by, much more briefly, an assisting process. Would you agree with that?

Lord Joffe: I would agree with that, yes.

Q72 Lord Carlile of Berriew: Why is it that the decision-making on the evidential process is placed in the hands of the medical profession as opposed to somebody who is more accustomed to making crucial decisions in relation to what may be evidentially difficult matters, such as a judge or a coroner?

Lord Joffe: I think basically the underlying approach to the Bill has been that doctors are in a close relationship with their patients. They know their patients, particularly if they are general practitioners, and it is particularly appropriate for them to discuss these issues in a non-aggressive, caring way with patients whose lives, in the main, they would wish to prolong rather than to end. This is the underlying principle, and doctors are particularly well equipped to form a view on issues like diagnosis and prognosis and many of the other issues which they need to address.

Q73 Lord Carlile of Berriew: Given that the consequence of this process is the ending of a human life, do you not feel that it would ensure much greater public confidence, if your Bill is enacted in principle, were the actual decision to be taken by somebody

¹ *Note by Witness.* This research was, in fact, published in 2001.

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who is far removed from the patient, on the basis, hopefully, of cogent evidence beyond reasonable doubt?

Lord Joffe: I do not think this is a case where we are talking about evidence beyond a reasonable doubt. What we are talking about is the exercise of the patient's autonomy. This is the underlying principle. We are looking for a patient to make an informed decision, not anyone else, and the doctor simply to be satisfied that all the processes have been complied with.

Q74 Lord Carlile of Berriew: Given your lack of confidence in the private medical profession to carry out this regime satisfactorily, what is the foundation for your greater confidence in practitioners in the NHS?

Lord Joffe: It is not a question of not having confidence in doctors practising privately. In fact, as you and the Committee will well know, a great many consultants who practise in the NHS actually have a private practice as well. What we are seeking to do is to ensure—and it is just one of a number of safeguards that I would be quite happy to take out if you felt that was necessary—is an added precaution that we should not have individual consultants who specialise in assisting patients to die.

Q75 Lord Carlile of Berriew: What proportion of unlawful killings by doctors in the last 10 years has taken place in the private sector and the NHS respectively? Is it not the case that the vast majority has taken place in the National Health Service and that there are very few cases which have been before the General Medical Council where gross negligence by doctors and unlawful killing has taken place in the private sector?

Lord Joffe: I think if there is total confidence in the private sector, I would be very happy to amend the Bill.

Q76 Lord Carlile of Berriew: But that is not your starting point? You told us with force, if I may say so, that you thought it was inappropriate for this to occur in the private sector. The point I would like to put to you is that there is very little evidence that one could have total confidence in either sector and that there is a danger of mavericks operating in this field, both in the NHS and anywhere else, even in British medicine, is there not?

Lord Joffe: There are always the occasional mavericks operating everywhere and in every field of law; people can murder other people. There are always maverick people out of step with society. I accept that. I am not sure what the point is that you are making.

Q77 Lord Carlile of Berriew: Like Dr Shipman, they find their niche, do they not?

Lord Joffe: No. Dr Shipman might have found his niche but the point about it is that he found his niche under the existing law. In my view, it is highly likely if this Bill had been in force that he would have been found out earlier and, what is more, the last thing that Dr Shipman would have wanted to do was to call in another GP, a palliative care consultant and a solicitor before, sadly, he killed his patient.

Q78 Lord Carlile of Berriew: I have two further questions, if I may, at this stage, and one relates to a solicitor. The question before that relates again to the NHS. If this procedure were to be carried out in the NHS, then presumably in many cases it would be carried out in an NHS hospital, which is under the direction of an NHS health care trust. If an NHS health care trust is unable to agree that this procedure should be carried out in their trust area, as seems very possible for a great many NHS health care trusts, is it your view that they should be forced to agree to carry out this procedure as part of their NHS responsibility? If so, what protection does that give to directors of NHS trusts?

Lord Joffe: I think that is a very valid point which needs to be considered and looked into².

Q79 Lord Carlile of Berriew: Have you not considered it?

Lord Joffe: No, I have not considered it.

Q80 Lord Carlile of Berriew: Why now? It seems such an obvious point to me.

Lord Joffe: No, I have not considered it because of the evidence in The Netherlands and the evidence in Oregon that the medical profession in the hospitals when a law is in place seek to apply that law, not to oppose that law and obstruct it.

Q81 Lord Carlile of Berriew: This would create postcode euthanasia, would it not, under your proposals as they stand?

Lord Joffe: Could you perhaps explain that question?

Q82 Lord Carlile of Berriew: Yes. If the NHS trust in Area A does not agree to allow this procedure to take place in its DGH and if the NHS trust in Area B does, then you have postcode euthanasia, do you not?

Lord Joffe: I do not understand what postcode euthanasia means. Perhaps you could explain it to me?

Q83 Lord Carlile of Berriew: It is just like the complaints about postcode elective surgery. Surely you understand that?

² *Note by Witness.* In Oregon 94% of patients who have an assisted death die at home; only 1% die in hospital.

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Lord Joffe: No, I do not.

Q84 Lord Carlile of Berriew: I will move on to one further question, my last question for the moment. Would you look at the schedule which relates to the clause dealing with witnesses to the declaration? Would you look, please, at paragraph (a) of both the solicitor's declaration and the other witness's declaration? The requirements are that the person, the patient, is personally known to me or has proved his identity to me. Is that correct?

Lord Joffe: Yes.

Q85 Lord Carlile of Berriew: This, my House of Lords membership card, proves my identity to you, and I could present that to anyone. But they would not know me by that presentation. Is not (a) an extremely weak provision, given that position?

Lord Joffe: Basically we have to look at the circumstances where this is happening. We have a patient either in a hospital or at their home. We have family around and the nurses know this patient. All we want to be satisfied about is that the person he is talking to is the person who has asked to be assisted to die. There does not seem to me to be any conflict. It is not very complicated.

Q86 Lord Carlile of Berriew: But do you not see there is a huge difference between someone being personally known to a witness, which presumably means known not merely as to identity, and simply identifying them. Otherwise it is a virtually valueless provision, is it not?

Lord Joffe: Basically we have witnesses all the time signing wills and signing all manner of documents. There are no such requirements. What we are trying to do here is just to add an additional safeguard, an additional precaution.

Q87 Lord Carlile of Berriew: This is ending of a life.

Lord Joffe: Indeed, it is a question of life but actually wills are also a question, in a way, of life and death. Let us look at the position of a patient signing a consent to life-endangering surgery. They sign this consent without any witnesses and certainly not with a procedure of this sort. Would you think that that is reckless?

Q88 Lord Carlile of Berriew: It is very different. When you sign a consent to elective surgery, or to surgery of any kind, you are signing to have your life preserved and not to have your life ended. What I would suggest to you, Lord Joffe, is that (a) and (c) of the declarations are no more than window-dressing and extremely weak. Identifying someone as who they are and their appearing to be of sound mind does not require any in-depth knowledge of that person, does it?

Lord Joffe: There is no intention that they should have in-depth knowledge of that person. We are asking them to sign a document saying that they were there at that particular time and that the patient appeared to them to be of sound mind and to have made the declaration voluntarily. That is all we are asking. We are not asking for anything beyond that and it is a great deal more than happens in other end-of-life decisions. You are clearly concerned about this. Could you suggest what we should put there?

Lord Carlile of Berriew: I am not suggesting you should put anything there. I think this is a valueless certificate and an insufficient safeguard.

Q89 Lord Taverne: Lord Joffe, the Bill, as you have put it forward, contains extra safeguards which go beyond those in place in The Netherlands and Oregon. Of course, extra safeguards mean extra delay and extra delay means extra suffering. If we find, after hearing evidence from The Netherlands and Oregon, as appears to be the case at the moment, that there is in fact no abuse there, do you not think perhaps you may be over-egging the pudding? and would you be willing perhaps not to insist on extra delay?

Lord Joffe: I have been criticised by many people who have supported the principle of assisted dying over the fact that in their view the Bill does not go far enough, that it should go a great deal further, and that many of the safeguards are not necessary. I feel, however, that we are starting off; this is a first stage; it is new territory. I think that there is legal guidance, and I think it might have been Lord Keith who said that normally with new types of legislation one should go forward in incremental stages. I believe that this Bill should initially be limited, although I would prefer it to be of much wider application, but it is a new field and I think we should be cautious. That is why we have introduced all these safeguards, despite criticism from many people who feel we should have gone a great deal further.

Q90 Bishop of St Albans: Lord Joffe, thank you for the presentation. I want to go back to the fundamental premise of the Bill which relates to personal autonomy. I wonder if you could tell me what you think the changes have been in moral thinking which lead you to suppose that the conclusions reached by the 1993–94 committee are no longer well-founded or relevant? It is the moral thinking I am concerned about just for the moment. You did outline that there are the changes in legislation in Belgium and Oregon and so on but I did not hear anything which said it is as a result of a particular moral change.

Lord Joffe: Moral changes, in my view, should represent and should be driven by the views of society as a whole. I think there is clear evidence that the

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overwhelming majority of society is in favour of assisted dying. Values change all the time. If you take a look at what has happened with religious beliefs, originally contraception was opposed; abortion was opposed; homosexuality was opposed. I could go on and on with things that were opposed that have changed over the last 20 or 30 years. I think the climate of opinion in relation to assisted dying has significantly changed. It is also very interesting to look at recent legal decisions in this area. In the case of Ms B, the President of the Family Court, Dame Elizabeth Butler-Sloss, laid out the principles very clearly and they were recently referred to by Judge Mundy in another decision where he says that personal autonomy trumps sanctity of life. I think these traditional pronouncements and the views of society lead me to believe that what may 100 years ago or 2,000 years ago have been a moral principle, determined in quite a different environment where patients' lives could not be extended almost indefinitely as at the moment, may no longer be of application today.

Q91 Bishop of St Albans: It is possible, therefore, on that basis, to assume there will be a change in how we regard the importance of personal autonomy. Therefore it is possible to assume that there may be a change in such a way that personal autonomy is no longer the highest good but that something else may be in which human life is no longer regarded as of very great significance?

Lord Joffe: I am sorry, I missed the last part. I thought you were saying that the view of personal autonomy might change.

Q92 Bishop of St Albans: If other things—

Lord Joffe: I accepted that. What was the follow on?

Q93 Bishop of St Albans: I obviously do not agree with some of your remarks, but I am just taking for the moment the assumption—that I believe to be accurate, of course—that certain opinions change.

Lord Joffe: Yes.

Q94 Bishop of St Albans: If that is the case, then the current assumption in society that personal autonomy is self-authenticatingly the highest good is a moral judgment which could in future change.

Lord Joffe: I think it could change. You cannot exclude the possibility that there will be change, as you correctly point out, but that is a matter for future legislators to take into account and not us.

Q95 Bishop of St Albans: Precisely. We are legislating not for yesterday or today but for the future.

Lord Joffe: Yes.

Q96 Bishop of St Albans: If it is conceivable that views of personal autonomy will change, it is therefore conceivable that what we are looking at here could be used for very deleterious effect.

Lord Joffe: No, you could not use anything over here for that purpose. This Bill is very tightly drawn and is very limited in its application: to terminally ill patients who are competent adults suffering unbearably. It is very limited.

Q97 Bishop of St Albans: Unless the Secretary of State happens to come to a different view.

Lord Joffe: The Secretary of State might come to a different view and he might introduce new legislation, but we cannot today say that we should not introduce legislation today because somebody in the future might decide to change that legislation.

Bishop of St Albans: I think I have been misunderstood, but I ought to stop.

Q98 Baroness Jay of Paddington: I wonder if I could return to some of the practicalities. We discussed the issues of autonomy quite extensively when we met before, but I am quite concerned, Lord Joffe, about the point you are making about what I think you described—and I may have misheard you—as a “different standard of concern” that is used in medical practice and other practice, towards what I think you described as “other end-of-life decisions”, rather than what you are proposing in this Bill. Could you expand on that.

Lord Joffe: Basically, there are a number of other end-of-life decisions which take place; such as withholding treatment, and withdrawing treatment. There are also decisions taken, indeed, in relation to double effect which have the effect of ending a person's life, and there are decisions taken in relation to terminal sedation which in my view are indistinguishable from assisted dying as we have defined it. In all these cases, there is no legislation; no safeguards whatsoever. There are guidelines in relation to withholding treatment, and advice given by the General Medical Council or the BMA—I am not sure which, or perhaps both—but there is no legislation. There is no requirement for second doctors actually to be there, as we have provided; there is no requirement for palliative care specialists to explain the benefits of palliative care. And these decisions are end-of-life decisions, just as assisted dying is, so it is disturbing that all these objections are raised in relation to assisted dying and not raised in relation to these other end-of-life decisions which happen to be all in the power of the doctor—and that might perhaps be the key—whereas, with assisted dying, the essential point is that it is the patient who makes that decision.

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Q99 Baroness Jay of Paddington: May I follow that up because, as I understand it, that reflects—as I would have imagined your Bill primarily reflected—on the relationship between the individual clinician and the person involved. I wonder how this impacts on what Lord Carlile was saying about the disparity of practice that might arise if you had to be, as it were, orchestrated at a local level, by a formal decision of a local strategic health authority or a local trust. My understanding would be, following your concerns about what you have just described—the other end-of-life decisions, that you would presumably have what Lord Carlile would see as disparities or anomalies in that system. Am I in an area where it is not appropriate to discuss it because it is not discussed? Or is that in fact what is going on, that withholding treatment, for example, is differently practised in Area A and Area B?

Lord Joffe: I am not an expert on what happens in all the different parts of the country in different trusts, but I think there are almost inevitably going to be differences of approach. But I know of no cases where these end-of-life decisions are taken with the extent of the care and the range of safeguards that we have in this Bill.

Q100 Baroness Thomas of Walliswood: Could I ask you a more tightly drawn question relating to a particular subject. Some of the evidence we have received has shown that in the eyes of the people producing the evidence there is an absence, incorrect absence, of reference to the nursing profession in the Bill. The sort of point that is made is that, in effect, while doctors might prescribe the dose or prescribe the treatment, it is very often the nurse who delivers the treatment. The other element that struck my attention in this range of evidence was that it is very often the nurse who is maintaining the detail of the record which is kept of the patient and of the progress of the patient and of the treatment given to the patient. It therefore seems odd that you do not mention the word “nurse”. In order not to disconcert nurses and to ensure that their professional expertise and the level of care which they deliver to extremely ill and terminally ill patients is not, as it were, put on one side and undervalued, would you agree that it might be sensible to try to alter some of the terminology, so that you have “consultant physicians, nurses and other members of the team” or something like that, so that they are actually drawn in? Of course it will affect their views as well. Some nurses might not wish to be involved, and I think therefore their position as conscientious objectors should also be protected in the same way as is the case with physicians. This is a very down-to-earth kind of point compared with the points that have been made before, but I think it is nevertheless one which may

have an effect on the acceptability of the Bill, if that is what you want to achieve.

Lord Joffe: I certainly agree with you. I think nurses have a key role to play. They are often closer to the patients than the doctors: they are with them all the time. They are only mentioned, as I can see, once specifically, in relation to the palliative care specialists; they are mentioned by implication under the medical care team. The last thing I would want to do is to suggest that nurses should be overlooked in this process, because they will actually be part of the process, and, as you correctly point out, they administer the drugs. They are often key to the treatment of the patient. I would like to think about how we can draw attention to this in the Bill, if there is a sense that nurses have been overlooked, because that is the last thing that we intended.

Q101 Lord Patel: My questions relate to the practical aspects of the Bill. You started by saying that this Bill is about patients in whom palliative care has not been the answer to the distress: the pain continues despite the palliative care. Could you say to what percentage of patients who are terminally ill this Bill would apply?

Lord Joffe: Yes, the evidence that I have studied suggests that it covers something between 3 to 7 per cent of patients who are terminally ill.

Q102 Lord Patel: My second question concerns the rights of the patient to be referred if the physician caring for the patient has a conscientious objection. In that case, the physician who has looked after the patient is no longer to be involved in the process of assisted dying and there may well be a physician who is totally unknown to the patient. Will that be a satisfactory situation? As we understand from the evidence presented in The Netherlands, it is a physician who is known to the patient who is—

Lord Joffe: As you correctly point out, in The Netherlands, where general practitioners tend to be in small practices, they really do know their patients. In Oregon, of course, the position is different, and the relationship, I think, is not dissimilar from the position in this country. I think it will always be preferable to have a physician involved who knows the patient, but that should not be a bar to a patient who is suffering terribly and measures up to all the requirements set out in this Act. But I think one can do other things. I think one must have access to the records of the general practitioner and the hospital records so that the doctor taking over can be conversant with what has happened in the past. I think it would be necessary in those cases—and I am sure the guidelines which will be prepared will cover it—that they talk to the families. It is not ideal. One needs to look for ways to close this advantage which

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applies to physicians who are assisting a patient whom they know well to die.

Q103 Lord Patel: My last question is on the very point to which you have referred, where the majority of these procedures are carried out by general practitioners who are well known to the patient. Today and several times before we have heard in the chamber that many of the patients who are terminally ill wish to die at home, and yet the general practitioner involvement would appear to be much less because the Bill refers continuously to the consultant.

Lord Joffe: I think if you counted the number of times reference is made to “attending physician”, it is referred to several more times, but that is because they have additional responsibilities. To the best of my knowledge, there is only one case where the consulting physician is solely mentioned in an important way and that relates to the determination of the illness. We ask that the consultant should be a specialist in the particular area of illness from which the patient is suffering, and therefore we think that the opinion of the consultant is the most important one in relation to that diagnosis and prognosis.

Q104 Earl of Arran: Following on from Lord Patel’s point, I have a slight layman-like anxiety about the consulting physician, in that so often when one goes for a consultation on whatever is wrong with one and you go to two or three different consultants, you very frequently get two or three different opinions. Do you consider there would be any merit in having two consultant physicians, thereby making three altogether: the attending physician and two consultants? It is a pivotal point of the whole process of the right to die.

Lord Joffe: I think it is a pivotal process of the whole process of medicine. If in every case one wants several consultants to make the decision, I think it would actually tax the resources of the NHS considerably. I see your point, but I think there are limitations to the number of safeguards we can have—and I come back to the comparison which we have. Doctors, in the nature of their work, cannot ever be certain. They are making diagnoses on the basis of their experience and their assessment of the patient and they are not infrequently wrong. Indeed, I saw a report published recently in the BMJ that said that 40,000 patients die every year in the United Kingdom because of clinical or other errors. I am not an authority on this, but I just mention this in passing. My view is that one has to strike a balance. We have already introduced so many safeguards—and, remember, always, underlying it all, is the patient’s autonomy: the patient making the decision. I think the average patient who is asking to die, after considering all the factors that have been brought to his attention,

would probably not feel the need for a second consultant. That said, it is a question of judgment. Just by way of comparison, if I may come back to the position of all the other end-of-life decisions, there is no requirement for more than one consultant and sometimes, perhaps, not even a consultant to make a decision which leads inevitably to the death of a patient.

Q105 Earl of Arran: So you do not see, therefore, a worrying dissent between the attending physician and the consultant physician if they disagree.

Lord Joffe: If they both disagree, the process cannot proceed.

Q106 Chairman: Lord Joffe, I would like to ask you a number of questions about the detailed drafting of the Bill. I think this is probably the best opportunity to do that. You may well have a wish to consider, in the light of what we have looked at, just if any further changes can be made. I think it is clear that this Bill deals only with competent adults.

Lord Joffe: Yes. I think it is very clear.

Q107 Chairman: Therefore, there is immediately a distinction between the plight of those who may be suffering unbearably but are affected in their mind in such a way as no longer to be competent.

Lord Joffe: That is correct.

Q108 Chairman: Your Bill does not attempt to deal with that.

Lord Joffe: No. The reason why it does not attempt to deal with that is that it is based on the principle of autonomy and only a competent patient can make a decision in relation to his or her own life. For people who are mentally incompetent there needs to be, perhaps, a different system, but it cannot be based, in my view, on personal autonomy.

Q109 Chairman: Your Bill is also based on the principle of humanity, you have explained to us, and that would apply to the incompetent as well as the competent. Anyway, it is clear that at the present moment this Bill deals only with those who are competent, in the sense that their minds are in such health that they can take a reasonable decision.

Lord Joffe: That is the basis of the Bill.

Q110 Chairman: The next point is on the preamble—the long title, I think we have called it: “...to receive medical assistance to die at his own”—taking the masculine—“considered and persistent request . . .”—and I think that is related to the time. That is why we have a 14-day period provided for in the Bill, is that right, so that one could regard the request as persisted in over a period?

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Lord Joffe: Yes, I think there has to be a serious request which persists after the 14-day period.

Q111 Chairman: We then come down into the sections. First of all, clause 1, sub-clause (1): “Subject to the provisions of this Act, it shall be lawful for a physician to assist a patient . . . to die.” The general law is that assisting someone to commit suicide is an offence.

Lord Joffe: Yes, I am aware of that.

Q112 Chairman: Do you envisage this Act as providing a defence to a medical practitioner who might otherwise be accused of committing an offence?

Lord Joffe: That is the intention.

Q113 Chairman: So that the burden of proving that all the qualifications have been met will be on the medical practitioner seeking to defend himself against a charge of complicity in suicides?

Lord Joffe: If he were charged, that would be the position.

Q114 Chairman: The next point I want to make sure I understand is in sub-clause (2) of clause 1, where it says “if the patient is physically unable to do so”—that is to take his or her own life—then, in effect, the attending physician can do so?

Lord Joffe: That is correct.

Q115 Chairman: In the case of a person who is unable because of physical weakness to end his or her own life, the doctor actually deliberately ends their life?

Lord Joffe: That is correct.

Q116 Chairman: You have dealt with this already, but I just want to be clear about it. The attending physician need not be, according to the Bill, a National Health Service practitioner?

Lord Joffe: No, they do not have to be. That is correct.

Q117 Chairman: I know that you made a distinction to do with a sort of specialisation in assisting people to die. That is what I took to be a reason for requiring it in respect of the consulting physician. What is the scope of that consideration in relation to the attending physician?

Lord Joffe: The attending physician seemed to me to be a physician who is already in place. The patient has a GP, and therefore the GP, if it is a private GP or an NHS GP, is already the doctor of that particular patient.

Q118 Chairman: I can see that would be the normal situation, but of course you might have a general practitioner who had a conscientious objection to becoming involved?

Lord Joffe: That is correct, and they would have to look for another doctor.

Q119 Chairman: I am wondering about the scope of the National Health Service situation in that connection?

Lord Joffe: Yes, I see what you are leading to. I think we need to consider the implication of what you are saying because it suggests that there could be a specialist general practitioner.

Q120 Chairman: That is right. I am not doing more than raising this issue.

Lord Joffe: That is very helpful.

Chairman: Lady Finlay, do you want to add something, because I am going to stop for a while, and I have a number of questions on this sort of line that I want to ask so that we understand fully the provisions of the Bill.

Q121 Baroness Finlay of Llandaff: Thank you, my Lord Chairman. You say much about the autonomy of the patient being paramount and you did say in your initial opening remarks that you saw this as the beginning of a stage which would extend in incremental stages.

Lord Joffe: At the beginning of the legislation.

Q122 Baroness Finlay of Llandaff: Yes.

Lord Joffe: It was a first stage and possibly the final stage but there could be subsequent stages.

Q123 Baroness Finlay of Llandaff: The previous Bill did not restrict the euthanasia or physician-assisted suicide to the terminally ill. I wondered why you felt that those people who deem themselves to be suffering unbearably but have a long prognosis are not eligible, whereas those people who will be dying anyway in the foreseeable future would then be eligible to be killed?

Lord Joffe: May I first say that to use emotive language, “to be killed”, actually sounds almost pejorative. I think it is “being assisted to die that” I would prefer, for myself, but obviously it is a matter of personal preference.

Q124 Baroness Finlay of Llandaff: Perhaps we should stick with “having their life ended”?

Lord Joffe: Yes, “having their life ended” would be fine. When we considered the opposition to the previous Bill, we felt that there was such strength of feeling in the debate about extending it to younger people who had a long lifetime ahead of them, that we thought it wise, coming back to my point about

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moving in incremental stages, to limit it to terminally ill patients who were already suffering terribly and had a very short time to live. But I can assure you that I would prefer that the law did apply to patients who were younger and who were not terminally ill but who were suffering unbearably, and if there is a move to insert that into the Bill I would certainly support it.

Q125 Baroness Finlay of Llandaff: Could you tell me just a little bit about the cost background to your Bill, the costing of the implementation of your Bill?

Lord Joffe: We have no adequate information at the moment on costing. I think with a Private Member's Bill one is concerned, I am told, to deal with the principles of the Bill. You come to it without any real resources as a Private Member and you raise what you think is an important and ethical matter which will hopefully subsequently be taken up by government, who will then consult widely and will address matters such as cost.

Q126 Baroness Finlay of Llandaff: The reason I come to cost is that I am not sure in your safeguards quite where you will safeguard against a perception by a patient, which may not be said to them by any one individual, that they are costing their family or the NHS a large amount of money by their ongoing care, and that therefore their death should be expedited out of some sense of duty to prevent this ongoing expenditure.

Lord Joffe: In talking about the expense—and it is admirable to think that any patients would be bothered about the expense to the NHS—it is important to appreciate that the patient has only a short time to live, so the amount of expense is limited by the time period that they will survive. The question of expense, on the experience, as I understand it, in Oregon and The Netherlands, has not been a major issue with almost any patient, although I could think of circumstances in which it would influence a decision. But if when the consultant speaks to the patient about their unbearable suffering, they say they are suffering about the cost to them, I do not think that would be sufficient reason by itself to persuade anyone that that justified their being assisted to die. It might be a factor, together with a number of other related factors.

Q127 Baroness Finlay of Llandaff: You say in the Bill that the patient must be informed of the process of being assisted to die. Could you take me through exactly what information they should have to fulfil the conditions within the Bill?

Lord Joffe: At that stage they have been taken through all the other processes already, but it comes up early in what the doctor is saying, so the doctor would tell the patient about all the safeguards in the Bill and then would say at the end of it, "If you still

insist on dying, you will be provided with drugs which you may or may not take."

Q128 Baroness Finlay of Llandaff: I think there is a little bit more, with all due respect, to the process of being assisted to die, in terms of the need to inform the patient that if they take the drugs orally they may fail.

Lord Joffe: It would depend on the statistical evidence, but there is a very remote chance that it would fail. If you refer to the evidence in Oregon, it has never failed so far, although it did take one patient 48 hours to die: he was in a coma all the time, and the doctor had explained this to the family that it could happen—and the family, as it happened, were quite satisfied with what eventually happened and the patient was unaware of it.

Q129 Baroness Finlay of Llandaff: Given the concerns about the doctor having to be convinced that there is unbearable suffering—which is a subjective judgment at the end of the day, and therefore he would be obliged to take the patient's word for their perception of their suffering being unbearable—I had wondered why in fact you had not suggested taking the whole thing outside medicine and having a completely separate service. Because you are talking about a single lethal dose which would be vastly higher than any therapeutic dose, and if you are going to give barbiturates and curare—and curare certainly is not used in the community, I would have thought, almost never—so that it would be a drug solely limited to the process of assistance in dying?

Lord Joffe: I am not sure what the question is. I am sorry. It might be because I am not medically educated.

Q130 Baroness Finlay of Llandaff: I am wondering why not take it completely outside medicine, so that you do not change the tenor of clinical care and you have a completely separate service—you could call it thanatology service.

Lord Joffe: I think that is an interesting thought which deserves further considerations. We have thought about it and we have learned that in The Netherlands doctors really worry about assisting patients to die—it is not something they move into enthusiastically and it causes considerable concern. But on the surveys which have been taken in The Netherlands, and certainly in Oregon, the sense is that doctors often feel that actually that is part of their treatment of a patient whom they have known for a considerable time (if they have known them for a considerable time), and they feel that they have done the right thing by their patient. Some doctors might feel that actually they want to be involved; it is part of the treatment for the patient of whom they are very

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fond and want to assist. That said, there would be some doctors who did not feel that, and I think that further consideration should be given to the point that you make.

Q131 Baroness Finlay of Llandaff: If you view physician-assisted suicide and euthanasia as a therapeutic option, do you accept then that every doctor has a duty to inform the patient of the therapeutic options available in their situation?

Lord Joffe: I have thought about that very carefully and have taken medical advice on that subject from an expert in this field, and they say that, in the stages of an illness, at the beginning one would not raise it. Gradually the patient might become worse and worse, and they would have the benefit of palliative care hopefully, and they may then feel that they really wanted to ask for assistance to die—and of course if at any stage the patient raises the matter, then there is a duty on the doctor to discuss it openly with him or her. If, on the other hand, the patient does not raise it and is suffering unbearably towards the end stages of their life, then I think there would be a duty on the doctor to raise this as one of the other options—not the preferred option, but an option that exists. It is interesting to see the way they do it in Oregon. In Oregon everybody who enters into a hospice is given a form. Over here, if you are undergoing treatment your doctor will give you a description of what is involved and the side effects, and in Oregon there is a form, which is prepared by the Hospice Association, which goes to the patient which sets out in, I think, the most compassionate way the various options, including the option to die. I would be very happy to distribute this standard form which they use in Oregon to the members of the Committee.

Q132 Baroness Finlay of Llandaff: I have a slight difficulty with “option to die” because, sadly, all the patients who are terminally ill automatically have that option.

Lord Joffe: I am sorry, I was endeavouring to be briefer than I normally am: “all the patients who are asking for assistance to die” if that covers the point that you wish to make.

Q133 Baroness Finlay of Llandaff: The last point I would like to come to is the assessment of competence and the recognition in the Mental Capacity Bill that the competence required to take a decision relates to the size of the decision taken. I wondered, therefore, what safeguards you would have in for the clinician, where the family have not been informed and not been involved in the process, whereby after the event they would come and challenge that the patient was not actually fully competent to take such an enormous decision, even though they may have been perfectly competent to

decide where they want to go, what they want to wear and what they want to eat, and, indeed, to be informed about their symptoms and the effective symptom control that they have?

Lord Joffe: I think that is a point that we have been considering. I think that it is implicit in the Bill that, at the time the patient is assisted to die, and certainly actively being provided with the drugs, they should be competent and that the doctor should give attention to that, because they are given the option to revoke their declaration at any stage and in order to revoke it they have to be competent. I think that is an area which does need attention and which we might feel should be included in the Bill. Might I add, again, let us compare it with the lack of safeguards in all the other end-of-life decisions, where competence apparently is not something which is raised continuously—although the case might be that it ought to be.

Baroness Finlay of Llandaff: I think it will be.

Q134 Chairman: Lord Joffe, I have a number of questions of the same type, as I was asking earlier. Could we go back to clauses 1 and 2. The consulting physician is said to be required to be independent of the attending physician, and you gave the illustration of not being a partner or anything like that. What else? One of the ideas that I think this is dealing with is the sort of idea of two who have very much the same idea—you know, that if the attending physician thinks the suggestion should be in favour of assisted dying, then he knows the consulting physician to get who would support that. You want really to strike at that, I imagine, and suggest that they should be utterly independent, one from the other?

Lord Joffe: It is a question of balance. I think it might be difficult to get the right consultant and in that event you should be able to use someone who is known to you as the attending physician regardless of the fact that you have used them before. But I think independence seems to mean that there is no financial relationship certainly between the two. I would hope that the GMC/BMA in preparing the guidelines would give attention to this question of what in the real world does this mean, and give guidance to doctors.

Q135 Chairman: Basically, it is the absence of any financial connection anyway?

Lord Joffe: Yes.

Q136 Chairman: That is essential?

Lord Joffe: I think that is right.

Q137 Chairman: Could we come on to the definition of terminal illness, please, which is quite fundamental to what you wish to have in this Bill. You say “inevitably progressive”?

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Lord Joffe: Yes.

Q138 Chairman: "... the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) ..." I have the impression that some of these illnesses anyway can have considerable, what is described as, "remission". Is that intended to be covered by "relieving symptoms temporarily" by treatment?

Lord Joffe: That was the intention, yes.

Q139 Chairman: The next point is immediately following, and it is the point to which Lady Finlay referred—the "unbearable suffering" definition depends on the patient's subjective view of the matter?

Lord Joffe: It does.

Q140 Chairman: We come on to the qualifying conditions. "The attending physician shall have (a) been informed by the patient that the patient wishes to be assisted to die." One would expect that that kind of request would not come out of the blue completely. I do not think there is any particular discussion in the Bill of any parameters under which the attending physician might discuss these matters with the patient prior to the patient's request?

Lord Joffe: I think that point is one which has been exercising my mind as well. It seemed to me that what we are talking about here is a formal request. I imagine the process—and Lady Finlay would be much more conversant with what happens with palliative care—that the patient at some stage might express an intention/ask for assistance to die, but it might not be a serious ask—it might be a cry for help: that could be how they feel at that particular time—and this would be discussed with the attending physician and with the nurses, I am sure—because the first request might be to the nurse and at some stage there would be a formal request. I think perhaps we should be amending the bill to say that it is the formal request which should start the process. I think that is right.

Q141 Chairman: It is worth considering anyway. I do not know what the right phrase might be, but you would want to consider it maybe. (d) is related to the definition of unbearable suffering.

Lord Joffe: Yes.

Q142 Chairman: My understanding is that the attending physician has to conclude that the patient is suffering unbearably. But it is the patient that really has to conclude that he or she is suffering unbearably. What is the decision that the attending physician is required to have? Is it that in his or her view it is reasonable to believe that the patient has concluded that the suffering is unbearable?

Lord Joffe: I think that is right, with one proviso:—whether it is reasonable for that patient to have come to that conclusion. I would imagine that if a patient, for example, said they want to die because they have got a cold and it is causing them inconvenience, and they told the doctor that, that would not be a ground. On the other hand, if they were Dianne Pretty and they told the doctor that they wanted to die, suffering from Motor Neurone, as she was, and in this terrible state, there would be no problem. There is a range of areas in between. I think the doctor must put himself in the position of that particular patient and, looking at it from that perspective, say ...

Q143 Chairman: It is the patient's feeling that it is unbearable that is important?

Lord Joffe: It is, yes.

Q144 Chairman: Therefore, it is the question of whether the general practitioner, the attending physician is satisfied that the patient has really reached that conclusion. That is the idea?

Lord Joffe: Yes, that is very much the idea. It must be reasonable, as you point out.

Q145 Chairman: Then the consulting physician is in the same position in (3)(b)?

Lord Joffe: It is the same test.

Q146 Chairman: It is the same kind of question. Clause 3 deals with the offer of palliative care. I feel certain concerns about this "to discuss the option of palliative care". One would expect, and perhaps you will help me as to whether that is your expectation, that before a patient got into the situation of considering anything along the lines of this Bill, he or she would have experienced such palliative care as it was possible to provide?

Lord Joffe: I am not sure that is actually the position. I have read an article by Lady Finlay which refers to areas where palliative care is virtually non-existent or so poor that she does not blame them in the first place for asking for assistance to die, even though she does not believe that is the solution. I think palliative care is not an offer in the sense—and perhaps that word needs to be changed—of "We can give you palliative care and that will give you precedence over all the other people waiting for palliative care." It is to say "Palliative care does exist, this is what it could do for you, perhaps you would like to explore whether it is available."

Q147 Chairman: I personally would find it difficult to get into the situation where there were areas of the country which were suggested in which palliative care was very poor or non-existent and there were a certain number of requests for assisted dying in these.

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That would not be a situation, I think, that you would wish to contemplate under your Bill.

Lord Joffe: No, I do not think that is what I am suggesting. I am saying that everybody who wants to qualify under this Bill has to have considered palliative care and decided whether they want to take advantage of that particular care rather than proceed with assistance to die.

Q148 Chairman: It is on the assumption, is it, that if they wish palliative care that is what they will get?

Lord Joffe: In a country where palliative care is totally inadequate in many parts, we cannot, through this Bill, attempt to give a right to palliative care to everyone because it would be a right which could not be met. All we can say is that if the patient wants to have palliative care he should ask for it and they should try to arrange it, but if they do not, if it is not possible, then the patient must make up his mind. That is what autonomy is about. It is about choosing between the options available to you rather than the ones you would like to have.

Q149 Chairman: Clause 5(c) says, “ . . . asked the patient immediately before assisting him to die whether he wishes to revoke the declaration.” There is quite a lot of provision about the declaration but there is not much provision about protecting the physician in relation to whether or not the physician has informed him about revoking the declaration immediately before he proceeds to administer the dose or make available the prescription. Would you like to consider what the situation is if there should be a dispute about that?

Lord Joffe: I think it does need consideration. It seems to me we do provide that the doctor must verify—that is 5(b) “verified immediately”—so we would assume, again dependent on the guidelines, that he would ask the medical team whether there has been any request for revocation of the request. He would look at the file as well. But I think your point is a valid point which needs to be considered, because it could place a considerable responsibility on the doctor without necessarily giving him the means to check the position out. I think we will be assisted in this regard by our visits to Oregon and to The Netherlands, where we can explore that particular point.

Q150 Chairman: In clause 8 the position is that if either the attending physician or the consulting physician has doubt about the competence of the patient, then a psychiatrist has to be called in. In relation to sub-clause (2) of clause 8, when the psychiatrist has arrived he is also to consider whether the patient is suffering from a psychiatric or psychological disorder, causing impaired judgment, and that the patient is competent. These seem to be somewhat distinct; in other words, you can

distinguish between competence and impairment of judgment that might arise, say, from depression. I am not clear why that concern is only to be considered in a situation where the physicians attending and consulting have a doubt about the competence of the patient. Should they not also seek psychiatric advice if there is any possibility in their minds that the patient is suffering from some psychiatric or psychological disorder that could impair their judgment?

Lord Joffe: Wherever there are indications which suggest that the patient may be suffering from one sort of illness or another which could affect their competence, I think they should be referred to the psychiatrist.

Q151 Chairman: It seems to be to be assumed in (2) that you could be competent and still suffer from depression or something of the kind.

Lord Joffe: Yes, I think we have to look further into that point and take medical advice on it, because I think the key to it is really competence to make the particular very serious decision which has to be made, and we might not need anything about psychiatric illnesses, which I think muddies the position.

Q152 Chairman: If you would go down to clause 11(3): “A person commits an offence if he wilfully conceals or destroys a declaration made under section 4.” It is obvious that if the declaration has been revoked it should be destroyed, so that clause is a bit too embracing in the way it is phrased at the moment?

Lord Joffe: Does “wilfully” not suggest “with bad intent”?

Q153 Chairman: I am not sure that it does. It just means to have intent. Intent need not be bad, need it?

Lord Joffe: I see the point. Thank you.

Q154 Chairman: It is worth looking at that. Clause 11(5): “No provision of this Act shall be taken to affect a person’s liability on conviction to criminal penalties for conduct which is inconsistent with the provisions of this Act.” That means conduct which is not protected by the provisions of this Act?

Lord Joffe: Yes, that is correct, my Lord Chairman. Basically, the approach is that this Bill is not intended to give anyone any rights other than these very limited rights which are set out in the Bill.

Q155 Chairman: If a person was accused, he or she would have to bring themselves within the conditions specified in the Act?

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Lord Joffe: They would have to do that and that is one of the purposes of requiring all the documentation to be maintained and to be sent to the monitoring commission.

Q156 Chairman: I expect you have proposed an amendment to clause 14(3). It has a bit about Scotland in it and you were going to take out the application to Scotland, so I assume that bit has gone as well?

Lord Joffe: Yes. I think it is in the Notice of Amendment but not in here. It should be correct in the one I have circulated. Thank you.

Q157 Chairman: The last thing I want to ask you about is in relation to clause 15: "A patient suffering from a terminal illness shall be entitled to request and receive such medication as may be necessary . . ." Who has this duty?

Lord Joffe: It would be, in my view, the attending physician and the medical team. It is only where a patient is suffering and either the GP or the hospital are not providing sufficient and adequate medication to control the pain that they would seek to invoke this right.

Chairman: There is a problem about transition from one physician to another. If the attending physician has a conscientious objection, for example, there may be a certain time-lag between another physician coming in. I would have thought that this kind of clause is directed against public rights.

Lord Carlile of Berriew: Chairman, if I may, exactly the same point arises in relation to clause 7, as amended in manuscript. Forgive me for interrupting, but I am interested in the answer in relation to clause 7, which is crucial.

Q158 Chairman: Yes. That is a question of who is obliged to provide an alternative attending physician if the attending physician you have has a conscientious objection to becoming involved in this process at all? It is basically the same point. I am grateful to Lord Carlile for pointing it out.

Lord Joffe: Yes. First, it would be my assumption that most attending physicians even with a conscientious objection would not like to leave their patient totally unattended. I feel that in carrying on attending to them, they are not actually participating in the decision to assist them to die but they are carrying on with the care which they would be giving in any event.

Q159 Chairman: The transition might be of some importance. This does look like an obligation which would transcend the particular physicians that were involved. Certainly the one in clause 7 would do that. It looks as though the obligation should be put upon some authority or other, the Secretary of State as the

National Health Service, is perhaps the most obvious one?

Lord Joffe: If I might, I think what this particular clause says is that "No person shall be under a duty to participate in any diagnosis, treatment or other action authorised by this Act". But it does not say that this in any way absolves them from their duty to care for the patient.

Q160 Chairman: No, I follow that, but of course if the patient is wanting to have the benefit of this or the process provided in this Bill, it may well be that there will be a hiatus. In any case, the real point is that if the existing physician does not think it right to do something or other, the ultimate responsibility must surely be on the Secretary of State as the National Health Service?

Lord Joffe: I think that would be the position.

Chairman: Thank you very much. That is all I wanted to ask.

Baroness Jay of Paddington: Could I make a general point, my Lord Chairman, and I hope you will not think it is disobliging. I have found many of the points that you were making extremely helpful and, I do not know, Lord Joffe may want to incorporate some of them. On the discussion you had about the duty on the Secretary of State as well, for example—as an ex-Minister of Health who has taken legislation related to duties of care in health matters through the House of Lords—I think that is always something which is complex and often subject to amendment and provisions of detail which are often not on the face of the Bill in primary legislation. I do think we should not lose sight of the point which Lord Joffe made, that this is a Private Member's Bill, that, as was said right at the beginning—I think Lord Joffe expressed this hope—if the principle of it was accepted, then it might become something which either became a proposal from the Government or became something which was subject to detailed drafting by the Public Bill Office or, anyway, in a sense came within what one might describe as a more formal process of legislation. I do think, for example, that this last discussion about the duty of the Secretary of State or the relevant person is exactly the kind of thing which would have to be done in a slightly different context from the one we are discussing about the principle of the Bill. As I say, I hope I am not making disobliging or general points about the very helpful points that you made in some areas.

Chairman: I understand that, of course, but I just wanted to have Lord Joffe's comment on these points which have occurred to me on reading through the Bill. The fact is that the terms of reference of the Select Committee are really dependent upon the terms of this particular Bill, and of course the degree to which it may be acceptable or otherwise may

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depend, in an area like this, to some extent at least, on the detail. It is quite obvious that Lord Joffe and his advisers have taken a great deal of trouble to circumscribe the Bill and to provide safeguards and so on, and to an extent these may determine in many people's minds whether or not it is acceptable.

Baroness Jay of Paddington: I absolutely agree with that point and of course the point Lady Thomas made about including nurses, for example, under the provision. I was really thinking about the determinants of responsibility and practice within either the private health care sector or the public health care sector that might be things which would be included in a bill under schedules or under the relevant regulations as circumscribed by the Department of Health or the regulating health authorities.

Q161 Dr Hillier: There is one very practical thing which might be a hiccup: as I understand it, we have not mentioned coroners. They might regard this as an unnatural death and therefore a reportable death, and if that happens then it will have to be reported—which will involve the police and possibly an autopsy. I guess these are things you would want to avoid. I wonder if you have had any thoughts about that?

Lord Joffe: I actually have not thought about that. Thank you very much for raising it. It needs consideration. I think the approach I am adopting to this Bill is that I really would value suggestions as to how it can be improved. I am not a parliamentary draftsman and I am sure it can be improved and other issues can be raised which I would like to consider and then think of adding to the list of amendments.

Q162 Chairman: Of course the coroners' system is under review at the present time and obviously there would be some degree of connection between a Bill in this area and what is being done in relation to the coroners.

Lord Joffe: Indeed, it is one of the points that I raised, that if the Coroners' Bill moves in a particular direction it creates real issues for doctors.

Q163 Baroness Thomas of Walliswood: Apropos the point made by Dr Hillier about the Dutch description of the process, the way in which the law was amended and how it works in Holland, it does say—and this is relevant to what has been said—that the physician who has ended the patient's life has to report the case to the medical examiner. I do not know what the English equivalent of a medical examiner is, but it does suggest that it is submitted to what one might call "peer review", as it were, and that is the first stage. Then it goes on to a regional evaluation committee. That is rather like the monitoring committee that you set up. And within six weeks the committee decide whether or not the physician has acted in conformity with the legal requirements and if not it goes to the next legal or criminal investigator stage. I do not know what the British equivalent of a medical examiner might be, but it is obvious that a doctor's peers might well feel that he had done the wrong thing and might want to make objection to that. I am not quite sure where the rule is for that to happen or whether you think it is desirable to allow it to happen. I am not a doctor. I know nothing about the medical profession, except as a patient, so I should not make assumptions, but it is something which might arise.

Lord Joffe: It is the practice in the Netherlands for the doctor immediately after he has assisted a patient to die to get in touch with the medical advisor, or the coroner's office I think it is, or the equivalent, and they have a meeting and interview. But then it still goes to the monitoring committee.

Lord Patel: A facility as in the provision of this Bill does not exist, so there is no such monitoring committee. I would say that it would be inappropriate to go to a regulatory authority such as the GMC, because their role is quite different. It would have to be another authority if that was the case.

Baroness Thomas of Walliswood: That might not be appropriate, to set up a special authority.

Q164 Chairman: The Bill proposes a monitoring commission which would be in the nature of a regulatory authority, I suppose?

Lord Joffe: Yes.

Chairman: Thank you very much, Lord Joffe, for helping us.

THURSDAY 14 OCTOBER 2004

MORNING

Present	Carlile of Berriew, L Finlay of Llandaff, B Jay of Paddington, B Joffe, L Mackay of Clashfern, L (Chairman)	McColl of Dulwich, L Patel, L St Albans, Bp Taverne, L Thomas of Walliswood, B Turnberg, L
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Memorandum by “Right to Life”

“RIGHT TO LIFE” IS OPPOSED TO THE ASSISTED DYING FOR THE TERMINALLY ILL BILL

1. “Right to Life” is not a religious group and has supporters from many different denominations and of no faith. Nonetheless, we agree with the Joint Statement of the Roman Catholic and Anglican Churches that was submitted to the House of Lords Select Committee on Medical Ethics (1995) in which they stressed that:

- (a) while both churches oppose euthanasia, they do not support excessive action in maintaining life “by all possible means and for as long as possible”;
- (b) they do not believe that “the right to autonomy is absolute. It is valid only when it recognises other moral values, especially with respect to human life . . . whether someone else’s or not”.

The same view on autonomy was expressed by the House of Lords in their judgement on the Dianne Pretty case. This was upheld by the European Court of Human Rights when Mrs Pretty appealed. Both the Lords and the European Court asserted that there is no “right to die”. The European Court—in particular—considered that to grant such a “right” would undermine the rights of the disabled and other vulnerable groups.

2. The current campaigns promoting the legalisation of euthanasia have had some extremely adverse repercussions. The Voluntary Euthanasia Society (VES) have widely publicised claims implying that doctors are practising clandestine euthanasia on a wide scale. However, available evidence clearly shows that most doctors are opposed to euthanasia and to assisted suicide.

The most recent large survey¹ was conducted by ORB (The Opinion Research Business) through Doctors.net, which is regarded as the foremost medical Internet company in the UK. A total of 9,000 doctors, selected at random, were approached and 986 medical practitioners completed the survey over a two-week period from 26 March to 9 April 2003. The 11 per cent response rate was typical of this type of Internet study. It revealed that a majority of doctors are opposed to both euthanasia (61 per cent) or assisted suicide (60 per cent). Only 22 per cent of doctors were in favour of euthanasia and only 25 per cent were in favour of assisted suicide. A significant number (13 per cent) were undecided, mainly because they were not directly involved in the decision-making process. Most doctors would refuse to perform either euthanasia (76 per cent) or assisted suicide (74 per cent) if it were legalised.

On a number of occasions the VES has asserted that euthanasia is practised widely in the hospice movement—although the above survey showed that not one palliative care doctor who responded was prepared to perform euthanasia or assisted suicide. However, the VES seems to equate euthanasia with the “double effect principle” in which drugs given to relieve pain and symptoms may sometimes shorten life. They ignore the fact that the intention or purpose of administering drugs in these circumstances is not to kill the patients but to make them comfortable.

3. Nonetheless, the VES campaign has resulted in the elderly and the disabled becoming increasingly frightened of admission to hospital. This has been referred to in statements from Dr Jane Campbell, a Commissioner on the Disability Rights Commission, and in statements from disability rights groups, such as Disability Awareness in Action and People First. They insist that rather than “assisted dying legislation” this country needs “assisted living legislation”.

¹ The ORB survey was financed by “Right to Life”. ORB had the final decision on all questions and Doctors.net was responsible for the random selection of respondents.

4. In recent experiences of the signatory of this submission, it has also had the result of causing unnecessary grief and concern to relatives of the dying.

A niece of the signatory of this document died in a West London hospice on Sunday, 22 August 2004. She had a primary cancer in one lung, with secondary tumours in the brain, the liver and elsewhere. On the day of her death the hospice medical and nursing teams concentrated on making her comfortable and easing her breathing. However, her daughter (aged 25) became extremely distressed because she thought that they might be shortening her life. Fortunately, by that time the hospice staff had established a strong relationship with the family and were able to console the girl and explain the situation. Nonetheless, it is highly unlikely that the daughter's concern and suffering would have developed had it not been for the claims she had read from the pro-euthanasia lobby. There must be many similar situations. As it was the patient's death was very peaceful and painless as is so in all the cases of hospice care of which we have heard.

5. It is unfortunate that the Assisted Dying for the Terminally Ill Bill lends itself to the pro-euthanasia propaganda which implies that terminally ill patients are not entitled to complete pain relief. In the opening paragraph of the Bill it states that it is "... to make provision for a person suffering from a terminal illness to receive pain relief medication". No such change in law is required. It is completely irrelevant. In 1997 the case of Annie Lindsell who had Motor Neurone Disease was heard in the High Court of Justice Family Division when she applied for her doctor to be allowed to give her full palliative care to relieve her symptoms as far as possible. In his judgment, Justice Sir Stephen Brown, stressed that this was lawful and always had been. He made it clear that it had been totally unnecessary for her to bring such a case.

6. However, the euthanasia lobby continues to make highly questionable claims regarding patients with Motor Neurone Disease (MND). The VES constantly runs press campaigns in which they give the impression that a very high proportion of MND patients either suffocate or choke to death. In relation to such claims, Dr Nigel Sykes—Medical Director of St Christopher's Hospice—told a meeting in the Houses of Parliament that not one of the 300 or so MND patients who had been treated by him had ever choked to death or suffocated. At a meeting of the All-Party Parliamentary Group on Motor Neurone Disease, Dr David Oliver, a Consultant in Palliative Medicine from Wisdom Hospice in Rochester, Kent, informed the meeting that in a survey conducted on 171 deaths from MND in the UK and Germany, none choked. At a further parliamentary meeting—attended by Dr Brian Iddon MP—the audience was told by a hospice consultant that the chances of MND patients dying from choking is about the same as the chances of an ordinary person choking to death on a fishbone. Nonetheless—as hospice doctors can confirm—MND patients are constantly being frightened by the VES propaganda.

There have also been persistent claims that Mrs Dianne Pretty—an MND patient—died in pain, whereas the hospice in which she died have stated repeatedly that her death "was peaceful and painless". This has been repeated in statements from the Motor Neurone Disease Association which has also asserted that the majority of patients with MND die peacefully in their sleep.

7. We consider that there is a grave danger that the legalisation of euthanasia could cause major changes in society's attitude to the disabled and terminally ill. The effect of legalised euthanasia has had an adverse effect on the development of Hospice Care as can be seen from studying countries and regions where euthanasia has been legalised. In Holland, for example, the hospice movement is negligible. In Oregon palliative care certainly does not compare with that in this country; one quarter of patients who have assisted suicide suffer uncontrolled pain and half have had no specialist psychological support. This is appalling when one considers the quality of palliative care in the United Kingdom.

8. Through recent experiences in hospices and hospitals (see the above case—point 4) we witnessed cases of depression in patients who had few visitors. But all were offered and helped by counselling and psychological support. This was also offered to families to help them through the trauma of supporting a terminally ill relative. We need to make society more aware of the need for showing personal care to the sick and disabled and their families. In Oregon the effect of legalised euthanasia has been an increase among those opting for euthanasia because they "feel a burden on their families"; the most recent figures show that over a third of euthanasia patients in Oregon opted to have their lives ended on these grounds.

9. In the ORB survey referred to above (point 2) two in three doctors (66 per cent) felt that the pressure for euthanasia would be lessened if there were more resources for the hospice movement. Over 50 per cent (52 per cent) also considered that the pressure for euthanasia would be lessened if there were more resources for geriatric care. There is lamentable ignorance shown by the VES and passed on to the media about the success of modern palliative and geriatric care. (This is regrettable but we feel it is quite deliberate.) We consider that it is also significant that doctors who supported euthanasia in the ORB survey were far less interested in the development of hospice care. Only about half of them thought it would ease the pressure for euthanasia.

10. We find it remarkable that the euthanasia lobby constantly cite Holland as the example this country should follow. Overwhelming evidence shows that in the Netherlands patients are killed without or against their wishes—indicating that where euthanasia is claimed to be a right it endangers the lives of others. This is precisely what the Disability Rights Groups maintain. It was also the considered view of the European Court of Human Rights as expressed in the Dianne Pretty Judgment.

11. We consider it imperative to comment on the High Court Judgment on the Case of Mr Leslie Burke by Mr Justice Munby. In it he maintains that personal autonomy overrides all other rights—including the right to life. It is important to note that before being appointed a Judge, Mr Justice Munby was active in the euthanasia lobby and spoke for them in debates. It is evident that the Judgment reflects more his personal views than it reflects English Law and he certainly contradicts the House of Lords ruling on the Dianne Pretty Case. His judgment also contradicts that of the European Court of Human Rights in the Dianne Pretty case when it ruled that there was no “right to die”. This is extraordinary in view of the fact that Mr Justice Munby claimed to base his ruling on the European Convention of Human Rights as scheduled in the Human Rights Act (1980).

12. We recommend that the Select Committee should reject the Assisted Dying for the Terminally Ill Bill. We urge that the main recommendation of the Committee should be a call for greater resources for the Hospice movement with further development of hospice care in patients’ homes. Substantially greater resources should also be granted to develop more geriatric care, particularly in view of the increase in the aging population.

September 2004

Examination of Witnesses

Witnesses: MRS PHYLLIS BOWMAN, Executive Director Right to Life, MRS CLAIRE CURTIS-THOMAS, a Member of the House of Commons, All-Party Parliamentary Pro Life Group, MRS PAMELA VACK, PROFESSOR TIMOTHY MAUGHAN, Professor of Cancer Studies, University of Cardiff and PROFESSOR ALAN JOHNSON, Emeritus Professor of Surgery, University of Sheffield, examined.

Q165 Chairman: Good morning. I think we should make a start now. Yesterday afternoon the Right to Life group sent in a report of a survey which had been done of a hundred Members of Parliament and I think we should circulate that, please, whenever it is appropriate. Mrs Phyllis Bowman, I think you are the Executive Director of Right to Life. We have invited you to give oral evidence to us and you have arranged for the group who are going to speak. I should say that we expect a short opening statement from either one of you or from each of you depending on how you can arrange matters. It is important that it be reasonably brief because we have your written submissions, and then there will be an opportunity for members of the Committee to ask questions in elucidation of what you have said or in seeking further information from you. The evidence is being recorded and a record of the evidence in draft will be submitted to the witnesses so that they can correct any misreporting. It is not an opportunity, you understand, for altering the substance of what you have said, simply for ensuring that what was said is correctly recorded. As skilled as the recorders are in getting things right—they normally get it right—occasionally something happens which is not absolutely accurate and there is an opportunity to change that. We hope to finish about twelve-thirty so you can adjust your submissions in accordance with that. I cannot, of course, say how long the questions will be but nevertheless that is our aim. Mrs Bowman, would you like to start and introduce your group?

Mrs Bowman: Lord Mackay, members of the Select Committee, I would like to begin very briefly by introducing the members of our panel. On my right is Alan Johnson, who is Emeritus Professor of Surgery at Sheffield University. He was President of the Association of Surgeons of Great Britain and Ireland; he is President Elect of the Christian Medical Fellowship and he will be speaking very briefly. On my left—I sound like a boxer—is Professor Tim Maughan. He is an oncologist and he is Professor of Cancer Studies at the University of Cardiff. Claire Curtis-Thomas is Labour MP for Crosby; she is Deputy Chairman of the All-Party Parliamentary Pro Life Group. She became concerned about the dignity of human life and euthanasia through involvement in the care of her mother over a period of five years after an extremely serious stroke which left her totally incapacitated apart from being able to blink one eye. Sitting in the wheelchair is Pam Vack. Pam is a former model; amongst other things she has also been a writer. She became involved with Right to Life after being diagnosed with Motor-Neurone Disease, the disease most often highlighted by the Euthanasia lobby in trying to obtain legalised euthanasia. Professor Johnson will first speak very briefly, followed by Professor Tim Maughan. Pam is more than anxious to answer questions but because of the condition of her throat she would like to begin by giving a very brief presentation about herself. Claire and I will answer questions.

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Professor Johnson: For 40 years I have practised as a general surgeon in the National Health Service and for over thirty years I have taught medical ethics in the context of clinical care to medical students; I have written extensively on the subject. Just to explain, the Christian Medical Fellowship is an inter-denominational organisation of some five thousand doctors from a wide range of specialities and has a thousand student members. I think the central issue in this debate is patient autonomy, the right of patients. The impression has been given that obeying patients' wishes is the over-riding ethical imperative for doctors. Of course it is important, but it is not paramount. If it were, I would have done many unnecessary operations and some harmful operations in my time as a surgeon. Within health care we are used to limiting the autonomy of a few for the sake of many others. By not passing this Bill you will be limiting the autonomy and the rights of a few—in my clinical experience very few—for the sake of protecting the rights of the many in the future who would increasingly feel pressure, real or imagined, to agree to having their lives shortened. Most patients do not live in isolation; we must not ignore the rights of the family and relatives. There is only one brief mention in the Bill of the family. If the doctor is seen as the agent for killing a father several months before he would otherwise have died, without his wife and children knowing, I can see significant repercussions on the doctor. I do not know about doctors in Holland and Oregon but British doctors are not paragons of virtue; they are fallible human beings. We knew that even before the recent high profile cases. For society to give one group, like doctors, the legal right to kill and assist suicide is very unwise. Doctors themselves are only too aware of how poor they sometimes are at prognosis and diagnosing depression in ill patients. Doctors' attitudes would change if this Bill became law, but subtly. Once assisted suicide is accepted, both doctors and society would take a very different attitude to threats of or attempted suicide cases. The message I am hearing is "Please do not give doctors this power; in the long term we may not be able to handle it". It will change the profession. Our responsibility as doctors is to put all our energy into improving palliative care even more. This is in tune with all the rest of Europe apart from Holland. At the standing committee of European doctors recently 25 countries and seven associates signed a declaration that they would not be involved in euthanasia. Even in those countries where euthanasia is legal they would recommend their members not to take part in it. Only Holland refused to sign this and even the Belgian delegation signed up to it. We were represented by the British

Medical Association. I am unhappy about the conscience clause. If this became law, would the doctor's attitude be a question at interview for a job? Would hospitals advertise for doctors who are prepared to undertake euthanasia or assisted death? How would we prevent discrimination in practice? Although I am representing a Christian organisation I am conscious that there are many other major religious groups within the medical profession who are equally unhappy with the concept of killing patients. The latest figures show that nearly a quarter of doctors in Britain are of Asian origin and, in the care of the elderly speciality, this rises to nearly 30 per cent. Should the NHS be charged with providing a service I can foresee discrimination against doctors applying for certain jobs and I have no faith in the conscience clause really being followed up in practice. Finally, I find clause 10.3 extraordinary—and I quote—"A physician . . . shall be deemed not to be in breach of any professional oath or affirmation"; when he clearly is. Dismissing them in one sentence shows little understanding of the importance of these oaths and affirmations which have guided our profession over thousands of years and which came into being because of abuse and lack of respect for human life in the first place. I did not know that the law had the power to silence a doctor's conscience as easily as that. Thank you.

Professor Maughan: I am also a member of the Christian Medical Fellowship and I practise as a consultant clinical oncologist in Cardiff, where my main practice is the care of patients with bowel cancer, many of whom have secondary cancer and will be dying, sadly, of their disease. I want to make four points briefly, if I may. The first one is that this Bill clearly crosses the Rubicon. As we look after people who are approaching death, there can be seen to be a hierarchy of decisions: refusal of life preserving treatment; withholding of life prolonging treatment; withdrawal of such treatment because it is futile and burdensome; pain relief amounting in some cases to terminal sedation; withdrawal of food and fluids by artificial means. All of these are situations in which the issues of informed consent, recognition of the futility and burden of treatment and symptom control are our primary concerns. The nearer these decisions come to the point of death, in some ways the greyer the issues become and the more difficult these decisions become; they are not easy. At the moment we have a clear line, a clear line where we do not kill people actively by the ending of a life by a fatal injection, which is what we are talking about here. Legalising this—PAS and euthanasia—would remove that clear line. To me as a doctor and to my colleagues there is a very clear

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distinction between what we do now with the removal of treatment and allowing nature to take its course, and the active commission of death in this situation. Once we step over this line we will diminish the value of life and that will threaten the disabled and the vulnerable. The second point is that this is a step which may lead to incremental change. As you read this Bill as it is currently drafted, you may think that maybe there will be 10 or maybe fifty desperate patients—such as Dianne Pretty or Reginald Crew—who will get through all the so-called protection in the Bill. However, I note that it has been clearly stated that this may lead to an incremental increase in the allowance of euthanasia; not a slippery slope but a step-wise progression always pushing the boundaries with the expectation that three to seven per cent of deaths due to terminal disease would occur in this way in the not too distant future. We are not talking about a few; we are talking about potentially thousands of deaths in this situation. My third point is the quality of the evidence with which you have been presented. One of the responsibilities that I have is that I am Chairman Elect of the National Cancer Research Network's steering group, which is the committee that oversees clinical cancer research for the UK. The National Cancer Research Institute was established in 2001 and undertook a strategic review of cancer research in the UK and identified a critical weakness in research in palliative care. As a result a group has been established in the last 12 months to develop research in palliative and supportive care, and there is about to be an announcement that MRC, Department of Health, CRUK, Macmillan and Marie Curie are jointly going to be putting five million pounds on the table to try to rectify this weakness in palliative care research in the UK. What evidence have you been presented with? It is largely observational studies of people from Holland and Oregon looking at data in other health care systems which may not apply to the UK. The UK data is largely derived from questionnaire, often supported by one side or the other in this debate and I think that it is so open to abuse that it lacks credibility. My question is: whom do we believe, in this evidence regarding palliative care and end of life care, a lobby group supporting euthanasia, or do we value and support the combined weight of DoH, MRC, CRUK et cetera in their analysis of the research evidence in this area? My final point regards remaining weaknesses in the Bill. My main point here is about the palliative care consultation. I think this is inadequate and it is tokenism. I have seen so many people who have been seen by a nurse or a doctor on the ward and just to talk about palliative care on one situation does not address the

issue. If I illustrate with one case from my last two weeks of practice, just two weeks ago in my clinic I was talking to a lady with advanced bowel cancer who lived alone and was a very independent minded person; she was very ill. She was very, very reluctant to undertake any palliative care or to be admitted to the hospice, which is what I believed she needed. She did agree. I saw her last week and she was completely different. She was radiant; she was smiling. She had received the benefits of an in-patient palliative care admission and the transformation was dramatic. Our experience with the people who talk to us about these situations is that, when they have the full support of the services that are available, these requests disappear. I think that the Bill in relation to the psychiatric assessment is also missing the point about the depression that many of these people feel as a reaction to their terminal situation that takes time to work through and time for the treatment to work. To allow just 14 days is entirely inadequate. I think I will stop there. *Mrs Vack:* My Lord Chairman, ladies and gentlemen, it is a privilege to be invited here today to give evidence to your Committee. I personally support and uphold our present laws on euthanasia making it a criminal offence to be implicated in assisted suicide. I see no good reason to change our laws in order to give way to a right to kill. I personally speak for a vast number of vulnerable, elderly, disabled and infirm, knowing that if euthanasia is legalised we can never put in place sufficient safeguards. We go down a slippery slope towards a minefield of problems occurring where safeguards would be open to much abuse as they have been proved in The Netherlands, where a third of all euthanasia is conducted contrary to a patient's wishes. Sadly we live in a disposable society; life is not valued and many elderly sick feel they are a burden. Their lives are not worth living; they are made to feel an inconvenience. I deplore the loud lobby for voluntary euthanasia attempting to cause panic and fear among those suffering chronic illness: "Why do you not end it all when the going gets tough, the pain unbearable?" Or: "You may even choke to death". It is not surprising that some people are panicked and made to think that they just want death without proper knowledge and much needed information to reassure, as I have been, that all pain and respiratory problems can be alleviated at all levels. I have no fear whatever of choking to death. Anyone seriously ill should have the choice and option of free medical help available. Personally I am reassured that we have the finest hospice care, the envy of the world, where doctors minimise suffering and maximise the quality of life. Their priority is for the maintenance of health and

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preservation of life, controlling symptoms when a cure cannot be achieved. Defining suffering is impossible; it is what a patient says it is. Seventy-four per cent of doctors would not want to be turned into destroyers of life, rather defenders of life as they have always been. Let us retain our confidence as we approach those vulnerable years of ageing and loss of health, knowing that our laws are set in place to protect and value life at all stages. Thank you.

Q166 Chairman: Thank you very much. From what you said earlier I assume that completes the preliminary presentation.

Mrs Bowman: Yes, it does.

Chairman: I now invite members of the Committee who wish to ask questions of those who are witnesses. Baroness Finlay?

Q167 Baroness Finlay of Llandaff: Perhaps I might start by asking Mrs Curtis-Thomas, whom we have not heard from yet. Thank you very much for your personal account, which is recorded in Hansard from Monday and certainly made very moving reading; it is very powerful. I wondered whether you felt the role of Parliament is in putting in safeguards and looking at the practicalities of a change in the law in an area such as this, and also whether you felt that a committee like this should be seeking the views of the Department of Public Prosecution, the Crown Prosecution Service and the Home Office in our deliberations?

Mrs Curtis-Thomas: Thank you very much for your kind words. I think some of the difficulties that face both Houses in relation to this issue is that there are not only technical matters that need to be considered but there is this whole ethical dimension, which certainly I feel personally very ill-equipped to deal with. I have a very personal experience and as a parliamentarian we are asked to set those aside and look at the larger picture; I find it impossible to do that. The Mental Capacity Bill that is currently going through the Commons at this time and your considerations here are seeking to improve and safeguard individuals from unnecessary prosecutions, and I think that is a commendable activity. We do not want necessarily to criminalise individuals for executing something that they believe in passionately. However, at the same time, if we actually go forward and legalise euthanasia, I think what we actually do is send an incredibly poor signal to the rest of society about the disposability of life. I very much concur with the view that legislation in this area would do us greater harm than it would do greater good.

Q168 Baroness Finlay of Llandaff: Could I follow up with a question perhaps to Professor Maughan? When you were talking you spoke about requests that disappear, and I wonder if you can tell us from your own experience what euthanasia requests you have had.

Professor Maughan: Three patients have asked me to end it all in the last 12 years of my work as a consultant. All three had advanced cancer and were responding to that and were in a relatively depressed state at the time. Perhaps I can illustrate with one just to show the way I think this can be helped. Here was a man who was paraplegic, with spinal weakness, had lung cancer, could not breathe and just felt there was nothing to live for. We were able to discuss with him the situation at home, the fact that he was a golf pro, he wanted his autonomy but he lived in a tied house and his wife had nowhere to live once he died. He also had a son whom he had issues with. Discussing with him the wider context, relieving his physical symptoms, all of those requests to end his life just disappeared. I think this is what we see again and again. When we look at people in the round in the vast majority of cases—certainly in each of the cases that I have seen—that request has disappeared. The other point is that doctors can be wrong. In my clinic last year I had a patient who came in with her husband. The husband was in a wheelchair; she had advanced pancreas cancer. Seven years before, that husband had made a request for euthanasia because he had a spinal tumour, and he was told by his oncologist and his orthopaedic surgeon that he had three months to live. He did not; he was still alive and well. The tumour had in fact been controlled; he was paraplegic. Doctors can be wrong, we must remember that.

Q169 Baroness Finlay of Llandaff: Can I ask you what the attitude is of your other colleagues in the oncology sphere, because you could be considered to be a lone voice?

Professor Maughan: I know that my views are shared by all my colleagues at Velindre Hospital, which is the cancer centre; there are 15 other consultants there. Geriatricians have published a survey which shows that 81 per cent are against euthanasia and, in the Right to Life survey, of the sub-set of doctors who are in palliative care 100 per cent were contrary to euthanasia. I think there is widespread opposition to this, particularly among doctors who are dealing with people who are dying. As you get further away into general practice there are different issues because people feel out of their depths sometimes dealing with people who have very difficult symptoms. But when you are in the specialist world

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where most of these patients are being dealt with, the doctors are very strongly against this.

Q170 Chairman: Could you give us details of the various surveys to which you have referred? I do not mean just now, but could you send them to us?

Professor Maughan: I have references to the geriatricians and to palliative medicine; my own colleagues' views are from informal conversations.

Mrs Bowman: I can leave behind the results of our survey that was carried out by the biggest doctors' IT network in the country. They had the final say on the selection of the doctors, and also the company which carried out the survey had the final say on the questions.

Q171 Chairman: I just want to be sure that we can refer readily to the details.

Mrs Bowman: I have the details of the survey here.

Chairman: Thank you. And also to what Professor Maughan is referring to, so that we are as complete in our record of these surveys as we can be.

Q172 Baroness Finlay of Llandaff: Mrs Vack, thank you very much for your evidence and making the effort to come to us today. I was glad to hear that you are aware of the evidence that people with Motor-Neurone Disease do not choke to death and that this is mis-information which is very widespread. I just wondered why you felt that so many of the public feel that the only way to die with dignity is to have euthanasia, where you feel, as a patient who has been subject to needing to get information, this has been coming from.

Mrs Vack: I have stressed that it is imperative that people who have chronic or terminal illness are alleviated of those fears. If only they could be fully informed of the care, the alleviation of pain, as I have been totally reassured, thank God, and I have no fear at all as I know I am increasingly getting worse in my own situation. I have had those fears alleviated knowing full well that all the care with regard to possible choking, breathing problems, pain, will be alleviated.

Mrs Bowman: I wonder if I could say something on this and then Professor Maughan. I have been interviewed frequently on television and on radio regarding this and I have had two people very, very close to me who have died. My sister died. She had bowel cancer for eight years; she was on massive doses of morphine. She had lived in Spain for 29 years and she used to go to Spain for about three weeks every year to see all her friends, taking her morphine with her. She died in a hospice and she died without pain. Only six weeks ago my niece—whom I regarded as my daughter, she grew up with

me—died from cancer and she died without pain. On the last day of her life the hospice doctor and nurses explained that all they could do now was to make her comfortable. Because of the stories that she had heard on radio and other things from the Euthanasia lobby her daughter went into the most appalling panic and demanded to see the doctors whom she had known for some weeks, to make sure they were not shortening the life of her mother. They said they were not; they were just making her comfortable. The fact is that, when I have told these stories on radio and on television—BBC in particular, I have been greeted with astonishment: “They had no pain at all?” I have said, “They had no pain at all”. They are getting a medieval interpretation of medicine which bears no reality whatsoever to what is happening and what is available today. I am not saying that that is always so in hospitals, so far more should be done to promote palliative care. I know from my own experience, two people very close to me, they died without any pain and suffering.

Q173 Lord Carlile of Berriew: As a former lay member of the General Medical Council I have a question which I think is primarily aimed at Professor Johnson and Professor Maughan. It seems to me that if euthanasia is permitted by law there will be an array of complaints of various kinds—possibly from both sides as it were of the argument—to the General Medical Council. I wonder if our experts—and perhaps particularly Professor Johnson with his deep and long experience of medical ethics—could comment on the capacity, or possibly even the adequacy, of the sole medical registration body in this country for dealing effectively with such complaints and producing policy which would be sufficiently clear in ethical terms to guide doctors at all levels.

Professor Johnson: I think one of the problems we are coming up against is that law has difficulty in the way it defines and controls behaviour. I think, as you rightly say, we would get complaints from both sides in different ways and I think doctors would be put into very difficult situations—as I mentioned before—by relatives possibly complaining that they had done this and from patients complaining that they had not. I think the General Medical Council is a body that has looked at a lot of things but I am not sure it is set up correctly for this sort of decision. It largely deals with obviously gross deviation from good medical behaviour, and I think you might have to alter its terms of reference perhaps to look at these ethical issues in more detail because the law would not be clear enough, to guide it in what to do.

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Professor Maughan: I would certainly share those concerns about the ability of the GMC to be able to oversee this situation effectively.

Q174 Lord Carlile of Berriew: One of the experiences one has had with the GMC—and I admit I am now five years out of date, but I spent 10 years there—is that rather more complaints than people realise are made by doctor against doctor—very properly in many cases, but this seems to me to be an area which would cause particularly great difficulty?

Professor Johnson: I think that this would split the profession. There are already signs of it in Belgium particularly, that doctors are polarising, even within the same hospital. In Belgium one unit has already put up a notice saying they are not going to do it to reassure patients; but if, in the same hospital or even in the same department, you have people with different views it is going to be extraordinarily difficult and the team work, that we have been so long striving to obtain, would break down. I think it would split the profession.

Q175 Lord Joffe: I will start asking questions of Mrs Bowman as she put in the original submission. Mrs Bowman, do you accept that there are some patients for whom palliative care will not meet their needs?

Mrs Bowman: I am sorry?

Q176 Lord Joffe: I said, do you accept that there are some patients for whom palliative care will not meet their needs?

Mrs Bowman: It is possible, but here again Professor Maughan has referred to the call from his own ethical bodies calling for more research to extend that. I do not think that killing is an answer to the fact that palliative care does not necessarily reach everybody at this stage.

Q177 Lord Joffe: I do not think you have answered my question. I asked you, do you accept that there are some patients for whom palliative care will not meet their needs?

Mrs Bowman: There may be some at this stage.

Q178 Lord Joffe: As a result they suffer terribly. What should be done for such patients?

Mrs Bowman: Which patients are you referring to? The patients we are hearing about at present from the media and from the Euthanasia lobby are mainly Motor Neurone Disease, where there are terrifying stories of them. Dianne Pretty said that she was terrified of choking to death; so did Reginald Crew, who also said he was terrified of

choking to death—and that is not an option, that is not the reality if people are given proper care now.

Q179 Lord Joffe: What I am talking about is what the BMA acknowledge, that there are some patients for whom palliative care will not meet their needs and wishes. The National Council for Hospice and Palliative Care have also made a similar statement. Macmillans have made a similar statement. I am talking about those patients.

Mrs Bowman: I would accept what they say.

Q180 Lord Joffe: Bearing in mind then that these patients are suffering terribly, what would you propose should be done for them?

Mrs Bowman: Everything possible to alleviate their suffering. I would prefer to pass that message on to Professor Johnson and Professor Maughan because they will know more about the medical care which is available to them. However, I do not think that equating killing with palliative care is a sensible course to go down.

Q181 Lord Joffe: Do either Professor Maughan or Professor Johnson wish to come in on that?

Professor Maughan: Yes, we know in all spheres of medicine that medicine is limited and there are patients in whom the symptoms are very difficult to control. We know that palliative medicine is actually a relatively young speciality and, as I have indicated, is a speciality with a limited research base which is improving and developing quite rapidly at the moment. Yes, we do have patients who do have very difficult needs and very difficult symptoms, and there are times when patients' needs for pain control are such that their pain control needs to be increased so that they are almost asleep, because you cannot distinguish the two. I think anybody working in the field would recognise difficult cases and recognise the shortcomings. But the situation now is that we are constantly striving to improve the level of care and improve the ways of looking after such patients. Advances are being made.

Q182 Lord Joffe: Until those advances are to be made—assuming they will be made—what is to happen to these people?

Professor Maughan: One of the problems with palliative care is that it is very patchy. In our own environment in Cardiff we have a fantastic palliative care service, and I know and am confident that even the people with the most difficult symptoms will have their needs addressed, even if it means making them very sleepy. The problem at the moment is that there is a lack of palliative care; the provision of palliative care is variable across the country and that

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is something we need to bring up to a certain level. Surely our first response to this is— let us let everybody have access to the same high quality of care that is currently available in certain centres. That should be our first response.

Professor Johnson: I would like to make the point from experience of 40 years how the changes have taken place, and we are looking forward with this Bill—we are not looking back. When I first started in practice, the whole idea of palliative care in hospices was just starting, and I can think of some examples where we were very bad at managing symptoms at that time. The improvement and the effect on general care in hospitals has been dramatic; it is not just in hospices and palliative care institutes, it is in the general care of our pain relief as general surgeons. The effect has been right the way through medicine. Now all our students go through a palliative care module as part of their medical training. The next generation will be much better trained than we were in this area.

Mrs Curtis-Thomas: Lord Joffe, you referred to individuals who were experiencing unbearable suffering, I think, and what was the solution for them. I think implicit in your question was that we were dealing primarily with people with a very degenerative condition and an inevitable death. However, there are of course thousands of people in this country today who have very difficult lives through a disability that they may have acquired through a stroke, and historically the treatment of people who have been rendered exceptionally physically incapacitated has been far from perfect. People who have had a stroke and are severely disabled by it may live with that condition for many, many years. However, in the last 10 years we have seen enormous improvements to accommodate people with a range of a disability so what would have been considered by many as unbearable suffering 10 years ago has rapidly changed in the last 10 years. People like my mother, and many others who are rendered totally incapable through a stroke, today have very different lives; they are no longer at the margins of society because people, I think, generally recognise that such people have a contribution to make to society irrespective of their physical capacity. Unimaginable suffering can be alleviated not through drugs but through society's response to that disability and the structures that we create to enable those individuals to lead far more constructive and positive lives.

Q183 Lord Joffe: I accept that there have been great advances in medicine and a great deal which was not possible to control in the past is now possible. But what we are talking about for the purpose of this

Bill is to enable people who are suffering terribly and who do not see palliative care as the answer to their suffering. The patients we are talking about, their main concern is not pain, which I accept in time it might be possible to almost completely control; it is about lack of control, total dependence, incontinence, no quality of life. It is this particular group of people who suffer most, and some of them wish to have the opportunity to die and to bring their suffering to an end. It is about this I am referring. Let me make it clear that I am totally in support, and the Voluntary Euthanasia Society among others are totally in support, of palliative care and feel that more resource should be applied and that it is the solution for most dying patients, but there are some who fall outside that.

Professor Maughan: What you are talking about are people who are seriously disabled by a progressive condition and who feel that their disability renders their life valueless. Is that what you are saying?

Q184 Lord Joffe: Yes, and who feel that their quality of life is not worth living. That is their view.

Professor Maughan: Some of those people are expressing a desire to die. If we take a broad group of disabled people, most of those are saying that they very much want to live. If we extrapolate and if we look across the whole range of humanity, there are some people who desire to die. Our response to them, out of this situation, is that we address that issue of their desire to die and we give psychiatric support and care to them. We recognise that that is an issue, and in some situations they may sadly commit suicide. But what you are saying is that this group of patients, because of the disabilities resulting from their illness, are very depressed, we should actually listen to them and just get on and kill them.

Q185 Lord Joffe: That is not at all what I am saying. What I am saying is that these individuals—who are competent adults only—have thought carefully about their position and feel that it is not acceptable to them to carry on in a life which has no quality left and they ask for assistance to die in order to bring their suffering to an end. That is what I am talking about. To suggest, as you are suggesting I think, that they must be mentally disturbed and need psychiatric treatment is quite remarkable. Some would benefit from psychiatric treatment and some would not. Do you believe in personal autonomy to make decisions?

Mrs Curtis-Thomas: Could I just add something further? The conversation we are having is centred on the physicality of an individual, the function of a body, and for many people they are either born

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or acquire a dysfunctional body. That body may be progressively dysfunctional. However, what we seek to do is to support the spirit that exists within that body. They are two entirely different entities. Physical difficulties should be and can be overcome. Because somebody is incontinent it does not make them less viable; it is not something to be ashamed of, it is just a condition to be managed. What should be celebrated and developed is the spirit of the individual contained within that. If the body lets them down, does that really make any difference? Should we say, "It's all right for you to end your life?" I think it would send an incredibly bad signal to others who are facing similar disabilities and do not see their lives as worthy of ending, because it is just a body and nothing more than a body that captures a spirit.

Chairman: This is developing into somewhat of an argument, and I think at the moment the function of the Committee members is to ask questions and to have them answered. Lord Taverne?

Q186 Lord Taverne: First of all, I would like to ask a question of Professor Johnson. He made a very important point when he said that he thought that if the Bill were passed it would change the medical profession. Would he not agree that the most important thing to do in looking at what the effect would be of a change is to look at the experience we already have? The country which has had most experience of this is The Netherlands. Does he not think that we should pay quite a lot of attention to the fact that a very careful study which has been done showed that out of 11 countries studied—including the United Kingdom—the country where there was much the highest regard for doctors and the greatest trust in doctors was The Netherlands? Again, another careful study showed that it was doctors in the Netherlands who discussed end of life medical decisions with their patients much more freely than in any other country. Is that not something which suggests that his fear may be displaced?

Professor Johnson: No, my fear about introducing it into this country is that I do not think that there is that trust in doctors that there appears to be in The Netherlands and we are introducing it into a very different situation. The trust in doctors over recent years is not nearly as high as it was. We do not actually know what attitudes are changing in doctors; we have not looked at the slight, subtle changes that go on. To take an example, if we legalised assisted suicide, gradually the attitude of both ourselves as doctors and society to attempted or threatened suicide would change. Today, if somebody is threatening to jump off London

Bridge, we send a policeman up to try to coax him down. The logic, if we accept assisted suicide, would be to say that he means to do it, he wants to do it, so we will send a policeman up to give him a push and help him.

Q187 Lord Taverne: Do you not think that it is rather remarkable that after many years' experience, far from decreasing trust in doctors, trust in doctors in The Netherlands is much higher than anywhere else?

Professor Johnson: I think Holland is a very unusual place in many ways. Belgium is not nearly so consistent. I was talking to someone who runs a special neurology unit in Leuven, for people with severe neurological disease and after their law was passed, two people who came in asked about euthanasia.. Ten said "When you see me, are you going to liquidate me?" That was a real fear coming from patients, who did not trust their doctors. If you start with a very strong trust in doctors, then it may stay there if it is done well. If you are starting from not so great a trust, I think there is a very good chance that that trust will diminish.

Mrs Bowman: I would like to make a point on that. I have been to Holland a number of times and the official figures there show that about a third of the patients who are given euthanasia do not ask for it and have never brought it up. When I was there I was also told of older people—when you talk about trust in doctors—who went over the border to Germany because they were frightened of going into hospital to be euthanatised. I met one doctor there who told me about patients who are frightened to go into hospital because of euthanasia. He talked one of his patients into going in and assured her that she would be in his care. Apparently on the Saturday she was quite happy in her bed. He was not in on the Sunday and, when he went in on the Monday, there was somebody else in her bed. She had been given euthanasia during his absence.

Q188 Lord Taverne: One hears a lot of anecdotal evidence but in the end one has to look at what this picture shows as a whole. Is it not surprising—if what you say is true—that again another very careful study done in the year 2000 shows that non-voluntary euthanasia was far more common in other countries than it was in The Netherlands? There was no country in Europe in which it was found that there was a lower rate of involuntary euthanasia than The Netherlands. For example, in Australia, New Zealand and a number of other countries there is a much higher incidence of non-voluntary euthanasia than where they have a euthanasia law.

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Mrs Bowman: I believe you have also referred to a recent study, a very careful study, which claimed that there were 20,000 cases of euthanasia in this country at present and referred to the fact that a lot of these were being conducted in hospices.

Q189 Lord Taverne: There are two particular studies which I can give you the details of, one relating to The Netherlands and the question of the trust in doctors, and there are several studies about the incidence of non-voluntary euthanasia.

Mrs Bowman: Who conducted these studies?

Q190 Lord Taverne: There was one done in 2000 by Mr Deliens, another one in 1997 by Mr Couse, another by Mitchell and Owens in 2003, another one by Mr Van Der Hyde in 2003. All these are very carefully conducted studies and the evidence from them is very compelling.

Mrs Bowman: All pro-euthanasia people.

Q191 Baroness Jay of Paddington: I think it has been very helpful to hear about the progression in palliative care and in hospice care and I think that is something which would be very difficult for anyone to say that it was not an advantage to all members of society. I wonder, though, if the members of the panel—particularly the medical members of the panel—would agree with the statement by the Royal College of Physicians (whom we will be hearing from this afternoon) who said in their written evidence that they thought that this Bill was a matter for society as a whole to look at, in the sense that it was not simply something which should be looked at purely from a medical point of view.

Professor Johnson: My evidence was particularly from the medical point of view and I agree that it involves wider society; but I am also saying, why should it be the doctors—particularly those who are caring for the patient—who are the ones that should be involved in this? I think there is a strong case for it not to be doctors involved in this at all.

Q192 Baroness Jay of Paddington: Are you suggesting that it is not the principle, then, that you find objectionable in the kind of circumstances that we have been hearing about but more the method and the practitioners?

Professor Johnson: There are two things. One is society having the right to do this. I think the College of Physicians was saying that they were not going to make the decision about it—and they will discuss this further with you this afternoon. But I think the real issue is: should society give to any group—as I said in my opening statement—or any

professional this really awesome right to take people's lives. Should it go to lawyers? Should it go to any group? Why should society decide to do this and then give it to a group to do? Again we come back to this autonomy that Lord Joffe has mentioned. I do think there are situations where a few peoples' autonomy has to be overridden for the sake of the good of many. There are many examples that you and other colleagues will be aware of, decisions we have taken in the health service. Take the issue of antibiotic resistance, where we said we would not agree to people's requests for antibiotics when they come in with sore throats and colds, because we would produce resistant organisms which might have quite a serious effect on people further down the line. That is a similar sort of creeping effect, which we have to prevent despite there being some hard cases at present; we hope there will not be many in the future as things improve. We still have to say that we cannot give overriding power to somebody's autonomy: society cannot do that. We have to limit autonomy in all walks of life for the benefit of the whole of the population.

Q193 Baroness Jay of Paddington: I am sorry to quote from other evidence, but we had an interesting piece of evidence from one of our most prominent moral philosophers who can put it much better than I can, saying that: "I do not believe that individual autonomy is of the highest moral value and it should often be postponed to another higher value, such as consideration of the common good if these are in conflict. However, in the case of a patient who is and knows that she is terminally ill and who would quite deliberately end her own life if she had the means or physical competence to do so, then it seems to me there are no seriously conflicting values."

Professor Johnson: There may not be in that one instance but the on-going effect of this happening is what affects the whole attitude of society.

Q194 Baroness Jay of Paddington: Yes, but if you agree with the Royal College of Physicians that this is a matter for society . . .

Professor Johnson: I do not agree with that. In a sense, doctors have to be involved. I think they have rather washed their hands of the situation by saying that, because doctors should have a view on this.

Bishop of St Albans: I wonder if I might make a statement and then ask a couple of questions. The statement is that, when I was a parish priest, I had the privilege of also being a part-time chaplain of a hospice. Although it is a huge privilege to be a bishop—as one might imagine—the privilege of

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being a hospice chaplain is beyond description, because I have spent huge numbers of hours sitting at the bedsides and with patients as they died.

Chairman: Is it not possible for a bishop to continue that role?

Bishop of St Albans: Yes, indeed, I do.

Chairman: I am sorry to interrupt your question

Q195 Bishop of St Albans: It may not happen north of the border but it certainly happens in the south. I would like to ask two questions following that statement. The first question is, would you not think it necessary and desirable that members of this Select Committee should not only visit places such as Oregon, Belgium and Holland, but they should also spend equal amounts of time in palliative care units and hospices to see for ourselves the work that is currently done? My second question relates to that: right at the very heart of this is a philosophical question about the nature of personal autonomy and therefore the nature of human worth and value. My own experience in hospices—which echoes what Professor Maughan has said—is that my exercise of personal autonomy is not as significant in my view as that moment when I have to place myself in the hands of others and then discover not only my autonomy enhanced but my understanding of myself and society enhanced. In other words, I am not an island to myself. Would you be willing to comment on both of those questions and statements, please?

Mrs Curtis-Thomas: If I could just make a short observation on that, I think that when people enter or have to endure a most appalling condition, one of the great things is when they do actually find the response to society to that condition. In many cases it is absolutely overwhelming. I have to say, after five years of my mother's life where she shared a hospice with many people in a permanently vegetative state or an equally debilitated state, was that it was the best time because there was unrequited love, a wealth of services that you could not possibly imagine and undiluted care. I think that is possible, and I would clearly want to see far more of that available to all. I think generally there is a consensus of opinion, certainly the pro-life groups, that we are not advertising that sufficiently, that we have failed to block the pro-euthanasia group and their rhetoric with counter rhetoric which we know to be the truth.

Professor Maughan: I think there are patients without number who go through a terminal illness who actually value that time very significantly. I can quote you many examples of that. If I could just expand on this slightly, it relates back to why so many people want euthanasia. A healthy person

looks at somebody over there in a hospice bed or in a sick bed. They may feel—and it is a very natural feeling—“I don't want to be there and, if I were there, I would be better off dead”. That is a very easy reaction for people in the community, particularly fit and healthy people in our society, to feel. That feeds into the high numbers that have reported supporting euthanasia. But, when you actually walk alongside people who are walking this road and as they do experience a gradual step-wise diminution in their abilities and they accommodate to those, the human spirit responds to that and the relationships and the issues that flow out of that are immensely valuable; and even as you come to the last days of life—and that is what you are talking about—some of the most amazing moments and relationships and the ability to say words are the most important things. Those things cannot be quantified, and they are very precious.

Professor Johnson: You talk about people seeing no value in themselves. But, of course, as I mentioned about relatives, they are valuable to other people and for them to be able to take a decision without the relatives being involved is really a very difficult thing when relationships are looked at.

Q196 Lord Patel: I would like to explore a couple of things. One is related to the comment about assisted dying adversely affecting the development of palliative care in this country and that the situation in The Netherlands and Oregon is very different from that in the UK. Of course, we all accept that development of palliative care to the highest standard is very important. Why do you say that in this country it is different and this Bill would hinder it?

Professor Johnson: I do not know Oregon. In Holland, of course, there was very little palliative care at all. They were right behind in the development of hospice and palliative care.

Q197 Lord Patel: That is contrary to the evidence we have heard.

Professor Johnson: No, I do not think so.

Q198 Baroness Jay of Paddington: From something I read this morning, the evidence from Oregon from the hospice societies there is that the majority of people who not only ask for euthanasia but have euthanasia have been in hospice care.

Mrs Bowman: Could I bring in a point here? Twenty-five per cent of them have opted for euthanasia because of pain. What kind of hospice care is that? Thirty-three per cent have opted for euthanasia because they felt they were a burden on their families. What kind of a society are you

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breeding there? In Holland—I have been to Holland a number of times—on one occasion I visited a hospice and they had a crowd of people outside marching up and down from the Euthanasia lobby with banners declaring that they were denying people the right to die. The hospice movement in Holland has not developed anywhere near the hospice care in this country.

Professor Maughan: To answer your question about whether this would undermine palliative care research and development, I think at the moment going into a career in palliative care is very much a vocational thing. It is very much a thing of the spirit of the individual, and there is tremendous commitment to stand by patients, to walk with them and to support them. Of course, we all learn and often we learn most from our hardest cases. I think it would affect palliative care by undermining the views of the people who are going into palliative care, maybe by affecting recruitment. I think it would undermine palliative medicine because of that desire to improve the situation and to really grapple with these difficult cases. I am not saying that hard cases should be the subjects of research but we do learn from the hardest cases, and that is the way things improve.

Q199 Lord Patel: Can I put to you another point that Lord Taverne referred to, which is the trust in doctors and the evidence that he quoted that trust in doctors in The Netherlands is quite high. I do not think you meant to suggest that the trust in doctors in the United Kingdom was not high, because the evidence suggests that of all professions the public trust doctors most. Why do you think this Bill or assisted dying, if it were legalised, would undermine that trust?

Professor Johnson: Yes, doctors are trusted more than most but there have been a lot of high profile cases and I think that has actually shaken, to quite a large extent, the trust in doctors because of the way the media have reported these things. A lot of the trouble is that we get our information from the media about all this. I think there would still be this doubt about what the doctor is really going to be doing. Doctors will see assisted dying after a time, for the difficult cases that Professor Maughan referred to, as a relief, a way out, also for the doctor. We lose sleep over patients, we look after them and we know what caring can be like. If this becomes an option, there is going to be the temptation to say, “I need not try that hard; I need not go that far,” but, I think that in this country, at the present time, the trust in doctors is at the lowest it has ever been since I started practice.

Professor Maughan: One of the issues about the data from The Netherlands and these thousand patients who have not given explicit consent is that there has been a move right from the beginning—it remains stable, I recognise that—that the patients who request euthanasia train the doctors in a certain way, and then the doctors say “here is another patient like them”, and they make the decision to go ahead with the euthanasia because of the condition of the patient rather than because of the request of the patient. That is what feeds into some of these anxieties about patients’ lack of trust, I think.

Q200 Lord McColl of Dulwich: For many years I have been involved in palliative care and was part of setting up the first hospice for people dying of AIDS in Europe in Hackney. I must say I am rather irritated by constant criticism that I was a hypocrite in saying that I was relieving symptoms with heroin and morphine when really I had in mind to kill them. It seems to be that this criticism was based on an ignorance of elementary pharmacology, because the dose of heroin to relieve symptoms is a fraction of the dose required to kill—which is, after all, the definition of a good drug. My specific question to Professor Maughan is—could he say something, as he mentioned something about sedation, about the difference between sedation and killing?

Professor Maughan: In all good palliative care and in all good medicine we should be giving the dose of treatment that accomplishes the relief of the symptom. What we want to do is provide the minimum effective dose. For most patients that is very easily achieved without any perturbation of their consciousness, and so we have patients driving cars around the place on stable and relatively high doses of morphine because it controls their pain. There are a few patients where that is not achievable and where you have to increase the dose gradually to a level where actually the patient is sedated, because their pain is such that you cannot get that therapeutic window that we want, that we are aiming for. That is the situation that we are talking about. The intent is still the same; the intent is to relieve suffering. The principle of practice is still the same—you are looking for the minimum effective dose but the situation is such that the minimum effective dose is a sedation dose. Although it is a hard case, it does not alter the principles or the practice of standard palliative medicine.

Chairman: Does anyone who has not asked a question yet wish to do so? I am going to ask one or two. Lord Joffe?

14 October 2004

Witnesses: Mrs Phyllis Bowman, Mrs Claire Curtis-Thomas MP,
Mrs Pamela Vack, Professor Timothy Maughan
and Professor Alan Johnson

Q201 Lord Joffe: I would like to ask a number of questions. Mrs Vack, I respect your courage and your views in respect of your own life. At a previous session of this Committee a Mr Barclay, who was a retired surgeon who has Motor-Neurone Disease, gave evidence that he would wish to end his life before he became totally incapacitated. Clearly, as a surgeon he knew all about the available options. Would you respect his views in relation to his life?

Mrs Vack: Yes, I would respect his own personal view point and the evidence that he would be well aware of. I have been asked this question on a number of occasions in interview. When things get worse, which they will, one loses ground quite quickly with all this and loses movement. When this happens, I am personally completely confident that I would—even if I lost all movement, which is quite possible—still retain my mind with Motor-Neurone, my sight and my hearing. I would say that those three faculties are precious and they can provide me with some quality of life. The answer to that question is—No, at no point would I request assisted suicide.

Q202 Lord Joffe: Your own views are very clear and your courage is something we would all greatly respect, but the question related to Mr Barclay.

Mrs Vack: I would accept his views.

Q203 Lord Joffe: Could I then move to Professor Maughan? Professor, when you were responding to the question of what could be done for those cases who want assistance to die and for whom palliative care is not the solution, you said that they could be sedated. It seemed to me that you were talking about terminal sedation. Is that right?

Professor Maughan: No. The issue about the patients where palliative care is not the preferred option is usually not the pain issue; it is other issues related to a person's view of the world, their relationships and issues about personal autonomy and dignity. Those are ones for which sedation and pain relief of any sort are not relevant issues. It is about dealing with that person as an individual, relating to them and exploring other ways. Very often the patients we see in the hospital whose physical symptoms are most difficult to resolve are the ones where there is a family or an emotional dimension to their pain which takes time to uncover and to deal with. As you get to know these people and your relationship with them, then you are able to explore and help those dimensions of pain or dimensions of distress which are not on the physical level. It is as you explore those that you get to the bottom of what is making people think like this. In many cases you are able to break through to help people. By dealing

with those underlying family relationships or emotional stresses you can help them with the angst of the situation that they are in and those requests can still be resolved, not on the physical level but on the emotional and other levels.

Q204 Lord Joffe: So what you would do with one of these patients who was insisting that they really were suffering terribly and their suffering was not pain but really a question of dependence, of lack of control, of lack of quality of life, and they wanted assistance to die. My understanding of what you said is that you would refer them to the psychiatrists.

Professor Maughan: I think there is a psychiatric dimension to it and that you need to have your eyes open to that. Remember that depression (a) is very common and (b) is very under-diagnosed by most of us doctors. We are not very good at it and so we need help. What is required here is the holistic approach to the individual, which is what palliative medicine has been all about really; it is not just about pain and symptom relief, it is about the holistic approach to the whole person with the resolution of the whole raft of issues. In the vast majority of patients, everybody in my situation—and in the case of many of us—these issues can be resolved. Obviously there are cases which come to the public attention and I do not know to what extent those issues have been delved into. I know that in my experience usually these things can be resolved with patient work and assistance.

Lord Joffe: With the leave of the Chair I just want to ask you one more question and one question to Mrs Vack.

Chairman: I think your quota must be coming near to an end Lord Joffe. I think one more question. Lord Taverne wants to ask another question and I, on the whole, would like the advantage of asking a question or two before twelve-thirty. Please bear that in mind.

Q205 Lord Joffe: Yes. In your evidence you said that the dividing line between the cases of end of life decision, such as withdrawal or withholding of treatment and acceding to the patient's request to be allowed to die, you said that the line was very thin and you would be crossing over it if this Bill were to be introduced. Can you tell me the difference between the case of Miss B—who was kept alive on a ventilator by doctors, who refused her request to turn off the ventilator and eventually the ventilator was turned off by doctors—where the doctor turned off a ventilator and the case of assisted dying?

14 October 2004

Witnesses: Mrs Phyllis Bowman, Mrs Claire Curtis-Thomas MP,
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and Professor Alan Johnson

Professor Maughan: The issue here is that she is subjected to an intensive treatment and that there was a judgment to be made about the burden and futility of that treatment. Those are difficult judgments and maybe there were differences of opinion. The decision to switch off the ventilator was one that was taken and which, I think, as a principle is not something that I would oppose. However, in withdrawing interventions your intention is to reduce the futility and burdensome treatment and also, because the intention is different, the outcome is not entirely predictable. There are stories that abound about people where the ventilator has been switched off and the patient has carried on breathing. The outcome is in doubt when you withdraw intervention. You do not know that it will lead to death. What you are doing is primarily withdrawal of burdensome and futile treatment. When you come very close to that line, I acknowledge that there are areas of very grave difficulty where situations are grey. But to have that clear line which says that we do not kill is extremely helpful. If this Bill goes through, that line will be moved.

Q206 Lord Taverne: I want to ask a fundamental moral question of Mrs Bowman. Am I right in thinking that your view is that it can never be morally right to help someone to die who asks for help?

Mrs Bowman: My sister was helped to die. She was in a hospice. If you mean the statement about killing, then yes, we are morally opposed to that.

Q207 Lord Taverne: In the first hearing we had the case was put to us from America where a lorry driver was trapped in a lorry and the lorry caught fire. There was a policeman on the scene. There was no way of freeing the driver and he was going to be burned to death. He asked the policeman to shoot him and the policeman did. Was that policeman morally wrong to save him from being burned to death?

Mrs Bowman: I do not think literally that is the kind of medicine that we are dealing with, doctors deciding whether or not patients are being burned to death in their beds.

Q208 Lord Taverne: But it is unbearable suffering, is it not?

Professor Johnson: I really think that to argue from an example like that is just extraordinary. You might argue that because in one particular case it was right to lie to save a person's life—and that is a classic dilemma of philosophy that goes back a long time—therefore lying becomes the right thing in all

sorts of situations. We are not talking about somebody who is burning to death in a lorry; we are talking about people who are alert and being cared for.

Q209 Lord Taverne: Suppose it is unbearable suffering, which is what the lorry driver was afraid of?

Professor Johnson: The person who gave that example concluded that society had no objection in principle to euthanasia. That was the argument from that individual case, and I do not think that is a logical argument.

Q210 Chairman: There are not many countries that have an actual law dealing with that situation. Obviously, if it arose it would have to be dealt with *ex post facto*. I wonder if I could ask the doctors to help me about the way in which the amount of time a patient still has left in life is estimated. Do you follow me? How do you go about it?

Professor Maughan: I have this conversation with people very, very often and it is very difficult to prognosticate. We can quote people survival data. There is a lot of clinical trial data where you can plot the line but you have no idea where that person will come on the line. Although you can say that your cancer is at such-and-such a level and this is expected, unexpected things happen all the time. There are negative things, like sudden pulmonary embolism, which lead to early death, and sometimes there is the reverse where people live very much longer. The longer I practise, the less good I am at this and the less I do it. I try to avoid it. I will talk in terms of days or weeks or months or years, but I reiterate very clearly how bad we are at this.

Professor Johnson: I agree with that. We are talking about an average and there is a wide range around that average, and you do not know where on that range that person is.

Q211 Chairman: What is the scientific approach to doing it? How do you go about it? If it is on the basis of an average, it is an analysis of cases past, I suppose, by reference to conditions at a particular time?

Professor Johnson: But, of course, everybody is an individual and you have to try to see if there are extra factors in that person that affect the average. Often these averages have quite a wide range and it is very difficult to say where on that range they are. We may tell a patient there is a range but I do not know any doctor who will say to a patient, "You've got three months to live" or "You've got two months to live".

14 October 2004

Witnesses: Mrs Phyllis Bowman, Mrs Claire Curtis-Thomas MP,
Mrs Pamela Vack, Professor Timothy Maughan
and Professor Alan Johnson

Q212 Chairman: To be very precise about it would be difficult, as you have explained. But is it possible to say, “You’re going to die within the next year certainly”.

Professor Maughan: The situation with patients with lung cancer is that 10 per cent of those presenting with inoperable lung cancer are alive at one year, so you can say to a patient that from past data we know that nine out of 10 people will have died with a year. But we do not know which patient is going to be one of the nine or the one.

Q213 Chairman: I follow that. Is that the best that can be done?

Professor Maughan: That is the best that can be done. There is no way of predicting an individual’s prognosis because that individual is unique.

Q214 Chairman: From the point of view on oncology is it possible to identify even the make-up that may give rise to particular troubles—cancer, for example?

Professor Maughan: You can dissect out prognostic factors, but all that does is provide you with an indication as to whether this person has a 50 per cent chance of being alive in five years or a 20 per cent chance or a 5 per cent chance. But you still do not know whether they are going to be one of those 5 per cent or not at the end of the day. You cannot tell.

Q215 Chairman: The other question I wanted to ask you. The name of the organisation, Mrs Bowman, of which you are the Executive Director, is Right to Life?

Mrs Bowman: That is right.

Q216 Chairman: Who has the right to life?

Mrs Bowman: All of us have the right to life.

Q217 Chairman: The individual?

Mrs Bowman: Yes.

Q218 Chairman: Then the question is— if a person has a right, normally they are entitled to give it up?

Mrs Bowman: That was not the decision of the European Court of Human Rights. They said that the right to life did not equate with the right to die. They pointed out that the right to die undermined the rights of vulnerable people. I would mention that the Disability Rights Commission have pointed out repeatedly that in the present day atmosphere disabled people are becoming more and more frightened of being admitted to hospital because of what could happen to them.

Q219 Chairman: I am anxious to get the idea of the name. When you speak of a right to life, you mean a right that belongs to the individual who has it and it cannot be terminated by anyone else?

Mrs Bowman: No, that is correct. Not deliberately.

Q220 Chairman: Or by themselves?

Mrs Bowman: We have not legalised suicide and you cannot necessarily control what people are going to do personally. You can control what other people are going to do to them, and that is the point.

Q221 Chairman: You mean that the title is intended to imply that no-one else has a right or a power to interfere with the life of the person who has the right. Is that what you mean?

Mrs Bowman: Yes, that is correct.

Chairman: I see. Well, it is twelve thirty-one, which is not too bad. We have to thank you very much indeed for coming and, as I said at the beginning, you will get a chance to look at the record taken of your evidence and a chance to correct it if the record is wrong. Thank you very much indeed.

THURSDAY 14 OCTOBER 2004

AFTERNOON

Present	Carlile of Berriew, L Finlay of Llandaff, B Hayman, B Jay of Paddington, B Joffe, L Mackay of Clashfern, L (Chairman)	McColl of Dulwich, L Patel, L St Albans, Bp Taverne, L Thomas of Walliswood, B Turnberg, L
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Memorandum by The Royal College of General Practitioners

1. The Royal College of General Practitioners welcomes the opportunity to submit written evidence to the Select Committee on the Assisted Dying for the Terminally Ill Bill (HL).
2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. It aims to encourage and maintain the highest standards of general medical practice and to act as the “voice” of GPs on issues concerned with education; training; research; and clinical standards. Founded in 1952, the RCGP has over 21,500 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline.
3. The College stance on the desirability of the Bill is one of “neutrality”, recognising that it is a matter for society to judge the ethical and moral issues surrounding this important subject. The comments we set out below are, therefore, focussed on practical issues arising from the Bill in which medical professionals are likely to have a special understanding and expertise. Our comments are not to imply either support or opposition to the Bill but we hope the issues we raise are given serious consideration by the Committee in its deliberations.

Clause 1: Authorisation of assisted dying

4. It is genuinely difficult for doctors to estimate death in the medium term (definition of “terminal illness” in line 27 of page 2 of the Bill refers). It is possible to give reasonably accurate prognoses of death within minutes, hours or a few days. When this stretches to months then the scope for error can extend into years. It is only in the case of death over the medium term that the Bill is of any help to patients. If the patient’s life is within hours or a few days of its end, then the proposals in the Bill would not greatly assist.

Clause 2: Qualifying conditions

5. Key difficulties for physicians will be in assessing whether or not a patient is suffering unbearably as a result of a terminal illness, and in establishing that a request for assisted dying is genuinely voluntary.
6. With reference to the latter point, we note that in his book “A Good Death: conversations with East Londoners”, Michael Young writes about the huge fear of becoming a burden which he finds to be felt keenly by those who are dying:
7. “The peace of mind which is both so desirable and so difficult to achieve for a person so ill would be more fraught if the patients were all the time wondering whether, for the sake of their carers, they should seek an earlier death than nature unaided will grant them. The right to die could become a duty to die. It could nag continuously, so much so as to make the last phase of life a torment on that score alone.”
8. Perhaps it would be useful to include in Clause 2 a section to the effect that physicians have a duty to avoid advising the patient on their decision to make the declaration or not. Their role should be to inform as best they can, and while it may be impossible to avoid some personal preference for any particular outcome, they should strive to let the patient make up their own mind. Often when decisions are particularly hard, patients resort to asking their doctor what they should do, but it is just such decisions that are most important for the patient to make an informed, as opposed to advised, choice.

9. Consideration also needs to be given as to how this process of meeting the qualifying conditions is to be met. Clause 2 (2) says that “The attending physician shall have been informed by the patient that the patient wishes to be assisted to die”. How does the patient know that this is an option? Does the physician inform the patient? If so, could that be construed by the patient as a suggestion, or even a recommendation? One practical solution to this could be to provide terminally ill patients with a nationally produced leaflet of options for their care, covering a wide variety of aspects, such as allowances and benefits, prescription charges, hospice and palliative care, NHS and non-NHS nursing services, and a section on assisted dying.

Clause 4: Declaration made in advance

10. This clause provides for a written declaration. We believe that consideration should be given to a patient, who is unable to sign a form, to be able to make a verbal declaration (recorded as necessary) countersigned by a solicitor and another witness in accordance with Clause 4. Without such a provision, patients dying of paralysing diseases such as Motor Neurone Disease may be unfairly excluded.

11. With regard to sub-clause (4) dealing with witnesses other than a solicitor, consideration should be given to including a requirement that no person is allowed to act as a witness or signatory if they have a financial or similar interest in the patient’s death. It is true to say that a beneficiary need not be a relative. Consideration should also be given to making it a criminal offence to fail to disclose such an interest.

Clause 5: Further duties of attending physician

12. Here we consider the question of the qualifications or expertise of the doctor who assists the patient to die. Clause 5 implies this will be the attending physician, defined in Part 1 as “the physician who has the primary responsibility for the care of the patient and the treatment of the patient’s illness.” As patients with terminal illness are, for the majority of their remaining time, cared for by their GP, then the responsibility for assisting the patient to die will fall to the GP. However few GPs will feel they have sufficient knowledge or skill to assist, so there would clearly be an important training issue. Furthermore, it is likely that only a minority of GPs would take up such training, so it will be necessary for the attending physician to refer to a colleague who does have appropriate skill for reasons other than conscientious objection. GPs who have undertaken such training would be one option, but alternatives include Consultant Anaesthetists, Palliative Care Specialists, or Oncologists.

Clause 6: Revocation of declaration

13. We question whether it is possible, legally, to destroy any entry in a patient’s records or if this provision in the Bill will set a precedent in this matter.

Clause 13: Requirements as to documentation in medical records

14. Sub-clause (2) requires the attending physician to send a full copy of the file to the relevant monitoring commission within seven days of the assisted death or attempted assisted death: would it not be worth consideration to require each event to be medically and legally assessed before the assisted dying takes place?

Clause 14: Monitoring commission and reporting requirements

15. The College takes the view that the third, lay, commission member should not be restricted to someone “having first hand knowledge or experience in caring for a person with a terminal illness” because there is no such restriction on the other two commission members (the registered general practitioner and the legal practitioner).

Schedule: Form of Declaration

16. We suggest that “control of all symptoms” should be added to the reference to (successful, not just attempted) palliative care.

3 September 2004

Written evidence collated by The Royal College of Physicians of London

ON BEHALF OF THE ACADEMY OF MEDICAL ROYAL COLLEGES

BACKGROUND

The Royal College of Physicians of London (RCP) has considered this Bill both in its original 2003 version, and in the amended version of 2004. It has been considered by RCP's Committee on Ethical Issues in Medicine, and its Council.

Throughout what has been extensive discussion, there has been considerable sympathy for the considerations that have informed the proposed Bill: humane concern for the possible unnecessary suffering of patients; respect for the autonomy of patients in this most important area of decision making; and the need to protect doctors who may be uncertain of their duties in an unclear legal situation or who may be driven to activities that are currently illegal by their wish to serve what they perceive to be the best interests of their patients.

The first version of the Bill was unanimously rejected both within RCP's Committee on Ethical Issues in Medicine and within our Council on a variety of grounds including the fact that there were serious ambiguities in the formulation of the Bill. Many concerns were also raised about the impact the Bill would have, if enacted, on the relationship between individual patients and their doctors, between the medical profession and society and also upon society itself.

The College reconsidered the Bill in detail when it was proposed in an amended form, which had addressed some of its concerns. Moreover, the initial response elicited some extremely useful, and in part reassuring, information on the impact of comparable legislation in other countries on the relationship between doctors and patients and the medical profession and society as a whole.

When the amended Bill was considered, there was no longer a unanimous opinion. Setting aside empirical issues regarding the impact on society, there was a clear division of views as to its desirability from the ethical point of view. Extensive debate both within the Committee—including presentations from the Lord Joffe and Ms Deborah Annetts (in favour of the Bill) and Baroness Ilora Finlay and Dr Rob George (against the Bill)—and within Council did not bring agreement any closer.

One area where there was strong and overwhelming agreement, was that the Bill was essentially a matter for society as a whole to decide and that the College should not assume a position for or against.

The comments in our submission are therefore confined to areas in which the medical profession could claim to have a special understanding and expertise. It does not signal support for, or opposition against the Bill, but instead highlights those issues for practising doctors which would have to be carefully thought through both within the Bill and any subsequent Code of Practice, if assisted dying were legalised under the terms of the proposed legislation.

Members of the Select Committee should note that our submission incorporates the views of the Academy of Medical Royal Colleges (AMRC) whose members were consulted in the course of our deliberations.

MEDICAL ISSUES

Diagnosis

1. When a patient seeks assistance in dying, it is important to diagnose the reasons for this before discussing this option. In many cases unbearable suffering may be due to remediable symptoms. These should be identified and adequately addressed. Doing so requires considerable expertise and this expertise is unfortunately at present not available to all dying patients.
2. Many dying patients, are, for entirely understandable reasons, depressed. This depression may not simply be a reflection of their medical condition and may be amenable to treatment by antidepressant drugs or by counselling. It is essential, therefore, that a treatable depression should have been identified and managed. This again requires considerable expertise.
3. It has to be recognised that autopsy studies have shown that in a small minority of cases people who are thought to have had terminal cancer turn out to have had a treatable non-cancerous cause of death. This places the onus on the clinical team to make an accurate diagnosis before even considering assisted dying.
4. The request for assisted dying may be the reflection of a fear of the process of dying: these fears should be identified and in many cases may be allayed by discussion and reassurance.

5. Palliative care specialists have noted that unbearable suffering prompting the request for assisted dying is often a reflection of unresolved psychosocial issues. These should be identified and resolution attempted.

6. Finally, it is important to ensure that the request for assisted dying, and the decision to grant it, is the not the result of external pressures; for example the feeling that one is a burden to others or that one is pointlessly consuming resources.

There should be clear documentation that all these concerns have been identified and addressed as far as possible.

Training

It will be evident from the foregoing that the management of the dying patient, and, more specifically a clear understanding of the issues surrounding the request for assisted dying, both require a high level of competence in making the complex diagnoses. Anyone involved in the assisted dying process should have received rigorous training in how to discuss these issues with patients and with their supporters; in the legal framework of assisted dying; in the appropriate methods of assisting patients to die; and in the context and settings in which this should take place.

Any facility where it is likely that patients will be requesting assisted dying should have a team of doctors and allied professionals, who have willingly opted to belong to the team and who could be well trained and might even be “on call” when their specialised decision making assistance was required. This of course would be necessary only if the Bill were enacted.

Implementation

Consideration should be given as to who would be responsible for assisting a patient to die. Not all physicians will wish to be involved and this is acknowledged in the “conscientious objection” component of the Bill. This should be clearly supported in practice as well as in theory.

It follows from this that, other attendants than those usually overseeing the patient’s care (eg hospital consultant, general practitioner) may be involved in assisted dying. Co-opting others to assist in dying should be the subject of careful consideration and even more careful scrutiny. The extension of a nurse’s role to encompass this assisted dying, for example, would be a major step. Involving others less directly concerned with patient care, such as pharmacists, is an even greater step. How will this be arranged and how will this be perceived? How will those requested to assist in dying cope with the impact on themselves? As care is increasingly delivered in multidisciplinary teams it is imperative that there are clear lines of responsibility.

Finally, we ask that the Committee give careful consideration to the current recommendation to have two co-signatories to sanction an assisted dying procedure, as a number of people have questioned whether this constitutes a sufficient safeguard against potential abuse of the law.

Audit and documentation

Many believe that the enactment of the Bill would be a leap into the dark. There have been widely expressed concerns about a “slippery slope”; that assisted dying may be extended beyond those groups envisaged in the Bill to those who seek euthanasia voluntarily while not terminally ill; or, more worryingly, to those whose request for assisted dying is not truly informed or even truly voluntary. There have been additional worries that these concerns could have an adverse impact on the doctor patient relationship and the relationship between the profession and society as a whole.

There should therefore be sufficiently detailed documentation and audit of the uptake of assisted dying in order to address purposefully, rather than merely incidentally, the concerns expressed with respect to “slippery slopes”. Audit should include a clear examination of the availability of palliative care services to patients who have received assisted dying to make sure this was genuinely a comprehensive service and was truly accessible. In addition there should be proper evaluation of the impact of the availability of assisted dying on the attitudes of patients who have a terminal illness and on the relatives of those who have died with and without assistance. Finally, there should be regular surveys of public opinion about the impact of the Bill in the areas indicated.

We also seek clarification as to whether assisted deaths would require notification to the coroner. Since the immediate event resulting in death would be unnatural, we presume that notification would be required and that each individual death would be subject to medico-legal scrutiny.

Campaigning for palliative care services

Even those who are opposed to the Bill welcome the acknowledgement that there are patients who have unacceptable deaths with unalleviated, prolonged and unbearable and pointless suffering. Irrespective of whether the Bill is or is not enacted, it should be seen as a trigger to campaign for better care for dying patients. This includes not only an extension of first-class palliative care services to all patients beyond those who have traditionally received such care, but also a more rational, human and intelligent discussion of a wide range of end-of-life issues. The medical profession is not alone in experiencing increasing uncertainty as to the proper approach to decision making in this area. Technological advances, changing values and increasing ethnic diversity of viewpoint have left many clinicians feeling bewildered and at times unprotected when they wish to do what they see is their human best for their patients.

CONCLUSION

The Royal College of Physicians and the Academy of Medical Royal Colleges very much hopes that these essentially medical consequences of a change in law should receive at least as much attention as the ethical debate.

Examination of Witnesses

Witnesses: PROFESSOR RAYMOND TALLIS, PROFESSOR JOHN SAUNDERS, Royal College of Physicians, and DR IVAN COX, Royal College of General Practitioners, examined.

Q222 Chairman: Thank you very much indeed for coming. In the first session we expect to have the colleges, the Royal College of Physicians and the Royal College of General Practitioners, for about an hour, we thought; and then the Royal College of Nursing at 3.30. The precise time is not absolutely definite. I am sure the physicians and the general practitioners know that the nurses need to be well heard, so we will not unduly encroach on their time. I should explain that the evidence that witnesses give is recorded, and the witnesses will have an opportunity of checking the record, not in order to improve their evidence, but in order to check that the record of it was accurate. If you would like now to proceed, we would invite you each to make a short opening statement, if you wish, and then the Members of the Committee would like to ask questions; and we are aiming at 3.30 for completion of this particular session. Who would like to start?

Professor Tallis: Thank you. May I start? My name is Raymond Tallis and I am Chair of the Committee on Ethical Issues in Medicine at the Royal College of Physicians; and I have come with Professor John Saunders, who is the Secretary of the same committee. I am going to make a statement on behalf of the Royal College of physicians and Dr Cox is going to make a statement on behalf of the Royal College of General Practitioners. Professor Saunders and I are very grateful to be invited to give oral evidence to the Select Committee on behalf of the Royal College of Physicians. As I have indicated, we are respectively the Secretary and the Chair of the Committee on Ethical Issues in Medicine. This committee reports to the Council, which is the decision-making body of the Royal College of Physicians. What I want to do is very briefly summarise the position of the college as has been

established in council, though, of course, I will not reiterate everything that is in our written submission. We want to, first of all, emphasise that throughout our extensive discussions there has been much sympathy for the considerations motivating the Bill: a humane concern for the suffering of patients, which may in some instances be unbearable, unrelievable and, given the expected outcome, pointless; respect for patients' autonomy as the cornerstone of medical care; and also the need to protect doctors, who may be uncertain of their duty in an unclear legal situation or who may be driven by their wish to serve what they perceive to be the best interests of their patients, to actions which are currently illegal.

Q223 Chairman: I wonder if perhaps you could speak slightly more slowly, Professor Tallis, because the young lady is taking it down and it is a bit of a challenge.

Professor Tallis: Yes, of course. The second point is that our response to the later version of Lord Joffe's Bill was different from our response to the earlier version. Whereas there was a unanimous rejection of the first version of the Bill, attitudes to the second version among members of the committee were not unanimous. For example, some, such as myself, are in favour of the Bill and others, such as Professor Saunders, are opposed. Nevertheless, there is unanimity in the college as reflected in the Committee and in Council on two things. Firstly, it feels strongly that the Bill is essentially a matter for society as a whole to decide; and, secondly, that the particular contribution of the medical profession as represented by the college, which does not assume the position for or against the Bill, is to highlight those areas in which the profession could justly claim to have special authority. We have therefore

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focused on those issues for practising doctors which, we believe, would have to be carefully thought through in formulating the Bill and in developing any code of practice or guidelines if the Bill became law. Our position, therefore, is neutral as regards the desirability of the Bill, but we do welcome the opportunity to highlight the clinical and, more widely, the practical issues associated with assisted dying. In particular, we have been concerned about the safeguards necessary to protect vulnerable patients, and in our submission you will see that we have identified issues that need to be addressed in several areas: accuracy of the diagnosis of the reasons for assisted dying; the need for specific training of any individuals who may be involved in assisted dying; certain aspects of the practicalities associated with assisted dying, the need for audit and documentation of the actual use of the legislation if the Bill is made law; and the question; of the parallel development of palliative care services. Each of these is more complex than may appear at first sight. I know that Dr Cox, who will be speaking on behalf of the Royal College of General Practitioners, will address these in his opening remarks and some of them in more detail. For the present I want to focus on just two areas: diagnosis and palliative care services. Diagnosis goes beyond simply determining the nature of the patient's illness and the physical cause of the symptoms from which she or he is seeking relief. While acceding to a patient's request for assistance in dying demands well-founded confidence in the nature of the underlying disease and the specific cause of the symptoms, much more is required. For example, it must be clear that the symptoms cannot be resolved by any other means. Depressive illness must be identified and treated. Fears about the actual process of dying, which may be unfounded, must be elicited and discussed and allayed where possible; and this may go a long way towards relieving the patient's suffering and may indeed obviate the need for assisted dying. Unresolved psychosocial issues which may contribute to suffering must also have been identified, as they may be resolved through discussion. Finally, and most importantly, clinicians should be alert to the possibility that the request for hastening death may be in response to real or perceived explicit or implicit external pressures which may be internalised as the desire to not be a burden to others. This implies a high level of appropriate training in all aspects of end of life care as well as in the specific skills required for assisted dying; and it follows from this that careful consideration should be paid as to who will be involved in receiving and implementing any request for such help. Let me say something very briefly about palliative care services. Clinicians working with

dying patients are acutely aware of the shortfall in such services in the UK at present, especially for patients dying from non-cancer deaths outside of hospital. Both those who are in favour of and those who are against the Bill are united in their concern that assisted dying should not be seen as a substitute for optimum palliative care, and, what is more, that the availability of assisted dying should not diminish the pressure to develop universal, high quality palliative care service or reduce the sense of urgency to ensure that they are available to all patients wherever they die and whatever their cause of death. One final preliminary remark: we felt it important that the Committee had both perspectives on the clinical consequence of the Bill being enacted, both the pros and cons, in order that we should uphold the college position and of what we might call "ethical equilibrium". For this reason, we would like to beg your permission for both of us, John and myself, to respond if necessary to your questions, particularly if one of us feels that the other is making too light of or overemphasising the difficulties. This in other words is intended as a means of preventing ourselves from drifting into advocacy of one or other position with respect to the Bill, because, I cannot emphasise too strongly, the position of the college is that of neutrality.

Q224 Chairman: Thank you. Professor Saunders.

Professor Saunders: Thank you, Lord Mackay. I do not wish to add to that. Professor Tallis has spoken on behalf of both of us and I would like to lead on to my colleague.

Dr Cox: Thank you, Chairman. My name is Ivan Cox. I am a GP of 30 years standing from the City of Birmingham, previously an officer of the Royal College of GPs, with particular interest in palliative care for the last 12 to 15 years, working with London Cancer Relief on developing projects for GPs in palliative care. Thank you very much for inviting our colleagues to submit evidence. I will try not to repeat the stuff that was in the original written evidence, although I may do so deliberately in order to emphasise its importance. Our college was unfortunate in that it received the Bill, was not able to discuss it in council and in depth but, nevertheless, the Bill went to over 30 members of our college who gave their opinions on it and went to several committees, including our Ethical Committee, who also made comments about it. We too as a college want to take a similar stance to the Royal College of Physicians, and that is a studied neutrality. I am not going to go into detail now about the reasons for that, and perhaps you might like to question us later on this particular issue. Our college became more concerned about the practicalities associated with the enactment of a Bill like this, probably at two levels. The first level really

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is related to issues that might need to be considered before proper drafting of the Bill to do with definitions and wordings; and, secondly, issues that are related to its implementation which may or may not actually be better considered when considering regulations or codes of practice. Nevertheless, I think they should be considered at this stage. Professor Tallis has already mentioned issues to do with definitions and with regard to diagnosis, so I will not repeat that, but members of our college also have difficulties with proper definitions of what we might call terminal care, or terminality, as it is sometimes described. A doctor deciding that a patient has reached a terminal state is very difficult. In some of the work that I personally have done with doctors on this we have recognised that doctors make arbitrary decisions about when a patient has reached a terminal stage. This can be when the patient is discharged from specialist care, when the patient moves from a curative state to a palliative state; some actually just use the position when what is known as the DS1500 form is actually prescribed, or some just use the point where patients have become bed-ridden or immobile—so it is not easy. The other issue is related to the definition of “unreasonable suffering” which is in the Bill. Most people recognise that anybody who has a disease or any illness actually is suffering, and where “unreasonable” comes into this is sometimes a matter of opinion. It is not an objective state. We wonder whether Lord Joffe might not mean “unbearable” or “unrelievable”. There are also questions about competence and how one arrives at a state, an understanding of whether a patient is competent to make such a decision. For instance, if someone had a long history of psychiatric illness—depression or a psychotic illness—how would one then decide that the decision that their life-threatening disease would make them competent? If at times they had been depressed and they were depressed because of the illness, would a psychiatrist not say they are not competent because they are depressed and they had been depressed previously? Then there are issues to do with the implementation and the regulation of the Bill, and I think probably one of the crucial things that we GPs are concerned about is what is meant by “the attending physician” and “the consulting physician”? Certainly some of the papers that I have read and others of my colleagues have read about this Bill and about the doctors concerned seem to make the assumption that the attending physician could well be the general practitioner and that the consulting physician may well be perhaps a specialist, like a specialist in pain care and pain management, although, again, it is not clear. The implications of this are that, if it is to be GPs, then we need to be very clear about that, because there are a number

of GPs who would opt out, as they opt out of providing services through the Adoption Bill. We need to be very clear as to how those GPs would handle patients who had requested assisted dying, because some may well feel that the request coming from the patient would mean that they could not make a choice because, if they passed them on to a doctor who did support assisted dying, that would compromise their ethical stance. So it is important to be absolutely clear which doctors would be providing the service. A lot of discussion has been about the erosion of trust (and we may well come back to that a bit later) and the changing doctor/patient relationship, but I think several of my colleagues feel that there would be significant erosion of trust in the doctor/patient relationship, although others feel that this is a dynamic and may not change as much as people expect. There is also concern about the regulatory framework and the implications of enactment of this Bill. Dare I mention it, but there is a post-Shipman effect, and I have to be very careful about using that term in a context like this. No-one can actually quite measure what the Shipman effect has been, but there are certainly anecdotal stories amongst the public and amongst doctors that patients now are fearful that general practitioners coming along with morphine may well actually want to put them to death and those sorts of things. We do need to consider the implications of a Bill like this on what I have described as the Shipman effect. Finally, Chairman, I just want to reiterate what my colleagues have already said about palliative care. A lot of what this Bill seems to say is predicated on the provision of adequate, if not very good, palliative care before the patient reaches the point of making a decision that they want to die. Unfortunately, there are not adequate palliative care services in this country at the moment. Most GPs would consider this a part of their core service, but in a number of places where what you might describe as basic palliative care could be provided, there is not specialist palliative care to add to that. I am sure they would actually reiterate that. Thank you, my Lord Chairman. That is my introduction.

Chairman: Thank you very much indeed.

Q225 Lord Taverne: The first thing I would like to explore is a lot of the points which have been raised by the fears which patients have, and also the question about how far patients are competent to make decisions. These points have been raised, which are obviously of very great importance. Does that not really mean that it is extremely important that the doctor should be in a position to discuss matters with the patient? And is it not really rather an important fact that all the evidence suggests that in The Netherlands, where they have now had seven

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years experience of euthanasia, doctors are far more ready to discuss matters with patients and patients are far more ready to discuss matters with doctors, than they are elsewhere? Just quoting the figures, a study of medical decisions across six European countries found that in 92 per cent of the cases in The Netherlands doctors discussed end of life decisions for competent patients, 78 per cent in Switzerland, 67 per cent in Denmark, and then it declines into the other countries down to 38 per cent in Sweden, where one does not discuss this at all because there is very strong opposition to euthanasia. Is not this ability to discuss also reflected in the fact that the Dutch doctors are the most trusted of any doctors in Europe? Is not this therefore an argument in favour of changing the law rather than resisting?

Professor Tallis: John, would you like to lead on that one on behalf of the Royal College of Physicians?

Professor Saunders: Yes. The first assumption there is of cause and effect. You could, of course, be right that having a law of this sort opens up and makes discussion more likely, and on balance I would have thought that that probably is true. I would certainly take the view, and I think the College would take the view, that the more discussion there is between doctor and patient about these issues the better. I think we would also agree, and I think it is probably a College view too, that there is very good evidence that even in the UK practice there is more discussion about end of life issues of all sorts with patients than there was, for example, 10 years ago. The specific documentation, of course, comes with a separate issue, the discussions that are based around non-resuscitation or attempted resuscitation orders. We know that these things are better discussed than they ever were 10, 20 years ago; so we are improving, in an improving position. There is, of course, great difficulty in international comparisons, which I would simply flag up. There are different systems of healthcare in place across Europe; there are different cultures, subtly different cultures in some cases, and I suppose you might suggest that Northern Europeans might have a more common outlook than perhaps others. Certainly there are differences and I would not wish to draw too firm a conclusion from the suggestions you make, but I think it is plausible that enactment of this Bill will improve discussion, and that at least might be one of good effect. Can I just add one foot-note to that. The foot-note I would like to make is that, in order to assess a patient fully, there are great advantages in a long knowledge of the patient. I think we all acknowledge that that is good practice, that patients you have known for five, 10, 15 or 20 years are far easier to assess, far easier to evaluate their critical interests as opposed to their momentary experiential interests, and that, of course, is difficult in this Bill

with the role of the consulting physician in particular.

Professor Tallis: May I reinforce that last point? It has implications for those who will be involved in the actual implementation of assisted dying. John and I have a different reading, in a sense, of the data that reflects perhaps our different positions. I have been very impressed by the international comparisons and, in particular, by the level of trust of Dutch doctors, the way they are viewed by the population as a whole and by their patients. Having said that, we all know that measuring trust is not an easy thing and there will always be methodological problems. So, whereas I am impressed by the data, it may well be the case that we need more information in that area. I know Ivan has some views about the complexity of measuring trust.

Dr Cox: There are two things I would like to say. One is to reinforce what John was saying earlier about interpreting the data in the sense that there may not be cause and effect. We have done some work within our College in training doctors, training general practitioners particularly, in palliative care, and we have recognised that training in palliative care has encouraged doctors to discuss issues relating to the dying of their patients. The whole issue of learning about breaking bad news has helped doctors actually approach the subject with their patients. But, again, the issue in relation to trust between doctor and patient and the development of a doctor/patient relationship is always a dynamic; it cannot ever be seen as something static. There have been a whole series of events in healthcare in this country which have supposedly shifted the relationship between doctor and patients: new contracts, the Shipman affair, the Bristol affair, and whatever, would seemingly have undermined the public's trust in their doctors. But actually, if you do straight surveys of patients and what they think of their doctors, particularly their GPs—I have got to say that because I am a GP—then you discover that well over 90 per cent actually still respect their GPs considerably. So you do have to take the information a little carefully. As I have said, the issue of trust is a dynamic. There are all sorts of different things going on at any one time, and it is like society—society evolves. So one thing may provide a negative influence on the doctor/patient relationship, but then equally in relation to the evidence that you are producing would suggest that in The Netherlands things have improved, doctors do discuss it much more efficiently and effectively, and I am quite sure the same thing will happen in this country.

Q226 Lord McColl of Dulwich: Very briefly on this one question, the idea of a long knowledge of a patient being an advantage, would there be

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something to be said for having a patient who wishes assisted suicide being admitted to a hospice for a week, where you would get a very good assessment and you would also see the effect of treatment?

Professor Saunders: I think the one word answer to that is, “Yes”, if that was possible. Unfortunately, as a practical issue, I suspect it would not be possible, and it is one which I think will have to be considered as a practical issue if this Bill becomes law. But I entirely agree with you, Lord McColl—I think that the assessment by the attending physician is all too easily going to be a superficial issue. One can use the words “rigorous”, “thorough”, “detailed”, and all the rest of it, but I think we all know how people do rigorous, detailed and thorough examinations of bodies before bodies are cremated. We know that those words become rather meaningless in practice, and this is the point at which, if enacted, this Bill may be assisted by a code of practice to outline what we actually mean by a thorough or detailed assessment by that attending clinician. It seems to me that to come to see somebody and assess them over a 15-minute or 20-minute or half-hour period may be grossly inadequate, that there may be conflicts that it would be foolish to pretend you would uncover in that time, and the patients’ interests would accordingly be misinterpreted. These patients, after all, we can all agree, are particularly vulnerable, and the second opinion is going to be a key person in it. I think one also has to say that there is a danger in that second opinion, unless there is some sort of code of practice in place, as a purely practical issue, that the same person would be providing the second opinion, because there are going to be a limited number of such patients, I suspect, and when a second opinion is asked for it is always going to correspond with the first opinion by virtue of the choice of second opinion who is approached; and I do see that as an important practical issue.

Professor Tallis: I think that relates to a key issue about the context in which this takes place, and I am very interested in the Oregon experience, that a very high proportion of people who have assisted in death actually do so in the context of palliative care—they will have either received palliative care or do so in the context of palliative care, and it seems to me that this illustrates perhaps the non-conflict between palliative care and supporting someone through assisted dying.

Q227 Bishop of St Albans: I am absolutely intrigued about the notion of studied neutrality. I think you were inviting us to raise a question or two about that. Professor Tallis, you talked about respect for personal autonomy as being the cornerstone of medical care, so presumably the College has a

common mind on that. If it can have a common mind on that, why does it find it so difficult to have a common mind about this particular issue? Is it that actually having a common mind is not important, or what? I am just intrigued by the kind of tensions that lie within the kind of statement that you have made.

Professor Tallis: I think the big problem is the question of whether autonomy is, as it were, the sovereign bio-ethical principle, and I think there is not an agreement on that. There is no doubt about it; autonomy is the cornerstone of general medical practice, it is in a patient’s actual care and so on, but there are certain issues where there may appear to be conflict between the value of autonomy and other values, and that is where the College, I think, have recognised that there will be no consensus on that particular area of conflict. Therefore the role of the College is to give good clinical advice if the Bill were enacted.

Q228 Bishop of St Albans: So does that mean that the College is abdicating its sense of responsibility to think through bio-ethical issues of this magnitude?

Professor Tallis: Individual fellows and members of the College will have their views and will express them. The corporate body, as it were, so far anyway, has not reached a consensus on that particular issue, and for that reason we act both as private citizens, as it were, and also as representatives of the College, and I think the college has a particular concern about training and quality of medical care. That is its central role and that must be the focus of the intervention that it offers in the debate.

Q229 Bishop of St Albans: I recognise that. Because you invited us to ask why you were neutral, I am just trying to find out why you are. Does this mean, therefore, that—I think I am right in saying—in the Patient Assisted Dying Bill 2003 the College said there would be difficulties over the issue of personal autonomy when there are individuals suffering learning difficulties, or communication problems, or, indeed, issues of psychiatric concern? Have you changed collectively your view on those difficulties now? Or are we to take it that the views are still certainly those of individuals and not of the College?

Professor Tallis: I think there was an effect of the cumulative impact of several changes in the Bill, including the definition of the kind of patients who will be appropriate, who may be related to assisted dying. There seem to be more safeguards built into the Bill. This is a quite significant change in the Bill, and that is why it was felt that the College should revisit the Bill, and that is when, if you like, the balance of opinion, or the range of opinions, became more balanced than in the case of the

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original Bill, when there was fairly uniform rejection of the Bill.

Q230 Bishop of St Albans: Thank you very much.

Dr Cox: I am sorry Bishop, if I may come in too to reinforce much of what Professor Tallis has said, and to add the fact that within the College, our college, the Royal College of GPs, our studied neutrality has come through in some circumstances an examination of the experiences of Oregon and of The Netherlands and to some extent the Euthanasia Laws Bill in Australia and attempts in New Zealand to change things. We see ourselves as an academic college, not a democratic institution, I think is a better way of putting it, in the sense that we try to achieve decisions by consensus. When it is quite clear that there is a significant division, almost 50:50, as it would be in our College now, we do not feel we can make definitive statements, and that is where we come from.

Professor Saunders: One further foot-note on that, if I may, Chairman, and that is to say that we do agree that autonomy is the key cornerstone of medical practice, but within the committee of ethical issues in medicine over the years there has inevitably been debate as to actually what we mean by that concept. I do think that word is very easily traded about as though it has a rather obvious meaning. We have debated over the years the definitions and nature of autonomy as to whether we understand it simply in the terms of personal liberty, as I suppose most memorably described by John Stuart Mill, or whether we actually think of it as having a tension between autonomy which we may construe as some sort of atomistic individualist consumerism (or something of that sort) verses autonomy in society, in which there is inevitably a social animal, a social human being, exercising choice but within the perspective of community responsibility and some sense of solidarity; and as a College we have debated that over the years. Certainly it does seem to us that this word “autonomy” is not capable of some simple off-the-shelf understanding in the way that it is often construed.

Q231 Lord Carlile of Berriew: I do not know if Dr Cox’s 50:50 was a scientific estimate or a guesstimate, but let us suppose that it is a reliable guesstimate. In an academic institution that seeks to make change by consensus, would Dr Cox agree that a 50:50 division shows such a huge absence of consensus that it would be extremely difficult to deliver ethical rules which commanded anything like the consensus that is necessary for such rules?

Dr Cox: Lord Carlile, I am not sure I can answer that, in the sense that what we have tried to do in getting information about this Bill is to ask a number of general practitioners, senior general

practitioners within the profession. They have responded with a wide range of responses. As we have not had the opportunity to discuss this fully in council, it has been decided that at this stage we would not feel able to make a definitive statement about the ethics and morality about this. We would, if we had the opportunity, have gone to council and had a full debate on this. There was a debate on this some years back at which time the council decided that it would not support a Bill of this particular nature, but, as we have not had the opportunity to discuss it in detail at this stage in full council, this is one of the reasons we have decided to retain a neutral position.

Q232 Lord Carlile of Berriew: May ask one other question. I understood Professor Tallis to be saying that he would prefer the test of “unbearable suffering” to be replaced by a test of “unrelievable suffering”. Does he agree that to do that would completely change the character of the Bill? The definition of “unbearable suffering” is plainly subjective; “unrelievable suffering” would plainly be objective and, therefore, surely would place on a doctor the intolerable—for many—and, in my view, ethically incorrect responsibility of making a judgment as to whether a person should be killed irrespective of that person’s wishes?

Professor Tallis: I am not aware that I made that point explicitly.

Q233 Lord Carlile of Berriew: I took a note of what you said. You did actually say that.

Professor Tallis: I said “unrelievable suffering” in my summary.

Q234 Lord Carlile of Berriew: Yes?

Professor Tallis: Fine. It seems to me that my choice of adjectives--

Q235 Lord Carlile of Berriew: You can change your mind if you want to, but we need to be clear?

Professor Tallis: I did not change that. Perhaps I should have done. The principle behind your question is a very serious point, which is that of how do you evaluate suffering and what is the point from which you can most safely evaluate it? Should it be based on objective criteria or on subjective criteria? I think you have put your finger on what is one of the central difficulties of pretty well all of medicine; it is not unique to this particular issue. In other words, when you are deciding what the patient’s interests are, what you should do for the patient, do you, as it were, adopt the subjective viewpoint of the patient? Or do you try and determine, on the basis of objective pathology or whatever, what you expect they should be suffering? It seems the whole trend of medicine, I think, over the last few years, which

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has become much less paternalistic, much more patient-centred, is to respect the subjectivity of patients, which is really, in a way, to rely on a patient's testimony above all as to what counts as "unbearable", "unrelievable", or whatever, and I think that is the position from which I am coming. I do not know whether John may wish to develop that.

Professor Saunders: I think the interpretation of experience for all of us is filtered through our role as members of society and responding to the language and mores of society around us. That is why autonomy is such a very difficult concept. Let me give a rather trivial example to illustrate what I mean; may be it is not so trivial. I can remember many years ago somebody telling me how they had been brutalised by a British soldier at a check-point in Northern Ireland. When I asked them what had actually happened, it appeared that they had been searched rather like I was today on entry into this House. But, of course, it was the language of the time that what British soldiers did to Irish subjects was brutal so, by definition, this person had been brutalised. Language of that sort rapidly acquires the meaning of the context in which it is occurring and it reflects the social mores of time, and the word "unbearable" is a word that is going to have that sort of meaning put upon it. I hope I have made that point clearly. It does seem to me there is an inevitable subjectivity about defining "unbearable" which we sort of understand in practice but which in trying to put into so many words and trying to litigate for is fraught with enormous difficulties. I have great difficulties of a practical kind in saying if we have the power to put into people's hands to authorise killing on these grounds, what is the test—what is the test by which they can defend themselves in the event of having killed that patient, and what is the test that would stand in law? What also is the test that stands ethically, and I think that is exceedingly difficult.

Dr Cox: Could I respond to Lord Carlile's comment in a sense, because I also mentioned the difficulties in this definition of "unreasonable". Our view would be that, yes, it does place a considerable burden on the doctors in helping the patient to make decisions. Using the terms "unrelievable" or "unbearable" seem to us to be terms that are more measurable. One of the things that we doctors often want to do is to have guidelines and to have tools that we can use to measure certain aspects. Using the term "unreasonable" is, as you say, a subjective one which does not have within it abilities to actually measure it effectively, but using "unrelievable" you can define issues relating to the patient that you could measure and you could give scores to. You can actually use pain scores, for instance, which are used quite often in palliative care, so there is a

possibility of using these terms instead of the "unreasonable".

Q236 Baroness Jay of Paddington: I wonder if I could just ask you a brief factual question to start with. The written evidence we have is on behalf of the Academy of Medical Royal Colleges as well as the Royal College of Physicians, so that simply includes the Royal College of General Practitioners? Or are you in a sense representing others as well?

Professor Tallis: The Academy is an umbrella organisation and the document we presented from the Royal College of Physicians was submitted to the Academy by our President, Professor Black, and she invited them, as it were, to adopt it collectively. Some suggestions for modification were included, but it did not preclude in any way separate submissions. You will be aware, for example, that the Royal College of Anaesthetists have made a separate submission in which they take quite a different view from that of studied neutrality.

Q237 Baroness Jay of Paddington: This is, as it were, a general umbrella?

Professor Tallis: It is an umbrella organisation basically to coordinate responses to inquiries and documents and so on. Because we have a multiplicity of something like twenty plus colleges, it is a way in which there can be a single voice, if you like, within the medical profession on issues which are of common interest.

Q238 Baroness Jay of Paddington: I wonder if we could just return to this difficult question about autonomy, and I must ask forgiveness from my fellow members of the committee for quoting again from one of our senior moral philosophers who has submitted evidence to the committee and, I think to me at least, helpfully tried to identify its relevance in this document, and I would be very grateful for comments from you all on it. It says, "I do not believe an individual autonomy is the highest moral value. It should often be postponed to another higher value, such as consideration for common good if these are in conflict. However, in the case of a patient who is and knows that she is terminally ill and who would quite deliberately end her own life if she had the means or physical confidence to do so, then it seems to me there are no seriously conflicting values."

Professor Saunders: I have volunteered to take that question. I do not agree with the premise, and that, of course, is not my position representing the college, though there has to be a personal response in that I do believe that the main ethical doctrine today's Western Society, I think, is probably best articulated through Kant's concept of respect for persons, though Kant, of course, is respecting a

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much longer old tradition in the West— we are all aware of that. But I do think that the common good verses autonomy—if the two are in opposition, I think autonomy would win. I think I would have to add that my understanding of a Kantian perspective, to which you would get a far better answer from Lady O'Neill in your own House, would of course be that the Kantian view is that autonomy must be principled, and to be principled there must be some concept of a general moral law that can come from the use of that autonomy. I would acknowledge that in the implementation of this Bill, or indeed in the opposition to this Bill, there is inevitably a tension, if the Bill is not enacted, between some people, and proportionality is all-important, I think, which is an empirical issue. There is a proportionality issue between thwarting the freely expressed wishes of some people against the common good, and I think the proportional issue is morally extremely important. From my perspective, of course, I think it is not of such a scale as to pass the Bill but others will take a different view, and on that the College can have no view.

Q239 Baroness Jay of Paddington: Quite, and I wonder if Professor Tallis would like to add to that.
Professor Tallis: I cannot dissent from anything that John says, and we have had a lot of discussions on autonomy. For example, the fact remains that autonomy is always compromised, is always contextualised and so on, and so there is never absolute autonomy, but indeed it has to be principled, exactly as John has said. The question is—does this deliver us a decision about this particular issue? Does the relationship of autonomy to other values such as the common good give us a way of deciding on this particular issue? I think on balance, in our discussion within the Committee on Ethical Issues in Medicine, on which we have theologians, ethicists, people like John, and so on, this was probably unresolvable and that is why we have taken the stance of studied neutrality and said that our role is to contribute as individuals in the debate while, as a college, our special authority comes not from resolving these meta-ethical questions but from giving advice on the clinical implications and consequences.

Q240 Lord Joffe: Professor Saunders, I have mentioned to you this article¹ on pain and palliative care, and it relates to section 15 of our Bill, which deals with pain relief. In this article, if I may read part of the relevant extract, it says, “In a national survey of hospital patients it was found that, of the patients who suffered pain, 33 per cent were in pain

all or most of the time and 87 per cent had severe or moderate pain. From a palliative care perspective, moderate to severe pain has been identified as a major symptom in 50 per cent of seriously ill patients who are conscious during their last three days of life. Even patients who are able to talk with their doctors about their pain and suffering did not necessarily have optimal or even satisfactory pain relief at the end of life”. Do you think, if that is the position as you see it in the Royal College of Physicians in 2000, that that does not make the case for section 15?

Professor Saunders: I do not think there is any particular problem with section 15 in your Bill, Lord Joffe. It seems to me that there is nothing in section 15 that is not already available to patients. I see section 15 as entirely superfluous. Section 15 says that the patient suffering from a terminal illness shall be entitled to request and receive such medication as is necessary to keep him from pain and distress as far as possible. I think that is already entirely possible under the law. I simply do not see the necessity for this clause within the Bill itself. The section that you quote does in fact highlight very vividly the deficiencies in training in palliative care in the UK at the moment. It highlights, as I think that article does earlier on, the omission of palliative care in the major textbooks on medicine. It highlights the need for better training both in the techniques of pain relief *per se*, and also in the very difficult communication issues that we have in a multicultural society, where views on death and dying are so very varied. I would be the first to admit that I do not think I am fully competent myself. I think it is very difficult, and there are huge educational issues in there; and I think I can say that as a College we feel very strongly about the need for better education, better standards.

Q241 Lord Joffe: Could I just put two questions to Professor Tallis? Could you just give us a bit of background about the College and its membership?
Professor Tallis: It has got approximately 20,000 fellows, and members and it is the fellows who have voting rights. It is governed by a Council which consists of about 30 individuals, most of whom are clinicians, and includes senior officers of the College. The vast majority of the College fellows are hospital doctors or senior clinicians. It represents quite a significant swathe of UK medicine. There is an under-representation of general practitioners, who have their own college, but there is a significant number of general practitioners within the Royal College of Physicians.

Q242 Lord Joffe: To that would be added the significant number of members of the other royal colleges which have come through via the academy?

¹ Note by Lord Joffe: “The control of pain in Palliative Care” John Saunders, Journal of Royal College of Physicians Lond. Vol 34 No. 4 July/August 2000.

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Professor Tallis: Yes.

Q243 Lord Joffe: The other question I wanted to ask you relates to the point that was raised by Dr Cox, but I would be very interested to have the views of all the witnesses, and is on the question of the difficulty of predicting life spans covered by the “terminal illness” definition that we have over here. Perhaps I should read it out and ask for your comments as to the feasibility of applying it. I have spoken to a number of medical consultants and oncologists, who say that there are very real difficulties with many diseases in predicting life spans but that particularly with cancer, which is the main killer in this country at the moment, it is possible to form a reasonably reliable (though not perfect) prediction, particularly at the time when curative treatment has ceased. Are you familiar with the definition or should I read it out?

Dr Cox: Perhaps you would read it out.

Q244 Lord Joffe: It says, “Terminal illness’ means an illness which in the opinion of the consulting physician is inevitably progressive, the effects of which cannot be addressed by treatment, although treatment may be successful in relieving symptoms temporarily, and which will be likely to result in the patient’s death within a few months at most”.

Dr Cox: We would accept that as a good definition of terminality. The difficulty arises in perhaps the last phrase of that, which indicates that the patient will die within a few months. Unfortunately, all of us as physicians have been in the position where we have predicted a death for a patient. Two years later they have come banging on our door and said, “Here I am, doctor. I am still alive. Things have not gone the way you expected”. Similarly, you can predict to a patient and explain to a patient that they are likely to die within a few months, and in some senses sometimes that takes away hope and they have gone downhill a lot more quickly. Your definition seems to be the best that we have at the moment. What we were trying to highlight is that sometimes it is a little more difficult in practicalities than that definition gives credit for.

Professor Tallis: The worry behind this, of course, is that you might be wrong, and seriously wrong. Of course, medicine is a probabilistic art. It is never absolute and 100 per cent and in making all sorts of decisions, whether it a decision to do a potentially dangerous operation or withdraw treatment or whatever, it depends on assessment of probabilities. I think this Bill should stimulate one to try and get a better grasp of these probabilities and indeed to make the best use of experience from elsewhere. How often in The Netherlands, Oregon and so on, have people found evidence that they might have been seriously wrong; that somebody has been

considered as a candidate for assisted dying who has then defied expectation. In most cases the vast majority of prognoses are right but there will always be situations where the diagnosis is wrong. That is an aspect of medicine as a whole and it inevitably is reflected in this particular issue. It places a huge burden of requirement on as much information as possible and making sure our ability to prognosticate continues to improve.

Professor Saunders: Can I add a footnote to that, Lord Joffe? First of all I would like to correct you on a factual issue. Cancer is not the main cause of death in the UK. I cannot quote the exact figure, I am no epidemiologist. But I would guess that it must be around 20 or 30 per cent of deaths. Cardiovascular disease is far more common. And, of course, there is a large burden of chronic disease to which this Bill potentially applies—in particular, chronic lung disease, chronic bronchitis, emphysema, which is very distressing throughout its final phases—and a very large burden of chronic congestive heart failure, which causes enormous suffering. If the mental picture behind this Bill is one of cancer, some re-thinking may need to be done. I personally think that prognosticating in those situations is fraught with the most extreme difficulties. I can think of many patients that I have expected to live two or three months with chronic heart failure or with chronic lung disease and I have been spectacularly wrong. You are correct in saying that prognostication is probably somewhat more accurate in advanced cancer but, of course, it begs the question as to how advanced. Certainly prognosticating may be better when somebody is within the last two or three weeks of their life. I have to say that, when they are six or eight months away from it, it is actually pretty desperately hopeless as an accurate factor. Although I accept what my colleague says about medicine being probabilistic, the degrees of standard deviation from the prediction do get very large indeed when you are moving up to the six, seven, eight month mark, which I think the Bill does imply. I think there is a very important practical issue there in the Bill, which a number of members of the College have expressed anxieties about.

Q245 Baroness Thomas of Walliswood: We have had a lot of discussion about the patient’s autonomy versus the common good. In real life—and I am asking a question, although I may sound as though I am making a statement—is it not the case that what goes on is a relationship between the doctor and the patient which is a form of negotiation? Am I right in thinking that the terms of that negotiation are changing in the modern world? The patient is becoming more demanding—if you like, less obedient, less willing always to accept what the

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doctor says is correct; and there is a lot of evidence of that from people who are told one thing by their doctor and then go away and research it on the internet and come up with a totally different approach to the disease. That sort of attitude would have been unheard of 15 years ago, certainly 20 years ago. There is this negotiation which is going on. In effect, when you come to a decision which, heaven knows, is going to be a difficult one, about assisting a patient to commit suicide, which is what this Bill is about, that will be the result of some kind of agreement, will it not, between the patient and the doctor? Looking at it in a human kind of way, how would any of you tackle that sort of negotiation? The heart of this Bill is something to do with how these decisions are arrived at, when I guess that these rather grand considerations of ethics or the common good actually will not be the subject of discussion at all; it will be something much different from that. How do you safeguard the activity, which is really what I think the College of Physicians was talking about—not as to whether it is virtually moral or not but how you would actually handle it?

Professor Tallis: First of all, your view of the general social trend is absolutely right: the willingness to subordinate one's autonomy to the common good seems to be attenuated with time. That is an epidemiologically ungrounded observation but one gets the feeling it is true. That is certainly the context and I think it probably explains a lot about why this issue has come to the fore. It is a reflection of general social trends. The issue of how one arrives at a decision seems to me to be that, when principles fail, one has to resort to conversation, and I am a greater believer that within the interstices of principles one has to have a conversation on ethics. The decision and the agreement as to what the patient wants, the sense of what the patient wants, emerge during this very long conversation. It will not be a one-off conversation. It will not necessarily begin at the time of the patient seeking assisted dying or even at a time when the patient is perilously ill. It may well begin a long time before, and that is why it is very important that it should be part of a longer relationship with the physician. I would see this kind of decision emerging out of a larger conversation, encompassing all end-of-life decision-making and indeed encompassing things far upstream in the management of an illness. It would not just be a one-off visit and a decision. It would be something that is, as I say, part of a much longer conversation between a physician who cares and a patient who is cared for.

Professor Saunders: Can I add two footnotes to that? One is the enormous practical one, which presumably is the problem landing on Lord Joffe's desk, if I may say so. In my understanding at the

moment, the issues surrounding conscientious objection in the Bill have been temporarily suspended, or a line has been put through them, while new arrangements are in place. But access to the provisions of the Bill, if enacted, will of course depend in the first instance on being under the care of a doctor who is actually in sympathy with that Bill and is prepared to discuss it with you. That is necessarily the case, so that if you have a patient with a long-standing chronic lung disease who has a long term relationship with a chest physician, if you are a nephrologist who has a patient with long-standing chronic renal failure or an endocrinologist who has a patient with long-standing hormonal complications, etc, etc, there will be a need to say that, if the patient has a right under the law to assisted suicide, how can that right be realised if their long term doctor is actually not sympathetic to their request? That I see at the moment as simply a practical issue. I cannot express an opinion because as far as I can see the proposal has not been redrafted and we would want to look at any proposal that is made in the redrafting.

Q246 Baroness Thomas of Walliswood: In the case of abortion, which is an equally divisive issue, there certainly are doctors who will say to a woman seeking abortion, "I am not going to counsel you on this matter because I do not believe in it, but I will refer you to somebody else who will be able to talk to you about that because he or she has different views than mine". Do you not think that might be one of the things that might be a solution? You are shaking your head.

Professor Saunders: No, I do not, Baroness Thomas, because I do not actually see the two situations as being in parallel. I can only give a personal answer rather than a College one. The reason I do not see them in parallel is that the one thing we can all agree on is that, if I give barbiturates and curare to a competent adult, I am killing that person. We can agree that; I do not think anyone can contest that that is killing somebody. It is killing a human person. I think even the most vocal opponent of abortion, despite the rhetoric, which at times is extremely powerful with inappropriate violence in certain countries of the world, I do not think people in their heart of hearts actually do think that destroying a six-week foetus is truly akin to murder. I know that many people say it is but I must say I doubt whether they truly believe that. In the case of assisted dying to say, "I am not going to murder this patient but I will arrange for another murderer to do so" strikes me as a very strange position to be in.

Q247 Baroness Thomas of Walliswood: With respect, I think that is way beyond what the Bill says. The Bill exempts a doctor from legal penalty

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if he conducts himself in the way that the Bill determines. It is a very narrowly drawn little Bill.

Professor Saunders: Indeed it is.

Q248 Baroness Thomas of Walliswood: I am sorry to protest but I thought that was a little bit over the top.

Dr Cox: If I might come in here, going back to your original contention that the relationship between doctors and patients has changed over recent years, that would certainly be my experience and that of a lot of other general practitioners. With respect, I think what you were pertaining to was an ideal relationship perhaps between the general practitioner and the patient which is of long standing, which is one of trust, where the patient and the doctor had gone through a lot of different things together. Unfortunately, some of the changes that have taken place in our Health Service in the relationship between doctors and patients of late do mean that there is more frequently just a spurious relationship between the patient who comes to see the doctor that is on duty that particular day or the doctor that is only temporarily in the practice. And, again, I do not wish to draw a distinction between social communities but it may well be that some of our poorer communities may find that, though they request assisted dying, they find it more difficult. We may still end up with what does happen to a lot of patients who request abortion at this stage, which is that they are referred to two family planning doctors, and their own general practitioner would not be able to assist in that. And that in a sense, with due respect to what Professor Saunders said, becomes almost like death on demand and we would not want that.

Q249 Lord McColl of Dulwich: I was a little puzzled by Baroness Thomas's protest at what Professor Saunders said. Would it be all right if he put it into Greek and said "thanatised the patient" rather than used the Anglo-Saxon word he used?

Professor Saunders: It was a little provocative using the word, I suppose. Yes, with respect to Baroness Thomas, I do not particularly understand her protest.

Q250 Chairman: We do not need to resolve that. It is really the advice that you are able to give us on the more practical and—what shall I say?—slightly lower ethical matters that would be of particular value. How you would describe the procedures in the Bill would be a matter on which you might have different points of view. Could you help me a little on this question of forecasting? As you say, medicine is a probabilistic science and the test here is "likely to die within a few months at most". It is the consulting rather than the attending physician

that may ultimately have to decide this question. But, whichever of you wish to answer it, how would you go about, in a particular case of a particular individual, assessing how long that person has to live?

Professor Tallis: This kind of context demands a very high level of diagnostic precision, higher obviously than many other decisions because the decision is a very grave one. However, we are talking about an individual who has often had a very long-standing progressive illness whose manifestations are very clear and who will have been fully worked up from the clinical point of view.

Q251 Chairman: I think you have pointed out that. I was laying that aside in your memorandum. It is possible to have mistakes in diagnostics but I was assuming that there was not a mistake in diagnosis at the beginning of the question, that a correct diagnosis has been made, and I was wondering how a physician or other specialist goes about assessing how long that particular individual has yet to live.

Professor Tallis: It depends on the overall statistics. I know that Baroness Finlay will know much more about this in terms of the overall statistics of life expectancy of somebody not with just a particular cancer but a particular cancer in a particular stage of development or cardiac failure or whatever; and, of course, there are outliers and there is quite a significant variation. John is quite correct that there is a huge variation in the case of something like cardiac failure. Whether there is that huge variation in those people who are so parlously ill and who have been probably worked up and all their symptoms have been sorted out as far as is possible with modern medicine I think is something that needs to be established. This is an empirical issue and I think it would be very important to draw upon experience from elsewhere. I am not in any way downplaying the difficulty of making a precise prognosis in some cases but more saying that one of the clinical requirements is that we should acquire as much knowledge as possible to maximise the precision of prognostication.

Q252 Chairman: I was hoping that you would be able to help us about how you go about it. I understand that you gather as much information as you can about the general knowledge of the particular condition in which the patient is but, having done all that, how do you then assess the amount of time over which that person still has life?

Professor Tallis: It is based on general experience of those particular conditions at that particular stage of development; but people are biologically variable, that is true. In many cases where people do have unbearable suffering which cannot be alleviated and so on, I guess they themselves will have made the

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decision that they would take the risk of trading off a longer prognosis perhaps than expected against continuing suffering.

Q253 Chairman: I think it is fairly fundamental now that in any treatment or course of treatment on which a doctor or physician is going to engage they must receive the informed consent of the patient. I know there is a bit of discussion about exactly what that involves, as there is about most other consents in this area. What would you think would be required in the way of discussing the need for informed consent in this situation where you have someone who is being offered, as a result of their own request, assistance to die?

Professor Tallis: Total honesty to say, “This is what I think is going to happen but I have a certain level of uncertainty about this”. It seems to me fully informed consent is unachievable in most situations because one is always dealing with uncertainties, but if one hedges about one’s prognostications with a statement of their probability or certainty as far as one knows, then I think it is very much for the patient to decide whether they want to take that kind of risk. I imagine that is how it would work out.

Q254 Chairman: Does the overall view of the physician about the nature of human life have any part in it or not?

Professor Tallis: I suspect it might well do. I expect that without wishing to do so we often influence patients’ decisions by our own world view. I think it would be almost impossible not to put something of oneself into the interaction of the patient, but that is always there and, given that it is always there, it factors out.

Q255 Baroness Finlay of Llandaff: You have outlined the burdens and difficulties and problems here. One thing that I read in one of your pieces of evidence was the need perhaps for prior notification rather than post-event notification. I just wonder why you feel that doctors should do this given the discrepancy that there is, the difficulties for doctors and so on. Why not have a completely separate thanatology service outside of medicine if that is what patients want? I would suggest to you that it is fundamentally different from abortion in that you have two lives—the life of the mother which is at risk by the procedure, and that may require medical intervention and sometimes intense medical intervention to save the mother’s life—and therefore we are talking about two completely different things, whereas here one person’s life is going to be ended and there is not somebody else’s life that in the process of doing it is jeopardised and would require medical intervention potentially to

resuscitate them. I fail to see why you have not been advocating the view that society sets up a completely separate service.

Professor Tallis: This has come out of some of the conversations we have had but it is very much about the relationship between the patient and an individual who has been involved in seeing them through. I know from experience internationally that people see assisted dying as part of the whole end-of-life care. It is one of many options—terminal sedation, control of symptoms and so on—and to hand somebody over to somebody else for this separate thing would be seen as a way of abandoning your patient.

Q256 Baroness Finlay of Llandaff: So you are viewing it as a therapeutic option?

Professor Tallis: I am viewing it as a therapeutic option, yes.

Q257 Baroness Finlay of Llandaff: Because therapy has good intent in it. If it is not a therapeutic option, then there is no good in it. You would not consider something as a therapeutic option if there was no evidence of good in it. So I wonder whether you see the therapeutic good in this as that it needs to be administered by medicine itself?

Professor Tallis: I am aware that in a sense I am going off message here by now acting as an advocate as opposed to maintaining studied neutrality, and I am sure John may have a view. To me it does seem to be a therapeutic option, as are many other forms of treatment that may hasten people’s deaths. That is a personal view. For that reason I do feel it should be regarded as part of the therapeutic alliance between the patient and the doctor. I do see, without trivialising the phrase, that it is part of a whole “package of care”. This is not our position from the College which, I hasten to add, is very much that we are neutral as to the desirability of this being available.

Q258 Baroness Finlay of Llandaff: If we took the past five years in your own clinical practice, how often have you felt you would want to do what Professor Saunders outlined, which is to go up to a patient and inject him or her with barbiturates and curare because you felt that there was absolutely no other therapeutic option available to you?

Professor Tallis: I have felt despair and I have felt grief at some of the unbearable suffering some of my patients have had, but I have never thought of this option because it has never been an option that has crossed my mind. It has not been an available option though one has often had a sense of defeat at failing to deal adequately with a patient’s appalling end-of-life experiences. But I have never

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considered this option because I am not somebody who would naturally think outside the law.

Q259 Baroness Finlay of Llandaff: So what did you consider?

Professor Tallis: The patient continues to receive palliative care.

Q260 Baroness Finlay of Llandaff: From a specialist service or from the service that Ivan Cox outlined, which is generalist education?

Professor Tallis: Within our own service we have some very good palliative care nurses, who are involved very early on in our wards and connect with the wider palliative care services.

Q261 Baroness Finlay of Llandaff: Do you have a specialist consultant service?

Professor Tallis: We have access to it through the palliative care nurses and we are able to access the full palliative care service, so we are very fortunate in that sense.

Q262 Baroness Finlay of Llandaff: Professor Saunders, do you have a comment?

Professor Saunders: No, only to say that we have discussed this issue within the College. Yes, we have no view on it and that reflects the divisions within the College. Again, I do not particularly want to go off message and give you a personal opinion but I do not see that there is any logical objection to the idea of a separate service. I do not think this has been adequately evaluated anywhere. I just make that as a statement of fact. There are those who feel that it is the physician's job to accompany their patient on the journey as far as they can, and that may mean to the end literally. There are others who feel that this in some way contaminates medicine. I do not think we have any empirical data from other jurisdictions that would inform whether such authorised assistance in suicide or active killing should be done by another profession—as I said in

my submission, obviously not a funeral director, but perhaps pharmacists and nurses and so on. In all seriousness, there may be a role for other professional groups.

Dr Cox: If I could come in and also make a comment, I do not think we have any definite evidence that there are doctors who would want to be the doctor that carries out the assisted dying. In some respects we have got ourselves mixed up with two different entities here. One is discussion of what used to be called assisted suicide. It seemed to mean that the doctor left a prescription for some tablets for the patient to take as and when they wanted to. We now are talking about the doctor deliberately killing the patient in the same way, almost with a contagious element to it, as someone carrying out an execution. We do need to address the difference between those two because it does have emotive issues although they are one and the same thing. As I say, we have not got any evidence as to how many doctors in this country would want to participate in this as far as I am aware, and no doubt the committee will achieve this at some stage or other. There was a paper in the BMJ not long ago which had asked the question of about 400 or 500 New Zealand GPs whether they actively participated in assisted suicide. Remember, of course, that in New Zealand assisted suicide is not legally available. Roughly 50 per cent of the GPs who were asked said that in the terms of their definition they had in fact carried out assisted suicide. When you talk to GPs in this country they will say that they have assisted patients in dying but this may be what some of us would call a double effect; in other words just raising the dose of morphine in already dying patients simply to make quite sure that they do not suffer and it is almost a coincidence that they die as a result of an excessive dose of morphine. Again, it all relates to definitions. I hope that Baroness Finlay understands where we as GPs come from.

Chairman: Thank you very much indeed. We have been much helped by your submissions both in writing and orally.

Memorandum by the Royal College of Nursing of the United Kingdom

EXECUTIVE SUMMARY

The RCN is against the proposals in this Bill. Our primary concerns are:

- More attention needs to be given to the provision of high quality palliative care, available to all who need it. This must include proper pain control and psychological care. We feel that it is imperative to address the palliative care needs of dying people in order to make their last days more comfortable, rather than clinically assisting death. Patients want control, dignity and comfort.
- There is a real danger that the proposals in the Bill could undermine the nurse-patient relationship, leading to a culture of fear amongst vulnerable people at a time when they most need to feel supported by their clinical team.

- The proposals in the Bill will be unacceptable to many nurses on moral, ethical or religious grounds. Nurses in all clinical settings—not just specialist palliative care nurses—could potentially care for dying patients. It is not a discrete area which is easy to opt out of in the way that, for example, abortion is.
- Respect for the intrinsic value of all life is central to nursing. The proposals in the Bill normalise the concept that the lives of those affected by serious illness are not worth living.
- These proposals could put pressure on many vulnerable patients, who might feel a duty to use the provisions in the Bill to avoid becoming a burden on their families. Further, relatives who can't bear to see their loved ones in pain may put pressure on clinicians to inappropriately assist death—rather than addressing the core problem, which is ensuring appropriate pain relief and symptom management.

1. INTRODUCTION

1.1 With a membership of over 370,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector, and in educational settings. The RCN promotes patient and nursing interests on a wide range of issues by working closely with Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

1.2 Nurses deliver 80 per cent of hands on care to patients, and are often the closest clinicians to them towards the end of life. Nurses can support patients and families, and have a key role to play in communicating and information sharing. The comfort and dignity of dying patients is potentially a responsibility of registered nurses and health care assistants working in all settings, as well as for specialist palliative care nurses.

1.3 The RCN has a wide membership which naturally reflects a variety of views. We have looked at a wide range of comments from our members and have decided to maintain the position reflected in this paper on behalf of both nurses and patients. Overall, our membership is opposed to the proposals in the Bill.

2. PALLIATIVE CARE AND PAIN RELIEF

2.1 RCN members feel strongly that high quality, easily accessible palliative care services, which meet people's physical and psychological needs, should be in place for all patients who need them. Adequate pain and symptom control management could alleviate some of the concerns which lie behind this Bill.

2.2 Patients do not always have adequate choices in palliative care. Differing provision across the UK has created a system where the level of palliative care received is often dependent on location. Nurses want to ensure that all their patients receive the appropriate high standard of care wherever they live, and irrespective of illness, both in acute settings and in the community. Patient choice is particularly important in palliative care; however a shortage of community palliative care teams means that patients who want to die naturally at home are not always given that option. In particular, while adults with a cancer diagnosis for the most part now receive good palliative care services, many patients with other terminal diseases—such as degenerative motor neurone disease or chronic obstructive pulmonary disease (COPD)—are not able to access appropriate services. This gap in provision needs to be urgently addressed. RCN members debated this at our annual Congress in May 2004 and voted overwhelmingly to lobby for improved palliative care services.

RCN member: "I have nursed at least one patient who was adamant he wanted to die, but when his quality of life had been improved completely changed his decision. How many more cases are there like this?"

RCN member: "Unrelieved (intolerable) pain is often cited as a reason for people wanting to die. However, hospice doctors tell us that even intractable cancer pain can be relieved in 90 per cent of patients and significantly relieved in the other 10 per cent¹. Once a patient's symptoms are under reasonable control, few people who requested euthanasia on initial contact with a hospice persist in doing so. The answer would appear to be to increase the provision of hospice care rather than legalising voluntary euthanasia."

¹ Twycross, R (1994) *Pain Relief in Advanced Cancer*. London, Churchill Livingstone.

² Commons Health Committee (2004) fourth report of session 2003–04 HC 454-1HMSO.

2.3 These issues were highlighted recently by the thorough report on palliative care produced by the Commons Health Committee.² This report also noted that palliative care services are often not culturally sensitive, and this must be addressed.

2.4 The Bill contains provision that a patient with a terminal illness shall be entitled to receive pain relief. This right already exists and all patients who need it should be able to access pain relief without the need for this legislation. The responsibility of nurses, working with others from the multi-disciplinary team, is to ensure that the final weeks of those with a terminal illness are as pain free, positive and dignified as possible. Clause 15 is unnecessary.

2.5 What is needed is better training, education and resources for all clinicians to ensure that they have a proper understanding of pain control. This must go hand in hand with a properly funded service across the UK for all who need it. Complementary therapies also play a significant part in palliative care sought by patients and this area should be given more attention.

2.6 A situation where a clinician delivers drugs deliberately to end someone's life is very different to a situation where a person administers drugs with the aim of relieving pain, even if that action may have the secondary effect of hastening death. The RCN does not consider that Clause 15 changes that distinction; nor that it should.

2.7 In particular, we must guard against the provisions in this Bill being used as a substitute for universal provision of palliative care services. Several members raised the fear that provisions in this Bill could be inappropriately used to ease the economic challenges of providing long term and palliative care.

3. PSYCHOLOGICAL SUPPORT

3.1 For some patients, social issues or psychological distress may lead to feelings of wanting to end life. This is indicative that appropriate mental health services and psychological support are not being provided. Culturally appropriate psychological support is a key component of care, and must be provided as part of the care package. We do not feel that adequate provision has been made for this in Clause 8, which deals specifically with patients who lack competence.

3.2 As an RCN member pointed out, the desire in terminally ill people to die is recognised as being transient for many:

“A study reported in the *American Journal of Psychiatry* noted the ‘inherent transience’ of the desire for death in many terminally ill patients. This desire, it said, is closely associated with depression—‘a potentially treatable condition’—and often diminishes over time.”³

3.3 This highlights the need for a comprehensive care package.

4. NURSE—PATIENT RELATIONSHIP

4.1 The Bill anticipates the potential assistance of nurses in assisted dying; however nurses as a professional group have little mention in the wording of the Bill. For example, there is no mention of counselling or education for nurses expected to be involved in these procedures.

4.2 The RCN feels strongly that the proposals in the Bill could jeopardise the nurse—patient relationship, eroding public trust in nurses. It is nurses' duty to protect the weak and vulnerable, and any perception that they would not act in this way could generate a culture of fear among vulnerable people. Some members commented on the vast shift in the cultural and ethical basis of nursing which would need to be made in order to justify participation in assisted dying.

RCN member: “Would there be a lack of trust between patients/carers/practitioners once the ‘goalposts’ have moved?”

RCN member: “As a nurse I would be very uncomfortable working in a health system that assisted people to die when surely we should be striving to care for people's physical, mental and spiritual health in this life.”

² Commons Health Committee (2004) fourth report of session 2003–04 HC 454-IHMSO.

³ Chochinov, Wilson *et al* (1995) *Desire for Death in the Terminally Ill*, *American Journal of Psychiatry* 152:8, 1995.

5. CONSCIENTIOUS OBJECTION

5.1 The proposals in this Bill would be objectionable to many nurses on moral or ethical grounds, or for religious reasons. Although Clause 7 touches on the right of objecting physicians to refer patients on, it does not adequately deal with the rights of the wider clinical team. Further, nurses in all settings potentially work with terminally ill patients. This is not a discrete area which is easy to opt out of in the way that, for example, abortion is.

5.2 The difficulty in opting out of assisted dying could create real tensions in settings such as small nursing homes, where there are fewer numbers of registered nurses. If even one or two wish to opt out of dealing with those patients who request assisted dying, maintaining an appropriate level of care would be a challenge.

6. EQUALITY AND PROTECTION OF THE VULNERABLE

6.1 RCN members have expressed concerns that the proposals in the Bill devalue life by normalising the concept that the lives of those affected by serious illness are not worth living. Nurses feel strongly that all individual lives have intrinsic value, with equity of access to treatment being a cornerstone of nursing.

RCN member: “As nurses we want to promote patient rights but not at the expense of our responsibilities as nurses (our duty to care) and in society to protect the weak and vulnerable.”

6.2 Ageing, sickness and dying are part of life and several members were wary of trying to inappropriately intervene clinically in their due process. Members commented that, however emotionally difficult, a natural death with time to say goodbye can ultimately be peaceful for patients and therapeutic for families.

RCN member: “palliative care medicine/nursing provides end of life care that, in most cases, provides relief from the distressing symptoms of terminal malignant disease, allowing precious time with loved ones. And for those without carers or family, it is my experience that some isolated, lonely people have died in an environment where they feel loved and cared for. Is this not what the medical and nursing profession is about? It is my conviction that knowledge of the skills that produce effective palliative care are still widely unknown amongst medical and nursing staff and even less so amongst the public.”

7. PRESSURE ON PATIENTS TO COMPLY WITH ASSISTED DYING

7.1 Many RCN members voiced the fear that vulnerable patients, and especially older people, would feel a duty to use the provisions in the Bill in order to avoid becoming a burden on their families. We do not consider that there are sufficient safeguards to avoid this. Further, we have concerns that relatives could inappropriately place pressure on relatives to request assisted dying, and that again safeguards were not in place to prevent this.

7.2 Such pressure would be exacerbated if the necessary palliative care package was not in place. Again, there is a real concern that assisted dying could inappropriately replace properly funded and implemented quality end of life services.

RCN member: “The most important people to consider are the patients. If they were to think that this was a possibility, would they also think there was a responsibility on them to die quicker so that they wouldn’t be a burden?”

7.3 Families would also come under pressure to relieve their relatives of pain where appropriate palliative care services were not available. However this would not be addressing the core problem, as one RCN member put:

“I have absolutely no doubt that introducing legally acceptable assisted death will put unbearable pressure on both patients and their families at a time when they are at their most vulnerable. This was brought home to me in a most tangible way with death from heart failure of my own father eight years ago. It has long been known that death from heart failure can be an agonisingly slow and painful process and that none of the palliative care so effective in cancer sufferers is currently available to them. My father had a horrible time dying and it was an extremely difficult time for the family. The GP was unwilling to provide morphine (in case it depressed cardiac function) and he suffered a great deal of pain. Had assisted death been legal at the time I would have felt under

extreme pressure to ask for it, and indeed many was the time that I contemplated in my mind at least, smothering him with a pillow to put him out of his pain. However we persevered with the GP and eventually morphine was prescribed. I cannot begin to describe the difference that this made. Suddenly my father was pain free, he rallied enough to receive the family and died in peace knowing that the end was near but free from the fear that the constant pain of a failing heart. Our family was left with memories of a good death.”

7.4 Again, this highlights the need for a comprehensive care package.

8. LEGAL ISSUES

8.1 Competent adults already have the right to refuse any medical treatment even if that refusal results in their death. It is important that patients understand their right to refuse treatment, so that they are not in fear of inappropriate and unwanted medical intervention. Conversely, it is legal for clinicians to administer medication with the purpose of relieving pain, even if that medication may have the secondary effect of hastening death. Nurses can play an important role in communicating this. The Mental Capacity Bill currently progressing through Parliament will enshrine in legislation the authority of advance decisions by patients to refuse certain treatments. The RCN welcomes this inclusion as a valuable tool to help those people who may lack capacity in the future. We consider that the Mental Capacity Bill further strengthens the argument that the Assisted Dying Bill is unnecessary.

8.2 The RCN does not consider that the safeguards in the Bill are robust. For example in the Schedule the expression “appears to be of sound mind”, in the opinion of the legal and other witness to the declaration, is vague and undefined. Further, the definition of “competent” is also very vague, and appears to bear no relationship to the understanding of competency either at common law or under the forthcoming Mental Capacity Bill (and its Scottish equivalent, the Adults with Incapacity (Scotland) Act 2000). The expression “terminal illness” is imprecise given the role it plays in this Bill’s criteria for eligibility. Many patients have been told they have days to live and have gone on to live for months or years.

9. CONCLUSION

9.1 For the most part nurses do not consider that the proposals in this Bill will better support patients, but that the imperative should be to provide improved palliative care for those with terminal illness. Culturally appropriate palliative care and psychological support should be available to all who need it. The RCN does not support this Bill.

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Examination of Witnesses

Witnesses: Ms MAURA BUCHANAN, Deputy President, and Ms CAROL BANNISTER, Manager, Professional Nursing Department, Royal College of Nursing, examined.

Q263 Chairman: Thank you very much for coming this afternoon. We are very sorry that our deliberations with the physicians and the general practitioners have slightly delayed our start but it is possible that the deliberations with physicians and the general practitioners has whetted our appetite to hear what you have to say. Please feel free to express your views within a reasonably limited time. The evidence is being transcribed, and so each witness will have an opportunity of correcting any mistakes that may happen in the transcript, although of course not altering the main thrust of your evidence. The intention is that you might wish to give us a short presentation, and then members of the committee will wish to ask you some questions.

Ms Buchanan: Good afternoon. I am Maura Buchanan, Deputy President, Royal College of Nursing. With me is Carol Bannister, who is an adviser in our Professional Nursing Department. I

am the Deputy President and have just been re-elected. I have been Deputy President for two years. My day job is as a senior nurse in the Oxford Radcliffe Trust. Clinically my background has been in neurosurgery, neurosurgical intensive care, general intensive care. Currently my position is senior nurse in a private patient unit which takes in virtually every type of patient you can imagine that comes through the Trust, many of whom are terminally ill, who have cancer and all sorts of other serious conditions. Ethics has been an interest of mine ever since I started nursing. I do have a Postgraduate Diploma in Health Law and Ethics. To put in summary the evidence that we have put to you in writing, I will highlight some of the points from the executive summary and maybe elaborate on them. There are some key concerns that we have around the Bill that we have summarised under some bullet points. We believe that more attention

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needs to be paid to the provision of high quality palliative care. That is and has been a key message from our members. By palliative care we do not just mean new structures, new hospices and new buildings. Palliative care is a philosophy. It is about key skills and knowledge that allow you to deliver that type of care. The Bill talks about unbearable suffering. That is a terribly subjective term and is different from pain. Pain control within the Bill is a totally unnecessary addition. We are entitled to give pain control, and indeed I would say that as a nurse or a doctor you are failing in your duty of care when you do not deliver pain control. We do not need laws to do it. We have the right to do that. There is a real danger in the Bill that it will change and undermine the nurse/patient relationship. It is a privilege to nurse patients. It is a privilege to be there at the end of their lives and to help families and support them and to work in the best interests of patients. We believe—and this is again the evidence from members—that patients trust nurses. The fear for nurses in this Bill is that that trusting relationship would be put at risk. The Bill would be unacceptable to many of our members on religious and moral grounds. We have not even started to consider in the Bill the religious and ethnic backgrounds that many of our nurses come from. Your Health Service, particularly in this part of England, is kept together because you have overseas nurses here. In my own Trust that is at least 30 per cent. Nursing homes will come to a standstill unless they can recruit people from overseas, and in fact they are bringing in nurses and using them as health care assistants. These nurses are from countries, mainly the Philippines and Kerala in India and some from Africa. A large majority of them come from countries where 90 per cent of the population are Roman Catholic. They would have huge problems working in any organisation that was delivering on this Bill. You cannot have conscientious objection when you work in this environment the way that you can for the Abortion Bill. You can choose not to work in a gynaecological unit, but people die everywhere in health care, so how will you take the nurses and look after them in a nursing home where the local GP comes in to practise euthanasia or, in a nicer phrase, hasten death? Who will counsel the nurses? How will we deal with them? They will not want to work there, so we will lose them. As a nurse I believe in the intrinsic value of human life. That is central to the code of nursing; it is central to our values. Some lives are not as valuable as others just because they are suffering? just because they are dying? The relief of suffering is what we are about; caring is what nurses are about. To come from the point of view that some lives are not worth living I am afraid is against the ethos of nursing. One of our great

concerns is that the Bill would put pressure on vulnerable individuals. They might feel that they had to use the Bill when the cost of nursing home care started to eat away the family's inheritance. It would be easy to succumb to pressure and feel that you had to give up or feel that you were a burden when the family in today's world do not sit at home looking after mother or elderly relatives, because everybody has to work now to keep the mortgage going. This Bill is called the Assisted Dying Bill. That is a misnomer. I assist patients' dying. I assist them through a process. Dying is a process. It is the inevitable and inescapable process that results from living and that is what nurses do—assist the dying to have a pain-free, dignified death. This Bill is about assisted or hastened death. In talking about palliative care and relief of suffering I would add that there are other ways besides loading somebody up with morphine to relieve pain. My colleague, the President, has just helped open the new wing at Bart's for cancer patients and it has been her absolute ambition and drive to give complementary therapy as part of that unit. Indeed, she has raised the money for it. There is much more to be done to help relieve the pain and suffering that goes with dying. I have with me words that I think better express these sentiments than perhaps I can. They came from an elderly nurse who wrote a letter to me just last week and sent me some words from Dame Cecily Saunders, whom you will know was the founder of the hospice movement. In a previous paper that she delivered for the Templeton Prize she said, "We believe that euthanasia or assisted suicide is socially dangerous and a negative answer to a problem that should be tackled by other means, but we have a responsibility to work so that no-one should reach that desperate place where they felt they had to ask for that sad way out". I believe that is where we come from. There is a lot of mythology surrounding death. The proponents of this Bill would have you believe that dying absolutely requires you to be in pain and suffering. It is frightening people and they think that that is what is ahead of them. That is not the case. It is not the case when you have proper terminal care, proper palliative care with people who are caring for you and caring for your relatives. We are absolutely opposed to this Bill. It is not good for patients, it is not good for nurses, and it certainly is not good for the nurse/patient relationship or, in the long run, for the public.

Ms Bannister: I just want to explain to you a little bit about the process that we undertook to arrive at our conclusions, to enable you to understand how the RCN has taken this fairly strong stance given that we know that there are nurses who hold different views from the one that we are expressing today. Certainly some of our members hold

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different views and it would be completely wrong of the RCN to say that we were completely overwhelmed by people opposed to the Bill. I have to say, though, that the overwhelming number of our members who contacted us—and I will deal with lobbying groups separately—were against this Bill for the reasons that Maura and our written submission describe. If you were to pin me down, as I suspect you might, and say, “What does that mean? How many are you talking about?”, I would want to say to you that I do not think the number matters. I can give you that if you really want to push me on it, but I think what matters is the process that we undertook and how comprehensive that was in terms of enabling those people who wanted to say something to say it and also the balance of those for and those against. It is fair to say that this is the first time the RCN as a body representing nurses has gone very openly out to its membership on an issue as sensitive as this which causes very polarised views, and we have done it in a way that I think tries to embrace all the views of the membership. We used two or three of our main communication systems, including websites. We have a bulletin which goes out weekly to all our members and we expressed the view that we would like to hear from any member about what their thoughts were on the Bill. Also, because the RCN has specialist nursing groups within its structure, we wrote to each of those specialist nursing groups. They included groups that represent nurses in palliative care, nurses who work with older people, nurses that work with children. We targeted those particular groups to say, “What are your views?”. The views that we are expressing therefore are coming from those places. They are coming from members directly who wrote in to us following our asking for views. They represent views that are from a group of members who work in particular areas of practice, such as palliative care. They also were, importantly, given to the leadership and governance part of the RCN. For our purposes, that includes the RCN General Secretary, Dr Beverley Malone, and her executive team, but also, more importantly, the governance committee of the RCN—the RCN Council, made up of RCN members. It is the RCN Council, along with the executive team of the RCN, that made the policy and the decision based upon our members’ opinions. If we were to say what was the balance of opinion, we would say that approximately 70 per cent of our members were against the Bill and 30 per cent were for the Bill. We did a thematic analysis of what those members were saying, and if we look at those who were for the Bill the majority of those people were expressing concerns about the lack of palliative care. The overwhelming message was lack of palliative care.

Q264 Lord Patel: Just before you we had evidence from the Royal College of Physicians and the Royal College of General Practitioners, and the Royal College of Physicians’ evidence also included evidence from other colleges. Because of the difference of views expressed within their membership both of them and the other colleges took a stance of neutrality. You are not doing that, although you accept that there are differences of view in your College. Secondly, they made the point that this is an issue where society should have a voice and not necessarily the professions. What is your comment on that?

Ms Buchanan: The issue is one for society to make decisions on, yes, as it is probably the biggest issue ethically in society today. No-one is forbidding someone to take their own life. The Suicide Act allows you to decide that you end your life, but you are asking professionals to take that life for them, so you cannot ignore their involvement. In the College we did open this up to views from the members and, as Carol has said, of those who were saying that it was probably OK to be pro this legislation, some had obviously thought very carefully through it but, for some, their comment was, as Carol said, built on bad experiences of patients in hospital where they felt, “I do not want to see that happen”. Their argument was not really saying that this was a good way out. It was, “We cannot have our patients die in that way. We need to do something about it”. What we as a College feel at this stage is that we cannot support nurses being involved in ending of life. That would be the wrong thing for the profession; it would be the wrong thing for the relationship of the profession with patients.

Lord Taverne: Following up on that point, you have very eloquently expressed your own views, which are very similar to others we have heard expressed about the right to life, and you have clearly done as much as you can to consult your members on it. But just to go by the strength of reaction in terms of letters you get and protests you get seems on the face of it a rather poor guide. We have had a huge quantity of letters from people opposed to the Bill, and yet the opinion polls show that 82 per cent of people are in favour. I gather you have not conducted a MORI-type poll of your members, although there has been a poll by the *Nursing Times* which showed that two-thirds of United Kingdom nurses did in fact support the Bill. Do you not think that under these circumstances—

Lord Carlile of Berriew: One third.

Q265 Lord Taverne:— you should not take a stance as an organisation without conducting a proper poll of your members, which is an independent poll that does not reveal in any way any sort of prejudice on

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the part of the pollsters? Do you not think that is something you ought to do before you as a College take sides, unlike the College of Physicians and the College of General Practitioners?

Ms Bannister: I think the point that you made right at the beginning was very well meant, that actually counting numbers is not necessarily the way to show leadership. I would, given time, be very interested in conducting a much more scientific poll than the *Nursing Times* could do. The *Nursing Times* has a readership of a particular group of people who may have a particular set of views, in the same way as the RCN may have a set of people who may have a particular set of views, in the same way as the Voluntary Euthanasia Society has people within it that have a particular set of views. I am not disputing those people's right to have those views. I would say that it would be really useful to have the time to have a much more structured look at what nurses are really saying. That is part of the reason why I would not particularly want you to have numbers of people we have canvassed, because it does not help. What we do know is the themes that have come through from the people that have corresponded and the leadership that is being shown by the Royal College of Nursing on this issue.

Q266 Chairman: I think the membership of your College is of the order of 370,000?

Ms Bannister: It is 377,000.

Q267 Chairman: Do you know what the total size of the nursing profession in the United Kingdom is?

Ms Buchanan: It is over 600,000 on the register but they are not all necessarily practising at the moment or in fact on the register. They are not even all in England. They may be on the register but elsewhere.

Q268 Baroness Hayman: Could I ask you to reflect a little on the issue of patient autonomy, which has been a thread through the evidence and the argument that has been put to us? When you were speaking, there was a lot of emphasis put on appropriate palliative care and I wanted to ask you whether you believe, because it has been argued to us that this is not so, that if good palliative care was available to everyone this problem would completely disappear? It seems to be the experience of other jurisdictions that that is not so, that this is not always a failing of palliative care. It is the case that for some people loss of dignity, feelings of loss of support, whatever those feelings are, lead them to wish to end their life. You did envisage the possibility that those patients could commit suicide, and I recognise that there are a group of patients for whom suicide is not physically an option and they need assistance. But I wonder if you could just give me some thoughts on those sorts of issues,

because it may well be that the suffering is existential and not simply an issue of pain, and I am not certain that is so easily resolved by improvements in palliative care.

Ms Buchanan: There will be people who want that, but nothing that we could do as professionals would take away their wish to have their life come to an end. It is about control at the end of their life. It may be the same people who have control during their life and they want control of their death. When we go to Oregon, for example, where there is that option, in the 2003 report, a report that they are required to put down every year, something like 67 people had lethal prescriptions made up for them. The fact is that, out of 31,000 deaths in Oregon every year, around a tenth of 1 per cent actually choose death by this manner. Of the 67 that had prescriptions, 25 of them did not use them. The suggestion could be that they decided that it was enough to have the prescription, to have control or whatever. What I would ask is—having a law to allow a tenth of 1 per cent of the dying population to have control of their lives sufficient reason to leave the other 99 per cent vulnerable? What we are saying is that those people who want control can often find other ways of having it. I think what people want is control of how they are treated at the end of their life, of treatment decisions. They do not want actively aggressive intervention when they say it is time to give up. As I said before, there are myths around the end of life and I think that is something that we have to address as well. Coming back to Lord Patel's question, nurses are part of the general public. They are exposed to the *Nursing Times*, if they choose to read it, they are exposed to *Panorama* or any other documentary that talks about it, so to look at a poll and take numbers and decide a majority or whatever is not necessarily a considered opinion on an issue, because not all nurses have been through any ethical training or think wider than the experiences they have had. What we are saying is that we looked at the issues that were being raised and that were important for us, what issues they were having to address in their daily lives with patients, and the issues that kept coming out were about end of life palliative care and support, support for the nurses as well as the families in being able to deliver pain control without fear and to have knowledge about how to relieve symptoms. We feel that the Bill would not protect vulnerable people and that is a fear that nurses have. We have taken our knowledge of what is going on out there and looked at the pros and cons of changing our opinion. It was not just about getting numbers in the results.

Q269 Lord Turnberg: Coming back to this point about the numbers who fit into the category of wanting to die and have exhausted all other

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opportunities for relief and still wish to die, your concern was what impact it would have on the remainder of the population who were dying but did not want it who might be put in that position. If there were some sufficient safeguards against danger to that group but leaving this subset with access to this degree of autonomy, would that answer the problem?

Ms Buchanan: In 1993–94 the Select Committee for Medical Ethics looked at this issue and the decision of the committee then was that the safeguards could not be put in place that would prevent abuse, that would prevent vulnerable people from coming to harm. At that time they felt there was no question of moving down the road for euthanasia to be legalised. I do not think things have changed and, in fact, I suspect have even more gone the other way perhaps. In a retrospective study of doctors in The Netherlands, despite not having had legislation until two years ago but a process that allowed them to report deaths, to have them scrutinised and not be prosecuted, when they retrospectively talked to the doctors, outside of that ruling they had gone ahead and helped people to die and did not report it. I do not believe that the safeguards are there. The Bill is quite narrowly focused on people who are terminally ill, within a few months of dying. There are a lot of people with neurodegenerative diseases who are nowhere near terminally ill but they can see the progression of the disease ahead, and I wonder when they would decide that they have got six months left to live—when would they become terminal? The disease is going towards a terminal conclusion but that might be a year or two years away. I think of Stephen Hawkins, the professor, who has Motor Neurone Disease; he has done amazing things with it, but if you give somebody a diagnosis of Motor Neurone Disease, for many and most, that is a diagnosis of a few years. When do you become terminal? There are not too many doctors who often get the exact number of weeks and months you have to live. I would also say that in Oregon it is the same issue, terminal illness. In fact, a large number of the people who had prescriptions were given them over nine months from the date at which they finally died, so the three months or six months or whatever time you put on it is not too precise. I would argue that you cannot put confines on it. People are acting outside the law in places that have laws, and in this country you may say that some people are already acting outside the law, and I do not believe it would stop them doing that just because you have a law that is slightly more narrowly-defined.

Q270 Lord Turnberg: Certainly we are going to look at the evidence of experience in other countries, and there are obviously variable interpretations of

that experience, and we hope to be able to tease that out. But do I take it that your view is that experience does not give you any confidence? Is that what you are saying?

Ms Buchanan: Absolutely.

Lord Turnberg: Thank you.

Q271 Baroness Finlay of Llandaff: We have heard already from Lord Joffe himself that he views this Bill as part of an incremental process in terms of who would be eligible to have their life ended, and we heard from the College of Physicians this afternoon that there is a view that this could be viewed as a therapeutic option and, therefore, potentially as a therapeutic good. Within that context I wonder where you feel that nurses could be placed, given, as you have pointed out, the intimacy of the conversations that occur between patients and nurses that is very often at a much more comfortable level than it is between a patient and a doctor in our current health system? I was also interested in your figure that 30 per cent of nurses come from overseas, and perhaps I might return to that in just a moment. Perhaps if we can take one bit at a time.

Ms Buchanan: Sorry, what was the start?

Q272 Baroness Finlay of Llandaff: I was interested as to where you felt that nurses would be placed if this was a therapeutic option and was part of an incremental process in terms of the intimacy of conversations between nurses and patients?

Ms Buchanan: I think that those words “part of an incremental process” give me the very reason why I think we are right, and I am even more concerned that we see it as part of an incremental process. Does that mean that today it is six months’ terminal illness, competent patients, but tomorrow, as has been seen in The Netherlands, it is incompetent patients? There were quite a large number of babies, who obviously were not competent, put down, could I say, for reasons that they were disabled and their parents did not want a disabled child, and there is evidence of that. That fails me as a nurse, and I think most of my colleagues would support that. I have to say I found a lovely quote from, of all people, President Ronald Reagan, when he wrote in the American Human Life Review: “Regrettably we live at a time when some persons do not value human life, they want to pick and choose which individuals have value.” That is what I would say this incremental drift would be—whom we see as whose life has no value at this stage; and I do believe that is the intent of the Bill—let us get this on the statute, and then we can start looking at who else. For example, somebody who has depression, and has had a bit of a bad life, they are competent. They are not necessarily incompetent with depression, but

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maybe we should let them go and help them on their way. It is proof for me that this is the wrong way. This is the door open to the most awful journey that I would not want to take as nurse.

Ms Bannister: Can I say something in respect of your question around the comments that people make to us. Again, it was a very recurrent view of members that the compromising of the relationship between the nurse and the patient was very fundamentally risked here in relation to the trust, and that is a very clear theme that came through to us from our members. I have worked for the RCN for nine years, taking on board responses to all sorts of issues to do with government changes, government bills and so on. This is the only one that I have ever come across, as a policy and practice adviser, with people with serious stories to tell about their experience and their fears and real life stories, which is why we put some of those stories in our response, because they are very powerful. It was clear to me that nurses would feel very compromised in their relationship with the client in that position of trust, if they felt that the client thought they were party to a potential assisted death at some point. That was a strong feeling. I do not know whether that helps to answer your question?

Q273 Lord Carlile of Berriew: I just wanted to ask one question. It is one, My Lord Chairman, concerned with the “lower issues” with which we are concerned. It is an employment rights issue. Clause 7 is a conscientious objection clause and I do take into account in my question a manuscript amendment that we saw at some stage from Lord Joffe. Neither the conscientious objection clause nor the manuscript amendment we have seen gives any right to a nurse to refuse to work as part of a team led by a doctor prepared to perform assisted death. Is that an acceptable position either to the Royal College of Nursing, or to any other representative body of which you are aware?

Ms Buchanan: Absolutely not. If I could say on the second point, I was a bit concerned about it because I think it is fundamentally wrong—the conscientious objection.—It talks about “in accordance with the Act” or “to receive pain relief under section 15” as a conscientious objection. Nurses have no right to conscientiously object to giving pain relief—that clause is nonsense. We do not object to caring for people. You may disapprove of people’s lives. You personally may not understand their life, but it is part of our code of conduct that we would never stop caring for people or delivering care. What you would have is that nurses would be so compromised in their own values that they would not go to work in these places, they would leave places. I am telling you the health service is held together by overseas nurses at the

moment. They will go to America, because State after State is rejecting any attempts to introduce a Bill similar to Oregon. America is sitting there with a cheque book waiting for our nurses. We do not need another reason for them to go and that is exactly what will happen.

Q274 Lord Joffe: It is clear what your views are, but I would like to come back to your members’ views. Why did you not accept the invitation of the Committee to bring someone representing the views of what you consider to be a minority of the nurses to talk to us today?

Ms Bannister: I am not sure that we received an invitation saying that. We were asked to come and present our evidence, which we have done. The decision-making about who would come was that we would have one member of staff who was involved in the process of collecting the data and theme-ing our evidence, and that would be me, and the Deputy President, who is on a number of our specialist ethics groups and is also a Council Member. I do not believe we were asked to do that.

Q275 Chairman: I think you are right. I think what you were asked to do was to ensure your presentation included the description of the extent to which the views expressed were the views of the body as a whole and to what extent there was general dissent; and you have done that extremely clearly in my view.

Ms Buchanan: My Lord Chairman, it is how we work altogether in the College. We look at issues and then we decide on policy. It would not be for us to set someone up in the minority view, to have to argue what is against what is now clear RCN policy. I think it would be unfair. We have considered the issues and this will be the RCN policy. While accepting that, members may have thought that they would rather it was otherwise.

Chairman: You made it very plain that there are a number of people in the Royal College of Nursing who do not share the views you have expressed today. That was what we wanted to be made clear by the invitation to give evidence.

Q276 Lord Joffe: With respect, that was not my understanding of what was agreed. Obviously, I accept the position. If we can come back to the numbers of members. Why I ask these questions is because I have been told that there is significant and possibly majority support for the Bill amongst nurses. Could you tell us a bit about the numbers? You have told us the percentages.

Ms Bannister: Yes. I can come back and give you those numbers. As I said earlier, we did not feel it was particularly helpful to just use numbers because we were not counting responses in a scientific way;

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but, indeed, we can come back and, if it is possible, I will send a written note with those numbers. Certainly we were lobbied, Lord Joffe, significantly by lobby groups, and I think that I expected that to happen; and particularly there were “paid for inserts”, that were run by the *Nursing Times*, which were about enabling those people who wished to to lobby both for and against the Bill. In fact, we received boxes of lobbying papers through that means, and we had some concerns about the *Nursing Times* entering into paid advertisements to lobby the Royal College of Nursing. But, then, that is politics and we understand that is going to happen, that is not a problem and we have heard those lobbyist messages. For our point of view, we are interested in what our verifiable members are saying to us and also what members of the public, who are going to be patients, are saying to us. We will come back to you with some figures if you would find that helpful.

Q277 Lord Joffe: You understand it is part of this that you reject some of this, what you call, lobbying?
Ms Bannister: I am not sure that I understand what “reject” means. We would not count boxes that arrived to us with cards as verifiable member returns from us. As I say, we were lobbied by different groups. We were lobbied by pro-groups and we were lobbied by for-groups. Therefore, to me that is lobbying. What we were trying to do at the Royal College of Nursing was to hear the members’ voice and to “theme up” for you what our members were saying.

Q278 Baroness Jay of Paddington: Following on from this point, you may think we are niggling about this, but I think that is the contrast we have between what you are saying and how you are saying it and the way in which the Royal College of Physicians and the Royal College of General Practitioners represented their position earlier this afternoon, which is, of course, as we all understand, about politics and lobbying, and it is all about verification or otherwise and mass card-sending et cetera. We have all been subject to that in our own eyes in many ways. I think it was Lord Taverne—or it may have been Lord Patel, forgive me if I have got it wrong—who asked at the beginning: would it not perhaps be more sensible, given the considerable difficulty that you have obviously had in getting an accurate picture, for you to present a neutral position in the way that the Academy of Medical Colleges did, and whether or not you felt you should have brought someone to represent the minority view? One of the ways in which the Academy did that, which I thought was very helpful, was that they had two presenters, both members of their Ethics Committee, who did take different views and very

clearly identified when they were speaking from a personal position and when they were representing the view of the Academy. In retrospect, do you think that might have been more helpful to us?

Ms Bannister: I think that if, I was asked to reflect what the experience of the RCN has been over this exercise, I would have to say that we can reflect to you what our members’ opinions are. The overwhelming majority of our members’ opinions are here. If we had had much more time, and we did not have sufficient time, to conduct an appropriate study which would have allowed us to have that sense of what members our doing—and we are not afraid of doing that, we could certainly do that. That would have been wonderful but, as it happened, we were left with a very short period of time in which to canvass views and opinions. I think we have used those views and opinions appropriately. Also, we have reflected the leadership of the RCN’s views on what is currently RCN policy. We will continue to have debate and discussion on this. I have said that there are nurses who do not reflect that majority view. However, having been the person who analysed all of those responses, I know that even those that did not reflect that view, the majority of those people were talking about the weaknesses in palliative care services. The strength of our response, the experience of our response, is different from that which the physicians are getting.

Q279 Baroness Hayman: Could I pick up on that very point because I do find it slightly concerning, I have to say, that there seems to be a gloss being put on some of the evidence that we have received and the interpretation that people were only saying that because they had had very bad experiences and had mentioned failures of palliative care—let us call it that, rather than failures of the existence of palliative care—but you were not subjecting to similar scrutiny the opinions that were in line with the view that you have given to us. So you were not doing an analysis of whether people already had a particular stance—ethical, religious or moral stance—that would take them in a particular direction, nor looking at their particular experiences which you referred to as having coloured their views. I think this makes one slightly uncomfortable and it is something that we are all coming back to. Certainly I find it perfectly acceptable for the leadership to say “This is our ethical position. We are the Council of the RCN and we are charged with doing that.” But I must say I feel a slight discomfort about this interpretation of views, as indeed there seems to be some interpretation in your evidence of what patients really want, “Although they may say they want X, we know they actually want Y”, and

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that seemed to me something, I may say, that was a theme that was coming through.

Ms Bannister: I think that is a fair point to make. As I say, we are expressing what the leadership of the RCN believes to be the view and the voice of the RCN, which included hearing the predominant comments from our members to explain what our members are saying. All but the most rigorous scientific survey, which we have not had a chance to do in the time available, would have that problem. Someone has to sit down and make sense of viewpoints which are sometimes expressed in extremely emotional ways, and that is what we have tried to do.

Ms Buchanan: Nor did we lay out the issues. We just said, "This Bill is coming before the Committee and we are asked to give evidence to it, would you like to comment?" We did not lay out, "Here is what might happen if there are changes" or any of the ethical dilemmas that might be raised by the Bill. It was purely and simply an invitation for members to just fire off. As I say, nurses, as is the case for many doctors, have not done ethics in their training, in their backgrounds, so necessarily thinking through the implications of their heartfelt response to something they have experienced and thinking "Oh, yes, that might be OK", we have to consider what would that mean for us as a profession. We have to take another view, and as an organisation we take the view that this is not good for the profession.

Baroness Hayman: I understand that, but surely your caveat about not having explained the situation applies equally to people who say, "No, this would be a good idea." They have not had it laid out for them either. It affects both sides.

Chairman: I understand that so far as numbers are concerned you did not really want to emphasise the actual numbers. But, if you want to give them to us later on, I am sure nobody will refuse to receive them.

Q280 Baroness Finlay of Llandaff: Could I just return to the very practical issue about the role of a nurse to patient. If a patient says to you that they want to die, how do you, as a nurse, respond now? How would you, as a nurse, respond if there was a therapeutic option as outlined in the Bill?

Ms Buchanan: It is a difficult question because I have to say that in 20 years no patient has ever said to me "I want you to help me die". It has not happened. I have nursed many patients and I have never had that, although I am sure that some of my colleagues have. I hope the care that I gave at the time meant they felt they were not suffering unbearably or whatever. I think my response would be to sit down and say, "Why do you feel this?" and have some dialogue and see who else could come to talk to them. I think that is the difficulty. How would somebody with religious principles faced with that question respond when they know there is an option and that option is against their beliefs? I have to say the Nursing Association of The Netherlands, because this has come up there and in the Council of Europe where the European nurses group sits on that, have currently advised their nurses to take no part in either passing on that request, in preparing the medicine or doing anything at all in relation to the current law in The Netherlands, because nowhere in that law is there any protection. Doctors are protected but nothing protects nurses. Their advice right now, until there is much clearer clarification, is that nurses back off and do nothing in relation to that. That would be the dilemma for me or any other nurse: what do you do if you have that on the statute and somebody asks that, because by implication you are passing on and fulfilling that wish. I believe that would be the reason that many nurses would go.

Chairman: I said about an hour and we are at just about that. Thank you very much indeed for the help you have given the Committee and we thank the public who have come today. There will be a further sitting a week today.

THURSDAY 21 OCTOBER 2004

Present	Arran, E Carlile of Berriew, L Finlay of Llandaff, B Hayman, B Jay of Paddington, B Joffe, L Mackay of Clashfern, L (Chairman)	McColl of Dulwich, L Patel, L St Albans, Bp Taverne, L Thomas of Walliswood, B
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Memorandum by the British Medical Association

INTRODUCTION—THE BRITISH MEDICAL ASSOCIATION

1. The British Medical Association (BMA) is a voluntary professional association representing UK doctors in all branches of medicine. It has 128,000 members—almost 80 per cent of UK practising doctors. It is a democratic institution in which members elect the colleagues who decide policy. (See [http://www.bma.org.uk/ap.nsf/Content/About + the + BMA + - + History + and + structure](http://www.bma.org.uk/ap.nsf/Content/About+the+BMA+-+History+and+structure))

2. Like any sector of the population, doctors express a range of views on sensitive moral and social issues, including the care of people at the end of life. The BMA seeks to reflect this in its policies while also providing as clear guidance as is possible about the majority view of its membership. Policy is established at annual meetings by its Representative Body (RB) which consists of 589 BMA members elected or appointed to represent all branches of medicine. Prior to the annual meeting, issues under consideration and work done by the BMA are publicised in the annual report to members, as well as on the web, in journals and circulars. Local Divisions discuss topics raised in the annual report and any other issues they consider important for national debate. These are submitted by divisions as motions to the annual meeting where debates get wide coverage in the medical press and other media.

BMA POLICY AND THE VIEWS OF UK DOCTORS

3. The concept of a “good death” is a vital part of health care (see “Caring for patients at the end of life”, chapter 10 of the BMA’s 2003 edition of *Medical Ethics Today*.) The association does not accept, however, that deliberately bringing about an individual’s death is a valid or essential part of that concept. It opposes euthanasia and physician assisted suicide (PAS). Details of BMA policy on euthanasia and PAS are set out in *Medical Ethics Today* where chapter 11 outlines the BMA’s views.

Distinction between withdrawing treatment and actively ending a patient’s life

4. Health professionals can withhold or withdraw life prolonging treatment if the patient refuses it or if it fails to benefit the patient. They may foresee that death will result but, in the BMA’s view, this recognition of medicine’s limitations is fundamentally different to using medical skills actively to assist suicide.

5. The BMA recognises that some people think that, where death is the inevitable outcome, the decision to stop active treatment is morally equivalent to euthanasia or that it necessarily involves a judgement that the patient’s life is not worth living. Some also argue that active steps to end a patient’s life—if dignified, quick, painless and at the patient’s own informed request—may be preferable to withdrawing treatment which may result in a more prolonged death.

6. However appealing this argument may appear, the BMA does not agree that the acceptance of an option for treatment withdrawal is inextricably linked to an acceptance of euthanasia or PAS. The association’s approach to end of life treatment decisions focuses, not on anyone’s assessment of the value of the patient’s life, but rather on the effectiveness or otherwise of the treatment. Thus, an assessment for an individual

patient that treatment has become ineffective or is more burdensome than beneficial is not equivalent to engineering that person's death or saying that the patient's life is not worth living.

7. Rather, it is a recognition that there comes a point for all patients when further active treatment is unable to help them.

History of BMA stance

8. BMA policy opposing euthanasia was established by the RB at the 1969 annual meeting. In 1971, the BMA reviewed the arguments and issued a report rejecting medical participation in euthanasia. In 1988, a BMA working party again reviewed the issues, especially the increasing recognition of patient autonomy in all aspects of decision making. It took evidence from a wide spectrum of opinion but finally recommended that euthanasia should remain illegal.

9. By 1997, PAS was also the subject of policy. At the annual meeting, the RB recognised "that there is a wide spectrum of views about the issues of physician assisted suicide and euthanasia" but nevertheless it strongly opposed any changes in law "for the time being". This wording meant the issues had to be kept under review and in 1998 the RB called for a national PAS conference.

10. Accordingly in 2000, 50 doctors from all sectors of medicine participated in a two-day BMA debate on PAS. Nominated by local BMA Divisions, these participants reflected a wide range of ages, medical specialties, personal opinions and professional seniority. The aim was for them to examine the arguments, the evidence from other countries and reach a workable consensus.

11. Prior to this, a discussion pack setting out the main arguments, highlighting sample cases and information from other jurisdictions was disseminated in electronic and paper form. An electronic debating forum was opened on the BMA's web site at http://www.bma.org.uk/ap.nsf/Content/_hub+physician+assisted+suicide. The resulting 200 substantial contributions were used in the planning of the conference.

12. The conference consensus was a rejection of any change in law on PAS. A common anxiety shared by all participants—regardless of their personal moral stance—focussed on the risks for very vulnerable or dependent individuals, if assisted suicide were legalised.

13. At the 2000 annual meeting, the RB endorsed the conference's recommendation opposing any change in law on physician assisted suicide.

14. At the 2003 annual meeting this view was re-iterated again, following further debate. The RB resolved "that the BMA should take clear note of grass roots concern against euthanasia".

15. By such methods as local Divisions debating policy and drafting motions, democratic election to the BMA's representative body and BMA council, by electronic consultation, articles in BMA journals and frequent presentation of policies to grass-roots members in ethics fora, considerable efforts are made to gauge any changes in members' opinions.

16. Early BMA policy statements categorically rejected the notion of euthanasia whereas recent ones are less dogmatic and acknowledge the existence of a wide spectrum of views within the profession. Nevertheless, repeated discussion within the BMA has led to the current consensus that the law should not, at present, be changed to permit euthanasia or PAS.

Other surveys of doctors' views

17. The BMA keeps abreast of relevant surveys of doctors and patients' views although these are not invariably reliable markers of public opinion since much depends on how questions are presented. It recognises, however, that some doctors believe that euthanasia and PAS are morally justified in exceptional circumstances. Chapter 11 of *Medical Ethics Today*, for example, notes a 1996 survey of health professionals' views. (McLean SAM, Britton A. Sometimes a small victory. Glasgow: Institute of Law and Ethics in Medicine, 1996.) Although this indicated that 48 per cent of the 804 doctors surveyed favoured legal change to allow PAS in specified circumstances, the BMA maintained its opposition. The association argued that even though there might be strong arguments in some individual cases, the potentially harmful effects for society as a whole lead it to oppose any lessening of the ban on intentional killing. Whilst a convincing argument might be made for justifying euthanasia or PAS in an individual case, the BMA considers it more difficult to justify its availability as a matter of public policy.

18. We note in the same survey that some respondents perceived a moral difference between euthanasia and PAS and that among those who supported the possibility of hastening patients' deaths, there was a preference for PAS over euthanasia. We felt that this might be explained as doctors considering themselves less responsible or culpable where the patient rather than the doctor takes the actual step to end life. Nevertheless, in the BMA's view, even if there is a perceived distinction about who is ultimately in control, euthanasia and PAS are inextricably linked and the moral arguments for and against each are similar.

THE ARGUMENTS BEHIND THE BMA'S POSITION

19. The notion of ending a human life deliberately is a profound and disturbing concept, particularly for health professionals whose training is generally orientated to improve and prolong effective human functioning where possible.

20. Arguments for legislation permitting voluntary euthanasia and PAS are generally based on competent individuals' rights to control what happens to them. Respect for autonomy, patient empowerment and informed self determination are salient features of such arguments. It may also be suggested that society's respect for their human rights entitles patients to obtain assistance to end their lives in certain circumstances.

21. As its publications show, the BMA welcomes the recognition given to patient autonomy and the greater informed participation of individuals in their own health management. Nevertheless, it sees individuals' autonomy as carrying less weight where their preferences seriously affect others' ability to choose freely. Clearly, the rights of some should not disproportionately undermine the rights of others. Permitting euthanasia or PAS might benefit some well informed and articulate people who are sure of their wishes. It might also impinge pejoratively and seriously on others.

22. Thus, although there may be (and many believe that there are) exceptional cases in which euthanasia or PAS is perceived to be the best option for the individual, the BMA fears that the impact of a general lifting of the ban on intentional killing could detrimentally affect the rights of very vulnerable people to be free from pressure. Logically, if PAS is seen as a good option for the strong and determined, it may also be seen as best for the depressed and unsure. The disadvantages for the impressionable or undecided could well outweigh the benefits for the minority wishing to commit suicide with assistance. Legalising PAS could also fundamentally alter the ethos of medicine, which might disadvantage society.

23. In the BMA's view:

- Legalising assisted suicide would affect some patients' ability to trust doctors and to trust medical advice.
- If assisted suicide were an available option, there would inevitably be pressure for all seriously ill people to consider it even if they would not otherwise entertain such an idea.
- PAS might be seen as desirable not only for people able to choose for themselves but for others who are vulnerable in terms of being elderly, dependent, disabled or extremely ill.

Doctor-patient relationship

24. If doctors are authorised to kill or help kill, however carefully circumscribed the situation, they acquire an additional role which the BMA believes is alien to the one of care giver and healer. The traditional doctor-patient relationship is founded on trust, which risks being impaired if the doctor's role also encompasses intentional killing.

25. Even a loss of trust based more on patients' fears and misperceptions than on the reality of PAS could be damaging. In debates preceding the brief legalisation of euthanasia and PAS in Australia's Northern Territory, there was evidence of considerable disquiet from the indigenous Aboriginal population. The Australian Select Committee on Euthanasia reported that some Aborigines were afraid to attend health clinics and hospitals for fear of doctors having "the power to kill" (Select Committee on Euthanasia. *Report of the inquiry on the right of the individual or the common good?* Vol 2. Darwin: Legislative Assembly of the Northern Territory, 1995).

Unwanted choices

26. Health professionals explaining all options for the management of terminal illness would have to include mention of assisted suicide if this was available. The BMA is concerned that patients might feel obliged to choose that option if they feel themselves to be burdensome to others or concerned, for example, about the financial implications for their families of a long terminal illness. By removing legal barriers to the previously “unthinkable” and permitting people to be killed, society would open up new possibilities of action and thus engender a frame of mind whereby some individuals may feel pressured to explore fully the extent of those new options. The choice of exercising a right to die at a chosen and convenient time could become an issue all individuals would have to take into account, even though they might otherwise not have entertained the notion.

27. Of patients who made use of Oregon’s Death with Dignity Act during its first five years, 44 per cent cited their fear of being a burden to their family, friends, and carers as part of their reasoning for wanting to end their life (Department of Human Services. *Fifth annual report on Oregon’s Death with Dignity Act*. Oregon: DHS, 2003: 20). Clearly, it is common for sick people to worry about the effect of their illness on relatives but the BMA would be unhappy about a situation where such worries trigger premature deaths.

The vulnerable

28. As is made clear above, the BMA fears that a change of the law would make PAS an option to be considered by any seriously ill person and some might feel pressured to choose it, contrary to their own inclination. The UN Human Rights Committee considering the Dutch criteria for euthanasia and PAS, concluded that the Dutch system “may fail to detect and prevent situations where undue pressure could lead to these criteria being circumvented” (United Nations Human Rights Committee. *Concluding observations of the Human Rights Committee: Netherlands*. Geneva: United Nations, 2001. (CCPR/CO/72/NET)).

29. If PAS were available, society’s apparent endorsement of premature death, could confirm some patients’ sense of worthlessness. It could contribute to a perception that some individuals are less valuable or it might influence decisions about medical research funding for some apparently intractable health problems since the sufferers might be seen as having an alternative way out.

30. Patients may have a misplaced fear of PAS being chosen for them. Despite euthanasia being only permissible at patients’ request in Holland, families apparently request it more than patients themselves, presumably perceiving their loved one’s circumstances as intolerable. (Fenigsen R Mercy, murder and morality: perspectives on euthanasia. A case against Dutch euthanasia. *Hastings Cent Rep* 1989;19(1)(suppl): S22–30.) As a result, some elderly people fear their lives will be ended without their consent. (Segers JH. Elderly persons on the subject of euthanasia. *Issues Law Med* 1988;3:429–37.) Patient groups who feel marginalised within the health care system may be susceptible to such anxieties. The fact that such fears may be ill-founded does not necessarily diminish their impact.

PROVISION FOR TERMINALLY ILL INDIVIDUALS TO RECEIVE PAIN RELIEVING MEDICATION

31. The Bill’s second proposition is that there needs to be legal provision for pain relief. In the BMA’s view, this is unnecessary and plays on public fears about the possibility of intolerable or unrelieved pain at the end of life. We believe that the law and ethical position are already clear on the right of patients to receive effective pain and symptom relief. BMA publications and advice strongly emphasise this and if doctors have any uncertainty, they can discuss them with the association’s ethics advisory service. Patients’ rights to effective symptom control—and doctors’ ability to prescribe appropriately—are not compromised by the fact that medication might have the side effect of shortening some patients’ lifespan. Control of pain and other distressing symptoms must continue to be a paramount consideration for health professionals in order to achieve the best quality of whatever life remains for their patients.

SUMMARY

1. Withdrawing life-prolonging treatment is accepted and not considered morally equivalent to euthanasia or PAS.
2. Doctors have their own personal views on the moral acceptance or otherwise of assisted suicide. Despite the wide range of views among the BMA’s membership, the BMA has had clear policy for many years that the law should not be changed to permit euthanasia or PAS in the UK.
3. The issue has been repeatedly debated within the association over recent decades and present policy that the law should not be changed “for the time being” implies that it will continue to be so.

4. The BMA has great respect for the concept of patient autonomy and recognises that patients are not only benefited by physical and clinical improvements but are also benefited by having their own values respected. Nevertheless, the association fears that in the case of euthanasia and assisted suicide, the potential benefits for some are only achievable at a high cost for others.
5. It would be unacceptable to put vulnerable people in the position of feeling they had to consider precipitating the end of their lives.
6. Provision in the Bill to permit pain relief is unnecessary.

3 September 2004

Memorandum by the General Medical Council

1. We understand that the aim of this Bill is to make it lawful for terminally ill patients to receive medical assistance to end their life. The question whether assisted dying should be legally permitted in some form raises difficult ethical and moral issues concerning the rights and freedoms of individuals.
 2. The General Medical Council licenses doctors to practise medicine in the UK under the provisions of the Medical Act 1983 (as amended). Our objective, as defined in the Medical Act, is to “protect, promote and maintain the health and safety of the public”. Our four main functions are:
 - To keep up-to-date registers of qualified doctors.
 - To foster good medical practice.
 - To promote high standards of medical education.
 - To deal firmly and fairly with doctors whose fitness to practise is in doubt.
 3. One of the ways in which we foster good medical practice is by giving advice to the profession, primarily through our published guidance, on the standards of practice expected of them. We require doctors to observe the law (paragraph 11, *Good Medical Practice*) and our guidance will always be consistent with the law. Consequently we have not developed policy or issued guidance on euthanasia.
 4. The proposal to legalise physician-assisted dying is an issue which raises strong views. These views are predominantly based on personal beliefs and individual moral values, rather than the knowledge and experience particular to doctors or patients or any other professional or social role. We believe that it is for society as a whole to determine, through its democratic processes, how best to respond to the conflicting wishes of its citizens.
 5. In order to address the difficult dilemmas faced by doctors about how best to meet the needs of a terminally ill patient we published guidance on *Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-Making*. The aim of the guidance is to provide a clear framework for professional practice within the current law, and therefore starts from the premise that any medical intervention where the doctor’s primary intention is to end the patient’s life is unlawful.
- (As the Committee will be aware, this guidance document was recently judicially reviewed, and the judgement handed down from the High Court specifies parts of our guidance which will need to change, although Justice Munby called the booklet “. . . overall . . . a document whose contents, indeed whose whole approach, should greatly reassure patients and their relatives.”)
6. A change in the law to allow to physician-assisted dying would have profound implications for the role and responsibilities of doctors and their relationships with patients. Acting with the primary intention to hasten a patient’s death would be difficult to reconcile with the medical ethical principals of beneficence and non-maleficence.
 7. If the law were to be changed, a balance would need to be struck between the autonomous right of an individual to decide how they wish to die, and the impact—on those close to the patient, those involved in making and acting on the decision, and on society as a whole—that the granting of such a wish might have. The Committee will need to consider whether allowing killing under any circumstances will affect the value of human life in society.
 8. Implementing the proposals in the Bill would depend on the participation of doctors and other healthcare practitioners, and a crucial consideration would be the degree of support amongst these groups for the legalisation of assisted dying along the lines described in the Bill. We cannot offer a view about the position of doctors on this issue, but no doubt you will have approached the British Medical Association and other representative bodies for evidence.

9. It is likely that there would be a significant number of clinicians with a conscientious objection to involvement with assisted dying, and we are pleased to note the inclusion of clause 7(1-3) relating to this. We would expect a doctor to respect a patient's wishes, including their right to refuse life-prolonging treatment, but it would not be a doctor's duty to assist a patient to die. As the Bill is currently drafted, a doctor with a conscientious objection would need to 'take appropriate steps to ensure that the patient is referred without delay' to a doctor with no such objection. We understand the need to ensure continuity of care for a terminally ill patient, and agree that it is a doctor's duty to ensure it. However, we believe that this clause would be of great concern to some doctors with a conscientious objection who would want a statutory right to withdraw entirely from the situation. The Committee will need to consider whether such a doctor, by ensuring the patient's referral, would still feel complicit in the act of assisting the patient to die.

10. We assume that the Committee will consider, along with the general question of principle, any concerns about the scope of the draft Bill and the adequacy of the projections it proposes. In recent years there have been a number of high profile legal judgements, interpreting Articles 2, 3 and 8 of the European Convention on Human Rights, which the Committee will no doubt take into consideration.

11. We are grateful for the opportunity to participate in this debate, and look forward to the outcome of the Committee's deliberations on this important issue.

September 2004

Examination of Witnesses

Witnesses: DR MICHAEL WILKS, Chairman, Medical Ethics Committee, DR VIVIENNE NATHANSON, Director of Professional Activities, British Medical Association, PROFESSOR SIR GRAEME CATTO, President, and Ms JANE O'BRIEN, Head of Standards, General Medical Council, examined.

Q281 Chairman: Good morning. This morning we are expecting to hear from the British Medical Association and the General Medical Council. I think you will know that the system is that the evidence is transcribed and witnesses have an opportunity of studying the transcript in order to correct any errors in transcription, but not, of course, to revise or improve or otherwise alter what they said at the time. Our meeting is for about an hour and a half for the evidence session, although that is not absolutely rigid. We would invite the witnesses to give short presentations—we have, of course, the written submissions already, but it is sometimes useful to start off with short oral presentations—and then I would invite the members of the Committee to address any questions to the witnesses, possibly to one or more depending on the nature of the questions. I leave it to you to say who is to start and perhaps you would please proceed.

Dr Michael Wilks: Thank you. I am Dr Michael Wilks and I am Chairman of the Medical Ethics Committee of the British Medical Association. I am also Chairman of what is called the Representative Body of the BMA. That is an important thing to say because the Representative Body is the policy-making body, about 500-strong, of the British Medical Association and it is a body which has regularly reviewed our policy on both physician-assisted suicide and on euthanasia. There are a number of areas I would like to highlight in relation to the written evidence we have provided. The first is to note that the BMA is a professional association that represents about 80 per cent of practising UK doctors, and we have a strong representative process

and a political process in which policy-making is carefully considered and reviewed. I say that to make the point that this issue has been consistently and regularly reviewed by the BMA. That said, we are aware both within the BMA and within society as a whole that there are widely varying beliefs about both physician-assisted suicide and euthanasia, and different types of questionnaires and polls bring up different results. But I think it is fair to say that there is a perception in medicine and a perception in our patients and in society generally that the ground on which we base a lot of our judgments about euthanasia and assisted suicide is shifting. That is inevitable, because of the changes in medical technology, the ability to preserve life where we could not otherwise preserve life, and particularly issues around palliative care. You will be aware—and this is really my second main point—that both the BMA and the General Medical Council have issued very detailed guidance on the withdrawing and withholding of life-supporting medical treatment. Decisions around whether to continue treatment or whether to withdraw treatment, whether to withhold it, not give it at all, in a whole variety of clinical situations, where to continue treatment would provide a burden to the patient, are a matter of very careful consideration by us; and the law, the Common Law. The law that has been consistently backed up by court cases, is that obviously patients with competence can make decisions that they do not wish to have treatment, even if that treatment will result in their lives ending.

Q282 Chairman: Even if the absence of the treatment—

21 October 2004

Dr Michael Wilks, Dr Vivienne Nathanson,
Professor Sir Graeme Catto and Ms Jane O'Brien

Dr Wilks: Yes. Perhaps I could refer you to the fairly well known case of Miss B, who was a fully competent patient who wanted to have her ventilation ended, knowing that would end her life. Her medical carers were unhappy about that. The case went to court and it was, of course, quite properly found that she had full rights under the law to have her treatment switched off, terminated, and that would result in her dying, which indeed it did. The interesting thing about that case is that there was found to be a trespass by the doctors on Miss B in refusing her request. So the Common Law is absolutely clear that a competent refusal of treatment should be upheld, should be respected, even if the patient will subsequently die. That is not the same as a medical team intending that a patient should die. When we make decisions about withdrawing or withholding treatment—and this, I think, was very well rehearsed in the recent case of Charlotte Wyatt—we are making, first of all, clinical decisions based on the value of the treatment and the value of continuing the treatment and whether continuing the treatment will actually be beneficial or a burden. That is a clinical judgment, but we have to do that through the view of the patient as far as we can ascertain it. In other words, it is all very well for doctors to make clinical judgments about what is good and bad for people but they have to be tested against what the patient might feel. In the case of people who lack competence, that obviously requires more consultation with family and, in the case of children, with parents, but the “best interest” judgment must always be made on the basis of how we the doctors would feel the patient would view the benefits or harms of the treatment decisions that we are proposing. That, of course, is something that we can do quite confidently when the patient is competent. That process is entirely legal, entirely proper, and is covered by very careful guidelines. Some people say—and this is where I think the ground is shifting—that if patients can make competent refusal decisions to have their treatment ended and the consequence is that they will die, why does medicine not allow an extension of that principle to the autonomous right to have one’s life ended? This is where we come up against some difficulties that the BMA has rehearsed in our guidance, but, to be brief, there are two main areas of concern. One is that it moves medicine and medical care into a different field, in that an option that would always have to be presented to all patients for whom care at the end of life was being considered is the ending of that patient’s life actively by the doctor; in other words, withdrawing or withholding treatment might be an option but also euthanasia would be an option. My second main point is that that creates for our members,

consistently voting against euthanasia and physician-assisted suicide, a different type of relationship between the doctor and the patient, and one that, once established, has fairly unpredictable consequences. My final point—and I could make other points but I am sure they will come out in questioning—is to point to the difficulty of adequately legislating for euthanasia from other jurisdictions, particularly in The Netherlands, where this has happened. If you examine the outcome of the changes to the law in The Netherlands, you will see, from the point of view of those patients who feel that the law has now provided them with an option they would wish to have their lives ended in certain very tightly regulated circumstances, such as terminal illness that obviously provides a benefit to those patients from the perspective of those patients. The down side is that we know a number of patients have their lives ended outside the law. Estimates in 1992—which I appreciate is a long time ago, but there is no evidence that the situation has greatly changed—show that about 1,000 patients in The Netherlands had their lives ended involuntarily. In other words, while we may have a reasonably rational conversation about voluntary euthanasia (euthanasia which is the ending of the life of a patient by a doctor at the patient’s competent request), involuntary euthanasia appears to be a practice in The Netherlands that has not died out simply because the law has been changed. My underlying point in raising that data is that it therefore seems difficult from previous experience to create a law that adequately delivers to those people the right to die without trespassing on vulnerable people for whom the assumption has been made that they would wish to die but they were never actually consulted about the process. I think that is a damaging result of well-intentioned legislation of which we should be aware and which we should take into account when we consider the consequences of a change in the law. I think that is all I really want to say at this stage, my Lord Chairman.

Q283 Chairman: Thank you very much.

Dr Wilks: I will pass on to Sir Graeme Catto.

Q284 Chairman: We have the General Medical Council and the British Medical Association together. Is that quite convenient, Sir Graeme, from your point of view?

Professor Sir Graeme Catto: It is sometimes uncommon.

Q285 Chairman: It may still be an advance.

Professor Sir Graeme Catto: I am Graeme Catto. I am the President of the General Medical Council and I am a physician to trade. The GMC is

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responsible for maintaining a register of doctors who are fit to practise in the United Kingdom. We take action where there are concerns about the doctor's ability to practise; we set the standards for education; and give advice to the profession on standards of professional conduct and performance and on medical ethics. The General Medical Council has never discussed euthanasia and consequently has no policy which I can reflect. I suspect there are two reasons for that. First, the General Medical Council expects doctors to comply with the law: a conviction for a criminal offence automatically raises a question about a doctor's fitness to practise. The General Medical Council discusses matters of professional conduct and ethics where this will affect guidance issued by the council, but on matters such as euthanasia or assisted suicide we would only ever advise doctors to follow the law. Secondly, matters of such fundamental importance as euthanasia are really not issues which should be determined by the professions or through bodies such as the General Medical Council. Only Parliament, we believe, should be able to determine these issues for our society. The GMC has, as Dr Wilks has already indicated, issued guidance to doctors on withholding and withdrawing life-prolonging treatment. This provides a framework for doctors to help decision-making in this very difficult area. That we have issued such guidance does not imply that we have a view on wider issues of euthanasia or assisted suicide. We understand the view that there is no moral difference between withholding life-prolonging treatment and taking active steps to end a patient's life or that there is a continuum which spans both withholding treatment or providing drugs which may have a double effect and taking active steps to end a patient's life. We understand that view but we do not share it. We believe that active steps to end a life raise questions for society on the value it attaches to human life and the role and responsibilities of those curing or restoring health indeed, those who are responsible for caring for individuals who are nearing death bear special responsibilities. Legislating to enable doctors to assist patients to die, whether directly or indirectly, goes further than to acknowledge that in some circumstances it would be generally regarded as humane to end a person's life. A number of issues, apart from the wider issues of society's attitude to the value of life, need to be considered. These include possible effects on patients' trust in the medical profession; the impact on the development of palliative care and on the psychological effects for individuals. The General Medical Council claims no particular expertise in these issues, nor by raising them do we imply that we have answers to them: I raise them simply as matters that may be of

importance for the Select Committee to address. Thank you, sir.

Q286 Chairman: Thank you very much. Would either of the ladies wish to add anything at this stage?

Ms O'Brien: Not at this stage, thank you.

Dr Nathanson: Not at this stage, thank you.

Chairman: In that case, the stage has been reached for members of the Committee who wish to address questions to the witnesses to do so.

Q287 Lord Taverne: I would like to put two questions, the first one to Dr Wilks. Clearly the BMA attaches a lot of importance to the social consequences of a change in the law. It is in your written evidence that, even though one survey found that 48 per cent of doctors surveyed—this is the Glasgow example—favoured a change in the law, that would not change the view of the BMA because of the potentially harmful effect to society. Dr Wilks, you have stressed in your evidence that in fact the Dutch law had apparently resulted in undesirable consequences of continued involuntary euthanasia. But if in fact the evidence suggests that there is no worsening position of involuntary euthanasia and, indeed, the position may be somewhat better if the law were changed, does that not fundamentally undermine your case? You must be aware of the studies which show, in so far as one can tell these things, that the rate of involuntary euthanasia in The Netherlands is much lower than it is generally, and that there is no case in any other country in Europe where the rate of involuntary euthanasia is lower than it is in The Netherlands or significantly lower. The rate of involuntary euthanasia in some cases appears to be about five times as high as it is in The Netherlands. If in fact it shows that there is no harmful effect on the rate of involuntary euthanasia—which of course is a very important issue—is your case not undermined?

Dr Wilks: You used the words like “apparently” and “as far as one can judge”, and I think that is an important point, because “as far as we can judge” is not very far, in my view, as to the rate of what really we are saying is the number of patients who are killed by their doctors in ways that are kind of covert. We have no evidence on that whatsoever. Evidence is offered that there are high or low levels of involuntary euthanasia in a number of countries, and certainly the supporters of the Dutch legislation would argue that they are simply legitimising something that was happening before. But even then it is difficult to see the evidence for that. I think also that we need to be very careful about definitions. I went on at perhaps too long a length about the issues of withdrawing and withholding treatment,

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but there are a whole variety of decisions at the end of life that may result in the death of the patient but not intending the death of the patient. The number of times that doctors do things intending the death of the patient is actually, I think, very small, and I would think, given the highly controlled regulatory structure around hospitals—particularly as we remember that in this country most people do die in hospitals—highly unlikely. I do think that in a lot of these surveys there is confusion about the ways in which doctors might appear to be hastening the death of the patient by removing treatment, by withdrawing treatment, which are all perfectly legal, and I have a concern that some of these accusations of involuntary euthanasia are actually perfectly legal and very robust and sensible decisions about simply withdrawing treatment.

Q288 Lord Taverne: But do you not contradict yourself? In your statement you made a lot of the fact that the rate of involuntary euthanasia in The Netherlands was high, and then you say, “But we can’t tell how high it is.” In so far as there are studies—and these are not worthless studies—they show that actually the rate of involuntary euthanasia in The Netherlands is quite low.

Dr Wilks: Yes. I think that has now been established quite convincingly by kind of surveys, but I do not regard 1,000 patients a year as particularly low.

Q289 Lord Taverne: No.

Dr Wilks: The argument is made—and it is quite correct—that because the vast majority of those patients are very close to the end of their lives, probably within two or three weeks, the assumption is made that it would be a perfectly compassionate thing to do to end their lives prematurely but only a little bit prematurely. That may be a perfectly justifiable way of looking at it and very compassionate, but it does mean that doctors are prepared to work outside established legislation, and that bothers me, that doctors are given that opportunity by legislation which may not be tight enough.

Q290 Lord Taverne: Even though this happens in other countries which do not have involuntary euthanasia?

Dr Wilks: My second point on that would be that this may or may not be true but I am not convinced that that necessarily justifies the creation of a law that in itself might cause problems, simply because we have an unsatisfactory situation. I think that is perhaps a not entirely logical argument: that, if things are happening that you do not like, you create a law in which other things are going to

happen that you do not like. I think that is not necessarily a good way of looking at it.

Q291 Lord Taverne: My question to Professor Catto is this: you rightly place a great deal of emphasis on the importance of the effect of a change in the law and what it would have on trust in the medical profession. Again, one has to go on what evidence there is about the impact of a change in the law. It does seem to be well established that The Netherlands, where they have changed the law, is a country where there is the highest rate of trust in doctors in any country in Europe: 92 per cent of the Dutch trust their doctors—which is much higher than in other countries, even though generally speaking trust in doctors is fortunately very high.

Professor Sir Graeme Catto: I raised it not to dispute what you just said but because I think it is an issue which needs to be addressed and which will be raised by my colleagues if by nobody else.

Q292 Bishop of St Albans: I wonder if I could address a question to Dr Wilks. I enjoyed your contribution on the *Today* programme this morning. Thank you for that. One of the philosophical foundations of our contemporary society, to which you referred in that programme, is that personal autonomy is a kind of “highest moral good” in our contemporary society. I wonder whether a study has been made by the BMA to determine whether the major motivating factor which leads people to become doctors is that they wish to exercise personal autonomy or whether they wish to exercise care of others.

Dr Wilks: Professor Nathanson is head of our professional department, which also looks after medical education, so I would like to refer to her, if I may.

Dr Nathanson: Thank you. It is a very interesting question. We have done a great deal of work with both older doctors and younger doctors, including medical students, and we find, in fact, that, of the values which they bring into medicine, the reasons they give for becoming doctors are consistent across generations—which I find quite comforting—and it is about service, caring, compassion. In fact, we went through a whole list of values, and nearly all of them began with “c”, but there were all these very positive words of compassion. But they felt their job was more than that: maybe they did not use the word “vocation”, if we were talking to younger groups, but that it was about caring. They did not use the word “autonomy” about themselves; they talked about understanding their patients’ needs and providing for those needs, but providing to all members of society not just to individuals. I think one of the big things which is addressed more today

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at medical school in debate—and I teach at several medical schools as well—is: How do you balance the rights of individuals against the rights of society? and a recognition that autonomy is not always the trump card but sometimes the individual's autonomous rights are lost because of the damage that could do to the rights of others.

Bishop of St Albans: Thank you very much indeed.

Q293 Lord Carlile of Berriew: I have three short questions. The first relates to terminology. Dr Wilks and, to a lesser extent, Professor Sir Graeme Catto used the term “euthanasia and assisted suicide”. For the purposes of this proposed legislation, do you see that as a tautology? or do you see two different issues to be addressed?

Dr Wilks: My understanding of the proposed legislation is that the majority of patients would have assisted death by the provision of the means by a doctor, and that the only time that a doctor would take the life of a patient at their request would be if the patient was physically incapable of administering the medication themselves. It is interesting that data that were published this morning by the Voluntary Euthanasia Society back up an impression that we have had, that still a minority of doctors, but a larger number, would support a change in the law on physician-assisted suicide than would support a law on euthanasia. We can see no moral difference between the provision of the means and actually being the agent of the means; I think it is probably just a feeling of comfort that there is a partnership involved between the doctor and the patient, as opposed to the doctor being the agent. Was that the point you were trying to explore?

Q294 Lord Carlile of Berriew: Yes. You have answered the question.

Professor Sir Graeme Catto: I think, sir, to the extent that it has not been discussed by the Council, it would simply be my opinion, and I think I too would not see any great moral difference between the two. In a sense, the term used here “assisted dying” is probably an all-encompassing term that would apply to the way we see it.

Q295 Lord Carlile of Berriew: My second question is to Sir Graeme. Applying possibly the test of the cases that have been to the Preliminary Proceedings Committee—if it is still called that—of the GMC—

Professor Sir Graeme Catto: Until the end of this month, sir.

Q296 Lord Carlile of Berriew:—or to the Conduct Committee or possibly the Health Committee, do you see your GMC guidelines, to which you referred

earlier, as still being fit for purpose and meeting need? or is there evidence of doctors being disciplined as a result of complaints made by fellow professionals or members of the public, particularly relatives, as a result of problems over the absence of lawful euthanasia or assisted suicide?

Professor Sir Graeme Catto: I am just checking with my colleague here. I think we have no evidence to that effect. The number of cases coming forward in that area, I think, has remained very small. We have no evidence to support that suggestion.

Q297 Lord Carlile of Berriew: My third question is, again, a practical question. As I see it, if this proposal becomes law, one will face, for example, in brain injury teams or in spinal injury teams, sub-specialists of great skill and with differing opinions on the issue, some possibly favouring assisted suicide and being able to square it with their consciences and others having considerable and deep conscientious objection to it being carried out. Although there is a conscientious objection clause in the Bill, do you think that is sufficient to meet the practical problems which might arise, if you think they would arise, in such circumstances?

Professor Sir Graeme Catto: Once, again, sir, it is my personal opinion. When we are looking at patients with complex medical conditions in that situation, then I think potentially there is a problem with that kind of clause, at least in the short term. Nevertheless, I am quite sure that from a professional point of view it is essential to have some kind of conscientious exclusion clause along the lines which you indicate but I think there may well be practical problems where you have a small group of doctors looking after critically ill patients whose continuity of care matters.

Dr Wilks: If I may add to that. We deal ethically and practically with certain conscientious objection scenarios, such as abortion and contraception. Both the BMA and, more particularly, the GMC (because the GMC has the power to interfere with our ability to practice as doctors; all the BMA does is just provide disapproval of its members, which is not perhaps quite such a harsh penalty) would always argue that it is part of the doctor's responsibility, where conscientious objection is present, that another doctor should be found to take on that care. If there are practical difficulties in providing a doctor of the same level of specialty and competence, I can see there is a theoretical problem. I do not know how often that would happen.

Q298 Lord Carlile of Berriew: Would you regard it as right for a doctor who has conscientious objection to carrying out this procedure to be required to refer the patient to another doctor who

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does not have conscientious objection to the procedure?

Dr Wilks: Yes.

Q299 Lord Carlile of Berriew: You would?

Dr Wilks: Yes.

Professor Sir Graeme Catto: The analogy, which is a poor analogy, is the abortion analogy. I think it is a poor analogy because it is a relatively acute situation, whereas the picture you paint is of relatively long-term continuing care and we do not require doctors to refer forward. I think that would well be an issue that we would wish to discuss and debate. I would not like to say what the conclusion to that would be, but, of course, it is at the heart of your first question.

Dr Nathanson: Could I add one other point. There is also the problem that in many of the cases that you are suggesting (for example, in spinal injury and so on) you are not talking about one doctor, you are talking about teams of doctors, and I think there would also be great difficulty in deciding who was, if you like, the primary doctor and decision-maker because the nature of these teams is that they do work as equals—they bring different skills and expertise—and so it would often be difficult to say who was the primary doctor. I think that would be a particular problem in these circumstances.

Q300 Baroness Jay of Paddington: Thank you very much for everything you have said, obviously representing a very substantial part of the medical opinion and medical regulation in this country. But I do find myself very confused about the position of the profession. We heard last week from the Royal College of Physicians and the Royal College of General Practitioners and we ended up by saying—in fact they used the words themselves—that their positions were one of “studied neutrality”. Having heard your comments this morning, particularly, for example, your response to Lord Taverne’s inquiry about the hypothetical nature of some of the remarks you were making, and your answer just now to my colleague who spoke about whether or not you would feel it important to refer a patient to another doctor, do you think it would be more . . . I do not know what the word is . . . more sensible, more professionally legitimate, if both your organisations took a studiedly neutral position on all of this, given that you believe that society as a whole should be dealing with it?

Dr Nathanson: If I may start with the answer to that one. I think the Colleges and the BMA are in a different position here. My understanding is that the Medical Royal Colleges have, generally speaking, not had major debates or ways of ascertaining the views of the majority of their membership: they may

have had debates in their councils but they do not have our democratic process. We have had numerous debates, from certainly the 1960s—although I am pleased to say that was before my time. Certainly over the last 20 years I have witnessed very many debates. We have had conferences, where we spent many months, with debate papers on the internet available to all members, seeking people’s views—specifically on physician-assisted suicide, in that case. So the difference, in terms of legitimacy for us, is that we are here to represent the views of our members as expressed repeatedly in an open democratic process which encourages dissent rather than consent.

Q301 Baroness Jay of Paddington: If somebody was a member of the BMA and a Fellow of the Royal College, what would their position be?

Dr Nathanson: Individuals have different views.

Q302 Baroness Jay of Paddington: I am sorry, it may sound rather trivial, but I think it is important that we get, as far as possible, a general view of what the position of the medical profession would be.

Dr Nathanson: I think the views that come through at our meetings are as representative as you can get, simply because there is 80 per cent of membership, all of whom are free to put up policy motions to inform and direct the person who will represent them at the meeting on how to vote, and because any four members—literally, it is as few as that—can get together and put a motion up to the annual meeting, which will be debated; and those debates are robust and vigorous.

Q303 Baroness Jay of Paddington: May I make one, I hope, quick point about the hypothetical nature of the assumption that any change in the law would lead to a decline in the trust between patient and doctor. Obviously, as you have said in your response to Lord Taverne, this is something which is bound to be based on different polls, different surveys of opinion. But presumably you would accept that in relation to this country it must be entirely, at the moment, hypothetical. I think it is interesting—I do not know whether anyone has drawn it to your attention; I have only recently had my attention drawn to it too—that in a UGOV survey which has apparently been taken just in the last month or so of over 1,500 members of the UK public—and again we come back to my point that this is an issue for society, I think we agree—the figure which was quoted was that 79 per cent would trust their doctors the same or more than currently if the law was changed and 11 per cent did not know.

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Dr Wilks: I accept that here is another piece of evidence which sits with other pieces of evidence that do not necessarily help us to know what the general public feel and what doctors feel about very specific scenarios. My concern, I think, goes back to the point I have tried to make before, that when we talk about end-of-life decision-making we can talk about a whole variety of decisions that doctors might or might not make with their patients which may result in their death. One of the things which concerns me about some of these surveys is that they are not balanced by questions around good palliative care. The assumption seems to be behind these questions that you are in a position where doctors can do no more for you: "Would you support euthanasia?" Given the option of a question which said, "If you were in intolerable pain and the doctor could not help you, would you like to carry on like that or would you rather have a painless injection to end your life?" I think most of us, faced with that scenario, would know what our answer would be. But that is not real life. Real life, which comes through in our members' response, is that patients very, very rarely request euthanasia but they very, very frequently require reassurance that they will receive good palliative care, that their pain will be dealt with, that their other symptoms will be addressed. Also, I think, another very important point is that the treatment would be proportionate; in other words, they will not be, as they would put it, "interfered with". Those are the two overwhelming concerns that patients at the end of their lives express to doctors. The fact is that, if you look at the Oregon experience—the latest report came out earlier this year and it was the sixth report into the Oregon assisted suicide legislation—you will see that a very tiny number of people availed themselves of that legislation. A very tiny number.

Q304 Baroness Jay of Paddington: But you would accept that palliative care need not necessarily be universally available or universally successful?

Dr Wilks: Yes, I would accept three things about palliative care. One is that it is not universally available—as we would want—and that is a matter of resources and political will. The other is that there are patients for whom even the best palliative care is not dealing with their pain. A third group of which we must be aware is that, in spite of excellent palliative care, the position is not necessarily one which those patients regard as beneficial to them—you know, the loss of autonomy. We have to address those three issues. Whether you then say that, as a consequence of being unhappy about those three, you then provide an alternative strategy for those patients, which is to have their lives ended, and put at some risk the difficulty in the law that

protects the vulnerable, I think for our members is a step too far.

Q305 Lord Patel: Following on from there is the comment that Sir Graeme Catto made in his presentation about the effect this legislation may have on the development of palliative care. Would you like to expand on that?

Professor Sir Graeme Catto: I fear I should not have walked in that direction because, as I indicated at the time, by raising these topics, which I think are important topics, it does not imply that the General Medical Council has a view on them. We have no view on that. I raise them simply as issues that will be raised by our members if and when this comes to be discussed by the Council, so there are others here who have more experience.

Q306 Chairman: We are happy to hear, I am sure, your own personal view. You have explained, quite plainly, the situation of the General Medical Council. But we have to consider these issues, and if you are able to help us about them, then we are very happy to have that help, because we are probably—at least, I speak now for myself entirely—very much in need of it.

Professor Sir Graeme Catto: On the ground that it is a personal opinion and there are others here with much greater experience in these lines than I personally have, I tread with some trepidation. But I think the two things need not be in conflict. It would seem to me it would be perfectly possible to proceed along the lines being considered on the Assisted Dying Bill without in any way impeding the progress and desirable developments in palliative care. I do not see that there is a necessary conflict between these two.

Dr Nathanson: Among the points that many of our members make to us is their concern, however, that with palliative care it is often difficult to get the resources that are necessary, and the quality of palliative care delivery and the prompt availability of it. By the nature of palliative care, it is not something that people should be waiting for: it needs to have sufficient resources to be available promptly to people in need at the time that they are in need. Palliative care does a great deal more than pain control or symptom control; it also gives a great deal of psychological support, helping people to come to terms with what has quite clearly been a devastating diagnosis or with devastating news at the end of a process of treatment. It is in fact a great British success story, because much of the palliative care movement has been British led, but the sad fact is that we have not had a sufficient investment to guarantee that every patient who could benefit from this gets that treatment, those assessments and

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advice at the time at which they need it. There is a great concern that if there were another option, then, instead of really getting the best palliative care, some patients would instead be more persuaded towards not what was their first preference, simply because palliative care is not available, and that, whatever else we do, we must concentrate on making sure that palliative care is available. Because, as Michael has said, the fact is that for most patients it is far and away the best option and the option they would most want.

Q307 Baroness Hayman: I would like to take Dr Wilks back to the distinction that he drew between competent patients who requested that treatment should be ended, even though that would end their lives; competent patients who accepted dual-effect treatment, if you like, who were informed that pain relief might have the effect required and accepted that; and competent patients who committed suicide themselves because they had the means and the physical ability so to do each of which, as I understood it, as doctors you could accept, but you felt that it was a step, a bridge too far, actually to be involved in the administration of prescription or actually to help the patient. If I said to you, "I can see that distinction from the doctor's point of view; I find it more difficult to see the distinction from the patient's point of view," I wonder if you could reflect on that for me.

Dr Wilks: I entirely accept that perspective. Certainly it is a great deal easier within the discourse that we have within our profession to know the difference, to feel the difference, between not intervening excessively, withdrawing treatment, ensuring adequate pain relief—all of which may contribute to the patient's earlier death—and actually taking an action to end life. Doctors feel that very strongly, and the majority of our members feel that so strongly that they would not wish to move into that arena: what they would not regard as treatment. I want to pick up, if I may, the point you made about what I think you called dual effect, double effect. This is a slight side journey here, but I think it is very important actually because much of the debate about euthanasia and assisted suicide has centred on what, I think, is a very fundamental misunderstanding that adequate pain relief necessarily ends life. I hesitate to say this, with a distinguished palliative care physician on your right, but it is absolutely not the case. In fact, good palliative care extends life, because you are using levels of drugs that will not kill. I just wanted to make that point because there is often this double-effect argument that I think is actually very bogus.

Q308 Baroness Hayman: I was putting it very much in terms of patient autonomy.

Dr Wilks: Yes, I am sorry.

Q309 Baroness Hayman: Not in those particular terms.

Dr Wilks: If I could return to the main road, as it were. When I discuss these issues with other doctors, the language appears to be fit for purpose. But one of the things I enjoy doing a lot as Chairman of this committee is talking to patient groups, and I entirely agree with you, when you present the issue of autonomy, the absolute autonomous right, ethically, morally and legally, to refuse treatment, even if it results in death, as a competent patient, and under certain circumstances to direct that ahead with advanced directives and living wills, and then they say, "What is the difference between that and me coming to you and saying, 'The consequence of me refusing treatment is that I will die in a few days time, why can I not die now?'," that is a very powerful argument. The main argument is, of course, a rather static one, which is: "One is perfectly legal and with the other I could be sent to prison for 14 years if I did this, or even for life if I kill you." But I think doctors feel that they have crossed a line. And remember that this opposition to euthanasia and assisted suicide comes from working doctors who practise in this field all the time and do feel that there is a powerful moral difference between actively killing people and not intervening too powerfully to prevent their death. In other words, there comes a point with all our patients where we no longer are struggling, if you like, to help them to stay alive but accepting the inevitability of their deaths and then supporting them through their deaths. Accelerating the death is another step.

Q310 Baroness Hayman: That is very interesting that your first response was: the difference is the law. We are talking about a position in which we could change that. Ethics is not a fixed point in time?

Dr Wilks: No, absolutely.

Q311 Baroness Hayman: The interaction between the legal framework and the ethical framework and the acceptability is one that is iterative?

Dr Wilks: Yes.

Q312 Baroness Hayman: So that I can clarify it in my own mind and without being contentious, you said that it was very rare for someone baldly to request assisted suicide. Presumably it is also pretty rare for someone to say, "I want my ventilator turned off."?

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Dr Wilks: It is a rare situation for a competent person to be in that position clinically. It is very rare.

Q313 Baroness Hayman: That rare case can be encompassed; in the other rare case we draw a distinction. To put it baldly, you are saying that there is a small subgroup of competent patients whose autonomy cannot be respected because of the potential effect on others?

Dr Wilks: Yes, that I think is the balance that the BMA has drawn in terms of the benefits. It is almost like a clinical decision: What are the benefits and harms of this treatment? What are the benefits and harms of the change in the law? I would accept that.

Q314 Baroness Hayman: On the issue of whether regulation is an improvement or a detriment to the current situation . . .

Dr Wilks: Do you mean the professional regulation process?

Q315 Baroness Hayman: No. Could I ask you whether you feel that it is preferable for there to be a complete ban on this practice and an acknowledgment—and I would be interested in your view, and I know you will not have precise figures here—that on occasion that ban will be breached—and we do see rare prosecutions brought—and we will have to deal *ex post facto* with that situation rather than have a tightly drawn piece of legislation?

Dr Wilks: As far as the BMA is concerned, we are opposed to a change in the law, so we are in favour of a ban. In terms of a regulatory process, another aspect of the Netherlands legislation that I think has caused some concern is the variability of their process of checking, of validating whether euthanasia has been operated within the law or not. That has improved, but there was considerable concern about regional variations within the Netherlands, about whether that was a robust process; and there was some feeling that it was not being properly regulated even under the law. So that would give us some concern. The second answer to your question is that, as a consequence of a ban, obviously the place that inappropriate end-of-life decisions would end up would be the courts. It is interesting to observe that, where doctors and also relatives of terminally ill patients have assisted their death, the courts have dealt with that extremely leniently where it has been clear, as clear as possible, that that ending of life was consistent with the patient's wishes. In other words, the courts deal very leniently with doctors who end life in circumstances that this Bill is actually promoting. I think that is an interesting disjunction between what the law now says about assisted suicide being a major crime and

how the courts deal with doctors who on rare occasions do assist suicide in the circumstances that this bill is trying to promote.

Baroness Hayman: Maybe my concerns are about doctors who assist in circumstances that the Bill is not willing to promote—and I am not sure that recent experiences make us feel that our processes are absolutely robust or that much better than The Netherlands in picking those situations up. Thank you.

Q316 Lord McColl of Dulwich: Could I come back to the Royal College of Physicians. Nine months ago they decided unanimously that they were against the Joffe Bill. Nine months later, they suddenly changed and said, "We are neutral", and we were told that was because of the radical changes in the Joffe Bill. Actually, if you look at the changes, they are pretty minimal. The question is why this radical change has come. Those of us who have worked in medical committees for many years can have a pretty shrewd guess as to why that was, but my question is what does the GMC and the BMA think of the view—and the Royal College of Physicians have managed to persuade all the other colleges to adopt this view to be neutral—that we are happy for the community to decide and, whatever they decide, we will do? Is the GMC and is the BMA happy to go along with that? and, if the people say "Yes, we want euthanasia", then you will go ahead and agree to dispatching patients? That is the first question. The second: the conscientious clause in the Joffe Bill as originally drafted is exactly the same as the clause in the Abortion Act. word for word. We know what happened in the Abortion Act. We know of the widespread discrimination against obstetricians and midwives who were not allowed to take consultant jobs and obstetric jobs because they were asked in the committee "Will you take your share of abortion?" and, if they replied "Yes, I will do abortion within the law", they were never appointed and hundreds had to emigrate. The lives of two professors of obstetrics, one in Birmingham and the other in Aberdeen, were made living hell. Why? Because they insisted on living within the law.

Professor Sir Graeme Catto: I will try to answer some of these first. Why the change in position? I have no idea, of course, is the honest answer to that. But let me try to speculate, if I may. The guidance that the General Medical Council puts forward for all doctors is called *Good Medical Practice*. It needs to change and be modified from time to time but it is important because it is not aspirational. If doctors do not abide by the guidance, then action may be taken against their registration: they may have restrictions put on their ability to work or there may

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be more severe measures. Over the course of some years, that guidance has changed. I was interested when we were talking earlier about medical education and the “c”s—the caring and that. I think the General Medical Council has moved in the direction of partnership with patients, so you come immediately into a conflict here where some patients may be requesting something that at the present time is unlawful and that precludes further conversation. I think there is a trend within society. Certainly, within the General Medical Council we are coming to revise our guidance next year, and I do not want to anticipate what is happening. But I am sure we are going to be emphasising more and more that need for doctors to work in partnership with patients and to respond to their needs and not just provide high quality care. That is essential, of course, but perhaps not in itself sufficient. I think the movement in society generally may be in that direction, but that is speculation. If I could just pick up one of the other points, this difficulty in raising issues of end-of-life events. My background as a physician was on dialysis and transplantation, so patients were not on ventilators but they were competent, and conversations about withdrawing treatment were very frequent. That did not frequently result in treatment being withdrawn but the topic was raised—and generally raised by patients. And, of course, patients themselves speak amongst themselves: they have groups, patients’ associations, and these topics do arise from time to time. I do understand the difficulty between withdrawing treatment and what we are talking about here, but, nevertheless, I think society is discussing these topics in a much more open way than perhaps they were.

Dr Nathanson: In terms of “happy for the community to decide,” quite clearly, with all ethical issues, it is a mixture: it is a partnership between the professions and the public that we serve. Whether that actually means that you then derogate any interest or any responsibility to try to influence that decision . . . Of course it cannot mean that, and the role of doctors, when looking at a law that would have an impact on the way that they practise, the relationship they have with their patients, or any other element of medical practice, is clearly to comment on that law and, indeed, to lobby for changes in that law if we believe it to be completely wrong. Generally speaking, we have never been in the business of saying to doctors “You should disobey the law”, but there are occasions, perhaps rather more frequently, that we will work very hard to get potential legislation changed when we think it might have a devastating impact on the delivery of care to patients. For example, 20 years ago, with the first Police Bill, the Association was extremely

active in getting major changes. It was eventually withdrawn and we have a Police and Criminal Act which is considerably different. Because of the ability in the first draft legislation for the police to trawl medical records and the impact that would have had on doctors entering sensitive information in patients’ notes, or, indeed, patients being prepared to say to doctors things that they did not want potentially to be seen by the police, it was clearly important to change that. In a sense, that is why we are here today, because we feel that there is a risk—and you cannot prove it until something has happened—that this legislation could undermine that trust, which is particularly important for the most vulnerable members of society, that they are able to have in their doctors that the doctor will act in their interests, and in an informed way in their interests, helping them to make decisions based upon the balance of what they believe to be beneficial and what they believe to be burdensome.

Dr Wilks: May I make two very quick points. I speak as a member of the Ethics Committee of the Royal College of Physicians. I was not particularly surprised about their studied neutrality; I was a bit more surprised about the College of General Practitioners, because my impression was that they had more of a robust view against assisted death legislation. But I think the Royal College of Physicians, being unencumbered, as it were, with a political process that requires them to consult their members about policy—which is a burden I have to carry—did have a very balanced debate. I think their perception, rightly or wrongly, Lord McColl, was that changes to Lord Joffe’s Bill did allow them to adopt a position of neutrality because they felt that some of the kind of autonomy issues—you know, the power being given to the patient to make decisions—was improved, and I think that produced the kind of balanced response. I do think what you say about the consequence of being a conscientious objector historically is really important. Appalling discriminatory actions were taken against doctors who held certain beliefs. I may not agree with their beliefs, but they have a right to have them, and they certainly should not lose their positions in the NHS as a result of that. I would only say that, with the kind of equality legislation that we have and the anti-discrimination legislation we have and the increasing frequency of tribunals that are dealing satisfactorily with cases of doctors who have been discriminated against, I would hope that is a thing of the past.

Q317 Lord Patel: My Lord Chairman, as we are on record, I think, if you do not mind, I would make a comment about that. Whilst that may have been the case in the early days of the implementation of

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the abortion law, also there were accusations made about discrimination the other way: doctors who did not have conscientious objection were not appointed to consultant points because in the region it was found that they did not wish to provide a service. There were both sides represented. I think we should put on record that the status now is that included in the college guidance produced by the Royal College of Obstetricians and Gynaecologists, which I believe has not changed which is that, at the appointing committee, conscientious objection to abortion is not a reason not to appoint the person.
Dr Wilks: Yes. Absolutely.

Q318 Baroness Thomas of Walliswood: Dr Wilks, when you were speaking, you made a difference between the phrase “physician-assisted suicide” and “euthanasia”. As you continued, you seemed to use the word “euthanasia” as though it covered both. In your mind, what is the difference? Is there a difference between the two? If so, what is it?

Dr Wilks: There are three differences. The first is a definition that physician-assisted suicide is the provision by a physician of the means for a patient to end their own life. Euthanasia—and we have to sub-define that as voluntary euthanasia, which is the only type of euthanasia that we are prepared to engage in a debate about—voluntary euthanasia is the ending of a patient’s life by a doctor at the competent request of that patient; so there is a difference there. I have already said that morally we perceive no difference: the doctor is engaged in the process in which the patient’s life is actively ended, rather than passively—if you like to use that rather bad term. The third difference is that assisting a suicide is punishable by up to 14 years’ imprisonment and euthanasia by rather longer because it is actually murder.

Q319 Baroness Thomas of Walliswood: I wanted to ask another question, in view of comments made by several people. One of the other people who came to talk to us referred to a factor whereby, once a patient knows that he or she can talk to a doctor about the possibility of physician-assisted suicide—and let us keep it at that because that is what this Bill is about—that is reassuring to the patient, and they do not necessarily go on ever to request the suicide which they have discussed with their doctor. However, the current law in a sense forbids the discussion; since you are trying to invite your doctor to do something that he will probably tell you straight away is illegal. Do you think that might have had an effect, where the take-up of physician-assisted suicide has not been very great; but because people are reassured it also leads them to discuss in greater detail the situation around their anticipated

death too; and then maybe they do not ever have to claim what they have talked about? Do you have any thoughts about that?

Dr Wilks: In the State of Oregon, where assisted suicide has been the law for about seven years, a very small number of people knowing that it is available actually take it up. That said, quite a high proportion of the prescriptions issued in Oregon for assisted death are not used, so you are quite right there appears to be some reassurance in having that discussion. I would argue with your point that it is not possible to have that discussion. Obviously, you cannot have a discussion which goes to the end point of saying, “yes, of course, I will help you to die”, but it is absolutely crucial that we have discussions about all the options with patients, even if those options are not available, because the questions that come from patients—and Baroness Finlay will be far more expert on this than I—and the discussions that patients want to have must be very wide-ranging and designed to offer them reassurance that there are a whole variety of things that can be done that do not necessarily include taking that patient’s life, but which is part of the reassurance that they will get good care. I would not regard it as acceptable that patients are sitting in hospital wards afraid to have these conversations, simply because doctors do not have the confidence or the will to initiate them. That is one of the failures in our hard-pressed National Health Service—that failure of proper communication about what patients sitting in a hospital are thinking, as opposed to what we think they are thinking. Sometimes you have to be quite sensitive about asking them and exploring what they are thinking. There are so many fears about end-of-life treatment that are false and based on a basic misunderstanding about what medicine can do. I think what you are really pointing at is poor communication, and I would hold my hands up and say that that is something that we sometimes do not do very well.

Q320 Baroness Finlay of Llandaff: Sir Graeme, can you tell us how many of the new registrants with the GMC are UK graduates from UK medical schools, and how many are graduates from schools elsewhere?

Professor Sir Graeme Catto: I think it still remains around 50 per cent. It is about 6–7,000 that are UK graduates and about an equivalent number coming from overseas.

Q321 Baroness Finlay of Llandaff: Of those coming from overseas, do we know how comprehensive their training is in palliative care and in communication skills?

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Professor Sir Graeme Catto: We have no direct evidence. We no longer inspect overseas medical schools in the way that we did, but there is an assessment, an exam, before those doctors can work here, so we do assess their competence at the point of entry before they work within the United Kingdom system.

Q322 Baroness Finlay of Llandaff: Does that exam include a section on palliative care?

Professor Sir Graeme Catto: It includes all aspects of the care that they may be expected to provide in this country, so there are questions relating to palliative care included in the assessment, yes.

Q323 Baroness Finlay of Llandaff: Dr Nathanson, from your experience of teaching students, even graduates from this country who have had some exposure, do you feel that they feel competent to have some of the complex discussions and take the decisions on their own? or do they feel they need input from other professionals, such as the nurses who are closely involved in the care of the patients?

Dr Nathanson: I think that you are absolutely right that, particularly after a little experience of clinical medicine, doctors are very aware that the key issue here is about team-working, about different members of the team with different skills and different experience, giving the patient different levels of information in different ways; and that the best palliative care is offered in that team sense. Nurses can give assurances and reassurances that are different from those that are wanted from doctors. With experience, I think all doctors would say the same thing: many patients who raise questions about the end of life and euthanasia or suicide, sometimes in very heavily coded ways and sometimes more explicitly, are very often asking quite simply, "what services will be available to me if I develop symptoms that I cannot accept, that are intolerable to me?" It is not always pain; it is very important to recognise that symptoms that people are most worried about are very varied. They want reassurance. I remember well one patient saying to me, very explicitly: "What I want to know is that I will not be abandoned; there will not be a stage at which people say, 'there is nothing more we can do for you'"—they can just go away quietly, into a corner almost. That is a very important reassurance to give, to say that we do not abandon people; that we will always look for what else we can do; and that sometimes those solutions are high technology but very often they are low technology and are about reassurance. That is one of the key issues that these discussions, whether they have in them the possibility of physician-assisted suicide or not, are all about reassurance; that you are valued as an

individual and treated as an individual and will not be abandoned.

Q324 Baroness Finlay of Llandaff: Given that we are looking at this Bill, which focuses in large part on the patient being able to take whatever medications are prescribed themselves and therefore physician-assisted suicide, but accepting that there will be some who, for reasons of physical disability, need the medication administered to them, and therefore that is euthanasia, do you feel from the response coming from your membership that a separate independent service to deliver such lethal medication would answer society's request and the small number of patients who say that they want to be killed. It would mean that the doctor was not the vector and was not therefore intending to kill the patient within the terms of euthanasia? What is your response to that?

Dr Nathanson: That has been raised several times in the debates we have had on these issues because, although it is still a minority, there are more doctors who are comfortable with the concept that they might prescribe drugs which the patient could self-administer; but there are very, very few who say that they would ever be prepared to then administer those drugs themselves. There have been discussions as to whether there should be a separate service. What doctors find it impossible to consider is who would want to provide that service. They find it almost impossible to conceive of the person who would want to spend their life administering lethal injections. Whether such a service could ever be set up, and who would be the people who took part in it, raises very serious questions.

Q325 Baroness Finlay of Llandaff: Sir Graeme, Lord Taverne has spoken about the figures suggesting that there are a lot of doctors who are killing their patients covertly; and this Bill is talking about it becoming overt. I just wondered what the GMC is doing about the numbers that we have seen in the papers at times which state that there are several thousand doctors in the country who are covertly killing their patients.

Professor Sir Graeme Catto: We have no evidence that that is the case, and we have had a discussion this morning about the anecdotal nature of some of these reports. No doubt there is some truth behind them, but we have no objective evidence of which I am aware that this exists. I wonder if I might pick up the point about the teams of doctors who might go around administering this service. From the General Medical Council's point of view, our interest would be to ensure that the patients had given properly-informed consent to that. As I indicated before, my personal experience of dealing

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with patients on dialysis is that it was frequently a topic about withdrawing treatment, to which they would return but not frequently make use of. I think society would want to be absolutely sure that patients who did consider this had a long-term relationship with the doctor, and that these considerations were fully understood before an irrevocable decision was made.

Dr Wilks: I would be very uncomfortable with that kind of service, I have to say. Obviously, if one says, "we would not be in favour of euthanasia", then we are in some people's minds abrogating responsibility for looking after patients who want to die in that way. I do think that the establishment of a separate service is a kind of signal that there is a different group of patients who do not deserve the same kind of overall assessment and communication and discussion about options, and that they can go off to the euthanasia service instead. I would be very concerned that that process could be so easy for patients to take advantage of it if it is there. Part of our concern would be that a lot of the evidence we have had about patients' desire for euthanasia is based on their perception that they are a burden to their families, to the Health Service; and that would be reinforcement of that feeling—"ok, if you feel a burden, you know where to go". I think that would be a very worrying development.

Q326 Lord Joffe: I have a couple of statistical questions of Dr Nathanson, and then to Dr Wilks, arising out of a couple of responses to the questions from Baroness Jay about studied neutrality and weight of opinions. Is it correct that in 1992, at the annual conference, 54 per cent voted against euthanasia, assisted dying, and 46 per cent in favour? For some reason it is on both sides of that in the submission, but not that particular statistic.

Dr Nathanson: I do not have that statistic with me. We will look it up in the records. There has always been a majority voting against, and that majority has varied slightly from year to year. I do not have any information on that particular vote. We have quoted all those that we thought we had records of, but we will certainly look it up.¹

Q327 Lord Joffe: You could write to me?

Dr Nathanson: Absolutely.

Q328 Lord Joffe: Dr Wilks, does the BMA accept that there are some terminally ill patients who ask for assistance to die for whom palliative care is unable to address their unbearable suffering?

Dr Wilks: Yes.

Q329 Lord Joffe: What does the BMA suggest should be done about these patients who are suffering unbearably?

Dr Wilks: That they should be offered the best care that we can provide. I think that, having said that, we accept that there are such patients. Obviously, one is too many, but the numbers are not very great. I think that very often further exploration with the patients about what kind of tolerability they have, whether it is physical pain or whether it is other types of distress, can improve their care. One of the issues here is that we do know that there are a small number of patients who may request euthanasia who will suffer as a result of not having euthanasia. This gets back to the balance of harm and benefit in legislation, as in the case of medical treatment. The harm that the BMA believes will accrue from providing to that sort of patient the facility to die at their request and at the time of their request, is counterbalanced by the potential harm of creating a bill in which the sort of regulatory problems we have already rehearsed here would be very real. It is a tough call to say that some people might have to suffer as a result of protecting vulnerable people, but it is the kind of honest judgment that professional bodies such as the BMA should make.

Q330 Lord Joffe: If one looks at a patient like Dianne Pretty—and the facts are well known—she should just be left to suffer!

Dr Wilks: No, absolutely not. Dianne Pretty was someone who requested the ability to choose the time of her death, but behind your question is something that we talked a bit about before here today, which is that there is an assumption that not providing assisted death for a patient is synonymous with abandoning them. It may be inadequate in the eyes of someone in Dianne Pretty's situation, but it is simply not good enough in medicine to say, "we will look after you the best we can but we won't kill you". It is not right, I think—and it is getting into common parlance—that medicine will say, "once we cannot do anything for you, we have nothing to offer". Our guidance and the GMC's guidance on the withdrawing and withholding of treatment makes it absolutely clear that the obligation of the doctor to the patient continues well beyond the withdrawing and withholding, or no further treatment, in the context of basic care—warmth, palliative care, pain relief and food, and all the things that will make that patient comfortable and preserve their dignity. We could not offer all the things that Dianne Pretty wanted, but we also could offer a lot.

¹ *Note by witness:* The issue of euthanasia or assisted suicide was not, in fact raised during the BMA's 1992 annual meeting. It was raised in 1997 but, prior to the use of electronic voting, no permanent record was available of the voting numbers, once it had been verified that a clear majority opposed both euthanasia and physician assisted suicide.

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Q331 Lord Joffe: This Bill contains an array of safeguards. What safeguards are there in place in other end-of-life decision-making such as withdrawing or withholding treatment, or terminal situations?

Dr Wilks: A number, and they are enshrined in the BMA's guidance on withdrawing and withholding life support and medical treatment and in the GMC's guidance on the same topic. Both contain a fair degree of commonality in the area that you are asking. The first is that a careful clinical judgment is made about the benefits and harms of continuing treatment, of alternative treatments, including no treatment at all. That is the medical part of it, and what doctors do best—making that kind of balance of judgment. As I said before, that is not good enough. You then have to go on and see that clinical decision or those clinical options through the eyes of the patient and, when you have got a competent patient, obviously that is achievable, depending on good communication. Where you have patients that are incompetent or children, you have other ways. Our guidance on withdrawing and withholding artificial nutrition and hydration requires a further assessment by an independent doctor. It requires that, if there is disagreement between patients and their families, the case goes to court and is arbitrated by a court—which we have recent experience of, as you will be aware. And, of course, from the General Medical Council's point of view, doctors who have strayed outside those rules—and we have one example of that where they had their licence threatened by the GMC. There are safeguards built in.

Q332 Lord Joffe: If there is no legislative safeguard it is left solely to the BMA and the GMC, why is there such insistence and concern by the BMA about the legislative safeguards that are incorporated in this Bill, when, after all, one would hope that the BMA and the GMC in principle would draft similar guidelines to those excellent guidelines you have at the moment?

Professor Sir Graeme Catto: Were this Bill to become law, it would present no insurmountable problems for the GMC. There would be challenges we would be required to meet, but there is nothing that would cause us at the present time insurmountable problems.

Q333 Lord Joffe: In relation to this Bill?

Professor Sir Graeme Catto: In relation to this Bill.

Dr Wilks: There are two things. If the Bill were to become law, the duty of the BMA would be to draft guidance to doctors on how to operate within the new legislation; but our job in representing our members' view is to come here today and look at

the practical difficulties around the legislation being enacted in the first place, and I hope that is what we are doing.

Q334 Earl of Arran: Dr Wilks, you have said the ground has shifted—your words—in relation to opposition to this Bill. Would you accept, as the arguments sway backwards and forwards, that probably assisted suicide is inevitable?

Dr Wilks: I have a personal feeling—and I would like to stress, a very personal view—that some form of assisted death legislation in this country is inevitable at some stage. That is a very general statement, but I say that because partly it comes from the discussions Baroness Hayman initiated. People do have difficulty with the difference between the legal right to refuse treatment, even if it results in your death, and requesting that death a little bit sooner. When you look at society's views, as far as one can test them and judge them, we in medicine talk very clearly and quite passionately about people's autonomous rights to make a decision for themselves. That is something that the BMA's ethics department is constantly saying is a very powerful right, and it can only be compromised when it comes up against someone else's autonomy in a very distinct way. The autonomous right to refuse treatment, even if you will die as a consequence, and the autonomous right to ask for death, are in many people's minds much closer together than the law currently declares that to be. My personal belief is that that process will develop momentum, which will take us towards Oregon type legislation at some point. I think it is absolutely right that we flag up, on behalf of our members, the problems that we see that producing now. I would like to say one more thing, which I hope is not inappropriate. We have talked a bit about trust here today. Trust in doctors is very high, and we know this; but trust is quite a fragile thing. There are peripheral issues around this debate that are important to just mention. One is trust in doctors generally following certain problems, like Shipman, Alder Hey and Bristol. There is the need to maintain trust, that doctors will always be doing something that is primarily in the interests of the patient, where there is no hidden agenda and it is focused entirely on the patient's wishes and best interests. That is something that needs to be preserved at all costs at the moment. I have a concern that re-defining the role of the doctor in the way that this Bill would do might pose some threat to that trust. That is a very general statement, but it is one that bothers our members quite a lot, as they feel rather beleaguered at the moment.

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Q335 Baroness Hayman: I think you have just said that patient trust depended on believing that what a doctor will do will be entirely in the best interests of the patient?

Dr Wilks: Yes.

Q336 Baroness Hayman: But in reply to an earlier question of mine, you accepted that for a small number of people, their definition of their own best interests, properly arrived at, was something that had to be sacrificed in the interests of society as a whole: therefore is there not a disparity between those two things?

Dr Wilks: There is a general statement in there, and there is a specific point at which we have to draw some lines. I do not think that the two are in opposition to each other. I make the general point about trust, but we have accepted, from the BMA's perspective, that we cannot help all patients as much as they would wish to be helped in palliative care; but it is a very small group. I would hate to use the word that you have used—"sacrificing" those patients for the good of society as a whole and not creating vulnerable groups that might be considerably larger than the patients who are disadvantaged by not having euthanasia legislation, but that is a balance that we feel is appropriate at the moment.

Q337 Baroness Hayman: I suggest to you that that should engender trust that doctors would always behave to the highest professional standards of what they believe to be in the interests of society as a whole, but it does not quite fit the bill of how you described it a couple of sentences earlier. What is better in the overall is something that is obviously not a simple answer, which we are all debating and expressing our different views on.

Dr Wilks: Indeed, I would accept that. There are many, many doctors—and I still think it is a minority—who would see that provision of assisted death, whether it was assisted suicide or to a lesser extent euthanasia, as an extension of the normal medical professional obligations of a doctor to a patient in respecting their autonomy. There are many doctors who feel that very strongly, that you cannot draw a line with autonomy just because it causes you difficulties. You are either autonomous or you are not, and autonomy extends to the point of also being able to decide the time and method of your death. You can decide the method of your death by refusing life-prolonging medical treatment, and rather callously, you can choose your time of death by committing suicide; but many doctors feel that those are thoroughly unsatisfactory situations, which should be dealt with by the autonomy also extending to being able to receive euthanasia. We

are flagging up difficulties with that in terms of the practicalities of the relationship between doctors and patients generally and the sheer practical difficulty of providing a legal framework in which that can occur safely.

Q338 Bishop of St Albans: Can I have some clarification from Sir Graeme about his statement, because I seemed to hear you say that, should this proposal become law, the GMC would have no problems with it whatsoever? Is that the GMC itself or you personally, or did I misunderstand that statement?

Professor Sir Graeme Catto: I think what I said was that, were this Bill to become law, it presented no insurmountable problems for the General Medical Council, and that in a technical sense is what I meant. It does present challenges, many of which we have discussed round the table, but there is nothing inherently present in the Bill that causes problems for the General Medical Council as it exists.

Q339 Chairman: You referred earlier to the areas in which a patient is treated by a team, as for example with spinal injuries or something of that kind. This Bill draws a distinction between the attending physician, who is the person primarily responsible for the patient's care, and the consultant physician, who has other responsibilities. Are there any practical difficulties that any of you can see in relation to a team situation in determining who would be the attending physician and who would be the consulting physician? Sir Graeme, that is probably primarily something that the GMC would like to talk about.

Professor Sir Graeme Catto: Yes, and it may be that Jane O'Brien will wish to correct me on this. Working in teams and working in partnership is very much part of our guidance at the present time. That does not mean that it should not be clear at any one time who has responsibility for patient care, and indeed our guidance indicates very strongly that at any given time the patient should be very well aware of who has prime responsibility for his or her care.

Ms O'Brien: That is absolutely right. We would see a normal situation as being one person who is designated as having the overall lead. We do understand that that is not universally the case. In some areas of medicine it is more practical to have slightly different arrangements, and that is something that we are talking to a number of the Royal Colleges about at the moment, about looking at team-working and responsibility within those teams.

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Q340 Chairman: I must say that, when I came to look at this Bill first, I had rather assumed that the attending physician would be in the nature of a general practitioner who has the care of the patient year after year, and would probably have quite a considerable relationship with the patient and would know well the patient's attitudes and so on. I assume that in the sort of cases we are discussing now of spinal injuries or a terrible accident or something it might not be the attending physician, in the definition in the Bill, applied to these circumstances, and it might not be the patient's general practitioner at all.

Professor Sir Graeme Catto: Indeed, probably would not be. It comes back to the point that Lord Carlisle made earlier about acquired referral. It may be very much more complex in a practical sense how this might be implemented, were this to become law; but in theory it does not present any greater challenges to the General Medical Council than that. There are significant practical implications in the delivery of this, when it does become law, allowing for the conscientious objection clause.

Q341 Chairman: I wanted to understand the relationships for the purposes of the Bill established in relation to these particular cases, where this might be an issue. Spinal injuries and the like are cases where this particular matter might be well an issue, if it was a legal—

Professor Sir Graeme Catto: It is quite likely that in a spinal injuries case there will be a definite attending physician. There will be a consultant in charge of the case at any one time—but there will be exceptions to that, as we have just discussed.

Q342 Chairman: The person in charge of the case would be the attending physician, and then a consultant physician is required, to whom reference has to be made to, as it were, check the decisions of the attending physician. Then I assume there would not be too much difficulty in finding that sort of person in this situation?

Professor Sir Graeme Catto: I imagine that to be the case. These will be long-term cases, not in an acute hospital situation, I imagine.

Q343 Chairman: I wanted to ask a bit more about the question of informed consent. You referred to that at least in passing, Dr Wilks. If this Bill became law, there would be an option in some cases for this course of action to be taken rather than palliative care. Did I understand you to say that, if that were the situation, it would be incumbent on a doctor, in seeking informed consent from the patient in relation to the course of action proposed—the

option of assisted dying, under what would then be an act, would have to be brought forward?

Dr Wilks: It is not so much specifically in terms of obtaining consent for treatment—I think that is a slightly later stage. I was referring to the discussions that necessarily need to take place between a clinician and a patient about the options for treatment. I would see that, maybe not in every case but in a large number of cases involving patients who were approaching the end of their life or had a life-threatening illness or a terminal illness, because euthanasia or assisted suicide with or without euthanasia was now part of the law of the land, that it would be incumbent on doctors to offer and inform all available treatments, to at least make the patient aware of that availability. To do otherwise would not be giving all the information that the patient deserved.

Q344 Chairman: If that is the situation, what would be the position of an attending physician who had a conscientious objection to the law in relation to assisted suicide, and was therefore exempt under the law from having any part whatever in that sort of situation?

Dr Wilks: Accepting the detailed concern that Lord Carlisle produced about the kind of level of speciality and difficulty of finding alternative doctors, I do not believe that would present a difficulty in terms of the doctor's duty to explain and inform and discuss options. The difficulty would present itself when it would be for the doctor to say, "I have discussed these options with you"—and we believe it would be the rare circumstances if this was an Act—and the patient would say, "I would like to discuss further the practical issues around assisted suicide". The doctor would then conscientiously have to withdraw from that discussion and refer the patient to another doctor who was prepared to not just have that discussion but to follow the discussion through to a decision.

Q345 Chairman: Is it your view that the conscientious objection might not, or need not, or would not cover discussing at all with the patient the option of assisted suicide?

Dr Wilks: To take an every-day example of abortion, the discussion about abortion being either a sensible option for the patient or a bad option for the patient is something that can occur in a discussion with a doctor who might have objections to it. In practical terms, patients tend to go to doctors who are supportive of abortion if they want an abortion; so I guess you might well find in certain circumstances that that shift would occur. The discussion of euthanasia would be a common discussion, an everyday discussion, in the sort of

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clinical environment that Baroness Finlay works in because we would be required to discuss it if it was an available option. Not to discuss it would be unprofessional.

Q346 Chairman: That is what I had rather taken from what you said earlier. This option would be an obligatory subject of discussion for any doctor?

Dr Wilks: With many patients in certain scenarios, of course.

Q347 Chairman: Yes, that I understand. It would only arise as an option in the cases in which it applied?

Dr Wilks: Yes.

Q348 Chairman: That brings me to the question of the safeguards in this Bill, because it is not offering this option except in very closely defined circumstances. An essential part of this option being available is that the patient should be suffering unbearably?

Dr Wilks: Yes.

Q349 Chairman: From the point of view of the attending physician, they have to conclude, to use the words in the Bill, that the patient is suffering unbearably as a result of that terminal illness. The definition of “unbearable suffering” is that the suffering is such that the patient finds it so severe as to be unacceptable. Have you looked at that from the point of view of the attending physician?

Dr Wilks: We have difficulty with any terminology that is too vague, but “unbearable suffering” is necessarily vague because suffering is not necessarily purely physical; it can be emotional suffering or loss of autonomy. The important point is that it is what the patient feels to be unbearable that is the issue here. When we talk to patients about their perception of their illness, it may be very different from the way the doctor might feel the illness is perceived, and it is terribly important to listen to the patient’s view of the impact of their condition on their quality of life, and their perception of the value of their continued existence. One can only say in response to your question that, if on persistent questioning—not just one consultation but on persistent questioning there was a consistent belief by a patient that their condition was unbearable, one would accept that they found it unbearable. This is not that it is unbearable because they are depressed or because they have some other illness that they have some phobic view about. The rest of the Bill makes it absolutely clear that it is in the context of a diagnosis of terminal illness, so the Bill narrows down the group of patients in terms of the unbearableness, that the unbearable nature of the

illness relates to the fact that it is a terminal life-threatening illness, not one that is treatable with a whole variety of other available therapies. I do not have a particular problem with the slightly vague notion of unbearable suffering or other terminology that has been used in recent court cases such as “intolerability”, which I think is a very general term. What I think counts for the doctor is that there is a consistent expression by the patient in a competent, unprejudiced, unbiased way, that this for them is an unbearable situation for them to continue.

Q350 Chairman: The attending physician would be entitled to conclude that the patient was suffering unbearably within the definition in the Act if he or she, the physician, thought that genuinely that was the patient’s attitude?

Dr Wilks: Yes.

Q351 Chairman: So far as this option is concerned, the option would arise only in that situation?

Dr Wilks: Yes.

Q352 Chairman: So the matter would not require to be discussed until that happened?

Dr Nathanson: Absolutely, and in those circumstances these are already where very sensitive discussions do take place. It is a little earlier than the time at which you have concluded that it is unbearable because it is a complex process of trying to understand what it is the patient finds unbearable, and why they find that unbearable, because it is only when you know the answer to both of those questions that you can start to think of the options for dealing with that symptom—to give it a medical name, as it were. Sometimes, the thing that is unbearable is open to quite a lot of management of change. It may not be medical treatment; it may be completely non-medical—it may be social engineering almost, as it were. That is why a lot of these conversations already take place, because it is the patient testing with the doctor, and the doctor testing with the patient, what options are available, and starting to decide the direction in which the individual needs to go. It may well start to take place well before the situation gets to that terminal phase. To some extent throughout medical treatment options become available at different times, and will be chosen or chosen against because at that time they do not offer relief from the thing that is distressing that patient most. That is one of the difficulties that doctors often face, that the treatment the doctor says scientifically may well be the best treatment may not be what the patient wants because it is not dealing with what they perceive to be the major problem. In fact, although it looks like it becomes something that you only talk

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about at a very late phase; our concern is that it will have to be discussed somewhat earlier because it would affect some of the other decisions that might be made by the patient.

Q353 Chairman: From what you have told me, I take it—but I want to have this confirmed—that it would be perfectly appropriate, if this Bill became an Act, for the issue of physician-assisted death to be raised by the doctor rather than by the patient in the first instance. Although of course ultimately the patient's consent would require to be obtained, the issue could first be raised as a matter of discussion between physician and doctor by the doctor?

Dr Wilks: Theoretically, yes, but in most circumstances the first thing that happens between a doctor and a patient, where there is clearly a

terminal illness, is a discussion about how the patient is reacting to that, providing basic information about the treatment options that are available; and I would not expect necessarily euthanasia or assisted suicide to be very high on the list of options, when actually the patient requires information about the available treatment of their condition, which is much more immediate, such as pain relief or chemotherapy—all the things that we would do in those kinds of cases, for example with an untreatable cancer. Then the exploration of options would inevitably lead to patients saying, “If this is intolerable for me, if there is some point I find this intolerable or unbearable, what could we then do?” That is when it would be an absolute obligation for the doctor to discuss assisted suicide.

Chairman: Thank you very much indeed. We are very grateful to you all for your help.

THURSDAY 21 OCTOBER 2004

Present	Arran E	McColl of Dulwich, L
	Carlile of Berriew, L	Patel, L
	Finlay of Llandaff, B	St Albans, Bp
	Hayman, B	Taverne, L
	Jay of Paddington, B	Thomas of Walliswood, B
	Joffe, L	Turnberg, L
	Mackay of Clashfern, L	
	(Chairman)	

Memorandum by National Council for Hospice & Specialist Palliative Care Services

SUMMARY

1. There is a dearth of methodologically robust research into the impact that Physician Assisted Dying (PAD) would have in the UK.
2. Because of the absence of sound evidence, there has not been a properly informed debate, whether between professionals or amongst the wider public, of all the issues that must be resolved before a decision whether to proceed with PAD can safely be made. Legalising PAD would represent a radical departure from UK practice, which should not be undertaken unless and until all the implications have been properly researched and considered.

THE BILL

3. The necessary subjectivity in assessing the degree of a patient's suffering means that the requirement that a patient be suffering unbearably cannot be a wholly effective safeguard.
4. There should be a waiting period. Consideration needs to be given as to its length and starting point.
5. There is no safeguard for patients who are competent, but depressed.
6. Clause 15 is unnecessary, and encourages misconception about the role of pain relief in end of life care.
7. If PAD is legalised, health professionals will be under a duty to raise it as an option with patients. This will have a significant impact on the patient-health professional relationship.
8. Clarity is required about the degree of formality necessary to trigger a request for PAD.
9. By presenting palliative care as an alternative to PAD, the Bill risks reinforcing the misconception that palliative care is solely concerned with the process of dying.
10. The Bill fails to address practical issues about the means and place of death.

INTRODUCTION

1. The National Council for Hospice & Specialist Palliative Care Services ("National Council") is the umbrella organisation for palliative care in England, Wales and Northern Ireland.
2. It is a multi-professional and collaborative body, being born out of a partnership between national charities in the field, Macmillan Cancer Relief, Marie Curie Cancer Care, Sue Ryder Care, and Help the Hospices; professional associations in palliative care; voluntary hospices; the NHS (including Primary Care Trusts, NHS Trusts, palliative care teams, Strategic Health Authorities, and cancer networks); and the Department of Health. The Board of Trustees consists of members representing those organisations. It has about 500 subscribers, and consults regularly with its Area and Country networks.
3. This submission has been produced by National Council's ethics working group, which advises the Board of Trustees. It has been circulated to the Board of Trustees, National Council's clinical advisory groups, and its Area and Country Representatives. However, the time made available for evidence to be submitted following the publication of the terms of reference has not allowed for full discussion, feedback and approval.

4. In 1997 National Council published a position statement which set out its opposition to any change in the law to permit euthanasia. This statement is now out of date. The Trustees have therefore withdrawn it, with a view to carrying out further research and work in this area. This should not be taken to signal support for euthanasia, nor for the Assisted Dying for the Terminally Ill Bill (“the Bill”).

5. National Council recognises that diverse views on euthanasia are held by palliative care professionals (health and social care) in the United Kingdom. We consider that there is a dearth of methodologically robust research into the impact that legalisation of Physician Assisted Dying (“PAD”) would have in the UK; and that because of the absence of sound evidence, there has not been a properly-informed debate (whether between professionals or amongst the wider public) of all the issues that must be resolved before a decision whether to proceed with PAD can safely be made.

6. Accordingly, National Council will not comment now on the principle of whether PAD should be legalised in the UK in the future. Instead, this document will comment on:

- (a) Areas which must be researched and clarified before any decision to legalise PAD can be made; and
- (b) Practical issues raised by the current Bill.

THE BILL

“Assisted dying”

7. Conventionally, a distinction has been drawn between a physician providing the patient with the means to end his own life—physician assisted dying or suicide—and a physician acting directly to end the patient’s life—euthanasia.

8. Notwithstanding its title, this Bill provides for euthanasia as well as PAD, albeit in the limited circumstances that the patient is physically unable to end his own life.

“Terminal illness”

9. The Bill’s definition of a “terminal illness” is wholly dependent upon the opinion of the consulting physician.

10. Hence, it is impossible for the attending physician to form an independent determination that the patient has a terminal illness, as he is required to do under clause 2(2)(c). This would necessarily preclude the attending physician from informing the patient of his prognosis, clause 2(2)(e)(ii); and from making the referral to a consulting physician, clause 2(2)(g).

“Unbearable suffering”

11. The Bill’s definition of “unbearable suffering” is dependent both on the ability of the patient to express the level of his suffering to the attending and consulting physicians, and also on the subjective interpretation of that expression by the physicians.

12. Inevitably, assessment of suffering must always depend upon the patient. It is impossible for any health professional to assess objectively whether or not a patient is suffering to an unbearable degree. It would be impossible to agree any objective professional standards or benchmarks against which the extent of suffering could be assessed.

13. Whilst it may be possible for the attending physician, based on a longer relationship with the patient, to assess changes in his level of suffering, such an assessment cannot be made during the course of the single visit to a consulting physician that the Bill envisages, during which all the activities detailed in clause 2(3) must be undertaken. The time available for such a consultation may vary between only 15 minutes and one hour.

14. This necessary subjectivity in assessing the degree of a patient’s suffering means that this requirement cannot be a wholly effective safeguard.

“Waiting period”

15. We strongly support the principle that there should be a waiting period as a safeguard. Careful consideration is needed as to the length of that safeguard, and the point from which it starts.

16. In the Patient (Assisted Dying) Bill 2003 the waiting period was only triggered once a declaration had been made.

17. In contrast, the 14-day waiting period in the present Bill runs from the moment that a request for PAD is first made. It is probable that patients making a request to be assisted to die will come to expect that this 14-day period is the maximum they will have to wait. The implication is then that all the procedures required in clauses 2, 3, 4 and 5 must have been completed within two weeks. It is clearly possible that the 14-day period will have expired by the time the patient is able to make his written declaration, and so qualify for immediate PAD.

18. It is possible that the period leading up to the signing of the declaration will become focussed heavily on process as the patient and his professional carers seek to ensure that the Bill's requirements have been complied with. Consideration should be given to whether there should be a waiting period after the declaration has been signed, which would enable the patient to focus not on the process of qualifying for and making a declaration, but on the decision whether then to proceed with PAD.

“Competent and Incompetent”

19. The definitions of “competence” and “capacity” must be consistent with those contained within other legislation currently in statute or under consideration eg The Mental Capacity Bill.

20. The Assisted Dying for the Terminally Ill Bill leaves the assessment of a patient's competence to the consulting physician and of incompetence to the attending physician, neither of whom is required to have any special expertise in such assessments.

21. Importantly, the Bill contains no safeguard for patients who are competent, but suffering from depression. Depression is a recognised part of the disease journey which may take considerably longer than 14 days to resolve.

22. The Bill requires a psychiatric referral only for those patients whose competence is in doubt. Any patient who requests PAD, and whom is thought to be suffering from significant depression, should receive a psychiatric referral.

DISCUSSION OF ETHICAL ISSUES:

Pain relief: (cl 15)

23. This is an unnecessary clause. The administration of pain relief is well-established in clinical practice, and need have no bearing on or connection to PAD. It is unprecedented that a therapeutic course of action requires an act of legislation. All patients have the right already to appropriate management of any symptom including pain.

24. There is absolutely no need for a conscientious objection clause in relation to the administration of pain relief (cl 7(2)). This clause risks confusing the administration of pain relief with PAD in the public mind and in statute. That would harm the physician-patient relationship, and encourage popular misconceptions about the role of pain relief in end of life care.

Death as a deliberate intervention

25. If PAD is legalised, it becomes a legitimate form of treatment given with society's approval. It will be a recognised way of bringing an end to suffering. Physicians will be under a professional duty to raise it as an option with their patients if they complain of suffering unbearably, as it will be considered to fall in the category of “best interests”. It will be a patient's right to be informed of all available options.

26. The means by which a patient receives information about assisted dying will be of immense importance. It will have a significant impact both on the patient and his relationship with his healthcare professionals. The Bill does not deal with this.

27. There is a risk that, if healthcare professionals are to be required to raise the issue of PAD for discussion with their patients, the conscientious objection clause (cl 7) might be undermined.

28. Whilst the Bill's emphasis is on the role of doctors in providing PAD, responsibility will inevitably be placed on all health care professionals, particularly nurses, whose specific responsibility it is to care for and support patients and families at the end of life.

29. The title to clause 7 refers to the duties and conscientious objection of “physicians”, rather than more broadly to healthcare professionals.

What amounts to a request?

30. Clarity is required about the degree of formality that is required for a patient to have informed the attending physician of his wish to be assisted to die for the purposes of the Bill. This is important because the date that such a request is first made triggers the 14-day waiting period. It is therefore essential that the date of first request can be identified with certainty.

31. Professionals will need to clarify whether a patient is making a formal request for assistance to die, as opposed to expressing unhappiness in a general way.

32. The following statements might be expected in the setting of distress when faced with the many practical, physical and psychological complications of a life-threatening illness. . .

“I wish it were all over”

“Can’t you end it all?”

33. Whilst such comments must always be taken seriously, and investigated, they would not necessarily amount to a direct request for PAD.

34. The Bill requires physicians to make enquiry, every time such sentiments (or similar) are expressed, to establish whether a patient is making a formal request for PAD that would trigger the process set out in clause 2. The Bill does not say whether such a request needs to be serious or persistent.

Palliative care and PAD

35. The Bill places considerable emphasis on palliative care, and identifies being “informed of” palliative care as a safeguard. However, palliative care is of benefit throughout the course of a disease and not just at the end of life. Appendix A contains a definition of palliative care.

36. By presenting palliative care as being an alternative to PAD, the Bill risks reinforcing the misconception held by patients, carers and some health and social care professionals that palliative care is solely concerned with the process of dying, whereas in fact palliative care benefits patients before they reach the terminal stage of their illness.

37. That this misconception has significant implications for acceptability and access, and so may inhibit the development of palliative care, has already been identified by the National Institute for Clinical Excellence.¹

Information about palliative care and care in a hospice (clauses 2(2) and (3))

38. The Bill requires both the attending and then the consulting physician to “inform” the patient “of alternatives”, including palliative care and care in a hospice.

39. This requirement begs a number of questions:

- (a) What is meant by “inform. . . of”? A single sentence to the effect that “there are alternatives to PAD, which include palliative care and care in a hospice” could amount to adequate information. That is scarcely a safeguard at all.
- (b) If it is intended that more information than that be given, the Bill should specify what information is required.
- (c) If the attending physician has not already considered the option of palliative care for the patient, it is unlikely that he will be able to give an adequate description of the potential benefits of this care.
- (d) The reality is that access to a palliative care specialist might not be instantly available, or indeed available at all. Similarly, care in a hospice is not currently available to all who request it². The Bill does not recognise the reality of current palliative care provision. 95 per cent of specialist palliative care at present goes to patients with some types of cancer. Many patients are excluded from palliative care by their diagnosis.
- (e) Could a request for PAD be used to prioritise a particular patient over others needing palliative or hospice care? Would it trigger an entitlement to palliative care? This raises clear issues of justice and equity. Why should a request for PAD enable one patient to supersede another?

¹ NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer, March 2004, para 114. See also Appendix A.

² See also paras 43–46 below on current palliative care resources.

“Discussing the option of palliative care” (clause 3)

40. The patient must also have been attended by a palliative care specialist “to discuss the option of palliative care”

- (a) Again “discussing the option” is too vague to be an effective safeguard. Nothing is said about the length, depth, or substance of discussion required.
- (b) Clarification is needed as to when this consultation must take place, to ensure that it is in the context of a request for PAD. The Bill is silent as to whether this must take place before or after a request for PAD has been made.
- (c) This requirement does not reflect the reality of specialist palliative care practice. Palliative care depends on continuity and relationship. It would not be possible to undertake a full and proper assessment of a patient’s full palliative care needs in the time allowed for a short consultation.
- (d) As above, palliative care might not be (instantly) available.

41. The intention behind the Bill may well be to ensure that patients are given full information about palliative care, and receive a proper assessment of their palliative care needs. However, this Bill does not achieve that.

Minimum compliance

42. In order to assess whether adequate safeguards exist, the Select Committee must consider what the minimum requirement would be for each condition of the Bill to be met. Safeguards must be devised which require substantial information discussion and reflection over an adequate period. Safeguards which can be satisfied by the barest of lip service are not sufficient.

DISCUSSION OF PRACTICAL ISSUES

Allocation of resources

43. Although palliative care provision is more advanced in the UK than in any other country, it is still underfunded and unable to meet the needs of all those who would benefit from palliative care. Implementing this Bill would carry with it considerable costs in terms of training, facilities, staff time and compliance. Those advancing the Bill have not sought to quantify these.

44. There are 237 palliative care consultants in England, with a whole-time equivalent to 169.³ At least 100 posts for consultants in palliative medicine remain unfilled.⁴ There is no set definition of a specialist cancer nurse and it has not been possible to collect national figures on numbers of specialist palliative care nurses.

45. There are 3,195 palliative care beds in the UK, of which 2,522 are in the voluntary sector. The average stay in a hospice is 13 days.⁵

46. The availability of Day Care and Home Care Services is also relevant here, as they will have considerable impact upon a patient’s quality of life.⁶

47. This Bill will make demands on those limited resources. The Committee should consider whether resources would be better expended on improving access to palliative care, which would have a broad benefit for a large number of patients, or on establishing PAD, which even the Bill’s supporters argue would benefit only a few.

³ 2002. Source: Association for Palliative Medicine.

⁴ Evidence by Dr Keri Thomas to House of Commons Health Select Committee.

⁵ Hospice Directory 2004.

⁶ For further information about these services, see National Council’s Evidence to the House of Commons Health Select Committee, which is enclosed with this submission.

Process of being assisted to die

48. The Bill says nothing about the means or place of death.

MEANS

49. We assume that the lethal dose will be a barbiturate to be self-administered by drinking, unless the patient is physically unable to take the dose himself. In cases where a physician euthanases a patient, death might be administered by injection. In either case, the means by which death is to be provided needs to be tightly regulated.

50. The same applies to the prescription and dispensing of the medication. A terminally ill patient might not be able to collect the prescription himself, but wish to use an agent. The lethal dose would be in the hands of a member of the public for whom it was not intended.

51. Despite the language of the Bill, the attending physician is not required to be present at the moment the patient ends his life. For obvious reasons, the patient is under no obligation to use the medication that he has been provided with.

52. This raises the possibility that the patient will be provided with a lethal dose, which will then be kept in a non-secure place for an open-ended period.⁷

53. Safeguards are required to ensure that lethal doses are not misappropriated, deliberately or accidentally.

54. The Bill does not address these issues at all. Nor does it provide any power for regulations to be made.

PLACE OF DEATH

55. Very careful consideration needs to be given as to where the lethal dose is administered. It may often be in the patient's own home, but the potential impact, on other patients and staff, of offering PAD in buildings where healthcare is undertaken must be researched.

RESEARCH

56. Legalisation of PAD would have a significant impact on clinical practice in the UK. The impact would be widespread, affecting the provision of medical services, professional ethics, and the patient-professional relationship. This is a societal issue, not simply a health or palliative care issue. Public debate has been largely based on opinion poll findings and much influenced by strongly held, and expressed, opposing views. Much of the research that is available is based on weak methodology.

57. There is a need for robust research into attitudes towards PAD in the UK, amongst patients, carers, professionals and the wider public. Likewise, very careful consideration is required of the practicalities involved, should PAD be introduced into UK practice.

58. We do not have the evidence to assess fully the probable extent and nature of the impact of PAD on UK practice. Until we do and there has been a full and informed debate of what PAD would involve in practice, we will not as a society be in a position to decide whether or not to legalise PAD, nor will we be ready to adjust to the impact that legalisation will have.

59. Anecdotally, we are aware of colleagues in Belgium who have expressed shock at the speed with which legalisation took place, and have encountered significant problems because they were not adequately prepared for legalisation and had not had the opportunity to think through all the issues that legalisation raises.

60. In particular, but not only, research is needed in the following areas:

(a) Patient views:

- (i) How do views change along the disease journey?
- (ii) Do physical symptoms and psychological symptoms differ in their influence on a patient's wish for death?
- (iii) How do different social, cultural and religious backgrounds affect a person approaching the end of his life?
- (iv) How do views change once patients have received palliative care, as opposed to being told about it?

⁷ The Oregon Reports show that 67 patients received lethal dose prescriptions in 2003. 28 (41.8 per cent) of those did not ingest the prescribed medication. 18 died of their illness. 10 were still alive on 31 December 2003.

- (b) Carer views:
 - (i) How do carers' views influence patients?
 - (ii) How do those views change during the course of an illness?
 - (iii) How does the availability of supporting services influence the views of carers?
- (c) Professional views:
 - (i) more accurate understanding of the actions and intentions of doctors who state that they have ended a patient's life.
 - (ii) An understanding of the consequences of requiring doctors to offer and then bring about the ending of a patient's life
 - (iii) An understanding of the impact on other healthcare professionals who would be involved in PAD. The Bill places a very heavy onus on doctors, as opposed to other professionals. Is it right that doctors should shoulder so much of the responsibility in relation to this issue?
- (d) The general public:
 - (i) How will permitting assisted dying affect society's view of the sick, frail and elderly?
- (e) Experience in other countries
 - (i) To what extent can experience and research in other countries, both where PAD is legal and where it is not, inform our understanding of the impact that PAD would have in the UK?
- (f) Practical implementation
 - (i) How would PAD be introduced into UK practice?
 - (ii) How would PAD safeguards be consistent or compatible with current practice?
 - (iii) What lessons can be drawn from other jurisdictions?

61. Legislating for PAD would represent a radical departure from medical practice in this country. Such a step should not be taken until there has been thorough research into the issues raised above, based upon robust methodology. National Council would be willing to participate in any steering group meeting to agree methodology and oversee research.

62. Properly robust and detailed research would take considerable time and money. However, the controversial nature of these issues means that many funders are reluctant to support research in this area.

63. Much further consideration is required of the whole area of how, as a society, we care for those who are approaching the end of their lives. When considering whether to legislate in favour of PAD, Parliament should proceed with great caution and on the basis of robust and complete evidence. In particular there must be careful consideration as to whether PAD can be introduced without an adverse impact on medical services and those patients who do not wish it.

August 2004

APPENDIX A

DEFINITION OF PALLIATIVE CARE

112. Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

113. Palliative care is based on a number of principles and aims to:

- Affirm life and regard dying as a normal process.
- Provide relief from pain and other distressing symptoms.
- Integrate the psychological and spiritual aspects of patient care.
- Offer a support system to help patients live as actively as possible until death and to help the family cope during the patient's illness and in their own bereavement.
- Be applied early in the course of the illness in conjunction with other therapies intended to prolong life (such as chemotherapy or radiation therapy), including investigations to better understand and manage distressing clinical complications.

114. It is now widely recognised that palliative care has a crucial role in the care received by patients and carers throughout the course of the disease and should be delivered in conjunction with anti-cancer and other treatments. In the minds of patients, carers and some health and social care professionals, however, it tends to be associated with care for dying people. This has significant implications for acceptability and access.

The above definition is taken from the NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer, March 2004, paras 112–4.

Memorandum by the Association for Palliative Medicine

1. SUMMARY AND RECOMMENDATIONS

1. The Association for Palliative Medicine (APM) welcomes the opportunity to debate the complex issues surrounding euthanasia and physician-assisted suicide and recognises the ongoing interest expressed by society in debating end-of-life issues.
2. Confusion exists surrounding the terms used in the euthanasia debate and in the wording of the Bill.
3. The effective and proper use of analgesics is well established and is a consequence of the work of hospices and specialist palliative care. There is no need for new legislation to facilitate the appropriate use of drugs to relieve pain.
4. In some of the countries that have legalised euthanasia, palliative care services are poorly developed.
5. The appropriate scope of respect for individual autonomy requires further scrutiny and debate in the light of the present-day circumstances of dying and the care of vulnerable patients in society.
6. The APM welcome the conscientious objection clause in the Bill since palliative care physicians should not be required to be involved in the administration of euthanasia and physician-assisted suicide
7. The Bill postulates the ethical concept that death is a “moral good”. There is the danger that if death and “medicalised killing” become regarded as in the best interests of competent patients there will be a moral obligation to extend this to incompetent patients.
8. Little robust evidence exists on patients’ decision-making at the end of life. This debate needs to be informed by rigorous research into patients’ views and attitudes to euthanasia and physician-assisted suicide.
9. There is a need to improve communication and advanced care planning of end of life care. In this way patients may have enhanced autonomy that is specific to their needs without violating the autonomy of others.
10. All patients who need palliative care should have access to this care at an appropriate level to meet identified needs. There is a need to develop and expand palliative care services at all levels, including funding research into improving care of the dying.
11. The Bill does not provide adequate safeguards to protect vulnerable members of society.
12. Existing legislation in Holland and Belgium has not prevented significant numbers of cases of “medicalised killing” being carried out where the patient has not given consent.
13. The resource implications of this Bill in terms of time, staff and facilities are significant and have not been addressed by the Bill.
14. The Bill threatens the integrity of the medical profession and the future of palliative care.
15. The Bill could disadvantage the palliative care of patients who did not request euthanasia by distorting clinical priorities
16. The Association for Palliative Medicine remains opposed to the legalisation of euthanasia and physician-assisted suicide.

2. BACKGROUND

2.1 The Association for Palliative Medicine of Great Britain and Ireland (APM) is the national professional organisation for over 800 doctors working in, or with a particular interest in, specialist palliative care. The Ethics Committee of the Association is elected by the membership. (Appendix 1) This submission has been ratified by the Executive Committee of the Association and reflects the views of the large majority of members. (Appendix 2) The APM submits this report to the House of Lords Select Committee to express our views regarding The Assisted Dying for the Terminally Ill Bill.

2.2 Since the last House of Lords Select Committee report on euthanasia 10 years ago, there have been some changes in the legislation of euthanasia and physician-assisted suicide in other countries. These may be summarised:

- Rights of Terminally Ill Amendment Act 1996, Northern Territory, Australia made euthanasia and physician-assisted suicide legal.
- 1997 Law made ineffective by Parliament of Australia.
- 1997 Physician-assisted suicide (but not euthanasia) legalised, Oregon Death with Dignity Act.
- April 2002 euthanasia and physician-assisted suicide legalised in the Netherlands.
- May 2002 legalisation of euthanasia in Belgium.
- Also, Article 115 of the Swiss penal code condones assisting suicide for altruistic reasons. It does not require the involvement of a physician nor that the patient be terminally ill.

2.3 The legalisation of euthanasia and physician-assisted suicide has been debated since the 1970s and polarised into two opposing views; “for” and “against”. The principal arguments “for” euthanasia and physician-assisted suicide concern respect for autonomy and the relief of pain and suffering. Those arguing “against” argue from the intrinsic wrongness of deliberately taking innocent human life, the integrity of the medical profession and the potential for abuse (which may be framed as a slippery slope argument).(1) We do not propose to repeat all of these arguments but rather to highlight the practical and ethical difficulties which, in our view, make legislation of euthanasia unworkable. We have taken the opportunity to suggest positive measures, including the need for further research, which would improve our understanding of these complex end of life issues and to deliver better care for all patients at the end of their lives

2.4 Since the House of Lords Select Committee reported ten years ago, the APM share the concerns expressed in their report and remain opposed to the legalisation of euthanasia and physician-assisted suicide.(2) Furthermore, the European Association of Palliative Care and the British Medical Association are opposed to euthanasia legislation. Our opposition to legislation is based on our clinical experience in caring for dying patients and their families and on overwhelming evidence from the peer reviewed literature. We present our specific concerns regarding the proposed legislation.

2.5 Across Europe there is little evidence of concerted attempts to bring about the legalisation of euthanasia through parliamentary processes.(3) Those countries which have legalised euthanasia generally have poorly developed specialist palliative care services.(4) In contrast in the United Kingdom models of palliative care have been developed at generalist and specialist levels. Nevertheless, significant challenges and difficulties remain [RG1]:

- (a) Access to this care is mainly limited to patients with cancer and some advanced chronic neurological diseases and provision of care remains patchy, due to inadequate resources.(6)
- (b) Whilst the specialist services that are available are generally of a high standard, the specialty still has much research and development to do in the areas of suffering and symptom control. Sadly, this need is not reflected in research funding for palliative care.
- (c) Most palliative care is delivered primarily through primary health care and in hospitals by general clinicians. Whilst there have been programmes funded from central government to assist in education on the basics in palliative care, the general quality of care remains variable.
- (d) Consequently, bad death and unnecessary suffering continue to occur, as the testimonies of those in favour of euthanasia demonstrate. We cannot hope to confer on people the dignity in their disabilities and their dying that they deserve when support services for community nursing, out of hours care, occupational therapy, the provision of aids in the home and continuing care packages remain at the current inadequate levels. This has been brought to the attention of the Commons Health Committee that looked at Palliative Care recently.(5)
- (e) There are also failures in specialist palliative care services. Recruitment into practice is as difficult as any other specialty.(5) Consequently, due to inadequate resources, poorly qualified or inexperienced staff, patients and families that should have had well-managed death have not. This is a continuing concern to us, and a matter for training and supervision that falls to the specialty as it develops.(5)
- (f) Priority for access to specialist palliative care should not be solely determined by a request for euthanasia or physician-assisted suicide.

3. THE LANGUAGE OF THE DEBATE

Confusion exists surrounding the terms used in the euthanasia debate and in the wording of this Bill.

3.1 *Palliative Care: World Health Organisation definition 2002(7)*

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

3.2 *Many definitions of euthanasia and physician-assisted suicide have been formulated.*

The European Association for Palliative Care Ethics Task Force recommends the following definitions (3):

Euthanasia

“A doctor intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request.”

Their inclusion of a “doctor” as the agent is based on the Dutch model and has provoked controversy in the literature.(8) Medicalised killing of a person without the person’s consent is not euthanasia, it is murder.(3)

Physician-assisted suicide

“A doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person’s voluntary and competent request”

3.3 The APM believe that palliative care physicians should not be required to be involved in the administration of euthanasia and physician-assisted suicide. It is significant that the word “euthanasia” does not appear in the proposed legislation which covers both euthanasia and physician assisted suicide in the “softer” but confusing term “assisted dying.” This Bill is actually about medical help to end life, since it is about both the prescription and possibly administration of lethal doses of medication ie assisted suicide and euthanasia. It is about deliberate acts to end life, not about assisting in the natural dying process which the term “assisted to die” could be taken to mean.

The Bill also seeks to confuse the issue further by suggesting that new legislation is needed to ensure patients with terminal illness receive analgesics. Existing law enables doctors to give pain relief, even if doing so may risk shortening the life of a terminally ill patient, and to deny patients such relief is negligent.

3.4 *Terminal*

Clinical evidence shows that consultants are often inaccurate in their estimation of a patient’s prognosis. Defining the terminal phase is often much more difficult than people might imagine, particularly in patients with non-malignant disease such as cardiac or respiratory failure.(9)

3.5 *Unbearable suffering*

Objectively determining the severity of suffering is not possible; it is what the patient says it is. Suffering is an entirely subjective concept which is determined by a host of factors including most importantly the patient but also the society in which he/she lives, the healthcare professionals view and the levels of support available. In 35% of euthanasia requests in Holland doctors refuse requests on the basis that the suffering of the patient is insufficiently severe.(10)

3.6 *Terminal or palliative sedation*

Terminal or palliative sedation in those imminently dying must be distinguished from euthanasia. In palliative or terminal sedation the intention is to relieve suffering, the procedure is to use proportionate doses of a sedative for symptom control and the outcome is alleviation of distress.(3) In euthanasia, the intention is to kill the patient, the procedure is to administer a lethal drug and the outcome is immediate death.

4. DEVELOPING THE ARGUMENTS

4.1 *Arguments derived from the appropriate scope of respect for Autonomy*

The appropriate scope of respect for individual autonomy requires further scrutiny and debate in the light of the present-day circumstances of dying and in relation to the wider interests of vulnerable patients and society.(1)(11)

4.2 *Death as a moral good*

There is a danger of reclassifying death from euthanasia and physician-assisted suicide as a potential moral good.(11) In Holland, death and “medicalised killing” is considered to be in the best interests not only of competent patients who request it, but also in incompetent patients, where the doctor(s) judge patients to be suffering or in possession of a life no longer worth living.(19)

4.3 We do not believe that killing is the best treatment for the sufferings that are part of our humanity. Particularly when poor clinical care has reduced a patient’s dignity and social isolation has led to a loss of personal relationships.

The APM suggests from the clinical experience of its members that with the proper provision of palliative care services, and adequate and timely access to practical and necessary support for patients and their family, persistent requests for euthanasia are infrequent. Where they do exist, the solution lies in providing support and the best possible care to engage with issues such as hopelessness, helplessness, loss of meaning and existential distress, not in euthanasia or physician assisted suicide.

The APM welcomes the conscientious objection clause in the Bill. Euthanasia and physician-assisted suicide should not be part of the responsibility of palliative care physicians.

4.4 Relief of suffering is an important goal of medical care. However, palliative care cannot, and does not claim to be able to relieve all suffering. There is no sort of care that could ever alleviate all suffering (especially some expressions of social, psychological and spiritual distress), but the first step to addressing the majority of this suffering is to ensure effective support and skilled interventions are available to those who require them, rather than introduce a way to end these individual’s lives. The inability to relieve all suffering is inevitable and is part of the human condition. We believe that implementation of this Bill could increase suffering in vulnerable patients and their families by reducing trust, increasing fear and inhibiting patients from disclosing their concerns to doctors and other healthcare professionals.(11)

4.5 *Patient’s views*

We have little reliable evidence as to how most dying patients feel about euthanasia and physician-assisted suicide. Such evidence that does exist indicates that requests for euthanasia and physician-assisted suicide relate to feelings of “disintegration” which results from symptoms and loss of function and a “loss of community” which describes the progressive loss of opportunities to initiate and maintain close personal relationships.(12) These factors contribute to a feeling of a “loss of self”.(12) Thus the decision to have euthanasia or assisted suicide could change with meaningful changes in an individual’s social circumstances independently of disease progression.(12)

Existing studies into patients’ reasons for requesting euthanasia or physician assisted-suicide, suffer from significant methodological weaknesses. They describe features such as depression, hopelessness, psychological distress and need for social support. However how these factors lead people to request euthanasia or physician assisted suicide has not been explained.(15) What seems to be clear is that the relevant factors can change as the patient approaches death.(13)

The criteria in this legislation fail to provide a framework to address the social circumstances that contribute to the desire for euthanasia or assisted suicide. This vital part of end of life care needs to be informed by rigorous research into the patient’s views and attitudes to euthanasia and physician assisted suicide.(15)

4.6 Individual requests for euthanasia and physician-assisted suicide are complex in origin and demand careful attention with open and sensitive communication. The complexity of the notion of a “loss of self” means that there is a need for clinicians to consider the evaluation of a request for euthanasia or assisted suicide as an important clinical skill. (14) Sensitive exploration of the request can help to identify the real needs of an individual patient.(14) The request for euthanasia or physician-assisted suicide seems to point to a series of concerns that the patient has about dying; relating to loss of self, loss of dignity and the social context of dying. Understanding these concerns may help us to improve the care of dying patients.(14) Communication

surrounding end of life issues is a core skill in palliative care and depends upon a trusting doctor patient relationship. There is a need to improve communication skills of doctors and advanced care planning of end of life care to enhance patient autonomy.

4.7 *Lack of protection for the vulnerable*

The Bill does not provide adequate safeguards to protect vulnerable members of society.

1. The Bill contains a requirement that a specialist in palliative care must “discuss the option of palliative care” with the patient before a declaration can be signed. The purpose of the single consultation is unclear. Is it to give the patient some basic information about palliative care, or; to provide more detailed information; or to assess the patient to establish what precise options might be available to that individual patient? To discuss options appropriately necessitates assessing the patient in order to be able to discuss relevant care. If the assessment is to be carried out by a clinical nurse specialist this will have implications for provision of training.
2. The assessment of the euthanasia request as envisaged in the Bill can create a barrier which subtly alters the doctor-patient relationship and may paradoxically impair the possibility of discussing the hopes and fears driving the euthanasia request. It can be even more difficult to assess a patient’s needs when the goal of euthanasia dominates discussion.
3. Assessment in specialist palliative care depends upon continuity of care and is an ongoing dynamic activity. It is unrealistic to imagine that a single consultation with a patient could reveal all the factors behind a request for euthanasia or physician-assisted suicide. It often takes weeks to establish a sufficiently trusting relationship with some patients. Compounding these difficulties is the lack of time, continuity and the fact that many patients have a number of attending physicians and other healthcare professionals necessarily involved in their care.
4. The Bill makes no mention of what is to be done when the experts disagree in their assessments.(16)
5. Commonly in clinical practice many patients are apprehensive and may be reluctant to accept palliative care. However they almost always change their minds once they experience this type of care. Thus it may be that many patients might initially reject palliative care when given basic information about it at a single interview. Another common manifestation of this scenario is the frequent expression by patients who have received palliative care. “Why did no-one tell me about this care earlier on”.
6. There is no allowance made in this legislation for depression which falls short of incompetence. Depression may be difficult to diagnose. The attending physician and the consulting physician do not need to have had any psychiatric or palliative care training, if they miss the diagnosis and presume competence the existing safeguards of the Bill are ineffective.
7. The attending physician cannot form an independent opinion as to whether the patient is terminally ill, because the Bill’s definition of a terminal illness is wholly dependent on the view of the consulting physician.
8. The waiting period is too short, and could be completed at the moment that the patient signs a declaration, without any subsequent cooling-off period.
9. A monitoring commission is useful only to the extent that cases are reported to it. The Dutch experience demonstrates that almost 50 per cent of cases are not reported to the authorities.(17) Indeed it could be the most borderline cases which do not fulfill the criteria for euthanasia which are concealed.
10. Why does the monitoring commission review cases retrospectively? It would be much fairer and a better safeguard to monitor applications to ensure the qualifying conditions had been met for euthanasia or assisted suicide before the death, not after.

4.8 *Legislation abroad*

Looking at the effect of different laws in different countries will not necessarily predict the effect of the proposed Bill in this country and so is of limited value. However the Dutch data from 2001 are cause for concern.(18)(19). Euthanasia was carried out in 2.6 per cent of all deaths (3,640), physician-assisted suicide in 0.2 per cent (280) and “life-terminating treatment”, where there is no explicit request, 0.7 per cent of deaths (966).

Legislation has been unable to prevent life-terminating treatment without consent. Furthermore there is evidence that approximately 50 per cent cases of euthanasia are not reported by doctors who feel it is a matter between themselves and the patient.(8, 10) Thus the exact extent of euthanasia being carried out without consent is unknown (17).

4.9 *Resource implications*

- (a) Palliative care resources are limited and in reality largely confined to a proportion of those people with cancer. Further resources would be needed, both to enable assessments to take place, and then ensure that adequate palliative care is available to meet identified needs. What would happen if following the consultation, the patient decided to have palliative care, but none was available?
- (b) The Bill does not state where the euthanasia or physician assisted suicide will take place. We would be concerned about the effects on other patients if assisted dying took place in the same ward or even building as the one in which they receive treatment. Much of hospice care is provided by charitable monies currently—and charities are highly unlikely to accept euthanasia and physician assisted suicide within hospices.
- (c) Patients wishing to remain in a hospice/specialist unit could avoid discharge simply by making a euthanasia request, thus denying more needy patients access to care. The Bill states that the patient must be informed of the alternative of “care in a hospice”. If all patients who say they might want euthanasia thus become entitled to “care in a hospice” then it is likely that more hospice beds will be needed and possibly for longer periods of time per patient. The Bill does not limit the length of time the “care in a hospice” is to be made available for. The average length of stay currently in a specialist palliative care unit is around 13 days, but this could lengthen considerably if the Bill becomes law and the patients are seen to be entitled to care in a hospice if they are considering euthanasia. It is of course also unjust that patients who are considering euthanasia become automatically and legally entitled to care in a hospice regardless of their actual care needs, and so they effectively “trump” all other patients who have no right similarly enshrined in law to ensure they will get a hospice bed, however desperately they might need it.

4.10 *Integrity of the profession and impact on medical practice*

The potential effect on relationships between patients and their doctors and the impact on current medical practice should be considered:

1. The risk of losing trust and damaging care is high. This is an area of practice where research is needed to establish the consequences of legislation.
2. Would euthanasia and physician-assisted dying be legitimate treatment outcomes that doctors would be obliged to raise with all dying patients?
3. How will the new law be enacted if a majority of doctors conscientiously object to performing euthanasia and physician-assisted suicide? There would be a legal requirement for an “objector” to refer on to someone who has no objections. There would need to be local lists of participating doctors and nurses. The stress on these professionals could be enormous.
4. There is a strong possibility that some palliative care doctors could also refuse to carry out the required assessment consultation, fearing that they might become implicated in euthanasia.
5. The Bill only makes it legitimate for a doctor to provide the patient with the means to end his life. Despite the language (“attending physician”), the doctor is not required to be present at death, and the patient is not required to administer the lethal dose immediately. What safeguards are there to ensure that the lethal medicine is kept secure and administered properly? For how long should the patient be allowed to keep the lethal dose without administering it?
6. There is no mention in the Bill as to the methods involved in either assisted suicide or in euthanasia. It is worth noting that complications such as failure of completion, myoclonus and vomiting may occur in both assisted suicide and euthanasia in 3–16 per cent of patients resulting in traumatic experiences for patients.⁽²⁰⁾
7. What would the costs (time, staff and money) be of training, implementation and compliance including the costs of staff and facilities?

4.11 *Social implications*

What will be the effects on society of permitting direct acts of killing, and so weakening the prohibition against killing which currently protects us all? There are strong cultural, moral and legal prohibitions on killing but this Bill introduces the concept of death as a moral good. Will this new Bill change the way in which society views the sick and dying as an inconvenience that have to be disposed of?

Will patients feel more of a burden to their families and society and feel that they ought to ask for euthanasia, and feel guilty if they don't? In other words, will the proposed new law actually increase the mental suffering of the patients who would not necessarily want euthanasia but need care and can easily be distressed by feeling a burden? As we have stated there is much that we need to learn about the impact of a patient's social circumstances in generating a request for euthanasia or physician-assisted suicide. Good qualitative social research is much needed in this area.

5. CONCLUSIONS

Palliative care is concerned with enabling patients with advanced life-threatening conditions to live with the best possible quality of life until they die. Clinical experience and research suggests that the majority of requests for euthanasia or physician-assisted suicide arise as a result of poor symptom control, depression, poor social and family support and a loss of autonomy. Palliative care concentrates on improving these aspects of a patient's life and the provision of this care should be the starting point for any debate on assisted dying.

Such care involves working closely with patients and their families' suffering. When a patient is in the terminal phase then the goal of care is to enhance the dignity of the individual. If this legislation is passed there is a risk that some patients will die against their wishes.

The Association for Palliative Medicine opposes this legislation and suggest that the interests of dying patients, their families and our wider society would be better served by increasing access to palliative care, improving the communication between healthcare professionals and patients, gaining a better understanding of the needs of dying patients and informing the public about these highly complex issues in an honest way.

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ACKNOWLEDGEMENTS

The APM ethics committee would like to thank Dr Rob George, Dr Fiona Randall, Simon Chapman, Dr Pat Alquist, Dr Neil Jackson and Sheila Richards for their help in producing this report.

APPENDIX 1

MEMBERS OF THE APM ETHICS COMMITTEE AT 19 AUGUST 2004

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APPENDIX 2

VIEWS OF APM PALLIATIVE CARE PHYSICIAN MEMBERS

The APM executive committee have supported the initiation of a research project to assess the views and attitudes of doctors working in palliative care.

An initial postal questionnaire of APM members carried out in 2003 to get a feel for the views of the membership revealed that over 90 per cent of respondents were against legalisation of euthanasia. The postal survey was not intended for publication, as it suffered from all the methodological limitations of questionnaires. It was a preliminary short survey prior to conducting a properly designed piece of work. For the sake of completion the survey results are included.

The draft submission has been circulated on the APM website, highlighted in the APM newsletter and members have been made aware of the Bill at the APM Annual General Meeting in Warwick 2004 and during a keynote address to the delegates at the Warwick conference.

Survey of APM Members Views on Euthanasia/Physician Assisted Suicide

SUMMER 2003

Question 1

Do you believe that the interests of patients with advanced incurable progressive diseases would be better served were legislation to be enacted to permit

(a) euthanasia?

Yes 42 = 7% No 565 = 92.6% not sure 3 = 0.4%

(b) physician assisted suicide?

Yes 48 = 8% No 557 = 91.7% not sure 2 = 0.3%

Question 2

How many patients in an average year make a rational persistent request for you to end their lives?

140 replied	0 requests for euthanasia	23%
193	1 or < 1	32%
108	2	18%
47	3 or < 3	8%
25	4 or < 4	4%
51	5 or < 5	8%
9	6	1.4%
6	7	1%
1	9	0.1%
14	10	3%
6	12	1%
1	15	0.1%
3	20	0.3%
1	50	0.1%

Question 3

If euthanasia/physician assisted suicide were to be legalized in the UK which of the following groups do you think would be most appropriate to perform it? Please tick one

The doctor looking after the patient at the time 107 = 18% of those who answered question, 17.5% of total responses

Another doctor not involved in the patients clinical care at the time 191 = 33% of those who answered question, 31% of total responses

Someone who is not a doctor but has specific training for the job 286 = 49% of those who answered question, 47% of total responses

Question 4

If euthanasia /PAS was legalized and Palliative Care Specialists were asked to be part of the assessment process, would you be prepared to participate?

Yes 154 = 28% of those who answered question, 25% of total responses

No 394 = 72% of those who answered question, 65% of total responses

Survey of APM members views on Euthanasia/Physician assisted suicide—Summer 2003

COLLATION OF COMMENTS

The following is a summary of the main points made by respondents. It is not the product of a methodologically sound qualitative analysis but rather an overview produced by Jim Gilbert having read all the comments. The raw data remains available via Sheila Richards.

COMMENTS ON THE QUESTIONNAIRE

- Many did not answer question 3, several explaining their refusal on the grounds of there being no ‘appropriate person’. Several alternative suggestions were put forward for people to perform euthanasia including philosophers, politicians, a soldier and even someone titled “professional killer”.
- Question 4 was frequently commented upon. The following summarizes the responses of many; “if by participate you mean actually performing euthanasia or PAS, then no, but if you mean participating in the assessment process then yes”. Others variously commented that palliative care professionals must be involved and others that they felt they could not morally be involved.
- In relation to question 2 several drew attention to the probability that requests are reduced by knowledge of the prevailing legal position.
- Several supported and encouraged the active involvement of APM members in the debate.
- Several respondents drew attention to the difficulty of requesting brief, tick box responses to complex questions.
- Several respondents expressed thanks for being asked their opinion in a systematic way.
- One respondent thought the whole questionnaire too narrow to assess such a subject.

GENERAL COMMENTS

- Several responses were that although a small minority might be helped by a change in the law overall the majority would be disadvantaged. Several respondents drew attention to parallels with termination of pregnancy suggesting that apparently tight safeguards may rapidly be loosened—one specifically opposing the possibility of having to fill in a “green form” (as for a request for termination of pregnancy).
- Many respondents drew attention to a resulting loss of trust in doctors, all suggesting that trust would be lessened by doctor’s involvement in euthanasia/PAS.
- Palliative care was conceded by some not to be a panacea whereas others equated requests for euthanasia with a failure of palliative care.

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- Several made the point that requests come more frequently from relatives than from patients.
 - Some suggested that palliative medicine doctors were better to work on change from within whereas others refused any association with the process for fear of being seen to condone it.
 - The probability of increasing pressure, perceived or real, on vulnerable patients were euthanasia/PAS to become an option, worried several respondents.
 - Several explicitly related their views to their religious beliefs—all opposing euthanasia/PAS.
 - One respondent was unhappy that the debate smacked of fundamentalism and inflexibility.
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Examination of Witnesses

Witnesses: DR TERESA TATE, Chair of the Ethics Working Group, National Council for Palliative Care, MR DONAL GALLAGHER, Specialist Palliative Care Social Worker; Palliative Care Service Manager at the Wisdom Hospice, Ms VICKY ROBINSON, Nurse Consultant in Palliative Care at St Christopher's Hospice and DR ROBERT GEORGE, Consultant in Palliative Medicine at UCL Medical School, the National Council for Hospice and Palliative Care Services, and DR DAVID JEFFREY, Chair, Ethics Committee of the Association of Palliative Medicine, examined.

Q354 Chairman: Today this is our opportunity to hear from the National Council for Hospice and Specialist Palliative Care Services and also the Association for Palliative Medicine. First of all, I would mention that the evidence will be transcribed and the witnesses will have an opportunity to see the transcript so that they may correct any errors that may have crept into the transcription. We would propose a session of around an hour and a half—it could be flexible; it is not absolutely rigid. But that is what we have in mind—and we would have in mind that you would wish possibly to make short opening statements. We have, of course, your written submissions, but short opening statements, either each of you or one or two, just as you feel inclined—obviously, we would expect something from each group represented here—and then we would have an opportunity for the members of the Committee to ask questions in elucidation. Thank you.

Dr Tate: Thank you, Lord Chairman. I will begin and my colleagues will then introduce themselves and address you briefly, if that is acceptable. I am Teresa Tate. I have been a consultant in palliative medicine at Bart's and the London NHS Trust for 14 years, with 10 of those years also spent in a hospice. I am now the Medical Adviser to Marie Curie Cancer Care, and I am here as the Chair of the Ethics Working Group of the National Council for Palliative Care. This is a multi-professional umbrella body for palliative care services in England, Wales and Northern Ireland, which is made up of all the professional bodies and major charities involved in the delivery of specialist palliative care. Help the Hospices is a member of the National Council and has submitted evidence to this Committee. All of my colleagues will be happy to give evidence based on our experience of hospice practice, and Help the Hospices would be happy to provide written answers to any question about their evidence that you may have. In compiling the National Council's evidence we have focused mostly

on specific aspects of the Bill but wish to open by emphasising our general concern that there is almost no robust evidence to properly inform the debate, either among healthcare professionals or the wider public, on all the issues which must be resolved before a decision to legalise physician-assisted dying is taken. Specifically, we have identified concerns about the inadequacy of the Bill's definition of the required qualifying characteristics of patients. For example, the phrase "unbearable suffering" has no measurable objective measures and, thus, no safeguards in practice. There is no secure definition of "competence" and no protection for patients who are considered competent but may be depressed. We also do not believe that the waiting period of 14 days allows an adequate time to complete the requirement of Sections 2 and 3 in an optimal way for the patient. We have particular concerns about the way in which the speciality of palliative care is presented as an alternative to physician-assisted dying. The Bill does not recognise that the practice of palliative care is of most benefit to a patient and his family when it takes place in a trusting evolving relationship during the course of advanced illness, and not just in the terminal phase, with the multi-professional team providing care which allows complex psychological and spiritual issues to be aired and addressed over time. We want to emphasise that there is absolutely no need to introduce legislation to entitle patients to adequate pain relief, the provision of which is soundly based in evidenced clinical practice, and that to propose to do so in this Bill risks confusing two very different concepts and perpetuating any misconception which may exist in the mind of the public about the role of the hospices and palliative care. Finally, we are concerned that the practical, financial and manpower implications are not addressed by a Bill which would place considerable pressure on an already under-resourced and inequitably distributed small speciality. The National Council wishes to record that a diversity of views on assisted dying is

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held by palliative care professionals. However, whatever their views about the underlying principles, there is a broad consensus that the introduction of physician-assisted dying would represent a radical departure from clinical practice in this country. If it is legalised, health professionals would be under a duty to raise it as an option with their patients. We do not believe that health professionals or society have fully assessed the implications of this change, and we reinforce the call for properly funded and methodologically sound research as a first step in the debate.

Dr Jeffrey: Lord Chairman, I am David Jeffrey, Chair of the Ethics Committee of the Association for Palliative Medicine of Great Britain and Ireland. This is a professional organisation for over 800 doctors either working, or with a particular interest, in specialist palliative care. I am a consultant in palliative medicine at the Edinburgh Cancer Centre at the Western General Hospital, and I have worked as a Macmillan consultant at the Three Counties Cancer Centre in Cheltenham. I also have twenty years experience as a general practitioner. Thank you for inviting me to give evidence on this complex issue. The Association for Palliative Medicine believes that the Assisted Dying Bill is detrimental to the care of dying patients. The terminology of the legislation is misleading; the practicalities of the Bill, including patient assessment and implementation of medicalised killing, unworkable, and resource issues have not been addressed. The issue of pain relief is provided for in existing law and is already part of good practice. Regulation is ineffective, as monitoring occurs retrospectively after the patient has been killed. The safeguards are inadequate to protect the vulnerable. There is a great need for research into the views and decision-making process of dying patients. Exploring and engaging with a patient's suffering are core elements of palliative care. We believe that this Bill would make this vital work even more difficult. Palliative care physicians do not intend to be involved in the administration of physician-assisted suicide or euthanasia. The Association for Palliative Medicine is opposed to this legislation for the reasons summarised in our submission, and I am grateful to the Committee for this opportunity to answer questions.

Dr George: My Lords and Ladies, I am Dr Robert George. I am a consultant in palliative medicine and a clinical ethicist in the Centre for Bioethics and Philosophy of Medicine at UCL. I am on both ethics committees represented here and I advise extensively on the law and ethics of end-of-life care. I have cared for almost 20,000 patients over 17 years, and I am one the pioneers of non-cancer and adolescent palliative care worldwide. For brevity I make a series of statements from my evidence and,

in response to available transcripts on the web, I have circulated the series of cases I referred to in my original submission today, as I understand that they have not reached you before, and I apologise for that. Should any wish to discuss them in detail outside this meeting, I will be most happy to oblige. The effects of legalising assisted dying and therapeutic killing will be profound and costly on society's view of its members and its proposed demands on the caring professions to reverse the various code and duties relating to life and death. In this the responsibility of this Committee is enormous and unenviable. To my mind the heart of this debate lies in the preservation and promotion of the human rights and freedoms for all. To begin with some facts, first, death is inevitable, and in that dying the burden of disease, or causal gradient, as death approaches, is so great that the matter for the patient is not bringing death on but either clinging to life or letting go of it. Palliative care clinicians know this; academics and other clinicians tend not to. I cannot emphasise this more. All patients are able to die when they want to by letting go of life. Second, palliative medicine in the UK requires four years' training for accreditation, and units have to meet clear standards to be classified as specialist. Despite being recognised as a world leader, general training in palliative care in this country is paltry, services are patchy and inconsistent and thousands do not get the care they deserve. Nevertheless, the disorders of magnitude are better than that abroad. For example, in Europe or America hospice and palliative care clinicians have nothing like the level of training and specialisation. Claims, for example, that patients are in receipt of palliative care in Oregon demonstrate this. One in four applicants for therapeutic assistance to die have uncontrolled pain. Furthermore, multi-disciplinary assessment seems questionable, with half not being assessed by psychologists. This is most disturbing as incapacity and impaired judgment from psychological distress are subtle, and depression is very difficult to exclude in the dying. Oregon psychiatrists report confidence in the diagnosis in only 6 per cent of cases. Third, the "heart-sink" cases that I describe in my submission show, on the one hand, that skilled specialist practice is capable of engaging suffering, promoting true autonomy in dying and, in even the most difficult situations, without resorting to therapeutic killing; but, on other hand, they demonstrate that this Bill would profoundly hinder or abolish this ability to assist dying properly. Turning to broad issues, I have reviewed the literature systematically and may be able to offer additional comment on previous unresolved questions. For example, the desire for death, aside from the minefield of psychological distress,

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demoralisation and depression, revolve around poor symptom management, loss of control and dissatisfaction with care, but, most worrying in Oregon, a rise in applicant's feelings of being a burden to the family, from less than one in five after their first year to over one in three within four years. Second, double-effect plays little, if any, role in specialist practice, as my cases show. Nevertheless, the distinction of killing and letting die in medicine remains valid. Academics tend not to appreciate this, as they have no experience of enacting ethical decisions at the coal face. However, many doctors and nurses are also vulnerable to emotive feelings, for example, in terminal care, because they confuse temporal links, such as death soon after an injection, with that injection having caused death. The majority of junior and, regrettably, many senior clinicians worry and report that they have given lethal injections when they are actually falling into this temporal causal fallacy and shoulder the burden of this misconception throughout their careers. Third, I show a figure on page six of today's submission. I propose that, because this Bill reclassifies in statute death as a potential medical treatment, we cannot restrict therapeutic killing ethically to any one group; hence safeguards and restrictions are meaningless. These will not stand the scrutiny of the courts, for they cannot. Case law and the epidemiology in Holland show this clearly. Predictably, Dutch doctors are now increasingly worried by economic pressure, now that therapeutic killing can reasonably be seen as part of health economics. Unfortunately, Oregon's data do not record these risks to vulnerable patients' autonomy. Finally, as we know that one in five euthanasias in Holland are not voluntary and considered the best interest, I believe that the central human rights question to answer is: how many patients in the UK are we willing to have killed without their permission as the cost for a tiny minority wanting their suffering resolved by euthanasia ie autonomy as self-determination, rather than asserting their autonomy as self-government to engage it and let go with help and specialist palliative care? Such is authentic dying.

Ms Robinson: My Lord, my name is Vicky Robinson. I am a nurse consultant in palliative care and have worked exclusively with the dying for sixteen years; prior to that I was a District Nurse. I am also a member of the Ethics Working Group of the National Council for Palliative Care. My principal purpose here today is to represent the view of the National Nurse Consultant Body in Palliative Care. We are a group with a collective experience of over 200 nurse-years in specialist practice. We have considered the matter at length and are unanimous in rejecting the benefits that are claimed for assisted

dying. As the nursing experts in this field, we have grave concern for the extent, quality and sustainability of palliative skills in the nursing workforce. Specialist training in palliative care and terminal care is not nearly as available as it should be. The relief of suffering with the physical, social, emotional and spiritual is central to the nurse/patient relationship. However, when the burden of witness is great, suffering is sustained or the skills to engage and manage it are absent, the natural role that a nurse will adopt is to identify with and voice that pain rather than to step back and evaluate it. However, this does not translate into the commonly held myth that between 60 and 80 per cent of nurses support euthanasia. What it does imply is that 80 per cent of nurses carry emotions accrued from entering into an important, laudable but unresolved psychological relationship with the dying. All too often nurses respond to an act upon the raw emotion that flows from the imperative to serve and care, which leads many to consider euthanasia as a necessity because they do not know how to manage suffering. This is likely only to get worse as nurses' time with patients is squeezed by the resource issues in the NHS and poorly-trained staff are drafted in from other cultures to provide care. In our experience, suffering is temporal and fluctuates. Research shows that skilled nurses can deliver care in the manner that encourages patients to talk intimately about their concerns. Patients attach importance to such relationships, value them and feel supported by them. This therapeutic relationship is crucial in care of the dying. I wish to emphasise at this point that there is no suffering that cannot be relieved or removed if patients have the opportunity for expert clinical support and care by suitably trained staff. Our efforts should be focused on raising the levels of skill amongst the health care seen to relieve suffering, not eliminating the problem by assisting in the elimination of the patient. Turning now to care for the family, according to the Bill a patient need not inform his or her next of kin. We recognise that this takes account of patients' right to confidentiality, but we are astonished that the Bill does not acknowledge that suffering is both an individual and a collective experience. It is nurses who attend to the deceased, support the family through the process and through to bereavement; and not infrequently it is nurses who face the anger of relatives and friends who may have been unaware of the patient's death. The Bill states that it is a requirement for people seeking assisted death to be seen by a specialist in palliative care. Is this to complete a requirement for the process of attaining assisted dying or to assess how a person's suffering may be supported, and if possible relieved, through palliative care? If it is the former, it is not a palliative

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care assessment. If it is latter, then assessment takes, at the very least, a week and, in proportion to the severity of the suffering experienced, may take months. The association between assisted dying and palliative care will confuse people. This will be to the detriment of our speciality and the work that has gone into establishing it at the very time when it is starting to bear fruit. We have to recognise that palliative care is far from the standard and quality it should be. Doctors will assume that nurses will also prepare injections for therapeutic killing or administer oral medications for assisted dying. In Holland the lack of recognition of the breadth and depth of these roles has caused significant confusion over the legal status of the nurse's role in what are called "preparing acts". There is a tendency to view such acts as technical ones associated with the killing itself. The wider counselling, supporting and comforting roles of the nurse are far more significant. The resource implications of implementing the change in law advocated by this Bill would, in our view, be far greater than those required to extend the good work started by the hospice movement, advocated by the NICE guidance for supportive and palliative care and the National Council's strategic decision to emphasise the extension of palliative care to all. Finally, I want to emphasise that assisted dying is a misnomer. Midwives assist birth; palliative care nurses assist the dying with specialist palliative care: assistance is not killing. The use of the term "assisted dying" is offensive to those of us who are giving good care at the end of life and is a deception to sanitise the killing to make it more palatable to the public, the implication being that you can only die with dignity if you are killed.

Mr Gallagher: Finally, my Lord Chairman, my name is Donal Gallagher. I have been a qualified social worker for thirteen years and nine of those years have been in specialist palliative care based at the Wisdom Hospice in Rochester, Kent. I have also been an active member of the Association of Hospice and Specialist Palliative Care Social Workers; and, whilst I am here today in the context of the National Council for Palliative Care, my presence is also to ensure that this evidence is reflective of the nature of palliative care services in the UK—that is, holistic and multi-disciplinary. The written submission from the Association mentioned to this Committee made it clear that from the small piece of research that has been conducted there is a diversity of views on the principle of assisted dying. The main finding of this research suggested a need to continue an informed discussion about the professional, practical and philosophical implications of this process. Those working with the psycho-social needs of those affected by terminal

illness wish to contribute to the deliberations surrounding assisted dying, but at present specialist palliative care social workers are not in a position to offer a mandated view. This echoes the absence of sound evidence into the impact of assisted dying identified in the National Council's written submission. Nevertheless, the whole persona approach of palliative care and social work's specific role in working with the non-physical aspects of those affected by a life-threatening illness does provide a framework in which this Bill can be viewed. There is only a passing recognition in this Bill of the range of causes of pain at the end of someone's life. "Unbearable suffering" is "by reason of pain or otherwise". A more explicit recognition of the emotional, social and spiritual context of pain and suffering is required. If "unbearable suffering" is to have any meaning in these circumstances, it must acknowledge directly total pain, whereby suffering can have a psycho-social or spiritual origin. The social factors which could cause and have in my experience caused someone to want to die prematurely include the absence of significant supportive relationships in their life or, conversely, the presence of hostile and pressurising relatives. If this were recognised in the Bill, it would be equally imperative to ensure these needs are suitably assessed by specialists. Once again, the Bill's emphasis is on the physical and medical. Doctors and nurses play an essential role in the care of those who are dying, but, with such a vital issue as assisted dying, discussing the option of palliative care must be multi-disciplinary if the discussion or assessment is to be meaningful. Independence in the Bill to ensure the dying person's total needs are appropriately listened to and assessed is missing. The requirement for one of the witnesses to be someone other than a member of the medical care team or the patient's relative or partner hints at the need for independence in the process, but is diluted by the fact that an unmarried partner of a patient could legally be a witness. The relationship between assisted dying and palliative care is complex. In practice, I have often heard voiced by patients and relatives the belief, and for some the fear, that hospices already engage in a form of assisted dying through the administration of drugs. It is therefore reasonable to assume that legalising assisted dying and creating the association with palliative care would add credence to this pre-existing belief and compromise or complicate the various relationships between those receiving palliative care outside any legislation and the multi-disciplinary team. Once again, it is important to carry out robust research with those currently receiving palliative care if the effects of legalising assisted dying are to be fully understood and considered. Thank you.

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Chairman: Thank you. Would members of the Committee who wish to ask questions please begin?

Q355 Lord Carlile of Berriew: I must confess, I am in a bit of a muddle having heard your evidence, because we have heard number of witnesses, including representatives of various royal medical colleges and medical bodies, accepting that there is some pain that cannot be relieved by palliative care. Dr George said, “All patients are able to die when they want to by letting go of life”, which certainly would appear to be inconsistent with Dianne Pretty’s position, which included not just being not being able to let go of life but having to go to court to try and persuade the courts that she should have assisted suicide; and Miss Robinson said, “There is no suffering that cannot be relieved”, which again seems to be contradicted by the Dianne Pretty case and is possibly also contradicted by your own other statement, Miss Robinson, that palliative care is “not what it should be”, which suggests that in various parts of the country at least less satisfactory levels of palliative care may be available. So my fundamental question is: is it right that there is no suffering that cannot be relieved? and, if so, I would be interested in your comments on cases like the Dianne Pretty case, which has provided the impetus for this Bill?

Dr George: Thank you for asking that question; it is a very important one. One of the things that I would like to say is this—and I did not look after Dianne Pretty, so I have the information that we have seen before us in the news and so forth.—The greatest concern and sadness that I feel for the case is that, in the majority of patients that we look after, there are reasons for being alive and reasons to die. For example, if you are English there is a peak of death after Christmas; if you are Jewish there is a peak of death after Jewish New Year; if you are Chinese there is a peak of death after Chinese New Year; people die after anniversaries; people die after fulfilling events. My great sadness around the situation with Mrs Pretty is that actually the process that she went through may well have been something that kept her alive, because it is ironic that she died within weeks of the judgment of the European court. I cannot comment upon that, but my concern is, particularly with patients who are having difficulty in, as it were, letting go and allowing the process of their dying to continue even though they want it to, that there are other reasons that are stopping them doing that. They may be social, they may be emotional, and they may be spiritual. There are circumstances that lead to these impediments. The point that I am making is that, if we are engaging suffering of individuals, then we are excavating into the reasons why that may be. If we

are then in a position (and, of course, the patient has to collaborate and cooperate with us in this) to go through the process of engaging those issues, then it may be perfectly possible for them, and indeed I would say is perfectly possible for them, to die with great ease and comfort. I can give you examples of patients who have a prognosis of—

Q356 Lord Carlile of Berriew: Can I pin you down on one point? Lord Joffe’s Bill is underpinned by the confident statement we have heard repeatedly that there are cases in which palliative care cannot relieve suffering. Is that true or not?

Dr George: I think if you look at the quality of palliative care across the nation there will be situations where that cannot be resolved. There are situations where suffering is partly resolved or is unbearable because a patient is unwilling or unable to look at the situations that are leading to that suffering. Patients that I have looked after who have requested assisted dying are people who wish to be in control, people who refuse treatments, people who are not willing or prepared to engage the issues that may underlie the problems that arise. That is an autonomous right that they have to say “no” to those things, but the consequence of that may be that their suffering is prolonged as a result of that. In patients who do address that, then these matters resolve themselves. If there are not the skills to deal with those things, the multi-disciplinary teamwork and so forth, then there are situations where unbearable suffering will exist. But the answer to that, surely, is to make sure the consistency and quality of practice across the nation, in specialist practice and in general practice and hospitals, is brought up to speed so that we are bringing up the quality of the specialist practice rather than dunning it down.

Q357 Lord Carlile of Berriew: Can I ask one other question which arose from something that Mr Gallagher said. I think it is a very important point and it is one that, frankly, I should have seen reading the Bill and that I had overlooked until now, and that is that the definition of “unbearable suffering”, I think Mr Gallagher is saying, could include, for example, being unable to suffer any more the attitude of relatives who would rather see you dead than alive, that sort of mental suffering, which can become unbearable, particularly for elderly people who feel that they are dissipating the wealth of their family as they remain alive.

Mr Gallagher: Certainly that has been my experience, that some people either feel pressurised, and that comes from a genuine source, or their perception is that they are a burden to their families, even though their families would say otherwise. So

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the feeling can come from a number of genuine sources or perceptions on behalf of parties.

Q358 Lord Carlile of Berriew: That is founded on the words “or otherwise”?

Mr Gallagher: Yes. My point is that it should be more specific.

Q359 Lord Taverne: On that question of pressures from relatives, we have had some evidence that in fact the pressure from relatives is not to speed up death but, when the patient wants to die, that the pressure is to dissuade them from such a decision. I do not know whether that evidence is correct or not, but would you not agree that this is something where one can look at the experience of other countries and find out? Do you not think that evidence from abroad is relevant to this issue?

Mr Gallagher: I am not familiar with the evidence from abroad. I am basing some of my submissions on my experience of working in palliative care, and that is that some people who are dying do feel that pressure from family members to die perhaps before they would do otherwise, or would want to do.

Q360 Chairman: Can I understand that, Mr Gallagher. Are you saying that you have experience of people actually suffering as a result of the attitude that they know of from their relatives who wish to hasten their death?

Mr Gallagher: Not to hasten their death; but they feel a burden at times. I think that is the more prominent feeling: they feel a burden to their families.

Q361 Chairman: So long as they are alive?

Mr Gallagher: Whilst they are alive, because they are going to become more dependent. Certainly there was one case I have worked with, where he did want to die before he would have done otherwise because he felt he would be a burden and become more dependent upon his family and affect their lives.

Q362 Lord Taverne: The other question I want to ask is of Dr Tate. She said that she was not happy that the “unbearable suffering” is left to be subjective criteria. Is it not inevitable that “unbearable suffering” is subjective? We have, for example, evidence from one person with Motor Neurone Disease who said that, however terrible the suffering might be that she was going to go through, she did not wish to have her death assisted; and we greatly admire and respect her courage. We had evidence from another person with Motor Neurone Disease, who knew exactly what was going to happen to him, who said that he was extremely

concerned that he should not go through suffering which he would regard as unbearable. This would seem to contradict the evidence that it is up to the patient and there is no patient who need suffer unbearable suffering because they can always let go. Taking those two cases, is it not inevitable that this, which a very important consideration, should be subjective? It cannot be defined any more, can it?

Dr Tate: Absolutely. There is no doubt that suffering is what the patient expresses as suffering. My concern, the concern from the Hospice Council in its evidence is—

Q363 Baroness Thomas of Walliswood: I am afraid I cannot hear you.

Dr Tate: I am sorry, is that better?

Q364 Chairman: Yes, that is better?

Dr Tate: The concern of the National Council was about the definitions that were included in the Bill and the requirement for the doctors to make a judgment about the unbearable suffering of the patient; and the point was exactly that, that they would have no measure to use except by hearing what the patient may say to them; and if the doctor, particular a palliative care physician, is being asked to do that in the very short time that may be allocated for a palliative care assessment, the supposition is that that is not going to be an adequate assessment of the patient’s suffering but that may take a week or more of knowing the patient and the situation before it can be effectively and properly judged.

Ms Robinson: Perhaps I could refer back to Lord Carlile’s question as well. I want to really emphasise the point that every suffering is unique, and it is in the context of a life lived that the whole root of the hospice movement is based on the management and the alleviation of suffering. Our job as palliative care clinicians is to build up a relationship of trust and, indeed, to help our colleagues who are working in our general hospitals and general practices to help people to discuss what the future might hold in terms of their symptom burden, what effect that might be on their family, and also to begin and to excavate what strategies they might want to put in place at a future date. In my experience a lot of people do change their mind once that therapeutic relationship is in place and people have the knowledge and the tools with which to manage each day as it comes.

Q365 Lord Taverne: A lot of people may change their mind. What about those who do not?

Ms Robinson: In my experience of 16 years and many thousands of patients, I can count on one hand the number of patients who have not changed their

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minds and have gone ahead and either taken their own lives or have gone abroad for assisted dying.

Dr George: Could I make a comment about the assessment of “unbearable suffering”? Doctors really are not the best people to look at global assessment. This is why we have multi-disciplinary teams and why it takes quite long time to assess all the shades and components of that which involve the family and all these things. Often patients reflect family suffering; the family reflect patient suffering. It is a very complicated area and it requires much more than just one doctor to assess that.

Dr Jeffrey: Lord Taverne, you were asking about experience abroad. It is interesting that in the studies from Holland doctors themselves decided that 35 per cent of patients requests for euthanasia had to be turned down because they were not suffering enough. I think one other thing that is at the back of my mind is that we talk in this debate as though it is all suffering and, if you have euthanasia and physician-assisted suicide, there is no suffering. But let’s not forget Groenewoud’s work that shows that between 3 and 16 per cent of patients who have physician-assisted suicide or euthanasia have distressing deaths: failure of the process to work, myoclonic spasms and vomiting—a distressing time¹. So it is not a question of either/or; suffering can be accompanied on both sides of this.

Q366 Lord Taverne: The other question I want to ask is on the question of pain relief and that there might be difficulties in that case. Is it not true that since the Shipman case there has been less willingness of doctors to give as much pain relief as they were willing to do before? There was some work done by a research company called Medics UK. It found that a number of doctors have reduced their pain-relief-prescribing since the Shipman case; so that in many cases patients were not given the pain relief which they wished?

Dr Tate: Perhaps I can start with that. I would suggest that that absolutely reinforces the need for an extension of palliative care education to the health care practitioners in order that we can understand that the appropriate use of strong pain killers is absolutely safe, that is fixing the dose according to the individual needs of the patient and continuing to reassess and to judge that, and that there is absolutely no evidence that by doing that one will shorten the life of a patient. Indeed, there was a paper very recently published from Israel which reconfirmed again that that was the case.

¹ *Note by witness:* Groenewoud JH *et al* Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands *New England J Medicine* 2000; 342:551–6.

Q367 Bishop of St Albans: My Lord Chairman, I address this question to Dr Jeffrey. I particularly enjoyed the paper that was produced by your Ethics Committee, not least the series of definitions that is provided. And, following the definition, you came to section 4 which was, I think, very, very carefully worded, I suspect, and it is about the wording that I would like to ask a question. You refer under 4(1) in your paper to arguments derived from “the appropriate scope of respect for autonomy”. Clearly the rest of it is very carefully worded, but I suspect that was as well. My question is: did you phrase that sentence in that way because you have doubts or concerns about autonomy being the sole definition of human purpose, etcetera?

Dr Jeffrey: Certainly I think there is a time now for a debate on the prominence of autonomy. Ethics, and particularly medical ethics, in this country have imported from Beauchamp and Childress in the States an American view of autonomy as having absolute primacy in any ethical debate. I think we are now beginning to realise that “no man is an island”; that we relate to a community and we have duties and responsibilities as citizens as part of autonomy. I think even Kant would not have wanted to look at autonomy as just striding oneness and choosing exactly what you want; it is also thinking about the effect of one’s choices on others; we want here to reflect this and we think there is a debate here to see. Let us look at this carefully. We all want patients to have choice. Palliative care is all about maximising patients’ choice and trying to maximise their autonomy but within the construct of how that affects other patients. Certainly that is the reason for phrasing it. It is about balancing between individual, private autonomy and a public morality and duty to others.

Dr George: Can I make an additional comment on autonomy? If you go back to Kant and from Kant onwards, there is a distinction between autonomy as, if you like, self-determination, which is what is the prime element or component of autonomy that now it is proposed. But there is a second component, which is the matter of self-government: because for freedom to exist in communities necessarily we all have to restrict our autonomy. There are zillions of examples of that. It is the appropriate balance of self-government as well as self-determination that makes it a healthy and appropriate society. If we are looking at these situations—I give this example of letting go and people, as it were, taking the word “autonomy” as self-government—people can let go of life; people do let go of life. There is very good evidence from Oregon, for example, of patients electing to stop food and fluids. Their deaths are rated as eight out of 10, with 10 being excellent, and they die within about two weeks. The interesting thing, if one talks to somebody

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about letting go, a component of that is stopping eating and drinking as you withdraw from the world. All of these kinds of things are achievable, and actually they are respecting the autonomy of the individual as self-government rather than purely self-determination.

Q368 Bishop of St Albans: Really a sort of statement, which is that I was once asked by a friend who is a lecturer at the University of Birmingham if I would give him an instant and gut-reaction to his question: what is the most important thing you know? I can assure you my response was not that I have personal autonomy. In other words, it related to other people, and I was therefore very grateful indeed to the comments that he made?

Dr George: The cases I referred to earlier on that I have given you in this submission from today give you number of examples of this kind of management.

Q369 Baroness Thomas of Walliswood: Dr George, I think you said—I was taking notes rather rapidly, but I think you made two statements. The first one was that, “An Act based on the Bill would not be defensible in court”. I am not quite sure what you meant by that. The other one was, I think you said, “How many people are we willing to have killed in order for the benefit of the Bill to be given to a few people”?

Dr George: Yes.

Q370 Baroness Thomas of Walliswood: That is, I think, the slippery slope argument?

Dr George: No, it is not the slippery slope argument.

Q371 Baroness Thomas of Walliswood: That is what I want to ask. If you could expand on those two, rather roughly?

Dr George: Yes. Thank you very much for that point. I am not happy with the slippery slope argument because it requires a causal initiator and it requires a gradient, and usually moral turpitude amongst medical colleagues is not something that I would consider. I consider my Dutch colleagues to be every bit as moral and decent practitioners as I am, I would hope, and my experience of them suggests that. Therefore, there must be another reason why the extension of euthanasia is from voluntary assisted suicide euthanasia, and so on, to non-voluntary or even involuntary euthanasia. It seems to me to be because there is a paradigm shift and that, once you redefine death as a moral good or a medical treatment, which is what it is here, then it changes its classification at a stroke. It becomes a moral good and therefore it becomes, under the rubric of our entitlement to health care, an entitlement potentially for anybody. For example, why should we subject

psychiatrically distressed patients, or children, or demented patients, or patients who have just had enough, or patients who are so miserable with the consequence of having lost a child with suicide and want to die because of their depression—what entitles us to restrict those patients, whom we would define as incapable, to have an assisted death, or what I would call, because it is a medical killing, a therapeutic killing? There is no position for that. If you look at Dutch case law, Dutch case law shows that demonstrably. And it is not that there is a slippery slope, it is that there is a paradigm shift from death, if you like, being seen as a harm to death being seen as a good. Once it is defined as a good, then it becomes a good that is reasonably available to everybody else under the grounds of justice; and anybody going to a court of law, even were this statute in place, under case law, I am sure, would make those arguments far more effectively than I have just made them; and we can see that in the development of case law in Holland over the last 15 years. I will give you the references, and there is a diagram that I have drawn which shows it a little bit more graphically and clearly. I do not think this is a slippery slope argument. I think it is a paradigm shift with an adjustment into a new medical paradigm. And, interestingly, the Dutch have hit a bottom-line on that paradigm, in that they rejected the wishes of a gentleman who is, I think, 83 or something, who was just tired of life, and the court said, “No, being tired of life is not a justification to die”. But 16 per cent in the UNWE Tickler(?) paper of 2003, Dutch doctors are now saying they are concerned about the economic pressure that is coming upon them as a result of assisted dying, and that is expected because it is a utility now. It is no longer a harm; it comes into the balance of utilities. And, if you have a resource problem, why waste it on the dying when you can use the resource elsewhere? Any economist could say that to you in the hard-nosed world we live in today.

Q372 Earl of Arran: Two quick questions to Dr Tate. Would you accept that it is very unlikely that palliative care will be rolled out across the NHS at any time?

Dr Tate: No, absolutely not. I think it is a requirement of the new NICE guidance, which was published earlier this year, the guidance on supportive and palliative care for adults, and there are already plans in place in order that the skills of general practitioners, nursing staff and non-experts can be increased and improved so that palliative care will be much more available.

Q373 Earl of Arran: So you are really optimistic that it could happen in the years to come, that it could be throughout the NHS?

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Dr Tate: I would certainly expect so, yes.

Q374 Earl of Arran: Expectation is slightly different?

Dr Tate: I am not responsible for the total roll-out, but my ambition would certainly be to contribute to that happening and to contribute to the education of all my generalist colleagues in order to improve the care.

Q375 Chairman: Can I just get it right. NICE is the Institute of Clinical Excellence?

Dr Tate: I am sorry; absolutely.

Q376 Earl of Arran: The second question is perhaps slightly unfair, because they are not here to talk on behalf of themselves, but my understanding is that Macmillan nurses, very close to you, are neutral on this subject. Is that correct?

Dr Tate: I am afraid I do not know the answer and I would defer to my colleague, who may be able to help.

Ms Robinson: As far as I am aware, Macmillan nurses have not been surveyed, and all the methods that have been adopted to elicit any nurses' views who care for people at the end of life need to be strengthened, because at the moment all we have are straw polls, telephone questionnaires and postal questionnaires.

Q377 Earl of Arran: But, of course, you are very close indeed to Macmillan nurses, not quite the same thing but very nearly. Marie Curie I am talking about naturally?

Dr Tate: Marie Curie Cancer Care I am not here immediately to speak of, but all of those who are involved in the delivery of specialist palliative care would be included, I think, in what Vicky Robinson was talking about, that we would need to do robust surveys of their opinions in order to be able to give you that evidence. We do not believe that such surveys exist at the moment.

Q378 Lord Joffe: If I could start by asking a question of Miss Robinson. You are appearing on behalf of the National Group of Palliative Care Nursing Consultants?

Ms Robinson: Yes.

Q379 Lord Joffe: How many members are there of that?

Ms Robinson: We have just got our fifteenth member

Q380 Lord Joffe: Fifteen?

Ms Robinson: Fifteen in England.

Q381 Lord Joffe: But your submission is signed by eight, I think. There must have been a rapid increase?

Ms Robinson: Right. There are 15. It was a consensus view, the submission. I will correct that.

Q382 Lord Joffe: Does it surprise you that Help the Hospices, which says it is the national voice of the independent hospice movement, recorded in the submission that, of the hospice staff consulted, which is a very intensive consultation, one-third would treat euthanasia as an ethical obligation and two-thirds did not consider that palliative care could provide relief in all circumstances?

Ms Robinson: Thank you for raising that. I think one of the major tasks within my group is to work closely with not only our NHS colleagues but also our hospice colleagues to better understand and assist with alleviating unbearable suffering, which is what is written down in the Bill. I have to say that it is my view that there are some specialist services who still find it difficult to engage matters of suffering and find it difficult to bring up issues of uncertainty with patients. And I see that particularly in hospice nurses, who will enter the speciality because they simply want to make life better for people and, because they have not really been challenged themselves to understand their own beliefs about the nature of the purpose of suffering and the meaning of life, if you like, find themselves in these terrible dilemmas where they have a patient in front of them for whom they have reached the end of their own resource in caring for them.

Q383 Lord Joffe: Are you suggesting that many of the nurses in the hospice movement are not sufficiently trained?

Ms Robinson: I think in areas of the manageability of suffering and dealing with personal autonomy, particularly in the context of the self-government side of autonomy, there is a huge deficit in all nurses, not just hospice nurses.

Q384 Lord Joffe: If I could turn to Mr Gallagher: your society, your association, rather, the British Association of Social Workers, have put in a submission.

Mr Gallagher: I am not here to represent them.

Q385 Lord Joffe: No, I am just asking you as a social worker what you think of your association's submission. In it they say, "On balance we are inclined to support this Bill, subject to rigorous testing of the proposed safeguards to minimise the possibility of unacceptable pressure being placed on any individual to offer assistance to die when they might otherwise not have done so." Are you out of step with your association?

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Mr Gallagher: As I say, I am not familiar with how they arrived at that position, whether they conducted research with their members or not; you might be able to tell me. I have a personal view on this issue and I have a view that is representative of the Association of Social Workers who work in specialist palliative care, and I do not know whether that reflects the views of some people working in the speciality. Certainly within the speciality of social work and the speciality of palliative care there is no agreed opinion on this at the moment.

Q386 Lord Joffe: If I might turn to Dr Tate, you did mention research into terminally ill patients, and I thought you might be helped by the research of DIPEX, which is part of the Department of Primary Health Care at Oxford, who have recently done considerable research into the subject, discussing and spending a lot of time with terminally ill patients. What they found was “a few people opposed to euthanasia for religious reasons or because it seemed they were discussing involuntary euthanasia; others expressed uncertainty. However, most people, especially those who had seen others die, felt strongly that the UK law should be changed to allow voluntary or assisted suicide”, and then they went on, “A few contemplated suicide but would have preferred a change in the law to allow them to end their lives with medical help and in the company of family and friends”.

Dr Tate: I think I did say “robust research”. There is certainly evidence, again from surveys but perhaps not yet as much as there should be, about the views of people who are terminally ill and approaching their terminal phase. We know from many other studies of people who are facing a life-threatening situation that their views may change and their views may evolve through time, depending on many different aspects of their social surroundings but also depending on the medical and clinical care that they have been receiving. They could be driven to assume different positions. We have had that evidence in relation to the kinds of treatments that people might choose to go for when they are actually terminally ill or when they are viewing that prospect in the future, and so the proposal from the National Council is that we need to consider many different aspects of how society views people at the end of life but also what people truly would wish to have in the true knowledge of what the end of life episodes might be. Many people, even as they face death, have not perhaps a very clear idea of how death may meet them because they have not been able to discuss that with their ordinary health carers.

Q387 Lord Joffe: I am sure this research will be very interesting for you.

Dr Tate: Perhaps Dr George might like to contribute as well.

Dr George: There is a lot of research in the literature on work with terminally ill patients over time. There are a number of things that come out of it. One is that the people, who request death, see Kelly’s work, are generally people who feel that they have been poorly investigated, their symptom control is poor and they lack confidence in the abilities of the doctors. Depression and disillusionment and hopelessness are common features. The response, for example, to the desire for death tracks almost exactly the fluctuation in pain day to day as you manage a patient. If somebody today feels one thing today and the same person tomorrow feels something else, the question of consistency and change over time is much more fluid than can be captured by a lot of these cross-sectional or even longitudinal surveys. It requires much more sophisticated research methods to get into what is going on here.

Q388 Lord Joffe: In clause 3(4) of the Association’s submission they deal with the question of what is headed as “terminal” and it reads, “Clinical evidence shows that consultants are often inaccurate in their estimation of the patient’s prognosis. Defining the terminal phase is often much more difficult than people might imagine, particularly in patients with non-malignant disease, such as cardiac or respiratory failure”. The source for this is given as research by Professor Glare and a number of others referred to in the footnote reference. Reading on in the research of Professor Glare and his colleagues, he then goes on to add in the case of cancer patients, “Doctors’ survival predictions become more accurate closer to the date of death and, though inaccurate, predictions of up to six months in length are nevertheless reliable as they are highly correlated with actual survival”. Would you accept that?

Dr Jeffrey: I would not accept that. A simple bit of practical evidence is one of the benefit forms that is filled in for patients assigned to the doctor thinking that the patient has six months to live. I would not like to count how many of those forms I have signed in my life for patients still living after a year, 18 months or even longer. It is something which is incredibly difficult. Even in cancer patients it can be very difficult to tell when a patient is dying. Dr Ellershaw, who has developed a care pathway for dying patients, comments on this and says how important it is for us to learn better ways of making a prognosis, of being more certain, because obviously when we are aware when a patient is dying, it is helpful for the patient, the relatives and the staff. The reality in clinical practice is that we can be wrong. I would agree entirely with what you are saying, Lord Joffe, that this gets easier the closer one gets, but

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predicting six months is not something that I would like to guarantee to any patient.

Q389 Lord Joffe: I am not talking about guarantees because there must be exceptions. I am talking more of the generality. This question is addressed to all the witnesses and I am not sure who will care to answer it. In the Bill itself there is an array of safeguards, but in other end-of-life decisions, such as withdrawal of treatment or withholding of treatment or terminal sedation, there do not appear to be any legislative safeguards. Are you concerned about this? and, if not, why not, bearing in mind your concern about all the legislative safeguards which are included in the Bill?

Dr George: The first thing is that withdrawal or withholding of treatment is allowing the disease process to continue. We are not causing a death by withdrawing treatment. I draw a clear distinction between causing death and withdrawing treatment, because it is the disease that is killing the patient. In terms of managing treatments—and you heard this morning clear guidelines from the GMC and the BMA on withholding or withdrawing treatment—we will apply and deal with those closely. We have clear guidelines from the National Council on food and fluid management around the end of life. We have clear guidelines on the use of opiates; we have clear guidelines on pretty well everything. Within the current NHS the application of clinical guidelines is now part and parcel of our practice. I do not think that something needs necessarily to be legislated for in order for it to be followed appropriately because what will happen if there is a change in the law is that guidance will be issued to doctors for the reasons of the paradigm shift I have mentioned. There will be circumstances where doctors will feel that it is in the best interests of the patient that their life be ended for a variety of circumstances, so I think the existence of legislation does not really make a great deal of difference to what we are doing because this is clinical practice.

Q390 Lord Joffe: So, if as the next step in this Bill it went further, the GMC would look at it very carefully, issue very clear guidelines and doctors would be assisted by those guidelines in applying this law?

Dr George: I think that, if any law pertaining to medical care does that, then the regulatory body's responsibility (which is the GMC's) is to ensure that we operate within the law. The BMA's responsibility, as our professional body, is to offer us guidelines about how to deal with that law. Whether or not that law is a good law or a bad law, or whether or not doctors end up doing other things or case law modifies it as you have said in your own evidence,

Lord Joffe, that you see this as an incremental process I am quite sure there will be guidelines that will follow that as time passes. My point is that, once we change killing from a medical harm to a medical good, we have a paradigm shift and we will be required to follow that unless we object to it in some conscientious way, and that will be extremely difficult to do, extremely difficult.

Q391 Baroness Hayman: On this debate about medical harm and medical good, and going back to your description of all patients being able to die by letting go of life, it seemed to me that you were suggesting that that in some cases could be a good?

Dr George: Yes.

Q392 Baroness Hayman: Would you consider it ethical to advise a patient on ways in which they could let go of life?

Dr George: Oh yes.

Q393 Baroness Hayman:—perhaps by refusing food and drink?

Dr George: I give some case examples in detail in the paper you should have today, which you can look at at your leisure. Part and parcel of the letting-go process really is to discuss the issues that might be impeding a person in their dying. Are there unresolved conflicts? Are there unfinished tasks? Are there some concerns about belief about themselves or, as it were, the process of dying, death itself, or worries about afterwards, those kinds of questions? Then working with that patient to resolve those things and encouraging them within that process to start, as it were, to let go of life, and within that patients quite likely will stop eating large amounts of food. They may have the odd morsel of this, that or the other but, once the letting-go process has started, that by and large resolves itself in two to three weeks.

Q394 Baroness Hayman: By and large? It is important for me to understand because there is a very small group of people here who may be intractable. I think you designated them as people who wished to be in control.

Dr George: I did not say specifically that. I said that was one of their characteristics.

Q395 Baroness Hayman: There will be some you cannot persuade to take—

Dr George: Of course, because they are free to choose what they are free to choose. That is a freedom that they have. It does not confer a duty upon me to do something.

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Q396 Baroness Hayman: No; I am just trying to understand the options that are open to different people who will see themselves in the same situation and whether it is correct that—and I took down exactly the same two quotes as Lord Carlile—there is no suffering that cannot be relieved and all patients are able to die; and whether that is the situation and, if only you were allowed to practise your skills properly with everybody, that would be all right; or whether we are back to the point that has been put by some other people (and that indeed in your evidence has come out) that there may be a small sub-set of people who are left unhappy by not having the option of assisted dying but for the generality of patients that is a price to be paid, if I can put it in that way. I am just trying to disentangle the two arguments.

Dr George: Can I have another go at that?

Q397 Baroness Hayman: Please.

Dr George: When I said “by and large”, I can give you many examples of patients that I have spoken to or cared for. I had one gentleman the other week. We spoke about this and he died the following day. Another patient may take three or four days. Another patient may take a week. Another patient may require more time to talk. Other patients have what we call prolonged death because they are waiting for something. They are waiting for somebody to come from abroad, they are waiting for a family member to arrive, they are waiting for an anniversary, all these kinds of things, and these patients may be semi-conscious. That group of patients may take a long time to die but, by and large, certainly from a biological point of view, if someone is not taking significant amounts of fluid other than to relieve their thirst, then ultimately they will die in something like 28 days as a maximum.

Q398 Baroness Hayman: Can I ask what the empirical evidence is—I of course respect the number of cases that you have seen yourself—that the differential in time people take to die, as you have just described, is related to the fact that they are waiting for something?

Dr George: I would refer you to my paper of 2001, in which we looked at a whole series of situations. If you look at the data on patients who have stopped food and fluids or who have stopped renal dialysis, for example, the lead-in time is a maximum of 28 days. If you look at the studies on the effect of food and fluids withdrawal from patients, then it seems to be that the cut-off of significant influence is round about one month. There is a fairly large body of data showing that.

Q399 Baroness Hayman: No; it was not quite that. It was what you were saying about some people taking longer to die than other people because they are waiting for an anniversary, which seems to suggest that there might be some hope in that reasoning.

Dr George: There is evidence in the literature showing this. Is that the answer you wanted?

Q400 Baroness Hayman: I am sure there is evidence that different people take different times. It is the causal relationship that I am finding difficult to be certain about.

Dr George: The causal relationships by and large that we find, if there are relationships that are known to us, are usually found out through the family. Dying is a family event as much as anything, and often the information that comes out as the process is going on is associated with the processing that takes place in this organic group, with the patient at the centre who is dying. The information that we will have around will come from other family members. That is as far as I can go, I think.

Q401 Baroness Jay of Paddington: My question follows on from what Lady Hayman has been asking you about, Dr George, and also I will ask Ms Robinson about this. I am interested in this concept of self-governance that you both referred to. Let us assume, just literally following on from what Lady Hayman has been saying, that you have patients who have resolved their family issues, have no concerns about the after-life, who are under your very expert palliative care in terms of their capacity to withstand physical pain, are not depressed, etc that is, you are dealing with a clean sheet of paper in so far as you can talk about it in that way. And yet they are, as you describe them, controlling personalities, A-type personalities, whatever are these semi-pejorative words we use about people who, I suspect, are also characterised as saying they put great value—not necessarily absolute or total value—on their personal autonomy. The way you have described your self-governance—and I may be misrepresenting you—is almost as though this is either a character failing or a character plus, that you may be able, if you are a certain character, to recognise that the end is coming, and whether or not you have all these other characteristics, you let go. Is it not possible that, human fallibility being what it is, you could be a controlling personality, all of whose issues, physical and mental, have been dealt with by your expert palliative care, and still not let go? Then what happens?

Dr George: I was not suggesting that there were some people who were good and there were some people who were bad at this.

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Q402 Baroness Jay of Paddington: I think, if you look at the language you used, you might feel that that was what you were saying. I see Lady Hayman nodding.

Dr George: In which case I apologise and withdraw that. If there was any bias in that, I did not intend there to be at all. In terms of people who have resolved their matters and are waiting to die or wishing to die, then they can die when they are ready. If people feel that they want to die, then they are able to do that. Actually, a lot of the conversations we have with patients are about the fact that they do have a lot of control over those last few weeks and days of their life in terms of when they live or when they die.

Q403 Baroness Jay of Paddington: What is the empirical or clinical evidence for that on a large scale?

Dr George: We probably need to get it.

Q404 Baroness Jay of Paddington: You do not have it now? You are asserting it but you do not have it now?

Dr George: No. I could give you a series of cases. I could give you a retrospective.

Q405 Baroness Jay of Paddington: I am sure we could all produce anecdotes.

Dr George: No, not anecdotes. In terms of prospective work, that prospective work has not been done. If one looks at the literature in terms of consensus or in terms of clinical experience, whilst that does not conform to the criteria of evidence that one would see in a randomised control trial, the corpus of that data is sufficiently large for one to say that there must generally be a truth in this statement. One of the difficulties we have in palliative care is that it is very hard to get research funding to do clinical research. 0.18 per cent of the research budget for cancer service goes to palliative care. We are very short on the ability and the funding to do this work, and so in a sense we are left with the things that I have said. That is a failing, I think, in ourselves for not going out and trying to get the funding but I would also suggest that some of the funders should see some value in this kind of research for us to understand these processes better.

Q406 Lord Taverne: Dr George, as I understand it, in some ways the nub of your case as you put it is that, if the Lords change things as the Bill suggests, there will be a paradigm shift to see death as a good; and you cited The Netherlands as an example of that?

Dr George: Yes.

Q407 Lord Taverne: We are going to go to The Netherlands and see what the position is there and try and assess the evidence. Suppose we find that that is not an accurate description of what is happening in the Netherlands. Would you agree that that undermines your case?

Dr George: From my understanding of the data from The Netherlands, consistently one in five of the euthanasias—and the majority of euthanasias are a very small percentage of assisted suicides—is non-voluntary. That means that the doctors are considering, in their proper consideration of patients' best interests, that that is an appropriate course of action. If they are considering it on the basis of the best interests of the patient and they have not consulted the patient, presumably the patient is incapable or in some way is unable to give a view. That means that the doctors must be seeing this as a generally applicable therapeutic measure in patients at the end of their lives.

Q408 Lord Taverne: Suppose that it is then shown, as the figures seem to suggest, that in fact the non-voluntary euthanasia rate in The Netherlands is much lower than it is elsewhere. Is that not also undermining your case?

Dr George: I do not think we have evidence from this country—and we are talking about this country after all—as to what is actually going on. I feel that the surveys that refer to what is happening with doctors, what they are doing or are not doing, have not been looked at in a systematic or even-handed way. That is research that needs to be done.

Dr Jeffrey: Can I make one comment about The Netherlands? I too have been over to The Netherlands and spoken to doctors and interviewed them and taped their interviews. I have met doctors who have carried out euthanasia. You will be carrying out these researches yourself. I can only reflect on the extraordinary distress and effort that it costs these doctors to undergo this process. It was personally enormously taxing to them. There were lots of ambiguities. The other concern that I have, if you are going to talk to people in Holland, is that you will need to try and find a group of specialists in palliative care to talk to. You may have to hunt far, because palliative care services are so less developed in that country as a result of their policy. In this country we have one specialist palliative care bed for every 18,000 people. In Holland it is one bed for 30,000 people. It is a big difference. The speciality is not recognised as a speciality as it is in this country. There are not the same training programmes; there is not the same thrust as there is in this country. In some ways I feel sad as a palliative care physician. We have

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a speciality in this country that we undoubtedly and unquestionably lead the world in. Every palliative care specialist around the world agrees: where do you come to? To the UK. I have had a team from Maastricht wanting to set up palliative care come to our hospital team to work. We are in severe danger of throwing that out and losing it because, make no mistake; this will have a huge impact on palliative care services if this legislation goes through.

Q409 Baroness Finlay of Llandaff: I was going to ask you what you saw as the impact on palliative services if this legislation went through. One of my concerns is that there is a clause in here about patients being assessed by a palliative care specialist, and I would like to ask Ms Robinson in relation to the nurses, given the small number who have undergone high level specialist training in nursing as opposed to those who work in the field and have their salary paid by one of the charities for a time and are therefore called Macmillan nurses, which is a separate group, what you feel will happen to developing specialist competences amongst the nurses, from the doctors and the nurses who are seeing the patients on a day to day basis.

Ms Robinson: If I can refer back to my evidence, we are gravely concerned in particular about the level of confidence and competence that there is in the nursing world. The society that we are practising in now is very different from the society that was around in the 1960s, when the hospice movement was first started by Cicely Saunders. I think it is a real problem for us in that there are only 15 nurse consultants in England who have studied a great deal the speciality of palliative care, and it is our job nationally to raise the issues, amongst our colleagues both inside and outside the speciality, of the difficulties that we are facing now with patients who are being a lot more vocal about what it is they want and what they do not want towards the end of life and how we can reconcile that with the philosophy of palliative care. All I can stress is that in 16 years' experience—and, as I say, we have nearly 200 clinical years of nursing experience—there is no suffering that cannot be alleviated or relieved if they are given good care in a context of specialist palliative care in a multidisciplinary practice.

Dr Jeffrey: If I could answer from a medical perspective on the impact of palliative care, as I alluded to in my brief opening statement, part of the core skill of palliative care is communication skills and listening to people express their deepest anxieties and distress, and exploring issues of how people want their lives ended. We perhaps do not do this well enough yet, and certainly in a general setting we almost definitely do not do this enough. It is very difficult work. The idea that this Bill promulgates,

that someone could come along and have a chat for an afternoon or visit a patient and their family and come away with some sort of realistic assessment of whether this person wants to live or die, or whether we should go ahead with euthanasia, just does not bear any relation to clinical practice. I talked earlier about the difficulty in making a prognosis. One of the other difficulties doctors face is in recognising depression. In the BMJ on 16 October there was a review of suicide in the elderly, and they commented on Breirbart's work, saying that doctors under-diagnose and badly treat depression. I know this may seem an old chestnut but it is another impact on palliative care. This assessment is absolutely crucial and the purpose of the assessment is crucial. It is part of our work. We do not call it an assessment for assisted dying. It is part of advance planning for a person's future. "What sort of death do you want in the future? We are doing this and this now; the time may come". Palliative care is all about anticipation of problems and discussing things. "What would happen if this happened?" "What would you like to have happen here?" "If the time comes, do you want a drip with fluids? Do you want that sort of thing or do you not want to do that?" This is the sort of direction that we would like to be going. The sad thing for me is that, because this is tied in this legislation in this way, palliative care physicians and a lot of my colleagues, nurses too, that I talk to are very worried about carrying out this assessment because they think "Will people think I am in the euthanasia bit?" because they certainly do not want to be in that. It is logically, completely contrary to the philosophy and ethos by which we practise. We cannot be involved in euthanasia and assisted suicide, it is just not part of our ethos and our way of working. That in itself might be enough to take palliative care physicians out of this valuable assessment work because they would be worried about being implicated in it. I think the other area which is of huge concern is in the implementation. There is very little said about this in the Bill. Is this going to take place in hospices? Is this going to take place in people's homes? Is it going to take place in an acute ward? Because let us remember that most patients now are dying in acute medical and surgical units in this country, so this is something that may have to occur in an acute ward in a Trust. I think these are reflections that we need to think about. We have a lot of concerns about the practicalities of the mechanics of this Bill. Are people going to be left with lethal medications in their home? Who is this fantasy "attending physician"? If you try and register with a general practitioner now, you register with a practice, it is a team approach to care. If you call at night you will get a different doctor, you will not get your own doctor coming to see you. Again, the Bill puts

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forward this fantasy that somehow a doctor will come who will know you and your family but this is becoming less and less likely given the pressures of general practice nowadays. It may still pertain in Holland, I do not know, but it does not pertain here. Your own personal experience may reflect that you may see that when you go to make an appointment with your particular GP and it may take three weeks to get in. You will see a doctor but you will not see the doctor that you are used to. I think there are these sorts of practical implications. Again, I alluded to what do we do when the process fails, as it can do, and fails to complete and the family are left struggling with that? The attending physician is not going to be hanging around the house or wherever this lethal medication is given. There are numerous clinical situations that I can allude to that raise problems in this, but I think particularly the assessment and the implementation of this Bill give us deep concerns.

Q410 Lord Carlile of Berriew: I have just one question that arises from what Dr Jeffrey has just said. Clause 3 of the Bill, and we are concerned here with an ethical principle, places a specialist in palliative care in the position of an advocate in effect, it interposes a specialist in palliative care to discuss the option, as it says in the clause, of palliative care. In fact, as I understand it, what that means is that a decision in principle having been taken that the patient wishes to have assisted suicide, a specialist in palliative care is then placed into the equation to argue against assisted suicide and in favour of palliative care. Is that a role which you recognise as part of the current disciplines of palliative care specialists?

Dr Jeffrey: Certainly not.

Q411 Lord Carlile of Berriew: Can you explain why?

Dr Jeffrey: I tried to allude to it before. We are coming to this with a view to trying to make the most of a patient's ability, with whatever life they have left to them, to allow them to make choices they can make to lead the life they can, to be free of pain and to express themselves as they wish. The idea of acting as some sort of gatekeeper role for euthanasia is quite contrary, and it is that very issue which worries palliative care physicians about being involved in any sort of assessment at all, that it might be misinterpreted as a gatekeeping role. We are looking at patients in this advanced planning role in terms of caring and trying to find out, tease out, what they want and it is difficult. Patients, like all of us, are inconsistent and what they say one day will change on another day. It varies even as to what discipline the specialist is who comes. I have done joint work with oncologists and been to see a patient

with advanced cancer who on one day might say to the oncologist, "I definitely want more chemotherapy" and the next afternoon will say to me, "I am really fed up with all of this, is there no way that we could just stop the chemo?" People say different things and it is a very, very difficult area to sort out. Certainly we do not want to be gatekeepers for euthanasia.

Dr George: Could I just comment how difficult it is to manage patients who are late referrals to palliative care. If we have people who are referred early in their disease journey, then we can establish a relationship and all of the advanced planning that we are speaking of, and many of the things that I did not communicate adequately to you, Lady Hayman, start to shake down and we have a much clearer view of how things are going to go for that individual and how they want those things to go; and the advanced planning becomes much easier because it is not in the heat of the moment on a bad day or a good day, or whatever else is going on. Irene Higginson's work shows very, very clearly, over several studies that I was involved in a lot in the early 1990s, the great difficulty of patients coming late to palliative care referrals. They have a heavy burden of symptoms, they have major psychosocial conflicts, and referrals in the last two to four weeks of life are a nightmare to manage because everything is moving simultaneously and often things are out of control for them, so the ability to help them to make sense and get things in order becomes that much more pressurised and difficult for them. Seeing ourselves within a process that has a timescale attached to it is going to put an enormous pressure on us as clinicians as well as the patients not that I would refuse to see a patient who requests or needs palliative care regardless of what was happening to them, I would be entirely happy to see them

Q412 Chairman: I wonder if you can help me. This really follows on from what you have just been saying, Dr George. If one was going to discuss with a patient the question of assisted dying, presumably one would need to give some picture to the patient of what the future would be for him or her if that particular course of action was not followed. Does that take time to evaluate?

Dr George: Yes. If you take a person with any clinical illness, regardless, then the variants and varieties of problems that may arise can be quite broad. In certain patients, as you get to know them and you get to know the way the disease is manifesting, then one has more certainty in talking about the likely situations that will arise, the ways in which they may want them managed, the areas that they would not want managed, and so on and

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so forth. That is very much individualised and it is one of the reasons why it is so difficult to do research in these areas, because individual patients have high levels of variability and, of course, the time at which people want to talk about this stuff varies and their intentions and views as time passes vary as well.

Q413 Chairman: Dr Jeffrey, you referred to some research that has been carried out into the success rate of prognosis. Can you give us a reference to that?

Dr Jeffrey: I can do. I will supply that reference².

Q414 Chairman: Obviously, in the past at least, you will have signed some forms with an estimate of how long a patient was going to live on these forms.

Dr Jeffrey: Yes. The underlying idea of these Attendance Allowance forms is that it allows for the speedy payment of benefit to families so that they do not have to wait in a situation that is terminal. By signing that form you are indicating that you feel the patient has less than six months to live.

Q415 Chairman: How do you go about that? Having a particular patient to consider, how do you go about estimating how long they may live yet?

Dr Jeffrey: I alluded to the difficulty of it.

Q416 Chairman: I am just wondering, could you enlighten us at all on the process by which one goes about it?

Dr Jeffrey: I think the process is that one first of all listens to the patient and you try to get an idea from the patient as to the pace of the illness, the pace of the disease: "How were you last year? How were you six months ago? How were you three months ago? If I had met you a month ago, how would you have been?" Overall there is a drift, and this is only a very rough guide because you cannot be certain with an individual patient, and that is what is so difficult and that is something that we need to acknowledge with each individual patient. You cannot sit opposite a patient and say "I know this is what is going to happen to you"; you can make a professional judgment on it. I think one gets an idea from the pace. Nearer the time of death there are signs that patients are dying when they become increasingly bed-bound, when their vital signs reduce, when they stop wanting to eat and drink and they take to their beds. Those are the sorts of clinical signs nearer the time that someone is approaching death and very close to death, but around six months it is much more difficult.

² *Note by witness:* Glare P, Christakis N, Predicting survival in patients with advanced disease Oxford Textbook of Palliative Medicine, edited by Doyle D Hanks GW, Chernyl, Calman K Oxford University Press 2004 pp 29–40.

Q417 Chairman: Is there some research that shows how long people may live after they stop taking substantial food or drink?

Dr Jeffrey: Yes, and Dr George has alluded to some of that already.

Q418 Chairman: You mentioned this question of a paradigm shift. I am not sure I absolutely understand what is meant by a paradigm shift, but perhaps that does not matter. What I do want to understand is what the basis of your evidence on this is. Hitherto, in the medical profession in our country, acting within the law, death has been seen as something that would not be brought about by the deliberate act of a doctor?

Dr George: Yes.

Q419 Chairman: Putting it very simply, that would mean from the point of view of medical practice that death was regarded as bad and something not to be brought about willingly. If this Bill were to become law here, death would be seen as something that in some circumstances would be a medical good because it is a course of action that would be taken to improve, as it is thought, the position of the patient?

Dr George: Correct.

Q420 Chairman: Is that the paradigm shift, that instead of death being seen simply as bad, it is seen in some circumstances as a good?

Dr George: In terms of the minds of doctors whom we tend to work with in diagnoses, treatment options and all sorts of things like that, the point I am making is that bringing death on, because of the situation in the law at the moment, as you said is considered to be bad. If under some circumstances assisted suicide or euthanasia is now considered to be an entitlement of the patient—bringing it into statute makes it an entitlement—then that becomes a therapeutic option and, therefore, it becomes a potential duty for us to perform.

Q421 Chairman: That conclusion, in a way, is just part of the logic; it is nothing to do with the evidence of any jurisdiction?

Dr George: Not at all, it is *a priori*, I would have said. In terms of saying; is this an explanation for why non-voluntary euthanasia should take place; I do not think they are increasing or reducing. If you look at the Dutch data, it is fairly stable over the last five to 10 years. But, of course, in Holland the decriminalisation of euthanasia sits quite a long way back from that. If you look at the case law, then the case law puts forward, for example in the *Shabot* case, a lady with resistant depression following the suicide of her son who made an application to the

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courts for euthanasia because life was no longer worth living because of her resistant depression, and that was granted. There are other examples of mentally incapacitated patients, psychiatric patients and so on and so forth. If you are saying that within society or within practice there is a treatment that some people can have access to and others cannot, and it is not based on the criterion of appropriateness, it is based on the criterion of fairness or equality, then you are giving people who are capable and able to ask for euthanasia a moral status which is different from people who cannot, because our duty is to act in best interests and if we see what we consider to be suffering in an individual which we feel unable to address and one therapeutic

option is to end that life then surely under best interests one of our duties is to end that life.

Q422 Chairman: Do I understand the point you make is that, if it were appropriate it, should not be restricted to those who are competent to ask for it but it should be available to those for whom it is appropriate even if they are not competent to ask for it?

Dr George: Exactly.

Chairman: I said an hour and a half and I think we have had great help from you. We would like to thank you very much indeed. The Committee has some deliberations to do. We do thank you and are glad to have had your help. Thank you.

 THURSDAY 2 DECEMBER 2004

Present	Arran, E	Mackay of Clashfern, L
	Carlile of Berriew, L	(Chairman)
	Finlay of Llandaff, B	McColl of Dulwich, L
	Hayman, B	Taverne, L
	Jay of Paddington, B	Thomas of Walliswood, B
	Joffe, L	Turnberg, L

Letter from the Department of Health

The question of whether or not to legalise euthanasia was considered in detail by the House of Lords Select Committee on Medical Ethics in 1993. The Committee took evidence from a wide range of people, including experts in the field and both supporters and opponents of euthanasia, and concluded for several reasons that the practice of euthanasia could not be supported. The Government supports the conclusions of the Select Committee and has no plans to change the current law.

However this is a controversial area that raises difficult ethical questions and the Government recognises the complexity of the issues involved and that people hold strong and deeply divided views.

Decisions around the end of life strike at the root values of our society and provoke strongly held and differing opinions. The profound questions raised by the Bill demand a profound debate and Ministers see the Select Committee as the right place for a thorough and balanced consideration of the full range of issues.

The Government would expect any legislation in this area to reflect the responsibilities and competences of the devolved administrations, as set out in the respective devolution acts. We note that the Bill specifically excludes Northern Ireland.

The Bill involves issues of conscience and the Government's stance is therefore to remain neutral and to listen to the debate. It is appropriate that Parliament should lead on debates of this nature and provide the forum where all shades of opinion can be heard.

Ministers see the Select Committee as a sensible way forward in informing policy in this area and will consider its findings carefully in due course.

17 July 2004

Memorandum from Department of Health

HEALTH SELECT COMMITTEE: HOSPICES AND PALLIATIVE CARE

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1. OVERVIEW

The need for palliative care

1. Around 520,000 people die each year in England. Cancer accounts for a quarter (130,000) of these deaths, coronary heart disease for 22 per cent (114,000), respiratory disease for 16 per cent (83,000) and cerebrovascular diseases, including stroke, 11 per cent (57,000). Most deaths occur in people over the age of 75 years.
2. Over the past century there has been a marked change in the relative frequency of different causes of death. A hundred years ago cancer accounted for less than 5 per cent of all deaths. Ninety years ago infectious diseases accounted for nearly a quarter of all deaths, now this figure is less than 1 per cent. In the early 21st century most deaths relate to chronic progressive non-communicable diseases. These have varying trajectories. Although the likelihood of eventual death from these conditions can often be predicted, the time course of the illness is often far from predictable.
3. Place of death has also changed radically over the past 100 years. Around 1900 almost 90% of deaths occurred at home. By 1950 this had fallen to roughly one-half of all deaths. The most recent figures show that less than 20 per cent of all deaths occur at home, with the large majority occurring in hospitals and care homes. Only 4 per cent of all deaths occur in hospices.
4. Patients with advanced incurable illnesses may suffer from a range of physical and psychological problems including pain, fatigue, loss of appetite, breathlessness, nausea and vomiting, constipation or diarrhoea, loss of bladder function, loss of memory or cognitive function, anxiety and depression. They may lose the ability to lead an independent life and to care for themselves. They may become socially isolated and may experience spiritual or existential concerns.
5. Much of the day to day care for patients with advanced incurable illness is provided by their families and informal carers. Although this care is often provided willingly, it can place a great burden on the carers. In addition the carers may experience difficulties in coming to terms with the likely loss of a loved one.
6. To meet these needs patients and carers should have access to a range of services which can provide physical, psychological, social and spiritual support to optimise their quality of life. These services need to be available in the community, in hospitals and care homes and in hospices. Coordination of care between all of these sectors is of paramount importance.

Definitions

7. The World Health Organisation (WHO) defines palliative care as “. . . the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.” (*WHO: National Cancer Control Programmes: policies and guidelines. Geneva: WHO 2002.*)
8. Palliative care is the responsibility of all health and social care professionals who deal with patients with advanced incurable illness. It may be helpful, however, to distinguish between two groups of staff:
 - Professionals who specialise in palliative care (eg consultants in palliative medicine; palliative care nurse specialists and staff working in hospices).
 - Other staff providing care for the patient and family/carers (eg GPs, district nurses, hospital doctors, allied health professionals, staff in care homes, etc). For these staff the provision of palliative care forms a variable part of their normal workload. Many of these professionals are specialists in their own field of expertise, but are “generalist” in relation to the delivery of palliative care.

Development of hospices and specialist palliative care services

9. The role of the voluntary sector in the development and funding of hospices and specialist palliative care services cannot be over-emphasised. The modern hospice movement owes a huge debt of gratitude to the vision and drive of Dame Cicely Saunders, who established St Christopher's Hospice in South London in 1967. At that time Dame Cicely felt that the NHS was not yet ready to provide the holistic patient-centred care which she recognised that patients needed.

10. There are now 172 adult inpatient units (2,637 beds), 27 children's units (201 beds) in England the large majority of which are managed (and predominantly funded) by the voluntary sector.

11. Alongside the development of inpatient units, specialist palliative care services have been established in the community and in acute hospitals over the past 30 years or so. Once again charities have had an extremely important role in these developments. Macmillan Cancer Relief has provided pump priming funds for many of these services and Marie Curie Cancer Care provides nursing services for patients in their own homes.

12. There are currently some 264 specialist palliative care home care teams, 81 hospice at home services, 211 day care services and 220 hospital support teams in England.

13. It should be recognised that the overwhelming majority of the workload of hospices and specialist palliative care services currently relates to patients with advanced cancer and their families/carers.

Service provision around 1999–2000

14. In 1999 the Department of Health commissioned the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) to undertake a survey of services in England. This showed marked variations in the levels of provision between the then eight Health Regions in relation to inpatient beds and specialist workforce availability.

15. Estimates made by the NCHSPCS for the year 2000 indicated that total expenditure on adult specialist palliative care services was around £300 million per annum, of this around £170 million was provided by the voluntary sector and £130 million was provided by the NHS. Around £215 million related to the provision of inpatient services managed by voluntary sector providers (£150 million voluntary and £65 million NHS) and a further £34 million related to NHS managed inpatient units. Expenditure on community specialist palliative care services amounted to £37 million (£20 million voluntary; £17 million NHS) and expenditure on hospital specialist palliative care teams amounted to £14 million (NHS).

CARE PROVIDED BY "GENERALISTS" IN PALLIATIVE CARE

16. It is extremely difficult to quantify the care provided by "generalists" in palliative care. Many patients with advanced incurable illnesses spend the vast majority of their time with the illness living at home or in a care home. Their healthcare during this time is provided largely by GPs (total around 32,000 in England) and by community/district nurses (around 53,000 (40,000 Whole Time Equivalent) in England at September 2002). On average around 17 patients on a GP's list will die in any one year, of which three will die at home and a similar number in older people's accommodation or nursing homes for which a GP is medically responsible. Most GPs consider that palliative care is a small, but important part of their workload. A survey of community nurses in Wales indicated that up to 25% of their time was devoted to palliative care.

17. Within hospitals the care of patients with advanced incurable illness and those who are dying is provided by a wide range of staff, including consultants (eg physicians, surgeons, gerontologists, oncologists, etc), junior medical staff, ward-based nurses and allied health professionals.

18. Many healthcare professionals who care for the dying have received little or no postgraduate training in palliative care and some (especially more senior staff) may not have received any training before registration.

CHALLENGES IN THE DELIVERY OF HIGH QUALITY CARE

19. Key challenges related to the provision of specialist palliative care services include:

- Extending specialist services to meet the complex needs of patients with diseases other than cancer where appropriate;
- The uneven distribution of specialist services across the country;
- The dependence of many hospices on voluntary fundraising for a large proportion of the care they provide;

- Constraints on workforce expansion, especially in relation to consultants in palliative medicine.
20. Key challenges related to the provision of palliative care in general include:
- Enabling more patients to live and die in their preferred place of care. Many patients who would choose to die at home or in a care home are currently dying in acute hospitals;
 - Improving symptom control for all patients with advanced incurable illness;
 - Improving assessment of patients' needs, eliciting their concerns and communicating with them effectively;
 - Improving inter-professional communications with regard to palliative care;
 - Improving coordination of care between teams and across institutional boundaries (including health and social care boundaries);
 - Improving coordination between daytime and out of hours services;
 - Ensuring that adequate out of hours medical, nursing and pharmacy services are available;
 - Ensuring that equipment needed by patients at home can be provided without delay;
 - Reducing unnecessary transfers from patients' normal place of residence to an acute hospital in their final days of life;
 - Improving the care provided for families and carers.

GOVERNMENT POLICY INITIATIVES TO IMPROVE PALLIATIVE CARE

21. National policy in relation to palliative care is set out in the NHS Cancer Plan and in the National Service Frameworks (NSFs) for each of the following areas: older people and coronary heart disease, and will be addressed in the forthcoming children, long term conditions and renal services NSFs.

22. In addition to this the Department of Health has commissioned the National Institute for Clinical Excellence (NICE) to develop guidance on supportive and palliative care services. This is due to be published in March 2004. Although this will focus on services for adults with cancer, it is anticipated that it will have wider relevance.

23. Three of the four key aims of the NHS Cancer Plan (2000) are relevant to palliative care. These are:

- To ensure people with cancer get the right professional support and care as well as the best treatments;
- To tackle inequalities;
- To build for the future through investments in workforce and in research.

24. To support these aims in relation to palliative care, the NHS Cancer Plan committed an additional £50 million for specialist palliative care services by 2004. By 2002 it was clear that spending on specialist palliative care by the NHS would fall short of this commitment. A National Partnership Group on Palliative Care was therefore established, chaired by the National Cancer Director, the first task being to ensure the commitment was met.

25. In 2003 a £50 million central budget for specialist palliative care was established. Primary Care Trusts, NHS Trusts and voluntary sector providers working through Cancer Networks, were asked to develop action plans in relation to their share of this budget. These allocations have now been made and the National Partnership Group is monitoring expenditure against the action plans.

26. A further £6 million was allocated between 2001 and 2004 as part of the NHS Cancer Plan to improve the training of district nurses in relation to palliative care. It was anticipated that this would benefit both cancer and non-cancer patients. Early indications are that this funding has enabled participation by about 10,000 nurses and other health care professionals in continuing professional development programmes and that this has been very well received. A formal evaluation is currently in progress.

27. As part of the Supportive Care Strategy outlined in the NHS Cancer Plan, work is being taken forward to improve provision of information to patients at all stages in their illness. Accredited training programmes in advanced communication skills are also being developed in association with NHSU and leading cancer charities.

28. In anticipation of the recommendations in the NICE guidance on supportive and palliative care, the Cancer Services Collaborative—Improvement Partnership (CSC-IP) is giving priority to the development of service improvement programmes for generalists in palliative care. The CSC-IP is working closely with

Macmillan Cancer Relief and Marie Curie Cancer Care to implement the “Gold Standards Framework” (GSF) and the “Liverpool Care Pathway” (LPC) for the dying.

29. The Gold Standards Framework aims to enhance the quality of palliative care services provided by GP practices. It is already being implemented in some 500 practices across the UK. The Liverpool Care Pathway is a tool to help front-line clinicians who are caring for patients in the last days of life. It has been successfully used in acute hospitals and is also suitable for use in care homes.

30. A new initiative to improve end of life care for all patients irrespective of diagnosis has recently been announced by the Secretary of State for Health. This forms part of the policy to improve choice, responsiveness and equity within the NHS which was set out in “Building on the Best: Choice, Responsiveness and Equity in the NHS” (December 2003). £12 million will be provided for the End of Life care programme between 2004 and 2006. This will build on the work being undertaken by the Cancer Services Collaborative. It will focus on enhancing skills and redesigning services to meet the needs of patients, irrespective of their diagnosis.

2. HEADLINE COMMENTS ON ISSUES RAISED IN THE HEALTH SELECT COMMITTEE TERMS OF REFERENCE

Choice

1. Over the past year the Government has given increased emphasis to the importance of patients being able to make choices in relation to many different aspects of healthcare. During the Autumn of 2003 a major public consultation on “Choice, responsiveness and equity” was led by the National Director for Patients and the Public, Harry Cayton. This led to the publication of “Building on the Best” in December 2003. This report highlighted the importance of choices at the end of life. In particular it emphasised the need to enable patients who are nearing the end of life to make choices about where they would prefer to live and die.

2. Further to “Building on the Best” the Secretary of State announced at the end of December 2003 that £12 million would be invested over the three years 2004–06 on an “End of Life Care” initiative to support this objective (see paragraph 113 and following).

Equity

3. Equity of access to health services on the basis of need is one of the fundamental principles of the NHS. This was re-emphasised in the NHS Plan and in “Building on the Best”.

4. The Government recognises that provision of palliative care services has not been equitable. The greatest inequity relates to the imbalance of services provided for cancer patients and those with other advanced incurable illnesses. In addition to this there are inequalities in specialist palliative care services across the country, as highlighted in the survey undertaken by NCHSPCS for the Department of Health in 1999.

5. The Government is firmly committed to tackling inequalities in palliative care provision. This was one of the key objectives underlying the NHS Cancer Plan commitment to spend an additional £50 million on specialist palliative care. The new End of Life Care initiative is a first step in providing access to high quality care for all patients, irrespective of diagnosis.

Communication between clinicians and patients

6. The importance of good communication between clinicians and patients was emphasised both in the NHS Plan and in the NHS Cancer Plan and will be covered in more detail in the forthcoming NICE guidance on Supportive and Palliative Care.

7. Although universities now routinely include communication skills training as part of the curriculum for healthcare professionals, this was not the case in the past. High quality research has demonstrated the benefits of communication skills training for senior clinicians working in the field of cancer.

8. Building on this the Department of Health, in association with the NHSU, is developing accredited training programmes for senior cancer clinicians. It is envisaged that once these are established they will be made available to clinicians managing other advanced incurable illness.

The balance between a patient's wishes and those of carers, families and friends

9. The ethos of palliative care has always been that care should be provided both for patients and for families and carers. The Government supports this principle. The topic will be covered in detail in the forthcoming NICE guidance.

Meeting the needs of all patients

10. The Government is committed to meeting the needs of different groups and individuals within society and to challenge discrimination on the grounds of age, gender, ethnicity, religion, disability and sexuality. It is recognised that patients from some ethnic minority communities have not in the past accessed specialist palliative care services in the numbers that would be anticipated. We are also aware of very good practice amongst specialist palliative care service providers in some parts of the country in relation to working closely with minority ethnic communities to make services available on the basis of need. We will seek to promote the spread of good practice across the country through the National Partnership Group on Palliative Care and the Coalition for Cancer Information.

Support services

11. The Government recognises that for patients, families and carers to be able to exercise choice over where they live and die they need adequate health and social services going into the home. Without the practical assistance inside and outside the home, such as cleaning, shopping, help with personal care, such as bathing and dressing, adaptations to the home and help with other dependants, it is difficult for patients to remain with their families in their preferred place of care. The Government has introduced freedoms and flexibilities through the Health Act 1999 to allow greater integration between health and social care services and increasingly other council services such as housing. In April 2004, a single assessment process for older people will be implemented which requires assessments to be person centred, exploring pain control, reactions to loss and bereavement, mental health and emotional issues.

Quality

12. National Service Frameworks and NICE guidance documents set the template from which national standards and competencies are derived. The NICE supportive and palliative care guidance, although focused on services for cancer patients, nevertheless will inform service models for other groups of patients with similar needs. We have developed standards from the NICE guidance that will be included in the Manual of Cancer Services Standards and assessed as part of a peer review process. The peer review approach is a driver for quality improvement and has strengthened team working across the country. We are establishing close links with the shadow Commission for Healthcare Audit and Inspection to ensure that quality is consistent across both the NHS and independent sector.

Age Groups

13. As already stated the Government is committed to equity and to ensuring that all those who require care receive the care they need, irrespective of age. The Government is aware of research indicating variation in referral to specialist palliative care services between different cancer types and on the basis of age. It is, however, difficult to assess whether this represents unequal service provision or age discrimination. The Government is committed to improving data collection processes in order that this can be better audited. The Government is also aware that women and people over the age of 85 years are less likely than others to die at home. In many cases this is likely to be due to a lack of a family member or informal carer within the home.

14. With regard to needs of children a National Service Framework is being developed which will include consideration about how palliative care for children can be improved. In addition NICE have been commissioned to develop service guidance on child and adolescent cancer, which will include palliative care and bereavement support. It is due to be completed by February 2005.

Governance

15. Governance issues relate both to the NHS and voluntary sector. In the voluntary sector as the vast majority are independent charities they are regulated by the Charities Commission. In addition, independent hospices come under the Care Standards Act and are assessed and regulated by the National Commission for Care Standards—soon to become the Commission for Healthcare Audit and Inspection.

16. The Government recognises that we need to work closely with these organisations to ensure that governance arrangements are in place in both the voluntary and statutory sector securing high quality, safe and responsive services for all patients.

Workforce

17. The Government recognises that the current numbers of consultants in palliative medicine is inadequate in relation to the demands on the service and is unevenly distributed across the country. However, based on the number of specialist registrars currently in training and the age profile of the existing consultant workforce, the number of consultants is expected to grow substantially over the next few years. It is also recognised that a large proportion of trainees in palliative medicine are women who may choose to work part time as consultants.

18. The Government's workforce census shows 155 consultants in September 2002. Looking at Specialist Registrars (SpRs) in training we would expect around 60 to complete their training by September 2005. Net retirements in that timeframe are likely to be in single figures, so this suggests we could have enough trained specialists to increase numbers by about a third by September 2005.

19. Between 1997 and September 2002 there was a net increase in nurses working in the NHS of 50,000 and last year there was an increase of 17,000 over the previous year. This increase will enable the recruitment of additional district nurses, additional nurses on wards caring for patients with terminal illnesses, additional cancer site specific specialists and palliative care nurse specialists.

Finance

20. The Government recognises that for too long the NHS has relied upon the goodwill and funding of the charities and is fully committed to see that the NHS contribution to the costs hospices incur in providing agreed services, increases. This, and tackling inequalities of access, was a key commitment in the NHS Cancer Plan. In 2000 it was estimated that the average contribution of the NHS to the costs of services managed by the voluntary sector was 28 per cent. Since then, an additional £50 million has been invested in specialist palliative care services (including hospices). This represents an increase of nearly 40 per cent in NHS funding for specialist palliative care over the 2000 figures and an increase of about 15 per cent on all funding for specialist palliative care.

21. To ensure that the funding commitments made in investment plans are delivered, a special monitoring exercise—set up with the approval of Ministers and the Review of Central Returns steering committee, is being conducted.

SUPPORTING MATERIALS

3. THE NEED FOR PALLIATIVE CARE, AND WHERE PEOPLE WITH ADVANCED ILLNESS LIVE AND DIE

- Around 520,000 people die in England each year.
- Many of these deaths are attributable to chronic diseases.
- Many patients experience severe symptoms and psychosocial problems in their last months of life.
- Over 50 per cent of all patients wish to be cared for and to die at home.
- In practice, less than one in five patients die at home and around two thirds die in hospitals.
- Only 25 per cent of cancer patients achieve a home death; more than 50 per cent die in an NHS hospital.
- There are significant variations in the percentages of home deaths across England.

The need for palliative care

1. Several major studies have been undertaken to assess the prevalence of symptoms amongst cancer patients and amongst those with progressive non-malignant disease in the last year of life. These have usually been based on reports of bereaved carers. These have shown that both groups of patients have very high incidences of some symptoms, including pain, trouble with breathing etc. These are detailed in Table 1, Annex 1.

Where patients die

2. In 1900, 90 per cent of deaths occurred at home, with most of the rest occurring in workhouses. In 1950, around 50 per cent of deaths (cancer and non-cancer) occurred at home. Now, less than 20 per cent of all deaths occur at home. This figure has been reasonably stable over the past decade or so.

3. Around 540,000 people die in England and Wales each year. Nearly two-thirds of these deaths occur in people over the age of 75 years. In 2000, 67 per cent of deaths from all causes occurred in a hospital or similar in-patient NHS or non-NHS establishment; 19 per cent occurred at home and 4 per cent in hospices. The remaining 21 per cent die in a variety of other institutions (eg care homes, private nursing homes etc). The proportion of patients who die at home decreases with age, with home deaths accounting for 29 per cent of all deaths in patients aged 45–64 years and only 11 per cent on those over 85 years. Conversely the proportions dying in care homes increases with age.

4. Amongst cancer patients, the figures for place of death are roughly:

- 50 per cent in acute hospitals.
- 25 per cent at home.
- 18 per cent in hospices.
- 7 per cent in other institutions (eg care homes).

5. The figures for all deaths and the age profile are given in Table 2 in Annex 1.

Children

6. The annual mortality rate for children aged 1–17 years with life limiting conditions is estimated to be 1 per 10,000. Accurate prevalence of severely ill children with life limiting conditions is not available. But figures tend to converge on 10 per 10,000 children aged up to 19 years per annum. This indicates that in any year there will be some 11,000 children with a life limiting condition, about half of whom will need active palliative care at any one time. This figure is likely to increase as we see the potential for even more successful interventions with children and more children who would have died in early-mid childhood living into adulthood.

7. There is also a move to enable more technology dependent/ventilated children to leave hospital, thus increasing the need for home support and occasional respite care breaks.

Where would people with advanced incurable illness choose to live and die?

8. We know that most people would prefer to remain at home rather than go into a hospice or hospital. For example, Marie Curie Cancer Care has carried out research projects that have looked at people's preferences regarding place of death. In their studies, more than 50 per cent of respondents—and in some cases more than 75 per cent—said they wanted to die at home. However, the reality is that only 25 per cent of cancer patients achieve a home death, with more than 50 per cent still dying in an NHS hospital (ref Julia-Addington-Hall, Care of the dying and the NHS. Briefing paper for Nuffield Trust, March 2003).

9. The Government acknowledges that many more patients would choose to die at home if they could be adequately supported in the home environment. However, there are significant variations in the percentages of deaths at home across England and—directly related to that—in the ability of patients to choose where they die. A study of patients dying from cancer at home by the National Centre for Health Outcomes Development (NCHOD) (February 2003) at the request of the Department of Health, showed that, at electoral ward level, the percentage varied from around 10 per cent to around 45 per cent. To tease out the cause and effect of why this is the case the Department of Health commissioned NCHOD to undertake further analyses, due to report in Spring 2004. The report will cover cancer and non-cancer deaths at home, the feasibility of including care homes deaths as home deaths, the impact of age factors and a comparison of area home death rates with indices of deprivation and ethnicity.

4. WHAT IS PALLIATIVE CARE?

- Holistic care by multi-professional teams for patients, their families and carers whose illness may no longer be curable;
- Care which enables patients to achieve the best possible quality of life during the final stages of their illness.

Definition of palliative care

10. The World Health Organisation (WHO) defines palliative care as “. . . the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.” (*WHO: National Cancer Control Programmes: policies and guidelines. Geneva: WHO. 2002*). Palliative care is holistic care by multi-professional teams for people, their families and carers whose illness may no longer be curable. It enables them to achieve the best possible quality of life during the final stages of their illness.

Specialist palliative care

11. Many patients need assistance from professionals who specialise in palliative care (consultants in palliative medicine, palliative care nurse specialists and staff working in hospices). These staff are specially trained to advise on symptom control and pain relief and to give emotional, psychosocial and spiritual support to patients, their families, friends and carers, both during the patient’s illness and into bereavement. Specialist palliative care services are most effectively delivered by multi-professional teams, bringing together the expertise of, for example, consultants in palliative medicine, nurse specialists, social workers, allied health professionals and experts in psychological and spiritual care. Specialist palliative care teams deliver care in hospices, in the community and in hospitals. In some cases specialist palliative care teams take a direct responsibility for the care of a patient. In others the team will advise the patient’s usual carers. Specialists in palliative care also have an important role in providing education for other health and care professionals.

General palliative care

12. Much of the care for patients with advanced incurable illnesses is provided by GPs, district nurses, hospital doctors, ward nurses, allied health professionals, staff in care homes, etc. For these staff the provision of palliative care forms a variable part of their normal workload. Many of these professionals are specialists in their own field of expertise, but are “generalists” in relation to the delivery of palliative care.

Supportive Care

13. The diagnosis and treatment of those chronic diseases can have a major impact on the quality of patients’ lives and those of their families and carers. Patients, families and carers need access to support from the time that the illness first manifests itself through to death and into bereavement.

14. The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) has defined supportive care for people with cancer as care that: “helps the patient and their family cope with cancer and treatment of it—from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment”. (*NCHSPCS “Definitions of Supportive and Palliative Care. Briefing paper 11”, London: NCHSPCS; September 2002*). This definition has been adopted in the draft guidance under development by the National Institute for Clinical Excellence (NICE): “*Improving Supportive and Palliative Care for Adults with Cancer*”.

Children

15. There are essential differences between palliative care for children and adults. Palliative care in this area supports children and young people with a variety of complex needs who are expected to die in childhood but who require quality of life and benefit from the activities and stimulation common to other children. Care may extend over a number of years.

16. For children with serious life threatening illnesses, the major burden of care and need for support arises in the community. Care and support for children with life threatening and limiting illnesses is often preferred in the family home. This is provided by paediatric community nursing teams.

17. Hospice care for children can be an important element of the care package. Children's hospices differ significantly from adult hospices. Cancer is not the major cause for hospice care in childhood. Children with life threatening illness increasingly live much longer than in the past. The hospice ethos is therefore geared to provide a child-centred environment meeting the needs of a growing, developing child, and to meet other needs such as allowing family members to either stay with, or visit the child in the hospice, respite care needs and care for siblings.

5. HOSPICE AND SPECIALIST PALLIATIVE CARE SERVICE PROVISION IN ENGLAND

- Three quarters of adult in-patient specialist palliative units in England are managed by the voluntary sector.
- There is inequity of service provision, with affluent areas better provided for than poorer areas.
- 90–95 per cent of referrals are for patients with cancer.
- Services provided include domiciliary support and personal care.

Who provides hospice and specialist palliative care services?

18. In the United Kingdom, palliative care is provided by a mix of NHS services, local independent hospices and national voluntary organisations. Services may be provided at home, in a hospice or palliative care unit, the hospital or at a hospice day centre. Palliative care was first developed in the UK by the voluntary hospice movement for patients with cancer and, importantly, three quarters of adult in-patient specialist palliative care units in England are managed by the voluntary sector. Since 1985 the number of available hospice beds has increased by over two-thirds, the number of day hospices has increased four-fold and the number of home care teams three-fold. However, because of the historic basis for palliative care, there is frequently significant variation from locality to locality in the provision of services and in their funding, often with a concentration of hospices in more affluent areas.

19. Service providers include:

Voluntary/Independent hospices

20. There are 130 voluntary hospices in England, providing 2,147 beds. These are usually local charitable organisations, although a number of hospices are also provided by Marie Curie Cancer Care (through 10 Marie Curie Centres) and Sue Ryder Care (through six Sue Ryder Palliative Care Centres). In addition to in-patient facilities, many local hospices also provide day care; various support therapies, including complementary therapies; social, psychological and spiritual support; and, community support, such as Hospice at Home (that is, a service which provides intensive co-ordinated home support to patients with complex needs).

The NHS

21. This includes in-patient NHS hospices and palliative care units (there are 42 of these in England, providing 490 beds); hospital Specialist Palliative Care Teams (or Support/Symptom Control Teams); and, a variety of community care services, including those provided by district and community nurses and through social services departments.

22. See Tables 3a-c in Annex 1 for further information.

Activity (adults)

23. There were approximately 41,000 new patients admitted to inpatient units during 2001, with a total of about 59,000 admissions and 29,000 deaths. 95 per cent of these patients were suffering from cancer. The average length of stay in a hospice was 13 days. About 150,000 patients are seen annually by home care teams; patients may be under the care of a home care team for an average of three to four months. About 151,000 people in the UK died from cancer during 2001 (*Minimum Data Sets, 2001–02, National Council for Hospice and Specialist Palliative Care Services*).

National voluntary sector service providers

24. There are three major national voluntary sector providers of palliative care services:

Macmillan Cancer Relief is a key service provider at both a national and local level. There are over 2,000 Macmillan nurses working in posts in almost every local health community in the UK, based in hospitals and the community. These nurses are initially funded by Macmillan with the NHS picking up their funding after three years. There are also 300 Macmillan doctors together with a large number of other posts, including GP facilitators, similarly supported. Macmillan also provides information services, professional education, the CancerVOICES project—which provides a forum for users and carers/and funds the building of facilities and information centres, including facilities on NHS properties.

Marie Curie Cancer Care is the largest single provider of hospice facilities outside the NHS, with 10 hospice centres providing in-patient and out-patient services. There are also about 2,000 Marie Curie Nurses who provide hands-on, round-the-clock nursing care for cancer patients in their own homes. Marie Curie nurses care for 50 per cent of all patients who die at home; 30 per cent of the funding for these nurses is provided by the NHS. Marie Curie also provides an education service and runs an important Research Institute.

Sue Ryder Care supports people with a wide range of disabilities and life-shortening diseases, including cancer, as well as their families, carers and friends both in this country and abroad. Sue Ryder Care Centres' range of services include long-term and respite residential care, day care and home care. It has eight neurological care centres and six hospices.

Spiritual support, complementary therapies and domiciliary support

25. For many patients receiving palliative care, spiritual support, complementary therapies, domiciliary support and personal care play key roles. Further information about these services is provided at Annex 3.

6. FUNDING FOR HOSPICES AND SPECIALIST PALLIATIVE CARE

- The NHS Cancer Plan recognised that for too long the NHS has relied upon the goodwill and funding of the charities.
- NHS Cancer Plan pledged to increase funding for specialist palliative care, including hospices, by £50 million pa by 2004.
- A £50 million central budget has been allocated to Cancer Networks by the National Partnership Group for Palliative Care.
- Primary Care Trusts are responsible within the NHS for commissioning and funding services for their resident population.

Funding for specialist palliative care services

26. Estimates by the NCHSPCS in 2000 (*The Palliative Care Survey 1999*) indicated that total expenditure on adult palliative care services was around £300 million per annum. £170 million was provided by the voluntary sector and £130 million by the NHS. The average contribution by the NHS to voluntary sector adult hospices was estimated at 28 per cent, although this varied considerably throughout the country.

ESTIMATED EXPENDITURE ON ADULT SPECIALIST PALLIATIVE CARE SERVICES (2000)

	<i>Expenditure (£ million)</i>		<i>Total</i>
	<i>Voluntary</i>	<i>NHS</i>	
Adult voluntary hospices	150	65	215
NHS bedded specialist palliative care units	—	34	34
Community specialist palliative care teams	20	17	37
Hospital specialist palliative care teams	—	14	14
Total	170	130	300

Source: National Council for Hospice and Specialist Palliative Care Services, 2000.

27. The NHS Cancer Plan, building on the principles of the Calman-Hine report (1995), set out actions that need to be taken to ensure high standards of palliative care across the country. It recognised the need to increase NHS support for specialist palliative care, including for voluntary hospices, and committed an extra £50 million per year for specialist palliative care services. This funding, together with the level of existing funding, would mean NHS funding would match that provided through the voluntary sector. The funding was to help tackle inequalities in access to specialist palliative care and enable the NHS to increase their contribution to the cost hospices incur in providing agreed levels of service. At a local level this investment must be based on the agreed strategic plans for palliative care provision within each Cancer Network's service delivery plan. This is the mechanism by which we will see inequalities in palliative care service provision addressed.

28. A survey by Help the Hospices found that statutory funding for independent hospices had increased in cash terms by 14 per cent over the two years from 2000. Total statutory funding was about £66 million in 2001–02 against £196 million charitable expenditure. Hospices continued to be very successful in fund raising and money raised in this manner increased by 22 per cent over those two years. However, it was clear that only very limited progress was being made across the country towards achieving the £50 million commitment in the NHS Cancer Plan. In a number of cases, funding was not reaching those services for which it was intended.

What action did we take?

Delivery of the £50 million for specialist palliative care for cancer patients, working in partnership with the NHS and voluntary sector

29. In July 2002, Ministers reaffirmed their commitment to ensuring that the full £50 million announced in the NHS Cancer Plan is spent on specialist palliative care. To this end, Hazel Blears—then Parliamentary Under Secretary of State for Public Health—told the All Party Parliamentary Group that “We [Ministers] have asked the National Cancer Director to work with all Strategic Health Authorities, Cancer Networks and with the voluntary sector through the National Council for Hospice and Specialist Palliative Care Services to develop a mechanism to guarantee this. We have asked them to report by the autumn in time for the planning round for 2003–04. We will be looking to maximise the benefits to patients and reduce inequalities in services across the country. And we will take account of the forthcoming draft palliative care guidance from NICE.”

30. To take this work forward, the National Cancer Director set up the joint NHS/voluntary sector/Department of Health National Partnership Group for Palliative Care (NPG). To support the NPG's work, and to speed progress towards the £50 million, Ministers made available an extra £10 million from central budgets for specialist palliative care in 2002–03. This was allocated to Primary Care Trusts on a per capita basis with clear instructions that it had to be spent on specialist palliative care.

31. The NPG was tasked with developing proposals for a new approach to specialist palliative care funding and planning. And, to ensure the NHS Cancer Plan commitment was delivered, Ministers exceptionally set up a central budget of £50 million per annum from 2003–04. The NPG agreed Aims and Principles in which to work and also set criteria for the use of this funding. The primary aim was to deliver the best possible range and quality of specialist palliative care services for patients, to enable them to live and die in the place of their choice. Patients in need of specialist palliative care will be served best by a strong partnership between the NHS and voluntary sector organisations, which values the contributions of all. The approach to achieve this aim was to reflect the following principles:

- Investment in specialist palliative care should be in line with local strategic plans. These should be in line with NICE guidance on Supportive and Palliative Care and agreed jointly by PCTs, working with Cancer Networks and all relevant local partners, including patients and carers;
- Specialist palliative care needs to be available wherever patients need it. Inequalities in access to specialist palliative care services need to be addressed, and it should be recognised that even the best services can improve;
- The planning and funding arrangements for specialist palliative care should be in line with the principles set out in *Shifting the Balance of Power*, recognising that local decision making and accountability for delivery are essential;
- Voluntary sector organisations should play a full role in the planning of specialist palliative care services so that the process is transparent and commands the confidence of both the NHS and its palliative care partners. The principles of the Government's compact with the voluntary sector, and the associated Codes of Good Practice, should guide this partnership at both national and local level and the NHS should recognise the burden placed on the voluntary sector in fulfilling its partnership role;

- Information on progress in implementing agreed plans should be shared with all partners;
- Local planning and funding mechanisms for specialist palliative care should encompass capital and revenue investment strategies. These strategies should balance the freedom of the voluntary sector to provide complementary or innovative services with their responsibility, as an equal partner, to be accountable for efficient and effective use of resources. They should also consider the future revenue implications of capital developments;
- The NHS will make a realistic contribution to the costs of agreed services provided by hospices and other voluntary sector organisations but does not seek to be the sole funder or provider;
- The voluntary sector can expect greater security of funding flows, and in return there will be clearer expectations about the contribution the voluntary sector will make to the delivery of the local specialist palliative care strategy;
- Local specialist palliative care planning and funding strategies should, over time, include specialist palliative care services for adults with conditions other than cancer.

32. Primary Care Trusts were required to work together through Cancer Networks and in partnership with local voluntary organisations to identify and agree local spending and development priorities for specialist palliative care in line with the Planning and Priorities Framework and the Local Delivery Plans (LDPs) requirements and to develop investment plans. The LDP states that PCTs should: “Set local targets to achieve compliance with forthcoming national standards on supportive and palliative care (to be derived from NICE supportive and palliative care guidance)”. Strategic Health Authorities oversaw this process and are accountable through the normal performance management arrangements. The new arrangements enabled local providers to work together to build on existing services and plan for the future. The NPG then assessed and approved the investment plans.

What the £50 million will buy

33. The investment plans from Cancer Networks for the use of the £50 million central budget stated that the additional funding would buy:

- an additional 66 whole time equivalent palliative care consultants;
- an additional 162 whole time equivalent Cancer Nurse Specialists;
- an extra 92 specialist palliative care in-patient beds;
- Additional funding support to the voluntary sector, including hospices, Marie Curie and equivalent local services;
- Increase the availability of out of hours provision, support hospital and community services;
- Contribute to meeting the specialist palliative care recommendations in the draft NICE guidance.

34. The £50 million—which is not exclusively for hospices, but for specialist palliative care in its entirety—represents an increase of nearly 40% in NHS funding for specialist palliative care over the 2000 figures and an increase of about 15% on all funding for specialist palliative care. The £50 million was additional to any existing NHS funding commitments for specialist palliative care and additional to any extra funding provided since 2000 prior to the allocation of the additional £10 million, meaning that the NHS Cancer Plan commitment was more than met.

35. To ensure that the funding commitments made in investment plans are delivered, a special monitoring exercise—set up with the approval of Ministers and the Review of Central Returns steering committee—is being conducted. In the main, funding was allocated to Cancer Networks during June and July 2003. At the six months monitoring point, all of the 32 Networks who had been allocated funding reported (the plans for the two remaining Networks—making 34 Cancer Networks in total—were not approved until late in the year) as per the table at Annex 2.

Other funding support for hospices and palliative care

- In 2002, the Government was able to provide other support for voluntary hospices by: (i) providing central funding for the full basic salary costs of specialist registrars in palliative care training in voluntary hospices; (ii) reminding Chief Executives of NHS Trusts that: hospices should be reimbursed full agreed pharmacy costs; there should be no charge for transport by ambulance of patients between hospice, hospital and home; and, NHS patients in hospices should get free those pathology and imaging services which NHS patients in other settings get;

- £45 million is being invested by the New Opportunities Fund (NOF) in total in initiatives to improve access to adult palliative care (with other funding being allocated specifically for children's services), particularly for disadvantaged groups in inner cities and rural areas. Hospices are/will benefit from this funding. The latest investment from NOF has been extended to conditions other than cancer;
- £6 million to train and support district and community nurses in the principles and practice of palliative care (see paragraph 84);
- £12 million over three years to fund End of Life Care initiatives (see paragraphs 113-117).

Other funding support from the Government for voluntary sector organisations—the Section 64 General Scheme

36. The overall aim of the Section 64 General Scheme (see Annex 4 for information on the Scheme) is to further the Department of Health's objectives in the health and social care fields in England by making discretionary grants that draw on the expertise and initiative of a purposeful and cost-effective voluntary sector. This in line with the principle of partnership between Government and the voluntary sector that the Department is seeking to encourage and develop.

37. Over recent years we have recommended and funded many large—and also smaller—voluntary organisations that meet the key cancer priorities of supporting people affected by cancer and helping to implement the NHS Cancer Plan. Many of these projects promote empowering patients and/or support the work of black and minority ethnic communities in line with the recommendations of the NHS Cancer Plan. Over recent years, we have allocated about £600,000 per annum to voluntary organisations in the cancer field. Prominent organisations that we have supported include The National Council for Hospice and Specialist Palliative Care Services, Help the Hospices, Macmillan Cancer Relief, Marie Curie Cancer Care and CancerBACUP. Funding has also been provided to the Policy Research Institute on Ageing and Ethnicity, Cancer Equality, Cancer Black Care and the Cancer Resource Centre, all of which provide information and support services for people from black and ethnic minority communities.

Workforce: the supply and retention of staff

38. The investment of £50 million pa for specialist palliative care is to help tackle inequalities in access to specialist palliative care and to enable the NHS to make a realistic contribution to the cost hospices incur in providing agreed levels of service. Across the country Cancer Networks are planning to invest in an additional 66 consultants in palliative medicine, 162 clinical nurse specialists and 92 specialist palliative care beds

39. Most Networks are still recruiting, but many—as anticipated—have met particular difficulties with regard to consultant recruitment where adverts have often failed to attract applicants. This is because there are presently insufficient consultants available to fill planned vacancies. Networks are being encouraged to take innovative steps to overcome this particular difficulty, including developing staff grade posts or nurse consultant posts or recruiting Specialist Registrars (ie growing their own consultants) rather than trying to recruit consultants direct.

Funding for children's services

40. The advent of Primary Care Trusts (PCTs) was very significant for palliative care, because, by 2004, PCTs will control 75 per cent of the NHS budget. PCTs are responsible within the NHS for commissioning and funding services for their resident population, including palliative care. They are at the centre of the local planning process, with voluntary healthcare providers such as children's hospices being viewed as important players and partners in the planning, provision and development of these services. The process of discussion leading to NHS funding agreements applies equally to hospices providing support and services to children with life threatening illness and their families as it does for those supporting adults in need of palliative care.

41. In 1994-95 central funding (over £47 million), which had previously been top sliced from general NHS funding and allocated from the centre to assist funding adult hospices, was built into health authorities' general allocations to allow them to commission hospice services providing palliative care—to reflect the identified health needs of their populations and to agree firm service contracts with providers, including the voluntary sector. This was to “include services for the care of children with life threatening illnesses (EL(93)14)”.

42. Statutory funding in support of children's palliative care services is therefore available via PCTs. There are no limits or restrictions placed on the level at which funding may be provided; this is for local decision. The Department of Health has actively encouraged the process of children's hospices engaging with PCTs.

43. PCT funding is being increased with the average PCT budget growing by almost £42 million within the next two years. This growth money has not been identified for specific purposes. PCTs will be able to use these extra resources to deliver on both national and local priorities including respite/palliative care for children with life threatening illness.

44. Local Authorities also sometimes fund hospices to provide short term break/respite care for disabled children or other children with major health care needs or life threatening conditions, who have been assessed as being children in need. Resources for social services will increase by 8.4 per cent in 2004–05. This builds on the 9.1 per cent cash increase in 2003–04. The resources available for Personal Social Services in 2004–05 will be £200 million more than the Government previously announced. Of this, £100 million will be for services for children. Disabled children are also a priority area in the Government's Quality Protects (QP) programme. The Disabled Children's QP ringfenced grant rose from £15m last year to £30m this year. One of the priority areas for the grant is short term breaks.

45. The New Opportunities Fund (NOF) children's palliative care project programme was launched March 2002 to improve the quality of life of children with life threatening or life limiting conditions and their families. In total NOF has awarded £45 million to 134 projects, including 70 awards to home-based palliative care teams, 39 awards to bereavement teams and 25 awards—totalling £15 million—to children's hospices.

Future funding challenges

46. There are several factors that will affect the future funding of specialist palliative care services. First the Treasury Cross Cutting Review has set 2006 as the deadline for Government departments to meet the core costs of work commissioned from the voluntary sector. In addition with the introduction of the Payment by Results programme, the arrangements for funding providers of care is being radically changed. The new system will comprise of a nationally set tariff for most service activity, including services provided by voluntary or independent sector providers. The tariff will be built on groups of treatments and activities called Healthcare Resource Groups (HRGs). It is envisaged that non-NHS providers will be subject to this programme in 2007–08.

47. Consequently a large volume of work is underway developing HRGs for the palliative care sector. The NHS Information Authority is working with the Department to extend and improve the coverage of HRGs and they are currently undertaking piloting work for specialist palliative care.

48. Future funding is one of the key tasks under consideration by the National Partnership Group. The group have attempted to estimate the total cost of providing specialist palliative care services in line with the recommendations in the draft NICE guidance.

49. The School of Health and Related Research (ScHARR) at Sheffield University was commissioned to develop a health economic model related to the provision of specialist palliative care. Although the results must be interpreted with caution and cannot provide accurate costings it does show the crude order of magnitude of the cost different levels of service provide. These are shown at Annex 5.

50. Building on this work we are, through the National Partnership Group for Palliative Care (NPG), validating actual costs incurred by a range of hospices which will inform the development of Healthcare Resource Groups (HRGs). Following completion this work will be considered by the NPG who will report back to Ministers on future funding.

7. THE RELATIONSHIP BETWEEN GOVERNMENT, NHS AND THE VOLUNTARY SECTOR

- Voluntary sector organisations are key stakeholders in the development of Government policy;
- Patients in need of specialist palliative care will be served best by a strong partnership between the NHS and voluntary sector organisations which values the contributions of all;
- Such partnerships have been greatly strengthened in recent years at local and national level.

How do the Government, NHS and voluntary sector work together?

51. A vibrant voluntary and community sector (VCS) is a crucial element of a healthy civil society. The revitalisation of the voluntary and community sector is essential for the renewal of civil society. *The Role of the Voluntary and Community Sector in Service Delivery—A Cross Cutting Review* launched by the Treasury in September 2002 sets out a joint (government and VCS) action plan to support this revitalisation.

52. The 2002 Cross Cutting Review distinguishes the value of good partnership relations between government and the voluntary and community sector. Forty-two recommendations were drawn up through extensive consultation with the voluntary and community sector and an action plan has been produced to implement the recommendations spanning over the next four years. Six of these recommendations related to the *Compact on Relations between Government and the Voluntary and Community Sector in England*, published in 1998.

53. The Department of Health and NHS have a long and established history of working with the voluntary and community sector on the development of health and social care policy and service delivery. The development of a partnership approach has been a feature for some years, prior to the introduction of the Compact. We do need to monitor, review and continue to develop and strengthen these partnership arrangements to help ensure healthcare service provision is in line with the needs of the population.

54. The Department of Health is, at present, working (within the Cross Cutting Review) to three broad objectives:

- Encouraging voluntary and community organisations to play a bigger role in delivering health and social care services and shaping policy.
- Supporting the development of the Compact and its associated Codes to create an environment conducive for voluntary and community activity to work in partnership with statutory organisations.
- Encouraging more people to participate in their communities by volunteering in health and social care activities.

55. For further information, see Annex 6.

How do the Government, NHS and voluntary sector work together in providing palliative care services?

56. Three quarters of specialist palliative care in-patient units are managed by the voluntary sector. Ensuring a co-ordinated, effective partnership between the voluntary and statutory sectors at both local and national level is, therefore, essential to providing a good quality, responsive service for patients. However, in the past the voluntary sector has often been taken for granted by the NHS. Sometimes local and national relationships have been strained and, at times, difficult. This has occasionally been caused by difficult interpersonal relationships, but more often than not it has been because of concerns regarding a lack of joint working, consultation and inadequate levels of statutory funding support. For too long the NHS relied on the voluntary sector to provide funding and to lead on innovative developments to meet local and national needs. All these issues were recognised in the NHS Cancer Plan—which, amongst other things, pledged to increase NHS funding for specialist palliative care, including hospices, by £50 million by 2004 (see paragraph 29 and following)—and in the strategic plan for palliative care within the Plan.

Joint working in palliative care in cancer: at national level

57. At a national level, partnership working has been greatly improved through the Supportive and Palliative Care Strategy Co-ordinating Group and the National Partnership Group for Palliative Care. Both groups are chaired by the National Cancer Director, and both include representatives from the NHS, local and national voluntary sector organisations and the Department of Health.

58. The National Partnership Group's current work programme includes considering:

- the rights and responsibilities of the voluntary sector working with each other and with the NHS and vice versa (this work will take on board the current legal position and guidance such as the Compact and Cross Cutting Review and will also feed into "Making Partnership Work" (see Annex 6));
- reference costs for core services as defined by the NICE Supportive and Palliative Care guidance (this will feed into the work being done in the Department of Health on issues such as national tariffs and Healthcare Resource Groups);
- issues of concern to the voluntary sector, such as continuing care, the potential impact on the voluntary sector of the delayed discharges legislation (see Annex 7) and Agenda for Change; commissioning and contracting between the NHS and voluntary sector; and, the development of good practice in Service Level Agreements between the NHS and voluntary sector.

59. The Department of Health has developed a good collaborative working relationship with voluntary bodies, although there have obviously been times when there have been policy differences and issues that have needed to be addressed. The Department particularly values the National Council for Hospices and Specialist Palliative Care Services (NCHSPCS) representative and strategic role for the whole hospice and palliative care

movement (NHS and voluntary sector), helping to bring consensus to the national table. Help the Hospices, the Independent Hospice Representative Committee, the NCHSPCS, Macmillan Cancer Relief, Marie Curie Cancer Care and representatives from individual voluntary hospices and the Association of Palliative Medicine are all represented on the National Partnership Group for Palliative Care. The NCHSPCS, Macmillan and Marie Curie are also members of the Supportive and Palliative Care Strategy Co-ordinating Group.

Joint working in palliative care in cancer: at local level

60. At a local level, cancer services in England are organised through a series of local Cancer Networks.

61. The Calman/Hine report (“A Policy Framework for Commissioning Cancer Services”, April 1995) broke new ground when it recommended Networks of cancer care, reaching from primary care to cancer units. Cancer Networks were identified as the organisational model for cancer services to implement the NHS Cancer Plan (September 2000). They bring together health service commissioners and providers, the voluntary sector and local authorities. Typically a Network services a population of around one to two million people. There are now 34 Cancer Networks. Networks are not statutory organisations.

62. Strategic Health Authorities and Primary Care Trusts, working through Cancer Networks are required to ensure that structures and processes are in place to plan and review local palliative care services. All relevant stakeholders in the provision and commissioning of palliative care services (health, social care and voluntary) are to be included in this endeavour. As much of palliative care is provided by the voluntary sector, Cancer Networks have established effective partnerships for service planning and provision. These groups bring together those specifically concerned with palliative care service provision ensuring that local voluntary and statutory sector services work in effective partnership and co-ordination. This is a challenging local agenda but one that will enable services to be planned and delivered based on the needs of a Network population.

63. The Government recognised the importance of ensuring that the needs of voluntary sector providers were fully reflected in Cancer Network strategic plans for palliative care services and therefore made available £100,000 central funding—through the National Council for Hospice and Specialist Palliative Care Services—to support voluntary hospice and palliative care providers in working effectively with Cancer Networks in the development of those plans. These local partnerships at Network level have been essential to the work undertaken to develop investment plans for specialist palliative care (see paragraph 29 and following).

Children’s services

64. The Department of Health also has observer status on the ACT Council. ACT (Association for Children with Life Threatening or Terminal Conditions and their Families) brings together the spectrum of palliative care services in a council forum.

8A. GOVERNMENT POLICY INITIATIVES RELATED TO THE NHS CANCER PLAN

- The NHS Cancer Plan sets out Government policy for the provision of supportive and palliative care for adults with cancer;
- Supportive and palliative care guidance being developed by NICE will provide further detailed actions needing to be taken by the NHS.

The NHS Cancer Plan

65. The NHS Plan identified cancer services as a high priority to benefit from the improvements it set out. The Plan promised progress on cancer prevention, on research, on access to services and improved patient experience of care. In September 2000, the NHS Cancer Plan (“The NHS Cancer Plan; A plan for investment, a plan for reform; September 2000, Department of Health”) was published setting out how these improvements would be introduced and how cancer services would benefit from increased investment, both in staff, in services and in equipment to enable faster access to diagnosis and treatment.

66. One of the key aims of the NHS Cancer Plan is to ensure people with cancer get the right professional support and care as well as the best treatment. The Plan announced the development of a supportive care strategy. The development of this strategy has been led by the National Cancer Director, Professor Mike Richards. The key strands of the strategy are:

- assessment of patients' views on the care they have received through the National Cancer Patient Survey (published in 2002);
- improving the provision of information to patients through the establishment of a Coalition for Cancer Information;
- enhancing face to face communication through the provision of accredited training programmes;
- involving users in shaping cancer services; enhancing the skills of community nurses in relation to palliative care;
- the development and publication of guidance on supportive and palliative care by the National Institute of Clinical Excellence (NICE);
- Taking forward the implementation of the NICE guidance through Cancer Networks and the Cancer services Collaborative "Improvement Partnership";
- Ensuring delivery of additional NHS funding for specialist palliative care.

67. As with all NHS health services provision, the delivery of the NHS Cancer Plan involves vital roles for both Strategic Health Authorities—whose remit is to quality assure the delivery of health services—and Primary Care Trusts—who are the main commissioners of health services. With cancer services, Cancer Networks also have an essential role to ensure the delivery of a co-ordinated service.

68. To secure this, the NHS is required to set local targets to achieve compliance with the forthcoming national standards on supportive and palliative care (to be derived from the NICE supportive and palliative care guidance).

69. The NHS Cancer Plan, therefore, sets out Government policy for the provision of supportive and palliative care for adults with cancer. It is against the aims set out in the Plan that we must measure progress in providing that care.

"Improving Supportive and Palliative Care for Adults with Cancer"—the NICE guidance

70. The NICE supportive and palliative care guidance is a major component of the NHS Cancer Plan. Work to develop the guidance is being undertaken by Professors Alison Richardson and Irene Higginson from Kings College London. National organisations representing patients, carers and professionals have all contributed to the development of the guidance and bring their own perspective to it. The guidance will provide evidence-based recommendations on those service models most likely to lead to high quality care and services—including recommendations on service models for palliative care. The guidance is also likely to inform the development of effective service models for other groups of patients with similar needs.

71. The guidance bases its recommendations on the needs and wants of patients, and covers: co-ordination of care, communication, information, psychological support services, specialist palliative care, general palliative care, social support services, rehabilitation, complementary therapy services, spiritual support services, care and bereavement support services and user involvement. The guidance is due to be published in March 2004.

72. The draft guidance includes 20 key recommendations. These are listed at Annex 8 and the full guidance, with executive summary, can be viewed at www.nice.org.uk (supportive and palliative care, manual, second consultation, October 2003).

Involving patients in the planning of cancer services

73. We have been working with Macmillan Cancer Relief to enable cancer patients to play an active role in Cancer Networks. With joint Government/Macmillan funding, partnership groups have been set up in every Cancer Network. The Cancer Services Collaborative is working with Cancer Networks and their patient partnership groups to implement local changes to improve patients' experience of care via its Patient Carer project. This project supports the involvement of service users in every Cancer Network. Representatives of partnership groups play an active role in the Cancer Network development programme.

Communicating with cancer patients

74. Patients give high priority to quality face to face conversations with clinicians. This is recognised in the NHS Plan, the NHS Cancer Plan and in the Department of Health's response to the Kennedy Report. Good communication is central to empowering patients to be more involved in decision-making. It is recognised that clinicians, like anybody else, find it difficult to give people—patients—bad news. We are, therefore, working

to develop advanced communication skills training courses for senior clinicians working with cancer patients. This accredited training will form part of continuing professional development programmes. The training will focus on key and sensitive areas of communication, including conveying complex information, breaking bad news and handling difficult and distressing situations. It will also enhance the confidence and team-working skills of clinical staff.

75. The pilot projects, commissioned jointly between the Department of Health and NHSU with Cancer Research UK and Marie Curie Cancer Care, are now nearly finished. One project is for multi-professionals, one for doctors and one for nurses. Although there are some differences, the projects follow very similar models and all are learner-centred, with role-play and wider work. The pilots will be evaluated. However, we recognise that we need to move this work on quickly and be innovative in how the programme is rolled out. Thousands of health care professionals, including more junior staff, need these skills. The cascade model developed in the pilots will enable leaders in the field to train communication skills facilitators, who will in turn train senior healthcare professionals and so on.

Improved information for cancer patients

76. A key recommendation in the NHS Cancer Plan is that all patients and carers should have access to a range of information materials about cancer and cancer services throughout the course of their illness. This should be high quality, accurate, culturally sensitive, specific to local provision of services, free at point of delivery and timely. The draft NICE Supportive and Palliative Care guidance also makes key recommendations regarding information for cancer patients and carers.

77. A Cancer Information Advisory Group set up under the NHS Cancer Plan recommended that a national Coalition for Cancer Information be established to take forward the work arising from the NHS Cancer Plan and NICE. The Coalition was formed in June 2002 and brings together producers and consumers of cancer information from national voluntary organisations (including Macmillan Cancer Relief, Breast Cancer Care, CancerBACUP and Cancer Research UK), the National Cancer Research Institute, the NHS and Department of Health. It was established to oversee the development of high quality information materials for those affected by cancer. Members of the Coalition are those who produce cancer materials for national dissemination, agree to work to define quality criteria, undergo a formal accreditation process and agree to share information on what they have produced or are intending to produce.

78. Although the provision and delivery of information to patients is recognised as a priority, the process—developing the information, disseminating it and delivering it to the patient—is more complex, as NICE recognises. The Coalition is working to address these issues. The remit of the group has recently been broadened and more members appointed. It is currently developing quality assurance and accreditation guidelines and has established an electronic community. It is working closely with the Department and NHS Direct looking at issues concerning the branding of information and dissemination. It is also working with the Cancer Services Collaborative (Modernisation Agency) on the issue of delivery, that is, ensuring relevant and timely information actually reaches the patient where and when it is required and also supported through appropriate explanations and advice. The Coalition also recognises the need to avoid duplication and to utilise the good resources available through the voluntary sector. It is also considering the effective use of electronic information, video and television and the need to ensure that patients and carers fully understand the information being provided.

Inequity in specialist palliative care in cancer services

79. The Government acknowledges that there are problems associated with the diversity and equity of palliative care provision. Hospice and palliative care first developed in the voluntary sector and services have often grown in a haphazard way. Hospices have, in the main, been established in areas where the general public has been very generous. There is frequently significant variation in the provision of services and in their funding, often with a concentration of hospices in more affluent areas. This has meant that areas of particular social deprivation have not always benefited. As a result, we have considerable inequality of provision throughout the country and an inequity in access to those services. The recognised difficulties with regard to people from black and ethnic minority groups and poorer parts of the community accessing appropriate health care apply equally to specialist palliative care services. And—as many hospices were founded, and are still often managed by Christian-based charitable organisations—there is the added difficulty of people from different faith groups feeling alienated from the hospice movement.

80. A survey conducted by the National Council for Hospice and Specialist Palliative Care Services on behalf of the Department of Health in 2000 showed wide variations between regions, with the percentage of health authorities with an agreed palliative care strategy ranging from 38% in London to 92% in West Midlands. Inpatient provision varied across regions, with similar variations in day care, home care and hospital support services. Addressing these inequalities in access to specialist palliative care services is one of the key aims of Government policy. However, just providing increased investment into specialist palliative care will not necessarily address the inequality of provision. That is why, in developing investment plans for their share of the £50 million (see paragraphs 29 to 35) Cancer Networks were required to plan to address inequalities across the whole network.

Cancer Services Collaborative “Improvement Partnership” programme

81. The Cancer Services Collaborative have established a national “Improvement Partnership” programme focussing on palliative care to ensure that better care for the dying is the touchstone in modernising the NHS. The programme, led by two national clinical experts in palliative care will implement the “Gold Standard Framework” in community palliative care supporting the last months or years of life at home and the “Liverpool integrated care pathway”, supporting the last days and hours of life. Both will enable more patients to die in their place of choice supported by a multidisciplinary primary care team. Discussions are in hand to see how these projects can be implemented nationally and sustainably (see paragraph 113 and following) and to extend the benefits to patients with conditions other than cancer.

Workforce development

82. Skills for Health (SfH) are currently managing the UK-wide consultation stage for National Occupational Standards (NOS) and National Workforce Competence Frameworks (NWCs) developed as a result of previous phases of work. SIR have been asked to develop a competency framework for supportive and palliative care. NOS help to establish the link between the aims and objectives of an organisation and what individuals need to be able to achieve and are of use in the design of education and training and in the design of qualifications. NOS can also be used in the management and development of organisations and individuals, for job design, recruitment, individual and team development, career planning and appraisal. Implementation of the NICE guidance will require upskilling generalists, providing better co-ordination of care, and developing specialists to lead services.

83. The North East London Workforce Development Confederation (NELWDC), as lead WDC for Cancer, are taking forward work looking at a managed career pathway in cancer nursing. The project aims to provide a structure for cancer specialist nurse training to ensure national standards of quality for training, assessment, clinical support, accreditation and awards. This would allow training to be led by workforce planning needs both locally and nationally. It aims to tackle some of the difficulties with recruitment and retention and the inconsistency in competency and educational achievement across posts.

84. The Department of Health has also invested £6 million over three years (2001–04) to provide training and support for over 10,000 district nurses (one in four of all district nurses) in the principles and practice of palliative care. This programme is proving successful in helping district nurses support people with cancer—and also other conditions—at home for as long as possible during their illness and to die at home, if that is their choice and circumstances permit. A formal evaluation of this initiative is underway.

8B. GOVERNMENT POLICY INITIATIVES RELATED TO OTHER NATIONAL SERVICE FRAMEWORKS

Palliative care policy for conditions other than cancer is set out in—or being developed for—the National Service Frameworks.

85. Although palliative care was first developed in response to the needs of patients with cancer, it is now a recognised and integral part of health service provision and the principles of palliative care apply equally across all conditions and in all settings. However, despite the excellent work being done, many patients continue to experience distressing symptoms.

Chronic Disease Management

86. Work is currently underway to improve the management (including self-management) of chronic conditions. This work draws together work on a range of conditions, including some such as heart failure, which existing National Service Frameworks have highlighted. Chronic disease management resonates with approaches used to support many cancer patients. There is, however, some debate as to what extent cancer should be considered a “chronic disease”. When someone is diagnosed with cancer the expectation is that treatment will be successful and that they will enjoy an active life—which is increasingly the case. Therefore, patients are living with an ongoing condition and—as the incidence of cancer increases with age and patients often have other conditions to cope with—cancer could be considered from this perspective.

87. Models under development for the care of patients with chronic conditions have potential application in relation to palliative care services. As patients with life-threatening conditions are helped to live longer there are benefits for patients in case management of complex conditions and careful self-management. Case management approaches, in particular, where new patient centred models are developed can help to actively manage the care for those with the heaviest burden of illness.

88. The key aim of these developing models is to keep those with chronic conditions healthier for longer, in their own homes and to prevent deterioration in condition.

89. Nine Primary Care Trusts are working to implement the “Evercare model” (developed from approaches in the United States) for managing the care of the vulnerable elderly. This model centres on a nurse, with enhanced clinical skills, working with the rest of the primary healthcare team to co-ordinate and manage the care of an identified high-risk caseload. Care plans are developed with patients and their families/carers to ensure proactive management of their conditions to prevent deterioration and to ensure they are cared for quickly in the most appropriate location when they do become ill.

90. Patients and carers have a central involvement in the delivery of care in this way through the development of care plans, coaching in self-management and early recognition of change in condition and discussion of end of life issues.

Coronary Heart Disease National Service Framework (NSF) (published March 2000)

91. The National Service Framework for Coronary Heart Disease aims to raise standards of care for patients within all aspects of heart disease. Work is concentrating now on heart failure, which affects large and growing numbers of people as the population ages and as more people survive heart attacks but are left with damaged heart muscle. Heart failure often has a poor prognosis, with survival rates worse than for breast and prostate cancer. There is also evidence that people with heart failure have a worse quality of life than people with other common medical conditions.

92. The NSF highlights the role of palliative care for these patients. This point is followed up in the Priorities and Planning Framework for 2003–06, which requires the NHS to improve the management of patients with heart failure in line with the NICE clinical guideline published in July 2003. That guideline notes that there is only anecdotal evidence that palliative care improves the care of patients with heart failure specifically, reflecting the fact that there has to date been little such provision. However, it recommends that the palliative needs of patients and carers should be identified, assessed and managed at the earliest opportunity, and that they should have access to professionals with palliative care skills within the heart failure team.

Renal Services NSF (Part 1 published 2004; Part 2 under development)

93. The risk of renal failure increases with age. In 2002 over half of all new patients starting dialysis treatment were over 65 years of age. Many of these people also had multiple co-morbidities and their prognosis for survival on dialysis was poor. The Renal External Reference Group is expected to deliver its advice on end-of-life care to the Department of Health soon. This will support work to develop Part Two of the National Service Framework for Renal Services which is likely to include a standard on end-of-life care for patients with established renal failure who are receiving treatment, and for those who choose to withdraw from, or not to initiate, dialysis treatment.

94. Renal services have in the past been concerned with prolonging life but there is increasing recognition that the skills and expertise of the palliative care team could be more broadly applied in the care of dying patients with kidney failure. This is a relatively new innovation in renal services, but the pattern of care is beginning to change. Preliminary data from the 2002 Renal Survey carried out by the UK Renal Registry show that 10 of the 51 renal units surveyed in England had the support of a palliative care team; 206 patients are reported to have used palliative care facilities.

95. One such team was created at the Nottingham City Hospital in May 2001. It provides a care pathway for dying patients with established renal failure. In particular it supports patients who chose not to commence dialysis treatment or who decide to withdraw from treatment completely. The team provides symptom control and emotional support to the patients and their families in both hospital and home settings. Since its establishment the numbers of patients in the Nottingham area choosing not to have dialysis has increased from 13 in the first year to 33 in 2003–04.

Older People NSF (published 2001)

96. The NSF for Older People stresses the need for personal and professional behaviour to take account of dignity in end-of-life care. Supportive and palliative care should promote both physical and psycho-social well being. All those providing health and social care, who have contact with older people with chronic conditions or who are approaching the end of their lives should provide supportive and palliative care. Specific elements of this type of care were highlighted in the NSF and included information and communication, pain control, supportive rehabilitation, spiritual care, bereavement support.

97. To underpin the work of the Older People NSF, and as part of the Department of Health's centrally funded policy-related research programme, three research projects have been funded and have commenced:

1. *"The palliative care needs of older people with heart failure and their families"*. The end of life care of a sample of people aged 60 and over with heart failure is being examined over a period of a year in various locations in England in order to determine their needs, how they change over the period studied and whether support services meet these needs. The finding will be used to help improve the quality of life of older people with heart failure at the end of life. The research is being conducted by the Sheffield Institute for Studies on ageing, Sheffield University—24 months from August 2003

2. *"Predicting the appropriate time for palliative care for older, non-cancer patients: a systematic review of the literature"*. This study will review the evidence on decision-making about transitions from curative to palliative care, examining the value—for defining palliative status and predicting survival—of tools designed to aid clinicians' decisions. The findings will contribute to improving end of life care processes. The research is being carried out by the School of Nursing, Midwifery and Health Visiting, Manchester University—12 months from September 2003

3. *"Impact on care of older people of the national education and support programme in palliative care for district and community nurses"*. This "before and after" project examines whether care received by older people (dying from conditions other than cancer) before the educational programme was implemented differed in carers' estimation from care received by older people who died after its implementation. The study uses a postal questionnaire to samples of bereaved relatives in England. Findings will help enhance education in palliative care. The research is being carried out by the Department of Palliative Care and Policy, King's College London—18 months from April 2003 (see paragraph 84).

Long Term Conditions (LTC) (due to be published December 2004)

98. The National Service Framework (NSF) for Long Term Conditions (LTC) will focus on improving the standard of services for people with neurological conditions across England, by addressing their acute, rehabilitation and long term support needs. It will also consider some of the generic issues that are important to people living with other long term conditions. The NSF is currently planned for publication in December 2004 for implementation from April 2005.

99. Relatively few people with progressive neurological conditions, with the possible exception of motor neurone disease and CJD, currently access organised palliative care services appropriate to their needs. In 1993, only 4 per cent of hospice admissions and 2 per cent of bed days were attributable to neurological conditions.

100. Many of the symptoms experienced by people in later stages of neurological conditions are similar to those experienced by people with other conditions such as cancer, but a number of symptoms are unique to neurological conditions. A partnership between specialist neurological skills and palliative care skills is therefore required to meet their needs.

101. The timescale of neurological conditions is different from most forms of cancer. The long term nature of many neurological conditions means that people often require a much wider range of support, including all aspects of continuing care (physical, mental, social, spiritual), residential, respite and terminal care at appropriate times over a much longer time period than provided by traditional palliative care teams.

102. The full range of continuing and palliative care issues appropriate to people with neurological conditions will be considered during the development of the Long Term Conditions NSF.

Children's Services (NSF still under development)

103. The Children's National Service Framework will develop new national standards across the NHS and social services for children. Most importantly, the Children's NSF will be about putting children and young people at the centre of their care, building services around their needs and maximising choice in how services are delivered. The particular needs of children with long term conditions and disabilities are being addressed and this includes consideration of how to improve palliative care services. We recognise that high quality palliative care can greatly enhance the quality of life for these children and their families.

104. Palliative care services for children are provided by a range of agencies across the NHS, the voluntary sector, social services and educational services. Palliative care is increasingly provided as an integral part of generic children's community nursing services, which are currently growing in number. In 2000 it is estimated that some 70 per cent of the country had access to a children's community nurse.

105. In order to define a better understanding of the options available in providing palliative care for children with life threatening illnesses (LTI), the Department of Health funded a £5 million programme of pilot projects which ran from March 1992 to March 1997. These projects explored and promoted different ways in which NHS services could care for children with life threatening illnesses, and provide the support necessary for families. Initiatives came from the statutory and voluntary sectors, and included community home nursing services, voluntary respite and sitting services, counselling and psychological support as well as projects with children's hospices.

106. The subsequent evaluation "Evaluation of the Pilot Project Programme for Children with Life Threatening Illnesses", was completed in February 1998. This went on to offer guidance on the further development of services for children.

107. Detailed proposals followed, to build upon the work undertaken during the pilot project programme. The proposals were endorsed at a meeting of voluntary and interested organisations held in September 1998. The key features were that more specialist nursing teams, working within the NHS, should be created to support children with LTI and their families. This would include, as required, nursing care, emotional support and practical interventions. A high quality, seamless service was envisaged which facilitated the children and their families in gaining autonomy, choice and respect. The teams would involve other agencies and service providers, drawing on other professionals and voluntary support when necessary. Additional funding (£1.4 million for England) was provided, enabling eight Diana Children's Community Nursing teams.

108. The £45 million provided through the New Opportunities Fund (NOF) children's palliative care project programme (see paragraph 45), launched March 2002, will enhance provision with 134 projects, including 70 home-based palliative care teams, 39 awards to bereavement teams and 25 awards to children's hospices.

109. The Department is currently assisting the Association of Children's Hospices with a project to provide a Quality Assurance Package—hard copy and CD format. This is designed to enhance the quality of care provided by children's hospices' services and will be made available to all children's palliative care providers.

110. The Department has also funded the voluntary organisation Action for Children with Life Threatening Illnesses (ACT) to further research, develop and publish care pathways for children's palliative care, and to publish and disseminate specialist literature and research findings on paediatric palliative care, also the ACT Guide to the Assessment of Children with Life-threatening and Terminal Conditions.

111. The National Institute for Clinical Excellence has commissioned the National Collaborating Centre for Cancer to develop service guidance on child and adolescent cancer for use in the NHS in England and Wales. The guidance will provide recommendations for service provision that are based on the best available evidence. This will include palliative care and bereavement support. The Institute's service guidance will support the implementation of the NHS Cancer Plan. The service guidance, clinical guidelines and technology appraisals published by the Institute after the Cancer Plan was issued will have the effect of updating the plan. The development of the service guidance recommendations began last summer. Guidance to be completed February 2005.

112. Cancer is responsible for the vast majority of adult demand for hospice services. This is not so with children where recovery is more likely and hospice care in the terminal stages is less in demand. Every year in the UK, approximately 1,500 new cancer cases in children under 15 years are diagnosed. Overall survival rate for children with cancer is approximately 70 per cent.

8c. Government Policy Initiatives Related to End of Life Care

- A new End of Life Care programme was heralded by the Command Paper, "Building on the Best".

The Choice initiative: Building on the Best

113. *Building on the Best: Choice, Responsiveness and Equity in the NHS* drew out the main themes that emerged from the Department of Health's consultation on what changes would do the most to improve the experience of healthcare for patients, users and carers. The consultation took place over the autumn of 2003 and received over 750 replies—the largest response to a consultation since the NHS Plan was published. The Department received responses from patients and the public, NHS staff and organisations, voluntary organisations and professional bodies. Running through all the replies were powerful messages about people's experience of healthcare:

- Health needs are personal so services should be shaped around people's needs instead of being expected to fit into the system.
- People want the right information, at the right time, as well suited to their personal needs as possible to make decisions and choices about their care and treatment.
- Everyone, not just the affluent middle classes, want the opportunity to share in decisions about their health and healthcare.

114. Some of the most powerful consultation responses came from people who were distressed and felt badly let down over the experience of relatives close to the end of life. Too few people are benefiting from the strong tradition and experience of end of life care within cancer and HIV/AIDS services.

Taking forward Building on the Best

115. The Command Paper arising from the recent consultation on Choice, Responsiveness and Equity in the NHS, "Building on the Best", stated that, building on work already in hand to develop specialist palliative care services for cancer, we will be working in partnership with voluntary and statutory bodies to build on current initiatives and extend them over time to all adult patients nearing the end of life. The project will, therefore, benefit all patients, not just those with cancer.

116. On 26 December 2003, the Secretary of State for Health announced an additional £12 million funding for end of life care. The funding to support this initiative will be available from April 2004 (£4 million per year for three years) and will enable so much of the good work being done in palliative care for cancer patients to be extended and built on. Working with key stakeholders, the national clinical directors, led by the National Cancer Director and the National Director for Older People's Services, and the Department of Health will be taking forward preparatory work over the next few weeks.

117. The extra funding will specifically help support implementation of the Macmillan Gold Standards Framework, South Lancashire and Cumbria Cancer Network's Preferred Place of Care and Marie Curie's Liverpool Care Pathway for the Dying tools. These tools can be adapted to meet the needs of a wide range of conditions and we are already working with the charities through the Cancer Services Collaborative to develop a national process to enable both initiatives to be implemented in a managed, staged and sustained way. This additional £12 million will provide a major boost to this work.

- The Gold Standards Framework (GSF)—developed by Dr Keri Thomas of Macmillan Cancer Relief—aims to improve palliative care provided by the whole primary care team, and is designed to develop the practice-based system of organisation of care of dying patients. The main processes are to, first, identify, then assess, then plan care for these patients, with better communication featuring throughout. The framework focuses on optimising continuity of care, teamwork, advanced planning (including out of hours), symptom control and patient, carer and staff support. A planned stepwise approach is utilised, with centrally supported facilitated groups, a toolkit and practice-based external education sessions. Over 500 general practices in the UK have participated to date in this project.
- The Liverpool Care Pathway for the Dying (LCP)—developed by Dr John Ellershaw of the Marie Curie Centre, Liverpool—is designed to develop, co-ordinate, monitor and improve care at the end of life. The framework enables the hospice model of best practice to be transferred into other healthcare settings, including hospitals, the community and care homes. Implementation and support of the pathway is facilitated by specialist palliative care services. The tool provides demonstrable outcomes of care to support clinical governance and should reduce complaints associated with this area of care.
- The Preferred Place of Care (PPC)—developed by the Lancashire and South Cumbria Cancer Network—is a tool which enables doctors, nurses and others to discuss with patients and their carers their preferences around end of life care so that they are able to make informed choices. The tool also invites the patient and carers to comment on their experience of care, thereby including users in the development of service provision.

Annex 1

Table 1

PREVALENCE OF PROBLEMS (PER 1,000,000 POPULATION)

I Higginson. *Palliative and Terminal Care in Health Care Needs Assessment* (1997) Ed A Stevens and J Raftery. Radcliffe Medical Press.

<i>Symptom</i>	<i>% with symptom in last year of life Cancer patients</i>	<i>% with symptom in last year of life Progressive non-malignant disease</i>
Pain	84	67
Trouble with breathing	47	49
Vomiting or nausea	51	27
Sleeplessness	51	36
Mental confusion	33	38
Depression	38	36
Loss of appetite	71	38
Constipation	47	32
Bedsore	28	14
Loss of bladder control	37	33
Loss of bowel control	25	22
Unpleasant smell	19	13

As per Cartwright and Seale study, based on random sample of deaths and using the reports of bereaved carers (Cartwright A. *Changes in life and care in the year before death 1969–1987*. *J Pub Hlth Med* 1991; 13 (2): 81–7 and Seale C. *A comparison of hospice and conventional care*. *Soc Sci Med* 1991; 32(2): 147–152).

The study looked at 2,805 patients who died from cancer and 6,864 patients who died from progressive non-malignant disease.

Table 2**ENGLAND AND WALES: DEATHS BY PLACE OF OCCURRENCE AND AGE, 2000**

<i>Age</i>	<i>NHS Hospitals (includes: hospices within NHS hospitals, general hospitals, psychiatric hospitals, mental nursing homes, geriatric hospitals and units, nursing homes)</i>	<i>Non-NHS Hospitals (includes: mental nursing homes, psychiatric hospitals, private nursing homes, general hospitals, military hospitals etc.)</i>	<i>Hospices (includes: oncology centres, voluntary hospices, palliative care centres, but not hospices within NHS hospitals)</i>	<i>At home (includes: usual place of residence, but not communal establishments)</i>	<i>Others (includes: aged persons accommodation, schools, homes for disabled, halls of residence, hotels, hostels, prisons, detention centres, public places, persons pronounced DOA at hospital)</i>	<i>Total Deaths</i>
All	298,956 (56%)	56,988 (11%)	22,895 (4%)	101,961 (19%)	54,864 (10%)	535,664
45–64	37,024 (54%)	1,796 (3%)	6,077 (9%)	19,660 (29%)	3,433 (5%)	67,990
65–74	60,682 (59%)	4,885 (5%)	6,958 (7%)	25,772 (25%)	4,470 (4%)	102,767
75–84	105,182 (60%)	18,038 (10%)	6,891 (4%)	32,820 (19%)	13,505 (8%)	176,436
85 and over	82,950 (50%)	32,053 (19%)	1,998 (1%)	18,208 (11%)	30,157 (18%)	165,366
					Total deaths aged 45 and over	512,559
					Total deaths aged under 45	23,105

Source: ONS: Mortality Statistics: General—DH1 Series No 33 2000; tables 17–19.

Table 3a**SUMMARY OF HOSPICE AND SPECIALIST PALLIATIVE CARE SERVICES IN THE UNITED KINGDOM JANUARY 2004: ADULT INPATIENT UNITS**

<i>Area</i>	<i>Units</i>			<i>Total</i>	<i>Beds</i>		<i>Total</i>
	<i>NHS</i>	<i>Vol</i>			<i>NHS</i>	<i>Vol</i>	
London	6	11	17		86	323	409
Midlands and East of England	12	29	41		152	432	584
North	12	50	62		98	741	839
South	12	40	52		154	651	805
England Total	42	130	172		490	2,147	2,637
Scotland	10	13	23		103	244	347
Wales	11	6	17		76	66	142
Northern Ireland	1	4	5		4	65	69
UK Total	64	153	217		673	2,522	3,195

Source: Hospice Information, Hospice Directory 2004.

[The voluntary units include 10 Marie Curie Hospices with 244 beds and 6 Sue Ryder Units with 113 beds. The remainder are independent local charities, including two services exclusively for HIV/AIDS with 54 beds].

Table 3b

**SUMMARY OF COMMUNITY AND HOSPITAL SPECIALIST SUPPORT SERVICES IN THE
UNITED KINGDOM JANUARY 2004**

<i>Area</i>	<i>Home Care</i>	<i>Hospice at Home</i>	<i>Day Care</i>	<i>Hospital Support Nurses</i>	<i>Hospital Support Teams</i>
London	29	9	17	5	40
Midlands and East of England	79	28	60	21	53
North	90	21	68	18	70
South	66	23	66	9	57
England Total	264	81	211	53	220
Scotland	52	4	223	12	28
Wales	30	7	20	4	19
Northern Ireland	10	2	4	2	14
UK Total	356	94	258	72	281

Source: Hospice Information, Hospice Directory 2004.

Table 3c

**SUMMARY OF HOSPICE AND SPECIALIST PALLIATIVE CARE SERVICES IN THE UNITED
KINGDOM JANUARY 2004: CHILDREN'S INPATIENT UNITS**

	<i>Units</i>	<i>Beds</i>
London	2	8
Midlands and East of England	10	83
North	10	69
South	5	41
England Total	27	201
Scotland	1	8
Wales	1	10
Northern Ireland	1	10
UK Total	30	229

Source: Hospice Information, Hospice Directory 2004.

Annex 2

**£50 MILLION CENTRAL BUDGET FOR SPECIALIST PALLIATIVE CARE:
ANALYSIS OF CANCER NETWORK REPORTS ON USE OF ALLOCATION AT SIX MONTHS
(NOVEMBER 2003)**

1. Allocation of funds to the voluntary sector (VS)

Networks committed to allocating to VS as per investment plans	32 out of 32 (100%)
Networks reporting delays in making allocations to VS	22 (69%)
Networks reporting minor delays	12 (38%)
Networks reporting more serious delays	10 (31%)
Networks expecting to have made all allocations to VS by end December 2003	8 (25%)

Reasons for delay in allocating funds include: funds still to be released by PCT/SHA (14 Networks); local discussions/planning still ongoing (7); funding given in instalments (2); no specific reasons given (4)

Footnote: Two of the 34 Networks did not receive their allocations until late in the year and were therefore excluded from this initial monitoring exercise.

2. Progress in recruiting additional specialist palliative care consultants and cancer nurse specialists and opening additional specialist palliative care beds at six months compared with proposals in original Cancer Network investment plans (England total)

<i>Specialist palliative care consultants</i>	
WTE staff prior to original plan	184.97 (191.87)*
Additional WTE proposed in original plans	70.43
Changes to original plans at 6 months	66.28 + 2 SpRs and 1 extra session
Additional WTE appointed by 6 months	20.52 (31%) + 2 SpRs and 1 extra session
<i>Cancer nurse specialists</i>	
Additional WTE proposed in original plans	162.15
Changes to original plans at 6 months	N/A
Additional WTE appointed by 6 months	70.15 (43%)
<i>Specialist palliative care beds</i>	
Additional beds proposed in original plans	86
Changes to original plans at 6 months	+ 6 (total 92)
Additional beds opened to date	18 (20%)

*191.87 = headcount

3. Reasons given for problems/delays in recruiting additional staff

Unable to attract applicants	9
Re-organisation of services caused recruitment delays	1
Job description still being work on	4
More planning or discussions required	6
Still advertising	16

4. Slippage

Networks reporting increase in slippage	23 (72%)
Networks specifically reporting that slippage is protected for specialist palliative care	19 (59%)
Networks reporting additional allocations to voluntary sector from slippage	12 (38%)
Networks reporting funding Gold Standards Framework from slippage	9 (28%)
Networks reporting funding Liverpool Care Pathway from slippage	10 (31%)

Other uses for slippage reported: equipment/IT; literature/audio-visual; education/training/information; patient/carer support involvement; syringe drivers; bereavement support; OT/other staff appointments; psychology sessions; moved to capital, including for voluntary sector; NICE initiatives; capacity planning/needs assessment etc; breathlessness clinics; website development; Hospice at Home development.

Annex 3

COMPLEMENTARY MEDICINE

1. For some years any scope for complementary and alternative medicine (CAM) to help cancer patients was overshadowed by claims that certain therapies could successfully treat cancer. Such claims are less common now, although a few lesser-known CAM treatments have been associated with remission by several well-publicised cancer patients. However, evidence of the efficacy of these therapies to successfully treat cancer is still very limited. Last-ditch efforts by terminally ill patients to try any supposed alternative cure for cancer, while understandable, leave them vulnerable to exploitation by charlatans.

2. With the development of palliative care, however, there has come a growing recognition that CAM therapies can play a useful role in alleviating distress and helping cancer patients cope with their condition.

3. In 1999, The Guild of Health Writers ran a competition to award good practice in integrated healthcare. One of the finalists was a team operating in Hammersmith and Charing Cross Hospitals to provide massage, aromatherapy, reflexology, relaxation and art therapy as part of a multidisciplinary approach to palliative care for cancer patients. The team has since given training and advice to nurses who aspired to provide a similar service elsewhere.

4. The voluntary and commercial sectors have developed a similar range of services. One example is Macmillan Cancer Relief, which offers advice on using CAM therapies, and can identify local self-help groups, many of which offer access to certain therapies. Some Macmillan nurses are also trained to administer certain therapies. Another example is the Bristol Cancer Help Centre, which offers private counselling and the use of certain therapies to support cancer patients. And the Haven Trust in London is an example of a small charitable organisation that offers a variety of therapies to support recovering breast cancer patients.

5. In 2001, two doctors who had suffered breast cancer established an organisation called DIPEX whose website (www.dipex.org) allows patients to share their experiences of major illnesses, including cancer. The website is supported by the National Electronic Library for Health and Macmillan Cancer Relief. A section on complementary therapies includes patients' experiences of using aromatherapy, reflexology, yoga, hypnotherapy, relaxation, meditation, and dietary approaches to help cope with breast cancer. All the accounts are supportive.

6. The National Institute for Clinical Excellence is preparing guidelines on supportive and palliative care. Amongst other things, the guidelines are expected to acknowledge the use of CAM therapies in supportive and palliative care. To complement the NICE guidelines, in June 2003 the Prince of Wales's Foundation for Integrated Health and the National Council for Hospice and Specialist Palliative Care Services jointly published guidelines for the use of CAM therapies in supportive and palliative care. The guidelines define the standards that all responsible CAM practitioners should meet, including ethical and professional issues relevant to cancer patients, and offers advice on selecting suitable therapies. The Department of Health endorses the guidelines.

SPIRITUAL SUPPORT SERVICES

7. In November 2003 the Department of Health issued "Meeting the Religious and Spiritual Needs of Patients and Staff" to the NHS.

- The modern NHS should be capable of responding sensitively to the diverse nature of communities it serves. Multi-faith support to patients and staff, via chaplaincy-spiritual care givers is recognised as a significant contribution to the patient experience in today's multi-cultural society.
- The new Department of Health guidance is aimed primarily at the NHS, however the potential for "crossover" of applicability to organisations providing hospice and palliative care is acknowledged and key stakeholders from the hospice community have contributed to the Department of Health guidance.
- The Association of Hospice and Palliative Care Chaplains has separately produced a "package" of documents, aimed specifically at developing and delivering a range of standards for hospice and palliative care chaplaincy.
- The Association's own standards (published spring 2003) recognise chaplaincy-spiritual care services within hospices as a specialist function and the standards aim enhance quality of local delivery.
- the South Yorkshire Workforce Development Confederation (WDC) leads on human resourcing and workforce issues on behalf of the NHS. The WDC has its own links with hospice and specialist palliative care services.

SUPPORT SERVICES, INCLUDING DOMICILIARY SUPPORT AND PERSONAL CARE

8. Patients who receive palliative care should meet local criteria for fully funded NHS continuing care, in which case their personal care will be the responsibility of the NHS. Guidance on fully funded NHS continuing care, published in June 2001, makes it clear that "Patients who require palliative care and whose prognosis is that they are likely to die in the near future should be able to choose to remain in NHS funded accommodation (including a nursing home) or return home with appropriate support. Patients may also require episodes of palliative care to deal with complex situations (including respite care)." It is the level of need for care, not the condition or prognosis, which is the criteria for NHS responsibility for care. Where the need for care does not meet criteria for full NHS responsibility; or additional support services, beyond care of the individual, are needed in the home, these may be provided by local authority social services.

9. The range of services, which may be commissioned by local authority social services, includes:

- Practical help inside and outside the home, such as cleaning and shopping.
- Help with personal care, such as bathing and dressing.

- Help to care for children and other dependants.
- Assistance with the practical and emotional support of relatives or other informal carers caring for the person with palliative care needs.
- Ensuring a safe living environment, through adaptations, if necessary. Local housing services may also play a part in this.

10. In addition, councils may offer a variety of social work support and advice, occupational therapy, and other social care services. Respite and day care, assisted transport, volunteer visitors, and bereavement care may be provided by local authority, NHS, or voluntary organisations. Practical aids such as wheelchairs and other equipment should be provided through a single integrated community equipment service by April 2004.

11. Support, information, and advice to secure financial support, such as benefits, may be provided through local authorities, voluntary groups, or other agencies, including the Department for Work and Pensions and the Pension Service.

12. The Government has created freedoms and flexibilities through the Health Act 1999 to allow greater integration between health and social care services—and, increasingly, other council services such as housing. The same Act established a duty of partnership for NHS bodies and local councils. Councils are expected to meet targets for the assessment and receipt of social care services and the Community Care (Delayed Discharges) Act 2003 requires social services to provide services within a specified time limit (see Annex 7).

13. Assessment of need should be integrated and cover the individual's needs as a whole. Department of Health guidance for the single assessment process for older people, which is to be implemented by April 2004, asks that assessments are person-centred and focus on the needs and issues of most importance to older people. In carrying out assessments where individuals require intensive support, professionals are advised to explore health conditions including life-threatening illnesses, pain, reactions to loss and bereavement, and mental health and emotional matters. Cultural and spiritual concerns and beliefs should also be taken into account as and when appropriate. Through such assessments, individuals with terminal illnesses and/or approaching the end of their lives, can be assured that important needs will be identified and addressed, and that their wishes will be respected as far as possible.

14. Department of Health guidance on eligibility for adult social care, issued to councils in May 2002 and implemented from April 2003, requires that adults with actual or potential life-threatening health conditions are given the highest priority by councils if their needs call for social care services in addition to any health support. This guidance requires that the same discipline of assessment outlined in the single assessment process is applied to adults of all ages.

15. The provision of personal care as part of local authority commissioned domiciliary care is of growing importance. The introduction from April 2003 of a regulatory framework for personal care provided as part of domiciliary care is vital, in particular:

- The requirement for care workers providing personal care to receive training and appraisal appropriate to their work (regulation 15(2) of the Domiciliary Care Agencies Regulations 2002)
- The expectation in National Minimum Standards for Domiciliary Care that newly appointed care workers providing personal care will be required to demonstrate their competence by registering for and completing within three years the relevant NVQ care award.

Annex 4

HOW THE VOLUNTARY SECTOR IS FUNDED

A summary of the legislative powers which enable the Secretary of State either to provide or to make arrangements for the provision of palliative care services in voluntary hospices.

NHS bodies are able to make arrangements with voluntary bodies, including hospices, for the provision of services by the voluntary bodies on particular terms and conditions. These provisions enable an NHS body to enter into arrangements with a hospice on such terms as may be agreed for the hospice to provide services which would otherwise be available on the NHS, or which it is desired should be provided to NHS patients by the hospice.

1. SECTION 23 OF THE NHS ACT 1977

This section provides that the Secretary of State (the functions in this section have been delegated to Strategic Health Authorities (SHAs) and PCTs under the NHS (Functions of Strategic Health Authorities and Primary Care Trusts Administration Arrangements) (England) Regulations 2002 (the Functions Regulations)) may arrange with any person or body (including a voluntary organisation) for that person or body—to provide, or assist in providing, any service under the 1977 Act. The arrangements/contracts are for the provision of services within the NHS and are usually referred to as SLAs.

“Section 23 (1) to (3) (as delegated to Strategic Health Authorities and PCTs)

- (1) *The Secretary of State may, where he considers it appropriate arrange with any person or body (including a voluntary organisation) for that person or body to provide, or assist in providing, any service under this Act.*
- (2) *The Secretary of State may make available:*
 - (a) *to any person or body (including a voluntary organisation) carrying out any arrangements under subsection (1) above, or*
 - (b) *to any voluntary organisation eligible for assistance under section 64 or section 65 of the Health Services and Public Health Act 1968 (assistance made available by the Secretary of State or local authorities),*
any facilities (including goods or materials, or the use of any premises and the use of any vehicle, plant or apparatus) provided by him for any service under this Act, and where anything is so made available, the services of persons employed by the Secretary of State or by a Strategic Health Authority, Special Health Authority or Primary Care Trust or Local Health Board, in connection with it.
- (3) *The powers conferred by this section may be exercised on such terms as may be agreed, including terms as to the making of payments by or to the Secretary of State, and any goods or materials may be made available either temporarily or permanently.”*

2. THE NHS AND COMMUNITY CARE ACT 1990—PARAGRAPH 13 OF SCHEDULE 2

This permits NHS Trusts to enter into arrangements for the carrying out, on such terms as seem to the trust to be appropriate, of any of its functions jointly with a PCT, SHA, another NHS trust or any other body or individual.

“Paragraph 13

An NHS Trust may enter into arrangements for the carrying out, on such terms as seem to the Trust to be appropriate, of any of its functions jointly with any Primary Care Trust, with any Strategic Health Authority or Special Health Authority, with another NHS Trust or with any other body or individual.”

3. SECTION 64 OF THE HEALTH SERVICE AND PUBLIC HEALTH ACT 1968

This section permits the Secretary of State to make grants to voluntary organisations providing any service similar to a service under the NHS Act 1977 on such terms and conditions as are determined (this power has been delegated to PCTs and to StHAs for performance management purposes by the Functions Regulations).

“Section 64 (as delegated to SHAs and PCTs)

- (1) *the Minister of Health] may, upon such terms and subject to such conditions as he may, with the approval of the Treasury, determine give to a voluntary organisation to which this section applies assistance by way of grant or by way of loan, or partly in the one way and partly in the other.*
- (2) *This section applies to a voluntary organisation whose activities consist in, or include, the provision of a service similar to a relevant service, the promotion of the provision of a relevant service or a similar one, the publicising of a relevant service or a similar one or the giving of advice with respect to the manner in which a relevant service or a similar one can best be provided.*
- (3) *In this section:*
 - (a) *“the relevant enactments” means:*
 - (i)–(xxi) *and included at (xviii) is The National Health Service Act 1977*
 - (b) *“relevant service means a service which must or may, by virtue of the relevant enactments, be provided or the provision of which must or may, by virtue of those enactments, be secured by the [Minister of Health] or the council of a non-metropolitan county, county borough, metropolitan*

district or London borough or the Common Council of the City of London or a service for the provision of which a Primary Care Trust or Local Health Boards, are, by virtue of Part II of the NHS Act 1977 under a duty to make arrangements; and

- (c) “Voluntary organisation” means a body the activities of which are carried on otherwise than for profit but does not include any public or local authority.”

Annex 5

SCHARR: PALLIATIVE CARE COSTS

PALLIATIVE CARE COSTS

(FOR A HYPOTHETICAL NETWORK OF 1.5 MILLION)

Table shows the costs to the hypothetical network of providing three different levels of each of the eight specialist palliative care service components. Costs are shown based on both the model estimates and using figures derived from the eight hospice study.

Service/Level		Model	Hospice Study
1	Inpatient SPC beds		
	30 beds/m	4.259m	3.400m
B	50 beds/m (national average)	7.080m	5.660m
C	70 beds/m	9.915m	7.930m
2	Community SPC Teams		
A	9 am–5 pm x 5 days/week	1.685m	1.600m
B	9 am–5 pm x 7 days + 24 hr telephone support ²		
C	24 hour visiting service x 7 days	2.485m	2.360m
3	Hospital SPC Support Teams	1.415m	N/A
A	9 am–5 pm x 5 days/week	1.630m	N/A
B	9 am–5 pm x 7 days/week + 24 hr telephone support ²	2.460m	N/A
C	27 hour visiting x 7 days		
4	Palliative Day Care		
A	8,000 places/m p.a	0.985m	0.760m
B	13,000 places/m p.a (national average)	1.575m	1.210m
C	18,000 places/m p.a	2.180m	1.680m
5	Outpatient SPC Services		
A	None		
B	Dedicated SPC clinics only	0.085m	N/A
C	SPC clinics + support to cancer MDTs	0.485m	N/A
6	Marie Curie (or equivalent) Nursing Services		
A	6.7 wte nurses/m	0.180m	N/A
B	10.7 wte nurses/m (national average)	0.285m	N/A
C	16 WTE nurses/m	0.430m	N/A
7	Bereavement Support		
A	5 per cent uptake by potential clients	0.220m	.200m
B	15 per cent uptake by potential clients ²	0.460m	.425m
C	25 per cent uptake by potential clients	0.700m	.645m
8	Education		
A	Basic infrastructure only	0.100m	N/A
B	Infrastructure + one programme	0.160m	N/A
C	Infrastructure + two ‘programmes	0.240m	N/A

Notes

1 For several services Level B has been set at current national averages (inpatient beds; palliative day care places; Marie Curie Nursing Service provision). Level A and Level C have then been set arbitrarily. Level A for inpatient beds (30/m) corresponds approximately with the level observed in the last well served Region; at Level C the best served region in a survey in 2000.

2. For community SPC teams and hospital SPC support teams Level B corresponds to recommendations in the draft Supportive and Palliative Care Guidance from NICE.

3. For bereavement support Level B corresponds with that provided by one existing service. Levels A and C are arbitrarily lower and higher.
4. For education the funding available to a network of 1.5 million (approx £60k p.a) has been factored in as “a programme”.

Annex 6

RELATIONSHIP WITH THE VOLUNTARY SECTOR

Key features of the relationship between the Department of Health and the voluntary sector include:

- “Making Partnership Work for Patients, Carers and Service Users—A proposed strategic partnership agreement between the Department of Health, the NHS and the Voluntary and Community Sector”. The aim of this document is to optimise the contribution of the voluntary and community sector (VCS) to genuinely patient-centred service delivery in a reformed NHS, where patient choice is the driving force for change, and to adopt and apply the principles of the Compact on Relations between Government and the Voluntary and Community Sector in England in all working arrangements between the NHS and VCS.
- Section 64 of the Health Services and Public Health Act 1968. The Report of a Review Group Established to Examine the Use of the Power to Make Grants Under Section 64 of the Health Services and Public Health Act 1968 was published on 10 September 2003. The Department of Health is developing a stronger strategic relationship with the VCS and the review was carried out with the help of the VCS as a whole.
- The *Compact on Relations between Government and the Voluntary and Community Sector in England*, launched in 1998, provides a framework to help guide the relationship between Government and the voluntary and community sector. It recognises that Government and the sector fulfil complementary roles in the development and delivery of public policy and services and that the Government has a role in promoting voluntary and community activity. The Compact is underpinned by five Codes of Good Practice which centre on Black and Ethnic Minority groups, Volunteering, Consultation and Policy Appraisal, Community Groups and Funding.

Annex 7

DELAYED DISCHARGE LEGISLATION

THE COMMUNITY CARE (DELAYED DISCHARGES ETC) ACT 2003

1. Patients receiving palliative care may have a strong preference to return home or to be cared for in a more homely setting than a hospital or hospice. This choice should be the guiding principle in discharge planning and community services should be put in place quickly if the person wishes to return home. Patients who receive palliative care should meet local criteria for fully funded NHS continuing care and their care package will be the responsibility of the NHS. Guidance on fully funded NHS continuing care, published in June 2001, makes it clear that “Patients who require palliative care and whose prognosis is that they are likely to die in the near future should be able to choose to remain in NHS funded accommodation (including a nursing home) or return home with appropriate support. Patients may also require episodes of palliative care to deal with complex situations (including respite care) and the number of episodes required will be unpredictable. The application of time limits to this type of care is not appropriate.” This makes it clear that it must be the level of need for care, which is the criteria for NHS responsibility, not an arbitrary time limit.
2. Patients receiving palliative care, for example in hospices or palliative care units, are currently excluded from the definition of acute care within the Community Care (Delayed Discharges etc) Act 2003, because in many cases they continue to be the NHS’s responsibility whichever setting they move to. This does not mean that their discharge should not be planned according to good practice as outlined in Discharge from hospital: pathway, process and practice, published in January 2003. Further information on good practice will be included in the NICE supportive and palliative care guidance.

NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE (NICE)

DRAFT GUIDANCE: "IMPROVING SUPPORTIVE AND PALLIATIVE CARE FOR ADULTS WITH CANCER"

THE KEY RECOMMENDATIONS

Key Recommendation 1: Within each Cancer Network, commissioners and providers (both statutory and voluntary) of cancer and palliative care services, working with service users, should oversee the development of services in line with the recommendations of this Guidance. Key personnel will need to be identified to take this forward.

Key Recommendation 2: Assessment and discussion of patients' needs for physical, psychological, social and spiritual support should be undertaken at key points in the patient pathway (such as at diagnosis; at the end of treatment; at relapse; and when death is approaching). Cancer networks should ensure that a unified approach to the assessment and recording of patients' needs is adopted.

Key Recommendation 3: Each multi-professional team or service should implement processes to ensure effective inter-professional communication within teams and with other service providers with whom the patient has contact. Mechanisms should be developed to promote continuity of care, including the nomination of individuals to take on the role of "key worker" for individual patients.

Key Recommendation 4: Mechanisms should be in place to ensure the views of patients and carers are taken into account in the development and evaluation of cancer and palliative care services.

Key Recommendation 5: Communicating significant news should normally be undertaken by a senior clinician who has received advanced level training and is an effective communicator. It is recognised, however, that this is not always practical; all staff should therefore be able to respond appropriately in the first instance before referring to a senior colleague.

Key Recommendation 6: The outcome of consultations in which key information is imparted and discussed should be recorded in the patient's notes and communicated to other professionals involved in the patient's care. The patient should be offered a permanent record of important points relating to the consultation.

Key Recommendation 7: Policies should be developed at local (network/provider organisation/team) level detailing what information materials should routinely be offered at different steps in the patient pathway for patients with particular concerns. These policies should be based on the findings of mapping exercises involving service users.

Key Recommendation 8: Provider organisations should ensure that patients and carers have easy access to a range of different information materials about cancer and about cancer services. These information materials should be free at the point of delivery and patients should be offered help to understand them within the context of their own circumstances.

Key Recommendation 9: Commissioners and providers of cancer services should work through cancer networks to ensure that all patients undergo systematic psychological assessment at key points in the patient pathway and have access to an appropriate level of psychological support. A four-level model of professional psychological assessment is the suggested model for achieving this.

Key Recommendation 10: Explicit partnership arrangements need to be agreed between local health and social care services to ensure that the needs of patients with cancer and their carers are met in a timely fashion and that the different components of social support are accessible from all locations (including hospital, home, care home and hospice).

Key Recommendation 11: Multi-professional teams should have access to suitably qualified, authorised and appointed spiritual care providers who act as a resource for patients, carers and staff. They should also be aware of the local community resources for spiritual care.

Key Recommendation 12: Mechanisms need to be implemented within each locality to ensure medical and nursing services are available 24 hours-a-day for patients with advanced cancer, and that equipment can be provided without delay.

Key Recommendation 13: Primary care teams should institute mechanisms to ensure that the needs of patients with advanced cancer are assessed and communicated within the team and with other professionals as appropriate. The Gold Standards Framework 4,5 provides one mechanism for achieving this.

Key Recommendation 14: In all locations, the particular needs of patients who are dying from cancer should be identified and addressed. The Liverpool Care Pathway for the Dying Patient 6 provides one mechanism for achieving this.

Key Recommendation 15: Commissioners and providers, working through cancer networks, should ensure they have an appropriate range of specialist palliative care services to meet the needs of the local population. These services should, as a minimum, include specialist palliative care inpatient facilities and hospital and community teams. Specialist palliative care advice should be available 24 hours-a-day. Community teams should be able to provide support to patients in their own homes, community hospitals and care homes.

Key Recommendation 16: Commissioners and providers, working through cancer networks, should institute mechanisms to ensure that patients' needs for rehabilitation are recognised and that comprehensive rehabilitation services are available to patients in all locations. A four-level model for rehabilitation services is the suggested model for achieving this.

Key Recommendation 17: Commissioners and NHS and voluntary sector providers should work in partnership across a cancer network to decide how best to meet the wishes of patients for complementary therapy. At a minimum, information should be made available to patients about complementary therapies and services. If services are to be provided within NHS facilities, guidelines should be developed and implemented relating to the training, qualification and competence of practitioners.

Key Recommendation 18: Organisations providing cancer services should nominate a lead person to oversee the development and implementation of services that specifically focus on the needs of families and carers, both during the patient's life and in bereavement.

Key Recommendation 19: Cancer networks should work closely with Workforce Development Confederations (the Workforce Development Steering Group in Wales) to determine and meet workforce requirements and to ensure education and training programmes are available.

Key Recommendation 20: Provider organisations should identify staff who may benefit from training and should facilitate their participation in training and ongoing development. Individual practitioners should ensure they have the knowledge and skills required for the roles they undertake.

Annex 9

CARE HOMES FOR OLDER PEOPLE: NATIONAL MINIMUM STANDARDS

DYING AND DEATH

The process of dying and death itself must never be regarded as routine by managers and staff. The quality of the care which residents receive in their last days is as important as the quality of life which they experience prior to this. This means that their physical and emotional needs must be met, their comfort and well-being attended to and their wishes respected. Pain and distress should be controlled and privacy and dignity at all times preserved. The professional skills of palliative care staff can help homes ensure the comfort of residents who are dying. There are a number of specialist agencies providing practical assistance and advice, such as Marie Curie and Macmillan nurses, which can be called upon.

The impact of the death of a resident on the community of residents may be significant and it is important that the home ensures that opportunities are available for residents to come to terms with it in ways which the individual residents find comforting and acceptable. Thus opportunities for meditation and reflection and for contact with local and religious and spiritual leaders should be provided.

Residents should be encouraged to express their wishes about what they want to happen when death approaches and to provide instructions about the formalities to be observed after they have died. Cultural and religious preferences must be observed.

There should also be an openness and willingness on the part of staff to talk about dying and death and about those residents who have recently died. Staff themselves, especially young and inexperienced staff, may also need support at such times. The needs of family and friends should also be attended to. Because each individual will have their own preferences and expectations, it is impossible to lay down standards for observances and practices which can apply in every circumstance. However, it is essential for homes to have clear policies and procedures about how they ensure that residents' last days are spent in comfort and dignity and that their wishes are observed throughout.

DYING AND DEATH (STANDARD)

Outcome

Service users are assured that at the time of their death, staff will treat them and their family with care, sensitivity and respect.

Standard 11

11.1 Care and comfort are given to service users who are dying, their death is handled with dignity and propriety, and their spiritual needs, rites and functions observed.

11.2 Care staff make every effort to ensure that the service user receives appropriate attention and pain relief.

11.3 The service user's wishes concerning terminal care and arrangements after death are discussed and carried out.

11.4 The service user's family and friends are involved (if that is what the service user wants) in planning for and dealing with increasing infirmity, terminal illness and death.

11.5 The privacy and dignity of the service user who is dying are maintained at all times.

11.6 Service users are able to spend their final days in their own rooms, surrounded by their personal belongings, unless there are strong medical reasons to prevent this.

11.7 The registered person ensures that staff and service users who wish to offer comfort to a service user who is dying are enabled and supported to do so.

11.8 Palliative care, practical assistance and advice, and bereavement counselling are provided by trained professionals/specialist agencies if the service user wishes.

11.9 The changing needs of service users with deteriorating conditions or dementia—for personal support or technical aids—are reviewed and met swiftly to ensure the individual retains maximum control.

11.10 Relatives and friends of a service user who is dying are able to stay with him/her, unless the service user makes it clear that he or she does not want them to, for as long as they wish.

11.11 The body of a service user who has died is handled with dignity, and time is allowed for family and friends to pay their respects.

11.12 Policies and procedures for handling dying and death are in place and observed by staff.

Examination of Witnesses

Witnesses: PROFESSOR IAN PHILP, National Director for Older People's Services, Department of Health, and PROFESSOR MIKE RICHARDS, National Cancer Director, Department of Health; Department of Palliative Medicine, St Thomas's Hospital, examined.

Q423 Chairman: Professor Richards, Professor Philp, thank you very much for coming along. Our primary purpose in having this session is to explore the situation with regard to palliative care in England and Wales: the status and the way in which this type of care is handled, as well as the general situation so far as provision of palliative care is concerned. Obviously, that is very relevant to what we are discussing, the Assisted Dying for the Terminally Ill Bill. It may be that other questions that fall within the remit of the Department of Health might arise, but if so, please feel free to refer these to others, and we might if necessary make arrangements for some of your colleagues to come if we want to deal with issues which you would not wish yourselves to particularly contribute. Would you like to start with a little introduction of your own. Then Committee members will have a chance to ask the question that they wish to be informed about.

Professor Richards: Thank you very much. Professor Philp and I welcome this opportunity to give evidence to the Committee, because it demonstrates our commitment that good end of life care should apply to everybody, not just those with cancer, for whom I am responsible, but Professor Philp is responsible for older people generally. Can I just say one thing: our remit technically is England, not England and Wales, so we can speak from an England perspective. What I would like to do is give you a very brief outline of the key issues related to delivery of care at the end of life, and particularly what the Department of Health is doing to improve care. The first thing to say is that all patients with terminal illness want and expect to receive the best possible treatment for their symptoms, whether that is pain or breathlessness or fatigue, a whole range of different symptoms, and they also want to receive psychological, social and spiritual care, according to their own needs and preferences. Alongside that,

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they rightly expect firstly, to be treated as human beings with dignity and respect. They expect to be given information, should they wish for it, on what is likely to happen to them and on the services that are available. They want to be enabled to make choices about where they can be cared for and where they will die. They also want to know that their carers will receive support, both during their life and after their death in bereavement. I think it is fair to say that very good progress has been made on end of life care over the last 30 years in this country, and much of that was initiated by the voluntary sector, and particularly the hospice movement, and their contribution to care continues to be huge. As a result of what they have done, we do now have specialist palliative care services across the country, in hospices, but also, very importantly, working in the community, in patients' own homes, and indeed in hospitals, because in fact, if you look at the figures at the moment, over half of all people in this country die in hospital, so that is a very important sector as well. We do also recognise the limitations of current services. Geographical provision is uneven and does not always match need. Much of specialist palliative care at the moment deals with cancer patients, and I think there is an inequity there in terms of patients, for example, with heart failure or emphysema, who often have similar levels of symptoms but do not necessarily go to specialist palliative care services. We also need to recognise the contribution of old age specialist teams to end of life care. Professor Philp can talk more about that, but there are over 900 consultants specialising in old age medicine. What are we doing? There are three key strands to our work to improve end of life care. Firstly, enhancing specialist palliative care services; secondly, enhancing old age specialist services; and thirdly, skilling up what we refer to as generalists, that is, a whole range of different people: GPs, district nurses, hospital staff who are involved in end of life care, and indeed staff in care homes as well. In each of those areas I think we are making progress. On specialist palliative care we have committed £50 million as a result of the NHS Cancer Plan and that is now getting through to the front line and there are more consultants, more specialist nurses and there has been a modest rise in hospice beds as well. We are also increasing the number of trainees in that field so that the consultant work force in specialist palliative care is predicted to double over the next 10 years. On the other strand, which is about skilling up generalists, this is where very recently we have started an end of life care programme, and Professor Philp and I co-chair the steering group, again, to emphasize that this is not just about cancer patients; it is about all patients. It builds on a programme that we have been running for the last three years for district

nurses, to skill them up in end of life care, which has been run extremely effectively and has reached over 10,000 district nurses and a further 2,000 other health professionals. Our new programme is really focusing on established things that work. There is a programme called the Gold Standards Framework, which was developed by a GP, Dr Keri Thomas, that enhances the care that general practices can give. There is a second programme called the Liverpool Care Pathway, developed by Dr John Ellershaw, a specialist in palliative medicine in Liverpool, and that programme really focuses on the care given in the last days of life. The new end of life care programme that we are jointly chairing is about spreading those tools, so that across the whole country we are looking for a step change in the quality of care given at the end of life. So we have come a long way in the last 30 years in providing better care at the end of life, but I am very much aware that we have a long way to go.

Q424 Chairman: Thank you very much. Professor Philp, would you like to give us your introduction, and then questions can be to either of you.

Professor Philp: Professor Richards and I agreed that he would cover most of the points we wanted to put to you. Let me just add two things. One is that in relation to the specialities of geriatric medicine and old age psychiatry, there is a need to cross-skill with the work of palliative care specialists, and particularly in relation to the care of people at the end of life within our acute general hospitals. The partnership that Professor Richards and I have embarked on we want to see modelled in the way our specialists come together, particularly as for many older people the place of death is within the acute general hospital, and it is very important that we establish good end of life care practice there. The second thing I would like to add is that I am responsible for implementing the national service framework for older people's services, one of whose standards, standard two, is about person-centred care. It contains within it the principles of good end of life care as articulated by Professor Richards, but it also underpins that with the introduction of a single assessment process into our health and social care system which will record the needs, the circumstances and the priorities of older people as they come into contact with the care system and as they move through it, and by having that baseline picture of the needs, the circumstances and the priorities of older people, it is easier to help make the right choices at the point of end of life. So that I think is one of the important initiatives that I want to highlight and it is something which is changing the way in which we care for older people.

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Q425 Baroness Thomas of Walliswood: An element of this which you have not mentioned is the patients or the older people who die in care homes. Care homes are not on the whole supposed to supply sophisticated medical care. In fact, they usually rely on a local GP, for example, or something like that, if their patients become ill in any way. How do the sort of services that you are talking about reach, or, indeed, do they reach, people who are living in homes for the elderly? There is a wide range of these homes, so it may be difficult to describe exactly.

Professor Philp: Yes, you are right that the medical and other aspects of health care to people in care homes are provided by mainly primary health care services, including general medical practitioners, which is right, because the care home is regarded as the person's place of residence and their home. The part of our programme that particularly addresses the needs of care home residents is the skilling up of generalists therefore through the end of life care initiative, including the training that we are spreading to care home staff and to general medical practitioners and to community nursing staff in the use of the Liverpool Care Pathway, the Macmillan Gold Standards Framework and the Preferred Place of Care initiative. These are the three developments that were worked up in the cancer field that we are looking to extend to other care sectors. For me, the top priority in extending best practice from the cancer world to older people is to extend that best practice into the care homes sector.

Professor Richards: Just to add to that, we have clearly already identified the care homes sector as being one of our priority areas for this programme, and I think there is a lot of willingness on the part of health professionals to work with us on that and to make sure we do get the learning in there and the skilling up.

Q426 Chairman: How do you do that? Do the general practitioners come in for particular courses or something of that sort, or is it literature you hand out to them, or is there a combination of both?

Professor Richards: The Gold Standards Framework, which is one primarily focused on general practices, works with groups of general practices at any one time, with a facilitator, and really what it is trying to do is to say first of all, can you identify the patients on your list who are approaching the end of life, within months of the end of life? Can you assess their needs? Can you then plan for their needs with them, according to their preferences? Can you communicate to all the other health professionals about that? It is a programme that helps practices do that. The Liverpool Care Pathway really focuses on the last few days of life and in effect it provides a checklist for the sorts of things that nurses, medical staff and others need to be thinking about

once it is recognised that somebody is entering the dying phase. Should they, for example, be thinking about stopping other treatments that are going on, blood pressure medication or something like that? At least they should be thinking about that. Are the relatives fully in the picture about what is going on? It helps to skill up staff so that they know what they should be doing and they can make sure that they have done it. Where this has been introduced already, I think staff are finding it extremely helpful, so that would really focus on the staff working in the care home itself.

Q427 Lord Taverne: I think everyone in this Committee agrees about the value of palliative care. However, since there are many cases in which people who are receiving palliative care still ask for assistance with dying, would you agree with other witnesses who have appeared before the Committee that there is not any necessary conflict, leaving aside one's religious views about the merits of the Bill, between the proposals of the Bill and the development of palliative care?

Professor Richards: I would challenge your opening comment on that, about the large number of patients who are asking for assistance with dying. Having been both an oncologist myself looking after cancer patients and then more recently working in the field of palliative medicine, that was not my experience, and I do not believe it is the experience of others. I think it is a very small proportion of patients who actually ask for assistance with dying. I recognise that there is a small group that do, but I think it is a very small group, and my own view is that the priority we should have at the moment is to make sure that good end of life care is available to all, and I do not think we are at that point yet.

Q428 Lord Taverne: Do you see any inconsistency between these cases? When you say large or small, it is as long as a piece of string. I appreciate that there are not masses of people queuing up, as it were, but there are cases in a number of different areas, as you agree. Do you see any inconsistency between the lines of the Bill and the development of palliative care, which everyone supports?

Professor Richards: I know that there are a lot of clinicians, and that is both doctors and nurses, working in the field of palliative care who do have very strong views on this matter, and I think one of the things we have to take into account is that, in the same way as when abortion was made legal, should this ever become legal, people may choose to opt out of being a part of that. I do not know what that would be like, of course, at this stage, but I suspect in the field of palliative medicine a very considerable proportion of consultants and indeed

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nurses might choose to opt out of having any dealings with this.

Q429 Lord Carlile of Berriew: Are you able to give us any kind of estimate as to the percentage of general practitioners who have undergone some kind of postgraduate training in palliative care so that they have a reasonable familiarity with the aspired system which you describe?

Professor Richards: What I can tell you is that the programme in the Gold Standard Framework, which has been heavily funded by Macmillan up to now, which the Department of Health is now taking on, has reached about 1,600 general practices across the country. That is out of a total of somewhere between 10,000–11,000, so it is still less than 20 per cent of practices, but it is now a considerable minority that have been affected by that and I think our aim is to push that number up as quickly as we reasonably can.

Q430 Lord Carlile of Berriew: Is it right that attendance at these courses is voluntary for general practitioners, given that they of course have compulsory professional development which they have to fit in somewhere?

Professor Richards: I think it is quite important to recognise how important a role it is for primary care but also how small a part of their overall workload is related to the care of the dying, particularly care of dying patients at home. An average GP might have one cancer home death per annum and probably about four home deaths from any cause per annum. So it is a small part of their workload. It is a much larger part of the workload of the average district nurse. In terms of whether something should be compulsory or not, that is technically a matter for training authorities and Royal Colleges to consider. I would certainly like to see GPs more skilled in this area. There are lots of areas that people would like them to be skilled in and it is very difficult for them, given the range of different issues that they have to deal with. I personally think the way is to go voluntarily, because so many practices are signing up to this programme. Maybe once we have got to 80 per cent, then is the time to say to the other 20 per cent “Come on,” and be more coercive, if you like, about that but I do not think this is the stage to do that.

Q431 Lord Carlile of Berriew: Bearing those very helpful answers in mind, and given that good palliative care is something that we can assume most doctors would wish to be part of, would you like to give us an estimate of how long it would take to devise and roll out a programme to train most general practitioners in a system which would meet the requirements of this Bill, if it became law, so that

they full understood the law and the clinical issues surrounding it. Would I be far out if I were to suggest that it was a pious hope ever to achieve it?

Professor Richards: I am sure it would not be just a pious hope. I think it would take a long time to get all GPs properly skilled in end of life care, and obviously on top of that they need to know about the legal framework here, then that would be extra education and training that they would receive, but that would not be a quick business.

Q432 Chairman: Could I just ask: you referred to district nurses; is there a special service of district nurses, or is it now attached the medical practices?

Professor Richards: The district nurses—I probably should call them community nurses now I think. There are about 40,000 community nurses in the country, and they are an extremely valuable work force.

Q433 Chairman: How are they marshalled, as it were?

Professor Richards: They are now run as part of the primary care trust. They were previously a community trust but it is now part of the primary care trust, and one of the advantages of having primary care trusts is that hopefully the integration between the community nursing service that is managed by the trust and the GP service is better than it might have been in the past.

Q434 Chairman: I am familiar with the situation in Scotland. I think district nurses disappeared, and that is why I wondered if I had fallen behind the progress in England.

Professor Richards: We estimate that the training programme that we provided for them over the last three years reached at least 10,000 district nurses, so about a quarter of the district nurses in the country participated in that course, and I think they were extremely keen to be involved because, from a district nurse’s point of view, caring for the dying, whatever the diagnosis, can form as much as a fifth or a quarter of their total workload, so for them it is very important, and in the past I think it would be recognised that they had not had sufficient postgraduate training in this area.

Q435 Baroness Finlay of Llandaff: Can I ask a bit more about the education of staff in communication skills, and in being able to discuss death and dying with patients? Do you have any estimate how many doctors, nurses and other health care professionals across the board at the moment have undertaken such training?

Professor Richards: I do not have a figure for that. What I can say is that communication skills training was identified as a very high priority in the NHS

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Cancer Plan and I think it is important to recognise that people working at different levels need different levels of training. All staff working in health and social care need a certain level of training in communication as they come into contact with patients, but I think that consultants either in cancer medicine or in older age medicine or in palliative care do need particular skills. What we have done about that is to build on the very good work that has been done by experts in the field, often funded either by Cancer Research UK or by Marie Curie Cancer Care to develop a national accredited training programme in communication skills, and we are working on that with the NHSU. It has gone through its pilot phase, and the idea is to train first of all a tier of facilitators who can run communication skills courses. That is not an easy business, as you will understand, but then we can cascade that out across the whole country. So we are on our way with that, but as yet it has not reached a large number of clinicians, either doctors or nurses.

Professor Philp: I just wanted to add something. I would like to come back to the point about care homes and care home staff, because we are not just talking about the NHS. We are talking about staff who are commissioned and usually employed through the independent sector but commissioned by social services. Care home staff as well as care assistants working in community settings are often involved in the care of people at the end of their life. Within the older people's programme we have a care group work force advisory team, which I have chaired for the last three years, and we have made a priority of developing within the skills and competences framework for NHS staff and in parallel through the training organisation for personal social services having national occupational standards that sit alongside these that set out the skills and competences that all staff in the NHS and in social care should have in relation to the care of older people. Included within these training programmes in skills and competences are skills and competences in the care of people who are dying. I think we need to recognise, as Professor Richards said in his introduction, that a lot of the challenge here is up-skilling generalists as well as up-skilling specialists, but recognise the large number of generalists. We are talking about 600,000 care assistants working in the care system, so there is a big job in numerical terms to reach all of these people and ensure that we have the skills and competences that people should have appropriate for their level of work.

Q436 Baroness Finlay of Llandaff: Can I ask Professor Richards how long you think it is going to take to have equity in access to specialist palliative care for all patients who have ongoing

unrelieved distress after 48 hours of the instigation of the measures to try to relieve their distress, which is being used as the standard in some of the frameworks for care provision?

Professor Richards: I think it is extremely difficult to give you an accurate estimate of time. We have to recognise that at the moment specialists in palliative medicine are a relatively small group. There are very roughly 250 of them in the country. If you compare that to the number of people dying in the country, which is over 500,000, you can see that for every specialist in palliative medicine, there are over 2,000 people dying. It is quite impossible for specialists in palliative medicine to assess the needs of each one of those, if you work out the numbers that they would have to see per week. Although I think it is extremely welcome that the specialty is going to be growing over the next 10 years, and probably doubling in size, even then, you can still work out what the sums are in terms of assessing all patients who are dying. I do not think that is feasible. That is why I think one of the key roles of specialists in palliative medicine is to skill others up, which they already do. As you know, they tend to look after patients with the most complex problems, often in hospices, but also by giving advice on wards of hospitals and in the home, and alongside that, looking after those patients, they have a major role in education for GPs, for other hospital staff, a whole range of different people. So I cannot give you a figure for when that will be the case.

Q437 Baroness Jay of Paddington: I really wanted to go back, Professor Richards, to something you said when you were describing what sounded like a very hopeful development in the gold standard, particularly vis-à-vis general practice, etc. From what you said—and I may have misunderstood you—you seemed to be saying that it was fairly clear for general practices, when you were instructing them in what they should be doing, to be able to identify in the diagnosis sense when someone had reached a terminal point in an illness so that they could institute these various practices which you are recommending under the gold standard. Is that in fact what you were saying?

Professor Richards: I think there are two steps. There is identifying that somebody has an advanced progressive illness which is no longer going to be responsive to treatment, and that somebody might then have weeks, months, even possibly a year or more to live. That is one assessment that needs to be made, and from there a whole lot of planning needs to be done about how to meet their needs and their preferences from that point onwards. There is a second step, which is identifying the fact that somebody is actively dying, and that in itself is quite a difficult thing to do, particularly as given a lot of

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conditions like heart failure, for example, people can be slowly getting worse but then they can have acute dips down, and it is very difficult to know whether they will recover from that particular incident or not. My own father, who died of emphysema, is a case in point, where he had a number of dips down from which he did recover, and he then had months more of good quality life, and I think that is one of the very difficult things about prognosticating, particularly outside the field of cancer, and knowing how long somebody has got to live.

Q438 Baroness Jay of Paddington: What I am trying to get to is that you are assuming in your training programme that it should be perfectly possible for the trained—skilled-up, as you describe it—medical team to make a diagnosis which assumed that someone was not going to recover.

Professor Richards: I think very often that is possible. It should normally be possible, but I think saying how many months somebody has to live is almost impossible.

Q439 Baroness Hayman: Can I take you back to the area Lord Taverne was dealing with earlier. As I understood your reply, which seemed totally coherent, it was that, for the majority of people, high quality palliative care would be their priority, and that therefore that also ought to be the Department of Health's priority. You also indicated that resources and a lot of effort were going into providing that on a basis of equality across the board, although you acknowledged that you cannot say how long it would take. However, I think you agree that even within that scenario (having reached the gold standard, with no postcode lottery or anything else) there would be a minority of people who, if they were articulating their choices as part of their patient-centred care, would, as a result of their existential distress, want a choice of when they would die, not simply where they would die. If that is correct, I wonder if you have, first of all, any sense of how large or how small that minority might be, and secondly, how you determine the priority given to the choices of where to die—which is articulated in all the documentation—and of how to die—which is implicit in the choice given to patients about receiving progressive treatment or not—whilst giving the patient no choice over when to die.

Professor Richards: If I can first deal with the question of the number who might wish to exercise choice about when to die, the honest answer is I do not think in this country we know at the moment. We can look to other places in the world, and I am sure this Committee will have done so, but one can look to Holland or to Oregon, and of course, one comes up with very different numbers. I believe that the figure in Holland is that about 2.5 per cent of

people are making that choice at the moment, but I think that is on the background of not having good end of life care services. They are undoubtedly getting better, but I think when they brought in their measures in Holland, that was not the case. If you look to Oregon, it is a different picture, and from what I have seen, the numbers who choose the point in time of death is extremely small. I think the hospice and palliative care services—the terminology is different between the two countries—are better advanced in Oregon than they are for example in Holland. I suspect there will be a small proportion, and I think that small proportion interestingly is often not because of pain *per se*, or indeed other symptoms. It is, from what I have read about it, and I have no first-hand experience of this, often the sense of wanting to be in control, and it is an issue of autonomy, and I think that is the issue that obviously this Committee faces.

Q440 Earl of Arran: Just a general question following on from the other questions. In a Department so heavily laden with a host of competing priorities for resources and funding, is palliative care now starting to climb the list of resources much more quickly than two or three years ago? When you mentioned the figure of £50 million towards palliative care of cancer patients, that of course is a drop in the ocean.

Professor Richards: I think it is more than a drop in the ocean, but I would agree that more is needed. In terms of the priority, undoubtedly it has come up the priority list. I think the very fact that the commitment was made for the £50 million is evidence of that, and the fact that Ministers then set up a central fund so we could be absolutely sure that that money would get through to the front line for the purpose for which it was intended again was a demonstration of the priority that is given to this area, and I think further evidence is this time last year, when the paper on choice, which was called *Building on the Best*, was published, the very fact that within that they committed funding for the end of life care programme that Professor Philp and I have been describing is again a demonstration of the importance that is being given to this area.

Q441 Lord Joffe: Professor Richards, in areas where unfortunately palliative care is inadequate, what can patients do who desperately want such care?

Professor Richards: It is very difficult for patients in those areas. There is palliative care in all parts of the country. The difficulty we have is that there are varying levels of staffing in different parts of the country. We drew attention to that at the time of the NHS Cancer Plan. In fact, there was a graph in the Cancer Plan illustrating the variations between

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regions. Since then, with the assistance from the National Council for Palliative Care, a needs assessment tool has been developed that helps localities look at what their provision should be because clearly, if you have got a larger number of older people, you are likely to have more people dying in that population and more people needing palliative care, and so the population of Worthing might need more palliative care consultants per head of population than the population of Milton Keynes, to give examples. So we have developed that tool, or at least the National Council for Palliative care have developed that tool, and that is now available so that localities can look at their provision and see whether it is adequate.

Q442 Lord Joffe: But terminally ill patients do not have that choice, do they?

Professor Richards: If there is a service that is very stretched locally, no, very often they do not have that choice, and that is why we are giving this priority to improve those services. I think it is important to say that, out of the £50 million that has been given, we know that extra consultants, extra nurse specialists and extra hospice beds have been provided, so it is not just money; it is services that are happening out of this.

Q443 Lord Joffe: I am conscious of the excellent progress that has been made in palliative care. I am worried about the people who want it and cannot get it. Can I ask you one more question? Why is it that so much of current palliative care and hospice treatment is concentrated on cancer patients, and can you explain how and why this came about? Is there some particular need in the case of cancer patients that is not present elsewhere?

Professor Richards: I think this is an historical anachronism, if you like. It started largely through the work of people like Dame Cecily Saunders, who focused her attention on cancer patients, because, I think, at the time, of the pain that they were suffering that was very acute, and what she observed was the importance of regular pain control, but also the importance of whole-patient care and not just thinking about the symptoms but also dealing with the psychological, social and spiritual care that patients needed. That focused on cancer patients to begin with—not exclusively; it also for example involved patients with motor neurone disease. But what we have recognised in recent years is the need to spread the expertise and experience that has been gained in that field to other areas, and that is what we are now trying to do, and that is why the two of us are jointly here.

Q444 Baroness Thomas of Walliswood: To go back to your description of the training of general practitioners and their staff, which is obviously something of great importance, there is a great difference, if I am not mistaken, between those areas where much of general practice is organised in quite large groups of doctors—three, four, five—and those areas, often in the poorer parts of the country, where you still have single practitioners. Does the single practice present particular difficulties when trying to up-skill? The doctor is going to be, by definition, extremely hard-worked, and some of these practices have very long lists. Again, I hope I am describing the situation as it actually is and not erroneously, but that is my impression. How do you get to the training of those doctors, who may be in the very areas in fact where those skills are particularly desirable?

Professor Richards: I think that is a very good point. If I can go back to my experience before I took on my current job, when I was working in the field of palliative medicine in south east London, we ran a programme for GPs in Lambeth and Southwark—this is with a colleague—and we did manage to engage a very large number of GPs in that programme, but there was no doubt that it was more difficult to engage those who were single-handed practitioners. It is also fair to say that the number of single-handed practitioners is decreasing with time. When we looked in that particular study, I remember, almost all of the single-handed practitioners then were over the age of 50 and those working in large practices tended to be younger, so I think this is something that is disappearing with time anyway, but it is a distinct challenge to get to those practices, because it must be even more difficult for them to attend educational sessions.

Professor Philp: It is also true that single-handed general practitioners, like practitioners who work in a group practice, are required to undertake ongoing professional development, and that arrangements are in place. So, recognising that there may be some particular difficulties, it is still the case that it is not impossible to ensure that there are opportunities for single-handed general practitioners to undertake further training and development in palliative care.

Q445 Baroness Finlay of Llandaff: Can you tell us what the impact has been of the European Working Time Directive and the New Deal on the ability for medical staff to provide continuity of care?

Professor Philp: If I can perhaps talk about the specialty of geriatric medicine, as Professor Richards said in his introduction, there are about 920 consultant specialists in old age medicine, who largely work within our acute general hospitals, and we have been increasing the numbers in training recently—I think 125 extra training places have been

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put in place—so this is an expanding specialty, but it is a specialty that not only has faced pressures because of changing working practices, European Working Time Directive and so on, but also because of the high volume of work that is undertaken within our acute general hospitals. Patients stay in general hospitals for shorter periods of time. More and more people coming through acute general hospitals with medical emergencies or needing surgery are elderly with complex problems. So there is a stretch issue, and it has meant that the specialty has withdrawn some of the work that used to take place in the community setting. But the key to the specialty fulfilling its potential to better meet the needs of people who die is to ensure that the specialist skills are available for the care of people with complex problems in old age, coming through particularly our acute general hospitals, and it is about therefore the specialty refocusing its work, moving away from undifferentiated general adult medicine to concentrating on the care of people with complex problems that are associated with old age. About two-thirds of people occupying acute hospital beds in England are older people with complex medical problems, and above the age of 80 about one in five will die during that admission to hospital. So I am working with the specialty and its leadership to look at ways in which we can identify early on those people who would most need the specialist skill, and that would include those people who are at highest risk of dying following admission to an acute hospital. The other side of that equation is about developing services in the community. We have invested over £1 billion in England per year in increasing the volume and range of community services, particularly for older people, that provided better care in community settings. It has included the development of new ranges of specialists and allied health professionals working in intermediate care, new types of nurses specialising in the care of older people in the community, who will provide and potentially can provide better care for people in the community. But in turn, that has led to a reduction in pressure on both admission to hospital and in shortening length of stay. So we have to look at it as a whole system, and look at all the professional groups that can be involved in this. The European Working Time Directive, to come back to your specific point, does of course create an additional challenge, but it is only one factor amongst many, whereby we are looking at specialists redefining their work, but according to the central principle that we must match specialist skill and knowledge to those people that have the greatest needs. I see that as the particular challenge and one that we are addressing.

Q446 Baroness Finlay of Llandaff: My concern relates to continuity of conversations with patients though, because we know that patients who desire

death, or express a desire for death, often do not have complex medical needs. Rather they have complex psychological needs and need continuity of conversation.

Professor Richards: I think things like the European Working Time Directive do present a challenge, as does the new GP contract, the GMS contract. But equally, with these challenges, it has given us the opportunity to look at radically different ways of delivering care. For example, the European Working Time Directive made us look at care at night in hospitals, and to see how many calls different sorts of junior staff were getting overnight. I think the new GP contract is making us look at how we can have much more co-ordinated care in the community out of hours. The important thing is to say that out of hours care represents over three-quarters of all hours. There are 128 hours out of hours, and only 40 hours in hours, and it is impossible to provide care 168 hours a week with continuity, though in our junior hospital days it probably felt like it. I am impressed by how some primary care trusts—there is one in west London—have really tackled this and have started developing a much more co-ordinated approach between all the different services so that you do get continuity of care, although you cannot have the individual clinician providing 24-hour care, seven days a week.

Q447 Lord Turnberg: Could I ask you to focus on this small subset of patients who are dying who wish to choose the moment when they die. We are told by the palliative care people that they can offer all sorts of symptomatic relief for most if not all symptoms, and certainly for pain and depression. They seem to be convinced that they can treat those, and most patients take advantage of that, of course. It is the subset that we are concerned about who, despite that, want to choose the moment when they die, and we spoke about autonomy. Could you help us by telling us anything about this group of patients: why they would make this choice, what are their motives, and is this the best thing for them? That is our problem.

Professor Richards: There is a subset. I would agree. I think it is a small subset. Again, from my reading about what has happened elsewhere, particularly in Oregon, it is far more about the patient's sense of control and autonomy than it is about specific symptoms. Sometimes it is also about not wanting to be a burden on their carers, but that is linked with the sense of autonomy in any case. I do not know how large a number that will be in this country. I am acknowledging that there is a subset that feel that way. Certainly the experience in Oregon has been that, if people know that that is available to them, they very often do not take up the option in fact, and that in itself is interesting. It is about

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having the confidence that they could if they so chose. But my own view is that we are a long way off knowing that number in this country because we do not yet have the end of life care that we should have.

Professor Philp: If there is one thing I should add to that, it is that “Doctor doesn’t know best.” That is something I was taught early on, as a medical student, by a great professor of geriatric medicine, Jimmy Williamson, in Edinburgh, to talk to older people about their views about death and dying. I have done that throughout my career, and I have always been surprised at what my patients have told me about their views. That was operationalised more recently when we have started as doctors more formally to ask people’s views about resuscitation decisions in advance when they would be at risk. It is a constant surprise to you as a doctor what people say about their views about whether they would choose to live or to die if they had a heart attack and whether they would want to be resuscitated. That essential point I would make there, to build on Mike’s point on this issue of autonomy, is that it is very easy to make assumptions about people’s views about death and dying, if we do not ask them what their views would be. That is not to say anything about my views, right or wrong, about people’s decisions about assisted dying, but it is just to say that that basic point, that unless we ask people what their views are, we will not know.

Q448 Lord McColl of Dulwich: You mentioned the Abortion Act, which failed to prevent discrimination against doctors and midwives who felt unable to go outside the law. They were quite happy to do abortions within the law but not outside it, in other words would not do abortions on demand. How confident would you be that this Bill would protect health care workers who did not agree with it, bearing in mind we have had a report

recently from Holland where a university doctor was excluded from teaching medical students because he did not agree with euthanasia?

Professor Richards: I would hope that any legislation that did come in would make it absolutely crystal clear that this was a matter of conscience, and that there should be no discrimination, and I think it would be up to your Lordships to work out how best to frame that so that people did get the protection. I am quite clear that some people will feel very strongly about this, and I know that within the field of palliative medicine, there are some, probably many, that feel that way and that they must be protected.

Q449 Chairman: Professor Philp, you mentioned the care assessment in the course of your initial address to us. I was just wanting to be sure that I understood it. It is done by the social work people in cooperation with the Health Service. Is that right?

Professor Philp: That is right. As of April of this year, 2004, 80 per cent of councils in England reported that they had agreed a common approach to assessing health and social care needs with their local NHS partners, and that number is going up and we will reach 100 per cent fairly soon. What happens is when an older person comes into contact with the care system, a record is initiated and then it is gradually built up over time, and it covers a holistic assessment of the needs, the circumstances and the priorities of the older person, and it gives the older person an opportunity to say, not only their current circumstances but an opportunity to say what they would like to happen to them in future if their circumstances or their health changed.

Chairman: I would like to thank you both very much for coming, and I must say I would like to thank the Department of Health for the high standard of witnesses that we have been afforded by them. Thank you very much indeed.

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Present	Arran, E	Mackay of Clashfern, L
	Carlile of Berriew, L	(Chairman)
	Finlay of Llandaff, B	McColl of Dulwich, L
	Hayman, B	Taverne, L
	Jay of Paddington, B	Thomas of Walliswood, B
	Joffe, L	Turnberg, L

Examination of Witnesses

Witnesses: DR GEOFFREY LLOYD, Department of Psychiatry, Royal Free Hospital; DR ELAINE McWILLIAMS, Consultant Clinical Psychiatrist, The Rowans Hospice; and MRS CHRISTINE KALUS, MacMillan Consultant Clinical Psychologist, The Rowans Hospice, examined.

Q450 Chairman: Thank you for coming, Dr Lloyd. I think you are representing the Royal College of Psychiatrists, and Mrs Christine Kalus and Dr Elaine McWilliams the British Psychological Society. Dr Lloyd, would you like to make an opening statement, and then I will invite questions. Then we will go on to the British Psychological Society. It may be convenient to do it all together, but we will see how we get on starting with you, Dr Lloyd.

Dr Lloyd: Thank you very much. I am Dr Geoffrey Lloyd. I am a consultant psychiatrist, specialising in liaison psychiatry, which is the area of psychiatry which impinges on medical practice, the care of people with medical conditions. I am the Chair of the Liaison Psychiatry Faculty of the Royal College of Psychiatrists. The only other thing I would like to say at this point is that our College really has not a position on this Bill. It has been the view of the College that we have left any statement about the Bill to the Academy of Medical Royal colleges, which Professor Carol Black has co-ordinated on behalf of the Colleges, but it is not a topic which has yet been debated within our College.

Q451 Chairman: Thank you. So the situation is that you can help us with any technical matters, rather than any policy matters?

Dr Lloyd: That is correct, Chairman, yes.

Chairman: In that case, I will invite questions from members of the Committee. We will see how far we get, and then we will turn to the British Psychological Society.

Q452 Baroness Finlay of Llandaff: Dr Lloyd, can you tell us about the incidence of suicide amongst patients who are medically ill and the incidence of suicide among patients who are in specialist palliative care units?

Dr Lloyd: In general, the suicide rate is increased for those people who are suffering from a chronic medical condition. Virtually all medical conditions of any chronicity and seriousness are associated

with an increased suicide rate. What impresses me is how rarely it actually happens. People seem to be able to cope stoically with a great deal of suffering, a great deal of chronicity, and a great deal of disability associated with diseases such as cancer, neurological diseases, AIDS and so on, which I have some experience of dealing with. Nevertheless, the rate is increased. Your second point was about patients in palliative care. I cannot answer that but I work in a hospital which has a very good palliative care service, and I think the rate of suicide is low.

Q453 Baroness Finlay of Llandaff: These patients, though, have enormous quantities of drugs at their disposal and they often express verbally a desire to die. Why do you think that, given they are expressing a desire to die, and they have all these drugs there, they do not take them?

Dr Lloyd: That applies to a lot of people who express a desire to die. Psychiatrists' work, not just in relation to medically ill people but in relation to people suffering from depression, is often involved on a daily basis in dealing with people who have expressed a desire to die, and they usually do so in the context of a depressive illness. These are the people that we see, and that is one of the reasons why they are referred to us. The desire to die covers a spectrum of intent. There are people who express a desire to die in the sense that they would rather not wake up in the morning, or they would rather not be here. That is a passive desire to die. At the other extreme there are people who have worked out very careful plans and know exactly what they are going to do to end their life, and these people are at extremely high risk. In between those poles there is a spectrum of intent, and far more people express a desire to die than actually make an attempt to kill themselves.

Q454 Baroness Finlay of Llandaff: Why do you think some patients express a desire to be killed rather than a desire to commit suicide themselves,

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with no intervention from those providing medical or clinical care?

Dr Lloyd: For most people, there is a barrier to harming oneself. There is some psychological protective mechanism which stops people actually attempting to damage themselves. It happens often enough, but in the great majority of people there is something about their personality strength which prevents them from harming themselves. For those who express a desire to be killed by someone else, I think it is probably because they wish to shift the responsibility to another person rather than take on that responsibility themselves.

Q455 Baroness Finlay of Llandaff: Could you just tell me how many liaison psychiatrists there are in the country and whether there are unfilled vacancies, and whether you feel you have enough to undertake assessments within 24 hours of referral as part of your routine practice?

Dr Lloyd: At the last assessment, there were 80 consultant posts in liaison psychiatry throughout the United Kingdom. That means that there are many hospitals, many trusts, which do not have access to a liaison psychiatry service. I chaired a joint working party which published a report last year, a joint working party between the Royal College of Physicians and the Royal College of Psychiatrists, which made recommendations that every acute hospital trust should establish a liaison psychiatry service, led by a consultant with special training, with junior medical staff, specially trained nurses and psychologists and so on. That is the ideal, but we are far from achieving that ideal.

Q456 Baroness Finlay of Llandaff: How competent do you feel that those without that degree of specialist training are in making diagnoses of severe treatable depression on a single visit to a patient who has severe medical illness?

Dr Lloyd: To put it the other way round, the more experience one has in assessing and treating people who are medically ill and assessing their mental state, the more likely one is to do it. Psychiatrists who do not see these people on a regular basis are probably less well equipped to do so, but nevertheless, they are properly trained in diagnosing depression in general and a whole range of other psychiatric disorders which these people may have.

Q457 Lord Turnberg: Can I follow up this business of patients who want to commit suicide? You describe a spectrum, and at one end we have patients who have planned it very carefully and will do it for themselves. I suspect that the sort of patient that we are thinking about here is the patient who has gone through palliative care and had as good

care as possible but is still determined that life is not for him or her. Do you see the sort of case where a rational person decides that they do not want to live any more, even without a terminal illness? Can you prevent that or do you have anything to offer them? What happens to them?

Dr Lloyd: We do not see them very often. Our remit would be to try to establish whether they are in fact making this decision in the context of a depressive illness or other psychiatric disorder, perhaps a confusional state or generalised impairment of intellectual function, as in dementia. There are occasionally people who are psychiatrically not unwell, not ill in a psychiatric sense, who make what seems to be a rational decision to want to die, but that is, I must stress, very rare; it is unusual. I think in those one would make every attempt to get them to change their mind, because that is what doctors are for, basically.

Q458 Lord Turnberg: That is what they do, but that is not what they are for.

Dr Lloyd: That is what I would hope they are for. One would try to provide them with whatever symptom relief they would require. One would try to provide them with counselling. If they have a religious persuasion, one would wish them to see a minister of religion appropriate to themselves.

Q459 Lord Turnberg: Faced with a patient who has a terminal illness, who has suffered, and whose physical side of suffering has been helped, do you think the reason that they still want to die is because they are depressed, or because they have some other treatable problem, or not?

Dr Lloyd: In some cases it will be because they are depressed, and that needs to be addressed.

Q460 Lord Turnberg: Do you think there would be a group of patients who have their depression treated but still wish to have the control over their lives to say that is the end?

Dr Lloyd: Yes. Everything we learn from the literature about this area does suggest that there is a small group who have received good care in terms of palliative care, symptom relief; they are not depressed, or if they were depressed, their depression has been treated to the best of our ability, and it does seem that there is a small group who, despite all that treatment, still wish to end their life.

Q461 Lord Taverne: Do you see any difference in cases of those who express a wish to die or to be assisted in dying, and those who refuse life-prolonging treatment?

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Dr Lloyd: In terms of their mental state, there is very little difference. They both have the wish that they do not want to live any longer. The one group wants treatment withdrawn, and presumably they know the consequences of withdrawing treatment will be death, and the other group will presumably want something more active done. I think in terms of the ethical position, there is very little difference. In terms of a doctor's perspective, there is a difference. There is definitely a difference in the way a doctor perceives the two different situations, the withdrawal of treatment on the one hand, and active intervention on the other.

Q462 Lord Taverne: But in both cases the same procedure would be gone through to try to persuade them to change their mind.

Dr Lloyd: Yes.

Q463 Baroness Hayman: Can I take that a little further and ask whether you think that, as a Society, we should look at it from the doctor's point of view in those circumstances where it is really a matter of complete chance whether you have a terminal disease for which there is treatment that is keeping you alive and therefore you can withdraw from that treatment, or you have a terminal disease for which you are not receiving treatment but is equally terminal. From the patient's point of view, the ethics and, as you were saying, the motivation, does not seem to be very different. What is the argument for looking at it from the doctor's point of view?

Dr Lloyd: I think that the medical viewpoint is that this is a matter for society, not for doctors. I am just telling you what the doctors' position is because whatever doctors feel about the Bill, if this becomes an Act of law, doctors are going to be involved, it seems to me, physicians, palliative care doctors, general practitioners, psychiatrists. From what I have read of the position of various medical bodies, there is a distinction in those two practices. Ethically, there may not be, morally, there may not be and in the eyes of the general public, there may not be, but in the eyes of doctors, there is.

Q464 Baroness Hayman: I do not know if you have seen the reports, particularly from Oregon, that the first-stage uptake of assisted dying involves much higher numbers of people than the second stage of carrying that through. I wonder if you would like to comment on that as to what are the psychological forces at work there and whether you can see a more general good in giving people a sense that, "If this became unbearable, I would have an option", and whether that could in fact allow people the strength to bear things.

Dr Lloyd: Yes, I read with a great deal of interest that the uptake at the second stage is much lower than one might have expected. Why is that? Well, one reason is that people change their minds in any intent to kill themselves or harm themselves, and we see this frequently in people who have actually tried to commit suicide, not in the context of a terminal medical illness, but in the context of some very distressing life circumstance. The intent to commit suicide varies, it fluctuates from day to day. Of course if it is done, it is done and there is no second chance. Where people make an attempt and survive it, it may have been very serious at the time, but if they survive it, within a day or two, their suicidal intent may have changed dramatically, usually lessening.

Q465 Lord Taverne: Is it not also the case that they may derive some comfort from the fact that they know that if they are in a situation which they regard as unbearable, they can be assisted and, therefore, having that comfort, they do not feel the need to resort to suicide?

Dr Lloyd: I was coming on to that point. The first point is that there is fluctuation of intent. The second reason why they do not take it up is for that very reason, that there is a sense that if they want to do it, they have got the means, so there is a sense of autonomy and independence, which having a prescription for a lethal drug obviously gives them.

Q466 Baroness Hayman: We are also often told that it is controlling personalities for whom autonomy is particularly important. Is there an accepted definition of what proportion of the population have a controlling personality?

Dr Lloyd: The short answer to that is no, there is no definition of how many people are controlling. It depends on the circumstances. Some people are submissive in certain circumstances and very controlling in others.

Q467 Lord Joffe: Dr Lloyd, a professor of psychiatry at Oregon Health, has conducted a great deal of research into end-of-life decisions and has found that patients who persist with their requests for assistance to die value control, they dread dependence on others and they assess their quality of life as poor. Would this profile fit with the group that you have mentioned who plan their death and think about it carefully?

Dr Lloyd: Yes, I think it probably would, yes.

Q468 Lord Joffe: The other point that she makes is that the people who are acting more impulsively have not thought it through, and that those who are depressed tend to be screened out as they go through

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the process of safeguards incorporated in Oregon law and they just do not carry on with it.

Dr Lloyd: Yes, I think if there is a longer period of assessment than is usual, say, in normal psychiatric practice for assessing people who have tried to kill themselves, I think you are going to be able to identify those for whom this has been an impulsive decision.

Q469 Baroness Finlay of Llandaff: Can I follow this up with a question? If there are patients who repeatedly attempt to kill themselves they are not the ones who are changing their minds, and given that those who are terminally ill have got the means, but seem not to do it, maybe they have the security already because they have got all the drugs there. I do not quite see the logic of saying that this Bill should be restricted to those who are terminally ill because it seems as if you are saying that if you are terminally ill and you are going to die anyway, then you can have your life ended, but if you are psychiatrically ill and absolutely intent on being dead and repeatedly attempting it, then we are not going to let you kill yourself, let alone help you in the process. There seems to be an illogicality in that.

Dr Lloyd: I am not recommending that this Bill should be restricted to either group; I do not have a position on it. The point about people who make repeated attempts to kill themselves, other than those people who are suffering from a terminal medical illness, these are the people who are the bread and butter of psychiatric practice, if you like, and they have a range of psychiatric disorders which psychiatrists like to think they can do something about. The law, as it stands obviously, provides psychiatrists with the provision to treat these people for a psychiatric illness, like depression, or a psychotic illness, not so much a personality disorder, but we do take those into treatment if they wish to, but we want to try to manage these people in such a way that their suicide risk will be reduced and their psychological symptoms of depression or psychosis will be alleviated.

Q470 Baroness Finlay of Llandaff: I was taking you back to a comment about rational suicide and there are some who do not fit into that category.

Dr Lloyd: Well, yes, the people that we deal with in psychiatric practice usually wish to commit suicide in the context of a psychiatric illness.

Q471 Baroness Finlay of Llandaff: But there are some who do not?

Dr Lloyd: There are some who do not.

Q472 Chairman: Could I ask about the question of examining a patient from the point of view of competence to deal with decisions about whether or not to ask for assisted dying, Dr Lloyd. For this Bill we are thinking in terms of people who are suffering very severe symptoms of one kind or another, not necessarily physical pain, but symptoms. Is there any particular skill required to discern whether such a person is competent to make a decision or whether in fact they are suffering from some form of psychiatric condition which damages their competence to make a rational decision?

Dr Lloyd: Well, this is part of the training of doctors at the undergraduate and postgraduate level, the ability to take a proper psychiatric history and examine somebody's mental state. There is a very clearly defined way of doing this and students are taught it at undergraduate level, so it is something that all doctors should be able to do once they qualify as doctors, and particularly then during the course of psychiatric training as trainee psychiatrists. This is something which is part and parcel of a psychiatrist's expertise. Taking it one stage further, for those psychiatrists who then spend part of their training working in a general hospital, the issue of assessing a patient's capacity is something that they get exposed to and are supervised on and they learn to acquire the skills necessary to do that, but it is an extension really of performing a proper, comprehensive psychiatric evaluation.

Q473 Chairman: So would there be any difference in the level of skill in this particular area between a general practitioner who, as you say, has been trained in it from undergraduate level and a person who has done the postgraduate training in preparation for a psychiatric specialisation?

Dr Lloyd: Yes, there is a variation of skill, as there is in most medical skills. I think all doctors are capable of making decisions about mental capacity when it is fairly straightforward. Those who have had a bit more experience, and general practitioners very frequently acquire training in psychiatry during their general practice training, they are able to make these decisions if the case is a bit more complicated and then in more complicated cases, that is when psychiatrists, particularly liaison psychiatrists, have an expertise to bring to this area of practice.

Q474 Earl of Arran: Do more males or females attempt suicide?

Dr Lloyd: In general, more women attempt suicide and more men commit suicide.

Q475 Chairman: Dr Lloyd, thank you very much. Perhaps you would be kind enough to remain with us while we invite from the representatives of the British

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Psychological Society to speak now as there may be some interaction. You have obviously heard what Dr Lloyd has said and if you have any comment on it, it would be handy to have that. If you would like to make an opening statement, one or both of you, you have a chance to do that and then perhaps you can answer any questions that members of the Committee would like to address to you.

Mrs Kalus: Thank you. I have actually prepared a statement which I am very happy to read out and I have brought along copies. This is on behalf of myself and Dr McWilliams. Firstly, I would like to say how pleased I am to be here with my colleague, Dr McWilliams, and to have the opportunity to talk with the Select Committee on such an important issue. It is heartening to know that our profession is seen as having something positive to add to the debate. Despite that, my colleague and I must add the caveat that there has been no opportunity for consensus discussion within the profession, and thus we are presenting our views in the context of expert witnesses. I am a Macmillan consultant clinical psychologist with eleven years' experience in the field of specialist palliative care (SPC), and my colleague, Dr Elaine McWilliams, is here in a similar capacity, having worked in the field of oncology and chronic pain for several years and, for the last four years, in specialist palliative care. However, to try and obtain the widest representation in the time given, Dr McWilliams and I have consulted with colleagues from the speciality both here and abroad, as necessary. We have also been in consultation with colleagues who have an interest in the Mental Capacity Bill and the Mental Health Bill, which, you will be aware, has been addressed by the British Psychological Society in other fora. We would also like the opportunity to talk about the role of clinical psychology within specialist palliative care. Whilst we are a relatively new profession to the speciality, given that many of us come from an oncology or older adults background, there is recognition that we have a considerable expertise to offer because much of the knowledge and skills gained from those fields are transferable to SPC. The recent NICE guidance makes explicit reference to the need for psychological services to be an integral part of palliative and specialist palliative care, including the need to influence bereavement services. Increasing numbers of commissioners and cancer networks are investing in clinical psychology to take a lead in the development of such services. The specific expertise we offer is being able to take a multi-theoretical approach to understanding the individual within the context of their life history, personal psychology, socio-economic status, cultural background and so forth. We are also highly trained in interpreting evidence from the professional literature, to find

ways of formulating problems for individuals and families and, where appropriate, to offer interventions. To this end, we have training in different therapeutic approaches and, thus, are able to offer bespoke assessments and interventions based on the best available evidence. In terms of my own experience, as stated above, I have worked in SPC for the past eleven years, prior to that working in the field of mental and physical health services for older people, thus, I have worked with issues related to loss, death and bereavement for most of my career. Over these past eleven years I have specialised in the field of bereavement and psychological issues, including depression and anxiety at the end of life. This also includes helping individuals and families manage difficult communication issues in situations of high stress and emotion. Over the years my colleague and I have rarely encountered people who want to end their life, although many express a wish that their suffering was over. Thus, once appropriate symptom control has been achieved, in so far as this is possible, people are able to regain some semblance of quality of life. However, it is also important to note that, in our combined experience, there have been very few people, probably less than ten, where there was no evidence of clinical depression or anxiety, their mental capacity apparently being intact, who had an express wish to die, and would have welcomed assisted dying, had it been available to them. The reasons for this are complex and relate to quality of life, intractable pain and other symptoms and loss of personal autonomy. We are also involved in the bereavement follow-up with some of the families, and this was a view held by significant others in their grief, in other words, the existential suffering of the client at the end of their life contributed to painful recollections for the families in their grief. A typical, and understandable, quote would be, "They did not deserve a death like that". The issue of assisted dying is a controversial and emotive one, which understandably has the propensity to polarise individuals, professionals, organisations, pressure groups and communities. This is for reasons of human rights, professional responsibilities, which are implied as a result of legislation to legalise assisted dying, and religious and cultural beliefs. This paper does not set out to address human rights, religious or cultural beliefs specifically, although we are aware that they have a significant impact on the way in which we conduct our lives both as professionals and as citizens. Rather, what we hope to do is consider the evidence that is available to call on when considering the issue of mental capacity and the ramifications of trying to make a comprehensive assessment and draw helpful and appropriate conclusions. We also hope to draw attention to areas where there is a lack of evidence about related and important issues, such as

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the impact of assisted dying and bereavement outcome, other end-of-life decisions, such as withdrawal of treatment, nutrition etc, and consider what needs to be done to ameliorate this. In addition to the Assisted Dying Bill, there have been a number of other potential challenges to the medical profession in recent years that push for a wider societal debate about issues of autonomy and rights of the patient as opposed to the professional, for example, to choose treatments that may be considered to be counter to the patient's best interests by the doctors, or requests for end-of-life sedation to be withheld and/or given. This has brought the debate clearly into the public domain, and when one is talking about issues of life and death, there is an understandable expression of emotion on behalf of the professionals, particularly the medical profession, who currently hold the responsibility for treatment, however that is defined, and the lay person, or patient, who is potentially in receipt of treatment. This brings into focus the doctor-patient relationship, recognition and management of difficult psychological issues, and ultimately the trust that needs to exist between patient and doctor/professional, for the necessary help to be given and received. In addition to the above, it is also important to be aware that the Mental Capacity Bill is currently going through Parliament and is likely to be on the Statute Books in the next two to three years. This has significant implications not only for those who may be suffering from severe and enduring mental illness, but also for those of the population who have episodes of reactive depression as a result of the diagnosis of a life-limiting disease. Estimates vary, but within the population of cancer patients, this is thought to be in the region of 25 to 40 per cent at the time of diagnosis, and similar at other times in the cancer journey, eg on confirmation of metastatic disease. There are similar figures for populations diagnosed with diseases such as HIV and related diseases, Motor Neurone Disease, Multiple Sclerosis and other degenerative diseases. Whilst the course of these diseases is often unpredictable, the trajectory, and psychological reactions to episodes of "bad news" may well prove to be the trigger for an intense, distressing and debilitating emotional experience. However, despite this, the incidence of attempted or completed suicide in these populations is relatively low. It is also important to be aware that episodes of reactive depression and anxiety *per se* do not imply that the individual is unable to make rational decisions about their life. There is also evidence that multi-modal interventions, such as psychological therapies, supportive counselling and good social support, psychoactive medication and symptom control can mediate more severe depressive reactions. However, this is predicated on a good

mental health assessment being undertaken by suitably experienced and qualified practitioners (clinical psychologists, liaison psychiatrists, community psychiatric nurses, et cetera), and dependent on good psychometric and psychological assessment tools being available. We do not at present have sufficiently robust questionnaire-based tools with which we can confidently assess depression and other psychological states in this population as 'stand-alone' methods of assessment. The most reliable method of assessment remains the combination of standardised tools alongside a clinical assessment by a mental health practitioner. One also needs to be aware that serious illness and life-limiting disease is not the experience of the individual patient alone; rather, it is something that is part of a family's experience. Thus, the way in which the breaking of bad news is handled, diseases are managed and the family patterns of communication are recognised and constructively approached will all have an impact on the way in which the patient copes with the end of their life and for the significant others (usually the family) into their grief. The issue of mental capacity and mental illness is a significant and difficult one to address and, as stated above, the Mental Capacity Bill is currently taking this forward. When one combines the difficulties of mental capacity with consent to treatment or the withholding/withdrawal of treatment at the end of life, this becomes even more complex and emotive. It is an issue of conscience, moral, religious and ethical beliefs as much as having an evidence base on which to draw. Despite this, it is important to try and stand back from the emotion and take heed of the evidence that has been garnered thus far in order to enable patients, families and clinicians to make sound judgments. We believe that it is more helpful to talk about mental capacity, and the functional interpretation of this, than mental incapacity or impairment when talking about a person's ability to make informed decisions with regard to their health care. As stated above, there is a significant incidence of moderate to severe depression and anxiety at various stages throughout the course of many diseases. Measurement of these difficulties is problematic, particularly at the end of life, because many of the "symptoms" of depression are confounded by the symptoms of disease. One also needs to consider that the issues of despair and suffering are, for many of us, natural and expected consequences of facing the end of one's life and may not be indicators of depression. It is important to recognise this and allow the individual to express their despair rather than medicalising it and thus make the individual vulnerable to inappropriate treatments. Thus, there are a number of paradigms from which one can understand depression and

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anxiety at the end of life. The issue of suffering is profoundly complex and multifaceted, and to medicalise it and see it as potentially another illness could be to trivialise or ignore other aspects of the human condition, including the wish to have one's life ended sooner than the disease trajectory might indicate. Similarly, a person may have a wish for their suffering to be over and see the only option available to them as death, but, when this is discussed with them in detail, they may have different views. Therefore, an expressed wish to die may not indicate an express intention to die, or be assisted in one's dying, or be indicative of clinical depression or anxiety. One may also argue that having a degree of clinical depression does not imply lack of capacity to make rational choices about one's treatment, wish to live or die or to be able to engage in a discussion about options, including assisted dying. Often the anxiety about these kinds of discussions rests with the professionals who are called upon to talk them through. It may also be naïve to underestimate the effects of treating end-of-life symptoms, which often have a component of existential distress, with medications that may also, as a side-effect, hasten the end of life (the law of double effect). This prepared statement has sought to outline a number of the psychological issues relating to the end of life and the role of assisted dying. In doing so, we have considered mental capacity, the incidence and effects of depression in life-limiting disease and the relatively few people who still have chosen to take their own lives as a result of having the disease, despite not having a clinical depression. We have also outlined the difficulty in making an assessment of mental capacity in such a population, and this is largely because current assessments are not sufficiently robust to make definitive diagnoses. We believe that it is fundamental that any assessment should be the responsibility of the multi-disciplinary team and not a single clinician, and this would conform to the ethos of multi-disciplinary team-working as discussed by the Division of Clinical Psychology. This assessment must also involve the family and/or significant others in the person's life. Clearly, when undertaking and interpreting specific test results, clinical psychologists play a key role, particularly given our professional training, as outlined above, and involvement in the development and use of psychometric and psychological tests. If the clinical psychologist also has expertise in specialist palliative care, this can only enhance the richness of their understanding of the issues. Given the above, neither Dr McWilliams nor I believe that we are currently in a position to take a stance with regard to assisted dying in this country. We also understand that this would be a view held by significant members of our profession. Neither does the Bill in its current form appear sufficiently

developed with regard to the current complexities outlined above, although we do believe that it offers a great opportunity to widen the debate within society as a whole. It is also the case that the NICE guidance is relatively new and requires time in order to assess its impact on oncology, palliative and SPC services. Over time, we hope that information and research that becomes available from the implementation of the guidance will more fully inform this current debate. However, in addition to all this, we would welcome a wider public debate on the issue and, as stated at the outset of this paper, this is likely to happen because of a variety of other pressures from the human rights and other domains. Additionally, there is pressure from users of services to have a greater voice in decision-making in healthcare, and this is likely to be a more positive influence in the coming years. If this were to be the case, and the Bill were to be redrafted in the future, we would encourage the formation of an all-party working group on the matter, and we are confident that the British Psychological Society would be very pleased to convene a working party, much as the American Psychological Association did in response to the issue of Assisted Suicide and End-of-Life Issues. This latter would allow for the profession to offer a more considered and representative opinion on the issue and, perhaps of greater importance, give the opportunity for clinicians to reflect on these issues, not only with other colleagues, but also with the clients that we serve. Thank you.

Chairman: *I think you have been kind enough to furnish sufficient copies for everyone to have one but we do have questions.*

Q476 Baroness Finlay of Llandaff: I wonder if you could outline the effect on somebody of being told there is nothing more that can be done for them and the effect on them of being offered to be killed, offered assisted dying?

Mrs Kalus: It seems to me there are two separate issues there. I think the effect of being told that one has metastatic disease, is that what you are asking?

Q477 Baroness Finlay of Llandaff: No. I was asking what the effect is of being told there is nothing more that can be done, specifically?

Mrs Kalus: Specifically, other than palliation or nothing at all?

Q478 Baroness Finlay of Llandaff: No. Many doctors say to patients there is nothing more that can be done, rather than "there is nothing more that I can do, and I will refer you onto somebody else".

Mrs Kalus: I think that was what I was trying to think through in response to your question because I guess one has to think about definitions of "done".

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Nothing more to be done or maybe there is something that can be done needs to be thought of very clearly.

Q479 Baroness Finlay of Llandaff: I was wondering from your perception as a clinical psychologist what you saw as the effect of that on a patient's thinking?
Mrs Kalus: My hesitation is that it so much depends on the context and the way in which that news is given. It depends on the person's previous understanding because if the patient themselves previously had some hope and this consultation, if you like, takes away hope then there may be one possible reaction but, if it reinforces what the patient and family believed in the first place, it may have a different effect. If it is the former case where somebody has perhaps been given reason for hope for further treatment, extended periods of remission or whatever—I am thinking specifically about the case for people with cancer not necessarily other diseases—and then that hope is taken away, potentially I think that can be the trigger for an episode of depression and anxiety or hopelessness in that individual.

Dr McWilliams: Could I add to that. If I look from my experiences within an acute hospital setting, as a consequence of being told news in that way. The psychological sequelae has been quite severe. It is an issue of communication training for medical practitioners who are in the position of giving that news. It is interesting to me that the news should be given that way, but I know from my clinical experience that it is. I do not think there is any real reason why news should be given in that way at all. I think it is inexcusable but I do know that it happens and I do agree the psychological sequelae of that is severe.

Q480 Baroness Finlay of Llandaff: I realise you do not have experience of patients being offered assistance in dying but I wonder if you can extrapolate, from your own clinical experience, what you think that effect may be on patients' perception of their future?

Dr McWilliams: Within the context you have just described?

Q481 Baroness Finlay of Llandaff: Within the context of the Bill.

Dr McWilliams: Within the scenario which you just described?

Q482 Baroness Finlay of Llandaff: Maybe linked to it, but not necessarily.

Dr McWilliams: I think that is quite hard to second guess. If I go back to the scenario which you have outlined, I think that it would be extremely unhelpful

for news to be broken in that way, followed by “but there is assisted dying”, I think that would be unprofessional within the context of a specialist palliative care service, which is both mine and my colleague's more recent experience.

Q483 Baroness Finlay of Llandaff: I was not thinking of it in that context because I was hoping nobody working in the specialist service would have such poor communication skills.

Mrs Kalus: For me it is about—as we talked about in the paper—doctor/patient relationships. Hopefully, people are becoming or will become much more skilled in the management of breaking bad news. I would hope that it would not happen that way around, that somebody would be offered assisted dying, that is why I see them as two separate issues. It maybe that somebody, who in time, once they have had time to process the information, would have made that as a choice for themselves. Although, I think as we have said, we have racked our brains and our combined experience of working in specialist palliative care and there have been very few people who would have chosen to go through with assisted dying, who were consistent about their wish to die or to be helped to die had it been available for them, and that may have been the right outcome for them. The majority of people we find fluctuate and it fluctuates on the basis of symptom control, pain management, but also much more around issues of quality of life, relationships and communication within the family and with other professionals.

Q484 Lord Turnberg: I am interested in your broad experience in the field. We have tended to focus on the fact that there is a group of patients who wish to preserve their autonomy and control of their daily lives. I am interested in the business of relievable and un-relievable suffering. We seem to be getting the message that most suffering is relievable but can that be the case? Is there not a kernel of patients who have un-relievable suffering?

Mrs Kalus: Yes. I think there will inevitably be a small number of people whose suffering remains unacceptable to them.

Q485 Lord Turnberg: What form does that take? We are told that pain can be relieved.

Mrs Kalus: Both in my clinical experience and also from reading some of the work that has come from Oregon and other places, it is for a very small number of people, almost irrespective of their experience of physical pain. One can talk about spiritual pain and one can read about emotional pain, but it is something around one's sense of hopelessness and one's sense of being able to manage oneself in terms of issues of dignity, self-respect; autonomy is a really

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difficult one, I think that is a whole other debate. People feel that aspect of their lives has diminished to the degree that it becomes unacceptable. For others, for the majority of people, if they make incremental adjustments to what is happening, they are not necessarily happy but, I think that suffering can become manageable. I am not trying to diminish it.

Q486 Lord Turnberg: I am thinking of non-pain suffering like incontinence, breathlessness, inability to swallow and inability to eat, those sorts of symptoms, are they all relievable?

Mrs Kalus: They are not all relievable. They can be better managed and sometimes particularly issues around breathlessness—it depends on the nature of the disease—some of the issues that can manifest themselves around anxiety, that can also manifest themselves as specific symptoms, if people have their anxiety better managed, it may be by medication but more often than not it is around communication and reassurance that death can be managed in a dignified way. I hope it is the expertise, particularly of specialist palliative care, but who also are trying to enable other health professionals to do that.

Q487 Lord Turnberg: I am thinking of a patient who cannot swallow, who has dysphagia, who is incontinent, who is unable to speak properly. You are able to help those people?

Mrs Kalus: There would be a significant minority of those people who we cannot help and I was thinking about people with, for example, diseases like motor neurone disease which is particularly difficult to manage. They may be a group of people who would make a choice to have assisted suicide, then you get into issues of proxy and advanced directives and many other ramifications.

Q488 Lord McColl of Dulwich: If the relatives of the patient who is going to be helped to kill himself are not to be informed or do not need to be informed, what effect do you think that suicide will have on the relatives?

Mrs Kalus: Can you clarify about “are not to be informed”?

Q489 Lord McColl of Dulwich: Where they do not need to be informed?

Mrs Kalus: Where would that decision come from?

Q490 Lord McColl of Dulwich: The Bill.

Mrs Kalus: Within the Bill, yes, I am sorry I was still thinking as a clinician. I think we do not know is the answer to that. The research on bereavement outcome from countries where assisted dying has happened is so poor I think at this stage, that it is an open question. Certainly were this to go into another

phase—this Bill—a wider possibility for debate, I would hope that would be one of the areas of research that we could look at from Oregon, from Holland and the various places where that is happening. At the current point, most of the research is actually cross-sectional, and I think when you are doing research with people who are bereaved, bereavement is a process, it is not a one-off experience so you need to have longitudinal studies, and I think we do not know that yet.

Q491 Lord McColl of Dulwich: Would you hazard a guess that a lot of relatives would be rather upset by it?

Mrs Kalus: Hazarding guesses is dangerous but, if we extrapolate from the information we have got where people with more severe mental health problems complete suicide, and working with looking at literature on bereavement from those people, in so far as it is possible to extrapolate, it could be a contributory factor to complex grief and long term difficulties. Certainly, from my own clinical experience, I have worked with people who are bereaved as a result of somebody committing suicide, it has been an extremely difficult issue for them. They are very small numbers and I am only going to see a skewed population of the bereaved community. I think that would be as far as I felt comfortable to go.

Q492 Lord Joffe: In relation to that last point, what the Bill says is that the patient should be recommended to speak to their relative but, it is up to the patient in the final result. Would that affect your view where a patient has decided he or she does not want their relatives to know?

Mrs Kalus: Affect my view in?

Q493 Lord Joffe: The view which you have just expressed to Lord McColl on it causing greater grief amongst the relatives?

Mrs Kalus: I think it is only possible to respond to that on a case by case basis, on an individual basis. My concern would be it could make bereavement more difficult to manage. However, often, particularly in the situation where somebody has a life limiting disease—if this does not sound too back to front—there is a lot of communication that does not happen overtly within families. It is as if people need to protect each other from the difficult emotional reactions that are happening within the family. For example, it might well be if the families were spoken with, assessed—or whatever word one wants to use—after the death or even around the time of the death of that person, they would say “We thought something like that might be happening, but we did not want to discuss it because we thought it might be too upsetting.” People often know more

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then they let on that they know. Does that answer the question.

Q494 Lord Joffe: Yes. Can I move on to one other point which was about the importance of multi-disciplinary teams in making assessments. Did you interpret the Bill as you have seen it as excluding the reference to multi-disciplinary teams?

Mrs Kalus: No, not at all. It is something that we would welcome and want to reiterate and it is something that is also very important. Certainly, I know specialist palliative care best, and working within a multi-disciplinary team is very important when you are providing support and care interventions for people who are experiencing very complex problems and living and a very complex life.

Q495 Lord Taverne: We have not yet visited The Netherlands so we do not speak with any authority about evidence from The Netherlands but, so far on the literature, there seems to be some suggestion that as a result of the Dutch law there is much more open discussion between doctors and patients about the process of dying, with the families very much involved, is that not something which would ease the question of bereavement?

Mrs Kalus: We would hope so, and certainly what limited evidence there is from The Netherlands in the bereavement and as I say, research we have to have the caveat that the methodology is not all that it could be, but it has opened up the discussion, it has not necessarily made a big difference to uptake of palliative care services. Certainly I think that is the case in Oregon and I am aware there are some longitudinal bereavement studies going on.

Q496 Lord Taverne: To open up the discussion, is this not a good thing? It eases the process.

Mrs Kalus: Absolutely, it opens up the discussion. Hopefully, one of the things we discuss in our paper is that often it is quite difficult for the professionals to open up the discussion. Hopefully, it eases things on both sides and makes it much more overt because I think what is covert is not always helpful.

Dr McWilliams: I just wanted to add a couple of points with regard to issues of discussion and capacity. I do not know whether this is a good point to bring this in. I had conducted some research several years ago with dementia sufferers, with their psychiatrists and their carers, which indicated that dementia did not preclude ability to consent or to have knowledge of their disease and—to pick up on my colleague's point—that others were trying to protect them. In fact, they had good knowledge of their disease which was beyond what others thought they had, they had picked up, in other words. I think I would like to add something to Baroness Finlay's

question about not disclosing the wish to have assisted dying with relatives and just to add to what my colleague has said on that. My concern when I read the Bill was that potentially there could be a conflict situation and I think it needs more debate. I do not have a view but it was something when I read the Bill that did stand out for me. Finally, I think the bereavement issues, for me the research is still in its early stages because we still have so few places where assisted dying is legal and it is quite difficult to come to any conclusions at the moment. That is all I want to add.

Q497 Baroness Hayman: I would like to follow this up with a question about research on bereavements. Mrs Kalus referred to bereaved people who felt very bad after a relative had a bad death because they have not been able to help them access services, or allow them to fulfil their wish to die. I wondered if there was any longitudinal research going on about how bad people feel when they have seen a death of someone who was in great distress whether it was pain, other symptoms, loss of dignity and control or indeed a legitimate—not imposed by relatives—concern that they were dragging out and putting great emotional distress on their relatives.

Mrs Kalus: There is current research going on. I think research into bereavement became more well established about 30 or 35 years ago with work by people like Colin Murray Parkes and Elizabeth Kubler Ross in America who have all looked at complex and less complex grief and one of the factors from then, and it has gone through the literature consistently up until the present day, that can predict complicated grief, or a complex reaction to a bereavement, is the nature of the death. That clearly will include sudden death, murder, suicide as we have discussed earlier but also where there are difficulties in terms of the last few weeks, 8–12 weeks of life, and if there has been difficulty with symptom management, or if the death itself is traumatic as a result of unmanageable physical or psychological distress.

Q498 Baroness Hayman: It would be fair to say there are emotional sequelae of the current legislative position?

Mrs Kalus: Absolutely, not just emotional sequelae there are also very well documented physical sequelae as a result of complex grief, it seems to have an effect on the auto-immune system.

Q499 Lord Joffe: Might I ask one question arising out of this particular point. I do not know if you are aware of the research paper, I think it was in The Netherlands, by somebody called Koenig who researched this precise point and came and set up one

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sample of relatives who had died of natural deaths and another set from relatives who died through assisted dying or euthanasia as it is in Holland. Finally, his conclusion was that the relatives of the patients who had had an assisted death were much more able to come to terms with that death than the other group of patients.

Mrs Kalus: Those would be the early indicators and I find it interesting to draw a parallel between that work and the work that is more robust in the field of adjustment to bereavement and organ donation. Often people who have died and are involved with organ donation have died a more traumatic death which would be an indicator of complicated grief. However, a mediating factor seems to be there is more of a sense of meaning. It is possible to integrate the trauma of the death and some sense of control, and that seems to be the issue in the bereavement outcome, some sense of control. One may be able to argue the same once more research has been done in terms of adjustment to bereavement and how we then understand our role in the dying process with the person who has died, and how we integrate meaning and, if you like, recreate a story around the person's dying which is potentially less traumatic. That would

be my hypothesis but I think, as I keep saying, the work needs to be done over a longer term. That would be my hypothesis, it would also be my hope but we just do not know.

Q500 Chairman: Are you going to be able to give us reference to the literature on research into bereavement that you have been referring to, Mrs Kalus?

Mrs Kalus: There is a fairly extensive reference list with the document that we have given you. Certainly I can, through the Clerk of the Committee, send some more references specifically within the bereavement literature.

Q501 Chairman: I just want to have some way into that.

Mrs Kalus: That is fine.

Q502 Chairman: Is there anything you would like to add, Dr Lloyd?

Dr Lloyd: No.

Chairman: Thank you all very much indeed for being so helpful to us. We will have a chance of studying your initial statement more fully than we have earlier. Thank you very much indeed.

 THURSDAY 2 DECEMBER 2004

Present	Arran, E	McColl of Dulwich, L
	Carlile of Berriew, L	St Albans, Bp
	Finlay of Llandaff, B	Taverne, L
	Hayman, B	Thomas of Walliswood, B
	Joffe, L	Turnberg, L
	Mackay of Clashfern, L	
	(Chairman)	

Memorandum by the Disability Rights Commission
1. EXECUTIVE SUMMARY

1.1 The DRC opposed Lord Joffe's Patient (Assisted Dying) Bill. While the new Bill contains notable revisions and an attempt to provide some safeguards for disabled people it does not overcome our concerns and the DRC position has therefore not changed. We believe that to legalise assisted dying at this stage is too risky and could threaten the lives of many disabled people.

1.2 The DRC is committed to the principle of autonomy for disabled people. Individual disabled people should be able to make autonomous choices, including potentially choosing the manner and time of their death. Therefore we do not oppose, in principle, legalisation of euthanasia for people who freely choose it.

1.3 However we believe that in the current climate of discrimination against disabled people, and where lack of access to palliative care and social support means that free choice does not exist, the threat to the lives of disabled people posed by such legislation is real and significant.

1.4 In contrast to Lord Joffe's opinion that this Bill will not place the vulnerable at risk, the BMA has stated in 2004 that "the benefits [of legalising assisted dying] for an individual in terms of having their wishes respected, is only achievable at too high a cost in terms of the potential harm to society at large" and that "in particular, it could undermine the trust that vulnerable, elderly, disabled or very ill patients have in the health care system".

1.5 The previous Select Committee that looked into this issue in 1994 concluded along similar lines, saying that "we believe that the issue of euthanasia is one in which the interest of the individual cannot be separated from the interests of society as a whole".

1.6 Given the shared concerns of many disabled people, the previous Committee that studied the issue, and one of the most authoritative medical bodies, the DRC does not believe this Bill has addressed enough of the concerns of those that it might most affect to progress.

1.7 The new Bill's provision for palliative care and other options to be offered is welcome. However, there is no guarantee options would be available in practice, nor is there any "right" to palliative care. Having something offered and/or explained is far different from having the right—or even possibility—to receive it. Current demand far outstrips supply in the UK for palliative care, independent living support and hospice and respite care. Fewer than half the people that wish to die at home are currently able to do so. Informatively, 66 per cent of all doctors reported that they believed pressure for euthanasia would be lower if resources for the hospice movement were increased. People might request an assisted death in the absence of services, undermining the principle of autonomy and not representing a real choice for patients.

1.8 The DRC believes it is essential to improve palliative care, and make it available equally and accessibly across the country, before assisted dying is offered to patients. This is in line with the July 2004 House of Common's Health Committee report on palliative care recommendations, the 1994 conclusions of the Select Committee on Medical Ethics, and World Health Organisation recommendations. WHO recommend that governments demonstrate availability and practice of palliative care before considering assisted suicide/euthanasia.

1.9 Evidence from where assisted dying has been legalised shows that, however stringent, safeguards are not working effectively enough. Although Lord Joffe has worked hard on this Bill to produce what are believed by some to be strong safeguards, the DRC does not believe they afford better protection than other countries' legislation. The threat to disabled people remains too real and significant, especially given the current

inadequacies in palliative care, and the inequality, prejudices and discrimination faced by disabled people in society through assumptions of quality of life and standards of living. This would especially affect those newly diagnosed with terminal illnesses.

1.10 Furthermore, the DRC does not believe the current Bill to be a workable piece of legislation for the reasons outlined in section 12.

1.11 We hope the Select Committee will consider the substantial systemic changes and support services necessary to support the opportunity of all people with terminal illnesses to live as full lives as possible, to be active members of their families and communities, to not regard themselves or be seen by others as a burden, and to have genuine choices about the nature of their lives and deaths, including:

- Revising discriminatory aspects of guidelines on withholding or withdrawal of life saving treatment.
- Demonstrably reducing discrimination and inequalities in health services.
- Developing national criteria for continuing care to remove anomalies between strategic health authorities.
- Ensuring that people's needs for domestic help are adequately supported and that aids and adaptations are promptly made in people's homes to allow them to stay there during their last days.
- Improving the provision of hospice and specialist palliative care services to ensure a better match between need and provision.
- Implementing robust mental capacity legislation which empowers disabled people to make more free choices about their lives.
- Improving palliative care provision significantly.
- Providing adequate resources for hospice care.
- Implementing a right to independent advocacy and effective rights to communication support.
- Implementing a right to independent living with easy access to support services.

2. INTRODUCTION

2.1 The Disability Rights Commission's goal is a society where all disabled people can participate fully as equal citizens. The DRC was created by the Disability Rights Commission Act 1999. The Act imposes the following duties on the Commission:

- to work towards the elimination of discrimination against disabled persons.
- to promote the equalisation of opportunities for disabled persons.
- to take such steps as is considered appropriate with a view to encouraging good practice in the treatment of disabled persons.
- to keep under review the workings of the Disability Discrimination Act (DDA) 1995 and this Act.

2.2 The DRC works to improve the situation of all those afforded protection by the DDA. This includes those with long-term, significant health conditions and terminal illnesses. The DDA definition of disabled people covers people with conditions such as HIV/AIDS, MS, Motor Neurone Disease, cancer, heart disease and many other terminal (or potentially terminal) conditions.

2.3 This evidence provides:

- an outline of our general concerns about legalisation of assisted suicide and an explanation of why the DRC believes it remains unacceptable to legalise assisted suicide at this time; and
- an analysis of the new Bill and explanation of why it still presents threats to the lives and equality of disabled people.

3. LEGALISATION OF ASSISTED SUICIDE: BACKGROUND TO THE DEBATE AND GENERAL CONCERNS

3.1 Equality, rights and choices.

3.2 The DRC believes that disabled people should be treated equally and have equal rights to those of non-disabled people. We have a responsibility towards all disabled people. We are not making a general "moral" judgement on whether assisted suicide should be legalised. We base our view on the effect that such legalisation would have on the lives of disabled people, including those with terminal illnesses. The DRC takes very seriously the principle of autonomy expressed in the phrase "a right to die".

3.3 However, we believe that the right to live is equally important. Alongside the wishes of people like Diane Pretty, we hear the voices of people such as Leslie Burke (see 6.3), Jane Campbell and organisations of disabled people such as Very Much Alive and No Less Human, who say that to legalise euthanasia will lead to direct or indirect coercion of disabled people to express a wish to die.

3.4 The odds are currently stacked, legally, against people's positive choices to have access to treatment/services; and in favour of people's right to refuse them. Every patient capable of making decisions already has the right to request the withdrawal of treatment, even where to do so may result in their death. This legal tenet has been tested and upheld. Many people with terminal illnesses will decide that the time has come to withdraw a particular treatment, such as chemotherapy. They are entitled to do this and to receive any and all forms of symptom relief—resources allowing.

3.5 Any increase in rights to refuse treatment or die would tilt the balance further. In the view of the DRC the priority lies in establishing genuine choice, to ensure first that people have rights to agreed standards of palliative care and rights to independent living—ie rights to be supported to live (and die) at home (where possible), rights to respite services such that relatives are not exhausted, rights to the type of support that can make life worth living. Until such rights are in place it is risky to legislate in favour of assisted suicide. These rights must be in place before death should be sanctioned by the state and legal system.

3.6 There are other forms of “false” choices. Coercion might come through direct pressure from family, friends or health professionals, acting with malign or benign intent; or simply through the terminally ill person considering themselves to be a burden, eating into the financial or human resources of family or the state. The very limited representations of disabled people in the media also contribute to a context in which many contemplating serious ill health or progressive disease regard it as “a fate worse than death”.

4. CULTURE AND THE MEDIA

4.1 Culturally, we are still surrounded by narratives and images of “mercy killing”—by the notion that “of course”, “naturally” it is a kindness to help people who are terminally ill or significantly disabled (or both) to die. In recent months alone, major media stories have included the case of Jacob Wragg, a 10 year old with Hunters Syndrome, killed by his father who was cheered when released on bail. This story gained extensive coverage; most of it favouring Jacob's father's actions, speaking of his “private hell”, “pure relief” and how he “killed for love”. This is despite the fact that there is no evidence Jacob or his mother wanted him to die. The DRC suggests this is not “mercy” for the child, but an act—understandable or not—of desperation. We also saw publication of the inquiry into the killing of Sarah Lawson, a 22-year old with manic depression, by her father through first giving a drugs overdose and, when that failed, smothering her. He was not jailed as his act was also seen as one of “mercy”. He has since declared that “Looking back, I have no regrets”.

4.2 In a society in which deliberate killings of disabled or terminally ill people are viewed as benign acts of “mercy”, even when the deceased had not clearly stated this was what they were seeking, it is little surprise that many people with progressive conditions are afraid of making assisted suicide easier. It could mean their lives were accorded even less worth and the choice to die may become the most obvious response—the fall-back position. The choice to die could be “positively” offered, rather than given as a last resort. It would be hard to prevent that happening in a culture that believes mercy killing is acceptable. Furthermore, if someone was helped to die and later there was uncertainty about if this was their decision, how strongly the case was investigated might be undermined in a society which assumes that the death was a positive release.

4.3 While the situation in the Harold Shipman case was extraordinary, the fact that his behaviour went unnoticed for so long may not be unrelated to the fact that many of his victims had “terminal” conditions and were mostly elderly women.

4.4 To disentangle the genuine effects of living with a terminal illness from the impact of cultural/societal perceptions of disability, the effect of inappropriate housing and lack of support and respite care for families, is in most cases impossible. Dianne Pretty slept in an armchair in her living room and her husband provided much of her care. But the coverage of such high profile cases as hers may have increased many people's anxiety about what the end will mean. People naturally fear death and want to be reassured that it will be as easy as possible. The Motor Neurone Disease Association provides the following information on its website:

4.4.1 “MYTH—People with Motor Neurone Disease die by choking to death.

4.4.2 “MYTH—People with Motor Neurone Disease die from suffocation.

4.4.3 “REALITY—The most common cause of death in people with MND is respiratory failure due to weakness in the muscles and death is very peaceful. It is very rare for someone to die from choking to death. People will never suffocate as a result of MND”.

5. INDIRECT COERCION TO SEEK ASSISTANCE TO DIE DUE TO A LACK OF SOCIAL SUPPORT AND SOCIAL EXCLUSION

5.1 Many disabled people do not have access to good healthcare and adequate and properly resourced social support and this can lead to indignity and lack of independence. Many carers do not receive the help they need to support the person they care for and to have a good quality of life themselves. The level of support provided to those with caring responsibilities at home is often inadequate, especially as many carers experience ill-health themselves. Fifty-nine per cent of carers do not get regular visits from health, social service or voluntary agencies.

5.2 The DRC believes that disabled people and their families are subject to indirect coercion that could lead to a request for an assisted death. There is evidence that many disabled people are living intolerable lives, not because of their impairment, but due to lack of choice, control and autonomy brought about by the lack of basic amenities and support services including inaccessible and inadequate housing, insufficient help with personal care, and lack of essential equipment:

5.2.1 This leads to indignity and unacceptable reliance on others. Many disabled people and their families have inadequate income, are reliant on benefits or are in lower paid jobs. Disabled people face social exclusion through inaccessible mainstream schools, discrimination in employment and inaccessible public transport.

5.2.2 Disabled people and their families and carers are under impossible strain due to the above, which leads to disabled people feeling they are an unacceptable burden on loved ones. These forms of indirect coercion are of great concern to the DRC and nothing in the Bill seeks to address them. We believe it places disabled people in an unfair position in society and they would be made more vulnerable by legalising assisted dying. Indirect coercion forms one of the major reasons why the DRC believes that now is not the time for legalisation—even if a Bill was created that addressed our other concerns.

5.3 The DRC believes the Bill would reduce the autonomy of disabled people. It would represent the failure to portray alternatives to death as viable options and would add weight, through acceptance of the legalisation of assisted dying, to the belief that an early death is the only choice for people with terminal illnesses in the interests of themselves and loved ones. This situation could alienate still further some of the most vulnerable disabled people with terminal illnesses and reduce their perceived choices to just one—an assisted death.

5.4 It is impossible to guess how many people in the circumstances outlined above would choose an assisted death. However, there is a body of opinion among not only disabled people, but also ethicists and the legal and medical professions that believes there is such a significant risk that they have recommended euthanasia is not legalised. Apart from the 1994 House of Lords Select Committee that looked at the issue, opponents to legalisation have included the BMA and Royal Colleges throughout the passage of this Bill (and including in their most recent statements), the leaders of the main faiths in the UK and a plethora of disability organisations, including the DRC.

5.5 The recent House of Commons report on palliative care recommended the Department of Health consider the Marie Curie analysis of potential cost benefits of more patients dying at home, which Stephen Ladyman has said could provide “massive savings”. The report concluded that “while we sympathise with, and support, the aspiration to allow all patients to die at home if they choose, we question how realistic this objective really is at the present time” given the backdrop of a lack of support and care that mean “relatives and other carers will, understandably, be reluctant to take care of a patient at home”. Many people die in hospitals against their wishes as a direct result of a lack of care and support being provided. This Bill could lead to a “false” choice brought about by having no feasible alternative to an assisted death if the patient wishes to die at home. This could be changed if adequate support services were provided.

5.6 The consequences of a lack of support services, including lack of respite care, have a huge impact on family and other carers. There are many examples of ensuing pressures leading to desperate acts, including the Lawson case mentioned above (4.1). The inquiry into her death reported that she had been repeatedly let down by local service providers, as had her parents (as her carers) as their needs were not assessed. The answer to such circumstances is not to legalise euthanasia but to improve the support available to people requiring it.

5.7 The DRC are pleased the Government is looking to the Canadian success story of care and support and taking actions that could help the situation, eg highlighting the potential savings of allowing people the choice of full care and support to die at home. We believe it is inappropriate to pre-empt or undermine any benefits to people with terminal illnesses this work might result in, by permitting patients to request assisted deaths before the situation has had time to change.

6. FEAR OF DIRECT COERCION AND FEARS FOR VULNERABLE PEOPLE

6.1 There is evidence that direct coercion to die already takes place. The Cheney case in Oregon is infamous amongst those with an interest in assisted dying laws, their safeguards and ways people have found around them. There is also UK evidence of direct coercion. Baroness Finlay provided an example from her practice of an ill lady aged 59. Her family appeared concerned about her pain and constantly asked for her diamorphine to be increased. The medical team were unconvinced the pain was really that severe and the patient declined higher doses. Her 60th birthday passed with minimal celebration, after which the family rarely visited. The lady became depressed and explained the problem was that on her 60th birthday her fixed-term life insurance policy expired. The family would not now inherit what they thought they would if she had died—and if her drugs had been increased.

6.2 It is not unrealistic to expect that there will be individuals who would similarly attempt to use any legalisation of euthanasia to further their own interests. Equally, it is difficult to envisage regulation that could prevent all such incidents, and we do not believe that other assisted dying legislation has done so elsewhere.

6.3 The DRC intervened in the *Burke vs GMC* case this year. Leslie Burke was so concerned food and fluid might be withdrawn from him after he ceased to be able to express his own views that he took a case to the High Court in 2004, challenging GMC guidelines. Mr Justice Munby, in his judgement, praised the GMC guidance on the withholding and withdrawal of treatment as a generally compelling piece of guidance but stated:

6.3.1 “There is in my judgement unanswerable force in the point made by Dr Keith Andrews and by Jane Campbell . . . namely that the emphasis throughout the Guidance is on the right of the competent patient to refuse treatment rather than on his right—in the sense in which I have discussed it...to require treatment. One can see this error creeping into the Guidance in different ways”.

6.4 In this sentence the judge highlighted the fundamental difficulty with rights in relation to treatment: the presumption in favour of the right to refuse; the easier path to specifying a wish to die, than a wish to live:

6.4.1 The judge found in Mr Burke’s favour, which may suggest that the positive right to life-saving treatment is now legally accepted. However, he stated: “This is not a case about the prioritisation or allocation of resources, whether human, medical or financial”.

6.5 This means that there can be no guarantee as we become an ever older population that the threshold for entitlement to treatment will not be set very low. This could mean people request death in the absence of real choice through positive treatment or social service alternatives. It could mean Hobson’s choice between dying or living with inadequate treatment or support for oneself and one’s family.

6.6 British courts have not generally been inclined to grant positive rights to treatment or social service. It should not be forgotten that David Glass and his mother Carol were not helped by the British legal system. It was only when the case eventually reached the European Court of Human Rights that they successfully brought a claim of human rights abuse against the UK as the court held unanimously that there had been a violation of Article 8 (right to respect for private life) of the European Convention on Human Rights.

6.7 The DRC was interested to see Baroness Howells’ contribution to the second reading of the original Bill and does not believe her concerns have yet been addressed. She spoke of institutional racism leading to limited choices in all areas of life for some Black people. The fear is that this Bill would place those from minority ethnic communities with terminal illnesses more at risk than other people—in an already discriminatory society. The DRC is concerned that those facing multiple disadvantages, eg elderly disabled people with terminal illnesses from Black or minority ethnic communities, would be placed at a greater risk by the passing of this Bill and could, through societal attitudes (rather than personal choice or autonomy), be more likely to request an assisted death.

7. LACK OF PALLIATIVE CARE

7.1 Access to palliative care, including effective pain relief, is essential in supporting autonomy and enabling people to live with dignity. It is accepted by the Government that good palliative care is not available to everyone who needs it. There is evidence that people who do not receive good palliative care seek assistance to die in the UK due to lack of effective pain relief, depression, or both. Doctors who currently face being unable to treat patients who are suffering and ask for help to die would no longer be constrained by the law. It seems likely that if assistance to die were lawful, those who do not have access to good quality palliative care would be more likely to ask for assistance to die—extending the postcode lottery to the manner of one’s death.

7.2 The House of Commons Select Committee on Health published a report on palliative care in July 2004. The DRC believes its conclusions are so relevant and important that we would like to quote them at length. The Committee Chairman stated:

- 7.2.1 “The right to a good death should be fundamental. Care and respect of those with terminal illness is a key indicator of society’s values.
- 7.2.2 “We hear much of the “choice” agenda in the NHS at present. But for those who are terminally ill, choices are not being realised. Around 55 per cent of people die in hospital but many of these individuals would prefer to die at home—in fact, fewer than half of those wishing to die at home do so. A number of barriers prevent them. We would like to see more done to support people in their own homes.
- 7.2.3 “We call on the Government to consider advances in care currently being achieved in Canada and in particular to introduce a statutory right to a period of paid leave for carers. We have also—as so often—encountered problems in the gap between personal social care, which is means tested, and healthcare, which is free. It is high time this divide was overcome and an integrated structure produced.
- 7.2.4 We found worrying evidence of inequities in service provision. Some affluent areas have plenty of hospices, for example, while others have few. Those with complex needs, or from black and minority ethnic communities, seem less able to access services. We hope that the best practice that exists patchily will be rolled out nationally and that the representation of the National Partnership Group for Palliative Care will be widened.
- 7.2.5 Above all, there is a huge mismatch between provision for cancer services and that for other illnesses. Around a quarter of us will die from cancer, but over 95 per cent of hospice places are taken by those suffering from that disease. Those who are terminally ill with, say, Motor Neurone Disease, or heart disease are most unlikely to use specialist services. So we call for the NSF for long-term conditions to incorporate the key principles of the NICE guidance on supportive and palliative care as far as possible to remove the bias against treating other diseases.
- 7.2.6 The Treasury cross-cutting review in 2006 will entail the state paying for the services which it currently receives with a large subsidy from the voluntary sector. I hope that this will be used as an opportunity to provide more equitable provision, with funding being provided—and if necessary withheld—according to need.
- 7.2.7 I want to be clear that the Department deserves much praise for recent initiatives in palliative care. The workforce is set to double by 2015, over £50 million has been put into services . . . Protocols for care of the terminally ill are doing much to improve standards of treatment by non-specialist services and we call for them to be introduced as quickly as possible.
- 7.2.8 “Finally, it has to be acknowledged that death has become a taboo subject and that the fact of death is much less visible to young people today than it was in previous generations. So we call for moves by the Department for Education and Skills to examine the place of education about death both within the curriculum and teacher training.”

7.3 It has been claimed by some that palliative care does not always work and has been proved ineffective. The DRC believes that in the vast majority of cases this is not the case. It is stated by palliative care professionals that drugs can control most pain for most people—the ability to control physical pain is limited to a slight degree in just five per cent of people. Palliative care can ease the way to a painless and peaceful death even in the case of Motor Neurone Disease. Supportive care can also help to maintain the dignity and quality of life.

7.4 The DRC is concerned that, as some believe to have occurred in the Netherlands in particular, legalisation of assisted dying could lead to a decline in the availability of palliative care and the wider end-of-life care and support services. The DRC fears that the Government’s recent commitments to increasing the availability of and resources for palliative care could be undermined by this Bill.

8. EVIDENCE OF DISCRIMINATION IN MEDICAL ENCOUNTERS LEADING TO FEAR OF INVOLUNTARY EUTHANASIA

8.1 There is evidence that decisions by health professionals on whether disabled people live or die are sometimes being made on the basis of poorly informed assumptions of disabled people’s lives. Hospital Doctor reported in 1999 that 32 per cent of doctors judge a patients’ “usefulness to society” when considering treatment. Organisations representing elderly people have shown, and the Department of Health acknowledged, that age discrimination is an issue in the health service. Given the correlation between age and

disability, disabled elderly people could be doubly disadvantaged and the risks to this particular group most potent if the law were to change around assisted dying. Perhaps this is a reason Help the Aged oppose legalisation.

8.2 Of course it is hoped that Shipman was a one-off, but it should not be forgotten that he was a doctor and, as such, a trusted member of society with regular access to vulnerable people. We will probably never know his motivation, but the victims were mostly elderly women with medical conditions. It is concerning that in an anonymous survey in Holland, a quarter of physicians reported terminating the lives of patients without an explicit request. Clearly, there are those within the medical profession who act outside of guidelines and accepted practice.

8.3 There is further compelling evidence from research that discrimination in general health services exists. Research has recorded consistent testimony from disabled people and their families about the discriminatory attitudes they face from medical professionals, and poorer services they receive in the NHS.

8.4 Evidence of discrimination in routine health care:

- Breast screening uptake is 76 per cent of women in the UK but just 17 per cent for women with learning disabilities in family care. Cervical screening uptake is 85 per cent of women aged 20–64 but just 3 per cent for women with learning disabilities aged 18 and over in family care.
- 70 per cent of GPs do not provide accessible information despite, to give one example of its necessity, NHS figures showing that a GP with 2000 patients will have 40 with a learning disability.
- Health care professionals do not take some disabled or elderly people's health complaints seriously; "diagnostic overshadowing" takes place—ignoring health problems due to age or previous psychological diagnosis.

8.4.1 These points demonstrate that, even in what some people might consider "routine" medical encounters, disabled people can face discrimination and exclusion. Until doctors are fully capable of meeting the physical and sensory needs of patients, it is doubtful that many disabled people will trust assisted dying legislation.

8.5 The BMA reported in 2004 that "general attitudes towards disability . . . employment structures and procedures . . . lack of resources and facilities . . . have led to direct discrimination based on disability . . . [and] stigma towards people with disabilities" employed by or using health services. These points need addressing before many disabled people will be comfortable with, or have confidence in, medical professionals when discussing assisted dying.

9. WHY ARE SOME DISABLED PEOPLE CALLING FOR LEGALISATION OF EUTHANASIA AND ASSISTED SUICIDE?

9.1 Supporters argue that legalisation would allow people in intolerable pain, or suffering what they would consider intolerable indignity, to choose a dignified, peaceful and painless death at a time of their choosing.

9.2 However, with access to good palliative care, including pain relief, counselling and treatment for depression, and social support to aid independence and dignity, many disabled people could achieve a peaceful and dignified life and death; their anxieties relieved and their enjoyment of life enhanced. Many who currently would choose to die might want to live. The DRC believes it is important that the current situation and its inadequacies are recognised and addressed before assisted dying is offered in lieu of the above.

9.3 It is likely, though, that some people would choose to die even if the best palliative care and support were available. For the few where the ability to control pain is limited and for some others euthanasia may continue to be the choice they want. The DRC does not oppose decisions of disabled people with terminal illnesses to request assisted deaths in these circumstances and where they are viewed as fully equal members of society, which is not currently the case.

9.4 The argument that legalisation of euthanasia would uphold personal autonomy is a compelling one and cannot lightly be put aside. However, the DRC does not believe genuine autonomy is offered to patients by this Bill, given the current lack of support and care available to people that need it and ingrained societal prejudices for example.

9.5 The task force that looked at the issue of the balance of rights in New York concluded unanimously that "no matter how carefully guidelines are framed, assisted suicide and euthanasia will be practiced through the prism of social inequality and bias . . . [and] practices will pose the greatest risk to those who are poor, elderly, members of a minority group, or without access to good medical care". That is why courts here and elsewhere have come down on the side of recommending measures to improve the choices people have in relation to access to palliative care, upholding the right to refuse treatment, but have not supported active assistance to die.

9.6 The DRC and BMA have both stated that this Bill does pose a threat to the lives of some people. The BMA position was made clear in 2004: “the benefits [of legalising assisted dying] for an individual in terms of having their wishes respected, is only achievable at too high a cost in terms of the potential harm to society at large” and that “in particular, it could undermine the trust that vulnerable, elderly, disabled or very ill patients have in the health care system”.

9.7 Supporters of the Bill say that the extent of physician assisted dying taking place in the UK is unknown. They quote a BMA survey from 1996 which found that 3 per cent of doctors had ended the life of a terminally ill patient where the patient had made a request for help to die. This proves, they say, that the lives of many patients are being deliberately ended in the UK; that it demonstrates there is a gap between what the law says and what happens in practice; and that what happens in practice should be properly controlled.

9.8 The DRC does not believe that legalisation will mean the problem of not reporting assistance to die will be resolved. Evidence from countries where it is legal shows that physicians do not report assisting deaths, eg up to 50 per cent of assisted deaths being unreported in Holland.

9.9 If the current law is not being adequately enforced, then legalisation of euthanasia is not the way to protect against involuntary euthanasia. The answer may be to improve current enforcement mechanisms or consider whether the law on so-called “mercy killing” needs to be strengthened.

10. MIGHT IT BE POSSIBLE TO FRAME LEGISLATION AND REGULATION TO ALLOW SOME TERMINALLY ILL PEOPLE ASSISTANCE TO DIE, WHILST SAFEGUARDING THE LIVES OF OTHERS FROM INVOLUNTARY OR COERCED EUTHANASIA?

10.1 The DRC is not aware of any country that has managed to frame a law that allows assisted dying for people with terminal illnesses whilst ensuring that vulnerable people are protected from coercion, indirect pressure, and involuntary euthanasia.

10.2 The evidence from Oregon and the Netherlands shows quite the opposite—that doctors do not comply with registering procedures and many assisted deaths still go unrecorded. The DRC is concerned that until it is shown that adequate legislation can be provided (and be workable and effective) assisted dying should not be legalised here.

10.3 The DRC does not believe this Bill has provided better safeguards than legislation elsewhere. We think it would not protect the lives of many disabled people from involuntary or coerced deaths. The DRC believes that the Bill may, in practice, have the opposite effect, in placing an even greater onus on some disabled people and those with terminal illnesses to request an assisted death.

11. DOES THE BILL OFFER A REAL CHOICE?

11.1 Apart from on palliative care, doctors are still the only ones required to discuss options and this is based on medical prognosis. The Government has established targets on lowering the rate of suicide and, in general, people who say they want to die are offered (as first priority) help to live. There is no provision in the Bill for access to independent advocacy, or help with communication. There is no mention of access to independent information to support decision-making.

11.2 Clinical evidence suggests that when doctors offer assisted suicide to patients the discussion is “closed down” and patients are likely to accept death, whereas when a doctor offers hope of alleviation of suffering or further life, the patient is most likely to opt for life. This throws doubt on the validity of the choice made by the individual. (8.6 is relevant here in how the request comes about.) In addition, discussion relates only to medical alternatives and not to support in the form of personal assistance and other aids to independent living.

11.3 Evidence also suggests that a “polarisation” within the medical profession is likely to occur if legislation is passed, as is the case where it is legal. In the UK, an ORB poll reported in 2003 that 74 per cent of doctors would not participate in assisted deaths—and not one palliative care doctor. This could lead to a sector of medical professionals “specialising” in assisted dying—with perhaps little time or interest in offering alternatives to death seriously or convincingly. It has also been shown that those determined to die, or to coerce someone into it, are able to “shop around” until they find a physician willing to assist. “Compassion in Dying”, an Oregon organisation, helps patients find “supportive” physicians. The DRC does not believe this would be helpful to the medical profession here, or to people seeking genuine patient autonomy.

11.4 To make an informed choice, the person must receive full information on, for example, support available to enable them to live in a dignified manner, choices regarding independent living, and positive life experiences of disabled people. Physicians are seldom the appropriate source of such information. The Bill does not

recognise the context in which decisions are made, including the acute shortage of support services to enable people to live with dignity and control in their own homes.

11.5 There is no evidence that doctors will be equipped to provide unbiased information and effective choice. Indeed, research has shown repeatedly that some medical professionals display negative attitudes towards disabled people and the value of their lives.

11.6 Some disabled people report prediction of underachievement that proves to be incorrect, eg he/she will never walk, never work, never live independently. Medical diagnoses can be wrong. Also, despite Government policy and guidance requiring all consultants to ensure that resuscitation policies are in place and understood by all staff, reviews of the Commission for Health Improvement show that policy and practice regarding resuscitation is still poor. Fears of resuscitation policies are not just being raised by disability organisations; Age Concern raised concerns and received over 100 new cases in just two days.

11.7 As we have already outlined above, the DRC are aware that negative perceptions of life as a disabled person or with a terminal illness are not only held by medical professionals. The general public hold them and they are continually reinforced by the media. When Dr Ian Basnett became quadriplegic 18 years ago, he informed people that he wished to die. He is now glad that assisted dying was not legal and no one could act on his wishes. The image of being a disabled person or living with a severe health condition or terminal illness held by most people and reinforced/actively encouraged by the media, might lead to some people opting for an assisted death without due consideration of alternatives. The DRC believes that this Bill adds to the negative perceptions of disability and would lead to an increased vulnerability of some people if enacted.

12. PARTICULAR CONCERNS REGARDING THE ASSISTED DYING (FOR THE TERMINALLY ILL) BILL

12.1 We welcome the fact that amendments to the Bill acknowledged some of our concerns. Tightening the definition to include only terminally ill people and improving safeguards is helpful. However, we believe that the new Bill still does not provide adequate safeguards and is not able to address our concerns about equitable provision of palliative care and support services.

13. GENERAL

13.1 The Bill now only refers to “a competent adult who is suffering unbearably as a result of a terminal illness”. It no longer includes people with “a serious and progressive physical illness”. This change takes note of DRC objections and is to be welcomed. However, the definition of terminal illness remains problematic.

14. TERMINAL ILLNESS

14.1 In the Bill, terminal illness is defined as “an illness which in the opinion of the consulting physician is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will be likely to result in the patient’s death within a few months at most” 1(2). There are many examples of people predicted an early death, or given a short time to live when diagnosed, who go on to live a long and full life. There are also clear examples of illnesses and health conditions, such as AIDS, that have previously been considered to be “terminal” and are now treatable, if not curable. The DRC does not think that this Bill will prove practical or viable as advances in medical science will mean a constant revision of any stipulated definition. The DRC does not believe that the definition can or should be fixed.

14.2 There has been an attempt in the Bill at a tighter definition of “terminal illness” which reverts to the one provided by the 1994 House of Lords Select Committee, but some people could still erroneously fall under this definition. Some people are diagnosed as terminally ill from birth—their parents are told they will not live beyond a few years and they go on to live well into adulthood. Others experience recurring illness associated with their disability and each occurrence is considered terminal, eg life-threatening chest infections in winter, which was the situation for David Glass. In some instances where people have acute episodes in which they may die, as with DRC Commissioner Jane Campbell, who has spinal muscular atrophy, whether they are terminally ill is open to considerable debate. This is a different situation to someone progressively declining. It begs the question of how accurate a doctor’s prognosis can be. Doctors agree it is not an exact science and that they can get it wrong. It is concerning that GMC guidance admits it is difficult to predict accurately when someone is truly likely to die, but this Bill would insist physicians do just that.

14.3 The evidence from Oregon shows that, of those physicians actually working with assisted dying legislation and authorising assisted deaths, 27 per cent are not confident that they can give an accurate six month prognosis. A different pan-US survey testing the accuracy of doctors' prognoses found that of patients that were judged on standard criteria to have six months or less to live, 70 per cent lived longer. It worries the DRC that the Bill would permit physicians to make a prognosis that many admit they are incapable of providing—and which has been shown they are unable to accurately provide.

14.4 RC believes further research needs to be undertaken into the accuracy of doctors' prognoses of terminal illnesses before any Bill to legalise assisted dying on the basis of having “a few months” to live could be passed—given widely admitted evidence by the medical profession that this kind of prognosis is not possible with any degree of accuracy.

14.5 Furthermore, the DRC seeks urgent clarification of how the phrase “a few months” will work in practice. The DRC believes a more exact time period should be stipulated in any Bill to legalise assisted dying to avoid confusion or unnecessary legal or medical conflict.

15. COMPETENCE/CAPACITY

15.1 There is a new definition of “incompetent”, which falls short of the principles of decision-making and the definition under the Mental Capacity Bill. “Incompetent” means not having the capacity to make an informed decision. The DRC believes it would be more worthwhile using the Mental Capacity Bill's provisions on capacity and competence. Introducing too many definitions is not helpful to the medical or legal professionals that would have to work with legislation and deal with differing definitions.

15.2 The DRC is concerned that this Bill might not comply with anti-discrimination legislation—or might further discriminate against some disabled people. If the Bill is to promote choice and autonomy, it should do this equally for all. To possibly exclude all people with learning disabilities and mental health service users/survivors with terminal illnesses may introduce a new systematic bias to the health service and further exclude some disabled people from being able to make decisions freely available to other sections of society. To promote the Bill in terms of “fairness” or “autonomy” is undermined by the Bill's discriminatory principles.

15.3 In the particular circumstance of assisting the death of someone with a terminal illness, the DRC think that it would be necessary for more emphasis to be placed on making “informed” decisions. This Bill defines an informed decision in 1(2) as: “a decision by a qualifying patient to request medical assistance to die, which is based on an appreciation of the relevant facts and after being fully informed by the attending physician, and the consulting physician (save in respect of (c) below), of:

- (a) his medical diagnosis;
- (b) his prognosis;
- (c) the process of being assisted to die; and
- (d) the alternatives, including, but not limited to, palliative care, care in a hospice and the control of pain’.

15.4 The DRC is interested in knowing exactly what “an appreciation of the relevant facts” means. The DRC believes the Bill must clarify its exact meaning, as it could be read (at least) two ways: the first is that physicians have the duty to provide all relevant information to patients and ensure they are aware of the relevant facts as a result; the second is that physicians must ensure patients appreciate the relevant facts—which implies a duty on others to supply relevant information. This could, for example, include access to a counsellor or advocate for explanation of the issues involved.

15.5 If sole responsibility rests with physicians, the DRC is concerned that medical professionals could have the only “permission” (which some may see as a burdensome obligation if it is to be done thoroughly) to provide all the information involved in making a decision to end life. Evidence from countries with assisted dying laws proves informative; eg a Dutch doctor was filmed ending the life of a patient whilst discussing a wheelchair as a “stopgap” measure, given the patient was going to die, and an Oregon physician was recorded explaining alternatives to an assisted death in just three sentences—including derogative comments on their possible benefits.

15.6 The DRC believes that the way available options are presented is vital to the autonomy of a patient when considering future treatment—and any bias on the part of a physician in favour of one path of action is unacceptable. In resource-led services opinions are often presented in terms of available resources. It would be extremely difficult to avoid bias that would lead to a lack of “genuine” choice being offered by physicians. Balance needs to be added when options are given to heighten patients' autonomy.

15.7 The DRC believes that, if the Bill is to negate some of the above fears, and protect many vulnerable people, it must place an additional safeguard preventing physicians from offering assisted dying without patients first instigating its discussion. The request for an assisted death must come directly from the patient, and not be offered independently by the doctor.

16. UNBEARABLE SUFFERING

16.1 There is an important and welcome change in 1(2) from doctors making the judgement about what constitutes unbearable suffering to this being the individual's assessment. However, the Bill is confusing on whether patients can fully declare for themselves or whether the attending and consulting physicians have to agree. The Bill stipulates in clause 1(2) unbearable suffering is "suffering whether by reason of pain or otherwise which the patient finds so severe as to be unacceptable"—clearly meant to be from the patients' perspective. But, in clauses 2(2)(d) and 2(3)(d) the attending and consulting physicians must both have "concluded that the patient is suffering unbearably" before taking any action towards assisting death. This needs clarification.

16.2 The DRC believes that the previous Bill's wording that both physicians must have satisfied themselves, rather than just "concluded", that suffering is unbearable, offers a far stronger safeguard and would like to see this reintroduced.

16.3 The DRC believes that more needs to be done before assisted dying legislation is passed to ensure people are aware of the possible relief that can be available in the final stages of a terminal illness, and of the right people have to request the withholding or withdrawing of treatment.

16.4 VES quote a figure provided by CancerBACUP that 54 per cent of people in one survey believed their pain was not being well managed. This might lead someone to request an assisted death in the event of legalisation. This concurs with the findings of the New York task force. The DRC believes this is further evidence to support the need for increased availability and accessibility of good quality palliative care. Patients may request death because pain levels are unacceptably high and could be reduced through better palliative care.

16.5 The DRC has another fundamental objection to the control physicians appear to be given of the assisted dying process in the Bill. It sets out that patients can request an assisted death if they are unbearably suffering "whether by reason of pain or otherwise" as a result of the terminal illness. The DRC agree that physicians are reasonably placed to be able to conclude/assess a patient's physical pain, but we absolutely cannot agree that physicians are best placed to judge on all other criteria a patient might be experiencing. Suffering could be, for example, a direct result of the terminal illness that means housing is no longer appropriate and causes extreme discomfort/displeasure; feelings of being a burden are experienced; depression could be a factor; suffering could also be as a result of having accepted society's perceptions of disabled people with a terminal illness.

17. WAITING PERIOD

17.1 The minimum period is now 14 days, as opposed to seven in the original Bill. While some people asking for help to die may be close to death, this remains very short for someone who could be months from death. Indeed, it is less than the time most stores give to return unwanted purchases. The DRC does not believe it will always be possible to gather full and appropriate information, and to make a genuine and specific offer with regard to the provision of other support or services in this possibly extremely limited time span.

17.2 The DRC believes that those with a newly diagnosed terminal illness and a prognosis of living just a few months are likely to go through personal turmoil and that depression could possibly be a serious factor in requesting an assisted death.

17.3 Given that most anti-depressants take two to six weeks to take effect, this Bill may not give that course of action the chance to work. This is only even possible to offer if a psychiatrist is able to spend enough time with a patient to successfully diagnose depression (see 19.2). The DRC thinks the time span minimum of two weeks from request to assistance is likely to have the effect in practice of curtailing available options, rather than increasing genuine patient autonomy.

17.4 Available evidence suggests that many people may opt for an assisted death when first diagnosed with a terminal illness, but before careful consideration is undertaken, or a better understanding of living with an illness is reached. Many people change their minds over time and the DRC is concerned that their autonomy is not protected in this Bill. Baroness Finlay, in the second reading of the original Bill, raised the case of the 35 year old man who requested assistance to die in 1990 after being told he had three months to live. He was

referred to Lady Finlay's practice for treatment and is alive today, caring for his three children after the death of his wife. He is extremely happy that assisted suicide was not available, but good quality palliative care was.

17.5 As well as further personal accounts of this kind of situation (see 11.7) there is documented evidence available to support this point. Research with patients from the National Spinal Injuries Centre found that improvement in satisfaction with quality of life following onset of spinal injury rises over a period of years. Long-term follow up studies in Denver produced similar findings. The Bill's provisions could allow a person with a new condition to request and be assisted in death long before they would realistically have been able to adapt to it and change their mind.

17.6 The DRC suggests that the Bill gives an absolute minimum of eight weeks from a patient's request for an assisted death and any assistance being provided. This may not be enough for full consideration of all the issues involved but should allow better protection for the patient, giving more time to adjust to a new diagnosis or prognosis, a better chance for a psychiatrist to assess a patient's needs, and (where depression is a factor) for any anti-depressant to take effect.

18. PALLIATIVE CARE

18.1 The Bill provides in 3(1) that the "attending physician shall ensure that a specialist in palliative care who shall be a physician or nurse has attended the patient to discuss the option of palliative care." The patient cannot make a declaration asking for assistance to die unless this has been done. This is welcome.

18.2 However, there is no guarantee that options would actually be available as there is no right to receive palliative care or other support. The Bill introduces the "right" to have this service offered and explained, but this is far different from having the right—or even possibility—to receive the service. Current demand far outstrips supply for palliative care.

18.3 It is worth noting that the Royal College of Physicians core competencies already include a requirement for every doctor to know how to refer people to palliative care. In light of existing failings, the DRC would need to see evidence that access to palliative care had improved before we could accept that offering the service under the Bill would be met with its availability in reality.

18.4 Furthermore, given the evidence of discrimination that disabled people face in accessing healthcare (see 8.) the DRC need reassurance that all disabled people with terminal illnesses would be able fully to access palliative care. It is vital that any offer of palliative care is matched with sufficient local supply that is accessible to all disabled people. Without a connection between the offer and accessible supply, the offer is not "real".

19. PSYCHIATRIC REFERRAL

19.1 The Bill's provisions for psychiatric referral in clause 8(1) are extremely limited. The opinions of the attending and consulting physicians alone decide whether a patient should be referred to a psychiatrist, based on their perceptions of the patient's competence. This concerns the DRC. It would be more worthwhile to have a larger role for psychiatrists, based on automatic referral—especially for those coming to terms with a new diagnosis of terminal illness, or a negative prognosis. It would also be useful, where possible, to consult with those closest to the patient who might know if they are acting or considering something totally different to their normal or previously expressed opinion. This would be reliant on the patient informing their next of kin, but could allow for some greater measure of the impact of the health condition on the patient's overall health and therefore offer a greater safeguard.

19.2 The Bill states that the psychiatrist has to determine that the patient is not suffering from a psychiatric or psychological disorder causing impaired judgement, and that the patient is competent, before assistance to die can be given. Given the short time period the Bill could be covering (14 days) the chances of a psychiatrist being able to undertake a thorough investigation into the mental state of a patient who could be completely new to them are minimal. The DRC does not think it would be possible to identify the impact on someone of a newly diagnosed health condition/negative prognosis in such a short time span. Evidence from the US supports this, as just 6 per cent of MDs are confident that they can diagnose depression in a single visit and the New York task force concluded that in "elderly patients, as well as the terminally and chronically ill, depression is grossly underdiagnosed and undertreated".

19.3 The Oregon evidence also shows that, where a patient is refused assistance based on psychiatric analysis, they "shop around" until an alternative psychiatrist can be found to support them. It should not be forgotten that the coercion of Kate Cheney's daughter was identified by both a psychologist and psychiatrist but this did not prevent her death.

19.4 Furthermore, the Oregon statistics show a clear decline in the number of patients referred to psychiatrists—from 31 per cent in 1998 to just 5 per cent in 2003.

19.5 The DRC believes that this Bill needs to go further in respect of psychiatric referrals than any other assisted dying legislation in order to protect citizens. The DRC believes that automatic referrals to a psychiatrist for reasons other than just competence are a necessary safeguard. We also think consideration of a maximum figure for the number of physician and psychiatric opinions a patient can ask for within a given time would be worthwhile.

19.6 The DRC also believes the Bill's limited referral arrangements might be discriminatory. Physicians may use someone's history of psychiatric impairment to prevent a request for an assisted death being approved. In order to stop the Bill placing another level of discrimination on one of society's most discriminated against groups, and if it is genuinely to offer an extension of all patients' autonomy, this issue needs to be addressed.

20. INSURANCE

20.1 The provision that an insurance policy will not be invalid as a result of assistance to die if it has been in place for 12 months could be a welcome reassurance were assisted dying to be legalised. However, 12 months is a relatively short time, and this provision does not guard against the pressure some people may feel—or indeed may be directly exerted—to hasten their death and free up funds for family.

20.2 The dangers of direct coercion are apparent to the DRC. We believe that it is necessary, in line with the original Bill—but omitted in the revised one—that no one involved in the assisted death of someone with a terminal illness should stand to gain from involvement. The previous Bill included a clause under “Declarations made in advance” 3(5) that said “No witness shall be entitled to any portion of the patient's estate upon death”. The new Bill does not include this clause. The DRC is concerned at this omission and believes it represents a decline in the Bill's safeguards against possible coercion.

21. SAFEGUARDS AND THE REGULATORY FRAMEWORK

21.1 We welcome some of the newly proposed safeguards: the consulting physician must be independent of the attending physician; the consulting physician has more responsibility for informing the patient and checking their wishes; there is some tightening of procedures around witnessing of the declaration asking for assistance to die.

21.2 However, an important safeguard has been lost in the Bill's revision. The DRC supported the provision that attending and consulting physicians must be satisfied requests for assistance are made voluntarily and are not the result of external pressure. We believe this might help reduce coercion.

21.3 Furthermore, the regulatory framework proposed in the Bill has not changed and remains weak. The DRC believes it will not sufficiently protect the lives of disabled people. It relies on examination of the doctor's submitted records with no further investigation. There is no proposed independent survey of practices. Reviews will be based on information supplied by the doctors involved, and only individual cases, not trends, will be subject to review. Evidence from Oregon and Holland show that surveys can highlight problems.

21.4 The DRC believes those responsible for implementing assisted dying legislation should be vigilant over its use. Monitoring should follow trends (in reportage for example) to ensure problems are identified and prevented from recurring, and those who fail to report or misreport use should be penalised.

21.5 The reporting of use of existing legislation is an issue. In Holland it has been suggested that just 50 per cent of cases are now reported. We are concerned that those supporting the Bill believe it will introduce national standards for, and monitoring of, what is already occurring secretly and illegally. We believe evidence on this point from countries where assisted dying is legal does not support this.

21.6 The Bill proposes in clause 14(2)(c) that a monitoring commission must include a lay person with “first hand knowledge or experience in caring for a person with a terminal illness”. We believe only allowing representation of a carer's perspective is too limited and is not a substitute for the perspective of someone with a progressive and/or terminal illness and, where possible, that the proposed commission should include this perspective.

21.7 The DRC believes that the monitoring commission must always act unanimously. If one member dissents then there is room for doubt and the case must be investigated. The Bill allows for majority decision making and the DRC does not believe this represents a strong enough safeguard.

22. CONCLUSIONS

22.1 After careful consideration of the balance between protecting life and upholding the principle of autonomy, the DRC is unable to support the Bill.

22.2 Until disabled people are treated equally—their lives accorded the same value as those of non-disabled people, their access to necessary services guaranteed, their social and economic opportunities equal to those of non-disabled people—then the “right to die” may jeopardise the right to live. The revised Bill has attempted to answer many of our concerns, but its safeguards are not broad or far-reaching enough to guard against the dangers vulnerable disabled people would face should it become law, nor is it able to rectify failings of support services to address avoidable suffering and the lack of choice over issues such as where to die and care provision.

22.3 We hope the Select Committee will consider the substantial systemic changes and support services necessary to support the opportunity of all people with terminal illnesses to live as full lives as possible, to be active members of their families and communities, to not regard themselves or be seen by others as a burden, and to have genuine choices about the nature of their lives and deaths, including:

- Revising discriminatory aspects of guidelines on withholding or withdrawal of life saving treatment.
- Demonstrably reducing discrimination and inequalities in health services.
- Developing national criteria for continuing care to remove anomalies between strategic health authorities.
- Ensuring that people’s needs for domestic help are adequately supported and that aids and adaptations are promptly made in people’s homes to allow them to stay there during their last days.
- Improving the provision of hospice and specialist palliative care services significantly, to ensure a better match between need and provision.
- Implementing robust mental capacity legislation which empowers disabled people to make more free choices about their lives.
- Providing adequate resources for hospice care.
- Implementing a right to independent advocacy and effective rights to communication support.
- Implementing a right to independent living with easy access to support services.

Memorandum by the Disability Awareness in Action

SUMMARY

1. This Bill is suggesting that a competent adult should have the right to assisted suicide and also the right to pain relief medication. The former we believe to be in contravention of the European Convention on Human Rights and our own Human Rights Act, will be open to abuse on others who may not be dying (although their doctors have told them they are), and will open the doors to even more deaths of severely disabled people, especially those who are deemed incompetent.
2. The latter objective we support and is excellent. We hope that it could support the provision of palliative care for everyone who requires it rather than the postcode lottery that operates at the present time.

ARGUMENTS

3. The Report on the Situation of Fundamental Rights in the European Union and its Member States¹ in 2002 reaffirms the Court of Human Rights judgement in *Pretty vs United Kingdom* that Article 2 of the European Convention on Human Rights guarantees the right of every person to life but does not guarantee “the right to choose to continue or stop living”, in other words, the “right to die”. In considering the refusal of the UK courts to undertake not to prosecute Pretty’s husband if he helped her to commit suicide, the Court did not consider this to be inflicting inhuman and degrading treatment (article 3) on Pretty (as she petitioned).
4. Most importantly, in our opinion, the Court also considered the right to respect for a private life (Article 8), the notion of personal autonomy, the meaning of the right to make choices about one’s own body and to avoid what, in the eyes of the person concerned, would constitute an undignified and painful end to life. They judged that these rights could not be justified in relation to the protection of the rights of others given “the risk of abuses and the possible consequences of abuses that may be committed which a relaxation of the general prohibition of assisted suicide or the creation of exceptions to the principle would entail.” In so judging the Court recognised the “slippery slope” that would result—and, as research has shown, has resulted in Holland.

¹ De Schutter *et al*, *Report on the Situation of Fundamental Rights in the European Union and its Member States in 2002*, Official Publications European Communities, 2003, Luxembourg.

5. In the UK today people can commit suicide and be free from prosecution as a criminal, but the Human Rights Act, 1998 says (Schedule 1, Article 2.1) that everyone's life shall be protected by law and therefore society has a duty to prevent them from doing so by trying to alleviate the situation that they find intolerable. In the situation of someone wishing to commit suicide because of pain and suffering, it is the duty of society not to help them to die but to alleviate that pain and suffering—to, as Article 3 of the HRA says, protect them from inhuman and degrading treatment.

6. We do have concerns over the definition of “competent”. The present draft Mental Capacity Bill is suggesting that competence (or capacity) should be a given unless anyone else says that they do not feel that person does have capacity. There are no safeguards in the Assisted Dying Bill to ensure that the informed competence is real and not insisted on by family members who may be wanting to put an end to their own suffering at watching a loved one die. Nor is there any recognition of the pressures put on dying people by their family and friends by the extreme difficulties that so often arise out of the “caring” role because of lack of appropriate service provision and palliative care. We appreciate that as many safeguards as possible have been put in place to ensure that the person's wishes are in writing and witnessed by people who are not involved—but this is not enough to guard against emotional pressure. And there are serious concerns about definitions of competence in relation to people who do not use verbal communication or who do not speak English. And even if these people are deemed competent—what assurances are there that they will have full access to information.

7. If the medical practitioner makes a judgement that assisted suicide is in the competent patient's best interest, what is there to stop them thinking that it may be of “benefit” to some who would not be deemed competent but are suffering from similar conditions? As the Van Der Maas survey in 1990 in the Netherlands shows that there were 400 assisted suicides and 1,000 intentional life-terminating acts without explicit request.²

8. We have great concerns that insuring that the “qualifying patient” is fully informed is left to the attending physician and consulting physician. In the experience of many disabled people, most physicians know very little of available services and supports that are available to severely disabled people as well as having prejudicial views about the efficacy or application of proper palliative care. It is essential that information comes from other, independent sources.

9. We appreciate that everything has been done to ensure that attending physicians will not be pressured into taking a life against their consciences. However we have real concerns that this will produce a cadre of “doctors of death”. This could lead to their concentration on assisting suicides and implementing a culture of death—in contravention of their professional codes.

10. And it certainly could, as it has done in Holland, place emphasis on assisted dying rather than palliative care. As one Doctor in Holland is reported as saying: “We don't need palliative medicine, we practice euthanasia.”³

11. Another factor to consider is that many people in Holland who have been legally assisted to end their lives had the physical capacity to take their own lives (see published accounts from Dutch doctors who have practised assisted suicide/euthanasia). There has not been anything like enough discussion around this issue—are these suicides really taking control of their own deaths or are they handing the responsibility to someone else?

ABOUT US

Disability Awareness in Action is an international information network on disability and human rights. We were founded in 1992 by the leading international disability organisations: Disabled Peoples' International, World Federation of the Deaf, Inclusion International and IMPACT. These organisations all have representation on our Board of Trustees. Over the 12 years we have built a considerable reputation as a unique repository of evidence and information on disability and human rights which has been used by the United Nations and its agencies, governments, disabled people's organisations, the media, researchers and policy-makers in furtherance of their activities in support of disabled people's rights.

Most importantly, disabled people are at the heart of our network—exchanging with each other, through the pages of our newsletter, information on the violations of their rights that they endure and ways of implementing those rights that they have found effective. This evidence is based on that information from disabled people worldwide.

² Keown, John, ed, Chapter 16, *Euthanasia Examined: Ethical, Clinical and Legal Perspectives*, Cambridge University Press, 1995.

³ Ibid.

In the last years we have focussed particularly on bioethical concerns and have given presentations and produced evidence for the International Bioethics conference and many European Commission and Parliamentary consultative events.

August 2004

Examination of Witnesses

Witnesses: Ms LIZ SAYCE, Director of Policy and Ms JANE CAMPBELL MBE, Commissioner, The Disability Rights Commission and Ms TARA FLOOD, Information Officer, Disability Awareness in Action, examined.

Q503 Chairman: This afternoon we have the Disability Rights Commission, Liz Sayce and Jane Campbell; and the Disability Awareness in Action, Ms Tara Flood. We have about an hour to devote to this session and we would be glad if you would like to make opening statements, if you wish to, and then members of the Committee will be able to ask questions as they wish. I think we will have everybody together this time; you are all of the same general interest so please decide amongst yourselves who will start.

Ms Campbell: Thank you very much. I have an opening statement of about four minutes and I will do my best to get through. Because I am wheezy I have actually written it out so that if you cannot quite catch what I say then you will have my pearls of wisdom in front of you.

Q504 Chairman: We are glad to have the chance to hear you as well.

Ms Campbell: Thank you very much. Obviously I would like to thank the Select Committee for the opportunity to present our evidence to you today; it is a great privilege. I am here today wearing three hats: firstly, as a Disability Rights Commissioner of five years now, secondly as one of the founder member of the Disabled People's Independent Living Movement in this country and thirdly as an individual whose life could be put at risk should assisted dying become legalised in this country. I want to stress that there is absolutely no distinction between those of us described as "terminally ill" and those of us described as "disabled". The two are so inextricably linked that the terms are interchangeable the eyes of the public. It is certainly my experience that people see me one day as terminally ill and another day as a big, fighting disabled activist: so there is confusion. The results of the DRC's recent work on society's view of terminal illness and disability I think can be summed up in one word. That word is fear: fear of loss of opportunity; fear of denial of self-determination; fear of loss of control; fear of pain; fear of hardship; fear of being a burden to others. Many members of the public employed in the medical profession share these fears. Against such a background it is perfectly understandable that assisted dying may be viewed as an attractive option. What the public do not know, I feel, is that all these issues have already been addressed by disabled people in the Independent

Living Movement for the last 20 years or so. I would like you to know that I live and work amongst people who have very terminal conditions. I am talking about people with MS, motor neurone disease and in other stages of what are deemed to be the dying process. We have been working together to determine and campaign for services that enable us to have a quality of opportunity with our non-disabled peers. These efforts culminated in the Community Care (Direct Payments) Bill, a forerunner of which was introduced by the Lord McColl in the House of Lords and whom I had the privilege of briefing 15 years ago. So whilst certain individual disabled and terminally ill people may see assisted dying as a necessary option, collectively in the Independent Living Movement we are utterly opposed to it. Legalising assisted dying would condone this kind of discrimination. It will be harder to argue for much needed services if the counter-argument that we would be better off dead is given legitimacy. From my written evidence you will know that I am not just here as a spokesperson for organisations of disabled people. I am also here as someone who, whilst critically ill in hospital only two years ago, experienced first-hand the negative assumptions others have of my terminal condition. Fortunately my husband and I succeeded in countering the assumptions of the consultants treating me. If I had been too ill to communicate effectively the consultants' assumptions may have prevailed. That would have been much more likely, I feel, if assisted dying were on the statute books, for it would have somehow legitimised their prejudice.

Q505 Chairman: Thank you. Ms Sayce?

Ms Sayce: Thank you. The Disability Rights Commission believes that if assisted dying became legal decisions could be made through a prism of the prejudice and inequity that does still pervade our society. Also, the balance between the right to live with the services that are essential for dignity on the one hand and the right to die or to refuse treatment would be tilted further towards the right to die or to refuse treatment. The legislative priority we think is improved rights to live in situations of dignity. When I say there is an imbalance, I would like to cite as an example, the case of Leslie Burke. When he challenged the General Medical Council guidance earlier this year he sought assurances that he would receive food and fluid as a positive

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intervention: Justice Munby said that there was an emphasis throughout the GMC's guidance on the right of the person to refuse treatment rather than on his right to require treatment. Justice Munby went on to say that it was important to rectify that balance in the guidance. That might suggest that this was a kind of recognition of the significance of right to live with dignity, to have positive interventions but he of course went on to say that this is not a case about prioritisation or allocation of resources whether human, medical or financial. In other words, there is no guarantee—even given the Burke judgment—that the services actually required by individuals will be made available. Of course that judgment is being appealed and we have seen, for instance, a British Medical Journal editorial stating that if the judgment was left to stand it could lead to draconian restrictions on doctors' professional skills and, in the author's view, to a wrong allocation of resources towards artificial nutrition and hydration and other life prolonging treatments. In other words, current practices of not offering or not being able to offer life saving treatment in many cases should be allowed to stand in the view of that BMJ editorial. There are really very few rights positively to live independently and with dignity. What minimum rights there are amount to little more than being washed and fed. I think we need to remember the context in which choices to die might be being made. The Social Services Inspectorate 2003 Report found only four of nine regions achieved even acceptable standards of delivering support to disabled people who live at home. The numbers of people in the last five years receiving social service support at home has actually gone down. Many people we know wish to live at home and indeed to die at home and they are not able to do so. When people are making decisions about preferring to die in a situation of terminal illness they may be making a kind of Hobson's choice. We know of some of the situations in which people are living—a different carer coming each time or huge waits to get the care they need in their homes, et cetera, the very variable availability of palliative care (with some differences depending on what type of illness you happen to have or your ethnic background, et cetera)—and whilst these inequities persist the DRC does think that the choice to die would be a Hobson's choice between on the one hand living without dignity and on the other hand dying; or between feeling a burden and on the other hand dying. We do not think that is a choice which should be offered in 21st century Britain. Can I just make one final point that when other groups in our society contemplate taking their own lives because of the social and environmental pressures they are under—for instance young men who have no role, who are unemployed—the

Government sets targets to reduce suicide and to reach out to those people to prevent suicide from occurring. With the group of people we are discussing today, facing equally desperate social pressures like lack of services to ensure dignity, I think it would give an extraordinary message for Government to sanction and indeed to provide assistance for suicide for a group of people for whom the same kind of reaching out should be the top priority.

Q506 Chairman: Thank you. Ms Flood?

Ms Flood: Disability Awareness in Action—and I will refer to it as DAA because it is a mouthful—are very concerned about the premise the Assisted Dying Bill creates (a very dangerous premise). We believe that the Bill would create a new group of disabled people—Jane is absolutely right, we are not just talking about people with what are considered to be terminal illnesses; this will impact on disabled peoples' lives—whose lives will have so little value that the only option that there is for them is to opt for an assisted suicide. Supporters of the Bill talk about personal autonomy and how much personal autonomy it will give us, but is that really the case? Disabled people are constantly struggling against the kind of discrimination that 10 million people in this country face and yet we are expected to have personal autonomy handed to us. For us what it will actually give us instead of personal autonomy is coercion dressed up as choice. The Bill will not transport disabled people into this lovely euthanasia world where money and resources are not a problem, where health care professionals view disabled people as human rather than incurable objects; or where disabled people are never abandoned or made to feel a burden as Jane said; or where there is no other way of relieving unbearable suffering. At DAA we have a database of human rights violations; we have had it since 2000. I think it is very important for you to know some statistics from it which really support many of things that Jane and Liz have said. For example, in the UK alone the database shows that nearly 800 cases of violation have affected 616,371 disabled people (violations that have taken place since 1990). The real horror of those statistics is that 42 per cent of those violations in the UK are of degrading and inhuman treatment; 9.3 per cent violate the right to life itself. These are the kinds of violations that really happen because of the preconceived quality of life judgment made about disabled people's lives. I want to talk a little about what the international scene is around assisted suicide. Those people who support an assisted suicide bill in the UK they really should not be looking for reassurance to other countries where assisted suicide is currently legal. For example, in The Netherlands where assisted

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suicide has been around for a number of years there has been research that says that assisted suicide has led to nearly a quarter of overall intentional killings of patients that happened without request. The research also shows that there has been an increase in intentional killings by either withdrawal of treatment without the patient's permission or by deliberate overdoses during symptom control. Safeguards are a real concern in The Netherlands, for example a 2001 report shows that only 54 per cent of Dutch doctors actually recorded cases of assisted euthanasia. Their reason for that was mainly because of the bureaucratic paperwork that it involved. The Netherlands which, as I said before, has allowed it for quite some time, does have very strict guidelines to protect vulnerable people from abuse. I was speaking to a woman from Holland this morning who is part of the disabled people's movement in Holland and they are extremely concerned again in the same way we are that it is not just people with terminal illness, it is all disabled people. They are particularly fearful of the recent Groningen protocol which actually calls for the termination of people who are unable to give consent or without free will. That particularly relates, I am afraid to say, to newborn disabled babies with what they consider to have terminal illnesses, babies with extreme deformities and they actually included in that definition spina bifida. I have to say that when I was born, I was described as having extreme deformity. It also includes adults and children with what are considered to be severe learning difficulties. In Belgium—where assisted suicide has only been legal for three years now—they are already seeking to include disabled children and widening the eligibility criteria for assisted dying. In Oregon—where assisted euthanasia has been around for seven years—there is already a lack of transparency around those cases being reported. The reality for many disabled people is that what is happening is that people who are wanting to die are going to their GP—or the American equivalent—and the GP is saying no. They then go into a process of almost doctor shopping until they find a doctor who will give them the okay. That is including disabled people with early stage dementia, with Alzheimer's, not people with terminal illness. There is the very good example of Kate Cheney but I do not think I have time to talk to you about that. Dignitas in Switzerland is another service which supporters of assisted suicide constantly refer to. I do not see how it is anything other than a modern day death camp for disabled people. Disabled people are having to pay for the privilege of being put to death. There are no safeguards; there are very few medically trained staff involved in it. You are really putting disabled people who, for the reasons that Liz and Jane say, are feeling that their

particular situation is so intolerable that they want their life to end. No-one is making any effort to get the services in place that they have an absolute right to. Lastly, is it any wonder then that both the UK's Disabled People's Movement and the International Disabled People's Movement has been against the legalisation of assisted suicide for years now. It will potentially create an open season for the killing of disabled people; it will certainly impact and devalue our lives further. I think, as Liz said, what it will potentially do is limit our access to the community services that we currently have a right to. I think what we are most worried about—and what I am going to finish with—is that assisted dying does not take us down a slippery slope; it actually allows us to teeter on a vertical cliff. What disabled people want—what we all want—is a right to a life where we have real choice and control and where the protections of that right to life are the same as non-disabled people take for granted.

Q507 Chairman: I think, Jane, you talked about an equivalence in the public eye between terminally ill people and disabled people. It is fair to say—and I think you will know—that in this Bill terminal illness is defined. Terminal illness is defined as an illness which, in the opinion of the consulting physician, is inevitably progressive, the effects of which cannot be reversed by a treatment, although treatment may be successful in relieving symptoms temporarily and which will be likely to result in the patient's death within a few months at most. That is part of the definition of terminal illness in this Bill. You were talking about public perception, but I just want to point out that terminal illness in this Bill is specially defined so you need to take account of that in your approach.

Ms Campbell: Absolutely, but I can bring a hundred people into this room who have been told at one time or other in their lives that they had maybe three months or six months or maybe a year to live and five, 10 or, in my case 40 years later, they still seem to be hanging around. Medicine is not a science and I know too many cases of people who simply do not conform to their prognosis.

Q508 Chairman: I am not commenting on what you said; I just wanted to draw attention to that in fairness to the terms of the Bill.

Ms Campbell: I am absolutely aware of that, but thank you.

Q509 Lord Turnberg: You have expressed your views very clearly and that is enormously helpful. I just want to tease out the problem of patients suffering terrible symptoms towards the end of life—perhaps dying of cancer or suffering from motor neurone disease—who find life so intolerable

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despite good palliative care, who wish to end their lives. The question I want to ask is, is it the principle of agreeing to that that you are against or is it the practical consequences of setting out on that line of activity?

Ms Campbell: It is both actually. I think more than anything people in the DRC and certainly myself have nothing but admiration and empathy for people who do wish to take their lives and do feel that they have tried everything and this is the way to go. However, I always feel you cannot make social judgments on an individual situation and I am not sure that we have reached a stage in society where we do give people the very best palliative care or the very best support. My support is complex; it is delivered in a way that I feel very much in control but it is very, very rare. When I compare myself with other peers in very similar situations to be quite honest I get depressed because I can advocate for it and I have had 20 years of support and education to do that. I do not feel that we currently live in a society that has actually got there. There have been enormous moves to understand severe impairment, to understand that we can contribute—and can contribute well—and that we are not burdens, but they are a very small minority and it is a kind of incremental change. I have never said “never”; I have always said, when we have equality and when we have respect and when people do not tell me on a daily basis—even dear friends say this to me—“Jane, I understand what you say, but I would rather be dead than like you” and that really, really hurts. It cuts to the quick of what I think we are discussing today. It is very much a cultural shift that needs to take place first.

Q510 Lord Turnberg: The Bill would not be applicable to someone who did not want to die. It would not be applied to someone who said, “No, I don’t want it”.

Ms Campbell: Of course, Lord Turnberg, but what you do not realise is that we are very much subject to society’s view about us. It takes an extraordinarily courageous and strong person to rise above the prejudices that people think our lives are not worth living. Most of my work is spent encouraging and helping disabled people with extremely severe impairments, many of whom are in the last stages of motor neurone disease and MS, people who can barely move their heads and have to be fed and have to be cared for 24 hours a day (which, as I have said, is my situation too). There is not much difference between us. I could tell you a few things that would make you very squirmy about my life and you would say, “How on earth does she live with that?” But the truth of the matter is that you do not live with it, you learn to live another way. I am very much enjoying empowering

and emancipating people in this situation and I do feel that people come to me and they do want to die and many of them a year later, once we have got them a decent independent living package and they do feel that they have a contribution and they have met people in a similar state who are not wanting to die and they do change their minds. That is where my energy is going. My consultant said to me, “Jane, I am so glad you are doing this because that Lord Joffe Bill is making my life an enormous lot harder because I have to convince my patients with motor neurone that actually they do not have to go down that road. Ten years ago they would not even have dreamt of taking their lives.”

Q511 Lord Joffe: Picking up on the last point you made that 10 years ago they would not even have thought about it, do you not see that the whole purpose of the Bill is to give people autonomy and options, not to actually suggest that their life is not worth living.

Ms Campbell: Would it be all right if Liz began on the question of autonomy and then I will catch up in about a minute?

Ms Sayce: I think that everybody involved in these debates recognises that personal autonomy is absolutely crucial and the DRC’s commissioners—there are 15 commissioners, 11 of them disabled people—unanimously agreed the position on the Assisted Dying Bill but all said in principle we endorse the principle of autonomy and the significance of autonomy but there are constraints on autonomy and I think everybody in this debate sees there are some constraints. The debate is about where the constraints come. Nobody, I think, is saying that everybody should have free access to the means to commit suicide sanctioned by the state. The concerns from the commissioners at the DRC were that at the moment the balance of on the one hand the positive force of autonomy of the individual and on the other hand the experiences of disabled people defined broadly and including terminally ill people in Britain today, given the culture in which decisions are being made which does talk a lot about mercy deaths, it does seem to say that killing somebody who is disabled is putting them out of their misery—a lot of the media coverage is in that sort of tone—given the culture and given the issues I was speaking about earlier about the lack of availability of resources and so on, that actually that places real constraint on autonomy and that creates a kind of indirect pressure that people feel they are going to be a burden. Our commissioners were just so worried about that that they thought at this stage in history that principle of autonomy could not be progressed in the way suggested in the Bill.

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Ms Campbell: I want also to add to that that in the Independent Living Movement autonomy and the right to be independent is one of the founding principles and yet within all the Centres for Independent Living—and I set up the National Centre for Independent Living—these CILs are groups of disabled people who have come together to inform and to give support to people with severe impairments—people like me—to live their lives. You are talking about in each Centre for Independent Living between 200 and 1,000 members; they have all discussed this and they have all said, “This is not about autonomy at all. Actually, autonomy is about living in an inter-dependent society where we are all inter-dependent and this will not actually increase our autonomy, it will reduce our choice because we will begin to feel the pressure of a culture that would think that actually our choices should be limited and if we do not buck our ideas up and be more independent then we should jolly well think about using our euthanasia option.” So actually they feel quite threatened that this will reduce autonomy rather than actually give people autonomy. It is very complicated.

Q512 Lord Joffe: It sounds very complicated indeed. Is it not strange that a Bill which is in no way discriminating against disabled people, a Bill which wants to give disabled people the same rights as able-bodied people, is opposed on the grounds of autonomy?

Ms Campbell: No, I would disagree. You must realise the nature of being a severely impaired individual in this society; people have a lot of power over us, in incredible amount of power—social services, the health service, our relatives, our families—and we are just the one person. The strength that we derive often comes from people just like us, and if people just like me have to deal with all those pressures yet again, I do want it, it is a negative right that I am trying so hard to fight against. Certainly, two years ago in that hospital bed I felt the weight of the doctors’ assumptions that I was at the end of my life and it was time for me to choose that option. And it was real. So no, I do not agree.

Q513 Lord Joffe: Can we come back to that appalling time when you were treated in that way by the doctors. From reading your account you felt terribly insecure, as you were entitled to feel. Under this Bill there is an array of safeguards. If you looked at your position then when you thought you were at the mercy of the doctors, under this Bill if you were a terminally ill patient and if you wanted assistance to die you first have to make a request for assistance to die. You are then examined by one

doctor and if you persist with your request another doctor sees you. Then you see a palliative care specialist. Then you have to sign a written declaration asking to be assisted to die which you have the right to revoke at any stage. Then it would be up to you to decide whether or not to take the prescribed drugs. Surely all these safeguards would give you far more protection than the case that you have described in relation to yourself some years ago when the doctors seemed to be willing take a decision without any safeguards.

Ms Campbell: I completely accept what you say. However the Bill was not about that situation at that time; that situation was about treatment and giving treatment or not giving treatment. What I am saying is that it is not the safeguards in the Bill or lack of which would have affected my situation, what I am saying is that if you have an Assisted Dying Bill it somehow condones the idea that it is possibly the right thing for some people at some point in their lives to go for the death option. That will almost help exacerbate the situation that I found myself in two years ago. It is not the direct consequences of the Bill; it is the indirect consequences of exacerbating a society that feels that people in what is considered to be a dying stage—and, let us face it, that is what was expected of me—should want that option. It is the indirect inference, not the Bill. Also I have looked at the safeguards in the Bill and I know some very shaky individuals who, quite frankly, would easily pass all those safeguards and go down the road of assisted dying because, as I said before, we buy into what society thinks we should do.

Ms Flood: I think when you are battling every single day with the kind of prejudice and discrimination that we are talking about here, if that option is available to you it does somehow feel like the easier option. What concerns me is that there is less available information for disabled people going into hospital now about the community based services there are around Direct Payments. What guarantees would there ever be that that kind of information would be given to the person should they want to discuss the issue of suicide as a possible option other than assisted suicide. We are expecting a great deal of doctors—and it is rare that I come out in defence of doctors—to expect them to be fully expert in all community based services so that they can make sure that the individual who is contemplating assisted suicide would be able to make the kind of informed decision that is suggested they would be able to make.

Ms Campbell: I think I would like to add that to be quite honest I could convince any medical doctor when I am very, very ill that actually I would like to die. I get pretty depressed and I might well go for that option. I know there is a time limit in there. We

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have all been depressed for a year or two and I know I have friends and colleagues who could pass all those safeguards quite easily. We are quite clever at that sort of thing.

Q514 Bishop of St Albans: Thank you very much indeed for many of the comments. I was fascinated by one of the comments made by you, Ms Flood, that you see this as coercion dressed up as choice. I find that an extraordinarily helpful way of looking at it. Dr Campbell referred to autonomy being about living in an inter-dependent society. I wonder if you could say a little bit more—possibly you, Miss Flood, at this stage—about why you see this as coercive. This is something that troubles me deeply because it is a kind of attention grabbing headline. I wonder how far you are able, in order to shift society's perceptions, to get your case across in the media. I would put a PS to that which I notice—it is probably chance, but I do not think it is—that always the day before this Select Committee meets (pretty well always) there is a major article in one of the national papers about this subject, and it is only ever about one side of the subject. Is there any chance that you have noticed that as well?

Ms Campbell: Except for today. I managed to get an article in today, the first ever.

Ms Flood: It is very difficult as individuals and as organisations representing disabled people to get anything in the media with regard to our particular concerns about the Assisted Dying Bill. The same is also true for the Mental Capacity Bill. I think with regard to coercion that it is the subtle nature of coercion that concerns us most in that it is the images that you see on TV, the images that you see in the newspapers, it is the images that people see in hospitals and the images that relatives have seen (you know, a friend's cousin once removed), it is all those kinds of images that come together to suggest that it is absolutely better to be dead than to be disabled. It is pressure on family members when community services have not kicked in or the disabled person feels that they have to be grateful for being able to get up in the morning and having to rely on family members who find it difficult to provide that kind of care. It is the pressure that we all face every time we turn on the television. There are very few positive images around disability; it is always about suffering and the person being a victim, the person being a burden and the person really not being a powerful source.

Ms Sayce: Could I just add something to that, which is that one of the concerns that we have had firstly is that if people are actually offered the option of assisted suicide amongst other options—and I am not sure whether that is prevented by this Bill—people might interpret that as perhaps being easier because the hospital is short of beds, “I am a burden

to everybody”, everybody is having to look after me, that sort of thing. That, whilst completely unintended, might act as a form of indirect coercion and in particular—as I was outlining earlier—if there are not other services that can be offered that the person might appreciate (like being able to die in their own home with the support they need, for example,) even with the safeguards about being able to see a palliative care specialist, but what if the services that a person requires are not available in that particular area? Again that could become an indirect form of “So the best thing to do then is to opt for . . .”. It is that sort of decision making process that the person may go through in that sort of situation, given that the choice is always made in a context.

Ms Campbell: I meet with people who are very concerned about this Bill, people who identify that the Bill is dealing with people who would want it and someone said to me, “What really worried me the other day was when I went for a check up in the MS clinic the nurse was talking to me and I was sharing with her the concerns that I have for what might happen when I am at the very dependent stage. She said, ‘Don’t worry, there’s a Bill going through at the moment that will help you’.” I sort of looked and said, “Is this a new independent bill?” and the nurse said, “Oh, no, it’s the Joffe Bill so if you really want to make a choice at the end then that will be there, you will not need to be scared.” I was absolutely aghast at this”. I was looking at some recent articles in the Nursing Times and there is gathering support from nurses in favour of this. That is another possible form of coercion that we have come up against. Quite frankly, there are not enough of us to right these very powerful arguments and things in the press because we do not have the resources or often the ability to put into the public domain our arguments; it is quite tough and we do not have the resources that some other organisations—that I will not mention—do have, so it is tricky.

Q515 Earl of Arran: As for the Disability Rights Commission, do you speak for yourselves as individuals or as a membership or for whom do you put forward your views?

Ms Campbell: I speak from the Disability Rights Commission who have had a full debate on this and there is absolutely one hundred per cent consensus on the Commission Board.

Q516 Chairman: It is a statutory Commission and do all the commissioners take part in the debate?

Ms Campbell: Absolutely.

Q517 Chairman: I think you said they were all in favour of the stance you take here.

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Ms Sayce: Yes. The position was agreed unanimously by the 15 commissioners as I have mentioned.

Q518 Baroness Hayman: It seems to me that you have been very clear in your views today. In the DRC evidence to us at paragraph 1.2 you say that “The DRC is committed to the principle of autonomy for disabled people. Individual disabled people should be able to make autonomous choices, including potentially choosing the manner and time of their death. Therefore we do not oppose in principle legalisation of euthanasia for people who freely choose it.” Can I ask you—absolutely understanding the arguments you have made that that would not be appropriate unless and until a full range of services were available—whether you still stick to that because I thought from what Ms Campbell was saying was that the objection you are giving us today was one of principle as well as one of timing because the very existence of this potential avenue for people would in some way devalue the life of someone who was terminally ill and you allied that with someone who was disabled in the public perception. I wonder if you could answer that and also whether you feel that other things like advance directives, the ability to refuse treatment, to ask for life support to be turned off whether those things that do exist at the moment and are legal—suicide itself—undermine the position of disabled people in the same way.

Ms Campbell: We have always said whenever all these things are in place then we can have this kind of debate. We have always felt that this is absolutely the wrong time for this debate to be happening because all these things are not in place and we cannot experience what that means. We do hold that position. I have my doubts whether we will create a world that gives equality as such but I am happy to hope that we can. That is absolutely our position. We have never, ever been—and I have never been—opposed to refusing treatment but I have always wanted to assist those who ask for treatment. That is why we intervened in the Burke case. Obviously we are very concerned when people refuse treatment when there may be other routes to living with whatever condition it is with the support and help that they would require, but that is the individual’s choice. What we are opposed to is when you factor in another person taking another person’s life. That is very, very different. It provides and produces a very, very different culture and one that quite frankly frightens a lot of disabled people. We see withdrawal and refusal of treatment as very, very different.

Q519 Baroness Hayman: Could I just pursue how different it is if you look at it from the perspective of the individual? If their terminal illness is one that is treatable and one that is being treated they can

ask another person—a doctor—to cease that treatment, so it does involve another person. However, if they are not having life prolonging treatment and if they do not have the means to end their own lives, then they are in a different position and they need, if they wish to, to take the same decision as the person who is on life saving treatment; i.e. the choice about the time and the manner of their death in this case they may need to involve someone else in the way that Lord Joffe’s Bill would set out. Do you not see an inequity in the position for those two people?

Ms Sayce: First of all some of the same arguments about the need to have services in place that provide dignity do apply and that is why we think the first legislative priority is improved entitlements to services that provide dignity including palliative care but also very much including social services, particularly with the growing numbers of older people putting greater pressure on the social services’ budgets et cetera. This is an imperative so far as we are concerned to make sure people can make the active choice to live their lives in dignity. That would also apply to the person who is choosing to have treatment withdrawn perhaps because those services are not available. However, to go back to some of the points we were discussing earlier, I think that for the state actively to get involved in supporting suicides and enabling somebody to take their own life that is slightly different from the decision to stop having medical intervention. We all have the right to say yes or no to particular medical interventions and sometimes there are complex and varied reasons for that. I think it is a different set of questions than the state actively saying, “What we are actively saying is that we will support and enable you to commit suicide”. That is almost endorsing that choice for suicide from the state which is something we think is dangerous culturally as well as dangerous in terms of what it might mean for an individual. Whilst there are some similarities there are also some differences.

Ms Campbell: I was always very taken by Lord McColl’s arguments in the debate in the House of Lords when you were talking about well, often you have been in the situation of saying if you do want to die, then just stop taking the tablets. I think you said that that never happened.

Ms Flood: Can I make a point as regards advance decisions? DAA is also part of a coalition called Either Side which is representatives of disabled people’s organisations which has concerns about the Mental Capacity Bill which, as we know, will be a Bill which will potentially legalise advance decisions. I have to say, I do not share the same feelings as Liz and Jane because I do think that the issues around advance decisions are very similar in that the

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pressures that are on disabled people to opt for assisted suicide are the same pressures on disabled people opting to withdraw treatment.

Q520 Lord McColl of Dubwich: Can I take up that theme because in fact I did tell that story here in the Committee to a Professor of Ethics at Kings College. You are absolutely right. A man had advanced cancer and it involved his bones which mobilised his calcium so his calcium rose to dangerous levels in his blood. Of course, if you take the right tablets you can keep the calcium level down to a safe level. He came into the hospice, he asked for euthanasia and was told they did not do that. After a few days he kept on asking and the doctor suddenly said, “Wait a minute, those tablets you are having, they are keeping your calcium down. If you stop the tablets you will be dead tomorrow. So it’s very easy; just don’t take them.” He never stopped taking the tablets. When I told the Professor of Ethics at Kings—who was sitting where you are now sitting—he dismissed it as just an anecdote. It is not an anecdote; anecdote means something that is unpublished and this has been published and there are many places where it has been published, it is well known. However, could I go back to the business of this Bill? There is a phrase “hard cases make poor law”. Of course there are occasions when you feel that somebody might benefit from euthanasia, possibly just occasionally, but to pass a law to make that possible, hard cases make poor law. I came here as a professor of surgery 15 years ago; I am not a politician but I have seen some pretty poor laws. They come in, they are passed rapidly then they have to be revised and revised again and so it goes on. I think the problem with this Bill is, as you rightly said, you are standing on a cliff edge and not a slippery slope. The law is a great dam, it keeps back the wildest successes of the wild men but it also holds back that huge potential for evil inherent in us all and once you pass a law that allows killing that will continue as indeed it did in Europe. I agree entirely with what you say and thank you very much for saying it. Would you agree with that analysis of this Bill?

Ms Campbell: I think I might. I just want you all to know how wounding and hurtful it is every time I hear or see in the papers pictures of somebody that looks just like me. In fact only two weeks ago in the *Observer* there was a picture of a person and tubes were coming out in all directions and the big headline was, “You would want to be dead rather than like this”. In fact, that was me last year; that was me the year before; that is me at night. It is incredibly disempowering and I want to empower people like me and people who are in the last stages of their lives. Actually, that part of life is just as important as birth. Ten years ago my husband died

of AIDS; he was a haemophiliac who was sadly infected by the Factor 8 cock-up. He was obviously dying in the last year and we had some very, very sad and down moments, but that last year of his life I will remember with great love and attachment because we did all that we could to make that last year the best one. Yes, he was there with tubes, he was there with all sorts of horrible things but because I had the wherewithal to know what kind of independent living support that I could bring into the house he died at home, he lived at home and nobody ever got uppity about his tubes. That made it worthwhile and I think that is what we should be concentrating on, not on all this dying business.

Q521 Lord Joffe: Coming to the position which you say about empowerment, you have great courage and strength and can somehow miraculously cope with the thought of being in a bed with tubes coming out at all angles from you. However, there are some people who do not have that courage and do you not think in your opposition disabled people are being deprived of a choice and that far from you empowering them by your approach you are actually deciding what is right for them?

Ms Campbell: No, I do not because the people I talk with who are expressing exactly those kinds of fears are the people who have never been near a tube in their lives and have not got to that stage of experiencing and, believe me, experiencing is everything. The experience of having a few tubes and being assisted 24 hours a day, being taken to the loo and all those things that we all say we could not bear is nothing in comparison to the pain of losing my husband. Nothing. So I just think that we have got it wrong; we are placing such an emphasis on how intolerable these situations are. There are many disabled people who, as you know, are talking about this being right and they want this legislation. I do not deny them that but in my own experience of talking to people who are in those kinds of intolerable situations I would say 99 per cent would say to me that experiencing is everything and their experiences are not what I read in the paper.

Q522 Lord Joffe: Why do you think it is then that in the surveys that have been taken the majority of disabled people support this Bill: the British Attitudes Survey, the survey by at Oxford University, a survey which has just been undertaken by YouGov which will be distributed which shows that of a baseline of 2000 people and of the disabled people who were part of that group 79 per cent would support the Bill. There is not a survey that I have come across—including one which the Commission itself undertook—which shows that disabled people (as opposed to disabled movements) actually oppose this Bill.

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Ms Campbell: If I say to you that every survey that has been undertaken by organisations that are not run or controlled by disabled people have very different outcomes to those that are, that might give you an idea of what I think about statistics. I was in intensive care at the time, but what about the public debate?

Ms Sayce: Yes, I think that first of all one obviously has to look at how questions were asked and options people were given and so on; we do not have time to go through all the details of that. One thing that is notable about some of the evidence that we see is that when you ask people who are young, relatively fit—even if they might be classified as disabled under the DDA, they might have had a slight mental health difficulty or might have a bit of diabetes or something—their attitudes may still be more similar to the non-disabled public and I think you have to disaggregate in some respects because what the evidence does clearly show is that when you are young and you are not disabled you may think you would rather be dead if you could not play sport, but at least you would rather be dead than using a wheelchair. Once you are using a wheelchair you adapt to that but you think you could not be able to cope with life if you had a condition whereby, in addition to using a wheelchair, you had difficulty breathing and needed a ventilator. Do you know what I mean? People do adapt to each stage and this explains the apparent discrepancy with the figures in the survey. I think it is something like 90 per cent of people with quadriplegia say they are glad to be alive whereas only five per cent of the doctors treating them imagine they would be glad to be alive if they were in their position. There are all these kinds of differences of perspective depending where you sit. There is also the interesting question of how questions are asked and what people think they are answering. We had a debate with very, very powerful speakers on both sides of the debate and a mixed audience of disabled people and other interested parties. At the beginning there were fairly evenly divided views in terms of should there be legalisation of assisted suicide. This was a much more deliberative approach to how you gather public opinion. Opinion did shift in favour of the position that this was too dangerous at the moment. There were a lot of things people had not thought of or fully considered. It is the same as polling public opinion on things like capital punishment. When you do a citizen's jury you expose people to the arguments on all sides and there is often a shift in view. This is complex territory but I do not think we can take too much from polls of the wider public's views or even only of the position of disabled people in general. I think the people whose views really matter are those people who are in the

sorts of positions who are facing these kinds of difficult decisions about possible death, about very significant and long-term impairment. We need to know what they think. Personally I have not seen research which has really given the answers on that.

Ms Campbell: I bet you, if you came to our 60 CILs around the country—where they have had the opportunity to really think about this and have a good informed debate with others, people like me—you would not get that outcome. I think a lot of it is about informed debate, it is about self-awareness, it is about empowerment. When I met other disabled people in the Disabled People's Movement I was so turned around in my own self image it was almost phenomenal. That was getting to understand the social level. I believe that that is the same here and that is why we need far more debates and far more awareness about the possibility of living with very complex and severe impairments in this world before we go down this road.

Q523 Lord Carlile of Berriew: Those who have drafted this Bill place a high degree of responsibility in the hands of the medical profession. I have a two-part question about that. First, do you feel that the group of people about whom we are talking in this Bill, at that terminal stage of their life about which we are talking, are sufficiently autonomous vis-à-vis their doctors to be able to exercise true autonomy? Secondly, do you have any comments to make about the robustness or effectiveness of the ethical disciplinary procedures applied by the medical profession in this country to prevent inappropriate deaths?

Ms Campbell: The answer to your first question is no, I don't. I have plenty of experience and anecdotes to give you that would substantiate that. Secondly, when I went back to the hospital that, quite frankly, tried to kill me and tried to take disciplinary procedure against the two consultants, they closed ranks. It is almost impossible to bring doctors to book around their behaviour or their clinical judgment. You have to be extremely energetic and extraordinarily clever. I remember being in the room with the Chair of the Trust and the lawyer and they were phasing me with all these legal terms. I am pretty clever and it completely did my head in and I thought no, there are some things you can pass on, Jane, and I passed.

Ms Sayce: We have certainly done consultations and research and looked at research as well on disabled people's experience of health services generally and it is clear that many people have absolutely excellent relationships with their doctors and other health professionals but clearly not in all cases. As I think doctors themselves at the BMA recently said, doctors have some of the same prejudices as the rest of the population and therefore disabled people do

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experience prejudiced attitudes from the medical profession and that makes disabled people nervous and aware of how the odds are stacked in the negotiations and the discussions, if you like.

Ms Campbell: I think it would be right to say that that is why we are conducting a formal investigation into the primary care services experienced by people with mental health and learning difficulties. I think that probably answers your question. There are three really good doctors in this country—two of them are in this room—and that is not a lot, is it?

Q524 Baroness Thomas of Walliswood: We have heard some moving and impressive evidence. I would like to approach this from a slightly different point of view. We have heard a lot of evidence in previous sessions about how rare it is for people who are approaching death and in particular if they are getting good treatment to ask for suicide. It is not a common thing that happens in people's experience. However, what interests me is that people are, in fact, allowed to commit suicide; it is not an offence, it is not a crime to commit suicide. If, as a clinician, you do come across that rare person who does quite clearly wish—not because he or she has been pressurised or for any of these reasons—to commit suicide, is it right that the doctor should be pressurised by the fear of 14 years' imprisonment if he assists in that suicide? That actually is what this Bill is about; it is about the penalties and proper behaviour of doctors just as much as it is about anything else. It is written in fact in terms rather similar to the Abortion Bill.

Ms Sayce: I think that firstly there has obviously been a lot of discussion in the past in relation to these issues about so-called double-effect although I understand that the evidence for double-effect has been questioned more recently. I think the first point is clearly where doctors prescribe medication that is primarily for pain relief, if it did have the effect of shortening life that doctors would not be held to blame in any way for that. That would be the first point. I think though that it is very interesting that the major medical bodies have not come out making

the point that you are raising. There is clearly a very large number of doctors who would not want to participate in assisted suicide and therefore the representative bodies of the medical profession have raised some very significant concerns about assisted suicide so rather than wanting to be able to do this in order to meet the requests of patients, doctors are actually rather more anxious that they will not have to do this and that it will not be left—as I think Tara was saying—with patients shopping around to find one of the minority of doctors who are prepared to do this. In terms of whether doctors should be placed in that position, I suppose that what I am arguing is that the majority view of the medical profession is that the medical profession does not want to be in the position of administering death and therefore I think that what doctors are in the business of doing is alleviating suffering, providing treatment and that is what they can continue to do if the law stays as it is.

Ms Campbell: Can I also say something about committing suicide because although people can take their own lives without being in fear of legal redress, we would do, as a society, everything that we could to stop a person committing suicide, including grabbing them if they are about to jump off the bridge. I want the same for disabled people; I want the same for people at the end time of their life or in the time of their life where they are at that particular stage where they would want to take their life. I would want you all, if I said to you that I want to end my life now, to stop me one hundred per cent and I do not think we feel that way about people in that state.

Baroness Thomas of Walliswood: I think there was a rather wide discussion as to whether or not those who attempt suicide actually want to commit suicide. I think in some cases they definitely do and they get extremely angry if they are resuscitated in hospital. We are going a long way beyond the remit of this discussion so I will stop it there.

Chairman: Thank you very much indeed for coming along to help us with your evidence. We greatly appreciate your attendance.

THURSDAY 2 DECEMBER 2004

Present	Arran, E Carlile of Berriew, L Finlay of Llandaff, B Hayman, B Joffe, L Mackay of Clashfern, L (Chairman)	McColl of Dulwich, L St Albans, Bp Taverne, L Thomas of Walliswood, B Turnberg, L
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Memorandum by Dr Tom Shakespeare**AUTHOR**

Dr Tom Shakespeare is a sociologist at the University of Newcastle. He has written widely within disability studies, including on a number of bioethical debates: books include *The Sexual Politics of Disability*, *Exploring Disability*, *Genetic Politics: from Eugenics to Genome*. He was a member of the Nuffield Council on Bioethics Working Party on the ethics of research on genes and behaviour. He has the genetic condition achondroplasia, which is a static, non life-threatening condition. He has been active in the disability rights movement for 20 years. In 2003, he was awarded the RADAR People of the Year award for furthering the human rights of disabled people in the UK.

1. INTRODUCTION

1.1 The disability rights movement has expressed considerable concern about end of life issues, fearing that vulnerable disabled people will be killed against their will, or left to die without assistance.

1.2 The disability rights movement has not always drawn clear distinctions between different issues at the end of life:

- Do Not Attempt Resuscitation.
- Withdrawal of treatment.
- Assisted suicide.
- Voluntary euthanasia.

1.3 It is necessary to distinguish situations where the autonomy of disabled people is undermined (abuse of DNAR, non-voluntary euthanasia) from situations where disabled people themselves are exercising their autonomy by requesting assistance with death, or withdrawal of treatment (advance directives, assisted suicide).

1.4 In general, the disability rights movement have supported the autonomy of disabled people throughout life: the basis of independent living philosophy is support for the rights and choices of disabled people to have control over their own lives. It seems to me to be inconsistent to support autonomy for disabled people in all matters except at the end of life.

2. REASONS WHY THE DISABILITY RIGHTS MOVEMENT MIGHT OPPOSE ASSISTED SUICIDE (AS)

2.1 The disability rights movement is anxious about pressure being exerted on disabled people to end their lives against their will, and is anxious about a slippery slope to non-voluntary euthanasia. There are historical and contemporary precedents for so-called “mercy killing”.

2.2 There are fears that disabled people will be pressured to request AS, although evidence from Oregon and the Netherlands is inconclusive.

2.3 Many disabled people live throughout their lives with conditions which are defined as terminal. It is feared that it will be easy to extend the rights or cultural expectation of assisted suicide to disabled people in general, not just people who are in the terminal stage of a terminal illness.

2.4 Many disabled people are living with the pain and dependency, technological and physical, which is cited as evidence for the rationality of a decision by others to seek assisted suicide. They fear that their own lives will be devalued, or may even be at risk, as a result of the decisions or attitudes of others.

2.5 Many disabled people feel vulnerable and depressed. Many disabled people have at different points wanted to end their lives. With support and over time, most disabled people have come to terms with their impairments and learned to accommodate to their restrictions, reporting a good quality of life and no longer wishing to end their own lives. They fear other disabled people making irreversible decisions and denying themselves the possibility of living a better life as a disabled person.

2.6 There is a fear that making AS available will send a message that it is logical and desirable for disabled people to end their own lives. This will influence the attitudes of people who live and work with disabled people. These messages and attitudes in turn will feed back into disabled people's own views about their actions and choices, making it more likely that they will choose AS.

2.7 The disability rights movement has developed a social model understanding of disability, in which people are disabled by society, not by their bodies. This has made it harder for the disability rights community to engage with debates about illness, impairment and end of life. It could be argued that a social model philosophy enables some to disengage from troubling questions about bodies and mortality.

3. IMPORTANCE OF SOCIAL CONTEXT

3.1 People make decisions in a social context. If independent living options (housing, technology, assistance etc) are not available, then the lives of people with impairments and terminal illnesses will seem harder and they may be more likely to opt to end their lives. A person must have had access to the full range of care and independent living possibilities, prior to being entitled to request AS.

3.2 Similarly, fear of the process of dying is widespread. It is argued that palliative care and pain relief can ease dying. The availability of palliative care and of hospice care is very important. A person must have had access to these facilities, prior to being entitled to request AS.

3.3 Campaigns for assisted suicide and voluntary euthanasia have sometimes emphasised the pain, humiliation, and difficulty of disability in ways which are derogatory to disabled people, and cause fear and alarm in non-disabled people. Care should be taken not to express negativity about impairment and illness unnecessarily.

3.4 Fear of disability is widespread among non-disabled people who are unfamiliar with disabled people. Research has shown considerable cultural prejudice against disabled people and a commonly expressed belief that it would be better to be dead than disabled. These fears need to be challenged, and the positive aspects and contributions of disabled people need to be emphasised. Impairment and disability are part of the human condition, and society needs to come to terms with disability, not encourage people to think that disabled lives are not worth living.

4. ARGUMENT FROM AUTONOMY

4.1 The disability rights movement supports disabled people's choices in every other area of life. Where people cannot carry out physical tasks, the principles of independent living suggests that they should be able to employ others to carry out those tasks, under the control of the disabled person themselves.

4.2 Non-disabled people in an end of life situation are often capable of committing suicide. Disabled people with the same desire may be incapable of implementing that choice (for example the case of Dianne Pretty). If applied consistently, independent living principles might suggest that disabled people should be empowered to have assistance to end their own lives in certain situations.

4.3 It could be said to be inconsistent to limit the right of disabled people to assistance to commit suicide solely to cases of terminal illness. Why should disabled people not be able to choose suicide, just as non-disabled people can? Yet, there is a general presumption that suicide is to be prevented where possible. Even though suicide has been decriminalised, it is a moral duty for third parties to try to dissuade a person to commit suicide. Therefore it would not be right for society to help a disabled person to commit suicide on autonomy grounds. The only social sanctioned case where suicide becomes a legitimate choice is in the case of end stage terminal illness.

4.4 In practice, disabled people themselves have often requested the right to assisted suicide, to withdrawal of treatment or other ways of ending life. When the Disability Rights Commission conducted an online survey in 2003, 63 per cent supported new laws on end of life.

4.5 Different disabled people have different views and desires. The desires or decisions of one disabled person should not have direct implications for the desires or decisions of another disabled person.

4.6 Disability rights activists concerns about AS highlight the importance of protecting individual choice. It is feared that some people's choices will be denied, but the anti-AS position itself is a denial of choice.

4.7 The question becomes an empirical one: does the risk to the many of permitting AS outweigh the benefit to the few who may choose to use AS.

5. CHOOSING DEATH CAN BE RATIONAL

5.1 Some people cope well with restrictions, find value in enduring suffering, find alternative sources of meaning and pleasure. Others find this situation unendurable.

5.2 Even with palliative care, hospice facilities, support etc, some deaths are difficult and it is rational to fear them.

5.3 Views on end of life are personal and subjective. One person's judgement does not have implications for another person's right to life or dignity or respect

6. PRAGMATIC ARGUMENTS

6.1 In the absence of legal AS, terminally ill people will still attempt AS. This can lead to the complications, distress and difficulty of "death tourism", for example in the case of Reginald Crew and others.

6.2 Alternatively, "underground AS" may lead to the dangers of botched suicide, and the risks of prosecution of assisters, fears of which may make a terminally ill person's situation more difficult and anxious.

6.3 Many people who desire AS may never take advantage of it. Knowing that AS is available may reduce the anxiety of dying people. Fears of pain and other symptoms may be mitigated by the knowledge that there is another way out, if it all gets too much.

7. SAFEGUARDS IN AS

7.1 Given points made earlier (2.5, 2.6, 3.4) about fears of disability and the possibility of coming to terms with impairment and illness, people who have recently developed or been diagnosed with impairment/illness should not be allowed to exercise the choice of AS.

7.2 The distinction between "people with terminal illness" and "terminally ill people" is very important, and not easy to define. AS should be available to people in the end stage of incurable disease, not to disabled people in general. Questions of definition need close attention in developing an AS policy.

7.3 Depression and other mental illness may cloud judgement and may prevent a person with terminal illness making a competent decision to request AS. The right to request AS should depend on the mental competence of the person with terminal illness.

7.4 Any request for AS should be subject to calm and careful scrutiny from both medical and legal professionals. Where possible, there should be a "cooling-off period" for the person to consider their situation, at the end of which they should have to confirm once more that they understand the consequences of their decision and want to go ahead with AS. This cooling off period might be set at 24 hours, except where death is imminent within that time.

8. CONCLUSIONS

8.1 Disability rights-based objections to disabled people's exercise of autonomy at the end of life are procedural, not substantial.

8.2 With suitable safeguards and regulation, assisted suicide legislation should be supported by those who support choices and rights for disabled people.

8.3 Well informed, well supported, competent adults in end stage terminal illness should be able to exercise the choice of assisted suicide.

8.4 If legalisation does proceed, the situation should be monitored very carefully. Empirical evidence is needed of AS in practice, and the law should be revised if evidence of abuse is presented.

8.5 It is important for the views of disabled people to be heard in debates on end of life issues. But disabled people express a plurality of opinion on this, as on other matters. There is not unified opposition to AS from disabled people, or their organisations.

Examination of Witnesses

Witnesses: DR TOM SHAKESPEARE, Director of Outreach, PEALS (Policy, Ethics and Life Sciences Research Institute) and Ms ALISON DAVIS, National Co-Ordinator, No Less Human, examined.

Q525 Chairman: Welcome to you both. I think you have agreed to share this session together. As before, we would invite you to make opening statements and then the Committee will have the opportunity to ask you questions. Dr Shakespeare?

Dr Shakespeare: Thank you. I will be very brief. I do not think this Bill is a threat to disabled people. I think that the Bill is—as I have read it and understand it—carefully limited to people at the end stage of terminal illness which by no means is equivalent to being a disabled person. There are 10 million disabled people in Britain, a very small proportion of them are in that state. Terminal illness people could be seen to be disabled but disabled people are not necessarily terminally ill. I think Jane’s evidence and the evidence for the DRC generally is very moving and it is absolutely true that disabled people face discrimination in many areas of life and we should combat that in any way possible. However, I do not think that evidence or that testimony is relevant to this Bill. As I say, this Bill is about people in terminal states. As I understand it, statistics from The Netherlands say that 80 per cent of people who request assisted suicide have cancer and many others have motor neurone disease and other terminal conditions. I think that it is true that disabled people are very concerned and I think there has been a measure of scaremongering and misperception about the Bill and about the issue in general. I think that is unfortunate and I think this Committee and other discussions of the Bill need to be very clear that it is not an attack on disabled people and disabled people would not be vulnerable if it were to be passed. My second point is that the Disability Movement supports autonomy. It supports the rights of disabled people to control and define their lives in every area: where to live, how to be treated, how to be supported and care for. That is absolutely essential to the disabled people’s movements. Rights not charity; the right to have control over your life. Nothing about us without us. It seems to me inconsistent that the disability community would support autonomy in every other area of life but not the area of choosing when life becomes intolerable to end it. It does not seem to me to be consistent. I completely agree with all those people who have said that if autonomy is infringed, do not attempt to resuscitate is placed on people’s notes without discussion, against resuscitation council guidelines or if people are coerced into it or anything

like that, that is quite clearly wrong. I assume this Committee, the Bill and all right-minded people would agree with that. However, this Bill is about the autonomy, the autonomous choices of people towards the end of life. I think there is an inconsistency in the evidence we have just heard. If the people are so vulnerable, if the DRC is right, then logically they should oppose withdrawal of care, but they do not. From a philosophical sense there is no difference between acts and omissions except that to die of starvation and thirst is a far worse death than to have a terminal dose of barbiturates. It is wrong that a disabled person who is dependent on technology can ask for it to be withdrawn and hence die, but the disabled person who is not dependent on technology but is at the end of life and is suffering unbearably cannot do that. It seems to me inconsistent and against this fundamental principle of autonomy. My third point—and it has been made already—is that disabled people do support assisted dying in large numbers. It has already been pointed out that the DRC’s own survey found 60 per cent of respondents supported a change in the law. Lord Joffe has referred to the recent YouGov poll in which 80 per cent supported the proposals in the Assisted Dying Bill and it was explained what those were. Only a small proportion would trust doctors less if the Bill became law; most people—76 per cent—would trust their doctors the same amount. In terms of the impact on society’s view of disabled people, 47 per cent thought it would have no impact at all. It seems to me that these are careful testimonies. It is true that there is fear amongst disabled people and it is true that the disability community is divided, but I would not want you to take away the view from having heard the people we have heard already—whom I respect mightily—that they represent all disabled people. At best they represent half of them; at worse they represent a minority of them. It is true that most organisations of disabled people who have expressed an opinion are against, but that might mean that they are either wiser or less representative than their constituencies, I am not sure about that. I think it is a very difficult issue and I think introducing assisted suicide needs safeguards. I entered this debate agnostic; I am not a member of the Voluntary Euthanasia Society or any other pro-assisted suicide group, but having read the evidence and read a range of submissions to this Committee and having looked at the Bill, it seems to

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me that it is a much more tightly-worked proposal than pertains in Oregon or in The Netherlands. It combines the degree about prognosis, the six months left in Oregon; it combines the issue about unbearable suffering of The Netherlands. That seems to me to be a double safeguard. I do not think it is a slippery slope. If you look at the evidence from Oregon and The Netherlands there is not a huge rush to die, in fact fewer people are now dying. It seems to me that many people open up the conversation, fewer people put forward a request and even fewer people take the final step. In our organisation—which is part of a university research institute—we held a public meeting about whether medicine should give you a good death. We had a speaker, a philosopher, my colleague Dr Simon Woods (who has been a cancer nurse and has written on end of life) and anybody could have come. A lot of people did come—nearly a hundred people—predominantly older people. I would assume that the vast majority were not disabled but they were predominantly older people and almost unanimously when I asked them to vote at the end of the discussion (which was vigorous) they all said that they wished this to be a legal right. That is not to say that people would take advantage of it, but knowing it is there is something which reduces anxiety. Fear of death, of course, is amongst the most debilitating things. Of course I agree that palliative care should be available much more widely than it is. I honestly do not think that a considerable number of people would opt for assisted suicide but I think that at this stage of the development of the argument should be enabling that tiny minority for whom it is important to have that right. The one concern that I have noticed in the Bill as it stands is about consent. The question of consent is absolutely vital. I think that people who might be depressed—not depressed to the extent of not being competent, but depressed—should also be referred to a psychologist or a psychiatrist. I am referring to Section 8, clause 1 so they are referred to a psychologist or a psychiatrist if they are not competent, but I think they should also be referred if there is evidence of depression such that it does not reduce their capacity but does affect their state of mind. Section 2 seems to be a broader consideration. That is the only thing that I have noticed that I am unhappy about in the Bill as it stands. I would say that many disabled people would agree with the stance I am taking.

Ms Davis: I have two hats on. I am speaking as an individual today but I do co-ordinate a group for disabled people called No Less Human which is for disabled and terminally ill people, their families and carers. I have spina bifida and hydrocephalus, osteoporosis and emphysema. Nineteen years ago I wanted to die. I have severe spinal pain which is not well-controlled even with morphine. You will excuse me if I am a bit hesitant but I just took morphine 10

minutes ago so I am not quite as altogether as I might be. I have severe pain which cannot be well controlled. When it is at its worse I cannot move, I cannot think, I cannot speak and it can go on for hours; there is no prospect of it getting any better, in fact it is almost certain to get worse. Due to that and a combination of other factors, 19 years ago I decided I wanted to die. It was a settled wish; it lasted 10 years. In the first five of those years I tried to commit suicide several times. They were serious attempts, most of them, and I tried several different methods. I was saved only because my friends arrived in time. My door was never locked at that time and they came in and found I was losing consciousness and they took me to the hospital. At the hospital I was treated several times against my wishes. I told the doctors that I did not want to be treated. They asked for my permission to pump my stomach and I said no. They said, “If we don’t, you will die”. I remember at the time thinking in a very wry way that it was almost funny because that had been my intention; I had wanted to die. So they waited until I lost consciousness and then treated me anyway. Had the form of declaration which this Bill proposes been available at that time I would have signed it with no hesitation whatsoever because my intention was to die and I was suffering then the same pain which is unbearable—except that I have to bear it—that I am now. If the Bill had been law 19 years ago I would not be here speaking with you now. That, in a sense, would give my doctors, who at that time thought I was terminally ill, a very convenient self-fulfilling prophecy because they said I was terminally ill. Actually they were wrong and here I am 19 years later. Had my life been ended by the terms of this Bill nobody would have ever known firstly that my doctors were wrong and secondly that the future held something better for me than would have appeared to be the case 19 years ago. I was saved against my wishes. I lived on. For 10 years I wanted to die. I note that the Bill has a 14 day waiting period during which the person requesting euthanasia can change their mind. That would not have served me at all: 14 days to change my mind when I wanted to die for 10 years. I think this Bill is extremely dangerous. It sets out supposed safeguards to prevent what is called abuse of what would be the law but I believe that the law itself would be an abuse of sick and disabled people. I sat in at the earlier session and I heard the discussion about people who wanted to commit suicide but cannot and need assistance. By describing safeguards to the Bill in effect we are saying that the sort of people that are specified are right to want to die and should be helped to die, whereas people who are not specified who may well be equally desperate to die and possibly for much the same reason would be considered wrong to want to die and would be helped to live. I think that sends out a very negative message to people like me who suffer on a daily basis and who need help and support to live

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with dignity. We hear so much about dying with dignity that it almost becomes a slogan or a catchphrase and it suggests that people like me are only dignified when we are dead. I do not agree with everything that the Disability Rights Commission said, but I think they were right when they said that what we need is the right to live with dignity until we die naturally and that will not happen if this Bill becomes law.

Q526 Baroness Finlay of Llandaff: Could I ask you, Dr Shakespeare, whether you feel that the prejudice that we have already heard about amongst clinicians does exist or does not exist?

Dr Shakespeare: I think it is undoubtedly true that many disabled people have had negative experiences of clinicians but I think it is exaggerated. I think the vast majority of disabled people have good experience of clinicians. I do not think that clinicians or anybody else are queuing up to kill disabled people. I think the evidence is, for example in cases of advanced directives, that where a person has expressed a desire for withdrawal treatment in such and such a situation, it is usually the relatives who beg the doctors not to fulfil the wishes of the presumably not-able-to-consent person. I think that neither doctors as a rule nor relatives are going to wish to see people dying at all and certainly not against their will. Doctors are dedicated to the preservation of life. There are a few arrogant doctors who might think that this was a good role to exercise but I think they would be a tiny minority. I think it is sad that some disability movements think of doctors as the enemy whereas for the vast majority of disabled people doctors do not always get communication right but they are basically on their side.

Q527 Baroness Finlay of Llandaff: If we look at the way that information is communicated with patients do you feel that currently there are enough doctors with excellent communication skills to feel confident that the arrogant doctor would not be able to influence a patient who is vulnerable and, perhaps, facing a new situation to which they have not adapted?

Dr Shakespeare: I am not sure about that. I think the doctors that are being trained now—and in Newcastle University and in other universities I have played a role in that—communications skills and the whole ethical aspect of medicine is stressed to a much higher extent to that which it was in decades gone by. There may be doctors in the older generation who are residual and arguably prejudicial physicians. I think that the vast majority of doctors are not like that and whatever generation or age I do not think that we should overly fear that. I think there are safeguards built in in terms of other public professionals being involved. Education of doctors continues to improve and it should be a priority. I would assume—and I think the BMJ and the GMC have already suggested that this would be a role

that they could play—that were this to become law, doctors, nurses and others would receive training in how best to have these discussions and in the ethical and legal safeguards that have to be there. I would say that the training of doctors is absolutely essential if this were to become law.

Q528 Baroness Finlay of Llandaff: When you were talking before, if I have understood you correctly, you felt that you should have the right to be killed by a clinician. That is what you are arguing for and I wondered how you see the figures that come from Holland where quite a number of patients are turned down in their request because their clinicians deem that they are not suffering enough. This seems to me an inequity in that the doctor is passing judgment over the patient's suffering but the patient is the only one who can describe the suffering.

Dr Shakespeare: I would be in favour of making the regulations as tight as possible and if that meant turning down certain people then I would rather that than the fears that other people have expressed of it being so loose that others go in. The evidence as I understand it is that palliative care doctors and other professions allied to medicine have a different sort of relationship with their patients to the doctor patient relationship in other cases. It is far more of a partnership relationship than in other areas of acute medicine and so forth. Doctors have to do their professional duty and will have to think very carefully about whether the patient they are seeing comes within the terms of the Act if it were passed but given that autonomy is central to the Act I would assume that the guidance would suggest that they have to take the views of the patient regarding their pain very seriously indeed.

Q529 Baroness Finlay of Llandaff: I just wonder then why you would think that if doctors in palliative care have a partnership arrangement—and I hope that is true—why you think that 97 per cent of the doctors working in palliative medicine as trained specialists do not want to have the ability in law to kill their patients.

Dr Shakespeare: I have not seen that statistic; obviously I will take it as read that it is true. However, it seems to me that palliative care as I understand it is about relieving pain and giving people a good death. The fact that some people are not helped fully by palliative care is evidence that palliative care does not always work and it seems to me not surprising that palliative care doctors might be unwilling to recognise that.

Q530 Baroness Finlay of Llandaff: I would suggest that if you looked at palliative care five years ago the techniques available then and the techniques available today are very different.

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Dr Shakespeare: I have to bow to your greater experience but it seems to me that not all pain is controlled, that heavy doses of drugs—as we have just heard from Ms Davis—have other side effects which are not desirable and whether palliative care works or not it may not be the way that everybody wants to go. Everybody should have a choice. For some they may wish to end it quickly and painlessly and in their own way and I think that our society should allow you to do that.

Q531 Baroness Finlay of Llandaff: Do you feel that, at the moment, we have an adequate provision of palliative care to allow that?

Dr Shakespeare: No, I do not. I have already said that I think that should be extended but I think the fact that we live in a real world—a difficult world where not everybody gets what they need in all sorts of ways—is not a strong argument against allowing this. I do not see widespread abuse and I do not see why palliative care cannot go hand in hand with this. I think the evidence from Oregon is that palliative care has actually improved since the introduction of this measure. It seems to me that a very, very tiny proportion of people will opt for assisted suicide therefore the need for palliative care will continue to be huge and a major priority with the ageing population. Nothing will change that so I think we could hopefully have both.

Q532 Lord Turnberg: I do not know whether you heard the evidence from the previous witnesses but they were obviously somewhat different in their attitudes to the one you describe. A couple of their arguments were that if the Bill went ahead it would divert attention away from the need for more resources for handicapped people and palliative care services. The other argument—and perhaps more significant—was that they suggested that there was a subtle sense of coercion—and a not so subtle sense of coercion some felt—the people that feel this particularly are those who are the most severely ill or near to death. It seems to me that there may be differences in the community which includes handicapped people in the range of handicaps and the severity with which it approaches the terminal phase and that the fitter you are—that is certainly true in a society where people are not handicapped—the thought of having this facility available at the end of your life is very attractive, but the nearer you are to it the less you are keen on it. Do you think that is a reasonable assumption?

Dr Shakespeare: I do not have evidence to sustain that. I think probably—and this is a hypothesis—that people in society who are most keen on this measure are older people, people who are in their seventh and eighth decade who have had a very vigorous life and who have had control and choice in

all areas of their life and really want it at the end of life. I do not think it is just young men who go out partying every night who think it would be dreadful to be disabled. I do not think it is about that. We are not talking about people who cannot walk or people who are dependent on technology, we are talking about people who are at the end stage and who are in unbearable suffering. The folks that I spoke to and the older folks who came to our public meeting cannot see why they should not have the right to request this. They feel very angry that others are seeking to deny it. This subtle sense of coercion, I do not think disabled people are dupes; I do not think that most citizens in this country are dupes; I do not think they are going to be trotted off to die against their will. I cannot see that happening. Jane, whom I respect highly, is somebody with a hugely severe impairment but she is no dupe. She is the feistiest, strongest person you have probably seen in weeks. Are we really to believe that folks are going to be so vulnerable? I have friends with HIV AIDS again who have felt that this was a right that they wished to have at a certain time. Only a couple of them committed suicide, they obviously were not assisted to die. I think for many people at different stages of life it seems that they would wish to have the potential to choose it even if they do not ever choose it in practice.

Q533 Baroness Hayman: I wonder if I could ask Ms Davis something about the very powerful story that she told us about her own experience and the experience people have of changing their mind and having different attitudes at different phases. Obviously one understands that that is true and it is possible that some people, if they had not ended their lives, would have survived that particular point of despair and gone on and had a very productive future time. However, I do have difficulty in understanding why that risk would be significantly different for assisted dying than it would be for suicide itself (which could have been successful) or for refusal of treatment (which I understand you tried to implement and were denied) which again is something that the patient does have a right to refuse. I do not quite see in my own mind why it is a particularly potent argument in relation to this Bill rather than in relation to our laws of suicide in general or indeed our laws allowing people to have to consent to treatment.

Ms Davis: I think it is particularly important to this Bill because had voluntary euthanasia been legal when I wanted to die I would have qualified under the terms. If it had required signing a form, a declaration, I would have signed it. If it had required writing an advance decision or living will—whatever you choose to call it—I would have signed it. I would have qualified, I would have asked for it and I would not be here now and I think that is what makes my story

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particularly relevant to this Bill. I think it also has relevance to withdrawing and withholding treatment and the whole issue of the Mental Capacity Bill because clearly I was mentally incapacitated once I lost consciousness. I would have signed an advance decision and treatment would not have been instituted. It has relevance to both, I think.

Q534 Baroness Hayman: Without being impertinent—it sounds as if it is impertinent—had your autonomous request not to have treatment been respected then you would not be here and able to give us such powerful evidence today. That is the law at the moment. Indeed, if you had made an advance directive that equally would have been potent in those circumstances. I am just trying to explore whether this is different from those circumstances, whilst quite accepting your argument that people's emotions and feelings in this area may be transitory.

Ms Davis: I think there is perhaps not an adequate understanding of the concept of autonomy because many people believe it simply means that you make your own decisions, self-determination. However the concept of autonomy actually means that you should act in your own best interests and best interest as traditionally understood means such things as preserving life, maintaining health, restoring health, minimising suffering and I think those are the sort of things over which we have autonomy. What I do not think we have autonomy over is the choice to give up the right to life because the right to life is an inalienable right which I may not be deprived of even though I give up voluntarily. For instance, the Human Rights Act states that everyone's right to life shall be protected by law. No-one shall be deprived of their life intentionally except—although it does not apply in this country—as due punishment for a particular crime. We have in our own laws the understanding that the right to life is a primary right; any other right is meaningless without the right to life. There is no point in having any other right if you do not have the right to life itself and I think the question of autonomy is that we need to act responsibly in our own best interests and our own best interests include protecting the right to life. Obviously I am not saying that people should be forced to undergo futile disproportionately burdensome treatment; that is not what I am saying. What I am saying is that just as we cannot voluntarily sell ourselves into slavery because it would impact on other people, so we cannot voluntarily ask somebody else to kill us because it would impact on ourselves, because it would be denying our own right to life. Secondly, it would impact on other people and it would certainly have made a big difference to my life because I would not be here now.

Q535 Bishop of St Albans: I would like to ask Dr Shakespeare whether there is any medical situation in which you could imagine that there are no limits at all to the exercise of personal autonomy.

Dr Shakespeare: No, I cannot.

Q536 Bishop of St Albans: So the exercise of personal autonomy is absolute.

Dr Shakespeare: Sorry, I answered with the opposite. I do not think it is absolute; I am sure that there are areas in medicine.

Q537 Bishop of St Albans: Could you begin to enumerate what they are? You seem to be hinting, for example, that the exercise of personal autonomy when a person felt depressed was an area in which you would feel intervention was necessary.

Dr Shakespeare: I do not think that capacity is a general universal thing. I think capacity exists in regard to particular acts and particular desires. For example, we all agree that children—even at quite a young age—have capacity; they do not have capacity for everything, they have a limited amount of capacity. The context and your status and the particular thing for which you are requesting support all determine the judgment of capacity. It seems to me that in the case of depression I could see why somebody might feel that their life had no meaning and was best ended, but I would not support them in that because I think that their judgment would be contaminated by the nature of the condition they were experiencing.

Q538 Bishop of St Albans: But if they are exercising personal autonomy—which is the highest moral good—even though apparently depressed (by whose definition of depressed, one asks?) why do you wish to deprive them of that right?

Dr Shakespeare: Because I do not think they would be making a free and good decision in that context. They may be, but I think there is a risk that they will not and I certainly did not say that the value of autonomy was the highest value. I think it is a very important value and it is one that should not be restricted without good cause.

Q539 Bishop of St Albans: Could you say what the other values would be that you think might impact on that exercise?

Dr Shakespeare: Conventionally in medical ethics the issues of beneficence and nonmaleficence and justice would be seen to be ones which have to be taken into account alongside autonomy. For example, I have strongly advocated the autonomy of a small number of people to request and to be granted assisted suicide, if I thought that there was evidence that that autonomy would be at the cost of the autonomy of

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others who would be killed against their will then I would not be here.

Q540 Bishop of St Albans: But they would have to be killed by somebody else, so they are exercising their autonomy to impose an obligation on someone else without asking. They want to impose their will upon the medic to kill them.

Dr Shakespeare: Actually I think the Bill says that all doctors would be able to conscientiously object.

Q541 Bishop of St Albans: But there would be one person who ultimately would say, "Yes, I will".

Dr Shakespeare: Yes, and there are doctors who make life and death decisions all the time so I do not see that this is any different.

Q542 Bishop of St Albans: There is a difference, is there not?

Dr Shakespeare: I am probably being obtuse, but I do not see it. If I can come back slightly, there is already evidence in many countries in the world of what would be called underground euthanasia, of illegal acts performed by doctors or by others on behalf of people who wish to die. That is unregulated, it is unknown and it may involve all sorts of abuse. I think there is a strong argument that careful regulation would reduce the abuse and, indeed, the defence of mercy killing because here is a very clear legislative proposal to limit and regulate it and so if it were outside those limits and regulations there would be no defence in law that I can see.

Q543 Chairman: You could have mercy killing that was outside this Bill though, could you not?

Dr Shakespeare: Yes, but if there is not an Act which legitimates it and says that these are the channels and these are the considerations and this is legitimate then presumably illegal mercy killing—it may happen—would be much less defensible in a court of law.

Q544 Lord Carlile of Berriew: Just pressing that a little further, what is the difference between what is proposed in this Bill, Dr Shakespeare, and the following situation: a patient who, after good quality and intensive medical treatment, wishes to die from the extreme mental pain caused by an incurable mental illness? What is the difference?

Dr Shakespeare: I do not know.

Q545 Lord Carlile of Berriew: That is the slippery slope danger of your argument.

Dr Shakespeare: I think that you have to draw a line somewhere and I think acute depression or schizophrenia is a hugely problematic thing and I know there are people who wish to die as a result of it and as impairments go it is a very severe impairment. However, my worries about capacity and about

abuse and about people who are not competent lead me to feel that that it would be to go too far. Of course, if somebody is in that state then there is no obvious assumption why they could not commit suicide anyway. This is to cover people who are not capable of committing suicide themselves by virtue of their own capacity or their physical situation. It is true; your point is very germane to someone who had an acute psychiatric illness and an acute physiological restriction but I am afraid that any law has to be restricted and some people will have just claim but will be outside that law and I think that may be one of them.

Q546 Lord Carlile of Berriew: I am talking about the real world of mental illness in which somebody may be detained under the Mental Health Act and may be physically disabled from obtaining the means with which to commit suicide. Why should they not be put in exactly the same position as someone under this Bill? If, as you seem to accept, there is really no difference between the two categories, is that not the starkest illustration of what has been called the slippery slope?

Dr Shakespeare: I did not say that there was no difference. I said that it was a situation that I did not have a straightforward answer to. It seems to me that there is a question about their capacity and it seems that if this Bill had included such people I would certainly not have supported it; it would seem to me to be too open. It may be that your Lordships and others may wish to think carefully about that and extend this law. A slippery slope is one where we have no control over where we go next and where one thing leads to another without any consideration or way of stopping it. This is not a slippery slope because, as I understand it, it is a very tightly controlled Bill which will not give everybody what they are asking for. I am sure that many supporters of the Voluntary Euthanasia Society think this law is too restrictive and draconian and I am glad about that because if they were all happy I would be concerned.

Q547 Lord Carlile of Berriew: I want to ask you an entirely different question. You raised the point about training and you expressed some confidence that good quality training could be made universal to clinicians. You cited as your examples the General Medical Council (which is not in fact a training organisation, it simply issues pamphlets for this purpose) and I think you said either the BMA or the BMJ. I do not know if you were here this morning when we heard the Government's leading expert on palliative care telling us that something called a Gold Standard had managed to reach out so far to 16 per cent of primary care general practitioners in this country, leaving something like 80 to 85 per cent to

2 December 2004Dr Tom Shakespeare and Ms Alison Davis

access over the years to come. What is your paradigm upon which you base your confidence that training could be given to clinicians in the matters raised by this Bill within a reasonable time so as to provide for robust training and medical supervision over those clinicians who wished to practice it and protected totally those clinicians who refused to practise it?

Dr Shakespeare: I agree with you. I have tried to train GPs; I have offered to train GPs a lot and they are all too busy to take advantage of it. I think your point is germane but presumably the Bill can be amended to say that nobody can authorise a request to die if they have not been on an approved training course. That seems to me a practical problem and not a problem in principle. It may be that the law cannot come into practice for several years until that training has been achieved. So be it. I would be utterly supportive of resources and training going to GPs and to other clinicians. As I understand it, doctors are always going for periods of training. They are having to catch up with genetics at the moment which many of them do not know enough about. This will be another of the topics on which they will have to be trained but that does not stop us introducing new technologies or new possibilities in medicine because not everybody knows how to exercise them. It shows that we need to be careful about it, but it does not mean that we should not go down that road.

Q548 Lord Joffe: Miss Davis, you talked about best interests. Who do you think should decide on your best interests?

Ms Davis: I am happy with my best interests being regarded as traditionally regarded best interests. I am very concerned about, for instance, the definition of best interests which the Mental Capacity Bill proposes which would be the wishes and feelings of the person concerned. Nineteen years ago I wished to die and felt I would be better off dead but those wishes and feelings did not correspond with what was actually in my best interests.

Q549 Lord Joffe: You think that the doctors or other people should decide on your best interests and other patients' best interests.

Ms Davis: I think that a definition of best interests has already been set down, for instance in case law, and that is the definition that I think is correct, is safe

and gives vulnerable people the most protection. Talking about people's wishes and feelings militates against people who are as desperate as I once was.

Q550 Lord Joffe: Do you believe in the right of patients to refuse treatment even if the refusal leads to their death?

Ms Davis: If the treatment is, as I said before, futile or if it disproportionately burdensome then yes. What I think a person does not have a right to do—because as I explained the right to life is inalienable—is to either request a treatment or refuse it with the intention that that refusal will bring about their death. It may be that their death will be a side effect of their decision to refuse the treatment but I do not think it should be the person's intention that refusal will cause death.

Q551 Lord Joffe: The law is quite different in that. The law is that patients can refuse treatment and it is not a question of whether it is a wise decision, but it is their decision. So you disagree with the law as it is.

Ms Davis: I do not think that advance decisions have legally binding status.

Q552 Lord Joffe: I was talking about a request to withdraw treatment not advance decisions.

Ms Davis: I understand that. I am thinking of the case of the man who was schizophrenic and he had a gangrenous leg and he refused treatment to have it amputated. Presumably that is the sort of case you had in mind. That case has sometimes been cited as evidence that people may refuse treatment for any reason whatsoever, but in that case it had not been established that he wanted to bring about his death; he simply did not want to have the operation and did not want to have his leg amputated. I think we have to be very careful about what the person's reason is. That has been cited as a reason why, for instance, advance decisions are legally binding; I do not accept that they are. I think in that case the person's reason for not wanting the surgery were not probably to bring about his death.

Chairman: I am inclined to think that we have had a fairly long day and we should stop now. Thank you both very much indeed for your help. You will have a chance to correct the transcript of the evidence, not of course to alter what you said but just to make sure it is properly recorded.

THURSDAY 9 DECEMBER 2004

Present	Arran, E	Joffe, L
	Finlay of Llandaff, B	Mackay of Clashfern, L
	Hayman, B	McColl of Dulwich, L
	Jay of Paddington, B	

Letter from the Oregon Department of Human Services

Pursuant to your Call for Evidence, the Oregon Department of Human Services wishes to offer the following information about Oregon's Death with Dignity Act. The Department of Human Services is legally required to collect information regarding compliance with the Act and make the information available on a yearly basis. As a state agency, we are neutral on the Act itself. We believe that Oregon data may be presented before your committee as you consider this bill, and we want to be sure that you have accurate information about Oregon's experience over the last six years of the Act. These data are important and useful to both sides of the debate.

Physician-assisted suicide (PAS) has been legal in Oregon since November 1997, when Oregon voters approved the Death with Dignity Act (DWDA) for the second time. In our sixth annual report, we characterize the 42 Oregonians who, in 2003, ingested medications prescribed under provisions of the Act, and look at whether the numbers and characteristics of these patients differ from those who used PAS in prior years. Patients choosing PAS were identified through mandated physician and pharmacy reporting. Our information comes from these reports, physician interviews and death certificates. We also compare the demographic characteristics of patients participating during 1998–2003 with other Oregonians who died of the same underlying causes.

In 2003, 42 physicians wrote a total of 67 prescriptions for lethal doses of medication. The number of prescriptions written increased in each of the previous years: 58 prescriptions were written in 2002, 44 in 2001, 39 in 2000, 33 in 1999, and 24 in 1998. Thirty-nine of the 2003 prescription recipients died after ingesting the medication. Of the 28 persons who did not ingest the prescribed medication, 18 died from their illnesses, and 10 were alive on December 31, 2003. In addition, two patients who received prescriptions during 2002 and another who received a prescription in 2001 died in 2003 after ingesting their medication for a total of 42 PAS deaths during 2003.

There were four more patients who used PAS in 2003 than in 2002, and the number of patients ingesting lethal medication has increased over the six years since legalization. In 2003, 42 patients died from PAS, compared to 38 in 2002, 21 in 2001, 27 in 2000, 27 in 1999, and 16 in 1998. The 42 patients who ingested lethal medications in 2003 represent an estimated 14/10,000 total deaths, compared with 12.2 in 2002, 7.0 in 2001, 9.1 in 2000, 9.2 in 1999, and 5.5 in 1998. Compared to all Oregon decedents in 2003, PAS participants were more likely to have malignant neoplasms (83 per cent), to be younger (median age 73 years), and to have more formal education (48 per cent had at least a baccalaureate degree).

During the past six years, the 171 patients who took lethal medications differed in several ways from the 53,544 Oregonians dying from the same underlying diseases. Rates of participation in PAS decreased with age, but were higher among those who were divorced or never married, those with more years of education, and those with amyotrophic lateral sclerosis, HIV/AIDS, or malignant neoplasms.

Physicians indicated that patient requests for lethal medications stemmed from multiple concerns related to autonomy and control at the end of life. The three most commonly mentioned end-of-life concerns during 2003 were: loss of autonomy, a decreasing ability to participate in activities that made life enjoyable, and a loss of dignity.

During 2003, 37 patients (88 per cent) used pentobarbital as their lethal medication, four patients (10 per cent) used secobarbital, and one (2 per cent) used secobarbital/amobarbital (Tuinal).

During 2003, complications were reported for three patients. All involved regurgitation and none involved seizures. One-half of patients became unconscious within four minutes of ingestion of the lethal medication and died within 20 minutes. The range of time from ingestion to death was five minutes to 48 hours. Emergency medical services were called by one patient's family to pronounce death; neither resuscitation nor transport was requested.

Although the number of Oregonians ingesting legally prescribed lethal medications has increased, the overall number of terminally ill patients ingesting lethal medication has remained small, with about 1/7 of 1 per cent of Oregonians dying by physician-assisted suicide.

Additional detail on Oregon's Death with Dignity Act, including copies of all six annual reports, can be found at our website <http://www.dhs.state.or.us/publichealth/chs/pas/pas.cfm>.

25 August 2004

Examination of Witnesses

Witnesses: DR KATRINA HEDBERG, MD, MPH, Medical Epidemiologist, Bioterrorism Preparedness Program, MR DAVID D HOPKINS, Data Analyst, Center for Health Statistics, DR MELVIN A KOHN, MD, MPH, Oregon State Epidemiologist, Administrator, DR RICHARD LEMAN, MD, Medical Epidemiologist, Health Promotion and Chronic Disease Prevention, Ms DARCY NIEMEYER, Executive Assistant, Office of Disease Prevention and Epidemiology, examined.

Q553 Chairman: Before we begin, could I say what our situation is. As you know, we are a so-called Select Committee. The reason for calling it "select", I think, is simply that it is chosen by the House. Lord Joffe has introduced a Bill in our House which is on the lines of what happens here. We thought the best thing we could do in order to try to help our House understand the situation was to come and hear from you how the law operates here and the various ways in which it can be effective. Therefore, we are seeking your help to tell us what happens and how matters have developed here. Our report goes before the House of Lords, so we have with us a shorthand writer to take down what you say and it will become public property when our report is ready to submit to Parliament, so they know what our views are based on. The shorthand writer will take down what you say and you will have a chance to see it and correct it. As you know, we have a common language but sometimes our intonations of that language are a little different and it may be that we do not always get it exactly right. If you would be kind enough to introduce the team to us, Ms Niemeyer, and if any of you wish to make a short statement just to explain the relationship between this Act and other legislation in Oregon, and also the extent to which it operates, for example can people come from outside Oregon to Oregon to get the benefit of the law and that kind of thing, and then my colleagues will want to ask some questions for clarification. We hope to finish the whole session in about an hour. Thank you very much.

Ms Niemeyer: Starting at the end of the table here, we have David Hopkins. David is our Data Analyst who works in the Center for Health Statistics. He does the lion's share of the work at the end of the year and at the beginning of the next year collating, analysing and preparing all of the data that you see in the annual reports each year. On the other side of your stenographer is Dr Mel Kohn. He is the Oregon State Epidemiologist. Also, he is the Administrator of the Office of Disease Prevention and Epidemiology, which is a branch of the Department of Human Services where the state implementation of the Death

with Dignity Act rests. Mel can possibly provide some insight into the political implications of the Act. Next to Dr Kohn is Dr Katrina Hedberg. Dr Hedberg is a Medical Epidemiologist currently in our Bioterrorism Preparedness Program. Although that might seem like an odd fit, she has moved there, that is a new job for her.

Q554 Chairman: Is that a federal job or is it a state job?

Dr Hedberg: It is a state job but on a federal grant. We get federal dollars but, yes, I am a state employee.

Ms Niemeyer: Dr Hedberg is our historical person. She is the one who has been working with the Act here at the Department of Human Services since day one, since its inception, so she has all this fantastic historical knowledge of the Act. Next to Dr Hedberg is Dr Richard Leman and he is also a Medical Epidemiologist in our Health Promotion and Chronic Disease section. Dr Leman is here because he is an active member of the Task Force to Improve the Care of Terminally Ill Oregonians, which is a group of all kinds of health organisations. There are hospitals, hospice—

Dr Leman: Department of Justice.

Ms Niemeyer: State agencies. Many representatives from many areas of the state coming together to discuss issues related not only to physician-assisted suicide but the whole broad spectrum of issues relating to the terminally ill. I am Darcy Niemeyer, the Executive Assistant. I am the assistant to Dr Kohn, the State Epidemiologist, and currently I serve as the primary contact regarding death with dignity here in Oregon, so if people have questions about the Act, I am the person they start with.

Q555 Chairman: Thank you very much indeed. Perhaps one of you would like to start? Would it be appropriate for you, Dr Kohn, just to say a little bit about the way that you see it, or some of its historical perspective?

Dr Hedberg: If I could start at the beginning. The law first passed in 1994. It was a Citizen's Initiative, which meant that the Government really had no part

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in it, it was citizens who drafted this and you have to get signatures to put it on a Ballot. It passed by a margin of 51 per cent to 49. Then it was held up by a court injunction. People said, "Well, this law is very serious, do we want it to go into effect?" so it was held up in court for three years. At the same time, our State Legislature met and also said, "It is a pretty serious law, we want to put it back on the Ballot and see whether or not the people of Oregon want to repeal it". It passed the second time—or the repeal did not go through—by a margin of 60 per cent to 40. It was an even higher margin the second time around. The law passed first in 1994 but it was not implemented until 1997 and, in fact, the first participant did not take medications until 1998, a few months after it had come into effect. It is important to realise that this was not anything that the Government was putting on, it was from the citizens. That said, the law itself was what gave the Department of Human Services the responsibility for figuring out who was participating in this. At the time we did not do that in a vacuum, we pulled together this group called the Task Force to Improve the Care of Terminally Ill Oregonians to help us write the rules, and you are meeting with Dr. Susan Tolle of Oregon Health Sciences University, who was instrumental in that. We decided that participation meant there are several steps that people have to follow through. They have to have a voluntary request and it has to be in writing, two voluntary requests separated by 15 days. They have to have two physicians to make sure that they are acting voluntarily. If there is any concern at all that they have some mental health issues, they have to see a psychiatrist or a psychologist to be evaluated. There has to be a witness to the signing. There are a number of things and they are written down in here. With the help of the Task Force, we decided that once a person had gone through all the steps they needed to, that was the point when we would start our reporting system. If a patient who had cancer, let us say, talked to their physician and said, "I am interested in the Death with Dignity Act", we decided that we could not get reports to us of every conversation between doctors and patients, but the time when someone had gone through the steps and written a prescription was when they needed to fill out the form saying that all of the steps had been taken and report that to us. That is the main legal part of our reporting system. The second piece of it is that people want to know not only who got the prescriptions but who actually took the medication. Because we get death certificates, we have the names of people who have got prescriptions and at the time they die, which is supposed to be within six months, they have a terminal illness with six months or less to live in order to get a prescription,

we get hold of that death certificate and on that may be written that they have taken medication or it may be written that they have died of cancer, let us say, or their underlying illness. The second step, which is where Mr Hopkins comes in, is to call up physicians to say, "You have this patient and you wrote a prescription, do you know whether they took the medication or not?" That is the second piece of the reporting system. In addition, we are not a regulatory agency, at least not in this regard, so if we see that there are any problems that have happened, and there have been a number over the years, let us say that only one witness has signed or they did not wait 15 days, our role is to report that to the Board of Medical Examiners which is the licensing board for physicians. We do not call the police or take away their license, we are not regulatory in that regard. We have reported a number of physicians to the Board of Medical Examiners and it is up to them to have an investigation and follow it through. I do not know if people have any more questions about the historical side?

Q556 Chairman: I think if we have the presentations first and then the questions, if that is convenient.

Ms Niemeyer: Okay. That is fine.

Dr Kohn: I think it is worth saying a word or two about how the responsibility for this particular piece of the implementation of this Act came to be in our shop. I was not in Oregon at the time that this law was passed or even at the time that the rules were written, but my understanding is that we handle a great deal of highly sensitive health information about reportable diseases, about a variety of difficult topics, whether it is HIV infection or some other kind of disease, about which people would not want information known. We do have in place a variety of statutory protections that allow us to collect that information and use it for public health purposes. Also, I think we have a reputation for being as impartial as one can be in these kinds of matters. The way that these rules were designed, and I think the way that we have tried very hard to carry out these activities, was to try as much as possible to present the data and leave the public policy making to those organs that have the power to do that. I will say that is not an easy thing to do because people are constantly trying to draw us in to get us to give an opinion. Katrina has a famous story: "So, Dr Hedberg, is it not true that it would be much faster to kill somebody with a lethal dose of potassium instead of taking oral barbiturates?" These are the kinds of questions that are really way outside the purview of what our role is in this. For everybody involved, it is a constant struggle to try to keep those boundaries in place. That said, there are folks who are unhappy

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with the implementation of this law on both sides of the issue and from time to time we get attacked that somehow there is something wrong with our data, our data are incomplete, that we are not doing our job monitoring the implementation of this Act. I think our response is, "If you know anybody who has any better data, feel free to use those data". We think that our data are very solid. They do not answer every question about the Act and people can interpret the data in a variety of ways, but I feel strongly that having some objective data has been a very useful part of the public policy discussion and has put the whole issue in perspective in a way that without these data would be to the detriment of our citizenry. That is all I would say. From the political perspective, we try to stay out of the political end of this and stick with the facts and the data.

Q557 Chairman: I gather from what you have just said, Dr Kohn, there is a slight tendency that some people look to you as if you are a regulatory authority whereas Dr Hedberg has made it clear that you do not act as a regulatory authority, that is a matter for the Board of Medical Examiners if anything needs to be done.

Dr Hedberg: I think that is a very good point. Particularly the opponents, and I know you are going to be meeting with some of them, would like there to be more government oversight. It is up to the physicians to report to us, not only the prescription but that all the steps are followed and when we call them and ask "Did the patient take them and were there any complications", the opponents will say when we present those data that the people who are giving them to us have a vested interest in showing that this works well. You asked about the federal funding and we do not have any funding to do the work that we do regarding the Death with Dignity Act, the federal and state have given us none. Our role in this to try to provide data for everyone but it is on a shoestring. We do not have a team of investigators who can go out in every case.

Q558 Chairman: Would you like to say anything about the statistics, Mr Hopkins?

Mr Hopkins: In the first year the Act was passed we saw 16 Oregonians take advantage of it. Last year that number had increased to 42 and there will probably be a few fewer than that this year.

Q559 Chairman: When you say "take advantage", are these people who got the prescription and used it or just got the prescription?

Mr Hopkins: These are people who indeed used the lethal medication. Males and females are equally likely to use the medication. Asians are about three

times more likely than whites. College graduates, are about seven times more likely than those who have less than a high school degree. Urban folks are more likely than those east of The Cascades, which is a very rural area, to use the medication.

Q560 Chairman: Is age a factor?

Mr Hopkins: Although most of the people who use the medication are older, 65-84 typically, the rate of use is highest among the young.

Q561 Chairman: When you say "young", that is right down to?

Mr Hopkins: 25-34.

Q562 Chairman: Presumably children are not covered?

Dr Hedberg: No, you have to be an adult, over the age of 18. I was going to make one more point. One way that this differs from what you are considering is that this only allows for assisted suicide and that has been defined as taking an oral medication. If you read the statute it does not say specifically that but the way it has played out is not that someone could have an IV and put it in their IV fluids, it has to be taken orally. People who cannot swallow, as an example, cannot take advantage of this. I think the definition of voluntary euthanasia that you are considering in Britain is wider, encompassing the situation where a physician could also provide an injection provided there is a voluntary request for it. That is not allowed in Oregon. The only thing that is allowed is a prescription and in most cases it is for barbiturates that people take themselves orally and swallow.

Q563 Chairman: Then the ultimate decision is quite clearly their own because they have to take it?

Dr Hedberg: That is right.

Q564 Chairman: I am now starting to ask questions but I am assuming that everything by way of introductory statement that you want to say has been said. Is it the law in Oregon, generally speaking, that assisting suicide is a crime?

Dr Hedberg: In other cases, yes. It is only in this particular example when it is terminally ill patients, etcetera, that is right.

Q565 Chairman: In other words, the general law is against assisting suicide but if you come within the purview of this law you are acting lawfully and not subject to a crime?

Dr Hedberg: That is correct.

Dr Kohn: There is one other aspect of the statistics that relates to that point as well and that is that by statute these deaths are not called suicides, they are

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not listed as such on the death certificate and they do not have the ramifications for insurance reimbursement and other kinds of issues that suicides have. It is specifically written that way in the law.

Chairman: I understand that.

Q566 Baroness Hayman: Could I just follow up the issue about this being very specifically patient administered and ask whether there was debate about whether that was a limitation that was central to your legislation, where and when that took place, and whether the original draft was like that. I ask because one thinks about patients who cannot swallow, who cannot administer their own medication, and whether there has been pressure to extend the legislation to them? Also, could I ask about the very simple issue of written consent in cases of patients who are too disabled to write?

Dr Hedberg: Some of those questions might be better asked of some of the advocates who were behind writing the legislation, who I think you are meeting. What I do know is that at the time it passed as the initiative in 1994, that was already so in some of those discussions had happened before. I do not know if the concern at that time was in part because it was perceived that they did not necessarily want a doctor doing something to a patient, that would be an active role that the doctor has, and they thought it might be accepted more if it was patient self-administered. You raised a very interesting point about patients who cannot swallow who cannot participate in this. There was a case a few years back, and I only talk about it because it was in the media otherwise we cannot talk about any of the cases because of the confidentiality. This was a man who had Lou Gehrig's disease, ALS, and he could not swallow. His brother-in-law assisted him—I am not quite sure what that means—and then called the newspaper. At that time the newspaper called us and said "What are you going to do?" and we said "Our job is to make sure that all the steps happened up to the point the prescription was written". The District Attorney and the police heard the same and nobody ended up prosecuting. The issue at that point was whether this was in violation of our Disabilities Act. There has been a little bit of controversy over the fact that there are only certain people who can swallow and people with things like a brain tumour, for example, even though they might be capable of making a health care decision at the time they ask for a prescription, are they going to continue to be capable if they start having some cognitive and mental dysfunction? That is a very good question and those are some of the political issues that have been raised.

Q567 Chairman: The requirement for mental capacity is really at the time that the physician accedes to the request because the patient then has a means, assuming that they are capable physically, of self-administering the drug. There is no continuing assessment of their mental state and by the time they use it possibly they could be in a poorer mental state than at the time the consent was given, could they not?

Dr Hedberg: This brings up the issue that the Act only talks about writing the prescription. In fact, physician practice varies. There are some physicians who look at this and say, "The patient is asking for a prescription, I will write the piece of paper and they can either fill it or not" but it is giving the patient complete control as to whether they fill it and end up taking it, etcetera. We have other physicians who say, "If the patient is going to make this decision I want to be involved throughout. I am not going to write the prescription, in fact I am not going to even fill the prescription, until the patient says to me 'Dr, now I really want to take it' and then I am going to be there with them and their family to assist". Those are two ends of the spectrum and there are things in between the two where doctors may touch base with someone on an ongoing basis or maybe they are there for part of it. There is nothing in the law at all that talks about the physician practice from those two ends. In fact, after they write the prescription the physician may not keep track of that patient. There is nothing in the law that says they have to have an ongoing relationship with the patient, they write the prescription and that might be the end of it. Most physicians do know what happens to their patients and are quite involved, but I am saying that the law itself only provides for writing the prescription, not what happens afterwards.

Q568 Baroness Jay of Paddington: I am trying to follow up on some of the figures you have given us and I hope this is the right ball park, as it were. In the very helpful letter that Ms Niemeyer sent to us, which we had when we were looking at this to begin with, you said that during 2003 complications were reported in three patients and you gave some data about the nature of those complications. I am trying to pursue this question and I understand this is a political issue in terms of the opponents, but how many of those types of cases, some of which I know have been in the media, are then reported to the Board of Medical Examiners and what has been the outcome of some of those reports?

Mr Hopkins: The complications are usually few. When they do occur it is usually regurgitation or vomiting of the medication and/or stomach contents. The other complication that occasionally occurs—

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whether you call it a complication or not is debatable—is the person may live for some time after taking the medication before death occurs. We do not report to the Board of Medical Examiners if complications occur, no, it is not required by the law and it is not part of our duty.

Q569 Baroness Jay of Paddington: So the cases which are reported to the Board of Medical Examiners, what would they include?

Dr Hedberg: People who only got one witness instead of two.

Q570 Baroness Jay of Paddington: The legal issues.

Dr Hedberg: People who got the prescription after 10 days instead of 15.

Q571 Baroness Jay of Paddington: Has malpractice been ruled on in the Board of Medical Examiners?

Dr Hedberg: Those records are completely closed. The Board of Medical Examiners carry out investigations, they tell us that is the process and those of us who are licensed get a letter that comes out quarterly and it says which doctors have had their licence removed but they do not make a connection between “We have reported Dr Smith” and then “There was an irregularity but we are not going to sanction”. We do not get that information. All of those investigations are closed until action is taken and, to my knowledge, that has not happened in any cases.

Q572 Chairman: Do they publish the names of doctors who have been disciplined?

Dr Hedberg: Yes, who have been disciplined but not who are under investigation.

Q573 Chairman: If they are disciplined, do they also tell the public the reason?

Dr Hedberg: I do not think so. I think it just says “limited licensure”. It is usually for alcohol or drugs and most of them get into treatment programmes or those kinds of things. I am trying to remember from the newsletter that I get. It just says that they have a limited licence or their licence has been revoked.

Q574 Chairman: It is conceivable that they might take the step of warning the doctor, “You have made a mistake, you should not do this again” and that would not become public at all?

Dr Hedberg: Correct. We assume that is what has happened in most of the cases that we have reported.

Q575 Baroness Jay of Paddington: But you do not know?

Dr Hedberg: We do not know.

Q576 Baroness Jay of Paddington: Could I just ask one more factual question. Do you have statistics which reflect the number of patients who have taken prescriptions, or for whom prescriptions have been given but they have not used them?

Dr Hedberg: The answer is yes and no. The yes is when they write a prescription they are required to send that to us and then when the death certificate comes in we call them up. As I mentioned, there are a number of physicians who do not write the prescription until the patient is ready to take it. For those particular physicians, all of the patients for whom they write a prescription take them because technically they have not written it until they fill it at the time when the patient is going to take it. There are other physicians who might write several of them and their patients never take it because, once again, those are physicians who give the control to the patient. The answer is yes, there are some more prescriptions that have been written but, in fact, we do not know the number of people who have gone through the process and have really considered it and then elected not to take it.

Q577 Baroness Jay of Paddington: I know this is not your responsibility but one of the pieces of commentary on this is that people may take the prescription almost as an insurance policy, “If things get really bad then I will use it but I am keeping it on the shelf” or whatever, and you do not have an idea of what proportion of prescriptions written are actually used.

Dr Leman: Through to the end of 2003 there were 265 prescriptions actually written and 171 people who chose to take them. That is about 64 per cent.

Dr Kohn: There may be prescriptions written, however, about which we do not hear.

Q578 Chairman: They are supposed to let you know?

Dr Hedberg: If they have been written and if they have gone through all of the steps, but technically if the physician has not written on a piece of paper or has not given the medication then they have not written and they are not required to report to us. There may be many people who start the process but who never complete it and we do not know about those. We do not know how many people die during the 15 day waiting period or how many people start and then change their minds. Are you meeting with Dr Linda Ganzini?

Q579 Baroness Finlay of Llandaff: We were hoping to but she has decided not to.

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Dr Hedberg: Dr Tolle can probably address this too. She has done a number of studies interviewing physicians in Oregon and asking them how many. What we have found out is of 100 people who ask and go, the vast majority, 90 per cent of those, never ask again but are offered hospice care or palliative care and never pursue it any further. Of those, a fraction pursues it and it is a much smaller proportion that ends up taking it. The overall numbers who end up considering it are much greater than the people who actually end up taking it.

Dr Leman: It is required in the Act that the alternatives be presented to the patient, so if a patient is requesting a prescription physicians are required to review what the other options are in terms of comfort care and what might be available through hospice.

Q580 Chairman: When an incident is reported to you, at that stage the prescription has been written, is that correct?

Dr Hedberg: Correct.

Q581 Chairman: The consent arrangements may have taken place some considerable time before.

Dr Hedberg: Correct.

Q582 Chairman: What you get is the information that in effect makes lawful the writing of the prescription whenever that occurs. If you do not get direct information, if I have understood it right, of whether or not the prescription has been taken, what you ultimately get is the death certificate and once the death certificate comes in, in respect of a patient for whom a prescription has been written, you then check with the physician whether they have taken the medication, is that right?

Dr Hedberg: That is correct.

Q583 Chairman: That is the sort of ultimate record that you have.

Mr Hopkins: We also get reports from the dispensing pharmacist and sometimes that is before the physicians make their paperwork available.

Q584 Chairman: Are the dispensing pharmacists obliged to report to you?

Mr Hopkins: Yes.

Dr Hedberg: This is what gets to be a little complicated. Not every prescription that is written goes through a pharmacy, but most of them do.

Q585 Chairman: Does that differ between city and rural areas?

Dr Hedberg: Certainly what we have heard, and once again this is some of the press issue around this is they will say, "They are mail order drugs". A lot of

patients in rural Oregon, especially if they are terminally ill with cancer, will come up to the University to get treatment, so they may fill their prescriptions at the University. I know you are talking to Barbara Glidewell, who can explain some of that process. They may get their medication sent to a rural area as opposed to going to their rural drugstore in a very small town or they may get their medications from Portland or somewhere more central.

Q586 Baroness Finlay of Llandaff: Can I ask a little bit more about the drugs that are prescribed. Do you have a standard recommended dose within your guidance? How has that evolved and what is prescribed?

Dr Hedberg: No. It is very interesting because early on we said we are keeping track of the records and this is not our role, this would be the Board of Pharmacy, the licensing body, or there is an association that pharmacists can join, would they like to come up with some recommendations, but nobody wanted to because, in the United States, if you come up with a recommendation and there are side-effects people can sue or whatever. People were not touching this at all. What happened was the Dutch, who have a document where it outlines the medications they are giving in The Netherlands, and the advocacy organisation Compassion in Dying, are you meeting with them?

Q587 Chairman: Certainly we have read about them.

Dr Hedberg: They are the ones who put together some guidance material for physicians. What you will find is that most of the drugs that have been prescribed in Oregon are quite uniform, they are secobarbital, and people are not prescribing morphine, although they may be doing it in conjunction with some of the barbiturates. That is in part because the advocacy group was the one who stepped forward and said "This is what the Dutch have been using", so that was the standard because people in Oregon had never done this before and physicians did not know what to prescribe. There is a protocol too where they first take some anti-nausea medication and these tablets get mixed up. I am not sure of the whole thing, whether it is liquid or taken in apple sauce or something that is easier to swallow. I am familiar with the fact that they have it but I have not seen the protocol.

Q588 Baroness Finlay of Llandaff: If you have a prescription, do you know whether it was for secobarbital or pentobarbital?

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Dr Hedberg: That is what gets reported from the pharmacy and it is also what physicians write on the reporting form.

Mr Hopkins: I have a reporting form here.

Dr Hedberg: The reporting form does have the doctor write down what that patient is prescribed.

Mr Hopkins: And the amount.

Q589 Baroness Finlay of Llandaff: Do you interview the doctor to find out what was given and why? I was a bit confused because pentobarbital is an injection only formula.

Dr Hedberg: That is a very interesting question. Secobarbital was on the market for quite a while and then it got withdrawn and the company stopped making it. This was a couple of years ago. You are absolutely right that pentobarbital is injectable, so obviously it is in a much more sterile form, but people were using that as an oral medication because they were not able to get secobarbital.

Q590 Baroness Finlay of Llandaff: You know that was taken orally rather than by injection. Is that based on your interviews?

Mr Hopkins: Yes.

Q591 Baroness Finlay of Llandaff: Do you have a way of tracking what happens to drugs that have been prescribed but not taken? If the patient has this lethal dose but dies naturally, what happens to those drugs?

Dr Hedberg: Once again, that is outside our purview. That is a very good point. I think that is a very good question for Dr Tolle because when the committee first met, that was something the Task Force took care of. A lot of people are in hospice care and after a patient dies they have a way of disposing of medication. They are often on morphine drips, people outside the law. Eighty per cent of the people who participated are in hospice care, so we assume when they are in hospice care that the hospice has a way of taking care of the medication that they have not used. You are absolutely right, we do not have a way to track if there was a big bottle sitting in somebody's medicine cabinet and they died whether or not somebody else chose to use it.

Mr Hopkins: Most patients work with the group Compassion in Dying and that group does follow up after the fact to see that the medications have been retrieved or disposed of.

Q592 Baroness Finlay of Llandaff: You have your records that you have maintained confidentially, for how long will those records be kept? Do you have a decision to keep those for 20 years, 25 years or

whatever, complete records, or has any of that already been lost?

Dr Hedberg: That is a very good question. In fact, we received legal opinion about that and the law does not say how long, it just says we will maintain those records and then issue an annual report, and you have seen the sixth one here, and we have done that every year. After we issue the annual report, we destroy the records.

Q593 Baroness Finlay of Llandaff: So you cannot track back to see whether there are some individual doctors who are very heavily involved in this versus others who are not, it would only be on memory?

Dr Hedberg: We do it on a yearly basis. Have you done it back further, Dave?

Mr Hopkins: The first year the records were destroyed entirely, there is no way to go back and look at that. In the last several years that I have been working with the data we keep the doctor's name in code form.

Q594 Baroness Finlay of Llandaff: Can I ask why you destroyed them because it would seem an almost unique historic record that you had?

Dr Hedberg: At the time with the confidentiality around this, people were very, very worried about it. We had advocates as well as opponents who were looking at this, and the media. When the law was first passed they were calling me weekly saying, "Has somebody taken it? We have heard this" and they would be combing obituaries. We talked to our lawyer about it and made the decision that because people come and go, even within our office, although we try very hard we were very concerned that there would be breaches in confidentiality, so at that point we were told that the hard copy of the records—we still have the death certificates for those people—would be destroyed. We do keep track of the coded data. We do know there are some physicians who have come out very vocally as being advocates or proponents of this who have clearly prescribed for many people. I think the majority are physicians who have prescribed once or twice for their own individual patients. If somebody has pancreatic cancer, and I mentioned Lou Gehrig's disease—Do you call it that in Britain?

Q595 Baroness Finlay of Llandaff: It has got lots of different names.

Dr Hedberg: ALS. Those people probably do not have one physician, they may have several physicians. If they are going to the consultant then often people around the state have many, many different family physicians but end up going to one very similar oncologist or a neurologist and often the family physician may be supportive but, since they

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may only have one patient with this, they may not be comfortable writing the prescription themselves. Usually there are many physicians involved in care and the physicians who have done more of it may be more comfortable with writing the prescription and being involved in that part of it, even though the family physician may be comfortable writing out all of the steps and making sure that they are aware of everything.

Q596 Baroness Finlay of Llandaff: In the light of your experience now and with the benefit of hindsight, would you advocate going for a system of pre-event reporting from right at the beginning so that you would have a more complete tracking system, or do you feel that you have got adequate data to monitor compliance with the law?

Dr Hedberg: I think the question is what is it that the public wants to know or about how well this is going? I think people might be very interested in how many cancer patients actually consider this. Does one conversation with the physician mean they are really considering it or if the physician says, "Yes, you are right, that is legal, but let us look at hospice and palliative care" and they never ask again, do we want to have to keep track of the thousands of people who are diagnosed with cancer in Oregon, or even are terminally ill with cancer? There is a lot of concern about confidentiality because we are the government and because of what happens to their insurance and other things. That was the debate and we were a part of that but we got affirmative input from outside, people saying that most doctor/patient interactions are completely confidential too, they do not want that discussion to happen necessarily and to have this kind of scrutiny is best to happen after all the decisions have been made. Even with hindsight, it is useful for the general public to know more about what is happening with end of life care, whether that is done through a mandatory reporting system or whether it is done through the surveys that Dr Ganzini or Dr Tolle have done looking at end of life care in Oregon, that may be a better way to do it. I am hedging, I am not answering yes or no.

Q597 Lord McColl of Dulwich: Am I right in thinking that you have no systematic way of finding out and recording the complications of this procedure?

Dr Hedberg: Not other than asking physicians. We ask the physicians. You are absolutely right, that is one of the things that the opponents will tell you, that they would prefer there is more regulation of this particular law than there is.

Q598 Lord McColl of Dulwich: It is just part of the general practice now that we do audit everything, so this is not really systematically audited?

Dr Leman: We do not have anyone in attendance at an event to record what is going on.

Dr Kohn: Systematically in every case that we hear about the physician is contacted and the information is collected, but it is the self-report, if you will, of the physician involved.

Q599 Chairman: It is triggered by the report that a consent form has been signed and that the prescription has been filled out?

Dr Hedberg: That is correct.

Q600 Lord McColl of Dulwich: Can I go back to this six month business which seems to be the crucial thing. If they are deemed to be going to die within six months, there is no obligation to treat their suicidal intentions. If they had these wishes, that does not mean that the psychiatric condition has to be treated, is that right?

Dr Leman: Basically, first of all, they have to be evaluated by two different physicians who have to confirm the diagnosis and who have to confirm the prognosis, that both of them feel that death is expected to occur within six months. If there is any thought on the part of either of the physicians that the person's judgment is affected by depression or any psychological condition then it is obligatory that a referral be made to a psychiatrist or psychologist for evaluation and if, indeed, the psychiatrist or psychologist feels that the physician's opinion is correct and that is confirmed then you would have to treat the depression or the psychological condition and that is in the law.

Q601 Lord McColl of Dulwich: It says here, by Ganzini: "The evaluation should focus on assessing the patient's competency". It seems to me that competency is the issue.

Dr Hedberg: This is a very good point. What is written in the law is that the person has to be able to make and communicate a health care decision. You could argue that with depression that has been treated the person is still competent. Once again, that would be a concern: has that depression been adequately treated so that the person is competent or not. Another example that someone gave to me that I found very interesting was that with Alzheimer's you would say that a patient is not competent but, in fact, with some patients, you could say "Hi, I am Dr Hedberg. If it comes to the worst, would you want to be hooked up on one of those machines, mechanical ventilation?" and they could say "No, no, my time has come" and the next day they do not remember

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who you are but if you ask them, they could say “No, I do not want to be hooked up on a machine”. Is that patient competent to make a decision? They know exactly that they never want to be hooked up to mechanical ventilation even though at times they do not know who you are. Once again, I do not think there have been any cases where we have had patients with Alzheimer’s but there has been a lot of debate about this and whether or not a patient is competent is the same as being mentally healthy, if you will, that is not having depression and not having Alzheimer’s or any other mental conditions.

Q602 Lord McColl of Dulwich: Ganzini does state: “The presence of a mental disorder does not disqualify a patient from assisted suicide”.

Dr Hedberg: That is right, technically or legally.

Dr Leman: The way that the law addresses this is to say that no medication to end a patient’s life in a humane and dignified manner shall be prescribed until the person performing counselling determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment. If somebody has depression and that depression is in remission, that is they have had it treated and taken care of, and yet they still say “my quality of life is such”, then I think potentially it could be under the law if the condition is controlled in the view of a psychologist or psychiatrist.

Q603 Lord McColl of Dulwich: My next question is if they survive longer than six months and they have in their possession a lethal drug, how do you know they are not going to become mentally ill and want suicide for that reason? It seems to me there is no control there.

Dr Hedberg: That is a very good point. That is not part of the law.

Q604 Chairman: At the time the prescription is written the doctor’s responsibility in relation to writing the prescription ceases. As you have said, he may attend and so on, after he has written it, and quite a number will not write it until it is going to be acted on, but strictly under the law he could write the prescription and it could sit for quite a while, and in that time deterioration could occur in the mental condition of the patient and the doctor would not be required by the law to take any cognisance of that in relation to qualifying the right to give a prescription. Is that correct?

Dr Hedberg: That is correct. I do know of cases where physicians have retracted the prescription where, once again, they wrote it and then realised that the patient had deteriorated and took it away. I do know that has happened. Once again, that is a variation in

practice of care, which in my mind is very good medical care if they have an ongoing relationship and they are attuned to that. I do know that is not part of our official reporting system.

Q605 Lord McColl of Dulwich: You would prefer that the doctor who was prescribing wrote out the prescription at the time it was going to be used?

Dr Hedberg: I think the answer is yes. That makes more sense. Once again, the proponents will tell you that some of the intent is to give control to the patients. That is a little bit of an issue as to how much control you give to the patient and how much control you give to the physician. On the one hand, this is standard medical practice and in relation to what you were saying about medication staying on the shelf, perhaps I think it would be better medical practice to have physicians involved the whole time, including perhaps attending the death, not just to assist the patient but to assist the families as well. Talking about complications, in some families’ minds, a complication might be that there might be agonal breathing, they are breathing deeply or even gasping for breath, and it might not be pain at all but the families, if they have never seen someone die before, might not know what to expect at the time of death. Once again, I think that kind of support is way outside what the nuts and bolts of the law say.

Q606 Chairman: The law prescribes minimal conditions and then a good doctor, as we might think, might well do more than the law requires but the law itself has not required that of them.

Dr Hedberg: Very well said.

Q607 Earl of Arran: Getting right away from the medical side for a moment, and I hope this is the right forum in which to ask this question, one thing that does interest me particularly, and I know it does other Members of the Committee too, is why Oregon? Why, after seven years, has no other state in the country made this available? Is there something interesting and strange about Oregon, in the nicest possible way?

Dr Leman: Other people in other parts of the country might say so.

Q608 Earl of Arran: After seven years, why has no other state started this? Those who are coming to Oregon, have they been here for some time or are they just nipping over the border now and then and meeting the qualifying criteria?

Dr Hedberg: Richard and I both grew up in Oregon, so we are natives. I think one thing you can say about Oregonians is that we are very independent. There has been a lot of legislation in this state that people

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feel strongly about one way or the other. We had very strict land use planning, or we did until it got overturned very recently. We tend to have laws that are different from other parts of the country and I think some of that individualism may play into that. Oregon has very good end of life care and very high enrolment in hospice and very good access to hospice. I know some other states have considered something similar, for example Maine did a few years back, but their enrolment in hospice was about 25 per cent compared to our 80. The people who are not enrolled have to have been offered hospice and refused it but they may be people who are independent. Here hospice is not a stand-alone, you do not go to a hospice centre, people come into your house, you have a hospital bed and a nurse comes or a volunteer. For some people it is an intrusion into their privacy. We have pretty high levels of per capita morphine use, and it is not that all of us are using that but that is being prescribed at the end of life and in a state where we have pretty good end of life care people were less concerned that this law might be abused. When it was first voted on in 1994 it passed by a small margin, 51 to 49, and when the Legislature said, "Are you sure, citizens of Oregon, that you want this", it was voted on by a much higher margin, even though the law was not enacted. I am not sure whether people changed their minds or said, "We do not want the Legislature telling us what to do, we voted for it and we want our decisions to be listened to and heard". I am not sure completely what it is about Oregonians.

Earl of Arran: Finally, do you fear that Mr Ashcroft, who I see is rearing his head again this morning in the media, might be successful? Has he the power to overturn the State of Oregon?

Q609 Chairman: That is a legal question.

Dr Hedberg: My understanding of these legal issues is that medical practice is governed by the state. I have a medical licence to practise in Oregon and if I wanted to practise right across the Columbia River in Washington I could not do that because I do not have a licence. The practice is governed by the state. Where the federal government comes in is they have control of substances, narcotics and barbiturates and marijuana, the drugs that are abused or can be used or sold, or whatever. They have control of that and in order for someone to be able to prescribe those controlled substances they have to have a DEA number, a Drug Enforcement Agency number, that says you can prescribe them. What John Ashcroft wants to do is to say that controlled substances should not be used, but you cannot do anything without a medical licence, nor any doctor in Oregon, but what he can say is "This is an improper use of a

controlled substance" and that is where the Federal Government has jurisdiction. The question is if he says this is not a legitimate medical practice, who defines legitimate medical practice? Is it the state who defines it, which is the argument that the State of Oregon has, that the state is defining this as appropriate use, and the Federal Government would say, "This is not appropriate medical practice for use of this specific medication"?

Q610 Chairman: It is on the borderline really between medical practice and drug control?

Dr Hedberg: Exactly right.

Q611 Chairman: Which side the Supreme Court might take would be rather difficult for you to prophesy.

Ms Niemeyer: If they choose to hear it at all.

Dr Lemman: They may or they may not. So far the courts have come down on the side of recognising that states have been the jurisdiction which should determine the definition of legitimate medical practice.

Q612 Lord Joffe: The small number of deficiencies in reporting that you have reported on, in your view are they serious deficiencies or are they fairly insignificant?

Dr Hedberg: When we set this up we decided that it was not up to us to decide whether they were deficient. We said that we would leave that to the regulatory agency because if we said they waited 14 days instead the required 15, would you consider that an egregious error or not? If it was 13, 12 or 11, where do you draw the line? We decided that we would not draw the line, we would let the regulatory agency do that. If the forms are not filled out correctly, we first call the doctor and say "Did you really mean to write that it was 12 December as opposed to 3 March?" and we often do get misdates and those kinds of things, so we try to clarify the medical records with the physician first. If we cannot clarify the medical record, that is when we call in the licensing board. In my opinion, they have not been egregious errors but, once again, we have not made the decision as to whether one witness signing instead of two is egregious or not.

Q613 Lord Joffe: It is the licensing board that follows it up?

Dr Hedberg: Yes.

Q614 Lord Joffe: Overall, as I understand it, there have been a very small number of cases referred to them?

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Dr Hedberg: Yes, that is correct.

Q615 Lord Joffe: There has been a lot of criticism from opponents to the Bill of the work that you do. I see in this document from the Physicians for Compassionate Care that they say the State of Oregon has failed to provide any meaningful oversight of assisted suicide and has done virtually nothing to protect the vulnerable, and then they go on to say that you are not neutral. What is your reaction to that?

Dr Hedberg: The reaction I have is that, once again, we were not given the resources to investigate and do the work that the opponents might want us to do. They want this legislation to have more regulation and for us to have more authority and when we have talked to our lawyers and others, not only do we not have the resources to do it but we do not have any legal authority to insert ourselves. While that may be a criticism, they need to change the statute and provide resources for us or the Board of Medical Examiners or someone else to have more oversight.

Q616 Chairman: You are not responsible for making the law, you are only responsible for administering such responsibilities as the law has given you and it has not given you responsibilities of the kind that Lord Joffe has referred to. Whether that is good, bad or indifferent, that is not your responsibility.

Dr Hedberg: That is exactly what I would say.

Lord Joffe: You do not accept the criticism?

Q617 Chairman: It is a misplaced criticism.

Dr Hedberg: That is exactly right. As Dr Kohn said earlier, we have data from Oregon and when people ask “is there under-reporting”, physicians in the State of Oregon have a vested interest. If they follow the steps and report them, they are protected under the law, but if they carry out actions outside the law then they are assisting suicide and that is not part of this law. We do get pretty good data because, if anything else, it is insurance for physicians to report.

Q618 Chairman: Otherwise they are in breach of the law. Unless they come within the protection of this Act, they are in breach of the law, so it is in their interests, if at all possible, to come within it.

Dr Hedberg: Yes. I know all about the criticism and I think they have directed it at us because we are the ones who present data and we try to present data as neutrally as possible, including the language that we use is neutral. Clearly, if we were strong advocates we would not be reporting any physicians to the Board of Medical Examiners. We talked about complications a little while ago and Dave mentioned

a prolonged time between taking the medication and dying. When we initially wrote that, I think there was a woman who had survived 36 hours, and it may be even longer now, but the advocates called me up and said, “That is not a complication, that is a variable response to medication” and I thought we are probably neutral when we have got the opponents who do not like what we write and now the advocates are telling us that we should be talking about variable response as opposed to a complication if someone survives for two or three days after taking the medication.

Baroness Jay of Paddington: From our perspective, it is interesting that you are regarded by people who either think it is not going far enough or going too far as a regulatory agency because we have such different funding of our health care system, which as you know is tax-based funding, whereas regulation by statute is so much more intrusive that it is very different and I can see entirely why you are standing away from the independent doctors and their relationship with independent fee-paying patients.

Q619 Lord Joffe: This law and legislation has been in force for six years, from your perspective does it seem to be operating effectively and generally accepted as part of the law which society in Oregon accepts?

Dr Hedberg: I know when I was first involved with this people were wanting to confirm the first case and then we issued a press release after six months saying that there were a few of them who had participated. Each year we issue a report and press release but I think the media and news calls have dropped off to virtually none. In Oregon, it is not much of a debate any more because people have seen this has happened in this state but, as Dave mentioned, we are still in double digits. Last year there were 42 out of 30,000 deaths. We have a large number of deaths in our state and very few people participating. It is not that controversial in Oregon, both because lots of people are not participating and because there have not been any really egregious events. When you go and meet with the opponents, the Physicians for Compassionate Care, I am sure they will bring the several examples where they would say there has been misuse of this but, once again, our job is to collect the data, it is not to investigate all of the subtleties. While they may want that, we do not have that authority.

Q620 Chairman: There are just two matters I would like to ask about. First of all, do we know from the data that Mr Hopkins collects how many of the people who participated were not ordinary residents of Oregon but who came for that purpose?

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Dr Hedberg: One of the things that changed in the statute was initially it said you had to be an Oregon resident but then the statute got amended a legislative session later, so that would have been in 1998, to outline what defined residency, and that includes driver's licence, leasing or owning property, income tax returns, voter registration. It is up to the doctor to decide. It does not say you have to have one of these for at least a year or two years. What happens here is that people may move away and at the time they are very ill they move to be closer to their children to be taken care of by their loved ones. People move all around the country at the end of life for a variety of reasons. We do not have any indication that people are flocking to the state, the numbers are very small, but if they were they do have to have some legitimate contact with the state. If somebody really wanted to participate, they could move from their home state and all of their friends and relatives, etcetera, could set up in an apartment here in order to do this. I do not think it happens very much because the end of life issues are much bigger.

Ms Niemeyer: It is a not uncommon thing for people to call and ask about, whether it is okay to come here for the purpose of using the Act and, if so, how long does residency need to be established.

Q621 Chairman: As framed, the law is on the basis that the person is a resident in Oregon but for exactly how long and in what circumstances is not regulated. The other thing I would like to ask is this: if somebody is given a prescription and unable to use it because of the advance of their condition and the physician does not come, is it lawful under the law for, say, the husband or some member of the family to administer or is that outwith the law and they would be guilty of breach of the criminal law?

Dr Hedberg: I do not think it is legal. It is not specifically addressed. Going back to my example of the brother-in-law who helped, we do not know exactly how he helped this person swallow, whether it was putting a feed tube down or whatever, but he was not prosecuted, the District Attorney decided not to do it. My guess is that if someone had been really assertive about it they probably could have taken him to court for that kind of assistance because that is not allowed.

Chairman: We have fully occupied all of the time that you have kindly given us. We are extremely grateful for the clarity of the presentations that you have given and for the help that will be to us in trying to ascertain the facts as far as Oregon is concerned. We will hear more views later on in the day but I think you have given us a very impartial and full statement of the facts. Thank you very much indeed.

THURSDAY 9 DECEMBER 2004

Present	Arran, E	Joffe, L
	Finlay of Llandaff, B	Mackay of Clashfern, L
	Hayman, B	(Chairman)
	Jay of Paddington, B	McColl of Dulwich, L

Letter from Barbara Glidewell, MBS CEC

Assisted dying for the terminally ill is a contemporary topic in health care in the US. The state of Oregon is the only state that currently has legalized Physician Assisted Suicide (PAS) through the Oregon Death with Dignity Act (ODDA). As requested, the following summary includes:

Professional background statement.

Main issues surrounding Physician Assisted Suicide.

Conclusions and recommendations about Physician Assisted Suicide.

1. Professional Background and Credentials: As the Ombudsman and Director of Patient Relations at Oregon Health Sciences University Hospital I am administratively responsible for the advocacy of patients. Educational background includes a degree in Nursing, a Masters in Behavioral Science, and a certificate in medical ethics. Hospital roles include crisis intervention, patient-physician relations' facilitator, mediator, and patient/ family educator in relation to quality care and life support issues. In relation to PAS, my role is that of facilitator and family educator to follow the requirements of the law.

2. Legislative issues to be considered are three fold. First is the issue of physician protection. Legislations must be carefully scripted to prevent prosecution of a physician who provides a prescription for life ending medication. Second is universal access to Hospice care. It is beneficial for all terminally ill patients, especially those who request physician aid in dying, to be part of a hospice programme. Universal access to Hospice will help diminish criticism that alternatives are not adequately accessible to all those in need. Third is the question of insurance coverage for prescribed life-ending medication. Currently at OHSU patients are required to pay privately for the medication, but this may need to be explored and clarified in relation to the UK health delivery system.

3. Personal experience brings forth the following recommendations to facilities providing PAS. It is beneficial to the patient, family, physician, and pharmacist to have one central, neutral party to co-ordinate the process. This person acts in a neutral and confidential forum for patients and families to freely ask questions and discuss thoughts without a physician present. This central coordinator also can aid providers in the process to make sure all organisational and legal requirements are met. Of further importance is the role of the coordinator to spend time with patients and families to educate them on the need for a dying plan and to rehearse the plan, so families can enact the proper post-death sequence of events. Death certificates need to have an additional box to check labelled "other" under "manner of death" (see example) to allow for confidentiality now and in the future. Finally, the co-ordinator should provide follow-up contact to debrief with the family after their loved one passes.

Physician Assisted Suicide is a deeply personal choice available to Oregon residents through co-operation of voluntary and confidential physician and pharmacy partners. OHSU is proud to provide a full spectrum of legal treatment options to qualified Oregonians, including the terminally ill.

Thank you for the opportunity to describe my thoughts and feelings on this subject.

18 August 2004

Examination of Witnesses

Witness: Ms BARBARA GLIDEWELL, Director of Oregon Health & Science University, Department of Patient Relations, Oregon Health & Science University, examined.

Q622 Chairman: If it is convenient to you, we will make a start. As you know, this Committee has been set up as a Select Committee of the House of Lords to examine the proposals in a Bill that Lord Joffe has proposed which is related to what is done here under the Death with Dignity Act. Our job is to examine how this is done, its limitations and so on. We will be glad of your help on that. The shorthand writer will take a note of what you say and you will get a chance to correct the transcript, all being well. The purpose is that the record of what you say will be part of our report and it will show the factual basis on which our conclusions rest. Once we report to the House it will be made public in the United Kingdom. We need your help because, if we are going to give a proper view of the matter, where experience has already been had of the exercise of legislation of this kind must be useful to us, although conditions may be different in the United Kingdom from what they are in Oregon, and perhaps that is one of the things some of my colleagues will want to ask about. Would you like to say a little bit about yourself and what your position is in relation to the Death with Dignity Act and then my colleagues will wish to ask you some questions on the various concerns that they have.

Ms Glidewell: In 1997 this fell upon me in my role as the hospital ombudsman, as I provide all patients at OHSU, outpatients and inpatients and parents of children, with any legal treatment option available to an Oregonian and the Death with Dignity Act is a lethal, although legal, treatment option open to qualified Oregonians. I knew that the law was coming but after carefully studying it I, and some of the folks who you will be meeting in the city today—Kathleen Haley, Dr Rasmussen and others—travelled to the Netherlands to meet with Peter Armored(?), the Minister of Health, and others to try to understand the Dutch experience and to fully understand their extension of physician-aided dying to include euthanasia with an injection for those patients who wished it. In gathering that data and coming back, I prepared myself to be the sole person at OHSU to whom all requests from patients to their doctor or directly to me would come to maintain the confidentiality of all the parties—the patient, the family, the physician, the pharmacist, the second opinion physician, the psychiatrist—and to see that it did not get into the media or we did not have the media hanging out in the corridor trying to gather information. I believe you have a copy of our policy that Natalie may have given you. The Medical Board of Oregon speaks to all of our physicians requiring that they all come through the patient advocate—myself—to facilitate and arrange this process and that no resident, student or others would ever be involved, only attending senior professors. They

understand that there are actions for the willing physician, actions for myself, actions for the pharmacist, actions for the physician again and for myself in the paperwork for the Oregon Health Division. Everything that the physician must do is spelled out step by step. Physicians bring their patients, not to a clinical exam room but to my conference room in my suite of offices. There was not time to stop there today. I have a lovely suite of offices in a very relaxed environment and the conference room looks more like a living room, it is very gentle. There we talk to the patient and their family, if they bring them, about why it is that they might want to hasten their death, what would suffering look like to them that was so sufficient that they would want to choose a certain day rather than nature taking its course, and how do they feel that they might be a burden to others and is that the reason why they are choosing to hasten their death, which we feel is not a reason to hasten one's death but that it must be a freewill autonomous choice. Often the patients come with their family members, and often their family members are quite stoic and willing to support their loved one, even though family members are often very frightened and fearful of this. As we take the patient through the process of the physician interviewing the patient, often patients are highly anxious when they come for fear that they will not pass the interview. One woman said, "This is the most difficult job interview I have ever had". Quickly I responded to her and assured her that she was not on stage, she did not need to prove anything, we just wanted to understand where she was in her process. As you know, and probably have heard, many patients end up never using the medication which they receive but it is their piece of mind. In the United States we have a term called their "ace in the hole", something they can put up on the shelf, they know it is there if they need it, and then they can go on with the business of living. Our covenant to the patients is that we will see that they have adequate pain management, even if they want terminal sedation if the pain and the suffering is too intense but they prefer not to hasten their death. We offer them the option of understanding how they might stop eating or drinking and how that death might then occur, that they can stop taking their cardiac meds, their diabetic meds, their hypertension meds and ease into hospice and that hospice will be there for them and they might never need to ask for hastening their death. We have this give and take conversation and often we ask their family to step out of the room so the patient can speak freely. The physician is always probing for an appearance of untreated psychosis, that the patient does not understand the risks and benefits of taking this medicine. The physician often

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leaves the room and goes privately into my office to review the medical record again and I will debrief with the family what they have heard and what the patient understands and talk with them about how this might play out in their own family home and tradition, what plans do they have if they are going to set a date and who is going to be there and how that will be, so first forecasting and visualising what that might be. Then I thoroughly talk to them about the expectation that we have that they will have enrolled in hospice (1) because it will go more smoothly for them throughout their days until they choose to take the medicine or do not and, (2), hospice will support them throughout their time. Most hospice groups will choose to step outside the patient's room or bedroom when they ingest the medication and then step right back in to be there to support the patient and the family as the patient commences to expire. The hospice then makes the phone call to the funeral home once the patient has expired saying this was an expected, anticipated death and the funeral home then calls the medical examiner, coroner, to say this was an anticipated death. It goes smoothly, this phone call goes to the funeral home that they have made arrangements for in advance and the coroner is not concerned about the out of hospital death. The funeral home comes and collects the patient, and on it goes. We talk the patient and the family through making these advance arrangements, asking that they think carefully about not choosing their son's birthday for the day because of that memory, and to think carefully about when and if they may take it and under what circumstances. As you know, it can never be done in a public place, not a nursing home or a park or a motel, it must always be done in a private home. With most of our patients we are quite sure that they will follow this sort of dictum. There are a few of the younger ones that we follow closely to be sure that they do not decide to go up on a mountain peak or somewhere where it would not be well contained. I will stop for a moment because I am sure you have some questions.

Chairman: Thank you very much, that is very useful.

Q623 Baroness Finlay of Llandaff: If I might just ask you to clarify for us "hospice" because, as I have understood it, here the patient, before they can enter a hospice programme, has to be deemed to have a life expectancy of less than six months and they withdraw from active treatment, so they then cease to have oncological intervention or if they were a patient in renal failure and came off dialysis they would cease to carry on having intervention for any renal condition, is that right? If they then got a pyelonephritis they could not go back into active treatment because they opt out and it is a one-way ticket.

Ms Glidewell: It pretty much is a one-way ticket opting out into hospice. Hospice is not any curative form. The hospice teams are paid governmentally for treatments that are comfort only. You would not come back to hospital for a CT scan because it would not be paid for. Only the hospice covered services will be covered for that patient. Once they enter hospice we know that they have less than six months' survival, that is pretty much expected. Some patients exceed it by a month or two and hospice does not drop them off of the plan, but in order for it to be covered under any welfare or insurance plan you need to be pretty much within your six month time frame, and there is the rub. Often patients with ALS, Lou Gehrig's disease, may be progressively losing control of their legs but they are pretty functional in a wheelchair and it is difficult to determine when their days may end, but for those patients with those neuromotor diseases my experience is that they wait a while until their suffering is extreme in their minds but they are unable to swallow, so they would need to have NG tube or G tube placement and in order to ingest the medicine they would need to be able to squeeze that through a syringe, not a needle syringe but a large bore syringe, into the kangaroo pouch or the NG tube or the G tube, and have enough motor skills to do that because in Oregon no-one may assist the actual death medicine ingestion. Our patients must have accepted that their time is near, it is not just some philosophical time in the future, they know that we now believe they have less than six months. That is often the decision between the treating specialists, who are sometimes late to have that discussion with their patients that it is now time to look at comfort care, palliative care, and it is a difficult disconnect between the curative focus and the comfort focus.

Q624 Lord McColl of Dulwich: What do you do about people with AIDS? I should declare an interest, I was part of setting up the first hospice for people dying of AIDS in Europe. We have patients who are coming in at death's door but we treat them and often they go out, although they will come back eventually, so there is this to-ing and fro-ing all the time. Would that be a problem here?

Ms Glidewell: It is not a problem because we have that discussion with the patient for them to let us know when they are exhausted from treatment and when enough is enough and they would like us to provide whatever medication will, so to speak, ease them into a mellow state and if they then want to take the medication they may. Most are very protective by then and, to my knowledge, there have been very few AIDS patients who have utilised the Oregon Death with Dignity law, perhaps three as far as I know from our statistics. Often they have caretakers at home who are willing to stay the course until death comes

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but they qualify because we realise they are now very close. My memory is that two of these had the medication but never took it and then it is wasted at the time of death.

Q625 Chairman: Do I understand that to be admitted to hospice in this country signifies that for people such as Lord McColl described, who would come into the hospice there for a time and then get treatment and go back out again, you would not contemplate that kind of thing here?

Ms Glidewell: No, we would not. We would say that they are having hospice in home and let us say they got pneumonia and they wanted antibiotics for comfort only, not for curative recovery, the hospice group in all likelihood would provide medication for comfort only but without an expectation. Nearly all of our patients who go in, nearly every one of them, complete a Physician Order for Life-Sustaining Treatment, a POLST form, where they say that they would want comfort measures only, do not resuscitate, no antibiotics except for comfort, probably no artificial hydration or nutrition. For those who have an IV line, as those of you who are in medicine will know, the body is interesting in that it will survive on very little hydration, so with an IV line and medication going into the IV line they are sometimes sustained a few days longer. The POLST form remains on the refrigerator, so let us imagine a neighbour comes in to sit with the patient while the caretaker goes away and the patient starts to have respiratory arrest or cardiac arrest, the neighbour calls 911, 911 paramedics arrive and see the POLST form and it is signed by the physician like a legal prescription, so they know that they do not have to resuscitate and transport, that they will follow whatever measures are described and provide comfort.

Q626 Baroness Jay of Paddington: That is what we would call an Advance Directive.

Ms Glidewell: The Advance Directive is this and it shows intent and names surrogates and this legal document transplants into a Physician Order that providers can follow. We have found that some people have come into the emergency department at the end of their time, dying, and they have an Advance Directive but the family says no and the patient comes in with a POLST form, it is there, it travels with them.

Q627 Baroness Finlay of Llandaff: That is more a DNR.

Ms Glidewell: It really is.

Q628 Baroness Finlay of Llandaff: Can I clarify this. If you have a patient with advanced malignancy who has a life expectancy of less than six months and they

then develop a spinal cord compression with pain, are they no longer eligible for radiotherapy?

Ms Glidewell: If it is for comfort measures. If it is for comfort they could have radiotherapy but if it requires transport back and forth, hospice is likely to say "Let us medicate you" but they will not be able to be paid for it, so there is a little concern there. Let us imagine a patient falls out of bed and breaks her ankle, they could come to the hospital and get their ankle splinted and go back to the hospice centre, but for something that is more extreme, like spinal cord compression, we might be able to treat that by injections or something to relieve the discomfort.

Q629 Baroness Finlay of Llandaff: But you would not take them to neurosurgery?

Ms Glidewell: No, we would not, not at all. However, if they have fluid collection around the lungs, we can do pulmonary aspiration. One woman said "It is wicked, I don't want another one. I have had three, this is enough". It is a give and take. We try and work with hospice to do the best we can within their financial framework as to what will best comfort the patient.

Baroness Finlay of Llandaff: Palliative care in the UK is organised quite differently, so I think it is important to be quite clear. Thank you.

Q630 Baroness Jay of Paddington: I think the basic philosophy of what you are saying comes out in that expression you have used twice, that the patient knows when enough is enough and I think what we might call heroic interventions in British medicine are not necessarily involved. Obviously you have described a very civilised society in which you do this counselling with people in your suite of offices, etcetera, and you call in physicians, but is there discussion and, in a sense, active opposition to what you are doing amongst health care workers here or physicians or do you deal only with particular physicians who you know support this? How does that work in terms of physician responsibility?

Ms Glidewell: I am glad you asked me. The answer is yes, there are some physicians who are passionately opposed.

Q631 Baroness Jay of Paddington: Working in this place?

Ms Glidewell: Working in this facility. If a patient has contacted their own physician and that physician is willing, that physician calls me. If that physician is unwilling, he or she still calls me to locate a physician who will do it within our system. We are a secular hospital, not spiritual, and that is why we are able to do it here. There are other hospital systems in the city that cannot do it, including the Veterans' Administration, so many of those patients will seek out our physicians here. I find a physician who I

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believe would be a good arrangement for that patient and arrange for that and the patient comes in and we establish them as a patient of this new physician at OHSU. We have a conscientious practice policy which sort of fell out of this big large bill as a silver lining. It gave us the opportunity to allow any of our staff, from a transcriber who hears the dictation and transcribes it, to anyone else who says, "I choose not to be involved or to be aware of this process". We reassure our staff that no-one will have to be involved in physician-aided dying, but that they might hear of it or a patient might speak of it and they can opt out under the conscientious practice policy, and physicians too. Some physicians will not even discuss it with a patient but they know that they will refer the patient to me and I can negotiate and facilitate that. You will be meeting with some individuals tomorrow and you will hear quite an interesting presentation of their perspective, quite opposite from what you are hearing from me and others today. I know them quite well and they are adamantly opposed.

Q632 Baroness Jay of Paddington: Does this create tension between medical colleagues in the hospital, for example?

Ms Glidewell: We work on that diligently. Those individuals are not in close proximity to one another in their office suites, so that dialogue is often not discussed among them. It is well-known by most who are opposed and who are not, but there are many strong feelings among some chiefs of staff so we are very careful to manage that diplomatically.

Q633 Chairman: It is an area which generates quite strong feelings on both sides. Do not answer this if you do not feel inclined to, but is there anything in your mind that differentiates the people who are in favour of it from the people who are against it as a general rule? Would you be able to tell in advance before somebody opened their mouths to say what side they were on?

Ms Glidewell: From my perspective, working with all of these for 30 years in this facility, we have the luxury of being a more scientific academic facility so there is more academic appropriate argumentation, I would not call it discourse, in the scientific manner. It is more accepted and expected here. As I work for the physicians, I pretty much know, or they will give me a signal, that they would be happy to provide information as a second opinion perhaps but not be the physician who prescribes and they have certain feelings about that. Certainly they would subscribe if the patient truly does have a terminal illness likely to take them in less than six months and they would fill out the second opinion form, the consulting physician's form. Some have told me directly never to contact them, so I realise that.

Q634 Baroness Hayman: Obviously you have a great depth of experience in this field, but I wonder what proportion of patients each year would you see and would go through this process, which is a very detailed, structured one? Do you have a sense of people perhaps in rural areas or who choose to do something in a more localised or personal way with an individual physician and not get into the whole systematic process that you have described?

Ms Glidewell: I think I can answer that. Let me take the last point first. Those physicians in the rural areas, I believe there are a few who have done it on their own. Many have contacted either the Compassion in Dying group or me to say "Could you walk me through this, please? I am willing for this patient to have this choice but I have never done it. Will you observe and monitor and see that I take the steps" and generally I do that. On the first part, when you were speaking about the depth of how many we do, I am going to give you an estimate of approximately two individuals per month through me who are likely to explore this as a treatment option for them. Occasionally it is approximately three a month. Of those individuals, I would say maybe only two or three a year end up going through the full 15 days, obtaining the medication and utilising it through OHSU. It is a small number but it is quite a number of individuals with whom we have these discussions. In the Compassion in Dying group you will see that they work throughout the state, so there are probably more numbers. Those who get the medication often wait and nature takes them.

Q635 Baroness Hayman: In this Annual Report there were 42 Oregonians who were prescribed medication ingested under the Act. Of those 42, perhaps it would be only two?

Ms Glidewell: I would say perhaps ten 10.

Q636 Baroness Jay of Paddington: Per quarter?

Ms Glidewell: Proportionately. Probably one person per month actually goes through the entire process and takes the medication. We had a stage when there were two or three but then there was a long lull for some reason. It may rise and fall with what is seen in the media and often some patients fear that they may not meet the six month window and if they can get into their six month window they can get their medicine before something might happen and the Federal Government might prevent us providing it. There are some concerns that way.

Q637 Baroness Hayman: There are peaks and troughs?

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Ms Glidewell: Yes.

Q638 Lord Joffe: Those detailed procedures that you have got over there, they were developed by you and who else?

Ms Glidewell: Me and two other hospital administrators. It is step by step for physicians new to this, I guide them. I have copies for all of you. It allows the physician to be cradled with support that this is exactly the step. It is almost sophomoric but it is intended that way.

Q639 Lord Joffe: You did that, it was not part of the legislation?

Ms Glidewell: Yes, we did that for ourselves. I have something else that I have attached for you because I am so concrete. I created a working document for myself and as I interview these families and work with various physicians I take myself through every step to make sure everything is done. That is my worksheet that I keep in the file. I have provided that for you.

Q640 Lord Joffe: In your written evidence you mentioned one of the areas of your concern was the issue of physician protection.

Ms Glidewell: Yes.

Q641 Lord Joffe: Have there been any problems or prosecutions of physicians, anything of that sort?

Ms Glidewell: There have not. A promise that I made to the President of OHSU was that we would do it perfectly every time. It is difficult to be perfect but so far we have been so perfect according to the law that unless something changes in the law and anybody can go back retrospectively, our physicians have followed this to the letter and everything is perfectly documented. Let us imagine that our Federal Government comes to OHSU and subpoenas all of our pharmaceutical records and zeroes in on all those certifications and finds those physicians, in every one of those cases they would discover there is the concomitant documentation to prove that every step was taken during the term of the law.

Q642 Lord Joffe: You have a lot to do with patients as well as practitioners, have there been any effects, adverse or otherwise, on doctor/patient relationships?

Ms Glidewell: That is a great question. Actually, I think the doctor/patient relationship becomes even more relationship-based and close because now they are talking about the cycle of life and the meaning of life, whereas often patients and physicians are talking about "I need 10 more Dilaudid" or "I have a pain in my toe", but now they are talking about the meaning of life, what gives them joy, or physicians ask, "What gives you joy now? Are there any landmarks you would like to survive through, any holidays,

weddings? How may I serve you?" I have seen a profound richness in these conversations between the providers and the patients and it may be even more satisfying to the patient to now see this physician in a more relationship way.

Q643 Lord Joffe: Thank you. Some patients go ahead and persist with their request and others do not. Have you noticed are there any personal characteristics which tend to be common to those cases that persist?

Ms Glidewell: Absolutely. I see them as pragmatic, matter of fact persons who have always been in control of their lives and ordered their lives and want control. I see it over and over as the reason why people say they want control of their dying process and want to avert having to be cared for in a way that is offensive to them, and I am referring to toileting or feeding. We are careful that they do not consider themselves a burden because families relish the opportunity to care for their loved ones. We counsel the patient to be sure not to take that from their family members who want to serve them. Those individuals, male and female, are very matter of fact. It is crystal clear to them that they want to name the day and when they are finished, when life has served them, and enough is enough, they are done.

Q644 Lord Joffe: You touched on the whole question of different views within the hospital and how you tend to deal with that. Is it dislocating from the hospital's point of view? Does it upset the arrangements in the hospital to have these different opinions?

Ms Glidewell: No. We have invited this discourse and dialogue with all—I do not want to call it sides—positions. We have amicable discussions among us about other things and there are certain things that we do not discuss but leave to an arena where the Medical Board would be present, so it is not anecdotal and antagonistic, it is scheduled, if you will, to have certain discussions.

Q645 Lord Joffe: Obviously you deal with the relatives as well. Have you seen some relatives accept and others try to bring pressure on the patients one way or the other? After death also, what is the sense of satisfaction or disappointment?

Ms Glidewell: Most of the patients' family members, whether it is spouses and partners or adult children, are resigned to allowing their loved one the dignity of taking their life and to supporting them even though personally they may be grieving deeply about it. As we try to remove their fear about what the death will actually be like and they hear the words, they seem more relieved. We have had family members silently weeping as the patient speaks and then the patient exits the room and we talk with the family. We want

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to make sure that there is no family member who is so adamantly opposed that it would create acrimony in the home, who is the legal next of kin and are there some family members who should not put themselves in that situation and only the spouse or partner or adult child should be present. In nearly every case, in my experience, the family is relieved that the person has been able to relieve themselves of their indignity and their suffering and that they chose their exit and exited in the manner which they wished. Later when we interview families or they call us, they say that it was not a horrific experience. As you know, with liquid Nembutal the patient will fall asleep within four to seven minutes. I show them how much liquid they will be ingesting. We talk about practising swallowing this much in approximately a minute. One swallow, a rest, another swallow and a rest. We describe the taste and have them taste it, an evaporative, chemical, alcohol, bitter taste and they have to be prepared to rinse their mouth out if they like and to realise that they should not sip on this or they will fall asleep and not expire. Once they have taken the medication they will say "Oh, that is nothing" and fall into a sleep ever deeper until respiration ceases. They will likely not defecate or urinate and the family will simply see them slip into sleep. The family are relieved to project in their minds that death will not be this horrible thing that they anticipate it will be. I say the words that they want to ask but did not know to ask the doctor and then they can talk to the doctor again about this. Somebody said, "This medication is not enough, my husband weighs 250 pounds", another person said, "Is this enough", and I say actually for your petite size or my size, this is enough for anyone. Actually, we give them a little more than they need but they do not know that, just in case they do not ingest all of it. This seems pretty graphic and I do not show this until the time when they might take it but it makes it a more matter of fact process because we are talking about such an intense, personal family issue. Of course, there are the 90 Seconal capsules that some patients elect to use but they have to open those capsules, put them into a cup, make a slurry and then get that down. We find that this is easier but they can make the choice.

Q646 Lord Joffe: You must have started off on this whole exercise with some apprehension.

Ms Glidewell: I did.

Q647 Lord Joffe: Could you tell us a bit about how you felt and how you feel it has developed and how the legislation is working?

Ms Glidewell: When I discovered that it became my responsibility I was stunned. Who knew in my career that I would ever be involved in such an activity? I gave it a great deal of thought and talked with my

own pastor and my family and decided that if I could do this in a neutral way that eased and bridged the patient between the physician, the pharmacist, the other providers, in a neutral way in my role as ombudsman, that would be my gift. I was very apprehensive in the beginning because of the emotions coming from the families who spoke to me. I soon realised that my becoming an anchor in this was very helpful. We had the luxury of having a physician here, or such as me, maybe a physician's nurse in a rural facility, who could do that, but it needs to go smoothly and not allow real emotion, at least not from me, as I am working with them. I was talking to a couple the other day and the husband was going on and on about this and I saw her withdrawing. He was intellectualising all of this and talking about the Legislature but she was the one who was contemplating taking this medicine. I asked him to step out of the room and I said "What do you want to say to me" and she commenced to sob, not about her death but about the fact that her husband was doing the work-up that she needed to do personally. I took him into another room and spoke to him for a while and I asked him to relax a little bit and give her the opportunity to speak about her own life and death. You asked me a two part question and I have forgotten the other part.

Q648 Lord Joffe: With six years' experience, how do you think this is working? Is the legislation working well and helping to relieve the suffering of people who really want that?

Ms Glidewell: From my perspective, absolutely. I am convinced. About one half of one per cent of all deaths in Oregon seeks this. As I have had this experience with a variety of persons throughout these six and a half years, I see that the legislation fits for us. There are a few things I might suggest that would make it a little bit easier, and I have made those suggestions. I am not sure in the United States, at least from my education and background, that we will get to the point where we are ready for conversations about the act of euthanasia, of injection. I think that dialogue is quite some time down the road. As this is working for us in Oregon, and for me as a facilitator, it is precise, it is objective and it is supportive of those individuals who choose this.

Q649 Earl of Arran: When the fateful moment approaches, do they sometimes ask for the family's priest to be present?

Ms Glidewell: Yes, they do. Often they have a clergy present. Some of the clergy might choose not to be there because of their own personal positions, but in many cases their own clergy is there. If not, sometimes their own physician is there and sometimes just their family and hospice providers

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who have stepped outside the room and then come back in to support them after the patient has ingested the medication.

Q650 Earl of Arran: Going back to the opposition, is the opposition static or is it growing?

Ms Glidewell: I do not know. They talk among themselves and do not discuss that with them. I do not know if it is static or if it is growing, I know they have a firm belief and choose to express that to certain groups.

Q651 Earl of Arran: Are they allowed to express it outside the place of work here, to promote their opposition to the media if they wish to?

Ms Glidewell: They are free to do what they like.

Q652 Lord McColl of Dulwich: Where do you see this all going? For instance, eventually do you see that euthanasia will come in here as it has in Holland? What would be your attitude to that? What is your attitude to this rather disturbing experience in Holland where those who do not agree with euthanasia are precluded, and particularly recently there was a senior lecturer in a university who was precluded from teaching?

Ms Glidewell: It is rather awkward, of course. As I said a few moments ago, I think that here in the US we are quite a way away in our community dialogue from discussing active euthanasia or injected medication to end life. We are decades away from that. I feel that as we have this common dialogue and as we witness the statistics of Oregon and perhaps other states start to venture out on their own, we will have a collective body of information that will guide us nationally for legislation in terms of where we go. I do not have an opinion about what goes on in the Netherlands although I am concerned because from my perspective I would look at patient autonomy and patient privacy. Unless there was a written request by a patient and that was legal in that country, I would be cautious.

Q653 Baroness Jay of Paddington: This may be a question that is more appropriate for Dr Tolle, so forgive me if I am asking the wrong person. Going back to what you have just said about being decades away from active euthanasia, etcetera, I still find it difficult—thank you for showing us the actual bottle because that is a very practical way of understanding what happens—to understand how for people who have what we call motor neurone disease or some similar muscular problems, do you have to say at the beginning that they cannot be involved in this programme because they do not have the capacity to follow it through?

Ms Glidewell: Not necessarily. Our physicians follow the patient very carefully and explain to the patient, if he or she has chosen to do that, that they will need to decide for themselves a time to do it when they are still able to express the medication through a large bore syringe that would go into their G tube.

Q654 Baroness Jay of Paddington: But somebody would have to put that tube in, or do you think that would be there for some other purpose?

Ms Glidewell: Often it is there for another purpose. Often it is placed there for the patient's comfort and if they choose to use that port they may do so.

Q655 Baroness Hayman: Has written consent been a difficulty in any of those cases?

Ms Glidewell: I think Dr Tolle could answer that. In the Center for Ethics in Health Care, Dr Tolle is directly involved in this Act. I think she can explain the answer to that question for you because I am not clinical enough to answer that question for you. The patient has consented to the placement of the tube for their own comfort, for hydration if they choose, and it is there at the time to be used.

Q656 Baroness Hayman: I understood that the legislation was very clear that the only way in which a patient can give consent is written consent.

Ms Glidewell: Precisely. They give written consent at the time that they are talking about this at the inception of the request and they must be able to sign the request for medication to end their life and they sign that form and we retain it during the 15 day process.

Q657 Baroness Hayman: It has not been a difficulty that a patient has come when they have lost the ability to sign?

Ms Glidewell: Usually they come before that, before they have the lost the ability to sign.

Q658 Baroness Hayman: In some ways the paradigm of the patient for whom this is very important, as with ALS patients, and therefore provisions that are, in fact, quite difficult for an ALS patient to carry through is an area that I am particularly interested in and whether you have had experience of patients who have had difficulties because of that.

Ms Glidewell: Patients I have met with ALS came before they were so impaired that they could not sign their forms or do that.

Baroness Hayman: This assumes a fairly good knowledge of what the opportunities are, what the legislation is, and a rapport with your doctor.

Baroness Jay of Paddington: It could be longer than six months.

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Q659 Baroness Hayman: For an ALS patient it could be longer than six months. Some ALS patients take two years or three years.

Ms Glidewell: After becoming infirm, yes. Are there any more questions for me?

Q660 Chairman: I want to ask one or two questions. First of all, I think I am right in saying that there is no requirement of unbearable suffering or anything like that as a condition of having physician-assisted suicide in Oregon?

Ms Glidewell: That is often what the patient describes but if they are uncomfortable and still believe they have less than six months they still have to go through the qualification process.

Q661 Chairman: Six months is the determining factor. In some cases that you have come across, is it not so much a question of present suffering as anticipating that the suffering may become so great that they would like to have the prescription to deal with that situation if and when it arose?

Ms Glidewell: You have described it exactly. They are anticipating what may come and they want to be prepared if and when that time comes.

Q662 Chairman: Most of the patients that you see are in this hospital, are they?

Ms Glidewell: Correct.

Q663 Chairman: If they get a prescription and have it, as it were, under their control, do they have it with them in the hospital?

Ms Glidewell: Before you go on with the question, I meet the patients here in our facility because they are not hospitalised patients, they are ambulatory and they come to see me and the physicians in our facility but they are outpatients.

Q664 Chairman: Outpatients of the hospital. So they get the opportunity to take the material home?

Ms Glidewell: Yes.

Q665 Chairman: You mentioned earlier on that this was a secular hospital.

Ms Glidewell: Correct.

Q666 Chairman: From that I rather gather that there are other hospital institutions in Portland and in Oregon more generally that are not.

Ms Glidewell: Correct.

Q667 Chairman: Are these church supported?

Ms Glidewell: Episcopal, Catholic, Adventist and the Veterans' Administration.

Q668 Chairman: You mentioned the Veterans' Administration and I am interested in that. That is a government organisation, is it not?

Ms Glidewell: It is.

Q669 Chairman: The assisted dying procedures do not happen there, do they?

Ms Glidewell: Precisely. Their providers are cautioned not to attempt this or to discuss it, it is not permissible in Federal Government.

Q670 Chairman: The Veterans' Association is a Federal Government organisation and the Federal Government are not bound by the laws of the state and in particular the laws of the state with which they do not agree. I follow. As far as the church organisations are concerned, it is dependent on the church's outlook, I suppose, and up to now the various churches that run hospitals are not willing to accommodate this particular procedure, is that right?

Ms Glidewell: Exactly. My understanding is that they have advised their providers who work for them that they are not to engage in this activity. Dr Tolle is distributing a guidebook for the terminally ill which is a plethora of information for you and she will go through that with you.

Chairman: Thank you very much indeed. We are very, very grateful. In due course you will get a chance to look at the transcript to see that it accords with what you thought you said. Thank you very much.

THURSDAY 9 DECEMBER 2004

Present	Arran, E	Joffe, L
	Finlay of Llandaff, B	Mackay of Clashfern, L
	Hayman, B	(Chairman)
	Jay of Paddington, B	McColl of Dulwich, L

Examination of Witness

Witness: DR SUSAN TOLLE, Center for Ethics in Health Care, Oregon Health & Science University, examined.

Q671 Chairman: This group was set up by the House of Lords as a Select Committee for the purpose of looking into the factual circumstances of Lord Joffe's proposal for a bill which deals with subject matter somewhat akin to the subject matter of the Death with Dignity Act in this state. We are anxious to secure as much information about the understanding of the way it works here as we can in the hope that this will help our colleagues in the Lords if they have to consider this rather important issue. We are receiving your help on the facts. We have a shorthand writer here who will take down what you say in order that we may use that as an appendix to our report to indicate the factual basis on which our ultimate conclusions will rest. You will have an opportunity to look over the transcript to see that it accurately records what you say. We have a common language but sometimes our intonations are a little different. Mine is very different from those who come from the southern part of England. The shorthand writer will do her best but it may require some adjustment when you get the transcript. Would you like to say a little about your relationship with the Death with Dignity Act and then my colleagues will wish to ask you some questions and I imagine I will have one or two myself.

Dr Tolle: I am Dr Susan Tolle. I am a general internist by training. I am a native Oregonian. I did internal medicine residency at the University of California, San Diego. I did formal ethics training at the University of Chicago. I direct the Center for Ethics in Health Care, at the only medical school in the only state in the United States with legalised physician-assisted suicide. I had already been the Director of the Center for Ethics for five years when the first public initiative in 1994 was voted on. Obviously this changed my professional career and it had a huge impact on the need for a data gathering role, a public spokesperson role and a role of dealing with issues related to the potential impact of an error. Let me tell you who I am and where I come from and then if you would all be so kind as to indicate your own goals—I do not know if everyone here is in favour of the law.

Q672 Chairman: Neither do I!

Dr Tolle: I need to tell you that I have served as the spokesperson for what is called the Task Force to Improve the Care of Terminally Ill Oregonians. That

organisation is described in this booklet and the organisations and agencies represented are in the handout with contact information should you need something more. The bottom line is, for or against, we have had all of the major health care organisations and agencies at the table, including the major Catholic health system in Portland and the VA hospital, as well as nurses, pharmacists, the OMA and the five major health systems. If you knew our politics you would understand what that meant in the Portland area with managed care, and with included a number of others, like hospice. I notice that you will meet with five different Task Force members in your travels in other ways. You have met Dr Hedberg this morning. She was the lead person representing what used to be called the Health Department at that time. She and I authored one of the chapters in here about doctors who do not report properly, do not follow through properly, and what should be done about this. Dr Linda Ganzini is one of the lead people gathering data in the area of end of life care. She is not available today and Betsy Goy will be representing her. I lead on end of life research and did so before physician-assisted suicide was voted on by public initiative here in Oregon my research covers the far greater context. My personal agenda has been to explore whether anything else happens to end of life care, remembering that one person out of a thousand utilises this option and there are 999 who could benefit or be hurt by implementing this kind of legislation. For example we have studied the impact on pain management more broadly with the spotlight which has been on Oregon and end of life care and doctors. With that pressure, we have asked: is that good or bad for hospice or other things in end of life care? I and my colleagues continuously do random samples of death certificates and talk to families about end of life care, including some questions that we asked before the legislation of PAS. We have asked questions about the degree of comfort, advance care planning, use of hospice, and have added questions like did your loved one personally consider assisted suicide, did you ask for it, did you get it, did you end up as ineligible before you could get it? The last author on that paper is Katrina Hedberg, who you have just met. The Health Department data focuses only on those who have

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filed a report. I do advise them on things like the data gathering and their instruments. I personally, and the OHSU and our Ethics Center, have never taken a stand on whether Physician Assisted Suicide is the right thing or the wrong thing for Oregon to do. That is not what the state and the people need me to be doing. They need me to be saying honestly and very frankly, "Here is what we are finding". Both sides use our data to load their guns and shoot at each other.

Q673 Baroness Jay of Paddington: And at you.

Dr Tolle: Usually at Barbara! They use the data in ways that often overstate what it says for their purpose on both sides. I do not wish to suggest that either is blameless in the use of data for their agendas. You will notice on the Task Force to Improve the Care for the Terminally Ill that advocacy organisations, both proponents and opponents are not members of the Task Force to Improve the Care of Terminally Ill Oregonians. The Task Force is about health professionals dealing with implementation when it became legal, whether you like it or not, including organisations that have taken stands and continue to take stands. We do encourage and support research. We encourage active and complete reporting. Also, we are deeply concerned that if there were to be mistakes, the price with regard to other aspects of end of life care could be high. I will have to honestly declare to all of you that that my biggest personal agenda is making sure that "the other 999" do not have a profound adverse outcome because of scrutiny of an obvious error. Some of the things you will have read recently about the Dutch in the media suggest the adverse impacts that can happen, things all of us would agree were not what were intended. Often, I have a need for a detailed understanding of the politics if I am going to walk this razor's edge of neutrality and yet speak often about this issue. A couple of weeks ago I did a BBC interview. It is a place where information is wanted and needed but at the same time one always needs to look at what position we will be put against because wherever I am put I look as if I am counter to them. If you are in the middle and they only show pro, you look con; if they only show con, you look pro. You will be attending a reception this evening and I am leading a conference in Eugene about improving end of life care in the State, the eleventh major regional conference this year, so I am not able to attend, but politically that would be considered to be a conference that may not be evenly representative.

Baroness Jay of Paddington: Which, your conference or our reception?

Q674 Chairman: Our reception?

Dr Tolle: Yes.

Q675 Lord McColl of Dulwich: I did not follow that, could you explain?

Dr Tolle: Perhaps during lunch I can explain. I always need to be seen as neutral and be neutral, be a voice for the truth about what is going on, whether somebody likes it or not, whether I like it or not. I have pretty well memorised all of the data. When you ask how many people have died out of hospital, I can tell you it is one because I have memorised all the Health Department data. One person is reported to have died in an acute care hospital, all the rest were not in hospitals. That is Katrina Hedberg's and the Health Department's data, not my data. We do have a much richer context because this is a public initiative, a political process that may be somewhat foreign to you. A public initiative is a process where a group of people write legislation and the people of our state vote on it. However, you cannot amend the initiative, it is this or this, if the comma is in the wrong place and it does not make it clear what relates to what, all you can do on a public initiative is vote yes or no. That was what this process was and the first time in 1994 it was a very narrow passage, 32,000 votes in the first round, and that went back. Then it went back to the Legislature who said "We are not sure if people understood it", and referred it back for a second vote. The people were not pleased to vote again and the margin was quite wide the second time in 1997. It creates a volatile process here and you would just about have to live here to truly understand why Oregon and what is unique about it. The importance of understanding some of that is you are asking if Oregon is transportable and there are some things that are very unique about us that may not be. It is important to know that context to understand how things would play out in your own region of the world. You are different from us in that you have universal access to health care. That makes a very different backdrop but, more than that, people really do have a primary doctor and the amount of movement and changing health plans and shifting primary care physicians has a huge impact on whether your primary doctor is somebody you have known for a long time. There are also very big differences in the religious climate. It is important to look at what parts of the United States are more strongly church affiliated than other parts of the United States and if you think about that context it is relevant to why the Oregon vote might have passed here. Our demographics are likely to play a role. Some issues with other parts of the United States being more multi-ethnic than Oregon are also relevant to our context that would need to be looked at. It is interesting that the people who have universal access to health care in the United States are those over age 65. It is a very different kind of context. I just want to be sure that as you apply things you learn in Oregon you think about our difference. You will find your experience in The Netherlands is going to be very different from your experience of what you hear

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from us. The fact that we do not allow euthanasia, while blurred in the minds of the public, has huge implications for transfer, error and policy as well as for the number of people who ultimately utilise the law. As you know, our rates are far lower than the rates in The Netherlands, profoundly lower. They have not changed very dramatically if you round the numbers. I am going to give you background about this group and then open myself to questions. I will not tell you about my personal views because they are not relevant to our discussion and they are not useful. I am a person who does advise many organisations, not individual patients, but health systems like ours, which would then help design the policy that Barbara functions under. I work more at a policy application level than one-on-one dealing with any individual patient. If someone asks for medication they would be referred to Barbara. The Ethics Center would not give you information about how much to prescribe as that would be offensive to those opposed and tip the balance of our neutrality. That is not an appropriate role for the Center for Ethics in Health Care. We gather a great deal of data. Looking at the membership of the Task Force, I think it is worth taking a minute to glance through and see what this group consists of. The Task Force has met regularly since early 1995. It came together about three months after the first vote and while the legal injunction was still in place in Oregon. This gave the group time to write a guidebook and set standards for implementation. The Task Force includes professional organisations, including those opposed, and there are disclaimers at the end about the VA health system and others, even though they were authors. This listing outlines who wrote this.

Q676 Baroness Hayman: Can we stop you there for a moment?

Dr Tolle: I think that is a perfect time.

Q677 Baroness Hayman: The Task Force title is to Improve the Care of Terminally Ill Oregonians. Are there parallel documents about hospice care, about the 99 per cent? Is there a whole lot of work done by the group or, as you have described it, it sounds as if it came into being after the Act and is focused on the Act?

Dr Tolle: The Task Force has two sub-committees, one to write this Guidebook and one to write a document that we did even sooner which was all the resources by county in end of life care. This sub-committee also explores ways we could promote educational programmes to prevent errors and maximise the opportunity to improve good end-of-life care. Leading conferences is a part of what I am still doing, and the conference I am going down to Eugene to do, has nothing to do with assisted suicide.

Q678 Baroness Jay of Paddington: That does not actually answer Lady Hayman's question.

Dr Tolle: Everyone reviewed every document but we did an equal amount of work on seizing the opportunity when you are in the spotlight to build palliative care programmes in every hospital, to expand the use of hospice, to take media opportunities and turn them into whole page descriptions of how you enrol in hospice, to hold conferences where initially only the choir came, and by that I mean people who were already very interested and committed to hospice, but now lots of health professionals come to improve their skills in end of life care and pain management. We have seized the opportunity to train many thousands of practising health professionals in all aspects of end of life care. Another key thing is if you do not have a group positioned to lead, what has happened in Oregon might not happen and might lead to outcomes very different from what has happened in Oregon.

Q679 Baroness Hayman: What proportion of the work of this Task Force relates to the implementation of the ODDA?

Dr Tolle: Because boundaries blur, I serve not as the chair but as the bank for this Task Force. I raise all the money that supports everything, the Ethics Center has staffed it and many times when they discuss an educational programme that is needed I go and get another grant. Is that work of the Task Force or not? You will see what the problem is. This is a group that selected itself, convened itself, and is staffed by the Ethics Center. It is not a government appointed body. When the Ethics Center takes the role of work the group says to do, is that work of the Task Force? Some would say yes and some would say no. My identity, the Task Force identity and the agencies we work with to carry out the mission that is so needed, are so closely intertwined that I would argue the disproportionate work that has arisen out of the Task Force is to improve end of life care. Those efforts are by a large amount out of proportion to time spent on information about PAS.

Q680 Baroness Jay of Paddington: I think we are all misunderstanding what you mean by end of life care. Are you saying that if it had not been for the passing of this Act, in this state, you would not have developed the palliative care services and the other hospice support systems that you are talking about as being stimulated by this group?

Dr Tolle: That is correct.

Q681 Baroness Jay of Paddington: Are you saying that it was not until this passed that you had these services in place?

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Dr Tolle: I have published a paper called *Silver Lining*, which describes that exactly. This group came together with the primary agenda of being sure that good, not harm, would come out of the law whether we liked it or not and some on the group do not like it; some are more neutral, like me.

Lord McColl of Dulwich: Some on this group do not like it?

Q682 Chairman: Can you help me about this. I thought you said that the group had put out this guidebook in relation to the Death with Dignity Act?
Dr Tolle: That is correct, but it is only one of its products.

Q683 Chairman: That was precisely what I understood, that it also produced a book or a study dealing with many other aspects of end of life care.

Dr Tolle: Right. Until you look into this book you will not quite realise that there is a whole chapter written by Ann Jackson about hospice.

Q684 Baroness Jay of Paddington: But that would not have happened if you had not had the Act, that is the main question?

Dr Tolle: Let me turn back the clock to the early 1990s before the first vote. We had been struggling here at OHSU, and many other hospitals had, to build inpatient palliative care programmes, to strengthen our education on pain management, to expand the use of hospice, and when we held conferences and activities they were attended only by the already committed to a 90 per cent degree. We would have one or so a year and the hospice people would come. Now we are holding 11 major regional conferences this year, all but one of which has major or total elements addressing end of life education, none of which this year have anything to do with assisted suicide. We have gone from one inpatient palliative care programme, and I will explain the politics of the exact timing off the record if you would like, to 12 in this state pre and post the vote. I can explain some nuances of the first one and why.

Q685 Lord McColl of Dulwich: 12 hospices?

Dr Tolle: No. There are 51 hospices. When we say "hospice" you think St Christopher's and you may think inpatient.

Q686 Lord McColl of Dulwich: No.

Dr Tolle: Almost 90 per cent of those who die in hospice in Oregon die in their own homes or in the homes of family members. There are 51 hospice programmes. Hospice was strong and covered most of the Oregon geography prior to the 1994. We were sixth out of the 50 states at that time in use of hospice, so we were better than average and we have risen more since the initial vote. What I am talking about

are the educational forces inside acute care hospitals and health systems, programmes that consult and support families with difficult decision making in the face of serious illness, sometimes to stop, sometimes to enrol in hospice. Those are what we have strengthened and I have got multiple large grants to go round and ultimately help every hospital in Oregon have a strong palliative care programme. The programs are among the greatest possible strength in offering alternatives. The growth of these programs spins out of this group saying that is important and strengthening that. The Task Force has filled a leadership void that without a group like this could go in a very different direction as to whether end of life care improved, which I would argue that it has in Oregon, but I would not argue that you could say it is because of the law, it is because a group of individuals were committed to being certain that as much energy as possible went to the 999 and had the horsepower and the connections to make it happen.

Q687 Lord McColl of Dulwich: This is absolutely fascinating. If you just turn the thing around, in Holland euthanasia took off because it did not have a hospice movement. You have 50 hospices in the whole of Oregon, is that what you said?

Dr Tolle: Hospice programmes.

Q688 Lord McColl of Dulwich: Which is far, far less than we have in the UK. If you had as many hospices per population as we have you might not have had this legislation, is that a possibility?

Dr Tolle: First of all, because we have merged managed care there is one hospice for all kinds of hospitals in Portland that are Catholic and serve a huge number of people. We have one hospice in Florida that serves more people than Oregon has deaths per year. You should count the number of people in hospice, not the number of hospice programmes, in fairness, and the percentage of people who are in hospice at the time of death, which is 37 per cent.

Q689 Lord McColl of Dulwich: I accept all of that. The question I asked you was, as in Holland, they might not have had euthanasia if they had a decent hospice service and if you had a more extensive hospice arrangement in Oregon is it possible that you might not have had this legislation?

Dr Tolle: It would be possible for you to find that in the public record because the day after the vote I wrote an article in *The Oregonian* called Wake-up Call to Medicine in November. In that article I described the fact that when people voted, and remember you cannot change anything, you vote yes or you vote no on an initiative, many people were voting about a very tragic experience a loved one had had in end of life care and saying, "I vote for anything

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different". Many would say, "What you have said is too narrow for me, I would include poor pain management, I would include inadequacies in the hospital, I would include poor conversations and planning, I would include much more in the basket and then say yes". In some ways it was a vote of no confidence about some aspects of end of life care in Oregon.

Q690 Lord McColl of Dulwich: That is very interesting, thank you.

Dr Tolle: Not exclusively a vote of no confidence, there were those who meant it. I do not wish to demean it in any way. I do wish to introduce one other person who has come in. Mina is my executive assistant at the Ethics Center and the contact person for questions that follow up later.

Q691 Baroness Hayman: Obviously the Ethics Center has undertaken a huge amount of very important work in terms of spreading good practice and education and all of those things. When we talk about tough stuff, like access to services, it is money that comes into it and funding that comes into it.

Dr Tolle: Yes.

Q692 Baroness Hayman: You can take the 80 per cent of people in hospice care two ways as an argument. You could take it that it is only because there is good hospice care that people had the confidence to bring in the legislation, or you can say it was not enough. Just in terms of funding, have there been changes in state funding for hospice care or extended access to hospice care since the Act?

Dr Tolle: You are right, everything I say both sides will use to say it is because it is most utilised and therefore, it is because it is functioning poorly and it is the doctor's fault and therefore. You are quite right, very little that I say can prove cause and effect. I can prove association: this data at this time in this context. What we know is that several things were happening concurrently and one was that the Oregon Health Plan came into effect and increased the percentage of persons with insurance. One thing that often happens if you are terminally ill is—

Q693 Baroness Jay of Paddington: Under Medicaid and such like?

Dr Tolle: That is right. That increased the chances that if you were dying you became insured and we measured that and showed it went from 15 per cent to 2 per cent of people in hospice who lacked financial coverage because of the logistics of who becomes poor enough to qualify and how fast you become poor. It worked out logistically that they were much more likely to have insurance coverage for hospice care.

Q694 Baroness Jay of Paddington: If you are over 65 you qualify under Medicare anyway, do you not?

Dr Tolle: You do, but now the Oregon Health Plan covers younger people.

Q695 Baroness Jay of Paddington: I thought you said earlier that it was primarily the old people.

Dr Tolle: 75 per cent of deaths in Oregon are over age 65 and covered by Medicare. The group most likely to be uninsured are the 25 per cent who are under age 65 and cannot work as they become more ill because most private insurance is an employee benefit. They become uninsured and they were that gap group. That was who got picked up by the Oregon Health Plan.

Q696 Baroness Finlay of Llandaff: They were picked up by Medicaid?

Dr Tolle: Also, health systems put more money into these palliative care teams so more resources were available for consultation if you had a period of time in the hospital and the Oregon Health Plan also wrote certain very specific benefits about single consultations for pain management and comfort.

Q697 Baroness Finlay of Llandaff: Can you just clarify whether those consultations with a dedicated palliative care team would be happening at any stage in the patient's illness or would they only occur in what was prognostically predicted to be the last six months?

Dr Tolle: The institutions vary and I could walk you through 12 different programmes in answer to that question. Our own simply requires serious life threatening illness and the majority of patients consulted on by the OHSU palliative care teams are discharged alive. It does vary. Some of the palliative care teams are only consulted in the active phase of dying for comfort measures in the hospital, so it is not universal. What is unique is the number of health systems putting dollars into building those teams which tend not to be revenue neutral, they tend to be financial money losers for the hospital because the amount of billing for consultation time does not offset the fees of a multi-disciplinary team. The hospitals decided in an economically difficult climate for hospitals that this was an investment they chose to make. In Oregon this happened more often and out of proportion to the number of inpatient palliative care programmes elsewhere, partly because of the question of whether you would want to be the only hospital that did not have a palliative care programme in Oregon now? That pressure became quite strong.

Q698 Chairman: Who is the funding agent for this hospital?

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Dr Tolle: The funding agent for the Oregon Health & Science University could not be more complex. The current status is that it gets 5 per cent of its dollars, plus or minus a per cent, and it is being disputed what that will be, from the State. It is officially a public corporation and it is secular. It has a tremendous research capacity and has research dollars.

Q699 Chairman: For contracts for research?

Dr Tolle: For grants. It has tremendous dollars for education of dentists, nurses and physicians.

Q700 Earl of Arran: From whom?

Dr Tolle: Tuition primarily.

Q701 Baroness Jay of Paddington: Private endowments?

Dr Tolle: Medical students who are in state pay \$26,000 a year.

Q702 Lord McColl of Dulwich: Wow!

Dr Tolle: Out of state, it is \$10,000 more.

Q703 Chairman: When you say “out of state”, what do you mean?

Dr Tolle: That is what I am telling you, the context is different and you must understand that. Ethically, if I were to say “Does the United Kingdom provide health care as a whole more ethically than where I practise medicine, I would say yes”. You are more ethical because you have better dealt with issues about access to health care, but that does not mean that this is a good idea or a bad idea for you to legalize assisted suicide. I want to be very, very clear on that.

Q704 Baroness Jay of Paddington: I want to ask you a question that probably you will not answer. Given what you have said about how the original vote on this went—I hope I am representing you right—was partly a vote of no confidence in the medical system which was being offered in end of life situations, and given that what you have said about how this was a stimulus to improving end of life care, in fact the stimulus as far as I can make out—

Dr Tolle: A stimulus. I would argue that our education was already starting to change.

Q705 Baroness Jay of Paddington: When I asked you would this have happened without this Bill, you said no.

Dr Tolle: Not at this rate.

Q706 Baroness Jay of Paddington: Let us shorthand the question. What would you then say would be your view of the outcome were you to run the same kind of poll now. Would people still be voting on the

basis that they were voting for lack of confidence in the existing system?

Dr Tolle: I survey doctors and I survey patients and ask patients and families and I can give you some interesting percentages from research. One article that we published in the *Journal of Clinical Ethics* in September had a six per cent sample of death certificates and we asked family members of those who had died whether their loved ones would have favoured physician-assisted suicide and then asked would they pursue it and so on, and the majority said no.

Q707 Baroness Jay of Paddington: That is not the same question, is it, because that is not asking the electorate what they would do and whether their votes would now be determined by a lack of confidence in the system.

Dr Tolle: That vote has not been done.

Q708 Chairman: Can you tell us what surveys you have done and we have to make such conclusions from that as we can?

Dr Tolle: I will do my very best. Lady Jay, I do not have the answer to your specific question.

Baroness Jay of Paddington: No, but what you are talking about in those kinds of surveys is people who have had direct experience of either a person in their family who has died or who has taken advantage of the system. I am talking much more about public opinion which you described as being influenced by a lack of confidence in the medical services.

Q709 Chairman: At the time the vote was taken.

Dr Tolle: At the time the vote was taken I would say there was a definite dissatisfaction with some aspects of end of life care and some of those reflected dissatisfaction even 10 years earlier and some things had already begun to improve but people still remembered very graphically. We were held accountable for past and present sins at the time of the vote.

Q710 Chairman: Are you in a position to say, in answer to Lady Jay, what the public opinion balance is at this date or not?

Dr Tolle: Not on that specific question. I can tell you two surveys of doctors before and after. Their moral opposition was exactly the same within a percentage.

Q711 Baroness Finlay of Llandaff: I think that is interesting as well.

Dr Tolle: The third who believed it was absolutely morally wrong, some of whom you will meet tomorrow, still have not changed one bit in believing that it is morally wrong. I really want to give credence to that because of the discomfit in our own hospital and the level of acceptance appears not to have

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changed. I would answer Lady Jay's question as I have no measure that overall acceptance by any group has significantly changed. Some has not been measured and we do not have the best of the data but it is intriguing that a group that is eligible, a group known to be dying, had a minority of family members believe that their loved one would have voted in favour, which I think answers the question in part.

Q712 Baroness Jay of Paddington: It does really. Whatever the situation, either in this country or in the UK, this is not going to be determined by surveys of doctors or families who have been involved, this is going to be determined by the electorate.

Dr Tolle: Of course.

Q713 Baroness Hayman: Do you have any data to compare that with? As well as the surveys of families perhaps a sub-group, because it might have been even a smaller minority then.

Dr Tolle: It is possible.

Q714 Baroness Hayman: You do not know?

Dr Tolle: We do know by age that the older a person is the less likely they are to favour assisted suicide. We know that from national studies in the United States as well.

Q715 Lord McColl of Dulwich: It is the same in the UK.

Dr Tolle: Also, we know that certain religious groups are much less likely to favour assisted suicide than others and we know that certain racial groups are much less likely to favour assisted suicide than others.

Q716 Baroness Hayman: When you say that they have deep seated ethical objections, it does not surprise me at all that they have not changed because if you have an ethical absolute about this then you have an ethical absolute about it and experience is not going to change that. I am more interested to know whether there was a group who were undecided, if I can put it like that, and whether their opinion has shifted?

Dr Tolle: Yes, about equally in each direction.

Q717 Baroness Finlay of Llandaff: So they have become more polarised from the middle ground?

Dr Tolle: No. Some of the ones who were uncertain how it would play out now say that it seems acceptable to them. It looks about the same is the bottom line. Those who are most opposed are exactly the same. The other thing we do have significant information about, and Betsy Goy has some of this as well because Linda Ganzini and I have authored some papers together, is studies before it was legal about how often it happens. We did ask a question of

about 3,000 primary care doctors in Oregon in 1995 and published it in 1996, asking if they had written a prescription knowing the patient intended to use it to take their own life and we found that 87 doctors in this study said they had done it one or more times. Was it occurring prior to legalisation? Yes. Has any study done by any group about this question found a base rate in the United States? Yes. We have no good data, it is highly speculative whether that rate has gone up or down because the numbers would have to be so large when you are looking at a rate of one in one thousand. You would have to survey all deaths and you would still have errors. There is no evidence from the multiple datasets that we have that the rate of assisted suicide has gone up since legalization in Oregon.

Q718 Baroness Finlay of Llandaff: Did you ask what they prescribed with that intention?

Dr Tolle: No.

Q719 Baroness Finlay of Llandaff: It is interesting to see that the prescription is for barbiturates in different formats and I wondered if you have got any data on the prescribing of large doses of barbiturates prior to the legislation coming in.

Dr Tolle: I do not know.

Q720 Baroness Finlay of Llandaff: Is there any centrally held prescribing data?

Dr Tolle: The Drug Enforcement Administration, the DEA, nationally has that data. I call it "dirty data" because it was designed to monitor diversion, not to address the questions you and I are interested in. Because of that, it is measuring distribution from pharmacies. We do not know how much of the relatively small percentage of controlled substances is going to persons who are dying.

Chairman: I think our time has gone rather fast but Lord Joffe wants to ask you a question.

Lord Joffe: I will keep it very short. What is clear from what you have said, and you have said we should not draw conclusions, is that there has been a significant increase in the improvement of the extent of palliative care since the legislation was introduced.

Dr Tolle: Right. I would like to acknowledge that there was improvement underway but the speed of improvement was able to be harnessed. We made a deliberate effort to harness it. One of the things I would be extremely cautious about is whether it would have happened naturally. There is an association between a group deliberately attempting to use this in a way to improve end of life care in a very strategic and organised way and the fact that it improved more rapidly, although it was already starting to do so. If this just happened and no one tried to channel all these conferences and educational activities and deal with some of the political problems

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and work extremely hard to control the number of potential errors, I am not sure the outcome would have been anything close to the same. I spoke very clearly to colleagues in Maine when they were going to legalise assisted suicide that they were very different, they were among the lowest rates of hospice use, they had no leadership or organisation positioned to convene, and whether they would see improvements in their health care was very open to debate.

Q721 Lord Joffe: I have a follow-up question. I know you are not keen to ascribe reasons and say this happened, but it does seem reasonably clear that the legislation has not had an adverse impact on hospice care and palliative care.

Dr Tolle: The percentage of persons dying in hospice is greater now than it was in the past, however it is rising in every state. The rate of rise is a little bit faster in Oregon than the rate of rise nationally.

Q722 Lord Joffe: As I read the figures in one of the papers it has gone up from 8,000 to 13,000 in hospice programmes.

Dr Tolle: That is correct.

Q723 Lord Joffe: Which is a 66 per cent increase over this period.

Dr Tolle: You have to be careful because the Oregon population has gone up.

Q724 Lord Joffe: But that is a lot.

Dr Tolle: It is. It has risen and it has risen on a steeper slope than in the rest of the country. I would argue that with the Task Force setting very strict reporting requirements and with a lot of education about what you should not be doing outside the law, there has not been some egregious error. The Task Force has

played a significant role in educating people about what they should not be doing. With that, there has not been a situation that has had an adverse impact on pain management. However, something that led to an investigation, a loss of licensure and those kinds of things could mean that things could have played out very differently than they have here. I do not want to say that because it has played a certain way here in Oregon and that legislation was associated with an increase in hospice, that without a group like a Task Force and some of the other things unique to our state that it would play out the same way in the United Kingdom, because it might not.

Q725 Earl of Arran: Given the very fact that, according to you, Oregon's uniqueness has not been rolled out across any other state in this country after seven years, is it your judgment that Oregon is likely to remain the only state with this facility as things stand at the moment?

Dr Tolle: There are unique things about Oregon that made us first. It has a lot to do with our demographics. The vote was 10 years ago, implementation was seven. We are looking at 10 years since the first vote for legalisation in 1994.

Q726 Earl of Arran: Are you aware that any other state is about to accept this in this country?

Dr Tolle: Yes. Other states continue to review it as a legislative process and some get close. Maine got fairly close. California got close. Washington got close.

Q727 Earl of Arran: But they parted from it?

Dr Tolle: They parted from it, but in most cases they included euthanasia as well as physician-assisted suicide.

Chairman: I think it is time to stop. Thank you very much indeed.

THURSDAY 9 DECEMBER 2004

Present	Arran, E	Joffe, L
	Finlay of Llandaff, B	Mackay of Clashfern, L (Chairman)
	Hayman, B	McColl of Dulwich, L
	Jay of Paddington, B	

Examination of Witnesses

Witnesses: **Dr Elizabeth Goy**, Assistant Professor, Department of Psychiatry, School of Medicine, and **Ms Barbara Glidewell**, Director of Oregon Health & Science University, Department of Patient Relations, Oregon Health & Science University, examined.

Q729 Chairman: I think you know that our group is referred to as a Select Committee and has been appointed by the House of Lords to look at the facts and issues that arise in relation to Lord Joffe's Bill for assisted dying. We know that here in Oregon, at least, certain of the issues have been put into practice for some time. One of the issues that is important is in relation to a patient's competence to make the decision to request assistance to die and the effect of mental stresses of various kinds on this competence. We hope that you might be able to help us in this area.

Dr Goy: To some extent.

Q730 Chairman: The system that we have in seeking your help in getting the facts for our purposes is as follows: if you would be kind enough to say a little bit about what you do and what your interest is in relation to these matters and then my colleagues will want to ask you some questions. We have a shorthand writer to take a note of what is said so that we can append it to our report. It will become public property when we issue our report. You will have a chance to look at the transcript to ensure that the lady who is taking it down has been able to get exactly what you say. We very much appreciate the fact that you have come to help us. Would you like to say what your position is and the areas of responsibility you have that might be of concern to us?

Dr Goy: By all means. Welcome to Oregon.

Q731 Chairman: Thank you very much.

Dr Goy: I am a clinical geropsychologist. I was recruited in 2000 to work with Linda Ganzini, a geriatric psychiatrist, at the VA and at Oregon Health & Science University. I am here today representing a large body of hard research that Linda and I have been privileged to work with since 2000 on several layers. Some of it may answer the questions you have about competence, especially with regard to depression which I know is a large concern. I do have a synopsis, including some articles, and a bit of an overview of how the work ties together and answers some of the questions and concerns that people have had about assisted suicide. Would you like that?

Q732 Chairman: Yes, please, that would be very useful.

Dr Goy: Because this debate was so hotly contested and there were so many concerns raised during the decision making about our law—it was Linda's vision that this required some good hard science and she has taken a very firm neutral stance. As I say, I have worked with her since 2000 and I still do not know her opinion about physician-assisted suicide. I do not know whether she supports it or wishes to see it changed. I have to admire that because our desire is to do the most fully neutral job that we can on assessing the conditions and circumstances here. We have done this by more or less peeling away layers of the onion. We started by interviewing physicians who have worked with patients who have made requests for lethal prescriptions. Then we moved on to interviewing hospice nurses, who have worked directly with patients who have requested suicide, as well as hospice social workers. I did not participate in the study that she did with patients with ALS or motor neurone disease but I have provided a synopsis and one of the articles that has been published. All of this has been criticised to some extent because it is subject to some bias, and we understand that. It is the reports of physicians and their impressions of their patients, or nurses and their impressions of their patients and, of course, if they were poor at picking up on depression or unable to recognise that they were not adequately treating pain then they were not likely to report that their patients were in pain or depressed. We are aware that is a shortcoming of these kinds of surveys but they play a very significant role in the arrow that we are drawing towards our concluding work which is going on right now, and I am really thrilled to be part of it. All of these preparatory studies were meant to equip us with our hypotheses so that we could go and speak directly to patients who are actively making these decisions. Our desire was to be fully prepared with background information and all of these preparatory studies so that we knew what questions we wanted to ask and we did not waste the time of people who were making much more critical decisions. People have been very generous in allowing me to meet with them,

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sometimes for three hours at a time. Currently we have two studies going on. One involves family members of patients who have already died but who did make a request for a prescription during their terminal illness. We are trying to determine the motivation, the reasons, were there any problems involving depression, financial pressure, difficulties that they were worried about being a burden, and we have assembled all of this into a survey for family members. At the same time I am meeting with terminally ill patients who have made an explicit request for lethal prescription and asking them quite directly what their reasons were. I find this to be an incredibly fascinating opportunity to talk to people directly without all of the potential bias that influences other reports to find out exactly what is going on and what motivates them. I am in a good position to respond a little bit anecdotally about the study that we are in the middle of although we do not have good hard data yet. I have seen 28 terminally ill patients and 32 family members. We are halfway into the first year of a two year study. I have some impressions and information based on this.

Q733 Lord McColl of Dulwich: Could I start with a quote from the guidebook that I would like your help on, if I may: “If the mental health professional finds the patient competent, refusal of mental health treatment by the patient does not constitute a legal barrier to receiving a prescription for a lethal dose.” I should explain that I am a Professor of Surgery, not Psychiatry, but I have always been very interested. That worries me slightly because if somebody is suicidal and not suffering from a terminal illness, certainly we would treat them and, if necessary, put them away for a short period to make sure that they do not commit suicide, but if it is forecast they are going to die of a terminal disease within six months that seems to change it. Could you enlarge on this, please?

Dr Goy: I am not sure that I can provide you with specific legal ramifications but we are keenly interested in how well we are able to evaluate the capacity of a person who has made the request for a lethal prescription, especially in view of this issue of depression, as I mentioned, which can cloud one’s judgment. Also, we are keenly aware that people undergo a pretty acute adjustment reaction when they have been told of their prognosis. I have had many interactions with people across these stages of adjustment. I might address this by saying that it is important when you assess capacity to establish that the person is aware of his or her illness, can describe it, can describe the appropriate treatments that may or may not be available as well as the risks and benefits related to those. In addition the person should be able to state clearly their intention (in this case it would be a request for assisted suicide) and

be able to understand the risks and benefits involved in that decision. Then they must be assessed for depression. That is always tricky when you are dealing with someone with a somatic illness because you can have overlapping somatic problems that can complicate this. We do find that we have to focus very carefully on the thoughts and intentions that have to do directly with mood and, most importantly, loss of pleasure or the ability to feel pleasure. I started as a sceptic thinking that of course everyone will be depressed, they have just been told they are dying, but what I find is that there are many levels of robustness across people I have interviewed who have made this request. Some of them have that incredible ability to reframe their circumstances. We always wonder why some people in the general population are subject to depression while others are not and we do see some variations among terminally ill patients as well. Some of them are able to say, “Well, I no longer have hope to survive beyond six months but I do hope to minimise suffering” or “I do hope to minimise the burden I create on my family and my hope is to die as peacefully as possible in a way that creates the minimum amount of distress for my loved ones”. They find ways to reframe hope, and that is an important part of listening to the patient in terms of assessing whether depression is colouring their view. Also, we pay a lot of attention to how closely their stated intent matches up with their history. Is this something that is consistent and congruent with their Advance Directive, with their statements to their loved ones across their lifetime, or is it something that appears to be coloured quite directly by the new knowledge of this diagnosis. All of these need to be taken into account. In working with this current study, I do find that there are patients who are depressed who have made a request and that cannot be denied, I am sure that plays a part in it. What is important for us is to make sure that those people are caught in the safety net of assessments that we have and treated, if warranted, prior to ever granting physician’s permission for lethal prescription. From the data you have heard today probably, it is much more frequent to have a request made for a lethal prescription than it is for a person to leap through all of the hurdles that we have set up and meet all of the requirements and then for that person to decide to make use of it, so the numbers diminish as those steps go by.

Q734 Lord McColl of Dulwich: What I am getting at is that patients who are suicidal seem to be treated in a different way if they are within six months of dying of a lethal condition. Do you see what I mean? It is as though the six month thing makes a difference. Of course, medicine and prophecy are

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two quite separate subjects and we get it wrong quite often.

Dr Goy: Yes, and that is nerve-racking. I interview for depression using a structured clinical instrument, and I do not know if you are familiar with the Structured Clinical Interview for DSMIV which is the gold standard for depression in our work. When we ask questions about suicidality I get an unusual scattering of responses and that has to do with how do you define “suicidality” in a state where it is legal to ask for lethal prescription. Some will say, “Of course I am, I have asked for a lethal prescription”, but do they have other plans, other intents? I have some patients who say “If this does not work out, I have other methods”. I find those people to be quite at risk and very much in need of treatment and attention to their suicidal ideations. There are other patients who make a very careful distinction and say, “I am making a rational choice. I know what I need. I think it is a normal reaction to be a bit saddened and grief stricken but I am requesting this for this reason and this reason. Certainly I would not do it any other way but this option is available” and they are quite lucid about making that choice.

Q735 Lord McColl of Dulwich: That is very helpful. If I could go on just a little bit more. Supposing somebody gets the lethal dose which they do not use right away and they survive more than six months and have not been suicidal, but they then become suicidal and they have this lethal dose there and they are not dying, how about that?

Ms Glidewell: I have experienced one case where the person survived longer than six months and was puttering along very nicely, so the physician went to the home and asked to retrieve the medication to keep it for this person until such time as the terminal illness of their condition was more apparent. We do lose control of that medication once it is out of our hands. Often we say we can hold the medication for them until they call for it or hold the prescription but not fill it until such a time when they are ready, but there is no guarantee they are going to take it then and you have this lethal dose sitting in the medicine cabinet wondering what they are going to do with it.

Q736 Chairman: Does the six month period bring an end to the validity of the consent or is the consent given just a little before and then the patient lives more than six months? Does the consent still operate or not?

Ms Glidewell: It has for us. We have had very few cases such as that where people have gone on for seven or eight months but the consent was still valid.

Q737 Baroness Hayman: We have heard on several occasions that a far greater number of people fill the prescription than take the medication. The statistics that are gathered by the state only deal with people with a prescription once the prescription is issued. Also we heard that some physicians choose not to do this in advance but if they wish to be involved in the whole process they would rather agree, take consent and say, “When the time comes, I will fill the prescription and I will be there for you when you take it”. Do you have any sense of numbers on this because obviously you are interested in the people who want the insurance policy, to use the shorthand, the certainty that this is available to them? We know that there is a small number who actually ingest but there is a larger number who pick up a prescription. I am trying to get to the community whose life has improved by knowing that this is available to them, whether you have any research on those numbers?

Dr Goy: I cannot give you numbers yet because it is my current research work. I have seen almost 30 of each group. I would say that at least two-thirds of the family members I have spoken to, regardless of the outcome and regardless of whether the patient took the medication or not, when the patient obtained the prescription family members are reporting that this was the moment when the patient became so peaceful, as you say an insurance policy, and the stress was removed because he knew he had this option if circumstances became intolerable. I am sorry to say I do not know the numbers.

Q738 Baroness Hayman: The start point is rather difficult. How do you define this group of people who consider assisted dying but who do not take it through to the last stage? If you start with one conversation with a doctor on the day of diagnosis, that could go lots of different ways, that could be an immediate reaction that was never voiced again or it could go much further. How far back are you going in your sample?

Dr Goy: That is the beauty of doing a prospective study in that we are working with patients who have been referred to us by various agencies, including Compassion in Dying, who I know you will be interacting with if you have not already. They are probably our largest referral source. They are sending our letters to everyone who has made that very serious inquiry about obtaining a prescription. They have got far enough along that they have asked seriously for it, they have made a request. Whether or not they have gone any further in the process is unimportant to us, we want to enrol them as soon as they have made the request. Then we are able to follow them for outcomes and we are given consent to access physicians’ files so we will learn eventually whether they obtained the prescription,

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why they did or did not obtain the prescription and whether they actually took it.

Q739 Baroness Hayman: Do you have any data on the levels of public understanding of what the law is? Does every Oregonian know?

Dr Goy: Only anecdotally. I do not think they all know about it. Certainly they do not appreciate how many levels must be met and how many requirements must be met to obtain a lethal prescription.

Q740 Baroness Hayman: You are using the people who have come in with a serious request and that presupposes that they have an understanding of options and of what is available.

Dr Goy: Yes. I think that is going to be true for every person who avails himself or herself of this law. They tend to be well educated and not oppressed minorities or economically diminished and tend to be part of the population that is more likely to be aware of what the laws are.

Q741 Baroness Hayman: Is there an anxiety in terms of access?

Dr Goy: How do you mean?

Q742 Baroness Hayman: Is there a concern that there is a level of discrimination coming in, not because it is more educated people who want to do this, but because there are some sections of the population who would want it if they knew about it but do not have access because they do not read the papers or have a particular sort of relationship with their doctor. In other words, they are just unaware of the option?

Dr Goy: I think that is the kind of information that comes to light over a couple of years of appraisal of a programme like we have available to us now. Certainly it is clear that there are other ways that underprivileged people do not have access. For example, everyone has to pay privately for this medication, which is hundreds of dollars. If you cannot afford it you are ruled out at that point in this state.

Q743 Baroness Jay of Paddington: I am just flicking through your very helpful presentation and on page four there is a slide—I presume it is a slide—asserting “Poor, female, or minority groups request assisted suicide disproportionately because they lack access to health care options”. Then you give the statistics on the Physician Survey showing precisely the reverse, which is what Lady Hayman was asking you about. You have the data to show that those people are not excluded positively but they are the ones who are not involved.

Dr Goy: They are a minority of the group. Usually the concern runs in the other direction, that people may be pressured financially into making use of this so that they do not extend the burden on their family. In the other direction, I think it's possible that the law is leaving people out because of the way that it is set up.

Q744 Chairman: You mentioned that most of your information about people who have made requests comes through Compassion in Dying, is that right?

Dr Goy: The majority does but we have other sources as well.

Q745 Chairman: Can you tell me how they get to know?

Dr Goy: How they get to know about our study?

Q746 Chairman: No, how do they know that somebody has asked for assisted suicide?

Dr Goy: They are sending letters on our behalf to everyone who has contacted them making a serious request for help to go through the process.

Q747 Chairman: It is through their correspondence group, as it were, that you get this information?

Dr Goy: Yes.

Q748 Chairman: Who else can give you such information?

Dr Goy: Although we are never given the names of those who make a request for a lethal prescription, we have a system set up with Barbara. She gives letters of introduction about our study to patients who have expressed an interest to her. We are working with several other hospices in the area, like Legacy, Willamette Falls and other large hospital systems.

Q749 Chairman: Can you help me about this. In order to go through the procedure there needs to be a lapse of time from the first request to the second. Have you had an opportunity to study what happens in that time?

Dr Goy: No, not explicitly.

Q750 Chairman: It is a fortnight, is it not, that has been chosen. I do not know whether there is any scientific basis for that or it is something that has been thought right. I was wondering if there is anything in your study to suggest that a fortnight is a reasonable time and the extent to which the preliminary request is departed from within the fortnight? You have not had a chance to study that as yet?

Dr Goy: Not really and it has not been one of our specific testing hypotheses. We are aware that a good many people do change their minds within

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that interim and it appears to be the case at this point that the single most effective intervention, if you will, for turning people around, to changing their minds about this, is referral to hospice. Once folks are assured that they will have adequate palliative care, attention to pain control and so on, for a significant group of people who had initially made a request, that is sufficient to allow them to say "I will be fine".

Q751 Chairman: The first request may be made without that knowledge?

Dr Goy: Yes.

Q752 Lord Joffe: The Oregon data, as I understand from reading Dr Ganzini's article, do not support the assertion that patients who die by assisted suicide are depressed.

Dr Goy: That is the general feeling, that they may see depression in the sample of people who are requesting it but overall there is some confidence that the people who are seriously clinically depressed are being screened properly and treated rather than being given a prescription. Also, in their interactions with their patients they see other factors that appear to be much more important in terms of driving forces and I am seeing that in my interactions with patients directly as well.

Q753 Lord Joffe: Are there certain common characteristics of patients who persevere with their request?

Dr Goy: Yes. Now you are in our ballpark. That is where our current studies are going and it is really quite fascinating. There do appear to be some lifetime traits of the people who persevere right to the end. Those folks are quite determined. It is incredibly important to them. Their greatest fear and the thing they dread the most is being out of control. When I survey them about all the possible reasons why they may be making this request, they list a lot of things as being important, sometimes feeling depressed is one of them, sometimes pain or fear of pain is an important factor for them, but 100 per cent of the 28 people I have seen have said desire to control the circumstances of death is very important, between one and five of the most important. If I go back and ask "Does any one stand out as the most important?", it is not unanimous but most will say it is the desire to control or the desire to maintain dignity and the categories that fall within that; seemingly unbearable situations where they have to rely on others. That evidence fostered our hypothesis that there may be something going on and most folks said they find being cared for to be intolerable. They have had a lifetime of needing to be responsible and have learned one way or another not to depend on

others but to be self-sufficient, so when it comes to the time to accept care to the extent that they need help with toilet care or changing their clothes, that is anathema to them, it is a line they will not cross.

Q754 Lord Joffe: Moving on from that, in your research have you formed a view on the fact that this legislation tends to destroy trust in doctors by the patients?

Dr Goy: Certainly we not have researched that directly. We have added a trust in physician scale to our current survey that is underway because we are curious about what that relationship is with the medical profession and whether they find they cannot tolerate somebody else being in the position of telling them what to do and whether they can trust those people. I have been surprised how trusting they say they are of their physician. They appear to have fairly robust and good relationships so far. This trend could change after 30 more, just like that, but at this point people are not nearly as adamantly rebellious towards the medical profession as I had anticipated.

Q755 Lord Joffe: What about the family's approach to a patient deciding to adopt this course of assisted dying? Have you got any evidence of pressure being exerted by the family to dissuade the patient?

Dr Goy: I certainly have not, have you seen that?

Ms Glidewell: No, the opposite actually.

Dr Goy: If anything, families will express to me almost unanimously that they are trying to be supportive of their loved one's decision, but they may not personally agree with it. It is very important to them to be part of the support system in the loved one's final days.

Q756 Lord Joffe: Having regard to the experience of the now six or seven years in Oregon, do you feel that the safeguards appear to be working adequately and that the legislation is generally accepted?

Dr Goy: I think it needs more study and some of what we will be able to report on our prospective study will provide exactly that information with greater confidence than I can say now. It looks to be the case that people who are depressed are being caught in the safety net and being treated rather than prescribed (in terms of lethal prescription). Again, we will not be able to convince anyone of that until we have good solid, clean findings and looking at it objectively.

Q757 Lord Joffe: When are these results coming out?

Dr Goy: It is a two year study so we will publish it as quickly as we can after that.

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Q758 Lord Joffe: Is that two years from now?

Dr Goy: We began in May.

Q759 Baroness Finlay of Llandaff: Going back to patients' past experiences, and you said that for them receiving care is anathema, have you been looking at their own experiences of death and dying in people close to them? Is there a difference in their past experiences to the past experiences of those people who are terminally ill but are not requesting?

Dr Goy: I wish our studies were completed because we are asking that right now. We are asking whether one of the reasons that they are making this request is that they have witnessed another bad death. Also, we will be interviewing control patients, people who are terminally ill who have never made a request and we will be comparing them.

Q760 Baroness Finlay of Llandaff: It may be that many other questions will come to the same conclusion. I wanted to talk to you about the relatives. In the way that you were talking, it sounded as if the relatives had guilt at having failed to meet the needs of the person who is making the request.

Dr Goy: I do hear some echoes of that and the place where it hits people the hardest is that there is a huge discrepancy between the patient's perception of burden versus the family's perception. Patients worry about that. That showed up as a very important concern when we asked them for reasons for making this request, worries about being a burden. The families, on the other hand, say "He is never a burden", they hate the word and I have to find ways to rephrase it to try to get a legitimate response. Family members who have learned, accidentally perhaps, that one of the main reasons their loved one requested or took the prescription for that reason do have a difficult time.

Q761 Baroness Finlay of Llandaff: They have the option of not informing all of their family and I wondered what the bereavement outcomes were of those who stumbled upon it as opposed to being informed.

Dr Goy: We wondered that too and that is why we are doing the depression screening. I hate to give you information for the record that is anecdotal so far but it is my observation after interviewing 30 or so families, and this could change after 100, that there are some family members who meet criteria for what we call complicated grief, as opposed to regular garden variety grief, that requires treatment. This is much more serious and resembles in some ways post-traumatic stress disorder. That being said, the people who are suffering from that, without exception to date, are family members whose loved ones desperately wanted a prescription and for one

reason or another were not able to acquire it. They witnessed a death that involved great disappointment on the part of the patient and family members were upset on behalf of the patient. I have to say they probably contact us because they have an agenda: they want our research to record their experience that they are very unhappy with.

Q762 Baroness Finlay of Llandaff: These are the ones who were turned down?

Dr Goy: That for one reason or another failed to meet the criteria.

Ms Glidewell: I can echo that. Some time ago a patient kept asking his wife "Is it 15 days yet? Is it 15 days yet?" and her sadness at watching him trying to hold on long enough for the 15 days and then the 48 hour waiting period, she still grieves that she could not help her husband to achieve his goal before that experience.

Q763 Baroness Finlay of Llandaff: I should declare an interest, I am in palliative medicine myself. In those situations I wonder why the patient is not just letting go of life. I see a lot of people where they just let go of life.

Dr Goy: When you get a chance to read the packet I have provided, you will see examples of patients who made efforts to extend their lives so they could live long enough to acquire the medication and take it. That is the desire for control.

Q764 Baroness Finlay of Llandaff: Can I ask about the relationship with doctors because Kissane has described demoralisation as separate from depression. Are you seeing demoralisation? Is there any correlation between the attitudes of doctors and nurses around the patient and the patient's perception of their future?

Dr Goy: I am probably not equipped to address that. I do see patients who are hopeless and I would equate that as well as I can to demoralisation but we have not used a demoralisation measure. I am not equipped to give you numbers.

Q765 Baroness Finlay of Llandaff: You said that you are doing a survey of doctors as well.

Dr Goy: There has been one conducted and published.

Q766 Baroness Finlay of Llandaff: In a conversation after we had taken evidence this morning from David Hopkins, he said that, at the beginning, he had the feeling that doctors needed to tell the whole story because they were very traumatised by having been involved, but that, in the last year, that is not happening as they have become used to it. I wondered whether you felt that was echoed within your research.

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Dr Goy: Again, anecdotally, yes. This was a monumentally difficult experience for a doctor early on, even considering changing the direction of care from preserving life and extending life to helping someone end it. For many, they have done it maybe for one patient and cannot reconcile that they have done it and they are very uncomfortable with it. To me, that is one of the harder parts about this law, the agonising that occurs for doctors. I think that support is growing within the physician community for them to offer to one another a sense of collegial support. There is nothing formal set up for physicians here.

Q767 Baroness Finlay of Llandaff: The Dutch experience is that often doctors take the next day off because they cannot cope with taking any clinical decisions at all.

Ms Glidewell: There is nothing formal but here at OHSU I will ask a physician who has been involved if they would like to be in touch with other physicians who are willing to have their names known so that they can talk privately. I am not a physician, I talk to them at length but sometimes talking to another physician is important to help them go on. Sometimes they are overwhelmed by the impact of this which is contrary to what they normally do. Informally, yes, but formally would be remarkable.

Q768 Earl of Arran: Do you ever have the case of a patient who, having taken the first slug of that terrifying bottle, suddenly realises he or she has made the most awful mistake and wishes not to go on? Have you had a patient in those circumstances? If those circumstances existed, is there an antidote to the first slug?

Dr Goy: I have not heard that in my experience.

Ms Glidewell: In most cases we are so sure that the patient is absolutely convinced that they are going to take it at the time and they are so energised about it that, frankly, they really go for it. As far as I know, there has not been one patient who has stopped part way. We do not have an antidote but after they have taken the medication the hospice steps back in and will support the patient even if they are somnolent or comatose and not invoke any other treatment to revive the patient.

Dr Goy: That would be a good question to ask the folks at Compassion in Dying because they see almost 90 per cent of requesting Oregonians at one point or another and they have interacted with people who have made this decision.

Q769 Lord Joffe: I want to pick up on one of the questions that Lady Finlay asked and that was on this question of demoralisation. I think you indicated that you had not studied that at length.

There is an article by Professor Malcolm Parker commenting on that article in which he says that the categorisation of demoralisation as a medical diagnosis is a questionable extension of psychiatry's influence. I have seen an article by Dr Ganzini that says exactly the same thing. Are you aware of that?

Dr Goy: Yes, I am aware of that.

Q770 Chairman: When it says "questionable", what does it mean?

Dr Goy: I am afraid this is one where I am not going to be able to speak for her. This has been her arena and I have not been part of it. There is a pretty contested debate about demoralisation and whether it is a separate entity or not.

Q771 Chairman: Can you help me on another aspect. This morning we were told that a certain number of the institutions for the care of sick people in this city do not allow this practice in their institutions. In your interviews with patients, to what extent has their reluctance or their religion or their view, whatever you would like to call it, played a part in their decision?

Dr Goy: The patient's world view or religion playing a part in the decision?

Q772 Chairman: Yes, their religion or other world view, to what extent has that played a part in their decision, so far as you have been able to ascertain?

Dr Goy: These folks who are participating tend to rank religion as fairly unimportant in their lives, although I have taken to tweezing out organised religion from spirituality because many of them will say that spirituality is very important but they cannot tolerate the rules and rigidity of an organised religion. Many of them have no qualms about reconciling their actions with religion. On the other hand, family members sometimes do, particularly Catholic members and, for example, a wife very much wanted to support her husband in his decision but felt a tremendous amount of conflict of interest.

Q773 Chairman: Spirituality, which is a slightly less precise word, could you just say a bit more about that?

Dr Goy: I hate it when they ask me to define it!

Q774 Chairman: I am sorry to be hateful but I just want to get some idea if they have any view of the future beyond the immediate situation of dying. Normally, on the idea that you have to give a full account to people of the treatment you are going to give them, all aspects, this is a particular type of treatment in which your information at least as to what happens afterwards is bound to be somewhat limited. I wonder to what extent that kind of consideration plays a part in it.

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Dr Goy: Typically the people I have interviewed have been extremely self-confident about heading into a great void of nothingness with no recrimination or retribution for making this choice, they are quite comfortable with it. Typically they do not have a concept of heaven or the great beyond.

Q775 Chairman: Or any accountability for life below?

Dr Goy: Correct.

Ms Glidewell: Or redemption in suffering. Most folks do not bring that as an issue, they feel they have free will and it is their God given right to have free will. I have not had one person tell me what they thought about the hereafter, if there is a hereafter, that might be considered, it does not seem to enter the conversation.

Q776 Chairman: I think you are saying that the people who go in for it are people who do not have such a concept, is that right?

Dr Goy: For the most part, although they may have tremendous reverence for life and for the miracle of being on earth and having this chance at life. They do not see the ramification of this placing any bias or impression on their decision.

Q777 Baroness Jay of Paddington: It seems to me that this partly derives from the discussions and evidence we have taken in the UK as well as what we have heard from all of you this morning. It seems to me that one can almost narrowly define the groups of people to whom this is going to be relevant as patients. I was going to make a statement and see if you agree or disagree with it. It is a very small group of people on the whole whose situation, whether objectively or subjectively, is intractable to the normal conventions of the best palliative and hospice care; they tend to be secular in their beliefs about themselves and about the world and they tend to have what I suppose we would call in shorthand A type controlling personalities. Is that fair?

Dr Goy: I would like to have a copy of the transcript so that I can put it in my next paper, it is a very nice summary of what we are seeing so far. In addition, it is likely we are going to be reporting on shaping influences that people have endured in their childhood that have played an important role in their inability to tolerate loss of control. I do not think I should comment more about that, except that so far what we have seen has been unanimous in the patients we have interviewed in terms of patient histories. It is not something that is going to spill over into mass suicide with patient populations, I think there is a certain person who will persevere. If I may just describe a personal story of a woman who was given her prescription and decided she

would take it that night for various reasons, including the fact that she thought she was losing her ability to swallow. They took off to the grocery store to buy something to mix the drug with and the husband was telling me the story and said he finally found her in an aisle where she had a chocolate pudding in one hand and in the other an apple sauce container and she was reading the labels.

Q778 Baroness Jay of Paddington: The sell-by date?

Dr Goy: She was within hours of her death and she was reading the labels because every detail was important to her in her life, including the ingredients of her last meal. That is one of my experiences with the people I have interacted with and I think that is a very good description of how it is a desire for control and that is probably the most important point in the decision making.

Q779 Baroness Hayman: Before you leave the childhood experience, and it is intriguing what you have said, can I ask does it relate to an experience of death or is it something separate from that?

Dr Goy: It has much more to do with developmental experience throughout childhood.

Q780 Lord McColl of Dulwich: Is it not strange that if these are the type A personality people who are so much in control, that they do not just go and commit suicide without having to revert to this?

Dr Goy: Because it is illegal¹.

Q781 Baroness Finlay of Llandaff: Suicide is illegal?

Dr Goy: Yes.

Ms Glidewell: Yes, it is. If you survive you will find yourself in great jeopardy if you are unsuccessful in your suicide.

Dr Goy: That is why it is important to people here that we have this legal option.

Q782 Baroness Finlay of Llandaff: This is the only legal way that people can commit suicide without recrimination?

Dr Goy: Exactly, and only in Oregon. This is the only place where this is an option.

Q783 Baroness Hayman: In the whole of the United States?

Dr Goy: Yes.

Q784 Baroness Finlay of Llandaff: What happens if somebody takes a drug overdose?

Dr Goy: They can be prosecuted. Usually they are not, but they can be.

¹ *Note by witness:* Post hoc addendum: "Suicide is not illegal in the United States. However, because physician-assisted suicide is legal in Oregon, the families of patients who use physician-assisted suicide are eligible for life insurance benefits they might otherwise be denied."

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Ms Glidewell: A lot of fear goes into it. The authorities will talk with a person.

Dr Goy: If it fails they can be prosecuted.

Q785 Chairman: I think our time with you has expired. I am sure that all of us would like to thank you very much indeed for so ably deputising for the

lady with whom you collaborate. You will get a chance to look at the transcript, which I know you would like to get immediately.

Dr Goy: I am sure Dr Ganzini will be happy to answer questions if you wish to contact us later.

Chairman: That may well be a possibility that we will want to take up. Thank you very much indeed.

THURSDAY 9 DECEMBER 2004

Present	Arran, E Finlay of Llandaff, B Hayman, B Jay of Paddington, B	Joffe, L Mackay of Clashfern, L (Chairman) McColl of Dulwich, L
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Memorandum submitted by Ann Jackson, Oregon Hospice Association

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1. INTRODUCTION AND QUALIFICATIONS

1.1 Thank you for inviting me, on behalf of the Hospice Association (OHA), to submit written evidence concerning HL Bill 17: Assisted Dying for the Terminally Ill.

1.2 HA is a statewide, not-for-profit, public benefit membership organization, incorporated under US Internal Revenue Code 501(c)(3). OHA is dedicated to promoting and ensuring access to high quality hospice and comfort care for all Oregonians. OHA is recognized as an accrediting body for hospices and keeps the Hospice Registry on behalf of the State of Oregon. All Oregonians have access to hospice and comfort care.

1.3 OHA established a multi-disciplinary, multi-agency task force in 1990 that studied assisted suicide from a balanced perspective. The task force issued its report to the membership in 1993. OHA and Oregon Health Decisions (OHD), a task force member, convened simultaneous statewide community meetings via teleconference on 11 August 1994. A guide to voters entitled "Request for Physician-Assisted Death: How Will You Vote?" was a product of the meetings.

1.4 I have directed OHA for 16 years, during which time I've followed efforts to make assisted suicide a legal end of life option in Oregon and elsewhere. I was educated at the George H Atkinson Graduate School of Management at Willamette University and at Portland State University, both in Oregon. I am not a clinician.

1.5 I am a member of the Task Force to Improve Care of Terminally Ill Oregonians, convened in January, 1994, by the Center for Ethics in Health Care at Oregon Health Sciences University (OHSU). The purpose of the task force is to ensure responsible implementation of the ODDA. I authored the chapter on hospice and palliative care in the Guidebook to the ODDA.¹

1.6 I am a co-investigator, with lead investigator Linda Ganzini, research concerning the experience of Oregon's hospices with the ODDA, in partnership with the Portland VA Medical Center, Department of Psychiatry and the School of Nursing at OHSU, and OHA.^{2, 3, 4, 5}

1.7 I am the primary spokesperson for the Oregon Hospice Association and Oregon's hospices about the Death With Dignity Act. I have made presentations about Oregon's experience with assisted suicide throughout the United States. I have also written articles about end of life care in Oregon and edited *Hospice Care: A Physician's Guide*, published in 2004.⁶

2. GOAL

2.1 My goal in writing is to provide the Select Committee with fact- and experience-based information about assisted suicide, primarily from the hospice perspective. Oregon's medical community, including hospice, has taken seriously a responsibility to add data to the void that has existed because, prior to Oregon's Death With Dignity Act (ODDA), assisted suicide has never been practised within the law.

2.2 I am not writing to defend the ODDA or to support the proposed Assisted Dying For the Terminally Ill Bill. Nor am I writing to debate whether either is right or wrong. In Oregon, it no longer matters. The practice is legal in our state and dying Oregonians may and do have both hospice and assisted suicide.

3. PROVISIONS OF ODDA

3.1 Under the provisions of the ODDA, an adult resident of Oregon, with a life expectancy of less than six months, may ask his or her doctor for a prescription for life-ending medication. Three voluntary requests, two oral and one written, must be made within a 15 day waiting period. Two physicians must confirm the diagnosis and prognosis, determine if the patient is capable of making health care decisions, and consider a psychiatric or psychological referral if judgment may be compromised by depression or another mental health condition.

4. HISTORY

4.1 The ODDA was a citizen's initiative that passed in November 1994, by a margin of 51 per cent to 49 per cent. An injunction that kept the Act from going into effect was lifted in October 1997, a few days before voters defeated a legislative repeal referendum by a margin of 60 per cent to 40 per cent. A letter from the US Department of Justice promising prosecution of physicians delayed implementation until April 1998, when then US Attorney General Janet Reno reversed the opinion. US Attorney John Ashcroft reversed Janet Reno's decision in November 2001, at which time a temporary restraining order kept the law in effect. The temporary order was made permanent in April 2002. In June 2004, a panel of the Ninth District Court ruled in favor of Oregon. More recently, in August 2004, Attorney General Ashcroft's request for an en banc hearing of the Court was rejected.

5. END OF LIFE CARE IN OREGON: AN EVALUATION THEN AND NOW

5.1 On 1 April 1998, near the time the law was implemented, the headlines of *The Oregonian*, Oregon's largest newspaper, read "OREGON HAS COMFORTABLE LEAD IN NATION'S END-OF-LIFE CARE". The article described the findings in the first of a series of briefs issued under Community-State Partnerships to Improve End-of-Life Care, a Last Acts program funded by The Robert Wood Johnson Foundation. Last Acts is a national coalition to improve care at the end of life.⁷

5.2 Despite concerns that passage of the ODDA would compromise end of life care in Oregon, an 18 August 2004, article in *Forbes Magazine* identifies Oregon as #2 on the list of "The best places to die."⁸ Both studies cited Oregon's high hospice utilization rates, high home death rates, low hospital death rates, and legal protections for respect of wishes at the end of life, among other things.

6. OREGON DEATH WITH DIGNITY ACT

6.1 Prescription Recipients.

6.1.1 The Oregon Department of Human Services (ODHS), which assumes reporting requirements under the law, revealed that as of 31 December 2003, 171 individuals ingested medication under the ODDA, a rate of $\frac{1}{10}$ of 1 per cent, and far fewer than the 1,000 to 3,000 who were predicted to use the Act annually during the public debates in 1994 and 1997. A total of 265 prescriptions were written. Reporting requirements begin at the time a doctor writes the prescription. During those six years, approximately 180,000 persons died in Oregon.⁹

6.1.2 Research by OHSU's Center for Ethics published on 19 August 2004, in the *Journal of Clinical Ethics* (JCE) uncovered no unreported cases of assisted suicide. The study also confirmed estimates of Oregon's hospices that one of 100 of those who consider a request for assisted suicide and one of 10 who completes a request use medication to hasten death.¹⁰

6.1.3 In many instances, a prescription is not written until a patient intends to use it, accounting for the discrepancy between hospice estimates and state reports. In individual and group discussions about assisted suicide with Oregon's hospice workers, the consensus is that many individuals make a request in preparation for their worst-case scenarios. Once qualified, they are better able to get on with their lives, and most die of natural causes.

6.1.4 The Center for Ethics study also suggested that the rate of assisted suicide in Oregon is lower than in states where the practice is covert, which is consistent with stories I hear when making presentations about Oregon's experience in other states.¹⁰

7. PREDICTED OUTCOMES OF ODDA

7.1 Published research now includes the perspectives of patients with life-threatening illnesses, patient families and caregivers, physicians, hospice nurses and social workers. Those who ingest medication under the ODDA are not more likely to be poor, uneducated, uninsured, or denied access to hospice care and appropriate pain management, as had been predicted.

8. PATIENT CHARACTERISTICS, DEMOGRAPHICS, AND OUTCOMES

8.1 Race, gender and residence.

8.1.1 ODHS matched a cohort of 54,000 individuals who died with similar diseases with those individuals who ingested medication under the ODDA. Individuals in both groups were similar in race, gender, and urban or rural residence. The minority population in Oregon is small (+/- 10 per cent), but Asians are over represented in the group who used assisted suicide. A presumption that hospice was not available lead some to predict that rural Oregonians would more likely use a prescription. In fact, every Oregonian has access to hospice and comfort care, but access to physicians willing to write a prescription may be more limited in rural areas.

8.2 Age.

8.2.1 Individuals who used the Act tended to be younger, with a median age of 70, as reported in the state report. The median age of hospice patients in Oregon is 80.

8.3 Social support.

8.3.1 It was predicted that individuals who lacked social support would be more likely to use medication. ODHS reports that 43 per cent were married as compared to 48 per cent of the cohort. 24 per cent were widowed, as compared to 32 per cent; and 25 per cent were divorced, as compared to 13 per cent. The percentage of those who had never married was < 1 per cent, compared to 4 per cent. However, hospice nurses and social workers rated "lack of support" as the least important reason on a list of 21².

8.4 Education.

8.4.1 Those who used medication were far more likely to be well educated than the matched cohort. 40 per cent had at minimum a college degree (16 or more years of formal education), as compared to 14 per cent in the cohort. Fewer than 5 per cent had not completed high school (12 years), as compared to 25 per cent in the cohort.

8.4.2 Those who consider assisted suicide, but do not use it, tend to be less educated, as revealed in the recent OHSU study. Those who are better educated are more likely to be aware of their options and able to advocate for themselves.

8.5 Health insurance.

8.5.1 Only two of the 171 who used medication did not have health insurance. The lack of insurance or other means to pay for health care was considered a primary predictor for the use of assisted suicide, an inexpensive end of life option.

8.5.2 The Oregon Health Plan for poor Oregonians covers both hospice and assisted suicide. Lack of funding, however, is currently threatening access to the Oregon Health Plan. No one questions the fact that a prolonged terminal illness can impoverish a family. Federal dollars may not be used under a provision of Congress.

8.6 Underlying illness.

8.6.1 Nearly 80 per cent of those who ended their lives under the ODDA were cancer patients. This compares with 65 per cent of cancer patients in the matched cohort. Patients with amyotrophic lateral sclerosis (ALS) were over represented at 8 per cent, compared with fewer than 1 per cent in the cohort. The rate of chronic lower respiratory disease was approximately 2 per cent, compared to 17 per cent. Other diseases made up 8 per cent, compared to 15 per cent in the cohort.

8.6.2 Although conclusions have not been drawn as to why some diseases are more or less represented than others, Oregon's hospices are looking at ways they can better meet needs of those with diseases that are over represented.

8.6.3 Arguments against legalized assisted suicide often demand that palliative care needs of the majority must be met first, which is of little comfort to those in the minority.

9 HOSPICE AND ODDA

9.1 Hospice participation.

9.1.1 89 per cent of those who ingested medication to end their lives were hospice patients, 93 per cent in 2003. All were offered hospice care. OHA is taking steps now to correct concerns and perceptions that caused some to reject hospice. We estimate that nearly 50 per cent of Oregonians died in hospice care in 2003, a rate that is among the highest in the nation.

9.1.2 Although hospice is viewed as an alternative to assisted suicide, no Oregon hospice will turn a patient away because he or she is interested in exercising their rights under the ODDA. Oregon hospices respect a patient's right to choose from among all legal end-of-life options, but they are unanimous in their conviction that a patient should not choose assisted suicide to manage a symptom that can be controlled in a less invasive way.

9.1.3 Hospice policies differ most in whether hospice personnel may be present at the time a patient ingests medication. Some hospices that oppose assisted suicide because of religious affiliations require employees to leave the premises, but remain available to support family members and other loved ones.^{11,12}

9.2 Hospice workers' perspective is important.

9.2.1 They visit patients and family caregivers often in last weeks of life.

9.2.2 They can compare hospice patients who hasten death with other hospice patients.

9.3 Hospice workers' experience is significant.

9.3.1 Median length of stay for hospice patients who use ODDA is consistently high (49 days in 1999).

9.3.2 89 per cent of individuals using ODDA were hospice patients.

9.4 One explanation for the very low rate of assisted suicide in Oregon may be the high quality of care provided by Oregon's hospices.²

10 PATIENT CONCERNS

10.1 Losing autonomy, decreasing ability to enjoy life, and losing dignity are identified as primary reasons for choosing assisted suicide by more than 80 per cent of patients, as described by doctors and caregivers, in the ODHS annual reports. Losing control of bodily functions is identified by 60 per cent. Becoming a burden on the family is identified by 40 per cent as a factor in a decision to use assisted suicide. 20 per cent suggest that pain or the fear of pain is a concern. Financial implications are not a factor.

10.2 Ganzini *et al* asked hospice nurses to rate 21 reasons in order of importance. Controlling the time of death was overwhelmingly identified as the primary reason hospice patients used a prescription to end life. Being ready to die was #2. Dying at home instead of in a hospital was identified at #3. Existence being pointless at #4, losing independence #5, and poor quality of life at #6. Fear of pain was #8.

10.3 The least important reason, at #21, was lack of social support. Depression was #19. Perception of self as a financial drain was listed at #18.

10.4 When hospice nurses were asked to compare ODDA patients with other hospice patients, they described ODDA patients as more likely 77 per cent of the time to fear the loss of control and 66 per cent the loss of independence. They described ODDA patients as more likely to fear pain than other patients only 23 per cent of the time. The fear of burdening their families was more likely 36 per cent of the time.

11 FAMILY CONCERNS

11.1 Hospice nurses were also asked to compare the families of ODDA patients with other families. While burdening families was a significant concern of patients, only 11 per cent of families of those who received prescriptions were identified as more likely than other families to be burdened by patient care. Hospice nurses believed that 43 per cent of ODDA families found more positive meaning in caring for their loved ones than other families. Financial concerns were rated last at only 3 per cent more likely in ODDA families.

12 HOSPICE WORKERS ATTITUDES ABOUT ASSISTED SUICIDE

12.1 Ganzini *et al* asked hospice nurses and social workers who had cared for a patient who requested assisted suicide about their support of the practice.

12.1.1 Attitudes about the ODDA.

12.1.1.1 24 per cent of 122 hospices nurses strongly supported the law; 33 per cent supported it; 11 per cent neither supported nor opposed it; 15 per cent opposed the law; and 17 per cent strongly opposed it.

12.1.1.2 36 per cent of 49 hospice social workers strongly supported the law; 30 per cent supported the law; 10 per cent neither supported nor opposed it; 6 per cent opposed the law; and 6 per cent strongly opposed the law.

12.1.2 Attitudes about requests for assisted suicide.

12.1.2.1 1 per cent of 121 hospice nurses would actively oppose a request; 57 per cent would neither support nor oppose; 42 per cent would actively support a request.

12.1.2.2 No social workers would actively oppose a request for assisted suicide; 46 per cent of 49 would neither support nor oppose; 52 per cent would actively support a request.

13. QUALITY OF LIFE

13.1 Hospice nurses were also asked to rate the quality of life during the last 14 days of individuals who died by assisted suicide. On a scale of 0-10, with 0 a bad death, hospice nurses rated the quality of life at 8.

14. ACTUAL OUTCOMES AND SUMMARY

14.1 The number of individuals who choose assisted suicide in Oregon is very small. It is not disproportionately used by those who are poor; who are minorities; who are uneducated; who do not have insurance; who are fearful of the financial impact of a prolonged illness; or who are depressed.

14.2 Access to hospice or fear of pain are not associated with assisted suicide.

14.3 The decision to use assisted suicide is complex and related to concerns about autonomy; control of bodily functions; and a desire to control timing and circumstances of death.

15 CONCLUSION

15.1 Although not all hospices or their personnel support the ODDA, all are willing to care for patients who make this choice. OHA recommends that all Oregonians who consider assisted suicide be referred to a hospice program for evaluation, if not admission.

15.2 As a laboratory for the states, Oregon is putting every facet of end of life care in the spotlight, openly and honestly. But sometimes published reports out of Oregon are used dishonestly.

15.3 Because we measure the occurrence of pain over time, we know that efforts to improve pain management require constant vigilance. We suspect, however, that the alarmingly high rate of pain in Oregon is lower than in other states.

15.4 Because we measure hospice utilization, we know that hospices are not meeting the needs of some dying Oregonians, and we are beginning to understand why. We know, too, that hospice utilization rates in Oregon are among the five highest in the country.

15.5 Because we know who uses assisted suicide and why, we have learned that accessible and excellent hospice and palliative care cannot always provide the autonomy that is of importance to some Oregonians. But we respect those needs.

15.6 And we are gaining respect for those needs.

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Examination of Witnesses

Witnesses: Ms ANN JACKSON, Executive Director and Chief Executive, Oregon Hospice Association, Ms BARBARA FARMER, Director, Home Care, Ms JENNIFER TRAEGER, Clinical Social Worker, and Mr STEVE SEHM, Medical Social Worker, Hopewell House, examined.

Q786 Chairman: This group was appointed by the House of Lords as a so-called Select Committee chosen to examine and report on Lord Joffe's Bill for introducing into England and Wales the possibility of assisted dying. Since the matters covered by the Bill are quite closely related to some activities and the law that you have in Oregon, we thought it useful to come and see how matters are handled here and what the position is with a view to helping us come to some conclusions, possibly, about the situation in the United Kingdom. In order to help us with that, we would be glad of help from you. We have a shorthand writer with us to take a note of the evidence. The purpose of that is to provide a record which we can use to append to our report when we come to ultimately report. It will then become generally public and available. The purpose of the record is to help us come to conclusions in the light of the factual evidence we receive. Those of you who give evidence will have a chance to review the accuracy of the transcript because although we speak a common language, sometimes our intonations may be slightly different. Mine is different from most others here. The shorthand writer will take it down the best she can but we cannot altogether eliminate the possibility

of a misunderstanding, so you will have an opportunity to review the transcript before we include it in our report. With that introduction, I would like to say that the way we have dealt with the matter so far is within the time limits available to us, if you would like to introduce yourselves and give a description roughly of your position and relevance that you have to our inquiry, perhaps with a short statement of the way you see the position, and then my colleagues will have an opportunity to ask you questions that may be concerning them arising out of what you say.

Ms Jackson: I can start. I am Ann Jackson. Welcome to Oregon. I am very pleased that you are here. I am the Director of the Oregon Hospice Association. I have been in that position since 1988, at which time some kind of legislation that would make assisted suicide legal was beginning to be discussed in our Legislature. One of our legislators had cancer and he had introduced this law several times but it had never got out of committee. I think 1988 was the first time and then in 1989 and 1990, and then we had the other Bills coming through. The reason I am talking about this particular individual so much is ultimately he died in 1993 in hospice care. His wife was Governor

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of the State of Oregon at the time and her staff called us to say that for the first time in the past six years Frank was free of pain. We all thought that was quite disgusting, that anyone should have to wait until they got into hospice care to have their pain managed. It is rather rambling but, in any event, this is one of the things we have been working on in Oregon, trying to make sure that everyone has good hospice and palliative care. The Oregon Hospice Association recognised the debate over assisted suicide as an opportunity for us to teach people about hospice care and palliative care and what they should be able to demand at the end of life and move towards that goal. I became the primary spokesperson for the hospice movement in the State of Oregon at about that time and we became even more formal after 1994 when the law was first passed by the people of Oregon. It was an initiative. I do not think I need to go through any of those things with you, you are quite familiar with those aspects. Then again it went through in 1997. My personal qualifications are that I have been a member of the Task Force to Improve Care for Terminally Ill Oregonians since it was implemented in 1994. I am also a member of the POLST Task Force, Physician Orders for Life-Sustaining Treatment. This was another effort coming out of Oregon to make sure that people's wishes were respected at the end of life. It is important for you to know that I am not a clinician, I am not a doctor or a nurse. I am a lawyer, I have a NVA in not-for-profit management. In some respects that is an advantage because I can speak quite broadly. The Oregon Hospice Association itself is a public benefit organisation, not-for-profit, that represents all of the hospices in the State of Oregon. Membership is voluntary and we provide our services without regard to whether or not they formally join as members. In some respects, we have become a resource for them. There is a different distance, so we can speak for them and we are often called to do that. We have some authority in the State of Oregon in ensuring that laws relating to hospice are followed and we take complaints about hospice care. We are a very small organisation but we do work hard. Hopewell House is part of the Legacy VNA hospice system and they are a member of the Oregon Hospice Association and we work closely with them and all hospices in the State of Oregon. As far as assisted suicide is concerned, our position now is that it no longer matters whether we believe it is right or wrong, it is the law in our state and people who are eligible for hospice and eligible for the Death with Dignity Act are one and the same. No Oregon hospice would turn away someone who wanted to use assisted suicide. We always felt it was very important that no-one should feel alienated by a physician that we might carry, that they would be fearful of coming to us. 93

per cent of individuals who used the Death with Dignity Act in 2003 were hospice patients in Oregon. They can have both, and they do.

Q787 Chairman: Thank you.

Ms Farmer: I am Barbara Farmer. I am the Manager for Legacy VNA Hospice. We are part of the Visiting Nurse Association and we are part of a large Legacy health system, which is for hospitals, and our Legacy Visiting Nurse Association, which is a community homecare, hospice and inclusion organisation. The hospice in particular is based at three sites: one is the Portland site, which covers the Portland Metropolitan area; the McMinnville site, which is about 42-45 miles south-west of Portland; and the Hopewell House centre, where we are today, which is an inpatient facility. I am a nurse by background. I started hospice care in 1984, so I have been doing hospice work for about 20 years. In 1991 I became the manager at the McMinnville site and having been doing it ever since. About six months ago my duties were extended to cover the Portland site and Hopewell House. The other part of my role as far as relating to physician-assisted suicide and physician-aided dying is that we were integrally involved as one of the hospices and we participated with the Oregon Hospice Association round tables when the Bill and the discussions were first starting in our state. We represented and took forward a variety of other staff who participated with several different work groups and several folks from around the community and we came back and I was participatory with several others in developing our policy for Legacy. Legacy is a not-denominational non-for-profit organisation. Our stance that we came to, which is in your folder, and our policy for Legacy Visiting Nurse Association for hospice specifically is in your folder, is that we see ourselves as supporting education, supporting the patient and family decision and choice and supporting their specific right for self-determination. We will neither support nor deny folks' access to information. We participate in the law. We are not active players if someone chooses to initiate the law but we are the conduit for support and emotional care during that time period, if it is the patient's choice. To my left is Steve Sehm, a social worker. I believe that our hospice had the first patient in the State of Oregon who was on our service in McMinnville who chose to utilise physician-assisted suicide. Steve, who is now one of the supervisors for our agency, was the medical social worker involved in that case at that time.

Q788 Chairman: Thank you very much. If it is convenient for you, my colleagues will want to ask some questions. Before we go into any further detail, can I ask about the funding arrangements for both

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the Association and the particular hospice that you represent?

Ms Farmer: We are not-for-profit. About 70-80 per cent of our reimbursement is provided through Medicare reimbursement, the federal Medicare benefit.

Q789 Chairman: That is in respect of people to whom you give services?

Ms Farmer: Correct.

Q790 Chairman: Medicare reimburse you.

Ms Jackson: Yes. The other 20-30 per cent are folks who are either supported by the state through our Medicaid, Oregon Health Plan system, private insurance or personal/private self-pay. In addition to that, we do fund raise and we have a foundation set up to provide care. We aspire to the National Hospice and Palliative Care Organisation goals not to decline any hospice services based on inability to pay. We have our foundation services set up to be able to provide services to those folks.

Q791 Chairman: You mentioned Legacy health system, I wonder if that has anything to do with receiving money from people on their death by virtue of legacies, or is that just a coincidence?

Ms Farmer: That is just a coincidence. As far as I know it is just a coincidence.

Q792 Chairman: Thank you.

Ms Jackson: The Oregon Hospice Association is primarily funded by the public. 11 per cent of our funding comes from membership dues so that we are able to maintain our arms' length distance for our members. Our first responsibility is to the public and the public is primarily who funds us. We have a few grants for some programmes but most of it comes from donations.

Q793 Baroness Jay of Paddington: This is a general question and I do not know to whom it is best addressed, either Barbara or Ann. In the United Kingdom there is still what I would call a tension between those people who think there is some way forward on what we are generally calling Lord Joffe's Bill or the way that you have gone in relation to assisted suicide and the hospice movement, which is very strong in Great Britain, we have a very good hospice movement and a very strong tradition of that. Yet, one of the things that you volunteered in your remarks was that no-one who came into hospice care would in any way be denied the opportunity to use the death with dignity provisions. How was this resolved in terms of the aims and ambitions of the hospice care approach and the death with dignity approach?

Ms Jackson: The Oregon Hospice Association began a task force in 1991 looking at all of the aspects of assisted suicide. We looked at it from economic considerations, from ethical considerations, and the chairs of that particular task force, one was opposed, one was tolerant of the practice, and we issued a report in 1993. As I said, we were very concerned about alienating any part of the group and we did not want to pit hospice against assisted suicide. We knew that at least 50 per cent of people were on one side or the other and we did not want anyone to believe that they would have to forego the kind of care that hospice has to offer because they wanted to use this particular option. It was a very wise decision on our part. Very few Oregonians use the Death with Dignity Act. Hospice has been offered as the primary explanation for that. People do not need to use assisted suicide because they are in pain or because their needs are not being met in other ways, because there is always the hospice, there is a hospice that is set up in every area. Oregon has hospice throughout the state. We cover the State of Oregon with more hospice and palliative care than any other state in the country. Every Oregonian, in even the smallest community, has access to hospice care. We have one county that has 10,000 square miles and maybe 7,000 people and Medicare hospice funding is available for them. In many respects hospices feel that if anyone should use this law because they are in pain then that would mean that we were not doing our job, we would have failed that person, so no-one has. Pain has been an issue that has been brought up as a reason, the fear of pain by people who have used it, but no-one has used it because they were in pain. Incidentally, in your packs I did include the Medicare hospice pack that talks about the Medicare hospice benefit that most of our hospice benefits are based on.

Q794 Chairman: The hospice provides care for people using the option but the actual physicians who are involved in assisting are not members of the hospice, is that right?

Ms Jackson: Ordinarily it is going to be the attending physician of a patient who is going to write the prescription. There are approximately 50 hospices in the State of Oregon and different hospices have different policies as to how their employees can be directly involved. Most of them would not allow the medical director of the hospice programme to be the one who writes the prescription. Some of them would allow that individual to do the consultation. It varies. The policies have evolved over time in the past six or seven years as we have seen what we thought might happen and attempted to anticipate every one of the issues and prevent them from occurring. In some ways they have changed a little bit in practice. The hospices are involved in different ways. It is the

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physician who has the responsibility for writing the prescription. It is the hospice generally who has the responsibility for caring for the patient and making sure their psychosocial needs, their physical needs and their practical needs are being addressed.

Ms Farmer: If the person that we encounter is wishing information and wishing their individual attending physician to participate and they are opposed, either by their organisation or personally, often we have advised them to work with Compassion in Dying, which is an agency in the State of Oregon that helps facilitate communication.

Q795 Baroness Jay of Paddington: There is no conflict or problem for you as an administrator to the hospice in recommending Compassion in Dying, is that right?

Ms Farmer: Not at all.

Ms Jackson: Early on there was an issue and the Oregon Hospice Association was another agency that accepted requests about assisted suicide. Some of the hospitals, some of the agencies, did not want their employees to have a direct connection or communication with an advocacy organisation, such as Compassion in Dying, so they went through our organisation instead.

Q796 Earl of Arran: After a patient has died through assisted suicide, to what extent are you able to help his or her family with counselling and aftercare? Is it your responsibility or does it go elsewhere?

Ms Jackson: The hospice provides that care up to a year or so following the patient's death. One of the practices that has been occurring is some hospices allow their employees to be present at the time the patient ingests the medication and some do not, but in every single one of them, once the patient has taken the medication, the hospice can move right back in to provide support for the family.

Q797 Earl of Arran: In their home?

Ms Jackson: In their home, wherever it occurs. Hospice in the United States is provided primarily in the patient's home, especially in Oregon. Two per cent of our patients die at an inpatient facility or in hospital, so it is a very small number. The social workers are involved in that and bereavement counsellors are available.

Q798 Chairman: These are social workers of the hospice?

Ms Jackson: Yes.

Q799 Chairman: Is there a state social worker service as well?

Mr Sehm: Publicly funded, do you mean?

Q800 Chairman: Yes.

Mr Sehm: No.

Ms Traeger: Not specifically for bereavement. There are state social workers who deal with other kinds of practical aid matters, like housing and food stamps and things like that, but not specifically for bereavement counselling.

Q801 Chairman: I see. But there is a state social service that provides for some matters?

Ms Traeger: Yes.

Q802 Chairman: Not provided by the hospice?

Ms Traeger: That is right.

Ms Jackson: Hospices are providing a lot of the medical kinds of social work, psychosocial needs, looking at patients who might have a mental condition, like depression, monitoring those maladies and making sure that they are addressed.

Q803 Baroness Finlay of Llandaff: Could you just clarify for us exactly what hospice at home means in terms of the number of hours of hands-on nursing care in the home people are entitled to and for how long?

Ms Farmer: We receive folks into the programme if they are deemed certifiably as terminally ill within a six month time frame or less. As long as they meet that criterion we will provide care to them for as long as it takes. It can be beyond that six months until the time of their death and then we follow up with their family. A lot of folks do not live six months, they come to us for a very short time frame. In a home hospice programme, we work very closely with the patient and the family in identifying what their needs are, assisting them in identifying what their needs are, and they are able to pick and choose the services that we have and we match our services available from registered nursing to social workers to personal care volunteers, all the different gamut of services that we provide. Our services are intermittent but we are available to them 24 hours a day, seven days a week, when they can call and we will visit whenever they need us to. We have routine scheduled visits that are based on the needs of the individual. For instance, if a person is having some active symptom management or pain management issues, nausea or other medical needs, the nurse will go two or three times a week on average. They may go daily or multiple times a day or they may stay right at the bedside if they frequently require nursing assessment. If someone is fairly functional and doing pretty well, they may only check in about once every two weeks or so and maybe with a phone call but that changes and evolves each day as time goes on. All of the disciplines and services

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we have to provide are set up in that same way. It is very specifically geared to that particular patient and family and what their individual needs are.

Q804 Baroness Finlay of Llandaff: So if a patient required 24 hour nursing at home with a registered nurse you can provide it?

Ms Farmer: That is one of the avenues that some would take. We would encourage them to go into an inpatient unit. We do not have all of the support staff to be able to provide all of our patients with 24 hour round the clock care at their bedside. We can do it in short snippets or we have agencies that we work with that can provide the 24 hour care. For the most part, in most of the hospices in our particular area we do not have the volume of nursing staff to be able to do that at any given time for all of our patients, so we encourage them to be inpatients at that stage.

Q805 Baroness Finlay of Llandaff: Do you have any patients who enrol in hospice because they want to have physician-assisted suicide and see that as a necessary step in the way of obtaining it?

Ms Traeger: I have had that experience. One of the requirements is that the physician has to say that you have that six month prognosis, so by virtue of being a hospice patient you have met those criteria. Often physicians will encourage that hospice support as well just to make sure that all of their needs are being met and that the person is not choosing aided dying for some other reason.

Ms Jackson: In the more rural areas of the state where hospitals are smaller they tend to use the continuous home care benefit that is offered by most insurance companies, in which case it is primarily nursing care. The nurse will go into the home round the clock for a few days at a time. There are alternatives to inpatient care. In the Portland area we have more inpatient facilities but sometimes the patient does not want to leave their home.

Q806 Baroness Finlay of Llandaff: I was just wondering with the patients who are enrolled as a gateway, whether you notice a difference in trying to provide support to them. Do they want support as much as the others or are they harder to support?

Ms Traeger: That is an interesting question. I would just be giving you my anecdotal experience. My experience has been that often these are people who are very clear about what they want and do not want and may have strong support around them and do not necessarily feel that they need the whole hospice team coming in. I would not say that they are more difficult to support, just that they have very clear ideas about how they want their life and their death to be. Often it seems to be more about an independent

streak than some kind of suffering that has happened necessarily.

Ms Jackson: I have provided you with hand-outs of some presentations that I have made and they talk about some of those issues. Also, I have the data report from the State of Oregon that profiles what people look like who die in hospice care in the state that I can give to you at some point. I do not want to overload you with paper. There are some slides. The primary reason that people use the Death with Dignity Act is for reasons of autonomy, people trying to maintain their dignity because they are losing control of their body. The other pain issues, most of the issues that we are especially good at taking care of, are not the reasons that people who use the Death with Dignity Act actually use. We estimate that only one out of 100 individuals who ask for a prescription, who seriously ask for it, actually use it. The data that you get from the state, which is included in the hand-out, indicates that approximately 275 people received a prescription and most people who qualify for a prescription never get one at all. The hospice will often describe to me a phenomenon that on day one they make the request and on day 15 they qualify and, now they have a plan for their worst case scenario, they can tuck it away in their pockets and get on with their lives. They are not using assisted suicide because they need it for the usual medical kinds of reasons, they are using it because they tend to be people who have always controlled the circumstances of their lives and they prefer to control their death in the same way.

Q807 Lord Joffe: In any way has the Oregon Death with Dignity Act and the Act that has followed adversely affected the hospice movement?

Ms Jackson: No. Hospice is growing throughout the nation, there is no question about that. One of the unique things about Oregon is that we count, so we will have data that other states will not have very often. We are always trying to establish benchmarks and determine where we are. You have a hand-out in that pack that shows how hospice has grown. When I started this job in 1988 2,000 people used hospice in the State of Oregon and we estimate this was up to 15,000 in 2003, which is 50 per cent of all of those who die in the State of Oregon. The only states that are ahead of us are states like Florida and Arizona where they have very, very large populations of retired people and the services tend to go where those people are. In Oregon we have worked hard to make sure that every Oregonian has access to hospice care and the Oregon Hospice Association has been one of the groups that has worked at doing that. We have had grants to make sure that even the smallest community has access to hospice. We have continued to grow. We are still very high. Oregon has been identified

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twice as the best place to die in the United States. The first one occurred in 1988, the Robert Wood Johnson Foundation, and on 1 April, and I thought it was an April Fool's joke, I opened my newspaper to see "Oregon leader in end of life care". There were a number of reasons for doing that. Our hospice utilisation is very high, hospice access is very high, palliative care is very high. We were the first state to offer palliative care teams, for instance. Our respect for wishes is very high. Oregonians have Advance Directives and we respect them. A support study that was done in the mid-1990s revealed that what people said they wanted in their Advance Directives bore no correlation to what they wanted. In Oregon that is not true. 85 per cent of care givers, people in the study in 1997, believed that their loved one's wishes were respected. When the POLST was in place wishes were respected virtually 100 per cent of the time. Morphine consumption in Oregon, in the United States, is a crude indicator of physicians' willingness to prescribe strong medication for pain and Oregon has been the leader in that area for many years. We were the leader before the Death with Dignity Act was passed and we are still the leader. There is a slide in there which compares that. Part of that is because of the restrictive laws that get in the way of doctors prescribing, they have to jump through too many hoops, so there are problems. In some respects, people have felt that the Death with Dignity Act is a step down a slippery slope but I am not too sure, I think that Oregon was already the leader and it may have been almost the logical next step moving into that. When I have been in other states where they have not had the kind of care that Oregon has to offer as far as palliative care, they have felt that they are putting the cart before the horse. There is no question that it has been a catalyst. People who ask for a prescription, and they can do it openly, are taken very seriously. The average length of stay in hospice care in Oregon, or the median length, is 16 days and this is terrible. The median length of stay for people who have asked for prescriptions to end their life is 49 days. They are the ones who tend to talk about what their needs are and to put it on the table. There is no question that people are reluctant to talk about the end of life. I do a presentation called Straight Talk and of everyone who is diagnosed with a life threatening illness I would ask them what is the first thing that crosses their mind when they are given the diagnosis of cancer and it is "No, I am not dying from this disease" and yet dying from that disease is not something that someone brings up early. Having the conversation makes a huge difference and I think that is one of the things we do best in Oregon.

Ms Farmer: For our particular hospice, both in the Portland area and McMinnville, when the Act first came into place, we saw a huge escalation, we literally

doubled within a month. It was two-fold. The McMinnville area is a little bit more of a religious, conservative population and the Portland area is a little bit more liberal in their thinking, so that is the theory or the agreement. In the McMinnville area what we saw were for the folks who were relatively opposed it was an opportunity for us to do education about what hospice could provide, the amount of support to help manage pain and symptoms so that people do not feel that they have to suffer or end their life because they do not feel they are being taken care of. The other thing that happened was that as the physicians were being asked as the topic came up, they were more willing to refer to the hospice because we were more comfortable with the language and we could share the information. We had worked on work groups and the individual physicians had not and could not really speak to those things. For the more liberal folks, as Steve said earlier, it acted as a segue into hospice care and almost all of the physicians, when someone was deemed terminally ill, remembered to refer people to hospice at that time. We saw a significant escalation and opportunity for education and information sharing.

Q808 Lord Joffe: Apropos that, I think it was stated that there were a number of nurses and social workers who opposed the legislation but when it came into force did this opposition affect the smooth running of the hospices?

Ms Farmer: You bet it did. We had several round tables even within our hospice organisation from agency to agency, and within our teams, and this was where our staff became very intimately involved. We had numerous, numerous sessions having people talk about their beliefs and values, political things that came up as political hot potatoes, so to speak. That was where we really broke up the task force into work groups to work on a policy and part of our policy does contain a provision that if you are comfortable with the idea of supporting your patient, you can continue to support them and participate within the actions of the law, or you can choose to step back and someone else from the hospice team will step in for that particular patient and supporting that family.

Q809 Lord Joffe: At the moment it works well, does it?

Ms Farmer: At the moment it works very well.

Ms Jackson: Also, we do other things. I was one of the co-investigators and Linda Ganzini was the lead investigator on this and we looked at hospice social workers' attitudes and nurses' attitudes and more recently we have been looking at chaplains' attitudes. There is a difference in how they perceive this. Most of them now support the Death with Dignity Act but there is a significant number, and I think it is less than

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50 per cent, who do not approve of it but, nevertheless, out of that group only one of them would have refused to take care of the patient who was going to use the Death with Dignity Act. Hospice personnel are always asked to set aside their own needs to meet the needs of their patients. This was a different thing and it took a little longer to be able to say "That is true", but now they are able to do that. The goal for some of them is, "We are going to make sure that patient is not using this for a reason that we can fix". Very often the question that comes up about assisted suicide is a patient has jumped to a conclusion as to why they think this is the answer they need although it is not addressing the right problem, so there is that shift. Most people do not use it. Most people only ask about it and we are willing to entertain that and listen to that when a person contacts us and the hospice person listens to that. It is not usually about assisted suicide, it is usually about something else.

Q810 Lord Joffe: I noticed in your written submission that you talked about the predictions made by opponents of the legislation and what has emerged. Do you think you could tell us a bit about those predictions and what has actually happened?

Ms Jackson: I have also included a hand-out on this. For instance, it was predicted that people who were uneducated would be more likely to use the Death with Dignity Act but, in fact, the opposite is true, which may be showing a different side. People who have a college degree and more are more likely to use the Death with Dignity Act, probably because they have better access to the information. Most Oregonians have a high school education and one of the hand-outs has a comparison between those individuals. It was predicted that people who were minorities would be more likely to use the Death with Dignity Act. If you look at the demographics, there is a slide that compares people's place of residence, their race and their sex. It was predicted that more males would use it but that did not occur, the two groups are very, very similar. Oregon does not have a large percentage of minorities here, it is probably ranging now at ten to 15 per cent. All of the minorities who have used it have been of Asian descent. It was predicted that people who did not have insurance, who did not have the means to have access to hospice or palliative care, would be more likely to use this. There have been two individuals who did not have insurance in the six years out of that 171. Financial implications are not an issue. As Barbara said, Oregon's hospices try to provide care without regard to a patient's ability to pay. The Oregon Health Plan has made it unnecessary for people to not have income. Hospices can identify people who are eligible for the Oregon Health Plan

on admission so that they are immediately eligible for state support. There are issues with the economic situation in our Legislature now, and I am not sure whether that is going to continue, but I know that hospices are going to make every effort they can to make sure that no-one is denied access to hospice care. It was predicted that people who were depressed would be more likely to use it. Hospice nurses and social workers' studies ranked reasons for using the Act between one and 21 and depression ranked number 19 in the reasons. People who are clinically depressed just do not have the get-up and go to be able to jump through the hoops that they are required to do this; people who are clinically depressed can hardly get out of bed in the morning. There are people who may have signs of depression but that does not mean that their ability to make decisions about their health care is impaired. I talked about financial implications and that was ranked number 20 on that list. Pain was also an issue and pain is not ranked. The fear of pain is ranked at six or eight, but having pain is not an issue. There are many, many things going along here and none of these things have happened. It was also predicted that people would move to Oregon, that there would be droves of people coming to Oregon to take advantage of this opportunity to die but the fact is people want to live. This is not one of those issues and we have not seen that. Our residency requirement means people are required to be a resident, however they only need to provide evidence of residency. This was one of the things the Oregon Hospice Association were opposed to, although we did not fight hard, upgrades in the law that would have made it more difficult if people had to do more things to prove their residency. What we see is that when people are dying they often come home to die, or go to a favourite place to die. We did not want to put any barriers to having access to hospice care by residency requirements that might create barriers for other populations as well, but it is not something that we have seen.

Ms Farmer: The only other one that I can think of is they felt that it would get out of hand where it would not be utilised by folks who were truly terminally ill, it would be used as a euthanasia measure by folks who were chronically ill or disabled folks.

Ms Jackson: How could you predict when somebody had a life expectancy of six months or less? When you see this median length of stay of 16 days or less and when they are eligible they have a life expectancy of 183 days, maybe it is erring on the other end, not on too soon. People can leave hospice or if they hate it they can quit, if they get better they get kicked out, and some people do get better under hospice care. For the most part, people who get into hospice are going to die.

Q811 Baroness Jay of Paddington: Just on that six month point, this is something that is quite controversial in the UK. When we have taken

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evidence from physicians they have been very wary about the idea that you can somehow write into a statute or a regulation, or whatever, the concept that only people with a six month diagnosis are eligible. You may not be the right people to answer this, although I am sure you know. On the Medicare hospice benefits, that is a federal document, is it not?
Ms Jackson: Yes.

Q812 Baroness Jay of Paddington: The federal document specifies a particular financially driven regulation.

Ms Jackson: There is no limit.

Q813 Baroness Jay of Paddington: What I am asking is the people who drew up this programme, who may not be enthusiastic about the way in which it is being used in Oregon in terms of the way in which the six month diagnosis may be used, are nonetheless prepared to sign up to the fact that it is a concept that is legitimate.

Ms Jackson: There has been much research into this and how easy it is to predict life expectancy. Mostly people do err on the side of life, which is one of the reasons why people are referred so very late. I have given you a book called *Hospice Care. A Physician's Guide* and in that there are local coverage determinations and they cover a whole series of diseases and identify certain things within those diseases that would indicate that an individual is entering into that six month prediction. Also, there are several letters in there from the Federal Government that were very alarmed because of this very short length of stay. What happened was in the mid-1990s there were two instances where patients had been on hospice care for a number of years. One of them was in Puerto Rico and out of the goodness of their hearts the people in Puerto Rico were referring people to hospice care because there were no other support systems in the country for people who were chronically ill or very ill, so they were in hospice for a long period of time. The other was in New York City. There was a chilling impact on both sides, on the side of doctors and on the side of hospices, that they were going to make sure that these individuals had a life expectancy of six months rather than to use their best judgment, and this translated into the fact that many people did not have access to the Medicare Hospice Benefit or any other hospice benefit which was a great disservice to these people.

Q814 Chairman: You mentioned that for those who had requested assisted dying, the median length of stay in the hospice was 49 days, is that right?

Ms Jackson: Correct.

Q815 Chairman: Is that people who got a prescription?

Ms Jackson: This is people who got a prescription. There is a gap in the United States. Doctors wait until their patients indicate that they are ready to hear bad news or they ask specifically, "What is my condition?" On the other hand, patients assume that their doctor is going to tell them what they need to know when they need to know it. There was a talk on the Bill Moyer's programme on the Oregon Public Broadcasting System nationally and one of the palliative care specialists stepped out of the room after they had been having a discussion with a family member and they were going round and round about this and you know that they really wanted to talk about the fact that their husband was dying and it was the doctor and her colleague who were talking about this outside the hospital room. This just threw me for a loop. Why was that doctor not in there saying "You know, Mr so and so, you are not going to get better, I think you should go into hospice care or something like this"? People are trying to be sensitive, they are trying not to take away hope, but what happens is there is a false hope. Many times, the people who we see who come in hospice in the last week or last couple of weeks are very, very sick because they have probably been over-treated, getting treatment that was not doing them any good, radiation, chemotherapy, that has caused them even more difficulty. I do not think that you have so much of that in the United Kingdom as we do here, that they will continue to treat and treat.

Q816 Chairman: I think there are legal reasons, perhaps, why doctors continue treatment in the United States.

Ms Jackson: Yes, there are legal reasons. It is interesting that I will hear a doctor say that the patient was demanding another round of chemotherapy but when the doctor says "We need to look at hospice care. We are going to discontinue this treatment", and the patient and the family say "No", I think they are saying "No, I do not want to die", rather than "No, do not give up on me". I think it is not fair and it is not ethical to continue prescribing because I think what the patient hears at that time is that the doctor thinks there is still a chance or he or she would never have prescribed another round of treatment because, "It is a burden for me to get out of bed every day, it is a burden to get to the doctor's office to have this done".

Q817 Chairman: If I have understood right, it is a condition of entering the hospice system in Oregon, and perhaps in the United States generally, that death is expected within six months?

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Ms Jackson: Yes.

Q818 Chairman: But if the six month period expires and you have already been in, you continue?

Ms Jackson: You continue. You are certificated at a period after 90 days under Medicare when the doctor and the medical director of the hospice review the patient's case to determine whether or not this patient still has a life expectancy of six months or less, and after 60 days they do it again, after 60 days, after 60 days, after 60 days, so there is an unlimited number of periods. The other thing that they need to do before they come into hospice is to agree the kind of care that they are getting in hospice care is comfort care, palliative care, so they are waiving their right to treatment for a cure.

Q819 Chairman: Any curative treatment, yes. You said the situation so far as requesting assisted dying goes has financial implications. I got the impression from some earlier evidence that some people at least have to pay for their medication that is used in assisted dying, is that right?

Ms Jackson: Right. It is not covered. No federal dollars can be used to pay for the drugs or for anything for assisted suicide. The State of Oregon, under the Oregon Health Plan, will buy the medications but they have to be segregated dollars so when the Federal Government comes in to look at any federal matching funds they can see that this money was not used. The drugs are very inexpensive.

Q820 Chairman: Inexpensive?

Ms Jackson: Inexpensive. The drugs are very inexpensive to accomplish assisted suicide. I have not heard of it being a burden but, then again, you are looking at someone who may have more funds. There were only two people who did not have insurance. It did not address whether or not those were people who had so many dollars that they did not need to have insurance, they may have had plenty of resources available in their families.

Q821 Chairman: Is it your impression that people who are asking for assisted suicide, generally speaking, are people who have college degrees and the like and the reason is that they are better informed than the ethnic minorities or the poorer people and that is the reason why the poorer people are not getting the information that is necessary for them to initiate requests for assisted dying? Is that your impression?

Ms Jackson: I do not know that I would go that far but we do have six years of data that we have been studying very carefully and this is one of the questions that we will look at in future research, if

there is this kind of bias that is going on and lack of information.

Q822 Chairman: In respect of poverty and in respect of minority?

Ms Jackson: The very poor in Oregon have access to the Oregon Health Plan, so that is not creating a barrier. The biggest issue when I am talking about whether financial implications were a reason for why people would use this is the fact that prolonged terminal illness can devastate a family, bankrupt them, use up all of their resources. There are some people in the United States who are not insured, we do not have a national health system. Oregon has tried very hard to close that gap. The Oregon Health Plan was not a programme when it was first envisioned that was only for the poor people, it was a programme of universal health care so that we made sure that those people who were working whose employers do not provide them with health care plans would have access. That gap has been growing a little bigger.

Q823 Baroness Hayman: If financial cost is not a disincentive, going back to this issue of access and information, knowledge, about the availability of assisted dying, do you have any sense of the level of understanding of the provisions of the Act amongst the general hospice population?

Ms Jackson: I do many, many presentations about this issue and about end of life care in Oregon. When I first started doing these, when I was going out of state I would provide a hand-out similar to what I have given you. Now I would give the same hand-out in the State of Oregon as well. Rarely have I met anyone in the State who is not aware that we have this kind of a law. I cannot remember anyone who was ignorant of the law itself. Rarely have I met anyone who understood the provisions of the law, understood that they have a 15 day waiting period or there are the witness requests and these other kinds of things.

Q824 Baroness Hayman: In a way that does not matter because once you have made the request then the people here are quite capable of explaining it. It is the basic parameters and the basic availability.

Ms Jackson: They understand that there is hospice, they understand that there is the Oregon Death with Dignity Act. Very early on, there were a number of cases where somebody would call and say, "Ann, we have a patient who has decided they want their prescription today, they did not know there was a 15 day waiting period" and this was very devastating for those people who did not understand the provisions of the law.

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Q825 Chairman: They might have left it over. Thinking that they could ask for it at any time, they might have left it over.

Ms Jackson: I do try to make sure that I convey that information.

Q826 Chairman: You did say that poorer people, generally speaking, have not taken up the death with dignity option to quite the same extent as the others, did you not?

Ms Jackson: I do not think that is necessarily true. I would say that if you are over the age of 65 you have access to Medicare Hospice Benefit, so you also have access to care. When you are looking at the population that is younger there is less likelihood that they are going to be using the Death with Dignity Act anyway, although the median age of people in Oregon who are in hospice is 83/84, I think, and I have that information here, whereas the median range of people who use the Death with Dignity Act is in the early 70s, so there is some difference there.

Q827 Baroness Finlay of Llandaff: Could I ask what the impact is on staff? In palliative care provision one is trying to help patients have the maximum quality of life for as long as that life is there until they die naturally of their disease, but here the patient is effectively opting out of that because they want to foreshorten their life. I wonder what the impact is on those staff who have been looking after them and trying to find aspects of quality of their life. Am I right that the rest of you are involved in clinical?

Ms Farmer: Yes. One of the things that we have seen that Ann alluded to is often when people have chosen or requested a prescription, they get it and do not utilise it and often we do not know if they are going to use it or not. Care is provided unconditionally. I can speak for our particular hospice, that we really aspire to supporting every individual and every family and support their needs and goals to the nth degree. If someone is very connected to the idea and have gone through the steps and are within that range, I honestly feel that most of our staff are supporting them with it, because it is their choice, it is their control. That is what most of our patients tell us: "I just want it to be my choice. I want to know when I am going to die, or at least have control of that".

Ms Traeger: My personal experience, and what I hear from my colleagues, is that it is a unique kind of stressor and while intellectually and professionally I support people's choice, it is a very different experience from what we usually have with our patients. Personally, I think there is a lot that we do not know about what the impact is for families in terms of bereavement outcomes. We just do not have enough people to know. It has been really important for our staff to be supportive of one another and to

have avenues to work through that experience of what it is like to have someone choose the moment of their death.

Q828 Baroness Finlay of Llandaff: Are there hospice groups who say, "We do not have any part in this"?

Ms Traeger: None that would discharge a patient, but there are some that will not allow staff to really participate even in terms of discussing the issue with patients and families. That is not our policy.

Ms Jackson: It used to be more so early on when the policies were addressed, that hospices would not take part in it. Ironically, one of the first cases that occurred when the hospice was not aware that the patient was going to do this changed the hospice's attitude. They did want to be part of the discussion and it was far worse for them not to know what was going on than it was for them to watch their patient die.

Q829 Baroness Finlay of Llandaff: Was this the Kate Cheney case?

Ms Jackson: No. I think in the Kate Cheney case the hospice was quite aware. The hospice was very supportive of that. It was a different one.

Q830 Baroness Finlay of Llandaff: Going back to this six months, there are some patients whose prognosis is longer than six months but their lives are hell, they may have been multiply bereaved, they have chronic disease with no good outlook, they are poor, they can see absolutely no future for themselves and feel they would be better off dead and the world would be better off without them there, and that may be a very rational suicide. What happens to those patients in terms of being supported in their despair because it sounds as if, by law, you cannot be involved in providing them with any support?

Ms Jackson: There are palliative care programmes being developed through the state and there is nothing in Oregon's law that would prevent the hospice programme from doing that. What we saw, and I included some data on this as well, was that as we were doing the study with the hospice nurses and social workers, and talking with physicians about this, we heard about patients who were deliberately stopping eating and drinking for the purpose of hastening their death. One of the first was a woman who had very severe arthritis and her pain was managed but she was not able to do the things she had done before, she was not able to walk any more, she was not able to do the things that gave her life meaning, she was done living. I was called because she had decided that she was not going to eat any more and her daughter called and said "I know she is not eligible for hospice care because she is not terminally ill", and I pointed out that if she was not

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eating or drinking she was terminally ill and, yes, she should be eligible for hospice care. The hospices have reported on twice as many individuals who have stopped eating and drinking, not because their bodies were no longer able to tolerate food but for the purpose of hastening their death. That was another study that we did that you should have copies of. That was published in the *New England Journal of Medicine*. There is all kinds of suffering that people have. Again, in Oregon you are more likely to have these kinds of conversations because we have put this on table.

Q831 Lord McColl of Dulwich: If the Federal Government overturns this Oregon Death with Dignity Act, what do you think you will do?

Ms Jackson: We have not really talked about that particularly. I think that it is rather alarming that as I have been going round the country I have had the feeling that assisted suicide occurs more outside the State of Oregon than it does in it because of that lack of transparency and that it is done under the table. Also, I have been contacted by people who were afraid to go into hospice care because the hospices have fought the proposed legislation in their own communities. When we did the study of people who stopped eating and drinking, before we published it we went to colleagues around the country to see whether or not we should publish anything so very controversial, “You do not need assisted suicide, you can just stop eating and drinking”, what an awful thing to invite people to do, and yet we could see that it was occurring. Also, we could see that it was occurring without medical support and we felt that these people should be able to do this openly so that their doctors, nurses and health care professionals could adequately treat the kinds of symptoms that they had. Our organisation does not take a position on assisted suicide, I want to make that very clear, but these are observations that we have been looking at and we have not drawn any conclusions on this. There are some things that I can look at that look to me like we have an advantage here.

Q832 Baroness Hayman: If someone successfully stops eating and drinking, would they be guilty of the offence of suicide in Oregon?

Ms Jackson: No, they would not. Assisted suicide is against the law in the State of Oregon but these are things that people do of their own accord.

Q833 Baroness Hayman: I am talking about unassisted suicide.

Ms Jackson: No. People have the right to choose not to eat and drink. In Oregon they have the right to withhold treatment and eating and drinking have been considered a form of treatment. They have the right to as much pain relief as they require, which would include medication, as much medication as they determine is appropriate, and a lot of these are people who are terminally ill who are at end of life. They do have those rights in the State of Oregon.

Q834 Lord Joffe: Is there any evidence that the safeguards in the Bill have been, or are being, abused?

Ms Jackson: No. Oregon is a very, very small state and we have hospices all over and they have big mouths! Not really. We do keep confidentiality very carefully, but I think if there were any abuses in the law we would hear about it. The state does an annual report and people have challenged that because they have an incentive to make sure that things go right because it is the state. We have the Oregon Health & Science University, the Oregon Hospice Association, the VA, Portland State University, Oregon State University, various hospitals that are all doing independent research and we are verifying each other's data. I doubt that there have been any abuses, I think we would have heard about it. There have been no calls to 911. There is one issue that perhaps I should bring up that we do talk about and this is the fact that total sedation, palliative sedation, terminal sedation, is legal in the State of Oregon and the POLST also is there. We recommend that every individual who does ingest medication under the assisted suicide law should also have a POLST completed so that if something did go wrong they would be able to manage to continue their pain medication and maybe other kinds of things. I do not know whether this has occurred or not. We know that no-one has awakened, there have been no problems, and every outcome has been as it was supposed to have been, even though in Oregon there have been some delayed deaths, but in the Netherlands, of course, they have the provision that after a certain period of time that they would use an injection.

Chairman: Thank you very much indeed for your help. Thank you for the hospitality of a very suitable location to have this discussion. Thank you very much indeed. We will not want to trespass on your hospitality for very much longer.

FRIDAY 10 DECEMBER 2004

Present	Arran, E Finlay of Llandaff, B Hayman, B Jay of Paddington, B	Joffe, L Mackay of Clashfern, L (Chairman) McColl of Dulwich, L
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Examination of Witnesses

Witnesses: Ms BARBARA COOMBS LEE, President, Compassion in Dying, Dr PETER RASMUSSEN, Oncologist, Palliative Care Specialist, Dr ROBERT H RICHARDSON, Director, Kaiser Permanente Ethics Service and Palliative Care Physician, Dr NICK GIDEONSE, Medical Director and Associate Residency Director, OHSU Richmond Family Health Center, and Dr DARIEN FENN, Assist Professor of Psychiatry, OHSU, examined.

Q835 Chairman: I think you all appreciate why we are here. We have been appointed by the House of Lords to examine on its behalf and report to it on Lord Joffe's Bill which deals with matters which are at least related to the Death with Dignity Act which operates in this state. Our job will be to provide a report upon the circumstances that seem to us to be important in relation to the Bill which, of course, if it became an Act, would be applicable to England and Wales. The experience here may be of importance in assessing what these factors might be. The help that you give us today is intended to form part of our ultimate report. The evidence will be noted by a shorthand writer in as accurate a manner as possible but you will have a chance to look at the transcript to see that it coincides with what you thought you said, or at least as near as it can be. The shorthand notes, as extended, will be published as part of our ultimate report saying the basis on which we reach our conclusions which our report will ultimately contain. It is on that basis that we proceed. On the whole, we have found it useful to start with a short introduction from each of you about who you are and what your responsibilities are and then give an opportunity to Members of the Committee to ask you questions about the matters that particularly concern them. It is over to you.

Ms Coombs Lee: My name is Barbara Coombs Lee. I am President of an organisation called Compassion in Dying which is a national organisation. I would like, just very briefly, to recognise the people who are here and then we will begin our three to five minute dialogue. To my right is Dr Nick Gideonse, who is a family practice physician in a rural area of Oregon. To my left is Dr Robert Richardson, who is a palliative care specialist and ethicist who works at a large institution in town, Kaiser Permanente. Next is Dr Darien Fenn, who is a psychiatrist who works at the Oregon Health & Science University, who is both a practitioner and researcher. Next is Dr Peter Rasmussen, who is an oncologist and palliative care physician who works in Salem. We asked the consul administration if they would allow us to bring a

guest and friend. Mr James Meyer is here, he is from Oregon and has a particular interest in this issue.

Q836 Chairman: Is he going to participate in this session with us?

Ms Coombs Lee: No, we thought he would not participate but he has a deep interest, if that is all right with you.

Q837 Chairman: Certainly it is all right with us. I just wanted to be sure that he did not feel unnecessarily excluded.

Ms Coombs Lee: Compassion in Dying has served, since implementation of the law, as primarily stewards of the law. We have found it very, very helpful to have some kind of institutional support for families and patients and physicians to ensure that physicians understand exactly what is required to be in full compliance with the law and also to make sure that the law is available to people in more rural areas of the state or for people who need a little bit of help in navigating and negotiating their way through our bureaucratic health system. At this time, and over the last six years, Compassion in Dying has participated in a consultative way with about three-quarters of the patients who have made a request under the Assisted Dying Act to take medication under the Act.

Q838 Chairman: Who have taken medication?

Ms Coombs Lee: Who have taken medication under the Act.

Q839 Chairman: You mean taken it to use and used it?

Ms Coombs Lee: Ingested it. I was not necessarily going to get into numbers but shortly before I came we started to compile some numbers and, as you know, this is a very closely watched figure and the question has always been will there be escalation, will there be a lot of increase in the numbers of cases. It is our estimate, and as you know there were 38 instances last year in which patients actually took medication to hasten death, that for 2004 it will be

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substantially less than that because on our figures, figuring that we account for probably we are familiar with about three-quarters of the cases, we are about 25 per cent below where we were at the same time last year. We anticipate that we will not reach 30 this year, but of course that final figure needs to await the determination of the state regulators that you met yesterday. In that capacity, Compassion in Dying and its volunteers throughout the state have gained a certain perspective and a lot of familiarity with individual patients, individual families and also a broad overview of how the law works in Oregon. I would encapsulate my testimony by saying there are a few things that we learned that we did not necessarily expect. One of the things that we learned that we did not necessarily expect was the enormous emotional and psychological transformation that people would experience once they had made a request and established their eligibility. Whether or not they ever decided to take medication, whether or not they ever found themselves in a situation that they regarded as unbearable suffering, there seems to be a substantial sense of comfort and control and personal empowerment, a sense of peace that overcomes people once they feel as though their worst fears have been somehow settled by the fact that they are now eligible to hasten their death if they find themselves in intolerable circumstances. We did not anticipate the enormity of that psychological and emotional transformation. Also, we have learned that a common way to think about assisted dying as some kind of a choice between palliative care and comfort care, or assisted dying, is absolutely a false dichotomy. Patients do not feel that way and professionals have not come to feel that way. People do not feel as though it is an either/or, people want both. They want both the very best end of life care, the very best that medicine has to offer in addressing the sources of their suffering, their symptoms, their pain management, whatever their agonising symptoms might be, but also they want the choice to have a humane hastened death if that excellent comfort care fails to address their suffering. This dichotomy of either/or has really been put to rest over the last seven years in Oregon. Also, we have learned that there has been a tremendous evolution over the last seven years of the public's perception. I would say that over the last seven years the way that the public has changed its opinion, has changed the sense of this as a very extraordinary and sensational event to a sense that it is part of the continuum of care in Oregon, very, very few people find themselves in a situation where they want to avail themselves of it, and it seems to have been assimilated into the social fabric and, quite frankly, just is not considered to be a big deal any more.

People may talk about it frankly and we know now that one in six dying patients in Oregon talk with their families about their options and whether they might want to use the Act, one in 50 begin the eligibility process, but only one in 1,000 eventually use the Act to hasten their death.

Q840 Chairman: Where do these figures come from?

Ms Coombs Lee: These figures come from a study by Susan Tolle and her colleagues that was recently published in the *Journal of Clinical Ethics*. It was a very exhaustive study in which they interviewed 1,400 surviving family members of patients who had died who had not used the Act. One other extraordinary finding of that study was that there are no unreported cases in Oregon. In closing, I would also point out that there has been an enormous transformation politically in Oregon with the position of politicians, the way that the issue is perceived in the political calculus that people make. Seven years ago, ten years ago, it was considered a very courageous and chancy thing for a politician to say "I am in favour of legalisation of assisted dying". Today in Oregon, opposition to the Oregon law, for Republicans and Democrats alike, is a political liability. There is an enormous understanding or sense that Oregonians have voted this in for themselves, they have implemented it responsibly, it has been a service to the citizens of this state, and when people run for office in this state, regardless of whether they are Democrat or Republican, if they are opposed to the Act they must do some damage control because that is perceived and corroborated in polling as a political liability. Certainly it was an issue in the senatorial race and it continues to be an issue where there is opposition. I would close and say that at the end of all of our short opening remarks we will be welcoming your questions.

Q841 Chairman: Thank you.

Dr Rasmussen: I think I am next. I am Peter Rasmussen, in private practice in Salem. I wanted to use my time to talk about the issue of prognostication. Some people have been concerned that our admitted inability to be very precise about estimating when a patient is going to die is a fatal flaw for Oregon's law and I feel that it is not. One of the things you may hear is a reference to the SUPPORT study where experienced physicians in the intensive care unit had difficulty predicting the death of a patient, even when that death might be a day or two away. I would point out that clinical situation is really not applicable to what we are talking about here because in that situation the patient is being aggressively treated, is in this

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downward spiral and it is fervently hoped that one more antibiotic or renal dialysis will reverse the spiral, the patient will recover and leave the hospital. People who are interested in planned death understand that their disease will not be reversed and that the course of their disease will be a steady decline.

Q842 Chairman: A steady decline?

Dr Rasmussen: Yes, a steady decline. The SUPPORT study, if you hear about that, really does not apply to this situation. When we prognosticate for a patient about end of life care we really do two different time courses. The first one starts when a patient recognises that he is terminally ill, that the cancer or whatever it is will not be cured and that all reasonable efforts to alter the course of the disease have been exhausted and he is truly entering the final phase of his life. This is a time when a patient can plan the end of his life and plan his final chapter in his life and can determine how his personal ethics and values can be used to determine how he will end his life. Admittedly, we are inaccurate in prognosticating the time of death under those circumstances, we can easily be 100 per cent off, but I do not think that is a problem. If we say a patient has six months to live and we are off by 100 per cent and it is really three months or even 12 months, I do not think the patient is harmed in any way because what the patient is doing at that point is making this transition to making plans for the end of his life and if that planning period, that end of life, is three months or 12 months, there is no harm done. The second prognostication we make is at the other end, when the plans that were made months before are now being considered and put into effect. That prognostication is perhaps where the patient has perhaps days or weeks to live. We are much more accurate at making that kind of prognostication. The performance status, which is a combination of how much the patient is eating, how much weight they have lost, whether they can engage in activities of daily living, such as bathing themselves, dressing themselves, feeding themselves, and how much time they spend in bed, these are powerful predictors of life expectancy towards the end of life. Again, even if we are 100 per cent off and tell a patient that he is within a week of death, say, if it is really three days or two weeks, I do not think the patient is harmed in any way. The reason is the patient who is interested in assisted death like this has already made a decision in the past, and reconfirmed at this time, that it is not as important for him to live a few more days or a few more weeks, it is more important for him to have control over the circumstances of his death. The person wants to be able to determine that he will die at home and

who will be with him when he dies. That prognostication is much easier to make. If you hear concerns that our inability to be precise about the time of death will result in people dying months or years before they otherwise would have died, I think these people are misunderstanding that the prognostication really takes place in two phases. The way this can fall apart is if you have a patient who may be a long-term smoker who has told himself for 30 years, "If I get lung cancer, I am going to off myself" and so he gets lung cancer and he wants to die right away. The law has safeguards to protect against that because I do not think any of us want the law to be used under those circumstances. Not only does the patient have to be an adult and have the capacity to make his own decision, there have to be waiting periods of at least two weeks that give the doctor the opportunity to initiate palliative care, typically in the form of hospice, to demonstrate to the patient that not only can his symptoms be controlled but they will be controlled, so the patient need not worry about dying in horrible agony. We know that many patients who say they want to die now because they are afraid of what their dying process will be like, with good hospice care find that another day of life is worthwhile and they wait as long as they can and they die naturally of their disease. If you have any questions I will be happy to answer them later on.

Q843 Chairman: Thank you.

Dr Richardson: I am Robert Richardson. My career began as a pulmonologist and critical care physician in the 1960s. Through that experience I became aware of the innumerable ethical dilemmas which face patients at the terminus of their life and then pursued education and a career in medical ethics. As more and more of the cases of medical ethics that we dealt with were end of life issues, I saw a need to begin addressing those issues and trying to improve continuity of care and to ensure that patients had effective care at the end of their life, that we took that seriously. I was not, and am not, a specific proponent of the assisted suicide law. I remain still balanced and neutral and evaluative. In our organisation—I work with Kaiser Permanente, a large health maintenance organisation—we decided long before the ballot measure was passed that we needed to address end of life issues to be sure that patients had every option available to them and I was chair of a committee on end of life care in our group. After the ballot measure was passed, and ultimately became law, that committee evolved into a group which decided that on any request within our organisation this was an ethical matter, this was a perplexing concern and it should be addressed through the ethics service. Every request in our

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organisation has to go through my office. If a patient requests assisted dying under the Oregon law they must contact our office or contact their physician, but we speak with every patient in our organisation who makes this request. This is to determine, first of all, as much as possible whether this is an appropriate request and then to be sure that this patient's physician understands the law so that he or she can proceed with the direct on-site clinical evaluation. I feel that this has worked extremely well. About one in ten of the patients who ultimately enquire of our office actually see a physician to discuss the Oregon Death with Dignity Law, a much smaller number of those patients ever decide to pursue a formal request for life-ending medication. Before the ballot measure I worked with an organisation called Oregon Health Decisions that set up town meetings and community telephone calls to try to evaluate what Oregonians—that is what we call ourselves—were concerned about in the law and what they feared and what they hoped for in the law. Out of that we then developed a task force after the ballot measure was passed which is called by the awkward title of the Task Force to Improve the Care of Terminally Ill Oregonians. This is not an assisted suicide task force, it is a task force which consists of representatives of all of the religious and health care professional organisations in the state. We meet at least quarterly, sometimes more often, to try to evaluate what is happening to health care in general for patients who are dying and also whether or not the law is working and whether there appear to be any abuses of the law. That is my background and experience. My practice now is devoted entirely to the ethics service and to the development and evolution of hospital based palliative care programmes.

Q844 Chairman: What is the nature of the organisation itself? The ethics is part of it, but it is a health—

Dr Richardson: Kaiser Permanente is a globally capitated health maintenance organisation. It was the first of these. It began in 1946. It was created by Henry Kaiser, and Dr Sidney Garfield as a means of providing health care for the dock workers who were working in the Kaiser ship yards during and after World War II.

Q845 Chairman: That is a general health service?

Dr Richardson: It is a total health service. It was a comprehensive health service in which initially the patient paid one premium, or their employer paid one premium, and there was one uniform health package. Now, as the non-system of health care in this country has progressively dissolved, we have

been forced into creating different packages, but still if a patient comes to us his or her cost for a physician visit, whether that be for a flu shot or for a heart transplantation, still will be the same. There may be differential hospital costs but globally it is a totally comprehensive health care system.

Q846 Chairman: Basically what you do is pay for the service. They can go to any physician they want, can they?

Dr Richardson: No, they have to begin with a physician in our organisation and if they are referred outside of the organisation, that referral has to occur by a physician within our group. For example, with the Death with Dignity law, since it requires a consultative opinion, we decided immediately that to prevent any appearance of conflict of interest we would require that any consultative opinions, whether they be psychiatric or general medical, would have to be referred outside of our system to someone who was not associated with our system.

Q847 Chairman: Thank you very much.

Dr Gideonse: Thank you very much for giving me a chance to be here. I am a general family physician. I had my medical training in Boston and Cleveland Ohio. I came here trained as a general practitioner, what we call a family physician, in 1994 prior to the Act. I practised in rural Oregon from 1994 to late 2002. I come to you as someone who cares for families, cares from cradle to grave. I delivered a baby early this morning. I am very acutely aware of family needs around the dying process and the number of things that we can bring to that process as caring general practitioners. I have prescribed for five patients, four of whom have taken the medication, three in my presence. I am here to talk to you about the evolution in both the acceptance and the great security I have in how this law has actually worked with patients on the ground, so to speak. A couple of things that I would encourage questions about are the effect of the Act in its passage at the time of the more heightened political debate and then the somewhat less, significantly less, political debate around that now and how that affects doctor/patient communication and trust, particularly how in many ways I feel it has freed us to talk about and do a better job of end of life planning. Our simple non-review literature is full of articles like that that simply say that Oregon's law yields better end of life care and that is based on Susan Tolle's work. The importance of the multi-disciplinary team, the role and the way care is integrated with hospice care, with pain relief specialists, with oncologists and how that has evolved, I can give you some specific examples

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about that. The issues around assessment of competency and I think Dr Rasmussen referred to assessing terminality of illness and assessing prognosis, I would be happy to talk about the context of that, and particularly the idea of degrees of certainty. I heard the testimony to your group on 21 October when a person mentioned how hard it is when assessing whether to cash in a life insurance policy or eligibility for hospice, to make the six month terminal prognosis. That is true because, as Dr Rasmussen said, they can be off. The assessment of prognosis of patients we are talking about using this Act is a very different matter, and we can talk about that. There is a degree of how certain are you that you know what you know. In the context of this, the certainty is very, very high, different than one would apply for, let us say, applying for a life insurance policy. A little bit about where my patients have led me, both in my understanding of the Act as it came on line and the implementation of it. It was three years after the passage of the Act when I first wrote a prescription and that progress, that evolution, is patient-led. A lot of the subtext for this conversation is about who is in charge at what time, what is the role of the physician in terms of aiding a patient in their wishes versus perhaps the more paternalistic model, that evolution. Much of my feeling about the Act itself has been very much guided by what my patients have told me. I invite questions about whether all suffering can be relieved, whether all suffering can be treated palliatively. I have clinical examples here of issues of pain relief, but also some of the central issues for the very small number of people who use the Act, but the much larger number of people who are free or have communication with their care team improved by the Act, around other kinds of suffering about the loss of autonomy they go through with terminal illness, the types of illnesses we are talking about here. Last, I have heard concerns about how non-system of coverage in the United States can affect this: are patients isolated; are they making decisions out of purely financial hardship, for example. I would be happy to answer on that. I do not think that has been a significant factor and I can explain, if you have not heard already, how Medicare and hospice and other things become available to people should they be suffering a gradual decline from a terminal illness. You have heard a little bit about the lack of opposition politically and I can flesh that out a bit. I have heard it said in testimony to your group before about whether something like this makes death a social good or an economic good. That is so not true. In every case I have been involved with, death is absolutely the enemy and in no way seen as a good. These are deeply grieving families, these are

deeply grieving patients. Were there another choice, were the option of not dying available, they would gladly take it. A good death does become valuable. Given the inevitability, the near term inevitability, of death in these cases, the ability to exercise autonomy or to achieve what is seen by them and by their family as a good death does become a strong good and one that we can now talk about knowing that there is a legal pattern that we can follow and talk about.

Q848 Chairman: Thank you.

Dr Fenn: I will be very brief. My role is as a psychologist and primarily I have conducted research into some of the end of life questions and reactions to the Oregon Death with Dignity Act and opinions of various professional groups on end of life decision making. Currently my role is somewhat of an analyst of the current research findings that relate to this. I think most of the points that I would make I have made in my written submission to you. The one thing I would like to add as a recommendation is a study that I came across more recently that I think is worth reviewing. It was a study done in Washington by Anthony Bach and colleagues entitled Physician-assisted Suicide and Euthanasia in Washington State that was published in the *Journal of the American Medical Association* in 1996. I have got the complete reference if you need it. It is a survey of physician-assisted suicide as recorded by physicians in a state where the practice was, and continues to be, illegal. It is a very well done study and has a lot of colour in terms of the anecdotes and the experiences of physicians. It highlights an important part of the decision making that you will be facing. I believe that you are really making a choice not between whether or not you are going to have assisted suicide but whether or not you are going to regulate it. One of the interesting findings from the Washington study was extrapolating from their sample the authors concluded that the rates of assisted suicide clandestinely conducted were approximately equivalent to the rates of assisted suicide in The Netherlands. If so, that raises some rather interesting questions, the first being whether or not legalising assisted suicide will make it more available to people. It may well be that patients who are going to seek assisted suicide will do so whether or not it is legal. If that is the case, then comparing the way the procedures are conducted, whether they are in the open or clandestine, becomes an important consideration. In particular, the Washington study noted that physicians who were engaged in assisted suicide did not consult colleagues, did not seek second opinions, did not seek mental health consultations, and the patients themselves also faced

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inconsistencies in available care because some physicians would simply refuse to talk to the patients about it. That is primarily what I would say at this point.

Chairman: Thank you very much indeed. Now it is open to my colleagues who wish to ask questions, if they would like to do so, please.

Q849 Baroness Hayman: May I kick off, my Lord Chairman. Could I ask for your comments, following up from a totally unregulated situation where a degree of physician-assisted suicide goes on to a very highly regulated system, as you have here, and ask two questions about that? One is that it has been put to us, and I think you said it too, that it was a political good now, if you like. I have to ask myself why this message has not gone to politicians anywhere else in the United States. It is still a question in my mind certainly as to why there has not been an uptake. It has been suggested to us that the only reason the Oregon law has been acceptable is because it is based on patient administration and not on doctor administration, which is different from The Netherlands. I wanted to ask you (a) whether you think that is true and (b) whether you think the unacceptability, the crossing of the Rubicon for doctor administration, is a barrier because of the feelings of the medical community or a barrier more generally with the population? Then a separate question on whether you have any experience from the people who have contacted you of a lack of access for some patients who very much value this service, whether there have been difficulties with ALS patients, for example, who have contacted you? I think you have written about that in your evidence, Dr Gideonse, whether there has been inequity of access? Certainly we heard talk of family members who had a difficult grief because this had not been available to their relative who had wanted it. Those are two different questions.

Dr Gideonse: I think I will start with the second part. Yes, this barrier, which I would interpret as primarily a political barrier in that on many of the concerns about volition and subtle societal pressure, family pressure, all of these things, the fact that the patient self-administers in a way that is not easy to do, drinking ounces of a bitter liquid, provides a final piece of clear evidence that this is completely volitional and self-administered. Self-administration does that. Also, there is a lot of understanding in the ethical community. My understanding has grown that that line between actively helping by administration versus actively helping by allowing a prescription to occur, there is some falseness to that line but it is a very clear line. The physician's role is just one step further back. I think there are very good political reasons and very important reasons

within the medical community about why that line is in our law so clearly. There is no doubt that it is a significant barrier to patients. The moment at which they no longer can comfortably succeed in this task of drinking six to eight ounces of bitter liquid may not be the moment when they would choose to no longer see life as worthwhile or their suffering is nothing but unbearable. I can think of two, three, four cases that come immediately to mind where in many ways that barrier was extremely frustrating for the patient and family and there was some great disappointment about that. In that sense, the addition that you have in your Bill under consideration about if unable then can, makes a lot of sense to me and if that is not seen as a specific political barrier but more a specific point about the position from the medical community then I would keep that option in place, it would help additional people and change people's calculus. I hope that answers your question.

Dr Richardson: I would just like to address the issue of access because that is something we have considered in the state-wide task force. There is no question that in small rural communities where there is limited access to any medical care, a physician would feel very restricted in identifying him or herself as someone who would prescribe because there is such an emotional component to this issue. Even though the voters of Oregon approved the last ballot measure by 60 per cent, that still leaves 40 per cent of the population who are opposed, and many of these very adamantly opposed. I think Compassion in Dying, by making itself available as a resource for information, has bridged some of that gap but they cannot bring someone 300 miles from a distant corner of Oregon to meet a physician to do this. A related issue is physicians' opinions regarding this. In Oregon, as in every other state which has been surveyed, a modest majority of physicians support the right to do some sort of physician assisted death, although a much smaller proportion are willing to directly participate. Among those who state that they are opposed, some of them started out vigorously opposed. I would like to mention one case, if I may, of a physician that I am aware of who was very strongly opposed. His father was a member of the Oregon Medical Association and was adamantly opposed to physician aid in dying on a religious and professional basis. He did not hold the same religious views as his father but he was vigorously opposed to the law. When he had a patient who had a devastating, horrible head and neck cancer, a young man whose life had become horrible even with hospice help and all the palliative surgical and radiation procedures, he approached us and said that he felt this man's continued request for death

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really was the only humane answer for him. Physicians, although in a survey will respond one way, when they are actually faced with the decision they respond differently. Sometimes they would respond like this physician and there are other physicians who in a survey would say, “Yes, I support that right” and yet when they are approached there is a gut feeling that they would not be able to do that.

Ms Coombs Lee: From my perspective, I would say that having that last firewall, if you will, of having very clear self-administration, in this society, in this state, at this time is important to people, to have that assurance that it really is a volitional act that a patient must take. The trade-offs are minimal, from our perspective. The second most common diagnosis of patients who take medication to hasten their deaths in Oregon is amyotrophic lateral sclerosis, I think in the UK you call it motor neurone illness.

Q850 Lord McColl of Dulwich: They are two different things.

Ms Coombs Lee: ALS is different from motor neurone illness?

Q851 Lord McColl of Dulwich: Yes.

Ms Coombs Lee: Lou Gehrig’s disease. It is a deteriorating illness, death usually occurs through respiratory failure because the muscles of respiration start to fail. Those people have been able to avail themselves of the Act even though it is commonly thought of as one of those difficult situations.

Q852 Baroness Jay of Paddington: Can I pursue the question that Lady Hayman raised, which I do not think you have quite addressed, and it was something I wanted to ask you about too, which is the broader political context. You said that being opposed to this law had become almost a political liability in Oregon. We all know that Oregon is a very blue state in American terminology, and that there were not many of those in the Presidential election, but I do think it is a legitimate point that Lady Hayman raised. What is the evidence that you have of this being a political plus in Oregon and why does it not get picked up in other places?

Ms Coombs Lee: Those are two different questions. There is evidence that it is a political plus. We have seen it played out in polling and we have seen it played out in state-wide elections. Dr Gideonse told me that one of our most politically partisan Republican state leaders, whom you would expect to take the other side, several days ago in *The Oregonian* issued a statement to the effect that there

was solid support here and there would be no reason to oppose it in the state.

Q853 Baroness Jay of Paddington: I do not want to burden you with additional research, but if it was possible to see some of that recent polling, particularly in the context of the state elections, that would be very helpful.

Ms Coombs Lee: Some of it is public. We know anecdotally, for instance, in the state-wide senatorial election when Gordon Smith was running against Bill Bradbury, who is currently the Secretary of State, that the polling that Gordon Smith did alerted him to the fact that this was his chief political liability that he needed to overcome in his race against Bill Bradbury. That is not publicly available, that is a little bit of insider knowledge. This statement by a Republican leader is certainly not.

Q854 Baroness Jay of Paddington: And the broader question about the national situation?

Ms Coombs Lee: As you all know, for some reason, although the people throughout the country have come to understand in many ways that decisions that result in the death of a patient are made all the time, decisions to withhold life sustaining therapy, decisions to withdraw life sustaining therapy, have become incorporated in normal medical practice—patients are allowed to discontinue their kidney dialysis, for instance, without the kind of rigorous safeguards on eligibility that we require here—nevertheless, the idea of assisted dying that in a graphic way, in a specific way, transfers authority and power to a patient to take an action that would hasten their death has a certain emotional cachet in the United States. The evidence from Oregon overcoming that perception that there is something inherently different about this end of life decision from all the thousands of other end of life decisions is a political barrier. I do not think that it is ethically qualitatively different from all of those decisions that patients make.

Q855 Baroness Jay of Paddington: I wondered if you would pick up on the research that Dr Fenn very kindly provided to us before we left London in his submission to the Committee. In his research he saw the distinction between those who supported it and those who did not based on an almost exclusively religious basis. Was what you were going to say, and I am not leading you, were you going to say that it was the influence of religion in politics in the United States that has an effect which, at least from the outside, we see a resurgence of?

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Ms Coombs Lee: There are 20-30 per cent of people whose opinions really are based on their own ethical standards and their own religious beliefs and those are not movable. However, there are 30-40 per cent of the population in the middle who are waiting to be persuaded, who have fears about abuse and coercion and whether the safeguards actually work and things like that and are persuaded by the Oregon data. It is going to take time. As you know, in order for a cultural change, a change in cultural perceptions, to actually assume prominence in a political milieu, that takes time.

Dr Richardson: May I speak from the standpoint of Oregon Health Decisions. This was not an advocacy group, this was an opinion seeking group to identify what attitudes, what fears, what concerns, there were among Oregonians regarding the impending— at that time—Bill. One of the major fears that people had was that physicians would take control of the dying process. Both the way the law is stated in Oregon and our practice of it since then has shown that is not the case, that this is not physicians taking charge, this is patients who have taken charge.

Dr Rasmussen: I would like to expand on that and suggest that one of the differences between Oregon and the rest of the country is not necessarily religion but experience with home deaths. In the United States there has developed a tendency for people at the end of life to be treated very aggressively, put in hospitals, put in the intensive care unit, where death is viewed as a defeat, and in certain geographic areas of the country the idea of talking with the patient about avoiding all of that before their death is really a very new concept. It is not a new concept in Oregon, we have been offering that for years, long before this law was available. We have more home deaths in Oregon than in almost any other place in the nation. Our populace has been there. Our populace has stayed up nights caring for their loved ones as they were dying, whereas in other parts of the country their experience of the death of a loved one is from a waiting room in an intensive care unit. I think that is one of the differences and that may be applicable for the UK because I think you have more home deaths and you are probably closer to Oregon's experience.

Dr Gideonse: We were a swing state until late this summer. I think the margin was seven per cent in the election. It was really very close. Our congressional delegation is quite thinly split between Democrat and Republican. We have talked about how the debate was very partisan at the initiation of that but now that is not so.

Q856 Baroness Jay of Paddington: That is the interesting point.

Dr Gideonse: I believe that most of the other states are stuck in that early part where there was some very strong vocal opposition but it has now melted away and the law is working well, in addition to there not being legal cases around it or families who have said that the law is not working well, or that there is not a consistent legislative effort to overturn it, unlike something controversial like abortion where there is always that consistent effort but that does not occur with this law.

Dr Fenn: I just want to point out that you will probably want to think about opposition to assisted suicide from the general public as something distinct from the opposition that you might see from physicians because I think the stakes are quite different. With physicians, if you read through a lot of the discussion I think what you see is that the closer you get to the physician being put in the position of administering euthanasia, which is the worst case, the opposition rises almost in a linear fashion. In part, I think that is because a lot of physicians feel that this is a violation of their role and of the implied contract that they have with the public as to what their role is. I think the public's view of that contract is different, and this is something that is not openly discussed, and what you are seeing right now is something of a power struggle about who gets to make these final end of life decisions. With regard to whether euthanasia should be part of what you are considering, you are talking at the public level about something that is fraught with very emotional implications. Although on a careful analysis you can make a good logical argument that there is reason to include that as an option, I think it will not fly politically, we are still too close to Nazi Germany and the implications of "euthanasia" as a word.

Q857 Lord McColl of Dulwich: I declare an interest, I have been a Governor of the American College of Surgeons, I have worked over here and I have a great number of friends who are doctors. I think they would be somewhat surprised to hear you say that one of the main features is that they regard death as a defeat. I would suggest that that is not a good attitude for a doctor to take. Perhaps I misunderstood what you said, but you cannot really generalise like that in the medical profession.

Dr Rasmussen: That is true. I did not mean to generalise but there are American physicians who do view death as a defeat. They view their role as prolonging life as long as possible. Even if they know death is inevitable, their role is to delay it as long as possible. There are other physicians who see that delaying death is valuable but also helping the patient have a quality end of life is perhaps just as important for many people.

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Q858 Lord McColl of Dulwich: Could I take up the point about Germany that you mentioned?

Dr Fenn: Yes.

Q859 Lord McColl of Dulwich: I am not sure that it is right to say that one of the reasons why the Germans are so opposed to this is because of their religious views, I think it is mainly to do with the historical and scientific evidence that they focus on?

Dr Fenn: I would not disagree with that. I did not mean to imply anything about Germany.

Q860 Chairman: That was really what you meant, that it is the history.

Dr Fenn: What I am saying is that in the public's perception the word "euthanasia" still echoes some very bad memories and, for that reason alone, this may be politically unviable.

Q861 Baroness Finlay of Llandaff: I wonder if you could clarify something for me which I do not understand. Before the law came in, if a patient who was terminally ill committed suicide by taking all of the medication (and given the nature of these patients they must have had large quantities of drugs in the house) what was the consequence for them and their relatives? Is that different if they commit suicide with a physician administered prescription now?

Dr Rasmussen: I think I can answer that. Many of my patients with cancer have large quantities of narcotics at home and we all know that excessive narcotics can cause respiratory depression and death. Before the law came into effect I did have several patients who in a suicide attempt took all of their narcotics and typically they would wake up a day or two later and feel better because they had had a good sleep. If you have been on narcotics for a while, narcotics simply are no longer lethal because you have developed enough tolerance to the drug that it is not a way to commit suicide. If they use other drugs, if they use digitalis or amitriptyline, other antidepressants, there is ample evidence that often results in a very agonising death. I do not know if that is what you were getting at.

Q862 Baroness Finlay of Llandaff: The studies around the world show that the incidence of suicide in people who have a severe medical illness is always slightly higher than the rest of the population. I was just wondering what the legal consequences were for these people because we have understood that suicide is illegal here?

Dr Rasmussen: No, it is not.

Ms Coombs Lee: No, it is not. Suicide is not. Really it is the only crime for which assisting is a crime but being the primary actor is not.

Q863 Baroness Finlay of Llandaff: So things like life insurance and so on would still—

Dr Rasmussen: If there is fraud, if a patient takes out a life insurance and then shoots himself the next week then they would not be paid, but if there is no fraud involved the insurance is paid.

Ms Coombs Lee: I would add one of the lessons that we have learned that I did not articulate. It is anecdotal but we do have some trend analysis that substantiates it and some anecdotal evidence from hospice workers throughout the state. It appears that you are right, a certain percentage of patients who are terminally ill in hospice take their lives, often violently, with guns or automobile accidents. It is one of the understandings among hospice workers that some people just do that for whatever reason, they do not want to face whatever they anticipate for the future. That has pretty much disappeared in Oregon. Hospice workers among themselves talk about how there are no longer any violent suicides in Oregon.

Q864 Baroness Finlay of Llandaff: Those who are determined to commit suicide seem to have transferred across, is that right?

Ms Coombs Lee: We have tracked 69 people who came to Compassion originally with a plan and the means for a violent suicide and at this time none of them have carried out their initial plan and only a minority of them have actually taken all of the steps through the Death with Dignity Act and died with medication; the vast majority have died natural deaths. Again, this was what I alluded to, this enormous sense of comfort and control and empowerment that people achieve that seems to give them the endurance to go on with their illness and experience it to its end.

Dr Gideonse: This brings me to a point I very much want to make. Now we have a mechanism. With a gentle approach from a patient before carefully saying, "How will I maintain control? Would you help me?", I would have been in a scary legal position, I would not have wanted to open that up, my response would have been "That is illegal, that is wrong, we could both get in trouble", and I can see that could be perceived as abandonment and my message to the patient would have been "Don't go there", but now I can have the very open discussion about "What are your fears? Here are the facts about the law. How else can we meet your needs?" if I sense that someone might have no place to turn when their personal situation is so bad. That is not true any more, I have a set of guidelines that I can work with about an open way to have this discussion much earlier with the patient because there is no fear that we will be giving a mixed

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message based on a fear of illegality. I think that is very important.

Q865 Baroness Finlay of Llandaff: Can I pursue the relationship of the person requesting the prescription and the prescriber. In your book you describe someone called Jake and it describes the way he obtained his prescription with the doctor having tears in his eyes, which sounded as if the doctor was trying to resist giving this prescription for quite a time and then gave in, which seems to be quite a pressurised situation. I just wonder if it is something that is arising and if you can comment on that?

Ms Coombs Lee: The story in the book of Jake was not written by me, it was written by a friend of his who accompanied him to the physician. I think the point of the story is that, yes, the doctor was finally persuaded by the degree of suffering and by the intimate relationship that he felt with Jake to overcome his own reluctance to participate in the Act. I did not get the impression that the doctor felt particularly pressured into it, I guess that he was persuaded by the agony of this gentleman in front of him.

Dr Gideonse: This is deeply emotional work. We are facing patients who are suffering and very bravely asking to maintain autonomy in the face of that suffering, surrounded by loving family, very much wishing this is not a place they are at and coming to that realisation. As I think back on another case I have been involved in, none are easy. It is deep work, especially in an ongoing relationship where perhaps the goals come together over a longer period of time that would be a very emotional moment.

Q866 Baroness Finlay of Llandaff: Do you think that these patients are much more difficult and much more emotional to look after than those patients who may have great distress but are not opting for physician-assisted suicide?

Dr Gideonse: No. The clarity and purpose that a patient pursuing this brings—Earlier we talked about how the screening screens out so many early on by explaining that there are other ways to address pain or concerns about pain or autonomy or what issues they can and cannot have control over. It is tremendously rewarding to meet the needs of these patients.

Q867 Baroness Finlay of Llandaff: How many of them have mental health assessments?

Dr Gideonse: I think the statistics around the number of formal mental health assessments through an outside party, through a psychological or psychiatric assessment, were initially 30 per cent

and now decreasing. Often the patient is someone who has been with the physician for a long time but they do not feel, perhaps because of a fear of what John Ashcroft might do to their licence, prepared to write the actual prescription.

Q868 Baroness Finlay of Llandaff: I have a concern that it looked as if sometimes these psychological assessments were at a distance, they were not face-to-face, and, in other words, a psychologist or psychiatrist did not go to the patient's home and visit in the patient's home.

Dr Gideonse: I cannot speak to that but I do carry out psychological assessments and assessments of competency and assessments of depression on all the patients. Yes, one could argue about how good general practitioners are at recognising depression in the general population but if you give me someone in this position, it is not terribly difficult to assess whether they understand the circumstances, what their alternatives are, what this medication is all about, what the risks and benefits might be, and this repetitive request to state what they are trying to accomplish is very valid evidence of full competence.

Dr Richardson: These do not take place at a distance. If a psychological or psychiatric evaluation is done, it is done either in the patient's home or in the office of the practitioner. It is not at a distance.

Q869 Baroness Finlay of Llandaff: I ask because one of the cases, and I cannot remember which one, referred to the family doing the assessment with the patient at a distance from the psychiatrist and it sounded as if it was done over the phone.

Dr Richardson: I do not know about that.

Q870 Lord Joffe: It has been raised in evidence we have taken, not so much here but in the United Kingdom, that it is much easier for a general practitioner to make a decision, particularly on competency, in relation to his patient if they have had a long experience over many years and that it must be very difficult when one sees a patient for the first time ever to assess competence. How would you approach a patient for the first time?

Dr Gideonse: First of all, some of the initial questions we talked about in relation to screening questions for depression and establishing whether a person can communicate their situation and playback, discuss, their prognosis, the name of their disease and that sort of thing, at least some of the initial assessments on that are fairly easy to do at a first meeting. However, in every case that I have been involved with I have had contact with their previous treating physicians, many were ongoing, whether they played a formal consultation role or not. For example, if a patient has approached their

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family physician and their family physician says, “Personally, I am not willing to do this but let me help you find out where you can go”, if the patient were to come to me I would be in touch with that previous physician, I would ask is the patient consistent with their previous wishes, do you think they have an intervening depression. Additional information from previous or concurrent treating physicians is extremely helpful. Additional information from the family, speaking to the family, although in the presence of the patient, is extremely helpful. The most important thing is the intensity of contact as we go through the process weeks or months prior. I am talking about multiple visits. I have never had a patient when I did not make a home visit at least once, if not multiple times. I would check that there is a consistency in the declaration as well as consistency in their mental state.

Ms Coombs Lee: It is important to recall that 93 per cent of these patients are enrolled in hospice and the essence of hospice is a multi-disciplinary team caring for the patient, part of which is ongoing mental status evaluation.

Q871 Lord Joffe: My other question arises out of the responses put to questions from Lady Hayman and Lady Jay in relation to the position in other states and why they have not followed Oregon’s example. I think you have pointed out that often there is a distinction between the views of the medical profession and the public at large. Are there any surveys that have taken place in relation to other states which give an indication of the views of the public as a whole that you know of?

Ms Coombs Lee: There have been polls done regularly as far back as the 1940s asking the consistent question, “Do you think a terminally ill person who is suffering unbearably should have the right to ask their doctor for a prescription?” Those polls quite consistently are much larger than 50 per cent, usually 60-65 per cent. Getting to the question about why the political process lags so much behind the scientific evidence and the experience coming from Oregon really speaks to the imperfection of the political process and how susceptible it is to sensationalism and sound bites. This is why I really applaud and congratulate this Committee and the House of Lords for the depth and integrity of the inquiry that you are conducting. This is quite apart from the sound bites and sensationalistic advertising and partisan rhetoric. You folks are doing it right.

Q872 Earl of Arran: You mentioned that you were very surprised indeed by the huge take-up of prescriptions, particularly from the reassurance point of view. Are you now equally surprised by the

actual cases that have happened seven years down the track? There are very few, some 170-odd over seven years. Do you think that you now have sufficient figures that this current amount per annum, which looks like between 25 and 40 approximately, will be a constant figure from now on rather than seeing any tremendous change?

Ms Coombs Lee: I am sorry, I did not mean to imply that I was surprised by the numbers because the numbers, as you know, have been quite small. What I was surprised at was the degree of psychological impact that achieving eligibility seemed to have on individual patients, that was what I meant. As I said, I believe that the numbers for 2004 will not only level off but will actually diminish. What we are seeing, approximately one in 1,000, reflects the actual true utilisation rate when patients have the choice of assisted death in the continuum as an option of last resort in end of life care.

Dr Fenn: I think you might compare the Dutch experience as perhaps a high end estimate. There are some aspects of their culture and their medical practice that make it much more acceptable at a public level that we may never achieve.

Q873 Lord McColl of Dulwich: You mentioned that there have been no unreported cases and I am not quite sure how you can be certain of that. Can you tell me the percentage of cases that underwent autopsy?

Ms Coombs Lee: No unreported cases comes from an article. I am going to leave you folks with a study that was prepared for the Vermont Legislature by the Vermont Legislative Council. It is a very nice survey. One of the most recent pieces that they cite is a study by Susan Tolle, whom I think you met the other day. She did a retrospective study, a survey study, interviewing the relatives of people who had died during a certain period of time in Oregon who had not been on the roll as participating in the Death with Dignity Act. It was astounding how many family members she was able to reach. They interviewed the family members of 1,400 individuals and they found no cases in all of those interviews of any patient who had completed the inquiry process, the eligibility process, and taken medication outside the law. It absolutely correlated with the reported cases. The way the Oregon law is written, I am not surprised that there are no unreported cases because there are absolutely no incentives for not reporting. The way physicians achieve immunity from disciplinary sanctions and criminal and civil prosecution is by complying with the law, and reporting is part of the compliance process, so essentially they would be opting out of their own immunity if they were to fail to report. If

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there is anything physicians like, it is legal immunity.

Q874 Lord McColl of Dulwich: Except there were 1,022 Dutch cases where it was not reported.

Ms Coombs Lee: I think the Dutch system is so very different from its inception to its conclusion.

Q875 Lord McColl of Dulwich: My argument is that they would be protected if they had declared it, but they did not declare it.

Ms Coombs Lee: I see practically no parallels between The Netherlands and Oregon.

Q876 Baroness Hayman: But there would be no incentive to report if you had a patient who could not administer the pump for their IV line, someone who could not swallow, who had their prescription and wanted to it take it but could not actually deal with ingestion other than by swallowing and the doctor helped them. There is no incentive to report that, is there?

Ms Coombs Lee: You are talking about covert euthanasia now.

Chairman: That would be outside the law. Even by reporting that you would not get immunity.

Q877 Baroness Hayman: Precisely.

Dr Gideonse: I doubt whether that can be happening in a significant way. There are a couple of things I would like to say. Once I have written a prescription I have done significant reporting on simply writing that prescription and were that to be used in some other way—We have got hospice involved in 75 per cent or greater, and for me it is tremendously important to account for where that prescription went, that there has been accurate disposal witnessed by a couple of hospice people. You do not want that medicine floating around out there. You are right, there would be no incentive to self-report if you are working outside the law, but if that was happening with any great frequency I think there are a number of ways that would have been caught and brought to light.

Q878 Chairman: Our time is up, therefore if you would be kind enough to try to answer this as briefly as possible. Compassion in Dying was set up after the law was about ready to come into force, is that right?

Ms Coombs Lee: We were set up in the State of Washington in 1993. Our concerns go far beyond the Oregon Death with Dignity Act. We advise patients and their family members all over the nation about negotiating end of life decisions. We get them in hospice and we litigate on their behalf if their pain is untreated. As an organisation it has a much broader scope and wider application than the Oregon Death with Dignity Act.

Q879 Chairman: Have you got any brief statement of the objects of the organisation that we could have a look at?

Ms Coombs Lee: Yes, indeed.

Q880 Chairman: If you could perhaps let us have that, I would like to see that.

Ms Coombs Lee: Before you have access to the packs that I would be happy to send you, you can find our website, www.compassionindying.org, which is very thorough.

Q881 Chairman: Are you a campaigning organisation?

Ms Coombs Lee: For legislative change?

Q882 Chairman: Yes.

Ms Coombs Lee: Yes, we do sponsor legislative change in other states.

Q883 Chairman: In this State of Oregon, are you campaigning at this present moment for any change in the law?

Ms Coombs Lee: No.

Chairman: I think our time is up, we have got to go to another place and I gather the time we have allowed is just about right to get there. I would like to thank you all very much. As you see, the time passes quickly in discussions of this kind. I am sure there are other questions that we would like to discuss but we have to suffer the discipline of time. Thank you very much indeed.

FRIDAY 10 DECEMBER 2004

Present	Arran, E Finlay of Llandaff, B Hayman, B Jay of Paddington, B	Joffe, L Mackay of Clashfern, L (Chairman) McColl of Dulwich, L
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Examination of Witnesses

Witnesses: Ms KATHLEEN HALEY, Executive Director, and Dr PHILIP PARSHLEY, MD, Medical Director, Oregon Board of Medical Examiners, examined.

Q884 Chairman: It is very nice to see you, thank you very much for having us here. As you know, we are appointed by the House of Lords to examine the circumstances that would be relevant to take into account in deciding what should happen in relation to the Bill proposed by Lord Joffe. As you know, some of these activities at least are experienced here in actual practice and, therefore, it is of interest to us to know how things are running. The situation is that we will invite you to make a short presentation and my colleagues will then wish to ask some questions. The note that we will take will be used as part of our ultimate report to show the basis on which we are reporting. You will have an opportunity to check the transcript to see that it accords with what you thought you said in due course. If you would like to start for us, Ms Haley, that would be very helpful.

Ms Haley: Thank you, Lord Chairman, Members of the Committee, My name is Kathleen Haley and I am the Executive Director of Oregon Board of Medical Examiners. I have been in this position for ten years and I am an attorney by training. With me today is Dr Philip Parshley, who is our Medical Director, and he has served as Medical Director for the last five years. Prior to that, Dr Parshley was a surgeon and established the Oregon Burns Unit in this state. If I could make just a few brief remarks because I know you would like to get to the questions. In 1995, when the Task Force to Improve the Care of Terminally Ill Oregonians was established, the Board was a part of that and has remained a part of that task force. In 1997, the Board had a case in which a physician, at the request of a patient's family, administered Succinylcholine and thereby terminated the life of that patient. The patient had had a stroke and was in the emergency room at that time. The Board found that act of euthanasia by that physician was unprofessional conduct and disciplined that physician. In 1997 the Act was found to be effective. In 1999 the Board was the first in the United States to discipline a physician for under-prescribing medications at the end of life. A physician who was treating a number of patients, and I believe there were six patients, at end of life care was not responding to the hospice staff member's call for more medication. I say these things to you to set some of the parameters

that the Board was establishing with physicians in the state before we actually had cases involving the Death with Dignity Act. Since the Act has been implemented we have had four cases, two of them have resulted in letters of concern to the physician and those are not public, and two of the cases have been closed with a finding of no violation of our Medical Practices Act. That is where we are today. I do want to keep this brief but I would also like to ask Dr Parshley if he has any remarks?

Dr Parshley: I do not think I have, except to say with my experience in the burns centre I was familiar with a lot of physicians in the state who were referring patients and my sense in knowing all these people, and knowing how they feel and act, is that there is very little negative feeling about this Act. In fact, many people feel that it is very, very beneficial for the patients.

Q885 Chairman: How many practitioners are there? I know that you regulate more than just what we would call physicians. How many physicians are there in the state?

Dr Parshley: Licensed in the state, and this is a vast group of licences, there are about 12,000. Actually, there are 8,000 MDs and about 600 Doctors of Osteopathy in the state.

Q886 Baroness Finlay of Llandaff: Thank you for telling us about the four cases and the one that was disciplined. Am I right that the one with the Succinylcholine had two months' suspension of his licence?

Ms Haley: We did provide you with a copy of the public record of that case. There was reprimand, a fine and, I believe, a suspension.

Q887 Baroness Finlay of Llandaff: Can I ask you whether you monitor the prescribing doctors and then end of life practice in general in terms of decision making and are you monitoring whether the doctors who are the ones prescribing this medication are ones who have known the patients or the patients are shopping around and these doctors are coming in to give the prescription and effectively not providing continuity of care later on either?

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Dr Parshley: The Board does not go out specifically to monitor any particular issue with physicians. We react only to complaints received.

Q888 Baroness Hayman: Obviously there is confidentiality about the two cases that you sent letters to. Is there anything you can tell us, broadly, about the nature of the cases? I am interested whether these were technicalities or more serious issues about witnesses? Anything you can tell us would be helpful. Also, you said there were two cases where there had been findings of nothing wrong. Was that the limit of the cases that you have had referred or reported to you?

Dr Parshley: Those are the only cases we have had reported to us. My sense of the complaints was they were all relatively minor and they were technicalities purely.

Q889 Baroness Hayman: Yesterday we heard from the state in terms of their responsibility if they picked something up in their monitoring to pass it over to you, but I presume that a relative who was unhappy or a friend or a nurse would be equally free to raise the issue with you if they wish?

Dr Parshley: Yes. We get about two-thirds of our complaints either from the patient or their families.

Ms Haley: In one of the cases in which there was a letter of concern sent to the physician, there was more than one patient, there were multiple patients, and primarily there were problems with the forms and the physician not following the guidelines and mandates by the statute. In the other, in which the letter of concern was sent, it was also on forms and witnesses not being appropriately signed. In one case the patient never even used the medication.

Q890 Earl of Arran: Were these four cases early on in the first few years? When was the last case?

Dr Parshley: The last one was this year and that was the one where there were multiple patients and problems with the forms. We had one in 2000, one in 2001, one in 2003 and one in 2004.

Q891 Baroness Jay of Paddington: Does that number reflect the number of complaints that you have or is that simply the number of cases that you pursue? What triggers an investigation by the Board?

Ms Haley: Any time we have a complaint we have to investigate it. These four would be the only complaints we would have had.

Q892 Lord Joffe: In the first complaint which you referred to the doctor was disciplined, is that right or not?

Ms Haley: I am sorry, no-one has been disciplined. These are four cases in which there has been no discipline. Two of them have had letters of concern

but letters of concern are not public and they are not official disciplinary actions, they are more letters of advice.

Dr Parshley: I think you are referring to the physician who performed euthanasia.

Q893 Lord Joffe: Yes.

Dr Parshley: That was not done in relation to this Act.

Q894 Chairman: It was before?

Dr Parshley: It was at about the same time.

Q895 Chairman: Before the law became effective, is that right?

Ms Haley: It was right about the same time that the law became effective, which is why I think it was a significant case. First of all, it was a very difficult case for the Board but also it set the parameters in terms of the Board's view. The Board took no position on the Death with Dignity Act. We did participate in the original guidebook, which you have probably got a copy of, and we helped edit that. We were instrumental in trying to set up the guidelines once the law would be enacted to make it be able to work well.

Q896 Lord Joffe: I asked that because that was the case I was thinking of. I have got something which was on the Internet by Physicians for Compassionate Care and they suggested that this particular case in the transcript of the entry was after the legislation had been passed. You are saying that very first case of euthanasia was not in any way related to the legislation, is that right?

Ms Haley: That is correct.

Q897 Lord Joffe: They raise a number of subsequent cases about which they have deep concerns. I do not know whether it is proper for me to ask you about these cases because they mention names, and they are very unhappy with the outcomes and not entirely complimentary about all the bodies who have investigated these cases. Can I ask you about this?

Ms Haley: You could ask us but the problem we have is if we do not get the complaint we do not investigate it. There may be instances in which there are problems, but if they are not brought to our attention there is no way for us to investigate them. In any area of medical practice, we do not go out and affirmatively go looking for trouble, so to speak.

Q898 Lord Joffe: They would have had the opportunity, if they so wished, to raise the complaint with you?

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Ms Haley: Absolutely.

Q899 Lord Joffe: On that basis, presumably I can ask if a complaint was lodged and that would not upset any convention on confidentiality.

Ms Haley: No, because we are not going to speak to any names.

Q900 Lord Joffe: I see. For example, the one case which they refer to is a Mrs Kate Cheney. Can I ask whether that case was investigated by you or not?

Dr Parshley: Is that the patient's name?

Q901 Lord Joffe: That is the patient's name, yes.

Dr Parshley: I do not think we could—

Ms Haley: We have certain confidentiality guidelines that we have to adhere to. We are not allowed to speak to any patient or physician names relative to any complaints unless there is a public action.

Q902 Lord Joffe: That is why I did ask first whether it was proper for me to raise this.

Ms Haley: If you asked us the circumstances of a case, we could say whether or not that fit, but once you start getting into the names it becomes problematic for us.

Chairman: I think it is possible that this could be resolved in this way: if I have understood Lord Joffe's question correctly, it is in relation to complaints about conduct under this statute.

Lord Joffe: Yes, it is.

Chairman: Ms Haley and Dr Parshley have said that there were only four and they have told us the outcomes of all four, so it should be possible to eliminate at least some of these in that way without involving embarrassing questions about confidentiality and the like.

Q903 Lord Joffe: Yes.

Dr Parshley: If you know the circumstances and you can discuss the circumstances we can perhaps give you some information.

Q904 Baroness Jay of Paddington: If I could also interject following the Lord Chairman. If only two of the four cases that have been referred to you have received what you describe as letters of advice and you have also described in answer to Lady Hayman that these were mostly concerned with the technicalities around what one might almost call the clerical aspects of the legislation, the form filling and so on, then I suppose it is legitimate for us to deduce that you did not find gross professional misconduct, for example.

Dr Parshley: Not in relation to the Act.

Baroness Jay of Paddington: No, exactly.

Q905 Lord Joffe: I am sure there is no purpose in my proceeding with questions on these particular cases because, as you say, the complaints that you have received have not resulted in any disciplinary action by you.

Ms Haley: That is absolutely correct. If another one of these came against a physician who and we had already had a lot of concern about there would probably be more in-depth investigation in terms of bringing the physician into this room and meeting with the Board of Medical Examiners and discussing the particulars, but, where we are today, this is two letters of concern.

Q906 Baroness Hayman: Perhaps we can try to tie it up in the way that the Lord Chairman was suggesting. The other two cases that you did not issue letters on, could I ask you to let me know again in broad terms what the gravamen of the charge or the concern raised was? Equally, was it around the technical administration and record keeping or was it around issues of competence, for example whether competence had been properly assessed?

Ms Haley: The first one was only one witness signed a form. There were an adequate number of witnesses but only one witness signed the form. I am looking at this now. That was really the only issue in that case. It was also noted that it was the first case, so it was in 2000. I think the Board would have looked upon that as, "This is the beginning of implementation and we are going to have these kinds of little slip-ups". The other one was in 2003 in which there was no violation and no letter of concern. Again, that was also the issue of forms. Also, it became an issue of was this patient too ill at the time to be able to self-administer. I think that is so important in this Act, that the patient has to be able to self-administer the medicine so that the physician is not the one either passively or actively euthanising the patient.

Q907 Baroness Hayman: That is a very interesting area that we have been talking about, if I might just pursue it for a moment. The patient has to be able to self-administer at the time that the doctor writes the prescription, am I correct?

Ms Haley: Yes.

Q908 Baroness Hayman: As I think we have understood it from other witnesses, the doctor, after having written the prescription, if they have completed all the requirements of the Act, does not have an ongoing responsibility to monitor that patient, for example as to ability to self-administer what has been legally prescribed.

Ms Haley: That is my understanding. In the guidebook, also we were advising physicians that if, and or when the patient was going to use the medication, it would be a good idea for the physician

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to be present as a resource, if necessary, for the patient and the family.

Q909 Baroness Hayman: The status of that advice if the physician did not take it?

Ms Haley: There would probably be no discipline, probably not even a letter of concern would be my guess. I would like to turn to my colleague to see if he has a different view.

Dr Parshley: No.

Q910 Baroness Hayman: You are offering best practice guidelines but not obligatory requirements for professional conduct in that suggestion?

Dr Parshley: It would be extremely hard to monitor. If a complaint came, it would be reviewed.

Q911 Baroness Hayman: I am sorry, my Lord Chairman, I am monopolising this. One can envisage a situation with a patient with a degenerative disease who did have a prescription lawfully provided for them at a time when they still had the capacity to swallow and then wanted to self-administer at a time when they had declined to a point at which they had difficulty in so doing. Although it is difficult to monitor, given the proportion of these patients who are in hospice care and are seen by professionals, presumably that is a circumstance that could arise?

Dr Parshley: Yes.

Q912 Chairman: Strictly speaking, so far as the physician is concerned, the physician is concerned only with the granting of the prescription. If he fills the prescription up the understanding is that the patient is going to self-administer the prescription and if that becomes impossible then, strictly speaking anyway, the object of the exercise is frustrated. I suppose it is just possible that some person other than the physician might become involved. We have not had much discussion about this and perhaps it is not wise to raise it. The intention is that the patient himself or herself is to self-administer. You may be able to comment on this. We have been told that quite often physicians, although they go through the first part of the procedure earlier on, do not actually give the prescription until nearer the time when the patient is showing a desire to use it and, of course, that helps to minimise the kind of situation that Lady Hayman has described. Is that according to your understanding of the way the system works?

Dr Parshley: That is not my understanding. I can see where that could happen but my understanding is that the prescription is given to the patient, the drug is given to the patient by a pharmacist at the time that all of the record keeping is carried on and—

Q913 Chairman: Part of the record keeping will be the actual grant of the prescription.

Dr Parshley: That is what I am talking about.

Q914 Chairman: That may be some time after the consents have been given, the 15 days and the rest. It is my understanding of what we have been told that the physician may not complete that part of the procedure until, in his judgment, the patient is wanting to use it. Apparently others make the prescription available and the patient can have it by them until a time when, if ever, they may want to use it. As Lady Hayman said, at that stage it could be that they have lost the capacity to use it by themselves.

Dr Parshley: That is why I say that my understanding is that they are supposed to receive it at the time that all the paperwork is completed. I have heard of nothing to the contrary. If that is going on, we are not aware of it.

Q915 Chairman: I suppose you do know that quite a few prescriptions are issued which are not used?

Dr Parshley: Yes.

Ms Haley: We do know that.

Q916 Lord Joffe: Could I ask a point of law. We seem to have had different interpretations from different witnesses as to whether suicide, that is actual suicide, is legal or illegal in Oregon.

Ms Haley: That is a great question and I do not know the answer to that. I have never heard, so it has not been notorious, that someone has attempted suicide and then been charged with a crime. I think the reaction would be to seek mental help for that patient. I cannot imagine that. I am not aware of any.

Lord Joffe: I just thought that was a good opportunity to get some legal advice.

Q917 Chairman: There is no doubt that assisting suicide is a crime in the State of Oregon unless you are covered by some statutory exemption, such as the ones that we are considering presently?

Ms Haley: That is correct.

Q918 Baroness Finlay of Llandaff: Could I ask for some clarification because I am not sure what falls under your jurisdiction and what does not. Would the way that a patient had their competence assessed be something that you would view as falling under your jurisdiction or only if somebody complained to you that competence had not been assessed? That is the first part.

Ms Haley: Do you want an answer to that?

Q919 Baroness Finlay of Llandaff: Yes.

Ms Haley: The initial attending physician needs to make that assessment: "Is there some issue of depression here that needs to be addressed?" If we got a complaint from a family member that said, "I think mom was very depressed and the attending physician

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who became engaged in this process did not address that” the Board would be investigating that physician on that issue.

Q920 Baroness Finlay of Llandaff: If there was a situation where one person felt that the patient was not competent and then they were reassessed by another person who said that they were competent, but without receiving a complaint, is there any way that you would know about that?

Ms Haley: No.

Q921 Baroness Finlay of Llandaff: If you then received a complaint, given that somebody had assessed them as competent, would that be something that would then be dismissed?

Ms Haley: With conflicting psychiatric assessments?

Q922 Baroness Finlay of Llandaff: Yes.

Ms Haley: I think that would be a very interesting case for the Board of Medical Examiners to have to review. We have, not on staff but on contract with us, a psychiatric consultant who sits in on every meeting of the Board, so we would use that consultant as well as bringing in another one probably. It would be a tough case.

Q923 Baroness Finlay of Llandaff: Completely separate from that, can I just ask who is responsible for determining specialist competences. If somebody calls themselves an oncologist or a specialist in palliative medicine, or whatever, is it your job to ensure that they have reached the specialist competences and have had adequate training to use that label, or is it somebody else’s job?

Ms Haley: The Board does have responsibility over the whole practice of medicine in the state of Oregon. The only speciality accrediting group is the American Board of Medical Specialties, that is the only one that the Board recognises. If someone says they are an oncologist and Board Certified, it needs to be by that group only.

Q924 Baroness Finlay of Llandaff: In effect, palliative medicine does not exist because I understood that it does not exist as a recognised speciality with a specific recognised training programme.

Ms Haley: It would not, but let us say that a physician said “I am a palliative care specialist”, unless there was evidence to the contrary there would not be a problem with him saying that as long as it was clear that he was not representing himself as Board Certified in that speciality. He could say Board Certified by whoever that accrediting body is, as long as it was not left vague because the assumption is that it has to be American Board Certified.

Q925 Chairman: Is it clear that the American Board of Specialty does not certify palliative physicians as a specialty?

Dr Parshley: I do not believe they are one of the 26 specialities under the American Board of Specialties.

Q926 Chairman: I assume that plastic surgeons are.

Dr Parshley: They are.

Q927 Lord McColl of Dulwich: You and I are surgeons, Dr Parshley, and we spend a lot of our time attending mortality and morbidity meetings. If any physician tried to make out he had no complications in a series of 200 cases we would wonder if he had very much insight. We understand that there have been nearly 200 cases under this Act with no complications and we just wondered quite what is going on.

Dr Parshley: We have not had complaints to identify the complications.

Q928 Lord McColl of Dulwich: How does that strike you, as a surgeon?

Dr Parshley: I am not sure that I totally understand your question.

Q929 Lord McColl of Dulwich: It is just having a large series of procedures without complications is a very unusual occurrence, is it not?

Dr Parshley: I see what you are saying. As we have said before, if there is a complication in one of our surgical patients there is always somebody who wants to make a complaint about it, or frequently, whether it is a professional person, a family member or the patient themselves. At the Board, we have not heard of any complications of any significance, or any complications, period. It may be true, but we have not heard them.

Q930 Chairman: It is clear that your remit is to deal only with complaints, but we were told in our first meeting since we arrived in this beautiful city that the Department of Human Services collect the data about the number of consents given and prescriptions issued under the Act and that they report these to you. I think I am right in saying that. In that sense, you have a certain review available without direct complaint if it appears on the face of the report that they make to you that in any particular case some part of the Act’s procedure has not been fully carried out. I imagine, for example, in a case in which the form was signed by only one witness, that would be an instance of something that would come to your notice through their report, is that correct?

Dr Parshley: Yes. In several of those cases the complainant was the Health Division.

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Ms Haley: When we were drafting the original guidebook, one of the issues that came up was how we were going to deal with this whole reporting issue. The feeling was to go back and rely on our existing statute that says that physicians have an obligation to step forward when they find instances of negligence or incompetence. It is under that guideline or statute that we get this reporting done. I think that it is the integrity of the physicians administering this programme at the Health Services Office that enables this to happen so that they are not going to let anything go by there and if there is a problem they send it over to us.

Q931 Chairman: What is the relationship between this office and the prosecuting authorities, the District Attorney and so on?

Ms Haley: That is another interesting relationship. When I took this position I went to the local District Attorney and said “I understand we have this obligation that if we find criminal acts we are supposed to bring them to your attention”, but in practice they really do not want to get involved. When we find things that are potential criminal violations we do report them. What they do with them is their business really.

Q932 Baroness Jay of Paddington: Following the Lord Chairman, we, perhaps inappropriately, have seen the analogy between your position and our General Medical Council in Britain. Is that roughly correct, that the General Medical Council and your authority is roughly the same, that you would have the capacity to investigate things that involve gross professional misconduct if, in a sense, that was on the border of criminal activity?

Ms Haley: We could investigate it in terms of the licensure and the Board has to take away the licence but we do refer the other cases to the District Attorney’s Office, the criminal cases.

Q933 Baroness Jay of Paddington: In our shorthand, the general practitioner could be, as we would say, “struck off” the medical register, which would be a fairly massive sanction against them. That could be done by you, could it?

Ms Haley: Yes.

Q934 Chairman: If it was sufficiently serious, in addition he might suffer criminal penalties?

Ms Haley: That is right.

Q935 Chairman: It seems as though the role of the Board of Medical Examiners is so clear that we have completed what my colleagues wanted to ask you about. Is there any possibility in the State of Oregon of private prosecutions or is it only the District Attorney who can institute prosecutions?

Ms Haley: There are only public criminal prosecutions. There could be a private right of civil action and a physician could have a malpractice case brought against him or her for this behaviour. Again, we are not aware of any because they all come through this office also.

Q936 Chairman: I follow that. The only area that one might think of as a possibility is if there were some groups who were very anxious about the law and they saw technical infringements—not serious—which nothing was happening about. I was wondering whether here it would be possible for them to raise a private prosecution, and I think not, whereas in some other jurisdictions that might be possible.

Ms Haley: If they had concerns about that they would probably go to our Secretary of State and ask for an audit of this agency.

Q937 Baroness Finlay of Llandaff: Could I just ask you whose responsibility it is to prospectively monitor the implementation of the law to ensure that there is not a violation in the more subtle clinical aspects of its administration? Given that you are very clear that you respond to any complaints that come in, I am not clear who has responsibility for prospectively monitoring, for example, what happens to drugs that have been prescribed and not taken, how those drugs are monitored, that they are not leaking out to diversion and so on.

Ms Haley: I do not know that anyone is really doing that. The physician is required to fill out that form and send it to the Health Division and then they can call and ask questions of the physician. Depending on the responses that they got physician to physician, if there were concerns about that they would notify the Board. In terms of the medications being out and not used, that is not something that we have neither heard of nor would have jurisdiction over.

Q938 Baroness Finlay of Llandaff: Is there anyone in particular that it would fall under or would it only be if, say, a homicide occurred using one of those drugs that only at that time would come to light?

Ms Haley: Probably that would be the way in which it would come about, I do not know but, Compassion in Dying, who you have probably met with, would be counselling the family about disposal of those medications.

Q939 Chairman: We have been told, I think, that the control of drugs, such as these medications, is, in fact, a federal responsibility in this jurisdiction. I suppose the federal agencies have some way of looking at this, but exactly what or to what extent or how deeply, I would not know, but you may be able to help us about that.

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Ms Haley: You are raising a very good point because that is who was challenging the law also. You might know more about that because you deal with the DEA.

Dr Parshley: The DEA is basically in the same boat we are, they have to have some type of flag come up to salute. I believe that they do monitor some prescribing of certain individuals who they have had problems with in the past but a single issue would not come up on their screen.

Chairman: I rather felt that might be so.

Q940 Baroness Hayman: On that issue of monitoring, is there anyone who has a responsibility for, rather than an interest in, looking at the profile of which doctors in the State of Oregon are particularly active in involvement with patients who take advantage of the Act, whether there is a spread or there is a specialist practice, if you like, developing? I am sure the question is asked and of interest to people. Is there anyone who has a responsibility for looking at that? Would it be of concern to you if it was three doctors doing 90 per cent of the cases?

Dr Parshley: If anybody had any type of responsibility it would be the Health Division who are collecting the data on these cases.

Q941 Baroness Hayman: They keep telling us that they are not regulators.

Dr Parshley: If they find a problem they refer it to us and then we investigate and pursue it.

Q942 Chairman: According to what they have told us, you are getting these reports of the certificates so if it was only one doctor who was doing it all it would become pretty obvious to you as you got the reports from the Health Division.

Ms Haley: We get pretty much raw data until they have specific concerns that they may turn over to us for possible investigation. Let us say that a physician that the Board investigated had multiple patients in which the forms were not quite right, the Board would have the ability and the authority to be able to go and run pharmacy checks on this physician—it is not that easy but we could do it—to find out how many more. We could subpoena his records to determine whether or not that is 90 per cent of his practice or something like that. We would be able to investigate. That is why I said where we have closed a case with a letter of concern, if another concern arose that physician probably would be subject to more investigation, such as you are talking about.

Q943 Baroness Hayman: One of my interests was if all the paperwork had been perfect and there was not a letter of concern, it was simply an issue of volume, do I understand that there is no ground on which you would consider that by itself an issue for you to warrant investigating?

Ms Haley: That is correct, there would not be any investigation on that basis.

Chairman: We are very grateful indeed for your kindness in having us here and for the clarity of the presentation of the facts that you have laid before us, which I am sure will be useful for us in seeking to fulfil our report on Lord Joffe's Bill. Thank you very much.

FRIDAY 10 DECEMBER 2004

Present	Arran, E	Joffe, L
	Finlay of Llandaff, B	Mackay of Clashfern, L
	Hayman, B	(Chairman)
	Jay of Paddington, B	McColl of Dulwich

Examination of Witnesses

Witnesses: DR GREG HAMILTON, DR KENNETH STEVENS, DR WILLIAM TOFFLER, MS KAREN BELL, and MR RON SUNSERI, examined.

Q944 Chairman: Thank you very much indeed for coming this afternoon. I am sorry that we running a bit behind schedule, which is due to circumstances not entirely within our control. We are glad to see you here. The system we have is that the help you give us is noted, because we will put it along with our report and it will be published in due course and form part of the basis on which we come to views. The system we have adopted is if you would like to give short introductions as to who you are and what your relationship is to the issues that we are concerned with, which is Lord Joffe's Bill for promoting certain activities as legal in the United Kingdom, which are not unrelated to what happens here in Oregon. We want to get your views about it to help us form a view. You will get a chance to review the transcript to see if the shorthand writer has managed to get your information accurately. We hope that it will be pretty much what you thought you said, but if it is not, by any chance, then you can correct it. If you would like to introduce yourselves and make any short submissions you wish to make I will then ask my colleagues to ask questions, because that is the primary purpose of this exercise.

Dr Hamilton: I am Dr Gregory Hamilton. I am a psychiatrist in Oregon and co-founder of Physicians for Compassionate Care, an organisation that educates professionals about how to provide optimal palliative care in life. I have provided some written testimony which I will pass around to you and documentation of our views which, in summary, are that we will urge you to reject the Assisted Dying for the Terminally Ill Bill for two reasons: one, because it is unnecessary, we can treat pain, and, two, because it jeopardises the lives and rights of not only the mentally ill and the depressed but also everybody who is in need of pain treatment and palliative care.

Q945 Chairman: Would you like to go next?

Dr Toffler: I am Dr William Toffler. I am a professor and educator at Oregon Health & Science University. I am a family physician, that is analogous to your general practitioner in England. I am proud to be that. I train medical students and

residents, and have been doing that for the past 19 years. I am in my twentieth year here and practised full-time in Sweet Home, a small town in the foothills of The Cascades for six years before going into full-time academics. Also, I was one of the members who helped start our organisation in early 1995. We had been caught off guard by a well-organised movement promoting this particular paradigm. As I shared with some of you last night, the movement's origins in Oregon came from a man who emigrated here from Great Britain, Derek Humphry, who now resides in Oregon. I find it ironic that Derek was promoting the very same ideas that are being discussed here at this table more than 20/25 years ago and he left Great Britain at the time when he had just assisted his wife's premature death as suicide and discussed it quite candidly in the book *Jean's Way*. The irony for me is that you are coming here some 25 years later when it was roundly rejected as an idea and did not take hold in Great Britain because I think all of you are a model for the rest of the world with the hospice movement that Dame Cicely Saunders has founded. I was talking to Karen Bell, one of our colleagues here at the table, about what a wonderful system you have. It is ironic that you would come here when in this state we have learned much in the last ten years. We have educated the other 49 states when these issues have come up and we have helped them to understand that the seductive sirens that caused our populace to embrace this really are not as attractive when you look at the details. We feel very strongly about this and the people at the table have spent a lot of time this week to give you the best look at some of the details that we cannot possibly cover in this hour. I would judge that most of the people who disagree with me—us—have not read what is in these documents. If you read these documents thoroughly you will know more about some of the tactics and misinformation that is going on in our state by people promoting this particular paradigm. I am glad to have the opportunity to scratch the surface with you. I have also submitted testimony that is in front of you. Because my colleagues had been so thorough I was able to express things at more of a 30,000 foot level rather than some of the details that Dr Stevens will give you.

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Dr Stevens: I am Dr Kenneth Stevens. I am a radiation oncologist and Chair of the Department of Radiation Oncology at the only medical school in Oregon. I have been involved with treating cancer patients for 37 years. I have probably treated about 10,000 patients. When this became legal I wanted to become a scholar on it. I am a medical scholar and I feel that I have tried to do that. In addition to my physician background I also have personal experience. About 22½ years ago my wife had been suffering from advanced lymphoma for about three years. We had six children. She had had a lot of chemotherapy, brain and spinal radiation as well as a biopsy from the maxilla. She was getting towards the end. She was very emaciated. She was getting pain medication and she was on antidepressants. We went to the doctor and said, "Is there anything more that we can do in terms of cure?" It was really obvious that nothing more could be done. As we were about to leave he said, "I can give you an extra large amount of pain medication" and we said "No, the pain is controlled". It was said very subtly. As I helped my wife to the car, she said "Ken, he wants me to kill myself" and that devastated her, that her trusted doctor would propose that she end her life. She had had a lot of suffering and a lot of heartache through this time but I do not think she ever felt as much in despair as when her trusted doctor suggested that to her. She died about a week later in our home, in comfort, in dignity.

Q946 Chairman: How long did she have this doctor?

Dr Stevens: About a year and a half. She actually had symptoms for about a year and a half before we realised that was what it was.

Mr Sunseri: My name is Ron Sunseri. I was a member of the Oregon Legislature in 1997. I chaired the Family Law Committee. I am the one who wrote the Bill that brought this all to the surface in Oregon, or at least brought to the surface what was being debated among the people. I will just tell you that the reason I came to the place where I was willing to write this Bill and present this was it had been brought to my attention that there were people participating in physician-assisted suicide who were dying grotesque and horrible and painful deaths. I listened to that until I talked to a person who had to use a pillow to smother her daughter because her daughter was in extreme pain and this person had concocted to end her life. The mother could not stand the suffering so she ended her daughter's life with a pillow prior to the chemicals or the drugs that she was given doing that. When I heard that story first hand I realised that there were things that the people in the State of Oregon were not allowed to evaluate before they made this decision. We had

some lengthy hearings, I chaired all of those hearings, and we had wonderful testimony. The Legislature agreed that this was something that needed to go back to the people of the State of Oregon and be voted on again. Unfortunately, in the way that the campaign was run that issue never surfaced as the issue at hand. In our particular instance, what surfaced, and this is political not medical, was that the Legislature was trying to overturn the will of the people and that became the issue, not the fact that there were people who were dying unmercifully, that this was something that was absolutely unnecessary because it was demonstrated in testimony time and again that sufficient drugs are available to alleviate any pain that one is suffering. Pain should not be an issue at the end of life. We evaluated all of that and we submitted it back to the people but because of this erroneous campaign the issue was voted down in Oregon so today we have physician-assisted suicide.

Ms Bell: I am Karen Bell. I am a nurse and I am the director of the hospice programmes for the Providence Health System here in Portland. We have about 375 patients at any given day in hospice care. I have been involved in hospice since 1976, so I have a long history of being involved with it. I am part of an organisation that does oppose physician-assisted suicide, however we do have patients who choose this option. I have brought you a copy of our policy so that you can see how we try to balance the organisation's position opposed to it but also recognising that patients do have rights, so we have to live within that. Very few patients actually avail themselves of this option. We probably had two last in my organisation. In previous years since it has been in place we did have two patients who took the medication and did not die right away, one lived for 36 hours and one lived for 12 hours. Sometimes we are not even aware that the patient has made this choice, and that is another situation. I do believe that pain can be controlled. I do not know that it can always be controlled 100 per cent of the time but certainly we can do a lot to relieve suffering and pain. When hospices are involved in good end of life care and palliative care is provided this is not a necessary option.

Q947 Chairman: How does your organisation work? Is it an organisation that provides health care for people or does it finance it?

Ms Bell: We provide the care. Here in the United States Medicare, which is the primary payer for older people, has hospice coverage and all the insurance companies in the State of Oregon provide a hospice benefit. I have nurses, social workers, chaplains, volunteers, all going out into the community. We probably serve a little more than

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1,500 patients a year. Primarily we go into patients' home or nursing homes, we do not own a facility where patients can go and reside, we go to the facility where they are living.

Q948 Chairman: That is including physicians and nurses?

Ms Bell: Physicians, nurses, social workers, chaplains, the whole contingency.

Chairman: Thank you very much. I think my colleagues will want to ask you some questions.

Q949 Baroness Finlay of Llandaff: Dr Toffler, because in your opening remarks you said that this had had an adverse impact on relationships, I wonder if you could clarify that in terms of doctor to patient and also doctor to doctor? I ask because we have become aware of a certain degree of tension between different groups of doctors in the last 24 hours.

Dr Toffler: Those are both absolutely true. They are unprecedented in my medical career. I have been a practising doctor for 25 years and in the first half of my patient I never had a patient request assisted suicide. I took care of terminal patients and gave them care to the fullest extent that they desired. I accepted their wishes when they did not want to have interventions. Even before it was popular I understood the notion of not artificially prolonging life. There is a bright line between ending someone's life actively and allowing the natural process to die. Our Supreme Court understood that nine-nothing as eclectic as that court is. Is there tension between patients and their doctors? Only this week one of my friends, a patient with metastatic cancer—not a patient of mine—called me because she was worried that she was being cared for by—in her words—an oncologist caring who was one of the “death doctors”. I am just paraphrasing what she said. She got a second opinion because the first opinion from the oncologist was not very favourable, he recommended she just accept the natural end of life. The second opinion was much more sanguine, he actually believed that she had an 80 per cent chance of responding to intervention. That reinforced her concern. I do not know which opinion is correct, I am not saying that the first man is not right, my point is that the tension and the fear that patient has is not unique, it is not the first time I have heard it. With respect to the relationship with patients, some of you heard me speaking with my colleague, Nick Gideonse, last night, who you heard from this morning, and I said to him what I have said to many colleagues over the years, that in every other aspect of medicine, if we were talking about heart disease or a brain tumour and the best treatment options available, we could discuss the risks and benefits,

and we would talk and accept what we were saying to one another as colleagues, but something is different about this. Something causes my colleague, who is not necessarily coming from some organised traditional religious point of view, to have a religious conviction about the merits of this paradigm, so I cannot discuss in a collegial fashion the risk and benefits. I have felt that tension for ten years now. It was the first time that I have ever experienced the phenomenon about a practice like this. The only thing I can think of that might parallel that kind of discussion that does not have to do with the scientific facts, merits, good or bad, is abortion.

Dr Hamilton: I can give you another example of tension between patients. This patient's name was Michael Freeland and he was in the hospice programme and he did not have much pain and he was being given large amounts of pain medicines. Even though it was not the case, he was afraid the hospice was trying to overdose him because of this law and because hospice has accepted the paradigm of assisted suicide. Granted this man had other problems but he let go of hospice because of his fear that accepting assisted suicide meant that the doctors were in favour of euthanasia. This was a guy who was depressed, he had a lifelong history of depression, he had had previous suicide attempts in his life that were documented, they were documented in his medical records, he was hospitalised against his will and a judge found him to be incompetent to make his own medical decision and yet his assisted suicide doctor left him home alone with 90 barbiturates to kill himself with for weeks. Originally this man was not in any pain but he became in pain near the end of his life and he called up the assisted suicide doctor and he told us that he responded to his complaints about uncontrolled pain by saying “I will come and sit with you while your take your overdose”. This kind of thing is callous. Physicians for Compassionate Care volunteers, had to go to this man's home where he was found alone in a deplorable condition in uncontrolled pain, delirious, and afraid to take his pain medicine. We had to physically give him his pain medicine. We did. The hospice did not do it, the assisted suicide doctors did not do it, volunteers did it. We had to insist that he received an IV infusion, we had to insist that he received 24 hour care. We had to argue about that but we got that for this man and he became comfortable. This man was not in pain because his pain was not treatable, he was in pain because nobody bothered. This is in his medical record too, that the palliative care consultant said that because he had the assisted suicide drugs available to him, the option of good attendant care at home was a “moot point”. This is

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just one case among many. In my report there are a lot of cases of patients with mental illness that are in jeopardy, but not just them: anybody who ever needs pain care, including us, may not have that pain care available to us because the doctor will now consider it a moot point. It has been documented that our once very fine pain care in this state is often times perceived as inadequate now, and that is in the medical literature. It is very concerning.

Dr Toffler: I just want to add to that. Lord Joffe made a important point last night when he said there are only a few very cases where we have documented problems. There are only a handful of cases, only a handful out of the total number of 171 that have been documented, as of the March report 2004. At this point based on the growing rate over the last six years, I would guess that right now we are above 200 and in the March report of 2005 we will learn whether I am correct or not. The point I am trying to make is every case that has come through the shroud of secrecy that has been imposed by the Governor's office, Governor Kitzhaber who actively supported assisted suicide followed by Governor Kulongoski's, and I believe you heard from Richard Leman this morning and I spoke with him this morning, he happened to come into my clinic for some blood tests, confirmed that it is true, that we are only listening to self-volunteer reports and that is what we know when we say 171 cases. Every case that we know about, and it is close to a dozen cases now, has serious problems. Not minor problems, serious problems where you would look at the case and say "This is bad. It is bad care, it is substandard." It would not pass muster even by the boundaries of this so-called circumscribed law. Patients who have been given a diagnosis of cancer and cannot remember their cancer, patients who have a known history of depression. Only one out of 20 of the patients in the last year got referred for formal psychiatric evaluations. That is almost at the level of background suicidal ideations in the population that I take care of that has no medical problems. I teach behavioural science, I love the subject, I love taking care of depressed patients, but that is not ubiquitous among my colleagues. They do not always have the ability to identify always people who have subtle forms of depression. They cannot do what Dr Hamilton does as a full-time job as a psychiatrist. We have no way to ensure that such an assessment happens. Every study that has ever looked at doctors' ability to detect these issues shows that we have much room to grow. Yet we somehow assume that doctors can wear both hats, they can be the defence lawyer, the client's lawyer, metaphorically, they can be the judge trying to arbitrate between the two models of giving unabashed care and intrinsic respect for the patient

no matter how ill they are, or advocating for their hastened death. By way of analogy it is like try to be a trial lawyer, not just for the defence, but also for the plaintiff, as well as the judge and even the executioner—the same person trying to wear all of these hats. To me, it is a delusional model. Even if you believed in this model I would advocate that it not be one person trying to wear so many different hat.

Dr Hamilton: We need to keep in mind that the Bill that you are proposing does allow for euthanasia and does bring in the spectre of the thousands of deaths in The Netherlands that have not been given consent for. It is very well documented by Hendon and his colleagues, not in this state. When you allow that it is very, very difficult. Even if you were to amend the Bill and disallow lethal injection entirely, you would still have the problems that we are having here in Oregon of case after case being depressed. All of the cases are basically for psychological and social reasons, even according to these inadequate reports, and there is not one documented case of a patient dying from assisted suicide because of uncontrollable pain.

Q950 Baroness Finlay of Llandaff: We heard that control was a key motivator, that the patients felt that this law was giving them more control, the implication being that thereby doctors' control over the situation is decreased, that the locus of control transferred to the patient. I wonder whether you feel that is true?

Ms Bell: I do not know that it is control. When patients opt for it in the organisation that I work for, what they express is losing control over their ability to function in their healthy role and fear being a burden to their family. Our experience has been that a significant number of patients go for it and get the prescriptions but a very small number actually take it. I do disagree with Greg in that I think hospices have had a very positive effect. If a hospice programme is involved then the patient and the family are given support and their needs are being met so they are less inclined to follow through on this, their fear if allayed, their pain is controlled, the family is given physical support to take care of the person.

Dr Hamilton: The argument that handing somebody lethal means to control their suicidal ideation is based on ignorance. Our Surgeon-General issued a report about helping prevent suicides and the availability of lethal means of any kind, whether it is drugs or guns, increases the suicide rate. When you give these patients lethal means, you will see an increased suicide rate. The idea that you are going to make somebody feel happier and better and in

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control and this is somehow going to make them less likely to commit suicide is hogwash.

Mr Sunseri: One of the things that became very clear in testimony before my committee was that doctors cannot predict. They think they can predict but they are not accurate in predicting who is going to be terminal and who is not because too many people recover. I had the opportunity to have a man testify before the committee who had been diagnosed and told that he had less than six months to live, probably three or less, and this was about two years before the testimony. He recovered. This goes to the point about control. At the point when he was having unbearable pain and no-one was really addressing the pain, they were just trying to persuade him to go ahead and end this early so that he could avoid the pain, he was out of control because the pain was affecting his ability to think. His testimony at that point was, "It did not matter to me whether it was right or whether it was wrong, whether I was up or whether I was down, I just wanted to end this, that was all that was in my mind". I think we can sympathise with the idea of someone losing control, so to speak, but to try to make a decision in that state to end your life when the verdict may not be as serious as you think, and this man recovered from that, to have ended his life would have been to truly end a life that continued on, it would have been totally unnecessary.

Q951 Chairman: We have been told that by no means everyone who gets the lethal prescription actually uses it?

Ms Bell: That is true.

Dr Stevens: We have had some patients who have had it in their possession for two years.

Q952 Chairman: And have not used it?

Dr Stevens: Is that a terminal condition to have it for two years?

Q953 Chairman: That is a separate question as to whether or not it was right to give it in the first place having regard to the statutory provisions because it is supposed to be in a case where death is likely to ensue within six months. I am more concerned with the idea that people who have been given the prescription do not necessarily use it. I was getting the impression from Dr Hamilton that the presence of guns and lethal materials and so on could increase the risk of suicide, and I can see that in some circumstances, but what we have been told is that in the case of many people who have come under this statute, they have received the prescription having consented, 15 days having elapsed and so on, yet having got it they do not use it to kill themselves or to commit suicide but they

seem to feel that they are now in control and if the pain got too severe or something else happened that made them want to end their lives, they had it within their power to do so. We were told that this gives them a kind of peace and relaxation from concern that otherwise affects their attitude and the people who do this are often people who have a feeling of control of their lives up until then. They are anxious not to lose this and, therefore, they feel better in control of their future if they have this prescription than if they do not have. Have you got any comment on that, Dr Hamilton?

Dr Hamilton: Exactly. You give people a sense of control and hope when they are seriously ill by treating their life as meaningful. What people really live for in the final stages of life is for their people, usually because they love people, and they need to be reassured that their pain is controllable by their doctors and that we are going to be with them and take care of them. By handing them a lethal overdose, many, many patients feel abandoned. The pro-assisted suicide folks are going to testify to you that is not the case because they are promoting an agenda and in America we call this assisted suicide thing a scam. They have made up this whole control issue. Patients can be given a sense of control without being handed a deadly weapon. The Supreme Court of the United States of America in 1997 was very concerned about this issue about whether we could control people's pain or help them control their pain in 100 per cent of cases, and the American Medical Association told Justice Senator Day O'Connor (who was the turning vote on this) "yes, we can. By using non-terminal sedation we can control pain 100 per cent. We can do that without handing somebody a lethal prescription. When you hand somebody that prescription you are handing them the message that their life does not matter. They can kill themselves: other people cannot."

Q954 Chairman: According to what we have been told and from what the Bill said, quite a number of people handed this prescription do not use it, in fact.

Dr Hamilton: That is wonderful because we help them. 99.9 per cent of people in Oregon do not die with assisted suicide either and that is because nobody needs it. The other 0.1 per cent could die without it too. Also, thanks to the help of Senator Sunseri we were able to get out to the people that taking 90 barbiturates is not a harmless procedure: it causes vomiting; it tastes awful; it is painful. If you are going to have a quick and easy death from some kind of euthanasia or assisted suicide you have to have lethal injection and if you are going to have lethal injection you are going to have all the problems that The Netherlands has.

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Dr Toffler: We have to be candid about these problems with overdoses. The state of Oregon has been less ingenuous about the problems of overdoses. It took six years before the Oregon Health Division's flawed tracking system even reported one case of vomiting. Can you imagine any pills that you give, even for overdoses, that never cause vomiting? That is what the Oregon Health Division would have us believe from their tracking system.

Dr Hamilton: We already knew about a man, Patrick Matheny, whose overdose failed. He made three attempts and his brother-in-law said "I had to help him die". Normally what that means is that he either smothered him or he gave him a lethal injection, both of which are against the law. We demanded a coroner's report and the body was cremated within 24 hours and we could not get that.

Q955 Lord McColl of Dulwich: This is the question that I have been asking since I arrived here. What is the complication rate?

Dr Hamilton: 15-25 per cent, but not in the records.

Q956 Lord McColl of Dulwich: As a surgeon, all my professional life we have met every week to discuss all the complications, deaths, at mortality and morbidity meetings. If any surgeon or physician told me that he did 200 procedures without any complications I knew that he possibly needed counselling and had no insight. We come here and I am told there are no complications. There is something strange going on.

Ms Bell: They are not reported.

Q957 Lord McColl of Dulwich: Do these patients have any autopsies? You have not answered that question.

Dr Toffler: They are given cremations within 24 hours sometimes. In the Patrick Matheny case, when it was in the papers and concerns it leaked out of the shroud of secrecy surrounding the manner of his death, he had been cremated within 24 hours and there was actually zero opportunity for investigation. The only investigation was limited to telephone calls talking second-hand to a person reporting what had happened.

Dr Stevens: Last year the doctors were present at the time the medicine was taken, not necessarily at the time of death but the time the medicine was taken, 29 per cent of the time. What would you think of a surgeon who was present at surgery 29 per cent of the time?

Ms Bell: In Oregon if a patient is terminally ill and dies, one of my hospice nurses can call the medical examiner and the coroner and all it takes is for the hospice nurse to say "This patient has died", it is

not a medical examiner case, there is no autopsy required or anything because it is considered a predicted death. I am very much opposed to it, although I understand I have to work within the system. We do not even know that some patients have taken the medication. The family will call us and say "My husband has died" and because they were on hospice care and it was a predicted death, we call the coroner and that is the end of it. It is not listed. When I said that patients have the medication and do not take it, and that is true, but my concern is the medications are left in the home because there is nothing in our Oregon law or statute that requires that medicine to be returned or disposed of. That has been one of my biggest concerns because who knows who has access to that at that point.

Dr Stevens: An assisted suicide death is not recorded on the death certificate in any place.

Dr Hamilton: Some of the same assisted suicide people that you heard testimony from this morning put on a class about assisted suicide and one of the speakers in that class described a case where the dying process was so grotesque that the woman called 911 because she could not tolerate seeing her husband dying in agony from this overdose. The man was taken to the emergency room and resuscitated and sent home but later he died from other causes. They reported this case. Fortunately, my wife tape recorded it, which she was allowed to do in a public classroom, and George Eighmey, who some of you may have met last night, who is the executive director of Compassion in Dying in Oregon, went on a local radio show, the Lars Larsen show, and said that it did not happen, that my wife was delusional, that was not the case. Fortunately, Mr Larsen said "We do have the tape recording" and played it and he dropped off the air. He avoids that case now. That case is a documented case that they presented. After that, they started reporting a few after Sherwin Nuland, who is a pro assisted suicide Professor of Surgery at Yale in the *New England Journal of Medicine*, said that the Oregon reports of no complications are not credible and the Dutch reports are.

Q958 Lord Joffe: Your organisation, the Physicians for Compassionate Care, I think you said it is there to educate?

Dr Hamilton: Yes.

Q959 Lord Joffe: It is a campaigning organisation?

Dr Toffler: Our primary purpose is educational. I am a co-founder as well. There was a ballot measure underway and we formed a 501(c)4- Yet such political activity is the smaller part of what we do— For example, in this very building we held our first

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dinner at which we had an out of town speaker, we had Dr Fenigsen from The Netherlands who has recently published a book on this topic of the government reports in Holland, who came to speak in this very area. Our primary purpose was to start an organization where we could support one another, those of us who would like to defend a consistent ethic, a couple of millennia year old ethic, in medicine. That was our first thing. We met, a very small group of us, in Dr Hamilton's psychiatry department and then we started networking with other doctors in the state and we have affiliates in other states, such as we have in California, Michigan, Vermont, and there are active members of our organisation from other countries.

Q960 Lord Joffe: So you do campaign?

Dr Toffler: I am guilty as charged if educating all of you about what we have experienced in ten years is campaigning.

Mr Sunseri: There is no political campaigning.

Dr Hamilton: We have two organisations. We have Physicians for Compassionate Care. Educational Foundation in which we do no campaigning, and it has the largest budget by 99 per cent, and then we have the smaller organisation called PCC in which case we are allowed to campaign and it has a miniscule budget with a bank account of about \$500, but we do not do much campaigning.

Q961 Lord Joffe: I have got a document over here which purports to be a transcript of a lecture given by Mr Petrie, Dr Hamilton and Dr William Toffler which talks all about the campaign, that was the campaign against the original legislation. As for very limited resources, it mentions that you have a campaign budget of £5 million.

Dr Stevens: That was not our organisation.

Q962 Lord Joffe: This is what the document says. It sounds very much like your document and I can read it to you. It says you have a campaign budget of \$5 million mainly provided by the Catholic Church. Is that correct or not?

Dr Hamilton: The portrayal of it is not correct. PCC participated in that campaign and may have donated around \$1,000. The entire campaign budget for another organisation—I think it was called Yes on 51 Campaign—had a \$5 million budget but that was not our budget.

Dr Toffler: With many members, hospitals, hospices, businesses, organisations that were as eclectic as the fabric of Oregon. That was where the \$5 million came from. If the document states that we raised the \$5 million, we are here and we should correct the document.

Q963 Lord Joffe: It is your document. Let me tell you what it says. It says: "At the outset, I would like to acknowledge Drs Greg Hamilton and Bill Toffler, co-founders of PCC, for their untiring and ongoing leadership in the battle against the evil of PAS and euthanasia". What does that sound like?

Dr Hamilton: We do that through education.

Dr Toffler: What I am doing right now, and what I have been doing for ten years, is trying to talk to anyone who will visit with me, and I appreciate the time you are giving me, however limited it might be, to handle what I consider the most important ethical issue that I have faced in my career in medicine. I think the absolute wrong thing to do is to try to look at this thing with a superficial cut that depends on sound bites or talking about issues where they may not reflect accurately what happened, like the \$5 million that the Yes on 51 Campaign had as though it came from PCC.

Q964 Lord Joffe: The bit that I read you is in your document, is that correct?

Dr Toffler: If the impression we are giving people is we raised the money, we will correct it, I can assure you. What we are trying to do is to talk about an issue that goes far beyond the one on which you are focused.

Q965 Lord Joffe: I do not want to spend too much time on this other than to say that this sets out very clearly that some of you gentlemen over there are saying how to campaign in the future and the mistakes made in the Oregon legislation and deals with a number of cases. Let us get on to the cases now because you have told us some stories which are truly appalling about the terrible things which have been happening. What have you done about that? Who do you report it to?

Dr Hamilton: I have reported that but there is no-one to whom to report. In the case of Michael Freeland, that case was reported. I have written a letter to the Department of Human Services offering to give them funding to do research on the psychiatric background of all of these patients and they said they did not want to look that deeply into the subject basically. We brought the case of Patrick Matheny to the Legislature. We brought the cases to the press. We are bringing the cases to you. The fact of the matter is that even in the Michael Freeland case, I even talked with the assisted suicide doctor himself, Peter Reagan, who was my classmate, but he did not do anything illegal. The abominable care that patient received is legal in Oregon. If you are planning to make it legal in your country, God help you, I hope you do not.

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Dr Toffler: Also we have just held an educational conference for two days, and brought in Dr Sulmasy, who is a renowned ethicist in the United States and we held a conference at Providence Hospital, Karen Bell's hospital system. That case was the featured part of a full hour and a half's discussion. Even in a religious hospital system, if you can still call Providence one, it took a great deal of political manoeuvring to even get them to accept talking about a simple case because it was embarrassing to think that a hospital would have a doctor caring for a patient who was willing to actively have the police help remove 32 dangerous weapons from the home and in the notes have the full knowledge that a massive overdose is sitting there and that is not removed. It is a dichotomous model that actually breaks down. To me, the greatest failure is to think somehow you can have your feet on both sides of the fence. Even if you all believe, as ministers of Great Britain, that autonomy is so powerful that anyone who wants to end their life should be allowed access to overdoses. Or you should not impose your morality by constraining them in some way, like has artificially been happening here in Oregon, and I say artificially because we have not found a case yet that has to come to public light that has met the criteria that is so eloquently expressed as being a model legislation that you should adopt.

Q966 Baroness Jay of Paddington: I am sure Lord Joffe has some questions which are extremely well-founded in reading but mine are really in response to the points which have been made in the conversation this afternoon and really address Dr Toffler. There are two things, one which is practical and one which is perhaps more broadly philosophical. I was interested that you said in the paper you have submitted that you feel the act has degraded the quality of medical care and yet in the very brief time, admittedly, that we have been here we have visited a hospice and talked to a lot of people involved in palliative care, and you have a representative here this afternoon from what is clearly an effective hospice care system, and you have spoken in your documentation about Cicely Saunders and her beacon of good practice, as it were. Why do you say that what has happened has degraded medical care? The second question which comes out of what you said is about abortion. What is your position on the whole approach on this issue, is that related to this?

Dr Toffler: I am excited about everything that is positive that is happening here in this state and in every state. Oregon had excellent care before assisted suicide was passed. When this was passed

in 1994 we had the highest or one of the highest opioid per capita rate of usage.

Q967 Baroness Jay of Paddington: You had the same number of hospices.?

Dr Toffler: Roughly the same number of hospices. I am ecstatic about any progress that we make in end of life care, that is what Physicians for Compassionate Care is all about. On the other hand, there are things that are not so reassuring, such as this article on Increased Family Reports of Pain and Distress in Dying in Oregonians 1996-2002. Susan Tolle, who you have heard from already, is one of the co-authors.

Q968 Baroness Jay of Paddington: It is a pretty black and white statement that it has degraded the quality of medical care.

Dr Toffler: I mentioned specifically this week where I think it has been adverse when a patient calls and has no confidence in the motives of a doctor. Personally, I have had patients who had debilities who were treated differently by my colleagues—as well intentioned as they might be about trying to make guided decisions, in one case I can recall a woman who had burned out juvenile rheumatoid arthritis, who was in her mid-40s with pneumonia, who did not want to be let go but was never given the opportunity to make it through her very first case of pneumonia with respiratory support because people did not value her body that was diminutive, but she was a woman who in her residential care facility was in an electric wheelchair and loved to rule the roost, she enjoyed life, she had chain smoking as a habit and this was her first episode of pneumonia.

Q969 Baroness Jay of Paddington: Obviously I do not have the anecdotal evidence to respond to that.

Dr Toffler: I say that the care is degraded when some of my colleagues, and I do not necessarily know which ones, are treating some people's lives as less valuable. When you get right down to it, as I did with Nick last night, I said, "We have a difference of opinion. I have an unabashed belief that all humans at all stages have an inherent worth",—

Q970 Baroness Jay of Paddington: Is that a religious belief?

Dr Toffler: I did not say anything about religion.

Q971 Baroness Jay of Paddington: I am asking the question.

Dr Toffler: My colleague, when he writes an order for an overdose, is behaviourally saying exactly what Dr Stevens said.

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Q972 Baroness Jay of Paddington: I am sorry, I do not know who Dr Stevens is.

Dr Toffler: Dr Stevens is the oncologist who shared the anecdote of his wife.

Q973 Baroness Jay of Paddington: I am sorry, I thought you were talking about someone else.

Dr Toffler: I am speaking about Dr Stevens and his wife—who were offered an overdose by one of my colleagues in the State of Oregon to devalue his wife's life. That is what I am speaking of when I talk about degrading. We used to have a consistent ethic and this was not in doubt, that is what I am getting at. What is more, as the numbers go up, as more hospices perhaps compromise their consistent ethic—I have confidence in the Providence Hospice, that is the only one I know of that has publicly said that they will not go down this path. Maybe there are others but I have a lack of trust. I have had to say to a residential care facility, “Do you have a policy on this paradigm because I am concerned if the doctor on call has this ethic”, and that was indeed a concern I had for my parents. I hope I am answering your question.

Q974 Baroness Jay of Paddington: You are, yes, indeed. Can I just ask you very briefly, because I know my other colleagues want to come in, you brought in the issue of abortion, what was the relevance of that?

Dr Toffler: It was an analogy that I think I was making with respect to having difficulty having open and honest discussions about the risk benefits. In my university now we have a topic that we teach to our second year students called Controversies in Medicine: Abortion. It was very difficult to have that come into the curriculum because the prevailing mentality was that it would be divisive. We have been successful and we have given national presentations on how you can talk about subjects like assisted suicide. There is also a Controversies in Medicine section on assisted suicide where we allow people to have an open discussion, but that is rare. That is not something that happens to the degree that I believe it should. That is what concerns me and that is what I shared with Dr Gideonse and with Richard Leman: why do we not have openness about what is going on.

Dr Stevens: I am Chair and Professor of Radiation Oncology at the Oregon Medical School. I most humbly say that I probably know more about this than anybody in the world. I have read and studied thousands of articles trying to be a scholar on this subject of assisted suicide and euthanasia. I hope you will read what I have prepared. I have offered to give a major lecture on this at the medical school but I have not been permitted to do that.

Dr Toffler: Nor have I. We are both full-time faculty and have both been there for over 20 years now. I have been invited to speak internationally about the topic but I have yet to be invited in my own medical school. Susan Tolle never invites us because we have a point of view and the only point of view is one that accepts this is a paradigm.

Dr Stevens: Susan Tolle wrote an article earlier this year that said that the number of patients dying with moderate or severe pain in Oregon had doubled between 1996 and 2002, that is documented.

Dr Hamilton: She has also come out with a report saying that the increase in opioid use in Oregon—

Q975 Earl of Arran: It is perfectly obvious from the conversation so far that in no way are you as a group of five people ever likely to condone this facility for even a few patients who want an alternative end to their life. What is your agenda? What are you hoping to achieve? Are you hoping to stop this in Oregon?

Dr Stevens: I am a cancer doctor and I view this topic, assisted suicide and euthanasia, as a cancer. I think there is a great analogy to it: cancer is autonomous and we are trying to keep assisted suicide from spreading.

Q976 Earl of Arran: What are you hoping to achieve? Do you want to stop this in the State of Oregon, is that your agenda?

Dr Stevens: It may be the next generation that does it. I have tried to educate myself, I have tried to educate my colleagues and other professionals, both here and internationally.

Q977 Earl of Arran: You want an end to this, full stop?

Dr Stevens: Yes.

Q978 Earl of Arran: Tomorrow if possible, in spite of the fact that there is general support across the state for it?

Dr Stevens: Support has been decreasing. A New York Times' poll two weeks ago said for the first time there has been a significant decrease in the number of those that they surveyed. This was a CBS New York Times' poll.

Q979 Baroness Hayman: Of Oregonians?

Dr Stevens: This is nationally. This was a CBS New York Times' poll.

Q980 Chairman: Across the United States as a whole?

Dr Toffler: Correct. It is not the first time but it is the first time it is below 50 per cent.

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Ms Bell: My agenda would be that we would be promoting palliative care and hospice care to the extent that people would not even see that they need to do this. If it stayed on the books in Oregon, so be it, but I would like to see good palliative care, good nursing care, good medical care provided to patients and families and they would not even want to consider this as an option. That is what I think needs to be promoted, that we provide the level of care people need.

Q981 Chairman: Can you help us a little further as to why do you think that might happen? Is the idea that if the palliative care arrangements were as good as you would like them to be, no-one would need to fear that they would get to a stage in their illness where they would be suffering from unbearable suffering, either pain or in other ways?

Ms Bell: I do believe that. I graduated from nursing school in 1963 in the days when patients were not told that they were terminally ill, generally used Demerol, and you could probably spit on the patient—excuse the expression—and did as well with pain management as what we are doing now. I have been involved in hospice for well over 20 years. We provide much better care and patients are not afraid. My grandfather did not even know he was dying and he died a very painful death. It was in the early 1960s and we did not treat pain very well then. Physicians now rely heavily on hospice staff. They will call the hospice nurse and say, “What would you recommend” or the hospice physician and say, “How should I manage this patient?” The quality of care has improved tremendously. In the early 1960s and even in the 1970s patients did not die at home, they all stayed in the hospital, but now they are home, being well taken care, they have the support of the families and there are very positive feelings about it. I do believe that if we support this, which we have done in Oregon, hospices in Oregon have probably doubled in the last 15 years—

Q982 Baroness Jay of Paddington: You would not agree with Dr Toffler’s statement?

Ms Bell: Not necessarily, no, I would not.

Mr Sunseri: I would like to address the question about the agenda. I believe that there is a bigger picture here and that is the picture of progression which Dr Hamilton alluded to briefly. Today we are talking about physician-assisted suicide. If you look at what happened in The Netherlands they started with physician-assisted suicide and they moved to euthanasia and when they moved from euthanasia they moved to doctors making determinations based on the need for hospital beds, who they were going to eliminate, and then it got to the place where they

did not even consult with the families, they just eliminated people. I believe that we have got a serious, serious situation on the horizon. If you look at the writings of the people who lead this effort in Oregon—Derek Humphry and Barbara Coombs Lee—they will tell you from the very outset that this is not where they intend their agenda to stop, they intend to move this to euthanasia because that is where it is 100 per cent effective and where will it go from there? It will go exactly to where it has gone to in The Netherlands. To answer your question on my agenda, if I were capable of stopping it in Oregon today I would because I believe it is unnecessary. The changing attitude across this country where less and less people are supporting this is because more and more people are being educated because people like these good doctors are truly dedicated to bringing out the truth, the facts of what is happening. You have all been subject to some deceit, I believe, in the fact that you were told that with 200 cases there have been no complications. You have already been subjected to that. You may be willing to believe or not but in the State of Oregon those who control this also control the record keeping and they have an agenda. They do not want anything negative out in our newspapers or on our television waves saying that this is failing. These are the people who have the facts and, unfortunately, there are some people who are not willing to listen to the facts in our state but more and more the sentiment of the people is changing because they are being educated as to what is the truth.

Dr Stevens: Compassion in Dying is really controlling the information. George Eighmey, who I saw you met last night, stated on June 1st in an article in the New York Times that he had been present at 25 of the assisted suicides in Oregon. Another one of their individuals said that she had been present at 20 of them. It is really not the doctors who are running this, it is Compassion in Dying volunteers who are in place and they do not like to say anything that is going to be embarrassing to them.

Q983 Baroness Hayman: I would be very grateful if you could let me have the documentation about these attempts to broaden the law in Oregon because it is an issue that I have explored with witnesses and have not had any response about attempts.

Dr Hamilton: We have the written documentation.

Q984 Baroness Hayman: That is actual legislative proposals, is it?

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Dr Toffler: There are several different levels of documentation. I read the book by Derek Humphry before I debated him in 1994, *Lawful Exit*.

Q985 Baroness Hayman: Could I stop you for a minute. You talked to me about Derek Humphry last night and I did not quite understand his locus. I understand he is an immensely potent figure for you but what is his locus in terms of either being a legislator or a state official?

Dr Hamilton: He is the founder of the Hemlock Society.

Q986 Baroness Hayman: I know who he is.

Dr Toffler: We would not be sitting in this room today if it were not for Derek and Ann Humphry, Ann being his second wife who became despondent enough that she ended her life as well. She had breast cancer.

Q987 Chairman: He was the founder of the Hemlock Society?

Dr Hamilton: Yes. He said that the goal is to get oral overdose, which they know does not work, and then through judicial revision to bring in euthanasia. That is in an article published in one of their publications.

Q988 Baroness Hayman: I can understand that is his agenda, but the citizen's initiative that brought forward the Oregon legislation, he orchestrated that, did he?

Dr Toffler: Yes, he did. There was a small group of people who met at a home within five miles of where we are sitting. They met repeatedly over the course of a year: Barbara Coombs Lee, George Eighmey and Derek Humphry. They got very upset with Derek Humphry because he was too candid and too ingenuous about his agenda. Barbara Coombs Lee is a very much more clever, more effective, politically astute person. She recognised that she could not go at it as openly as Derek Humphry had gone, so while he started the movement and was a very effective force in developing and learning what worked and what did not and moving forward an agenda campaign, Barbara Coombs Lee tried very hard to put a lid on that kind of candour because it does not serve their goal well.

Q989 Baroness Hayman: We are into motivation here, which is extremely difficult for us to assess, as you will understand. In terms of what is on the record, I understand that there have been several attempts through the legal system to challenge the law. I was just asking whether, on the record, there were any attempts to extend it. I would be very grateful for the documentation. Could I just move

on to one other issue that I was very interested to explore with you which was about the contention that one of you made that of the 171 cases recorded so far, there was not one that had met the criteria.

Dr Toffler: Of the ones that have come to public attention, all we know are those 171 cases and we know very little detail about that other than some took secobarbital and some took pentobarbital, that is the level of detail we know. We have self-reported second hand, sometimes third hand, report of how long it took for a person to die. The amount of demographic facts that are required to be reported are six:: name, address, diagnosis, the overdose and then it is up to a phone call perhaps to explore 15 other factors.

Q990 Baroness Hayman: I understand the system but what was said was "fit the criteria of the legislation", I did not think the legislation laid down how long the patient had to take to die.

Dr Toffler: It does say that you are limited to patients who are competent to take care of themselves. There was a report by a Board Certified psychiatrist who works at my institution—I know that from inside knowledge, not from the Board of Health Division report—when Dr Ganzini interviewed a woman she could not tell who was the person who was requesting it, was it the daughter or the patient. The daughter seemed to be coercive.

Q991 Baroness Hayman: In those cases where to the lay person it seems like an allegation of serious medical malpractice, have they been reported to the Board of Medical Examiners?

Dr Stevens: It is in the press.

Q992 Baroness Hayman: There is an awful lot of stuff in the press.

Dr Hamilton: Making a malpractice claim in this instance is outlawed by Oregon law. The Oregon law says that you cannot accuse someone who participates in the assisted suicide law in good faith compliance, not malpractice—malpractice is a matter of medical standard, not of good faith compliance—you cannot bring a medical lawsuit against him.

Q993 Baroness Hayman: Not a lawsuit, but I understand there is a regulatory body that is concerned with the practice that has indeed had four cases that have been reported and they have investigated. I am asking whether—

Dr Hamilton: We report them but they are not investigated. That is your answer. I have reported it many times, and that is the answer.

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Q994 Baroness Hayman: Could I ask how many because we did have very specific evidence on this about four cases, all of which were reported, two of which ended up with letters and two of which did not?

Dr Hamilton: The reporting bodies are the bodies that are protecting the institutions of Oregon, covering up their policy. We have mentioned, published, discussed, written letters about, numerous cases.

Q995 Chairman: To the Board of Medical Examiners?

Dr Hamilton: To all kinds of people.

Q996 Chairman: In particular, have you written about specific cases complaining to the Board of Medical Examiners?

Dr Hamilton: The Board of Medical Examiners favours assisted suicide and they do not consider—

Q997 Chairman: I am not asking about their policy, I am asking have you written to them to complain about any specific case.

Dr Hamilton: No. I am educating the public about it because I think the Board of Medical Examiners is failing on this because the Director of it is in favour of assisted suicide, in my view.

Q998 Baroness Hayman: Ethically, how do you justify not reporting these cases?

Dr Toffler: You may not trust the papers but that is the level of disclosure we have sometimes, when a family comes forward and is willing to tell the facts about the case. That is how we found out about the Kate Cheney case. Whether you or I believe the papers, the families are not refuting the facts, Derek Humphry is not refuting the facts when he was reported in the *New York Times* as saying “We have taken the first step, we are on our way to the next step”.

Q999 Baroness Hayman: He is not a doctor. That is a political position.

Dr Toffler: Those are the facts. A brother-in-law helped the patient to die in the Patrick Matheny case. No-one is debating the facts reported in the paper. What is the case is that these facts by themselves should have sparked an investigation without having to write a letter to anyone because it is public information.

Q1000 Chairman: I do not know the details of the remit of Board of Medical Examiners but I understood that they depend on receiving complaints. If that is correct, then surely if you have a basis for thinking that in any particular case there

is conduct which occurred which is subject to censure, it would be right to bring that in a letter to the Board of Medical Examiners? You say they are in favour of assisted dying but their responsibility is to deal with complaints and if they do not get a complaint they cannot investigate it.

Dr Hamilton: The law in the Oregon statute says it is against the law for us to censure someone. It is against the law for me to formally censure somebody like Peter Reagan for giving a patient an overdose when she is depressed. It is against the law. You can read the statute.

Q1001 Baroness Jay of Paddington: Can I just interrupt and say that if you are depending on the press, surely you are not being asked to give a value judgment if you simply forward a press cutting to the Board?

Dr Hamilton: My ethics were questioned because I am not reporting this. I am saying that it is illegal for me to report it or for any health care provider to censure a colleague for participating in assisted suicide, that is how the law works.

Q1002 Chairman: That is not quite the same thing. I would just like to get to the bottom of this if I could. To censure somebody for participating lawfully in assisted suicide is one thing, but if you are saying, as I understood you to be saying, that at least in some cases what happened was not authorised by the law, that is a different kind of complaint and, so far as I have heard from you up to now, it is not in any way precluded that you should make a complaint of that kind to the Board of Medical Examiners and they have a responsibility to deal with it when it comes in.

Dr Hamilton: In the Freeland case I did not make any accusation that anything illegal was done. The case was so shocking that you and everyone else who has heard the case think that it should be illegal, but it is not.

Dr Stevens: The Board of Medical Examiners took the case of Dr Gallant who in 1996 gave a lethal injection. The Board of Medical Examiners suspended his licence for two months for euthanasia.

Dr Toffler: Which was absolutely illegal.

Dr Stevens: The county attorney said that he could not get anybody to convict him based on the atmosphere in Oregon.

Dr Toffler: I just want to make one point if I can. The idea that the Board does not react to newspaper press, whether it is someone complaining in the press that they are not getting adequate pain relief or someone is over-prescribing prescriptions for marijuana, I think is disingenuous because they

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would pick up on press releases that were variant from standard medical practice, and have.

Q1003 Baroness Hayman: Going on to that case, by describing it you obviously accept that physician-assisted suicide existed in Oregon before it was illegal, when it was illegal?

Dr Toffler: I have no specific knowledge of that.

Q1004 Baroness Hayman: Except for this one case.

Dr Stevens: This was euthanasia after the law had been passed.

Ms Bell: I do know that has been done.

Baroness Hayman: And that euthanasia happened, at least in one case?

Baroness Jay of Paddington: Dr Gallant?

Q1005 Baroness Hayman: Yes. Do you have any view about the argument that is sometimes put that given that doctors were assisting patients in the past and that the demand was there, and that this was totally unregulated in any way, however inadequate, and I understand this depth of feeling about the adequacies of reporting, that there are built into the statute some safeguards and some regulatory processes in the current situation and it is unlikely that there has been an explosion of cases given that we are talking about 171 in the whole course of the legislation and that this existed as a phenomenon beforehand?

Dr Toffler: Why do you say that there is unlikely to be an explosion, based on what?

Q1006 Baroness Hayman: I would be very interested in any evidence you can give me of under-reporting of cases under the Act.

Dr Toffler: Dr Hamilton has given you a case that never showed up in the Oregon Health Division's report of a 911 call.

Q1007 Baroness Jay of Paddington: One.

Dr Toffler: We do our best to educate about things we know. Ken will tell you the facts in a second about this very question but we do not have a network out there. Richard Leman said they did not have the funding to do this at the Health Division. We do not know the answer to your question. You may say why accept this at face value, why would anyone not do this? I can tell you why. It is much easier to simply give a couple of prescriptions that are supposedly for sleep and say "Just keep these for a couple of months and then you will have enough to do yourself in", why would a doctor bother to report it?

Q1008 Baroness Hayman: That would have been pre-legislation and post-legislation.

Dr Toffler: In The Netherlands, it is at least ten per cent of the deaths. We are students of history and we can see where it has gone from a very rare case in The Netherlands to being a fifth of the deaths in The Netherlands are in some way, passive or active, euthanasia. It has come to light this week that we have up to 12-year olds where a committee can make judgments about whether they should actively end their lives. This is astonishing, even to my colleagues who have been neutral up to now about saying anything in the paediatric department at Dornbecher. They have come out this week and they are just astonished that this is where it has gone in The Netherlands. The number of deaths has gone up virtually every year and why should it stop? We have celebrated the fact that we have managed to slow the trend here in Oregon. We have celebrated the fact that we have educated others in other states not to go down the path that we believe has been detrimental to our field of medicine, our profession, our patients.

Q1009 Baroness Hayman: At the moment you have one in 1,000 people and you have very good terminal care in the hospice but even in your hospice, with very high quality care, you have said that there are a couple of patients who have gone down this route?

Ms Bell: Right.

Q1010 Baroness Hayman: That takes me to the other question. I understand your view that all pain can be controlled, and I think you were talking of physical pain. I wonder whether you accept that there are some patients, however small in number, for whom the distress of the circumstances in which they find themselves, whether it is incontinence or loss of what they view—maybe they should not—as their dignity is beyond the reach of clinicians such as yourselves?

Ms Bell: I agree with you, that is true. It is distressing to think that and I would like to think that we would be able to help those people see the value of their life and the quality of their life so they would not make that choice. As opposed as I am against this measure, I also recognise that I cannot say what I might do if I had some horrendous situation. I would like to think that I would never do that and I would have the care that is the same as I am providing to people now. I have to agree with you. At the same time that we have had two patients who have opted to do this legally, we have had patients who have chosen violent means to end their lives in the past year, which surprises me knowing that there are other choices for them. I think there are going to be people who will choose this path whether it is legal or illegal.

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Q1011 Baroness Finlay of Llandaff: Can you just clarify that for us. We had been told that there had been no violent suicides?

Ms Bell: That is not true. In the organisation that I work for, we have had two patients in the last six months who have shot themselves.

Q1012 Baroness Hayman: We were told that there were none.

Dr Stevens: In terms of uncontrollable pain, this is a book edited by Barbara Coombs Lee called *Compassion in Dying* and on page 60 one of the volunteers said that she had been present at 20 deaths. She says “the people I have worked with have not been in uncontrollable pain”.

Q1013 Baroness Hayman: I think it is the use of language here that is perhaps difficult. We all have our anecdotes and experiences. Pain control is not the whole picture, physical, measurable pain is not the whole picture of the distress of an individual.

Ms Bell: The suffering.

Q1014 Baroness Hayman: I think that is what the hospice movement is about really, understanding holistic care.

Dr Stevens: The poster child is the person in uncontrollable pain and we know that is not the case.

Q1015 Chairman: That is not a condition of the Oregon law, is it?

Dr Hamilton: No, it is a condition of the Bill.

Chairman: I am talking about the Oregon law.

Q1016 Lord Joffe: Just coming back to reporting. You do recognise as doctors that the right place to report to is the Oregon Board of Medical Examiners, do you not, if you have concerns about the appalling cases which you have raised where there is medical neglect and all sorts of other allegations? You do understand that. You have reported once to them, is that right?

Dr Hamilton: I am here to offer my expertise, not to be cross-examined by you or accused by you and I will not tolerate this kind of questioning. Someone else can answer it.

Q1017 Lord Joffe: Let someone else answer it.

Dr Toffler: I take care of patients and in the last two years I took care of my mum and dad who died. My mum said things repeatedly like “I want to die? Why does not God take me?” How I responded to her had everything to do with how she valued herself. The first few times she did this, and she did this so many times that even with the currency problems we could probably all go for lunch if I had a dollar for

every time she did that, I said, “Mom, tell me what is going on?” and within a few minutes I was able to dissuade her from having the sense that her life was over. She became increasingly demented. When people say things like “I want to die”, what does it really mean? Does it mean “I want Kevorkian to come” or does it mean “I feel my life no longer has a meaning”? Do I reassure them or do I collude with their feelings, essentially? How do I respond? I talked about some of these things once in a meeting with 30 people at a talk I was giving at a nearby university and one of the psychiatrists came up and realised that she was responding to her own parents was going to change based on not accepting the content. When people say “I don’t think I can go on living, I am fearful that I cannot cope”, do I respond, “I will help you, I will be there. I will be a supporter” or do I respond at a content level, like Kevorkian would, and say “Gosh, you have said this several times, let me to help you end your life”. My concern is this: my colleagues do not respond with a consistent discipline about what is the process behind a request. It is not being taught explicitly and, in fact, if I were to try to teach this concept in our medical school, many would say that my trying to accept the word of the patient when they do not is something I should not do and I am imposing a judgment. My experience so far, and I have had no exceptions to it, even a Hemlock Society board member I took care of did not fail to respond to my recognising her worth and changed her behaviour with me for at least the time I took care of her.

Q1018 Baroness Hayman: How do you deal with someone who does not say “I want to die, do something, give me the prescription”? How do you deal with the person who says, “I want to cease treatment”, they are also devaluing life in that sense?

Dr Toffler: There is a bright line between the reality that we are all terminal and you have every right, as I do, to refuse kidney dialysis, surgery or intervention, chemotherapy, Dr Stevens’ radiation therapy, and that is your right. My neighbour had pancreatic cancer and had a wife with early Alzheimer’s, when he found he had pancreatic cancer he decided to make arrangements for his wife’s care and chose to stay at home and allow the natural course of pancreatic cancer to end his life. He had no intervention, he died peacefully at home with support, hospice support at home. He did not choose surgery, he did not choose radiation, he did not choose chemotherapy, and that is fine, that is normal, we are all terminal.

Q1019 Baroness Hayman: If he had chosen to say “I am in extreme pain. The dosages that you are giving me are not helping at the moment, I would

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like you to give me further pain relief” and you said, “I can do that, but I have to warn you that if I do that it may have an effect on the length of your life”—

Dr Toffler: I am glad you bring that up because I would do exactly that. I would say “Let us increase in the dose” and we would have opioid progression generally by about 50 per cent of whatever the previous baseline was and generally that will give you a response and if not I will shift medication, I will get pain consultation or whatever else might be needed. The truth is when we studied this phenomenon about whether I hasten their death when I use appropriate pain management strategies, people actually live longer, they do not have hastened deaths. The doctors who study the issue know that this rhetoric is specious, it is part of the speciousness that Mr Sunseri talked about when he spoke about what is misleading many people who do not study the issue carefully.

Q1020 Baroness Hayman: I know it is a contentious issue.

Dr Toffler: It is not contentious. Susan Tolle would agree with this. If you give appropriate pain management people cough better, they expectorate better, they do not get pneumonia as easily, they are more mobile, so they are not as constipated, they do not have bowel obstruction. Aggressive pain management, while it has a risk, admittedly, of possibly having untoward effects, the chances of it helping are far greater. It has to be done correctly. It cannot be done, as one of my colleagues in town

did, by having a drug she had never used by IV for supposed pain control and it was a sedative, it was not a pain medication. Clearly walking away from a drip, that you would never do if it was an anaesthesia case, would be malpractice, to hang a drip and go home.

Mr Sunseri: I would like to address your question about reporting to the Medical Examiner, Lord Joffe. I hope that you will appreciate the frustrations being expressed here because these gentlemen have had to work with this and I, as Chairman of the committee, also had to work with the Medical Examiner. I will tell you openly that our Medical Examiner here, and for some time, has been less than willing to work with those who have a different opinion. As the Chairman of the committee I requested numerous types of documents and personal interviews with him and he was less than responsive either to the Chairman of the committee which was considering this, when we were looking at some very serious testimony. In defence of these men, I think that their reporting these situations to our Medical Examiner in the State of Oregon presently would be absolutely worthless because they would not garner the response that would even be appropriate to the issue itself.

Chairman: I think we are going to have to stop. Our time has now come to an end and we will have to move on. I would like to thank you all for coming and for your helping us, and also for the documents you have produced for us, it is very much appreciated that you have taken such an effort to let us know your point of view. Thank you.

FRIDAY 10 DECEMBER 2004

Present	Arran, E	Joffe, L
	Finlay of Llandaff, B	Mackay of Clashfern, L
	Hayman, B	(Chairman)
	Jay of Paddington, B	McColl of Dulwich, L

Examination of Witness

Witness: MR JIM KRONENBERG, Chief Operating Officer, Oregon Medical Association, examined.

Q1021 Chairman: As you know, we are appointed by the House of Lords to examine and report upon the Bill that Lord Joffe has proposed which deals with matters that are not entirely unrelated to the practice that you have here in Oregon. We would like you to make a short presentation about your position in relation to the present practice, if you feel so inclined. A note will be taken by the shorthand writer and our report will have appended to it the oral evidence we have taken, including your evidence. In order to ensure that the transcript appears to be what you said, you will get a chance to correct it. We will have some questions from my colleagues when you have finished what you have to say. Just a short introduction is what we want.

Mr Kronenberg: For the record, my name is James A Kronenberg. I am Chief Operating Officer of the Oregon Medical Association. We have 7,200 physicians and surgeons who are members of our organisation. We are a voluntary organisation. It is not part of the licensing process. It is a voluntary professional association. We have an affiliation with the American Medical Association.

Q1022 Chairman: That is United States-wide?

Mr Kronenberg: Right. Our organisation was founded in 1874, so we have just celebrated our 130th anniversary. The specific issue of physician-assisted suicide is something that I have followed throughout my career. I have worked for the Oregon Medical Association since 1969. I was 12 when I started! Actually, that is not true. After you work for a group of professionals of any kind, and physicians specifically, after a while you think you know pretty much how they think and how they would react to changing conditions. In 1994 we had the ballot title which resulted in the gathering of signatures, and I am sure you understand that process, that put the Physician-Assisted Suicide Bill on the ballot for a vote. That had just been issued in March shortly before our annual meeting in 1994 and, not much to my surprise, there were a couple of resolutions that were introduced by physicians which asked us (1) to affirm the American Medical Association's longstanding opposition to physician-assisted suicide and (2) specifically to oppose the measure. Much to my surprise, the debate was far

different than I expected. I was taken by the number of physicians who, in many cases, used their own clinical experience in specific cases but also with members of their families who had grave doubts that there were not occasions when assisting a patient in their death at the end of the life might be appropriate. Certainly most people did not feel that way but we were struck by the number of physicians in that representative body of about 150 delegates from throughout the state who spoke on this issue. As a result, officially we chose to take no action on either of the resolutions, thereby saying that we neither supported nor opposed the AMA's position and we neither supported nor opposed the ballot measure. As you are quite aware, in November 1994 the people passed the measure by a very, very small margin, a matter of a few thousand votes. Both those opposed and those supporting the measure, in large measure blamed the Oregon Medical Association for that, since our position was absolutely unique in the entire country. No main line medical organisation had ever taken a position supporting physician-assisted suicide or, for that matter, being essentially neutral on it. I am sure by now you are familiar that in the ensuing years the ballot measure was immediately challenged in the courts and in 1997 the Legislature, which at that time was very conservative and in large measure opposed to the Bill for reasons that were politically not very wise in retrospect, chose to refer it back, in essence asking the voters "Are you sure you want to do this?" As you will also be aware, the voters were somewhat offended by that and proceeded to affirm the Bill by a three to one margin, a very large margin. At about the same time, the United States Supreme Court declined to rule on a previous Ninth Circuit Court decision that in essence said it was within the purview of a state to regulate physician-assisted suicide. The measure essentially became effective in late November 1997. I am sure by now, having reviewed your agenda for this visit, that you are very much aware of the experience that we have had with physician-assisted suicide here and I will not reiterate that. Instead I prefer to talk about how we, as an organisation and practising physicians, have tried to cope with it, given the fact that like the rest of society there are huge variations in opinion

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regarding physician-assisted suicide. I thought one of the things that would be useful for you is an excerpt from our *Medical Legal Handbook* which is something that most of our members refer to every day. Rather than try to give physicians some kind of moral direction or otherwise, we try to give them legal direction to the effect that if you choose to do this at any time, these are the things that you have to do to strictly obey the law, and clearly if you do not strictly obey the law you still may be subject to prosecution for manslaughter. That has remained our position since 1994, nearly ten years now. Judging by my anecdotal experience in speaking with physicians about this, sometimes daily, I would say there is a small group of physicians who are represented by Dr Toffler and others, who you met earlier, who are adamantly opposed to this measure, either on moral grounds or on ethical grounds and they feel very strongly about it. There is another relatively small group of physicians who you have also met, and I would say a good advocate for the other side is Dr Rasmussen, who feel that this is not only appropriate but medically and ethically the right thing to do in certain cases. It is my judgment that the great majority of physicians in this state, practising physicians, perhaps 85 per cent of them, are relatively ambivalent about the issue, in many cases because it does not affect them. If you are a radiologist, for example, or an anaesthesiologist, a psychiatrist, although that may not be a good example, it is something you will never be faced with. It gets down to family practitioners, internists, those physicians who we look to for our care on a regular basis and then some of the medical and surgical sub-specialties, certainly oncology would be one, who are more likely in the course of their career to be faced with the dilemma of what to do. In talking with many of them, my experience is that they do not know what they are going to do until they are faced with the circumstance. Also, it is my experience that in the great majority of cases, physicians who choose to move ahead do it on the basis of a long relationship with the patient. Typically that would be one's primary care physician who they have known and worked with for a long time where they feel they know a great deal about the patient, not only from a medical standpoint but from a behavioural standpoint and what kind of people they are. As you are aware, some physicians, even under those circumstances, choose not to participate. There are physicians who refuse to provide any assistance to a patient who wants to look at that option and the law is quite clear that they can do that and, for that matter, so can other health care professionals. Also, there are provisions in the law that certain institutions, particularly hospitals, can ban the practice on their premises, most notably the Sisters of Providence,

which is a very large hospital system here in Oregon, perhaps the largest, that has two very large hospitals here in Portland, another smaller one and then perhaps half a dozen other affiliate hospitals around the state. I think I can end my formal remarks with that. Having followed this very closely, based on the fact that I have known many of these physicians for most of my adult life who are faced with this, I think in each case it is a very difficult decision for most of them. You get the drift when a physician that you know calls and you have a nice chat about the weather and all that and then it comes around to, "Jim, exactly what do I have to do if I choose to participate in the physician-assisted suicide law?" I whip out my checklist, the guidelines, which I am going to share with you, and say "These are the things you have to do", and I admonish them regarding the fact that should they choose to proceed they need to follow the letter of the law in order to protect their own professional and personal interests. It does not happen every day or every week but it does happen fairly frequently. I take from that, that in most cases physicians who are faced with this give it very careful consideration, whatever decision they finally make. Under the law, that is not mine to know and I do not care to. I think the majority of the physicians in the state view this, as I have said, with a certain amount of ambivalence until they are faced with the circumstance and then they feel an enormous need to know just exactly what the rules are, if you will, before they make a decision about how to proceed. With that, I think I can stop.

Chairman: Thank you very much indeed, you have made that very plain to us.

Q1023 Earl of Arran: The group of physicians that you specifically mentioned who were related to Dr Toffler.

Mr Kronenberg: Yes.

Q1024 Earl of Arran: Do they have amongst them any common characteristics or common denominations? For instance, are they Catholic or deeply religious that you are aware of?

Mr Kronenberg: That is a very good question. I cannot recall exactly but I suspect you have talked to Bill Toffler, William Petty, probably Greg Hamilton and I can name a couple of others. In fact, I may have suggested to your staff that these were people you really would want to speak with because they are very articulate and feel very strongly about this.

Q1025 Baroness Jay of Paddington: Dr Stevens?

Mr Kronenberg: Yes.

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Q1026 Lord McColl of Dulwich: Dr Sunseri?

Mr Kronenberg: Yes. Dr Toffler is perhaps the most devoted religious Catholic I have ever known and I think it is fair to say that his abhorrence of not only physician-assisted suicide but abortion is based on that. I have known Bill for a long time. He has very extreme views on this, there is no question about it. I respect him for that and, as a matter of fact, I consider him a friend. If you do not talk about physician-assisted suicide or abortion, he is one of the most charming people I have ever met and an extraordinarily highly respected teacher of students and residents. Bill Petty happens to be a very close personal friend of mine.

Q1027 Baroness Jay of Paddington: I do not think we have met him.

Mr Kronenberg: His attitudes are not based on religion, this is an ethical consideration for him. By training he is a gynaecological oncologist. As a matter of fact, he supports *Roe v Wade*, which is the underpinning of our abortion laws in this country, he feels very strongly opposed to abortion. I am not sure about Dr Hamilton. I think his opposition may be moral as well, I am just not sure about his religious persuasion.

Q1028 Chairman: What about the other side, would they have any characteristics about them of that kind? I will put it very straightforwardly: do you know if there are any ardent Catholics who support the measure?

Mr Kronenberg: I think there may be one. I do not know if you have met with him or not. As a sideline, we are in the process of reviewing and updating, as organisations like we do, all of our policies and one of the policies that is very controversial is the whole body of policies that we have established over the years on end of life issues, durable powers of attorney, physician-assisted suicide and the like, and we have chosen one physician from the pro and one from the con on this issue, and one very neutral statesmanlike position who will try to come up with a policy that everyone can live with. He may be Catholic, I am just not certain. The others who I know feel strongly about this, I am reasonably sure that Dr Rasmussen is not a religious man. I do not mean that unkindly, I just do not think he sees that as part of his life. I do not really know about the others.

Q1029 Baroness Jay of Paddington: We are very getting very contrary opinions about the status and the way in which the professional oversight body, the Oregon Board of Medical Examiners, is viewed. What is the view of your organisation of them as a regulatory professional organisation?

Mr Kronenberg: First of all, generically the Oregon Medical Association, unlike many other state medical societies, does not view the Board of Medical Examiners as our cat to their dog. We have a relatively collaborative and positive relationship with the Board generally, and have over the years. It has always been our attitude that if you have a strong and effective Board of Medical Examiners whose job it is to protect the public, understanding that in general it is our job to protect the profession, if they are doing their job, our job is easier. We work very closely with the Board on legislation. I think you will find that by any measure we have one of the strongest and most effective licensing authorities in the country. With respect to the specific issue, as you are also aware the Board has very little jurisdiction over this Act because in essence, assuming the physician is following the law, they cannot take action against the physician based on his or her participation under this law.

Q1030 Baroness Jay of Paddington: They can only act on a positive complaint, is that right?

Mr Kronenberg: That is right. When those who are opposed get wind of an occasion when a physician-assisted suicide has occurred, they make a complaint to the Board. I do not know that for a fact but as you are also aware probably, as you have met with Ms Haley, its investigations and actions until they take disciplinary action are privy and not a matter of public record, which means we cannot get at them either. I have the suspicion that when those who are adamantly opposed to physician-assisted suicide find a case and can identify the physician they automatically make a complaint to the Board.

Baroness Jay of Paddington: That was not what they told us, they told us that they did not. What they were saying was they did not feel it was a legitimate organisation to regulate it because it was biased.

Q1031 Lord McColl of Dulwich: They also said on the legal side that they were not allowed to criticise anyone who was acting within the law and, therefore, they felt they could not make complaints.

Mr Kronenberg: Again, that would be a fair statement. The Board does not have jurisdiction in a matter that relates to physician-assisted suicide unless it can determine evidence that the physician has violated the law.

Baroness Hayman: No, but they can inquire and find out.

Q1032 Baroness Jay of Paddington: Taking the point that Lord McColl has just raised, given that they were apparently quite keen on using the media we asked them whether in a sense, because of their particular difficulty about referring matters about fellow colleagues in the medical profession to the

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Board, they could not simply send a press cutting about a case which they found inappropriate but they seemed not to have ever used this route.

Mr Kronenberg: You are saying that those you spoke with who are opposed do not make complaints to the Board because they do not think anything will happen?

Q1033 Baroness Jay of Paddington: Yes.

Mr Kronenberg: That is interesting.

Q1034 Chairman: There is a problem, I suppose, in that so long as the procedure is followed, the 15 days and the written request and the proper witnesses and so on, and then the giving of the lethal material, if all of that is done in accordance with the Act the Board of Medical Examiners have no jurisdiction that could in any way find fault with that because it is made legal by the law as it was passed in this state.

Mr Kronenberg: That is correct.

Q1035 Chairman: I have the impression, although I may be quite wrong, that the sort of criticism that those who are opposed to the Act want to make is that everything has not gone quite as smoothly for the patient as those who are in favour of the legislation would want to make out. It is "Once you get this material it is all quiet and confident and peaceful and there is a great general satisfaction with the whole thing". My impression is that the people who are opposed to it doubt whether that is always the case and, for example, wonder whether from time to time there is not a difficulty about the ingestion of the poisonous material and there may be sickness, nausea, in the course of taking this and the result is not a smooth and early death but rather a prolonged and unpleasant circumstance. Perhaps you can help me further about this. I can see that is not really a matter for the jurisdiction of the Board of Medical Examiners because, in a sense, it is a complication that has occurred when the physician concerned has been carrying out a lawful procedure under the Act. The criticism, the contention they have about it, is not really something that the Board of Medical Examiners would have any jurisdiction to look into. Is that in accordance with what you would think?

Mr Kronenberg: That may well be true. I begin to understand why they are saying that. You hear particularly the group of physicians you have already spoken with very often in the media talking about their concerns about this very thing and I think I understand the point they are trying to make. Without taking sides on this issue, I would say, given the way the law works, their guess is as good as mine. I am not sure that they have evidence that that is true. The only way they could get it

would be if someone in the patient's family were to decide that things did not go well and wanted to make an issue of that, for example. There has been one case, which I am sure you are familiar with, where the patient had rather advanced ALS and the question was how could he actually ingest the drugs in that state. Did his brother-in-law help him along? Other than that, I am not aware of any evidence that things have either gone extraordinarily smoothly or extremely badly in any of the cases. As you are aware, the way the law is set up there is really no way to determine that unless there is some kind of disaster. You are all aware of the drugs of choice that are used and certainly as a lay person I do not understand the chemistry but I realise how not being able to keep the medication down long enough to have the desired effect could happen. One assumes, and this may be just be an assumption, that physicians who choose to participate take the time to find out how to make the process very effective and as comfortable as possible. There are any number of recipes, if you will, available on the Internet and in other places that can be used. I do not know which ones are used. Understand that because of my position and the fact that many of these people are people I know better than casually, personally I have never had a report where there was a true disaster. Certainly that does not mean that you should infer that there has not been, I just do not know.

Baroness Hayman: Could I follow up that issue about the level of transparency and the level of scrutiny that there is because we have been given two diametrically opposite views on this. One is that, in fact, what is happening in Oregon has been very closely researched, that there has been a lot of work done by Linda Ganzini and other colleagues looking at patients who avail themselves of this option, and there has been detailed and interesting work on what has provoked them to do it, what their motivation has been, and the circumstances and there is proper evidence and records kept by the Department of Human Service and certainly there is supporting evidence that the figures are probably robust about the number of instances of physician-assisted suicide that have taken place. The other view is diametrically opposite, that this is all part of a cover-up, which I think is the term that was used, that no-one knows what is going on, that there is no transparency and terrible things are happening.

Baroness Jay of Paddington: Almost that there is a conspiracy between various arms of the state.

Q1036 Baroness Hayman: Indeed, this was in relation to the Board of Medical Examiners because of prejudice and not being willing to perform their function. I wonder if you could comment on those two opposing views?

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Mr Kronenberg: I have to speak personally in this regard, please understand that. I cannot represent the Association's viewpoint on this particular issue. I do not believe that is true. My belief in that regard is based largely on knowing physicians, where I hold a position of trust with them, who have discussed their experience in this particular case. As you look at the process that is in place, I think you have to agree that it is relatively rigorous, the various steps you have to go through to get this completed all the way. Insofar as physicians are concerned, I think that those physicians who choose to participate, and there may be exceptions but at least those physicians that I know, take this very, very seriously and feel a responsibility not only to observe the law but to do this in a way that ultimately achieves the interest that the patient has in having control of their destiny at the very end of their lives. By and large, it would be inappropriate to criticise physicians who have chosen to participate in this because they have been cavalier about this, I just do not think that is true knowing the quality of some of the people I know who have participated, certainly including the people that you have talked with.

Q1037 Lord McColl of Dulwich: If I had introduced this Bill, one of the things that I would have taken enormous trouble over was to make sure that each death was actually witnessed by the doctor prescribing. At the moment it is only 29 per cent of doctors. I would insist on that so there was real evidence that there were no complications, because anyone who tells me they do 200 procedures and there are no complications, as a clinician I would think that is unique in the annals of medicine. Is it not a pity that they did not really home in on this to make sure that it was perfectly obvious to the world that there were no problems, or if there were they were documented so we can learn from them?

Mr Kronenberg: First of all, I think we would agree that we would have to find that fellow who is doing 200 procedures with no complications and get his name for future reference. To respond: again, if I were to write the Bill, if I were to have been a part of this, and I hope I am not revealing my own personal feelings about that, I have got very good at not doing that, I would have to agree with you. I think that would be an appropriate amendment to this law if for no other reason than it would give the individual who, in essence, has been authorised by the state to take on this enormous responsibility, the responsibility of seeing it through to the end. Of course, the argument against that is that flies against the presumed spontaneity that the patient may have to choose the time and place and circumstance of his or her death. I have a great deal of respect for the people who wrote this law. They wrote a remarkable law in terms of how tight it is, but as an

individual I would have to agree that there should be some official person or entity present at the end of life.

Q1038 Baroness Finlay of Llandaff: Could I just follow that up. We saw the Oregon Department of Human Services who are responsible for cataloguing the forms submitted and personally I was surprised to learn that they have destroyed the data from the beginning of the process, they have not kept it. I wonder if you have any views on who really should be responsible for holding an archive of such data because it does not seem to fall to them? The Oregon Board of Medical Examiners, who we saw today, respond if a complaint is taken to them. I am not clear who is responsible for the clinical audit, not the financial audit but the clinical audit in terms of quality standards of care following on from the issue that Lord McColl raised of documenting the decision making process beforehand and complications that could occur.

Mr Kronenberg: The fact that the Health Division destroys the original data is news to me. I am very surprised by that. I would have thought it would be kept in perpetuity.

Lord Joffe: It was on legal advice.

Q1039 Baroness Finlay of Llandaff: I was interested that they did that, it seemed odd. I would just ask about the clinical versus the financial.

Mr Kronenberg: I think in order to maintain the confidentiality of the parties, which as you must imagine, not only for the patient and their family, but particularly for the physician is extraordinarily important. As an example, essentially when you get into a small town in Eastern Oregon where there may only be half a dozen physicians and everybody knows everybody and 75 per cent of the people in that county are Catholic, a physician who was known to participate in physician-assisted suicide in essence would be committing professional suicide in that community. From our standpoint, the confidentiality of physicians who choose to participate or, for that matter, choose not to participate is absolutely critical. On the other hand, my own personal opinion is that this is such an extraordinarily important and significant piece of social legislation that data regarding its effect over time should be saved and should be available for future study given the fact that it has to be blinded, which certainly can be done. I know a number of you are scientists and will understand that. Quite frankly, I am surprised that any of the data has been destroyed by the Health Division, that is shocking. If it was on legal advice, as you say, I think they got bad advice.

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Q1040 Baroness Finlay of Llandaff: When you said it was a piece of social legislation, I wonder if you can comment from your perspective on the social effects that legislation has had?

Mr Kronenberg: It is interesting that in the debate that we had which, since I watch public television, was not unlike the debates that your Parliament has—

Q1041 Lord McColl of Dulwich: In the House of Commons?

Mr Kronenberg: Yes. I am sorry. Excuse me. In my country the senators and representatives pretty much do the same thing. My point is in the debate that we had among these physicians we heard from both sides and a physician who was relatively young then, but is not so young now, said a very significant thing that I have always remembered. He said, “I think it is said of war, war is too important to let the generals decide. Maybe this is an issue that is too important for us to decide and our patients should decide”. That probably had more than anything else to do with coming up with the corporate decision, if you will, to be neutral on the issue because there was a general shaking of heads, “Yes, maybe this is not so much a medical issue as it is a social issue”. I have always been struck by that.

Q1042 Lord Joffe: My recollection, and it might be wrong, was that it was only the first year’s records that were destroyed because of some legal opinion. That is obviously something we must look into when we see the transcript of the evidence. The other point is it is not 100 per cent correct to say that no complications were reported. In fact, it was reported, I think it was, that two or three patients had initially regurgitated part of the medicine, but it did not have an adverse effect, and there was one other case which was reported where one patient took 48 hours to die, so it is clear that there were complications and some were reported, so that perfect doctor you are looking for is not going to be found in that particular group.

Mr Kronenberg: Having worked for them for 36 years I realise precious few of them are perfect. One of the things that has always struck me as a lay person, who has more than a passing interest in this subject at this point, is the huge disparity or the huge range in the time from ingestion until death, really a remarkably long time. I have talked to a lot of physicians who say “Well, if you take a shot of whisky, you take so many milligrams of ACE inhibitors and you wait for a bit and then ingest 50 secondal or whatever it happens to be, by the time you get them down there is little chance that you will regurgitate anything, you will just go to sleep”, and yet I look as a lay person at this huge disparity because two days seems like a remarkably long time

to go on. One wonders whether the patient was dosed right or took the appropriate dose. That is one of the things you do not know because it is not necessarily witnessed.

Q1043 Baroness Jay of Paddington: Picking up on your vivid picture of this community in another part of the state, a small eastern place with few doctors and a lot of people would know, do you have a feeling as a professional organisation that doctors who do not wish to participate in PAS have sufficient protection? Is it easy to opt out, if you see what I mean?

Mr Kronenberg: Yes. Again this is anecdotal, but in my personal experience the majority of the physicians I have counselled, and I hesitate to say that, I am not qualified to counsel people but I do know a great deal about this law, who have chosen to talk to me about it, the majority of them chose not to. I think that the majority of those chose to refer to someone else, that is my impression. Still, I am reasonably sure that a number of physicians who I have spoken with proceeded, mainly because they called later and asked more questions.

Q1044 Chairman: You must find yourself discussing a lot of matters with individual members of the Association. I have the impression from the way you have been describing it, but I want you to say whether it is the right impression or not, that this business of assisted dying has been quite a frequent subject of fairly earnest discussion with you from some of your colleagues.

Q1045 Mr Kronenberg: Yes.

Q1046 Chairman: By comparison with other subjects it is quite a prominent thing in your recollection, is that right?

Mr Kronenberg: Yes. Perhaps this will explain a little bit by way of background. Going back to 1994, what the Oregon Medical Association did that Sunday in April was essentially to say that as an organisation that represents most of the physicians in a state of the United States, we are not so sure that physician-assisted suicide is good and we are not so sure that it is bad, essentially we are neutral. The most remarkable thing is amongst other things that I do here, I am primarily the chief media spokesperson, I am usually the one who talks to the media, and that night it was remarkable. I do not think I went to bed on that Sunday night until about four o’clock in the morning. I spoke with newspapers and television.

Q1047 Baroness Jay of Paddington: London, I am sure.

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Mr Kronenberg: In London, in Belorussia, with interpreters and the like, and that went on for months. On a subject like this, if you work for 7,200 bosses it does not really matter what you say but you had better have it right. I must say, because I have been, as they say here in the United States, pretty high profile media-wise, I want to be really sure of what I say because, as I have said, we have a number of members who object to some of the things I say to the media on both sides. Without very many exceptions, I have been able to defend myself based on facts. That is why I know a fair bit about it, it is a matter of self-preservation.

Q1048 Baroness Hayman: We have had it put to us that for physicians there is a very clear and deep divide in two different places and I would like to know your view on this. We have heard from one group of physicians that there is a tremendously clear and deep divide between acceding to a patient's request to cease treatment, to cease dialysis, not to have antibiotics or whatever it is that would inevitably hasten their death, and filling in a prescription form under the terms of the Act. We have also had it put to us that actually the tremendous divide is between filling in the form and allowing the patient to take their lethal dose away and self-administer and being the agent, doing the lethal injection. If that were to be so, it would solve some of the problems about not being there, not witnessing, not knowing what happened. Whenever we have discussed this, even with proponents of the current legislation, they have said that would completely tip the balance, that would make it unacceptable. Going back to that fateful meeting in 1994, I wonder if the proposition had been for doctor participation in the final act rather than patient administration, do you think the debate would have gone differently?

Mr Kronenberg: Yes. I have thought about that a lot and my conclusion is our position on physician-assisted suicide would be the same as it was in 1970, that we opposed it on ethical and moral grounds. It is a very great leap. I think that physicians would feel the same way, that there is an extraordinary difference, at least to me, in providing someone with the means to end their life and actually ending it.

Q1049 Baroness Hayman: Let me put the patient's perspective to you, as an ALS patient I would not see that divide perhaps in quite the same way.

Mr Kronenberg: No, and thank God we are not. One of the dilemmas I have had myself is we have this essential need for fairness and equality in this country and whether it is good or bad, if you create a law that is available to some people and not all, is it a good law? I have had ALS in my family, which

I think is the reason I have thought about it, but, of course, there are other clinical conditions.

Q1050 Baroness Hayman: I used that as an example.

Mr Kronenberg: That is the one that comes to my mind. In essence, as I see it, a physician could not comply with the law completely, or its intent, and participate in the end of an end stage ALS patient's life. I do not know how they would do that.

Q1051 Baroness Jay of Paddington: Just looking at it as you are, a lay person's view, although obviously you have more experience, I think you agreed with Lord McColl that it would be better if you were writing the legislation now if a doctor, in a sense, could be present so that there was some observation of the state of the person.

Mr Kronenberg: Yes.

Q1052 Baroness Jay of Paddington: It becomes a very grey area, does it not? If you are physically present and are taking steps to ensure that this procedure, although self-administered, is effective in the way which we have discussed, not regurgitated or whatever it may be, it is an extremely grey area, is it not?

Mr Kronenberg: It is. I think you have already met with Barbara Coombs Lee who speaks about this issue very eloquently and articulately, perhaps more so than I. Speaking personally, I have always felt discomfort at putting a physician in a position where he or she was authorised to do this, but was not responsible for carrying it through—this may be a bad word. It makes me uncomfortable. On the other hand, intellectually I can understand the real issue in this legislation is to provide patients at the end of their lives with a choice, with control over the end of their lives, and to a certain degree I guess you cannot have both. Certainly, unless you hire a physician to attend you 24 hours a day for the rest of your life until you decide to proceed, it would be pretty difficult to enforce that. Still, as a lifelong Oregonian who, for better or worse, lives with this law, I think it would be better if the person who was authorised essentially to assist in this process had to see it through.

Q1053 Baroness Jay of Paddington: But you would agree that it is a grey area?

Mr Kronenberg: A very grey area.

Q1054 Baroness Hayman: Would another advantage of that be to overcome a concern that has been raised, this issue of competence being assessed at the time of the request and the prescription being filled and there is no further examination of

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competence at all, and possibly for quite a long time?

Mr Kronenberg: That is an interesting thing. Again, I am not a clinician but my response to that would be that the law is quite clear that the person at the time the decision is made to proceed after they have gone through all the steps and the waiting period has to be competent. There are checks and balances certainly, but whether the patient and physician choose to use them or not is another issue. There is an assurance at a specific point that the patient is competent. This has always been a remarkable stretch for me, that the physician has to prognose that the patient has less than six months to live, which most physicians tell me is a stretch. Two hours, a day, yes, but six months is difficult to do. I guess in response, if all the steps are followed and we have sound clinical judgment here, the time between the writing of the prescription and the patient's demise, whether they choose to use the prescription or not, is relatively short.

Baroness Hayman: Not necessarily. We have had evidence that several months have elapsed for some people and, given the large number of people who do not fill out the prescription, presumably it is

possible for a patient to become depressed, mentally ill in that time and for their competence to have changed completely but the law is silent on this.

Q1055 Chairman: It is all within six months at the very most, that is the point you are making, is it not, and that is why you say it is relatively short?

Mr Kronenberg: Yes.

Baroness Hayman: I thought we had established that the consent exists even if someone lives longer than six months and they can still take it.

Q1056 Chairman: Assuming that the six month period has expired. The six months is supposed to be a condition of the lawfulness of the procedure and if the six months expires there must be some question. From what we have heard, it might be that the material was not taken for more than six months after it was originally prescribed. I think we could be here a while and be helped continuously over that time but we have to go. Thank you very much indeed for helping us so much and for giving us personal views which we do appreciate are your personal views and not expressed on behalf of the 7,200 bosses that you have.

Mr Kronenberg: Thank you very much.

FRIDAY 10 DECEMBER 2004

Present	Arran, E	Joffe, L
	Finlay of Llandaff, B	Mackay of Clashfern, L (Chairman)
	Hayman, B	McColl of Dulwich, L
	Jay of Paddington, B	

Examination of Witnesses

Witnesses: Ms JOAN BOUCHARD, Director, Oregon State Board of Nursing, Ms KIMBERLY COBRAIN, Programme Executive for Compliance, Investigation and Practice, Oregon State Board of Nursing, and Ms SUE DAVIDSON, Oregon Nurses Association, examined.

Q1057 Chairman: We have to thank you very much for having us here. As you know, we are a Committee appointed by the House of Lords to examine and report on the Bill that Lord Joffe has proposed for assisted dying to apply in England and Wales. We know that you have legislation here which deals with matters which are at least related to Lord Joffe's Bill, so we were hoping to get some help from you about the way in which you perceive the legislation and its surrounding circumstances as working in this jurisdiction. We have got a shorthand writer here to take a note of the help you give us as we go through the matters. The transcript will be available for you to check that it says what you thought you were saying and we expect to use that as an appendix to our report, showing the basis of fact on which we reach such conclusions as we may eventually reach. We have got quite a lot of distance to go yet before we finish that. Some of us are going to the Netherlands next week where they have a rather different system in operation and we will hear about that. I just want you to understand that you can have the transcript and see that we faithfully record what you say. The usual procedure we have is if you would like to make a short opening statement saying who you are and what your position is relative to the workings of the Bill. I am not asking for your opinion about the Act or anything, that is a matter for you, but the way in which it has affected you in your work, a short presentation, and then my colleagues will have a chance to ask you to answer some questions that will be helpful to them in trying to reach a conclusion about this matter. Who is going to start?

Ms Davidson: I have prepared for each of you a folder that has in it the Oregon Nurses Association position that gives nurses guidance about how to respond in the situation where a patient asks them about this and they were willing to proceed and support the patient by giving nursing care as they go through that process, or whether they did not. What you will find in here is that position statement. What I included were four research articles, one of them coming right out of Oregon, by some nurse researchers about the experience of hospice nurses and social workers with patients who had received assisted suicide. Those two

pieces are Oregon based in the left-hand pocket. In the right-hand pocket are some other rather old pieces of nursing research from 1966–67 which explored what might be the dilemmas that a nurse would face in the situation of assisted suicide.

Q1058 Chairman: Thank you very much.

Ms Davidson: How this came about was the Bill was sent to the Oregon citizens to vote on and they voted it up at 51 per cent in favour of assisted suicide between the time of that initial vote and when the second vote that was taken, just in case we got it wrong. You need to understand something about Oregonians, and perhaps you feel the same way. We did not like that, it was a questioning of the wisdom of the body politic, I guess, and clearly did not sit well. What happened was a group of nurses within the Oregon Nurses Association came together from our cabinet. We have four cabinets: education, human rights and ethics, nursing practice and health policy. Those cabinets deliberated on how they would advise a nurse who was with a patient in this statement, and you will find that statement on the inside of the folder. There were about 20 nurses involved in that. It was adopted by our House of Delegates, which is the decision making body in our Nurses Association, and then disseminated widely in our publication to everyone. It is on our website. We receive many requests for this. Now that it is on the website we do not know from how many people, but people have asked for copies of this. There was widespread misunderstanding among nurses across the country who believed that there would be hundreds of patients who would take advantage of this possibility when, in fact, there have not been hundreds. I do not know what the number is now, I think it is in the fifties. The bigger issue that this is embedded in is end of life care and changing the level at which nurses provide that care and the competency with which they provide it. About two years ago ONA embarked on a survey of attendees at our annual convention asking them how they would rate their competency with respect to end of life care and what would be helpful to them, do they feel that their facility is doing its best in terms of that. What we

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discovered was that nurses are actively talking to patients about assisted suicide, some of them have been involved in advising the patient about it, others have been involved in terms of helping the patient get the prescription, that is they went to the pharmacy and got it, and some indicated that they had assisted in the taking of it. That is inconsistent with our position, which is that we may nurse the patient but the patient must administer the medication him or herself and that you provide nursing care as that unfolds but you are not directly involved in that act. I am sorry to tell you that we do not have what I would call an expanded view of the scenario that unfolds when a nurse is with a patient, at least from the perspective of our members, there is a gap in the literature about that and we would like to fill that gap but have not done so as at this time. That is the short version, a very small picture of how this has affected nurses in our organisation. Over the last five years, we have not had anyone at a microphone at our House of Delegates saying, "We have to do something about this". There have been some concerns voiced by nurses to our cabinet but it has been over what if a patient attempts assisted suicide and it does not work, what does the nurse then do? It is obvious that they are not going to abandon that patient but are there many different rubrics through which you view that situation or is it just "this patient now needs my care no matter how they got there". Those are the only things I want to say at this time.

Q1059 Chairman: How many nurses are there in Oregon, in your Association?

Ms Davidson: There are about 10,000 in our Association.

Q1060 Chairman: Nearly all of the nurses are in the Association?

Ms Davidson: No. Roughly a third, about 37,000.

Ms Cobrain: Almost 38,000.

Q1061 Baroness Hayman: Could you explain who typically joins and who typically does not? Is there an answer to that one?

Ms Davidson: One of the major conduits through which we achieve members is because of collective bargaining. Our Association does collective bargaining for just over slightly half of the acute care facilities in the state and we do have some public health departments and the American Red Cross. That is a major way through which members join ONA. In addition, we have educators, advanced practice nurses, about 1,900 nurse practitioners who are licensed by the Board and roughly 400, maybe 500 of them, are members of ONA.

Q1062 Baroness Hayman: Hospice nurses?

Ms Davidson: Yes, we have hospice nurses. I cannot tell you the number at this moment, it is not in my brain at the moment.

Q1063 Baroness Finlay of Llandaff: Is there a separate Hospice Nurses Association?

Ms Davidson: Yes.

Q1064 Baroness Finlay of Llandaff: Are the nurses registered with something that is the equivalent of the Oregon Board of Medical Examiners?

Ms Bouchard: The Board of Nursing is the regulatory agency in the state, so we are equivalent to the Oregon Board of Medical Examiners, who you met earlier today. There are about 38,000 nurses in the state that we give licences to. We are the ones who give the licence to them. When this Bill passed, at first there was a flurry of activity around the Board of Nursing because we wanted to know what did that mean in terms of regulation. We got a task force together and we were thinking about issuing a position statement and doing a survey and we thought of what we would have to do in terms of administrative laws to change around this. We probably spent about a year studying this issue and what it might mean from a regulatory perspective for the Board of Nursing. When it was all over and done with, we took a very simple approach to this Bill. We decided that a prescription under the Physician-Assisted Suicide Bill we would treat just as any other legally authorised prescription. It came down to something as simple as that as far as the Board of Nursing was concerned. If nurses call us, and we have very few calls about it, and want guidance about it, we say "You treat this like any other legal medication".

Q1065 Baroness Jay of Paddington: You have nurse prescribing, you are authorised to prescribe, are you not?

Ms Bouchard: We do. Nurse practitioners, yes. Under the law, they are not allowed to write a prescription for this, only physicians can do this. Nurse practitioners can write prescriptions for everything else, all Schedule 2.5 drugs, controlled substances of any kind, but they are not allowed to prescribe under the Physician-Assisted Suicide Bill.

Q1066 Baroness Hayman: When you say you treat it like any other prescription, how does that tally with what I think I heard you say, that some of your members report assisting in the administration of the prescription under the Assisted Suicide Act, and you said that was against your advice?

Ms Davidson: The part that is not acceptable—I believe the registered nurse would view it the same way—as it now is given, it is a number of capsules, so

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it may not be possible for a patient to get all of those down in the traditional way with water. If it was necessary to mix it into apple sauce or something like that, a nurse could do that, but it would be the patient who would need to put the spoon in their mouth to take it into their body without the assistance of the nurse. That is where the line is drawn, you do not give it to them physically.

Q1067 Baroness Hayman: It is not quite like any other prescribed medicine because if any other prescribed medicine needed some help in administration you would do that.

Ms Bouchard: The law says that the patient has to be in control and the patient has to self-administer. Probably the question we get asked the most is what that level of assistance is and how far the nurse can go with that assistance.

Q1068 Baroness Jay of Paddington: And the answer is?

Ms Bouchard: The answer is the patient has to give it. We get very detailed questions about can the nurse put her hand under the patient's hand and help the patient get it to his mouth, very detailed questions like that, but the law states that it has to be the patient who gives it.

Q1069 Earl of Arran: This is a very grey area.

Ms Bouchard: It is a very grey area. We have had no complaints under this law about nurses and we have taken no disciplinary action against any nurse.

Q1070 Chairman: What sort of level of disciplinary action generally are you faced with here in respect of nurses? In an average year, how many would there be?

Ms Cobrain: I am with the Board. I am the Programme Executive for Compliance, Investigation and Practice. I always feel the need to confess that I used to be the Board's legal counsel but I am not any more, although I was the Board's legal counsel at the time that the Death with Dignity Act came into being, so I do have that experience as well.

Q1071 Chairman: Is it promotion to come from where you were to where you are now?

Ms Cobrain: It is great. I can now be the client to the Department of Justice instead of the solicitor.

Q1072 Chairman: Giving instructions to other people.

Ms Cobrain: It gives me a great platform to argue with them. We have approximately 700 conduct complaints against nurses in this state per year. By conduct, I mean they are substance abuse issues that are showing up at work, they have done medication in error, they have documented in error. These are

nursing acts that are wrong. Of those, the Board ends up taking about a third of them to formal disciplinary action. That can go from anything as small as a reprimand all the way to revocation of the licence, which means you are no longer able to practise nursing in this state.

Q1073 Chairman: That is the extreme discipline. On average, maybe it is not easy to have an average, what ultimate sanction do you have of that kind?

Ms Cobrain: I would correlate it more to the type of offence. The majority of the offences we have are typically related to substance abuse issues, diversion at work and use at work. We have a nurse monitoring programme which helps people who are in the process of helping themselves in treatment and such. Those people go into a type of probation, if you will. What the Board looks at in putting forward discipline is the extent of harm, if the nurse can be re-educated or saved back into the population. It is more remediative than punitive in nature. If you have someone who is incompetent and does not recognise their own incompetence or is unable to cure that incompetence, the Board will revoke them in a heartbeat because they see their mission as protecting the public. They take that quite seriously.

Q1074 Baroness Jay of Paddington: You have described it as a grey area in which nurses come to you or get in touch with you about where they can or cannot help around assisted suicide. Do you get a lot of inquiries from nurses saying "Do I have to be involved at all?" Is there a sense of people wanting to stay away from the whole process?

Ms Bouchard: When the law first came into effect we got some of those calls. They wanted to know if they could not participate and we said "Yes, you have the right to do that". They wanted to make sure that they were not going to be abandoning their patients. We said "You have the right not to participate but you have to be there to offer pain and comfort care until you can transfer that patient". That would be what the standard of care would be.

Q1075 Baroness Jay of Paddington: Do I understand that those inquiries have diminished?

Ms Bouchard: Yes. In the last year I do not know that we have got more than one call regarding this.

Q1076 Chairman: Generally they all know what the position is now. When it was new they would be asking but I suppose they get that sort of information from one of their colleagues now, if they are young nurses.

Ms Bouchard: It could be that they talk among themselves but they are not raising that up to the level of the Board of Nursing. From what I am hearing Sue say, you are getting very few calls about it even from

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the professional association, so it is not that they might be afraid of what a governmental agency is doing but even the professional association is not getting those calls. They are probably getting their support among themselves and among other colleagues in the multi-disciplinary setting.

Ms Davidson: Issues around end of life and palliative care have not gone away, those are there, decisions about sustaining therapy or ending therapy are still there and enormously difficult for nurses, but about this circumscribe situation, no.

Ms Bouchard: We do get calls about pain management. Our Board of Nursing has just issued a position paper on pain management and the rationale for that position paper is that we are saying to the nurses, "We do not want you to be afraid of the Board of Nursing regarding pain management for your patient" and we feel that under-medicating patients is just as unacceptable as over-medicating patients and you need to have a balance in doing that. We have been round the state in the last three months talking to the nurses and I think they truly appreciated that. I think we did get our message across of "Please do not be afraid of the Board regarding this issue".

Q1077 Chairman: How is the nursing profession structured in Oregon? Are there nurses attached to family practitioners' practices or is there an independent community nursing service? We have understood that hospice arrangements are mainly at home, people are looked after in their own home. The nurses who help to look after them, are they normally employed by a particular hospice or is there some more general arrangement?

Ms Bouchard: I think that they are all employed by hospice organisations or home health care organisations.

Ms Davidson: Some are attached to a facility and some are freestanding and then, of course, some have a business which visits the patient in their home.

Q1078 Chairman: A nursing business?

Ms Davidson: Yes.

Q1079 Earl of Arran: Obviously you are aware that some doctors are not awfully keen on this idea. Do nurses at any time ever feel pressure from those doctors who are perhaps trying to encourage them not to take part in this particular area? Is there any pressure upon nurses from any doctors that they should not get involved?

Ms Bouchard: I have never heard of a nurse complaining about that. That is not to say it has not happened but it has not risen to our level as an issue.

Q1080 Earl of Arran: Am I right in thinking that the day after the nurse has the day off after she has taken part in this?

Ms Bouchard: I do not know because nurses have not come to us to talk about their participation. We know that they are participating.

Q1081 Earl of Arran: I may have misread that.

Ms Bouchard: They have not come to us to talk about it.

Ms Davidson: Potentially hospice nurses might be staff nurses in a hospital, not that it would occur there. I am not aware of that. What I am aware of is that the argument over which patient is legitimate to consider for assisted suicide is a matter of ongoing contention. As little as a year ago, I attended a breakfast of the healthcare community on the subject and presentations were made that sustained the argument that if people who want to consider assisted suicide would just come to their senses and recognise how depressed they are, they would not think that way, they get treatment, versus there are people who want to do this and they are not depressed, that is what they want to do. I believe nurses do get caught in that argument. I cannot locate for you where I think that is occurring, but in facilities that are founded on a very strong religious base that is an issue for them. This is not an easy thing for people who work in those facilities because fundamentally it runs against the grain in terms of those religious beliefs. I am aware that there are conflicts that can occur in terms of conversations between professionals and I think that is largely where the conflict occurs. It could play itself out in the reluctance of a physician or a provider to write the prescription.

Ms Cobrain: The Act itself has provisions to address people who do not wish to participate and whether they can be sanctioned by a licensing board or professional organisation for either choosing to participate or not to in this process. These were some of the considerations that folks went through here when they were considering this issue. There is a whole section of immunities that might answer some of those questions as well.

Q1082 Baroness Finlay of Llandaff: We have heard about some of the difficulties of the six month prognosis and for patients who have got severe debilitating chronic disease the nurses will be the ones who will have many more interactions with those patients and over time will get to know them better. Is there a view amongst the nurses whether that six months is acting as a false arbitrary division in terms of trying to define who is and is not eligible when faced with a patient expressing the desire for death?

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Ms Cobrain: I have not heard of any such thing.

Ms Bouchard: I do not know. We have no nurses who have come to us with that issue. I suppose the Hospice Nurses Association would be the ones to best address that to.

Q1083 Baroness Finlay of Llandaff: By the time they get to hospice there has been a declaration that they have a six month prognosis. I was wondering about those who have got severe chronic debilitating disease who may feel that their life is worthless and want to participate. I wonder whether there is some difficulty for the nurses at that point in saying, “I think this person should be going into the hospice system”, but that would mean to do that they would have to opt out of what you might call acute type care and, therefore, the patient would have to be denied the ability to have some input.

Ms Bouchard: It would seem to me that what you are talking about is the nurse being an advocate for the patient, which they are always needing to do, whether they think the physician is paying attention to what is going on here and doing things that the nurse believes need to be done and that could cause that transition to occur.

Ms Davidson: I think there are many scenarios that I am aware of, partly because for a while I was visiting hospices with nursing students so I was privy to those conferences in which a patient had been admitted to the hospice because they were at the ending phase of their life and that trajectory was ending towards death, only once they got there they were hydrated and had a change in their physical status and they did not look like they were heading downhill any more. In the hospice setting it could play out that they were then discharged from the hospice and no longer considered. This is just the dilemma that you are talking about. Others that I have heard nurses talk about, and this is generally in the category of anecdotal information, were when a patient does achieve the ability to do assisted suicide and they have the medication but are not yet ready to take it. Depending on their physical status some may improve for who knows what reason but they still have that medication and essentially do not quite fit the rubrics that were envisioned initially. I do not know how that unfolds. I do not know if they give it up and relinquish the medication to someone having realised “I am not going to achieve death in the four weeks” or if they simply squirrel it away and keep it for a time when they are ready. I am saying there are some people who I believe may have achieved the recognition that they are wanting to do this but whose readiness to make it happen has extended for a long period of time. Am I right about this? I am remembering that there are people who have extended it for a very long time.

Q1084 Baroness Finlay of Llandaff: That fits in with what we have already heard. The medication is bought by the patient, is it not?

Ms Davidson: Yes.

Q1085 Baroness Finlay of Llandaff: Do you know how much it costs them?

Ms Davidson: It is a relatively inexpensive medication. It is secobarbital, seconal, and that stuff does not cost much, I would guess 20 bucks or less. It is put in capsules, it is a powder, five or six capsules.

Baroness Jay of Paddington: That is contrary to what we have been told, which is that it is a liquid.

Lord McColl of Dulwich: You could give it to them both ways.

Q1086 Baroness Finlay of Llandaff: We were quoted a higher figure.

Ms Bouchard: I have talked to nurses who have said that they were in the home at the time they were crushing the pills. I think maybe it is given both ways but more often now it is the liquid form.

Q1087 Baroness Finlay of Llandaff: The nursing care of these patients, is that on Medicaid and Medicare?

Ms Bouchard: If the patient is declared to be a hospice patient they then enter the benefit package that is part of Medicare, the package that is called Hospice Care, which is a series of a pretty broad range of services offered to a patient who is deemed to be—

Q1088 Baroness Finlay of Llandaff: That would cover all their nursing costs?

Ms Bouchard: Absolutely.

Q1089 Baroness Finlay of Llandaff: Irrespective of age?

Ms Bouchard: That part I do not know but I believe that is the case.

Q1090 Chairman: Do they have to be anticipated to be within six months of death if they enter a hospice arrangement?

Ms Davidson: Yes, I think so.

Q1091 Chairman: I was wondering what happens to people who have a long-term disabling condition but who are not yet seen as within six months of death, how are they looked after in this state.

Ms Davidson: I think in some instances they receive a series of provisions through home health nursing and they can be small or large, depending on the need of the patient. When a patient slides over into the hospice benefit is by determination of the physician and social worker and others who conclude that they are over that line from just being very needy because of the chronic and debilitating illness.

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Q1092 Chairman: The nursing care for them before they were crossing the line would be some form of home care provision and it might be done by one of these businesses you mentioned where nurses provide that and get paid from wherever the person has a source of income, either of their own or is there Medicare available for that?

Ms Davidson: There is. There are some long-term insurance packages that include benefits that have to do with just this situation.

Ms Bouchard: Also we have what we call the Oregon Health Plan at a certain poverty level that the state pays for.

Q1093 Chairman: Under a certain level of income or source of income?

Ms Bouchard: Yes.

Q1094 Baroness Hayman: Can I ask two separate questions. You were talking about the advice you had given to nurses about under-provision of pain relief, was that related to what has been described to us as in some ways a diminution of satisfaction with end of life care in Oregon as evidenced by more people surveyed as saying that pain relief had been inadequate, that there has been some evidence of that recently? Am I correct?

Ms Bouchard: That is correct. We had a senator in the Oregon Senate who had some personal issues and some family issues with pain management who felt that pain management was being poorly managed in the State of Oregon, so she put a law through that said all health care professionals are going to have mandatory continuing education credits in pain management starting in 2006. She passed it through the Legislature because her belief was that all health care professionals needed to know more about pain management. One of the research projects that OHSU did showed that one of the reasons why patients were not getting enough pain management was because they were afraid of their Boards, they were afraid of the Board of Medical Examiners, they were afraid of the Board of Nursing, that if they adequately treated for pain we might see it as being too aggressive and we would then come after them and take disciplinary action on their licence. That was why we decided to issue this position statement.

Q1095 Baroness Hayman: It has been put to us that the inadequate pain management and evidence of it resulted from the availability of assisted suicide. Have you any reason to believe that to be so?

Ms Bouchard: No.

Ms Davidson: From my perspective, there were other factors, one of them was John Ashcroft who wanted to come after the assisted suicide law. Obviously you need to provide humane treatment to somebody who is in that category, so there were external factors and

political factors. The first time that John Ashcroft began to contest the law in this state, nurses talked about the change they felt had happened in physicians and their willingness to go to the hilt in terms of ordering all that was necessary and needed in terms of pain management. I recall that at about the same time the Joint Commission on Accreditation of Hospitals also began to ramp up its focus on pain management and it became one of their major principles that were audited when they made visits regarding the quality of care in a particular hospital and their credentialing of that hospital. At the same time physicians were feeling nervous and so were nurses. I believe there was a period of time when there was a backing away from the vigour with which you treat the patient's pain.

Q1096 Baroness Jay of Paddington: Just to clarify a bit about the potential federal intervention, we understand that this is because the only locus that Ashcroft would have is on the drug laws and the drug administration?

Ms Davidson: Yes.

Q1097 Baroness Hayman: If you like, from the patient's view the decline in service would be related not to doctors and nurses who were involved with patients going through the process of assisted suicide, but a general anxiety that the spotlight would come on practices that were going on and, therefore, self-protection. Is that a fair summary?

Ms Davidson: In my view, that rings true with me.

Q1098 Chairman: If they wanted to protect themselves against charges of excessive drug prescription. So often if you want to protect yourself against over-prescribing you may end up under-prescribing, and that was what was happening, was it not?

Ms Bouchard: That is what we think was happening.

Ms Davidson: I think historically nurses have come to the pain management issue under-doing. This is a complicated picture because at the same time the Joint Commission—we call it JACO—has a focus on removing what I call orders with a range. So a physician could have written “Demerol, 50-100mg” and the decision about what you gave as a registered nurse was up to you in your judgment as to what you thought was needed. That has been pretty much removed. I do not remember all the reasons why JACO has done this, I think probably because of their concerns over error. We do have a very large database of the way in which a nurse who is giving care on a unit can in his or her assessment say, “The staffing on this unit is insufficient”, either as their own assignment pertains or for the unit as a whole. We have over 2,000 reports and the reports include, “Why do you think this is happening? What shift?

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What day? What is the turnover of patients on the unit?”, so we are looking at all the variables that put pressure on nurse staffing. Their perception of this has to do with consequences. What are the unintended consequences of staffing? We have had a consequence called “Unable to meet patient’s pain needs effectively” for probably four years and initially the percentage of nurses who said this was the case, either delayed or omitted pain management, was about 20 per cent. It is now up to 50 per cent even though the emphasis on pain management has remained the same or is slightly more vigorous. I am suggesting that the dynamics of when pain management is not done is more complicated than scared over too big a dose and ranges, it has to do with sufficient numbers of people to lay eyes on a patient and work out what is the deal, how can I effectively relieve this pain. In addition, nurses told me just a couple of weeks ago that their concerns are with these complicated patients who have pain when the pain is not relieved, they are doing everything within that protocol for relieving the pain and it will not go away, what are their liabilities, what do they do, how do they get out of the consultation. Most of the small hospitals in the state do not have pain consultation teams at all. This is a therapeutic dilemma with all of these other issues.

Q1099 Baroness Hayman: You have given a very interesting and complex answer. To put it very crudely, it has been suggested that the evidence, the results that are there, arises from a change of attitude that at its worst is “Why bother to be concerned about pain relief because these patients can have assisted suicide”.

Ms Davidson: That is not my intention. The linkage between these two—

Q1100 Baroness Hayman: Is more subtle as you have described it to us.

Ms Davidson: If it is there, I would say it is untypical of the nurses I talk with to be in a setting, other than home health, where those patients are side by side with others, so the notion that “They have this other option and, therefore, I do not have to deal with it”, I do not want you to have that impression at all.

Q1101 Chairman: It is really because of scarcity of resources in other ways, they feel they have not got an opportunity to deal properly with the patient’s needs.
Ms Davidson: Essentially, we know the major reason why people choose this is they do not want to be dependant, but pain can be a part of that reasoning and if you just leave patients suffering, suffering, suffering, they will leap to any solution that looks good to them if they are hurting. Clearly there is that dynamic.

Q1102 Baroness Hayman: I can understand that dynamic but in terms of the professional attitude, you are very clear that you have not seen that?

Ms Davidson: I do not want you to have that notion.

Q1103 Lord Joffe: In the article to which Lady Hayman was referring, it was suggested that one of the explanations for what was alleged to be deterioration in pain relief was due to staff shortages in Oregon. Is this the position, that there are considerable pressures on nursing staff in Oregon?

Ms Davidson: Yes, and that was why in 2001 the Oregon Nurses Association, through our Legislature, put forward legislation having to do with nurse staffing. There are a number of rubrics to that law. It does not prescribe how many nurses you will have to how many patients. We did not go down the route of what is California’s great error called ratios. What was required in the law was that there had to be a written staffing plan, that the needs of patients had to be met by a sufficient number of nurses and there had to be some method by which if there were not enough nurses the hospital immediately had to pursue getting others to replace those who were ill or unable to come to work that day. We do have that Bill and we are facing a new legislative session and we are going to go back over some enhancements of that Bill.

Q1104 Lord McColl of Dulwich: Is the practice in Oregon that of Cicely Saunders to try to maintain a constant level of analgesic in the blood rather than give them doses when they get pain? Do you accept the Cicely Saunders’ principle here?

Ms Davidson: I believe that is the case, especially by pain consultation teams who advise the staff. It is a mixture of agents that compliment one another and synergistically provide a level of relief that is constant.

Q1105 Lord McColl of Dulwich: Why is it that they cannot do that? Is it that they do not have machines to give constant infusions or is it that they do not have enough nurses to go and give the medication every four hours or whatever?

Ms Davidson: The dilemmas that nurses talk about are patients who have not received the right array of drugs, of which there are multiple varieties. There is a great science around this. There are those who are very good at it and then there are practising physicians who are not that good at it. It is really that there is a great gap between the knowledge about how to do this effectively and a whole lot of people in our state doing it effectively. I think there is a gap there.

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Q1106 Baroness Hayman: You talked of the dilemmas that nurses have put to you about how far they could assist patients to self-medicate, and one can imagine very clearly there are dilemmas there. I wonder if you could give us any idea whether there have been discussions in the Association of particular cases where there has been a concern about a patient totally unable to self-medicate or being ineligible because of their inability to self-medicate. Obviously I am thinking about neurological degenerative disease in particular and what your views and experiences are, whether there are limitations to the current legislation in respect of that particular group of patients?

Ms Cobrain: The Bill, like so many Bills, was not designed to catch 100 per cent. It is going to catch a certain group, a group of people who are still cognitive, who are still competent, and who can still make these decisions. The idea is that it is not euthanasia, it is “I know I am dying, and these are the circumstances within which I want to die”. Because of that, the key component is the voluntary issue of it. That is one of the pieces that you are looking at in saying what the nurse can do. If you are going so far that it is no longer a voluntary act, then you have gone too far. There is a group of people who are not able to make the request because they have to make an oral, a written and a second request.

Q1107 Baroness Hayman: I was thinking more of physical competence than mental competence.

Ms Cobrain: Even people who have met that piece of it, if they cannot finish it off, if you will, they will fall back out of the Act. It is not intended to catch everybody. To write it such that it would catch everybody would be to take away some of the fail safes, the protections, to make sure it is not abused, some of the fear factors if you will. I do not want to make light of them, but there were concerns about how this would work and there are safeguards built in so that it is not abused and you have got a balance there.

Q1108 Baroness Jay of Paddington: It gets a little bit metaphysical, does it not, if you are talking about volition because somebody can understand that they are dying in the way that you have described and wish to choose the time to die but, as Lady Hayman said, may not be able to fulfil that practically.

Ms Cobrain: That is true.

Q1109 Baroness Hayman: I imagine it must be very difficult for the nurse in those circumstances seeing the patient struggling to implement what is at the end of a long process but unable so to do and barred from offering the assistance that perhaps goes with some grain of nursing treatment, although I understand very well other grains of nursing practice.

Ms Cobrain: There is a whole universe of people who are dying and a universe of people who can make these decisions and participate in this so they do have a resolution option should they choose. You are left with that piece of the universe of persons who are not able to take advantage of this option, as it were, so their realities have not changed any because of this Death with Dignity Act because they do not fall under its pieces and you are left with the dilemma of watching the person dying and perhaps wishing you could do something more for them and not being able to.

Q1110 Baroness Finlay of Llandaff: Given that this has been on a balance of harms from what you have been describing, is there pressure to extend to allow assistance for those who cannot actually get the drugs to their mouth or into their own gastrostomy tube?

Ms Cobrain: We have not seen that come across our desks from a regulatory point of view. We had a lot of discussion about that when it was a new idea because when you are trying out a new idea you go into the hypotheticals: what if, what if, what if. Then you get into the real world where it is actually being used and you are dealing with the facts that are in front of you and a lot of those questions remain in that hypothetical world. We have not seen that. That is not to say those questions have not been out there somewhere and were just never brought to our attention, that is entirely possible.

Q1111 Baroness Finlay of Llandaff: As far as you are aware there is nobody campaigning?

Ms Davidson: I am not aware of anyone. I am remembering, have you seen the Bill Moyer's series on death and dying? It is a stunning series. He is a wonderful reporter, I do not know what to call him, he is a marvellous man and there is a story and a series of vignettes about the whole issues around death and dying, of a physician who had Lou Gehrig's disease—I am not going to go down the ALS route—who unfortunately did not time his descent so that he could make the request he needed to and take the medication he wanted, and the story ends up seeing what the consequences were for him and his wife and they were not good. Clearly there is a paradigm there that frightens everyone about making that decision. I think that particular video series is available for purchase and it is quite stunning.

Ms Cobrain: Something we have seen, which is almost a reverse of what you were talking about, is because practitioners out there know that there is this option—I hate this is going to be on the record but I know it must—there has always been a certain amount of euthanasia that has occurred, that is the dirty secret that we are trying to get out of the closet and deal with. With the fact that there is this option

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there now, anecdotally what I hear is that there is less of a desire or need for the practitioner to think “If I don’t do something there is no other choice, there is no other alternative”. For that group of people you were talking about that is still an issue, but for this other group of people who do have this option, in a way it takes the pressure off the practitioner to think “This is my responsibility somehow and I need to try and deal with this” and it clearly keeps the care self-directed by the patient and Oregon is real big on being self-directed.

Q1112 Baroness Hayman: We are getting that message. These issues have been explored already. You are not shocking us with the idea that before the legislation nothing happened.

Ms Cobrain: That is the truth of the matter.

Q1113 Baroness Finlay of Llandaff: After a patient’s death, who is responsible for the drugs that are left and what happens to them? We have heard about patients who have the prescriptions and they also have opioids and other drugs, but what happens about removing them?

Ms Bouchard: They are supposed to be destroyed.

Q1114 Baroness Finlay of Llandaff: Is the nurse responsible for witnessing that destruction?

Ms Bouchard: It depends on the hospice policy of the organisation. I do know cases where nurses have said they are the ones who took the medication and flushed it down the toilet.

Q1115 Chairman: I suppose it depends who has the medication at the time. A nurse cannot be expected to search out the recesses of somebody’s apartment or something like that if they have not got responsibility for the medication at the time. Presumably the law requires it to be disposed of by those who have responsibility for it?

Ms Bouchard: I think that they have professionals take that responsibility. In terms of hospice, there are policies that they have to follow to do that.

Q1116 Chairman: When you say “hospice”, that includes home?

Ms Bouchard: Yes.

Q1117 Lord McColl of Dulwich: When one gets round to the question of when drugs are out of date, we are hearing that some people survive as long as two years. Is there some system for making sure that the drug is still active?

Ms Cobrain: Survive after they have been given a lethal drug?

Ms Davidson: No, they have not taken it yet.

Q1118 Chairman: They get the prescription having gone through the hurdles and then they do not use it. We have been told that quite a high proportion of the people who get the prescription do not use it. The question is, if you had it for two years it may be less than clearly effective.

Ms Cobrain: The prescriptions come with dates on them.

Q1119 Lord McColl of Dulwich: Yes, I know, but whose job is it to make sure that the drug is still within date?

Ms Cobrain: It would be the patient.

Ms Bouchard: The patient or the health care professional.

Q1120 Lord McColl of Dulwich: That is the problem, because the health care professional is not allowed to take part in this process.

Ms Davidson: They can look at the bottle or the capsules or whatever.

Ms Bouchard: I do not think that would be termed as assisting.

Ms Davidson: Out of the dredges of my memory bank, seconal is really stable.

Q1121 Lord McColl of Dulwich: I am thinking if they go walkabout.

Ms Davidson: Clearly there would be a pharmacist involved here. I am not sure that most hospice teams have a pharmacist or access to pharmaceutical consultations, so it is possible. From my own personal experience with hospice teams, the physician was extraordinary and all of those details were as much of a concern to him as anyone else.

Q1122 Chairman: Some physicians have dispensing powers and there are others who have to get it from the pharmacy.

Ms Davidson: The dispensing thing usually happens for people who are isolated, out there in the boonies. Wait a minute, you do not have boonies.

Q1123 Chairman: We know what you are saying.

Ms Davidson: Good.

Lord McColl of Dulwich: We call it the sticks.

Q1124 Chairman: In the Highlands region. I think we have very much profited from the help you have given us. It has all been noted down to be studied even further later. We thank you very much indeed for your kind help.

Ms Bouchard: We are honoured that you came and we are glad that you wanted to hear our perspective.

Chairman: Thank you very much.

TUESDAY 14 DECEMBER 2004

Present	Arran, E	St Albans, Bp
	Finlay of Llandaff, B	Thomas of Walliswood, B
	Jay of Paddington, B	Turnberg, L
	Joffe, L	
	Mackay of Clashfern, L	
	(Chairman)	

Memorandum by the Association of British Neurologists

Thank you very much for asking the Association of British Neurologists to submit written evidence to the Select Committee on the Assisted Dying For The Terminally Ill Bill. Members of the Association possessing E-mail addresses were all informed of this Bill and asked to send comments to myself, the Secretary of the Association of British Neurologists. There was a total of 24 replies which, although not many, was larger than anticipated. We would have provision to debate this Bill at one of our Annual General Meetings next year and would be pleased to do so if this would give us an opportunity of submitting further comments then.

I have made a summary of the various comments made by members of our Organisation. Overall, out of the 24 who replied, 14 were in favour and 10 against. Members were concerned about the definitions of the following:

1. *Competence*—How should or could this be assessed? It was thought essential that patients should have been previously seen by a Psychiatrist or Clinical Psychologist to ensure that there was no psychiatric disorder, such as depression, which might impair their competence or alter their beliefs. We do not consider that other physicians involved will necessarily have the competences to adequately assess the patient's mental state. Section 8 is not an adequate safeguard for a patient whose judgement in this matter is impaired by a depressive illness, all too common in this situation and we consider such an assessment should be mandatory.
2. *Attending Physician*—The Attending Physician is not specified in the document but by implication (2(2)) will be the General Practitioner. However, the current definition of Attending Physician could be interpreted to mean either the General Practitioner, or the Consulting Physician or Palliative Care Physician, all of whom are likely to be involved in the patient's care.
3. *Means of Assisted Dying*—There is no definition of the means by which assisted dying would be achieved or whether Attending Physicians would require training and certification to do this.
4. *Terminal Illness*—There was concern about the timing of when assisted dying might be considered and, "within a few months", would need to be more carefully and precisely defined.
5. *Unbearable Suffering*—Assessment of this requires good communication with the patient which is not always possible. It is always a subjective and contentious issue, about which Members had reservations in respect of making a judgement. Whilst not wishing to be prescriptive, it might be helpful to give examples of what might be construed as "unbearable suffering".
6. *Provision for Pain Relief Medication*—It was the opinion of the Members that there was adequate provision for this already, in the sense that doctors can treat patients' symptoms if they require relief, although this may hasten death in some circumstances. This, we believe, is widely accepted and does not require a Bill.
7. *The Second Witness, Other than the Solicitor*—This is not defined, other than being personally known (but not a relative or partner) to the patient. There could still be a conflict of interest with a friend, for example, and this might be a major difficulty.
8. *The Duties of the Attending Physician*—The duties of the Attending Physician assisting the patient to die are considerable. He has to ensure all aspects of the process have been completed and also give assistance to die. Many general practitioners will feel that they do not have adequate training to achieve this. This raises the possibility of certain certified Physicians being requested to do this who are not normally the patient's Attending Physician throughout the rest of the illness, which would be unsatisfactory. The clinician who it is to undertake the patients with assisted dying needs to be more clearly defined.

9. *Conscientious Objection*—Some Members felt that if requested to assist in this process, even to refer the patient elsewhere would be against their principles, a point which needs to be taken into consideration. It might be difficult for some local Neurologists to opt out of the process, particularly if they were single handed, without adversely affecting their reputation or otherwise.

10. *Right of Appeal*—There was concern about the consequences of objections by relatives for those involved in the assisted dying process which is not considered in the draft Bill.

OTHER GENERAL COMMENTS

11. *Whether the Bill Is Necessary?*—The necessity of the Bill was questioned. The experience of Neurologists is that most patients in well managed palliative care programmes do not wish to die artificially. Although there have been occasional well publicised recent cases, this is not thought to be sufficiently common to necessitate the Bill.

Some Members thought the Bill might be counter-productive and make it more difficult for people with progressive terminal illness to die peacefully and quietly. Legalising the situation would make the whole process more protracted, prolonged and difficult. It was thought that it would, “muddy the waters”, cause a loss of common sense and endless squabbles about meanings of words which have already been commented on earlier in the evidence. Is it the role of a doctor to assist patients to die in this kind of way, or should we not continue to assist them in dying peacefully, as is current practice?

12. One of our members made the following points:

- “If we take Motor Neurone Disease (MND) as an example, then it is broadly true that the model of care which most patients will experience in the future will be a multidisciplinary team based approach, centred around the clinician (usually a Neurologist) with a special interest in MND. Given the complex nature of the condition, it is my experience that GP’s often take a marginal role in patient management, including the terminal phase of the illness. Therefore the Attending Physician referred to in the document will be the Neurologist looking after people with MND. A Neurologist with a special expertise in MND would be looked upon as the arbiter of whether the patient’s illness was terminal, within the definition of the proposed Bill.
 - Because it is a rare condition, there are a limited number of neurological centres offering comprehensive care for patient with MND and, once the initial diagnosis has been made, patients increasingly gravitate to these centres.
 - If the Bill became law it would therefore be the burden of a small group of specialist Neurologists to become the focus of the “right to die” issue. Taking a stand one way or the other would lead to distortions in clinical practice. Patients would travel the country looking for someone to help them die and therefore it would not be substantially different from the current situation with patients travelling to “Dignitas” in Zurich.

MND clinics run by a Neurologist who objected to assisted suicide on conscientious grounds might find the other care that they are offering is undermined.
 - Neurologists specialising in terminal conditions might also find themselves becoming the local “consultant for assisted suicide”. Again, this might place an unreasonable burden on a small number of Physicians.”

He thought, therefore, that the proposals contained in this Bill, would distort clinical practice and impose an intolerable burden on a relatively small number of Neurologists who specialise in disorders with malignant progression.

1 September 2004

Memorandum by the Motor Neurone Disease Association

1. Few disorders are as devastating as Motor Neurone Disease (MND). It progressively attacks the body removing the ability to walk, talk or feed oneself, but the intellect and senses usually remain unaffected. There are estimated to be around 5,000 people living with MND in the UK. Half of people with MND die within 14 months of diagnosis.¹

2. The MND Association neither supports nor opposes any attempt to change the law regarding euthanasia or assisted suicide because we believe it is a matter of individual conscience and it is not for the Association to make judgements.

3. However, in advance of any change in the law, we are campaigning to ensure that the very best palliative and terminal care is available to everyone who needs it. Only then will anyone considering ending his or her life early genuinely have a choice.

4. Although the Association neither supports nor opposes a change in the law, we have a responsibility to ensure draft legislation takes into account any issues of concern to people affected by MND. We have therefore set out below our comments on the draft Bill.

1. INTRODUCTION

1.1 MND is a rapidly progressive neurological condition that kills three people everyday in the UK. MND affects the motor neurones (nerve cells) in the brain and spinal cord. As the motor neurones die, the muscles stop working.

1.2 It can affect any adult at any time and leaves people unable to walk, talk or feed themselves, but the intellect and senses usually remain unaffected.

1.3 There are currently more than 5,000 people living with MND in the UK, with a prevalence of around 7 per 100,000.

1.4 The cause of MND is unknown and there is no known cure. On average it takes 16 to 18 months from first symptoms to diagnose MND² and half of those with the disease die within 14 months of diagnosis.

1.5 The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland. Our mission is to ensure that people with MND can secure high quality co-ordinated care and to promote research into causes and treatments.

1.6 The Association provides funding for 13 MND Care Centres across the UK providing co-ordinated care for people with the disease. The Association has published Standards of Care for MND and is currently developing clinical guidelines for the management of the disease.

2. MND ASSOCIATION'S POSITION ON ASSISTED DYING AND EUTHANASIA

2.1 The MND Association neither supports nor opposes any attempt to change the law regarding euthanasia or assisted suicide because we believe it is a matter of individual conscience and it is not for the Association to make judgements.

2.2 However, in advance of any change in the law, we are campaigning to ensure that the very best palliative and terminal care is available to everyone who needs it. Only then will anyone considering ending his or her life early genuinely have a choice.

2.3 Whether or not there is a change in the law, the MND Association will continue to support anyone affected by MND regardless of their views on this issue.

2.4 Although the Association neither supports or opposes a change in the law, we have a responsibility to ensure all draft legislation takes into account particular issues of concern to people affected by MND. We have therefore set out below our comments on the Bill.

3. COMMENTS ON THE BILL

3.1 Definition of "terminal illness": Section 1(2) of the Bill states that an illness is terminal if it will "result in the patient's death within a few months at most". MND is an unpredictable disease and it is difficult to anticipate likely survival. We are concerned that there would be variations in the interpretation of this definition and hence people with MND will be treated differently depending on the doctor being consulted.

3.2 Definition of "unbearable suffering": Section 1(2) defines unbearable suffering from the patient's perspective—"suffering... which the patient finds so severe as to be unacceptable". But in sections 2(2d) and 2(3d) the "attending physician" and "consulting physician" also have to conclude that "the patient is suffering unbearably". However, the Bill does not set out a process for resolving a situation where the opinion of the three parties differs. (NB It should be borne in mind that this is separate to determining a patient's competency).

3.3 Measuring "competency": The Bill states that the "attending physician" and "consulting physician" decide whether or not a patient is competent in respect to the Bill. If either are of the opinion that the patient may not be competent the patient is referred to a psychiatrist. We believe the Bill needs to achieve the right balance between ensuring there are sufficient safeguards to prevent people with clinical depression (and who might respond to treatment) seeking help to die without creating unnecessary bureaucracy.

3.4 Because many people with MND experience communication difficulties, particularly towards the end of life, determining their competency may present a particular challenge. The Association would like the Bill to promote access to a speech and language therapist, where necessary, to facilitate the process of determining competency.

3.5 Section 3 (palliative care): The Association believes section 3 on palliative care needs to be considerably strengthened if it is to offer people with terminal conditions real choice at the end of life. At the moment the Bill says that the “option” of palliative care must be discussed with the person requesting help to die. However, we believe this needs to go much further, with high quality specialist palliative care actually being available to the person, at a time and in a place of their choice. The Bill should make reference to disease-specific best practice guidelines for the provision of palliative care and include the requirement that this must be available to the patient. Only then will there be real choice at the end for life.

3.6 The declaration: The Bill currently states that “the declaration” seeking help to die must be in writing. However, some people with MND are unable to write because of weakened muscles. In addition, some people with MND are unable to write or speak, particularly towards the end of life. There therefore needs to be provision in the Bill for people in this situation to be able to make a declaration. The Human Tissue Bill allows people to give consent to donate tissue by the “appointment” being “signed at the direction of the person making it”. We believe a similar form of words should be used in the Assisted Dying for the Terminally Ill Bill. This would then enable people who cannot write or speak to make a declaration.

3.7 Support for carers and families: If someone is seeking help to die, the strain on their carer and family is likely to be significant. We believe the Bill should include a clause on supporting carers and family members during this time, particularly if there is disagreement amongst affected individuals. This support should be available before, during and after the decision-making process.

4. TESTING THE OPINION OF MEMBERS

4.1 The Association has 22 Regional Care Advisors (RCAs) who are in direct contact with people affected by MND. The experience of the RCAs is that views on assisted dying amongst people affected by MND vary greatly—some people are very supportive and others are totally opposed. However, the Association has not sought the views of its whole membership.

5. CONCLUSION

5.1 The MND Association neither supports nor opposes any attempt to change the law regarding euthanasia or assisted suicide because we believe it is a matter of individual conscience and it is not for the Association to make judgements.

5.2 However, in advance of any change in the law, we are campaigning to ensure that the very best palliative and terminal care is available to everyone who needs it. Only then will anyone considering ending his or her life early genuinely have a choice.

REFERENCES

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² Adriono Chino, *ALS Journal* Volume 1, Supplement 1, March 2000.

August 2004

Examination of Witnesses

Witnesses: Ms TRICIA HOLMES, Director of Care Development, Motor Neurone Disease Association, PROFESSOR CHRISTOPHER KENNARD, Division of Neuroscience and Psychological Medicine, Faculty of Medicine, Imperial College London, DR DAVID BATEMAN, Department of Neurology, Cumberland Infirmary and PROFESSOR NIGEL LEIGH, Department of Neurology, Institute of Psychiatry, the Association of British Neurologists, examined.

Q1125 Chairman: Good morning. We are grateful to you for coming along, first of all the Motor Neurone Disease Association and that is Tricia Holmes; and the Association of British Neurologists, Professor Kennard, Dr Bateman and Professor Leigh. The system we have sought to adopt is to invite you either as a group or individually to give a short oral presentation of the principal points relevant to our

inquiry that you would like to make and then my colleagues may wish to ask questions on matters in your area that concern them. A note is taken of the responses as well as your initial statements and in due course you will get an opportunity to correct the transcript. The final transcript will be appended to our report to indicate the basis in evidence upon which we will ultimately—hopefully—reach our

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conclusions. We have about an hour so you can judge your spacing in that way. Tricia Holmes, would you like to begin?

Ms Holmes: Thank you very much. I am Tricia Holmes; I am Director of Care Development with the Motor Neurone Disease Association. As you may have seen from our written submission we neither support nor oppose the change in law. This is because we feel that as an Association we have the responsibility to support everybody with motor neurone disease whatever their opinion on this particular matter. We recognise that there is great variation in opinion on this matter. We have some particular points that we would like to make regarding the Bill and they are particularly about access to palliative care because we feel if people have access to a comprehensive palliative care support they are then able to make informed choices about their lives and, indeed, the quality and timing of their death. There are some smaller points about definitions that we have cited and also how people with motor neurone disease who will be losing the ability to communicate would be able to make a written declaration about their wishes. Those are the key points that we would like to discuss.

Q1126 Chairman: Thank you. Who is next?

Professor Kennard: Shall I start because I think Professor Leigh will say some things that are his own views as well as the views of the Association. I will speak on behalf of the Association first of all. I am Christopher Kennard; I am the President of the Association of British Neurologists. You have already had some points that we want to raise about this Bill. I think, like the Motor Neurone Disease Association, we are not in a position, nor do we wish to take a stance about the rights or wrongs of such a Bill. As physicians it is our duty to look after the patients as best we can. If the law is changed then that is something that those who do not have any conscientious objection would wish to be involved with. There are, however, a number of issues that we raise. I think one that concerns us most is the issue of competence because as the Bill stands at the moment there is a possibility that some patients will wish to sign up for assisted dying who may have mild or moderate depression. Although there is the opportunity for the attending physician and the consultant to call in a psychiatrist it is our view that many of the doctors who would be in the position of signing the documents would not necessarily have the expertise to be able to ascertain mild or moderate depression.

Q1127 Chairman: In other words to know whether or not it was required to call in a psychiatrist.

Professor Kennard: Yes, and therefore we think that if a patient wishes to go down this line it ought to be mandatory that they are seen by a clinical psychologist or a consultant psychiatrist. This will ensure that they are not mild or moderately depressed and that, therefore, their competence is intact and they can make a proper informed decision. With a number of the neurological conditions there is also the whole issue of cognitive impairment. For example, there are patients who, to the lay public, appear to be relatively normal but could have severe cognitive impairments and therefore would be unable to give informed decisions in an area such as this. We think that there need to be safeguards to make sure that this has been ascertained. I think also there is an issue about the attending physician and who that person is. The implication in the Bill as it stands is that it will be the patient's general practitioner, but if the patient is brought into a hospice and is there for a considerable length of time the general practitioner probably will have very little, if any, involvement. Therefore the attending physician would be one of the consultants associated with the hospice, and there would also be the consultant physician—and in the case of a neurological disease a consultant neurologist—who would also be involved. There does need to be some further clarity. The other points that we raise in our submission about definitions of various things I think we could perhaps leave for discussion later.

Q1128 Chairman: Professor Leigh?

Professor Leigh: I endorse, as a member of the Association of British Neurologists, that position and share some of the concerns. However, I think that I was also asked to speak outside the bracket of the Association as a physician who looks after many patients with motor neurone disease. As background I am a director of the King's Motor Neurone Disease Care and Research Centre and have been there for 10 years. Before that I was involved in the care of patients with motor neurone disease. As you know, sadly we do not yet have an effective treatment although we have palliation so that end of life issues come up in almost all the patients I see (and that would now be several of thousands over the last 10 to 15 years). I guess my original view was great discomfort about the assisted dying issue and about the need to confer this right, if you like, but discussions over the years really changed my mind because it is quite clear that a small proportion of our patients are quite clear that they wish to exercise this option and that preventing them doing so is adding significantly to the burden of suffering and probably to the burden of the family as well. It is a very small minority. Some patients have now gone abroad for example to *Dignitas*. We brought this back to our

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multi-disciplinary team and discussed these issues and the team as a whole, I think, feels that we have now to support the principle of autonomy with the appropriate safeguards and checks. From my personal viewpoint as a physician very involved in the disease my view is that we should support the Bill in principle but, like my other colleagues in the ABN I have some concerns about the specific process and the conditions that have to be met to safeguard patients. If I can comment briefly on the issue of competence, again I agree with my colleagues. I think it taxes us greatly because on the face of it most of our patients with motor neurone disease are intellectually intact, very much on the ball and able to make decisions. However, we know from research in our own group as well as internationally that about 30 per cent of those patients actually have significant cognitive, neuropsychological impairment and we do not actually understand how that impinges on the decision process. Nobody really knows that; it has not yet been researched. I think that is an area where further research needs to be done and therefore I think there is going to be a slightly grey area in some patients where a judgment will have to be made on competence and I do not think this is distinct from many other areas of medicine where you have to judge competence even though you do not fully understand the process that is going on in the brain. I think that what one therefore has to do is to make sure that the processes are as safe as they possibly can be and that at least this issue of neuropsychological or cognitive impairment has been taken into account alongside the issue of depression, whether it is mild or clinically evident. I would hope that that could be built in to the process.

Q1129 Chairman: Are you able to give us any help specifically about what the process should be because, as you say, in the Bill at the moment it requires competence but we have not as yet had much in the way of description of a process and you obviously have in mind some fairly considerably detail that we have not got as yet. Certainly for my part—either now or later—I would quite like to know what are the steps you would like to see set out as the process in order that we might consider whether or not that could be put in to our suggestion as an amendment to the Bill.

Professor Leigh: My own view would be that it would be advisable to have a consultation with an experienced psychiatrist or clinical psychologist as suggested by Professor Kennard. That really is required, I think. I am sure guidelines could be produced as to what the interview should cover so that there was some sort of checklist. Obviously one is going to be relying on the clinical experience and judgment of the individual but nevertheless they may

not have seen many patients with neurological diseases of the types we are dealing with (not just motor neurone disease) and therefore some sort of guideline about checking that they are satisfied that if there is cognitive impairment the individual is still capable of making a decision. Indeed, it is true that one can be cognitively impaired and still have enough insight and understanding of the implications to make a decision. The judgment as to the threshold has to be left to an individual who is experienced in the field; I do not think there is a figure that you can give like a psychological test. That would be my view.

Q1130 Chairman: Thank you. Dr Bateman?

Dr Bateman: Thank you very much. I am the Secretary of the Association of British Neurologists and it was my job to try to seek the views of as many members as was possible within the short timeframe that we were given. Although you may not think that we were able to get evidence from many, I was very pleasantly surprised at how many people did actually spend their time and sent their comments back. As you can see, members were fairly evenly divided in their support and clearly we, as an organisation, cannot take any particular stance either in favour or against the Bill. Our main concerns are, as you have already heard, to ensure the necessary safeguards are in place. We have discussed that and it would seem, as Professor Leigh suggested, that you would need assessment by the consultant in charge of the case, by a psychiatrist, by a neuropsychologist, by a palliative care physician and probably by the general practitioner to make absolutely certain that the consent was informed and was valid. I think that would be fairly rigorous and necessary to ensure that there was no problem. There were some other comments which I think are worthwhile making. How would the Bill deal with differences of opinion which obviously could arise. I think that is an issue that would need to be discussed. That might occur when the consultant might not agree with the psychiatrist and vice versa. I think that if there is to be an assessment procedure—and there are all sorts of stages to go through before the assisted dying process can be invoked—it would sensible to have all that documentation sent to a registrar who could then actually check that the documentation was correct and that all the appropriate procedures had been gone through before the actual assisted dying process was performed. I think it would be better to do that before rather than afterwards as the Bill presently envisages. The other concerns were whether there would be adequate protection for the physicians who were involved should the relatives take issue with the process or what happened. I think that is obviously important to consider. Then one of

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our members felt that because there are now multi-disciplinary teams for most chronic neurological diseases that certain neurologists may find themselves very much in the firing line as the people who would be expected to give authority for the assisted dying process to be invoked and those particular individuals may, for conscientious reasons or otherwise, not wish to be involved and it might obviously make their position quite difficult if they are trying to run a particular service and then the patients within that service do not feel that they are necessarily going to be supported in this kind of action. They felt that it might actually make their work much more difficult. Of course, there is the additional work that is required of people who are already extremely busy and committed; that needs to be taken into consideration. Those are just some of the additional points that I think members would like to inform you about.

Chairman: Thank you very much. Would you like to begin, Lady Finlay?

Q1131 Baroness Finlay of Llandaff: You have spoken about motor neurone disease at length, but there are other neurological diseases. Could you tell how you determine a prognosis of less than six months? What are the markers in something like MS?

Professor Leigh: I think it is extremely difficult and I think that that is one of the issues that is unclear in the Bill. I think the Bill stated a specific period of time and I think that in most cases it is very difficult to give a prognosis. With somebody who has severe multiple sclerosis you have a rough idea that they might survive another year or a couple of years but it all depends on other things: whether they get an infection or whatever (for example septicaemia). You cannot actually judge. I think that is a very difficult scenario. I suspect that dealing with patients with cancer is probably on slightly safer ground—roughly knowing how long a patient is going to survive—than neurological conditions.

Q1132 Baroness Finlay of Llandaff: I wonder if Professor Leigh could tell me what proportion of your patients are under the care of multi-professional specialist palliative care as well as neurological care and whether that figure translates to the rest of the country.

Professor Leigh: I think the figure for us now is well in excess of 70 or 80 per cent but I take Tricia Holmes' point that this is not uniform and it is something that still needs a lot of work. Our policy specifically through our multi-disciplinary team is to refer people into palliative care right from the outset so we have discussions not necessarily about dying but about the need for coordinated care as early as we possibly can. Most of our patients are now referred within some

months of the diagnosis, depending on the individual, but that is not the pattern everywhere, as you know.

Q1133 Baroness Finlay of Llandaff: Across the country are you able to tell me how many services are able to access liaison psychiatry? I mean liaison psychiatry and not ordinary psychiatry because I think it is only liaison psychiatrists who have that degree of additional training.

Dr Bateman: I am now a consultant neurologist in Northumbria; liaison psychiatry does not exist there so it is very variable and very patchy and I would have thought it would be present in relatively few areas. It may only be as many as 50 per cent of neurologists who might have good, easy access to liaison psychiatry. I would like to echo Professor Kennard's point about prognosis. In somebody with dementia, Parkinson's disease or multiple sclerosis it is a terribly difficult problem. You can be very mistaken about it; it is a very tricky thing to estimate. I do not think we could ever say that it was easy or clear and that there could not be differences of opinion about it.

Ms Holmes: Adding to the point about multi-disciplinary team working, we have been surveying and trying to map what numbers there are around that would be supporting particularly people with MND. We have 13—hopefully soon to be 14—care centres and probably around 65 multi-disciplinary teams. Many of those are set up because those health and social care professionals have an interest in the disease so they are supporting people who are attending generic neurology clinics. Some may be based within palliative care but I think where access to appropriate support works well is where palliative care is introduced from the outset and you have links into palliative care services. It is very variable across the country.

Q1134 Baroness Finlay of Llandaff: Turning back to Professor Leigh, you have discussed this in your team so I wondered who in your team would be the person who would administer the lethal dose and what you would do. Could you just talk us through who actually is going to do this in your team?

Professor Leigh: I think that touches on the unease that others have had, because we would feel very uneasy at the moment about taking on this role. We see almost all the patients who are diagnosed as having MND in the southeast, as well as many from further afield. The southeast patients would all come to us at some stage although we would always refer them back for local care because our policy is to have good local care with liaison. We could become responsible for the actual assisted dying for a lot of patients. We have not really talked that through but

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what we have come up with is a sense of great discomfort about taking that role on, rather than the actual prescription or the actual enactment of assisted dying being done by, for example, the general practitioner or the local palliative care team. We have not seen ourselves as the people who take on this responsibility.

Q1135 Baroness Finlay of Llandaff: If the palliative care teams around the country are quite clear, 97 per cent of consultants in palliative medicine—with an 84 per cent response rate—have said they do not want to be involved.

Professor Leigh: Yes.

Q1136 Baroness Finlay of Llandaff: So it would fall to you.

Professor Leigh: I am afraid we are saying the same thing.

Q1137 Baroness Finlay of Llandaff: Somebody is going to have to do it.

Professor Leigh: Exactly, and I think that is precisely the issue that I think has to be debated further. We do see ourselves as the people who dispense good care and provide interventions that prolong life—for example non-invasive ventilation where you support people's breathing which can prolong life for one to two years—we are not just about saying that we are going to ease your passage to death. We are also saying to patients that we have things that can prolong life and—we have evidence—improve, enhance or at least maintain quality of life. Quality of life is actually the key issue. At the same time are we going to be saying that we are the people who will actually give you the draught? I think we are very uncomfortable about that and I do not think we have debated it through. It is a discomfort about the Bill.

Q1138 Baroness Finlay of Llandaff: Could you tell me how much it costs per day or per week to have a patient in the highly dependent group, both a home and in hospital?

Professor Leigh: Setting them up is going to cost something like £4000. That is not an exact figure; I could easily find that for you. Then maintaining them is not expensive because it is home delivery and the machine requires virtually no maintenance, so it is a question of liaison. It is not an expensive treatment; it is going to be in the realm of a few pounds per week.

Q1139 Baroness Finlay of Llandaff: I was thinking about their care costs; nursing care, medical care, physiotherapy and so on.

Professor Leigh: There are almost no reliable health economic studies on care costs in MND I am ashamed to say, but we do have data from a very

thorough study of another condition known as progressive supranuclear palsy which is a very severe progressive fatal disease that tends to go on over about 10 years. We know that the total care cost of that—and I am just quoting from memory—is about €40,000 per year and 80 per cent of that falls upon the carer so only a small proportion of that—about €10,000—is actually the health and social services cost. That is a rough estimate.

Q1140 Baroness Finlay of Llandaff: It just strikes me from that, given that we are in a financially strapped climate in the Health Service and relatives are subsidising more, this might actually be a health economist's dream?

Professor Leigh: Yes.

Q1141 Baroness Jay of Paddington: Thank you very much, Professor Leigh and your colleagues, for what I hope I am summarising correctly in saying that you described your professional view as a collective view as being neutral, having a neutral stance on the Bill. You have very helpfully gone on to describe what I suppose one would call professional disquiet about some of the implications of that. You may not, in a sense, want to get into comparisons with another jurisdiction, but some of us were fortunate enough last week to have the chance to go to Oregon and to see the system which is working there. Without making any judgment about it I wonder if I can put to you some of the practicalities of that arrangement. Doctors or medical practitioners write a prescription; there is not a requirement for them to take any active part in administering that prescription. I wonder whether that would help you at all in your general ethical concerns which I think you have expressed very well, and also what you would feel the implications of that were if such a system were adopted here for patients with neurological problems who might have difficulties in actually administering it themselves.

Professor Kennard: Speaking personally I think that it would be a reasonable stance to take, if the doctors were being asked to give prescriptions. Clearly there would be colleagues who would not be prepared to do that but I think there are grades of disquiet and the greatest grade, as Professor Leigh was saying, would be if one were actually administering it oneself. If one were giving a script to the patient then I would expect that a significant proportion of neurologists or physicians would be prepared to accept this if that were the law and if all safeguards had been fulfilled and it was the patient's wish. At the end of the day we are there to assist the patients and if that is what they really wish to do then I think it is wrong for us to say that we are not going to assist them.

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Q1142 Baroness Jay of Paddington: Can I just ask one other thing—because it was one of the things which arose from our discussion with members of the medical profession and so on in America—what is the situation with people who do have neurological impairment and, to put it at its most basic, may not be able to drink due to an advanced stage of some of the situations you find.

Professor Kennard: In that situation there clearly would have to be a physician or somebody on the team who would be involved in administering it either through a nasogastric tube or tubes into the stomach (many of these patients have gastroscopies) or intravenously. Then I think there would be increasing difficulty in actually deciding who would be responsible for that and who would take it on. Although there would be disquiet I am sure that if that was really the patient's wish then somebody would be prepared to administer it. I do not see that the Bill would anticipate real problems with finding people to administer it if, on the whole—the majority of patients—were being given a prescription, but there were only occasional patients (as with the neurological ones in particular) who would need assistance.

Dr Bateman: I would like to add one point there. There was quite a lot of evidence that came to me and I am sorry to slightly disagree but I think people would have considerable misgivings. It was made very clear to me by a lot of the members that as doctors we assist people who are dying and we try to relieve their suffering, but there is a big difference between doing that and actively ending somebody's life. A lot of disquiet was expressed about that precise difference and people did still see that as a major difference.

Q1143 Baroness Jay of Paddington: Sorry I am not following you. What was the major difference?

Dr Bateman: There is a major difference between giving somebody an injection that is going to kill them with the intention of doing that, and easing somebody's suffering and pain by giving them drugs that would make them more comfortable, that are necessary to make them more comfortable and ease their suffering.

Q1144 Baroness Jay of Paddington: That is not really what I was asking. I was asking about the nature of the lethal prescription.

Dr Bateman: I think there would be considerable disquiet about it. I think there is a real difference of opinion. I do not think that we could give you a unanimous view on that at all. We are not in a position to do so; we have not consulted our members precisely about that issue.

Q1145 Chairman: Did I pick up correctly the feeling that to provide a prescription would be perhaps more easily accepted than the idea of deliberately injecting someone with a view to their immediate or very early death. The second of these, I got the impression from what you were saying, you felt might, in very exceptional circumstances, be something that neurologists would be prepared to do but on the whole there would be much more disquiet about that than there would be about the possibility of prescribing a drug which would be administered by the patient, self-administered either ordinarily or through one of the tube arrangements that Professor Kennard described. That would be less burdensome to the physician.

Dr Bateman: It would certainly be less, but it would still be an issue.

Professor Kennard: Of course, it is illogical. If you are prepared to give a prescription for somebody to take themselves which will lead to their death then it is illogical to say that because the patient is incapable of actually taking that drug themselves that you would not be prepared to administer it. Certainly there would be those who would not be prepared to be involved in it, but I think there would be others who would see the illogicality of taking that stance and want to do the best for the patient.

Q1146 Bishop of St Albans: Speaking as a complete layman in this area about competence and it is the phrase you used I think, Professor Kennard, about mild depression. It seems to me as a layman that there are some life circumstances in which to be mildly depressed is a perfectly reasonable reaction to life's circumstances. In the case of mild depression how frequently would you feel it necessary to see a patient in order to determine whether that mild depression was significant or not in the kind of decisions they reached?

Professor Kennard: If a clinical psychologist or a psychiatrist was involved, there are various questionnaires that are well validated that can be used for assessing this. I think one obviously would have to consider this in relation not only to one's interaction with the patient him or herself but also talking to people around them—if they are in a hospice there would be their carers there; if they are at home there would be their family—they would see to what extent they had changed over a period of time. You are absolutely right; anybody who is in this situation where they are actually contemplating assisted dying is highly likely to have a mild depression. I think that my experience would be—although I am a neurologist and not a psychiatrist—that the people who are being asked to sign up for the patient—the two physicians, a general practitioner and a consultant physician—do not necessarily have the expertise to identify not only mild but probably moderate depression. Whilst I

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would agree that mild depression would, I suspect, be almost universal amongst these patients I would still be very unhappy that somebody with a moderate depression would have their judgment impaired as a result of this and it would not necessarily be picked up by somebody who did not have the expertise. At the moment the way the Bill stands is that this could happen.

Q1147 Bishop of St Albans: Are you saying that there are sufficient numbers of people with expertise to deal with all the possible demands upon their time?

Professor Kennard: Clearly this is a problem. I think as Professor Leigh has said that the numbers are probably not going to be that huge and my understanding is that in countries or States in America which do have assisted dying the numbers are relatively small. I am not sure that it would be a huge burden. Clearly everybody in the Health Service is doing more than enough already, but I think the numbers would not be that great and they would be dotted around the country.

Q1148 Bishop of St Albans: So you think that everything could be safeguarded that needs to be?

Professor Kennard: I think that one can do the best one can. There are always opportunities for things to occur that one has not thought of, but to my mind—and I think to a number of our members' minds—that was a critical issue in relation to defining competence.

Q1149 Bishop of St Albans: I would imagine that in your field, your professional understanding of humanity must be acute because you are dealing at the very edges both of our own self-understanding and the way bodies, minds and brains work. Would you at any point allow a phrase like “sanctity of life” within the kinds of discussions you might have, or would you always bracket that out as not being a relevant mode of discourse?

Professor Kennard: I think personally I would not introduce that as an issue. I think I would have a discussion with the patient on the grounds of what it is they wanted.

Q1150 Bishop of St Albans: Sorry, I was meaning not so much doctor/patient relationship as peer relationship between neurologists.

Professor Kennard: I think that will undoubtedly become an issue. There will be those who would feel that it was against their Hippocratic Oath and that they are there to heal. It is a judgment as to whether you consider that part of the healing in chronic conditions is actually to assist in death if there is no prospect for improvement.

Bishop of St Albans: Thank you. I would love to go on, but I must not take up any more time.

Q1151 Earl of Arran: Professor Leigh, you mentioned the fact that of 2000 patients that you have known or do know who have this disease, it is a very small minority who might at the present moment like to take advantage of assisted dying if it were available. Can you say what kind of percentage this minority is?

Professor Leigh: The caveat is that we have not gone out to do a survey to ask specifically how many have been thinking this but have not wanted to say it to us. What I could say is that we do discuss end of life issues with virtually everybody who we look after in the long term. I would estimate that it is about one per cent who have taken action on this already outside this country, or even inside. My strong impression is that the fundamental question they ask is: how am I going to die? Can I die with some dignity and without undue suffering? Most people do not like to have that conversation—of course, it is not an easy conversation to have—and will not ask that until it is put to them. However, if you do put that to them and ask if they have thought about the end stages of the disease, they will say: how is it going to be and how is it going to be controlled? This comes back to Tricia Holmes' point. If you can then say to them that they can have excellent palliative care, we will do our best to arrange it, it is there locally, it is their right, (although there may be glitches because it is not the same everywhere in the country), it is possible to have morphine and other drugs so that they can be kept reasonably awake and will not suffer, that is what most people want to know. They just do not know that to start with and they are frightened. The remaining people who are not satisfied with that approach, are a very small and very often pro-active group of people for whom the simple burden of the disease—not the dying bit—is what really hits them hard and really makes life intolerable. They cannot bear the continuous loss of function. It is often way down the line before these last few months (which we find so difficult to judge anyway) that they want to make these decisions or have the right to make that decision. I think this does come back to the point that I am very uneasy about: we say “a few months” but we cannot possibly judge that in many of the patients we see and we will end up by perjuring ourselves—or being tempted to—by saying it is a few months when we know it might be anywhere between six months and 18 months. I think the Bill does need to take that into account because if people have a right to assisted dying at the very end, why should they not have the right, when they are severely disabled but maybe two years away from death? I would be happy to sign up to that. I have some reservations about the physical doing of the deed—as my other colleagues have—but that is a detail; the principle is that they should have that right if they are competent and if we can judge them to be competent.

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Q1152 Earl of Arran: Amongst the families of the patients would there be a greater number who would actually like to see the suffering of the beloved one disappear and therefore there might be greater numbers of families wishing for this to happen than the actual individual patient himself?

Professor Kennard: My impression is—and I stand to be corrected by my colleagues who know more about the whole field of palliative care than I do—that actually the families are often the ones who are most reluctant; it is the individuals who feel they can take the decision and the families have a lot of difficulties getting their heads round this. I do not know if others here feel that is correct, but that is my impression.

Q1153 Baroness Thomas of Walliswood: Thank you for that last comment because it leads me into the question which I wanted to ask of Professor Kennard. It is all very well saying that somebody who asks to be given the ability to die at their own moment of choice is—or may be—depressed, but that sounds to me—or could sound to me in some circumstances—like a doctor saying (in his mind, not saying to the patient), “Well I know better; she or he doesn’t really want to die and therefore we must bring in all these clinicians to test the level of mental capacity or depression of the patient”. All through our lives we all do things all the time and we may, at any given moment of our lives, be slightly depressed; it is not difficult. The rest of the world does not say, “She can’t buy a house because she’s too depressed” or “She should not get on aeroplane or take a journey because she’s too depressed”. If somebody said that to me I would tell them that it was my business and not theirs. I did not go on the trip to Oregon but I have heard that there the people who actually go ahead with this taking the pill, as it were, or the dose, are of quite a well-defined type and one of the things that defines them is the habit of autonomy lived through their life. I can think of at least two people in my immediate family who would be angry if they were told they were depressed just because they had taken a decision which they had thought about over the years for a very long time indeed. There is also the other way round, that some patients do not get the chance to do it when they would have liked to have done it and then they lose their reason—or whatever it is—at which point of course it would more or less amount to murder to give them some dose or other. I can quite understand that, but to watch that happen is actually a very tragic situation. I think we have to be very careful on how we define patient attitude. I wonder if Professor Kennard who raised this topic could tell me what he thinks about the points I have just made.

Dr Bateman: Can I help out? I think all we are saying is that there is a difference between being mildly depressed and having perfectly valid and

understandable reasons for wanting to end your life, and somebody who becomes very seriously morbidly depressed as a consequence of the fact that they have a fatal illness and all they are going to have to endure and then, because of that feeling, they decide they want to end their lives. That is the difference and somebody who actually became quite psychiatrically depressed as a consequence of a very unpleasant diagnosis could actually be made better with anti-depressant treatment and could have subsequent good quality of life. I think that is what we are trying to say and that we would have to have provision to make sure that those two are not mixed up and that there is a safeguard within the Bill for those particular groups of patients to ensure that they are recognised and treated appropriately.

Professor Kennard: Can I give an example of two physicians that I have known who both become unwell, one with not a terribly serious disease and one with a more serious disease. They clearly—as it turned out—became depressed about this and they took early retirement. The disease improved—disappeared in one and the other one became much better—and they greatly regretted having made that decision. They signed the papers, they left as a consultant so here are people whose judgment was impaired by the depression. Subsequently they felt they were okay and they had made a wrong decision. That is what I think we are trying to prevent. Talking to these doctors socially, they did not seem particularly depressed, but if one had actually assessed them formally I think you probably would have found that they were depressed. Therefore, as a consequence of that they made an ill-judged decision. Giving up your job is one thing; to actually ask for assisted dying is a completely different thing.

Q1154 Baroness Thomas of Walliswood: You are talking about people who had received a diagnosis. This Bill, so far as I am aware, is definitely directed towards patients whose death is relatively imminent so it is a little bit different.

Dr Bateman: I appreciate that, but I still think it is possible that somebody may become depressed at that stage of the illness and as a consequence they realise that the end is nigh—for want of a better word—and they just foresee increasing difficulties.

Q1155 Lord Turnberg: If I understand you correctly, you are saying that of the patients you meet with motor neurone disease, when you talk to them about end of life issues the vast majority—whether depressed or not—are not interested in assisted dying but there is a small sub-set who are. That suggests to me that the mild depression issue may not be entirely valid; that despite mild depression—which most will have, even moderate depression—very few actually

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have thought of trying to kill themselves. Is that a correct assumption?

Professor Leigh: I think it has passed through the minds of most of them. There are options which are obvious to them: could I end this prematurely? So if you ask people most of them will have thought about this but will have apparently rejected it and are much more concerned about comfort, quality of life and dignity in dying than they are about actually committing suicide. So yes, I would say it is a very small minority who might be coming back and back to the question of suicide. I think it must pass through the minds of everybody with this disease that suicide is an option; this is a fatal disease. I think that is natural; all of us would think the same. That would be my response.

Q1156 Lord Turnberg: The other point about this is that if it is an option on the table do you think it would encourage more people to take it?

Professor Leigh: I have read the literature on the experiences of other countries and my interpretation of the evidence is that that does not seem to be the case and therefore I doubt it.

Dr Bateman: I agree. I think it is very unlikely to encourage more people.

Q1157 Lord Turnberg: We have heard witnesses suggest that they have a sense that they are a burden on themselves, on society, on their families and on the Health Service and that this would encourage people to offer this more freely or easily or that they would be under some obligation. Do you feel that that is a possibility? The type of patient you describe, incidentally, does not seem to be the sort of person you could put upon but on the other hand there is this fear. Can you help us with that?

Dr Bateman: It is very difficult. I can well understand the scenario and I think there would be people who might be in danger of making those kinds of decisions for the very reasons you say and it would be important to have appropriate safeguards to prevent that. That is certainly a real possibility that people would seem themselves as a burden and want to end their lives.

Professor Leigh: Patients are a burden and they are well aware of it. I have had relatives say to me: "You told me this was going to last three years; it is now five. I scheduled my fortitude for three years and I am afraid it has overshot the mark and I can't stand it." I think it is only human to feel that sense of burden. If you are a relative it is not necessarily a wrong thing to say: "I would like to relieve the burden on the family". It may be a perfectly rational and reasonable way of expressing autonomy. Of course, if they are pressurised in some way—and that could be very subtle—then that is very different. The subtleties here are what make it such a difficult and fascinating issue. Could I just comment on the autonomy issue? It seems

to me that while I totally support a patient's right to have that autonomy they also have responsibilities to the people who are going to have to do something which is traditionally—and probably always will be—fundamentally against the traditional medical ethic, that is not to harm, to try to help, relieve and alleviate pain. This is where the sanctity of life does come in I think, and we have seen the abuses of that. I think there is tremendous concern amongst all of us about the potential abuse of medicine, the potential to abuse our position or to have others do it. Therefore, the people who are going to exercise that autonomy also have a responsibility to go through the hoops to enable people who have to help them to feel that they have done the right thing morally and ethically. I think that is a constraint on autonomy for me.

Q1158 Chairman: Ms Holmes, we have been hearing the neurologist but is there any comment you would wish to make on anything we have heard?

Ms Holmes: Only in addition to the fact that I think many people with motor neurone disease and their care givers are spending most of their lives living with this disease fighting to get basic access to information and practical services. Certainly from our care information service and our regional care advisors those are the key issues. People do talk about how they are going to die and it is a small proportion of people who talk about wishing to die. That is not to say, though, that that is not the situation. I think the additional point is that care givers themselves are carrying the burden of care throughout the life of somebody with MND in the main and we need to be thinking about how we provide appropriate support for them in the decision making process and what happens thereafter. I am sure they would wish to support the person they are caring for but they are left with having to deal with that. They may not have agreed with it themselves so we need to be thinking about how we can properly support care givers beyond the death of somebody however they die.

Chairman: Thank you. Lord Joffe?

Q1159 Lord Joffe: Professor Leigh, I understand that it is very difficult at the time of first diagnosis of any disease to prognosticate the likely date of death. Does there come a stage in the course of the illness when an experienced physician could form an opinion that the illness would be likely to result in the death of the patient within a few months?

Professor Leigh: The answer is yes. The threshold really is the obvious beginning of respiratory muscle weakness so when your diaphragm and your other breathing muscles become weak you know it is only a matter of months before someone will go into respiratory failure and that will begin the dying process. They will have a lifespan of weeks or, at most,

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a couple of months. The problem now is that we have non-invasive ventilation. We can support people. We even have invasive ventilation where although the disease progresses around the ventilator they will be alive on the ventilator indefinitely. That is not usually an option that people exercise in this country but it is a potential option. To the individual who comes to me with a very weak diaphragm I would say, "Normally you'll be dead in three months but I can extend your life for a year or 18 months or two years". They may then decide not to have that and to take the option of assisted dying. Personally I think that is a perfectly reasonable choice over and above an intervention that will keep them alive for much longer, but it would be a very small minority who would turn down non-invasive ventilation at present.

Q1160 Lord Joffe: The patients you speak to who are strong willed and want the option, what does it do to them when you have to tell them that it is against the law?

Professor Leigh: Some of them will go elsewhere and they have done that. I think others are despondent. The only thing one can offer them is to tell them to talk to their palliative care physician and I would talk to them as well. We would work out a policy that enables them within the law to have relief of suffering albeit the consequence will be that death will come sooner. That is the best we can do at the present. For those who really wish to exercise autonomy it puts them in a very different position and creates great unhappiness.

Q1161 Lord Joffe: You have set up a centre for palliative care in neurology with Professor Higgins so you are particularly well-qualified to look at the question of palliative care and last resort options. Would you see any consistency in vigorously promoting palliative care and the benefits of it but having a last option?

Professor Leigh: Irene Higginson, my partner in this venture is much more expert than I am in that field but I would certainly agree that I see no contradiction in that—although I cannot speak for Irene—and it would seem to me that in a way it is part of good palliative care to give people autonomy and to support their wishes as far as possible within the caveats and constraints that society wishes to put on them. I do not see any conflict in that.

Dr Bateman: I think it is rather the other way round: you must have good palliative care before you could even consider this and if you do not have good palliative care then it is not appropriate. You have to have good palliative care before you could even consider assisted dying. If you have not and the patient has not had access to that or received it then it is inappropriate.

Q1162 Lord Joffe: Are you saying that if there is not good palliative care throughout the land then patients must just suffer?

Dr Bateman: Nobody would wish any of the patients to suffer but unfortunately palliative care provision is not perfect for the whole of the country and we all felt in discussion amongst ourselves that unless patients have had the opportunity to access palliative care and see what it has to offer and see how it can relieve their symptoms and enable comfortable dying with dignity and relief of pain and suffering, then they are not really in a full position to be able to make a decision about whether they should end their lives by other means.

Q1163 Lord Joffe: You recognise the illogicality of the situation, that the patient who asks for the option to die is refused it because there is not good palliative care. The patient suffers two ways.

Dr Bateman: I see what you are driving it. It would be very hard to invoke that process if you did not have good palliative care because you would be in a very difficult position to have the appropriate safeguards, checks and balances to make sure that all the things we have been talking about—competence and appropriate decision making in this situation—could be gone through. I think we would have a lot of concern about that situation.

Professor Leigh: I guess my response to that would be that I share David's concern that there should be full access but I think that what one would need to say to these people—because one has to respect their decision making—is that they must know what palliative care has to offer even though there is not a team "next door". That does presume that the person giving that discussion knows what they are talking about. It may not be a neurologist I have to say, although I would hope it would be. They need to know what can be done with palliative care I think. I do not think one has to say, "At this minute I could send you round the corner for palliative care" but you can almost always arrange things with enough hard work in the NHS even if there is not something around the corner. If they said, "Yes, I will do the palliative care route after all" I am sure it can be made to happen. However, I think for the actual process what one needs is an intelligent discussion of palliative care so that the patients know what can be achieved in terms of comfortable and dignified death with palliative care should they wish to choose that option. It is the question of the detail and the accuracy of the information that is given to the patient.

Q1164 Lord Joffe: Professor Kennard, would you agree with what has just been stated?

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Professor Kennard: Yes and I think that if this Bill is enacted what would happen is that there would need to be an expansion of palliative care facilities in the United Kingdom. I think it would be a stimulus for that and that is all for the good. The way that the Act is currently written would lead to this as a consequence.

Ms Holmes: I would just add, I think, to that that I think there is an assumption that it is available and in many cases people with neurological conditions generally—let alone people with MND—do not necessarily have access to a broad array of palliative care services so we cannot make the assumption that it is just sitting there ready for the take up by anybody who would like to take that option and be informed about the opportunities there. I think we need to be promoting much closer links between palliative care and neurology to ensure that anybody who is referred and takes that option is going to get appropriate care and support when they are there because it may be that the techniques for looking after people with cancer are not going to be replicated for looking after people with a wide range of neurological aggressive conditions.

Q1165 Chairman: I think I am right in believing that most of the diseases like motor neurone disease and so on are progressive but not necessarily at a uniform rate and various factors can affect the rate at which it progresses. Professor Leigh mentioned infections and so on. One of the problems that I would like to ask you about is this: this Bill requires that before the procedures are embarked upon the patient must be thought to be within a few months at most of his or her death. With this kind of advancing trouble it may be that if you have to wait that long it is already too late for you to self-administer. Is that possible?

Professor Leigh: Absolutely. Likely, in fact.

Q1166 Chairman: Secondly, it may also affect your means of communication and in particular writing anything down so that if that condition that I referred to of being within a few months at most of death as part of the arrangement you may be preventing the very people who would want this particular course of action at an appropriate time in their progression to have it because they would need to have it consented to earlier. They foresee a time when they would want to use this particular course of treatment but not yet. Is that a problem in your view?

Ms Holmes: I think we would say it is a significant problem. Firstly we would hope that everybody would have access to a speech and language therapist at some point during the progression of their disease so that if they are having difficulty communicating they are provided with appropriate options. They may be low-tech such as alphabet boards or it may be a high-tech communication aid a bit like a computer (a bit like Stephen Hawkins, for example). To be able to utilise those you need to understand how they work, you need to be fairly competent in using them. As the condition deteriorates there are options for switching and so on so that you can change your method of operating. However, if you do not have access to any means of communication that becomes a real problem and if you do not have access to the support of a speech and language therapist (which is one of those professions which is often in short supply) then that becomes increasingly difficult. It may well be that the person providing your care actually spends so much time with you and is very aware of what you are communicating by whatever means you come up with, but that might not be viewed to be appropriate, to be communicating through another person.

Q1167 Chairman: It might not be appropriate for the doctor or whoever was in charge of the treatment to be relying on the carer to interpret what the patient was wishing to communicate.

Ms Holmes: That is correct.

Q1168 Chairman: I follow that. The other thing I was wanting to ask you, does the Association of British Neurologists include physicians?

Dr Bateman: We are all physicians.

Q1169 Chairman: There are no neurosurgeons.

Dr Bateman: No, there is a separate society which is called the British Neurosurgical Society.

Q1170 Chairman: So it is physician work that all of you do.

Dr Bateman: Yes.

Q1171 Chairman: Then it may be necessary in some cases to refer to a neurological surgeon.

Dr Bateman: Yes.

Q1172 Chairman: I think you have helped us very clearly and we would like to thank you very much for coming along and helping us in this way.

Dr Bateman: Thank you for giving us the opportunity.

WEDNESDAY 15 DECEMBER 2004

Present	Arran, E	Patel, L
	Finlay of Llandaff, B	Taverne, L
	Jay of Paddington, B	Thomas of Walliswood, B
	Joffe, L	Turnberg, L
	Mackay of Clashfern, L	
	(Chairman)	

Memorandum by the British Geriatrics Society

The British Geriatrics Society (BGS) is a professional association of physicians, general practitioners and scientists with an interest in Geriatric Medicine. It is the only society offering specialist medical expertise in the whole range of health care needs of older people, from acute hospital care to high quality long-term care in the community. It now has over 2,000 members worldwide.

Geriatric Medicine is that branch of general medicine concerned with the clinical, preventive, remedial and social aspects of illness of older people. Their high morbidity rates, different patterns of disease presentation, slower response to treatment and requirements for social support, call for special medical skills. The purpose is to restore an ill and disabled person to a level of maximum ability and, wherever possible, return the person to an independent life at home.

The BGS is pleased to have the opportunity to respond to this Bill and makes the following points:

1. The BGS accepts the rights of individuals to determine the choice of treatment and care they receive. We further accept that sometimes, but very, very rarely, some symptoms are difficult to control and that even if they are, people may still find their life unbearable. Yet a policy which allows patients, in certain circumstances, to choose death, and to be helped to die by their physicians, is not the ethically correct answer. The BGS believes the duty of the physician to care for his/her patients is incompatible with a duty to bring about death even at the request of the patient. It is argued by proponents of euthanasia that curing disease and bringing about death are not mutually exclusive roles, the intention in both cases being the relief of suffering. It is further argued that the primary role of the physician is to care for his/her patient, which must therefore entail respecting their autonomous wish to die. However, the BGS believes that crossing the boundary between acknowledging that death is inevitable and taking active steps to bring about death changes fundamentally the role of the physician, changes the doctor patient relationship and changes the role of medicine in society. The focus would shift from providing the best palliative care ie easing symptoms to providing death on demand. Such a shift will inevitably dilute the sanctity of life doctrine. Once quality of life becomes the yardstick by which the value of human life is judged, the protection offered to the most vulnerable members of society is weakened.
2. In the experience of many geriatricians, the feeling for many older people that life is unbearable in its later stages is a direct result of the reaction of others to their frailty and the care and treatment they are afforded. Our concern then is that many older people, because of the care given to them by society in general and the NHS and Social Care system in particular, will perceive themselves as a burden and feel under pressure to end their lives. The BGS considers the best way of helping these vulnerable people is to maximise their independence and health, rather than acceding to their expressed wish to die.
3. The BGS believes that Older People are often unduly influenced by their families and carers. It is important to remember that not all these people will necessarily have the older person's well being at heart. Even if they do, it is noteworthy that almost all requests to end life—made either directly or indirectly to us as Geriatricians—come from the patients' families and not the older person themselves. Often such requests are then forgotten if such degrading symptoms as urinary and faecal incontinence, depression and unremitting pain are relieved. The BGS thus questions the true need for the bill.
4. Whilst many older people are competent to make decisions about their wish for assisted dying, many will not be. The proposal in the Mental Capacity Bill is to appoint a health attorney with the legal authority to take health and welfare decisions for a person in the event of his or her loss of capacity. This could mean, under the terms of the Assisted Dying bill, that a decision to end an older person's

life could be made by a nominated health attorney. The complexities arising from such conditions could therefore lead to serious abuse of this power. Furthermore, such situations might interfere with the beneficial use of the Mental Capacity Bill.

5. We are concerned about the addition of Section 15 to the Bill. The right of any individual, whether terminally ill or not, to have their symptoms controlled is undisputed. In our opinion there is no overlap in clinical practice between symptom control and the wilful termination of life (or assisted dying). To muddle the two is to cause considerable confusion and to risk the danger that symptom control becomes an easier way to hasten death than completion of the declaration and all the safeguards therein—especially for people who are deemed incompetent.

In the same vein, the BGS would emphasise that the right of a patient to choose or decline prolonged treatment and or intervention whatever the consequences, supersedes all other guidance and wishes.

6. Finally the BGS is concerned that the “Assisted Dying for the Terminally Ill Bill”, whilst it does not apply directly and solely to Older People, will lead to a change in attitude to death in society and also within the medical profession. The prohibition on intentional killing is the cornerstone of society and it is worth preserving the notion that all lives are precious. The BGS accepts that this denies a very small number of persons the right to have their life ended by their physician if it is their autonomous wish. However it must be noted that every society puts some limits on respect for autonomy, which must be balanced against the greater good of society. The BGS urges Parliament instead to strive to improve the medical and social care of older people, placing them back in the centre of a society, which respects their wisdom and experience. Rather than defining the conditions under which physicians may become killers, our efforts should focus on improving all aspects of palliative care, such that the debate on assisted death becomes irrelevant.

In Summary therefore the British Geriatrics Society is totally opposed to the introduction of the Assisted Dying Bill.

Nonetheless it is recognised that the decision is for Parliament. If, despite our objections, the Bill is enacted into law, we recommend the following additional safeguards and caveats.

(A) FOR THE PROCESS OF SIGNING THE DECLARATION

- (i) A cooling off period of at least 14 days, after the declaration has been signed and witnessed.
- (ii) A mandatory psychiatric opinion to exclude a depressive illness—from a specially trained psychiatrist
- (iii) Involvement of the patient’s general practitioner in any discussion around the signing of a declaration.
- (iv) Written confirmation from the doctors and solicitors involved that they, their families nor any charity with which they are associated or connected, will benefit from the patient’s will.
- (v) Obligatory assessment by a specialist palliative care team.
- (vi) In the case of older people, where the attending doctor is not a geriatrician, there must be obligatory assessment by a consultant geriatrician.
- (vii) A much clearer definition of a “terminal illness”. The prognosis of a “few months” is not in our experience very easy to determine.

(B) THE ACTUAL PROCESS OF DYING

We are concerned about the nature and process of the “assisted death”. Will there be clinical and or best practice guidelines outlining the best method?

We emphasise strongly that the BGS believes that should the bill become law—no doctor should be obliged to participate in the process of ending life. To do so would risk confusing the role of the doctor and damage the patient’s trust that their doctor is always working in their best interests. Indeed we question whether the process should be undertaken by doctors at all.

(C) THE ENDURANCE OF THE DECLARATION IN TIME

The Bill proposes that a period of no more than six months should elapse between the declaration and the act of assisted death. Whilst accepting that there should be some time lapse—we suggest that there needs to be provision for the eventuality that the patient becomes incompetent in the intervening period. In our opinion the declaration should become invalid in such circumstances. Likewise we would be most anxious to avoid the use of Advance Directives (proposed as a statutory principle under the Mental Capacity Bill) as a mechanism to request assisted dying. We cannot and should not assume that a person could reliably determine in advance their preference for dying in the event of an actual situation they have not yet experienced.

August 2004

Memorandum by Help the Aged

ABOUT HELP THE AGED

1. Help the Aged's vision is of a future where older people are highly valued, have lives that are richer and voices that are heard. Working with older people, we champion their needs so that they can better their lives. Through research, campaigning and fundraising we develop solutions, drive activities and inspire others to do the same. Our strategy is to attack and remove the major barriers to active and fulfilled later lives, and to concentrate our efforts on those older people most at risk of disadvantage or social exclusion. Our four urgent priorities are combating poverty; reducing isolation; defeating ageism; and promoting quality in care.
2. Help the Aged does this by providing a range of direct services in the UK to help older people live active and independent lives, funding vital research into the illnesses and social context of ageing, and funding international activities.
3. Help the Aged has not specifically canvassed the views of older people on the issue of assisted dying, in developing this response. However, we are currently engaged in a consultation with older people on issues related to death and dying, and are developing a programme of work in this area. We have also received several telephone calls and letters from older people expressing their views on this Bill.

HELP THE AGED'S POSITION ON EUTHANASIA AND ASSISTED SUICIDE

4. Help the Aged has set out its starting point in issues relating to the end of life in a position statement, which is available on request. In line with this statement, Help the Aged is opposed to euthanasia, and does not favour any change in the law relating to assisted suicide.

HELP THE AGED'S POSITION ON END OF LIFE CARE AND SUPPORT

5. Help the Aged believes that older people have a right to expect that their views and wishes will guide others in their treatment and care when they are dying. Planning and decision-making around the end of life are deeply personal issues, and the views of the individual are paramount.
6. The desire to retain control, autonomy and choice in daily life is strong amongst people of all ages, including older people. Help the Aged believes that older people have the same legal and moral right to retain control over their lives as other adults. We therefore believe that, while relatives may be consulted about care issues if the older person agrees, the views of relatives and carers should never be a substitute for those of the older person themselves.
7. Help the Aged believes that older people should be offered quality care and support at the end of their lives. We were struck by the findings of the Health Select Committee on Palliative Care, which highlighted the current failings in the provision of care and support for older people at the end of their lives.

DECISION-MAKING AND COMPETENCE

8. A good death is one in which people are enabled to die with dignity and a sense of completion, retaining their autonomy. Therefore, making decisions is central to the experience of a good death. Talking about and planning how one wants the end of one's life and funeral rites to be arranged, should not be taboo, and Help the Aged is working to encourage older people to discuss and plan for their deaths. We agree that all older people should have the opportunity to make their wishes known about their own death, and that care staff in all settings should receive training to ensure that older people's wishes are central to decisions made at the end of life.

9. As a member of the Making Decisions Alliance, Help the Aged has supported the proposals within the Mental Capacity Bill to give greater protection to the individual's right to make their own decisions.

10. Every competent older person already has the right to refuse medical treatment if they so choose. Advance Directives (also known as advance statements or living wills) are a formal way in which people can indicate what medical treatment they would or would not be prepared to accept in the event of losing the capacity to decide for themselves. Help the Aged believes that advance directives are a useful tool, for those that wish to use them, however the use of an advance directive should always be a personal choice. As a member of the Making Decisions Alliance, Help the Aged has campaigned for better recognition of advance directives and advance statements.

11. We have also campaigned, through the Making Decisions Alliance, for the ability for individuals to nominate somebody close to them to take decisions on their behalf when they may be unable to do so themselves.

12. We believe the variation across the UK in the rules allowing people to nominate somebody to act on their behalf when they no longer have the capacity to make decisions, is unhelpful. In Scotland, it is possible to nominate someone who can take decisions about personal welfare on behalf of an individual, including granting consent to medical treatment. However, in England at present, there are no mechanisms to allow other people to take such decisions for somebody else. In Help the Aged's view, this lack of clarity around decision-making hinders the pursuit of informed debate about death and dying.

HELP THE AGED'S COMMENTS ON THE CONTENT OF THE BILL

13. As stated above Help the Aged does not support a change in the law in relation to assisted dying. Notwithstanding this, we offer the following comments on the detail of the Bill as drafted.

14. Help the Aged has some concerns relating to the provision for "Qualifying Conditions" as set out in clause 2. In particular, the proposed duties of the attending physician and consulting physician do not, in our view, place sufficient weight on the patient's own views. We would wish to see a far greater emphasis on the dialogue that should take place between the physician and their patient. Clause 2(2)(d), for example, appears to suggest that the determination that the patient's suffering is unbearable rests with the attending physician. In our view, it could only be the patient that would be in a position to make such a subjective assessment of their own circumstances.

15. Furthermore, we would wish to see the inclusion of a right to information and advocacy for all patients in the prescribed circumstances to which the Bill relates.

16. We warmly welcome the status offered to access to palliative care contained within clause 3. However, we would recommend that this clause should be used to further the issues raised in the House of Commons Health Select Committee Inquiry into Palliative Care, by granting patients a right to palliative care where that is their wish, rather than simply placing a duty on the physician to ensure that the option has been discussed.

17. Clause 4(6) sets out the limitations on those able to witness a declaration of their wish to be assisted to die. The definition of "partner" contained within this clause is, in our view, too narrowly defined, and fails to take account of those patients who may not be married to their partners.

18. We are concerned about the facilities for revocation of a declaration, and particularly in those circumstances where the patient may have lost competence, as defined. It is our understanding of the current situation that an individual who is legally defined as incompetent does not necessarily have the ability to make decisions about their care. For example, a patient with a degenerative condition such as dementia may sign a declaration while they remain competent, but would have no mechanism in the current law relating to decision-making to revoke that declaration if and when they lost competence as a result of their condition.

19. We are also concerned that clause 7(2) suggests that an attending physician may have a conscientious objection to administering pain relief as set out on Section 15. We recommend that the reference to objections to the administration to pain relief should be removed, as it would surely be unethical for a physician to refuse to relieve pain.

20. We have concerns about Clause 14, as it relates to the creation of a monitoring commission to review to implementation of the proposed Bill. We agree that there would be a need for such a commission to oversee the implementation of the Bill were it to become law, but believe that such a commission should have an opportunity, where requested to do so, to review cases before the patient is assisted to die. This would introduce an additional safeguard in to the system to the benefit of patients, and to avoid abuse of the provisions contained within the Bill.

CONCLUSION

21. As stated above, Help the Aged does not support any relaxation of the laws relating to assisted suicide. Our principal objection relates to the absence of robust and effective protective mechanisms against potential abuse.

22. However we very much welcome the emphasis given within the Bill to the need to give people choice and control at the end of their life. We also welcome the increased emphasis on palliative care options.

23. Furthermore we recognise and welcome the opportunity this Bill presents to debate and discuss these complex ethical and moral issues. We hope that the Bill will spark a wider public debate on these important issues, and help to break down the taboos which surround the issues of death and dying.

September 2004

Examination of Witnesses

Witnesses: DR JERRY PLAYFER, President, and DR GILL TURNER, British Geriatrics Society, and MR JONATHAN ELLIS, Policy Manager, Health & Social Care, and MR TOM OWEN, Research Manager, Policy Unit, Help the Aged, examined.

Q1173 Chairman: Good afternoon. We are grateful to you for coming along to help us, Dr Jerry Playfer and Dr Gill Turner from the British Geriatrics Society, and Mr Jonathan Ellis and Mr Tom Owen from Help the Aged. The system we have sought to follow is to give you an opportunity, either in respect of your particular association or individually as you wish, to make short opening statements on the main emphasis which you would like to put on your position in relation to the Bill and then give colleagues the opportunity to ask some questions. The evidence is taken down in shorthand and you will get a chance to correct the transcript of the evidence that you have given. In due course the transcript will be published when corrected as part of our Report to show the basis on which we have reached such conclusions as we may reach. Who would like to start?

Dr Playfer: I am the President of the British Geriatrics Society and I thought I would set the scene of who we are and what we do. The document we have provided to you was provided by our Policy Committee and Dr Turner was Chairman of that committee when the policy was formulated, so she will give the detail of our response. The British Geriatrics Society has about 2,500 members. It has virtually all the consultant geriatricians and trainee geriatricians in this country but it also relates with other professions in medicine through associate membership and through our special interest groups. We obviously have a mission to provide the best care we can for older people. Geriatric medicine is the biggest speciality in general medicine in British medicine so we have got more consultant geriatricians than there are any other type of consultant. Geriatric medicine is quite complex in the fact that we are often dealing with end-of-life situations, distressing situations, and as a group we aim to provide the very best care we can to older people, in doing that this Bill faces us with quite a challenge because it can affect the relationship

between our patients and our client group and how we are perceived in what we are doing and our response largely concerns those aspects.

Dr Turner: The stance that we are coming from depends on the fact that most of our patients will be older people and therefore we do not make any attempt to speak on behalf of younger people with terminal illness. Our concern was to point out that we totally support the concept of patients having a choice in the treatment that they choose and the treatments and decisions that they determine. We feel that nothing that we can say should ever surmount that. However, it is important to recognise that many older people, probably because of the care that we in the United Kingdom offer them, often feel burdened and often feel a burden to their families, and consequently we are anxious that the choices they make may not truly reflect their wishes but may reflect the way they have been led to feel by the way they are treated within the health and social care system. We feel that older people can be very vulnerable to adverse influence from outside, families and carers, and many of our members have felt that requests to end somebody's life artificially have usually come from families and carers rather than from patients themselves. We also have found that quite often the complications of illness in old age mean that many things which are potentially reversible can present themselves as a heap of difficult symptoms which, if dissected out and addressed by a multi-disciplinary team with a geriatrician as part of that, often can be reduced, or at least in relation to the health part of life. We also feel that the role of palliative care for people who are terminally ill cannot be overstated but we recognise that there are some symptoms that even palliative care cannot help address. Our view is that for the people for whom palliative care cannot offer very much the number of those people is so small that we would not want to increase the vulnerability of other older people by a change in the law as it

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stands. One final point we wish to make as doctors, because most of our members are practising clinicians, is that we would feel that the relationship between us and our patients would be irreversibly changed if the question of assisted dying was made part of our armamentarium. That is all I want to say outright but I am, of course, very happy to answer questions.

Q1174 Chairman: Thank you very much. We now seek help from Help the Aged.

Mr Ellis: My name is Jonathan Ellis and I am the Policy Manager for Health & Social Care at Help the Aged. My colleague, Tom Owen, has been leading on Help the Aged's work on exploring the range of issues around end-of-life issues to which we refer briefly in our written submission. As we also made clear, although we have not specifically canvassed the views of older people on this question of assisted dying we are opening up a wider debate about end-of-life issues which my colleague will talk to you shortly about. Help the Aged as a charity works domestically and internationally to remove the barriers to active, healthy ageing, and to give a voice to those older people who could be deemed to be the most disadvantaged or at risk of social exclusion. We are not a membership organisation but rather work to ensure that older people are heard in the decisions that affect their lives in policy, practice and, of course, their everyday existence. I will not rehearse the content of what we have submitted already in our written paper but I thought it would be helpful to give you an overview of why Help the Aged believes what it believes. It is important to stress that our objection to the central purpose of the Bill is not an ethical or moral one. We recognise that there are strongly held views on all sides of this debate and it would simply be inappropriate for us to attempt to homogenise such diverse moral views or to try and present a definitive view of older people. Our objection is more pragmatic than that based on the belief that there are insufficient safeguards in the proposed system and indeed, importantly, within the wider health and social care system, to ensure that potentially vulnerable older people do not fall victim to abuse or neglect. Also, it is important to stress that we very much have welcomed the debate that this Bill has triggered and initiated and the importance of this question of choice and autonomy right throughout life. We believe that the wider health and social care system has many failures which must be addressed adequately before as a society we will be ready to move to such decisions as this, such as access and the availability of palliative care services, improved decision-making and ageism and age discrimination. We know that ageism and age discrimination has a

huge impact on older people's access to services and on their own views of their self-worth, and I will hand over to my colleague, Tom Owen, to pick up on that point.

Mr Owen: I would like to add a bit of substance to what Jonathan was saying. Since the written response to you we have commissioned a piece of academic research from Jane Seymour of the University of Sheffield to undertake a review of literature around older people who are dying and their needs and their experiences, and also how older people communicate around death and dying. I have also been out talking to a number of older people who are at the end of their lives, talking very generally around some of the issues they face, not specifically assisted dying but other issues. That has helped us in understanding and informing our position although our position remains as it was in the written response. If I can give some context to some of the experiences of older people: Academic research quite often describes older people as the "disadvantaged dying". They might have a diagnosis of a terminal illness but they might also experience a lot of other conditions at the same time—arthritis, hearing impairment, visual impairment. They might also experience social isolation if they have lost spouses, if they have lost family and friends, and also they are more likely to have to deal with financial hardship. All of these things make dying very difficult for older people, not just their terminal condition. With that in mind one would hope that Health and Social Care services would actually focus on and target older people more but what we find from the evidence is that older people are less likely than younger people to receive palliative care, and they are less likely to die in their place of choice. There is some American evidence to suggest that older people are less likely to receive pain relief than younger people and there is a feeling that that is probably the same in the UK. Outside of the whole palliative care debate we know that people who are over 85, who are the most likely to be socially isolated, are no more likely to receive visits from GPs and district nurses than younger people, and beyond that with the practical aspects of life, things like getting dressed, sorting out the rubbish, the basic things, a lot of them struggle to get help from social services. What you have therefore are a lot of older people who are in a situation where their lives could be improved and our concern, I guess, is that they might end up making a decision to terminate life based on circumstances which could be avoided if proper services and proper support were in place; that is our key concern here. Obviously, we appreciate that within the Bill there is a clause which ensures that palliative care needs are discussed with older people.

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However we think that palliative care needs to be discussed way before any discussion around end-of-life and assisted dying, that it should be mainstream for people who are experiencing pain and terminal illness. The other issue which is of a very similar nature is around the experience of depression. We have just undertaken some research which suggests that older people are more likely to experience sub-clinical depression than younger people. A lot of people would refer to that as "low mood". The evidence suggests that GPs often do not pick up on this and even if they do, they are less likely to refer to specialised services. A lot of this low mood has to do with social isolation, with the practical problems, the daily hassles of life. Again, if this is not being recognised then we feel that this might impact on their decision-making, this low level of depression. A final point refers to the whole issue around feeling a burden if you are living in a world where everything around you is falling apart in terms of your health, family and friends not being around, in terms of the age discrimination that you are experiencing from services and society at large. Certainly there are a lot of messages now around the burden of the ageing population, the crisis in the pensions system and so on. All of this may be internalised by older people and may in itself lower self-esteem. We feel that while we have no evidence to suggest that older people feel that they have a duty to die, the progression from feeling a major burden on family and friends and society could lead, if the Bill were enacted, to the feeling that one had a duty to die for the sake of society. That is all I have to say around the whole area of age discrimination and how it impacts on older people. We have one final point to make around the issue of communication and decision-making in older age relating to death and dying. The research that we commissioned from Jane Seymour seems to suggest that older people do not talk about death or dying with family and friends, that they sometimes wish to but friends and family quite often dismiss them, saying they are being morbid, or jolly them in some way. It has also been suggested that nurses quite often do not feel confident in talking about issues around dying with older people and that professionals and practitioners also do not. My concern here is that within the Bill an emphasis is being placed on the need for good communication; that right at the centre of the Bill is the absolute need for an open discussion between the older person or patient, physician and family around the circumstances the patient finds himself in. If society is not able to communicate on sensitive issues around death and dying it means that decisions will be made without having proper discussion around them. We are concerned about that; that is why

Help the Aged are trying to increase the public debate around these issues. Dying is a frightening thing and older people that we have spoken to fear dying more than death. Not being able to talk about dying with close friends makes it more scary. We are also worried that if this Bill is enacted some vulnerable older people might pick up little bits of the story. They might pick up in the same way as they are picking up around "do not resuscitate" stories. This fear of going into hospital, "What is going to happen to me?", is a fear that if they went into hospital a doctor would have the right to take their life. Of course, we know that is not true in terms of the accuracy of the Bill but this is an anxiety for older people. That is something that we are aware of, that older people pick up on certain things and worry about them, and this might make them feel more vulnerable and socially isolated.

Q1175 Baroness Jay of Paddington: I do not have any central points to put to you but something which interests me is the comparison between what you have said and the evidence we have received from, for example, Baroness Greengross, in support of Lord Joffe's Bill who, I am sure you will be aware, was for a very long time Executive Director of Age Concern, an organisation similar to yours and I think you would regard as a pretty well known authority on these issues. On some of those points that you raised about vulnerability and confidence of patients, one of the things she said which struck me was that decisions about dying should be patient-led and a confident patient is central to decision-making, but that too often elderly people are assumed to be incapable of making informed decisions and suffer unacceptably patronising attitudes not backed up by evidence. I wondered what your evidence was in support of what you said and also what your evidence was for saying that you thought relationships between doctors and their patients would be disturbed or made worse by an enactment of a piece of legislation of the type Lord Joffe is proposing because our evidence is that in those jurisdictions where this has happened it is accepted patient/doctor relationships have improved?

Mr Owen: In terms of vulnerability, this is a tricky one because in some ways a lot of the people that we talk to on this are very confident and have specific views. I go back to a certain degree to my previous work which was 12 years of working in community care and work around the fact that older people who are frail lose self-esteem and confidence and are more likely to be depressed. It is backed by research evidence to suggest that you go into a vicious cycle of social isolation, loneliness and depression. In the work that I have done prior to

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this as a social worker I found that there are many older people who either do not feel confident in making decisions themselves because they have low self-esteem or do not understand. We are talking about a minority; this is certainly not the general older population, but there are people out there who are worried about going into hospital. That is a typical thing that you hear regularly, that the doctor wants them to go into hospital but they will not because they are scared about what is going to happen to them. One main fear is, of course, about going into residential care, not feeling that they have any power over decisions even if the systems try their best to help them to make decisions. We are at the stage now where we still have problems trying to empower older people to take decisions.

Q1176 Baroness Jay of Paddington: But would you agree with the evidence which we have heard from Holland, for example, and from Oregon, where some type of legislation of the kind Lord Joffe is proposing is in place? The general view of the evidence taken there from the epidemiological surveys people have been involved in is that the patient/doctor relationships and therefore the confidence of people to talk about any life decisions and their general care have improved rather than the opposite.

Mr Ellis: I would just add in response that obviously we support any steps to increase the ability of older people, as indeed of any patient, to have more control about their care and treatment, and that is something that we would all support, but unfortunately we know also that many older people are disempowered in the present system, in the health and care system, very often as a result of poor health and of a general fear of speaking up or, most importantly, simply being unaware of what their rights are and what they are entitled to.

Q1177 Baroness Jay of Paddington: But is that an argument for improving their capacity for being informed and the openness of the situation rather than being opposed to what Lord Joffe is suggesting?

Mr Owen: Improving it is important. I think testing it out on something as fundamental as assisted dying --- we have demonstrated that there are failures in communication currently in the health and care systems. I have a quote here from the Health Service Ombudsman who said, "The failure of communications can cause hardship and distress to patients and their families and carers. It is clear from the complaints I have received that poor communication, both between professionals and their patients, remains at the heart of many patients' experience of health care". Knowing that, does it

feel right to start talking to people about something as fundamental as assisted dying? Surely, with all the other types of decision-making we should get those right before we start talking about something as important as that.

Q1178 Baroness Jay of Paddington: I do not want to persist with this. I just picked up on what you said about ultimately patients having the right to have more control over decisions about their care and I thought perhaps it was more to do with the circumstances and perhaps we should look into that.

Dr Turner: I would like to respond to the two points that have been made. One is that I think it is important to recognise that for an older person who is frail, vulnerable and in hospital and possibly has had a stroke, if the choice they are being offered or is potentially being proposed is not to live any longer or to go to a nursing home 40 miles away from where they live because that is what the reimbursement legislation requires of them, which may not necessarily be very high quality or the social care fund does not allow that, then it is not really a choice. That is the trouble, that we feel that we are not offering a real choice of going on living in decent circumstances versus not going on living.

Q1179 Baroness Jay of Paddington: I do not think that would arise under Lord Joffe's Bill but I see your point.

Dr Turner: The other thing about the physician/patient relationship is that it is really hard to get evidence in the UK health system which is quite different from the American health system. They do not have geriatricians in the same respect. Obviously, I am still talking about older people. They do not have geriatricians in the same context that we have in this country. They have a much bigger history of intervention whereas in this country there might have been a decision between a physician and a patient to allow somebody to die peacefully and not continue to intervene. In a way they are starting from a different point. I think we all fear as doctors that the relationship between us and our patients will change and I think it will be very hard for anybody to know because the evidence from the States cannot be comparable.

Q1180 Lord Taverne: Referring to something that Mr Owen said, I could not agree with him more that it has got to be very desirable that there should be proper discussion where possible with people before dying about the whole process of dying. If it should turn out, contrary to speculation about what might happen but from actual experience of what has happened, that the opportunities for proper discussion are improved by a Bill of this kind, would

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you then change your attitude to the Bill or lessen your opposition to it?

Mr Owen: Our concerns beyond the issues around communication are paramount. I think those are the most important things around the inequality of services for older people.

Mr Ellis: It comes back to this question of choice and what is available to people. At the moment we have a system which is heavily rationed in which the things that would make a difference to people's lives, to their wellbeing, may not be available. As such the alternatives may not be fully explored. I was reviewing some of the calls we get to our help line which receives many tens of thousands of calls a year, and I think a very good example of what I mean is a gentleman who called saying that his father was in the last stages of a terminal illness and his mother was unable to provide all of the care requested but the NHS advised that she should really arrange and pay for a nursing home privately. There was no mention of options for different kinds of care and support. Whatever we have, if it is this very constrained and incomplete choice of a range of options available to support people, then there is real danger in funnelling decisions down to this critical point around the event of death itself and the choices that may not be available at that point.

Q1181 Lord Joffe: Mr Owen, I have been listening to you about the terrible social problems that elderly people face and one feels a great deal of sympathy with the social problems which cause such suffering. What we learnt in Oregon, for example, was that it was only elderly people who were really competent, who were forceful and dynamic, who ever had the stamina and resilience to go through the processes which are set out in their legislation, which is not that different from our legislation, in order to get a prescription which would allow them to die, and that the weaker, more vulnerable people were inevitably screened out because they did not have the drive or energy to take the process through. What would your reaction be to that?

Mr Owen: My first reaction would be that the older population in the States is very different from that of the UK in terms of their cultural background, particularly the oldest cohort of older people, people who are in their eighties and nineties who developed an understanding of society pre-war, which was a very different understanding of what the responsibilities were and a very different understanding about individual rights. America has got a much more progressive rights movement. It is much more part of the whole status quo there than we have here. It is dangerous to compare older people over there with older people over here. In terms of the fact that we might lose the most

vulnerable groups in terms of those not wanting to wish to pursue assisted dying, I find it very hard to comment, to be honest. It is very difficult to know how it would operate and whether that would be the case.

Q1182 Lord Joffe: Do you think logically it would?

Mr Owen: I think that is a possibility but I would not feel confident that that would necessarily be the case.

Q1183 Lord Joffe: You talk about the views of elderly people. Every survey which has taken place has shown something like 70 or 80 per cent support by elderly people in favour of this Bill. The question is, who you are talking on behalf of?

Mr Owen: We are not talking on behalf of the whole of the older population. We specifically said that there is a minority that we are particularly concerned about and these are the people who find themselves experiencing failures in the system. I hope I am correct in remembering the statistic that you quote. I worry about that statistic a little bit in that you are asking the general population about an issue that they probably have no real understanding of in terms of the fact that if you are not there at that time, if you are not in a situation where life is becoming unbearable --- older people regularly tell us that younger people do not know what it is like to be old, and actually I think that people in their sixties do not know what it is like to be in their eighties.

Q1184 Lord Joffe: The surveys I am talking about say that 80 per cent of elderly people support it.

Mr Owen: I have concerns about the statement. I think it was an agree/disagree statement that was used there, "Do you agree with the idea of assisted dying in a certain scenario?". I worry about putting that within a public opinion-type poll out to the older population. The understanding of the real dilemma, the real dynamics, the real issues around the subject are much more than a simple agree/disagree solution and that is probably not the best way to get people's opinions. The older people that that Jane Seymour, who did the research for us talked to, were confused by issues around assisted dying, euthanasia and advance planning. They did not know what was what and we need to inform them; basic public education is needed before we can take the answers and responses from older people on this important issue.

Q1185 Lord Joffe: If I might turn to the doctors, you said that you do recognise that there are a number of terminally ill patients for whom palliative care is not the solution and who suffer as a result.

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What do you suggest should be done with these people? What care should they receive?

Dr Turner: I think it is a very small number for whom properly trained palliative care, easily available, could not solve a significant number of problems. I think that is really important to say. At the moment, as has already been said by colleagues, a significant number of older people do not have access to high quality palliative care by trained palliative care teams, nor do they have access to the social care which backs up palliative care teams. I think the number would probably be quite small were we to make palliative care readily available. However, I freely accept that there may still be a handful of people who feel that their life is an intolerable burden but my personal view and the view of members of the British Geriatric Society have put forward is that that is not a reason to change the law. In other words, the benefit for the majority must outweigh the benefit for the very few and it may not be very many were we to get the systems right.

Q1186 Lord Joffe: You have no solution for that really, just views.

Dr Playfer: The job of a geriatrician is to manage this part of life in a humane way and to use all our skills to make this process of dying as best we can. I think there are very few situations where as practising doctors we cannot succeed in doing that. I have been practising in geriatric medicines for 30 years and I have only ever twice been asked to end a person's life. Both those cases were resolved once we dealt with the issues and optimised other aspects of their care. I think there are huge dangers because one needs very sophisticated assessment at the time of this decision. I understand your Bill and I understand the safeguards you bring in the Bill but it is a very cautious line that we have to cross and it will make the management of the majority of older patients very much more difficult for our group of doctors.

Q1187 Lord Joffe: Could I come back to the question of relationships between doctors. You say in your submission that "... taking active steps to bring about death changes fundamentally the role of the physician, changes the doctor-patient relationship and changes the role of medicine in society." Why should this be so when the overwhelming majority of the public supports assisted dying?

Dr Playfer: "Assisted dying" is a slippery term, is it not? Undoubtedly, as doctors, we help people through the process of dying but that is a different matter from commissioning an act which terminates a life. I think there is still a line within our group

of practitioners that recognises that boundary and feels extremely anxious about that boundary being crossed.

Q1188 Lord Joffe: You accept that patients have a right to refuse, even irrationally, treatment and die as a result, yet you oppose the right of patients to make an informed decision to ask for assistance to die. If, for example, we had a patient who refused treatment on a ventilator, and as a result of refusing to continue to be attached to this ventilator which keeps her alive she would die and the doctor would have taken part in that death, and you compare that to the situation where a patient is not on a ventilator and is desperate for assistance to die and that is refused, what do you see is the ethical difference which makes the one action, the first action, okay and the other one very reprehensible?

Dr Turner: I see the situations as being completely different. One is that the patient is only alive because of medical intervention which can be withdrawn; the other is the patient is alive because of whatever keeps us all alive, and ending that person's life would be a positive act of commission, not a withdrawal of treatment. I see the withdrawal of treatment at a patient's request as being completely different from the imposition of an act of killing.

Q1189 Lord Joffe: The result in both cases is identical.

Dr Turner: From our point of view the acts are quite different.

Lord Joffe: Thank you.

Q1190 Baroness Finlay of Llandaff: I wonder if I might pursue that a little bit further. I wonder if you would agree with me that many patients are fearful of being a burden and fearful of becoming confused, and fearful of being abandoned, so fearful of not having care in the future, and that can lead them to feel speculatively that they may be better off dead, and with some people they are very frightened of confusion, of losing their mind? The difficulty is that if they express a wish and then they do become confused, they are no longer competent anyway under the terms of this Bill but also it would be almost impossible clinically to decide at what point they now fitted the criteria where they had said that they would not want to carry on living. I wonder if you have any comments on that?

Dr Turner: I think this is a little bit what Mr Owen was saying. It is very difficult to imagine how you would feel in a situation that you have not yet experienced. It is the experience of geriatricians that life is often an intolerable burden for the families of those people who have confusion or dementia more so than for the person themselves. I mean, that is

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not a universal truth, but . . . Of course that is a real anxiety because then one has to ask whose burden one is relieving with assisted dying. I think the safeguard in the proposed Bill which means that somebody has to be competent to make that decision, at the time when it is appropriate rather than in advance, is absolutely vital if the Bill were to be enacted—and obviously the Mental Capacity Bill which is still going through its stages and so on is tied up with this. We feel very strongly that the whole issue of competence is really important here. Not only do people have to have proper choices to make to make the decision, but they also have to be competent to do so at the time when the act is to be committed, assuming that we are moving on to that situation.

Q1191 Baroness Finlay of Llandaff: I wonder, Dr Playfer and Dr Turner, if you could clarify for us an issue around prognosis. If you take somebody who is perhaps 85, has a fall and fractures their femur, what would their prognosis be on average terms if you look at the outcomes of somebody like that being admitted to hospital with a fracture?

Dr Turner: Of course, you know what I am going to say, which is that it is not possible to give you an average prognosis because everybody is different, and of course people who fall and break their hips are often a very frail, vulnerable group of people, especially if they have a pre-disposing condition like Parkinson's disease or they have had a stroke or something, in which case the outcome is much grimmer than if you are a fit person who slipped on the ice and just happened to have osteoporosis. It is really difficult but I think one of the things that doctors are very good at is knowing when someone is imminently dying (that is, within the next few days or hours); I do not think doctors are very good at all—and I would be interested to hear what Dr Playfer thinks—about saying that someone is going to die within the next few months. We all know that there are average life expectancies from diagnosis from various diseases, various cancers and so on—and they can range from anything, from a few months to a few years—but of course one is constantly regaled with stories of people who have had miracle cures and defied their doctor's prognostications. So actually that is a concern: How do you know that someone has only a few months to live? I do not think we know.

Dr Playfer: I would agree very much. It is the one thing that people expect doctors to be accurate about and which it is impossible to be accurate about—apart from, as you say, at the very last breath. With all illness, actually, people lose control. Even if you have flu as a younger person, you lose control for a period. We are dealing in later life with

a much more complicated loss of control and a spectrum of that loss of control, and the most fearful thing is if you lose your mind when you have lost control. But I do not think this is an excuse to legalise killing in such circumstances.

Q1192 Baroness Finlay of Llandaff: One of my concerns has been that, if you take somebody of 85, the difficulty is that once they have had the fall they will probably come into the terms of this Bill, in that they may well have a very short prognosis, particularly if they have concomitant disease.

Dr Turner: Yes: if they have had a stroke, for example. That would be very specifically covered by the Bill, would it not?

Baroness Finlay of Llandaff: Thank you.

Q1193 Baroness Thomas of Walliswood: Could we go back to this business of the doctor-patient relationship. We have had a number of medical practitioners before us during our inquiry. None of them has been a geriatric specialist; they have been specialists in various other branches of medicine. Many of them have said that, in fact, if as a practitioner you can discuss a patient's fear of death—which might lead them otherwise, as it were, on to choose their own moment of going because they do not want to die in some untidy, miserable way which they cannot deal with—an ability to talk about this with the patient is actually reassuring to the patient, and once they realise that there are other things that can be done for them to enable them to die decently, as it were, they get much less interested in the idea of asking the doctor to assist them to die. And that makes sense. It is mostly uncertainty, I would think, that might drive people to say that they want to end it now while they are still in control of their own mind. I am wondering really whether a proper handling of these problems with elderly people, who in many cases are dying of old age—and old age, as we are all beginning to know, I think, around this table, begins to set its claws into you at a certain point, and you begin to think, "Oh, dear, I cannot do that as well as I used to be able to," so that is what you are dying of in many, many cases—and maybe if they felt greater security that their death could be made, as it were, acceptable, that whole conversation around that topic could not be obstructive to the doctor-patient relationship but enriching to the doctor-patient relationship. Therefore, could there not be great benefit in training doctors—particularly general practitioners and so on, who often are the first persons to whom an elderly person is brought or who they need to go to see—in how to deal with these sorts of subject rather than shying away from a new legal possibility

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because you are afraid of how that will affect the doctor-patient relationship?

Dr Playfer: This is a seriously profound point you are making. Communication around this area is absolutely key. In areas of practice where there was good communication and good services and good provision of alternatives, the demand for assisted dying would be very, very small. Where services were inadequate and communication was inadequate and people felt helpless and their esteem was down, the demand for assisted suicide might be quite high. There would certainly be a lot of variation and that would point to variations in practice. I think our job really is to improve the communication at all levels of the medical profession with patients. I work in Liverpool where we have a new curriculum and we have had some students who have done issues on communication in dying and that has been profoundly interesting. So the new generation of doctors is engaging on this problem a lot more than, say, when I was taught. I am very hopeful that improvements in practice will make this Bill rather unnecessary.

Q1194 Lord Joffe: There are no legislative safeguards in other end-of-life decisions, such as refusal of treatment or terminal sedation or the withdrawing or withholding of treatment. Bearing this in mind, why do you feel that the literal array of safeguards in this Bill are inadequate? Is this not perhaps applying double standards?

Dr Turner: I do not think we have felt that the safeguards are necessarily inadequate; we just sought in our evidence to make some proposals as to how to make them even more watertight. Most of the other things are not enshrined in statutes really, are they? I mean, they are all case law and stuff. I think we sought in our evidence, humbly, to give advice about how we thought things might be even safer.

Q1195 Lord Joffe: If they were safer, would you then support this Bill?

Dr Turner: No, because we do not support the principle that assisted dying is a necessary part of life in the United Kingdom, but we recognise that if a decision is made that goes against our view we would suggest those safeguards that we have outlined.

Dr Turner: It is very important that the individual conscience of the individual doctor is preserved because there are strong ethical viewpoints around this.

Q1196 Lord Patel: I have two points of clarification. First of all, in your submission you say that “ . . . should the bill become law no doctor

should be obliged to participate in the process of ending life” and: “Indeed, we question whether the process should be undertaken by doctors at all.”

Who do you suggest would undertake this process?

Dr Turner: I think this is an interesting point that we have thought about. Obviously there has been the recently highlighted case of a patient with motor neurone disease who wanted to end her life. One questions why it needs to have medical involvement. People can be given the wherewithal, or they and their families can be given the wherewithal, to end someone's life, but I am not entirely sure why doctors need to be involved, because effectively it is a social decision not a medical decision. I recognise that people may feel comfortable that doctors are involved doing it, but I think we as a society wanted to question why does it need to be a doctor at all. I do not think I have a proposal that it should be a solicitor or any particular person; I just think there is an assumption that in ending life these are clinical decisions or clinical processes, but I am not sure that I totally agree that they should be.

Q1197 Lord Patel: In the same context, do you think we, as a profession, should be making the decisions as regards this Bill or is it wider society who should be making these decisions? We may have an opinion but do you think we should do that?

Dr Turner: I am sorry, I do not understand that question.

Q1198 Lord Patel: Most of the evidence we have heard that is against the Bill, like you today, has come from some groups of doctors—not all of them, because, as you know, in the evidence two major colleges have now said they do not feel it is a decision the profession should make. You just said that society should make these decisions. Would you agree that, as far as this Bill is concerned, it should be the wider society or do you think it should be the doctors?

Dr Turner: Do you mean make the decision about whether the Bill should be enacted?

Q1199 Lord Patel: Yes.

Dr Turner: I think we are only offering an opinion. I do not know that I have understood the question.

Dr Playfer: It is clearly society's prerogative, and we are a part of society, but society is expecting us to act on this Bill so I think we have a legitimate view of what we think are the rights and wrongs and how it affects our practice. But it is clearly society's prerogative.

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Q1200 Lord Patel: Thank you. The other point I needed clarification about is that, if I heard you correctly, you said the practice in this country in terms of doctor-patient relationship is different from other countries, such as the United States, and therefore we could not make direct comparisons, such as with the laws in Oregon and those the Bill proposes here.

Dr Playfer: Yes.

Dr Turner: I did say that, yes.

Q1201 Lord Patel: If I have understood you correctly, you said that what was key to the relationship of doctor-patient in this country, particularly geriatric practice, was that the patients often after discussion agreed not to proceed or to withdraw treatment. Did I hear you correctly?

Dr Turner: You did.

Q1202 Lord Patel: If that is the case that you make a decision with a competent patient not to continue the treatment or to withhold treatment, how far is that from this Bill?

Dr Turner: As I said to Lord Joffe, I think there is a complete difference between not offering treatment or withdrawing treatment and actually commissioning an act to kill somebody.

Q1203 Lord Taverne: Could I just follow that up. That is a difference to the doctor but not to the patient, is it?

Dr Turner: I am not sure that it is different to the patient. I am not sure whether the patient would regard those as the same thing. I think it is very difficult to know.

Dr Playfer: On the international evidence, there is actually very much wider international experience than the two papers quoted. In fact, I was recently in Vienna with the European Union Geriatric Medical Society where a session was devoted to terminal illness and there was a very wide variation throughout Europe on this issue, on the practice and management of dying. So I think it is very difficult to draw from, particularly, the American experience to European experience.

Q1204 Chairman: I would like to ask particularly the doctors about the concept of unbearable suffering, which, as you know, is used in this Bill. I am sure you have come across people who feel they have suffered a great deal, but I understood you to be telling us that your responsibility was to try to reduce such suffering and so far as possible make it bearable. Would that be right?

Dr Playfer: That is correct.

Q1205 Chairman: The specialty that you profess is that of a geriatric physician: a physician for geriatrics.

Dr Playfer: Yes.

Q1206 Chairman: Is there any particular definition of geriatric that you would use as a practical matter?

Dr Playfer: In our submission our society definition is: "that branch of general medicine which is concerned with the clinical, preventive, remedial and social aspects of illness of older people."

Q1207 Chairman: Older people. Because you could have older people with illnesses which were very specific where another physician or surgeon was required.

Dr Playfer: Yes.

Q1208 Chairman: So yours is the somewhat more general aspect.

Dr Playfer: Ours is the complex bit of it. If you are 80 and you just have coronary artery disease, you may well need an interventional cardiologist.

Q1209 Chairman: You have a more general remit for the person, the eighty-year old or those approaching that.

Dr Playfer: Yes.

Dr Turner: If you were 80 and you had coronary artery disease and you had had a stroke and you also fell over and broke your hip, you might want to be under the care of a geriatrician because it is pretty hard to keep all three specialists on board otherwise.

Q1210 Chairman: Unbearable suffering may be due to the fact that the particular patient has not been given some assistance that is available.

Dr Playfer: Yes.

Q1211 Chairman: It is your job to try to obtain that.

Dr Playfer: Yes.

Dr Turner: Yes.

Q1212 Chairman: The concept of unbearable suffering is related to what is available to the patient in the way of palliation at the time.

Dr Playfer: Yes.

Q1213 Chairman: Do you find that there are variations in that availability across England and Wales at the present time?

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Dr Playfer: That is undoubtedly so, yes.

Q1214 Chairman: If that is right, is it possible to do something about it? If you know that some particular treatment would be required for a particular patient—and I think you said you practice in Liverpool . . .

Dr Playfer: Yes.

Q1215 Chairman: If you know that such a treatment is available in Manchester but not in Liverpool, it would be your job, I assume, to try to get that assistance for your patient in Liverpool.

Dr Playfer: Well, you are always the advocate of your individual patient. You try to optimise the treatment of every individual patient you have. That is your function.

Q1216 Chairman: Of course unbearable suffering might arise because an available treatment did not happen to be made available to that particular patient.

Dr Turner: Sometimes the treatment may not be a medical cure, as such, but may be a service, a service that is not available. For example, an older person who is unable to get in and out of bed in the middle of the night to go to the toilet becomes incontinent at night because of the inability of us as society of the UK to provide night carers to help people get in and out of bed at night.

Q1217 Chairman: Yes, I follow that.

Dr Turner: So it may not just be that there is no drug available; it may be that we are talking about an incurable disease—

Q1218 Chairman: And it is some form of support that is not available.

Dr Turner: Yes.

Dr Playfer: Yes. And that is a spectrum from the latest technical medical developments right through to providing a grab rail in a toilet.

Q1219 Chairman: So you might have two people with very substantially the same underlying medical condition, yet one person is suffering unbearably because they could not get the necessary support services and the other person is not suffering unbearably because they could get the necessary support services.

Dr Turner: That is absolutely correct.

Q1220 Chairman: Could you help me a little bit further about the conversations between doctor and patient that you said are now becoming more common than they were when you originally were taught, Dr Playfer, around the subject of dying.

Under the present arrangements what sort of things are you seeing happening that you regard as favourable developments?

Dr Playfer: I think the first thing is that every doctor has a different style. It is like every profession, you would have different approaches and different styles. There is no doubt that the medical profession with a bio-medical model has seen death as a failure and I think the bio-medical model is changing to a broader perspective of what we are actually doing in our intervention with patients. That goes right to the basic level of medical education. We are trying to look at interventions across a much broader spectrum than just targeting a molecule—and that is paradoxical because the science of medicine is going very much to that end of what we are doing. Communication studies are universal I think in medical curricula now, which it was not formerly. It is also becoming universal in post-graduate training. In the curriculum training for our specialty, palliative care, dying and communication are included in that curriculum. So the spotlight of medical attention is very much more on this than it has been previously. It is also true, I think, that putting the patient at the centre and giving patients autonomy is very much more at the centre of medical practice. The paternalistic practice of previous years is disappearing very, very quickly, so I think often public opinion lags behind what actually is in practice. Certainly, from our society's point of view, one of the members of this Committee gave us a talk on palliative care, for instance, and we are always wanting to get in ideas from as many sources as we can to improve our practice. We have dialogues with nurses and other parallel professions about these issues, and, as I have alluded to, we have international discussions about these issues. So it is not a neglected issue. We are very much aware that we need to give the patients the best care in the terminal part of their life. Now that society is anxious in general, we are anxious to improve our care, rather than to try to terminate this, stopping in an unnatural way.

Q1221 Chairman: You were asked by Lord Patel about who should decide the issue of what the law should be and I think the suggestion was that that should be decided by society. I suppose, strictly speaking, in our system, if there is to be a change in the law this time, it would have to be done by Parliament. If Parliament were going to do that, and particularly if it were going to put the responsibility on doctors to carry it out, would you expect Parliament at least to have some regard to the opinion of doctors in deciding what the law should be in this area?

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Dr Turner: Yes, I would expect Parliament to have some regard to the opinion of doctors. I agree with you.

Q1222 Chairman: But not necessarily would that opinion determine the issue because Parliament may have other concerns as well as the issue of what the doctors feel about it.

Dr Turner: Of course, yes. I think we sought to express an opinion based on our experience.

Q1223 Chairman: You were asked about the possibility of someone other than a physician or doctor undertaking this responsibility if the law were to be changed. I think—well, I gathered anyway—that you seemed rather attracted to that position, although I think you were not . . . What should I say? . . . in a position to suggest any particular group who might be responsible. Solicitors were passed over quickly, I noticed—which I was glad about. Some people think they cause early death to people in any case, but of course, I do not subscribe to that point of view! You cannot think of any particular group that would be putting themselves forward as undertaking this particular responsibility.

Dr Turner: We were trying to challenge the view . . . Before I finish that sentence, I would like to say this is all about the decision of Parliament to enable people to express their autonomous wish to end their life. To some extent, this happens because medicine as a whole and the health service is unable to relieve the unbearable suffering. We were simply trying to make the point that the issue about committing an act of killing or ending life does not have to be a medical commission. For example, there is no reason why families could not be involved in this, if that was what patients and their families wanted. There has been an assumption that it should be a medical act, and I, on behalf the British Geriatrics Society, was simply trying to question why there is that assumption. If we are trying to de-medicalise some of these decisions, because of the possible paternalistic attitudes, because of the fact that we are talking about people's own autonomous decision-making, then why does a doctor need to be involved? My own personal view about whether or not I would be prepared to do this for my patients is not really the point that I was making.

Q1224 Chairman: I follow that. You were asked by Lord Joffe about other end-of-life decisions. Those who have the geriatric specialty must be involved in that a great deal. Is it your understanding that other end-of-life decisions are not regulated by the law?

Dr Turner: It is my understanding that they are regulated by case law.

Q1225 Chairman: Common law, in fact.

Dr Turner: Common law, in fact, yes. I am not sure I have my legal terms right here.

Q1226 Chairman: You do not regard yourself as free in end-of-life decisions to act outside the law?

Dr Turner: No.

Dr Playfer: Not at all.

Dr Turner: We act within the guidance of the General Medical Council, which, as you know, has recently been considered and highlighted and challenged. But of course that guidance itself was formulated by common law.

Q1227 Chairman: Thank you very much indeed for your help. I should ask perhaps if Mr Ellis or Mr Owen want to say anything in supplement. We have tended to go latterly towards the doctors, and we were cautioned against doing that by one of our doctor members, so I do not want to let you go away without you having a chance to make any comment you would like to make in relation to what we and the doctors have been discussing.

Mr Ellis: I would just make one brief comment around this issue of the range of options that is made available to older people at the end of life and the way in which that is offered. We know through our communication with older people and their families that sadly a great number of care professionals, be that doctors or any of the other range of professionals working with people, have a misunderstanding of the nature of the ageing process. The example being, perhaps, an assumption by a GP that losing one's hearing is a normal part of ageing or that pain and low mood is a normal part of ageing. We are very concerned in our main comment around safeguards and the inadequacy of the safeguards, I would say, that that goes further than the safeguards that are proposed in relation to the Bill itself. These are about the wider safeguards to ensuring that older people get fair treatment and the care to which they are entitled and that they are offered that in a way that does not discriminate against them. So the safeguards question for us is much broader than the confines of the Bill itself.

Chairman: Thank you very much indeed for your help. As I say, you will have an opportunity of reviewing the transcript to see that it accurately reflects what you said, not of course allowing an opportunity to change what you have said. Thank you very much.

THURSDAY 16 DECEMBER 2004

Present	Arran, E	Patel, L
	Carlile of Berriew, L	St Albans, Bp
	Finlay of Llandaff, B	Taverne, L
	Joffe, L	Thomas of Walliswood, B
	Mackay of Clashfern, L	
	Chairman)	

Letter from the Royal Dutch Medical Association

It is the policy of the Royal Dutch Medical Association not to interfere in discussions in other countries regarding the question whether euthanasia should be allowed (and/or legalized) or not. But of course we are quite willing to inform foreign persons and organizations about developments in the Netherlands (about 10 years ago we also spoke with the previous UK Committee, during a meeting at the British Embassy in The Hague).

Attached I send you the most recent and comprehensive text available in English. It is an article I have written December 2003. It has been published in the *Journal of Law and Medicine* 2004; 11: 312–323.

Royal Dutch Medical Association

5 August 2004

THE DUTCH EUTHANASIA ACT AND RELATED ISSUES

JOHAN LEGEMAATE

In 2002 the Dutch Euthanasia Act came into force. This Act is the result of a lengthy developmental process. It codifies the requirements that have evolved in case law and medical ethics since 1973. Empirical data indicate that the Dutch euthanasia practice is stabilising. Euthanasia and assisted suicide occur in 2.7% of all deaths. Now that the Act has been passed, the focus is on improving the quality of medical decision-making. From an international perspective, the Dutch legislation is exceptional. However, it appears that other countries and international organisations are considering euthanasia legislation as well. It remains to be seen how influential the Dutch model will prove to be.

INTRODUCTION

In April 2002 the Dutch Euthanasia Act came into force. This Act, officially named the Termination of Life on Request and Assisted Suicide (Review Procedures) Act,¹ is the result of a development that started in 1973, when the first court case in The Netherlands regarding euthanasia was decided.² In that case the court concluded that the average Dutch physician no longer considered it as her or his duty to prolong a patient's life under all circumstances. This led to a fierce debate at all levels of Dutch society. The 2002 Act can be seen as the final stage of a longlasting development, but at the same time it raises new questions and discussions. This article analyses recent developments in The Netherlands, focusing on legislation and case law. Furthermore, it attempts to place the Dutch situation into perspective, by comparing it to viewpoints and activities at the international level.

HISTORY

In the 1973 court decision it was recognised that a physician could be allowed to prevent serious and irreversible suffering, even if this meant shortening the patient's life. At that time euthanasia and assisted suicide were punishable under all circumstances. In this particular case the physician was found guilty of breaking the law but the court gave her only a more or less symbolic punishment (a suspended sentence of one week's imprisonment). The decision prompted the establishment of the Dutch Voluntary Euthanasia Society and provoked a broad debate regarding the acceptability of physician-assisted death. Later, other court decisions confirmed that, under certain circumstances, euthanasia and assisted suicide, although forbidden by

law, could be justifiable. However, the legal reasoning remained unclear until 1984, when the first euthanasia case³ reached the Dutch Supreme Court. The Supreme Court reasoned as follows:

- (i) As a general rule euthanasia and assisted suicide are punishable. The Penal Code defines both activities as a crime.
- (ii) However, when a physician is confronted with a conflict of duties he or she may invoke the so-called “defence of necessity”. A conflict of duties arises when honouring a patient’s request to die with dignity is the only way available to end unbearable and hopeless suffering.
- (iii) The criteria for accepting the defence of necessity are to be derived from professional and medical-ethical opinions formulated by the medical profession.

This legal line of reasoning served as the foundation of the practice of euthanasia until the 2002 Act came into force. As shown below,⁴ the Act introduces a new legal framework but at the same time retains certain elements of the previous situation. In 1984 another important event took place. In August of that year the Royal Dutch Medical Association (RDMA) published a viewpoint on euthanasia and assisted suicide. This viewpoint dealt extensively with the requirements a physician had to take into account before being allowed to perform euthanasia or assist with suicide.⁵ These requirements were based on earlier court decisions and insights from the medical profession. The publication of the RDMA viewpoint resulted in a very interesting interplay between the existing legal framework and the rules and opinions of the medical profession. In court cases that followed, judges often referred to the RDMA viewpoint. However, later additions to the viewpoint were inspired by case law. The RDMA viewpoint has been regularly updated, most recently in September 2003, and still provides guidance to physicians who are confronted with a request for euthanasia or assisted suicide.

Also in 1984, the first initiatives to change the law were launched. Proponents of permissive legislation argued that in a democratic society the rules regarding important and fundamental issues like physician-assisted death should be set by the Parliament. Pointing at polls that indicated broad support for euthanasia in all layers of society, they advocated that the gap between the Penal Code (euthanasia forbidden) and actual practice (euthanasia allowed under certain circumstances) should be bridged by new legislation. However, at that time there was no political majority to change the law. Between 1984 and 1991 several proposals were introduced and rejected. In 1994 a minor change of the law came about with formal legal status being given to the notification procedure. This procedure was introduced on a voluntary basis in 1991. Its aim was to encourage physicians to report cases of euthanasia and assisted suicide to the medical examiner and the district attorney. The 1994 Act did not address other issues. It was limited to changing the voluntary status of the notification procedure into an obligation for the physician to report cases. In 1998 another change took place. The notification procedure was amended to include a multidisciplinary evaluation committee, made up of a lawyer, a physician and an ethicist. It was the committee’s task to advise the district attorney about reported cases. The rationale for this change was the wish to replace a strictly legal way of assessing reported cases with a broader perspective. The government hoped that such a change would increase the willingness of physicians to report cases. The notification induced changes in the prosecution policy of the government. Already at the beginning of the 1990s the government indicated that, in spite of the punishability of euthanasia and assisted suicide under all circumstances, only those cases in which the physician had neglected the existing requirements (as formulated in case law and in the RDMA viewpoint) would be prosecuted. Since then the number of prosecuted cases has remained low: an average of three to five cases per year.

Real legislative progress was made possible by a rather dramatic change in the political arena. Following the 1994 parliamentary elections, a government without the Christian Democratic Party was formed, for the first time in 75 years. The new government was made up of parties (Social Democrats and Liberals) which had supported permissive legislation earlier on but, due to the influence of the Christian Democrats, had never been able to realise a political majority in Parliament. In its second term (1998–2002), this left wing-liberal government decided to change the Penal Code and to decriminalise euthanasia and assisted suicide. This resulted in the 2002 Act.

It should be noted that in the Act, as well as in the case law that preceded it, euthanasia and assisted suicide are and have always been treated alike. In both cases the same requirements and procedures apply. Unlike other countries and jurisdictions, in which a sometimes rather sharp moral distinction is made between euthanasia (the physician administering the medication) and assisted suicide (the patient taking the medication supplied by the physician),⁶ Dutch physicians, judges and policy-makers have never made a fundamental distinction between the two. Whether a physician and a patient opt for euthanasia or assisted suicide is left up to them, depending on the circumstances of the case, the characteristics of the patient and her or his medical condition. In cases in which a choice can be made, the Royal Dutch Medical Association advises physicians for psychological reasons to favour assisted suicide, but this is not a binding rule.

THE 2002 ACT

The coming into force of the 2002 Act is a landmark moment in the Dutch euthanasia debate. Being the result of a lengthy development rather than the beginning of a new period, the Act has not led to big changes in daily practice. The Act incorporates into the law developments and opinions which already were accepted in practice many years ago and is therefore more of a symbolic nature. The Act introduces only a limited number of new issues. It is often stated that the Act legalises euthanasia but this is not entirely true. Euthanasia and assisted suicide remain criminal offences. What the Act does is to create an exception to the punishability of euthanasia and assisted suicide for those physicians who have complied with the requirements of due care mentioned in the Act. Only if these requirements are met and the case is reported will the physician be exempted from criminal prosecution.

The requirements of due care in the case of euthanasia and assisted suicide are laid down in Art 2 of the Act. Essentially these are the same requirements that are mentioned in the RDMA viewpoint of 1984:

- the patient has made a voluntary and well-considered request;
- the patient's suffering is unbearable;
- there is no other reasonable solution to the situation;
- the patient has been informed about her or his condition and prospects;
- the patient has been seen by at least one other (and independent) physician, who provides a written statement about the applicability of the requirements of due care; and
- the physician, when performing euthanasia or assisting with suicide, has to do so in a medically justified way (using the right medication etc).

After he or she has ended the patient's life, the physician has to report the case to the medical examiner, using the form that is prescribed by law (in the Burial and Cremation Act 1991 (as amended in 2002)). The form contains a number of questions to which the physician has to respond. These questions relate to the requirements of due care and related issues. The medical examiner hands over the reported case to the regional evaluation committee. Within six weeks the committee decides whether or not the physician has acted in conformity with the legal requirements. The committee normally makes its judgment on the basis of the written report of the physician. If the information provided is unclear or incomplete, the committee can ask the physician to provide additional data in writing or in person. Before the Act came into force, the opinion of the committee had the status of an advice to the district attorney. This has been changed. If the committee holds the opinion that the physician acted correctly, the case is closed and other authorities (such as the district attorney and the Medical Inspectorate) will not be informed. Only if the physician has neglected one or more of the requirements will the committee send its judgment to the district attorney and the Medical Inspectorate. Depending on the severity of the violation, they may decide to take action against the physician, by starting a criminal prosecution (district attorney) and/or a procedure before the Medical Disciplinary Board (Medical Inspectorate).

The Act addresses several other issues as well, such as the legal position of a minor who requests euthanasia or assisted suicide and the validity of advance directives.

CASE LAW

Case law has played an important role in developing the legal framework for euthanasia and assisted suicide. The 1984 decision of the Dutch Supreme Court, in which the legal opening for euthanasia and assisted suicide was created (the defence of necessity), was mentioned above. Ten years later, in June 1994, the Supreme Court published its ruling in the famous *Chabot* case.⁷ In this case the Supreme Court confirmed that physical as well as mental suffering can justify euthanasia or assisted suicide.⁸ Only a few months after the 2002 Act came into force, the Supreme Court had to decide another controversial issue. This case involved a general practitioner who assisted with the suicide of an 86-old former senator, Edward Brongersma. Brongersma had no serious physical or mental illness. He suffered from physical decline and struggled with his "pointless and empty existence". Brongersma, in other words, was "tired of life". After assisting with suicide, the general practitioner reported the case. The district attorney decided to prosecute him, stating that the law did not allow the "tired-of-life" criterion. The regional court acquitted the doctor, deciding that he had acted within the limits of the law. This verdict was overturned by the Appeals Court of Amsterdam in December 2001. The doctor appealed against this decision to the Supreme Court.

On 24 December 2002 the Supreme Court rejected his appeal.⁹ The Supreme Court held that neither the previous rules (before 2002) nor the present Act covered “tired-of-life” situations. Physicians, the court found, must limit themselves to requests for euthanasia and assisted suicide from patients suffering from a medically classifiable physical or psychiatric sickness or disorder.

Mr Brongersma’s suffering was existential rather than medical. According to the Supreme Court, physicians do not have the experience to judge non-medical suffering. The Supreme Court decision in the Brongersma case prompted mixed reactions. Supporters of the decision were glad that the Supreme Court has drawn a line, making clear that a physician should not overstep her or his area of expertise. Critics pointed out that there is no black and white distinction between medical and non-medical suffering. In practice, they say, these are very complex situations in which physicians have to operate in a grey area. No doubt this debate will continue in the years to come. It is likely that, under the influence of “tired-of-life” cases, the emphasis of the debate will shift from physician-assisted death (or, as critics say, physician-dominated death) to possibilities and options which limit or even rule out the role and influence of physicians.

EMPIRICAL DATA

For a long time empirical data regarding euthanasia, assisted suicide and other medical decisions concerning the end of life were lacking. This changed in 1991, when the first of a series of independent research projects was carried out. The aim of this research was to gain insight into the quantity and quality of medical decisions concerning the end of life. The research was done in 1991, 1996 and 2003. The most recent results can be summarised as follows:¹⁰

- The Netherlands has 16 million inhabitants. Each year 140,000 people die.
- At current rates, approximately 9,700 patients request euthanasia and assisted suicide each year. In about 3,800 of these cases a physician-assisted death takes place (euthanasia 3,500; assisted suicide 300). In the remaining cases the physician refuses to go along with the patient’s request, the patient changes her or his mind or the patient dies of natural causes before the request can be considered or honoured.
- Euthanasia and assisted suicide occur in 2.7 per cent of all deaths. This percentage remained more or less stable between 1991 and 2003.
- The number of reported cases of euthanasia and assisted suicide increased from 41 per cent in 1996 to 54 per cent in 2003.
- Other medical decisions concerning the end of life take place much more frequently: decisions to forgo or stop treatment (21 per cent of all deaths); treatment aimed at alleviating pain or symptoms (20 per cent of all deaths).
- In a small percentage of cases (0.7 per cent of all deaths) physicians end a patient’s life without an explicit request. This happens mostly with patients suffering from cancer in the last days or hours of their life.¹¹

It is common knowledge that medical decisions concerning the end of life, including physician-assisted death, occur in other countries as well. A recent comparative study revealed the incidence and main background characteristics of end-of-life decision-making practices in six European countries: Belgium, Denmark, (parts of) Italy, The Netherlands, Sweden and Switzerland.¹² The percentage of deaths that were preceded by a medical end-of-life decision varied between 23 per cent (Italy) and 51 per cent (Switzerland). Administration of drugs with the explicit intention to hasten death (euthanasia, assisted suicide and ending a patient’s life without request) occurred in all countries, but the rates varied: 1 per cent of all deaths in Denmark, Italy, Sweden and Switzerland; 1.82 per cent in Belgium; and 3.4 per cent in The Netherlands. The ending of life without a patient’s explicit request happened more frequently than euthanasia in all countries except The Netherlands. The incidence of this was somewhat higher in Switzerland, The Netherlands and Denmark and highest in Belgium.

INTERNATIONAL REACTIONS AND DEVELOPMENTS

Over the years many persons and organisations have criticised developments in The Netherlands. Most critical commentators stated that ending a patient’s life is not compatible with the duties and responsibilities of a physician. Others feared that allowing euthanasia and assisted suicide would result in a slippery slope. In 2001 the Human Rights Committee of the United Nations voiced concerns regarding the implementation of the new Dutch Euthanasia Act. The committee did not question the Act as such nor its legal requirements, but focused on the (im)possibilities of safeguarding individual rights in actual practice. Would it be possible, the

committee asked the Dutch Government, to guarantee the proper implementation of the Act? The committee appeared to be afraid that in practice the patient may be put under pressure to ask for euthanasia and assisted suicide. In its response, the Dutch Government emphasised the cumulative procedural safeguards and requirements mentioned in the 2002 Act: not only the physician's duty to report the case after the patient had died (screening *ex post facto*) but also the requirement to obtain the opinion of an independent physician before making a final decision about the patient's request (screening *ex ante*). The 2002 Act obliges the independent physician to see the patient and to send a written report to the physician who is considering the patient's request. The independent physician is fully responsible for the facts and considerations in her or his report. As will be shown below,¹³ initiatives have been taken to professionalise and strengthen the *ex ante* screening.

Major opposition to the Dutch developments comes from the World Medical Association (WMA). At its 2002 annual meeting in Washington the WMA repeated its earlier statements against euthanasia and assisted suicide. In this resolution the WMA "reaffirms its strong belief that euthanasia is in conflict with basic ethical principles of medical practice". The WMA "strongly encourages all national medical associations and physicians to refrain from participating in euthanasia, even if national law allows or decriminalises it under certain conditions".¹⁴

European developments seem to be moving in another direction. In 2002, not only in The Netherlands but also in Belgium, a Euthanasia Act came into force. The Belgian law is comparable with the Dutch one, using the same starting points and basic rules and only making different choices at some minor points. The one more fundamental difference is that the law in Belgium is limited to euthanasia and does not include the possibility of physician-assisted suicide, but this issue already has been resolved in practice. In 2003 the Belgian Order of Physicians recommended dealing with assisted suicide in the same way as with euthanasia, thereby implying an expansion of the requirements and procedures of the law to assisted suicide as well.

Quite different from the debate within the WMA are the developments in the Council of Europe. In 1999 the Parliamentary Assembly of the Council of Europe adopted a "Recommendation on the protection of the human rights and dignity of the terminally ill and the dying".¹⁵ This recommendation advocated the use of palliative care and proposed to uphold the prohibition of euthanasia and assisted suicide. The text stated that a terminally ill or dying person's wish to die cannot, of itself, constitute a legal justification to carry out actions intended to bring about death. However, under the influence of developments in a number of European countries, including the increasing existence of empirical data, the Council of Europe appears to be moving in another direction. In September 2003 the Parliamentary Assembly's Social, Health and Family Affairs Committee approved a report on euthanasia by its member Dick Marty from Switzerland.¹⁶ In this report it is proposed that the Parliamentary Assembly of the Council of Europe call on the governments of member states:

- to collect and analyse empirical evidence about euthanasia and other end-of-life-decisions;
- to promote public discussion of such evidence;
- to take into account, in particular, the results of the Belgian and Netherlands legislation, notably their effects on the practice of euthanasia; and
- to consider whether legislation should be envisaged to exempt from prosecution doctors who agree to help terminally ill patients undergoing unbearable and hopeless pain and suffering to end their lives at their request, subject to prescribed rigorous and transparent conditions and procedures.

Unlike the 1999 recommendation, the new text has a much more pragmatic basis, recognising that end-of-life-decisions, including euthanasia, are a widely known fact of medical life. These practices, the text mentions, are forbidden in most Council of Europe member states: "There is thus a striking divergence between the law and what happens in practice. This gap must be reconciled if respect for the rule of law is to be maintained." At a more fundamental level the text stipulates that "nobody has the right to impose on the terminally-ill and the dying the obligation to live out their life in unbearable suffering and anguish where they themselves have persistently expressed the wish to end it". This starting point differs substantially from the one formulated in the 1999 recommendation. The Parliamentary Assembly of the Council of Europe is to debate the new recommendation in January 2004. It remains to be seen whether the Assembly is willing to adopt the surprisingly favourable text of its Social, Health and Family Affairs Committee.

EUTHANASIA AND INTERNATIONAL LAW

Some critics of euthanasia and assisted suicide have stipulated that physician-assisted death under all circumstances contravenes the “right to life” as protected by Art 2 of the European Convention of Human Rights. Article 2 provides:

Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

During the parliamentary debate regarding the Euthanasia Act the Dutch Government took the position that physician-assisted death at the persistent and well-considered request of the patient is not prohibited by Art 2 of the Convention. The government stated that the safeguards mentioned in the Act satisfy the requirements of Art 2 concerning the protection of life. Article 2 of the Convention played an important part in the “right-to-die” case decided by the European Court of Human Rights in April 2002. *Pretty v United Kingdom* (ECHR, 29 April 2002, Application No 2346/02) involved a right-to-die-claim from a severely ill English patient.¹⁷ Mrs Pretty wanted to die with the help of her husband (who was not a physician). As was expected, the European Court rejected the notion of a right to an assisted death. However, the court’s judgment does not contain elements which lead to the conclusion that Euthanasia Acts as such are incompatible with the European Convention. The court explicitly declared that in *Pretty* it was not judging legislation as accepted in some European countries and underlined that it is a responsibility of national legislators to decide whether permissive legislation regarding physician-assisted death should be introduced. These considerations of the court do not exclude the possibility that euthanasia legislation, if carefully drafted and surrounded with appropriate safeguards, will pass the test of the European Convention. We will only know that definitely after the European Court has decided a case that is directly related to the Dutch or the Belgian legislation.

QUALITY IMPROVEMENT: THE SCEN-PROJECT

Now that the Euthanasia Act has come into force, developments in The Netherlands are shifting in another direction. The focus is now on the improvement of the quality of medical decision-making in cases of euthanasia and assisted suicide. The most important element is to professionalise the *ex ante* screening. Until recently the physician who was considering acceding to a request for euthanasia or assisted suicide could ask any independent colleague to act as the consultant required by law. With the financial support of the Ministry of Health, the Royal Dutch Medical Association started the so-called SCEN-project (Support and Consultation regarding Euthanasia in The Netherlands). The SCEN-project is aimed at creating regional groups of trained and specialised physicians. These physicians are available to advise doctors who are confronted with a request for physician-assisted death and have questions about any related issue. Furthermore, these trained physicians act as the independent consultant required by law.¹⁸ The advantage of this is that the independent consultation is not carried out by any available physician, as was the case in previous years, but by a doctor with special knowledge and experience. In the area of general practitioners, SCEN-groups have been formed in almost all regions of the country. It is intended that the SCEN-initiative will be introduced in other areas as well (such as medical specialists in hospitals and nursing home physicians). Evaluations of SCEN have shown a positive impact on the willingness of physicians to take the consultation requirement seriously and to report cases. The regional evaluation committees mentioned in the Euthanasia Act have repeatedly stated that, in cases in which the physician had consulted a SCEN-doctor, the quality and usefulness of the written report were much better than in other cases. This means that SCEN does not only have a positive influence on the *ex ante* screening, but on the *ex post* screening as well. Unfortunately, the future of the successful SCEN-project is unclear. At the time this article was finalised (December 2003) the Dutch Government was heavily cutting health care expenditure. As of January 2004, the government will no longer finance the SCEN-project directly. It is unclear whether an alternative can be found that guarantees both the financing and the independence of the SCEN-doctor.

CONCLUSIONS

The Dutch Euthanasia Act 2002 is the result of a lengthy development that started in the early 1970s. In The Netherlands physician-assisted death is broadly accepted, not only by physicians and policy-makers but by the general population as well. The Dutch are well aware of the risks attached to allowing physician-assisted death but feel that they have created a context in which the risks of abuse and arbitrariness are limited to an acceptable level. Of course, these risks cannot be completely eliminated. Every now and then a case occurs in which the physician has neglected one or more of the requirements mentioned in the law, but evidence for abuse on a larger scale is lacking. In almost every case so many persons are involved (the patient, close

relatives, the acting physician, the independent consultant, other health care workers etc) that it is not easy to neglect the core requirements and get away with it. The fact, however, that this cannot be completely excluded has never been a reason in Dutch practice or politics to continue to forbid physician-assisted death under all circumstances. Such a policy would probably not result in the elimination of physician-assisted death. Otłowski had stated that the real choice is whether we seek to regulate and control the practice of physician-assisted death or whether it is left unregulated and unchecked. Furthermore, she favours the replacement of the prevailing policy of criminal prohibition with a more open and honest approach: "Importantly, such an approach would reduce the risk of unacceptable practices and thereby afford greater protection to patients. It would also enhance the quality of medical decision-making in this area, encouraging professional discussion and guidance."¹⁹ At a more fundamental level the Dutch population positively values the opportunity for patients who are severely and hopelessly suffering to ask for physician-assisted death and to die with dignity. As long as this opportunity is not turned into a right, a large majority of Dutch physicians are willing to consider requests for physician-assisted death.

Given the fact that euthanasia is based to a large extent on the universal feeling that a sick person should have a say about the amount of medical interference at the end of her or his life, it is understandable that the discussion on whether physician-assisted death should be allowed is emerging in other countries as well. Although typical Dutch circumstances (such as the emphasis on personal freedom, the social solidarity, the comprehensive health-care system, the quality of public discussion) may explain why the developments in The Netherlands occurred as they did, it is clearly an issue that also has relevance in other countries and jurisdictions. However, as the Dutch euthanasia practice is embedded in a specific and elaborate network of relations, standards and values, it is difficult to simply export this to other countries.²⁰ The most distinctive characteristic of the Dutch situation is probably the broad support from the medical profession.²¹ Other countries do not necessarily have to go the same way, but they surely can learn from the Dutch experience.

APPENDIX

Termination of Life on Request and Assisted Suicide (Review Procedures) Act

CHAPTER I. DEFINITIONS

Section 1

For the purposes of this Act, the following definitions shall apply:

- (a) Our Ministers: the Minister of Justice and the Minister of Health, Welfare and Sport;
- (b) assisted suicide: intentionally helping another person to commit suicide or providing him with the means to do so as referred to in article 294, paragraph 2, second sentence, of the Criminal Code;
- (c) the attending physician: the physician who, according to the notification, has terminated life on request or has provided assistance with suicide;
- (d) the independent physician: the physician who has been consulted about the attending physician's intention to terminate life on request or to provide assistance with suicide;
- (e) the care providers: the persons referred to in article 446, paragraph 1, of Book 7 of the Civil Code;
- (f) the committee: a regional review committee as referred to in section 3;
- (g) regional inspector: a regional inspector employed by the Health Care Inspectorate of the Public Health Supervisory Service.

CHAPTER II. DUE CARE CRITERIA

Section 2

1. In order to comply with the due care criteria referred to in article 293, paragraph 2, of the Criminal Code, the attending physician must:

- (a) be satisfied that the patient has made a voluntary and carefully considered request;
- (b) be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;
- (c) have informed the patient about his situation and his prospects;
- (d) have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;

- (e) have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in (a) to (d) above; and
- (f) have terminated the patient's life or provided assistance with suicide with due medical care and attention.

2. If a patient aged sixteen or over who is no longer capable of expressing his will, but before reaching this state was deemed capable of making a reasonable appraisal of his own interests, has made a written declaration requesting that his life be terminated, the attending physician may comply with this request. The due care criteria referred to in subsection 1 shall apply *mutatis mutandis*.

3. If the patient is a minor aged between sixteen and eighteen and is deemed to be capable of making a reasonable appraisal of his own interests, the attending physician may comply with a request made by the patient to terminate his life or provide assistance with suicide, after the parent or parents who has/have responsibility for him, or else his guardian, has or have been consulted.

4. If the patient is a minor aged between twelve and sixteen and is deemed to be capable of making a reasonable appraisal of his own interests, the attending physician may comply with the patient's request if the parent or parents who has/have responsibility for him, or else his guardian, is/are able to agree to the termination of life or to assisted suicide. Subsection 2 shall apply *mutatis mutandis*.

CHAPTER III. REGIONAL REVIEW COMMITTEES FOR THE TERMINATION OF LIFE ON REQUEST AND ASSISTED SUICIDE

Division 1: Establishment, composition and appointment

Section 3

1. There shall be regional committees to review reported cases of the termination of life on request or assisted suicide as referred to in article 293, paragraph 2, and article 294, paragraph 2, second sentence, of the Criminal Code.

2. A committee shall consist of an odd number of members, including in any event one legal expert who shall also chair the committee, one physician and one expert on ethical or moral issues. A committee shall also comprise alternate members from each of the categories mentioned in the first sentence.

Section 4

1. The chair, the members and the alternate members shall be appointed by Our Ministers for a period of six years. They may be reappointed once for a period of six years.

2. A committee shall have a secretary and one or more deputy secretaries, all of whom shall be legal experts appointed by Our Ministers. The secretary shall attend the committee's meetings in an advisory capacity.

3. The secretary shall be accountable to the committee alone in respect of his work for the committee.

Division 2: Resignation and dismissal

Section 5

The Chair, the members and the alternate members may tender their resignation to Our Ministers at any time.

Section 6

The chair, the members, and the alternate members may be dismissed by Our Ministers on the grounds of unsuitability or incompetence or other compelling reasons.

Division 3: Remuneration

Section 7

The chair, the members and the alternate members shall be paid an attendance fee and travel and subsistence allowance in accordance with current government regulations, insofar as these expenses are not covered in any other way from the public purse.

*Division 4: Duties and responsibilities***Section 8**

1. The committee shall assess, on the basis of the report referred to in section 7, subsection 2 of the Burial and Cremation Act, whether an attending physician, in terminating life on request or in assisting with suicide, acted in accordance with the due care criteria set out in section 2.
2. The committee may request the attending physician to supplement his report either orally or in writing, if this is necessary for a proper assessment of the attending physician's conduct.
3. The committee may obtain information from the municipal pathologist, the independent physician or the relevant care providers, if this is necessary for a proper assessment of the attending physician's conduct.

Section 9

1. The committee shall notify the attending physician within six weeks of receiving the report referred to in section 8, subsection 1, of its findings, giving reasons.
2. The committee shall notify the Board of Procurators General of the Public Prosecution Service and the regional health care inspector of its findings:
 - (a) if the attending physician, in the committee's opinion, did not act in accordance with the due care criteria set out in section 2; or
 - (b) if a situation occurs as referred to in section 12, last sentence, of the Burial and Cremation Act. The committee shall notify the attending physician accordingly.
3. The time limit defined in the first subsection may be extended once for a maximum of six weeks. The committee shall notify the attending physician accordingly.
4. The committee is empowered to explain its findings to the attending physician orally. This oral explanation may be provided at the request of the committee or the attending physician.

Section 10

The committee is obliged to provide the public prosecutor with all the information that he may require:

1. For the purpose of assessing the attending physician's conduct in a case as referred to in section 9, subsection 2; or
2. For the purposes of a criminal investigation.

The committee shall notify the attending physician that it has supplied information to the public prosecutor.

*Division 6: Procedures***Section 11**

The committee shall be responsible for making a record of all reported cases of termination of life on request or assisted suicide. Our Ministers may lay down further rules on this point by ministerial order.

Section 12

1. The committee shall adopt its findings by a simple majority of votes.
2. The committee may adopt findings only if all its members have taken part in the vote.

Section 13

The chairs of the regional review committees shall meet at least twice a year in order to discuss the methods and operations of the committees. A representative of the Board of Procurators General and a representative of the Health Care Inspectorate of the Public Health Supervisory Service shall be invited to attend these meetings.

*Division 7: Confidentiality and disqualification***Section 14**

The members and alternate members of the committee are obliged to maintain confidentiality with regard to all the information that comes to their attention in the course of their duties, unless they are required by a statutory regulation to disclose the information in question or unless the need to disclose the information in question is a logical consequence of their responsibilities.

Section 15

A member of the committee sitting to review a particular case shall disqualify himself and may be challenged if there are any facts or circumstances which could jeopardise the impartiality of his judgment.

Section 16

Any member or alternate member or the secretary of the committee shall refrain from giving any opinion on an intention expressed by an attending physician to terminate life on request or to provide assistance with suicide.

*Division 8: Reporting requirements***Section 17**

1. By 1 April of each year, the committees shall submit to Our Ministers a joint report on their activities during the preceding calendar year. Our Ministers may lay down the format of such a report by ministerial order.
2. The report referred to in subsection 1 shall state in any event:
 - (a) the number of cases of termination of life on request and assisted suicide of which the committee has been notified and which the committee has assessed;
 - (b) the nature of these cases;
 - (c) the committee's findings and its reasons.

Section 18

Each year, when they present their budgets to the States General, Our Ministers shall report on the operation of the committees on the basis of the report referred to in section 17, subsection 1.

Section 19

1. On the recommendation of Our Ministers, rules shall be laid down by order in council on:
 - (a) the number of committees and their powers;
 - (b) their locations.
2. Further rules may be laid down by Our Ministers by or pursuant to order in council with regard to:
 - (a) the size and composition of the committees;
 - (b) their working methods and reporting procedures.

CHAPTER IV. AMENDMENTS TO OTHER LEGISLATION**Section 20**

The Criminal Code shall be amended as follows.

A

Article 293 shall read as follows:

Article 293

1. Any person who terminates another person's life at that person's express and earnest request shall be liable to a term of imprisonment not exceeding twelve years or a fifth-category fine.

2. The act referred to in the first paragraph shall not be an offence if it is committed by a physician who fulfils the due care criteria set out in section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, and if the physician notifies the municipal pathologist of this act in accordance with the provisions of section 7, subsection 2 of the Burial and Cremation Act.

B

Article 294 shall read as follows:

Article 294

1. Any person who intentionally incites another to commit suicide shall, if suicide follows, be liable to a term of imprisonment not exceeding three years or to a fourth-category fine.

2. Any person who intentionally assists another to commit suicide or provides him with the means to do so shall, if suicide follows, be liable to a term of imprisonment not exceeding three years or a fourth-category fine. Article 293, paragraph 2 shall apply *mutatis mutandis*.

[Sections 21-22 omitted]

CHAPTER V. CONCLUDING PROVISIONS

Section 23

This Act shall enter into force on a date to be determined by Royal Decree.

Section 24

This Act may be cited as the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

REFERENCES

- ¹ See Appendix below at 319 for the full text of the present Dutch Act.
- ² Legemaate J, "Legal Aspects of Euthanasia and Assisted Suicide in The Netherlands 1973–1994" (1995) 4 Cambridge Quarterly of Healthcare Ethics 112. See the Postma Case, Regional Court of Leeuwarden, 21 February 1973, *Nederlandse Jurisprudentie* 1973, 183.
- ³ See the Schoonheim case, Dutch Supreme Court, 27 November 1984, *Nederlandse Jurisprudentie* 1985, 106.
- ⁴ See below at 314.
- ⁵ Dillmann RJM, "Euthanasia in The Netherlands: The Role of the Dutch Medical Profession" (1996) 5 Cambridge Quarterly of Healthcare Ethics 100.
- ⁶ Hurst SA and Mauron A, "Assisted Suicide and Euthanasia in Switzerland: Allowing a Role for Non-physicians" (2003) 326 *British Medical Journal* 271.
- ⁷ Dutch Supreme Court, 21 June 1994, *Nederlandse Jurisprudentie* 1994, 656.
- ⁸ Griffiths J, "Assisted Suicide in the Netherlands: The Chabot Case" (1995) 58 *Modern Law Review* 232.
- ⁹ Sheldon T, "Being 'Tired of Life' is Not Grounds for Euthanasia" (2003) 326 *British Medical Journal* 71.
- ¹⁰ Onwuteaka-Philipsen BD, van der Heide A, Koper D *et al*, "Euthanasia and Other End-of-life Decisions in The Netherlands in 1990, 1995 and 2001" (2003) 362 *The Lancet* 395.
- ¹¹ van der Wal G, "Unrequested Termination of Life: Is It Permissible?" (1993) 7 *Bioethics* 330.
- ¹² van der Heide A, Deliens L, Faisst K *et al*, "End-of-life Decision-making in Six European Countries: Descriptive Study" (2003) 326 *The Lancet* 345.
- ¹³ See below at . . .
- ¹⁴ www.wma.net/e/policy/e13b.htm
- ¹⁵ <http://assembly.coe.int/Documents/AdoptedText/ta99/EREC1418.htm>
- ¹⁶ <http://assembly.coe.int/Documents/WorkingDocs/doc03/EDOC9898.htm>
- ¹⁷ See Freckelton I, "Casenote: *Pretty v Director of Public Prosecutions*" (2002) 9 *JLM* 275; Leenen HJJ, "Assistance to Suicide and the European Court of Human Rights: The *Pretty Case*" (2002) 9 *European Journal of Health Law* 257.

- ¹⁷ Onwuteaka-Philipsen BD and van der Wal G, "A Protocol for Consultation of Another Physician in Cases of Euthanasia and Physician-assisted Suicide" (2001) 27 *Journal of Medical Ethics* 331.
- ¹⁸ Otłowski M, "The Effectiveness of Legal Control of Euthanasia: Lessons from Comparative Law" in Klijn A et al (eds), *Regulating Physician-negotiated Death* (Elsevier, Amsterdam, 2001) pp 137–155.
- ¹⁹ Kater L, "The Dutch Model for Legalising End-of-life Decisions" (2003) 22 *Medicine and Law* 543.
- ²⁰ Griffiths J, Bood A and Weyers H, *Euthanasia and Law in The Netherlands* (Amsterdam University Press, Amsterdam, 1998).

Examination of Witnesses

Witnesses: DR PETER HOLLAND, Chairman, and DR JOHAN LEGEMAATE, Legal Counsel, KNMG, examined.

Q1228 Chairman: I would like to thank both of you for coming along to help us. Our system, if you are agreeable, is if you would like to make short opening statements about the position that you hold and the position as you see it in relation to the questions that we are considering, that would be useful. Then members of the Committee will have their own questions they would like to ask you, if you would be kind enough to help us with these. The shorthand writer is taking down what you say and, all being well, that, in the ultimate form, will be appended to our report, so that it will become a public document in the UK in due course; not for a little time yet, because we have some way to go before we ultimately report to the House of Lords that set us up for the purpose of reporting. We are seeking to ascertain as much in the way of the facts surrounding the operation of the law in this country as we can, with a view to considering the extent to which that might be relevant for proposals in the United Kingdom. I should also say that you will have the opportunity to look at the transcript before it is finalised, just in case there has been a failure of completely accurate transcription of what you said, so that what ultimately becomes public is something that you know you have said. Could I invite you to begin, and just tell us a little about your position and the general situation here?

Dr Holland: Thank you very much. My English is very poor and I apologise for that. Actually, I have not spoken English for 50 years, and I started in March again, so I propose that Dr Legemaate gives his remarks first, if you agree.

Chairman: Very well. I may say that your English is a great deal better than my Dutch!

Lord Patel: We have not heard your Dutch yet!

Q1229 Chairman: I do not propose to harm you with that!

Dr Legemaate: I would be glad to mention a few points. We have already written them down in a handout that has been given to you, so I will not repeat them in order to give you as much time for your questions as possible. Peter Holland is the Chairman of the Royal Dutch Medical Association and he is a doctor. I am a lawyer. I am chief legal counsel to the Royal Dutch Medical Association and I have worked for the Association for 12 years.

Q1230 Chairman: Full-time?

Dr Legemaate: At the moment full-time, yes; part-time in the past, combining it with a professorship in Rotterdam, but now working full-time for the Association. You may already be aware of the fact that our euthanasia debate started more or less 30 years ago, in 1973. That was a time when the medical profession was fairly reluctant about euthanasia and assisted suicide. What was actually happening at that time was a kind of shock. There were court cases and we were fairly reluctant but, over the years, this reluctance has, more or less, transformed into a more neutral position and even into a position of acceptance. That is based on the two pillars that we mention in the first bullets of our handout, which are fundamental ones. It is the fact that we accept that there may be moral justification for assisting people to die when they are in a situation of hopeless and unbearable suffering. However, there has always been a more pragmatic pillar which is that, even as early as the 1970s, 1980s and 1990s, we knew that it was happening in our society. It was happening in practice, and happening in other countries as well. We were at the crossroads of either forbidding it and turning a blind eye, or accepting it and trying to make it as good as possible. We have chosen the latter position and have said, "If it is happening, then it is our duty as a medical organisation to improve the quality of medical care and to improve the degree of carefulness which is attached to the situation". That is the main reason why in 1984 the medical profession published their first guidelines on euthanasia. I think it fair to say that these guidelines have still not been changed after 20 years—at least, their core has not been changed. We have updated the guidelines, due to new insights and new developments; but the core requirements of the 1984 guidelines are still present today, and they have been incorporated into our law. The core requirements of the new law which we have now had for two years are almost identical to the ones we identified in 1984. There is much to say about what has been happening over the years, but perhaps one final remark is that our main preoccupation is with the transparency and quality of what is happening in actual practice. We try as much as possible to stimulate physicians to report cases, and we take

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Dr Peter Holland and Dr Johan Legemaate

initiatives which are aimed at improving the quality of what physicians are doing. That is therefore our main concern at the moment. Much can be said about our practice, but our main position is to provide guidance to physicians in the area of carefulness and the quality of care. The most recent initiative—and you may already be familiar with it—is the so-called SCEN project, which is aimed at professionalising the independent consulting physician who is brought into the process when a physician may be thinking of performing euthanasia or of assisting a suicide. So we have shifted the emphasis toward looking at each individual case very carefully before the actual decision is made. We see that as our main responsibility. It is perhaps the government's responsibility to look at the cases after euthanasia has taken place, and we have the review committees which are government committees. We feel that we should be there in an earlier phase, trying to improve what is happening as much as we can. In a nutshell, that is something of our history and also of our present position.

Q1231 Chairman: Before we get into a more general discussion, could I ask you about the general law in The Netherlands with regard to suicide? Apart from the involvement of physicians, what is the general law at the present time in relation to suicide, attempted suicide, and assisting suicide?

Dr Legemaate: The general law is that there is no provision on suicide. You may kill yourself or you may try to kill yourself without any legal consequence. The legal consequences are there for people assisting you. What we have done in the euthanasia Act is to make an exception to the general law on suicide, saying that physicians, under certain circumstances, may assist you to die. No other citizen of The Netherlands is allowed to assist you with suicide. The general rule, therefore, is that it is not allowed and we have made an exception for physicians in certain circumstances.

Q1232 Chairman: One other question of a more general kind, in order to get the background of the law. In a situation, for example in relation to prisons, if people are taken into prison there is usually thought to be some risk, particularly high in some cases, that the person may commit suicide. Is there an attempt made to protect people at that stage against committing suicide in prison?

Dr Legemaate: Both in prisons, but perhaps even more so in mental institutions, many attempts are made to prevent people from committing suicide; but that has never been linked to the euthanasia debate. It is, let us say, an element of the standard of care in these institutions that target number one—especially in psychiatry—is perhaps that you have to prevent people from killing themselves.

Q1233 Earl of Arran: Could I ask a question for clarification about this? The clinical difference between euthanasia and assisted suicide, vis-à-vis the patient and the doctor—how does it work in both cases? That is, in practical terms, from the point of view of the delivery of the final dose?

Dr Legemaate: Unlike other jurisdictions in other countries, from the medical and ethical point of view we never make a distinction between euthanasia and assisted suicide. Our law does however, because the amount of imprisonment for euthanasia is 12 years and for assisted suicide it is four years. So from a criminal law point of view there is a rather big difference; but from a medical or ethical point of view we have never made the difference, because we feel that when the basis is the suffering of the patient it is not a very big issue whether, at the end, it is euthanasia or assisted suicide. I think that many doctors prefer euthanasia for practical and clinical reasons, because when it is assisted suicide you hand over the medication to the patient and he has to take it himself. It may have side effects which will lead to the doctor acting anyway. For that reason, most doctors prefer euthanasia—unless perhaps the patient himself says, “No, I just want to take the medication by myself”.

Q1234 Earl of Arran: But is it going more towards assisted suicide than euthanasia? Do patients more readily wish to do it themselves? Like in Oregon, for instance, which I am sure you know about?

Dr Legemaate: As I have mentioned, we have updated our 1984 guidelines. We updated them twice—in 1995 and in 2003. In these two updates we emphasised more strongly that perhaps assisted suicide would be preferable to euthanasia—in the psychological sense for the physician, and in the sense that it emphasises a little more the responsibility of the patient. It still remains rather theoretical, however; because in practice, for the reasons I have already mentioned, physicians do not want to get into a situation where the patient takes the medication, the cocktail he consumes does not work well, and then the doctor has to administer the medication himself anyway. The practice as we know it is that in most cases it is euthanasia, unless the patient himself says, “No, I want to do it myself”.

Q1235 Lord Taverne: Can I ask about some overall figures which are quite important to us? First of all, you said that most doctors have now come round to supporting the law. Has there been an opinion poll amongst doctors to show what the percentage is who support and who do not support? I also understand that there are some doctors who refuse to implement the law. What percentage of doctors is that? The second question is whether you have

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statistics about the level of trust in doctors in The Netherlands? How does that compare with levels of trust in doctors elsewhere in Europe? I understand that it is unusually high in The Netherlands. Lastly, the last figures that some of us saw were that 54 per cent reported the cases in which they had acted under the law. Is that percentage still going up? If it is not reported, do you know why it is not being reported? Those are my overall questions about the figures and statistics.

Dr Legemaate: In general, regarding all of your questions we have very precise statistics, but we derive them from the empirical research that has been done in The Netherlands every five years. It is done by the EMGO Institute of the Free University of Amsterdam by Professor van der Wal. I can cite some of the figures but not—

Q1236 Lord Taverne: We will be seeing him, I think.

Dr Legemaate: He can give you all the details you want on the statistics. In general, however—now I think I have missed your first question.

Q1237 Lord Taverne: The first one is what is the level of support amongst doctors and, second, what is the level of trust in doctors?

Dr Legemaate: As far as the first question is concerned, from the van der Wal research—Professor van der Wal and his companion Professor van der Maas from Rotterdam carried it out together—a very high percentage of physicians, somewhere in the region of 80 per cent, accept that euthanasia is an option, which is not the same as 80 per cent of doctors willing to do it themselves. The percentage of doctors who want to do it themselves is somewhat lower than the 80 per cent. However, a large part of the medical profession finds it acceptable that there is, in our society, the possibility of euthanasia. Twenty to 25 per cent—again, van der Wal can give you the exact figures—are opposed, mostly for religious reasons and also for some non-religious reasons, for instance that it is not compatible with their medial oath or the medical profession. The main reason for objecting to euthanasia as such, however, is based on religious reasons. As far as the level of trust is concerned, I do not think that we have exact figures. It is possible that this was never really looked into, but Professor van der Wal could give you that answer. What I think is important is that, without a sufficient level of trust, we would never have had the development we have had over the past 30 years. What is also important is that there has never been, as a consequence of the euthanasia debates, any debate in our society relating to problems regarding the level of trust. Perhaps that is also the reason why we have never investigated it fully, because it was

never raised as an issue. The background is mentioned in one of the bullets in our paper. Our euthanasia situation is grounded in the context of very long-lasting relationships between patients and physicians. The figures will show that we have a 95 per cent cancer situation, and a 70 or 80 per cent general practitioner situation. These are the characteristics of the Dutch euthanasia situation. Mostly as a general practitioner, you have had a relationship for ten, 20, 30, or even 40 or more years. That is the context in which the patient and physician, at a certain time, talk about euthanasia, or it is requested. I think that it is fair to say that, over the 30 years, we have never had any big debate on any negative influence on the level of trust. It is the other way round: without a certain existing level of trust, we would never have had this development anyway. Your third question related to the number of cases reported. We have the 55 per cent figure, which is from the year 2001 and which is the most recent we have. It was the year before our Act came into force, and it is generally assumed that the impact of the Act will be that physicians will be more secure in the situation and will be more willing to report, but that will be researched next year, again by Professor van der Wal. We have the feeling that the number of reported cases is still increasing. By “still” I mean—

Q1238 Chairman: As a proportion of cases, you mean?

Dr Legemaate: The number of cases reported is increasing. We have been witness to a process in which we started with a reporting percentage of zero at the beginning of the 1990s, and now we are gradually moving to perhaps 54, 60 or 65 per cent. At the moment, we do not know but we suppose so. We count our blessings in that sense, because what would worry us is if there were a declining number of reported cases; but we do not have an indication of that.

Q1239 Chairman: Does the law that has been introduced—that is the law introduced by parliament—require reporting?

Dr Legemaate: Yes. Not reporting is a criminal offence. None the less, not all doctors are reporting. We have the feeling that, given the sensitivity of the issue, it is an illusion to think that you will ever have a 100 per cent reporting system. That is illusory, but we can get higher than we are at the moment. We see that in a context in which the number is increasing over the years, and we feel confident that it will continue to do so.

Dr Holland: In general, I can tell you that patients' trust in doctors in Holland is very high. I have never heard about negative effects of euthanasia in this respect. Eighty to 90 per cent of the patients are very

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satisfied with the way the doctor has treated them. That is in general.

Q1240 Baroness Thomas of Walliswood: You make the distinction between euthanasia and assisted suicide. The paragraph in your note connects euthanasia with the very rare use of a decision, in effect to end somebody's life, associated with very heavily disabled newborn children and cancer patients at the end of their life. Your distinction of euthanasia is that the doctor administers the drug. Is that what you are saying? That is the different definition?

Dr Legemaate: Yes.

Q1241 Baroness Thomas of Walliswood: How does the question of not continuing care, or of giving a dose of painkilling medicine which is intended to reduce pain but will in fact shorten life, fit into your definition of euthanasia?

Dr Legemaate: As you mentioned, euthanasia is the doctor giving the drugs; but the second and more important element of the definition of euthanasia is that it is at the request of the patient. The debate regarding severely handicapped newborns is not within our definition of euthanasia. In this morning's paper there was a letter written by our former Minister of Health, Mrs Els Borst, who has reacted to a newspaper article of last week—in which it said, "Doctors ask for a reporting system regarding euthanasia of newborns"—by saying, "No, euthanasia is only at the request of a person". There are other cases which we know are happening—and perhaps you want to talk about that as well—in which the doctor ends the patient's life without a request. They are not within our law and not within the definition of euthanasia. As to the other question you mentioned, explicit in the definition of euthanasia is that you do something with the clear and explicit intent to end somebody's life. That makes a distinction between euthanasia on the one hand and, on the other, the decisions you have mentioned, like stopping treatment because treatment has become futile or useless—medically useless or medically futile—or giving pain medication with the primary intent to relieve pain but accepting, due to the kind of medication you are using, that a consequence may be that you shorten life a little. Shortening life is not the main intent of administering pain medication. You have to accept that. If you do not want to accept that it shortens life, the only consequence will be not to give pain medication to a patient, and that is not found acceptable in this country—nor is it in your country. Some of these decisions—stopping treatment because it is useless, or administering pain medication—are what we define as normal medical practice. Then you draw a line and on the other side

of the line you have euthanasia. Euthanasia is not normal medical practice; it is exceptional medical practice, but we allow it under certain circumstances. Take any patient in his last days or weeks, then you may take a number of decisions regarding that patient. The first decision may perhaps be that you stop treating the patient because it is useless. The second decision is, because he has cancer and is in pain, you give him pain medication. The next step may be that the same patient says, "You have given me pain medication but I am still suffering for several reasons, and I want my life to be ended". The third and final decision may be euthanasia. But these are three decisions with separate backgrounds, separate criteria and separate demands for carefulness.

Q1242 Baroness Thomas of Walliswood: What about patients who are dying of old age and the illnesses frequently associated with old age? Cancer is very specific, and the pain and the treatment of pain is something we have heard a lot about. What about other patients who are reaching the end of their life for different reasons?

Dr Legemaate: It is perhaps a pity that you are not able to read Dutch, because the front page of one of our national newspapers this morning reports that our Association is publishing a report today from a committee which has advised us about the people who are, as we call it, "tired of living". That is the result of a notorious case we had a couple of years ago in which our Supreme Court said that euthanasia on the basis of being tired of living is not acceptable, because it is outside the medical scope. It has raised a lot of discussion amongst physicians and, for that reason, three years ago the Association asked a committee to advise us—which is the way we usually deal with these new issues. We do not make a statement immediately, but we ask an expert committee to advise us. Purely coincidentally, that report is published this morning. The conclusion of the committee, however, is that the "tired of living" point in general is certainly not within the scope of the medical profession. However, they say that there is a grey area, where there is the balance between simply being tired of life and being tired of life in the context of a medical condition and that, when you move into that grey area, you move in the direction of our euthanasia law. That is perhaps their main conclusion: that there is a kind of grey area. However, we do not know how big it is; we do not know what angles to use to separate cases which are allowable from cases which are not allowable. For that reason, the report published this morning is the first of a series of steps which will perhaps take us five or 10 years.

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Q1243 Lord Taverne: Is it not right that the case, which was quite notorious, involved someone saying he was tired of life who was a member of the equivalent of the House of Lords?

Dr Holland: Yes.

Q1244 Chairman: I was wondering what you consider equivalent to the House of Lords here.

Dr Legemaate: That is our First Chamber of Parliament. We have the Second Chamber, which I think is more your House of Commons. The person involved was a former senator, as we call him.

Q1245 Chairman: He was no longer a member of the First House at that time.

Dr Legemaate: No, he was 86 years of age.

Q1246 Chairman: Could I ask you to elucidate for me? You said that the former Minister of Health has written to say that ending the lives of severely handicapped newborns was not euthanasia. What is it? What do they call it here?

Dr Legemaate: We call it “ending a person’s life without request”.

Q1247 Chairman: Is that against the law?

Dr Legemaate: It is against the law, yes, because in the legal sense it is murder. You have no request, you end a person’s life—it is murder.

Q1248 Lord Patel: May I clarify that in medical terms, particularly in the case of newborns, because this debate is also going on in Sweden and in the United Kingdom? Is it actively ending a life, or is it stopping treatment? This is neonates I am talking about.

Dr Legemaate: The cases the Minister was referring to are very exceptional cases of actively ending a life.

Dr Holland: But it is perhaps only one or two a year.

Dr Legemaate: They are very exceptional.

Dr Holland: Very, very exceptional. In that case, you expect that a newborn will die; he does not die; he has a lot of pain, and you can take away the pain. In that special case—and I suppose it is once or twice a year in The Netherlands.

Q1249 Lord Patel: But it is actively taking life?

Dr Holland: Yes, but it is against the law.

Q1250 Bishop of St Albans: Has any research been done on the changes, if any, in moral sensibility of the doctors who administer euthanasia? Has there been any research over, say, the last 10 years? Secondly, has any research been done on the impact upon families, where a family member has requested euthanasia or assisted suicide, and what those effects might be?

Dr Legemaate: Regarding your first question, there has not been a single research project, but for the whole 30 years of our euthanasia debate we had many debates, publications and articles about the moral implications of what was happening and whether or not our society as such was moving from one position to another, and whether it was good or bad or anything in between. It is not easy for me to summarise it, but there has been a kind of increasing acceptance of doing euthanasia, which I think incorporates a certain change of opinion about the moral aspects and how you balance that. I think that you have to differentiate between several sections of our society. When you talk to the Dutch Association for Voluntary Euthanasia, the NVVE, they will tell you that they know of many citizens of The Netherlands who have a living will in which they ask for euthanasia at the moment they prefer; but that the moment they prefer may not necessarily be within the possibilities of our law. The physicians are far more restrictive. That is why we mentioned in our short handout that, even after 30 years, 95 or perhaps 98 per cent of our euthanasia cases are still within the limits of what we call “traditional” euthanasia cases—mostly cancer patients and mostly with the general practitioner. We have had an extremely extensive debate over the years about people suffering from dementia, about those who are “tired of life”, and about mental suffering as grounds for euthanasia. In each of these areas we have had one or two cases, but it has not let loose a situation in which physicians have crossed that line in many cases. These are still exceptional cases. They are highly publicised, attract a lot of attention, and are seen as evidence of a slippery slope. However, I think that the practice for the past 30 years is stable, which we feel reflects a certain amount of reluctance on the part of physicians. They are willing to do it, but mostly in clear-cut cases. Only one or two of them, every now and then, are willing to cross the line. So in the sense that there is, let us say, a big paradigm shift on how we look at death and dying, my answer would be no, there is no such shift—at least, not amongst physicians. Perhaps there may be among the general population, and certainly among the members of the Dutch Voluntary Euthanasia Association, but of course they are self-selecting on the basis of being a member of the Association and moving in that direction. I think that physicians are reluctant. Both the Brongersma case, the case of the senator which we talked about, and an earlier case of a woman who was only suffering mentally, in the first instance had a kind of boomerang effect. The effect was not that we opened the door for these cases but that the door became a little more closed, because every time physicians feel that somebody is opening the door more and more, they have a hunch that it will land on their table and they do not want that to happen—at

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least as little as possible. No physician ever likes performing euthanasia. You do it because you have a patient with this long-lasting relationship, who is suffering unbearably. That is why you do it. You do not do it because of societal pressure or because of societal discussions.

Dr Holland: I have heard that some of you have visited the Rijnstate Hospital in Arnhem. There is a film from that hospital called “Dying with Dignity”, which I believe is in your possession. In that film you can very clearly see the restrictive attitude of the doctor.

Lord Carlile of Berriew: I notice from the papers we were given that 2.7 per cent of deaths in The Netherlands result from euthanasia now, which is several thousand deaths per year; in round figures, I would guess 7,000 or 8,000 deaths per year.

Lord Taverne: 4,000 deaths.

Q1251 Lord Carlile of Berriew: It is a few thousand deaths per year. I want to ask you a series of questions about the effectiveness of medical scrutiny on the conduct of doctors. You have told us that euthanasia is an exceptional rather than a traditional medical practice. You have told us that there was a legal duty upon doctors who carry out this practice to report it to the relevant body. I think you probably accept that there is not only a legal duty but an ethical duty to report it to the relevant professional body. Why, in that event, are so many euthanasia deaths unreported? It is a very significant percentage. If it is discovered that a doctor has failed to report, what sanction does the medical registration body apply to that failure? Is the very high failure-to-report rate a result of doctors being quite unsure of their ethical position, and therefore reluctant to risk finding themselves in trouble because of that very grey area in which they are operating?

Dr Legemaate: Regarding medical scrutiny, one element is that we have about 3,800 cases of euthanasia and assisted suicide on a yearly basis. The actual number of patients requesting euthanasia is 9,700—so almost 10,000. The first 6,000 requests are dealt with before even reaching the stage of euthanasia: sometimes because the patient dies between the time of asking for euthanasia and the time of being allowed to be given it; sometimes because the patient withdraws his request; but mostly because physicians tell the patient, “No, I have looked at the medical and ethical criteria of your request for euthanasia, and you are not within the sphere of these criteria”. The first step is therefore taken by the physician himself. If the physician thinks, “Yes, this may be a case in which I am willing to go along with the patient”, then the independent consultant comes in. That is not an exception; that is done in all cases. So there is no exception to that.

Q1252 Chairman: That is required?

Dr Legemaate: That is required and it is the project we are making operational at the moment, that is, the SCEN project. This project has been aimed at general practitioners—because this is where most cases occur—but which is now being extended to hospitals and to nursing homes. In one or two years, therefore, we will have 100 per cent coverage of all euthanasia situations in this country. The second element is the independent consultant. Then the doctor makes his final decision. Then he has to say, “Am I going to report it or not?”. Of course, you are completely right: legally as well as ethically there is a clear duty to report. I have already mentioned that the most recent percentage is 54 per cent, which relates to the year 2001 and before the law came into force.

Q1253 Lord Patel: To clarify, was that 54 per cent before it was made mandatory to report?

Dr Legemaate: No, it was already mandatory at that time. It has been mandatory since 1994, and since the beginning of the 1990s the number of cases reported is increasing. We do not know the actual percentage, because it is research from a couple of years ago and the next research will be carried out next year. Yes, some doctors are not reporting. What is the background to that? It may be through fear of legal consequences. Our position is that fear of legal consequences has greatly diminished over the years. It may also be due to worries that you may burden the family with procedures, with people asking questions, et cetera. One of the reasons may be that you do not feel sure about whether or not you have taken into account all the required elements, and why should you report yourself in a case in which you are not very sure about whether or not everything has gone wrong? That may seem a pitfall of the system, but that is not our view. Our view is that if we did not have the regulations we have, it would happen anyway. We would not see any of these cases—with much greater risks that things are going wrong, the wrong criteria used, et cetera. One issue you may want to clarify when you speak to Professor van der Wal is that, after his last research was published containing the 54 per cent figure, some critics said that they used the wrong definition of euthanasia—in the sense that the definition used in the research is far too broad, including, for instance, the cases in which you administer medication for pain accepting that you may shorten life. These cases are not meant to be reported and they will never be reported. These critics, in a number of publications in The Netherlands, have said that if you take away these cases and go to the more traditional definition of euthanasia, the number of reported cases may already be as high as 85 or 90 per cent. I mention that as a debate we are having, which I think that the researchers have to look into.

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Q1254 Chairman: That is really a challenge to the accuracy of the figures reported by the researchers?

Dr Legemaate: Yes. In terms of sanctions—your final point—not reporting is a criminal offence. If it is discovered—and it is discovered in a number of cases—the prosecutor will try to get you. Our system is that we, as a medical organisation, have nothing to do with sanctioning physicians. We have medical tribunals, which are a kind of a court system, including the medical professions. You may be brought before the medical tribunal by any person and, if it is obvious that you have not reported when you should have done, you will be sanctioned by a medical tribunal.

Q1255 Lord Carlile of Berriew: In what form? I have been a member of the medical tribunal equivalent in Britain. I am interested in the level of your sanctions.

Dr Legemaate: It ranges from a warning to the final sanction, which is that you are no longer allowed to practise medicine, and various instruments in between. It depends on how bad your behaviour has been. We have cases in which, for everyone involved, it was completely clear that all requirements were met: it was unbearable; it was hopeless; there was no alternative. Everybody agrees, “Yes, this was an acceptable euthanasia. You did one thing wrong, which was not to report”. In these cases you will get a very light sentence. If it is another sort of case in which the euthanasia as such was also open to discussion, where you should not have done the euthanasia anyway and you did not report—in these cases the sanction will be quite heavy. So it depends on the context of the individual situation whether you get a light or a harsh sentence.

Q1256 Baroness Finlay of Llandaff: I would like some very simple clarification. First, the percentage of Dutch graduates amongst your general practitioners. How many of your general practitioners are Dutch graduates and how many of them are graduates whom you have imported from elsewhere?

Dr Holland: Quite different from the UK. Not so many from outside. I suppose that 90 to 95 per cent of the doctors in Holland are Dutch.

Dr Legemaate: Or somewhat higher, I think. One or two per cent at the most are doctors coming from foreign countries.

Q1257 Chairman: Including the EU?

Dr Legemaate: Yes, including the EU. In the southern part of The Netherlands you have many Belgian doctors. There the percentage may be a little higher but, in general, it is a very low percentage.

Q1258 Baroness Finlay of Llandaff: With your SCEN doctors, who do they give their reports to? Is there a collecting agency that collects all the reports? Following on from that, I was wondering why you do not instigate pre-event reporting. You have after-the-event reporting; why not pre-event?

Dr Legemaate: SCEN doctors are invited to do their job by the physician who is considering going along with the request, and the SCEN doctor reports to that physician only. If the physician decides, “On the basis of everything, I am not going to do euthanasia”, then everything goes into the medical records and the case is closed. If the doctor goes along with euthanasia, then he has the duty to report; and the duty to report includes his duty to give to the reporting committee the advice that was written down by the SCEN doctor. But it is not the SCEN doctor directly going to—

Q1259 Baroness Finlay of Llandaff: So there is nowhere that the activity of the SCEN doctors is being collated?

Dr Legemaate: No.

Q1260 Baroness Finlay of Llandaff: So you do not know which SCEN doctors are being more hesitant about agreeing to a request and which are being more facilitatory?

Dr Legemaate: No, we do not know that. If we did, let us say, on a statistical basis, knowing that this one had said “yes” four times and the other had said “yes” twice or eight times, it would not say anything in itself. You have to know the underlying cases, to be able to qualify these figures. We have never done that.

Q1261 Baroness Finlay of Llandaff: Or the background.

Dr Legemaate: Yes. The second part of your question was on pre-reporting. We have had a number of debates over the years where someone has said, “Shouldn’t we convene the committee before the decision is made, instead of looking at the case afterwards?”. No one has promoted that, because the feeling is that, if you were on the committee, it would be a kind of, what the Americans call “God committee”—a committee giving the green light to physicians to “Go ahead”. Nobody feels comfortable with that. It should be your personal responsibility and your personal decision, in your relationship with the patient; it should not be the bureaucratic end of an administrative process in which, beforehand, a committee says, “You have our approval. Go ahead”. Nobody has ever felt comfortable with such a “green light” committee.

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Q1262 Baroness Finlay of Llandaff: When we were in Oregon we saw a situation where, if the patient did not have one doctor agree, they may transfer to another doctor. How much does that happen in Holland: that if a patient's general practitioner says no, they then try to transfer to another doctor?

Dr Legemaate: I think that it is happening in those cases where it is either for fundamental reasons or because some doctors may say, "I have nothing against euthanasia but I will never do it myself". If that is your doctor, we instruct these doctors to find a colleague who is at least willing to consider the patient's request. However, as a patient, you may also try to shop around because your doctor has considered your request and has told you, "No, I am not willing to do that, because your suffering is not hopeless or unbearable in my opinion". Then you may go to another doctor. Yes, I think that happens every now and then.

Dr Holland: It is rare, I think.

Dr Legemaate: Yes, the problem for this second doctor being that, when the case comes to be opened, it will become known that his colleague has turned the case down before him, and then the focus will very heavily be on him—"Why did you go along with the case that your colleague has turned down?". I think that mechanism means that not many doctors are willing to act as a second or third one.

Q1263 Baroness Finlay of Llandaff: I was interested in the position of an advance decision, where somebody may have requested in advance that, at the point they become incompetent, they would want their life ended. Also, what is the position in law over that—or whether the patient must be competent at the time that the euthanasia act takes place?

Dr Legemaate: Our law has a provision on living wills, advance directives, or whatever you want to call them. The law says that such a living will may be a replacement for your verbal request for euthanasia. Again, let us take a cancer patient who has made this living will. As a result of your illness you become incompetent in the last phase of your life, and the doctor knows that there is a request for euthanasia; but this living will does not replace all the other requirements. There still has to be unbearable and hopeless suffering. In most cases it is a rather useless instrument. You have this living will which only says, "Yes, I am asking for euthanasia", and it may be legally used in such a way; but, apart from that, the physician has to be satisfied that the other requirements are also met. For instance, last Friday there was a big conference on euthanasia and dementia. There you had exactly this problem. Somebody has made a living will saying, "When I suffer from dementia, I want euthanasia". All the nursing home physicians present last week at this conference said, "We cannot operationalise that,

because suffering from dementia is not within the definition of hopeless and unbearable suffering"—at least, that is what the physicians feel. That was a real disappointment for the Dutch Association for Voluntary Euthanasia, which has stimulated many of their members to make a living will saying, "If I suffer from dementia" or even, "If I am admitted to a nursing home, I want euthanasia". That is completely outside the scope of what is possible in this country.

Q1264 Baroness Finlay of Llandaff: Why do the organisations still campaign, when you have a law which allows euthanasia?

Dr Legemaate: You can ask them themselves, but I think they are campaigning for a wider situation, for more possibilities than our law permits. They have accepted our law as the final result of a 30-year process but, from their point of view, they want more. They will always be campaigning to have more possibilities—either in the "tired of living" situations or in the case of demented patients. I do not know whether they will ever get there, but it is completely understandable from their point of view that they are not satisfied with the situation we have at the moment.

Q1265 Baroness Finlay of Llandaff: It sounds as though they may never be satisfied.

Dr Legemaate: I do not know—perhaps.

Q1266 Lord Joffe: You say on the second page of your written document that the "Possible negative side effects of allowing euthanasia (such as a decreasing trust in physicians, putting pressure on the elderly, the dying or the disabled) have not materialised". Have there been no prosecutions, or cases over a period, which suggest that this might not be the position?

Dr Legemaate: We have had about 55 court cases in 25 years. If you look at these individual court cases, you see cases in which the physician clearly stepped out of line—either by having no request from the patient or for other reasons. However, none of these cases ever involved any element of pressurising people into asking for euthanasia. We therefore do not have any court jurisprudence on that issue; nor do we have any reports from society. We have to realise that euthanasia is within the doctor-patient relationship, but there are always a lot of bystanders, from the family or whatever—and nurses. We have had some cases in which nurses went to the authorities and have said, "What has been happening here is out of line". Yes, of course we have had some of these cases; but the point here is that it has never become a broad problem in the medical profession or in society. I think that it is inevitable that there will be some bad cases every now and then. You cannot exclude that. We try to exclude them by being as open

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and transparent as possible, but there will always be a certain number of bad doctors or bad nurses or bad family members.

Q1267 Baroness Thomas of Walliswood: Or just misjudgement.

Dr Legemaate: Yes, but misjudgement is somewhat different, in that we are exploring difficult concepts and difficult criteria. You may think, “I am on the good side of the line”, and afterwards the committee may say, “No, you have crossed the line”—which is not the same as a doctor with bad intent, ignoring all the relevant criteria, et cetera. Of course we have examples. There will unfortunately always be examples, but not to such an extent that the risk-benefit ratio of what we are doing is, in our view, moving in the wrong direction.

Q1268 Lord Joffe: What you are saying is that, over this long period, there were about 55 cases—out of the 2,000 or 3,000 a year where everything has not gone according to the system.

Dr Legemaate: Yes—at least, the cases that were prosecuted.

Q1269 Lord Joffe: I do not think that you answered a question by my colleague on the effect on families and grieving. I wonder if you are aware of the research done by Nikki B Swarte and Marije van der Lee, which suggests that the bereaved families and friends of cancer patients who die by euthanasia cope better with respect to grief symptoms and post-traumatic stress reaction than those of patients who die a natural death.

Dr Legemaate: Yes, that is a *BMJ* publication and it is one of the few publications in this area, but I think that it indicates what you are summarising. In a context in which a very large population of Dutch society supports the euthanasia system; *ipso facto*, when it is an issue in your family sphere, and somebody is dying and asking for euthanasia, it is understandable that there is a certain amount of acceptance there as well. What causes problems are situations in which the communication is not good enough with family members, either because the doctor does not communicate enough or because the patient himself asks his doctor for euthanasia but is not explicit with his family members. So when the doctor says, “Yes, I will go along with it”, that is a shock to the family members, simply as a result of the patient not communicating explicitly enough with his or her family. All parties involved should therefore be very explicit in what they are saying to each other. It is also the doctor’s duty to have a responsibility for the family members as well. It may happen, but this was a rather supportive piece of research. There is not much research on that.

Q1270 Lord Joffe: You have mentioned that there is some opposition to the practice of euthanasia by some doctors, mainly because of religious beliefs. Does this opposition seem to be increasing or decreasing? Have you any indication?

Dr Legemaate: I think that it is stable. If you look at the statistics from the van der Wal research, the percentage of doctors who favour it or who do not favour it has been rather stable over the years. There are no big changes.

Q1271 Lord Joffe: It is more or less 80:20 per cent?

Dr Legemaate: Something like that. Without having the exact figures, it is something like that, but van der Wal and his colleagues can inform you on the exact figures.

Q1272 Lord Carlile of Berriew: I am puzzled by your extrapolation from 55 reported court cases in 25 years of the conclusion that only 55 cases have gone wrong in 25 years.

Dr Legemaate: No.

Dr Holland: No.

Q1273 Lord Carlile of Berriew: That was the answer you gave to Lord Joffe. I accept that you did not mean that. However, would you accept that, taking the 54 per cent reported and 46 per cent unreported figure as an unqualified figure, given by yourself in the paper which we were given, it is more likely that there have been breaches of practice in unreported than in reported cases? If that statement of the obvious is correct, what estimate would you give of the percentage of cases in which there has been an eccentric as opposed to concentric practice in relation to the law and ethical requirements?

Dr Legemaate: That is not easy to answer. I cannot simply contradict what is your central position. What we know from the research projects—let us say the van der Wal researchers—they have spoken to doctors about all cases they have dealt with, including the unreported cases. From that research, it is not as simple as that the good cases are reported and the bad cases are not. It is much more complex than that. We accept that there are a certain number of cases in which it is not going well or not well enough, or even going very badly. We do not know how many. I think that these cases are present, and there are more than 55 over 30 years. Our perspective, however, is not to take care of these cases—which is completely impossible—but to create a climate and system in which the chance of these cases occurring is as little as we can realise. That is the position we have. You are completely right, however: there must be some cases in which the doctor is doing very bad things—certainly.

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Q1274 Chairman: I think you made it clear, in fairness to you, that the 55 were the cases that were prosecuted. You left the clear impression, in my mind at least, that there might well have been cases which could have been prosecuted but were not.

Dr Legemaate: Correct, yes.

Q1275 Lord Patel: Thank you for clarifying that. To pursue that point further, I think you said earlier that the 54 per cent was before the Act, but you also hypothesised as to the reasons for the non-reporting of the cases. Knowing that it is a criminal offence not to report, why do you think—if the figure of 46 per cent not reporting is true—the doctors are not reporting?

Dr Legemaate: Let us conclude that the mere fact that it is a criminal offence does not appear, for a number of doctors, to be a reason to report. They are taking the risk of being prosecuted on the sole ground of not reporting. The grounds for not reporting, as we know from the research projects, have to do with the reasons I have mentioned, namely fear of legal procedures or legal trouble; not wanting to lay a burden on the family; just being against the paperwork or not wanting to go through the red tape, or whatever—which are not very acceptable reasons.

Dr Holland: Not at all.

Q1276 Lord Patel: Or is it a lack of clear definition?

Dr Legemaate: That is my other point, but it is the debate we are having at the moment. If it is true that the researchers have used a definition of euthanasia which is somewhat broader than is in the doctor's mind, then that may also be a reason for not reporting some cases which, as a doctor, you simply do not associate with euthanasia.

Q1277 Chairman: It is really a question of whether the definition that the researchers have used as their baseline for the cases is the same as the cases that the law would require to be reported. I understood you to say—and you will correct me if I have misunderstood this—that there was an argument that the researchers have used, for the baseline of the 100 per cent, a definition of the circumstances which is broader than the circumstances in which the law would require one to report.

Dr Legemaate: For clarification, it is about the researchers' questionnaire. In their questionnaire they ask a doctor, "Did you have any cases in which you shortened"—note the "shortened"—"the patient's life?". The question was not "Did you have cases in which you actively ended the patient's life?". No, the definition is "Did you shorten the patient's life?".

Q1278 Lord Carlile of Berriew: You allow for that in your paper, in the statistics which you give in your own paper and which you do not question, and leave the 54 per cent as an unqualified figure. I am puzzled, because you seem to want to reduce that figure.

Dr Legemaate: No. The paper was written before this debate emerged in The Netherlands.

Q1279 Chairman: You are telling us about a debate that has been raised with the researchers. What the right answer is you are not going to answer; the researchers are going to help you answer it.

Dr Legemaate: In the paper I used the official figures which were published last year, not being aware of this present debate. We do not know where it is going. The debate is important because, for the fourth time in a row, the research will be done next year. We do not want to have the same misunderstandings about the figures again. So it is up to the researchers to respond to the criticism.

Baroness Thomas of Walliswood: And to ask the right question.

Q1280 Lord Patel: I do not want to pursue it further, but it must be a concern, not only to you as the medical association, but to society and to parliamentarians.

Dr Holland: Yes.

Q1281 Lord Patel: And you have to get to the bottom of it. My main question, however, related to the history and where you started from. You said this debate was going on for 30 years before it was enacted into law. You also said in your introduction that you knew there were lots of cases of euthanasia going on. How did you know that?

Dr Legemaate: That was a combination of a lot of anecdotal evidence, just talking to physicians over the years, about "What are you doing in your wards, in your hospitals and in your practices?". Also, over the years, minor research projects indicate that this type of conduct was going on in actual practice—and not for bad reasons. If you look into "Why are you doing that?", it always has to do with taking away hopeless suffering. That has therefore been a part of medical practice already for many decades.

Q1282 Lord Patel: Did that have any relation to the quality of services available for the elderly, or particularly the dying—people near the end of life?

Dr Legemaate: That is a more general question: whether alternatives in terms of care supply may take away the need for euthanasia. Even with our present level of palliative care, we still accept that—

Q1283 Lord Patel: What is the present level of palliative care?

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Dr Holland: I think that it is very good at the moment. In the last years the level has become much higher than a few years ago, and I think that the numbers of cases of euthanasia will decrease at the present time because of the effects of palliative care.

Q1284 Chairman: Could I understand a little more about the requirements? We have understood in general terms what they are. There has to be hopeless and unbearable suffering. There has to be a request from the patient to the doctor. What are the time intervals? You mentioned the possibility that sometimes the reason that the request was not followed up was that the patient died before the actual practice was invoked. What are the time intervals?

Dr Legemaate: The law itself does not contain a timetable—for instance like the 14-day period that you have in your own Bill at the moment. The law implies that there has to be no doubt whatsoever with regard to the request, which implies that the patient must repeat it over time, to give the physician the impression that it is not a one-moment thing, but something he really wants. “I said it six months ago. I said it two months ago. Now it is time for euthanasia for me.” On the other hand, especially with traumatic illnesses, the changes in the patient’s condition and in the patient’s suffering may be such that you ask for euthanasia this morning and it is performed tomorrow or the day after tomorrow, and everybody feels quite comfortable with that—as a result of what has been happening to the patient. So we would never create a minimum waiting period, as we do in our abortion law for instance. We would never do that, in order to be able to respond to these very acute and dramatic changes in the patient’s condition. The requirement is that, as a physician, you must be clear about the request. It could be a request from six years ago which is updated yesterday, but it could also—again, in some cancer cases—be a request which has been made this weekend and which will be performed this week.

Q1285 Chairman: Is there any requirement in your law about the length of life that still remains for the patient, according to the best medical evidence or estimate that can be given?

Dr Legemaate: No, there is not. That, I think, is a very fundamental choice in the Dutch law—but also previously in Dutch jurisprudence over the years—which is that if the main basis is hopeless and unbearable suffering, it has nothing to do with your life expectancy. In actual practice I think that our law is very close to your Assisted Dying Bill, in the sense that 95 or 98 per cent of the cases, 99 per cent perhaps, are patients within the last days or weeks of their life. So that is our practice, but we do not exclude the rather exceptional situations in which, for

instance, somebody who is 55 and has a very severe but incurable mental illness—which relates to a situation of hopeless and unbearable suffering—asks for assisted suicide. We have had these cases every now and then. Not many, but they are not excluded. We do not have any limitation to a terminal phase or to the last months of your life, or whatever.

Q1286 Chairman: I now want to ask you about the nature of the present law. What status does the patient’s competence to decide come into the matter? Is there any question of finding out whether the patient is competent to ask for and make a decision upon such a fundamental question as asking for termination?

Dr Legemaate: The legal requirement is that the request has to be well considered. Defining “being well considered” implies being competent to make the request. In many cases, competency is assumed unless you have indicators to indicate otherwise. In general, the competence is not questioned. However, if it is a case of a person with an illness or a background which may imply incompetence, then it would be a failure not to look into the competency. When such a case comes before the committee afterwards and the committee say, “You did not consult a psychiatrist beforehand on the issue of competency”, then the doctor would have a serious problem.

Q1287 Chairman: If there was a case of hopeless and unbearable suffering in someone who was not competent to decide, what would the situation be so far as your law is concerned at the present time?

Dr Legemaate: First of all, that is not euthanasia, but we have already discussed that. Let us take one of these very rare cases of the severely handicapped newborns—babies with multiple handicaps and with a very short life expectancy of some weeks or some months. Even in this very short life expectancy there may be a situation of unbearable suffering. These are the one or two cases per year in which the life of the baby is actively ended. In a formal sense, that is murder. Some of the physicians have been prosecuted, but were acquitted on the basis of what in our legal system we call the defence of necessity—which is a defence that anyone prosecuted with a criminal offence may invoke—saying, “Yes, I committed a crime, but I had the justification to do so. The justification was that it was the only way to take away the unbearable suffering in this severely handicapped newborn”. This defence of necessity, until 2002, was our legal basis for euthanasia. When we had no law, it was all operated under the defence of necessity. Now we have the law of euthanasia, but the defence remains for these other cases.

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Q1288 Chairman: Lord Patel was asking you earlier about the fact that some of the statistics were derived from a time when there was no legislation about it. However, the euthanasia has in effect been subject to the control of the courts and has been allowed, subject to the control of the courts. Then, with your guidelines, it has been regulated under the authority of the profession, until the statute came. If I have understood it correctly, the statute simply recognised and put into statute law what had been, up to then, the practice as regulated by your guidelines. Is that correct?

Dr Legemaate: Correct.

Dr Holland: Yes.

Q1289 Chairman: And there was a requirement then, in that form of the law, to report the instances of the practice that any physician had actually undertaken?

Dr Legemaate: Yes. To clarify, the first guidelines we issued were in 1994. Already then, euthanasia was taking place and regulated by our guidelines; but the reporting rate in 1994 was zero, or even less than zero. That only changed somewhere in the 1990s. You may wonder about that, but we accepted for a long time that there was no reporting afterwards whatsoever. Only in the 1990s did we say, “That is no longer acceptable. It is such an important societal issue and decision that you are making, it should be reported”. Then we stepped on a ladder which took us higher and higher in terms of the reporting rate. During perhaps two-thirds of the euthanasia debates from 1973 to 1992/93 there was no reporting issue at all, but none the less the developments went on.

Q1290 Chairman: You mentioned that the statistics—and we will get a chance to talk with the people who were responsible for that research in due course—were based on a questionnaire that seemed to assume that any instance of shortening life might be regarded as subject to the euthanasia law; whereas, as you have pointed out, it could be that, although the effect was of shortening life, the purpose was to relieve pain. Is that—perhaps “confusion” is the right word for it, I do not know—a misunderstanding that you would think quite common? That people think that if they indulge in a practice to shorten life, even if the main purpose of it is to relieve pain, it is something which the euthanasia law might well embrace?

Dr Legemaate: I think that there certainly is an amount of confusion which, in the most recent debate, is not related as much to administering pain medication but to what we call terminal sedation, which is the situation of making a person unconscious during the last phase of his life. Terminal sedation, using another type of medication than when administering pain medication, may also

have the effect of shortening life. This needs clarification, and it needs clarification in our next round of empirical research. What I was implying by mentioning the debate about the questionnaire is that the situation in terms of the reporting rate may already be much better than we know, simply because the present figure is not “clean” enough. That need not necessarily be true, but it is the debate that we are having at the moment. It points in the direction of confusion about what type of conduct is incorporated in the definition and what is not.

Q1291 Chairman: You mention advance directives or living wills, and the debate that has taken place quite recently about that. Do I understand right that what you are indicating is that the advance directive or the living will might deal with the question of competence, but it will not affect the conditions under which otherwise euthanasia would be allowable under the law?

Dr Legemaate: That is correct, yes. The living will only replaces the oral request by the patient. The patient cannot introduce into this living will his own definition of suffering. If the patient is saying, “For me, being admitted to a nursing home is unbearable and hopeless suffering”, he can write that down, that is not a problem, but it can never be—

Q1292 Chairman: No, but on the other hand if his living will says, “I wish euthanasia if I come to a stage in the progress of my disease, or my ageing for that matter, at which the suffering I have becomes unbearable and hopeless”, that would be okay?

Dr Legemaate: He can do that, but such a definition would create a very big problem for the doctor. Imagine you are the doctor involved, reading such a statement and having to look at the patient and say, “Is he in that stage or not? What is happening? He is suffering from dementia and he no longer recognises his family”. The living will is a fine concept, a fine theoretical mechanism, and it is of very great value in terms of refusing treatment. That is completely clear. “I don’t want to be reanimated.” That is clear and no problem. “Don’t do that to me.” But asking for something active from a doctor, “Ending my life when I have reached this situation”, for doctors—and we know this from our organisation—that is very difficult. You must specify the situation in which you want it realised to such an extent that it is understandable for the doctor and for the people round him—and that is very difficult.

Q1293 Chairman: It is not good enough to specify the language of the statute, as “hopeless . . .”?

Dr Legemaate: No, because what, in that case, is the suffering? You may define yourself as suffering if you no longer recognise your family. We had a recent case in the Supreme Court which related to a woman who

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was going to die within moments and she was in a coma. Then the doctor ended her life without a request. So that is not euthanasia, but it was actively ending life. The Supreme Court said, “She was not suffering”. It was certainly a horrendous situation for the family, standing round that woman; but she was in a coma, she was not suffering. You have always to experience the suffering yourself, and it should be visible and understandable to other persons that you are suffering. If that is not the case, you can define what you want in your living will but it will never lead to any—

Q1294 Chairman: No, but if the living will is framed on the basis of a time when the suffering becomes in the doctor’s opinion unbearable and hopeless, then the living will would authorise the euthanasia in these circumstances—if the doctor believes that that has actually now come to pass?

Dr Legemaate: Yes. The committee will ask the doctor, “You acted on the basis of the living will, so you must have concluded for yourself that it was unbearable suffering. Tell us why”. Then you have to have a good story.

Q1295 Lord Patel: This is why dementia is not regarded as suffering, because you might have the worst Alzheimer’s and you do not recognise your own husband or wife, but you are not suffering. It is the family that is suffering.

Dr Legemaate: The family is suffering, yes.

Dr Holland: The family is suffering. That is quite different.

Baroness Thomas of Walliswood: How do you know?

Lord Patel: From what we know there is no suffering. We can only tell from what we know.

Q1296 Lord Taverne: I want to come back to the question about possible negative side effects, which you say have not materialised. However, we have had some written evidence from The Netherlands that there are cases where patients are scared of euthanasia, and indeed we have had some rather dramatic statements that some old people are fleeing The Netherlands to Germany because they are so afraid of being killed off. Do you have any evidence of this? Have you had complaints about this? What would be your reaction to the statements which we have had that some patients are now scared out of their wits because doctors are going to kill them? And, indeed, that sometimes it is the pressure from the family which says, “They’re eating up our inheritance. Doctor, please administer euthanasia”?

Dr Legemaate: We do not have evidence emerging on a large scale. As I said, we can never exclude any individual or anecdotal situations in which some elements of that have entered the case. Over the years, the citizens of The Netherlands who are against

euthanasia in their own situation have also taken action. They have developed their own living wills—which is a living will in a true sense—saying, “I don’t want euthanasia”. Within certain religious spheres people have made such a living will, just to make clear that it is not something for them. However, it is not on the basis of a practice where we have received reports about either doctors or family members or nursing home personnel scaring them or pressuring them into something they do not want. If that was a part of practice, given the fact that euthanasia issues are highly publicised and attract a lot of attention, it is unimaginable that they are there in The Netherlands and have not come out into the open.

Q1297 Bishop of St Albans: I am sure that we would all agree that hopeless and unbearable suffering is completely and utterly unacceptable. If there had been as much pressure in The Netherlands for increased attention to be given to palliative care and pain control, do you think that, as a country, people would still have chosen to go down the euthanasia route rather than the palliative care route?

Dr Legemaate: Peter Holland has already briefly mentioned that, with the emergence of what we call terminal sedation, there may be a situation in which the number of euthanasia cases may drop a little, because of the fact that you offer patients a choice; you tell them, “Either, when you are suffering, it is euthanasia or you can opt for terminal sedation”. However, a lot of patients do not want to do that, because terminal sedation implies that during the last days of your life you are unconscious. You no longer feel your pain, but you are unconscious. Quite a number of patients say, “I hate my pain, but I also want to see my family members until the moment I die. I do not go for the strategy of being unconscious during the last week of my life”. Then you may reject that specific type of palliative treatment and say, “No, I prefer euthanasia”. We may go to some other balance or division between the possibilities, but never in the sense that palliative care will completely take away the reason for euthanasia. Also in that context, if you look at the reasons why people ask for euthanasia, pain is only one of the elements. Let us say, dying with dignity, suffering not from pain but from a loss of independence, and so on, also constitute suffering. So it is not only pain and not only something which you can take away with palliative care. However, it should be a choice for the patient. For instance, one of the SCEN doctor’s instructions is always to look into the possibilities of palliative care and to inform the patient about these possibilities. In your Bill you have a kind of mandatory conversation between a patient and a specialist in palliative care. That is also an option, of course; but palliative care, in our experience, does not take away all the justification for euthanasia.

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Q1298 Chairman: I think that you have used in the paper the phrase “hopeless and unbearable suffering”. Lord Carlile has said to me that the translation that he has is “lasting and unbearable”. I wonder if there is any difference, because “hopeless” in the context in which you use it may simply mean that it will not improve. It is hopeless in the sense that it will continue unbearable until the patient has been relieved in some way. So “lasting” and “hopeless” may not be very different. Have you any comment on that?

Dr Legemaate: I think that they are exactly the same. The implication is that there is no alternative to end the unbearable suffering. That is what we mean by “hopeless”. I think that “hopeless” or “lasting” can both be used as having exactly the same meaning.

Q1299 Lord Patel: Where did the need for this law come from? Did the pressure come from the profession or from society?

Dr Legemaate: Our first Bill was introduced in 1984. It did not come from the profession but from politics, with broad support from society. At that time the medical profession was rather neutral regarding the Bill. We did not object to the Bill, but it could also

have gone on without a Bill. Actually it did, because in 1984 there was no political situation in which to realise the Bill. We only had that Bill in 2002. At that time, the medical profession strongly advocated the Bill, the reason being that we had had 10 or 15 years of uncertainty. When we had another Minister of Justice, the number of prosecutions would rise. When there was a new Minister of Justice, the number of prosecutions would go down. There was an impact on physicians—“Should I report or not?”. These political changes had a very great impact on the willingness to report, because the uncertainty was created by our own politicians. The doctor would say, “I am not going to report my case because I do not want to be part of that political debate”. After that had gone on for a certain period of time, we said, “We want a broad ‘Yes’, because there should be an end to the politicising of the euthanasia debate and the politicising of the prosecution policy in the area of euthanasia”. So in latter times we have changed our position regarding the law from neutral to pro.

Chairman: I think that we have used up all the time, and somewhat more than was allotted. Thank you very much. We are very grateful to you for your very full answers

Examination of Witnesses

Witnesses: DR NICO MENSINGH VAN CHARANTE, DR JON BOS, DR RUBEN VAN COEVORDEN and PROFESSOR GUY WIDDERSHOVEN, examined.

Q1300 Chairman: The system we have adopted is for you to make a short opening statement of your position and relationship to this particular inquiry that we are involved in. Then my colleagues and possibly myself will want to ask you some questions of particular interest to us. The answers that you give, as well as your original statement, are taken down by the shorthand writer. You will have an opportunity of seeing the transcript. If you wish to amend it in order to bring it more into line with what you thought you said, you will have an opportunity of doing that. The transcript of the evidence, as finally corrected, will be appended to our report and will become public property when we report to the House of Lords, which will be a little distance away in time, because we still have quite a lot of work to do. We are very grateful to you all for coming along, and I hand over now to whoever wishes to begin.

Dr Mensingh van Charente: My name is Nico Mensingh van Charente. I have been a general practitioner since 1977, so for 27 years, in the beautiful city of Amsterdam. My story with euthanasia began in what I call my “criminal” period, that is, when euthanasia was not yet stated in our law.

Q1301 Chairman: In legislation?

Dr Mensingh van Charente: In our legislation—when we, as doctors, had patients who suffered very much, and where we did things like euthanasia. Seven years

ago, I was one of the founders of the SCEN project—that is, Support and Consultation in Euthanasia in The Netherlands. It is an organisation with doctors who are experienced in the consultation that is necessary for the euthanasia law. I am one of the doctors who have performed an average number of euthanasias, that is, one euthanasia in one and a half to two years. So I have experience in euthanasia myself, and I have a lot of experience in consultations regarding the law, and that is some 80 to 90 consultations.

Dr Bos: My name is John Bos. I have been a surgical oncologist since 1976 in the eastern part of Holland. Because of the oncology part of my work, I have very often been confronted with euthanasia requests and also I have performed euthanasia—I would not say on a regular basis, that does not sound right—but quite often it has been asked and frequently I have had to perform euthanasia. I think that I am here because I am chairman of the Medical Committee of the NVVE, the Dutch Association for Voluntary Euthanasia. In that sense, I have a lot to do with euthanasia, the questions around it, and that sort of thing—but I also have practical experience.

Dr Van Coevorden: My name is Ruben Van Coevorden. I am a GP. I have been a physician since 1981 and a general practitioner since 1984. I have also been involved with the SCEN project from the start.

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Dr Ruben Van Coevorden and Professor Guy Widdershoven

Although Nico Mensingh was one of the initiators, I shortly joined them and also have been active as a consultant for the SCEN project. During this project, I noticed that palliative care was a subject which was not very well known to the general practitioners, so I felt an urge to specialise or to look into palliative care more deeply. We joined together some of these SCEN doctors—and Dr Mensingh van Charante is also one—and we formed a peer group of palliative care. We specialised in palliative care. I specialised further, and became a consultant in palliative care in 2002.

Q1302 Chairman: Does that mean you have stopped being a general practitioner?

Dr Van Coevorden: No, I continue being a full-time general practitioner and, in addition, I am also a consultant for the SCEN project and also a consultant in palliative care.

Q1303 Chairman: Where is your practice?

Dr Van Coevorden: My practice is in Amsterdam. I had the privilege to be trained partly by the noble Baroness, Lady Finlay. One of the new initiatives is that I am one of the co-initiators of the very first European Jewish hospice, which will be in Amsterdam, and we hope to open at the beginning of 2006. So I am very much involved with palliative medicine.

Dr Widdershoven: My name is Guy Widdershoven. I am a philosopher and Professor of Medical Ethics in Maastricht University. I have been involved in the debates around end-of-life for more than 10 years. I am doing research in ethics of palliative care and also in discussions concerning euthanasia. I am a member of one of the review committees, that is the committee of Limburg and Brabant, so the southern part of The Netherlands, as an ethicist. I have seen many cases of euthanasia during the review process, after they have been performed.

Q1304 Lord Taverne: Can I start by asking a question in relation to palliative care? This seems to have developed very much in The Netherlands. With your experience of palliative care, do you see any conflict at all between the development of palliative care and the law about euthanasia?

Dr Van Coevorden: Not at all. If anything, it has very much stimulated palliative care and knowledge about the possibilities of palliative care. We have seen in the past few years that there has been an enormous boom in training, sub-training for general practitioners in general, and also we have trained a first group of about 50 GPs as consultants in palliative care. They are distributed all over Holland and, soon, a new group both of GPs and nursing home physicians will also be available as consultants in palliative care. We have about 80 hospices in Holland. There has

therefore been a boom also in hospice care. There is a lot of attention being paid to palliative care, and I think that this is in relation to life-end decisions and euthanasia in particular.

Q1305 Lord Taverne: Quite a lot of the evidence we have heard in Britain, from people who are very much involved in the palliative care and the hospice movement, has been hostile to the idea of some such legislation. They feel that if proper palliative care is available, there is no need for euthanasia. You do not take that view, I gather.

Dr Van Coevorden: No. First of all, I have read some of the testimony given by the palliative care doctors, and I was a little shocked. I personally had the feeling that this was more a prejudice which was being ventilated, rather than real fact. It stated that palliative care was at a very low level in The Netherlands. That may have been so, but my experience in the past five years is that palliative care in Holland has come up to a very high level—I would say at least the same level as in England, although in England there has been attention paid to this for years. I think that the Dutch have done their utmost to bring palliative care up to date, and available to Dutch society.

Professor Widdershoven: Could I add something from my experience in the review committee and, first, perhaps also for clarification? We do not have many palliative care hospital beds, because palliative care in our society is connected to the out-patient situation and the GP; but we do have consultation, as has been said. In the review process of euthanasia cases, we specifically note that a number of suggestions about palliative care have already been taken into account by the doctor—before even the euthanasia request has been made. Also, consultants, second physicians, often suggest things to try, and they are tried. So there is certainly a lot of attention paid to that area.

Q1306 Earl of Arran: Are you therefore saying that, with the advent of palliative care, you think that you are being successful in turning down some of the cases who would be potential believers in taking their own life? That palliative care is actually beginning to have an effect on euthanasia, or is that too extreme a suggestion?

Dr Van Coevorden: I can say from my own experience and also as a SCEN doctor that we specifically look at palliative care possibilities. The law also states that you can only perform euthanasia when you are convinced that all palliative care possibilities have been tried—unless there is a situation where a palliative measure is not acceptable for the patient. You can think of a measure, but it does not necessarily get the right balance between what you

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are doing and the benefit of it. So we explicitly look at palliative care possibilities and, if we cannot do any more, then we proceed with euthanasia—if the patient wants that.

Q1307 Earl of Arran: If you rolled out palliative care across the whole country, would you expect the cases of euthanasia and assisted suicide to come down?

Dr Van Coevorden: No.

Dr Bos: I agree with Dr Van Coevorden. Palliative care is not at all a substitute for euthanasia—not at all. Some people in Holland nowadays are suggesting that terminal sedation might be used. They are totally different things. I fully agree that palliative care, if you roll it out to a greater extent over the country, will not change the requests for euthanasia.

Dr Van Coevorden: In fact we make sure that euthanasia is not a strange alternative for bad care. We make sure that people get proper care. If you give proper care, you will see that the requests for euthanasia come down.

Q1308 Chairman: I think that was the point that the Earl of Arran was making.

Dr Van Coevorden: But it still exists, because there are a lot of people who still think that their situation and their suffering are unbearable, and no realistic options for palliative care are available.

Q1309 Lord Patel: Do you have a figure as to what that percentage might be?

Dr Van Coevorden: I cannot express this in percentages. However, I have prepared some existing figures for the Committee. I will give you a copy. It is in English. We have about 142,000 deaths in The Netherlands. Fifty per cent of these deaths occur without any involvement of a medical decision. People just die—in the street, at home, or whatever. In about 45 per cent a medical decision is involved, in one way or another; 20 per cent involve a decision not to treat—so a withdrawal of treatment or a decision not to treat; 20 per cent involve intensifying pain or system relief. Only 2.6 per cent involve euthanasia; 0.2 per cent involve assisted suicide. So these are very low figures. These figures are more or less stable. If there is any trend, they are coming down; they are not going up. The people who are very much in favour of giving greater attention to more palliative care, say that this is the result of better palliative care in The Netherlands. This may be so, but at least you can say that there is a more or less stable number of people who, at the end of their lives, say, “This is it. Enough is enough”.

Q1310 Chairman: You have a last, small figure of 0.7 per cent.

Dr Van Coevorden: Yes, that involves life ending without request, but it is outside the scope of this discussion because it involves newborn children, with defects and so on.

Q1311 Chairman: That is not euthanasia as you understand it?

Dr Van Coevorden: No, and it involves people who are not competent. We should leave this out, because you explicitly said that we would be talking about competent people.

Q1312 Chairman: The law here, I think I have understood, requires, for euthanasia or physician-assisted suicide, the patient to be competent?

Dr Van Coevorden: To be competent, and it has to be on request. I saw the testimony of one of the palliative care doctors, where there is a suggestion that doctors who go about with a syringe in nursing homes saying—for economic reasons—“It is cheaper to finish them off with a syringe, with an injection, than to give them good palliative care”. This is absolute nonsense. We are talking about competent people, who at their own request, of their own free will, ask their doctors to end their life, because enough is enough.

Dr Bos: Can I add something?

Q1313 Chairman: Yes, please. I would like you to understand that when one of my colleagues asks a question, then if any of you have any comment to make, please do so. The intention is that the full complement who are here can help us.

Dr Bos: About the 1,000 cases of euthanasia of euthanasia without request—the 0.7 per cent you were just talking about—that figure has not changed. It was 0.7 before the regulation of euthanasia and it is still 0.7 per cent at the moment.

Q1314 Chairman: We have understood, and you will correct me if I have misunderstood, that strictly speaking it is not right to describe these cases as euthanasia at all?

Dr Bos: That is right.

Professor Widdershoven: That is correct.

Q1315 Bishop of St Albans: I want to preface what I am about to say by explaining that I am the national chairman of the Council of Christians and Jews, and therefore totally committed to interfaith understanding. I also want to make explicit that, with others, I have been responsible for setting up in the UK a multi-faith hospital chaplaincy group. It is out of that that I ask this question. In the setting up of the hospice that you mentioned, what theological debate, if any, has there been amongst the rabbis who would be likely to be involved in offering some of the care,

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and/or the priests, and/or the ministers, and what state is that debate at?

Dr Van Coevorden: That is a very interesting question. In our talks with the different Jewish congregations, we notice that everybody is thinking along the same lines, from extreme orthodox to extreme liberal: that this hospice should open as soon as possible. As much as possible, optimum care is given. Even the most orthodox rabbi says that a dying person—for instance, let us stick with food regulations—is exempt from all Jewish rules. If on his deathbed he wants to have a pork chop with cheese on it—which is something which is absolutely not done—the orthodox rabbi says, “Go ahead. That’s okay”. Everything for the dying person is okay. Also explicitly, and this was also interesting, the most orthodox rabbi said, “If a gentile would like to spend his last days in the Jewish hospice, he is welcome”. It is not restricted to Jewish people only. Of course we will have a hospice that breathes an atmosphere of the Jewish culture, and so on; and, to bring up the subject of euthanasia, euthanasia is not performed in this hospice. That should be clear. It is not done under the Jewish law. On the other hand, optimal care, increasing pain medication and so on, is explicitly permitted.

Q1316 Chairman: Are there other institutions in The Netherlands, apart from the Jewish hospice to which you have referred, which do not allow euthanasia in their institutions?

Dr Van Coevorden: Yes, there are. Especially Christian-based hospices have a policy not to allow euthanasia within the premises. If someone is admitted to such a hospice, and at the very end decides that he or she wants to have euthanasia performed, the patient is transferred either to their former house, if it is still there, or to a different location.

Q1317 Chairman: Can you tell us roughly the percentage of deaths that take place at home in The Netherlands, as distinct from a hospice or hospital?

Dr Van Coevorden: Most people die at home.

Q1318 Bishop of St Albans: It is a very fascinating topic and I would love to have the chance, outside the meeting to take it further if that were possible. The hospice presumably—and I am just assuming this and I am checking to see if I am correct—would say that euthanasia would not take place within it because there are beliefs surrounding the nature of life, the nature of God, the sanctity of life, whatever word one wants to use, which would make the offering of euthanasia absolutely unacceptable. That would be a correct assumption, would it?

Dr Van Coevorden: Exactly. That would be correct.

Q1319 Bishop of St Albans: May I go to the next question, which is this. If our equivalent of the Voluntary Euthanasia Society has achieved so much in Holland already, what is the ideal scenario? Are there still yet further steps that you wish to move towards? What is the ideal situation in The Netherlands as envisaged by the Society that is pressing for greater opportunities for euthanasia?

Dr Mensingh van Charente: Is this the question of the slippery slope?

Baroness Thomas of Walliswood: What is the next ambition?

Q1320 Bishop of St Albans: Because behind it there have to be ideal notions of humanity. I fully accept that there have to be, for all of us. Also, there has to be an assumption about what equals an ideal society. All of us have utopian dreams, and it is absolutely right that we should; but what is the ideal society to which you wish to take The Netherlands? Patently you would not be campaigning if you thought it was already ideal?

Dr Mensingh van Charente: You mean that it is not especially a question for doctors, but—

Q1321 Bishop of St Albans: No, for society. But as you are some of the opinion-formers in Dutch society.

Dr Mensingh van Charente: Today we presented a report on dying, helping people, and we are talking more about the existential needs of people—and people want that. The next question is if they are to get it. I am not sure if that is an ideal situation. The only thing I can say is that in my practice, in my surgery, it is a live question. It is a question of people suffering. What is suffering is a personal perception, and that is the problem. Some doctors are going in that direction. Do you know the Brongersma case?

Q1322 Lord Taverne: The senator?

Dr Mensingh van Charente: We call it the senator case.

Q1323 Chairman: A retired senator.

Dr Mensingh van Charente: Yes. This report is about that case. I daresay that the society is going in that direction, asking doctors to be involved in it. Whether that is the ideal situation—I have my own opinion about that.

Dr Bos: Can I try to answer that question, as far as the NVVE is concerned? We have achieved the situation we now have, with the law in place. That is still not ideal. One ambition we have is to educate doctors in Holland, because not every doctor seems to understand the law and the way they should use it. That is a problem. It is not a very big problem but it

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is still a problem. Apart from that, we had a symposium just last Friday about euthanasia and dementia. That is the next problem we will have to tackle. It is possible within the law, but it is very difficult, as you will understand. However, it is one of the things we are dealing with at the moment. Further on, we have what we call nowadays the “end-of-life pill” or medication. There was Drion—you probably have heard that name before. I think that is the ultimate goal. In that sense, euthanasia is not a medical problem at all. At the moment, I personally feel that it is a normal medical procedure. I regard it as part of my duty to the patient. However, the patients need the doctors because we have access to the medication, if it is necessary. Eventually maybe—and I think that is one of the ideals of Dutch society in general at the moment—they can decide for themselves and have the possibility to do so, without consulting a doctor.

Q1324 Chairman: At any stage in life?

Dr Bos: At any stage in life. They can now also jump in front of a train or from a big building.

Professor Widdershoven: May I briefly comment on that, because I hear some positions taken which I think are not shared by everyone?

Dr Bos: I did not say that.

Professor Widdershoven: No, you did not say that, but I would like to comment a little. First of all, euthanasia is widely accepted because it has to do with an attitude of care towards people who are in great distress and trouble. I would say that is therefore an important issue. It does not have so much to do with patients wanting to decide for themselves; it has to do with terrible situations, terrible problems, and people want to be cared for. At least, that is my view, and that makes euthanasia acceptable for a lot of people. Not for everyone, but for many. Secondly, on these discussions which have come up, one positive aspect is that in our society we do have room for these discussions. People may utter their views, may think about it, may claim things, but whether it will be an extra to the euthanasia situation, personally, from my sociological and historical training—and I have a PhD student doing this research—I think it is very improbable that it will happen; although some people want an extension, in general, to people wanting to have their lives ended. There would have to be much more debate in Dutch society, because I think that we are not ready for that yet. All the commotion round the Brongersma case shows that. He was, let us say, not an average person and he had some troubles—but, again, there was a lot of commotion there. My own point of view would be that that will not be the next logical step. As to the debate, that is fine with me. However, so long as I have an influence on that debate I would act against

it, as would a lot of my colleagues. It is not the logical next step, although in some sense that is how it is presented. It may be the next logical attempt from certain areas, but I would not agree that it is the logical next step—which was not said by my neighbour, but it could have been inferred.

Dr Mensingh van Charante: You have a debate and you have doctors seeing patients. There can be a difference. If you ask about the situation—I fully agree that the debate is taking place, as Professor Widdershoven has said, and will continue. Doctors are asked in their surgery by individuals, and individuals ask for more than is possible at the current stage of the debate.

Dr Van Coevorden: In one of Holland’s better newspapers yesterday evening there was a report from the NVVE, the Dutch Voluntary Euthanasia Society, and 100,000 members explicitly said that they would like to have their autonomy, even when they are old, without ailments and so on, but just suffering from being alive in old age. As Nico mentioned, as doctors and as GPs we have patients. If we have patients who are ill, one way or another, euthanasia comes into the picture. But this is a completely different situation. As a doctor, as a physician, I have a tendency to say that this is more a problem for our society. How is our society going to deal with people in old age who wish to have their life ended? I do not know. I do not have a clear answer. I am a doctor. I am supposed to make people better. If I see that I fail and the suffering is very bad, although I have a Jewish background I still, as a doctor, will say that ultimately I will perform euthanasia, because I see that euthanasia can be a last step in good palliative care. However, as a doctor, I feel that this is something I have nothing to do with—although I agree that our society gives doctors the key to the medication cupboard. This should be regulated by our society. Dutch society has to say something about it.

Q1325 Lord Patel: Critics would say that this is exactly the problem of having a law related to assisted dying or euthanasia. That is the slippery slope. Do you agree?

Dr Van Coevorden: I do not agree with the slippery slope theory, because our law is very clear. It is only focused on sick people. If we look at the figures I have presented and if we look at who are the people who get euthanasia in Holland, 80 per cent of the patients have euthanasia with their GPs and these are cancer patients. Why do they want to have euthanasia? Because they have symptoms or a combination of symptoms that present for them—not for us as doctors—a situation of unbearable suffering which is also unacceptable for them. Eighty-four per cent of them have pain; 70 per cent have extreme fatigue; 50

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per cent have gastrointestinal complaints and loss of weight; 70 per cent have coughing, dyspnoea or suffocation; almost 70 per cent feel extremely weak. Each of these symptoms or combination of symptoms may lead to a situation that, for these patients, is unbearable suffering and unacceptable, and that is basically the reason why they ask their GP to have their life ended. We are talking about sick people. We do what we can but, again, under certain circumstances people say “enough is enough”.

Dr Mensingh van Charante: We have extensive discussions about what is terminal sedation and what is euthanasia. We have them because we do not want the slippery slope. As doctors, if you are treating some organ failure which you can no longer treat with the specific medicine, then you sometimes have to do terminal sedation. But you must know what you are doing: are you treating the patient or are you giving euthanasia? We have had very strong discussions about that because, as doctors, we see that it can be a problem. For years, we have heard the term “slippery slope” coming from the UK, and we are thinking about it. We are very principled in that and, for the doctors, it is “This is euthanasia. This is symptom treatment”. If you cannot treat a symptom with a symptom-killer, you can do a terminal sedation; but you must know then that it is not “Give some more morphine”, so that the patient dies earlier. There is a very principled and deep discussion about this, and we try to get all of our doctors who are doing euthanasia involved with this discussion. It is very important.

Q1326 Baroness Thomas of Walliswood: We have had this discussion in various forms, as you will understand, from doctors who have come before us. A great deal of hesitation, even objection, vis-à-vis the suggested Bill has come from some of those doctors. Do you think that, because you have a law which defines what a doctor may and may not do, that discussion becomes easier in some ways, because it is easier for each doctor to know what he or she is doing, why, and under what circumstances they are doing it?

Dr Van Coevorden: Absolutely.

Q1327 Baroness Thomas of Walliswood: So it leads to clarification ultimately?

Dr Bos: Of course.

Q1328 Baroness Thomas of Walliswood: Not to loss of clarification?

Dr Van Coevorden: Absolutely not.

Professor Widdershoven: In two ways: first, because the law makes the distinctions clearer, in line with what has been said—palliative sedation or terminal sedation, euthanasia, and other types of end-of-life. I

think that is important. Second, because within our review committee, for instance, we see cases and we also try to make clearer distinctions there. So things become clearer because things are visible, discussed, and also presented in public.

Q1329 Baroness Thomas of Walliswood: So there is an internal monitoring, self-disciplinary guidance system?

Dr Van Coevorden: And a self-educating system—absolutely. It makes it so clear. If you know the rules, you know how to play the game.

Dr Mensingh van Charante: What in my introduction I called my “criminal period”—in that period there was no law.

Q1330 Chairman: No statute law?

Dr Mensingh van Charante: We did euthanasia and then I would say to the police, “I did a euthanasia”. You were then one day out of your practice and there was an inquiry. Now, you know what you can do. It is good that you have to make a report on it and that other people look at it. For the doctor, that is nice. With that, you protect a doctor. It is a good feeling that there is a law for the doctor who is involved in euthanasia.

Professor Widdershoven: Perhaps I may give a quick example of what is being developed further. The whole SCEN project has been one of the developments from this legalisation. Within our review committee, for instance, we have to see what the period is between the doctor’s consultation and the actual euthanasia. We sometimes see that it is quite long and we then ask the doctor what has happened in between. There is a developing view of what is a normal period. This is not itself a law, but it helps people to become educated about what is good and to talk about it. The whole thing gives the opportunity to refine certain things, within the broad standards of the law—which of course are clear.

Q1331 Chairman: Did I understand you to say that the review committee’s proceedings are public?

Professor Widdershoven: No, the review committee proceedings are referred back to the physician, and that can have a learning effect.

Q1332 Chairman: But the actual proceedings are not public?

Professor Widdershoven: No, not for the cases; but there is an annual report in which we do discuss cases.

Q1333 Chairman: Without disclosing names?

Professor Widdershoven: Yes, anonymously. That also has the advantage of showing what is being looked at, what things should be considered, et cetera.

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Q1334 Lord Carlile of Berriew: We have been given some statistics which, without tying it down to figures, seem to indicate that a significant proportion of euthanasias are not being reported by the doctor carrying out the euthanasia. Given that there is a legal and ethical duty to report, what does that large-scale failure to report tell us about the state of the law here and of doctors' understanding of their ethical position?

Dr Van Coevorden: It is a difficult question to answer, but one thing is clear. We know that more than 90 per cent of the doctors who report their euthanasia are exactly within the scope of the law. It is very clear that they have followed the procedure correctly. These doctors are therefore absolutely free from any fear of being prosecuted.

Dr Mensingh van Charente: That is not the question.

Dr Van Coevorden: I know. We are talking about the other side—the doctors who do not report this. We have some figures from van der Wal and Maas—

Q1335 Lord Carlile of Berriew: Fifty-four per cent report, 46 per cent do not.

Dr Bos: I think that the problem is in the questionnaire and in the way the questions were asked. If you look at that carefully, the 46 per cent were often cases where the doctors were not even aware themselves that they were doing euthanasia.

Q1336 Lord Carlile of Berriew: Let us say 10 per cent, and cut the figures right down.

Dr Bos: What I want to stress is those people who did a form of terminal sedation, or other medical treatment, as a result of which the patient died. The question asked was, "Had you, in prescribing that medication, any second thoughts about the effect? Did you think perhaps the patient might die?". If the doctor said yes, they were added to the list of non-reported euthanasias. If you sort that out—and there are figures on that—more than 85 per cent of the euthanasias are reported in Holland. That 46 per cent is not a very clear figure.

Q1337 Lord Carlile of Berriew: Accepting your figure, 15 per cent is a lot of unreported euthanasias. Why?

Dr Mensingh van Charente: One point—not all of it, but one of them—is that some doctors say, "I have a patient. It is my patient. No one has to know. I took a medical oath". They say that, in the intimacy of dying, no one has anything to do with it. There are some doctors who go that far. In my opinion, that is good for anything but euthanasia, because with euthanasia we have a law. That is one of the points. The other point is that there is some administration to carry out. I say "some", but it is a lot of administration. For some doctors, that is too much.

Another point is that some doctors say that the procedure after euthanasia is not that much greater than it was before the law was created, and that families of the patient therefore have problems with that. A fourth point may be that doctors are normal people and do things they should not do, just like normal people do. It is a combination of all those things.

Professor Widdershoven: In my experience, these are valid explanations. They are not excuses, of course.

Dr Mensingh van Charente: No.

Professor Widdershoven: I think that we should be stricter on that. I talk now as an ethicist. There should be reports made and I think that we should try to encourage it, for instance by giving the right figures, so that doctors do not think, "Oh, I am one of the 50 per cent not reporting". No, they know that they are one of only 10 per cent. These are things which could be developed. Further, the real question is whether among these 10 or 15 per cent there are very bad cases. I do not know whether that would be the case. I suggest not. But, given that in the reported cases the majority are perfectly in line with the law and few give cause for very much doubt, I would think that in the non-reported cases there may be a slightly larger percentage but it is unlikely that all the non-reported would be problematic cases. However, the first point is that we do have to make it clear that this is not the right way to proceed in our society.

Dr Bos: I agree with that. I think that those 15 per cent may be doctors who are afraid to report, because they fear prosecution or whatever. It was said—and I know that it was meant as a figure of speech, "If you know the rules, you play the game"—but it is not a game at all. Sometimes the rules may prevent you from helping your patient; going by the rules might sometimes mean letting the patient down. That could also be the case in some of those 15 per cent. So I fully agree that they are not 15 per cent "bad boys"—the percentage who do not want to abide by the law. I do not think that at all.

Dr Mensingh van Charente: I have been to a lot of countries to talk about our law and the practice of the law, and I always hear this question. In all of these countries, after the conference, I hear a lot of doctors who are doing euthanasia. You can focus on those who are not reporting, but the very good thing about having this law on euthanasia in The Netherlands is that the good, willing doctors who are doing euthanasia have the protection of the law. So focus on what you have. For every law you have people who do not respond to it. I understand the question, but the point is: make a law and, for every law you make, there will be people who will not listen to that law.

Q1338 Lord Patel: May I pursue this further, because it is a crucial point? As Lord Carlile has said, we have been given figures which, on the face of it,

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sound pretty bad—only 54 per cent reporting. Yet the law is quite strict. There is a penalty and there are sanctions if, as a professional, you do not follow the law. So why are these people not following the law? How do you know that there are 46 per cent not reporting? What does the review committee do? What do the professional organisations do with these people? Do you know who these people are?

Dr Bos: This is not known. It is from the interviews in the report by van der Wal. They say it in confidence; but officially it is not known, and so the law cannot prosecute them.

Dr Van Coevorden: In England you have 100 per cent.

Q1339 Baroness Thomas of Walliswood: In England, 100 per cent of these cases are not reported. You are right.

Dr Van Coevorden: And you are not worried about that. That is strange.

Q1340 Baroness Thomas of Walliswood: I am quite worried, because you probably know of a very famous case on precisely this matter.

Dr Van Coevorden: Yes, you are talking about maybe our 15 per cent, but what about your 100 per cent?

Q1341 Lord Patel: We are muddying the water. Can I continue with my questions? You have a law which expects, demands, that every doctor reports. Yet you still have evidence that says that 46 per cent do not report. We have heard the argument about the definitions used, and I accept that might be an issue. So how do you know, and what does the review committee do about it? While I am at it, my secondary question is would you also tell us what the membership of the review committee is?

Dr Mensingh van Charente: Every five years there is an interview round, and Professor van der Wal interviews a lot of doctors and, in the confidence of this interview, they say, “I did some euthanasia but I did not notify”. The figures come in from the reports, but there is no doctor who is saying “I do euthanasia—

Dr Van Coevorden: “. . .and I didn’t report.”

Dr Mensingh van Charente: “. . .and I didn’t report.” This is the third of a five-yearly study and it is based on interviews. The interviews are confidential interviews. Doctors say, “I did euthanasia and I didn’t report”.

Q1342 Chairman: The structure of the statistic exercise is that the professor is in charge of it, he conducts it in the way that you have said, and that happens every five years or so?

Dr Mensingh van Charente: Yes.

Q1343 Chairman: I assume from what you have said that you have confidence in the independence and research quality of these reports; but even researchers are fallible, and they may have questions that are slightly, or more than slightly, ambiguous. One of the points that I think you made was that at least one of the questions appears to be ambiguous and might admit of the construction that something that is not euthanasia in law, and therefore would not be reportable, is returned as a result of the questionnaire as if it were euthanasia and should be reportable?

Dr Bos: That is right. However, given that problem, the figures over the past 10 years are very interesting. If you accept that, there is consistency in the way he uses the questions and the figures and you can look at the negative side: that only 54 per cent are reported. When they started in 1990, there were 18 per cent reported, and then 44 per cent, and now 54 per cent. So there is a growing tendency to report.

Q1344 Chairman: You are not questioning the authority or independence of the research organisation?

Dr Bos: Not at all.

Chairman: I understood that. I just wanted to be clear that that was so.

Q1345 Lord Patel: So, to finish off, the membership of the review committee?

Professor Widdershoven: As to the role of the review committee in this process, we only review cases which have been reported of course. However, we do try to make clear distinctions. In that respect, I hope that this discussion will result in more clarity about the number of reports, and so more stimulus for doctors to report. What exactly was your question about the committee?

Q1346 Lord Patel: What is the constitution of the review committee?

Professor Widdershoven: There is a lawyer who is the chairman of the committee—a legal expert. Then there is a medical doctor and there is an ethical specialist, or a representative from the ethical domain. So there are three persons on the committee.

Lord Joffe: Could you take us through the process from when the patient actually makes a serious request for help to have euthanasia, covering the time spent with the patient, right through to the SCEN doctor and how the independence of the SCEN doctor is achieved? Perhaps also touching on the stress, or absence of stress, on doctors in going through this process, and finally administering active euthanasia?

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Q1347 Chairman: Who wants to undertake that?

Dr Van Coevorden: We have three doctors here who can speak from their own experience. I might as well start. During the illness of a patient, we basically have two situations: either the patient themselves bring up the subject of euthanasia or life-ending or, if the patient does not bring this subject up—and we can see that this is going to be a terminally ill patient—we sometimes enquire how they see their life's end. We do not suggest, "What do you think about euthanasia?", because this might suggest, "You have to think about euthanasia because I would like to perform euthanasia"—not at all. We just want to have their ideas about their life end. If the subject of euthanasia comes up, we have a beautiful opportunity to discuss this subject. Otherwise, the patient themselves will bring up the subject of euthanasia. We will first have long discussions about what are their ideas on euthanasia; why they have brought up this subject; what they think is unbearable suffering for them; whether or not they think that this situation has already arrived. This all takes time. This is a process over time, while the patient is in a situation where he is or is becoming terminally ill. Then, when the suffering is very clear and seemingly unbearable for the patient, the GPs nowadays still have the possibility of consulting with palliative care consultants, to make sure that all measures are taken to reduce the suffering to a minimum. Then a patient may be very persistent in asking for their life to be ended. In this process, at some point where the doctor is convinced that this is the only way to help his patient properly, he will contact a SCEN doctor. A SCEN doctor cannot be contacted directly. You have to call a certain number and you get someone who is on duty. The doctor who is on duty, the second-opinion doctor, hears who is the family doctor or the doctor requesting a second opinion. If he feels that he is too close to that doctor and he cannot be really independent, he can say, "I will reject this consultation and give it to one of my colleagues who is also on duty". So we make sure that there is an independent doctor to perform the second opinion. The second-opinion doctor goes and speaks with the family doctor, hears the story, gets copies of the reports, and he can look at the medical file—to overview the process, and where he can see how this doctor and this patient came to the conclusion that euthanasia is an option. Then he visits the patient. He wants to see, face to face, what the patient is like. He wants to hear from the patient what is making him request an active life-ending. Then he double-checks that, in his opinion, all palliative possibilities have been taken into consideration and have been taken as far as realistically possible. Then, if there is unbearable suffering, he has to be convinced that the patient is doing this out of his own free will and that

the patient is competent. If the second-opinion doctor has any doubt, he can request another consultant, for instance a psychiatrist, to consider whether or not the patient is really competent, to make sure that he is not depressed. It really helps if there is some form of a written will. It is not absolutely necessary, but it certainly helps. The Voluntary Euthanasia Society in Holland has several forms already typed out and some only need a signature, but I know that the review committees are very much in favour of self-written statements. It is not absolutely compulsory, but it helps. The second-opinion doctor then has to conclude that, if this GP wants to perform euthanasia, he has complied with the law. He makes a report, discusses this with the GP, and the GP talks to his patient and they will discuss it again. He again makes sure that this is exactly what the patient wants, and then he sets a date for the euthanasia. Until the date of the euthanasia that is planned—some catastrophe may of course happen in between—the doctor makes sure that he does everything to make the suffering as little as possible. Sometimes the euthanasia is not even performed because he has to perform, for instance, terminal sedation—because suddenly someone has a bronchial bleed, and so on. As a doctor, you have to do something. You cannot say, "I cannot do anything now because we have planned euthanasia for three days hence". He still has to take care of the patient. Then euthanasia is performed. The coroner is called in. Sometimes he is called in beforehand, the doctor reporting that, "I am going to perform a euthanasia. The euthanasia will be at eight o'clock in the evening and will be in such-and-such an area". He will not state the name of the patient and he will not say where it is exactly; but this is to make sure that the coroner is in the vicinity, to carry out a quick procedure—not that the coroner stays away for another two or three hours, making it more stressful for the family and for the doctor himself. After performing euthanasia, the coroner is called. The coroner comes and convinces himself that the patient is dead. We must have a dead body, of course. The doctor who performed the euthanasia shows him the medication that he has used. This is also one of the explicit things which is written in the law. You have to perform euthanasia with the proper means. You cannot finish off someone—putting it very bluntly—with a high dose of insulin or a high dose of morphine, because this may present extra suffering. You have to give a barbiturate in a high dose, to make sure that the patient goes into a deep coma very quickly and, if necessary, you can finish the patient with some muscle relaxant; but usually a lot of patients are already dead from the overdose of the barbiturate. The coroner sees the medication, then he gets the written report from the GP who performed

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the euthanasia. He gets the report from the second-opinion doctor, and he brings this, like a delivery boy, to the review committee. That committee very quickly sends a letter to the doctor saying, "We have received all the papers and we will let you know as soon as possible". Usually within six weeks there is a verdict or a result from the review committee. The doctor is usually acquitted or, if they have questions, they ask the doctor to give a written answer to their questions, or sometimes they will ask a doctor to appear in front of the review committee and to explain, if there is something which is not quite clear. That is it. If the review committee finally decides that there is something which is not quite correct, then it is presented to the district attorney, who brings it to court.

Professor Widdershoven: May bring it to court.

Dr Van Coevorden: Yes, may bring it to court.

Q1348 Lord Joffe: You have answered most of my question, but you did not touch on the stress on the doctor. Also, while I am about it, do you consult with the family?

Dr Van Coevorden: Yes, there is consultation with the family. Basically, this is a matter between the doctor and the patient, but the doctor will also ask the nurses who are also present in the care, and they will talk to the family as well.

Q1349 Chairman: Is that required or is that medical practice?

Dr Van Coevorden: It is common practice, and it is good practice.

Dr Bos: But it is not required.

Dr Van Coevorden: It is not required.

Professor Widdershoven: Unless the patient refuses, of course. Then it is not possible, but that is very seldom.

Dr Van Coevorden: In a careful process, the doctor will try to get what we in Holland think is very important—consensus. The Dutch are known for their consensus policy. We will also confer with the family. Sometimes the doctor will also present his case to another colleague—"Look, I have a problem. This patient has asked for euthanasia. I am not really sure what to do in this situation", and so on. Talking about stress, sometimes the family puts the doctor under stress. I have personally been in this situation several years ago. There was extreme pressure on me, and I was very happy that there was a SCEN doctor to whom I could turn to discuss it because I felt extremely uncomfortable with the situation. There is another quality of the SCEN doctor—not only checking if things are going exactly according to the law, but also being of personal assistance to a doctor who may have problems during this process. That guided me in this specific situation through a very

difficult time. When doctors experience stress from outside, therefore—and this can be the family or other pressure from outside—this is something that doctors have to be aware of. If they are aware of it, they have to find ways to deal with it. It happens, but I also know that in most cases the doctor will not submit to this extra pressure, and they will focus on the patient. It is basically something which is between the patient and the doctor. It is making sure that doctors focus on their relations with their patient, and the whole procedure is very clear.

Q1350 Baroness Finlay of Llandaff: I want to ask you this. The first time that you performed euthanasia, how did you feel about it as a clinician?

Dr Van Coevorden: Awful.

Q1351 Baroness Finlay of Llandaff: And now? You were saying that it is about 1.5 per annum on average. Is that right, Nico?

Dr Mensingh van Charente: It never changes. You do not feel awful; you feel that you are doing something for the patient that the patient wants you to do. You want to do it, but it is never something that you could do every week. It is a process. Euthanasia is not a moment; for the doctor, euthanasia is a process. You are moving towards the date of the euthanasia. There can be a difference. Years ago, I did a euthanasia after a very long process on a young mother who was 25 years old. With an old man of 85 who is at the end of his years and very sick, of course there is a difference; but it is not a normal medical treatment. You are never used to it. On the other hand, it is the last thing you can do for a patient—what a patient wants and is looking for. That is the answer, therefore.

Dr Bos: I agree. It never changes. It is not easier now than it was before. It is always the end of a longstanding relationship. In my case, as a surgical oncologist in a hospital, the last case this year was a 37 year-old woman with two children. We talked about it for two years. In the beginning, she was not that ill, but it ended in euthanasia. The basic feeling is that it is a very emotional moment. You have a relationship with the patient. Otherwise, without that relationship, I do not think you can do euthanasia. But I never felt guilty.

Q1352 Baroness Finlay of Llandaff: I wonder whether I am correct in thinking that, because you use the term "euthanasia" only for voluntary euthanasia, you have avoided the muddle that we have seen in the UK, where there are other end-of-life decisions, such as withdrawing or withholding treatment or trying to treat and having adverse effects. You have not attached the word "euthanasia" to any of that at all.

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Dr Van Coevorden: Exactly.

Q1353 Baroness Finlay of Llandaff: Finally, two things for clarification. When you were talking about the 50 doctors who have graduated, is that from the course that Bernadine is running?

Dr Van Coevorden: Yes. These are the 50 new consultants. There were consultants existing already, mostly internists, oncologists and so on.

Q1354 Baroness Finlay of Llandaff: I wondered whether the society that Dr Bos was talking about is campaigning for the “pill”, as you called it.

Dr Mensingh van Charente: End-of-life pill.

Q1355 Baroness Finlay of Llandaff: Yes, not the contraceptive pill! Because you feel that, for those patients who would like euthanasia but who are turned down by the doctor—and you were very helpfully explaining the process of turning people down—the control is resting with the doctor at the moment. It is the doctor who decides whether you are suffering enough or the level—

Dr Van Coevorden: No, that is one step too far. It is different. The last-will pill or end-of-life pill—you have basically healthy people who, at the end of their life, say “Enough is enough”. This is not a medical problem. This is a problem for our society. “What are we going to do with these people?”. At this moment, we hold the key to the locker for medication. For this, perhaps our society will say that the government should open a small clinic, and it is, “You can get your pill here”. You show your papers, and so on. On the other hand, we have medical situations. There the doctor has his task in making sure that the patient does not suffer. If the patient says, “This suffering is unbearable and I want my doctor to do something. I want my doctor to perform euthanasia”, then we have a law to make it possible for doctors to do this. Doctors can still say, “I am not going to”. They are not going to decide what is unbearable suffering.

Dr Bos: The question was: is the NVVE campaigning for the end-of-life pill? The NVVE itself, no; but the members of the NVVE would like that very much. Of course we have to deal with that problem. I agree with Ruben that it is a problem for society and not just a problem for the doctor and patient. Doctors are also part of society, however, and so we will all have to participate in that debate. The suggestion was made earlier that I would like to have that end-of-life pill tomorrow. No, but I have realised that it is unrealistic not to discuss it. Of course there will be discussions, and the NVVE will probably do something about that as well—but it is not actively campaigning for it at the moment. They are certainly not denying the possibility.

Q1356 Chairman: I think you indicated that you are involved with the NVVE?

Dr Bos: I did. I am the chairman of the Medical Committee.

Q1357 Chairman: Are you connected with the NVVE?

Dr Mensingh van Charente: I have nothing to do formally with the NVVE, no.

Dr Van Coevorden: I am not connected. I used to be on the Medical Board of the NVVE as a consultant, but I am not any longer.

Q1358 Chairman: So you are not a member any more?

Dr Van Coevorden: I was never a member. I was one of the doctors who would give advice to the society.

Dr Bos: You do not have to be a member to be on the Medical Board.

Q1359 Chairman: No, I understand—because it is advisory?

Dr Bos: Yes.

Professor Widdershoven: You are a member as a lay person. Even if you were a doctor and a member, you would be a member as a person and not as a doctor. I am not a member and I am not associated at all with this society.

Q1360 Baroness Finlay of Llandaff: And not a doctor?

Professor Widdershoven: And not a doctor either! Well, I am a doctor.

Lord Taverne: I realise that time has now run out, but there is one point on which perhaps we might get some written evidence. We have practitioners here who have experience and I do not think that we are going to meet any others. One of the questions which we have not touched on is how far discussions with families, and indeed discussions on the end of life, have been affected by the introduction of the law. Has it become easier? Has it become more difficult? Has there been a change? That is something which has quite often been raised in evidence before us in Britain, and it would be very interesting to get a comment from these practitioners with experience about how they have found that the law relates to the discussion with relatives and with the end of life.

Bishop of St Albans: And the families.

Lord Taverne: The families and the patients themselves. Perhaps we could have that in writing?

Q1361 Chairman: Our time is up. That is the problem we have.

Professor Widdershoven: May I make one remark on this? I was on the committee which was installed before the law was in place—which was possibly

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complicated legally, but we started these committees before—and I have seen no difference over the past four years. There were two years before and four years after the law. I feel that the reports are not different, but of course these are the reports—in which the family is often mentioned and very important. However, it is only the report. My colleagues could tell you more about their experience.

Chairman: Sadly, as with everything, the time has gone from us. Lord Taverne is particularly interested in the medical practitioners. He has had the opinion of the ethicist. If you could come together and put a short note to us on that, it would be useful. The time has passed rather quickly, which is an indication of the extent to which we have been helped by your being here. Thank you very much indeed for all your help.

 THURSDAY 16 DECEMBER 2004

Present

Arran, E
 Carlile of Berriew, L
 Finlay of Llandaff, B
 Joffe, L
 Mackay of Clashfern, L
 (Chairman)

Patel, L
 St Albans, Bishop of
 Taverne, L
 Thomas of Walliswood, B

 Examination of Witnesses

Witnesses: DRS CILIE ALBERDA, and Ms IRENE KEIZER, Senior Policy Officer, Ministry of Health, Welfare and Sport, examined.

Q1362 Chairman: I believe that we are going to have a presentation first of all, as indicated on the screen.

Drs Alberda: Yes. Welcome to the Department of Health in Holland. I will first give a short presentation on palliative care in The Netherlands. We call it "Care for the dying in The Netherlands". First, I will give you the numbers of dying people in The Netherlands; then I shall tell you something about government policy, the history, the stimulation programmes, the underlying principles for government policy, and funding for palliative care. I will then deal with recent developments and, lastly, the initiatives of the Dutch Government. First, some numbers. About 16 million people live in Holland. The number of people who died in 2000 was 140,000. Approximately 55,000 of them died as a result of a non-acute disease. Nearly 40,000 Dutch people died as a result of cancer, which makes it the most common non-acute cause of death. Other common and non-acute causes are chronic heart failure, chronic obstructive pulmonary disease (COPD), and stroke. In 1979, 95 per cent of people died at home; 31 per cent died in hospital; eight per cent died in a nursing home, and two per cent died in a care home. We expect that this will change in the coming years, but we do not know exactly in which direction it will change. We think that there will be still more dying at home. We have different kinds of providers for palliative care. First, the voluntarily run hospices, of which we have 31, amounting to 100 beds. There are professionally staffed hospices, which we call "high-care hospices" with 24-hour nursing—of which there are 26, amounting to 174 beds. There are four children's hospices, with 44 beds. There are nursing homes with a special unit for terminal care, which are 53 in number with 212 beds. There are 35 care homes with 78 beds and three hospitals with 19 beds. In total, there are 152 providers and 627 beds. We think that will increase to 800 beds in the coming years. The history of government policy started in 1996. We had a first position paper, which I think you call a White Paper, from the government. In that paper we encouraged research and innovative projects from the Health, Research and Development Council. In

1998, a programme of stimulation started: first, an encouragement programme of research; second, the promotion and the guidance of palliative care by six university centres; lastly, the stimulation by a special project group of the integration of hospice facilities in regular healthcare. The underlying principles of the policy are: integration in a regular healthcare system; improving the access to and availability of palliative care. The approach is generalist, in a regular context. That means that all GPs and nurses must have been trained to give palliative care. Third, there is the advice, information, support and co-ordination by consultation teams who work all over the country. The financing is through regular budgets, through the normal budget system. Further improvements of palliative care are continuing over time. Next, government policy. Advice is provided by the Hospice Care Integration Project Group and the independent evaluation committee, and has been given in 2001 and 2002. What measures we did take after the advice? First, an encouragement of networks nationwide. Secondly, the systematic support of regional networks. We have a palliative care department in the nine Comprehensive Cancer Centres that we have. There has been a nationwide range since 1 January this year. The funding is through current guidelines for the Comprehensive Cancer Centres. There has been a national support point since 2002. We have invested extra millions in network co-ordinators; nine palliative care departments; nine regional specialist consultation teams all over the country; and the Agora Trust for information. We have increased the financial resources for the National Association of Terminal Care Volunteers Trust. We have increased financial resources for palliative care in nursing homes and care homes, and we monitor all the measures we have taken. Turning to the recent developments, from the beginning of this year our measures have been put in place. There is now a problem in terms of good planning for the provision of palliative care. Some regions have sufficient beds; other regions have insufficient. We must therefore decide how to plan for the whole country. Then there are changes within the

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Exceptional Medical Expenses Act and changes within the health insurance in The Netherlands at the present time—great changes. What are the initiatives of the Dutch Government? We are busy embedding the results of the stimulation programmes. There is a close relationship between palliative care and euthanasia policy. We are training all professionals, and harmonising in-service and refresher courses for doctors, nurses and care workers. We make working visits around the country to see how it is taking place, and there are regular meetings with the involved associations here at the Department. Finally, we monitor palliative care.

Q1363 Chairman: Thank you very much indeed.

Ms Keizer: Are there any questions?

Q1364 Chairman: I am sure that there will be.

Drs Alberda: You can read all this on the paper you have, and we have given you a brochure on palliative care in The Netherlands.

Chairman: Thank you very much.

Q1365 Baroness Finlay of Llandaff: May I ask for some clarification? On the dates, which was the important initiative from your Queen? I understood that your Queen had become quite involved in wanting the palliative care initiative. Was that 2001?

Drs Alberda: I think it was in the period when her husband died, but we had already started stimulating the programme.

Q1366 Baroness Finlay of Llandaff: Yes, but I could not remember which year that was.

Drs Alberda: About two years ago.

Q1367 Baroness Finlay of Llandaff: Could I ask you to describe why you decided not to have palliative care also as a specialty? I completely understand why you have had this fantastic push to educate GPs and nurses, but why did you decide that you would not recognise a separate sub-specialty of palliative medicine and palliative nursing?

Drs Alberda: Because, as you saw in the figures, most people die at home. We thought it important that that would also be possible in the future. That is why we have a generalist view.

Q1368 Baroness Finlay of Llandaff: First?

Drs Alberda: Still now.

Q1369 Baroness Finlay of Llandaff: So you plan in the future that you may have a separate specialist approach, as the service develops?

Drs Alberda: No. Separate specialists are in a regional consultant team, and the GPs and the nurses who are at home with the terminal patients can provide the knowledge from them.

Q1370 Baroness Finlay of Llandaff: How have you managed to have so many doctors and nurses comply with attending education, particularly those who are older? Has it been compulsory?

Drs Alberda: It is not compulsory, but all doctors meet dying patients and so they themselves want it.

Q1371 Baroness Thomas of Walliswood: I would like to understand what is meant by “changes within health insurance”. Has this to do with the distribution of costs? What has it to do with?

Drs Alberda: Our insurance financing is changing at this time. In our curative care we have two methods of financing: a particular financing system and a sick fund financing system. In about one year’s time, that will become one system.

Q1372 Bishop of St Albans: As the vast majority of people in The Netherlands die at home, as the vast majority of palliative care is apparently provided at home, and because pain relief is such a highly technically skilled activity, what proportion of your general practitioners would say are of a standard where you would say, “Yes, the pain relief being delivered is of the highest and best that it can be”?

Drs Alberda: That is difficult to say. But when high, technical medication is needed, there are other possibilities. Then you can go to a high-care hospice, to a hospital, or to a special unit in a nursing home with specialists.

Q1373 Lord Patel: Can I clarify that? You did put a lot of emphasis on developing networks. I presume these networks are between community care and specialist care, so that they work together—with pain relief advice, et cetera.

Drs Alberda: Yes.

Q1374 Lord Patel: Would it be true to say that much of your organisation of medical care is strongly community-based?

Drs Alberda: Yes.

Q1375 Earl of Arran: When the final dose or injection is given to the patient, is it the general practitioner, the doctor, who gives it or is it the nurse, or both, or can it be either?

Ms Keizer: Euthanasia can only be performed by a doctor.

Q1376 Earl of Arran: With a nurse present at times?

Ms Keizer: Yes, she can be present but she is not allowed to perform the euthanasia. She is not allowed to give the drugs, the medicine, to the patient. This has been a discussion in the last few weeks.

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Q1377 Earl of Arran: Is it possible that the nurse in the future might be allowed to do it as well as the doctor?

Ms Keizer: I do not know what will happen in the future, but we are not thinking about it. We are very strict about it. We think that the doctor should perform the euthanasia, because the doctor is the one who is responsible, who has to report the case, and who will be held responsible. So the doctor has to administer the drugs and has to stay with the patient during the process of dying. But this is another question. You can ask the review committees about these things later on.

Chairman: And your presentation is to come, so we will try to stick to the presentation we have just heard.

Q1378 Lord Taverne: I was wondering whether you would like to elaborate a little more on the question of the relationship between palliative care and euthanasia policy. It seems clear that you regard these as very closely interwoven and proceeding together, but if it is something where there was an initiative by the Dutch Government, what was new about this initiative? What new suggestions were being made or programmes being developed?

Drs Alberda: There is a close connection between both things. In 1996 our parliament asked the minister how to cope with palliative care in relation to euthanasia. The minister decided that she did not have a good answer to it, and so then the stimulation programme for palliative care was started.

Q1379 Chairman: Am I right in understanding that the euthanasia had been developed before there was legislation for it, and that the palliative care programmes have been developed to the sort of level that you have described in about the years 1996 to 2000?

Drs Alberda: Yes.

Q1380 Chairman: When the euthanasia practice started, there was much less palliative care available.

Drs Alberda: Yes.

Q1381 Baroness Thomas of Walliswood: You described the unevenness of the distribution of palliative care at the present moment. Is there any connection between that and any other social factors, such as poor housing or social class or racial origin? In our country we are concerned that there is a differential sometimes in the care which is offered to different groups of people. Do you have a similar problem to that in The Netherlands?

Drs Alberda: A big part of palliative care is volunteer-driven. In some regions, the neighbours help each other. There are then fewer beds needed for palliative

care because neighbours and family give a lot of palliative care. That is the reason, and not any other.

Q1382 Baroness Thomas of Walliswood: Not another social reason?

Drs Alberda: No.

Q1383 Chairman: How is healthcare financed in The Netherlands?

Dr Alberda: We are all insured—also for care for the dying.

Ms Keizer: There is no reason to be uninsured because of lack of money, because those people who have an income beneath a certain amount will get an insurance by the State.

Q1384 Chairman: So the insurance for those below a certain level of income is paid for by the State.

Ms Keizer: Below a certain level, yes.

Q1385 Chairman: But the insurance is run by insurance companies, is that right?

Ms Keizer: Yes.

Q1386 Chairman: So it is the insurance companies that actually finance the provision of healthcare generally?

Ms Keizer: Yes, but we also decide what things are those that are paid for.

Q1387 Chairman: The State decides what they require the insurance companies to pay for?

Ms Keizer: Yes.

Q1388 Chairman: I understood, for example, that a surgeon who provides cancer care would expect to get his income by payments from the insurance companies. Is that right?

Drs Alberda: Yes.

Q1389 Chairman: So far as the palliative care is concerned, you said that the family doctor, the general practitioner, would usually be expected to provide that. He would be paid for in that respect also by the insurance companies?

Drs Alberda: Yes.

Q1390 Lord Patel: Is the insurance company a government agency?

Ms Keizer: No.

Drs Alberda: They are private organisations.

Q1391 Lord Carlile of Berriew: Are euthanasia procedures paid for by the insurance companies, and what fees do doctors earn for carrying out these procedures?

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Ms Keizer: There is a certain fee for a consultation, but you will learn more about that I think from the review committees. There is a fee for the GP.

Drs Alberda: A GP has a fee for it, but a normal fee.

Ms Keizer: So the doctor who performs the euthanasia gets a fee for giving the treatment.

Q1392 Lord Carlile of Berriew: Does that fee take into account the high level of responsibility involved in the decision? The procedure is simple but the decision is complex.

Ms Keizer: No, the procedure is not simple and the decision is very complex. For instance, the consultation by the consultant, who is an independent doctor, is something on which they can spend a few more hours than on other decisions. So it is taken into account that the decision is very difficult, and there is the possibility that they have to go back and think about it. When the doctor wants to talk about it more than once, this is also paid.

Q1393 Baroness Finlay of Llandaff: Is that a fixed fee or does the fee go up the more times the doctor talks about it?

Ms Keizer: The more times.

Q1394 Baroness Finlay of Llandaff: The more times he goes back to the patient, the more he is paid?

Drs Alberda: Yes.

Ms Keizer: To pay for his time.

Q1395 Chairman: We probably ought to move on to your presentation now, Ms Keizer, and there may be time for questions at the end which might possibly overlap on the two different presentations. So would you like to start now, please?

Ms Keizer: I will give a short presentation about the policy but, because there will be presentations by the review committees, I will not go into the law very specifically. Otherwise, you will have two presentations which are the same. I will say something about the way the government is handling this subject. I will first tell you something about The Netherlands. Maybe you already know, but just to be sure.

Q1396 Chairman: You just assume that we do not!

Ms Keizer: I want to give some thoughts about why The Netherlands is so special in this. I think that it is quite important to see the whole context in which we have this law. As you might have seen in the last few weeks, there has been a lot of attention on euthanasia policy in foreign countries. Not all those who write about it go to the trouble of coming here to ask us about it. Sometimes people do not know the context in which the law is embedded. Next, I will say something about policy and the goals of our policy. I have read in the background note that your Clerk has

written that you are interested in our experiences with the law. So I will say something about that too. First, about The Netherlands: we have general practitioners; almost all the Dutch people are registered with a GP, and they are with the same GP for a long time. So the GP gets to know one person pretty well and is involved from the start with the person when he becomes ill. This is quite important, because we think that the relationship which is based on trust is very important for euthanasia to be performed. A doctor has to know everything about the situation of the patient and has to be able to judge the wishes of the patient, and the reason that the patient is asking for euthanasia. That is why we think that a relationship of trust is very important. The next thing is insurance, which we have already talked about. We think that someone having no money can never be the reason for euthanasia being requested. The doctor should always exclude that. However, we think that the way in which we have arranged the finance will not give people reason to ask for euthanasia from financial motives. The fact that everyone has insurance is very important. The next thing is informed consent in the law. We have a law regarding the agreement contract between the doctor and the patient. I have provided you with some information about this law. I did this because sometimes passive euthanasia is discussed. In this law we have provided that a doctor should always ask permission for treatment. It means that a patient can also refuse treatment. The law on euthanasia is only about active euthanasia: the doctor who ends the life of a patient at his or her explicit request. The first time that euthanasia came up in Holland was in 1973. It was the first time that a doctor was prosecuted because she had carried out euthanasia on a patient. From then, the court decided that euthanasia is possible under very strict conditions. After that, there were more cases and from those cases the jurisprudence has been formulated. That jurisprudence has been the basis of law that we have at present. The goals of our policy are that we want clarity about due care. There were doctors who found themselves in situations where they thought that they had no choice other than to fulfil the wish of the patient and to carry out euthanasia. The court also decided that this was possible, under very strict conditions. However, we wanted to give clarity about due care in those cases. The next goal is transparency. We want to have an open discussion about it. In the discussions, one sees that there is greater clarity about the due-care criteria; that there are situations in which euthanasia is not possible and other situations in which it is. Those boundaries become clearer during the debates. It is also very important that, when a doctor does something like ending the life of a patient, it is such a difficult decision that there should be a review and a committee should look at

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whether or not the decision was right. One of the things we have noticed since the law came into force is that even more people have become interested in palliative care. We see more hospices and more doctors educating themselves in palliative care. Some people wondered whether, where euthanasia was possible, palliative care would no longer be seen as necessary. However, this is certainly not the case in Holland. When you have euthanasia, you also have to have palliative care—because you have to do everything not to arrive at the situation where you want to consider euthanasia. This is why palliative care has gone up even more—because we dare to say that, yes, euthanasia is sometimes possible, but that you also have to do everything not to get into that situation. We also have discussions about the other decisions at the end of life, because of the discussion on euthanasia. People wonder whether the alleviation of pain, with the side-effect of hastening death, is something that should be reported. We are now creating more guidelines about what doctors are allowed to do. What we also see is that there is not a big increase in the total number of cases. The most recent research was carried out in 2001. There were 3,800 cases, and the number of reports is somewhat lower. Of course, this is not ideal. About 55 per cent of the cases were reported. Also, extensive research was carried out amongst Dutch society and public support for a law on euthanasia and for the possibility of euthanasia is very great. It is about 90 per cent in this research. All research has shown that more than 80 per cent think that we should have a law on euthanasia. We also found that surviving relatives are positive about the procedure. They felt that it was a well-considered request and that the consultation was careful. We have asked doctors what they think about the law and whether they think that it is an improvement. They think that the procedure improved after the law came into force. The review committees are working fast and are giving clear judgments. Doctors also expect that there will be more transparency and that the willingness to report will improve. We are now carrying out new research. The number of reports is not as high as we would want. We had expected that the number of reports would increase when the law came into force, but this has not yet happened. The law came into force in 2002. We think that we should give it a chance, because people have to get used to acting according to the law. We none the less want to carry out research, because this is such an important issue. When we do the research we will want to research the total number of reports, because it is possible that the total amount of euthanasia may have decreased. We hear from doctors that they cannot imagine doctors not reporting, because there are always more people involved. Everybody knows that you should report, and no one knows anyone who is not reporting. They

cannot imagine therefore that the percentage of reports has decreased. They think that, because of palliative care, the number of cases of euthanasia may have decreased. It is another reason why we want to do further research on the influence of palliative care. We will also carry out research on all the medical decisions at the end of life, because we think that there are some grey areas where a question might be raised as to whether or not it should be reported.

Chairman: Thank you very much. We have about 10 minutes left for questions.

Q1397 Baroness Finlay of Llandaff: There is an interesting study, which I do not know if you have seen, showing that the patients who had requested euthanasia had higher symptoms than a matched control group who did not request euthanasia—which I think completely supports the data you have given.

Ms Keizer: I did not know that.

Q1398 Baroness Finlay of Llandaff: It is just coming through the system into pre-publication.

Ms Keizer: Where was this performed? In Holland?

Q1399 Baroness Finlay of Llandaff: It is Dutch research, yes. I wondered what you did about monitoring the drugs that are prescribed. We have heard that it is barbiturates, sometimes with a muscle relaxant. Are you monitoring those prescriptions and matching those to the reports that come through?

Ms Keizer: We are going to do that. This is probably one of the reasons why we do not completely understand what is happening. We have found a few things. One is that in foreign countries they do not have a law on euthanasia but they sometimes use much higher dosages of drugs. We want to know what is really happening. We can call it euthanasia, or we can call it sedation, or whatever. We want to ask what is really happening, how many drugs are administered, and what drugs are administered.

Q1400 Baroness Finlay of Llandaff: I was wondering if centrally, in government, you have a way of monitoring the prescriptions for high-dose barbiturates.

Ms Keizer: No, but the pharmacists have their own responsibility. When they have a prescription that is not right, they will ask a doctor about it. But you are never sure, because in hospital there are so many drugs. You never know. People who have been ill for some time could have many drugs.

Q1401 Baroness Finlay of Llandaff: So those drugs are not controlled in a separate category, in law—the barbiturate?

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Ms Keizer: No, when the pharmacist gets a prescription for those drugs, he can ask the doctor. It is not that we get a call—

Q1402 Baroness Finlay of Llandaff: It is not a central register with the government?

Ms Keizer: No, we just have to read that in the pharmaceutical magazines.

Q1403 Lord Taverne: You said that surviving relatives are very positive about the law. Do you have figures for that?

Ms Keizer: Yes, it is in your information pack.

Q1404 Lord Taverne: Is it also coming through from the doctors' reports and reviews? It is mainly the research figures which show this, is it?

Ms Keizer: Yes, there has been research through doctors and the doctors had to ring up relatives. The doctors could make a separation between those relatives who were positive and those who were not positive. There has also been research directly with relatives. They had a group of relatives who stayed behind after a patient died a natural death, and they had a group of relatives who stayed behind after their relative died after euthanasia. They compared this.

Q1405 Lord Taverne: And the second category is more positive?

Ms Keizer: Yes. What we think is that euthanasia does not have a negative effect on the relatives.

Q1406 Lord Taverne: Do you also have any evidence about the depth of discussion about end-of-life decisions generally? This does seem to be more common in The Netherlands than elsewhere. Do you have any statistics about this or not?

Ms Keizer: We look at other countries and look at their culture with regard to talking about death. In Japan it is totally different. I met some people from Japan yesterday, and they do not want to talk about it. In other countries, people accept everything about death and, for instance, they can accept dementia much better. In Holland, we want to make decisions ourselves. That is a characteristic. However, I do not know about the depth. We have not done the research.

Q1407 Lord Carlile of Berriew: At the back of this little booklet [*Q&A Euthanasia*], for which we thank you, in Appendix III there is the form that a doctor who has carried out a euthanasia procedure is required to return to the review panel. It is a very short form, covering four small pages. Leaving aside the percentage, which is disputed, it is clear that a significant number of euthanasias take place without forms of that kind being returned. What conclusion do you as policymakers draw from the failure of

doctors to complete those returns, and therefore the failure of those doctors to report the euthanasia procedures?

Ms Keizer: First of all, I want to say something about the form. It is not how big the form is before you fill it in which counts. What counts is how much you write down when you give it to the review committee. When the review committee thinks that they do not have enough information, they will go back to the doctor and the doctor has to fill in a longer story. We are considering making it even shorter. However, that does not mean that the doctor has to write down a shorter story. It means that he has to write down the story, and that we are asking that the story should contain this, this and this. Then the review committee will see whether they think that this is a reasonable story. Please ask the review committees when they are here, because they will tell you what they have in their files when they decide on something.

Q1408 Lord Carlile of Berriew: Yes, but as a policy—

Ms Keizer: The other thing is that the number of reports is not enough. We have just talked about the drugs. Of course we are very worried, because our goal is that everything is reported. Only then, will we think that it is not punishable. It is punishable where you do not report. It is in the law. That is why we are very concerned, and why we are doing more research so quickly.

Q1409 Lord Carlile of Berriew: Does not the significant failure of doctors to return these forms—doctors, particularly if they are bringing people's life to an end, having record-keeping as an important piece of their work—show that they are unsure about the ethical framework in which they work?

Ms Keizer: I do not think that it is the ethical framework, because the cases are really so horrible. It is more the law side of it. They are afraid of being a test case, in front of a court, and all of that. I think that there are doctors who are unsure of what they have done, and they will be afraid to report. That is actually a failure that goes with a self-reporting system. However, we want to give as much clarity as possible, so that doctors can handle it according to the due-care criteria and they do not have to be afraid.

Q1410 Chairman: Do coroners report on every death that takes place in The Netherlands?

Ms Keizer: Who?

Chairman: Do coroners report on every death that takes place in The Netherlands?

Q1411 Lord Carlile of Berriew: A judge that is told about each death—the official.

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Ms Keizer: Yes, we have statistics about it. Every doctor has to complete a form when somebody dies. In that form they have to say how the person died: whether it was an accident, euthanasia, or natural death, just somebody who died from an illness.

Q1412 Chairman: Every death has to be reported in some way?

Ms Keizer: Yes.

Q1413 Chairman: Are these forms then compared?

Ms Keizer: Yes.

Q1414 Chairman: Is that where your—

Ms Keizer: This is where my figures are from.

Q1415 Chairman: That is where the 3,800 comes from?

Ms Keizer: Yes.

Q1416 Chairman: It is not—

Ms Keizer: Not from asking around.

Q1417 Chairman: Not from research?

Ms Keizer: No.

Q1418 Chairman: From the forms?

Ms Keizer: Yes.

Q1419 Chairman: We were told today, and also in earlier evidence, that 0.7 per cent of the total deaths involved life-ending without a request. Is that figure something that is familiar to you?

Ms Keizer: Yes, it is familiar.

Q1420 Chairman: What is the content? What sorts of deaths are involved in that 0.7 per cent?

Ms Keizer: You have to think of people who are not able to make a request. There are some cases in which it is not careful euthanasia; but most cases are people who are not able to make a request because they are not seen as able to make a request. For instance, people who are suffering from a psychiatric disease or people who are in a coma. Also, newborn babies are not capable of making a request—those cases.

Q1421 Chairman: Have you any idea, from the figures that you know of, how many in each category that you have just mentioned there might be?

Ms Keizer: Yes, but I do not have them in my head. I think that 50 per cent are not capable of making a request—that is, coma and—

Q1422 Chairman: That would be 0.35 altogether.

Ms Keizer: Yes. Twenty-five per cent are people who could have made a request but did not. So we are wondering about those. Fifteen per cent are newborn

babies, and 10 per cent are other categories, but I do not know what.

Q1423 Lord Patel: Pursuing that point a little further, the implication was that the figures were derived from the difference between the reported cases and the certificates that the coroners received—death certificates. That would identify the doctors who did not comply, because presumably every doctor has to sign the death certificate.

Ms Keizer: Yes, every doctor has to sign the death certificate. This is not “not careful” euthanasia; it is something else.

Q1424 Lord Carlile of Berriew: So if he writes “natural causes”, it is treated as natural causes?

Ms Keizer: No, they do not have to. There is also a category where you can say that it was the ending of the life of a patient without his request. It is on the form.

Q1425 Chairman: That is the 0.7 per cent.

Ms Keizer: Yes.

Q1426 Chairman: But I think that we are concerned at the moment with the other figure, the 3,800. I think that is what Lord Patel is asking about.

Ms Keizer: The 3,800 is on the form as euthanasia and sent to a statistics institution.

Q1427 Lord Taverne: But you said that you doubted, in the light of the controls that exist and the number of doctors involved, whether these really were cases of euthanasia. What other case might they have been? Terminal sedation? This kind of thing?

Ms Keizer: Yes, we are in doubt about that: that it might be terminal sedation and the doctors just do not think about reporting, because they see it as other drugs. They use other drugs and they think that it probably has hastened the death, but—

Q1428 Lord Taverne: So you think the figure for euthanasia might be quite a lot lower than the 3,800?

Ms Keizer: Some people think so. However, we do not do this research—the 3,800 research—every year, because it is very expensive.

Q1429 Lord Taverne: So you do it every five years?

Ms Keizer: Yes. We will be doing it next year again.

Q1430 Chairman: There are two possible sources. There is a research project that interviews doctors and so on, and sends out a form to doctors. That is a basis for some sort of figuring.

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Ms Keizer: Yes.

Q1431 Chairman: But I understood you to say—though I may have misunderstood—that the 3,800 figures you gave was based on the returns that doctors give, which include all deaths.

Ms Keizer: It is the same number. That is also why we trust the research and the returns.

Q1432 Chairman: So the research and the returns give the same result?

Ms Keizer: Yes.

Q1433 Lord Patel: It is corroboration.

Ms Keizer: Yes.

Q1434 Lord Patel: As a policymaker though, do you think that you have a lot of dishonest doctors or do you think that there are doctors who are not dishonest but who have not correctly understood the guidance?

Ms Keizer: When you look at GPs, they have been talking about this for some time and I think that they have found a way to handle this. There are other doctors, for instance in hospitals, who have a way of handling things and they have to make the space to allow other people to look at their actions. I think that this has to grow in the next few years. They are not dishonest, but they are not used to letting other people decide whether or not their way of acting is right.

Q1435 Bishop of St Albans: I have a very quick question, taking it from statistics to an individual example. If I were in a coma in The Netherlands and the physician thought that, in his or her opinion, I was suffering unbearably, they could then kill me and there would be no consequence for that physician. Is that what you are saying? It would go through the review process, but the chances are that there would be no problem, because I would have checked that they were suffering unbearably and, under those terms, I would have a duty to end their life.

Ms Keizer: One of the things that is necessary for a doctor not to be punished is that he has talked to many other doctors about this. He cannot decide this for himself, therefore.

Q1436 Bishop of St Albans: So he would check with a colleague and then—

Ms Keizer: No, not one colleague.

Q1437 Bishop of St Albans: No, a team.

Ms Keizer: A team, and a team from another hospital, not your own colleague.

Q1438 Chairman: I notice that on the screen it says “*Sneller beter*”. Is that suggesting that we should finish?

Ms Keizer: “Faster better”, but *beter* is also “healthier”.

Drs Alberda: It is a website.

Chairman: Thank you both very much indeed, and also for the documentation that you have provided for us.

Examination of Witnesses

Witnesses: MR JAN SUYVER, Chairman, Ms JET VAN DE MEERENDONK, Lawyer and Secretary, and DR GERRIT KIMSMA, member, Case Assessment Committee, The Hague, examined.

Q1439 Chairman: You have kindly given us a paper, but you may wish to start orally all the same.

Mr Suyver: We are honoured by your visit to the regional review committees which we represent. We will try to explain the committee’s position, role and task. You are legislators and, in my very brief introductory remarks, I want to draw your attention in particular to the new 2002 Dutch legislation on assisted dying. I think that you have a copy in the English language. If not, you will get it. The Act is the base on which the review committees give their judgments. I would start by expressing an important preliminary remark. There is no legal right—I repeat, no legal right—of the patient to be assisted in dying. This impression seems to be a widespread misunderstanding. It is, however, the exclusive competence of the doctor, and the doctor only, to decide whether or not he will terminate a patient’s life on request. With regard to the new legislation, the structure, as far as it concerns the review committee,

is very simple. You have only to read sections 2, 3, 8 and 9—four out of 15. Section 2 of the new Act is the very heart of our regulation. It defines the strict criteria that should be fulfilled by the doctor. They will each be discussed later in our presentation. Section 3 establishes the five regional review committees to which the doctor must report. Section 8 defines what kind of judgments the committees are allowed to issue. There are only two: did the doctor act, yes or no, in accordance with the criteria set out in section 2? The committees investigate each reported case and assess whether or not the criteria are met with. It is black or white, not grey. However, in its written explanation on the judgment the committee is entitled to mention all the relevant circumstances and dilemmas. Section 9 says that the committee’s judgments will always be sent to the doctor. If the committee finds all the criteria fulfilled, then the case is over—end of the story. There are no further investigations, no prosecution. If not, the

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committee must also notify the public prosecution service and the health inspection. The committees do not give advice whether or not to prosecute or to bring the case before a disciplinary tribunal. Those are the exclusive decision powers of the prosecution service and the health inspection. I now give the floor to Ms Jet van de Meerendonk, who is a lawyer and secretary to one of our committees, followed by Dr Kimsma, who is a doctor and a member of one of our review committees.

Ms van de Meerendonk: As Mr Suyver has told you, I am one of the official secretaries of the regional committees. First, I would like to present to you some facts and figures and I will give you a short description of the procedure of the review and the procedure of notification. As you may know, “euthanasia” comes from the Greek words *eu* and *thanatos*, which mean “a gentle death”. In The Netherlands the definition is a little more complex than that. It comprises the following elements. It is the termination of life by a physician at the explicit request of a patient, with the aim to bring an end to unbearable suffering where there is no prospect of improvement. In The Netherlands, this definition includes assisted suicide. I must emphasise that it is essential and crucial that the request of the patient is voluntary. For a better understanding of this definition it is important to know what euthanasia is not. In The Netherlands euthanasia is not the withdrawing or refraining from treatment, either at the patient’s request or when it is considered futile by the physician. Neither is euthanasia the relieving of pain by a physician, with the possible side-effect of hastening his patient’s death. These situations and decisions are considered normal medical treatment and normal medical care. The review committees assess the notifications that are submitted to them by the physician. There has been a decrease in the numbers of notifications over the past years. For 2004, the estimated number of notifications will be higher than the previous year, 2003. I do not know the exact numbers at this moment. In most cases the GP is the notifying physician—about 90 per cent—followed by specialists and, even less, nursing home physicians. This can be explained by the fact that euthanasia mostly takes place at the patient’s home. The illnesses associated with euthanasia are, as the main cause, cancer—about 90 per cent—followed by cardiovascular diseases, diseases of the nervous system, pulmonary diseases, and every year there are a few cases of AIDS. Euthanasia and assisted suicide are legislated in the criminal code and in the Act which came into effect in 2001. I will first give you some more information about the criminal code. It is still a criminal offence to take another person’s life at his explicit request. However, in subsection 2 of this criminal code where euthanasia and assisted suicide are regulated, the physician is exempt from

prosecution if he fulfils the due-care criteria and notifies the coroner. Article 293 rules the euthanasia and 294 the assisted suicide. Subsection 2 is the codification of about 25 to 30 years of case law in The Netherlands, as is the Act I have just mentioned, called the Termination of Life on Request and Assisted Suicide Act. In Article 1 of this Act, definitions are made. In Article 2, the due-care criteria are mentioned. There are six due-care criteria. Article 3 is the foundation for the installation of the review committees and the assessment rules. What is the procedure after euthanasia? The physician has performed euthanasia and then has to complete a standardised report. This report is done by answering relevant questions and, in doing so, giving the review committee enough information to assess. He then immediately notifies the coroner. The coroner visits the patient at home or in hospital, wherever the euthanasia took place. Then he performs an external medical examination. He then notifies the public prosecutor and the civil registrar—the registrar of births, marriages and deaths—so that the funeral can be arranged. He then compiles a standardised report, his own report, filling in the cause of death. He collects all the documents; that is, the documents he receives from the physician, the standardised report, and, if the doctor wants to give further information—for example, the patient’s file—he collects that as well. Then, together with his own report, he sends this file to the review committee. After receiving the file, the review committee sends a letter of confirmation to the notifying physician in order to let him know that his notification has been received by the committee, and furthermore the committee tells him that, within a period of six weeks, the conclusion and the findings of the committee will be sent to him. The relevant facts are filed into a database and the secretary of the review committee makes a draft of all the relevant information that can be found in all the documents. This draft is the basis for the concept judgment made by the review committee. A full copy of all the documents in the reports and the concept judgment is sent to all the members of the review committee. There are five regional review committees spread throughout the country. They were installed by the Minister of Justice and the Minister of Health, Welfare and Sport, but I must emphasise that the committees are independent. The members are appointed by the ministers for a period of six years and there are three members, each from a different discipline. There is a lawyer, who acts as chair, a physician, and an expert on ethical and moral issues. Each of these members has an alternate in case of absence. The review committee is assisted by a secretary. I am one of the secretaries. The secretary is a lawyer and preferably has a feel for healthcare matters. They prepare and attend the meetings, and have an advisory role. The

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review committees meet once a month and, in these meetings, all the cases are reviewed in order to assess whether or not the physician has acted with due care. It sometimes happens that the review committee do not have enough information, because it is not clear or the information is not sufficient. They are then authorised to request further additional information. They can request that from the physician or from all the people involved. They can do that, in the case of the physician only, in a personal interview. The rest takes place in writing. Eventually there are only two possible conclusions to be made by the review committee: either the physician acted with due care or did not act with due care. In the first case, when he did act with due care, he is notified of this judgment by the review committee, and that is that. In the case where the physician did not act with due care, however, then not only will the physician be notified about the judgment but the judgment will also go to the Board of Procurators General and to the regional healthcare inspection. These authorities, in the light of their own tasks and responsibilities, will then consider if further action has to be taken. The public prosecution service will determine whether or not an offence has been committed and whether or not they have to prosecute. The regional healthcare inspection determines whether or not it has to take disciplinary action. This can range from a personal interview to filing a complaint with the disciplinary board of the healthcare. So much for the facts, figures and procedure. I would now like to hand over to Dr Kimsma.

Dr Kimsma: Before I start, I will give you a handout, because I was afraid that you would not have sufficient papers! I am giving you papers which you simply would not have any other way. They are of this year, 2004, and the last paper has just been published in December 2004 in the *Journal of Clinical Ethics*. They also concern subjects which you do not hear about when you move in these circles. I would also like to take the opportunity—and I am doing this because the attention span is usually 20 minutes, and then one needs to have a new intervention in order to raise the awareness level!—to hand to my Lord Chairman a book which was published in 1998, entitled *Asking to Die*, about the Dutch debate on euthanasia. It also contains material which you will read nowhere else, especially interviews with families where euthanasia has taken place and interviews with physicians who have carried out euthanasia. I would have liked to give all the members of the Committee a copy of this book but, since the cost is £30 . . . !

Q1440 Chairman: You are giving it to a Scotsman!

Dr Kimsma: Yes. I hope that you will benefit from it.

Q1441 Chairman: Thank you very much. I may be able to share the benefit.

Dr Kimsma: I would certainly hope so. Also, to show you that we have a real heavyweight on the committee, I am a family physician; I am a medical doctor and I am a philosopher too. I teach medical ethics and philosophy at the Free University and I obtained my medical degree in 1974, when the first case of euthanasia came through the Dutch courts. So it has been there for all of my professional life. That is why, as a philosopher, I was forced to commit myself to the issues, and I am very pleased with the manner in which we, in Holland, have solved these issues. Back to business. What does a physician do in a review committee? The aim of having a review committee was to create some distance between the law and the medical profession, between medical practice and the legal scrutiny and judgment of it. The feeling and the assessment has always been that, within medicine, there are circumstances and issues that do not fall within legal definitions. The medical reality is not similar to the legal reality. Murder in medicine is not like murder outside medicine, in terms of concepts. What does a doctor do within the review committee? The doctor has a general obligation to establish the presence of the conditions for the voluntary act of euthanasia. Each member has that obligation. He has the specific obligation to assess the adequacy of the medical process. The medical process can be very long and very cumbersome, sometimes years. Those years are compressed into some lines on a paper, and the task of the physician is to reconstruct the medical process, to see whether the doctors have acted with due care according to the medical standards. There is also a legal obligation, which is a very simple one. It is to fill in the medical gaps for the other members of the committee. A medical doctor knows what a specific diagnosis implies. What is the type of suffering, for example, in a mesothelioma. What type of suffering metastases in the bones will cause, and so on. That is necessary information to assess the medical suffering. The doctor has a general obligation to guard the medical limits of euthanasia. I suspect that you have heard many times today the legal conditions for a voluntary act of euthanasia and physician-assisted suicide. However, I will say something about each of them. What you have to realise is that, in the committee, it is paperwork. We do not see doctors; we do not see patients or families. Of course, we do not see the patients because they have passed away. So it is a paperwork exercise. On the basis of what is in the paper, we need to assess whether the requirements have been fulfilled. So we check the voluntariness. We must be sure that there has been no manipulation, no pressure or undue influence, and that the request is well considered. It must have been expressed and dealt with several times, sometimes years before the actual date of the euthanasia or assisted suicide. The wishes preferably must be

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supported in writing. That is not exactly a legal condition, but it certainly helps and makes the assessment simpler. The assessment of unbearable suffering without the prospect of improvement is one of the difficult issues of the committee's assessment. What does "unbearable" mean? It has a very subjective, patient-related side, but it must always be a joint conclusion. In order for a physician to come to the conclusion that euthanasia is an option, there should be a joint, shared process of decision-making, where the physician also has to be very much in conformity with the wishes of the patient. "Without the prospect of healing" simply means, on the legal side, that there are no options for cure, given the status of medicine at the time. The assessment of adequate information is sometimes more difficult to reconstruct. Often the process takes months or years, as I said, and you can see from some of the medical records that the discussion has taken place many times. The position of the consultation of the second physician is a very important one. You have been to the Royal Dutch Medical Association today and you must have heard of the SCEN—the Support Consultation Euthanasia Network. I teach those physicians. I gave a course today, the third last-day course to a new group of physicians. What we want to make sure is that the consultation has quality. It is now legally possible that a physician without any training can do a consultation, but what we see in the committee is that those consultations on paper are inferior. So the consultations of the SCEN, the specifically trained physicians, are much more adequate and much superior. We can see that. What we need to make sure of is the independence of the consultant physician. The physician must give detailed information of the medical history, interviews with the physician and a personal interview with the patient. This medical information must be an echo of the medical information by the physician who ended the life. There must be an independent judgment on the consulting, whether the conditions have been fulfilled, and the report must be in the right form. The reports are usually a good read. What we also need to assess is whether the termination of life has been done according to medical standards. There is an absolute condition that it can only be done by the treating physician. It cannot be any other physician. We do not want to advertise euthanasia tourism. What we insist on is that it only takes place within a meaningful medical relationship. That is an absolute condition. In the case of assisted suicide, we insist that the physician should be present, or should be within reach if the patient does not die within a given number of hours. This is contrary to the state of Oregon, the only place in America where assisted suicide is possible. You have been there and have spoken to some of my friends in the Oregon termination of life committee.

In America, if you wish to participate in assisted suicide as a physician, you certainly should not be around when the patient takes the potion. The procedure and the means are according to medical standards, based on expert opinion and experience of the Royal Dutch Pharmacists Society. I now like to make some personal remarks. We have chosen this procedure in The Netherlands of five regional committees. The work in the committee is sometimes very tedious, because most of the time the procedures are very well done, are very carefully spelled out, and the assessment is not pleasant but it is an easy task. Sometimes it is more complicated. The necessity of a committee becomes very visible at those times. Also, we realise that we are dealing with a totally new subject, a totally new way in which society handles termination of life, as a personal event with a public nature, and making it transparent. We have chosen not to do all of this in hiding and I think that, in itself, is a good thing.

Mr Suyver: My Lord Chairman, I have observed some critical faces, but if it is true that The Netherlands only consists of drug-abusing, sex-obsessed people, whose hobby it is to terminate each other's lives, you would not have found here fairly normal people, walking along the streets. This is a normal society in which issues of life and death are not being dealt with in a less serious or a less respectful way than elsewhere. That is my conclusion. If you have questions, please put them to us.

Chairman: You can be assured that none of the members of this committee thought that we were coming to—

Mr Suyver: I was just joking!

Q1442 Earl of Arran: May I ask one question of the physician? Are you, as a member of one of the review bodies, allowed yourself to practise euthanasia?

Dr Kimsma: As a family physician I am allowed to practise euthanasia. I am not allowed to assess within the same region where I practise.

Q1443 Earl of Arran: If you were to get into trouble—which I am sure you would not—would your case be heard by one of the other review committees rather than your own?

Dr Kimsma: Yes.

Q1444 Chairman: You report to a different review committee?

Dr Kimsma: I report to a different review committee. I am practising in a different region.

Q1445 Chairman: So that happens even when you are not in trouble?

Dr Kimsma: Yes. If I were in trouble, I probably would make the wise decision to step down.

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Q1446 Earl of Arran: Are the notifications of cases across the five reviewing bodies more or less on a level basis in terms, say, of numbers per head of population? The actual number of cases reported to each of the reviewing bodies?

Dr Kimsma: I would say yes, with a nuance. In some areas in Holland there is more support for active termination of life than in others, depending, let us say, on the type of religion that is being practised. There is also the openness which is part of the issue. In some areas, not all the cases which are being carried out are being reported or dealt with.

Q1447 Chairman: So the amount of reporting varies a little from review area to review area?

Dr Kimsma: Yes. We have a Bible belt in Holland also.

Q1448 Chairman: Is that in the south, or in the middle, or where?

Dr Kimsma: That runs from the middle to the region below Rotterdam.

Q1449 Baroness Finlay of Llandaff: Could you explain whether, in the appointment of the committee, there is any criterion that you must never have been associated with the campaign groups for euthanasia, or are you allowed to have been associated with them? How are the appointments made?

Mr Suyver: We are supposed to be very reluctant in taking opinions in this respect; so we are really independent.

Q1450 Baroness Finlay of Llandaff: With the data that you collect, do you plot the doctor with the SCEN doctor over time? Do you have a log to make sure that the doctor is not going back every third or fourth case, in rotation to the same SCEN doctor?

Dr Kimsma: In order to make sure that there is an independent consultation, the consultants are on duty for a whole week. One calls a certain number and then one is connected with the consultant on duty. One never knows who that is. It is never the same. Even if it is the same, it is just by coincidence.

Ms van de Meerendonk: You do not choose your own consultant.

Q1451 Baroness Finlay of Llandaff: No, but you could choose the time that you telephone.

Dr Kimsma: No, you do not know. The schedule is not public.

Q1452 Baroness Finlay of Llandaff: Could you give us an example, from a form, of the degree of medical detail that you would normally expect against the question? Here you have a question, "What medical treatments were attempted?". I want to get a feel for

the amount of detail that you would expect to go in there, and perhaps you could give us an example?

Dr Kimsma: The medical information that we get is based on the model form of the reporting physician and it is usually based on the medical information of the carers in the hospitals where the patient has been. So the information of the carers in the hospital is very detailed. It is how doctors communicate.

Q1453 Baroness Finlay of Llandaff: Would you expect several pages to be attached to the form?

Dr Kimsma: No.

Ms van de Meerendonk: Sometimes that happens. With the model form the physician just fills in what the therapy has been; but most of the time there are addenda with it—letters from specialists and patients' files.

Q1454 Baroness Finlay of Llandaff: So the patient's whole case record comes to you?

Ms van de Meerendonk: Yes, sometimes.

Dr Kimsma: Sometimes the whole case record, but usually, let us say, the last stage of life, the last medical interventions that have taken place. But you have a point, and if you are ever going to develop a form, you should certainly not follow our form. The typography of it is limiting in the amount of information that you can provide. We also have it in electronic form now, which means that you fill in as much information as you want. If you have the physical form, however, that certainly does not invite you to be extensive.

Q1455 Baroness Finlay of Llandaff: Do you keep data against each doctor of the number of times they have performed euthanasia? So that if you had a doctor who had perhaps performed it nine times and most of your doctors were performing it two or three times, what would you do?

Dr Kimsma: We have data on the variety in numbers between physicians, but we do not keep track.

Q1456 Baroness Finlay of Llandaff: You do not track by doctor?

Dr Kimsma: No.

Q1457 Baroness Finlay of Llandaff: So you do not know if there is one doctor who is much more—

Ms van de Meerendonk: But you can put in a query and then you know how many times he performed euthanasia.

Q1458 Baroness Finlay of Llandaff: But that is not routine?

Ms van de Meerendonk: No.

Q1459 Baroness Finlay of Llandaff: That is not routine collected data.

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Mr Suyver: Although it is in our heads.

Ms van de Meerendonk: You see the names.

Q1460 Baroness Finlay of Llandaff: You have good memories!

Mr Suyver: Yes.

Dr Kimsma: But when the stories are complete and clear, and there is no question about it, that is the end of it. Elderly populations—the cancer ages between 65 and 79 when you have about 80 per cent of the cases of cancer—if you have a population of that age bracket, you will have a request more often.

Q1461 Bishop of St Albans: This is a philosophical question. It is fairly obvious from the way I dress that I come out of a tradition which would use words like “God” or “sanctity of life”, and that sort of language—a form of discourse which I will call, for want of a better word, theology. When you did your thinking around all of this, did you bracket out that form of human discourse in order to arrive at these kinds of conclusions and, if so, why?

Dr Kimsma: I think that you should maybe ask for the book or, if you give me your address, I will gladly provide you with it. One of the chapters deals with all the ethical arguments, pro and con, in the euthanasia debate over the ages. The religious arguments are very heavily represented. There is a very interesting philosophical point to be made, however, that dignity of life and sanctity of life within our Protestant tradition—and I am not talking about the orthodox Protestant religion but a more liberal Protestant tradition—does not rule out active ending of life. Some of our most progressive theologians have made it exceedingly clear that, on the basis of the Bible, you could be in favour of voluntary active euthanasia.

Ms Keizer: Perhaps I may say one thing? You asked about the Bible belt and the number of reports. I made a survey of the number of reports from different regions, and I found out that, when you look at the number of inhabitants and the number of reports, there is no difference between the Bible belt and the other regions.

Dr Kimsma: I am glad to hear it!

Q1462 Lord Taverne: In the minority of cases where you find that the law has not been complied with by the doctor, what is the main reason? What is the way in which they tend to fall short? Is there any particular pattern about it?

Dr Kimsma: That is a subject that has been extensively researched, both in 1995 and 1990. Usually, the reasons are psychological: fear on the part of the physician; physicians do not want the law involved; physicians do not think that the law has any authentic basis to be involved; families do not want it—

Q1463 Lord Taverne: That is very interesting. That is the reason why they do not report.

Dr Kimsma: Yes, that is the reason why they do not report.

Chairman: What Lord Taverne is wanting to know is, in cases where there has been a report and the committee has found that the doctor has fallen short of the legal standard, what are the principles?

Q1464 Lord Taverne: I would really like the answer to both.

Mr Suyver: The principal reason is that the consultation is not complete. That is the main reason. The consultation procedure is not in order. I think that the second question is about unbearable suffering.

Q1465 Lord Taverne: What is the percentage of people who break the law?

Mr Suyver: Very few.

Q1466 Lord Taverne: Ten per cent? One per cent?

Dr Kimsma: We know that there has been an increase. In 1990 it was 18 per cent.

Q1467 Lord Taverne: No, this is the reporting. I mean those who do report.

Dr Kimsma: They do not break the law.

Ms van de Meerendonk: In the previous year, 2003, there were eight cases of the 1,800.

Q1468 Lord Taverne: It is tiny.

Ms van de Meerendonk: Yes.

Q1469 Lord Taverne: As far as the research is concerned on those who do not report—I would like you to say what the results of that research are. You said that doctors felt that the law should have no place in these decisions. Confidentiality?

Dr Kimsma: Yes, that was in 1990 when 18 per cent were reported. In 1995, 42 per cent were reported. In the last research in 2000-01, it was 52 or 54 per cent.

Q1470 Lord Taverne: And the reasons much the same?

Dr Kimsma: The reasons were much the same, yes. It is very interesting. From other research it has become clear that in fact the type and the nature of the issues were not different between the cases that were not reported as compared to the cases that were reported. So actually there was no reason for the physicians not to report, except for, let us say, more psychological reasons.

Q1471 Lord Carlile of Berriew: I would like to ask a question about the appointment of your tribunals. In England and Wales it has been held that, as a result of Article 6 of the European Convention on Human

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Rights, it is not permissible for a lawyer who has written articles for legal journals about certain aspects of personal injury law to sit as a judge in relation to cases relating to personal injury law. We have heard that we have a distinguished writer here, who sits on a review panel and who indeed has authored an article, which I have just scanned, which is very much and plainly in favour of legal euthanasia in The Netherlands. It may happen from time to time that a relative is aggrieved by a euthanasia procedure. Have your review panel been tested under Article 6 of the European Convention?

Mr Suyver: You are completely right, but the only difference is that we are not judges.

Q1472 Lord Carlile of Berriew: You determine civil rights and obligations.

Mr Suyver: Our body is not a judge. We do not exercise a judicial function.

Q1473 Chairman: All you are doing is advising ultimately the prosecution authorities or the medical inspection authorities.

Mr Suyver: We are an experts' commission, as the legislator has pointed out.

Q1474 Lord Carlile of Berriew: So there has been no challenge?

Mr Suyver: No. But it is an interesting question.

Q1475 Lord Joffe: It has been suggested by a physician who opposes euthanasia, on the basis of research that she has done, that there are a number of physicians who are very enthusiastic about euthanising their patients and that a disproportionate number of their patients are assisted to die. Would your procedures help to identify physicians who were doing this?

Dr Kimsma: We can check the numbers of a physician. I know of one physician who has reported on his own cases, let us say years ago, that he had more patients in his practice than the average whom he euthanised. He has been held responsible for each case, and the cases have been scrutinised. He reported, and he has not been prosecuted. I would be interested in these figures, because we are very interested in having a practice that is transparent, so that we know exactly who is doing what—because this is not a light issue. It is a very important issue,

and we wish to be careful. If people have information like that, they should come forward.

Q1476 Lord Joffe: The question was would you be likely to notice this, if there were a significant number of cases coming through to you from a particular doctor?

Dr Kimsma: I think that would not go unnoticed.

Q1477 Baroness Finlay of Llandaff: But you said that you do not keep a database.

Dr Kimsma: We do keep a database but we do not have an obligation. We assess whether the conditions have been fulfilled, but we are not a police institution.

Q1478 Chairman: So long as the doctor had performed in accordance with his obligations, that would complete your responsibility. You might notice other things but, even if he or she had a very large number of these cases, so long as they were in accordance with what is required it would be all right.

Dr Kimsma: Yes.

Q1479 Chairman: I am sorry to say that the time is running out and we will have to go in a moment. Can you help me on one point? Do general practitioners in this country work in partnerships?

Mr Suyver: Sometimes.

Q1480 Chairman: If a patient is a patient of a partnership, he or she may not have the same practitioner all the time. Certainly that is the experience in the United Kingdom. Is the intimate, meaningful medical relationship that you referred to still possible, against a background where it may be a different doctor from week to week?

Dr Kimsma: Usually patients are written in the register of one physician and that physician would take care of a certain number of patients. If you join and you have that register jointly, you know your patients; and that is not a large group—two or three people. I might add that if you are in a partnership, you are not allowed to be a consultant for your partner.

Q1481 Chairman: The consultant may be a general practitioner?

Dr Kimsma: Yes.

Mr Suyver: They may be, yes.

Chairman: I am sorry that the time seems to have passed so quickly. On behalf of the whole Committee, may I thank you very much indeed?

 THURSDAY 16 DECEMBER 2004

Present	Arran, E Carlile of Berriew, L Finlay of Llandaff, B Joffe, L Mackay of Clashfern, L (Chairman)	Patel, L St Albans, Bishop of Taverne, L Thomas of Walliswood, B
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Examination of Witnesses

Witnesses: DR MARIA DEN MUIJSENBERGH, General Practitioner, DR BEN ZYLICZ, Hospice Medical Director, Ms MARJO GRIBLING-GOMMANS, Oncology Nurse, and PROFESSOR HENK JOCHEMSEN, Medical Ethicist, examined.

Q1482 Chairman: The practice we have followed so far is to invite each of you to say briefly who you are and what your interest is in the matters that we are concerned about. After you have done that, my colleagues and possibly I myself may have some issues on which we particularly wish to ask your views. The help you give us is taken down by the shorthand writer and you will get a chance to review the transcript, to see that it is in accordance with what you thought you said. In due course, we will publish the transcript as part of our ultimate report, showing what information we have gleaned with your help and the help of others. With that introduction, whoever wishes to start, please do so.

Ms Gribling-Gommans: Thank you for the invitation. My name is Marjo Gribling and I am an oncology nurse. I worked in a regional conventional hospital from 1990 to 2002 on a cancer ward. Since 2002, I have been working as part of a palliative consultancy team as a nurse—so for the past few years. I have not had much experience with euthanasia itself in the hospital, because I no longer work as a nurse at the hospital; but I know that, since 2002, for the first time we have accepted a euthanasia protocol in our hospital. This protocol contains the role and responsibility of the physician and also the role of the nurses. If you have some questions, I can tell you what my motivation is to give support as a nurse when there is a request for euthanasia, and what I think about it.

Dr van den Muijsenbergh: My name is Maria van den Muijsenbergh. I have been a general practitioner for 20 years and I have done research on palliative care in general practice. Based on that and on my experience as a GP and as a palliative consultant for other GPs, I am quite concerned about the practice of euthanasia in Holland. At the level of the patient-doctor relationship I see a growing anxiety among terminally ill patients, as well as other patients, that they think it is not decent not to ask for euthanasia sometimes, because they feel that they are such a burden to their families or to their carers. More than once a patient has asked me, “What do you think,

doctor? Should I ask for euthanasia now, because my wife is so tired and I am going to die anyway?”. I see that problem more now than before 2001, when this measure was not legalised. Another thing is that there is growing pressure from relatives to commit euthanasia even when there is no request from the patient. As we have recently seen in the papers, I think that the common belief is growing that doctors or relatives are able to decide that a patient is better dead, even when the patient himself has not asked or has not discussed euthanasia. Many of my GP colleagues find it very difficult to withstand that pressure. Some good news is that, because of the law, we now have SCEN doctors. You have perhaps heard of them.

Q1483 Chairman: Yes.

Dr van den Muijsenbergh: It is very good for GPs that you can consult them and get some backing against pressure. Those are the things that make it difficult, therefore. Another thing is that we notice—and it was also proved in my research—is that there is a wide variety between doctors in the way they respond to the sigh of a patient who says, “Oh, doctor, I don’t want to live any more”. Some of them are very quick and say, “Okay. You don’t want to live any more? When shall we come for the euthanasia?”. They see this as a request when mostly, in my opinion and that of my colleagues, a patient who asks for euthanasia the first time does not want to die but, more, is afraid of what is coming or cannot take the burden of the suffering any more—where an answer other than euthanasia is available. I see that more of my colleagues are willing to permit euthanasia. Even when there is no request, they often think, “Well, the patient would have liked it, even if I don’t know this”. That is what worries me at the level of the doctor-patient relationship. At the level of the community, I indeed see this slippery slope that is sometimes mentioned. For instance, euthanasia is in the papers today, but also there was a huge article a few days ago saying that people who are suffering from dementia should be permitted to get euthanasia, and it would

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be best if they asked for it at an early stage. So I think that the indications, so to speak, are growing. That has an impact not only on ill or old people, but also it is the wrong message. It is the message that we can decide if a life is worth living. What worries me most is that we extend this to the unborn. We see so much emphasis these days on prenatal diagnostics, and I think that there is the same thinking behind it: that we can decide that a baby with Down's syndrome or a baby with a muscle disease, and so on, is better off dead. I am afraid that by legalising euthanasia you legalise the principle that other people can decide that it is better to be dead, and that is what worries me most.

Q1484 Chairman: Where are you a general practitioner?

Dr van den Muijsenbergh: In Nijmegen, in the east.

Dr Zylicz: My name is Zbygniew Zylicz. It is not exactly a Dutch name! Originally, I came from Poland but I moved here 25 years ago. I specialised in medical oncology, so I am a hospital specialist. For 12 years I have been the medical director of a hospice, one of the first hospices in this country. I am also very much involved not only in patient care but also in teaching, especially of general practitioners but also of specialist nurses. I have witnessed big changes in the attitude of general practitioners towards euthanasia, in my eyes not such negative changes. Many GPs now, knowing the basics of palliative care, can better resist the pressure from the family if they can offer something instead of euthanasia. This process is slowly growing. We have also seen the number of euthanasia requests in the hospice really decrease in recent years. Maybe we have made this euthanasia law—and this is perhaps our fantasy—unnecessary. We can solve many problems now much better than 10 years ago. The reasons for euthanasia due to requested euthanasia are also changing, and also in the law—that is, physical pain, suffering, as the basis of most euthanasia requests. We are seeing that much more existential suffering is taking over from the physical. We can deal with the physical more easily than this existential suffering. Now we have a law which, in my eyes, does not fit with the reality at the moment. The law talks about suffering more in terms of physical symptoms and the physical dimension, while the needs and the suffering are much more existential, which is not covered in the law in this country. There were some noises this year about making revisions to the law and about re-examining it. Does it fit with reality? These are my general impressions from my hospice and from my practice. The introduction of the concept of palliative or terminal sedation has clarified a lot of this. This is what we have taught the GPs, and I must say that

knowledge is growing about these activities. That is also changing a lot in this country now.

Q1485 Chairman: Did you specialise when you were a medical oncologist or was it general? Did you specialise in particular parts of the body, particular aspects of cancer?

Dr Zylicz: I specialised as an internist in general medicine, in medical oncology, but later I left hospital to work in a hospice.

Q1486 Chairman: But when you were still a medical oncologist were you dealing with all aspects of oncology?

Dr Zylicz: No, for 12 years I have been dealing only with palliative care. I am still registered as an oncologist but I am not practising that.

Q1487 Chairman: Before you came to the hospice, at that time did you have any specialist type of oncology in mind or was it medical oncology generally?

Dr Zylicz: Generally.

Q1488 Chairman: Professor Jochemsen?

Professor Jochemsen: I am Henk Jochemsen. I have been an ethicist since 1987, leading a private institute for medical ethics and I hold the Chair for Lindeboom Medical Ethics at the Free University, Amsterdam. Over this time, I have been following the discussion in The Netherlands, and also internationally on the issue of euthanasia and I am really worried about the development that we have gone through in this country. Let me make one general observation to start with. In my opinion, this acceptance of euthanasia, apart from any specific medical ethical objections one could have, also fits the development of the de-professionalising of the medical profession. That, in itself, is a factor in a broader development of commercialisation and more market in healthcare, in which healthcare provisions are considered a product or a service offered for those who want to buy it, and in which the specific professional attitude and ethics are no longer paramount to the way the physician is dealing with patients. Underlying that, is an individualistic view of people in society in which social healthcare is based on solidarity. To me, this whole development fits into a development in which solidarity in society with those who suffer and those who are vulnerable is being undermined, in favour of people deciding for themselves—but also being left to themselves. We all know that the behaviour of people of clients, in buying is easily influenced by commercial advertisements and by social pressure. This is exactly what seems also to be happening, and has happened, in the field of healthcare and end-of-life care: that social pressure is leading people to ask for

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euthanasia. Not asking for euthanasia has become an option, which you have to choose and which you have to defend. I think that is worrisome in a society which should, in my view, especially protect vulnerable people who are at the end of their lives.

Q1489 Lord Taverne: What we have heard today does to some extent conflict with what we were hearing earlier. For instance, taking the development of palliative care, we heard from a number of witnesses that this has developed in The Netherlands as a result of the Act being introduced: that the two have gone hand in hand and they are seen as complementary. This is one of the things we have heard. Is that, in your view, incorrect? My second question is, if there are cases where the system has been abused and patients become scared that they are going to be killed against their will, has this been reported to the authorities and has it been ignored by them? My last question is to Professor Jochemsen. The KNMG said in their official evidence that, as far as they could see, the negative side-effects of euthanasia had not been realised; that the vulnerable groups had not been disadvantaged, and they saw no evidence that this was so. Have they ignored the evidence? Why do they make these statements?

Dr Zylicz: Trying to answer the first question, in this country palliative care started to develop at the same time as the euthanasia was endorsed.

Q1490 Lord Taverne: Is that right? I thought that the practice started in about 1990?

Dr Zylicz: Yes, the practice started earlier.

Q1491 Lord Taverne: Palliative care got the stimulus in about 1996, and the law was changed in 2001?

Dr van den Muijsenbergh: In 1996 there was a lot of money put into palliative care and this was started because of the discussion in parliament about the euthanasia law. So it is right that, because euthanasia was discussed, a lot of people said, "When we discuss euthanasia, we first have to improve palliative care". Then, for the first time, the government gave money. That has stopped already, at the present time.

Dr Zylicz: There was huge international pressure on the Minister of Health, while working on the euthanasia law, to pay for the development of palliative care. This was more or less a trick to get this through. Otherwise, the criticism was so strong that it would never have got through. That is one process. The second one is that the doctors, especially GPs, have noticed that, since the endorsement of the law, the pressure from the family and from the patient on the doctor may be very high, and they must have some way to resist it. They must have tools to work with. During this time I have noticed a tremendous amount more interest in courses on palliative care. I

was running one course with 35 places on it for three days. There were 800 doctors applying for it. It was unbelievable how much interest was triggered by this mechanism. However, they are probably two separate things. Now the money has finished, so many people are losing their jobs. Hospices are also rather under-financed, and it is not going very well—also because of a poor economic situation at the moment.

Professor Jochemsen: We had the euthanasia debate before palliative care was financed. The 1994 regulation was a legal regulation of euthanasia. It was not only from 2001 onwards. It was already regulated and accepted in the law in 1994.

Q1492 Chairman: That was a combination of court case—

Professor Jochemsen: And the law on the burial of the dead.

Q1493 Chairman: That was a combination of court cases and the direction of the medical authorities in laying down guidelines along which it would be functioning?

Professor Jochemsen: That is right, but in the law on the burial of the dead this was regulated. So it had a legal basis as well, even though the penal code still contained the prohibition of euthanasia.

Q1494 Chairman: Was there a statute in 1994 that had an effect?

Professor Jochemsen: Yes.

Q1495 Chairman: It is called . . . ?

Professor Jochemsen: It is a regulation where the physicians who had performed euthanasia had to report it to the legal authorities, according to a document that was based on a change of the law of the burial on the dead. So for all practical purposes we had the legal regulation of 1994 already. 2001 only brought the change in the penal code, which had hardly formal legal significance but in practice made a difference.

Q1496 Chairman: It also made a statutory requirement of reporting and the setting up of the review committee?

Professor Jochemsen: That is right.

Q1497 Chairman: But the review committee existed as part of the general structure introduced by the medical profession some time before that?

Professor Jochemsen: It was instituted by the government, not by the medical profession. It was a regulation, and in 1997-98 these committees were established; but they received a legal statute in the new law.

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Q1498 Chairman: The government set up committees. By what mechanism?

Professor Jochemsen: Just by agreement with the—

Q1499 Chairman: The medical profession?

Professor Jochemsen: With the medical profession, and the public prosecutor.

Q1500 Chairman: That is what I had understood.

Professor Jochemsen: Yes, they did not have a explicit legal basis but they definitely had a juridical basis it functioned as such. However, the formal, legal establishment of the committees was in 2001—that is correct. It meant that only after the acceptance of euthanasia was real attention paid to palliative care. Research demonstrates that in 1995 the number of euthanasia cases was more or less stabilising. From the beginning of the 1980s until then it had been increasing. That is why the law itself did not cause a further increase. It had already reached a kind of maximum, so to speak. The evidence of the KNMG has not been investigated. The research so far is that the physicians have been asked for their opinions and experiences, but not patients. What is happening is that the pressure on patients and families is not known. Furthermore, often the relatives are stressing it more strongly than the patients themselves. So they will not report any kind of social pressure. So I think that the evidence that the vulnerable groups are not disadvantaged depends upon how you look at it.

Dr van den Muijsenbergh: Perhaps I could add something from my research. I spoke with patients who were going to die and, after their death, with their carers. From those conversations it was clear that there were some persons who died by euthanasia. Afterwards, some of the carers were content. They said, “At least what my wife wanted has happened”, but most of them felt very bad about it happening and they said, “Indeed, it was what she wanted, but it was terrible to see”. The carers of patients who had asked for euthanasia but had not got it—where the physician had said, “I do not think this is what is best now. Let us try to see what else we can do”—were very relieved. They were all very glad that the patient had not died by euthanasia. I think that, among vulnerable people, there is therefore a lot more anxiety and, among people who are terminally ill, a lot more concern than we read about in the papers, for instance. It is investigated, but on a very small scale. What is coming forward is the opinion that it is very good. They have the right to have that opinion, of course. But, for instance, yesterday there was a meeting involving the NVVE and people who are asking for a pill to have in their homes when they decide to die. Those people are still very healthy and they can speak out for themselves. Those are not the patients I see in the homes for the elderly. They are

really afraid. For instance, in 1994, there were organisations of the elderly in Holland who protested and spoke out about their anxiety regarding the developments—but it is not a very strong voice.

Q1501 Lord Taverne: Opinion polls show something like 90 per cent support it.

Dr Zylicz: In . . . ?

Q1502 Lord Taverne: In Holland. We were told that some 90 per cent of the population is in favour of the euthanasia law, and the doctors who started off neutral are now in favour of the law. Is that correct?

Dr Zylicz: When looking at these numbers, you have to nuance it a little. That is if you ask the question—and this is what you refer to—“If there is no other possibility for the treatment of pain, would you be in favour?”. If there is an alternative, however, and if there is something else, then the number is much lower. This is the trick—how you ask your question. I am sure that most people, when they do not have any alternative or any possibilities, would see this as the only possibility. This is also the challenge for our medical society: to provide alternatives, so that people can make much better choices—not from one possibility, but from several.

Dr van den Muijsenbergh: Also, when you ask healthy people, I think that most people in Holland and most doctors would say that it is good as a law, because then we do not have misuse and it is well regulated. Even when you ask people—for instance, those patients I dealt with—most of them want to discuss euthanasia with their doctor, because they want to have this option open. However, in the end, when they are going to die, most of them do not want it and they are more or less afraid that it will be inflicted on them. So I agree that most people will say that it is good as a law, but that does not mean that they feel like that when the moment has come. On the other hand, it is not enough to look at the implications for society as a whole, as Professor Jochemsen has said. I am very concerned about our society. It is already happening that people with diseases which could have been detected before birth—for instance a family with muscular disease, a mother with two children in a wheelchair—are being told, “You could have chosen not to have these children. Why should we pay for you?”. That is what I am very much afraid will happen when economic circumstances deteriorate and home care is more expensive: that many people will think, “There is the possibility of euthanasia. Why don’t they take it?”.

Q1503 Chairman: You mentioned research that you had done. Can we have some more detail about that?

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Dr van den Muijsenbergh: I have spoken with 100 patients who were going to die. It was research in general practice. A group of 20 general practitioners reported to me all of their patients with cancer, from the moment that it was certain that they would die from it. In two years time they reported some 100 patients. I spoke with all the patients who were not too ill at the time; I spoke with the general practitioners about the care they delivered. After their death, I spoke with most of their carers, though not all. In those conversations, a great many topics were talked about. There was talk about death—dying, knowledge about dying, and euthanasia. It was striking that there was such variety among general practitioners in the number of patients where they committed euthanasia and in the way they dealt with the patient's request. Most striking for me was the relief of the carers of patients who did not get euthanasia. On the other hand, I also have to say that some of them died by euthanasia and the carers were content that what the patient had wanted had taken place. It was also very interesting that, whenever a GP explained to a patient why he or she did not want to commit euthanasia, it was very well accepted by the patient. Sometimes you hear that patients are angry with their physician because he does not want to help them. In my experience and in my research, when it is clearly explained to the patient why you do not want to do it, patients accept it and are glad for the help and support you give them. So I think that is another side of it.

Q1504 Chairman: I think that we have heard from all but the nurse now. Have you any comment to make on these matters that Lord Taverne has raised?
Ms Gribling-Gommans: I think that good palliative care will be very important and also a consultation from a palliative care consultant before a euthanasia request, because we see in our consultancy team that it is not only physical suffering but also psychological suffering. "Burden on the family" is often a reason to ask for euthanasia. So I think that a palliative care specialist or someone who has been educated in palliative care can see more than just the physical problem.

Q1505 Chairman: You said earlier that the institution at which you worked has introduced a protocol for euthanasia being practised in it. That was when? When was that introduced?
Ms Gribling-Gommans: It was in 2002.

Q1506 Chairman: Until then, had it been forbidden in your organisation?
Ms Gribling-Gommans: No, it was not strictly forbidden.

Dr Zylicz: It was not regulated.
Ms Gribling-Gommans: Yes.

Q1507 Chairman: So the protocol was a regulation of the practice in the institution?
Ms Gribling-Gommans: Yes.

Q1508 Lord Joffe: Dr Zylicz, in your very fair article in the *Lancet Neurology* in October last year you drew attention to the decline in requests for euthanasia to your hospice, which you welcomed and which you thought might continue in the future, as palliative care improved; although you did say that you thought there was no way that euthanasia, in The Netherlands at any rate, would ever come to an end, but it would be better balanced. You also went on to say that the euthanasia laws had stimulated the development of palliative care. You said that the attitude of 70 per cent of doctors to euthanasia had not changed in the previous five years, but those whose attitudes had changed had largely become more restrictive. You also said that, against the expectations, "There has been no slippery slope and that some patients, whose physical symptoms appeared in the eyes of their physicians to be properly controlled, still persisted with their request for euthanasia". Have I correctly quoted you from the article—which actually I have open here in front of me?

Dr Zylicz: Yes. Changes in doctors' attitudes—this was the research of van der Wal, whom you probably have spoken to.

Q1509 Chairman: We are going to do that.

Dr Zylicz: Because he is the person who is investigating this in the country. I was referring to him. We have seen—and this may be the very narrow view of a practitioner in palliative care—that the numbers of requests are decreasing. There may be several explanations for this, not only the improvement of palliative care. I am sure that there are more explanations.

Q1510 Lord Joffe: You raised one: such as that they know that your hospice does not approve of it.

Dr Zylicz: Yes. This is the narrow view that we do not practise euthanasia in our hospice. On the other hand, we never refuse a patient who is in crisis. We want to admit them and we want to help them. This is what I see in my own practice. I also see that there are many people who come to the hospice and, in the first phase, when everything is unstable and out of order, when people do not have hope or a target to aim at, to live for, they request euthanasia; but these requests melt to zero within a week, even three days, because safety is provided and because of the environment of the hospice. I think that this is the

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experience of many colleagues all over the world. What is also interesting is that there are several people who are in a more balanced phase of their terminal illness, their physical symptoms are more or less controlled, and their cognition is not too disturbed; but if this process goes on for a long time, some people will request euthanasia and say, "If it goes on like this, I will never die". There is this group of patients, who are perhaps a little impatient and, for them, it is taking too long to die. It is a very small group in comparison to the first one, where we have learned how to deal with them and, at the same time, to work on their suffering and their situation.

Professor Jochemsen: It is true that the number of requests in the palliative care units in hospices is certainly decreasing. I am also on the ethical committee of a hospice in Amsterdam, and the experience is that very few requests are continued after they receive good care; but the number of requests in the population in general is not decreasing. What has been decreasing recently is the number of cases reported. We do not know what the cause is for that. It may be that physicians perform fewer cases of euthanasia than before. It is also possible that they just do not want to be controlled. As we know, there are still 40 to 45 per cent of all cases of euthanasia—we are not talking about other forms of life-terminating actions—which are not reported at all, and so are not open to any scrutiny by the legal authorities. It is likely therefore that, recently, so-called terminal sedation is replacing what before was called euthanasia. It is not reported because it is not called euthanasia and so, according to the law, there is not an obligation to report it. Whether or not there is a slippery slope I think is open to debate. Just look at what has been debated in the Netherlands from the summer until the present time. First of all, it was again about life-terminating actions in newborn babies. You may have heard that in Groningen there is a protocol which is accepted by the legal authorities, and there is strong pressure from the medical profession—at least the KNMG—to accept it as a general rule. Second, euthanasia or assisted suicide for those who have the beginnings of dementia has been accepted by the authorities. A debate is starting whether this should not be done more generally. Just today, a KNMG committee has published its report on an investigation into the possibility of accepting "tired of life" as an indication for euthanasia. You may have heard of the case of Brongersma, in which the courts have not accepted the assisted suicide. In that case, a few years ago the KNMG, and the medical profession in general, were arguing that "tired of life" was outside the medical domain. However, this committee is now saying that that should not necessarily be considered the case: that "tired of life" could, in certain circumstances, be

an indication for performing euthanasia. We therefore see that the indication—whatever you like to call it—that the groups which are open to the possibility of getting euthanasia are definitely extending.

Dr Zylicz: My definition of the slippery slope was different. I agree with Professor Jochemsen about the general slippery slope in politics and the debate, which is still widening, but I do not see the slippery slope at the level of general practitioners being more lax in the use of the rules. Here there is no slippery slope. We were very afraid that the general practitioners would further extend their indications, but he is right that the slippery slope appeared at a completely different level to the one we expected.

Q1511 Chairman: It is a different type: the continuing pressure from some quarters to extend the law as it is at present to some other areas?

Dr Zylicz: Yes.

Q1512 Lord Carlile of Berriew: Can I ask you a question about the training of clinicians? To what extent are trainee doctors given specific training in, respectively, palliative care and the ethics surrounding the use of legalised euthanasia? Is that training adequate and, if it is given at all, does it continue in postgraduate training after qualification?

Dr van den Muijsenbergh: I can say something about training in the medical school. I would say that in both fields it is not adequate. Even in the Catholic University of Nijmegen, ethics are discussed very little. I am a teacher in the latter phases of training, and students are very eager to enter the debate about ethics, because it has been missing during the larger part of their studies. There is very little teaching in medical school of palliative care. In the curriculum there is only one four-week course, where two parts of a day are dedicated to palliative care—which is very little. It is getting better in general practice postgraduate training, but it is not the same everywhere and it is fragmented. There are very good postgraduate courses, for instance with Dr Zylicz, but it is up to the doctors to attend them. You are not obliged to attend specific professional courses. What you see, therefore, is that GPs who are interested in palliative care will go to these courses, and those who are not interested do not go and there is then a difference in the care that they provide.

Q1513 Chairman: Is there a requirement in this country for general practitioners to do post-training development?

Dr van den Muijsenbergh: Yes, but there is no specific area. You have to obtain 40 points each year, but you can get them in Africa or you can get them skiing, or

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you can get them in very good courses. There is a large variety.

Q1514 Chairman: The 40 points have to be assembled by some form of course?

Dr van den Muijsenbergh: Yes.

Dr Zylicz: But not specifically on palliative care.

Q1515 Chairman: No, I understand that. I was a little surprised at the precise width of the courses that apparently qualify.

Professor Jochemsen: Could I comment on the question of the ethics? As far as I know, there is no clear statistical evidence with respect to that. I do get students from four different medical faculties in my lectures. I know that the ethics teaching in general in the medical faculties is very poor, and especially that there is no specific teaching in the ethics of legalised euthanasia. I am afraid that the general attitude of medical students to euthanasia is that, for many of them, it is no longer an ethical problem—as long as it is within the boundaries of the law, which of course is interpretable.

Dr van den Muijsenbergh: Unless they see something in practice and they think about it for the first time. At present, all students are trained to learn from protocols. They jump from a protocol for this to a protocol for that and, in all fields of medicine, that is not the right way to treat patients, but especially when dealing with these kinds of problems. Students think, “There is a protocol; there is a law. It is clear. It is not difficult”.

Dr Zylicz: I think that the pattern in Holland is very patchy. Different universities develop some programmes; other universities do not do anything about it. On the other hand, there is a trend that palliative care is not seen as a medical speciality. This was the reason why I lost my job and I am moving to the UK, because there is no way to work here. I am not the only one, but this will have very profound consequences in the future. Most of the clinical teachers, the academic teachers, were specialists. The Ministry of Health, and also the KNMG, decided that palliative care was the domain of general practitioners and nursing home physicians, but not specialists. This means that hospitals in general will be totally devoid of input from palliative care specialists, and no GP would have any influence on what is happening in hospital. I think that this is a very big blow to developments in the future. The Ministry of Health can talk about how wonderfully palliative care has developed in this country, but that was only at a time when it was needed. Now, however, we do not get any money for further development.

Q1516 Chairman: Do I understand you to say that, when the proposal was under consideration for a statute to deal with euthanasia and assisted suicide, there was an upsurge in the funds that government made available for the purpose of palliative care?

Dr Zylicz: We were very glad, yes.

Q1517 Chairman: Once the statute had been secured, I get the impression—is this what you are saying?—that the funds have somewhat diminished?

Dr van den Muijsenbergh: As we say in medicine, *post aut propter*. We do not know if it is because of the law or because it is just coincidence.

Q1518 Chairman: Has a similar restriction taken place in other branches?

Dr Zylicz: Not to my knowledge.

Q1519 Chairman: Palliative care is funded basically by the insurance companies, is it not?

Professor Jochemsen: The development is funded by governmental funds.

Q1520 Chairman: I want to be clear about this, because it could be of some importance. There is an aspect of government financing in the development of palliative care. What is included in that phrase in this context? What do you mean?

Professor Jochemsen: Research, teaching.

Dr van den Muijsenbergh: And supporting teams. When you talk about patient care, for instance, general practitioners—who have most of the contact in palliative care—do not get any extra money. There has been a regulation for what was called intensive home care, and we received some extra money for a patient who stayed at home in the terminal phase; but that has diminished and, in most insurance companies, stopped. For instance, when a patient goes to a hospice, the medical care is paid for by the insurance company and some of the care costs are paid by the AWBZ—which is the general insurance for old people in Holland—but the patient also has to pay money himself for each day that he stays there.

Q1521 Chairman: So far as the funding of actual euthanasia treatment is concerned, do the insurance companies pay for that?

Dr van den Muijsenbergh: No. As a GP, when you do euthanasia, I think that the medicaments are paid for by the insurance company. The patient does not have to pay. The consultation—

Dr Zylicz: SCEN physicians are paid by the government.

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Dr van den Muijsenbergh: But the GP is not paid for it.

Q1522 Chairman: The insurance premium is paid for lower-income people by the government, and higher-income people have to pay the premiums for their own insurance. However, I was thinking of the other end of the matter, where treatment is being given which includes euthanasia. The payments in that case for a consultation with the SCEN doctor, the prescribing of the medicine and so on—that is paid for by the insurance company to the general practitioner or to the consulting physician?

Professor Jochemsen: Yes, but the consultation by the SCEN physician has a specific fee, paid by the government.

Q1523 Chairman: By the government?

Professor Jochemsen: Yes.

Q1524 Bishop of St Albans: May I ask about the hospice movement in The Netherlands? We heard this morning of the development of a Jewish hospice. No doubt there are Christian hospices, and possibly hospices of a Catholic variety. Is there any evidence yet in The Netherlands of Islamic hospices being set up?

Dr Zylicz: Not to my knowledge.

Q1525 Bishop of St Albans: Does that then indicate cultural differences about understanding of the value of human life or pain? What does that do to cohesion in society if your choice of hospice is dependent on your particular personal faith, as opposed to being a citizen of The Netherlands?

Professor Jochemsen: The hospices are open to any person. So, independent of the question whether they are established by people with a specific religious conviction, the patients can be any—and are. As far as we know, the Islamic population has not specifically established hospices for their own group; but certainly palliative care, by all kinds of providers, has been given to Islamic people in the cities where they live. My view would certainly be that, from the Christian point of view, the provision of care should not be restricted to any religion. But perhaps I did not quite answer your question?

Q1526 Bishop of St Albans: Of course, from my perspective, I agree with you utterly. I was concerned to see whether there were any particular groups within The Netherlands' society who are most vulnerable, as society's attitudes towards death and dying seem to be changing quite radically. You have given evidence that there are people pushing at other boundaries saying, "Maybe we will now look at that for euthanasia"?

Dr Zylicz: We do not know about this, but we have limited experience with muslim patients in our hospice. We admit them, without making any difference regarding faith or colour. What we see, however, is that when muslim people become terminally ill, they just jump on the aeroplane and go to Turkey or Morocco. Last year, for example, there were a lot of patients from Iraq and Iran, because they could not go to those countries. You do notice, however, that people are very afraid of our treatment—of receiving morphine and other drugs against pain—because maybe, although this has never been researched, they expect that this is part of euthanasia policy. That is a vulnerability of this group. I think that this would be very important research, but it is so difficult to do this. In the 12 years of our hospice, we have only had five or six patients from these groups, so it is not researchable.

Dr van den Muijsenbergh: In general practice we have more experience of Islamic people dying. What we see is that there is a tradition, even more than in other groups, that the extended family cares for the people. Also, what makes it difficult for the GPs to provide palliative care, for instance, is that death is not discussed. Most of the time, they do not want to discuss it—as we did not, perhaps 30 or 40 years ago. I agree with you, however, that it would be very interesting to investigate and to do research on that. There is, as there is in all aspects, a lot of dis-knowledge among people from other cultural backgrounds about how the Dutch medical system works. In many ways, they are afraid that what we do is not what they want or what they are used to. So it is a difficult and vulnerable group, but I do not think that they are exposed to more euthanasia.

Q1527 Earl of Arran: Do I detect from the conversation so far this afternoon that, as regards euthanasia, and albeit with reluctance, you do accept it but on the basis of better control and better balance?

Dr Zylicz: I am not sure that I understand your question.

Q1528 Earl of Arran: Do you accept the fact that it is probably going to remain as is, but that it should be better controlled and better balanced—from the point of view of palliative care being more available, et cetera—and hopefully thereby less needed?

Dr Zylicz: There is a lot to be done to get a better balance.

Q1529 Earl of Arran: But you accept it as part of the philosophy?

Dr Zylicz: I think it is unique in this country that—at least from my perspective from the hospice—we did not fight euthanasia frontally, saying "This is

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morally wrong and shouldn't be done". I think that in this country there is much more of a move always to depolarise discussion, to get round the table and talk with each other, to discuss how to prevent the situations which may lead to euthanasia. This is unique to this country, and so it is possible to talk about it. I am not a proponent of euthanasia; on the other hand, I am not totally against it. It does not mean that I accept it, but I believe that, with better care, you can make this much less necessary.

Q1530 Earl of Arran: I accept that.

Professor Jochemsen: I think that this better control is an illusion. Therefore, I think that a nation, a democracy, a state of law as we have in The Netherlands and in other European countries, cannot legalise euthanasia and maintain full control. I think that our practice has demonstrated that this is incompatible. That is a very important reason for me to oppose legalisation. Of course, the situation is as it is. It is legalised here, so our emphasis now is on trying to improve care, to prevent pressure on vulnerable people and to try to reduce the level of the practice of euthanasia—which, to my understanding, is the most sensible thing to do in the situation. But I am not happy with the law at all.

Q1531 Chairman: I want to give the nurse a chance, because there is a preponderance of doctors here. It is important that the nurse gets an opportunity.

Ms Gribling-Gommans: When I worked in hospital, talking about it with the patient gives the opportunity, when the patient is suffering, to give them a rest. As nurses, we have a lot of communication with them and we help to make the information from the doctor clear. That is our role, I think. Talking about it and being open about it gives the patient a rest. It is not at the point of the end of life; it is earlier. They will remember it later and, most of the time, the euthanasia itself will not be carried out. It is important that you can talk about it and be open.

Q1532 Chairman: I want to be sure that I have this right. If the patient is suffering very severe physical pain, for example, and if you have nothing else to offer in the way of help, then obviously that is a possibility under the existing law which would be considered?

Ms Gribling-Gommans: We also try to speak about things, to let the patient be comfortable, and try not to have to come to euthanasia. There are many more options to help them. If nothing is possible, then we discuss this. If there is a request for euthanasia, then it will be discussed several times after that, with the doctor and with the nurse. It is multidisciplinary: everybody has a role.

Q1533 Baroness Finlay of Llandaff: When we were looking at the reasons for euthanasia requests, we were given data which showed a high incidence of unrelieved symptoms. Do you think that reflects the inadequacy of true specialist training? It struck us that we have heard a lot about palliative care education but not about specialist competencies. I was wondering whether that was because the doctors do not know what they did not know?

Dr Zylicz: This is part of it. You are right. Inadequacy in palliative care can play a role, but I see something very different. People call it physical suffering and physical symptoms, because they need to have an argument to press on with a euthanasia request. If they do not get a euthanasia request, they will say that they have more existential suffering. So they name this as physical suffering. I think that these two things are indistinguishable at the moment, from the numbers we get.

Dr van den Muijsenbergh: Another thing is that a lot of doctors, at the moment the patient requests euthanasia because of unbearable symptoms, stop thinking about the possibility of relieving those symptoms because they think, "This patient wants euthanasia", and that is easily solved. No doctor will do it easily. I do not wish to give that impression, because it is really very hard. As has been said, when you go on and ask them what really is the problem, you can solve most of the physical suffering to a bearable point. The emotional aspects remain, but you can try to do something there. In my experience, there are still a few patients—but very few—who have the autonomous wish to end their lives in this situation. I think that those are the people that euthanasia should be meant for. For me, the question is whether that is a medical thing to do. Why should we, as doctors, do that? But that is another debate.

Baroness Finlay of Llandaff: We are all human beings and very complex.

Chairman: We think so anyway!

Q1534 Baroness Finlay of Llandaff: I am talking only about doctors, my Lord Chairman!

Ms Gribling-Gommans: And nurses!

Q1535 Baroness Finlay of Llandaff: Looking after complex patients can be exhausting. It can be physically and emotionally exhausting. I certainly know of a case where a patient was almost pressurised by the doctor, by being offered euthanasia. I wondered if that reflected the doctor's personal distress and whether you have come across cases where the doctor is thinking of euthanasia as the only solution?

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Dr van den Muijsenbergh: Yes.

Dr Zylicz: I was giving consultations in several situations like this, when the GP was calling me about a patient with gastrointestinal obstruction. He said, "The problem is that the patient is refusing euthanasia". I said, "What happened?". He said, "In the past, all these kinds of situations, when people were intractably vomiting, I solved by offering euthanasia. Now this patient does not want it, and I do not know what to do". That was really striking. Providing euthanasia as a solution to every difficult problem in palliative care would completely change our knowledge and practice, and also the possibilities that we have. This GP was not even aware of all the possibilities we have to control this kind of suffering. This is my biggest concern in providing euthanasia and setting a norm of euthanasia in medicine: that it will inhibit the development of our learning from patients, because we will solve everything with euthanasia. This kind of secondary alphabetism will come, if we are not careful and do not change these kinds of patterns.

Dr van den Muijsenbergh: It is inevitable that the personal beliefs of the doctor play a role in this. So you have doctors who are themselves convinced that there is no sense to suffering in life, and then they also apply that thinking to the patient.

Lord Joffe: I think you were saying—and correct me if I am mistaken—that resources for palliative care had not been increased and perhaps were under threat.

Chairman: For the development of palliative care, I think.

Q1536 Lord Joffe: Yes. We have just been to the Department of Health and they showed graphs into the future which suggested that there were a number of additional units which would come into place, which sounds to me like more resources?

Professor Jochemsen: Since there was a lot of money at the end of the 1990s and the beginning of this century, many institutions which were providing nursing care in general were opening palliative care units, because they got more money for the patients. The number of palliative care units has therefore increased considerably, but these people are mostly just continuing what they were doing—in the sense that there is no real specialist understanding, knowledge and practice of palliative care as it has been developed in hospices like Dr Zylicz's unit. So the number of places where palliative care is offered does not say very much about the quality of the palliative care in general in The Netherlands.

Q1537 Lord Joffe: I have one more question for Dr van den Muijsenbergh. I have had the benefit of reading a summary that you prepared to your thesis,

which I found very interesting. I noticed that in the part of the summary dealing with end-of-life care you mentioned that there were some doctors who you felt were far too enthusiastic about recommending euthanasia to their patients, and others who were doing a very good job, which obviously is important. Beyond that, however, I did not see, in the summary at any rate, any further criticisms of euthanasia as such. It was interesting to see that at the end—and it is always dangerous to select a single sentence and say that you can draw particular conclusions from it—you said, and this referred both to the doctors who had been enthusiastic and those who had been careful, "The doctors in the study proved to be willing and capable of administering intense and very personal palliative care that answered to the wishes and needs of the patients".

Dr van den Muijsenbergh: Yes, I think that is right. It was of course a selection of doctors, which is why it is restricted to those doctors. In general, however, I think that most general practitioners in Holland are very much attached to their patients and they provide very personal care. That means that, even if they work part-time, they visit the patients each day and they have good contact with the patient. That is what patients most value. They find their doctor supportive, and they find that more important even than whether all the physical complaints are resolved. That is important of course, but less than the personal attention. That is what all these doctors did and that is what the patients valued most. Despite that, however, I saw this huge variation in the doctors in this study. There were, as I said earlier, the doctors who were very willing to commit euthanasia—the doctors who themselves thought, "Suffering is useless"—and more than half of their patients died by euthanasia. The carers of those patients, when I spoke with them, sometimes said, "It was very sad that it had to go this way". As is well known, however, when patients have a good relationship with their doctor, they are content with whatever the doctor does. That does not mean to say that those cases of euthanasia were really necessary. GPs do not do it so badly, but that does not mean to say that euthanasia is good.

Q1538 Chairman: I think that our time has now passed.

Professor Jochemsen: I would like to make a very short comment, please. First, recent investigations have demonstrated that nurses are involved in the active performance of euthanasia, which they should not be. There is a regulation and they are trying to deal with that, but we again see that a practice has been developed here which is against the law.

16 December 2004Dr Maria den Muijsenbergh, Dr Ben Zylicz,
Ms Marjo Gribling-Gommans and Professor Henk Jochemsen

Q1539 Chairman: That is to say, allowing nurses to participate?

Professor Jochemsen: Right. Not in the direct performance, which should always be done by a physician; but in a certain percentage of cases nurses are directly involved in the performance of euthanasia—which is against the law. Secondly, I know from physicians who are opposed to performing euthanasia that they are afraid of saying so when applying for jobs and trying to find a post as a physician. In certain circumstances, that will make it much more difficult for them to get a job. Here again, in the reality of everyday life, I think that for the medical profession in our society there are many

more tensions and problems than often surface. Finally, a few years ago I wrote a chapter in a book on why euthanasia should not be legalised. I would be happy to offer this to you.

Ms Gribling-Gommans: I have just one comment to make. That is why in my hospital the euthanasia protocol has clearly stated what is the role of the nurse and what is the role of the physician. I think that is very good. The nurse has a role, but not in practising euthanasia.

Chairman: The clock has taken us to six o'clock. Lady Finlay said that advising or looking after very ill patients is stressful. It may be that helping us in this way by giving evidence is also stressful. It is very kind of you to give us your time and experience, and I am sure that we have profited much by it. Thank you very much.

FRIDAY 17 DECEMBER 2004

Present	Arran, E	Patel, L
	Carlile of Berriew, L	Taverne, L
	Finlay of Llandaff, B	Thomas of Walliswood, B
	Joffe, L	
	Mackay of Clashfern, L	
	(Chairman)	

Memorandum by NVVE (The Dutch Right to Die Society)

1. I, Rob Jonquière, MD, former family physician and currently employed by NVVE, the Dutch Right to Die Society as its Chief Executive Officer, would like to submit written evidence to the House of Lords Select Committee to consider and report on the Assisted Dying for the Terminally Ill Bill.

2. The NVVE came into being in 1973, as a reaction to the first court case in the Netherlands (Postma). It has grown to a not for profit patient organisation with a membership of over 103,000. NVVE is broadly respected in the Netherlands as a centre of expertise in the field of end of life choices in general and euthanasia in particular, and is as such consulted many times on these issues by interest groups, professionals and authorities.

3. Summary.

- (i) I am Chief Executive of the Dutch Right to Die Society (NVVE). I have been very involved in the debate around legislation of euthanasia in the Netherlands.
- (ii) The NVVE is a 30 year old patient organisation around end of life issues, with a membership of over 103,000.
- (iii) More than 20 years of experience in the Netherlands has shown that misuse and the slippery slopes of which so many were afraid, have not arisen and do not exist. The Dutch government studies have also found this. Where euthanasia (assisted dying) is an accepted choice, (eg through being legalised) the practice becomes transparent and open.
- (iv) When legalised, the possibility of patients to ask and for doctors to comply with, a request to die, without fear or danger has enabled an atmosphere where doctors and patients can together reach a decision about the end of life in an open and honest way.
- (v) Euthanasia being discussed as a possibility to end suffering if everything else fails generates peace for the patient, even if they never use this.
- (vi) The development of palliative care in the Netherlands occurred simultaneously with the development of euthanasia. It is not seen by the majority of professionals in the Netherlands as being the opposite of or an alternative to, euthanasia. Rather, it is complementary.
- (vii) The UK assisted dying for the terminally ill Bill states there should be a waiting period before the request can be acted upon, of 14 days. Dutch research shows that the shortening of life by euthanasia is in a majority of cases less than a week. This waiting list means that many requests for assistance to die will be in vain.
- (viii) Dutch surveys have found nearly 1,000 cases of “wrongful decisions” at the end of life. However, this figure is found to be up to five times higher in countries where there is no legislation for euthanasia.
- (ix) A recent European study found a surprising result in that except for the Netherlands and Switzerland, the percentage of doctors who did not communicate extensively with their patients and/or next of kin was disturbingly low.
- (x) I would be happy to give more evidence by way of an oral submission if you so wish.

My professional experience

4. In all my professional life, and thus in all four professional capacities in which I have been working, I have been involved in end of life care, and as such acquired extensive experience in the specific problems of end of life choices and its regulatory processes.

5. As a family physician (1972–1985) in my own practice an essential part of my work consisted of guiding people, many of whom were dying. During these processes, I found that patients were not only interested in treatment possibilities of their terminal conditions or anxious to lengthen their lives as long as possible. They were also interested and capable—when properly and openly addressed—to face the reality of nearing the end of their life and to discuss their individual ideas about possible choices: terminal care (as palliative care was called), pain treatment, and also actions to end suffering when this was becoming unbearable, by actively shortening life.

6. I followed training in terminal care (amongst others with Dame Cecily Saunders in St Christopher's in London) and—without professional guidelines and guidance, I discussed the possibility of euthanasia with some 10 patients who requested this. At this time euthanasia was illegal and not completely tolerated. Two of these requests and discussions resulted in euthanasia (active termination of life on request). The other eight patients died a natural death, mainly because of the peace caused by my promise to comply with the euthanasia request if the suffering became too severe.

7. Although I did not feel like a criminal in the two cases where I did perform euthanasia, the lack of a legalised possibility made me act like one: the euthanasia had to be done in secret, I had to report the death as natural, and I had to hope that nobody would find out about it and report it.

8. As head of the GP vocational training scheme both at the Free University Amsterdam and at the Leiden University (1985–1996) I taught future family physicians about the end of life care, including difficult emotional decisions such as to comply with euthanasia requests.

9. Many times, I experienced the lack of legalised euthanasia as a hindrance to an open and professional discussion on GP activities that were happening in reality (then, because of development of case law, more or less tolerated ["gedoogd"]). These discussions are necessary for good professional training of future GP's.

10. As General Manager of the Department for the Elderly in a Public Mental Health Institution in Leiden (1996–1999) I became involved with elderly persons who—being severely ill, suffering unbearably and certainly hopelessly—sometimes saw no other way then to end their suffering and thus their life by suicide, in most inhumane ways.

11. Because of the existing legal situation my department had no other formal duty than to prove to authorities that “we” could not have prevented the suicide. This deprived the patients/clients of the possibility for an honest and comforting discussion, let alone the possibility for a humane farewell to life. This caused more sorrow and distress to them and their next of kin.

12. Lastly of course, as full time Chief Executive Officer of the Dutch Right to Die Society NVVE (1999–to date), I have extensively and deeply been involved in the debates around the legalisation process: the research on the issue, the political discussions in Parliament, the professional discussions, and the debates in society and in the media (both national and international).

13. In this capacity I have seen that the legalisation of euthanasia in the Netherlands has been the result of a long-term development in which all groups and professions have been involved.

14. I have seen that the more than 20 year long experience with a tolerated (“gedoogde”) euthanasia practice has proven that misuse and the slippery slopes of which so many were afraid, have not arisen and do not exist.

15. I have seen that the now legalised possibility for patients to ask and for doctors to comply with that request without fear or danger to become “partners in crime” (as long as the criteria are complied with) have brought about an atmosphere in which doctors and patients together can reach a situation in which sound, honest, well considered and human decisions on questions around the end of life can be discussed.

16. The development of palliative care that occurred simultaneously was neither in my experience late in my country because of the existing euthanasia possibilities, nor seen by a majority of professionals as opposite or alternative for euthanasia. Rather, palliative care is seen as complementary.

Some comments on the Assisted Dying for the Terminally Ill Bill

17. Using my broad experience in this issue, I have the following comments to make on the Assisted Dying for the Terminally Ill Bill.

General comments

18. The development in the Netherlands has been one that can be called “bottom up” and was based on long-term grown case law and experience. The UK, on the contrary, misses these empirical data.

19. I think the choice for a more restricted bearing (only in cases of terminal illness) and for explicit inclusion of provisions for pain treatment (palliative care) in the Bill is therefore a good one.

20. Like in the Netherlands, the Bill looks like one that more defends doctors risks then patients rights.

21. That means that dignity in dying is a less crucial argument then would be wished for by patients. I have seen that such a position need not be detrimental to transparent decisions made together by doctors and patients and thus to situations in which both can “profit”.

22. Still, in the UK bill, more then in the Netherlands, doctors opinions’ (ie the consulting physician is the one to determine if the illness is inevitably progressive and thus terminal; next to the attending and the consulting doctor, also a specialist in palliative care has to see and assess the patient) seems to bear more weight than the unbearable suffering of the patient. It is exactly the equality in the Dutch law, in which one of the crucial criteria is the unbearable (patients side) and hopeless (doctors side) suffering, which makes the final decision many times more balanced and meets to the full both sides’ arguments.

23. Furthermore the duties to be fulfilled by the patient seem rather heavy (finding two individuals to witness the declaration after meeting the conditions set out in the sections 2 and 3 of the Bill and bring those together for the signing). This is especially since two doctors have already been discussing the request with a terminally ill patient.

Specific comments on the UK Bill

24. (section 1) I wonder if it is not more important for the consulting physician to be specialised in decisions around the end of life, than to be a specialist in the field of the patients disease. Often patients with serious and terminal diseases has been seen by many specialists, before even the request for assisted dying comes up. Of these contacts reportages will already be in the file of the attending physician.

25. In The Netherlands the SCEN doctors (doctors for Support and Consultation in cases of Euthanasia in the Netherlands, specially trained to be the second independent doctor in euthanasia) have proven to be crown jewels in the Dutch scheme. They are specialised in end of life choices: dilemma’s to be solved are mostly in the field of existence and the acceptance of the unbearability of the suffering of the patient and seldom in questions of diagnosis and/or prognosis.

26. The Bill defines that the suffering (correctly including other aspects than pain) needs to be unbearable and thus reason for a request for assistance in dying. However, at the same time the waiting period for this request until it can actually take place has to be at least 14 days. Dutch research shows that the shortening of life by euthanasia is in a majority of cases less than a week. If this waiting period is in place, many requests for assistance to die will be in vain.

27. Reading the Bill it is as if questions and discussions about end of life choices are only relevant, as far as they are taking place at the end of that life itself.

28. Experience (both generally accepted in the Netherlands and according to my personal experience) supports the fact that the whole issue of such choices is a matter of time. Both patient and attending physician should reach the joint decision (see paragraph 22 in this submission) together, which makes it into a sometimes time and emotional energy consuming process. The earlier these discussions start, the greater is the probability that the quality of care and the quality of the remaining lifespan will be optimal. In such cases the moment of the explicit need for “a solution” will not appear unexpected, the assessment of the request can be better done.

29. (section 6) It seems strange that the state of mind of a patient when asking for assistance has to be competent, but that the revocation can happen without regard to the patients physical or mental state.

30. (section 13) In the required documentation in medical records, I do not see where the report of the consulting physician would go. I suppose that this should be part of the file that will be sent to the monitoring commission, since the consulting physician plays a crucial role in the final decision, according to section 2.

31. (section 13 and 14) I do not see any value in reporting a case of assistance to die when that assistance did not lead to the patient's death

32. (section 14) One of the findings in Dutch research has been that the period between the doctor's report to the commission and the date of confirmation from that committee has an influence on the percentage of reporting. This period will therefore have to be as short as possible and preferably fixed.

Dutch data on assisted dying/euthanasia

33. I am often confronted with many arguments used to discredit the Dutch experience in this field, in order that other nationalities do not reach similar regulation on end of life choices.

34. Dutch developments, as I said above, have been going on over a long period of years, in a culture and structure in which juridical, medical and political transparency has led to a tolerated practice: doctor's have been able to build on medical experience, and together with juridical expertise, formulate criteria and case law through test cases up to Supreme Court Rulings. This has formed the basis of the new law and codification of existing practice.

35. During these discussions it was also possible to do three repeated surveys into euthanasia practice: 1990, 1995 and 2001. These surveys (the first one known as the Rummelink Report, the second and third as reports by Van der Wal and Van der Maas) are worldwide renowned for their statistical value. These surveys had a high response rate (> 90%), and included anonymous interviews of doctors by their colleagues and a promise of immunity of prosecution. All this made it possible to extrapolate the data from these surveys to the general population.

36. Through this the Netherlands were able to present a transparent picture of what is in reality happening in the field of end of life choices. These data also include figures of wrongful decisions (the notorious active termination of life without request in 1,000 Rummelink-cases in 1990).

37. The Dutch end of life surveys also show a steady rise in the reported numbers of euthanasia. Levels of reporting was 18 per cent in 1990, in 1995 it was already 41 per cent, with it being 54 per cent in the latest 2003 survey. There is no reason to believe that these numbers have since dropped.

38. The same survey procedure has been used in only two other countries (Belgium, Flanders and the Northern Territory of Australia, where there is not a situation of a tolerated euthanasia practice). In these countries, the percentage of euthanasia cases was lower than in the Netherlands, but reporting of this practice remained at zero. However, the percentage of termination without request was four to five times higher!

39. In a recent study (The Lancet, Van der Heyde *et al*, 2003), five other European countries studied showed similar tendencies (unfortunately countries like France, Germany or the UK were not included). The most surprising result actually was that in all countries, except the Netherlands and Switzerland (where assisted dying is conditionally legal), the percentage in which doctors did NOT communicate extensively with their patients and/or their next of kin was disturbingly low.

40. One of the essential conclusions from all this research is that it is generally accepted that in a situation where euthanasia is legalised or otherwise officially regulated and thus an accepted end of life choice, the practice becomes transparent and shows no real signs of slippery slope.

Palliative care and euthanasia in the Netherlands

41. Another allegation is that in the Netherlands euthanasia could develop, because there was no or at least poor palliative care. The practice of euthanasia developed in the Netherlands in the early 1970s. Palliative care as such did not really exist at this time just as it did not exist in the rest of the world.

42. Since Palliative Care became known as a specialised area of health care, it has also developed in the Netherlands. And whilst palliative care was not—as in the UK and Belgium—introduced into the legalisation of euthanasia, the minister of Health introduced an extensive programme to have palliative care (PC) implemented at a high level in the care sector.

43. For example, five University Research Centres into PC were started; clinical teams (including all sorts of disciplines) came into being everywhere in the country; Dutch General Practitioners followed training both in the Netherlands and in UK (Baroness Finlay of Llandaff). And also the SCEN doctors (see paragraph 25 in this submission) were trained in the field of Palliative Care, in order to be able to assess still existing possibilities for (palliative care) treatment when they see as second independent consulting physician a patient who made a request to die.

44. During this whole development the practice of euthanasia continued to exist; both proponents for euthanasia and for PC arrived generally at the conclusion that the two do not exclude each other, but are complementary.

45. Euthanasia is indeed a last resort, when all treatments, including PC are no longer capable of taking away the (unbearable) suffering of the patient. But also, euthanasia being discussed with the patient as a real possibility to end the suffering if everything fails generates peace for the patient, in which he will undergo palliative care uninhibited by unreasonable fears.

46. The same surveys, mentioned in paragraph 31, showed that pain is seldom the main reason for patients to ask for euthanasia.

47. It is important to realise that because of the social and health insurance system in the Netherlands, all patients can make use of all necessary facilities and provisions in end of life care, including 24 hour home care, which are widely recognised as being of high standards. Patients in the Netherlands do not have a lack of care. However, the pure fact that the patient can make a choice concerning their end of life is central in the Dutch system.

Conclusion

48. I have many more arguments to advise you on the basis of my extensive experience. However, I finish my submission now, with the offer to support my submission or add to it in oral evidence if you so wish.

17 August 2004

Examination of Witnesses

Witnesses: MR JACOB KOHNSTAMM, Chairman, and DR ROB JONQUIERE, Chief Executive Officer, NVVE, examined.

Q1540 Chairman: Would you like to introduce yourself, Mr Kohnstamm, and also your colleague for the record?

Mr Kohnstamm: My name is Jacob Kohnstamm, Chairman of the NVVE and President of the World Federation of the Right-to-Die Societies. We are very pleased to have you here and hope that we might be of some help to you, in finding your way through this difficult subject. I would like to introduce Rob Jonquiere, who is the Director of the NVVE. I was told that you would like us to introduce ourselves briefly, and then start any discussion.

Q1541 Chairman: That is right. We would like you to introduce yourselves and perhaps say a word or two about the situation, as you see it, in relation to the matters into which we are enquiring. The help you give us will be noted by the shorthand writer. The transcript will be available for you to look at when it is finished, in order that you may ensure that the transcript is in accordance with what you think you have said. In due course, it will be appended to our report and become public property when our report is put in to the House of Lords. Perhaps you would like to say a little about your position in relation to the subject matter, and then my colleagues may possibly have some questions of you.

Dr Jonquiere: I have sent you a written submission in which I introduced myself in four ways. I worked as a family physician and, after that, I worked in university training for family physicians, in public health, mental healthcare for the elderly, and now in

this capacity as Chief Executive of this organisation. In all four, I have been involved in all kinds of end-of-life decisions, and have been happy to be able to be involved in the legalisation process of euthanasia. After the experience in my former three capacities, I have discovered how difficult it is to follow the whole process of legalisation and the nuances that there are in the decisions that have to be made. On the other hand, I have also seen that, at least in The Netherlands and because of the culture of our country, the developments have meant that we have grown. Discussing difficult ethical and moral issues is part of our culture. It means that the regulation of euthanasia has followed a process, and this regulation process has been translated into a law. I think that has been the great advantage of the Dutch situation. After the legalisation was completed, the practice did not change greatly in The Netherlands. In principle there was a big change because, since April 2002, euthanasia has been a legalised option for doctors and patients, but in terms of the process it did not change greatly. Compared with the UK situation—because the legalisation process is one which has grown over a period of 30 years—we have seen the criteria developed by case law, developed by the Royal Dutch Medical Association, which together produced what we have now. In all four of my previous capacities I have seen how important it is that patients and doctors have the possibility of a choice at the end of life. I have seen that there is no need to be afraid that, when you give the option, an enormous number of people will choose that option.

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Mr Jacob Kohnstamm and Dr Rob Jonquiere

It is more important to have the option and, once you have it, you see that people are more at ease and are able to take a path to the end of their life, without any wish to finish it by euthanasia. I simply make that as a first statement.

Q1542 Chairman: Could I ask you for a little clarification? You speak about the legalisation process but, if I understand it correctly, the matter first came to the ordinary courts and the ordinary courts reached the conclusion that, subject to conditions, there was a possibility of this choice being allowed and physicians being able to give effect to it. Is that correct?

Dr Jonquiere: That is correct, yes.

Q1543 Chairman: That was a development, if you like, a case law development, of what was the actual law that had been a law in The Netherlands for quite a long time, but it had been seen to develop through the case law. Is that right?

Mr Kohnstamm: Perhaps I may introduce myself and then try to answer your question. I have been in parliament for nearly 25 years. Her Majesty the Queen appointed me as a data protection commissioner in August, and that is why I felt that I had to say to my party and to the Senate that I would not wish to combine these two functions. I was therefore a senator until last September. I have been involved in this discussion since 1979, as a very young member—

Q1544 Chairman: You must have been extremely young in 1979!

Mr Kohnstamm: Thank you very much! I was involved in this subject as a fairly young member of our Second Chamber, *Tweede Kamer*, and defended an initiative to legalise, under strict circumstances, euthanasia. Turning to your question, it is right that if you look at the way doctors, or even society, looked at the situation of Mrs Postma—the case which started the discussion—it is as something which was legalised by case law. In the meantime—

Q1545 Chairman: When you say “legalised”, I think you mean that the court recognised that the law allowed this particular option?

Mr Kohnstamm: No.

Q1546 Chairman: Is that not right?

Mr Kohnstamm: A very definite answer: no. First of all, it was a criminal offence. It was in our criminal code—and, by the way, still is under certain circumstances—that it is not allowed to do so. There was, at that time, a full stop at the end of that sentence. It was not allowed. In the meantime, however, in our code—which was proposed by

Napoleon, not by a crazy Dutchman or anything of that sort—

Q1547 Chairman: A Frenchman!

Mr Kohnstamm: These continentals! Putting it simply, it is the choice, in a certain situation, to drive much faster than is allowed, or to have your mother in the car die before you arrive at the clinic; and that you have the right, in that set of circumstances, to drive faster than is allowed by law. This was the situation of Postma. The court said, “It is not allowed. It is a criminal act and you should not do it. But in the situation where you have an ethical or moral dilemma between, on the one hand, someone’s request which you feel is an honest and honourable request and, on the other, something which is prohibited by law, then, because of the Napoleon part of the code, in certain circumstances you are acquitted. It is not that it is not criminal, it remains a criminal act, but you will not go to prison for it. The courts always said, “You are not allowed to do so. It is a criminal act but, in this circumstance, we will not send you to jail”.

Q1548 Chairman: If you are not going to jail, what else happens?

Mr Kohnstamm: If you do it a second time, you have even bigger problems. Finally, as to our business in parliament, the situation eventually arises where you say that if a certain development in society is no longer coped with by the law, there are two possible choices: one is to keep strictly to the law; the other is to change the law in order that movements in society should be made possible. That is why, as Rob Jonquiere said, we got used to the idea in The Netherlands that, under certain circumstances, euthanasia should be allowed. However, it was not allowed in the law and so it was dependent very much on the individual policeman, on the individual public prosecutor, on the individual minister of justice whether or not someone would be taken to court. That is why the law was changed. A doctor can no longer say to the patient who says, “Doctor, I want to die”: “There’s the door. Please leave my room, because you are asking for something which is a criminal act”. In that sense, there is a difference between the situation before the law and after the law.

Q1549 Chairman: When you speak of “the law” in that phraseology, you mean the statute that was introduced in 2001, do you?

Mr Kohnstamm: Yes. Case law is what we call jurisprudence, which can be changed overnight if there is another court decision. The law is there to stay, until parliament decides to change it. A law is something more definite than case law can ever be.

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Q1550 Chairman: I can see that. The statute law comes along in 2001. I think that there were some earlier statute variations, but the main development, as I have understood it anyway—and you will correct me if I am not right—was that the courts gradually recognised, in particular, the defence of necessity as justifying a doctor in giving effect to a request by a patient, in very defined circumstances. The circumstances were very closely defined, but the court ultimately accepted that as an entitlement, because of the existence of the defence. Is that right?

Mr Kohnstamm: That is correct. There is quite a difference between the British system and the Dutch system, which also goes back to Napoleon, that it is easier and faster for us to enter the lawmaking procedure. In Britain, case law is much more the usual way of finding your way than in Holland. In Holland, the judges only judge upon the law and they cannot interpret things that are not in the law, so to speak.

Q1551 Chairman: No, but the defence of necessity was in the law and recognised as applicable to these circumstances by the case law that preceded the activities of parliament?

Mr Kohnstamm: But there is a big difference between the decision of a court and the decision of a democratically chosen body which says, “It is now a law”. Although, looking at the history, cases as such perhaps did not change that much, I think the fact that a democratic decision has been taken that, under certain circumstances, this is allowed makes quite a difference. For example, the police do not go with flashing lights to the doctor when that doctor reports that it was euthanasia and not a natural death. There is also the commission which you have been informed about. I think that yesterday you spoke to the people involved in the second opinion process.

Q1552 Chairman: SCEN?

Mr Kohnstamm: Yes, SCEN.

Dr Jonquiere: I am not a lawyer or a member of the judiciary but—

Q1553 Chairman: That is an advantage you have over some of us!

Dr Jonquiere: On the other hand, I am a doctor—and that can also be a disadvantage! As I understand it, the defence of necessity has been a possibility in our law, but only in exceptional cases. What we have seen since 1990, with the surveys and research carried out by van der Wal, is that euthanasia, or acts of life termination by doctors, have happened about 3,000 or 3,500 times a year. You could no longer speak of “exceptions”. I understand also that one of the reasons for legalisation of the process was to make it a law instead of, every time, having it depend on the defence of necessity. I think that is why everything

came together. The big advantage has been that, at the moment the law came into effect, there already existed a practice of euthanasia which was well regulated, well monitored, and well known. Compared to what happens elsewhere in the world, one of the things that the Dutch have been successful in is in making clear and transparent what actually happens in this field—including, let us say, the bad decisions, where doctor has terminated life without request. We have made ourselves vulnerable in that regard: that everyone attacks us on the Rimmeling figure of 1,000. You have undoubtedly heard about that. It is a sort of side-effect of our wish to be open about what is happening. At the same time, however, we know what is happening and, when it was legalised, we knew exactly what we were legalising.

Q1554 Lord Carlile of Berriew: How far beyond necessity have you now gone, or are you only allowing euthanasia where there is necessity?

Mr Kohnstamm: I am not sure what “necessity”—

Q1555 Lord Carlile of Berriew: You cited the doctrine of necessity as an appropriate defence to a charge of homicide. As I understand it, you are saying that euthanasia was introduced as a lawful procedure, so that there would be a clearer and legislative understanding for what doctors could do. What I am trying to discover—and, to be fair to you, I should refer to your euthanasia statement, which I have been reading for the last 10 minutes—is in relation to the question of how far you have gone beyond necessity.

Mr Kohnstamm: I am not sure whether I understand the question.

Q1556 Lord Carlile of Berriew: Let me take you a little further. This is very important, because we need to understand what you are doing. Can we look at your euthanasia statement, which is what you recommend to your members? It is on the sixth page of the document you have given to us. If I read paragraph 1 and then paragraph 9 of your model euthanasia statement, I would respectfully suggest to you that you could not have a better example of the slippery slope argument than this. It includes, for example—forgive the caricature—being able to make a euthanasia statement because you are virtually blind and therefore cannot watch television or do handicrafts, which is a combination of 1 and 9(c); or if there has been, in (d), severe impairment of your mental faculties, as a result of which, for example, you must be “confined because you would otherwise go wandering”. That is not necessity by my standards, I am afraid; that is elective euthanasia and far from necessity—which I would be deeply opposed to. How do you justify that?

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Mr Kohnstamm: I have two comments. One is that, in our law, there are always two persons who have to judge whether or not it is allowed, in conformity with the law. So first there is a person who, for whatever reasons, starts the discussion with—in 85 per cent of the cases—the family doctor. As to a slippery slope, if I may say so, the question of your own death is the reverse side of the slope. As far as we can see, from our members and from the practice in Holland, before someone decides that he wants his life to be ended and asks the doctor to end his life, there is, in Dutch, a *remweg*. If you see the struggle of the person who finally decides that, taking into consideration everything that he knows, sees and feels, he wants to die, it is not a slippery slope. It is always something that people do not want to do. They hate being close to that situation. My second comment is that, again in 85 per cent of the cases, there is the family physician who, because of the law, has to judge whether or not this is a situation in which the law allows them to do what is asked. As to the statement, we firmly advise our members and those who go along with the statement to form their personal reasoning why they think there is this necessity for them, and only for them—not for you, not for me, not for anyone else—to decide that, at this point, he or she really wants to end their life. Even in the way you are talking about it—I think it might seem as not being able to watch TV any more—but, in the Dutch situation . . .

Q1557 Lord Carlile of Berriew: No, I understand, because I have read this. Perhaps I can ask one other question?

Mr Kohnstamm: May I ask Rob to answer this?

Dr Jonquiere: You refer to necessity and our statement. I would rather refer to the law, which stipulates that the reason for a legalised euthanasia process is that there is unbearable and hopeless suffering. We try to help our members formulate what in their view is unbearable. The identification of what is unbearable is for the patient. They are the person who says, “This suffering, for me, is unbearable”. This helps them to formulate what is unbearable. But “unbearable” alone is not sufficient to come to the conclusion that euthanasia is the solution. There you need the medical expertise in terms of the hopelessness of the suffering. As Jacob has said, it is those two people—the doctor and the patient—who come together, to compare and discuss, deal and wheel—whatever you may call it—about the unbearability and hopelessness. When they, together, come to the conclusion that there is no real alternative and no outlook for a better situation, then they may, because of the law, decide on it. If you speak about necessity, that was before the law and one of the bases of it—which pointed only to doctors who referred to necessity. In terms of the patient who

fills this in, it has nothing to do with necessity. He is the only one who tells the doctor, “This is what I consider to be unbearable and not compatible with my life”.

Q1558 Lord Carlile of Berriew: Perhaps I can follow that up with one question. Let us take a more serious example. The examples I have taken are from what you have written, not from what I have made up myself. If you take (a), “a life with serious, permanent paralysis”, I may find facing paralysis, as an able-bodied person, completely unbearable as a prospect and may sign a document like this, be rendered unconscious in a trauma and paralysed; but I know personally of numerous paralysed people who live extremely fulfilled and successful lives—for example, the chief prosecutor of Madrid. Having been paralysed, they have discovered something in their lives which they had never discovered before. If that person had made a euthanasia statement in The Netherlands, he might well be dead?

Mr Kohnstamm: No, sir.

Dr Jonquiere: No, the only thing is that, when he is found unconscious—having made this statement—the doctor sees a patient who has concluded that a life with a serious paralysis is unbearable. The doctor then has to comply with all the other legal criteria. When a patient is unconscious, it is something which in practice is presently considered not to be compatible with suffering, and so not a reason for euthanasia. It is not automatic. One of my members’ complaints is that when they fill this in they do not have the right to euthanasia. I tell them, “You do not have the right to euthanasia. You now have the right to ask for it. You have to ask somebody else and he has to comply with other rules before it can be done”.

Q1559 Chairman: The rules have to be complied with at the time the euthanasia is being administered?

Dr Jonquiere: Yes.

Mr Kohnstamm: Correct.

Q1560 Chairman: The written statement to which Lord Carlile refers, of which you have given an example here, is one which may be signed a considerable time before that situation develops. If I have understood the structure right, it replaces the need for mental competence at the time that the euthanasia decision is made—which would ordinarily be required if there was no advance statement. Is that right?

Dr Jonquiere: The law talks about there being a well-considered and voluntary request. It does not state that the request has to be written down, or whatever. There should be a request. During the legalisation process, people discovered that sometimes patients reach a situation where, at the moment the request would be made or discussed, they are no longer able

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orally to say what they want. The law then says that this statement must be considered as being a request—only a request, which is the first point in our criteria.

Q1561 Chairman: I think that is what we understand.

Mr Kohnstamm: So that, in the situation you speak of, there might be a request; but if someone is able to communicate by whatever means, that communication counts. Second, there is a doctor, who then has to look at it and decide whether this person is suffering hopelessly. There is therefore no need to fill in this request. You may or may not do it; but, if you are still able to communicate—not necessarily to speak but to communicate, and there are many ways of communicating besides speaking and writing—that communication counts, and not the fact that you have written it down, at whatever time in your life.

Q1562 Chairman: If you do not have the capacity to communicate later, the advance statement may suffice—to comply with the law so far as request is concerned?

Mr Kohnstamm: Like, for example, the declaration that I do not give consent to doctors to operate on me, for whatever reason. Even if I can no longer communicate, it is full stop after that. Like, for example, when you go to a notary to make a will. It is something which is taken as your decision regarding what will happen to your property, or whatever—even if you did it when you were 25 years old.

Q1563 Lord Patel: If I sign this advance wish, or whatever you call it, and if I become unconscious, as Lord Carlile has said, this would remain valid. If I cannot communicate, this will be valid?

Mr Kohnstamm: That is correct.

Chairman: As a communication.

Lord Patel: And the law allows that.

Chairman: But the law still requires—and it is quite important—that, at the time the actual injection is to be given, you must then have the suffering that comes up to the standard that the law requires.

Q1564 Lord Patel: Yes, but if I have signed this, according to what is written here, will that be accepted in law as unbearable suffering?

Dr Jonquiere: No, as a request.

Mr Kohnstamm: It will only be considered a request.

Q1565 Chairman: It also operates if your mental capacity has been damaged between times. As I have understood it anyway, a fully considered request is thought to be based on the idea that the person making it has mental capacity to make that decision. So, in this way of looking at it, the advance

directive—and this complicates the issue a little, because the two are a little separate—replaces the need for a consent or request at the time of the euthanasia by a person of competent mental capacity, but it does not in any way affect the condition of unbearable and hopeless suffering, which the law requires before the doctor can actually perform euthanasia. Is that correct?

Mr Kohnstamm: That is correct.

Lord Patel: But this request could be granted?

Q1566 Chairman: Yes, it could.

Mr Kohnstamm: Perhaps I might ask Rob, the doctor, to give an example of when the unbearable nature of the situation, which has been signed in an advance directive, could possibly end that person's life, because the doctor decides it is hopeless illness. What sort of a situation are we in then?

Dr Jonquiere: For example, in terms of mental capacity, if a patient signs a declaration or a statement saying that there are certain conditions in which he would consider his suffering to be unbearable, and if that person gets Alzheimer's disease, but at the same time develops a cancer process somewhere which obviously is causing a lot of suffering, then if that person has not written an advance directive, there is no request. No doctor in The Netherlands—even if the whole family asks for it and everyone sees that there is hopeless and unbearable suffering—will ever terminate a life, because there is no request. We tell our members that if they make this statement, they have a guarantee—not to have euthanasia but that there is a request, in case something like that develops. For example, paragraph 9(d) which talks about Alzheimer's disease—almost all our members fill in paragraph 9(d). Actually, in the last 10 years in The Netherlands, euthanasia has perhaps taken place four times in an Alzheimer's patient. It has happened at an earlier stage, where the patient was still capable of communicating with the doctor, and the statement was not necessary—because the patient could ask for it at a certain stage. That is perhaps the best proof that this considers only the request and the opinion of the patient, and the doctor has to agree—or whatever you would call it—before anything can happen.

Q1567 Baroness Finlay of Llandaff: I want to work through an example, if I may, because I am finding it quite difficult to follow. Say we take a 54 year-old lady with carcinoma of the breast, who has completed one of these statements. She has widespread bone metastases, and she becomes confused. She is already on opioids, various drugs, for symptom control. What is the doctor's obligation then, when she is confused, having signed this? She would fulfil the criteria of needing to be confined, because she may go wandering. What does the doctor

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do? She has now metastatic breast cancer; she will not be cured; she has signed one of these. Can you talk me through the physician's role?

Dr Jonquiere: First of all, you talk about "obligation". There is no obligation on the doctor. The law does not say that you are obligated to give euthanasia, and this statement never creates an obligation on the other side. That is one thing. Second, the case that you are describing means that that patient has been in treatment with a doctor or doctors, with family doctors, for a long period of time.

Q1568 Baroness Finlay of Llandaff: Yes.

Dr Jonquiere: I would like to emphasise at this point that the decision for euthanasia is not a decision which comes out of the blue. It is the result of a long discussion.

Q1569 Baroness Finlay of Llandaff: I understand all that, and that the doctor knows that the patient has said that her nightmare is to become paralysed or to become confused and be dependent.

Dr Jonquiere: I think that discussion would have already occurred between the doctor and the patient, before the patient was confused. So the doctor will probably know about the wish of the patient. You could say that, legally, when he is going to comply with the request for euthanasia—at a certain moment when the patient is incompetent—then he would refer to the request. But I would consider the possibility that, if he got this request early enough, with good communication you do not even need this statement.

Q1570 Baroness Finlay of Llandaff: So it would be the doctor's decision whether to investigate or not.

Dr Jonquiere: Yes.

Q1571 Baroness Finlay of Llandaff: The problem is that the patient may not have realised that that confusion may be reversible. In the discussion with the patient you cannot cover every eventuality of the whole textbook of oncology.

Dr Jonquiere: I agree completely.

Q1572 Baroness Finlay of Llandaff: Supposing then she has hypercalcaemia. The doctor treats her, her confusion clears, and she says, "I did not want to be treated, because I have this piece of paper. You have now treated me".

Dr Jonquiere: This is not what this paper says—"I don't want to be treated".

Q1573 Baroness Finlay of Llandaff: So this has no force in law?

Mr Kohnstamm: It has no force in law, that is correct.

Q1574 Baroness Finlay of Llandaff: So this is just an expression of wishes?

Mr Kohnstamm: Yes, exactly.

Q1575 Baroness Finlay of Llandaff: So the doctor treats. Let us move on. Six weeks later, she says, "My metastases have spread. I think that I would want to end my life". She had leg weakness and spinal cord compression. So she now also fits the criteria of a permanent paralysis. It has been there for days, so she will not improve with radiotherapy. She has already spoken about it and had that discussion. Would the doctor then say, if he is agreeing with the patient for euthanasia, "At this point we will go ahead and proceed", and may go ahead with euthanasia the next day?

Dr Jonquiere: Yes. The essential thing is that the doctor talks with the patient. The law tells you about the suffering situation. The reason for the suffering is only secondary. The core point is the suffering of the patient. So the reason for the euthanasia at the stage you describe is not a paralysis; the reason is the fact that the patient tells the doctor, "For me, this is unacceptable suffering", and the doctor agrees that he cannot do anything about it. That is the reason to make a decision—not a paralysis.

Q1576 Baroness Finlay of Llandaff: Where I have a difficulty is that I have had many patients like that. Then, as Lord Carlile says, we will go through rehabilitation with them, and I have had many patients say, "I never believed I could have such quality of life".

Dr Jonquiere: My patient maybe knows and I can tell her, "I can put you through rehabilitation and you may . . ." and so on, but—

Q1577 Baroness Finlay of Llandaff: But you do not believe it at the time, when you are devastated.

Dr Jonquiere: But says, "I don't want it". I have heard a patient say to me—and do not be offended by this—"I don't want to be cuddled to death". That is the personal choice of that person. I know that sometimes patients, making that choice, cause a lot of difficulties for the doctor who knows that he has possibilities. If the doctor finds that the possibilities are serious, the doctor should say no to the request and should argue.

Q1578 Baroness Finlay of Llandaff: But is it not easier for the doctor than to give in to the request—

Dr Jonquiere: No, never.

Q1579 Baroness Finlay of Llandaff: . . .because it is such hard work to look after these patients?

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Mr Kohnstamm: Would you ever want to terminate the life of your patient, as a doctor? Would you?

Q1580 Baroness Finlay of Llandaff: I do not, no.

Mr Kohnstamm: Dutch doctors are not very different.

Dr Jonquiere: When I received a request for euthanasia—and I hear this also from my colleagues—when a patient said, “Doctor, this is unbearable for me. Please help me die”, the first reaction as a doctor is, “Oh, my God! A request again!”, and I will find whatever I can to prevent it.

Q1581 Baroness Finlay of Llandaff: What I find difficult when we get requests like that is, if you ask the questions behind the request, the request vanishes. I have never had a persisting request.

Dr Jonquiere: I completely agree. That is what I would do. I would immediately ask, “Why is it unbearable for you?” and then we talk about it.

Q1582 Baroness Finlay of Llandaff: Are you monitoring that every Dutch doctor who looks after patients has the skills and competencies to ask behind the request? Do you have the evidence that they all have the knowledge, skills, and competencies to deal with the problem adequately?

Dr Jonquiere: If you talk in this sort of scientific way, my answer must be no, I have not. I do not have all 8,000 family doctors in my hand and cannot show you what they do.

Q1583 Baroness Finlay of Llandaff: No, I mean you in terms of the country. Is there a national standard to assess that those doctors performing euthanasia have the skills, competencies and knowledge to deal with the complex problems that these patients pose?

Dr Jonquiere: We do not have evidence for that. The evidence we have is only that we see that cases which have been monitored by SCEN doctors, for example, have been put through careful decision-making, and we see that doctors who are getting requests and who are prepared to comply with requests have, maybe not the capacity and skill in the particular field of palliative care and things like that, but know where to get that.

Mr Kohnstamm: There is perhaps another way of answering the question, if you would allow me. We are the only country in the world where there has been such investigation in the practice of life-ending decisions by doctors. Without being rude, you have not had the sort of investigation in your practice as we have had. Whatever you do, I would urge you—and I think that you will be talking to van der Wal later—to do that sort of research on the situation in Britain. Then we should talk again.

Q1584 Baroness Finlay of Llandaff: I am asking about medical competencies.

Mr Kohnstamm: One of the conclusions from that research was that, in almost all the cases of euthanasia, the length of life would otherwise have been another week or eight days. So the specific situation—which you are rightly talking about, because it is a very difficult situation—is that in Dutch practice, as we know from the van der Wal and van der Maas research, the person who asks for euthanasia and who gets it in the end will on average live only eight days less than he would have lived otherwise. In the vast majority, therefore, of up to 95 or 98 per cent of the cases, the situation you are pointing to would not in the end come to the decision for euthanasia.

Q1585 Baroness Finlay of Llandaff: I am not here to pass judgment on what you are doing in any way. I am here to understand the process, because we have a proposed piece of legislation in the UK and we have to understand it in the context of a UK system, which is very different to the system in Holland. You are fortunate in having a very high standard of general practice, with doctors who are mostly Dutch graduates. That is very different to the situation in the UK. What I was wondering about were the competencies, skills and knowledge of the SCEN doctors, the second-opinion doctors, in terms of their ability clinically to know all of the options, and to be sure that all of the options had indeed been offered to the patients.

Dr Jonquiere: SCEN doctors are specially trained to fulfil this duty and to have the skills you are talking about. You could argue that a SCEN doctor should have all the skills of palliative care and of psychology. However, the other side is that, as Jacob has said, first of all 85 per cent of euthanasia is performed by family doctors, and part of the skills you need are part of the training schemes for family doctors. In the last five to 10 years, and interest in training in palliative care—as one of the alternatives in treatment for patients with terminal illnesses, not alternative to euthanasia—has grown in terms of postgraduate education. Of course, it can always be better than it is at present. Doctors, especially when they are confronted with these sorts of requests, find that sometimes they are lacking certain levels of skill and they ask SCEN doctors to fulfil that duty instead of them, or they refer to specialists, and so on. My point is that, because doctors find the request so difficult—and the most difficult request you can get as a doctor—that, in itself, is the reason why they try to find whatever way they can not to do it. If they find that they lack the skill, they will try to find it with a colleague and ask a colleague about it. That is not evidence-based by research but it is what I hear from many colleagues and also from practices out in the field.

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Baroness Thomas of Walliswood: My question was in some ways a much simpler one. I apologise for going back to this euthanasia statement, but that is just the background. I am concerned about the possibility of performing euthanasia on patients who have lost their capacity, through Alzheimer's or any other similar kind of mental deterioration. That is definitely one of the aspects which people are referring to when they talk about the slippery slope—the concept that a doctor might be able to take a decision to terminate the life of a patient in that situation. Can you tell me if it makes a difference whether or not the patient has made a euthanasia statement? That is the first thing. Second, how can you determine whether a patient is really suffering when in fact they are not capable of communicating with you verbally?

Q1586 Chairman: There are two points. First, if there was no statement, would that make a difference? Second, if Alzheimer's disease, for example, has put you in a situation where you cannot communicate, how can the doctor make a judgment on whether or not there is unbearable suffering?

Dr Jonquiere: My answer is quite simple. If there is not a statement, there is no question of terminating a life. That is completely clear. Having this law also makes it completely clear for doctors. If there is no request, they will not do it—full stop. With regard to moving towards the slippery slope in this way, I am not afraid of that at all. What I always say is that we have 30 years of experience. If a slippery slope was going to happen in this way, it would certainly have happened in The Netherlands—because we have been involved in this process for 30 years. You do not need to be afraid of that, therefore. If there is an Alzheimer patient with a statement—so, legally, with a request—that is a dilemma in The Netherlands, on which we organised a symposium last week, attended by 300 doctors. They say, “We cannot judge what the suffering is”. Many doctors consider—and I believe that it is formulated as such in the Council of Europe—that dementia as such, Alzheimer's disease as such, is never a reason for euthanasia.

Q1587 Lord Carlile of Berriew: So why is it in here?

Dr Jonquiere: It is a request only.

Mr Kohnstamm: Why could not an individual think that, in a situation of dementia, he does not want to live any more?

Q1588 Lord Carlile of Berriew: The answer to that is that you are a campaigning organisation, and you are advising your members that any one of these (a) to (d) situations is a sufficient situation to make a request.

Mr Kohnstamm: No.

Dr Jonquiere: We are not advising, no.

Q1589 Baroness Thomas of Walliswood: I am trying to get my mind round under what circumstances, with this request—

Mr Kohnstamm: It would be sufficient?

Baroness Thomas of Walliswood: Yes, exactly—would be sufficient—when, as several doctors have said both on this and the other side of the table, when talking about this situation, you cannot tell whether or not the patient with dementia is suffering, and I think that some people reach the conclusion that they are not suffering. How can you then satisfy the criterion of the law which says that the patient has to be suffering—I have forgotten the exact phrase—

Q1590 Chairman: The translation we have been given is “lasting and unbearable”.

Mr Kohnstamm: “Hopeless.”

Baroness Thomas of Walliswood: It is obviously lasting, but is it unbearable? How can you tell that? I can assure you that there are many people in the United Kingdom who, when using the word “euthanasia”—which we are not using in this Bill, and we are talking about “assisted suicide”, which is not quite the same thing—

Chairman: “Assisted dying.”

Q1591 Baroness Thomas of Walliswood: Yes, “assisted dying”. This is exactly the sort of thing that people fear: that they or their loved ones could be living in a situation which seems perfectly intolerable, and they will be bumped off because they have lost their mental capacity. That is a real fear; it is not a false fear. How do you get over that problem under Dutch law?

Dr Jonquiere: I think we get over that problem because doctors are saying to families of Alzheimer patients—and it is the family of the Alzheimer patient which presents the statement—“I am sorry, I cannot decide whether it is unbearable or not”. One of the biggest guarantees, which I know from my own experience but also from that of my colleagues, is that if you finally, after a long discussion and after moral deliberation, decide to go forward with euthanasia, the moment you give the last injection—which is euthanasia from our point of view—you want to look your patient in the eye and to say, “Is this really what you want? If I now give you this injection, it is the finish”. If, at that moment, the patient says no, you stop the whole process. That is the big problem with an Alzheimer patient: you cannot ask an Alzheimer patient. That is what doctors say to us, and it is why doctors, in practice, almost never apply euthanasia to an Alzheimer patient.

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Mr Kohnstamm: I am also learning from this discussion, but you could also make the same law as the Dutch law—without the advance directive. It is very feasible. I do not like this discussion very much. I know that it is very important, but it only applies to 0.0003 per cent of the cases of euthanasia in Holland. If you are afraid of the slippery slope and if you want to concentrate on this discussion, you are welcome to. We are in your hands. However, if you want to regulate something—and I am not going into that discussion—you could easily do it without the advance directive.

Chairman: There is no question at the moment in this particular Bill of a proposal for an advance directive. What we are investigating here is the practice in The Netherlands, and you have presented this example. I think that it has produced a certain amount of—what should I say?

Lord Carlile of Berriew: Concern.

Q1592 Chairman: Concern, or discussion. However, in the light of the questions that Lady Thomas has asked you, my understanding is that, at the very most, such a statement as this could supply a lack of request in an Alzheimer patient, for example, but it does not replace the need for the doctor, at the time he is considering administering euthanasia, to satisfy himself—however he can do it, and I do not know whether he can or not—before euthanasia becomes lawful here in The Netherlands, that the patient is suffering unbearably and that that suffering is lasting, in the sense that it cannot have any hope of being ameliorated or improved. Is that correct?

Mr Kohnstamm: That is correct.

Dr Jonquiere: Yes, that is correct.

Q1593 Lord Taverne: You have referred several times to the elaborate discussions that take place between the patient and the doctor, and the transparency which is now part of the Dutch procedure. To many of us, and I think to many members of the public, the fact that there is this open discussion of end-of-life scenarios is one of the attractions of the Dutch system. The question I have, however, is how far is this great openness, this much more frank discussion with patients, a result of the practice and law of euthanasia, or how far is it simply a feature of Dutch culture, where directness is a national characteristic? Is it something which was going on anyway, or is it something which has been promoted or facilitated by the law and the practice of the law?

Mr Kohnstamm: It is a difficult question, because it goes back to the nature of a country, and the culture then comes into it. Speaking for myself, I think that the main difference in the situation before the law and after the law is that, before the law, an individual request was, as such, considered to be almost a

criminal act. That is no longer so. The difference is that frank discussions were already taking place between doctors and patients—I would think because of the Dutch culture of wanting, perhaps more than is reasonable, to have the discussion in public and to be as frank as possible in such a discussion. However, before the law, if I had gone into the family physician's surgery, he could have said to me, "What you are asking is a criminal act"—which makes it much more difficult to start the discussion at all, because almost no one would want to ask someone to perform a criminal act. Since the change in the law, there is less difficulty in having these frank discussions. As to the figures, as far as we know from the research, there is not very much difference in the number of cases of euthanasia. I think that you are right, therefore, that partly it is because of the culture and these frank discussions; but there is also a difference between the pre-law and the post-law situation.

Q1594 Lord Taverne: As far as the discussions and the knowledge of involuntary euthanasia are concerned—the 1,000 cases which have been referred to—what is the evidence about the position in other countries? There is reference to the fact that these are not out in the open and they are not discussed. There is very little knowledge about it. What research has been done on that?

Dr Jonquiere: Comparable research has been carried out in the Flanders and in the northern region of Australia, which had a law—for just six months, 10 years ago. They used the same kind of questionnaire as van der Wal has used. So, in a way, you can compare these three countries or regions. What he has found out—

Q1595 Lord Taverne: "He" being . . . ?

Dr Jonquiere: Professor van der Wal. He found out that the percentage of euthanasia—because it was not legalised in Flanders and Australia—was obviously lower than in The Netherlands, but it was still there, using the definition "termination of life on request". The involuntary euthanasia, or the termination of life without request, in those two regions was four to five times as high as in The Netherlands. As far as I can see, in the comparison of the research in the three areas, there was no evidence to believe that the high percentage of involuntary euthanasia in other countries was not the same as in these two. As I said earlier, one of the problems in discussing the Remmelink 1,000 is that we made ourselves vulnerable by presenting these bad figures—that is, "We do it 1,000 times a year"—compared with other countries where it is much higher, because there is no legalised possibility to make a pro-euthanasia choice. Secondly, if you take the 1,000 and look at what kinds of problems there

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are in involuntary euthanasia, these are the cases which I referred to as the sort of life which you would not let your dog have—the well-known comparison that dogs have an easier death than human beings. That percentage is still too high in The Netherlands. However, if you take it as a proof of the slippery slope, I always say that, although it is a very small percentage, the percentage in The Netherlands is going downwards and not upwards.

Mr Kohnstamm: As a politician, I have been talking about this issue in many different countries in the world. My main problem is that there is not a good answer to the question, “Can you compare it to what happens in other countries?”, because in the other countries there is not the same sort of research. I would argue that, to have a decent outcome to this discussion, the same research should be carried out in several countries, in order to see what the differences are, and if you could argue whether or not these differences are reasonable.

Dr Jonquiere: There has been research in six European countries and, unfortunately, not in France, Germany or the UK.

Q1596 Chairman: The advantage of our being here rather than in France or Australia is that we are trying to find out what happens here. What, if anything, we can find out about France or Australia we may have to see. So far as what happens here is concerned, I would like to ask you about the way in which, as a matter of practice, information is collected. If euthanasia has been performed under the statute law introduced in 2001, the doctor who performs the euthanasia has to prepare a report. That report has to show in what way his decision to perform the euthanasia was justified, including the written advice he or she received from the SCEN doctor. That has to go in. When the death occurs, the coroner has the duty of collecting that material and putting it before the review committee which, among other things, consists of a doctor. The review committee has to review what occurred and see whether all the conditions that the statute has laid down have been complied with. If they have, the doctor is informed; if not, they inform the prosecuting authority and the medical control authority. That is the way in which the euthanasia decisions are monitored. Am I correct in that?

Dr Jonquiere: That is correct, yes.

Q1597 Chairman: What I am not clear about is what happens in other deaths. There seems to be a requirement of a coroner being involved, to the extent of the death being certified—a death certificate of some kind. What I am not clear about, and perhaps you can help us, is what information requires to go on that death certificate in explanation of the way in which the person in question died.

Dr Jonquiere: The regulation in The Netherlands is that a coroner is only involved in a death certificate if there is a question of unnatural death. So if a treating doctor is confronted with a dead patient, he is allowed to make a death certificate saying that his patient died because of natural causes and, in a separate, anonymous form he fills in what the underlying disease is and the cause of death. This is for the statistical evidence. If the treating doctor is not convinced of a natural death, he has to report that death to the coroner. Depending on the opinion of the coroner as to what has happened, he can even have the body transported to a facility where—

Q1598 Chairman: For a post-mortem?

Dr Jonquiere: For a post-mortem. That is the decision of the coroner. The law regarding euthanasia states that euthanasia is still an unnatural death, and so the treating doctor is not allowed to fill out a death certificate. That is why he has to bring in the coroner.

Q1599 Chairman: There is a point about words in Holland, because I understand that, strictly speaking, “euthanasia” is used to signify a death in which there has been a request, either by advance directive or otherwise. The 1,000, or whatever the figure, is not strictly speaking euthanasia, in the Dutch terminology, because there has, in the nature of things, been no request.

Dr Jonquiere: Yes.

Q1600 Chairman: These figures that we have been given, which come to about 1,000, 0.7 per cent of the total—do these derive, as far as you understand from the coroners’ certificates and investigations, in unnatural death?

Dr Jonquiere: No, they derive from the research by van der Wal and van der Maas, which is a repeated survey performed by doctors interviewing colleagues with, before that, a statement by the prosecuting office that all information given in the case of this research would not be a reason for prosecution. There was such an enormous response to this research—which I believe is statistically famous internationally—that van der Wal has said that the numbers he received from a certain number of doctors could be extrapolated to the whole population. That is the reason why The Netherlands can produce figures about how many times euthanasia is performed and what percentage of that euthanasia is or is not reported, and how many times termination of life without request is performed. That is on the basis of research. Only a part of these cases are reported, I admit, but still the cases are reported.

Mr Kohnstamm: So it is not the coroner’s business, but it is research business.

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Q1601 Chairman: I do not completely understand, particularly in view of what the government people told us yesterday, what has happened to the information the coroner gets about unnatural deaths and what use, if any, is made of that.

Dr Jonquiere: It depends on what he finds out. If the coroner finds out that the unnatural death is because of a criminal act, he will certainly report that to the prosecutor.

Q1602 Chairman: Yes, but what happens to his record? Does the coroner's decision in relation to any unnatural death go into the central government data?

Dr Jonquiere: I think it goes into the prosecuting office.

Q1603 Chairman: You have responsibility for the data now?

Mr Kohnstamm: Yes!

Dr Jonquiere: He is defending it.

Mr Kohnstamm: That is correct. It is first the prosecutor's office, and then there is the Holland-wide CBS—the centre for statistics. The Remmelink 900 or 1,000 cannot be seen in the prosecutor's office or in the CBS office, because it is research—where doctors were interviewed by doctors, talking in depth about how life ended.

Q1604 Chairman: I understand that perfectly. The professor's research has figures, but I am still puzzled about the other way in which figures are collected that go into the central archive. They would not be of no use. They are done for a purpose.

Mr Kohnstamm: Once there is a reported unnatural death, the public prosecutor will then proceed and do whatever is necessary.

Q1605 Chairman: If he thinks it right to do so, but when—

Mr Kohnstamm: There are some cases where the chief of the public prosecutors reported that there was an unnatural death reported and they decided, for several reasons, in I think three or four cases in the last couple of years, that they had cases which they would not prosecute. Those are the only figures that come to my mind.

Lord Joffe: My Lord Chairman, I think that I can clear that up with a question.

Chairman: I am very happy to hear that.

Q1606 Lord Joffe: Would the case be that all these 1,000 cases are reported by the doctors concerned as natural death, so that there is no evidence on the certificate that these were unnatural?

Dr Jonquiere: I do not think all the cases are not reported. I am afraid that many of those are not reported because doctors do not want to be in danger of being prosecuted—which is understandable.

Because of all the discussions, however, we have discovered that, more and more, doctors are reporting those cases. Some of them are very brave in reporting them, and even go to court to defend their case. Then they find out that the defence of necessity is applicable in such cases—and in the majority of cases. Unfortunately, we do not yet have 100 per cent reporting on euthanasia. You will not have the 100 per cent on the involuntary euthanasia being reported.

Lord Joffe: Are you saying that, of the 1,000 cases, most of the doctors would write, "involuntary euthanasia"?

Q1607 Lord Patel: No. As I understand it, these 1,000 cases are not real cases; they are anecdotal, identified through an interview process, on the basis of a research project. They were never on any death certificate?

Mr Kohnstamm: No, and this afternoon you may—if I may advise you—ask van der Wal to go over the 900 cases. These 900 cases are not 900 cases as such. They are, for example, in neonatology, severely handicapped newborn babies—problems that are mainly in the medical sphere.

Chairman: You may rest assured that we will ask the professor about it. What I was concerned about was the other source of information. Yesterday at the government office, I understood from what the lady in the health department told us—and I may have misunderstood—that there were two sources of information. There was the research information that the professor has, which we will hear about later, and also returns to the government through the coroner in respect of all deaths.

Q1608 Baroness Finlay of Llandaff: Could I ask two short, completely unrelated questions? First, do you have a protocol for the doctors of what to do, what dose to use, and which drug you recommend?

Mr Kohnstamm: Yes.

Dr Jonquiere: As an organisation, we do not have it. However, the pharmacists' organisation and, from the beginning of the 1970s, Dr Admiraal, an anaesthesiologist, have advised in this regard. This society has a protocol, of what we call the gold standard of what to use when euthanasia is performed.

Q1609 Baroness Finlay of Llandaff: What do they recommend?

Dr Jonquiere: In euthanasia—the injecting?

Q1610 Baroness Finlay of Llandaff: Yes.

Dr Jonquiere: First, to cause a deep comatose situation by barbiturate or something like that.

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Q1611 Baroness Finlay of Llandaff: I wondered what the drug was and the dose that they recommend.

Mr Kohnstamm: Shall we try to get this information to you?

Dr Jonquiere: It is Nesdonal or something that is used in anaesthesiology. After this deep comatose situation is caused, then we give secondly a curare-like substance to paralyse the breathing muscles. Then the patient dies within a short period. That is considered to be the gold standard.

Q1612 Baroness Finlay of Llandaff: So the patient dies of asphyxia?

Dr Jonquiere: Yes.

Q1613 Baroness Finlay of Llandaff: Having had the coma induced.

Dr Jonquiere: Yes.

Baroness Finlay of Llandaff: Has there been any research doing EEG monitoring to be sure that the patient does not regain consciousness before they die? With a short-acting intravenous barbiturate, you could have the patient's induction time very short but, because they are completely paralysed, even if they regained consciousness you would not know—because there would be absolutely no movement. They would not be tearing, as you would have with a caesarean section, because you are not using a surgical knife and causing new pain.

Lord Patel: But he is not answering whether they are long-acting or short-acting barbiturates.

Baroness Finlay of Llandaff: No, but we all know that, if you have induced liver enzymes, even long-acting barbiturates have a remarkably short time of action.

Chairman: You say “we all know”, but—

Baroness Finlay of Llandaff: I am sorry!

Lord Patel: She was looking at me at the time.

Q1614 Chairman: I can understand that.

Dr Jonquiere: I do not know the research on that. As far as I know, the organisation has asked doctors to report on their experience with this medication. On the basis of that report, it is seen as the gold standard—which is so golden that, if the review committee gets a report from a doctor who performs euthanasia and who does not use these barbiturates and curare-like substance, it will certainly ask, “Why did you use potassium chloride?”, or whatever.

Baroness Finlay of Llandaff: Could I ask a completely separate and unrelated question? Why did you call it the “right to die”? We are all going to die. What I do not understand is why you did not call it the “right to euthanasia” or the “right to stop living”.

Chairman: It is not even a right to do that, is it?

Q1615 Baroness Finlay of Llandaff: No, but a right to euthanasia is what you are arguing for. We all have the right, in fact. Nobody has the right not to die.

Mr Kohnstamm: As far as the society is concerned, it is called NVVE—the Dutch society for voluntary euthanasia. So there you have your answer. We are not talking about right to die. In the international sphere, yes; but in the Dutch sphere, we stick to the words “euthanasia and assisted suicide”, because euthanasia and assisted suicide would always be voluntary.

Q1616 Baroness Finlay of Llandaff: This is clarity of Dutch thinking, which other people have not adopted.

Dr Jonquiere: The French talk—if I translate it into English—of the “right to die in dignity”. Internationally, maybe the “in dignity” is left out of “right to die”; but that is the meaning of the right-to-die societies.

Q1617 Baroness Finlay of Llandaff: I wondered what you were campaigning for next, having achieved what you have achieved.

Dr Jonquiere: Do you have another afternoon?

Q1618 Earl of Arran: In all the research that you have done into public opinion in this country, to what extent have you done research amongst the young about euthanasia? One day, “our problem” will also be their problem. Have you done much, and what is their opinion?

Mr Kohnstamm: The research that we as a society have been doing is mainly research amongst our members, and I must admit that the general age of our members is pretty high.

Q1619 Earl of Arran: I understand that, but do you know what the answer is amongst the research done in the country?

Mr Kohnstamm: That is the government or other organisations which have dealt with these sorts of interviews. Generally speaking, the support amongst younger and older people is more or less the same. You see it growing the older the age, where people are more affected by this discussion.

Q1620 Chairman: The time seems to have passed very quickly today, and I fear that we are going to have to stop.

Dr Jonquiere: We have done a survey or poll in The Netherlands, asking this question and we have it translated into English. We could photocopy these results and leave it for you to read. There is also an indication as to the difference between the age groups.

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Mr Kohnstamm: I am told that you have an interview quite soon after this one. We have therefore ordered a Dutch lunch, and we will leave you with your

discussion—perhaps preparing for whatever comes next.

Chairman: That is very kind. We are very happy to have you stay with us, but you may have something else to do. Thank you very much.

FRIDAY 17 DECEMBER 2004

Present	Arran, E Carlile of Berriew, L Finlay of Llandaff, B Joffe, L	Mackay of Clashfern, L (Chairman) Taverne, L Thomas of Walliswood, B
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Memorandum by Associate Professor B D Onwuteaka-Philipsen and Professor G van der Wal

1. INTRODUCTION

The decade of experiences with the safeguarding of EAS in the Netherlands, makes it possible to examine the feasibility of public oversight and legal control over EAS. In this submission we want to present results of our studies on euthanasia and other end-of-life decisions and the euthanasia review procedure in the Netherlands. This submission is built up in the following way:

- a description of the authors and their work;
- short description of the Dutch Euthanasia Review procedure;
- a summary of key results of our studies that are relevant to the Assisted Dying for the Terminally Ill Bill;
- a summary of key conclusions of our study that are relevant to the Assisted Dying for the Terminally Ill Bill; and
- an appendix with that relevant papers that were published in the Lancet in 2003.

2. THE AUTHORS

G. van der Wal is professor of Social Medicine and head of the department of Occupational and Public Health of the VU University Medical Center in Amsterdam. BD Onwuteaka-Philipsen is associate professor at this department. Both have been doing research on the topic of end-of-life care for over a decade. They have been, together with professor PJ van der Maas en Dr A van der Heide of the Erasmus Medical Center in Rotterdam, responsible for the two nationwide studies on the incidence and characteristics of euthanasia and end-of-life decisions and the evaluation of the euthanasia review procedure, that were conducted in 1995 and 2001 (Professor van der Maas was supervisor of the Rummelink study in 1990). They also have been, again with their colleagues from Rotterdam, the coordinator of an international study (in six European countries and Australia) on end-of-life decisions (the EURELD study). Besides research on euthanasia and other end-of-life decisions, professor van der Wal is also conducting research on palliative care. One of the few Dutch centres for development and research of palliative care is located at his department, under his supervision.

3. THE (CHANGES IN) THE DUTCH NOTIFICATION PROCEDURE

In the notification procedure (and in our research), euthanasia is defined as the administration of drugs with the explicit intention of ending the patient's life on his or her explicit request. Physician-assisted suicide is defined as the prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life. The notification procedure changed several times, but in all notification procedures the central question for review was and is whether the requirements for prudent practice have been met. In the first notification procedure, which started in 1991 and was legally enacted in 1994, the physicians had to report cases to the public prosecutor (through the medical examiner). The initial review was carried out by the public prosecutor, and the final review by the Assembly of Prosecutors General and the Minister of Justice. In this procedure euthanasia and physician-assisted suicide were punishable, but physicians could expect not to be prosecuted if the requirements for prudent practice were met. In November of 1998 the procedure was changed. Physicians had to report to one of five Regional Review Committees (RRCs) (through the medical examiner). These RRCs, consisting of a lawyer, an ethicist and a physician, reviewed reported cases and advised the Assembly of Prosecutors General. The latter still made the ultimate decision on whether or not to prosecute and the legal status of euthanasia and physician-assisted suicide was similar to the previous procedure. Since the beginning of April 2002, a new law on euthanasia was enacted. All cases are still reviewed

by the RRCs, but only those cases in which they consider that the requirements for prudent practice are not met, are subsequently reviewed by the Assembly of Prosecutors General. In this procedure euthanasia and physician-assisted suicide are legal provided that the requirements for prudent practice are met.

4. KEY RESULTS

- (a) Results concerning incidence and characteristics of euthanasia and other end-of-life decisions.

In the EURELD study it was found that in 2001 physician-assisted death (administration of drugs with the explicit intention of hastening death) occurred in all countries studied: in about 1 per cent or less of all deaths in Denmark, Italy, Sweden and Switzerland, in 1.82 per cent of all deaths in Belgium, and 3.40 per cent of all deaths in the Netherlands. In the Netherlands this is most frequently on the explicit request of the patient (ie euthanasia or physician-assisted suicide).

In the Netherlands, death-certificate studies showed the rate of euthanasia increased from 1.7 per cent of all deaths in 1990 to 2.4 per cent in 1995 and 2.6 per cent in 2001, while the rate of physician-assisted suicide remained stable (0.2 per cent in all three years).

The frequency of ending of life without the patient's explicit request remained virtually unchanged during all years (respectively 0.8 per cent, 0.7 per cent and 0.7 per cent of all deaths)

In 1990, 1995 and 2001, in the Netherlands, almost 10.000 explicit requests for euthanasia were done to physicians. In all years about one third of these requests resulted in euthanasia or physician-assisted suicide. While in 2001 3 per cent of all requests was based on a psychiatric disorder and 4 per cent was based on being tired of life, virtually all requests that resulted in euthanasia or physician-assisted suicide were based on a physical illness.

- (b) Results concerning the evaluation of the Euthanasia review procedures.

In 1996 the notification procedure that (unofficially) started in 1991 was evaluated. The notification rate increased from 18 per cent in 1990 to 41 per cent in 1995, and the substantive requirements for prudent practice were generally met in reported as well as non-reported cases. Most physicians seemed willing to have their cases reviewed, and even more so if the procedure would be amended in such a way that they would not feel criminalized and there would be less uncertainty about prosecution. These results contributed to the development of the new notification procedure that was enacted in 1998.

The notification procedure that was enacted in 1998, was evaluated in 2001. The notification had increased to 54 per cent. Especially general practitioners contributed to this. There is an association between the introduction of professionalised consultation and notification. In general, reporting physicians have no negative experiences with the euthanasia review procedure. The experience of reporting physicians were more positive than with the previous notification procedure. Of all Dutch physicians most were of the opinion that the new notification procedure is better than the previous notification procedure in achieving its goals. While in 1990, 25 per cent of Dutch physicians said that they had become more permissive concerning euthanasia and physician-assisted suicide, this percentage decreased to 18 per cent in 1995 and 12 per cent in 2001. The large majority of the general public (91 per cent) consider it important that control takes place over the practice of euthanasia and physician-assisted suicide.

5. KEY CONCLUSIONS

Euthanasia and physician-assisted suicide occur everywhere, albeit in different frequencies. Therefore in every country it seems opportune to consider whether or not to create ways of reviewing these practices. Two important issues in this consideration are whether creating a review procedure would lead to entering a slippery slope and whether it is actually practically possible to gain public oversight and legal control through a review procedure.

After 1995, the rate of euthanasia and explicit requests by patients for physicians' assistance in dying in the Netherlands seems to have stabilized, the rate of physician-assisted death without the patient's explicit request has not increased since 1990 and physicians do not seem to have become more permissive towards euthanasia. Therefore, it seems that the start of and developments in the review procedure did not result in a slippery slope in the practice of euthanasia.

The results from the evaluation of the two review procedures indicate that it is possible, at least to some extent, to reach public oversight and legal control. The changes in the procedures have turned out to lead to higher notification. However, still half of all physicians do not report their cases of euthanasia or physician-assisted

suicide yet. Therefore the perfect procedure has not been found yet. In light of the fact that the majority of the general public consider it important that public oversight takes place and the majority of physicians have positive attitudes towards review, at least for the Netherlands the aim should be to have a review procedure and keep working on it's further improvement.

Examination of Witnesses

Witnesses: **Professor Gerrit van der Wal**, Head of Department of Public Health, **Dr Bregje Onwuteaka-Philipsen**, Associate Professor, VUMC Amsterdam, and **Dr Agnes van der Heide**, Senior Researcher, Erasmus MC, Rotterdam, examined.

Q1621 Chairman: Thank you for having us here. The shorthand writer takes down the help you give us and you will get a chance to review the transcript when it is ready; and, all being well, it will be appended to our report as we give it to the House of Lords and it becomes public at that time. We would like to begin by inviting you to introduce yourself and to say what your interest is in the area with which we are concerned. We have a good idea of that. One of the questions which is concerning us somewhat is why this figure of roughly 45 per cent of euthanasia cases—and I use “euthanasia” in the sense of requested euthanasia—do not seem to be reported at present to the review committees. I know that you have researched this issue by conducting interviews, with doctors interviewing doctors, and you report on that. However, I definitely had the impression yesterday, when we were at the Ministry of Health, that they have a separate source of total figures: that is, death certificates or certificates that come through the coroner to the ministry—probably through other sources as well, but ultimately to the ministry—which may or may not be a confirmation, not of the detail but of the total number of cases. Perhaps you could therefore deal with that. We would also be glad if you had views to express on the level of trust that the people of The Netherlands have in their family practitioners, and whether or not that has been affected to any extent by the euthanasia law. When I say the euthanasia law, I do not mean only the statute law passed in 2001 but also the development of that law by the courts and through the courts, and with the aid of the medical profession's governing body, in the years before that legislation. Finally—at least for this purpose, though I have no doubt there will also be other questions—I would be glad if you would deal with the question of whether vulnerable groups, particularly the disabled, have been in any way adversely affected by the development of the euthanasia law. We have certainly had some evidence in the United Kingdom of disquiet amongst some disabled groups—I make no comment on the extent—that, externally, people would be apt to judge their lives as so restricted and hampered by their disability that they were not able to have a life that was “worth living”, and therefore there might be a tendency to make it easier for them to suffer euthanasia, possibly without consent in that situation. These are the issues. There are many

others, but we would be glad if you felt able to deal with these issues in your opening.

Professor van der Wal: Thank you for coming to have a debate with us. You did not ask, but I will take a few seconds to introduce my colleagues and to apologise for Paul van der Maas. He is our most senior researcher, but he is a dean at Rotterdam University and was not able to make the time to come—and he thought that we could do it! I would like to divide the three questions between the three of us. I will ask Agnes van der Heide to answer the third question regarding the vulnerable groups, because of our co-working on a paper. About that subject I hope that Bregje Philipsen can answer the question about the denominator, and I will try to say something about trust. Otherwise, it would be boring for you to be hearing me all the time!

Q1622 Chairman: Not at all, but you take the order with which you feel comfortable. Although I made them in that order—one, two, three—you may feel that we should start with number two.

Professor van der Wal: I think that it is best to start with the numbers and percentages of reporting, the way in which we have investigated that, and whether there is a misunderstanding between you and us, and you and the department.

Dr Onwuteaka-Philipsen: That is about the 45 per cent?

Professor van der Wal: It is 54 per cent.

Q1623 Chairman: I think that 3,800 is the denominator figure that we have been given and which we are working on. I think that is your denominator as well?

Dr Onwuteaka-Philipsen: Yes

Q1624 Chairman: The question, however, is whether there is more than one way of arriving at that.

Dr Onwuteaka-Philipsen: Not really. Our denominator is derived by a death certificate study, where physicians can anonymously report a death, and where we have asked them what happened in that case. We can therefore make a really reliable denominator, which we also used in 1990 and 1995. I think that what the ministry has said is that, for the last two years, a physician can also say on a death certificate, “This was a case of euthanasia”. But we do not think that is really equal to the anonymous

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denominator which we have made, because why would you not report a case and then put it on the death certificate? That would be strange. I think that what the ministry has said is that it is on the death certificate.

Q1625 Chairman: They seem to derive it from the death certificate. That is the way I understood it.

Dr Onwuteaka-Philipsen: In a way, our denominator is also derived from death certificates, because we take a sample from death certificates and then ask a questionnaire. However, we only did that study in 1990, 1995 and 2001. So we feel that we have good denominators only for those three years and not for other years. If you see how many cases are reported now—and in the last few years the number of reported cases has gone down a little—then we say, “We don’t know what the denominator is”. You cannot say whether the percentage stayed the same because there were fewer cases of euthanasia, or whether it went down because the number of cases of euthanasia—the total number of the denominator—was still the same. You would need another death certificate study for that, and that will probably take place again next year.

Q1626 Lord Taverne: What about the reasons for not reporting?

Dr Onwuteaka-Philipsen: It is difficult to study non-reported reasons, but we have found that there are three non-reporting groups. We do not precisely know the size of the groups. There are people who still do not want the administrative bother of it, or the idea that you report it. There are people who think that you should not report it, either because they feel that it is not really euthanasia or because it is something between the doctor and the patient. It is also possible that there are people who perhaps doubt whether the case would go through easily—whether they have exactly fulfilled all the requirements.

Q1627 Lord Taverne: Do you have evidence that there are cases here which are a breach of the code, where they have not complied with the proper procedure, and that is why they are not reporting it?

Dr Onwuteaka-Philipsen: We do not have evidence for it, but it is clear that sometimes some physicians think, “I am not sure about this or that requirement—whether it is fully fulfilled”. There were perhaps circumstances where they felt that they could not fulfil it. I think that those cases are also difficult to find in the study.

Professor van der Wal: We cannot say what the size of the proportion of non-reported cases is—and here I mean this sub-group. What we have found in some studies, however, is that, looking at what we call the substantive criteria for due care, the cases which are

not reported and those which are reported do not differ so much. It is more in the secondary requirements, like not having consulted another physician.

Lord Taverne: So it is not as if the inference from your studies is that the number of cases of euthanasia is actually lower than the official figure of 3,800? That a lot of these 900 or 1,000 are not really cases of euthanasia at all? They may be, but that is not a clear conclusion which you can draw?

Q1628 Chairman: There is some confusion, I think. I hoped to make clear at the beginning, in the questions I asked you, that I was using “euthanasia” in the sense of requested euthanasia. There is a figure of 0.7 per cent, or something of that sort, which is outside that. The cases that are in the 0.7 per cent are sometimes described as involuntary euthanasia, or there are other words that you can use to describe them. I was not thinking about that. I was thinking about the cases that are euthanasia in your sense, in which your studies appear to show that a proportion of these are not reported to the review committees, as the statute law presently requires.

Professor van der Wal: We did understand that and that is what we have talked about.

Q1629 Lord Taverne: I understood from your answer that, while there may be some cases where the doctors are not clear whether or not it was euthanasia within the meaning of the statute, there is not sufficiently clear evidence to say that the figure of 3,800 should actually be quite a lot lower, because some of the non-reported cases are not euthanasia at all. Is that right?

Dr Onwuteaka-Philipsen: If anything, it might be a little bit of an overestimation. It will not be an underestimation, because we use a pretty strict definition.

Q1630 Baroness Finlay of Llandaff: It may be helpful if you could explain very simply the methodology that you used, because it might clarify some of the confusion. Perhaps you could also tell us how you plan—if you do feel a need—to change or refine the methodology for the next survey that you do.

Dr van der Heide: One of the most crucial elements in our study is the definition of euthanasia. In our death certificate study we did not ask physicians, “Did you perform euthanasia in this case or did you not?”. That is not the question we ask, because we think that it is not suitable to use the term “euthanasia” in a written, anonymous survey, in which you cannot explain exactly what you mean. That is why we asked physicians the following question: “Did you provide in this case a drug with the explicit aim of hastening this patient’s death? And, if you did so, did you do

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this at the explicit request of the patient?”. If both questions were answered positively with “yes”, then we classify this case as a case of euthanasia. This is meant to be an objective classification scheme for euthanasia, but at the same time it means that our definition is not always similar to the physician’s definition. When the physician answers both questions “yes”, it is not that in all cases the physician himself also defines the case as one of euthanasia. That is why there is sometimes a misunderstanding of what is euthanasia and what is not euthanasia. We think that our definition—the two questions we have asked—is based upon the legal definition of euthanasia; but in the experience and the daily practice of physicians there is sometimes misunderstanding. For example, whether, when you provide morphine to a patient who is very close to the end of his life with the aim of ending life, it should be considered to be euthanasia. We think that providing morphine with the explicit aim of hastening this patient’s death, and if it is done at the explicit request of the patient, it fulfils the criteria for euthanasia and should be classified as such. However, it is conceivable that in this case the physician himself would not classify the case as euthanasia and, as a result, would not report the case either.

Q1631 Baroness Finlay of Llandaff: Do you plan to ask the physician explicitly what they did, to give you a list of the drugs that they used, and to describe their actions in that last time frame?

Dr van der Heide: In the subsequent study, you mean?

Q1632 Baroness Finlay of Llandaff: Yes, next time.
Dr Onwuteaka-Philipsen: We did that also in the other studies. We asked for the medication. Even then, it is difficult to know where you are sure that that drug did or did not make someone die. That can also be so, for instance with morphine.

Professor van der Wal: But we found cases in which the drug was morphine, and not for example a curare drug, in very low dosages, with a “yes” twice on the questions which Agnes presented. So we classified that as euthanasia, but it is conceivable that the doctor thinks that, although he or she has twice said “yes”, it is not euthanasia: that it is not euthanasia afterwards, because the patient was already almost dead or because it was only 5 mg of morphine.

Q1633 Baroness Finlay of Llandaff: Can you explain again how you got your total sample? The method by which you drew the complete group?

Dr van der Heide: All deaths in The Netherlands are reported to Statistics Netherlands. We drew a sample of those deaths over a period of four months; so it is a nationwide sample, not selected by a place of death or by an attending doctor, or whatever—

Q1634 Baroness Finlay of Llandaff: So you took all deaths in four months?

Dr van der Heide: Yes.

Q1635 Baroness Finlay of Llandaff: In four months. That was your frame.

Dr van der Heide: Yes.

Q1636 Lord Carlile of Berriew: A random sample from all deaths?

Dr van der Heide: Yes.

Q1637 Baroness Finlay of Llandaff: Did you sample or did you include all deaths?

Dr van der Heide: No, we sampled.

Q1638 Baroness Finlay of Llandaff: How did you establish your sampling frame?

Dr van der Heide: In a period of four months about 40,000 deaths occur in The Netherlands. We sampled about 6,000 of them. I do not know if you are interested in the technique as well?

Q1639 Baroness Finlay of Llandaff: Yes, I am.

Dr van der Heide: The total number of deaths was stratified into cases in which, based upon the information on the death certificate, it was more or less likely that an end-of-life decision had been made. Then, from the stratum in which the likelihood is high, a large number of cases are randomly picked; from other strata a lower number of cases are randomly picked; then the doctor receives a questionnaire and is asked to provide information on that.

Q1640 Baroness Finlay of Llandaff: So you used high probability and low probability?

Dr van der Heide: Yes.

Q1641 Baroness Finlay of Llandaff: Do you know how accurate death certificate data is in Holland? I ask that because we know that in the UK it is notoriously inaccurate.

Dr van der Heide: To some extent that is also a problem in The Netherlands, but we use relatively little information from the death certificate itself. We use only the cause of death and some data about the patient’s age, sex, et cetera. All other information—about which decisions were made, how these decisions were made, which drugs were provided, et cetera—is based upon our own questionnaire and not on the information from death certificates. It is a problem, but it does not really affect our results.

Q1642 Lord Carlile of Berriew: Once you have received the questionnaire from the doctor, do you then compare the questionnaire once again with the

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death certificate, or do you not look further at the death certificate?

Dr van der Heide: No, we only use, as I have said, the cause of death, age, sex and—

Professor van der Wal: Place of death.

Q1643 Lord Carlile of Berriew: Then you do not return to the death certificate at all, but rely totally on the questionnaire?

Dr van der Heide: Yes.

Q1644 Baroness Finlay of Llandaff: On the questionnaire you did not ask about the details of the cause of death?

Dr van der Heide: No.

Q1645 Baroness Finlay of Llandaff: It might be interesting in future to ask that, and then go back to the death certificate and try to match up to see?

Dr Onwuteaka-Philipsen: In the next round it might be possible.

Dr van der Heide: You must understand that the death certificate study is limited, first of all by very strict requirements for anonymity and, secondly, because the questionnaire has to be limited in size, we can only ask a few questions. We have many thousands of doctors and we want the response rate to be as high as possible. That is why in the study we ask only the key questions and are not able to go into all kinds of details.

Q1646 Baroness Finlay of Llandaff: If we were to do in the UK the type of study that you have done, would you have any advice for us as to how we could learn from your important experience and perhaps do it better, matched for the UK?

Professor van der Wal: I think so, yes.

Q1647 Baroness Finlay of Llandaff: Please!

Professor van der Wal: We could talk for more than one day about that. As you probably know, we used a different methodology in our repeated studies, but the core methodology is the death certificate study—to get good estimates of end-of-life decisions. So, about the cause of death and other circumstances, we performed physician interviews. These were samples from physicians and not from deaths. We have already used this methodology in five other European countries, so it must also be possible in the UK

Q1648 Chairman: The physician interviews were on a sample of the sample, were they? Did you interview physicians in each of the cases in which you sent out questionnaires?

Dr van der Heide: No, those were two separate studies. The death certificate study was a written survey, completely anonymous, so that we could not follow up any physician, and another study was—

Q1649 Chairman: So this 3,800 figure came from that study?

Dr van der Heide: From the death certificate study.

Q1650 Chairman: That came from the death certificates, which are themselves in the statistical archives of the state?

Dr van der Heide: Yes.

Professor van der Wal: But we also tried to make estimates from the physician interview study in 1990, 1995 and 2001, and on each of those three occasions the estimates were rather similar.

Q1651 Lord Carlile of Berriew: How many questionnaires did you send? I think that you did between 400 and 460 interviews.

Professor van der Wal: Yes, face-to-face.

Q1652 Lord Carlile of Berriew: How many questionnaires did you send out?

Dr Onwuteaka-Philipsen: In the death certificate study?

Q1653 Lord Carlile of Berriew: Yes.

Professor van der Wal: Over 6,000.

Q1654 Chairman: For each?

Dr van der Heide: For each study, in all three years.

Q1655 Chairman: And you did them over a four-month period?

Dr van der Heide: Correct.

Q1656 Chairman: And the 3,800 was done by multiplying by three?

Dr van der Heide: Yes, more or less.

Q1657 Chairman: That is an approximation. There were the other questions. Professor, I think that you were going to deal with one of them?

Professor van der Wal: Yes, I will try. That was about the trust?

Q1658 Chairman: Yes.

Professor van der Wal: In our general public study we asked specifically about this. In terms of our research results, we do not think that there is a distrust, or less trust among patients, nor among the general public, nor among individual patients, in the Dutch physicians—nor distrust because of the recent law, jurisprudence, or publications about practice. On the contrary: you may have read in the Dutch papers

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recently that there is a new debate about how to respond to old people who request help to die when they are tired or weary of life. In short, Dutch doctors do not like to get involved in those questions, but there are a lot of people, especially older people, who support this idea. I think that you could see this as reflecting a lot of trust in Dutch physicians.

Q1659 Lord Taverne: Are there any opinion polls?

Professor van der Wal: Yes.

Dr Onwuteaka-Philipsen: This is about the law; it is not really about trust. Regarding the law, 92 per cent think that it is good that a doctor will no longer be prosecuted for euthanasia, if all the requirements are met; 91 per cent think that there should be control on euthanasia. They do feel it important that there is some form of control.

Q1660 Chairman: That is attitudes to the statute?

Dr Onwuteaka-Philipsen: To the statute, yes.

Q1661 Chairman: People thinking, first, that it is good to be clear what the law is, so that prosecutions would happen within the law and, second, that the law is good, in that it has made a statute provision for review of the cases—a regulation of control. Is that right?

Dr Onwuteaka-Philipsen: Yes.

Professor van der Wal: That is right.

Q1662 Chairman: That is 91 and 92 per cent?

Dr Onwuteaka-Philipsen: Yes, it is a large majority; and I know that there is a large majority that has confidence in their doctor. We also asked that in this questionnaire, but I do not know the percentages.

Professor van der Wal: We can provide you with that.

Q1663 Chairman: The 91 and 92 per cent that you have just referred to—these are your studies?

Dr Onwuteaka-Philipsen: Yes. Also the other one, but I do not have the figure here.

Q1664 Chairman: The other question was about the vulnerable groups.

Dr van der Heide: Obviously one of the main ideas behind the judicial procedure is to protect vulnerable people from unjustified euthanasia, but in our studies—which are of course quantitative, large-scale studies—we do not have very specific details on these groups. But that is partly the result of it not being a major problem among these groups. As far as disabled people also suffering from terminal diseases, they are treated similarly to other groups of people. We did not encounter in our death certificate study or our interview study any indication or evidence that disabled groups are involved more than other groups in end-of-life issues—not in euthanasia but also not

in other types of end-of-life decisions. So it is not a topic on which we have very hard data but, on the other hand, we did not encounter any indication that there was a problem either. I am not aware of patient groups or any other groups that are really worried about this aspect of the Dutch system. There are no large public worries about this issue over here, I think.

Professor van der Wal: Do you consider older people to be a vulnerable group?

Q1665 Chairman: I suppose the older they get, the more vulnerable they get. That would be my feeling.

Professor van der Wal: Otherwise, we could say something about that issue.

Q1666 Chairman: Yes, please.

Dr van der Heide: We repeatedly find, from 1990 onwards, that euthanasia and especially assisted suicide are not typical for the elderly age groups but rather for people who die at a somewhat younger age. The number of cases among people over 69 or 70 years of age is relatively low, and the percentages are highest for people who are between 60 and 70. That is the group where the occurrence is highest. The frequency is relatively low among the elderly people.

Q1667 Chairman: Can you give us the percentages, roughly, in the last study?

Dr van der Heide: It is in the paper in detail.

Q1668 Chairman: We can get it then.

Professor van der Wal: You can get it.

Dr Onwuteaka-Philipsen: It is five per cent of all deaths until 64 years of age, and 3.3 per cent of all deaths between 65 and 79 years, and 1.4 per cent over 80.

Q1669 Baroness Finlay of Llandaff: Have you any studies that you did before the change in the legislation began to come in, so pre-1994?

Dr Onwuteaka-Philipsen: In 1990 we had a study.

Q1670 Baroness Finlay of Llandaff: And that was the same methodology that you were using?

Dr Onwuteaka-Philipsen: Yes.

Q1671 Baroness Finlay of Llandaff: Do you now have any studies going on longitudinally to look at bereavement?

Professor van der Wal: At bereavement?

Q1672 Baroness Finlay of Llandaff: Yes.

Professor van der Wal: No.

Q1673 Baroness Finlay of Llandaff: Any longitudinal studies of following families?

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Dr Onwuteaka-Philipsen: No, there is a study on bereavement done by somebody else.

Q1674 Baroness Finlay of Llandaff: That was a point incidence study, not a longitudinal study.

Professor van der Wal: It is an interesting question.

Q1675 Lord Carlile of Berriew: I am not sure whether this is longitudinal or not, but I wanted to know if any research has been carried out to ascertain the views of the families or carers of euthanasia-deceased people, to discover what their views have been of the process. Associated with that, having looked at the Dutch voluntary euthanasia society's advance directive documents I would be interested to know if there are examples of cases in which relatives did not wish euthanasia to take place, because they valued the continuing life, whatever the state of it, of a member of their family, whereas the person who died did wish euthanasia to take place and it was performed.

Dr Onwuteaka-Philipsen: In 2001 we did a study among relatives of people who died from euthanasia and of cases that were reported. There we generally found that they very much agreed. Of course they did not like that their relative was dying but they finally agreed with the decision and were okay with it. Of course, these are reported cases, so it might be a selection. I think that on most occasions the family is at least involved in the decision-making, although they do not officially have a vote in it, so to speak, or a say in it. Generally, however, I think that they are involved in it. I do not think that it is very often that they do not agree and that the person does agree, but we do not have very clear figures about it. We just know that they are involved. The other thing was about the advance directives. In practice it rarely happens—or, at least, we have not encountered it—that an advance directive is taken as a request by somebody who is, by that time, incompetent.

Q1676 Lord Carlile of Berriew: Is this because advance directives are a relatively new thing?

Dr Onwuteaka-Philipsen: No, I do not think so. The advance directive has to have been brought up by somebody, and then they also have to judge all the requirements for prudent practice, including whether somebody is suffering unbearably. That is very difficult in somebody who is incompetent. It mostly involves dementia patients.

Q1677 Lord Carlile of Berriew: We were presented with a pack by the NVVE which included three advance directives of different kinds, of which one is the euthanasia statement. I wondered whether these documents play any part whatsoever in euthanasia

decisions and, if not, what is the point of having them?

Professor van der Wal: The point is that there are so many people who support the idea of euthanasia for themselves, especially in situations in which they have become incompetent, having cancer in the last stage, or by becoming demented. In practice, however, especially in demented patients—and we have done some research into that subject—doctors are very reluctant to respond to the request. In practice, it turns out as a non-treatment practice.

Q1678 Baroness Finlay of Llandaff: We have become aware that there are some doctors who are performing euthanasia more often than other doctors, and we have heard about suffering, which has to be judged by the doctor to be unbearable in order, at the end of the day, to justify euthanasia. Is anyone studying the difference between the way in which those doctors who perform euthanasia more often make the decision that, yes, suffering is unbearable—against those doctors who perhaps have performed euthanasia only once or twice ever, and who have turned down more requests saying, “No, this is not unbearable suffering”?

Dr Onwuteaka-Philipsen: No. It would be good research, I think.

Professor van der Wal: You have very good research ideas!

Q1679 Chairman: Do you have a figure in any of the studies of the number of cases in which an advance directive was used as the request basis for euthanasia?

Dr Onwuteaka-Philipsen: We have not found them often. There is an advance directive, but there is also the patient who is still competent. Then it is the request of the patient, but the doctor also wants it to be written down for the files; they then use this advance directive for it. So it is not the advance directive that is the basis for the request; it is just to support. It is a document.

Q1680 Chairman: To support the request. So you have not found cases at all in which the advance directive has been the only basis for the request?

Dr Onwuteaka-Philipsen: No.

Q1681 Lord Carlile of Berriew: By a competent person. What about non-competent persons?

Dr Onwuteaka-Philipsen: By non-competent persons, we have not found it at all.

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Professor van der Wal: One.

Dr Onwuteaka-Philipsen: One, yes. That is true.

Q1682 Lord Carlile of Berriew: Is that the sort of case where you think the doctor may be reluctant to report, because he lacks confidence in the robustness of an advance directive as a basis for euthanasia?

Professor van der Wal: That might very well be, but I do not think that cases happen frequently.

Q1683 Lord Joffe: There are two sets of numbers that we have been talking about. One is the 3,800 cases of voluntary euthanasia—and I think that we have been addressing most of our remarks so far to those. There are also the famous, or infamous, 1,000 cases. Is there any evidence to suggest that there is any link between the introduction of euthanasia and that number? Is there any evidence to support that?

Professor van der Wal: We do not know whether these life-ending cases without request existed before we started our studies. Probably, yes. We found them the first time—the famous 1,000 Rummelink cases—but they remain stable over all those years. Maybe they have decreased a little. So, as far as we can see, there is no association between the development in jurisprudence and law and life-ending cases without a request.

Dr van der Heide: Perhaps I may add the European dimension because, in our European study, one of the most important findings was that life-ending without a request occurred in all countries we studied. Whereas euthanasia appeared to be a typically Dutch phenomenon, life-ending without a request occurred in every country and also in almost similar frequencies. You could therefore conclude from that that there must be a reason why life-ending without a request occurs anywhere. I do not think that it relates to the Dutch system or the Dutch liberal attitude towards euthanasia.

Q1684 Lord Taverne: We were told that there were some figures which suggested that in Flanders life-ending without consent was three times as high as The Netherlands, or five times as high, and the same is true of Australia. Is this correct?

Professor van der Wal: Yes.

Q1685 Lord Taverne: And that generally the studies of comparison showed that this was a much more frequent occurrence in countries which do not have a euthanasia law than in those which do?

Dr van der Heide: In our six-country study which we did in 2001, the percentage in Belgium was the highest. It was 1½ per cent of all deaths, whereas in The Netherlands it was 0.7 per cent, and in Italy it was the lowest, at around 0.2 per cent.

Q1686 Lord Carlile of Berriew: Was it not 0.06?

Dr van der Heide: In The Netherlands?

Q1687 Baroness Finlay of Llandaff: In Italy.

Dr van der Heide: Yes, 0.06.

Q1688 Chairman: That is per head of the population, or percentage of deaths?

Dr van der Heide: Percentage of deaths.

Q1689 Lord Joffe: Could I clear up something about which I am still confused? When we were at the Department of Health yesterday and asked a question about whether the doctor would record something about what I understood would be the cases of involuntary euthanasia, the lady who was presenting on euthanasia said, “Yes, they would put at the bottom of the death certificate ‘euthanasia without consent’”. We thought that maybe she had been confused or that we had confused her, but I wondered what your reaction would be to that—from your death certificate studies.

Professor van der Wal: I have not seen those death certificates, but my guess would be that this is not reported on the death certificate. No, that must be a misunderstanding.

Q1690 Lord Joffe: It would seem strange, because they would immediately be prosecuted.

Professor van der Wal: No. One could do that, because our Statistics Netherlands is free of prosecution.

Q1691 Baroness Thomas of Walliswood: You would not know who had done it.

Professor van der Wal: No.

Chairman: It would be anonymous.

Q1692 Lord Joffe: But you have not come across it?

Professor van der Wal: No.

Q1693 Chairman: It is quite clear now that the basic figure, the 3,800, is derived in two different ways. One is from the paper study of death certificates with the questionnaire and, secondly, from the study that proceeded by way of interview of physicians.

Professor van der Wal: Yes.

Q1694 Earl of Arran: When you are deciding which are the appropriate questions to put into your questionnaire, do you consult amongst other departments as to whether they also have suggestions to make, before you take the final decision within your own department?

Professor van der Wal: What do you mean by “other departments”? Other disciplines?

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Q1695 Earl of Arran: Yes, other disciplines, or other departments associated with euthanasia, as to whether they might have appropriate questions which could throw light upon the answers to your questionnaire—or do you decide here yourselves?

Professor van der Wal: No, there are hundreds of people who have commented on the drafts.

Q1696 Earl of Arran: Putting in suggestions to you the whole time as to what should be the data of the questionnaire?

Professor van der Wal: Yes, but at a certain moment we would stick to certain questions and we would not want to change it any more. Otherwise, we could not make comparisons between the replicated surveys.

Q1697 Chairman: You have to keep a reasonable framework that is constant from one study to the other, if you are going to compare the studies?

Professor van der Wal: Yes.

Q1698 Chairman: For example, the doctors' association commented on the questionnaire on the lines you have said—about the shortening of life. Shortening of life might include what was not strictly speaking euthanasia, but was the giving of a pain-relieving drug which the doctor knew would in fact, in addition to relieving pain, be likely to shorten life. They felt that possibly inflated the number of cases in which it was found by you that euthanasia had occurred and which were not reported. They obviously had an interest in considering that percentage. I suppose that is possible, from the way you have described it?

Professor van der Wal: Yes, that is right.

Q1699 Lord Joffe: Coming back to the 1,000 or 900 cases, do you have any research into what were the reasons? Also, how concerned are you that these cases are there?

Professor van der Wal: First of all, we are not labelling those cases as involuntary euthanasia. We say that they are cases without request. It is not ruled out that some cases are involuntary but, as far as we can see, that is mostly not the case. Roughly speaking, in about half of all those cases there has been some kind of discussion before the patient became incompetent; because most of the patients are incompetent—that is to say, no longer capable of making a request. We do not know whether they would have done it, but they are not capable of it. Before they became incapable or incompetent, there has been some kind of discussion about ending life—but not an explicit request for euthanasia. As I have said, almost all patients—and, in our last study, 100 per cent of all patients—were incompetent at the moment of that decision. It is about patients who are mostly very ill, dying, and

seen to be suffering very much, by vomiting their stools, having very bad bedsores, severe dyspnoea, and suchlike. As we also know from qualitative studies, doctors feel that they have their back against the wall; that the family and nurses are asking him or her to end this suffering and this unbearable state of life; and then they decide to hasten the end of life. Whether or not this is very explicit is not that clear. For example, we found that the drugs used in these kinds of cases are mostly opioids, as used for intense pain and symptom treatment, and not neuromuscular relaxants as used in euthanasia. So there are some differences. Are we disappointed or what do we think about it? We are neutral researchers, but we do not like these cases—I do not like these cases. We hoped that they would decrease in number, but it has not happened.

Q1700 Lord Joffe: But you did say that in your last study 100 per cent were incompetent?

Professor van der Wal: Yes.

Q1701 Baroness Finlay of Llandaff: The next time you do the study, how will you supplement your questionnaire to clarify some of the issues around exactly what was done, differentiating between symptom control, escalating drug dosages, and a specific intervention of euthanasia, as defined in the protocols that we have been given—which are very specific about an overdose of barbiturates, with or without curare to paralyse the patient?

Professor van der Wal: We finished a new research proposal two days ago, but we do not know whether it will be granted. We hope and think so. The people who have done most of the work are here with me, so perhaps they could respond to this question.

Dr van der Heide: The denominator of the death certificate study, the denominator for the euthanasia cases, has to be clarified—which cases are not reported and which cases are reported. One of the main insights our studies have given us is that, on the one hand, you have very clear euthanasia cases that fulfil all criteria and that could not be defined otherwise. On the other hand, you have cases that could be interpreted as being euthanasia or otherwise. It depends on who judges what happened, who has an interest in it, and how large or how small this part of this total number of euthanasia cases is a matter of personal judgment, or whatever. What we now plan to do is to follow up all cases of euthanasia we find, and to send physicians an extra questionnaire. We could not do so in the previous study because of the anonymity requirements, but we can probably be somewhat more liberal in this study, and that is why we can send subsequent questionnaires specifically to ask physicians, “Did you report this case or did you not? Why did you do

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so? Why did you not do so?”. Then we will be more able to distinguish the total denominator in the cases reported and those cases unreported, and the reasons.

Q1702 Chairman: The numerator is definite. The denominator in the previous studies is open to a certain question, and you may be able, in the new study, to firm up the denominator as well. If you did firm it up, would it probably go down somewhat?

Professor van der Wal: Yes, probably. At least—

Q1703 Chairman: Not up?

Professor van der Wal: Not up.

Q1704 Chairman: It can hardly go up. You raise a question in my mind. You are asking for funding for a research project. Is it the State that funds these projects or is there some other source of funding? Is it the State?

Professor van der Wal: Yes, the government.

Q1705 Lord Carlile of Berriew: Through the university or direct to the Health Department?

Professor van der Wal: No, there is an in-between organisation. In the previous studies, the funding was directly from the government to the university. Now they have an open procedure. So we have to write and to compete with others. There is a kind of research council, as you have in the UK, which divides the money and which will judge and review the proposal.

Q1706 Chairman: But ultimately, if the research project is funded, you will get the funding in your department through the university for that project?

Professor van der Wal: Yes.

Q1707 Chairman: And you will be able exercise the necessary control to get the figures that they are looking for?

Professor van der Wal: Yes.

Q1708 Baroness Finlay of Llandaff: I have so many questions, but may I ask one more?

Professor van der Wal: You know that you have my e-mail address!

Q1709 Baroness Finlay of Llandaff: Is anyone doing an observational qualitative study, prospectively, watching clinicians and their decision-making processes, amongst those who never practice euthanasia and those who practise euthanasia?

Professor van der Wal: No, but there have been two qualitative studies. One ended in a thesis which is translated into English. It has been done by Anne-Mei The. She is from our department. Maybe you know that book?

Q1710 Baroness Finlay of Llandaff: No, I would like to see it.

Professor van der Wal: I am sorry. I was mistaken: it is not translated. That is the other book. There is another study, done by an American colleague who is finishing her thesis at the moment, but we have not seen her results yet.

Chairman: Thank you very much indeed. It is very kind of you and, as I have said, you will get a chance to review the transcript in due course.

FRIDAY 17 DECEMBER 2004

Present	Arran, E Carlile of Berriew, L Finlay of Llandaff, B Joffe, L	Mackay of Clashfern, L (Chairman) Thomas of Walliswood, B
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Examination of Witnesses

Witnesses: DR DIRK RAYMAKERS, Medical Services Manager, DR MARIJANNE VAN DER SCHALK, Palliative Care Consultant, DR ROELI DIJKMAN, President, Dutch Society of Nursing Home Physicians, DR MARLIES VELDHUIJZEN VAN ZANTEN-HYLLNER, Nursing Home Doctor, DR TJOMME DE GRAAS, Nursing Home and SCEN Doctor, Ms MURIËL HOUTHUYSE and Ms HELMA HESLOOT, Palliative Care Nurses, examined.

Q1711 Chairman: Dr Raymakers, I understand you would like to make an introductory statement to us before we begin.

Dr Raymakers: It is a great honour for me to welcome you here to Sint Jacob. My name is Dirk Raymakers and I am a nursing home physician and manager of the medical services. Sint Jacob is a Roman Catholic house, built 140 years ago for the care of old and poor citizens of Amsterdam. Until 1968, the Sisters of Charity from the south of The Netherlands took care of the patients. From that time onward, Sint Jacob was a nursing home as well as a home for the elderly. At the moment, more than 450 people live and receive treatment here in the house. We have wards for somatic care, psycho-geriatric care, as well as wards for rehabilitation. We have a stroke unit and, for the last five years, we have had a unit for palliative care—a hospice within our home for the elderly. In front of you are five specialists. I will introduce them and they will speak briefly about our specialism. First, Marijanne van der Schalk, who is a nursing home physician and palliative care consultant. She will tell you something about how we work here in Sint Jacob and how we handle the end-of-life discussion. Next, Marlies Veldhuijzen van Zanten, former President of the Dutch Society of Nursing Home Physicians, will speak about developments in The Netherlands since the first euthanasia. Next to her is Roeli Dijkman, the present President of the Dutch Society of Nursing Home Physicians, who will speak about the profession of nursing home doctors in The Netherlands. Tjomme de Graas is a nursing home doctor and he will tell you about his experience as a SCEN doctor. Last but not least, Muriël Houthuyse will speak about her experience as a nurse on the palliative care ward here in Sint Jacob.

Ms Houthuyse: I am a nurse and have worked here for one year in palliative care. We call our department the Hospice Sint Jacob. Our department is independent and we have 10 beds. Four or five beds are occupied by the incurable residents. The other beds are for the residents who have to recover after an operation. They usually do not need a lot

of physical care, but they have a programme of physiotherapy. The rooms we have for the residents are fully equipped with furniture, and they have their own fridge, shower and toilet. The rooms for the incurable patients also have their own microwave ovens and stereo players. We have a common living room which everyone can use—the residents, their families, and the nurses and doctors. Our team of employees comprise different kinds of care workers. We have nurses, doctors, physiotherapists, psychologists, a social worker, two volunteers, and a pastor from Sint Jacob. How do we work? We try to create a home-like situation, and it means that people have a lot of freedom. They are allowed to bring their own furniture, and they tell us how they want to live their day. If they want to wake up at 10 today, or eleven or twelve o'clock, it is okay. The family can stay with us. If they want or if it is necessary, they can sleep with us or eat with us. The visits from family and friends are not restricted. The residents can even bring their own beds for their rooms, but they or their family have to take care of them themselves. The residents can use the facilities of Sint Jacob, like the hairdresser, the shop, the dietician, and so on. The care for each resident is different, because everyone has different needs. We make a personal care plan, and it can change hourly. It depends on the resident's situation. The family can also take care of the residents, but they have to talk about it with us. The nurses have had an education in palliative care. The team give physical care and take care of the psychological, the spiritual and emotional needs of the residents. We like to give residents a good quality of life in their last months or weeks of their life. The team also take care of the emotional needs of the family or friends. In the last part of life, we think it is important that people feel comfortable. So we offer medication and accompanying conversations, to reduce the fear of death or to reduce pain, nausea, dyspnoea, and so on. Sometimes we give a sedative, to try to take away the fear of death, or dyspnoea. This only happens when everybody agrees. Very infrequently we start

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Dr Dirk Raymakers, Dr Marijanne van der Schalk,
Dr Roeli Dijkman, Dr Marlies Veldhuijzen van Zanten-Hyllner,
Dr Tjomme de Graas, Ms Muriël Houthuyse and Ms Helma Hesloot

the euthanasia procedure. I have not seen it during my year here. It is a very careful procedure, but others can tell you about it. The work is, of course, an emotional burden for the team, and it is important that we can talk to each other. So we do. We talk to each other during the work, but we also have a regular meeting. We call it *kek op de week*—which, translated, means “a look back on the week”. Then we talk to each other about our experiences and our feelings. I do not want to sound arrogant, but we often hear from the people who stay with us that they have a good time in our place—so we think that we do our work very well.

Dr van der Schalk: I am Marijanne van der Schalk, and I am a nursing home doctor in Sint Jacob and I have been working here for 15 years. For four and a half years I have been running the palliative care unit. Sint Jacob is a combined nursing home and residential setting for the elderly. For the past four and a half years we have had a unit for palliative care with about five beds. Our unit is intended to be for people who are incurably ill and have a life expectancy of about three months. Since the opening, we have received about 160 patients. Half of these patients come from home and the other half come from a hospital. The general age on admission is 72 years, with a spread from 44 up to 102 years old. Most of our patients suffer from malignancy. Most patients come to die in our place, and the average length of stay in our unit is 28 days, ranging from one day to nine months. Muriël has described our team. Our team is specially trained in palliative care, and I myself did my training in Cardiff last year. Our main goal is to offer good palliative care, in a specially equipped, friendly, homely environment. Talking about the end of life and exploring the wishes of the patient and his family form a part of good palliative care. Most patients die from a natural cause, which of course is our preference. However, many people want to discuss the possibilities of euthanasia. Euthanasia is allowed at Sint Jacob. We follow the legal rules, which mean that euthanasia is performed when the patient is suffering unbearably; there is no prospect of recovery; the request is not uttered in the course of a psychiatric disease, dementia or depression; the request is durable and consistent and not uttered in a flash of despair. The request is put in writing. The doctor calls in a colleague who is not in any way involved in the case, and the second doctor evaluates the above and puts his or her findings in writing. That is done in such a manner, using the type of medication particularly suited to such a course of action. After the patient's death, the doctor reports to the authorities in the form of the coroner, who is called in to assess the procedure.

Although the possibility of euthanasia is discussed frequently in our place, in four and a half years we have only performed euthanasia once. In one other case we were preparing the procedure when the patient died from pneumonia. This was a patient suffering from motor neurone disease. The fact that euthanasia is a possibility here gives the patient the feeling that he remains in control and brings about rest and confidence. Very often, this subject does not need to be discussed any more, or is postponed indefinitely. I think that this attitude towards euthanasia reflects the character of the Dutch patient-doctor relationship, which I would describe as open, confidential, mature and equal. This relationship offers the patient the possibility to choose his own path, within reasonable boundaries. I would say that the doctor-patient relationship has been improved by our struggle to legalise euthanasia. It shows the patient our honest wish to travel with him in the final stages of terminal illness and to explore together the wishes and possibilities of the patient and his family. On the other hand, the fact that euthanasia is a possibility also puts a burden on the doctor who has to deal with it and to deal with patients who demand euthanasia and regard it as a right—which, of course, can never be the case—and, finally, to perform euthanasia, which is an intensely emotional and imposing burden. We doctors never consider euthanasia as a common medical procedure, and dying from a natural cause will always be our preference. All in all, I find that looking after terminally ill patients is an enormously rewarding task and, in my experience, euthanasia rarely comes into it—though there are exceptional situations in which euthanasia can be a blessing, because it provides a way of dying with dignity.

Dr Veldhuijzen van Zanten-Hyllner: Did you have any specific questions that you would like to ask first?

Q1712 Chairman: I think that you should say what you have to say first.

Dr Veldhuijzen van Zanten-Hyllner: I am Marlies van Zanten. I have been a nursing home physician since the beginning of the 1980s. I was involved in a project to enhance the medical students' curriculum with palliative care. I think that you may have heard of the COPZ movement when you were at the Royal College of Physicians and from Professor van der Wal at the university, because he was also involved in that. I have brought some of that material with me. In the letter that was sent to us there was mention of “recent legislation”, but the legislation in Holland has taken 25 years to develop and it is a practice that has developed very slowly, step by step. I also saw the term “slippery slope” used. It

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may be a slope in the sense that it is a trajectory, but it is not a slippery slope. It has been a course of development which has been taken bit by bit, and also evaluated bit by bit on the ethical and the legislative side. In the early 1980s, we started with the possibility of ending the life of terminally ill cancer patients. The category of people who were physically proven, diagnosed as infaust prognosis—people who were going to die—became the first category to get that possibility. That has been slowly widened, little by little, step by step, until this point in time—where we have reached an area where we are out of the medical jurisdiction, out of the area where we can determine the criteria which are weighed, but it is in our domain because we are the ones who are asked to perform this action. However, it has been a very gradual process and it has been a process which has carried the whole of society. I think it is very important to realise that. Otherwise, it does not give you the feeling of solidarity in the Dutch population, which I think is very relevant to it. The question was asked, “Do you see death as a harm or as a therapeutic option?”. I think that we have gradually grown not to see death as a harm in all cases, but sometimes as the only way out, where it is the last thing that we can do for the patient and, in that sense, it is our medical option.

Dr Dijkman: I am Roeli Dijkman and I am the President of the Dutch Association of Nursing Home Physicians. We are going to change our name, because we are not treating nursing homes; we are treating the elderly and the disabled with long-term care and we do some rehabilitation, as you have heard. So we will get another name. It is also good to know that not all the people in Holland go to a nursing home; it is just a few people, five per cent, who are 80 years old or more. When you look at the houses in Amsterdam, you can see why. When you are disabled, you cannot get up the stairs. We also have the care of people who live in normal homes which are adapted for disabled people. I think that we give good medical and social care for elderly people and for disabled people. There was a big discussion on television yesterday, and it was about widening the rules. At the present time, the criteria for euthanasia are a classification of diseases from which you die. There are also diseases which involve many functional disorders, which can make life a burden—and that was the discussion on the television. I am very honoured that you have come to Holland to hear our view on this matter. There is also a discussion of perspectives. When you are from Holland, the language is mostly explicit—and that is also the way in which this matter is handled. We are explicit about what we are doing. When I

look at other countries where the medical actions around the end of life are not explicit, you handle it in almost the same way but you give it another name. When terminal sedation came here from England as good palliative care, we asked, “How far away is that from euthanasia? Isn’t that a grey area legally?”. I would like to hear your opinion on that. I am not a native English speaker, as you can hear. However, it is a very delicate issue, so please excuse us if we do not use the right words or nuances.

Dr de Graas: My name is Tjomme de Graas. I am also a nursing home physician, a palliative care consultant and a SCEN physician. I will try to describe for you this unique concept of SCEN physicians within the euthanasia procedure. SCEN is an acronym for Support and Consultation in Euthanasia in The Netherlands. With the legalisation of euthanasia in The Netherlands, this specific medical function was initiated by the Royal College of Physicians. SCEN physicians are a special breed, with special training for a very delicate task. The reasons for creating this SCEN function are threefold. First, it is very important that physicians who are confronted with a patient expressing the wish for euthanasia have the possibility to contact a colleague, who is independent and capable of supporting this physician in his or her medical and also emotional process and judgment. Because of our training we can, with the physician, draw the complete context of the request for euthanasia, hopefully also to clarify some aspects that may be overlooked in such stressful and extraordinary situations. Second, in the case of euthanasia the law prescribes an assessment by an independent physician—the second opinion. SCEN physicians always carry out a bedside consultation with the patient, combined with the consultation of the physician and the medical file. This is in order to assess or evaluate or, if you like, investigate the procedure as stated by the law. Because of our training, but also because of our experience and the countrywide availability of SCEN physicians, this guarantees a uniform and independent view and, as you heard from Marijanne, control of the procedure. After we have carried out our consultation, we give the physician a written report in which we state whether or not the procedure has been completed. This means that we give our specific view of all the medical, social and psychological aspects, within the context of the law. If the euthanasia is effected, the SCEN report—as part of the complete file—will be sent to the committee which will give the final judgment. Third, by professionalising the second opinion, physicians are supported in following the procedure. We think that this initiates the effect that, by using SCEN

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physicians and where there is positive advice, there is less resistance to reporting the euthanasia. This facilitates the possibility of countrywide registration and investigation of our euthanasia procedure and law, but also investigation of the boundaries of the slope.

Q1713 Chairman: Thank you very much. You have given us a very interesting account of what I might call the practice, which we have been studying perhaps a little more theoretically until now. It is good to have an opportunity to discuss with those who are at the sharp end of the work, and to know how it is done. In particular, I am glad that we have one of the SCEN doctors with us. We have heard a good deal about that function and its importance in reviewing the details of what has happened, or is going to happen, in each particular case. We have been told that when the physician phones up—this is the physician who is contemplating carrying out euthanasia—he or she will not know who will be the SCEN doctor answering the telephone and responding to the invitation. There is therefore a degree of independence guaranteed by that. Once the conversation starts, it may be apparent that there is some connection, in which case, we are told, the SCEN doctor first approached will hand over the case to a colleague. Is that correct?

Dr de Graas: That is correct. It is the responsibility of the SCEN doctor to determine whether he thinks he is independent enough to do the consultation. We are almost militaristically trained to be sure that that is the first point. When, as a SCEN doctor, I think that I am not independent, I give the case to a colleague.

Q1714 Chairman: That is what we had understood and it is good to receive confirmation of that. Am I right in thinking, from what you have told us, that the SCEN doctors have received particular training in this work? I was not clear, and it is probably my fault, as to exactly what that training incorporates. It incorporates a considerable knowledge of palliative care, is that right?

Dr de Graas: It is not totally right—yet.

Q1715 Chairman: Also, does it involve knowledge of the possibilities of troubles, such as depression for example, that might damage the patient's competence to give a really considered request? Am I correct so far?

Dr de Graas: So far, so good.

Q1716 Chairman: The SCEN doctor will have an opportunity of seeing the patient and appraising for himself or herself the mental condition of the

patient; but do you expect a doctor who approaches you first to have done that, at least in a preliminary way, and to tell you in the first communication that you have with him or her what the situation is so far as the patient's mental condition is concerned, as well as the account of the physical condition, the pain, the suffering—whatever the nature of that is—and the possibilities of recovery?

Dr de Graas: I think that it is quite simple. As a SCEN doctor, when I am called by a colleague I have a lot of questions that I ask—as you said, about competence and depression. They are all involved in my list of questions. Also, the emotional aspects of euthanasia are so great that every doctor who is asked to perform euthanasia, who calls the SCEN doctor, is almost always the one who can highlight any subject with a patient in the deepest way. He knows what he is talking about. If, as the SCEN doctor on the telephone, I think that he is not, I ask him to do that first—even before I do my bedside consultation.

Dr Dijkman: The criteria are so clear for every doctor in Holland, they know that, before they consult a SCEN doctor, they have had to have fulfilled the criteria.

Q1717 Chairman: These are the criteria that are in the statute?

Dr Dijkman: Yes—always.

Q1718 Chairman: You consider these to be clear. The questions relate to whether or not the patient's case conforms to these criteria.

Dr Dijkman: Yes. As the performing doctor—what was the question again? I am sorry.

Q1719 Chairman: You consider the conditions laid down in the Act of Parliament clear, and the only real question is whether the patient's condition conforms to these, and whether or not there has been a well-considered request.

Dr Dijkman: And a SCEN doctor will test the performing doctor as to whether he has carefully looked at the criteria. So it is the question of voluntariness, of depression, of mood disorders—everything.

Q1720 Chairman: Will the SCEN doctor himself or herself from time to time be a family physician too, and carry out such procedures himself or herself?

Dr de Graas: Do I perform euthanasia myself?

Q1721 Chairman: I am wondering whether, when you are a SCEN doctor, you are only a consultant in these procedures or whether from time to time

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you can, as it were, cast aside the role of SCEN doctor and be yourself a dispensing doctor?

Dr de Graas: Yes.

Dr Dijkman: But not at the same procedure. A SCEN doctor can perform euthanasia himself, but not at a procedure where he is himself the SCEN doctor.

Q1722 Chairman: No, quite so. He becomes the dispensing or the original doctor then?

Dr Dijkman: Yes.

Q1723 Lord Carlile of Berriew: Thank you very much for your excellent presentation. I wanted to ask how many euthanasia deaths there have been in this establishment in the last three years?

Dr van der Schalk: In the last three years we have only had one euthanasia in the palliative care unit and, as far as I know, there have been no other euthanasias in our nursing home. In our nursing home there are the same conditions in terms of the procedure for euthanasia. I think that in general we have one euthanasia every four or five years here.

Q1724 Lord Carlile of Berriew: Approximately how many deaths do you have here in a year, on an average?

Dr Raymakers: In Sint Jacob, about 80.

Q1725 Lord Carlile of Berriew: So your euthanasia rate, if I can call it that, will be something well under one per cent?

Dr van der Schalk: Yes.

Q1726 Lord Carlile of Berriew: About that one death, was it a death which could in your view have been dealt with by pain control management but was a euthanasia, because that was the autonomous choice of the patient?

Dr van der Schalk: The euthanasia case was a very specific request of the patient. It was a patient who had been here for a long time. It was a young man, 48 years old. He had a very tragic life. He had suffered a stroke when he was 46. He recovered completely from the stroke and then he developed a very rapidly progressing stomach tumour. He had a young daughter of about six years old and he was very rapidly fading away, losing weight. In the end, he was only 33 or 34 kg, and his little daughter was scared of him. She did not dare enter the room.

Q1727 Lord Carlile of Berriew: But it was choice, rather than necessity?

Dr van der Schalk: Yes, it was his choice. He suffered from the fact that his own tumour—

Q1728 Lord Carlile of Berriew: I do not want to know any more about his particular situation. What I want to ask you, having established that, is why is it that 2.7 per cent of deaths in The Netherlands are by euthanasia generally when, with good palliative care in this institution, there are no deaths by necessary euthanasia? What is happening in the rest of Holland, or what are you doing here that is not being done in the rest of Holland?

Dr van der Schalk: Speaking about palliative care in nursing homes in The Netherlands, I think that is more recently at a high level. It can always be improved, and I have done a lot of excellent training in Cardiff. I think that the quality of palliative care in nursing homes is at a very reasonable level. In the rest of Holland, I think that for general physicians palliative care is a subject of growing interest.

Dr Dijkman: There is a difference between the population dying at home or dying in a nursing home. The people dying at home have more autonomy to think about what they want in life and how far they will go in terms of losing their dignity in dying. It has something to do with autonomy, and dignity in dying—and the thinking about that. Some people think that to lose functions or to fade away during dying is a concept of life. I can accept that, but some people cannot accept it. The example Marijanne gave you was an excellent one—of dignity, but also of having your own self-consciousness about your relations with your daughter, which conflicts with that. It is another population. When you have a terminal illness at home and you do not want to die by fading away, with palliative care, you decide to have euthanasia at home. Most euthanasias are by general practitioners.

Q1729 Earl of Arran: You are fundamentally a Catholic hospice.

Dr Raymakers: Yes.

Q1730 Earl of Arran: Is a prerequisite for your staff and your patients that they are Catholic, or does that make no difference at all?

Dr van der Schalk: No, it does not make any difference at all. Many people come to us in Sint Jacob because of a specific religious background, so we have a lot of religious inhabitants—which I think also counts for the staff. With the passing of time, I would not know exactly how many, but it is not a prerequisite—which was your question.

Q1731 Earl of Arran: And you have no worry about the delivery, from the policy point of view, of euthanasia?

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Dr van der Schalk: Myself or our house?

Earl of Arran: You are quite happy to conduct euthanasia.

Chairman: I think it is for the house—not just her own personal point of view.

Q1732 Earl of Arran: Yes, I mean the house.

Dr van der Schalk: Are we happy? I think that we are happy with the possibility, yes. It does not create a conflict with our religious background.

Q1733 Earl of Arran: There is no conflict?

Dr van der Schalk: No, not any more. There has also been a lot of discussion in our house. When I came here 15 years ago, our first euthanasia came after a long discussion. It took us weeks to come to a common opinion. We talked with one another for a very long time but, in the end, we reached a compromise.

Q1734 Baroness Finlay of Llandaff: May I thank you all for your presentations and for explaining the role of nursing home medicine, and particularly the nursing aspect as well. My questions are really of the SCEN doctor. The SCEN doctors whom I have known have said that, as they learn more about palliative care, they have become more aware of possibilities they are able to suggest when someone telephones to discuss a patient, when they are considering euthanasia. I wondered whether you thought that was true from your discussion among SCEN doctors in Amsterdam. The ones whom I know are in the north of Holland. Do you feel that is correct?

Dr de Graas: In principle, it is always correct. Also, I think that I am a young SCEN doctor and, talking to my colleagues who are nursing home physicians but also working on a palliative care unit, it is true that you need the insight of good palliative care to be a good SCEN physician. However, I cannot stress enough that the time factor is very important in the whole of our legislation and in thinking about the concept of euthanasia, but also the thinking about palliative care—how palliative care, SCEN and euthanasia, together, can provide the best care for the patient.

Q1735 Baroness Finlay of Llandaff: The doctors who have performed euthanasia have often described it, certainly initially, as being emotionally draining, emotionally difficult, and that they have taken some time off, have perhaps not worked the next day, to have a break and then to carry on working. Has that been your experience?

Dr de Graas: It certainly has been, but I think that a lot is changing in that regard. The first letter of SCEN is the “s” for “support”, and that is essential. Also as a nursing home physician confronted with euthanasia, I know that it is emotionally draining; but it is absolutely important to discuss it, not only with the SCEN doctor but with all your colleagues, to keep yourself healthy. I think that it is changing rapidly, because we have the possibility to talk about euthanasia and we know what we are talking about. We know what we are doing, and so we can go on in that sense—because it is essential.

Q1736 Baroness Finlay of Llandaff: Do you think that it has become less stressful, as the process has become more developed over the time that you have had it?

Dr de Graas: For the individual physician it never becomes less stressful. That is absolutely impossible. What we are learning as a group, however, is that, before we become emotionally worn-out, there are a lot of possibilities to keep yourself in a good emotional state.

Q1737 Baroness Finlay of Llandaff: Could you clarify this? There was some publicity over the euthanasia of babies who had multiple congenital abnormalities. I wondered whether, as a SCEN doctor, you would ever be consulted by those neonatologists or paediatricians and, if so, how you would respond.

Dr de Graas: To be honest, luckily I have never been confronted by such a case. I think that it is extremely exceptional and extremely difficult.

Dr Dijkman: Most of the time—and I know this from the Royal College of Physicians—it is not euthanasia, because it is the ending of curative medicine.

Q1738 Baroness Finlay of Llandaff: But we have been told that these cases were euthanasia. That is why I am asking about it.

Dr Dijkman: Who told you that?

Baroness Finlay of Llandaff: I think that we understood that there was a protocol.

Q1739 Chairman: Not euthanasia.

Dr Dijkman: It is not on request, so that is not euthanasia.

Q1740 Baroness Finlay of Llandaff: I am sorry, it is not on request. I am wrong.

Dr Dijkman: It is just palliative care and you do not—

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Q1741 Baroness Finlay of Llandaff: But the babies' lives were ended.

Dr Dijkman: Yes. The ending is when you look at tubal feeding or that kind of thing. It is a medical decision. It is futile at that moment, because the life has no prospect.

Dr Veldhuijzen van Zanten-Hyllner: It may be important to stress that it is not less stressful, but it has become legally clearer in terms of what you can and cannot do. You are being checked by a SCEN doctor, and that means that a lot of the nervous "Have I done the right thing?" part is taken away. You can concentrate on the patient and the process. That is a big difference with 20 years ago. As to the kind of example you gave, as long as it is outside the clear jurisdiction, you will not just call the SCEN doctor and say, "How shall we do this?"; you will call the Royal College and say, "Look, I have this very exceptional request. Who is your legal man? Who is experienced in this? Can you advise me?". Nobody wants to be the first case. It is a most horrific thing to have to break up the jurisdiction. You do not want to do that.

Dr Dijkman: I work in another nursing home and our palliative doctor has also been trained in palliative care. We do not see more euthanasia performed after the training. The palliative care differs a little, but the performance of euthanasia did not increase. What we do hear are a lot of requests and, from those requests, there are only a few performed. Each year we may have 25 requests, with the same frequency of euthanasia as Marijanne mentioned—once a year.

Q1742 Lord Joffe: Can I also thank you for your excellent presentations? I think that Lord Carlile suggested to you that the reasons for the lower percentage of euthanasia deaths in your nursing home was because the standard of palliative care which you offer was better than that of your colleagues elsewhere. I am not certain that I understood the reply. Could you just be clear about what your view is, and perhaps touch on the fact that, generally, my understanding is that the number of euthanasia deaths in nursing homes are less than in the rest of the country?

Dr Dijkman: That is true. My explanation is—and it is not evidence-based but based on experience—that patients who suffer from terminal illnesses make the request for euthanasia before they go to the nursing home. In principle, the patients who ask for euthanasia have a vision of dying and losing their dignity. Then the pain is relieved. That is my opinion.

Q1743 Lord Carlile of Berriew: But you do provide dignified deaths in this establishment, presumably? Very dignified deaths.

Dr Dijkman: Yes. We have to define "dignified".

Q1744 Lord Joffe: Presumably the physicians in the country also provide similarly dignified deaths?

Dr Dijkman: Yes.

Q1745 Baroness Finlay of Llandaff: My question is addressed to the nurses, because you have these close conversations which you were talking about. I wondered how often you see amongst the patients you look after an ambivalence towards dying, in that they would like to be living but then they feel that their lives are coming to an end. So they swing between wanting to live and accepting that their death is coming. Is that the sort of conversation that you are having with them, or that they are telling you about when they discuss their feelings, their worries and their concerns with you?

Ms Houthuyse: Not everyone is open to talk about it. If you have a special closeness with somebody, then you talk about it. You talk about fear and about acceptance; you talk about pain, when somebody is still not so ill that they are lying in bed all the time. When it is getting worse, or they are getting closer to death, sometimes you see that there is more fear; but sometimes you see that there is more acceptance. I have never had the question put to me directly, "I want euthanasia". They just want to talk about their feelings, and that is okay.

Q1746 Baroness Finlay of Llandaff: It is good that they can talk to you. How much training do you have as nurses in having these discussions with patients, within your nursing training as an undergraduate and then as a postgraduate—ongoing education?

Ms Houthuyse: I have had different training from the rest of the people in our team. I was a hospital nurse for 10 years and I worked in the department of cancer, lung cancer. I did not get special training but while I was working in hospital I did alternative training for two years. The lessons were one whole day a month, where we learned about dying—dying in all different kinds of cultures—to talk, and to know yourself in different ways.

Q1747 Baroness Finlay of Llandaff: How much care is given by trained nurses and how much care is given by care assistants, who have a small amount of training?

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Ms Houthuyse: I do not understand.

Q1748 Baroness Finlay of Llandaff: In the UK, we have nurses who have done three-year or four-year training, and then we have care assistants who help the nurses and who have done a course, but it is of variable length. They are not qualified as nurses.

Ms Houthuyse: One nurse and one—

Dr van der Schalk: We have slightly different names for it. I do not know the name “care assistant”. Muriël is our nurse. She is our only nurse on these wards; then we have—perhaps you would say care assistants—they have done special training of about two years, and we call them “illness nurses”. This is a lower level than a nurse. I think that they have done half the training. I would say that there are 10 persons on our team. We have one nurse and about eight qualified care nurses¹.

Q1749 Baroness Finlay of Llandaff: Those are halfway. They have done two years of training and they are halfway already?

Dr van der Schalk: Yes. They have done some special training. Muriël has been working with us for a year, and the rest of the team has done training which is organised by the cancer centre for Amsterdam. They did special training for our whole team, which focuses especially on care nurses—however you call it.

Q1750 Baroness Finlay of Llandaff: In that two-year training or your four-year training, do nurses now have training in talking to patients or listening to their fears about dying, or is that not yet in the curriculum?

Ms Houthuyse: When I was at school I had this training, so I think that they still have it.

Q1751 Chairman: Coming back to the nurses, you said that there is one senior nurse—a fully trained and qualified nurse—and then there may be a number of less qualified nurses in the same team. Generally speaking, are your nurses full-time in Sint Jacob, or are they sometimes people who give a part-time service?

Ms Houthuyse: Most of them are part-time. I think that two of us work full-time.

¹ *Note by witness:* Following the evidence session, Dr van der Schalk asked that we clarify this point. The hospice has nurses who have trained for three and a half years. There are also “ziekenverzorgenden” who have trained for two and a half years. In addition the hospice has “verpleeghulpen” and “assistant ziekenverzorgenden” who have less training, but who will normally do the full ziekenverzorgenden training. The team currently consists of one nurse, seven ziekenverzorgenden and one verpleeghulp.

Dr Dijkman: What is the reason for the question?

Q1752 Chairman: To see the extent to which patients are able to get a reasonably close relation of confidence with the nurses. I am conscious that, in some places, the nurse who is looking after you today will be off tomorrow and the next day, when you perhaps feel down and rather sad. Then she may be back on a day when you are feeling better again. I am wondering about the extent to which that kind of variation in the individual who is looking after an individual patient may be present here.

Ms Houthuyse: The part-time workers work 32 hours a week, and a few part-time workers work 24 hours a week. So we call it “part-time” when you work 32 hours. It is almost full-time.

Q1753 Chairman: So far as the other nursing homes are concerned, with which you have been dealing for example, are the statistics much the same as in Sint Jacob or is there a difference?

Dr Veldhuijzen van Zanten-Hyllner: I think that we must differentiate between palliative units and the general wards in nursing homes. The palliative units are usually better staffed, with better-trained personnel; they have a specific training. However, the general wards are generally understaffed, and I think that the risk in those wards would be as you have described. There would possibly be discontinuity.

Q1754 Chairman: Lord Carlile asked about the death here—just one in the period you cover. Is that consistent with your experience in the other nursing homes that you deal with?

Dr Veldhuijzen van Zanten-Hyllner: Yes, it is an exceptional occurrence in a nursing home. Also, I think because of the selection of the population. People who can anticipate what is going to happen to them might very well say, “I don’t want to get to the stage that I have to go to a nursing home. I want to make my decision before that happens”.

Q1755 Chairman: Perhaps I could come back to the SCEN doctor. You presumably are sometimes asked by a doctor whose patient is in their own home?

Dr de Graas: Yes.

Q1756 Chairman: Do you notice any difference in the situation as between patients who are in their own homes when they make these requests, and patients who are, for example, in Sint Jacob?

Dr de Graas: A difference in what way?

17 December 2004

Dr Dirk Raymakers, Dr Marijanne van der Schalk,
Dr Roeli Dijkman, Dr Marlies Veldhuijzen van Zanten-Hyllner,
Dr Tjomme de Graas, Ms Muriël Houthuyse and Ms Helma Heslout

Q1757 Chairman: I was thinking of the frequency. Are you able to judge that? You may not have sufficient information to be enabled to judge that. In your own experience, however, from what you think, do you think that people who are in an institution like this are less likely to ask for euthanasia than people who ask for it in their own homes?

Dr de Graas: I do not know if they are less likely to ask it. What I do see is that it has a lot to do with age. I do see people at home but, as has been said, it is a population bias. The people we see at home are younger than the people who live in a nursing home. I think that is the most important difference. It is a difference in the way the patient is being taken care of, because in the situation at home there is almost always a partner or a family who are very good carers. So I think that age is the most important factor.

Chairman: It only remains for me to thank you very much indeed for the presentations and the answers that you have given to our queries. As I said at the beginning, I am particularly glad that we have been able to come to hear what you have to say, because you are more directly involved in day-to-day work of this kind than most of the people whom we have seen. It is a particular privilege therefore to have had a chance to discuss these very important issues with you. I am sure that there are few more important issues than those of life and death, and to have a chance to hear about how you deal with these is of particular importance to all of us and to our inquiry. The help you have given us has been noted by the shorthand writer and, in due course, we would hope to publish, as part of our report, the responses you have given. In order to ensure that what you think you have said is what the shorthand writer has noted, you will get a chance to look at the transcript before we finalise it. Thank you all very much indeed. It is a great privilege to be here.

THURSDAY 13 JANUARY 2005

Present	Arran, E Finlay of Llandaff, B Hayman, B Jay of Paddington, B Joffe, L Mackay of Clashfern, L (Chairman)	McColl of Dulwich, L Patel, L St Albans, Bp Taverne, L Thomas of Walliswood, B Turnberg, L
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Letter from the Church of England House of Bishops and the Catholic Bishops' Conference of England and Wales

We are writing to send your Committee a joint submission from the Church of England House of Bishops and the Catholic Bishops' Conference of England and Wales.

We believe very strongly that respect for human life at all its stages is the foundation of a civilised society, and that the long-term consequences of any change in the law to allow euthanasia in limited circumstances would be immensely grave. This is a view shared not just within our Churches, but very widely among those of all faiths and none who share a moral outlook founded on respect for human life and the protection of vulnerable people.

As you know, having considered the evidence and the arguments against legalising euthanasia in great depth, the House of Lords Committee on Medical Ethics in 1994 firmly rejected any change in the law to allow euthanasia. They concluded:

“The right to refuse medical treatment is far removed from the right to request assistance in dying. We spent a long time considering the very strongly held and sincerely expressed views of those witnesses who advocated voluntary euthanasia . . . Ultimately, however, we do not believe that these arguments are sufficient reason to weaken society's prohibition of intentional killing. That prohibition is the cornerstone of law and of social relationships. It protects each one of us impartially, embodying the belief that all are equal. We do not wish that protection to be diminished and we therefore recommend no change in the law to permit euthanasia. We acknowledge that there are individual cases in which euthanasia may be seen by some to be appropriate. But individual cases cannot reasonably establish the foundation of a policy which would have such serious and widespread repercussions.” [HMSO, London, 1994, paras 236-7].

We hope and pray that your Committee will reaffirm and endorse that conclusion, given that the strength of the arguments against euthanasia are undiminished, and the empirical evidence of the damaging effects of legalising euthanasia in the Netherlands is even stronger now.

In our submission we have sought briefly to set out what seem to us the key fundamental principles and then we make some specific points on this particular Bill. We hope your Committee will find it helpful.

FOUNDATIONS¹

1. The arguments presented in this submission grow out of our belief that God himself has given to humankind the gift of life. As such, it is to be revered and cherished.
2. Christian beliefs about the special nature and value of human life lie at the root of the Western Christian humanist tradition, which remains greatly influential in shaping the values held by many in our society. These beliefs are also shared in whole or in part by many people of all faiths and none.
3. All human beings are to be valued, irrespective of age, sex, race, religion, social status or their potential for achievement.
4. Those who become vulnerable through illness or disability deserve special care and protection. Adherence to this principle provides a fundamental test as to what constitutes a civilised society.

¹ In 1993 we made a joint submission to the House of Lords Select Committee on Medical Ethics considering the question of euthanasia. In presenting some arguments specific to this Bill, we have drawn on and restated a number of principles set out in that original submission, which we believe are just as valid today, and apply equally to the Bill being considered by this Select Committee.

5. The whole of humankind is the recipient of God's gift of life. Life is to be received with gratitude and used responsibly. Human beings each have their own distinct identities but these are formed by and take their place within complex networks of relationships. All decisions about individual lives bear upon others with whom we live in community.

6. For this reason, the law relating to euthanasia is not simply concerned either with private morality or with utilitarian approaches. This is one of the issues—relatively few in number but fundamental in importance on which justice calls for a limit to moral or ethical pluralism. A positive choice has to be made by society in favour of protecting the interests of its vulnerable members even if this means limiting the freedom of others to determine their end.

TWO ARGUMENTS FOR LEGALISING EUTHANASIA

7. There are two considerations which are often appealed to in defence of euthanasia: individual autonomy (the so-called “right” to die at a time of one's choosing) and welfare (the view that at beyond a certain point some lives are not worth living).

8. In recent years there has been an increasing emphasis on individual rights and self-determination. In the world of medicine; this has had its impact with patient autonomy being accorded an ever higher priority in medical ethics. In the Assisted Dying for the Terminally Ill Bill, the emphasis on autonomy is evident in the way that “unbearable suffering” is given a purely subjective definition: it is suffering “... which the patient finds so severe as to be unacceptable...”. The Bill requires the patient to be informed of alternative responses including palliative care, but the patient must then be helped to die if this is his or her settled wish. The Bill does however restrict its scope to those who are terminally ill, where death is likely to result “within a few months at most”. But if the principle of autonomy is being invoked to justify the Bill it is difficult to see how this restriction could be defended. The suffering caused by a non-terminal chronic illness, whether mental or physical, may equally be “so severe as to be unacceptable” to those affected. Why should euthanasia not be made available to them too?

9. At this point the second consideration—welfare—comes in. If it is not enough simply for the patient to want euthanasia, then the justification often given is that it is in his or her best interests to die. It is argued that in some situations life has no value, especially if the patient cannot look forward to any improvement and faces a slow and lingering death. But if this is the justification, there is once again no basis for restricting the scope of euthanasia to the terminally ill, or indeed to those making a voluntary request.

10. Both autonomy and welfare considerations can lead in practice to much more widespread euthanasia than was originally envisaged. The submission to this Committee from the Linacre Centre for Healthcare Ethics contains ample evidence of this in the case of the Netherlands where, as they point out “we see both an extension of euthanasia to those who are mentally ill or ‘tired of life’ and its extension to those who are unable to consent such as infants and young children”.

THE LIMITS OF AUTONOMY

11. Neither of our Churches insists that a dying or seriously ill person should be kept alive by all possible means for as long as possible. On the other hand we do not believe that the right to personal autonomy is absolute. Patients should not be overtreated, and may reasonably refuse particular treatments as too burdensome. Having said this, life should be respected, whether in oneself or in another; the aim of giving or refusing treatment should never be to make the patient die.

12. The exercise of personal autonomy necessarily has to be limited in order that human beings may live together in reasonable harmony. While at present people may exercise their legal right to refuse treatment (although this may be overridden in special but strictly limited circumstances), the law denies that there is a legal right to die at a time of one's own choosing. The consequences which could flow from a change in the law on voluntary euthanasia would outweigh the benefits to be gained from more rigid adherence to the notion of personal autonomy. But in any case we believe (para 6) that respect for the life of a vulnerable person is the overriding principle.

13. The right of personal autonomy cannot demand action on the part of another. Patients cannot and should not be able to demand that doctors collaborate in bringing about their deaths, which is intrinsically illegal and morally wrong.

14. A serious consequence of introducing euthanasia would be to undermine the relationship of trust between doctors and patients. The value attaching to human life implies that the primary duties of doctors caring for those with terminal illness are to ensure their patients are as free from pain as possible, given the information

they and their carers request or require to make informed choices about their future lives, and are supported through the personal challenges which face them. But if doctors were allowed in some circumstances to kill their patients rather than care for them, this would inexorably lead to an undermining of trust. Medical treatment would come to be regarded by the vulnerable person as potentially life threatening rather than as conferring benefit.

15. A change in the law to permit assisted dying would also change the cultural air we all breathe, and affect attitudes to older people and those with chronic illness. For example, the law permitting abortion has profoundly changed society's attitude towards the status of the foetus.

PROTECTION OF THE VULNERABLE

16. Doctors are rightly concerned to do the best they possibly can for the actual patients in front of them, and so are the families and friends of those who are ill. It is hard to stand back from the trauma of the individual suffering and look at the wider picture; to think about the long-term implications of decisions made under the pressure of individual need. This is why the law has to play its part in providing a framework within which the medical profession can operate. A foundational guiding principle of the current legal framework is that we should not deliberately kill each other.

PALLIATIVE CARE AND BURDENSOME TREATMENT

17. Behind many of the arguments in favour of euthanasia lie powerful fears, and in particular the fear that the alternative to euthanasia might be a lingering and painful death, exacerbated by futile and burdensome medical treatment.

18. When death is imminent or inevitable, the withholding or withdrawing of medical treatment that is judged futile or burdensome is both moral and legal today as in the past. Doctors do not have an overriding obligation to prolong life by all available means. Treatment for a dying patient should be "proportionate" to the therapeutic effect to be expected, and should not be disproportionately painful, intrusive, risky, or costly, in the circumstances. Treatment may therefore be withheld or withdrawn, though such decisions should be guided by the principle that a pattern of care should never be adopted with the intention, purpose or aim of terminating the life or bringing about the death of a patient. Death, if it ensues, will have resulted from the underlying condition which required medical intervention, not as a direct consequence of the decision to withhold or withdraw treatment.

19. The hospice movement developed from a concern that people should be helped to die with dignity (that is, to live with dignity until they die). This work has enriched not only the lives of terminally ill people but also their carers, volunteers, and health professionals, who have found that caring for those who are dying can be a great source of blessing. Friendship, companionship and above all love are the key characteristics of a good death. Helping people to die well in this way is not the preserve of any particular faith. It is a profoundly compassionate and humane response to the reality of death which we all eventually face.

20. We are concerned that the lessons learned in hospices about pain control, and emotional and spiritual support should be applied throughout the health service to all dying people. This requires that medical personnel remain aware of how advice on pain control may be obtained, seek specialist help where necessary, and that adequate resources are made available for the care of sick and elderly people.

21. We believe that deliberately to kill a dying person would be to reject them. Our duty is to be with them, to offer appropriate physical, emotional and spiritual help in their anxiety and depression, and to communicate through our presence and care that they are supported by their fellow human beings and the divine presence.

CONCLUSION

22. It is deeply misguided to propose a law by which it would be legal for terminally ill people to be killed or assisted in suicide by those caring for them, even if there are safeguards to ensure it is only the terminally ill who would qualify. To take this step would fundamentally undermine the basis of law and medicine and undermine the duty of the state to care for vulnerable people. It would risk a gradual erosion of values in which

over time the cold calculation of costs of caring properly for the ill and the old would loom large. As a result many who are ill or dying would feel a burden to others. The right to die would become the duty to die.²

23. The Bill is unnecessary. When death is imminent or inevitable there is at present no legal or moral obligation to give medical treatment that is futile or burdensome. It is both moral and legal now for necessary pain relief to be given even if it is likely that death will be hastened as a result. But that is not murder or assisted suicide. What terminally ill people need is to be cared for, not to be killed. They need excellent palliative care including proper and effective regimes for pain relief. They need to be treated with the compassion and respect that this bill would put gravely at risk.

2 September 2004

Memorandum by the Office of the Chief Rabbi

1. The Office of the Chief Rabbi welcomes the opportunity to provide input on the Assisted Dying for the Terminally Ill Bill, as it raises fundamental issues about the balance between life and death, which goes to the very heart of the Jewish tradition.

2. The Office of the Chief Rabbi is the religious authority of the United Synagogue, and various other communities round the country. In total, it is responsible for over 140 synagogue communities in the UK. The United Synagogue alone is the largest synagogal membership body in the UK, comprising over 30,000 households. The Chief Rabbi also heads a Court ("Beth Din"), which makes rulings and decisions on Jewish legal matters, and provides guidance on moral issues within the framework of Jewish law.

3. Jewish tradition places at its centre the sanctity of life, viewing life as a precious gift from God, not something we can dispose of at will. Indeed, the value of human life is absolute and not relative to factors such as age and health. The commandment of the preservation of human life ("Pikuach Nefesh") is a central one in Jewish teaching. Furthermore the Ten Commandments emphasise the prohibition to murder; in addition, there is also a strict prohibition against suicide in the Jewish legal code. Therefore Judaism regards the value of human life as non-negotiable and insists that it cannot be compromised.

4. The Bill would enable, in specific circumstances, a terminally ill competent adult to request medical assistance to die. It would therefore introduce a form of euthanasia into UK medical law. Since Judaism regards human life as both absolute and infinite, it considers the deliberate termination of life as prohibited. Hence, in broad terms, Jewish law is opposed to euthanasia whether the physician acts with or without the patient's permission.

As an eminent authority on Jewish law and ethics, Rabbi J D Bleich has stated, in summarising the Jewish view on euthanasia: "Any positive act designed to hasten the death of the patient is equated with murder in Jewish law, even if the death is hastened only by a matter of moments. No matter how laudable the intentions of the person performing an act of mercy-killing may be, his deed constitutes an act of homicide." (Rabbi J D Bleich—"Judaism and Healing").

5. In addition, such legislation would place unfair psychological pressure on ill patients. An ill patient will, in all likelihood, find it difficult to make dispassionate decisions, and may be pressured to terminate his life, feeling that he is a burden to family, friends or society. No one should be placed in a position of having to choose whether to live or die.

Similarly such legislation would also raise difficult ethical questions for doctors. The traditional role of the doctor is to heal, and where that is not possible, to contain suffering and distress, but permitting a form of euthanasia would leave them to make the ultimate moral decision. Medical professionals have a special and unique role as "partners in creation", but they should not be asked to make decisions that go beyond their capabilities and moral horizons (ie to take action with the purpose of causing death). Furthermore, this legislation would create huge dilemmas for doctors with conscientious objections to euthanasia, whether grounded in religion or not.

6. Whilst Judaism prohibits action to deliberately terminate life, it also does recognise the need to relieve a patient's pain and suffering. There are circumstances in which action may be taken to relieve pain and suffering, but this should not be done at the cost of deliberately accelerating death. Even in those cases where the patient is in great distress, there cannot be a premeditated course of action to terminate someone's life. Therefore Judaism cannot purchase relief from pain and misery at the cost of life itself.

² It is noteworthy that the 1994 House of Lords Select Committee members came back from the Netherlands deeply disturbed that some doctors there were not following required procedures. The Committee was finally not persuaded that "it is possible to set secure limits on voluntary euthanasia" and remained "concerned that vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death . . . the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support." [paras 238-9].

7. Similarly, whilst action can be taken to relieve pain, no natural means of subsistence may be withdrawn from the patient. Therefore it is prohibited to withhold food or nutrition from terminally ill patients. The subject of withholding certain types of treatment from patients, including forms of medicine and machinery, is more complicated. In any such cases, a competent Rabbinic authority should be consulted to assess the facts on a case-by-case basis.

8. Having outlined the traditional Jewish opposition to euthanasia, the Assisted Dying for the Terminally Ill Bill obviously raises huge concerns. The Office of the Chief Rabbi is opposed to the Bill. The acid test of any society is how it protects and defends the vulnerable, and cares for those in need. Each patient should be assured that whilst everything will be done to minimise pain, life itself will be honoured and never willingly terminated.

Examination of Witnesses

Witnesses: REV PROFESSOR ROBIN GILL, representing the Archbishop of Canterbury, RT REV CHRISTOPHER BUDD, Bishop of Plymouth, representing the Archbishop of Westminster, DAYAN (JUDGE) CHANOCH EHRENTREU, representing the Chief Rabbi and DR KHALID HAMEED, representing the Muslim community, examined.

Q1758 Chairman: Good morning. This morning we have with us a group representing various sections of what is described sometimes as the faith communities. There may be alternative descriptions, but I will leave it at that. The system we have adopted is that I shall invite each of you, in such order as you care to embrace, to make short opening statements and then invite members of the Committee to ask questions to seek to deal with matters which may be of particular interest or concern to them. A full transcript is being taken of the help you give us and in due course, you will have an opportunity of reviewing that transcript to see whether it accords with what you thought you said when you were here, and eventually the corrected transcript will be appended to our report and become public property when the report is published in due course. Would you be kind enough to introduce yourselves and make your short opening statements in whatever order seems to be suitable.

Rt Rev Christopher Budd: I am Bishop Christopher Budd from Plymouth representing Cardinal Cormac Murphy-O'Connor and the Catholic Bishops' Conference of England and Wales. I think you have received a written submission from that quarter. I should just like to make three main points by way of introduction and I have my script here, so I can leave that with the ladies. I believe that we all start from the need of compassion for those who are dying as common ground. However, I think we part company as between those who are pro life and pro euthanasia when working out what is acceptable as compassionate. We do not believe that killing someone, even when invited to do so, is the hallmark of compassion. Compassion, as the word suggests, is "suffering with", accompanying someone on a journey, the length of which is not in our control. The journey of course is open-ended as we know, the dying process. As we know, the way we come to die is highly variable. It is love that gives dignity to everyone on that journey, especially the person who is dying. My second point outlines four

features of what I am calling the Christian moral tradition. The Christian moral tradition has the following moral wisdom for those accompanying the dying person. Firstly love is the overarching virtue, obviously construed in terms of compassion. Secondly, we do not intentionally kill anyone. Thirdly, we do not strive officiously to keep a person alive as long as technically possible through over-burdensome or futile treatment. Fourthly, we will always seek to sustain basic care to the end including feeding and hydration for as long as that is possible and in ways that are not burdensome. My final point, is that law must always seek to protect the vulnerable. The proposed change weakens that protection. It will also act as a corrosive force in my view in our society and gradually weaken the trust that is vital for patients, doctors, nursing and care staff and family members. Our experience of the abortion legislation has to be here a cautionary tale. I hope you do not mind me finishing with a quotation from the 1994 Committee recommendation "... we do not believe that these arguments" (that is those in favour of introducing euthanasia) "are sufficient reason to weaken society's prohibition of intentional killing. That prohibition is the cornerstone of law and of social relationships. It protects each one of us impartially, embodying the belief that all are equal. We do not wish that protection to be diminished and we therefore recommend no change in the law to promote euthanasia". I will finish there.

Rev Professor Gill: I am Professor Robin Gill, I am the Michael Ramsay Professor of Theology at the University of Kent. I am here to represent the Archbishop and the House of Bishops. I just want to focus on two issues, both of which the Bishop has just touched on. The first issue is that of compassion. I think compassion is the point that unites all four of us, but I think it probably unites everybody here and all you on Committee. Compassion is deeply written into each of our religious faiths. It is central to all of our holy books.

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For us as religious people, compassion is directly related to our belief that God is a God of compassion and requires us to be compassionate in response to others. It is also deeply in our humanist tradition that even without a belief in God, the notion of compassion is absolutely central to our society. As some of you know, I made a submission myself for Dianne Pretty. I did it entirely on compassionate grounds. I thought that her case represented a very, very strong case indeed for voluntary euthanasia and if it was simply a matter of her and no-one else and not other people, I believe that this was as strong a case as you get and on compassionate grounds one should certainly reach out for it. When I made my submission, I also made it clear that there are differences amongst religious people and that the issue of legalising voluntary euthanasia is not simply a religious versus non-religious issue, there are divisions on both sides, but that for my part, I was not finally convinced by the case for legalising euthanasia. I was not convinced on compassionate grounds. In the end I concluded, as my Church has concluded, that more people, more vulnerable people will be made more vulnerable if we change the law in favour of legalising euthanasia. The second point I want to make is on autonomy. Autonomy seems to me to be absolutely central to medical evidence. I think all of us have come to accept slowly and some people with difficulty, that properly informed consent is absolutely essential to medical practice, that properly informed consent on the part of the patient, that the patient is properly informed, has time to make a settled choice, is given full information and is treated fairly and confidentially and, finally, is told of outcomes, is absolutely essential to good medical practice, whatever happened in the past. We make a distinction in our paper, and it is only implicit in the paper, between individual or personal autonomy, and what Lady Onora O'Neill has increasingly taught us to call principled autonomy, and I think there is a crucial difference between the two. Lady O'Neill argues from the secular side that a purely individualistic understanding of autonomy never does justice to medical ethics and is increasingly looking out of date. In her very powerful Reith and Gifford lectures she argues that a proper understanding of autonomy, an understanding of autonomy which goes back to Kant, and the rights of the individual always go hand in hand with the duty of the individual to other people. It is again on these grounds that I believe once we understand autonomy properly as principled autonomy, as involving other people and our duty to other people, then we have to look extremely carefully about changing the law in ways which I believe will finally make more vulnerable people, more vulnerable.

Dr Hameed: My name is Dr Khalid Hameed. I am a medical doctor by training and I am a Muslim. I shall be brief in my submission to the honourable Committee and I have a few points. The power of life and death which this Bill proposes to give to a human being for snuffing out the life of another is the basic thought behind tabling this particular Bill. Throughout history we know that much human mischief has been prevented by our desire to reject the alteration of another human's physical existence for any reason whatsoever, except in the event of war or acceptance through qualified judicial processes. In spite of all the progress that we have seen in science and technology, humans have not lost any of their ability to kill with impunity. Any relaxation in law of measures to protect humans could lead to a slippery slope which could soon get out of hand. We have heard and read a great deal about the American experience of assisted dying and we should remind ourselves that amongst those who desired premature death or contemplated suicide very large numbers suffered from clinical depression. That is the experience from Oregon. The lesson from this is that though the disease in many of these patients was untreatable, the depression is very definitely treatable. Furthermore, large numbers are concerned about being a burden on their families and carers. They could therefore be burdened with the duty to die rather than a right to live. I have informed you that I am a physician by training and all we physicians have a belief in the Hippocratic Oath. I have spoken to a lot of my colleagues and many doctors in the profession are very concerned. Over hundreds of years, there has been a tradition of trust between a patient and a doctor, of being a confidante, of being almost like a family elder, a healer. For the families, the injection into this invisible halo around the head of the doctor of a shadow of an executioner, a lot of this will get very diluted. I spoke to many neurologists, as I am sure you have, and yesterday I was talking to somebody who is a leading neurologist in this town and like many other colleagues I asked him to recall any episode, any clinical story which produced miraculous recoveries and he was able to and he was equally concerned. So the patients in some of these stories recovered after a protracted period of hopelessness. What would happen to these recoverable cases, if there was a bottom line of economic prudence which could be applied to their cases? We have read a great deal about the end-of-life years and progress now has enabled us to challenge human suffering from pain, from breathlessness, from such like and there is to my mind a great hope for even greater progress in this area. What we need is probably a public debate on how to go about recompensing a lifetime

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of somebody's contribution to the community and to the country with tolerable end-of-life years. If the price is economic, perhaps the debate, the discussion should be about higher taxes or whatever it needs to keep these people and this is our modern duty and this is what our faiths tell us to do: look after those who are in need, not kill them. Islam, to which I belong, is very definite about human life and there are about 1.6 million people who follow Islam in this country. In Islamic bioethics, the physician has to render help regardless of the financial ability of the patient. He has no right to terminate human life, none whatsoever and there is equally a very clear instruction to all the followers of Islam, a very clear instruction against taking your own life. Thank you.

Dayan Ehrentreu: My name is Dayan Ehrentreu. I am the senior judge of the ecclesiastical court of the Chief Rabbi. I think the Office of the Chief Rabbi has already put in a submission and from a religious point of view, I think it is made quite clear that the practice of euthanasia is contrary to the teachings of Judaism. Any positive act designed to hasten the death of a patient is equated with murder in Jewish law, even if death is hastened only by a matter of moments. The value of human life is infinite and beyond measure, so that any part of life, even if only an hour, is precisely of the same worth as 70 years, just as any fraction of infinity, being indivisible, remains infinite, no matter how laudable the intentions of the person performing the act of mercy killing may be, his deed constitutes an act of homicide. This is from a religious point of view. I think it is quite clear that certain arguments have been put forward and I should like also to mention some of the arguments which are put forward, especially as I understand one of the arguments is that the opinion of the religious view is a vast minority compared to the majority of opinions. One of the arguments put forward supporting this Bill has been the right of personal and patient autonomy. I agree the touchstone of a democratic society is the concept of individual freedom and personal autonomy. Despite contemporary society's commitment to individual liberty as an ideal, it recognises that the interest of the individual cannot be separated from the interest of the society at large. In fact, the previous Select Committee in 1994 concluded "We believe the issue of euthanasia is one in which the interests of the individual cannot be separated from the interest of the society as a whole". To legalise assisted suicide, that is euthanasia, will lead to direct or indirect coercion of terminal patients to express a wish to die. Legislation would place unfair psychological pressure on all ill patients. An ill person will, in all likelihood, find it difficult to make dispassionate decisions and may be pressured to terminate his life

or her life feeling that they are a burden to society and a burden to family and friends. No-one should be placed in a position of having to choose whether to live or die. Hence, personal autonomy must give way to the interest of the society at large. The enactment of this Bill would also undermine, destroy and erode the doctor/patient relationship which is founded on trust. It could poison the atmosphere with suspicion and guilt. If doctors are authorised in special circumstances to assist in terminating the patient's life, they acquire an additional role alien to the traditional one of healer. Their relationship with all their patients is perceived as having changed and as a result, some may come to even fear a doctor's visit. For the interest of the society at large, personal autonomy in these matters must be set aside. We feel that it is essential to improve palliative care and make it available equally and accessibly to all who need it. Current demand far outstrips supply in the UK for palliative care, independent living support and hospice care. We believe that pressure for assisted suicide and euthanasia would be minimal if resources for palliative care and hospice care were increased. At present, people might request an assisted death in the absence of vital care services, undermining the principle of autonomy and not representing a real choice for patients. In fact, in July 2004, the House of Commons Health Committee report on palliative care and the 1994 conclusions of the Select Committee on Medical Ethics, together with the World Health Organisation, all recommended that governments demonstrate availability and the practice of palliative care before considering assisted euthanasia. The Office of the Chief Rabbi naturally is strongly opposed to this Bill. Compassion has been brought up. I think compassion is wanting the best for the other, having empathy with them in their suffering. Mercy or compassion entails staying at their side, offering good palliative care and through friendship helping them to recover hope, meaning and a sense of being loved. Another thing has been mentioned and that is dying with dignity or death with dignity. Judaism teaches that the human body must be accorded every sign of dignity in death as well as in life, but the struggle for life is never an indignity; the attempt to sustain life by whatever means is nought but the expression of the highest regard for the precious nature of the gift of life and of the dignity in which it is held. I just want to finish, that therefore each patient should be assured that whilst everything will be done to minimise pain, life itself will be honoured and never willingly terminated.

Chairman: Thank you very much. There is now an opportunity for members of the Committee to ask your help for particular questions.

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Q1759 Lord Taverne: At the very first meeting we had, one example was put forward to us which I find very compelling which I should very much like to put to the panel. It was the case in the United States where a driver was trapped in a burning lorry. There was no possibility of extricating him and he was about to be burned to death and suffer a very painful end. A policeman was on the scene and he asked the policeman “Will you shoot me?” and the policeman did. It seems to me that here is a case where somebody certainly was guilty of intentional killing. It was not a case of war, it was not a case of judicial process and according to your arguments, the result seems to me to follow inexorably that that was morally wrong. Now, I do not see how that can be an acceptable conclusion. If what he did was morally right because he prevented unbearable suffering, then it seems to be that you have to admit that there are cases where killing, as you call it, bringing about death to end unbearable suffering, is morally correct. How do you answer that point, because it seems to me absolutely fundamental?

Rt Rev Christopher Budd: Could I do the first reply to that? I do not think I would want to say it is morally acceptable: I would say it is morally understandable in that very tight situation which was not fabricated or brought about by anything but an accident. I would not want to take the guy to court for that. I would not want to endorse a direct killing of an individual.

Q1760 Lord Taverne: He should have left him to be burned alive?

Rt Rev Christopher Budd: Well he would have died, would he not? It is difficult. We have to set limitations on what we can do in a situation.

Rev Professor Gill: I really would not take that line. I would think what he did was right, but that is not the point. What we are here to argue is whether it would be right to change the law which allowed people to go round shooting people in accidents which clearly we do not do, at least I do not think we do. I hope the way the law would treat that person in that situation is in turn with real compassion. I think there is plenty of evidence to suggest that people who in desperation take the lives of dear ones, who are in intolerable situations, intolerable pain or distress, are treated leniently by the courts and I would hope that would happen. Clearly, a law which said and it would be a very clear instance of a difficult case making bad law, if we were to change the law and say “In any future accidents, the police are entitled to shoot drivers at their discretion whenever they find them in a burning car”. I do not think that is how law could possibly work. What we are here arguing about is not about the taking of life: What we are arguing

about is whether it is actually going to produce good benefits to society by changing the law on euthanasia. That is a very narrow question.

Q1761 Lord Taverne: But it is a case of unbearable suffering, which is what the proposed law is about.

Rev Professor Gill: It is a hugely compassionate case and I would do exactly as the policeman did and I hope you would too, but I would not expect the law to be changed to allow that; indeed it would produce absolute chaos in society if we really did allow the police the discretion of shooting people in that context.

Q1762 Lord Taverne: You would not say the police would be entitled to shoot, you would say it is not contrary to the law in certain cases to assist someone to die in a case where they are subject to unbearable suffering, which is what the law is about. I do not see what the moral distinction is.

Rev Professor Gill: It is not a moral distinction. I am talking about whether you actually change the law in the process and there are two ways of handling this. One is to say yes, we actually change the law. The other way is to say for heaven’s sake, we show compassion and discretion, which is what we judicially currently do in a situation like this and we do not want to end up prosecuting police or doctors and so forth, if we possibly can help it. If we do have to do it, then we must be merciful and compassionate in those very rare cases where any compassionate person would do as they did. It is the effect of changing the law which is the central problem here and, as you know, I start from a position of compassion, I start from a position of being not just compassionate but in favour of Dianne Pretty, but what I am still saying is that changing the law has implications which actually are more damaging in my view, both to the law itself, to the doctor/patient relationship and, I think, most importantly of all, to other vulnerable people.

Q1763 Lord Taverne: May I just follow this up a bit further? You say that it would have a damaging effect on the doctor/patient relationship. In our visit to Holland, we did not find that this was so, even in the case, for example, of a Catholic hospice, not a secular hospice but a Catholic hospice and care home. Those who had had experience of Dutch law, first of all said they found no conflict with their religious background to implement the law and, secondly, they said specifically that the doctor/patient relationship had been improved as a result of the law. So, on more practical grounds, there seems no reason why the principle of relieving unbearable suffering—

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Rev Professor Gill: I think you do know there is quite mixed evidence. I thought you might raise this issue and I am sure you already know the BMA's *Medical Ethics Today*. I think it really is the most authoritative publication we have in this area now in medical ethics. I am on the BMA's Ethics Committee, I know how it runs, I know it is staffed by four full-time people, there is no other comparable body in Britain and very few other comparable bodies around the world. It has an enormous range of experts on it, coming from very different angles and it has some excellent lawyers too. When it publishes things, it publishes them fairly and after a huge amount of discussion. If you look up *Medical Ethics Today* which came out last year, and I am sure you have it available to you, and you turn to their account of the evidence on page 396, what you will find is that they present factually the evidence from The Netherlands, from Oregon and from the Northern Territories in Australia and in each of those contexts, they document ambivalence.

Rt Rev Christopher Budd: Very briefly, on the Dutch experience, I have not been to Holland so I cannot speak, but the sort of input I am hearing from different quarters is that there is a lot of dodging of regulations going on in the Dutch scene. Obviously I can only take that on the grounds on which it has been presented to me. In regard to the hard case you present, and it is a very hard case, I think the old Catholic distinction between objectively immoral and subjectively excusable comes to bear on that, but that is getting technical.

Dr Hameed: I have not visited Holland, but I have worked here in this country for more than 30 years and I manage a hospital which is secondary/tertiary care here in London. We treat a lot of cancer patients. In all these years that I have been there, I have not had an official request or a personal request from either a physician or a patient to terminate their life, considering a lot of them have serious discomfort. Of course, one does everything possible to make their lives as lacking in discomfort as possible. On your earlier example of the burning car or truck, if the policeman was there, one can assume that an ambulance would not have been very far away and perhaps if shooting is more dramatic and killing in that fashion, there could have been large bolus of morphine which could easily have been given to him to make him unconscious, if this was what was needed. Certainly the experience that we have over here in the United Kingdom in terms of pain and suffering is that, and I have asked this question of many colleagues in the profession, the question of the families asking for the patient to be put away does not arise in normal practice. It can be clinical judgment, but certainly request from the patient or the family.

Dayan Ehrentreu: What I should like to say about this is the following. I do not think the Bill has been proposed just for people who are burning in a car where there is a question of shooting them or not; I am not going to go into what one should morally do in this case or not. We do have a Bill here which is for society and I have mentioned before already that the current demand for palliative care outstrips the supply which is here in the UK. I think it is for us before we even come to this Bill to make improvement in proper pain control, good communication, psychological support and then you will find that far fewer people would consider asking for clinical help to die. Therefore I would say that once this has been done, then you can start thinking about what you want to do. At this stage, I think it is our duty to improve palliative care and then we will find that the demand will be minimal because the resources will be there.

Q1764 Baroness Thomas of Walliswood: I wondered whether I could just continue the discussion about the Dutch experience, in the light of what Professor Gill has been saying. In Holland, as I am sure you are all aware, they had a long period when the cases of euthanasia—and I use that term, although it is a term which has very many meanings but I hope that that will not confuse the argument too much—were dealt with in the courts in an increasingly sympathetic way. It was not until such cases had continued over a period of a number of years, I think about 10 years from the first to the last, that the Dutch actually approached the question of changing the law itself. The law which they produced was in many ways very similar to Lord Joffe's Bill. I do not need to go into the differences and similarities but it has many points in common. I wondered whether you felt, (and I am addressing this question to Professor Gill, in the light of what you have said about the Dianne Pretty case), that we need a period where the courts are engaged in this subject because they have to be. (Because cases arise, where there is more discussion, which this Bill has of course prompted, about what you might call the rights and wrongs of the case.) I use those words as somebody who is not professing any Christian faith, although I am a member of a church, but I am not using it in the religious sense. So that would give us time as it were, or give society time, to come to a decision on the matter. There is some indication that public opinion, (although we have just had some fairly tepid support for this view given to us by a study which we commissioned), is fairly sympathetic to the idea of assisted suicide. Do you think that that process would be a useful one, or would it not really change views in any particular

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way as to the worth or not worth of changing the law?

Rev Professor Gill: Thank you for that. I think I agree with almost everything you have said and I agree with your assessment of the evidence; I suspect some of my colleagues do not. I have been convinced for some time that there is general public anxiety in this area and support and I think it is driven both by a strong sense of compassion and also I think a strong fear that medicine is becoming too clever at extending people's lives. Both those things are thoroughly justified. Where I differ is that having looked carefully at it, I am still convinced that changing the law will make more vulnerable people, more vulnerable. You say that we should move to the Dutch situation. In a sense we already have. We have done it by a different route and I also think that is correct. The Dutch had an agreement for 10 years not to prosecute if guidelines were kept. There are worrying features about this and they are extremely well documented features and they were of great concern to the previous select committee. I think if anything convinced people like Lady Warnock, who was known for her sympathetic views towards euthanasia, if anything convinced members who would otherwise have been sympathetic to changing the law, it was precisely by looking at the Dutch experience. They came to the conclusion, and this has been documented many times since, that the Dutch have regulations but they do not keep to them. They found first of all that it was a regulation for the competent, that there was an agreement not to prosecute competent people who requested euthanasia. What they found was that a third of their cases were people who were not competent. They found that they could not find any documentation at all for two or three per cent of the cases. Members of the committee came back appalled at the degree of mismatch between the intentions, what the Dutch said they were doing and what they were actually doing; these were seriously at variance with each other. I think this still remains the case; there is plenty of documentation on this to show that this still remains the case, that the law is about competence, the law is about voluntary euthanasia but the practice goes well beyond that. The law is about the terminally ill, but again the practice goes well beyond that. I think it is that kind of slippage which has been so damaging in terms of law. I think you are right, I think we do have a situation where we have moved, but we are responding as a society to the properly felt belief of the population at large which does incline towards a change in the law, towards strong feelings of compassion. I also believe that when people act in really deeply compassionate situations, you do not go around imprisoning them. That is already

recognised in the courts and is already recognised in the judiciary and there have been several cases where people have either gone abroad and manifestly aided and abetted suicide and have not been prosecuted, or they have actively and intentionally taken the life of somebody who is terminally ill and dear to them and desperate, where they finally have not punished them. That, in effect, is what the Dutch did. In the first instance, it is non-prosecution when you should be prosecuted and in the second instance, it does mean taking it to the courts but it has entailed being merciful in the process to people who go down this path. So I think we have actually moved to the Dutch situation already, but we have done it by a different route. I think the Dutch tale is cautionary and this is why I think the BMA evidence is so crucial to all of this: in every case around the world where they have legislated for voluntary euthanasia, there are considerable reasons for being disquiet about the outcome.

Q1765 Lord Patel: I should like to pursue this point a bit further. You say that you felt that in Dianne Pretty's case, her request for help to die would have been—I do not want to put words in your mouth—justified?

Rev Professor Gill: Yes.

Q1766 Lord Patel: Do you think in similar circumstances, you would feel exactly the same? In other circumstances similar to those of Dianne Pretty would you feel the same?

Rev Professor Gill: Absolutely; I think she was a very courageous woman and she clearly articulated her case. If we were simply considering her, I thought what she was asking to happen was deeply reasonable. But that is not my point. My point is that we are actually looking at changing the law in this area. If we are looking for a change in the law, which affects other people—

Q1767 Lord Patel: If the law were so tightly drawn, then it would be exactly for people like Dianne Pretty?

Rev Professor Gill: Well, your predecessors on this Committee concluded that it could not be.

Q1768 Lord Patel: And you do not feel that Lord Joffe's Bill, as drafted now—

Rev Professor Gill: I understand its intentions and I share many of those, but I think you face exactly the same problem as you faced 11 years ago, which is that you really do have to be convinced that changing the law will actually help people and not make things worse.

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Q1769 Lord Patel: My supplementary was to the Bishop of Plymouth on the comment you made about the fact that we might go down the same slippery slope as the law relating to the termination of pregnancy. Is it the slippery slope issue that concerns you most? Again the same question: can the Bill be tightened so that we do not go down the slippery slope?

Rt Rev Christopher Budd: If I could say something about the nature of law, though I am most likely trying to tell you things which you already know, the law relates to the common good. I think this is very, very important. What Lord Joffe's proposal seems to be saying means we will weaken the protection of the vulnerable. I think that is what I hear. Once you do that, you say you will slap a lot of regulations around it so that it is not abused, but we know from the abortion legislation that we are past masters at getting around regulations and extending the boundaries. We like going back to parliament or anywhere else for that matter and that is the slippery slope. Sometimes it is scaremongering but it can be used that way and I think it is a genuine risk that somehow we are going to lose that and vulnerable people will be much more exposed to unscrupulous people. That is the sort of dynamic which is set up and that would be my real fear.

Q1770 Baroness Hayman: Two issues really. I wondered whether I could ask Professor Gill's colleagues whether they accept what I think is the basis of his argument and it occurred a little in the Dayan's argument as well. This was that this is an issue of balancing goods. There may be a specific good for a tiny, or a very small number of people, whether it is Dianne Pretty or the man in the burning lorry cab, but in public policy terms, that is not justified, that would be outweighed by the greater harm and whether it is that utilitarian public policy argument that they are addressing, or whether we could only talk about this when there was very good palliative care for everyone and then the demand would be diminished. I accept that, and certainly the evidence we have from Oregon is that very, very few people would wish to avail themselves of this legislation, if it were here, but that a few would, however good palliative care is. So I wanted to try to tease out a little of whether the absolutely fundamental, religious prohibition, for example against suicide, ought to be translated into law or whether this would be very difficult to frame in law? That was one issue. Could I perhaps ask Professor Gill another question? It seems to me that what he was actually arguing for was *ex post facto* decriminalisation of the very hard cases; that may be an unfair designation, but that is what it sounded like to me: that there were very hard cases, but when

people acted very compassionately in them, there should be no way in which they were pursued through the courts or imprisoned or subject to harm. I just wondered how he squared that with the position of the person who was looking for assistance, who needed that compassionate help and the pressure on them to take a risk on what would happen to their doctor or their relative after this event and turning those people into potential criminals and whether that was a fair or unethical thing to do and whether he was concerned about the lack of regulation about a practice that we must believe goes on worldwide? Absolutely the last point, Chairman, is this issue about vulnerability. I have been terribly impressed by the evidence from Oregon that, far from it being the poorest, least educated and vulnerable people who take up assisted suicide, it is in fact the better educated and those who are very assertive and in control of their own lives and used to being in control of their own lives. I wondered whether you would like to comment on that?

Rev Professor Gill: I do not think I am a utilitarian. What I think I am doing, which is exactly the same as the Bishop, is trying to balance individual good and the common good. I think that lies at the heart of some of the most difficult quandaries in medical ethics. It was manifest in the MMR debate, it has been a problem constantly in the area of public health and this area is no different. Balancing the two, or the tension between the two, causes some of the most difficult problems in medical ethics. I think that is what I am actually doing. I was not really arguing for decriminalisation. What I was saying was that in effect decriminalisation has already happened in at least one area: those who go abroad and those who aid and abet others to go abroad to commit suicide has already been decriminalised, even in practice. In the other area, it is not decriminalised, and I think that is probably quite an important safeguard and for the very reasons you say. The very reason you give is that you do not want an open sesame that is not entirely regulated. The answer is that it is not unregulated; it is clearly regulated through the courts and clearly is at the moment regulated through the courts. They are well able to distinguish a Dr Shipman from a doctor who acts in good faith and gives somebody what somebody else considers to be too much morphine. They are well aware of the difference between the two already and I think it is probably quite important that was kept that. Just lastly, and I must not dominate this; on Oregon, again I think you ought to look at the BMA evidence. What the BMA came out with was rather important evidence pointing to the fact that in Oregon 44 per cent of those interviewed—this was the Oregon State's own

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review of it—who were going for voluntary euthanasia felt themselves to be a burden to others. I think we have to be very careful of this, but even rich and powerful people can be vulnerable.

Rt Rev Christopher Budd: I think it is crucial that there is a rock solid principle at the bottom of any legislation which says that we protect our citizens without any exception of who they are, what state of life they have got to and things like that. I think that is crucial. That is why I am very frightened of this project, because I think once you take that away and start making legalised exceptions, I think you are going to be surrounded with regulations and things to make sure all holes are blocked, but in fact it does not happen like that. I think it is a corrosive thing over the years. I suppose both Holland and Oregon are still fairly recent so it is a bit difficult to ascertain the long-term effect. You have to be a person with long-seeing eyes and not just short term, to say “This is a very safe thing and no-one is at risk”. Once there is a hole in the defence, all sorts of people start being at risk. You might call me a pessimist but I think the actual basis of law on principle is most important.

Dr Hameed: Of course we are concerned about the slippery slope and the concern is that the right to live can soon become the duty to die and the confidence of the people who are taking those decisions, their state of health, their state of mind, pressure of the family, pressure of the carers and a culture, if they are going to start a new culture, where it would be prudent and sensible and helpful to opt for ending life sooner than the biological cycle. So, all those things are a matter of concern.

Dayan Ehrentreu: I cannot comment on the Holland situation or in Oregon, but I do know that in the vast number of states of America, they have not accepted this, have they? Perhaps I could come back to what the BMA actually said. They were opposed to legislation because it threatens first of all the nurse/doctor/patient relationship, it will frighten vulnerable people and it will normalise the concept that some lives are not worth living and all these run counter to the principles of healthcare and the principles of medicine. I know some of the most distressing situations arise from individual anxiety about maintaining dignity at the end of life and this is combined with the concern about the availability of effective palliative care. I repeat that I think it is for us to see that we increase proper pain control, communication and psychological support and then far fewer people would consider asking for clinical help to die. There may be individual cases, but we are not going to change the law for society because of individual cases. I think it is important, and this is what healthcare is about, to value life and assure patients that they are going to be appropriately cared for.

Q1771 Baroness Jay of Paddington: I wonder whether I could just comment on the points which have been made, particularly by Professor Gill, about the position of the 1994 Committee of which I was a member. I would say, and there may be other members of this Committee who would not agree with it, that those of us who have, in a sense, not necessarily changed our minds entirely but certainly moved our positions from those which were represented in that report, have largely done so on the basis of the way in which the circumstances have developed, for example in Holland and in Oregon where, particularly in Holland, the use of the statutory approach as opposed to the rather piecemeal regulatory one which you rightly described which was in place a decade ago has made things seem much more secure. Certainly, as a member of that Committee in the 1990s, and indeed of this one, that would be the basis of the way in which my thinking has moved. On the question of Oregon, I wonder whether you could reflect on the point which I think Lady Hayman raised, but which you did not particularly address, about the narrowness of the group of people who do ask for assisted suicide there and the characteristics that they have? I think Lady Hayman described them as being above median educational average etcetera. The other point I would ask you to reflect on is that I am sure we all agree that the BMA’s evidence is powerful but of course when we personally interviewed the regulatory bodies in Oregon, the equivalent as it were of those committees that you have mentioned, they did not report any aberrations in the regulation and indeed had not dealt with any problems which came to them as necessary for regulatory action by them and that was a month ago. I think that is pretty up-to-date information.

Rev Professor Gill: Their own review did make that finding of the 44 per cent of people feeling that they had been burden.

Q1772 Baroness Jay of Paddington: No, sorry. I think you mentioned earlier—or perhaps it was the Bishop—the question of regulatory slippage in Oregon. It was reported to us that that had not occurred.

Rev Professor Gill: One of things which has puzzled us about the evidence from The Netherlands, for example, is that there have been two government commissions looking carefully at their own practice and what those commissions have argued is that there has not been any slippage during that time. I respect that, but it seems to me that really is not the point. There has not been any slippage because the situation really has not changed, and the situation has not changed in the sense that they never did, and still never do, stick to their own regulations. It is

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quite true that there has not been any slippage in The Netherlands, but they have not changed their ways either.

Q1773 Baroness Jay of Paddington: What about Oregon?

Rev Professor Gill: The proof of that point is that if you start asking “Do the Dutch confine themselves to competent terminally ill people?”, the answer is “No, they don’t and they never have done”. Oregon is much more tightly regulated and it is difficult to read from that one. There is the evidence the BMA points to which is that 44 per cent of the people coming for euthanasia feel themselves to be a burden. I understand that, and I guess all of us as we grow older—and I guess we are as a group getting older—will know that feeling. I do hope we would be worried about it.

Q1774 Baroness Jay of Paddington: What about Lady Hayman’s point about the vulnerable? You have several times used the expression “more vulnerable people become more vulnerable”. However, I think both Lady Hayman and I were impressed in Oregon, that it did not seem to be vulnerable members of society who came forward for this. It was a small number and they were characterised in the way we said..

Rev Professor Gill: No and we need much more careful monitoring and much more careful inspection of what is going on in Oregon. We know what happened in the Northern Territories.

Q1775 Baroness Jay of Paddington: No, I am specifically asking about Oregon.

Rev Professor Gill: There has been a lot of information about Oregon, how good their palliative care is, how developed that is. I want this group of people who feel they are a burden to be investigated much more carefully. A lot of things have to be in place before we go down this path of really being confident that we have something which is secure and does protect the law, doctor/patient relationships and other vulnerable people in society more widely. One of the other pieces from The Netherlands has suggested that evidence from interviews in old people’s homes in The Netherlands shows that people there are feeling extremely vulnerable in a situation where they know doctors can take life. It may be they are getting confused, it may be they are not themselves clear about how the law works and all those things happen to older people, but it is not clear that that group feels sanguine or happy or comfortable about the wider implications of the law which is directed, as you say, in Oregon to the very few. We need to know a lot about Oregon at that level other than from the

regulatory authorities. The Netherlands is the most inspected area in the world because it has had it so long, and I think there are, and continue to be, the kind of worries that your committee identified and clearly articulated and documented 11 years ago. I think they remain.

Q1776 Bishop of St Albans: I just want to say another thing about The Netherlands’ evidence about which you have heard a good deal of anecdotal comment from us this side of the table. It just needs to be borne in mind that the Jewish hospice that exists there, of course for obvious theological and cultural reasons, is not allowing euthanasia. One needs to reflect on that when one hears other forms of evidence and anecdote coming from The Netherlands. I want to say something else, if I may, which is that a number of you giving evidence have said things like “Love is the overarching moral virtue” and another quotation, I think from the Dayan, is “The value of human is infinitely beyond measure”. I suspect that within those statements is an implicit view of the nature of the Almighty that you have all made your statements about, the Almighty in implicit form. I understand why, because I think it is based on your desire to be enormously courteous and careful in circumstances such as this. Would you allow for the possibility that if, I preface it this way, if the Almighty is, might there be circumstances in which we are all required in society to take note of what various faiths have expressed by saying some truth is revealed? Would you want to lay claim to that kind of statement?

Rt Rev Christopher Budd: May I comment first on that? Yes, some truth is revealed and obviously I am sitting here as one who actually accepts that and tries to live it. I think these issues actually touch all human beings without exception, irrespective of faith or lack of faith, as the case may be. Certainly the Christian tradition, I suspect the Jewish and Muslim one as well, tells us to go into the marketplace and engage in discussions around some of the very vital human issues which are around. I am obviously driven by my Christian faith and therefore you must say yes, I am a very strong supporter of life and not changing law which protects it. I suppose ultimately it is rooted in my faith in God, but I think there are human issues which I can share and join arms with a whole wide range of people of different faiths and no faith at all and this is one of them. Again, if I can keep coming back to this, the project is saying we can change the law safely and still safeguard people against others who want to exploit it and get rid of them to use the rather colloquial way of putting it and I do not think that is possible. Once you have actually

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broken the protection, no matter how many regulations you put round it, we are devious. I am not saying that I am devious, but human beings are devious and if I have a further thing to achieve, I will find some way of getting round the regulations. I must actually go to Holland and find out what is going on, because I get different sorts of input from it, clearly from a Catholic hospice by the sound of it; it is very interesting. The protection of everyone in society needs that basic sort of premise of "Do not intentionally kill". I know we instruct soldiers occasionally, because they go to war and we also have our ethic of self-defence and things like that, but this is unique in a sense. We are going to say to our doctors "Given these circumstances, you may kill". That is a road I would hesitate to encourage anyone to go down.

Dr Hameed: I would certainly agree that life is sacrosanct in all the faiths that I have studied and there is no faith, including my own, which says that you can go out and kill, with certain riders which have been mentioned. If we are not very careful, we must appreciate that this could well be the beginning of a further dilution of human faith and religion. If you taking away the central plank of life itself from what has been agreed, understood and accepted over centuries as God's gift to man, it would be diluting religion as a civilising factor in our daily lives. We have seen laws, we have seen countries, we have seen dogmas, doctrines and it seems that the only thing which has had a constant message for supporting life has been religion. If we were to agree to a new law which gives away this gift of life to humans to take, then it is diluting religion, which can be construed as quite dangerous.

Dayan Ehrentreu: I should like to say the following. Yes, you are quite right. I did not put forward the religious point of view or did not stress it strongly because I understand that one of the arguments has been that the religious view is a minority and the vast opinion is opposed to it. From a religious point of view, there is no question whatsoever: mercy killing is proscribed as an unwarranted intervention in an area which must be governed only by God himself. The life of man may be reclaimed only by the author of life. Man does not possess absolute title to his life and to his body and hence man's life and body are not his to give. Therefore, as far as Judaism is concerned, we regard human life as absolute and infinite and we consider a deliberate termination of life as something prohibited. This is from a religious point of view. What we wanted to put forward was, not looking so much from a religious point of view, but for society as such, the vulnerability of society and the very fact it is going to affect the relationship between patients and doctors and nurses; this is going to have an effect

on everybody in society, not just people who are religious. The fact that for some people their lives are not valuable, they are not worth living, this concept is a terrible thing and therefore, for this reason we oppose this Bill most strongly.

Q1777 Lord Joffe: The Modern Church People's Union in their submission say that they feel that the Select Committee should be aware that there are also strong Christian arguments in favour of euthanasia and that these arguments are supported by 66 per cent of the members of the Church of England who worship on a weekly basis and 84 per cent of Christians of all denominations who worship once a month, that includes, Bishop, the Roman Catholics laity as well. What is your response to the statement of your congregations?

Rev Professor Gill: I think they got those statistics from me. Wearing another hat, I am a social scientist and I spent considerable time going through British social attitudes data and extracted this information which is reliable information and it is one of the reasons why I think that British social attitudes data is to be relied upon. I think we must take that seriously and not treat this as a simple religious or non religious issue. It does divide religious people. It does not divide theologians and church leaders as much as it divides lay people, there is no question of that, but there are church leaders, the retired primate of Scotland, and others in the past, who have supported changing the law in this area and there are still one or two theologians, both in the Catholic Church and in my own Church, who do as well. These divisions are there and we must recognise that; it is quite wrong to make this a religious/non-religious issue. Increasingly religious people, this is the language we used in our own joint submission, talk about life being given. Of course to us, as Christians, it is God given, but I think to secular people, life is still given, it is given by the people; you did not invent your life. Human life is in that sense special and to be treated with care. Intentional killing is not something any of us should be taking lightly, whether we are religious or not. We have to keep this firmly in mind and keep our eyes firmly on what we are actually debating. What we are debating is whether the law prohibiting intentional killing in a clinical setting should be changed. My answer to that is in the end, despite all compassionate reasons that have been advanced by others, no, because I fear that it is going to make things much worse for people at large, for the law itself, the doctor/patient relationships and especially for other vulnerable people. So, I do not make it in that sense, a strongly religious or non-religious thing, but there are reasons why religious people have special reasons to be careful in this area.

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However, we are not the only ones and I hope everybody has special reasons for being careful in this area.

Q1778 Lord Joffe: I follow that. May I come back on another important point which you raised? That, if this Bill were passed, more harm would be done to some vulnerable people than the benefit to the vulnerable people who benefit from it. You say with confidence that you are satisfied that that would be the position and I wondered what you based that view on? It sounded to me as though it has to be speculation and I should just like, before you answer, to touch on some of the other points you raised. You raised the BMA and the BMA's very carefully thought-through views. We had the BMA over here and it was conceded that there were very different views within the BMA Ethics Committee and the Chairman of the BMA Ethics Committee said that he supported it. That was his personal view. You mentioned, almost in support of the previous Select Committee on this subject, that even Lady Warnock had this view. Well Lady Warnock has very much changed her view and in fact she goes considerably further than we would even suggest in this Bill; certainly three members have changed, as Lady Jay has said. You referred to the views of the position in Holland at the time that the last Ethics Committee went there. Of course that was 10 years ago. We have been to The Netherlands and we got a completely different impression; at least I certainly got a different impression and I know some of my colleagues on that Committee felt the same. The question of the slippery slope was raised. The evidence in Oregon, in Holland and in countries like Switzerland where evidence will be brought on the position there, is that there is no slippery slope. Indeed one of the great opponents of the Bill in Holland, Professor Zillig, accepts that and has gone out to say there is no slippery slope. I would suggest to you that there is a lot of speculation about what might be the position, but when you look at all the speculation, you actually find, or I think I found, that the position is entirely different.

Rev Professor Gill: Speculation and strong views are on both sides of this debate and inevitably, when you have not done something, you do not know the answer to it. All we can do is look carefully and compassionately at the evidence of people who have done it, I agree entirely about that, and also, I hope, give some thought to what might happen. An old story which I was always told by my philosophy teachers was that they put a fence at the top of a mountain and nobody fell off the mountain. People came and said "We do not need that fence. Nobody has fallen off the mountain. We must take that fence away". Of course that was sheer speculation on their

part and not particularly good speculation on their part but when you have something in place, nobody ultimately knows what happens when you take it away. All we can do is speculate and look as carefully as we can at the evidence. You have had the evidence of The Netherlands, but it remains the case in The Netherlands, and that was what worried the previous committee, that they do not stick to their own rules, they do not stick to their own regulations. They do still have a large number of cases of people who are not confident and cases of people who are not terminally ill and this remains the case. It is not a slippery slope there; it is that they have always flouted their own regulations. That was what worried the last committee and it still remains the case. I am surprised you have not picked that up.

Q1779 Chairman: We have been to The Netherlands and have listened to quite a number of people, including representatives of their professional bodies and so on. Whether the statements you made about the facts there is correct or not, I think is a matter that this Committee will have to judge in light of the evidence that we have heard. If I may say so, the contribution that I was hoping that you would give us would not be dependent on what we might or might not have found in The Netherlands or in Oregon, but rather from the point of view of the approach that you have to the subject and whether or not this is a good proposal. I think you must take it that not all that you have said about what happens in The Netherlands is necessarily in accordance with the evidence given to us.

Rev Professor Gill: I understand that, and they clearly differ from the BMA in their *Medical Ethics Today*. My principle is based, and I think all of us are based in a sense, upon a concern for the good of the individual and a concern for the common good of society at large. Anybody who makes dogmatic claims about how we resolve those tensions is misplaced. Whether these are on the basis of religious dogmatism or secular dogmatism, it seems to me that there is a really serious tension involved in this of how we balance the two together: the good of vulnerable individuals, whom we are told, despite the best palliative care, remain deeply disturbed about their condition—there is a debate about whether there is pain there or not, but that is not for me to say—but manifestly articulate themselves to be deeply disturbed. How do we, at the end of the day, meet their demands while still being concerned with society at large and with the possible repercussions of changing something that has been a foundation of British law, the prohibiting of intentional killing and particularly prohibiting of

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intentional killing in a clinical setting and how will that change impact on society at large. Now that is the tension we are arguing about.

Rt Rev Christopher Budd: I have most likely made my position clear by now I suspect. It is absolutely crucial that you have a really firm foundation from which you can move and “You do not intentionally kill” is that firm foundation. Okay, Holland and Oregon have not been up and running in their statute law long enough for us to say. I am a speculator, because I really am very fearful that it gets more and more liberal, you remove more fences. Once you lose your moral compass, you do not know where you actually put the markers. It is not a psychological thing, it is a moral thing, where our morality is and where we actually take our stance.

Dayan Ehrentreu: I should just like to finish off and say the following. I cannot comment on Holland because I do not know what is going on there. What I do want to say is: how do you assess whether people in Holland are not vulnerable? It is a very difficult thing to assess. If a person says they agree to terminate their life, how do you know that this decision was not made because of certain coercion? Likewise, how do you assess that it has not affected the patient/doctor and nurse relationship? I think the vast Jewish community, certainly the traditional Jewish community, is of the opinion that euthanasia is something which should not be permitted and we strongly oppose this Bill. Compassion? Certainly we are compassionate; it is part of our religion. One thing which has not been mentioned is the following. If a doctor is allowed to terminate somebody's life and he does it once, twice and maybe a third time, he will become a person who has lost his compassion and that is also something which is vital for medical care. It is not just the trust, it is the care which he has to give to his patients. On that basis, leaving alone the religious aspect of this which is quite clear to us, we would certainly oppose doing something where you are going to affect society.

Q1780 Lord McColl of Dulwich: Could we have the reference to the illustration of the driver of the petrol tanker just for the record? I always understood that was just an illustration. Any policeman going to the site of an accident, a crashed car, first of all would never switch off the ignition, because that would cause an explosion. Secondly, he would certainly not fire a gun, because not only would that kill the driver instantly it would also kill him instantly. So it would be quite interesting to have the reference to that. My question to the Bishop. He mentioned the Abortion Act and the failure of the Act, however carefully it was worded,

to be enacted in the strict way it was intended. My question refers to the medical and nursing personnel, many of whom are forced to emigrate because of discrimination. Lord Patel quite rightly made the point in a previous meeting that now there is no longer any discrimination and as far as the ethnic minorities are concerned, there are plenty of obstetricians from the ethnic minority; so that is great. If there were only five out of a workforce of 1,500, one would say there was discrimination against the ethnic minority. My question is: how many Catholic obstetricians are there in the country? I have only been able to find five.

Rt Rev Christopher Budd: I think there are very few. A lot of the Catholic doctors post-1967 fled into other parts of medicine—“fled” is rather unfair—went into other parts of medicine because they felt they could not actually take part in the abortion legislation, even in its original very restricted formulation. The cautionary tale I mentioned when I was giving my opening remarks was that we must learn from what happened there. Again, I am not a prophet of gloom, but that could well happen to Lord Joffe's Bill, no matter how tightly, surrounded by barriers and boundaries. Given 20, 30, 40 years they will say “What has happened to the common good?”.

Q1781 Baroness Finlay of Llandaff: May I ask you to return for a moment to where we started out with statements. I think you all used the word “suffering” within the context of your statements. Given that we live in a secular society where many people would profess not to have any faith at all, I wonder why people who, when they are faced with the situation that would have been viewed as unbearable, may turn to chaplaincy services, or similar services provided by different denominations, or explore different theological paths that they have not explored before, or may explore other forms of medicine such as complementary medicine? My other question relates again to suffering, where I think Dr Hameed may find that he has had the same experience that I have had, where some of the people who appear to have the most overwhelming suffering are not terminally ill. They are people who have had terrible injuries, perhaps in a road accident, in which their relatives, particularly their children, have been killed and who can see no facet of their existence having any meaning except enduring ongoing severe neuropathic pain and other disabilities, yet we are not considering, within this Bill, allowing society to accede to their requests to end their lives. It seems sometimes a little strange that this Bill is considering speeding up the process for those who are already dying, but those whose prognosis is longer, and certainly uncertain, are

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excluded from this Bill. There are some people who have had a desire for death for many years, yet when they develop their malignant disease and it is advanced, find that a relief, their depression lifts and they feel that they are now at the end of their lives. The other question related to that is whether you feel that our ability to provide relief with drugs and with the care that we can give within the context of hospices and palliative care for those to whom it is available—and we know that it is not available to everybody—whether you feel that perhaps there is an onus on society to extend that philosophy of care beyond the boundaries of those who are facing their own death to those who are facing a lifelong complete disaster, which some do? My last question is: why do you think there is this pressure for physician-assisted suicide and euthanasia, when people who are asking for this have all their drugs available, they can stockpile drugs and yet they are not doing that? They are not committing suicide, they are asking for somebody else to kill them and that seems to be somehow a different situation psychologically. I wondered whether, within the context of your theologies, you have any light to shed on this?

Rt Rev Christopher Budd: How long do we have? This whole area of human suffering is a huge thing which we all share in one way or another. Obviously we are talking about those currently suffering in a very acute fashion and possibly chronic as well. I bring my Christian faith very much to bear on the understanding of suffering, whether it be my own or other people's. There are two key things I want to mention here. One would be the development of pain management and all the things you referred to as drugs, the drug dimension of that. Much more important is that circle of carers. I can quote this from my own personal life at the moment. My eldest sister has a degenerative disease which is galloping. She is being cared for by my younger sister, but it is not just interaction between the two of them, it is a whole range of other people who are coming in on the scene, which actually sustains my older sister. It is a community thing. One of the things about having on the cards the possibility of euthanasia and assisting someone to die, to kill someone, is that actually you are saying "You don't belong to our community any more". It may be because they feel they do not belong, but it is the strength of the community, the caring community, the medical community, the nursing community which surrounds people which should be our response on a human level to someone, no matter what the illness, what stage it has reached. As you say, the illness can be years down the road before approaching death comes onto the scene. The discussions here touch intimately on the caring

nature of our medicine, our nursing and our families as well. I know from the incidence I gave you the demands on family members taking care of a member, as some of them can be. I am sure I am not the only one in this room who has had that experience or is having it currently. I am not the frontline carer, I am just the brother who gives support to his sisters, but there has been tremendous care and it is that sort of model which we should be looking at rather than making inroads into the principle that we do not intentionally kill anyone. I shall shut up; I have been going on for a long time.

Rev Professor Gill: It was precisely the problem of introducing intentional killing into clinical practice that finally persuaded members of the BMA at their consensus conference. Do you remember that three years ago the BMA had a consensus conference on euthanasia, chaired by Michael Wilkes, who is personally more persuaded in terms of euthanasia? What overwhelmingly came out from that was the moment at which, thinking through the concept of euthanasia and thinking through the concept of voluntary euthanasia in a clinical setting, where finally it would be the doctor who was the one who had to go down the path of intentional killing. It was precisely at that point that a majority of those who came from all over the country, elected members to this consensus conference, decided that the *status quo* was preferable to changing the law. It was a very important moment. They had gone through the compassionate bit; Michael organised it absolutely brilliantly. They were forced to consider with an extremely articulate actor the whole problem faced by someone with motor neurone disease. There was overwhelming compassionate concern of wanting to reach out to somebody. That is not what you are being asked. You are being asked to change the law, if intentional killing comes into clinical practice. That is the implication of that and from the doctors' perspective it was precisely that which changed the consensus conference.

Dr Hameed: It is grossly unfair to ask the medical profession—you have probably heard this before—to be the messenger of death to a person or even the family. The family are affected if the person is in hospital and very often you will be asking them to deliver that verdict, to be the person who will judge the situation and if the patient is not in a condition to take their own decision, to take the decision for them. Whether it is a doctor or anybody else, it is unfair to ask another human being to be the executioner of someone who has only one guilt, the guilt of old age, infirmity or disease. As a society we have to decide whether we need to protect and support these people or whether we are going to get rid of them. Here it is important to consider the family support. We have just heard from the Bishop

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that it is so important for the family to be involved in the care of older people and the community. When you consider supporting this law or otherwise, these are the areas for deliberation.

Dayan Ehrentreu: May I add that from a Jewish point of view, relieving and mitigating a patient's pain and suffering is basic; certainly it is basic. What we are actually saying is that when the dual goals of avoidance of pain and preservation of life come into conflict with one another then Judaism recognises the paramount value and sanctity of life and therefore accordingly assigns priority to the preservation of life. Your question is: what about the suffering? Yes, we have to extend and we have to improve palliative care, as I mentioned before. Besides that we also have to offer them friendship, helping them to recover hope, meaning and a sense of being loved. Surely the response of a compassionate society is, besides alleviating pain, to love and comfort the patient and try to restore to that patient a sense of self worth until death comes naturally. If we try this and improve palliative care in the UK, I think we will find that those who request that they should be helped to terminate their lives will be minimal. I do not think we are going to change the law just for a few individuals.

Q1782 *Earl of Arran:* In those countries which now practise voluntary euthanasia or assisted suicide and where presumably, your colleagues in those countries were initially very much opposed to this like you are today. In the light of the experience in those countries now, four, five, six, seven years, whatever it is, have their views changed at all? Has their approach softened, or are they equally opposed, or frankly have they just learned to live with it?

Rt Rev Christopher Budd: The answer from me is that I do not really know, but I suspect their views have not changed. I suppose you learn to live. Obviously you are not politically in charge, so you learn to live with these laws, but you would oppose them every now and again, say a Catholic Bishops' conference would wave the Catholic banner and say this is just not on, especially when the slippery slope starts happening. I think you would find them still of the same mind. You obviously need facts and data about this, but I should be very surprised if they have changed their view, because it is a matter of principle. We hold this very dearly and very deeply as a matter of principle. Principles touching life and death are basic principles.

Rev Professor Gill: Unfortunately there are not too many Anglicans in The Netherlands, which is one of the problems. It is not an obvious place for Anglicans to be represented in the first place. Sorry about that. I am not sure about Episcopalians in

Oregon either; there are not many people in Oregon altogether really.

Q1783 *Chairman:* Three and a half million.

Rev Professor Gill: Maybe it is a question for those who know more about it than I do. Anglicans do not start with such a strong dogmatic stance, or strong principle about the sanctity of life. We believe that life is God given: we are divided on euthanasia. It is not something which unites Anglicans in that sense. There is no question that there is compassion for that and I have tried to represent that and it is there. The Netherlands is not really an Anglican territory.

Dr Hameed: I am sorry, I do not have the answer to that question.

Dayan Ehrentreu: The answer to the question, as far as the Jewish community is concerned, is that it does not make any difference. Those who are opposed to it are opposed to it and I do not think they have changed their minds.

Q1784 *Chairman:* There are one or two questions which I should like to ask. First of all, there are different provisions in different places in the area that we are considering. First of all there is the situation in which the doctor is authorised to provide a fatal dose for the patient, which the patient can take if he or she wishes. There has first to be a request to the doctor for this fatal dose and then the fatal dose is provided and the patient may or may not take it, according to what he or she feels as the time goes on. That is one category. The second category is where the doctor is authorised to inject directly or otherwise deal with the patient in such a way that the doctor brings about the patient's death; the patient having asked for this to happen has no further will in the matter. The doctor proceeds to carry out the patient's last stated request and the patient dies in accordance with that request. These are two different positions and the situation in the different countries where we have been is not the same in that respect. Do you discern a difference between these two from the point of view that you have expressed here?

Rt Rev Christopher Budd: They are both, in moral terms, formal co-operation which would be an immoral act. There is no difference morally. Whether there is any difference legally or clinically I am not sure; I am not a doctor.

Q1785 *Chairman:* There is a difference legally in the sense that different systems have adopted different attitudes to these different ways, but the law is what is laid down either by the courts or by the legislative body. I was thinking from the point of view of the

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views you are representing that it would not be any different.

Rt Rev Christopher Budd: No; it would be a completely unacceptable form of co-operation.

Rev Professor Gill: I think that there is no moral difference in the sense that both have the intention of ending a person's life and the doctor is co-operating with that. The primary intention is to kill a patient and the doctor is giving advice or direct treatment to that patient, so from the moral perspective there is really no difference between the two.

Q1786 Chairman: If the doctor simply provides the fatal dose, it may or may not be taken.

Rev Professor Gill: I understand that, but we are clearly talking about a competent and capable patient and the most difficult cases involve competent but incapable patients. Incompetent patients are also extremely problematic as well, but clearly for someone like Dianne Pretty, who feared she would get to the stage where she physically could not do anything for herself to remain competent, that was the nightmare scenario from the patient's perspective. That is why that case was brought and that is why it was so difficult to resolve. From the moral perspective, clearly if the doctor is intending to kill a patient or let the patient kill themselves and is co-operating with that, then morally there is no vast difference between those two things.

Dr Hameed: It would be unfair to put this burden on the medical profession. There would be a clear split between those who accept that in law and those who would be conscientious objectors. Then you would have the scenario of people shopping around, making sure, or some doctors might put on their letterheads that they are conscientious objectors to ending life. I think this would be grossly unfair.

Dayan Ehrentreu: It is not a question of unfairness; it is a question that morally and religiously this would be prohibited according to Jewish law.

Q1787 Chairman: Both methods?

Dayan Ehrentreu: Both methods.

Q1788 Chairman: Dr Hameed, is there quite a large proportion in this country of people following the Muslim faith who are in the medical profession or the associated caring professions such as the nursing profession?

Dr Hameed: Certainly there is a large group of medical doctors who practise medicine in this country and follow the Muslim faith.

Q1789 Chairman: You mentioned informed consent. I was wondering what Professor Gill had in mind in relation to informed consent, so far as procedure under this Bill was concerned if it became law?

Rev Professor Gill: Properly informed consent involves several features. The person is aware of all the options, including non-treatment altogether or doing nothing. The person who is capable of receiving those has the capacity to understand all those things. The person has been given a settled time to consider this carefully. The person is under no coercion. All those things are absolutely minimal standards for properly informed consent.

Q1790 Chairman: What if the proposal is to end the patient's life? What further information, if any, would be available at that stage?

Rev Professor Gill: I am sure you would consider all those important things and I cannot imagine anybody acting in medical ethics or law who would not properly do that now. There have been times in the past when none of those things were thought to be important for clinical practice, but now every working doctor assumes all of those things I hope.

Q1791 Chairman: Supposing, just for a moment, that you were a medical doctor.

Rev Professor Gill: I am afraid my wife will not like this as she is a medical doctor.

Q1792 Chairman: Assume this for the purposes of the question and I assure you that people are doing that. If you were a doctor, proposing to alleviate the person's pain in the ultimate sense of ending their life, what, if anything, could you tell them about what that would entail for them?

Rev Professor Gill: I presume you would be able to tell them how the drugs worked and what the effect of the drugs would be.

Q1793 Chairman: Which would be?

Rev Professor Gill: If I were a doctor, I could tell you.

Q1794 Chairman: What would it be? What would you have in mind?

Rev Professor Gill: How long it was going to take, what they were going to feel, what discomfort they would receive in the process.

Q1795 Chairman: What about after that?

Rev Professor Gill: I am not quite sure what you are driving at.

Q1796 Chairman: No, I am sure not. What would you have to tell them about the future?

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Rev Professor Gill: Do you mean the afterlife?

Q1797 Chairman: I do not know if you want to tell them about that. I am just asking what you would tell them, if anything?

Rev Professor Gill: I am rather assuming that in the context of a pluralistic society doctors discuss religious views when patients themselves broach them with them, but it is not standard medical practice in any situation, however strong the faith of the doctor is, to broach religious issues uncoerced, so to speak, unprompted. In a pluralistic society this seems to me to be at the heart of a caring compassionate doctor/patient relationship. Some people advocate more strongly than this and argue that there are health benefits to religion, which undoubtedly there are. It has never persuaded me that is the reason for doctors, unprompted, to raise religious issues themselves.

Q1798 Chairman: So far as this is concerned, the ultimate you would tell them would be that if this works in the way that is proposed, they will die and as to what happens after that you are not prepared to consider?

Rev Professor Gill: We are talking about a doctor in a pluralistic setting. We are not talking about a doctor in a religious setting or a doctor who knows that the patient is religious or a doctor who is doing it in a religious hospital. Is that right? We are talking about a doctor in a pluralistic, secular setting.

Q1799 Chairman: We are talking about a doctor faced with a position under this law, assuming it became law.

Rev Professor Gill: Yes, the doctor would be faced with exactly the same issue as with abortion. Religious doctors have one of two options. One is that they can decide, as many Catholic doctors have done, that they will not, they will always refer patients to somebody else if they are requesting an abortion. Others such as my wife, who is religious and not personally in favour of abortion, do not follow that path. If the patient raises with her the religious issues involved, of course she will discuss them or refer them to somebody else. She would not believe that, unprompted, this is something she should be raising with the patient, for one very good reason: it is not part of the pastoral relationship between doctor and patient to be raising guilt in the patients who come to them, even if you privately feel that what they are doing in this context is actually wrong. Clearly there comes a point at which you feel it is so wrong—and this is the position of Catholics who believe that life from conception is full human life, if you do believe that position—that you should have nothing to do with it. There is still a problem,

because you still have to refer to somebody else who will have something to do with it, so it still happens. There is still a problem and a very serious problem for conscientious Catholic doctors in this context. In a pluralistic society, where we try to respect each other, it seems to me this is the path we have devised which allows most people to feel comfortable.

Dr Hameed: I would not accept those instructions, whether they were coming from a law or wherever, because it is against my beliefs. If I had to give advice to a fellow Muslim patient, I would advise them strongly that we were both believers and we would both end up in hell. If the patient is another denomination, I would end up in hell and I do not know about him. Best of luck. By and large most Muslim doctors would refuse to administer that particular lethal dose.

Dayan Ehrentreu: Likewise. A Jewish doctor would not get involved and would try with all powers of persuasion to tell the patient to reconsider it and try to give that person comfort and love and to make him realise that every moment of life has dignity and there is also value in it.

Rt Rev Christopher Budd: I find it very difficult to put myself in a medical relationship. All I can say from pastoral experience is that around the end of life, suddenly, with patients who are able to communicate easily, you quite often get very important talk about the meaning of life. That is most crucial. Part of our opposition to any weakening of the law is that somehow that drives a coach and horses through that. It is like “I’ve come to get you ready to be killed by the doctor” or something like that. For those patients who cannot talk and communicate, the setting of the carers, whether they be family or others, or friends, is absolutely crucial, those discussions around “Where am I heading?”, to put it rather colloquially, are absolutely crucial. I do not think those can take place when in the background is “You’re actually going to be killed tomorrow” or next week, or whenever.

Q1800 Chairman: The theory is that consent would be required and therefore this discussion you are speaking of would not take place against a background of consent, but in a preliminary situation, before the question of consent is resolved.

Rt Rev Christopher Budd: It could be after as well; someone may have given consent and suddenly thought “Hang on. I’m not sure I really want this. Can I see the padre?”. That is very crucial.

Q1801 Chairman: So far as the Bill is concerned, if the Bill became law and the person was able, before the doctor actually did anything, to say they had

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changed their mind, then the doctor would be precluded from proceedings.

Rt Rev Christopher Budd: Sure. I think you would in fact have a hard job to put regulations to protect that. That is my gut feel.

Rev Professor Gill: May I add a slight rider to that? It would seem to me that you would probably have to go down the same path as abortion in the sense that doctors who conscientiously object to this must then refer their patients to other people. One of the difficulties for Catholic doctors is that inevitably makes them complicit in the act; inevitably.

Q1802 Chairman: That is the difficulty about conscientious objection, whether it is a Catholic one or otherwise.

Rev Professor Gill: Absolutely.

Q1803 Chairman: There may even be Anglicans who have conscientious objections.

Rev Professor Gill: I am sure there are.

Q1804 Chairman: You could have a situation in which conscientious objection, if it means that you must refer to somebody else, would in a sense be overruled.

Rev Professor Gill: Yes; absolutely. You cannot avoid that.

Q1805 Baroness Hayman: You raised a question before this very interesting debate which I just wanted to follow up, particularly with Professor Gill. You were talking about whether there was a distinction between the Oregon model of the giving of the prescription which then was totally in the patient's hands and where we had evidence that many people take and do not use, but derive some comfort and reassurance from and the physician-administered assistance to dying. You answered that in ethical terms and moral terms and that you did not see a distinction. Earlier—and I wrote it down because it was a phrase which was repeated a couple of times—you talked about the danger in a more practical sense of intentional killings in a clinical setting. I just want to explore that. What we saw in Oregon were not intentional killings in a clinical setting at all. Most of what happened was in patients' own homes. It was patient administered; it did not have physical doctor involvement there. I just wanted to explore whether you would still categorise the Oregon law, which is not what is in Lord Joffe's Bill at the moment, as intentional killings in a clinical setting that were particularly dangerous for the majority of society rather than for the individual?

Rev Professor Gill: You are right: there is a prudential side to this. I was just expressing the straightforward ethical argument and, as you know, in philosophy there is no difference between acts and omissions, for example, if you intend to do both. So omitting to save some people from drowning, when you know you could help them and stop them drowning, is really no different from pushing them into the pond in the first place.

Q1806 Baroness Hayman: But in legal terms?

Rev Professor Gill: You did ask me in ethical terms. In prudential terms, in terms of safeguards and so forth, there is some advantage in that in the sense the person clearly has to be confident that the patient is capable of taking it for themselves and it does not involve some of the knock-on effects. You still have problems though; it does not eliminate the problems. You still have the problem of whether or not you get slippage in terms of people who are not actually terminally ill and what you mean by terminally ill and how terminally ill they really are and whether they are just chronically depressed; all those things still have to be resolved. In terms of the actual Act "Yes, this is clearly somebody who is competent, somebody who can do it for themselves" yes, all those are prudentially there.

Q1807 Baroness Hayman: I do understand some of the complexities and I am not suggesting it is simple. The reason I explored it with you was because you were very vocal about the BMA discussions and how that intentional killing in a clinical setting perhaps in some ways tipped the balance there. In our discussions with clinicians in Oregon, it was interesting how firmly they felt that there was an important distinction between administration and the provision of means by which patients could help themselves and for the medical community of Oregon that seemed to be a pivotal issue. I just wondered in BMA ethical discussions—

Rev Professor Gill: You are probably right. I find it much easier to kill mice with mousetraps than bang them on the head.

Q1808 Baroness Hayman: Do not let us get into animals.

Rev Professor Gill: If you have mice in your house, it is difficult. You can of course use humane traps and give them to somebody else; I understand all that. Of course there are these things and all of us have that and I am sure that is right. I am sure doctors would be more comfortable with that.

Rt Rev Christopher Budd: A gloss on what Robin has said. I would give "clinical setting" a wide context: any intervention of a doctor and therefore the patient/doctor relationship is involved even if

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 Chanoch Ehrentreu and Dr Khalid Hameed

outside a strict clinical setting. That would be my gloss.

Q1809 Chairman: Would it make any difference if it were somebody else who made up the prescription?

Rt Rev Christopher Budd: A line of formal co-operation; they are all involved. The unifying intent is to kill this person.

Rev Professor Gill: It was the American, Dr Kevorkian, who thought we ought to have thanatologists.

Chairman: Thank you very much indeed. You will get a chance to review what the shorthand writers have taken down in order to ensure that it is what you said that we record. Thank you very much indeed.

 THURSDAY 13 JANUARY 2005

Present	Arran, Earl of Finlay of Llandaff, B Hayman, B Jay of Paddington, B Joffe, L McColl of Dulwich, L	Mackay of Clashfern, L (Chairman) Patel, L St Albans, Bp Thomas of Walliswood, B Turnberg, L
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Memorandum by the British Humanist Association
ABOUT THE BRITISH HUMANIST ASSOCIATION (BHA)

1. The BHA is the principal organisation representing the interests of the large and growing population of ethically concerned but non-religious people living in the UK. It exists to support and represent people who seek to live good and responsible lives without religious or superstitious beliefs. It is committed to human rights and democracy, and has a long history of active engagement in work for an open and inclusive society. The BHA's policies are informed by its members, who include eminent authorities in many fields, and by other specialists and experts who share humanist values and concerns.

CONSULTING OUR MEMBERSHIP

2. The subjects of assisted dying/assisted suicide/voluntary euthanasia are regularly aired in BHA newsletters, web forums and local humanist group discussions, although for most humanists these are not controversial matters and members rarely express opposition. The very few reservations that have been expressed by humanists over the years have focused on the adequacy of proposed safeguards, and we do not know of any members who oppose assisted dying on ethical grounds. The Executive Committee (trustees) of the BHA are members of the Association who have been elected at an Annual General Meeting, and three of them serve, alongside two staff, on our Parliamentary Working Group. Opinion in both groups is unanimously in favour of the principle of this Bill. A BHA members' web discussion in August 2004 received no postings arguing against the Bill. Individual members will also have participated independently in this consultation, and one member organised "Humanists for Patients' Choice."

HUMANIST PRINCIPLES

3. Humanists defend as important ethical principles the right of each individual to live by her/his own personal values, and the freedom to make decisions about her/his own life so long as this does not result in harm to others. Humanists do not share some of the attitudes to death and dying held by some religious believers, in particular that the manner and time of death are for a deity to decide and/or that interference in the course of nature is unacceptable.

4. The vast majority of humanists believe that we should have the choice of deciding these matters for ourselves, as do the general public.¹ A clear request to die with dignity is a rational choice when the postponement of an inevitable and imminent death can offer no benefit to the sufferer. This is a situation where personal autonomy is clearly important and does no harm to others—so most humanists support voluntary euthanasia and many would probably support an even more permissive Bill.

RELIGIOUS OPPOSITION TO ASSISTED DYING

5. The Roman Catholic Church has traditionally expressed the strongest opposition to assisted dying. It is worth noting here that only between 8.5 per cent and 10 per cent of the UK population are Roman Catholics, and that, according to a NOP survey in 1993 as many as 73 per cent of Catholics oppose official Church policy on assisted dying and agree that doctors should be allowed to help an incurably ill patient to die.

¹ 81 per cent in favour according to NOP, 28th October, 2002. *The Philosophers' Magazine* (Summer 2004) found that 84 per cent of 926 visitors to its website (rising to 94 per cent of professional philosophers) thought voluntary euthanasia acceptable.

6. Those with religious beliefs may sincerely hold that life is sacred and that people have no right to end it, but the law should not assume that all do,² or impose the views of the religious on other people, and cannot do so on the basis of supernatural arguments.³

7. It is also worth pointing out here that at least 15.5 per cent of the population is non-religious according to the 2001 census, making this the second largest “belief” group in the UK. Other surveys on religious belief in Britain have found 30–40 per cent of adults (and 61 per cent of young people⁴) declaring themselves atheists or agnostics.

HUMANIST SUPPORT FOR THIS BILL

8. The BHA supports the current Bill and believes that change is well overdue.

9. We believe that regulating assisted dying is better for patients and doctors than the current system, where the needs and autonomy of patients are often disregarded and where compassionate doctors risk being charged with assisting suicide or murder. The BHA maintains that the existing situation, where helping a patient to die is covert, unreported and unregulated, involves considerably greater risks to patients than does this Bill, which fully and openly involves the patient decision making.⁵ We believe that vulnerable groups will be better protected and treated as a result of this Bill.

10. The current system sometimes also results in close relatives being faced with immensely difficult choices: whether to assist a loved one who is begging for help to put an end to their suffering knowing that it is unlawful, or to deny their loved one the death they want. We do not believe that anyone should be put into the position of having to make such choices, or indeed into a position where they believe that they have no other option but personally to end the life of someone they love.

11. We note that the Joint Committee on Human Rights, having examined the issues in considerable detail, concluded that “the intentional taking of life at the request of someone who wants to die” was not incompatible with the right not to be intentionally deprived of life under Article 2 of the European Convention on Human Rights, and that the safeguards in the Bill were likely to be adequate to ensure compliance with the Convention.⁶ This was also the view of the Dutch Government when considering similar legislation.⁷

12. We believe that the Bill provides sufficient safeguards for patients and their doctors, with a regulatory system, provision for witnesses to requests, legal oversight and monitoring.

13. We also welcome the requirement to offer alternatives such as palliative care—no-one should request assistance to die simply because appropriate palliative care or medication is not available.⁸

14. We welcome the open definition of “unbearable suffering” (1, 2). This will include more than just physical pain.⁹ Quality of life is important, and the person best able to judge this and what constitutes “unbearable suffering” or is unacceptable must be the patient.

² For example, the Home Office Research Study 274, *Religion in England and Wales: findings from the 2001 Home Office citizenship survey* (<http://www.homeoffice.gov.uk/rds/pdfs04/hors274.pdf>), found that religion plays little part in the lives of most of people calling themselves Christians.

³ *Gilmour v Coats* [1949] AC 426, 444. Lord Simonds “The court can only act on proof”.

⁴ In a survey of 13,000 13–15 year olds, 61 per cent declared themselves atheist or agnostic (Revd Professor Leslie Francis and Revd Dr William Kay, Trinity College Carmarthen, *Teenage Religion and Values*, Gracewing, 1995).

⁵ Belgium is one of three countries to have commissioned extensive research into what happens to people at the end of life. The Belgian research found doctors were ending patients’ lives without the patient’s consent or request. Compared to statistics from the Netherlands, where assisted dying was regulated by legal safeguards, the Belgians found they had four times more cases of “non-voluntary euthanasia”. The Belgian Government was concerned that vulnerable people were at risk and so passed assisted dying laws in 2002.

“The main aim of the [Dutch voluntary euthanasia] policy is to bring matters into the open, to apply uniform criteria in assessing every case in which a doctor terminates life, and hence to ensure that maximum care is exercised in such cases” (Dutch Ministry of Foreign Affairs website: http://www.minbuza.nl/default.asp?CMS_ITEM=MBZ257609).

⁶ Joint Committee on Human Rights, Twelfth Report of Session 2003–04: <http://www.publications.parliament.uk/pa/jt200304/jtselect/jtrights/93/93.pdf>

⁷ See Dutch Ministry of Foreign Affairs website: http://www.minbuza.nl/default.asp?CMS_ITEM=MBZ257609.

⁸ The Dutch health care system is accessible to all and guarantees full insurance cover for terminal and palliative care. However, even where patients are receiving care of the highest quality, some still regard their suffering as unbearable and plead with their doctors to terminate their lives (Dutch Ministry of Foreign Affairs website: http://www.minbuza.nl/default.asp?CMS_ITEM=MBZ257609). In Oregon where “death with dignity” is permitted, the recent annual report of the Department of Human Services (<http://www.ohd.hr.state.or.us/chs/pas/ar-index.cfm>) found that a very small number (42) availed themselves of the law in 2003, that they were all covered by health insurance and most were being cared for in hospices. More than 90 per cent were able to die at home. This indicates that an assisted death is a genuine choice for some, and that a law permitting it need not lead to abuse or overuse.

⁹ The most common concerns expressed by those in Oregon requesting “death with dignity” were loss of autonomy, decreasing ability to engage in enjoyable activities and loss of dignity (<http://www.ohd.hr.state.or.us/chs/pas/ar-index.cfm>). Pain, degradation and the longing to die with dignity are the main reasons why patients request euthanasia (Dutch Ministry of Foreign Affairs website: http://www.minbuza.nl/default.asp?CMS_ITEM=MBZ257609).

15. We agree with the provision for opt-out on grounds of conscience for medical staff. The Bill should not interfere with the right of the religious to obey their own conscience. We support the requirement (7.2) that, in cases of conscientious objection, physicians must refer the patient without delay to another physician who does not have such objections. However, we point out that in some cases, eg hospices run by religious organisations, the entire staff may have conscientious objections to meeting a patient's request, and so referral to doctors from another institution would be required and must be enabled.

SOME RESERVATIONS ABOUT THE CURRENT BILL

16. We are concerned that the requirement to have a solicitor witness the declaration (4, 2) may deter some patients—those who have no experience or relationship with a solicitor and/or those worried about the cost. We would suggest that solicitors have no particular expertise in assessing the mental health or identity or the patient and that other disinterested witnesses would serve equally well.

17. We are concerned that the minimum 14 day “waiting period” (1, 2) after requesting assistance may cause unbearable delay and suffering to some patients.

18. We would prefer that such declarations could be made well in advance of terminal illness, not just during such an illness, and that they remained in force until revoked—not just the six months proposed (in 4, 8). This would permit someone with all their faculties intact to make advance decisions about their treatment in case of sudden accident or complete incapacity, physical or mental. It would also cater for those with degenerative illnesses who should be allowed to declare in advance the circumstances in which they would want assistance to die. The facility to revoke the declaration at any time (6, 1) allows for changes of mind.

August 2004

Examination of Witnesses

Witnesses: Ms HANNE STINSON, PROFESSOR SIMON BLACKBURN and PHILIP HAVERS QC (representing the British Humanist Association), examined.

Q1810 Chairman: Thank you very much for coming. Our usual method is to invite you to give a short oral presentation, either separately or together, as you feel inclined. Then I will invite members of the Committee to ask questions on which they feel that you may be able to help them. The help you give us is taken down by the shorthand-writers. You will have an opportunity of seeing whether the record they make is in accordance with what you thought you said in due course. Then the transcript of the evidence as approved will be appended to our report and will become public property. We expect it to be public property when our report is delivered, which of course will be as soon as we finish these deliberations. Would you like to make a start?

Ms Stinson: First of all, thank you very much for inviting the British Humanist Association to give evidence today. If I can introduce myself, my name is Hanne Stinson, I am the Executive Director of the British Humanist Association. I took up that post three years ago. Before that, I worked for a very long time with the British Red Cross, which I am just mentioning because for much of that time my remit included equality and diversity and I was also responsible for developing and delivering an education programme on international humanitarian law and human rights. The first bit of that international humanitarian law I am sure is not relevant, but the human rights may be. I am not a lawyer though. I might add that I am also a member of the steering group that is currently advising the

Government on the Commission for Equality and Human Rights, so again I think that demonstrates a commitment to both equality and human rights. My two colleagues, Professor Simon Blackburn and Philip Havers QC, will introduce themselves in a moment and they would both like to make a short opening statement as well. I should start perhaps by saying something about Humanism. In very simple terms, Humanism is the belief that we can lead good lives in both senses of the word good in the sense of ethical but also good in the sense of positive, happy, worthwhile lives, without religious or superstitious beliefs. Humanists are not religious. They do not believe in God, they do not believe in any kind of after-life, but they are generally not anti-religious, and I think that is important to state. Humanists believe that our moral values are based on our humanity and our experience and understanding of people and of the world. Our decisions are based on assessment of the evidence and consideration of the outcome of our actions and we believe in working with others to find solutions to problems. Since we believe that people and the world around us are all we have got, humanists tend to be very strongly committed to human rights, human dignity and equality those sorts of areas. The British Humanist Association very strongly supports this Bill. This view is consistent with the 2004 NOP poll which found that 95 per cent of the non-religious supported a change in the law and 82 per cent of the population as a whole are also in favour, and that includes 81 per

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cent of Roman Catholics and Protestants. Not all our policies have quite such widespread support. The opinion polls give us a picture of what the public thinks but we should also look at informed public debate, and these suggest similar conclusions. For example, the Liberal Democrat Conference in 2004 and the Townswomen's Guild annual meeting in 1997 both voted in favour of changing the law after considering detailed background papers and lengthy debates. A citizens' jury organised for Age Concern's Debate of the Age in 1999 also considered end-of-life issues, and the majority of the participants favoured a change in the law while a small minority was strongly opposed. I would like to outline some of the reasons why we support the Bill. The first reason is individual autonomy. I see this as a core human value, a human right. We should all be allowed to make decisions about our own lives unless those decisions are harmful to others. That is a basic principle of humanism but it is also shared by many others regardless of their religious or non-religious beliefs. It is also a key part of medical ethics, with treatment depending on the patient's informed consent. Indeed, patients can refuse treatment even if that decision will hasten the patient's death and regardless of whether the doctor considers this to be a rational decision. A generation ago medical practice was much more paternalistic than it is now, with most patients happy for their doctors to take decisions on their behalf. That has changed a great deal and there is every indication that this trend is continuing. Patient autonomy is growing all the time. Doctors are far more willing to inform patients of their choices and allow them to make decisions. I am certainly not willing to allow doctors to take decisions on my behalf without my input, and I know I am not alone. Secondly, the current situation is discriminatory and unfair. A patient can have life-saving treatment withdrawn without having given any indication that this is what they want, for example in cases of PVS. We also know that doctors end patients' lives by administering pain relief which they know may kill the patient (the principle of double effect), and they may do this without the patient's consent. A patient can choose not to be treated or to have their treatment withdrawn without any particular scrutiny of their decision provided they are deemed to be competent. A patient can end their own life, regardless of whether they are terminally ill at the time, provided they are physically capable of doing so. But a patient who is not physically capable of ending their own life cannot legally be assisted to die, in spite of having made a rational decision that their pain and suffering is unbearable and that they wish their life to end. This unfairness is illustrated by the Ms B and the Dianne Pretty cases. Ms B could hasten her death by refusing the treatment which was keeping her alive but Dianne

could not hasten her death because she needed a different kind of help. A significant number of patients like Dianne Pretty are forced to suffer unbearably and many people, including myself, see this as unfair and discriminatory. Philip Havers will be looking at the legal aspects of these situations in a moment. There are historic precedents to the situation we have. Certain religious beliefs used to, and in some cases still do, forbid vaccination, contraception, abortion, and blood transfusions, but society has legalised them all while at the same time respecting and protecting the wishes of those who do not want to use them. I respect absolutely the right of any individual to rule out decisions to end their life, but I also reject absolutely the right of people with particular religious beliefs to impose those beliefs on people who do not share them. Thirdly, we know that assisted dying takes place. Compassionate doctors and others assist people to die because they think it is the right thing to do. Because it is unlawful, we have no idea how often it is done and it is totally unregulated, unless someone is prosecuted. Strictly regulated assisted dying in carefully defined circumstances has to be preferable. Finally, in the current situation, those who assist a patient to die, whether a doctor or a relative, risk a long prison sentence. It is striking that the NOP poll found that 51 per cent of people would want a doctor or relative or friend to break the law to help them if they were terminally ill and suffering unbearably. It is even more striking that 55 per cent said that they would break the law to help a loved one. I would like to ask you whether you think it is acceptable that society puts anyone in the situation of having to make a choice like that, because certainly I do not. That concludes my remarks and I would like to pass on to Professor Simon Blackburn.

Professor Blackburn: My name is Simon Blackburn. I am the Professor of Philosophy at the University of Cambridge and I am a Fellow of the British Academy. I have written and lectured extensively on moral philosophy and other branches of philosophy, and that includes giving the Gifford lectures at the University of Glasgow. I am also Vice-President of the British Humanist Association and I appear at their invitation. I should like to start by saying how I understand my brief as a philosopher and as a humanist. My brief is far from opposing the moral precepts associated with any particular religious tradition. Many religious traditions incorporate profound thought about human life and its conduct and it is foolish not to learn from them. What we humanists claim is that we are not passive recipients of inherited teachings but must actively use our own experience, feelings and critical reason in assessing what they offer us. In saying this, we are of course saying no more than many people working within religious traditions who also have recognised the

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changeability and the changing interpretations that new experience demands of them. Where we differ is that we feel able to open our minds to embrace the wider human experience, including that of other cultures and other philosophies and that of our common law tradition. As a result, I expect that most of what I offer will be uncontroversial or familiar to you, and I hope that it is, but I believe we are dealing with an issue where our thinking may easily be taken over by uncertain meanings and entrenched but mistaken emotions and inferences. In this presentation, I should like to confine myself to some remarks about three examples. Two arise from my knowledge as a philosopher; the third is a piece of fire-fighting arising from what I have heard about this discussion. The first is the compassion and the sanctity of life. We all applaud this, and rightly so, but I believe it is much less clear how they bear on the discussion than many think. One quick, opening remark is that, centrally, opposition to this Bill is based not so much upon the sanctity of life, cannot be based upon the sanctity of life, but the sanctity of dying; in other words, the essential inviolability of the process of dying in whatever way nature and accident have determined, however long, degrading, undignified and intolerable. In Professor Hart's case, and I believe it is actually a constructed case, of the burning lorry-driver, one would not defend refusal to offer a painless death on the grounds of the value of life. You could only defend the refusal of, in that case, the policeman to act because of the sanctity of a process, because you believe that nature must be left to take its course. In England, simple suicide or the request to discontinue treatments were once deemed inconsistent with the sanctity of life on just those grounds. Now, they are not so in law and I do not hear of campaigns to repeal that, although some of the absolutist positions which you heard this morning might indeed wish that were so. It can be argued, and indeed has been argued by Professor Ronald Dworkin, that the sanctity of life is actually honoured when we give due weight to human suffering, human dignity and human self-determination, including what Onora O'Neill called principled autonomy, as Professor Gill reminded you. Indeed, in the much older, moral tradition of the Stoics, it was a crowning glory of human life, a source of liberty and dignity and an insurance against oppression by man or nature that we have the option of putting an end to misery and pain. On this view, it is proponents of the Bill who have the proper respect for human life. I do not want to insist upon that. The point remains that few, if any, philosophers would say that a simple, unqualified, three-word principle, sanctity of life, can by itself silence those other considerations and I notice that, in law, many recent cases, especially those of Bland and Burke, are ones in which eminent legal authorities have taken the

same view. There is a quite abstract but important point here, I believe, about very simple principles. Often their force derives from restricting attention to central or normal cases where that force can get an inertia of its own and can go on to inspire reactions to cases that are not central and not normal. A prohibition can gain a sort of symbolic horror which carries over to cases where its rationale is actually absent. To illustrate what I mean, perhaps I may remind your Lordships of the well-known mountaineering example of the film, "Touching the Void" and the difficulty people had in coming to terms with the idea that the forbidden action of cutting the rope was, in fact, the rational, compassionate and ultimately the successful and appropriate thing to do. It does not matter if you do not know about the example. I can return to it. Lord Joffe's Bill concerns only the extreme and fortunately atypical case of competent adults suffering unbearably as the result of terminal illness. Applied to such emergency cases, as we might call them, simple, moral reactions nurtured on a diet of more ordinary cases may be extremely unreliable. My final point on the sanctity of life is also a short one. The issue attracts a certain rhetoric. We should not play God with life and death, we must be patient before providence, we must put up with our allotted suffering, soldier on, take what fate has in store for us. Such thoughts have a historical pedigree, although many philosophers believe that they met their Waterloo 250 years ago in the famous essay on suicide by David Hume. In the present context, we must remember only that people still impressed by such ideas may indeed choose not to exercise the liberties this Bill would give them, but it is no part of our political or legal culture to enable them to force those views on others. If it were, we would be imprisoned by fatalism, unable to ameliorate our lives in countless ways. We would not have inoculations or anaesthetics nor, for that matter, houses or umbrellas. My second topic is the omissions/commissions doctrine, the division between failing to attempt resuscitation or other intervention and actually intervening to assist the process of dying. Some much respected philosophers have denied that this distinction carries any moral weight at all, and to my great surprise the view was heard from witnesses from the faith community this morning. I disagree. I think that division is serviceable enough in some cases and there can be pragmatic reasons for using it. Again, however this is not always true. Its moral significance can lapse and it lapses in cases where we do something by doing nothing, although the description then becomes moot and may appear paradoxically. Philosophers are familiar with the concept of levels of action in which you do something by acting, or equally do something by refusing, refraining or failing to do

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anything. You can betray someone by saying nothing, you can condemn the lorry-driver to burn to death by standing aside, and sometimes it is happenstance whether it requires an act or an omission to bring about a result. When that is so there may be no moral difference between exploiting the happenstance and doing nothing or instead doing what is needed. In October, your Lordships heard from Dr Wilkes, Chairman of the BMA Ethics Committee, answering the Earl of Arran, and from Dr Lloyd, answering Lord Taverne, that the public is mistrustful of the acts/omissions distinction in this context. I think the public shows wisdom, especially when, even if death is coming soon, doing nothing results in slow death by thirst or hunger or choking on saliva, when doing something could mean a swift and desired sleep. As has been suggested to you and will shortly be emphasised by my colleague here, it is surely discriminatory and unjust to allow deliberate omissions, as at present the law does, when a dying patient is lucky enough to be able to obtain merciful release, by people standing aside, but to forbid parallel commissions when he is not so lucky. In fact, the acts/omissions doctrine is more often used to provide a moral comfort zone for agents who believe they can shelter behind it than it is to indicate anything we are likely to wish for ourselves and those we care for. The third point, the final point, I would like to touch upon is that of autonomy and the relation between the patient and the doctor.

Chairman: We will have to stop for a short period for a vote in the House.

The Committee suspended from 2.53 pm to 3 pm for a division in the House.

Q1811 Chairman: Would you like to continue?

Professor Blackburn: If I could remind you of the first two points, one was about the sanctity of life and the other was about acts and omissions. The third and final point I would like to touch upon is that of autonomy and the relation between the patient and the doctor, and this is my fire-fighting point, as it were. This arises because I have heard this issue described as if it is a zero-sum game, a contest, in other words, either the patient gets autonomy and the doctor is downgraded to a servant of the patient's wishes or vice versa. I believe I am right, and I stand open to correction because this is not my area of expertise, that mistakes the logic of the situation. As I read it, the proposal gives a liberty to both the patient and the doctor. The patient becomes free to ask for an intervention and is largely reassured in advance that he, or she, can procure it should they wish it. They also know that in asking for such an intervention they are not asking somebody else to break the criminal law. The doctor becomes free to provide the service, or not, according to judgment and conscience, but again without fearing the very

real shadow of the criminal law. A corollary of that would be the predictable increase in trust between patient and doctor, of which you may have actual evidence from other countries. What the doctor loses is only a legal fig-leaf for standing aside and doing nothing, and I can sympathise with those desiring that protection or that comfort but the point of the Bill is that this is a fig-leaf that should not be desired or afforded. The only real loser, in terms of power, is of course the criminal law, although what it loses, if that is the word, in the range of its clutches it gains in terms of clarity and strength of principle. Thank you very much for your attention.

Mr Havers: My name is Philip Havers. I am a barrister and amongst the specialist areas in which I practise are human rights law and medical law. I have been asked by the British Humanist Association to say something about the current legal position in this area and the interrelationship between the legal principles of sanctity of life, on the one hand, and personal autonomy, on the other, as they apply now to end-of-life decision-making. I am delighted to do so because, although I am not a member of the Association, my views on this Bill coincide with theirs. I represented both Dianne Pretty and Ms B, their cases happened, curiously, to coincide in time, and the experience of doing so has led me to the very clear conclusion that the present state of the law which permitted Ms B to die is profoundly unfair, because it did not permit Dianne Pretty to do so. So where are we now? The present legal position, I think, can be summarised as follows. First, if, no matter what your state of health is, you want to die, you can do so and you can do so lawfully provided that you and you alone carry out the act which causes your death, see the Suicide Act. Secondly, if you are already dying or are close to death, you can refuse treatment which would otherwise keep you alive; this has long been the law. Thirdly, if you are not dying but you are only being kept alive artificially, you can insist that the doctors turn off the life support system with the result that you die. If physically you cannot commit suicide on your own because of your terminal illness then you can go abroad to Switzerland and get someone there to help you to die. Otherwise, you have no option but to endure the pain, the suffering and the indignity that you so desperately wished to avoid. In short, what it comes down to is this. Provided you are not too badly physically affected by your illness, you have the right to end your life when and how you choose. Even if you are but you can afford and you can find someone to help you to go abroad, you also have that right, but if your terminal illness means that you are physically unable to end your life yourself and if you can neither afford nor find the help to go abroad then you have no such right. It seems to me that this position is difficult if not impossible to justify. I have, of course, studied Lord

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Joffe's Bill and I have been struck by the many safeguards which it contains, not just individually but cumulatively. No other end-of-life decision-making practice or procedure, for example, the withholding or refusal of life-prolonging treatment, is underpinned by so many safeguards let alone legislative safeguards. It seems to me, for what it is worth, that those safeguards should provide a very high level of both reassurance and protection for the vulnerable. I would also like to touch briefly on the way in which the courts have been responding, under the common law and the European Convention, to what plainly they regard as people's wish now to have control over how and when they die. In the *Pretty* case, the European Court of Human Rights went out of its way to state that, and I quote: "The very essence of the Convention is respect for human dignity and human freedom" and to stress that the protection of that right by allowing people to choose how and when they die does not in any way negate the principle of sanctity of life. This approach is also reflected under the common law. For example, in the recent case of *Burke* the GMC, which was concerned with whether a patient can insist on being provided with life-prolonging treatment by his doctors, it was held that his decision as to where his best interests lie and as to what life-prolonging treatment he should or should not have is, in principle, determinative. The judge stated: "Important as the sanctity of life is, it has to take second place to personal autonomy." In the even more recent case of *Re Z*, the court refused to make an order prohibiting Mr and Mrs Z from going abroad to Switzerland so that she could obtain help to die, because to do so would interfere with her right of personal autonomy. "It seems to me" said the judge "that, within the context of a person of full capacity, whilst the right to life is engaged it does not assume primacy over the rights of autonomy and self-determination." I believe that the Bill would bring an end to the unfairness, and indeed discrimination, experienced by Dianne Pretty and others like her whilst protecting those who may be vulnerable. Thank you.

Chairman: Thank you.

Q1812 Lord Turnberg: Thank you very much for the presentations, which I found very interesting. You have obviously thought very deeply in the British Humanist Association about the issues and come to some very clear conclusions. I just want to press you a little about the certainty which you have in this area and whether you think really there is no downside to the passing of this Bill. It is an area which of course excites all sorts of controversy and people have different views from yourselves, as you are aware. For us, it would be helpful, for me anyway, if you could tell us something about the possibility that some of it may not be absolutely clear-cut. I am

particularly interested in the issue of autonomy, personal autonomy and principled autonomy, and the business about whether autonomy is absolute when what you do has an influence on others. We heard this morning and we have heard elsewhere the issue that my autonomy may have an impact on others which was inadvertent, which I have not intended but which the law might allow, and I think autonomy under those circumstances is not absolute. Really I wish to probe you on whether you are absolutely certain in your view, whether you think there is any downside to this Bill and, in particular, about the autonomy issue?

Professor Blackburn: I have talked about a number of philosophical issues. There are, if you like, sociological issues, issues of prediction. For example, would this Bill, if implemented, make one change or other, would it create more victims of some kind or impact widely upon the vulnerable or destroy patient trust in doctors? Those are questions which may be ones of speculation, partly ones of evidence from other cases, partly ones where one can make an educated guess, but as a philosopher I have no expertise in solving those questions. I cannot state positively that there will be no downside. I can imagine downsides to almost anything in human life. That is the first part. The second part about autonomy I think I can be more definite about. You are right, of course, there is no absolute principle of autonomy, people want to do things that they have to be forbidden from doing, there is no doubt about that. The famous John Stuart Mill Harm Principle is the leading principle which governs us there. I think, in this case and using Onora's distinction between personal autonomy and principled autonomy, we are dealing with principled autonomy, the desire not to be a burden, the desire not to be undignified, the desire not to suffer. Those are not, as it were, just whims which can be overturned if people do not like them. It seems to me they are a very, very important part of people's sense of their own worth, their own dignity, of the sense of the story that their own life makes. One might be very proud of being self-sufficient, of not being a vegetable, of not being comatose, of not being a great expense and burden to people around one, and people who are proud of that, contrary to what I think was implied at various times this morning, particularly by Professor Gill, are not the vulnerable. You do not make yourself vulnerable because you are afraid of being a burden to other people. I do not regard myself as a vulnerable member of society but certainly I am duly afraid of being a burden to other people in various ways. My pride would rebel against it and I would regard the narrative of my life as having gone much worse if it ended in these terrible ways. So I think we are dealing with principled autonomy. I do not think the decision, were it ever to come to that, that I might

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make or, God forbid, my wife might have to make and my doctor to terminate dying, suffering, intolerable moments of my life is a decision which has the kind of John Stuart Mill impact on other people, that is, by giving it to me you harm others. Any harm to others would have to be through such an indirect and improbable chain of causation that I think it would be wrong for public policy to take any notice of it.

Q1813 Lord Turnberg: Can I be a little clearer. It is not the act of personal autonomy in the way you describe it which would have necessarily a negative impact on others, it is the passage of the Bill which might. It is that which concerns me. If we had a Bill which ensured the sort of circumstance you describe, which I think is entirely laudable, would it have a negative impact on others who felt, as we have heard from several groups, that they would feel vulnerable or more at risk and feel that they were likely to be affected by this, albeit perhaps without good foundation but we are not sure?

Professor Blackburn: Without the safeguards, I believe there could be a risk; it was described this morning as a slippery slope. With the safeguards in place and in the light of the experience you are gaining from the operation of such Bills in other countries, I think the risk is very, very small.

Q1814 Bishop of St Albans: My Lord Chairman, if I might ask Professor Blackburn, it is really an attempt to be as philosophical as possible so please do not look at the uniform I wear or misread what I am about to say, it is about the notion, the concept, of sanctity. Would you feel at any point that the word itself should be bracketed out of any kind of language in this area?

Professor Blackburn: It is a dangerous word; it is a word that pushes buttons. I think it has to be used with great care. The interpretation of the principle of the sanctity of life is not in anybody's mind a simple matter. No, I think it is a good word and I would be sorry to see it lost. I am not so different from some Unitarian colleagues in this. I think there are some things which deserve treating as sacred, as it were.

Q1815 Bishop of St Albans: I am trying to be very sensitive to your particular position.

Professor Blackburn: You do not have to be.

Q1816 Bishop of St Albans: No, but it seems fair enough to be. Could you say then what meanings you would give to the word sacred from your particular position?

Professor Blackburn: I think there are some things which are so shocking that they rule themselves out of any decent person's decision-making. There may be quite surprising examples. In one of my books, I

give the example of an advertising concern which had the ambition of putting up a satellite in the night sky, about the apparent size of the moon, which could reflect advertising slogans, like Coca-Cola, or whatever, onto earth. That strikes me as a deeply shocking and, if I can use the word, impious suggestion. It is a distortion of our place in the cosmos, which would be attacked I think with repugnance by all right-thinking people and one could use the word impious and use the word desecration of such a proposal. It is not obvious why, because it would be very difficult to argue it on the grounds of harm, it might even do some good if it advertised Aspirin, or something. It is a delicate matter. I do think there are issues like that and I can see that they hover in this area so it is a very serious area.

Q1817 Bishop of St Albans: Could I push on a bit further on the word revelation, or disclosure, or whatever. Accepting that you personally would not perceive the use of that word in any sense as involving God or any concept of God at all, do you think that, again, it is a word that is evocative of meaning if it is used in current society, or do you think it is still a word that we can use with a degree of philosophical integrity?

Professor Blackburn: I think I am less hospitable to that, if revelation is the word that we are talking about. No, I do not like that word, it is used so often and I think so centrally as a device for closing off things.

Q1818 Bishop of St Albans: It is a trump card word?

Professor Blackburn: I am trying not to use it in those terms at all. It is a device for saying "Look, my texts have spoken and that's the end of it," which I dislike. I have got to dislike it; it is my profession to.

Q1819 Bishop of St Albans: Of course; to think about things. Thank you very much.

Ms Stinson: May I make a brief comment on that. Personally, I do not particularly like the word because of the implications it carries with it, but I think that a key belief, if you like, of Humanism is the importance of life, and we take the importance of life to exactly the same level as I think a religious person would take it when they talk about the sanctity of life. Life is crucially important. We do not end life unless there are exceptional reasons. In fact, from the humanist point of view, since we do not believe in an after-life, we believe we have got only the one life. So it is bound to be extremely important.

Q1820 Baroness Finlay of Llandaff: I wonder if perhaps you could clarify something for me. In your opening statement, Ms Stinson, you said we know that assisted dying takes place, and I think if we take

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out of that all the issues around unpredictable drug effects, and so on, we are left with people where the motive has been to kill them. I wonder how you feel we know that, from where is that evidence coming?

Ms Stinson: I think we know that a small number of cases take place, when they come to court, where people are prosecuted. In fact, I think there is a case coming up this very afternoon with somebody who assisted his wife, who was ill with terminal cancer to die, and who pleaded guilty. Only a very small number of people are prosecuted.

Q1821 Baroness Finlay of Llandaff: I thought you were talking about it in the context of the medical doctor/patient relationship?

Ms Stinson: There is some evidence from surveys, which I think the Committee has seen, that there are doctors who said they have done it and a slightly larger number of doctors who said they knew of doctors who had done it. The key issue is, I think, that we do not know how often it happens. Because it is unlawful, because it is unregulated, nobody can give you a figure for how often it happens, but there is evidence that it happens from what doctors said in those surveys.

Q1822 Baroness Finlay of Llandaff: Although I think we were surprised, when we took evidence from the General Medical Council, that they were not having these cases reported to them?

Ms Stinson: They cannot be reported while they are unlawful, can they?

Q1823 Baroness Finlay of Llandaff: Other unlawful things, such as sexual abuse, are reported to the General Medical Council, so it is surprising that they have not been, whereas things which you might say some people may feel were less serious have been reported, such as having an affair with your patient. Can I just pick up on Professor Blackburn, because you were talking about either acting or doing nothing when faced with a patient who is suffering. I was surprised you did not state that you viewed that as bad care and therefore malpractice, because the clinician who stands by and does nothing, as time marches on and therefore the patient's condition inevitably changes, will not be fulfilling a duty of care in any respect to do nothing and watch the patient suffer. I wondered also how you married that with the situation of triage, where inevitably there will be people for whom the attempts to resuscitate are so likely to be futile that those efforts are directed to those for whom the efforts are less likely to be futile, which is a balance of harms but cannot be taken as the absolute for one patient when you are faced with several people in front of you. I wondered how you married up those two?

Professor Blackburn: I may have misspoke myself. I intended doing nothing in that context to mean doing nothing relevant, that is, nothing to assist or hasten the process of dying. I did not imagine or intend to imagine a class of physicians who would not provide palliative care or balance very carefully the needs of one patient against others, as far as their time resources went. It was doing nothing, as it were, to assist the process which in the postulated cases is making the process of dying intolerable.

Q1824 Baroness Finlay of Llandaff: I just wonder why, given that we have heard evidence from those working in palliative medicine who do not want to have the ability to kill patients, you feel that this should be a medicalised option, why you would need a doctor, when you have been talking about people's ability to commit suicide and take what would be a fixed dose, a lethal overdose, administered to them?

Professor Blackburn: I have no views myself on the inevitability of the medical profession being involved in the actual termination of life. I think the Oregon model, as it is sometimes called, is one in which the medical profession provides the wherewithal but the patients themselves have to administer the drug or the injection, or whatever it might be, and that strikes me as a perfectly proper range of cases. Unfortunately, it does not meet the Dianne Pretty kind of case and that, I take it, is where the medical profession does get involved.

Q1825 Baroness Finlay of Llandaff: I wonder then how that marries up with the legal position, where you were saying you felt that the people who cannot physically commit suicide and do not have the finance to travel to Switzerland are the very ones who are so vulnerable, because you have to be able to swallow? It becomes discriminatory then, that position you are taking.

Professor Blackburn: That is right.

Mr Havers: I do not think they are any more vulnerable necessarily than those who can travel to Switzerland, one way or another, or who can take their own lives. What is so critically different is that, because of the law as it stands presently, they are prevented from doing that which otherwise they would be able to do, that is to say, to end their lives when they chose and how they chose to do so. Can I just pick up, if I may, one other thing which you said, when you referred to doctors surely being under a duty of care which would prevent them from standing by and doing nothing. If the patient has said to the doctor, "Look, I want you to stand by and do nothing," obviously not only would the doctor then not be in breach of his duty of care but, as the law stands and has done for a little while now, he would be obliged to stand by and do nothing.

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Q1826 Baroness Finlay of Llandaff: Even whilst he stands by and does not do whatever it is the patient has refused, he would be deemed to be negligent if he walked out and took all the staff away and left the patient alone. The patient still requires care, of whatever sort, so they may need turning, they may need help for the toilet, they may need fluid, even though you are not going to pursue a treatment for which the patient has refused consent?

Mr Havers: Not necessarily. It would all depend on what the patient had asked by way of continuing palliative or any other sort of treatment. It is quite feasible that the patient might say, "Look, I've had enough. You all walk out now and leave me. Turn off the switch, turn off the ventilator. That's it; I've had enough, please leave. I'm going to die." Then the doctors would have to walk out, close the door and leave him to die.

Ms Stinson: I think that is a very extreme case. I suspect what we are talking about more is the situation where a person wants and is receiving good palliative care but still makes the decision that their life is not worth living and they want to die. Is that more what you are talking about?

Q1827 Baroness Finlay of Llandaff: I was just trying to explore what you were talking about?

Ms Stinson: I would say, absolutely, that any patient should be entitled to the very best palliative care, but I think we also need to recognise that for some patients that does not meet their full needs. There are patients who receive the very, very best palliative care who still want to die and want assistance to die.

Q1828 Baroness Finlay of Llandaff: I think one can argue about setting standards, and so on.

Ms Stinson: No doubt standards can always be improved as well.

Q1829 Baroness Jay of Paddington: I am extremely grateful, personally, to Mr Havers for analysing so clearly the different stages of the law on all of this. I wonder if I could ask you to speculate. From what you said, in terms of describing the cases, first of all you mentioned ECHR but then you mentioned a third case and also Ms B whom you represented. In all of those cases it did seem as though the case law was progressively taking a particular position in favour of the absolutism, if I can use a sledgehammer word, of the autonomy of the individual patient. Do you foresee a time when it might be possible that a judge would make a different decision in the Dianne Pretty case, for example, or one that succeeded that, because we have heard quite a lot of evidence around the Dutch experience that it was the cumulative acceptance of a whole number of common law cases, cases of this kind, which eventually led to the statutory position being changed?

Mr Havers: Certainly, the reason why Dianne Pretty lost in Strasbourg was because the European Court of Human Rights, whilst on the one hand finding that the English law which criminalises assisted suicide interfered with her right of self-determination, her right of personal autonomy, went on to hold that, as things stood at present, each contracting State to the Convention was entitled to come to its own view as to how to strike the balance between, on the one hand, criminalising assisted suicide, which had the effect of preventing someone like Dianne Pretty from getting help to die, and protecting the vulnerable, on the other hand. One has to remember that at the time that case was decided there were no safeguards in place which would have protected the vulnerable. On the other hand, if this Bill, for example, were to become law then the factual situation, were there to be another challenge to the Suicide Act in Strasbourg, would be very materially different because the Strasbourg Court would be looking at a domestic position in which there were, I believe, very real and powerful safeguards in place to protect the vulnerable. The second answer is that the Convention is and long has been recognised by the European Court as a living instrument, that is the expression which the European Court uses, which is intended to change in its application so as to reflect the changing attitudes of society. This is what has enabled the Convention, through the medium of decisions of the Court, to adapt it so as to meet the different ways in which society adapts, the different values that it acquires, and the like. For that reason, it is conceivable, it seems to me, that were there to be a future challenge some years hence along the same lines as Dianne Pretty's challenge, firstly, attitudes may have changed in the meantime sufficiently to lead the Court to be prepared to look at the case again with an open mind. Secondly, because of the safeguards that will have been built in to protect the vulnerable, if, as I am hypothesising, this Bill were to become law, to conclude that the Suicide Act preventing assisted suicide was no longer justifiable. Under the Convention, whenever there is an interference with one of the Convention rights, in this case the right to self-autonomy, the State has to justify that interference, so the burden would be on the State to prove that interference was necessary to protect the vulnerable. If the safeguards had been working effectively, or if the experience from other jurisdictions, say, other European countries, had shown that such safeguards did work adequately to protect the vulnerable then, it seems to me, certainly one could foresee a different result.

Q1830 Baroness Jay of Paddington: I think what I am driving at is whether or not you can foresee (without the legal safeguards being built into domestic legislation), a process similar to that we

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understand took place in Holland, rather than the other way round? I can see clearly that if there is a change in the domestic law, for example, here, the European Courts obviously have a different standard against which to make their assumptions. Can you see a case, or indeed an accumulation of domestic case law, which would be influential in that way?

Mr Havers: If you mean an accumulation of domestic case law emphasising over and over again the right to personal autonomy, it is more difficult to foresee that because of what the European Court describes as the wide margin of appreciation which it allows to each country to decide how to manage its own affairs in what is a very delicate and difficult area. Certainly, if domestically the courts were to continue to support the right to self-autonomy in the future then I would be more hopeful of winning *Dianne Pretty II*, as it were, in a similar challenge in, say, 10 years' time than I am now.

Q1831 Baroness Hayman: I want to ask a question about the support you have given for the specific Bill that we are examining against the arguments which you have addressed to us, which have been arguments, in a way, of fundamental principle. I wanted to do it particularly in the context of Mr Havers' description of the inequality which exists currently between different people with terminal illnesses. It is a very powerful argument, which you expressed very clearly and with which I have a lot of sympathy, but there is one category of patient who cannot help themselves, if you like, who are denied access to something which is available to others. I wanted to ask, if you righted that situation, how you would defend the legal position of this being available for patients who were terminally ill? In other words, there could be patients who were in equal distress and suffering (and I believe we can all think of situations) who were equally clear in their wishes and equally competent and wished to assert their autonomy but did not have the physical capacity or were not in an environment in which they could so do and were not terminally ill.

Professor Blackburn: As a moral philosopher, I would say the difference is that, in the case of people who go through a period of life in which they may be suffering from some disease or some accident, some injury, they may be depressed, they may have lost the will to live, there is a very strong *prima facie* reason for not assisting them to suicide. It is that there is empirical evidence that people get through those stages and come out the other side and they are very glad that they did not succeed either in committing suicide or in getting assistance to commit suicide, so there is evidence of recovery from suicidal motivation. Of course, that does not apply in the case of the terminally ill. The dying do not come back and say "I'm jolly glad I didn't do myself in," because

they die anyhow. There is a big difference, I think, between restricting the liberty that the Bill would offer to those who are terminally ill and dying anyhow and extending it to those who may be going through a period in which they wish they did not exist.

Q1832 Baroness Hayman: Can I challenge that a little, because I think we have some evidence that, even in the context of being in a hospice, people's moods and desires and wishes could change. Certainly we have evidence I think that some people who are suicidal and attempt suicide do come back, do change their mind, do not continue with that, so some people who make suicidal decisions make them "wrongly", if I can put it that way, but we cannot do anything about that if they are competent. Equally, there are some people who might be in a residential situation, who need a great deal of nursing care, who are not terminally ill, but who are not depressed or whose competence could be absolutely the same level of competence, where their level of mental health could be absolutely as good as someone who had a cancer that was assessed as terminal within the next six months?

Professor Blackburn: I take it we are talking about people who have got what we might call a robust decision, that is, the safeguards have made sure that this was not just an after-breakfast expression of a wish, or whatever, and they are on a downward curve, they are dying.

Q1833 Baroness Hayman: They are not dying.

Professor Blackburn: No, but I think we can distinguish intuitively between, if I go to my wife's mother, who is in her nineties, or to my wife and say "How's your mother?" and she says she is dying, I do not expect to be met by her hale and hearty. I know that what is meant is that she is in a state from which, predictably, she is going to be dead very soon.

Q1834 Chairman: How soon?

Professor Blackburn: In less than ninety years, my Lord Chairman.

Q1835 Chairman: Certainly. There are not many people left of 180.

Professor Blackburn: A remark that we are all dying does not succeed, I think, in doing justice to our commonsense.

Chairman: "Very soon" is quite an important phrase. I just wondered what it meant. I agree.

Q1836 Baroness Hayman: I am inclined to accept that there is a difference between terminally ill and dying, because for me this is really quite an important issue. For example, you could be 90 with a life expectancy of three years and have a clear view that

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you wish to end your life, now you are not terminally ill within the context of this Bill or as commonsense would tell us?

Professor Blackburn: It seems to me that there are two flanks on which you are raising a doubt. One is whether the provisions of the Bill in logic or in consistency should be extended to people who are not terminally ill and I think the answer I gave originally is my answer to that, it may not be the final answer, which is, the empirical evidence from people coming through periods of depression. If you turn that evidence and say, "Well, in that case, you shouldn't apply it to the terminally ill either" then I would have to ask people who have much more experience of the dying than I have whether there is evidence of the kind of robust decision-making that the safeguards ensure has taken place—a serious statement of intent, witnessed, signed, certified by several professionals, and so forth—whether there is empirical evidence that people do that and in a state in which they are going downhill, so it is not, as it were, swinging with the swings and roundabouts of everyday life, and then live to regret having made such a statement. In the absence of quite a lot of evidence, I would be very surprised if the chance of what you might call a wrongful assisted suicide is very great.

Q1837 Lord Turnberg: The Oregon experience suggests that most people who start the process do not actually complete it?

Professor Blackburn: Yes. That is very good experience and I am very glad they do. We are amazingly robust animals and very few of us get into a state where we have a robust intention to kill ourselves.

Ms Stinson: I think the Bill itself and the whole issue requires a, very fine balance. On the one hand, the Bill is trying to ensure that a group of people who are suffering unbearably have the option of dying, but, on the other hand, I think the Bill succeeds extremely well in putting in very, very strong safeguards to make sure that this is not applied to other people. I think the balance works differently if you are talking about people who are terminally ill and who are going to die within a short and fairly clearly defined period than it works for somebody who is not terminally ill. I think that is why I would go for a Bill which is confined to just the terminally ill, even though I would have a great deal of sympathy for somebody who was not terminally ill and was also facing what they would consider unbearable suffering. I think one of the reasons, quite apart from the fact that they may get through it as we have said, is that medical treatments change over time.. The ability to provide really good palliative care, to go back to that point, may improve over time. The terminally ill person does not have that possibility to look forward to, but for somebody who is not

terminally ill it may make a difference in the longer term. That swings the balance, I think, so that it is right to have this Bill for the terminally ill, but there would be more risks in Bill which also covered people who are not terminally ill.

Mr Havers: Your point applies equally to those who ask for their life-support system to be turned off, the Ms Bs of this world, because they may change their minds, but they might have changed their minds otherwise. Indeed, in the Ms B case, the judge, the President of the Family Division, said very strikingly at the end of her judgment that she hoped Ms B would reconsider, and indeed she did reconsider a few months later and arrived at the same decision and asked for the machine to be turned off and it was. That has not stopped the law, as it were, from saying that those in that position are entitled to insist on the ventilator being turned off so that they can end their lives. The discrimination or the unfairness persists, because they can do it nonetheless, whereas those who cannot do it will be prevented from doing so if the view is taken that they should not be allowed to because later they might change their minds.

Q1838 Chairman: Professor Blackburn, you mentioned that you would not like to be a burden to people and I took it, from the way you said that, that on the whole that was a rather laudable way of looking at matters?

Professor Blackburn: I have read Seneca and Cicero, my Lord Chairman, and I am quite impressed by stoicism, which puts a great burden on trying to inoculate yourself against need, and I think that is a rather admirable philosophy, so I think, if there was a little touch of pride in my voice there, I have to own up to it, yes. I do not say it is for everyone.

Q1839 Chairman: Obviously, we have had some evidence relating to this. What about the severely disabled person who is bound to be, for the duration of their life, quite a heavy burden on somebody, either on the state or very often on their families, with prolonged caring? What have you to say to their feeling, if they were to be regarded as subject to complaint because they were willing to be a burden on other people?

Professor Blackburn: I think it is one of the terrible things about imagining the lot of the disabled those who do make great demands on other people. It is one of the terrible things when one imagines that situation to imagine the indignity of dependence. There may be disabled people who do not feel it, and in some sense they may be lucky. I think that we are also ambivalent about them. I think one of the characters in the current comedy series Little Britain is the wheelchair-bound person who is rather proud of being an extreme burden on his carer and makes life as difficult as possible for his carer, and the

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comedy is very sharp-edged and uncomfortable because we recognise that as having something inhuman about it itself. I think the sense of dependency is a curse and it is one of the curses that the disabled bear. I am sure many of them bear it with great dignity.

Q1840 Chairman: Can you see, that point may have a bearing on the view of at least some disabled people in relation to a Bill of this kind?

Professor Blackburn: The Bill is empowering, my Lord Chairman, as I understand it. It is not insisting that anybody, however grievous their position, should ask for assisted suicide or, still less, that they should feel they have to ask for it, it is simply for those people who would like to be able to ask for it.

Q1841 Chairman: If you apply your logic, the feeling that you are a burden is something which can cause embarrassment and a sense of deprivation in the person who has it. The disabled person has no option but to be a burden, and therefore is there not logic in the idea, which certainly some disabled people have, that a Bill of this kind would put pressure on them to end that burden on their carers, or on the hospice, or on the state, by deciding to end their lives? What is the best answer to that?

Ms Stinson: May I make a quick comment while he is thinking?

Q1842 Chairman: So long as you do not put him off his thinking!

Ms Stinson: In a sense, I think all of us sometimes, in some way, are a burden on other people.

Q1843 Chairman: Yes, I am sure that is true.

Ms Stinson: All of us, in some ways, also give things to other people. I have been uncomfortable about the way this conversation has been going about this last bit of the discussion, because I do not think that the majority of disabled people either do or should see themselves as a burden because they too contribute. I think, if somebody, whether they are disabled or not, sees themselves as a burden, that can be a very serious source of suffering, but I do not think we should assume, because somebody has a disability, even a very serious disability, that they see themselves as a burden on other people in a way that causes suffering. That is not to say that they may not need practical help but that does not necessarily imply a burden in that sense. Of course, the carers who assist that disabled person will also have a view of whether they are a burden or not, and in many cases they will say very definitely "This person is not a burden. This is a relationship that I enjoy. I want this person to go on living, I want to be with them," etc., etc. I think it is a very dangerous assumption when we start talking

about people with disabilities as being always a burden.

Professor Blackburn: I agree with what Hanne has just said. I think that is right. I want to insist, I was speaking for myself and it may be an element of stoicism within me, or admiration for the stoicism, which certainly I would not impose on other people and I would not feel that another person had fallen short because they did not share it. I do not think a feeling of burden is compulsory and it may not even be all that admirable. I was speaking very much for myself. Certainly, the principal, in fact the only, objection that I can see against this Bill which would carry weight in my own mind, although I think it is outweighed by its merits and the advantages they bring, would be the fear that people might feel not necessarily even pressured but a kind of duty to put themselves out of the way, to ask for a release which otherwise they would not have asked for. That has to be thought about very carefully, I quite agree, my Lord Chairman.

Mr Havers: As the lawyer, I have gone back to the Bill and reminded myself that, of course, it is focused on those who are suffering from a terminal illness the prognosis for which is that they are likely to die within a few months at the most.

Q1844 Chairman: Yes, I understand that.

Mr Havers: I appreciate that you do, my Lord Chairman, but when your Lordship referred to the handicapped and the disabled I think my lawyer's answer to reassure them would be that this Bill is focused not on the handicapped or the disabled in general terms but very, very specifically on those with a terminal illness, the prognosis for which is inevitable death within a very short period of time.

Chairman: Yes, I follow that entirely. I am just trying to analyse the difficulties that certainly some disabled people have had with this Bill, which is on the lines of the burden idea, I think, at least to some extent, and I just wanted to see how our philosopher would cope with that, and, obviously with help from the centre, we have had the answer.

Baroness Jay of Paddington: I was going to ask a supplementary question, which was, following this point about the burden and the disabled people. I wonder whether or not you would say perhaps, as you said just now, and I caught the Chairman's eye perhaps before you said it, that this was a permissive piece of legislation? Those who are permitted to act in this way through these proposals, as we understand it, looking at the characteristics, the demographics, or whatever, of those who do, are both extremely few in number and, as I think we characterised them when we talked to them, and I talked about them, on our various visits, are what in the popular jargon would be called A-type personalities, i.e., people who wished to have the kind

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of control over the lives which I think you are describing. Which is rather different from the concept of burden and the need to be looked after type of way that I think was perhaps the distinction that you were driving towards. Certainly it is one that I would recognise.

Chairman: Of course, the Bill does not attempt to distinguish the people on that basis.

Baroness Jay of Paddington: No, indeed, but I meant in terms of our observations of people.

Chairman: Quite so. I understand that and that is important, but the people who are looking at the Bill from outside, who in some cases are suffering from severe disability, may view it from a different point of view from those who have other aspects of it in mind. That is the reason I am asking the question. I am not suggesting that this Bill covers all such people necessarily, not at all, but I am trying to get at the basic reason why some disabled people feel very strongly that this Bill would put a shadow over their particular situation and I wanted to get to the bottom of that.

Q1845 Baroness Thomas of Walliswood: I would like to get back to what Mr Havers was saying earlier about the Bill providing protection and therefore that would have a beneficial effect in the eyes of a court dealing with human rights, and so forth. To come back to people with disabilities, we had very strong evidence from very formidable people with very considerable disabilities that they felt threatened by the Bill. In other words, they did not regard it as a protection, they regarded it as a threat, and I do not think it was entirely because of the aspect of it which we have just been discussing, that they feel obliged. One of them gave an example of having had to go into hospital to have a surgical intervention and she had insisted on her husband coming with her, who was not a disabled person, and the reason was that she feared what she had heard the doctor say, which was "Presumably, I don't need to resuscitate if this process goes wrong," or words to that effect, and she said, "Oh, yes, you do, I do want to be resuscitated" and she has had 10 or 15 years of life since that incident happened. I have not got all the details correct but broadly that is correct. How do you see this question of protection for the vulnerable, and in particular disabled people, towards whom other people may have quite different attitudes from those they have towards people who are not disabled, and therefore they may be tempted to use this Bill to justify an action which otherwise would not be justified? I think that was what they were afraid of.

Mr Havers: I suppose I can begin by contrasting the protection, the safeguards that are set out in the Bill with the absence of any such safeguards in relation to any of the other end-of-life decision-making procedures that are already in place.

Q1846 Chairman: For example?

Mr Havers: For example, Ms B, a patient who was on a life-support system or being kept alive artificially for some reason. If she says to the doctors, "I want to die," there are no built-in safeguards the doctors have to follow, let alone legislative safeguards, which require them to explain to the patient, for example, the pros and cons of the decision, the alternatives to the decision, and so on, which insist on a period of time before the decision is carried into effect.

Q1847 Chairman: Do the doctors not have to explain, as part of the informed consent arrangements, before the patient decision is called for?

Mr Havers: I think the doctors would need to satisfy themselves that the patient was competent, in other words, understood what the decision was that the patient was taking.

Q1848 Chairman: And what the consequences were?

Mr Havers: And what the consequences were.

Q1849 Chairman: That is the present legal position so far as these are concerned?

Mr Havers: It is an unwritten, legal requirement.

Q1850 Chairman: It is part of the medical practice, is it not?

Mr Havers: It is part of the medical practice.

Q1851 Chairman: They would be liable at law if they neglected that practice with consequent harm. I think there are some cases which suggest that the lack of informed consent is a ground of action against the doctor?

Mr Havers: Yes, but that is nowhere set out in writing, so that those who are in that position or their families can refer to, as it were, a code of safeguards.

Q1852 Chairman: The medical people certainly have got that sort of code and there are Department of Health circulars which set it out in some detail.

Mr Havers: There is a booklet which is issued to the doctors explaining what the steps are that they should take, but in terms of requiring more than one doctor, a consulting doctor as well as the attending doctor, to be satisfied that the patient is taking the decision voluntarily, to require that also a solicitor is involved to the extent of witnessing a written declaration, and so on, those are all safeguards which do not apply. The proposed safeguards in the Bill, I believe, do go significantly further. I am not saying that the other life-ending decisions do not have any safeguards but my point is that these safeguards go significantly further than they do. If those who are disabled feel threatened by the Bill, I would seek to reassure them by saying, firstly, the Bill goes much

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further than any other end-of-life decision-making procedure goes in terms of providing safeguards, and, secondly, it seems to me, these are really very extensive safeguards indeed.

Ms Stinson: I think what patients fear, very often, and certainly it sounds as though this is the fear in the example you have just given, is that a decision will be made about ending their lives without them having an input. This Bill is not about that at all, but I think the situation where somebody can have a “Do not resuscitate” notice in their notes or on the end of the bed without having been properly consulted, that is what a disabled patient or, for that matter, anybody else may fear when they go into hospital.

Q1853 Lord Turnberg: It is not quite that, it is that the disabled person in that position may feel that it is not worth struggling against what seems to them and everyone around them to be the inevitable, and that they may say “Yes, okay.” I think that was what they were worried about, a sense of coercion and the lack

of resistance at a stage when they were very low in their resistance?

Ms Stinson: Does not that bring out the importance of having an open, honest relationship between doctor and patient where these things are discussed? The importance of the patient being allowed to discuss the fact that they do want to die? At the moment they cannot do that because as soon as they bring the subject up they come up against a sort of brick wall. The doctor cannot discuss it, and can only say “I can’t do that, it’s unlawful.” That is what I think undermines the trust between the patient and the doctor.

Q1854 Chairman: That can come up in relation to refusal of treatment, certainly.

Ms Stinson: Absolutely.

Chairman: I think our time has gone. Thank you very much indeed. As I said, you will see the transcript in due course and have a chance to correct any inelegancies.

THURSDAY 13 JANUARY 2005

Present	Arran, Earl of Finlay of Llandaff, B Hayman, B Joffe, L Joffe, L McCull of Dulwich, L	Mackay of Clashfern, L (Chairman) Patel, L St Albans, Bp Thomas of Walliswood, B Turnberg, L
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Examination of Witness**Witness: PROFESSOR VAN DEN EYNDEN, examined.**

Q1855 Chairman: Thank you very much indeed for coming along, Professor. I am sorry that we are a little bit later than we expected to be, but you had the benefit of hearing the nature of the discussion so you will realise that it was not entirely within our control to bring the matter to a conclusion earlier. You are here, I think, to give your own views on the matters contained in the Bill in the light of your experience. You are not representing any other body than yourself, and the evidence you give us will be transcribed and in due course you will get a chance to look over it to see that it accords with your recollection. Then your evidence and the other evidence we have heard will be appended to our report and when our report is published your evidence will become public, in the sense that it is available in a published document, though of course you are giving evidence in public anyway so it is public from this point onwards, but it will be in writing in public in due course. Would you like to give us just a short introduction and then my colleagues and I may have some questions for you?

Professor van den Eynden: My Lord Chairman, thank you for the invitation. I feel honoured to be here today. First, I would like to apologise for my bad English. As you know, it is not my native language. I am from Antwerp, Belgium, the Flemish part of the country. To present myself, I am working there as a palliative care physician mainly and also, and these are my roots, in some general practice. I am responsible now for a palliative care unit of 12 beds and then of the palliative support team in an assemblance of about 1,000 acute hospital beds in Antwerp. Finally, I am also Professor in Palliative Care at the Antwerp University. That is my main situation. If you will allow me to, I would like to give some general consideration about the matter which is in the Bill and then I will give consideration to, some thoughts and feelings also, how some things have changed in the two years. As you know, in Belgian law we have euthanasia now and the way we are going and have to go on, because I understood from a witness today that you are doing the same process as we did three or four years ago, in trying to evaluate the social relevance and opportunity of a law

legalising euthanasia and assisted suicide, which is not the case in Belgium. I do not know whether you know but in Belgium it is only euthanasia and not assisted suicide which is legalised. First the general consideration. In a world of generally applicable, advanced reanimation techniques, chemotherapy, and so on, people can well understand the global fear of a human dying and thoughts towards euthanasia. Early bedside consultation is necessary to decide on an evidence-based medical dying, but this professional, medical dying is just the introduction to a much greater, total, social, natural, real dying, if a human being lives it is fundamentally in relation. Even in the latest phase of our lives, all palliative care-givers believe strongly in the phenomenon of the good death, not the soft, not the painless death, not the living, loving death in which no-one lives for himself, no-one dies for himself, can be felt. Therefore, the people suffering without any prospect of dying should not be regulated too excessively but it should be possible that the human warmth exercises maximally its pain-relieving effect. I am still convinced that palliative care is the right answer to the suffering without any prospect of dying, in co-pain, in compassion, perceptible at the place where the heart is beating. Palliative care is the pronounced facility near a patient without any prospect of the never deserting any more. Nevertheless, despite the good palliative care, some people, and it is extremely rarely, Dutch studies and even the Belgian one now, which are done in my country, are speaking about one to two per cent, remain asking for euthanasia. So not all those, and I think we should agree that, not all other prospective can be resolved by palliative care. This also should be admitted by palliative care-givers. Most requests for euthanasia are questions behind the questions. Only careful and patient evaluation disclose the real content of the suffering. Exceptionally, despite good palliative care, in spite of advanced pain-relieving methods, the horror of the approaching death will remain. Controlled sedation is a method of symptom control for persistent, unbearable suffering and even after extensive multi-disciplinary consultation this can be introduced and proposed. In the case of controlled sedation, not

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immediate deathly sleeping is aimed for but peace and rest are the purpose, together because the loss of outlook becomes bearable again. Controlled sedation is in the context and atmosphere of palliative care, waiting and caring. Nevertheless, implementing controlled sedation does not mean nothing, its impact on the caring team is strong and hefty. Some members of the team might hesitate, but only with the support of the whole caring team can the doctor feel himself a dignified healer in these extreme acts. That was the general consideration. Now I have some four or five points about the experiences of the actual law in Belgium. For me, the actual law is a missed chance. I mean by that, if there is a real need to regulate decisions concerning the end of the life of patients, there should be a regulation about the whole issue of the end of life and not just for the real cases, the one or two per cent, of euthanasia. Also, what the previous speakers said about not starting active treatment, assisted suicide, as I said, which is not regulated with us, but active sedation, giving patients pain or other symptom medication without the agreement of the patients, and so on. This whole matter is not regulated, it is just euthanasia for which there is a law. Secondly, I believe that society as a whole has walked into a trap in the whole discussion in the final decision about the law. People felt that there was a need for a quick and efficient solution for the awful pain and discomfort they considered the terminal oncological patient was suffering. Finally, politicians, and I heard from them of many of the witnesses to the traumatic experience of dying with one of their beloved, excuse me for the word, but I think it is, created a dragon offering a service needed to the patients, needed to the physicians. The law itself looks very liberal. For example, when you need two, real, consistent things, it is the subjective one, the unbearable suffering by the patient, and, secondly, there should be incurable disease. I do not know if most of you know this, it is also possible in non-terminal situations, then the procedure is much more strict than in terminal situations, but it is possible. As I said, it looks very liberal but at the same time the procedure is so rigid that in many cases euthanasia is not possible any more, and instead of what was the initial and final aim of this law, the suffering of the patient and his family is augmented. I would presume this, by stating that the whole movement for legislation of euthanasia in Belgium did not arise from a real caring for the suffering patient but started as a political concern and turned into an ideological debate with two opposite camps. I might hope that this will not be the case in your country. In many cases, when there is a euthanasia question there is less attention for the ethical and a companion discourse itself. I mean by this careful talking, discussion, negotiation and working together with the patient. Instead, there is

much more attention now for the legal, juridical and procedural aspects of implementing euthanasia at the moment that fragility and vulnerability of the patient needs nearness and warmth. Many physicians, even palliative care physicians, become accustomed to the idea and the act of actively ending the life of terminally-ill patients. It seems easier, it takes less time, less effort and less caring. It is real experience. I can see with some of my colleagues everything becomes quickly easier the second and the third time. This might be a first expression of the predicted slippery slope after two years of legislation of euthanasia in Belgium under specific conditions, euthanasia comes very slowly but for sure and will end as a normal medical practice. My third remark is that I will consider two groups of patients in more detail. We are confronted with a group of patients afraid of getting the syringe and of being euthanised without it being requested, of course, and not to be euthanised but to be killed without request, more than before legislation, a subsistent group of older people are expressing this fear. I would also mention that most of the so-called euthanasia questions are requests initiated by the family, and arguments can be, and are, that it is not human any more, it takes too long, "Mother has reached a nice age, now she is just a small amount of misery," but the patient themselves never expressed the wish to be euthanised. This is also arising after the legislation. There is also another group, to be honest, they are patients who are asking early on about how they can get euthanasia at the appropriate time in the future. These patients will never get an active ending of their lives, they are not coming to that situation and to finalising their request, but by receiving the assurance, the message, that euthanasia might be possible if they ask for it they feel they keep control, and for some of them palliative care, just care with good pain and symptom control, becomes much easier afterwards. In a society where keeping control at any time seems to become a very important value and a driving force, this group of patients will probably rise clearly in the future. My fifth remark is that another fact proving the slippery slope is the pressure to extend the law to people with dementia and to children, who now are not allowed to receive euthanasia according to the actual law. Professor van Nistal, who is an outstanding professor in law and a member of the Euthanasia Control and Evaluation Committee, talks about this issue, he is speaking about euthanasia and a Dutch word which means something like euthanasian obstinacy. In a recent article, he states that juridical wisdom learns that legal regulations about professional activities, that is medical practice, should not go too far. These regulations should leave space for a free and responsible deciding and acting. Juridicalisation, as he calls it, of medical acting at the end of life stimulates the defensive attitude of the physicians,

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enduring and harming finally the patient. In the case of minors and of patients with dementia, consultation, waiting, deliberation and reflection are necessary, even indispensable, to find the best solution for the patient and with the patient. When the actual euthanasia law will be extended to more and more kinds of patients and medically intolerable situations, physicians will be encouraged to be for the legal security of the euthanasia law to the patient, and time-consuming looking and negotiating what is the best for the patient. Careful and responsible medical acting will in that case often be right. Then we are organising a flight in the legal security if necessary at the cost of the ethical value of the definite medical decision. Finally, an ideological issue. As you know, there are two groups of hospitals and the spirit also of doctors working in it is assumed to be the same. You have the confessional one and then the one of the Government, which is assumed to be non-confessional but it is not that simple in reality, but okay. These confessional hospitals did not put themselves above the law, as they were accused of by someone; instead, they handled the law on a loyal base, making procedures and guidelines, building in the palliative filter, as necessary. I would conclude that, after two years of this law in Belgium and of the experience within, I am still convinced that a society should be very reticent in changing the law, making euthanasia a normal medical option.

Chairman: Thank you.

Q1856 Lord Turnberg: Thank you very much for that. I wonder if I could probe you a little. I have two questions, in particular. You talked about, for those doctors who are involved in it, it becomes easier as time goes on. Do you have any idea of what proportion of physicians are involved in taking part in this, and are you suggesting that somehow they are less caring than those who do not get involved? Is that something that you are proposing? The other is a quite different question. While you are thinking about that one, can I ask you about patients' attitude? You suggested that some of the public, those who are feeling vulnerable, are getting concerned that they are increasingly vulnerable now because of the existence of this facility. Are there surveys of opinion, is there published evidence on this which you have which suggests that?

Professor van den Eynden: To respond to the second question, there is a lot of research which is initiated now and which is going on but there are no results especially about this kind of more sociological-based research.

Q1857 Lord Turnberg: Why do you say that is happening, what is your feeling about that, is this your feeling from talking to some people?

Professor van den Eynden: Feeling, and being in contact with a lot of colleagues through my position within the country, a lot in palliative care.

Q1858 Lord Turnberg: There are surveys going on?

Professor van den Eynden: Yes, there are some surveys going on, certainly. To answer the second part of the first question, again, there is just agreed the kind of research which will try to explore this relationship of quality of care and the way people are thinking about and acting on euthanasia, but it is just initiated. Many colleagues, and the quantity, of course it is a small group, about one and a half years there is an evaluation which is telling us, because there is a whole procedure about registration and giving this to the Federal Government, that there were, let us say, about 350 cases which are registered, and so it is just a very small number of doctors who are already doing this.

Q1859 Chairman: Is it 350 patients or their doctors?

Professor van den Eynden: It is 350 patients which officially got euthanasia.

Q1860 Lord Turnberg: Out of the total number of physicians that are likely to be involved, is it half of them that are involved or less than that?

Professor van den Eynden: No, much less than a half. I cannot give you the percentage but it is a very small amount.

Q1861 Lord Turnberg: Patients are referred to them, are they?

Professor van den Eynden: In the law it is built in that as a doctor you are not obliged to act, but in the case, of course, it is not punishment built in but you are obliged to send, if you are not doing it yourself and you are not accountable, you have to send the patient to another doctor whom you suppose or you know is able to and will do it. That is built in, it is Article, whatever, in the law.

Q1862 Lord Turnberg: You know that group of doctors, do you?

Professor van den Eynden: There are lists and there is a group of about 200 doctors in what is called LEF, I cannot translate it. It is the F doctors who are saying publicly and one can say promoting that you can contact them for the act of euthanasia.

Q1863 Lord Turnberg: I take it that you have not referred any patients to them?

Professor van den Eynden: I did.

Q1864 Lord Patel: The view you have expressed, is it held by the majority of doctors in Belgium, two years after the law has been enacted?

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Professor van den Eynden: No. There has been, at least at that moment, and we are trying to see after two years if there is some evolution or maybe through the implementation of the law, there was a strong opposition of physicians against the law.

Q1865 Lord Patel: At the beginning, or now?

Professor van den Eynden: I believe still now, but again people, and doctors are also people, are more and more used to it.

Q1866 Lord Patel: My supplementary question was whether any law is being broken by the doctors? We hear evidence in other countries that the documentation is not completed or reporting is not complete. Is that the case?

Professor van den Eynden: As I said, 350 reported cases. There are assumptions that it is the same quantity as it is in The Netherlands. It means that at least 50 per cent is not reported and maybe it is more, but because it is not reported you do not know.

Q1867 Lord Joffe: Professor, I assume you are aware of the recent report by the Federal Inspection and Evaluation Committee on Euthanasia of Belgium?

Professor van den Eynden: Yes. I have it somewhere in my luggage.

Q1868 Lord Joffe: I have to rely on the translation, which I hope is correct. What it appeared to be saying is, and this was set up by the Government in conjunction with medical practitioners and lawyers, my understanding is that the Committee consists of 16 individuals, of whom eight are physicians, four are palliative care consultants and four are lawyers. In their first report, which covers the period from, I think, the inception of the legislation in September 2002 to 31 December 2003, it appears that the whole system is working well and they say they see no reason at all to suggest any new initiatives. Overall, it would seem to be an endorsement of what is happening with the implementation of euthanasia in Belgium. Would you agree with that?

Professor van den Eynden: I agree with the second thing you said, this was also in my, let us say, lecture, that new initiative, and they are making allusion to legalising it also for dementia patients and for children. On the other hand, this is also a conclusion of the Committee. I am a member of them. There are 16 and then 16 people who are taking the place when someone is ill and I am one of those.

Q1869 Lord Joffe: You are a deputy?

Professor van den Eynden: I follow the whole discussion and of course it is a consensus document. Mainly from the palliative care corner, there has been a lot of discussion about it, and, for example, Professor van Nistal, he is one of the most excellent

members of the whole Committee, he had also formulated a lot of criticism on the way the whole law is implemented now. On the other hand, it is only the first two years and the Committee decided not to be too critical and to give at least two more years. We have to report every two years.

Q1870 Chairman: Do I take it from what you have just said that you agree with the findings of the report from which Lord Joffe is quoting?

Professor van den Eynden: The report is just giving figures and some statistical analysis, it is not going in-depth because the time was too short.

Q1871 Chairman: I follow that. Anyway, you agree with the report from which Lord Joffe is quoting?

Professor van den Eynden: Not that, otherwise I would not have said what I have said here, not that the situation is perfect. When the document was floated, of course it is then the group of 16 which has to agree with the document.

Q1872 Chairman: Do I understand that the report recommended that no further changes should be made in the law at the present time, but that you understood, am I right, that there were two extensions of the law which were being proposed which this group has said should not be considered, at least at the moment, and that is an extension to those with dementia and to children?

Professor van den Eynden: We would call it two Bills which are now in our Parliament to be voted on or not to be voted on by politicians.

Chairman: Thank you. I just wanted to be sure that I followed that.

Q1873 Lord Joffe: My Lord Chairman, basically the point has been made that this report states specifically that they are not recommending any new initiatives, and that is clear. They are debating two Bills in Parliament. What is that?

Professor van den Eynden: There are now two Bills which will be discussed by our politicians in Parliament, one about broadening it to patients with dementia and allowing it for patients with dementia, and one for children.

Q1874 Lord Joffe: This Committee does not support that?

Professor van den Eynden: That is right.

Q1875 Lord Joffe: In your helpful evidence, you spoke about controlled sedation, which you thought could be appropriate for some patients. Is that the same as terminal sedation?

Professor van den Eynden: No. That is a whole discussion about definition but let us say it is the same. I think that one of our philosophers has written

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six months ago an article just about terminology. Let us not go in that trap but let us say it is the same. It is about patients with refractory symptoms, so it is a tool for symptom control, who are normal and then you can discuss what is a normal tool, a normal method to try to control that symptom has failed and controlled sedation is then the ultimate means to get control and to give the patient rest.

Q1876 Lord Joffe: They can die peacefully?

Professor van den Eynden: No. Just that is the difference between euthanasia, in the case of euthanasia, okay, then we will also reach symptom control by, excuse me, but it is so, killing the patient, which is another case in controlled sedation where you are giving just rest, you are letting the patient sleep and a sleeping patient is not suffering, is not getting any symptom problems.

Q1877 Lord Joffe: Would that sedation carry on until the patient eventually died of the underlying causes?

Professor van den Eynden: Yes, the natural disease, the natural process of dying is continuing, of course, because it is only applicable, as far as I can agree, in terminal situations. When for a patient in that situation you are not able to reach good symptom control, okay, then you are asking, because that is for me another very important thing which has been discussed with the patient.

Q1878 Lord Joffe: The patient remains unconscious until they die?

Professor van den Eynden: Yes.

Q1879 Lord Joffe: In order to use that means of dealing with a patient's suffering, are there any safeguards within the law, not like the euthanasia safeguards?

Professor van den Eynden: That is what I mean, that was my first point. The whole palliative world in Belgium would have liked and would have agreed that if they had tried to make some kind of regulation, whatever, some parts, doctors who were asking "Let's do it ourselves," it did not happen, but there is no regulation for palliative sedation, for assisted suicide, for stopping or not starting active treatment, or augmenting pain control when the patient does not agree. For all these end-of-life issues there is no global regulation, there is only for euthanasia.

Q1880 Lord Joffe: There are safeguards for patients with euthanasia only?

Professor van den Eynden: Yes.

Q1881 Lord Joffe: You were asked something about statistics and about the extent of support among doctors and society. The information that I have from Belgium is that at the time the legislation was introduced there was about 50 per cent of physicians in favour and about 80 per cent of society. Would those figures sound more or less correct to you?

Professor van den Eynden: As far as I was informed at that moment, I have not got the figures now, it was much less, and there has been some integration evaluated. I can look for you. Of course, a study is a study and even statistical studies do not always confirm each other.

Q1882 Lord Joffe: I see. Perhaps we can make some inquiries. You might be able to find out and let us know?

Professor van den Eynden: Yes.

Q1883 Bishop of St Albans: I wonder, Professor, if you could enlighten me about the history of palliative care in Belgium and for how long it has been a very significant part of the health provision in that country?

Professor van den Eynden: The history is not as long as it is here in Great Britain; that is one. I think it started, let us say, in the middle of the 1980s. We have the symbol of palliative care, like you have Cecily Saunders, we have Sister Leontine, it is a nun who is a medical doctor, a social worker and nurse at the same time and she was the director of the first in-hospital palliative care unit in Brussels. Then quickly it has been followed by two others, and I think in Antwerp we were the third one in 1994, so our unit is now almost 11 years old, we have just celebrated 10 years of our LEF care unit.

Q1884 Bishop of St Albans: Are there hospices for children involved in that?

Professor van den Eynden: There are no specific hospices for children. Most children, and mostly it is for children with oncological situations, are cared for in the University Hospital and you can call that a unit but it is not a hospice. There is a unit in the University Hospital in Leuven and one in Gent, and since they were created they are offering them the most high quality care, especially because the relative curative and palliative care for children is still more difficult than it is already for others.

Q1885 Chairman: Are there different legislative provisions or laws in the different parts of Belgium or is it a uniform law over the whole of Belgium?

Professor van den Eynden: The law we are speaking about here is the same, it is federal law.

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Q1886 Chairman: It is about two years old, is that right?

Professor van den Eynden: Yes. September or October 2002.

Q1887 Chairman: Up to now anyway it has not been changed?

Professor van den Eynden: No, not yet.

Q1888 Baroness Finlay of Llandaff: Can I thank you for having made the effort to come today and you got up very early to be here. In your opening remarks, you described a situation that you see now of some patients who express fear that they will be given euthanasia even when they have not asked for it. I wonder if you could tell us, in your own experience, how often you see that in your own clinical work and also in your own hospital, the University Hospital, whether there have been cases where euthanasia has been performed in the context of care?

Professor van den Eynden: To the first part of your question, there is no registration about that but it happens at least once a week within the whole Hospital as well as in the unit, and mostly nurses are reporting to me that all the patients, 70, 80 years old, really fear that when a nurse comes into the room with a syringe for whatever, of course not to do with euthanasia, or to give a pill, they are asking "Is this to end my life?" It happens at least once a week. Before, let us say three years ago, it was never reported. Of course it is just a factual comparison but at least I think really it is true. To be honest, it is a world of things most hospitals had to organise. Clearly we have a law and, as I said, we are trying to go on with loyalty, so there has to be prosecutors and ways to go on with that. I said, it is a complicated and rigid way which makes that, it does not happen once but often that patients one day are really suffering and requesting it, you have no time and no possibility to offer it any more. To explain that, I should go into detail and I will do that if there is time, but there are a lot often, it is okay, it is what you call the requirements, they are to protect patients against unwanted euthanasia, of course. In the hospital, it happened three times in this two and a half years.

Q1889 Baroness Finlay of Llandaff: Three patients have gone through the procedure?

Professor van den Eynden: Yes.

Q1890 Baroness Finlay of Llandaff: You know that in the Bill that we are considering there is a requirement that patients are told about palliative care at the time that they request euthanasia. I wonder if you have any comments from your own experience about the way in which patients would

view being told about palliative care then as opposed to patients who have been in receipt of palliative care previously and their reactions to it?

Professor van den Eynden: Politicians so the law-makers in my country decided, there has been much discussion, not to put the palliative filter in the law, so it should be mentioned but that is not what we call a palliative filter. A palliative filter is that you can really offer palliative care to a patient, who of course can refuse it, that is another thing, but not just to speak about, not just mention that there is something called palliative care, that is not what we call a filter. In my hospital and in the whole confessional group of hospitals, we made a procedure where palliative care is offered to the patients, the maximum is invested in offering palliative care, and most of the patients, especially these patients, are suffering from pain, from fear, from all these kinds of symptoms, 98, 99 per cent accept this kind of care and the offer which is given to them. Then, of course, I said not for 100 per cent but at least for 97, 98 and it is also in the literature, so the symptoms are relieved and the request is melting away.

Q1891 Baroness Finlay of Llandaff: Do you have any idea of the numbers of patients whom your own service has seen who have been asking for euthanasia who then have received full, intensive, palliative care intervention and that request has, as you put it, melted away? You have told us that three of them obviously went on but I wonder if we can get a feel of the size of the other group?

Professor van den Eynden: No, I cannot. We are registering that it is going on. I cannot give even a preliminary figure.

Q1892 Baroness Jay of Paddington: Just to follow up on this issue about palliative care, obviously we have not had the opportunity to visit Belgium so much of what we are asking you is on the basis of written submissions.

Professor van den Eynden: You are welcome.

Q1893 Baroness Jay of Paddington: Thank you. I may be mispronouncing his name but Professor Luc Deliens, the Chairman of the End-of-Life Care Research Group at the University in Brussels, did submit written evidence in which he said, and I wondered if you could help us with what exactly happened, the introduction of euthanasia legislation at the same time as palliative care legislation has resulted in all end-of-life care being placed central to Belgium's healthcare and has resulted in many new discussions on how to improve end-of-life care, suggesting that, in a sense, this has opened up this whole topic for discussion between patients and their medical advisers, and so on. What exactly do

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you see as having happened? I am just interested in this research document.

Professor van den Eynden: I know Deliens and his group very well who are co-operating. Only this fact makes me angry. You were not really saying it but the real fact is that when you see the written law on euthanasia it is seven, eight, nine pages, or something like that, the law about euthanasia, which I agree is voted, and going in regulation at the same time is just one page and it is an empty box, there is nothing in it. Until now in my country you have the law and then there is some kind of regulations which make the law work, so there is nothing until now, while euthanasia law, a solution and it works because it is written down in the legislation.

Q1894 Baroness Jay of Paddington: I am sorry, I think I am not following, I am so sorry. You are saying the palliative care provisions do not have teeth, or are very empty, to use your expression?

Professor van den Eynden: No, no. It is about the whole regulation, so the palliative care movement. They are working, as I said, it started up in 1985, something like that, and has built up. There are facilities for patients, that is okay, I agree, but this has not taken in the regulation and the law which has been created and which should stimulate and build up palliative care in a regular and official way. This is still an empty box saying that our King will enforce palliative care and make it possible, and that is all, and he is still trying to do it, I believe.

Q1895 Chairman: Am I right in understanding that the euthanasia law is quite detailed?

Professor van den Eynden: Yes.

Q1896 Chairman: There are seven to nine pages of legislative text. We are accustomed to long laws in this country also. That basically palliative care is a voluntary provision which has been built up over the years, and at least so far has not had any detailed legislative recognition?

Professor van den Eynden: No. As I said, there are practical provisions, for example, which existed before, like, just an example, the money for palliative care beds is coming out of our hospital funds, you would call it the National Health Service, but this was there already before and we did not need it. I still do not see why we needed this palliative care law till now.

Q1897 Baroness Jay of Paddington: I am just quoting from this research document, as I say, and obviously it is not something I have been able to explore myself. The Professor, with whom you are obviously familiar, says: "Further, palliative care and euthanasia legislation were passed at the same

time and as a result there has been much more discussion and focus on how to improve end-of-life care in Belgium." This is something which has brought this whole matter to a much more open discussion between the physicians and the patients?

Professor van den Eynden: Yes. Maybe I did not say that but that is one of the advantages of the whole discussion which resulted, I agree with that, because of the whole public debate.

Q1898 Baroness Jay of Paddington: It has stimulated better care. Thank you very much.

Professor van den Eynden: Yes, that is true.

Q1899 Lord Joffe: Just to clear up one point. You mentioned these 200 doctors and the LEF. Are they not similar to the scheme doctors in The Netherlands, and they are there for second consultations and there must be more doctors, I suggest, who actually are helping with the administration of euthanasia, these are the consultants?

Professor van den Eynden: Yes. Some of them also deliver the act of euthanasia.

Q1900 Lord Joffe: I just wanted to get it clear. The LEF, how do you spell it?

Professor van den Eynden: LEF.

Q1901 Lord Joffe: The LEF doctors, actually that whole scheme took five or six years to build up in The Netherlands but it is already operational in Belgium?

Professor van den Eynden: Yes.

Q1902 Lord McColl of Dulwich: I am going back to the question of patients being worried "Is the doctor, is the nurse, coming here to treat me or to give me euthanasia?" There has been a lot of discussion about whether we should have a special group of people who are trained to give euthanasia who are neither doctors nor nurses. Have you considered that in Belgium?

Professor van den Eynden: No.

Q1903 Lord McColl of Dulwich: Would that be helpful?

Professor van den Eynden: I do not think so, no. It may be but it is just speculation, maybe it would still aggravate the fear of people.

Lord McColl of Dulwich: At least they would know what they were coming for.

Q1904 Chairman: You would not be a volunteer to join this group, I do not think, would you, if it were to be set up?

Professor van den Eynden: No. They should not be afraid.

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Chairman: I think that is all we want to trouble you for, and thank you very much indeed for coming. We appreciate that you have come quite a long way

to help us and we are very grateful for that. You will see a copy of what you have said in due course. Thank you very much.

TUESDAY 18 JANUARY 2005

Present	Arran, E	McColl of Dulwich, L
	Finlay of Llandaff, B	St Albans, Bp
	Hayman, B	Taverne, L
	Jay of Paddington, B	Thomas of Walliswood, B
	Joffe, L	Turnberg, L
	Mackay of Clashfern, L	
	(Chairman)	

Examination of Witnesses

Witnesses: DR DAVID COLE, BARONESS GREENGROSS, a Member of the House, PROFESSOR RAYMOND TALLIS, DR GEORG BOSSHARD, and DR CAROLE DACOMBE, examined.

Q1905 Chairman: Good morning. Those of you who are kind enough to appear this morning as witnesses are doing so in a purely professional capacity—that is to say, not as representing any organisation. Professor Tallis has been here before representing an organisation and he is now here as an individual, perhaps with more freedom to express a view than otherwise he would have had. I want to be clear that all of you are representing no persons other than yourselves in the evidence you are giving here. That of course gives a degree of freedom possibly which otherwise people would not feel they have when they are within the constraints of representing an organisation. The evidence and help you give us will be noted and transcribed. You will have an opportunity of checking the transcript. The transcript will be appended to our report and, although this is a public session and what you say is public, the transcript of it will become public when we present our report to the House which we hope to do in due course. Baroness Greengross, are you going to begin?

Baroness Greengross: I am going to start, if I may my Lord Chairman, by thanking you and the Committee for inviting us here. I have been asked to respond first simply because I think I am more used to being here than my colleagues. It is a great honour to come and give evidence to you. If I may, I will just introduce my colleagues. Professor Raymond Tallis is a geriatrician and is here as a geriatrician in a personal capacity. Dr David Cole is a consultant oncologist based in Oxford. Dr Carole Dacombe is medical director of St Peter's Hospice in Bristol. Dr Georg Bosshard is an expert in assisted dying in Switzerland. I am not going to waste time by speaking now. I will come in, if I may, a little at the end and we will start with very brief introductions, if that is convenient to you.

Q1906 Chairman: Please.

Professor Tallis: I am very grateful for this opportunity to make a second appearance before the Committee. As Lord Mackay said, I am not

representing the Royal College of Physicians and I am no longer chair of the Royal College Committee on Ethical Issues and Medicine. I am speaking in an entirely personal capacity as a geriatrician. I have been professor of geriatric medicine in the University of Manchester since 1987 and an honorary consultant physician in health care of the elderly since 1982. I am in support of Lord Joffe's Bill in its present form but in these brief opening remarks I am not going to set out my general reasons for this. Instead, I want to address specific concerns that have been raised with respect to older people. The first is that older people will be particularly vulnerable if the Bill is enacted because they may feel under pressure not to be a burden to others. This view was expressed in the presentation to this Committee by the British Geriatric Society which stated that older people are often unduly influenced by their families and carers who will not necessarily have the older person's wellbeing at heart. Little evidence for this claim was offered and in contrast it seems to me there is abundant evidence to the contrary from countries where assisted dying has been legalised. Firstly, the average age at which people receive assisted dying is younger than the average age of those dying without assistance. In Holland, for example, people over 80 are less likely to receive assisted dying. The data from Oregon are compelling. Whereas the average age of patients in hospice care is 83, the average age of that small minority—I think it was 0.14 per cent in Oregon—who have assisted dying is 71. In another Oregon study, patients who chose assisted dying were also younger, their median age 64, than patients who voluntarily refused food and fluids as a way of hastening death, their median age being 74. This, to me as a geriatrician, makes clinical sense. One would anticipate for biological reasons that the older the age of death the less need in general there is likely to be for assisted dying. Younger people die harder than very old people. The major factor determining whether a patient receives assisted dying is, as the literature shows us, the condition from which they

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are suffering, not their age. Patients with the relatively rare motor neurone disease are 25 times more likely to use assisted dying than patients with chronic respiratory disease, a particularly common cause of death in old people.

Q1907 Chairman: Where does this come from?

Professor Tallis: The Oregon Department of Human Science, publication 2004. I am happy to provide all the references. The Oregon experience also shows that a successful request for assisted dying is associated with an assertive rather than a compliant individual and usually from a higher socio-economic class. As for external pressures from, for example, family members, these tend to be negative pressures. In Oregon, 25 per cent of terminally ill patients who were planning to have an assisted death modified or delayed their plans at the family's request, even when this prolonged their suffering. The second concern is that the Bill might undermine the confidence older people have in their doctors and indeed in the entire health care system. International experience suggests the opposite. Trust in doctors is highest overall in Holland out of 11 European countries and a full and frank discussion about end of life management which is necessary for respecting the patient's autonomy is greatly appreciated. A recent survey of six European countries indicated that this was best carried out in Holland. In a YouGov poll at the end of last year in the UK, 83 per cent of people said they would trust their doctor more or the same if the Bill became law and, most pertinently, this percentage was slightly higher in older than in younger adults. In general, older people seem to be more frightened of unbearable suffering protracted as a result of injudicious medical intervention than of being killed against their will. This is reflected of course in the current debate around living wills which will enable people to specify in advance the limits to life prolonging or invasive medical treatment. The fear of medical intervention incidentally is entirely rational. I have, for example, witnessed or been aware of many inappropriate efforts at cardiopulmonary resuscitation simply because doctors do not know when to stop or are afraid to do so for fear of being accused of not trying too hard. In the light of all this, it is hardly surprising that support for euthanasia or for this Bill does not decline significantly with age. Whereas there is 82 per cent support in the general population, there is 78 per cent support in people over 65. This very small difference is accounted for by the influence of religious beliefs which increase with age. The data I have cited are unexpected only if one takes a rather patronising attitude to older people and assumes that they are vulnerable to suggestion and do not

know their own minds. I am not aware of any evidence that increasing age is automatically associated with a decline in assertiveness over things that matter, as anyone who wants to impose upon an old person an arrangement they object to will discover. Indeed, the written response from Help the Aged on the Assisted Dying Bill emphasises that the desire to retain control, autonomy and choice in daily life is strong amongst people of all ages. Speaking as a geriatrician, I would be very sorry if the care of older people facing death proved to be the last bastion of unreconstructed paternalism in UK medicine.

Dr Cole: I am a consultant in clinical oncology. That is the practice of chemotherapy and radiotherapy in cancer patients. I have been a consultant since 1990 predominantly working at the Oxford Radcliffe Trust but also with quite a big district hospital practice in Swindon. I am chairman of the Thames Valley Cancer Network Urological Specialist Group. I have been programme director for training in oncology in the Oxford Deanery for quite a number of years. I have come into this via Lord Joffe. One of my colleagues in the hospital known to Lord Joffe asked me to offer an opinion about this Bill. I have not previously had a major interest in this topic. I would not claim specialist knowledge of the subject, except in the sense that it applies to my clinical practice. I do not have a strong personal view in the matter. My involvement is as a day to day doctor, providing cancer care and frequently therefore having to deal with end of life issues. In my own practice, I would roughly estimate that 100 to 200 of my patients die every year. I am not there at the end in all cases by any means but I do have a very extensive experience of managing, talking and communicating with dying patients. I do not have detailed records of numbers of patients who have discussed a wish to choose the time that they die, but I would estimate that perhaps one patient per year, in my experience. I get involved in a detailed discussion with about whether they might possibly want to avail themselves of what they would call euthanasia as a generic term for this subject—not that we think it is a good term. Choice of the time of death is a better way to describe this issue. I would emphasise that being an oncologist I do not really feel competent to advise about non-cancer patients. I would not want to start talking about patients with heart disease, chronic pulmonary disease or motor neurone disease. That is not my area of competence. From time to time, I have been involved in these discussions with patients and I feel my contribution to this debate is not to express my own opinion but to express their opinion. I am, if you like, an advocate on their behalf expressing the wish that could not be met in their case, that is to choose the

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time that they die, somewhat sooner than they would do naturally. I have over the last few months reviewed quite a lot of literature pertaining to this subject but I have only come to this subject fairly recently. I have a very strong sympathy for the few patients who do wish to die at a time of their choice, but there are implications for other patients as well, the large majority of patients who do not wish to die at a particular time and who wish to allow the disease to take its natural course. Considering this issue, those who do not want that choice are an important and very numerous group. This is not an issue about whether people are going to die of cancer or not; it is more a question of allowing patients the opportunity to choose when they would like to die. This is usually or almost exclusively when anti-cancer treatment has become ineffective and, in my experience, their health is deteriorating and their life expectancy is of the order of one to two months or so, perhaps nearer one month than two. Reference has been made to patients with a prognosis of six months or so. It has clearly been shown that the reliability of predicting prognosis deteriorates with the longer time to death and I would be reluctant to invoke this kind of legislation for people where one really did not have a good idea as to how long they had to live. These patients of mine who are failing with conventional oncology treatment are also moving into the realm of palliative care. For many of these patients, we share their care with the palliative medicine team. That becomes, in a lot of patients, a transition over a period of time from predominantly anti-cancer treatment to predominantly symptom control. I think the assessment of these patients by clinical oncologists, by palliative care specialists, is one that takes place over quite a long period of time and I would be quite concerned if this Bill allowed for, say, a single consultation with a patient with advanced cancer by a palliative care physician as part of the authorisation process. Palliative care provides its service in a multidisciplinary fashion over quite a period of time and it may not be appropriate for that to be provided by, say, a single or a small number of consultations. For this Bill to be successful, it would be very important for palliative care to be broadly speaking in favour of the measure and that is one of the concerns that I have. The other thing I have been asked to say something about in particular is actual assessment of prognosis at the end of life. I have alluded to the fact that the longer you have to live the more difficult it is for doctors to make that prediction. I would feel much happier predicting prognosis in patients who have one or two months to live and the data rather supports that, as I think you will have seen. As clinical oncologists, we use the World

Health Organisation performance scale in making judgments about prognosis. This is a widely used international scale from nought to five. Nought is perfectly well, perfectly functioning; five is dead and there are grades in between. Grade four is that patient who is predominantly in bed or probably exclusively in bed or perhaps in a chair, unable to move independently, unable to get to the lavatory, unable to feed himself or herself, unable to wash, so somebody who has become entirely dependent on nursing care. I am not particularly talking about those who have physical symptoms and hopefully not those who have psychological symptoms. I would hope those could be successfully addressed by expert palliative care. I think there is a group of patients who continue to have intractable distress, despite the input from expert palliative medicine, expert general practitioners etc. That small group of patients who continue to suffer intractable distress may express a wish to choose the time at which they want to die. I would feel extremely sympathetic to that view. I have a number of cases—one particularly about six months ago—where this was the situation. I did not withdraw from the discussion but I continued the support of that patient to try to deal with these difficult issues but of course I was unable to meet her wishes. In a sense, it is on behalf of that patient and others like her that I am here today.

Q1908 Chairman: You mentioned the World Health Organisation scale from nought to five and you said four was the description you gave us. How does that link to the prognosis of life?

Dr Cole: I have not seen much of the hard evidence behind this. It is used in clinical practice and proves to be a reliable scale to predict prognosis.

Q1909 Chairman: Does that mean that if it was four in the scale you would expect death within two months or so at the most?

Dr Cole: I would not be as categorical as that but it provides a good guide. I am excluding patients who are perhaps performance status four by virtue of toxicity from treatment or reactions to medication that can be dealt with or uncontrolled symptoms. I am talking about patients who are deteriorating because of their progressive cancer.

Q1910 Chairman: The four would be the one that would give you a pretty accurate idea?

Dr Cole: I would feel confident in predicting a very limited prognosis in a patient who was performance status four. There are performance status three patients who are perhaps confined to bed or chair more than 50 per cent of the time and have some degree of independence, but also quite a lot of

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dependence. If they are moving fairly swiftly, within a week or two, into performance status four, they are also a subgroup for whom this legislation might be appropriate in my view. Others have used more complex scales. The Karnovsky scale is well known. A five or six point scale is more easily usable in practice and I do not know many colleagues who use the Karnovsky scale in daily practice.

Q1911 Baroness Jay of Paddington: Dr Cole, you are talking specifically about oncology, are you not? For example, you could easily have someone in status four, as you have described it, suffering from dementia for a very long period of time. It is important that we recognise that.

Dr Cole: Oncology, yes.

Q1912 Chairman: All your evidence is in the area of oncology.

Dr Cole: Absolutely.

Dr Dacombe: I am Carole Dacombe, here as the medical director of St Peter's Hospice. As I believe that I am here to represent myself as an experienced grass roots practitioner in palliative care, I think it is important that I explain something about the service that I now work in and my own experience and history that have brought me to this position. I want to explain that St Peter's Hospice is a community based hospice offering a wide range of specialist palliative care services to all of the wider Bristol area. That gives us a catchment population of approximately a million. Within that area, we see patients right across the board within that population. That means people from a wide variety of faith or non-faith and cultural backgrounds. We do not only become involved with cancer patients; we also have patients with a range of other non-malignant, incurable, progressive diseases referred to our services. The services are run as a community based project. We have specialist community nurses who visit patients in their own homes so we are not simply a building orientated service. The visits to those patients in the community by specialist nurses are backed up by myself and a wide range of colleagues from a multitude of disciplines within our team. We offer domiciliary visits to patients by both senior medical clinicians and other disciplines, as well as the opportunity to see patients on an outpatient basis and to offer them support on both our major sites, one in the north of the city and one in the south, in a day hospice environment or indeed by admission to our inpatient unit facilities for assisting patients through times of crisis, be those physical symptom control crises, psychosocial crises or need for respite on the part of the patient and their family.

Q1913 Chairman: Are there similar facilities at north and south sites?

Dr Dacombe: Exactly so. That is the service I am involved with and within that service my own role is that of a senior clinician but also an individual who has executive responsibilities for the running of the service and also somebody who has people management responsibilities within our wider medical team, which means I am responsible for managing our team of doctors, our occupational therapists, physiotherapists, pharmacists and complementary therapists. I am involved in a wide range of our work. As an individual, my background is that I have been a doctor for 28 years. After working in a number of junior hospital posts, many of which are particularly relevant to discussions about palliative care, because I worked in oncology, neurology, haematology and care of the elderly before completing training to work in general practice, I then worked as a principal in general practice for over nine years before moving into specialist palliative care. Within general practice, I obviously was involved in the provision of generalist palliative care and developed further my interest in that area. I then moved into working at the hospice and I have worked at the hospice now for 14½ years. It is on the basis of that experience that I believe I am here as a grass roots practitioner with that experience. There are two points that I would like to make in this introduction. First, I want to totally and passionately endorse all the previous remarks that have been made here and indeed outside this Committee regarding the issue of there being a deficit of care in this country. There is undoubtedly a deficit of care and it is across the board in many areas of the delivery of health and social care to our population. There is in particular a deficit of palliative care. It is an indictment on our society that the vast majority of specialist palliative care in this country are still delivered by and funded by the charitable sector. That point needs to be made and cannot be made too often, particularly as there are multiple references to palliative care within this Bill that you are considering. The second point I wanted to make was that throughout those years of my experience I wish to acknowledge to you that I have consistently and persistently encountered a small number of patients who, despite the whole range of services that have been offered to them, both at generalist and specialist palliative care level, have felt a need to express a wish to see their life ended. That has been a consistent part of my experience. These people do tend in my experience to demonstrate some of the common characteristics that I know have been described to you before by previous witnesses both in this country and elsewhere. They often are people who have a long

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life history of seeking control over their own destiny, of wishing to plan their lives for themselves. They often are people who, despite having explored various faith structures or spiritual concepts that some of us find are a great help and support to us in life, have either rejected them or have failed to find in them sufficient solace and support to see them through the final stages of whatever illness it is that they are dealing with. They do make these requests. Given that it is a fact that unfortunately we have no living experts in dying as we will only, all of us, ever do it once and our patients have only ever done it once and are no longer here to tell us what it felt like, if I truly believe in the principles by which we work in palliative care which are to respect our patients, to respect their need for respect, for dignity and choice, I need to be prepared to listen to patients who wish to request. I need to acknowledge that I have heard those requests here today.

Dr Bosshard: My name is Georg Bosshard. I am a physician from Switzerland. In our country, we speak German, French and Italian but not English so if I am struggling sometimes with the language I apologise. My basic training is as a general practitioner and in legal medicine. I am working in the Institute of Legal Medicine in Zurich and today there we have to investigate on the spot, every week, one or two cases of assisted suicide. During the last few years, I have carried out research on the one hand on end of life practices in different European countries and, on the other hand, about the specific situation of assisted suicide in Switzerland. I am also a member of the Swiss Academy of Medical Sciences and I have been involved in the reformulation of their guidelines on the care of patients at the end of life. Today, the academy has something that we could call a neutral stance. The academy says it is not a physician's task to assist in suicide but if an individual physician decides to assist an individual patient this decision has to be respected. The academy also provides some safeguards that have to be met in such cases. Today, there is a quite well established practice of assisted suicide in Switzerland for a very small number of people, about 200 persons every year. There is broad public and political support. There are only very few people challenging the basic legal fact that in Switzerland assistance in suicide without motives of self-interest is not illegal. You might be more familiar with the situation in Oregon and the Netherlands than in Switzerland so I would like to stress three issues that in my opinion are crucial to the legislation in Switzerland or to the system we have in Switzerland. Firstly, the practice in Switzerland is restricted to assisted suicide but this term is defined more broadly than in Oregon. In

exceptional cases, it is also allowed to use drips or gastric tubes and this is assisted suicide because the patient has to start the infusion as the last step of the action leading to death. So, considering the action itself, no patients are excluded from the practice. Even people with an advanced stage of motor neurone disease, usually or always can have the assistance. On the other hand, no physician in Switzerland has to kill his patient. The second issue that seems important to me is that of the preconditions. The law does not restrict assisted suicide to the terminally ill. Practice shows that around 80 per cent of the people who died from assisted suicide were fatally ill. There are some people in Switzerland striving to restrict the practice to terminally ill people but they are a minority. The last point is the responsibility for the assistance. In Switzerland, not only the doctors but also members of right to die societies are responsible for the assistance. In many cases, this can be a relief for the physician involved and for the rest it is very important that as much responsibility as possible is kept with the patient anyway. Once the barbiturates are prescribed, the patient can decide independently from his physician where and when and if at all he wants to die.

Baroness Greengross: I did submit written evidence to the select committee. I am the only non-medical I think in this group of people and I speak as somebody who has worked and still works for about 30 years with older people fighting for them to be treated as adults, however frail they are and however vulnerable they are and fighting for them and all of us as we get older to have a better quality of life. "Life" is the important word there. We now live in an atmosphere when a lot of current and previous legislation is leading to greater autonomy and, in my experience, that is what most older people want: control, dignity and autonomy with regard to their lives. Autonomy is different from independence. You can be very dependent and you can still retain autonomy over decisions. That is terribly important to people. We are talking about people who are very vulnerable but who are mentally competent. In my view, mentally competent people who are dying should retain control for as long as possible over what happens to them. The dying process, again through a lot of experience, is what frightens people much more than death itself. There is a great deal of fear about how this is going to happen and we do live in a country where a lot of issues relating to this process are fudged. They are not clear, open and transparent. It would be of enormous help to many people to have permission to talk about these issues more openly with their family and their doctors. This Bill would encourage that. It took me a very long time

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to come to the decision I have about supporting this issue and this Bill. It is a very limited Bill, limited to a small group of people who are close to death. We heard very movingly about the circumstances where this Bill would apply. Very importantly as far as I am concerned, the Bill would make it easier for palliative care to be available to everybody who needs it because built into the Bill is the necessity to offer it. Palliative care practitioners would need to be partners if this Bill became law because you cannot offer a service to people if it is not available. Should it become law, it would immediately have that knock-on effect to make that available to the people who at the moment do not have access to it. The fact that it is limited to people in the very last stages of life is important. I know there is an enormous amount of worry about slippery slopes. The slippery slope argument applies to a huge amount of our legislation. There is always the possibility of it being abused. There is always the possibility of it spreading into areas where it is taken to extremes and these are dangerous. Controls and restrictions and regulation are always needed to stop legislation going wrong and in this case it is very important that those take place. This is extremely limited. We also know that this would lead I think to better care and it would also avoid a possible breach of the European Convention on Human Rights through loss of dignity caused by intractable pain. It is very much in line with a lot of thinking about compassion and humanitarian care across Europe. More people die at home, which is what older people on the whole want to do, in countries where assisted dying for terminally ill people is allowed than do in countries where it is not. It is very important because the whole thrust of this Bill would be for more openness, more transparency, more possibility of getting things right for people. We do know that, with all respect to people's particular religious views and views on ethics who oppose this Bill, the vast majority of the public when asked about it want this control over the dying process. I believe that the dying process is an essential part of life. Openness is very important. Stringent safeguards are hugely important. If there are areas where greater safeguards are needed, I would be the first to say they should be built in. We all want absolute safeguards from this Bill being open to abuse in any way. It would increase the ability to communicate openly with doctors. This is something that a lot of older people cannot do. People are terribly frightened of complaining about anything to do with health because a lot of very old people are still very grateful that there is an NHS at all and many are frightened of the repercussions that follow if they do complain. We have to bear that in mind. We have a very compliant older

population. Above all, the criminal law in this area could, if this Bill was introduced as law, be more consistent and more rigorously applied where at the moment it is not. I think that legalising this might stop the abuse that we know takes place at the moment. There is abuse. We also know that many doctors take huge risks in helping people to die because their conscience says they must but they are open to prosecution. This leads to my most important point which is that under English law people have a right to commit suicide. It is a tragedy if anybody commits suicide for the reason that they have been pressured into doing so, that they have been told they are a burden, that they are misused by grasping relatives or whatever. We know that this is a tragedy. We know it happens. It does not happen, I hope, too often but it does happen. If somebody is severely disabled and they need help, they do not have the same rights therefore as an able bodied person because an able bodied person can commit suicide. It is not a crime. We are in fact, although the disability lobby does not always agree with this point, discriminating against people who are disabled because they do not have the same rights as able bodied people in this country. If somebody makes a rational decision that they want to end their suffering only a little bit before it would automatically end, it is our humanitarian duty as people who are carers, doctors, nurses and family members, with our loved ones, to enable them to retain their dignity and die in the way they wish to die. Above all, with so much in the way of medical advances and increased longevity, we have to pay attention to the people who place a greater emphasis on the quality of their life as it draws to an end than merely on promoting that life for another very short period, be it days or weeks, in a way they do not wish.

Q1914 Baroness Thomas of Walliswood: Thank you very much for all your evidence which I thought was extremely interesting. I would like to ask a question addressed to the doctors present. We have had a great deal of evidence from people as to the potential ill effect of this legislation upon the doctor/patient relationship. It has been very frequently deposited before us as evidence. In Holland when we were there we asked doctors what they felt and how they regarded their own practice on those occasions, which I think we all agree are probably quite rare, when they do what the law permits them to do. They all said they did not really like it but one or two of them said, "But it is the last thing I can do for my patient." Can I ask the doctors here where they fall in that spectrum and how they feel the doctor/patient relationship in this country in particular will be affected by a change in legislation?

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Professor Tallis: First of all, it would be a harrowing experience for doctors but being a doctor is often a harrowing experience. It is part of the burden of being a physician or whatever. That in itself seems to me to be not an argument against the Bill. In terms of the overall impact of the doctor/patient relationship, in a sense this is an empirical question and one has to look elsewhere for data. I am enormously impressed -- it is one of the reasons I changed my mind about the Bill, partly because the Bill itself changed—by the positive impact it had on the doctor/patient relationship and also more widely upon the kind of thing that Sally has been talking about which is transparent end of life decision making, because we do other harrowing things. For example, the decision to withdraw treatment which can have ultimately the same impact. The knowledge that this takes place in a much more transparent context I think can only make doctor/patient relationships better and doctors feel better about themselves. It illustrates a general principle that this Bill, although it will only be applied to a very small number of people, may have a much wider knock-on effect. For example, picking up Carole's point about the inadequacy of palliative care services, wherever I have looked at the literature, it has been a major driver to improving palliative care services. I feel it can have only a beneficial effect on how doctors feel about themselves and their role and about the doctor/patient relationship both individually and more largely in society as a whole.

Q1915 Lord McColl of Dulwich: On the doctor/patient relationship, a lot of old people are now worried that when the doctor comes, is he coming to help them or to do something else. Could we get round this difficulty by precluding doctors and nurses from taking any part in this at all? This is not a new suggestion. It was considered in Switzerland. It does seem to me to have quite an attraction and indeed, if any doctor was against this, one might look at him askance. Why would he want to take part in it if there were other people who were able to do it?

Dr Dacombe: Could I respond firstly to Baroness Thomas who was seeking an answer to her question from all the doctors on the panel? I would endorse much of what Professor Tallis has already said. I would like to make the point that there is a sense in which, were there to be a Bill in place that offered legislative support to assisted dying, it could give a completion to the discussions between doctors and patients around this area which I have already alluded to and do occur and which in a sense are incomplete because they can only go so far as to be the patient expressing that wish and, ultimately, the

doctor saying, "But there is no structure in which that can happen." It does not necessarily have to mean that, as I know has been discussed in previous sessions, that same doctor who is having that discussion ultimately carries out the act. For there to be the knowledge that the process is available to the patient could enhance the length, depth and scope of the conversation that takes place.

Professor Tallis: There is a particular premise, Lord McColl, in your question. There is not any evidence, even in the post-Shipman era, that there is distrust of doctors. In the YouGov poll I referred to in my opening comments, there was no suggestion that patients, including older patients, would trust physicians less if they knew that part of the therapeutic alliance included assisted dying. There is no evidence of that, in so far as we can get evidence on these things. For that reason, I would be very sorry if assisted dying was something that was made separate as opposed to the whole care of the patient and preferably it should involve the doctors and nurses who had been caring for the patient earlier on. It is very important as part of the overall therapeutic alliance, which is a phrase I am sure you have heard a lot.

Dr Bosshard: In the first place, you mentioned elderly people being afraid that they are not sure what is the motive of the doctor visiting them, whether he has come to kill them or not.

Q1916 Lord McColl of Dulwich: There are old people who have expressed this.

Dr Bosshard: This, to me, seems to be exaggerated. I am not aware of such patients in Switzerland. In terms of the role of the doctor, you cannot regulate assisted dying without doctors but you can keep that involvement to a minimum, and I would say this was the aim of the Swiss regulation.

Q1917 Bishop of St Albans: The first question relates to some work done by Professor Nicholas Kristakis at Harvard on what he calls collateral health effects. This is the *BMJ*, July 2004. No one could have done more than Lady Greengross for whom I have the highest respect in caring for and putting the needs of elderly people absolutely firmly and centrally on our map in this country. It has been wonderful. One of the arguments for those who look at collateral health effects as opposed to arguments on personal autonomy is that there could be very significant social effects from such legislation going through. I think you would know, Professor Tallis, anecdotally and objectively, that when elderly people are moved from one ward to another or one hospital to another incidence of death goes up. Professor Tallis in particular, could you speculate on what you think the collateral health effects might

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be particularly upon elderly people should such legislation go forward?

Professor Tallis: My own feeling is the collateral effects would be beneficial, precisely for the kind of reasons that Sally and Carole referred to. There would be much more transparency in the kind of decision making towards the end of life—for example, withdrawing treatment which may have the same outcome as assisted dying. This seems to me an empirical question again, so far as I can read the literature, because I have not been to the Netherlands, there are empirical data to support that. The knowledge also that there is this available will support and help a much greater number of people than the number of people who simply avail themselves of assisted dying. I am very impressed, for example, by the data from Oregon—I may need to correct this—where a very small proportion of people who request assisted dying and even go through the process of having it agreed do not avail themselves of it. I think that is another potential benefit.

Q1918 Bishop of St Albans: I think you are saying that you think this would have no impact at all on the way the general public regard the value and worth of older people. It would only have a positive outcome. Is that what you are saying?

Professor Tallis: I think so. The data, such as they are—and they are always going to be interpreted in many ways—suggest even counter intuitively the very positive effects that exist in such a Bill in places like Oregon and the Netherlands. It is for those very specific, positive effects that I am in support of it.

Baroness Greengross: I wondered if I might come back to Lord McColl because I am horrified that there are elderly people who are worried now about whether the doctor is coming to care for them or to kill them. That is absolutely dreadful and terrible. It would seem to me that this Bill makes that much less likely because the doctor is going to be honest and say, “I am here to look after you but if you want to talk to me at a future time about your impending death we can be open. We can discuss it and there is not this lack of clarity about what my role as the doctor is or your role as the patient.” To open this up and be clear is what is needed because it is appalling if people are scared of doctors. We must avoid that at all costs.

Q1919 Lord McColl of Dulwich: Would you object if doctors and nurses were precluded from this activity? It would clarify without any doubt at all what the roles were.

Baroness Greengross: Speaking personally, I have a doctor I trust. I would rather, if I got to this stage, he was involved in some way. Hopefully, I could

take the prescription myself but if I could not I trust the doctor and I would want him to be the person who was there, in some way involved. Caring for someone is caring right until they take their last breath. I would hope that we could have those trusting relationships and that openness could only be of benefit.

Q1920 Baroness Hayman: Dr Dacombe and Dr Cole, you have both mentioned individual patients with whom you have dealt over the years, a small number who had a persistent, competent desire and who would have availed themselves of this legislation. I wanted to put to you a couple of things that we have received in evidence over the sessions and ask how they fit with your experience. I will probably over-simplify so forgive me. It has been put to us that patients who are in their last six months of life and terminally ill, if they wish to, can die. It has been put that they let go of life and that they can influence the timing of their own death. It has been put to us that if they do not there is almost something psychologically unresolved. These patients could refuse food and water and end their own lives that way. Sometimes they are in control of their own medication. I think that is an example that Lord McColl has given in the past. There is some shifting of responsibility going on here that represents an uncertainty. If the certainty was there, these patients would be able, whatever their disease, to take control of their own destiny in death. They would let go of life. I wanted to ask you, in your experience, whether that is a universal phenomenon that you have seen or whether there are hard cases that would remain despite that assertion or phenomenon, if you agree it exists.

Dr Dacombe: I acknowledge the comments that you are making and I am aware of some of the previous evidence that has been presented to you that has suggested that. Certainly in my experience and in the experience of my colleagues within palliative care whom I have spoken to about this, we are well aware that there are individuals who particularly very close to the end of their life, as in within a matter of days or perhaps at the most one or two weeks, that we have all seen who have appeared to be able to finally let go. That has to be some sort of mixture of physical, psychological and spiritual decision making and action on their part. They have been able to finally let go of life to some extent at will. In other words, those who have finally made it to a given anniversary or a given event and have then clearly let go of their final will to keep living. That certainly is a phenomenon that has been seen, reported and discussed at some length within all areas of health care but within palliative care. However, there have been other patients that I have

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encountered who have expressed powerful desires for their life to end, who have not necessarily been quite so clearly physically imminently close to death, but would still come within the sphere of a Bill such as this. They have clearly not been able to effect that process, even though they have declared a powerful wish to do so. In particular I can think of at least one person with whom I have been closely involved in the last year who spoke about this at length and who did, indeed, choose, as it were, to take to bed, to refuse food, to refuse fluid (other than that to deal immediately with discomfort from withdrawing from fluid), and he then subsequently took a long time to die, because that was the natural process that they had to follow. I am not convinced that all people can achieve the psycho-spiritual connection with their inner being, if you like, that allows for that letting go to be successful.

Dr Cole: I would not have a great deal to add to that. I certainly agree that in many specialties in medicine you see patients who decide to let go when they have reached a certain point in time, whether it is an anniversary or a big family event, and then they decide to “turn their face to the wall”—which is a very real expression that is used; not a very nice expression—but I would not otherwise have anything to add to what has been said.

Professor Tallis: In the correspondence we have had as a result of an article from the Royal College of Physicians last month, somebody wrote to me and suggested that the minimal period of 14 days should be regarded as an existential pause, and people should be positively encouraged very much to resolve those kinds of possibly resolvable psychosocial issues. In other words, that period should be used positively, and, it may be, as a result of which, the person would not want to take advantage of assisted dying. So there is still that opportunity, in the gap between the patient, as it were, signing up for assisted dying and its being implemented, in which precisely those issues could be actively explored rather than hoping they would just float to the surface.

Q1921 Lord Turnberg: I have a couple of questions. I think Dr Cole talked about the difficulty of judging when a patient’s illness is terminal, and, on the six months’ suggestion that we are hooked on, I think you suggested that maybe two months would be better. Is there anything particular about the length of time? Should it be two months, three months, four months?

Dr Cole: I think the prediction of prognosis is more reliable at two months than it is at six months. I think there is evidence to support that. The point comes when you can sufficiently reliably predict how long a patient has to live. I would suggest that this

legislation, if it were passed, applied to those patients for whom a reasonably reliable prognosis could be given. You can argue the details of that, but in my practice I would say it was within one or two months of death.

Q1922 Lord Turnberg: That leads on to my second question. We have heard from yourselves and others that the patients who may wish to take advantage of such a law are controlling individuals who wish to keep control of their own destiny and chose their own time of death. This leads us on to the question of whether it also has to be in someone who is suffering unbearably. Who is it that makes the judgment of unbearable suffering in that sort of person? This is the area. Because it may well be that the patient is not in pain, is not necessarily suffering horrendous symptoms of the characteristic case you have described, but really cannot bear the thought of continuing with the idea that they have a terminal cancer.

Dr Cole: I think ultimately the patient should make that decision. This is part of individual autonomy. That decision will need to be supported by professional people and witnessed by professional people.

Q1923 Lord Turnberg: Their support would be from professional people, that this patient really does have a terminal illness, not necessarily that they are suffering unbearably.

Dr Cole: I think intractable distress or intractable suffering is a subjective phenomenon. I think many have argued that that is something that the patient himself or herself can make a judgment about, but I think that professionals can appreciate what the patient is saying to a greater or lesser extent and support that.

Q1924 Lord Turnberg: That brings us to the Swiss situation, because there it is not necessarily someone who is terminally ill, it is someone who is unbearably suffering at any stage.

Dr Bosshard: I would add that I think physicians have no particular expertise for unbearable suffering.

Baroness Greengross: There is another bill going through the House at the moment, the Mental Capacity Bill. We were discussing this last week and a point was made, quite genuinely, that if somebody makes a decision and they are mentally competent, their autonomy must prevail. We may not like the decision, but they are adults and capable of making the decision. We are talking about mentally incompetent people here. In the end, self-pride and dignity are also very important to us as adults, and they do not go away as we get old or if we are dying.

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We cannot get into the skin of a dying person: they have to know what is acceptable to them, even if we do not always feel the same way as they do. I think the whole difficulty of this Bill really is the responsibility for that decision. That is what it is all about. I suppose I believe in the very end that it must be a competent adult who is finally responsible for the decision in this case. With all the safeguards and all the expertise being available, it is that person in the end whose view should prevail, because it is about the quality of that person's life.

Professor Tallis: Could I pick up on a couple of things. Of course the ultimate arbiter is the subjective experience of the patient, but I do not think someone would be considered for assisted dying if they did not have any objective pointers: appalling pressure sores, incontinence, being bedfast, or uncontrolled pain due to bony secondaries or whatever. Clearly, although the decision that something is unbearable lies with the patient, it has to have objective reasons. Then there is the issue of prognosis. It is very important to tease out two components of prognosis, it seems to me. One is the prognosis of how long you are going to live and the other is the prognosis for the extent to which you are going to recover from this unbearable situation. If, for example, somebody actually might have lived a little bit longer than you expected, that in itself is not an objection or refutation of the prognosis one is making, because one is saying: "Is this person ever going to get out of this unbearable situation? Has everything been tried?—all the recommended care." If the situation is unbearable and the prognosis is that it is going to remain unbearable, then that surely is the absolutely key issue. Clearly that will only happen, usually, within two months of death, but it may be a little bit longer than that. So I think it is very important not just to confine the notion of prognosis to life expectancy but to expectancy of quality of life: whether there is going to be an improvement or whether it is going to remain in the condition that the patient has deemed unbearable.

Q1925 Lord Turnberg: Should six months be on the face of the Bill or 12 months?

Professor Tallis: It is always very difficult. It always seems arbitrary, does it not? These are arbitrary decisions. And, I guess, six months is not the sole criteria. There is a whole pile of other things, all coming together. At the most six months, but with many other features. Of course, people particularly like David and Carole will have a much better idea, a feeling, for how long somebody is going to live and would, I guess, be rather unhappy if there was life within a year or whatever.

Dr Cole: My preference would be to say "usually less than three months" rather than the six months.

Q1926 Lord Taverne: I would like first to ask questions of Dr Dacombe. Some of the evidence we have had has suggested that the Bill is not needed because palliative care is the answer to people who are in the situation of unbearable suffering. On the other hand, the overwhelming evidence—and I hope I am not misrepresenting it—that we have had from the Netherlands is that they see no conflict at all between palliative care and euthanasia—or their particular form of euthanasia; in fact, they feel that they are completely complementary. What would be your view, from your experience? I know that Sally Greengross has argued that it is easy to provide palliative care under the Bill, but do you see any conflict between the palliative care and the Bill? That is the first question. Related to that: in the case of unbearable pain—and I know that in a lot of these cases it is loss of control rather than unbearable pain for people who ask for euthanasia—is it always true that palliative care can mitigate unbearable pain and relieve it?

Dr Dacombe: If I may take the first point first. I do not think myself there does have to be a direct conflict between this type of legislation and palliative care, but I do think there is a very great need for both those points, which I myself raised in my introduction, to be looked at in parallel. In other words, this Bill certainly should not be seen as the answer to the problem that we have a deficit of care. Were people to be seeking assisted dying because of a deficit in the care that could be provided to them, that would be the most frightful indictment on our society, would it not? So I think it is essential that both those things are looked at together, but I do also believe—and I am ready to recount the experiences to which I have already alluded—that, whatever volume and level of palliative care we do deliver, there will be some people for whom that is not providing the answer to their difficulty, in that it is not actually meeting their unbearable suffering. Therefore, though I may find that very sad and I may find it, indeed, disappointing, as a palliative care practitioner, I acknowledge that that problem exists and I believe that it will continue to exist. That is why I believe the two things ought to be looked at in parallel, and I do not necessarily find a conflict there as long as both are being addressed. In terms of the second point about unbearable pain, I would say that the vast majority of difficult-to-manage pain can be eased to a very great extent by one or a collection of measures that can be applied under the umbrella of specialist palliative care. There is undoubtedly a very small number of patients who are still left with, whatever measures you persist

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with, some degree of pain. Clearly part of what we are aiming to do in palliative care is to relieve all suffering, and there are many components of pain—and I am sure that is a concept that has been put to you before now—and it may be that some small number of those components are left in place but by easing a great many of them you relieve the total distress to a very considerable extent. But there are no panaceas for all forms of pain.

Q1927 Lord Taverne: My second question is to Professor Tallis. You have given powerful reasons why you are in favour of the Bill. Originally you were opposed to the Bill. You have given one reason why you have changed your mind: looking at the evidence, you do not think now it would weaken the relationship, the trust, between doctor and patient. Why were you otherwise originally against the Bill? Apart from that, what has made you change your mind?

Professor Tallis: Originally, it was the Royal College's response—although it was a response which I was entirely behind. The Bill itself has changed in some very important respects, and I think that was the first thing. There are more diagnostic safeguards put in. The change in the Bill to me was very important. The other is that my original response was not rooted in an understanding of what was going on elsewhere and I think my response contained empirical comments that did not stand up in the light of international experience, not just in relation to the potential threat, as I saw it, to the development of palliative care, but also the myths that perhaps one subscribed to that all patients in the appropriate palliative care setting could be managed to such a point that their suffering was bearable. I was very impressed by the Oregon data, which showed that the vast majority of people who sought assistance in dying actually did so in the context of hospice care, in a state which I think is regarded as the second best state in terms of palliative care throughout the States. For those sorts of reasons, I felt I could support the bill—partly on the basis of change in the Bill, partly on a better knowledge of what is going on elsewhere.

Q1928 Chairman: I would like to ask Dr Dacombe a little bit about this relationship between palliative care and this Bill. Is it the case that a good deal of suffering can be relieved by appropriate palliative care?

Dr Dacombe: Yes, absolutely.

Q1929 Chairman: The question of whether a particular patient has unbearable suffering, in the sense that it cannot be alleviated, will depend to a

considerable extent on the amount of palliative care service that is available to that particular individual.

Dr Dacombe: Absolutely. Both at the generalist and the specialist level.

Q1930 Chairman: I understood that to be the basis on which you said it would be very important, if a bill of this kind were to be made law, that patients would have available to them the best level of palliative care that could be given across the country.

Dr Dacombe: Absolutely.

Q1931 Chairman: Do you get satisfaction out of being a palliative care specialist?

Dr Dacombe: Yes.

Q1932 Chairman: What does that arise from?

Dr Dacombe: I think it arises from working in a speciality where team work is so important; where sharing problems with multiple other disciplines is so important. It comes from working in an area where, generally speaking, you probably have more time to give to patients and where the entire focus of what you are doing is around trying to meet the individual needs of an individual patient in their individual circumstances alongside all those others who are important in their life. I am very comfortable, as a doctor, that I have no sense of failure as a doctor in working with patients who have incurable disease. Clearly there could be people working in medicine who would like to believe that they can “cure” their patients—although in truth we know that a great many people in our population are living with some form of chronic illness that cannot be cured. I do not have any sense of failure in the sense that I have to work with patients who have incurable, progressive disease who will clearly die from that; rather, I actually appreciate the successes along the way that can be achieved by meeting their individual needs as far as is possible and achieving the successes that they would define for themselves in their remaining life.

Q1933 Chairman: When pain is relieved, what sort of quality of life does a person who may not have long to live have (notwithstanding the pain has been relieved to a certain extent)?

Dr Dacombe: Quality of life is a very difficult and complex subject, as I am sure has been said to you by many people before. As I am sure you are aware, quality of life cannot be determined only by physical symptom control. I think we have to recognise that, depending on your faith background and your cultural background, you may not seek loss of pain as a prime objective in dealing with your incurable disease. There are cultures where actually dealing

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with pain yourself and suffering through it is part of the way you achieve what you wish to achieve yourself spiritually in the afterlife. I think that is an important point to make because we do tend to focus on pain control as something that is all-important, and it may be all-important for the majority of Christians or those of certain faith backgrounds, but that does not apply across the board. But quality of life does relate to physical symptom control. Clearly, people do not wish to be in pain, they do not wish to be feeling sick, they do not wish to have symptoms that are actually interrupting their ability to think and to enjoy their surroundings. On the other hand, patients can have other physical symptoms which it is not possible to relieve. If they have intractable weight loss and they are developing a great deal of physical weakness, those are not necessarily things which it is possible to overcome, and they may perceive that that does burden them in a way that they would perceive was unbearable suffering. And clearly it is not my right to define their suffering for them.

Q1934 Chairman: We have heard about the system in Switzerland from your colleague. That is not exactly the same as what is proposed in this Bill. Have you any view about the merits of the different possibilities in this area of assisted dying; namely, the kind of situation in which the doctor may provide the necessary means with the kind of additions to which Dr Bosshard has referred, and the other type of legislation in which the doctor may positively take action directly to bring the patient's life to an end? Do you follow me?

Dr Dacombe: I think I do. I think there are some aspects of what you are alluding to which it is not in any way my place to comment on here today, in the capacity that I believe I am here. I am very well aware that you have explored yourselves at some length the systems operating in the Netherlands and Oregon, and obviously we have George here to answer questions directly about Switzerland. I think the comparisons between those systems and what might be perceived as the good or the evil in any of them actually rests with yourselves in making those comparisons.

Q1935 Chairman: I am thinking from your own point of view.

Dr Dacombe: From my own point of view, I think the safeguards I would want to see in any system, in terms of what would be expected of a doctor involved in the care of the patient, do actually exist in this Bill, inasmuch as I do believe it is very important, whether you are talking about a general physician or a palliative care physician, that it should be possible for you to have a conscientious

objection to being involved in the process. I think it should be possible for people to define for themselves within the limits of their own conscience whether or not they feel a need to do anything, whether they feel able only to provide a prescription which gives the patient the means by which they can choose to end their own life, or whether they would be prepared actually to carry out an act or assist the patient in carrying out an act to end their life.

Q1936 Chairman: I would like to ask Dr Bosshard about Switzerland and the methods that are used there. What is the general result, in the way of the process of actually dying, as a result of one of the actions taken under the Swiss law? What happens to the patient in the situation where this type of treatment is administered? How long does it take generally for the patient to die and what is the nature of the death?

Dr Bosshard: Usually the patient has to drink a cup of 10g solution of barbiturate. Then he will be unconscious within a few minutes and he will die within the range of between 10 minutes and a few hours. In some cases it can take several hours; usually the average might be around one hour; but it is important for the patient before—and in particular for the relatives—to be aware of the fact that it can last hours. But we did not come close in one single case to where the patient actually would not have died at all.

Q1937 Chairman: So far as this treatment is concerned, you said that for a patient who has very little in the way of physical ability left there are means by which the minimum physical action on his or her part is required.

Dr Bosshard: Exactly.

Q1938 Chairman: But always, at the very minimum, there is some so far as Switzerland is concerned.

Dr Bosshard: Yes.

Q1939 Lord Joffe: Dr Dacombe, if a patient says that he or she does not want palliative care, they have made up their mind that they have had enough and want to die, would you see that as a bar to them being given the option to ask for assistance to die?

Dr Dacombe: You are talking about a patient actually turning down, if you like, palliative care.

Q1940 Lord Joffe: Yes.

Dr Dacombe: No, absolutely not. Patients have the right to be offered services but equally they have the right to turn down services if they perceive that it is not for them. I do not see that as a problem.

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Q1941 Lord Joffe: Dr Bosshard, how long has the Swiss law been in force which enables patients to be assisted to die? Has that position now been accepted by society as a whole without any kind of parliament?

Dr Bosshard: On the level of canton laws, it has been implemented more than 100 years ago. On the level of the government, actually it has been implemented about 60 years ago. I would say it has always been accepted by the population as a whole—otherwise it would not have been law—but what has changed is the focus. You have just used the term “assistance to patients”, and “patient” is also a medical term. But article 115 was not made in a medical context 100 years ago, but rather in the context of matters of honour. What now has changed is that article 115 is discussed in a medical context.

Q1942 Lord Joffe: It has been extended, in a way, to allow doctors—

Dr Bosshard: I would not say extended but the context is different. But it seems to the Swiss population that this article still is very pertinent.

Q1943 Lord Joffe: Which article?

Dr Bosshard: Article 115, allowing any citizen to assist in the suicide of someone else as long as there are no motives of self-interest.

Q1944 Lord McColl of Dulwich: Professor Tallis, you mentioned the question of these folks being a burden on their family, friends and care givers. I think you mentioned that in the Oregon situation this was not a problem. Are you aware that in fact in one of the studies 38 per cent of the patients did feel that?

Professor Tallis: First of all, the Oregon data seems to suggest that the pressure from the families was a negative pressure, that they were reluctant to encourage the person to avail themselves of assisted dying. In the study to which you are referring I am not too sure whether burden was actually the primary reason for wishing to have assisted dying; there were other factors, including symptom control. I would have to check that out.

Q1945 Lord McColl of Dulwich: Twenty-one per cent in fact had inadequate pain control but 38 per cent felt they were a burden on their family and carers and friends.

Professor Tallis: If I recall, in that same study—and I may be quite wrong here—one of the main reasons, and probably above burden, was the feeling of loss of control. I may be wrong but I think I am thinking of the same study.

Lord McColl of Dulwich: This was the Oregon *Death with Dignity*: 6th Annual Report published around about the Ides of March last year.

Q1946 Earl of Arran: This is a question for Dr Dacombe, who has had so much experience, in a large hospice in Bristol for many years, at the sharp end of life and death. Obviously I would assume that your patients are aware that this Bill is in the public domain now—it is much discussed about. What is the interest? Is it one of a sense of relief that they might be able to take advantage of it if the Bill became law? Or is it one of a sense of anxiety from the point of view of that so-called “slippery slope”? Or in all honesty are they too old and too ill to really have views about this?

Dr Dacombe: I think it is important to say that obviously in responding to this question anything I say is going to be entirely anecdotal because in no way whatsoever have I carried out a survey of my patients.

Q1947 Earl of Arran: I understand that.

Dr Dacombe: And I am very conscious that actually some of the patients with whom we are involved will have an awareness and some may not. Their awareness levels will vary tremendously, as indeed I am sure awareness in the general public varies tremendously, as to whether they know nothing at all, whether they have heard the occasional interview on the radio or in the newspapers, or whether they have scanned the internet day by day, week by week to see what has been said to you. I think we know that the level of interest within the public generally in an Act like this will vary. Certainly amongst the patients who would choose to share conversations about the manner in which they are anticipating their life might end, the manner in which they are hoping their life might end, there has only ever been positive comment about the thought that this Bill is at least being discussed as it is at the present time. The patients who have chosen to make remarks to me entirely spontaneously or where remarks have come up during conversation it has been specifically at their request around the issue of end-of-life care and assisted dying, the comments have all been very positive, that their perception would be that they would like to be having the conversation knowing that this was within the legislation of this country.

Q1948 Earl of Arran: I find that helpful. Thank you very much.

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Dr Dacombe: Thank you. But that is very anecdotal.

Q1949 Baroness Finlay of Llandaff: Obviously we are looking at a bill that is before us at the moment. I wondered, Dr Cole, when you were talking about the patient's WHO rating 4, what percentage of those have any competence impaired and how accurately you are able in your routine clinical practice to measure competence.

Dr Cole: I think quite a lot of those patients do have impairment of competence, to be honest. Many of them, as you know, will be on opiates which may impair their judgment or that might make it difficult or impossible to participate in this process.

Q1950 Baroness Finlay of Llandaff: Some of them may have a degree of impairment of competence that may be difficult to detect.

Dr Cole: I think competence is a very difficult concept for physicians or lawyers to judge. There are patients with mild impairment of intellectual function for whom you think you can have a good discussion and they can express a reliable competent opinion. There is not, as far as I know, any widely used scale to judge competence. Perhaps there should be.

Q1951 Baroness Finlay of Llandaff: I think relating to the other bill before us, the Mental Capacity Bill, we have been assessing competence much earlier on as something which has challenged some people's thinking. Professor Tallis, you were talking about this being an option in the therapeutic alliance with the patient, and then you were talking about patients who are in bed, who have pressure sores and who may feel that their life is not worth living. I wonder whether you would agree with me that the existence of pressure sores is often a marker of bad care, and in fact has been used as an audit tool for bad care, and therefore I wonder how you are going to ensure that patients who are in that situation have not actually been coerced, perhaps indirectly, into being aware that they are too much of a burden for the current system to cope with and that the future therefore looks increasingly bleak because they certainly are not getting improvements in care.

Professor Tallis: I entirely get your point. You can imagine a vicious cycle: bad care leads to a sense of hopelessness, reinforces worse care, as a consequence of which people feel the only option is assisted dying. You could imagine, if there were not all the safeguards in the Bill, that this would lead to an increasing amount of bad care.

Q1952 Baroness Finlay of Llandaff: Could you explain how the safeguards in the Bill will protect a patient against that situation?

Professor Tallis: For a start, because it would be a relatively unusual phenomenon a very bright light would be shone on the care of the patient, not only from physicians, but also, of course, from psychiatrists if there were any question about mental function—depression and so on—and also from a visit from the palliative care team. It seems to me that the first thing a palliative care team might well do if they were unhappy about the care of a patient, would be to point out they are unhappy and make that very clear in the notes. I think it is an excellent mechanism for ensuring that palliative care intelligence penetrates the system more and more, even in advance of getting uniform good palliative care. I am very aware, being a geriatrician, of the deficiencies in the palliative care system, beyond a subgroup of patients who have cancer. It seems to me that that is a safeguard not only against a patient being driven by a sense of worthlessness, due to poor medicine, from seeking assisted dying, but also against bad care. There is a very small sub-group of patients who do develop pressure sores or disintegrate, even in the best possible facilities, when they have the best possible care. We are talking about a small sub-group of patients. It is very important to emphasise that. I think the Oregon figure was either 0.7 per cent or 0.4 per cent of all deaths that were due to assisted dying, so we are talking about a very small sub-group. And there will be that sub-group of patients in whom even the best team cannot assist to the point where the suffering is bearable.

Q1953 Baroness Finlay of Llandaff: I wonder if I might move on to Dr Dacombe, because you have spoken about the palliative care team being involved. Why do you feel that your views are in the minority in relation to other people who are doctors working full time in palliative care?

Dr Dacombe: I am not sure I can answer that question. I am not sure that I know. It is a fact that there are similar views to mine in palliative care and not all my colleagues would necessarily agree with me. I think the opinions that have been surveyed, for instance, by the Association of Palliative Medicine have obviously, by our own representative's free admission, only been surveyed in an extremely basic and relatively superficial manner. I think it would be interesting to have that surveyed at a greater depth and with a greater accuracy and perhaps an improved methodology. My colleagues from the Association of Palliative Medicine, who came representing the Ethics Committee and gave a very thorough presentation—and for whom I have enormous respect, I might add—referred to the survey, which they printed as an appendix at the end of their

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presentation. They acknowledged themselves that it was lacking in fullness and clarity. I do think it is an important point to make that, even within that survey, interestingly, although the first question asked about people's feelings about whether or not (a) euthanasia and (b) physician-assisted suicide was, if you like, for the good of our society, clearly, as you identify, the majority of our colleagues were determinedly against it and it was only a relatively small minority who were in favour. I would point out that in question 2, which asked: "How many patients in an average year make a rational persistent request for you to end their lives?" there were only 23 per cent of the respondents who were able to say "None." If you look at the figures, 50 per cent of the respondents had to state that somewhere between one and two patients had actually made that request. If you extend further up the figures, you get to 20 per cent of respondents who have to acknowledge that somewhere between three and five people had made those requests to them. Therefore, it is a fact that within society, within our population of patients, these requests exist, and in a sense that is what I am acknowledging here today. I acknowledge that I am in the minority of my palliative care colleagues, but perhaps I am not in a minority within society as a whole.

Q1954 Baroness Finlay of Llandaff: The Bill at which we are looking at the moment asks for palliative care to be involved. Within your own team, where I am sure you have discussed this, how does your team view you being the person who is the person who will give physician-assisted suicide or even a lethal injection to a patient?

Dr Dacombe: We have discussed these sorts of issues at some length. Generally speaking, I have encountered much more of a positive response to the concept of this Bill than a negative one across the disciplines, because there has been a universal recognition within our team that the patients to whom I have alluded do exist who make this request. I think that, generally speaking, the team would certainly like to see this in existence as an option for patients. Given the issue of conscientious objection which is built into the system, they are supportive, in being able to have a positive view of patients being able to access assisted dying and yet knowing that they or any of their colleagues could opt out of the process. I think that obviously is important, as has been encountered in other areas of medicine.

Q1955 Baroness Finlay of Llandaff: You gave us examples from your own clinical practice of patients who have persistently wanted to die. I wonder why you felt that these patients had not committed

suicide, given that they have a lot of drugs available to them. They may have a syringe driver attached on which they could easily depress the plunger. I wonder what you feel is happening in these patients who will talk about, "I don't know that I want to carry on" or who will express a desire for death but who do not, despite having enormous quantities of drugs sometimes, make any attempt to put them all in a drink and drink them all in one go as Dr Bosshard has outlined.

Dr Dacombe: I think some of the issue here is that, despite what you have said, of which I am very well aware, there are many patients within the small group we are talking about who do not feel they understand enough about their medication and how it could be taken to know what dose of what medication they would need to take to end their life. They may even have an awareness, or they may in the past have tried taking an excess amount of medication and simply failed to end their life and caused distress to those around them and, indeed, to themselves by that failure. I do think it is somewhat unfair to assume that our patients, in knowing that they are on a multiplicity of medication and to some extent what that medication is and how it acts—because I trust it has been adequately explained to them by their health care professionals—would feel confident that they knew how to take it specifically to end their own life.

Q1956 Baroness Finlay of Llandaff: Could I come back to the question of the way the patients feel and whether they feel a burden. When patients are discharged from an in-patient unit and go to a nursing home, I wonder whether, in your general experience, that is something which they feel is a good outcome, or whether you encounter patients who feel that they do not want to be in that situation of going to a nursing home, who feel they are a financial burden to their family, as well as emphasising the loneliness and perhaps desolation of some of the nursing homes that may be offered to them.

Dr Dacombe: I would completely endorse the thought that moving from a specialist palliative care in-patient unit to a nursing home for the continuation of their care is not for all people a particularly comfortable or wanted outcome. There is research into this. At a very superficial survey level, we ourselves at the hospice have looked at the outcomes for patients transferred to nursing homes. We have identified that a number of people do find that an extremely difficult transition. For a small number of people, it is seen as an entirely satisfactory outcome. It is a minority, I do not hesitate to say that, but where they are settled into a nursing home where they perceive they are in good

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care and they are closer to family and friends, within the community that they have associated as being in their home territory, clearly that is a comfortable outcome. For others it is not. I am not that the issue of finance is always as big an issue as the quality of care. I think we are very well aware in specialist palliative care that the level of staffing and the multidisciplinary nature of staffing is such that the care patients receive is truly all-embracing, and that is not necessarily reproduced within a nursing home. Although you hope they would receive good general care, they will not have as much of the other disciplines involved.

Professor Tallis: I do not think I can improve on what Carole has said, except you probably know that the same issues theoretically would arise in other end-of-life decisions, such as the withdrawal of medication and so on, and the whole point about this proposed law is that in fact these things are scrutinised much more carefully, far more carefully than they are in relation to the withdrawal of life-prolonging or life-saving medication. I do not think it is a very specific issue for this; in fact, if anything, the argument works the other way. Sally, you have a much more global view of the view of older people in this respect. I guess Carole and I look at a very small sub-group of these people and therefore, potentially, have a distorted view.

Baroness Greengross: I do not think I can back up my view in any way as well as you have. I feel we are talking about a very small group of people. The whole question of being a burden to society as a whole is something that is widespread amongst older people, especially in Northern Europe and North America. It is part of our culture where a lot of old people say they do not want to be a burden on their families, however loving, and we must accept that this is part of our culture. It is not a nice thing that in our culture this is so prevalent. It is about an inability to provide care in the culture that I think we would like where people feel wanted and loved and respected. The fact that that exists is very sad and we have to try to eliminate it. I just think this Bill, by promoting honesty and straight-talking, is going to be one link in a chain of improving care. I feel it is about improving care and improving communication. As I said to Lord McColl, people I think would feel better knowing that their doctor is caring for them and that if the doctor was going to be involved in saying, "Do you want me to help you end your life?" it would be in the open. Unless that happens, there is no question of it. I feel the burden question is a societal problem and a problem of resources in this country, in the way in which we allocate resources, and it has to be treated differently from this subject. There are lots of things that get muddled up together, like the disability

organisations feeling they are undervalued. They are. People with disabilities are undervalued. It has nothing to do with this Bill. We have to do something about that, with disability discrimination and the value of individuals altogether. If we start about the burden that individuals feel they are on society, that is about a re-allocation of resources, training care-staff better and changing our culture, and not about this Bill.

Q1957 Lord McColl of Dulwich: Has Baroness Warnock helped the situation of people feeling a burden on society, when she says they ought to push off, that they are a burden on society?

Baroness Greengross: If I may venture an opinion, I think Baroness Warnock was echoing a view which is widely held and which she believes should be more widely discussed. I spoke with her afterwards and she said, "But anything that makes people more open and makes people discuss these things more openly is good. That is why I did it." She has her views and I think the doctors here will often encounter patients who share her views: "I don't want to be a burden and I'd rather die." But I think she was saying it to get a more honest appraisal of where we are. Therefore, whether she was correct it is for everybody to make up their own view. But I think that is why she did it.

Q1958 Bishop of St Albans: We have been much helped in this Committee occasionally by the use of what I would like to call parables: stories that are illustrative and very illuminating. I would like to try one. I would ask you to imagine that you are walking across Westminster Bridge and you see somebody jumping off the bridge. You are next to one of the life belts. This is about autonomy. Do you throw the life belt? Do you jump in?

Professor Tallis: I like to make a diagnosis first.

Q1959 Bishop of St Albans: There is not time, is there.

Professor Tallis: In which case, I set the default position to stop them from killing themselves, and then we can look for a diagnosis.

Q1960 Bishop of St Albans: Of course, I would assume that any of us around this table would jump in or throw the life belt. We would do our utmost to save somebody in that situation. Which raises the question in my mind—and it is a totally open question, therefore—when somebody has exercised, in that case, as they have, their own personal autonomy, what is it about us that says there are other higher values—and I am not talking in a religious sense—values besides autonomy, to which we need to give attention? Would it be, for instance,

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unreconstructed paternalism to leap in and save him? I venture to suggest no. That is what any of us would morally wish to do.

Professor Tallis: In different situations there are different principles that come to the fore. It seems to me that in this particular principle of the person jumping over the bridge it is totally appropriate and the principle of beneficence would rise above the principle of autonomy until you sort through what is going on. In the situation of a person who is terminally ill and has unbearable suffering, then I think autonomy starts to push into the front and some principled concept of beneficence which overrides what they want starts falling behind. All these principles are in competition and they are appropriate ahead or behind in different contexts.

Bishop of St Albans: I was only trying to establish exactly that. That is exactly the problem, is it not?

Q1961 Lord Joffe: To what extent do you feel that you and your team can form a judgment on competence?

Dr Dacombe: Competence is a very large area. What we are essentially talking about here, and what I personally would feel comfortable to talk about, is the fact that an individual's capacity for decision-making, I believe, is "judgeable" at a moment in time. There are structures, check-lists, if you like, that you can use to help form that judgment, and that is to do with issues such as assessing whether a patient can hear information, take it on board, process it, repeat it and come out with a decision that clearly takes into account their circumstances and the information they have been given. That is a process that on occasions we do follow in quite a formal manner with patients. If you are uncertain about that, then clearly you would want to seek advice and support from colleagues, at consultant psychiatrist or consultant clinical psychologist level, to add to your assessment. In other words, if you have doubts, you would want to seek further support. I believe that at a moment in time it is possible. There is a very important issue to bear in mind which has been alluded to by Dr Cole, which is that clearly disease processes can change and the medication that they are on can change. Dr Cole referred previously to opioid-analgesia, for instance, the dose of which can obviously change, and, depending on the rate of change of that dose, it could clearly be affecting a patient's ability to be fully clear at any moment in time. The patient's capacity for decision-making can change over a period of time, but at a moment in time I believe it is possible for it to be assessed. Any of us could be doubtful after our own assessment, and we might clearly then want to refer to colleagues for assistance and back-up.

Q1962 Lord Joffe: The patients to whom you referred with whom you have had these discussions about wishing to die, would you feel that they were competent?

Dr Dacombe: I would. Certainly the discussions to which I have referred in my presentation have been discussions with patients whom I fully believed were competent.

Q1963 Baroness Jay of Paddington: I realise it is late in the session but I really wanted to raise with you two questions which have come out of this extremely helpful discussion about the concepts you have used this morning, which I personally have found extremely helpful. One is this concept of "intractable distress" as not opposed to but a differentiation from the one which is in the Bill about "unbearable suffering". Intractable distress conveys to me, in the way that you have conveyed it, a great deal. The other was on the points which Professor Tallis raised about the "prognosis for improvement"—again, a broader concept than something which limited a definition of availability for this kind of end-of-life decision to a period of time. I wonder if I could get your reactions to that concept as well. Beyond that, there is the more mundane issue, on which perhaps Dr Dacombe or Baroness Greengross may be the most appropriate to reflect, which is the whole question about how the health service and the social services, as I understand it—particularly in relation to hospice funding—do have concepts of terminal disease in the availability of funding, which they use precisely to define the way in which they can support people who are already in hospice care or, indeed, have a definition of their terminal prognosis. That is a more practical, mundane issue, but I would be interested if you would explore that a little. On the broader conceptual point, I realise it is rather later in the session to get into that, and it may be that I just want to put it on the record.

Professor Tallis: Why I prefer "intractable distress"—which is not my phrase but I think may be Sally's phrase—to unbearable suffering, is that it does show that it has both objective and subjective features. It seems to me you have to meet certain objective criteria first. If you do not have any obvious cause of suffering, then clearly it would be totally inappropriate even to consider somebody for assisted dying if they have not been through the whole process in terms of alleviation. You have to have objective criteria and then the person themselves says whether these objective criteria translate into something subjective: unbearable suffering. I do like the idea of intractable distress because it relates to attempts to alleviate it. On prognosis for improvement, there are, in a sense,

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two filters there as well. We have the filter: “Yes, somebody is very, very unlikely to live more than six months” or whatever the barrier is, but, in addition: “They are even less likely to get an improvement in these appalling symptoms which they cannot bear.” It seems to me there are two filters built into the criteria for qualifying for assisted dying.

Dr Dacombe: I am not sure exactly what you would like me to comment on.

Q1964 Baroness Jay of Paddington: I was asking you a factual question because of my muddled remembrance of health and social care funding—which is very complex anyway. I thought I understood that there was—which you would know as a director of a hospice—a specific understandable objective criteria for funding which was used by the social and health services on a time-based arrangement.

Dr Dacombe: Certainly, in terms of providing for the continuing care of patients who have a requirement for that, there is actually a cut-off point between health care and social service care which is set at the eight week mark in most areas. If a patient is to receive a package of care to support them in the community, in their own home, or is to be supported by the state in the funding of a placement in a nursing home, there is a point at which there is an expectation that the team in charge of their care—and specifically the doctor in charge of their care—will offer a judgment as to whether their prognosis is under or over eight weeks. Because the funding will come from a health source if it is under eight weeks and a social services support if it is over eight weeks.

Q1965 Baroness Jay of Paddington: But it involves a prognosis involving time.

Dr Dacombe: Which does involve a prognosis involving time, yes.

Q1966 Chairman: I am very interested in what Professor Tallis said a moment ago in answer to the Bishop’s parable, that the concept of suffering or intractable distress (whichever concept you use) pushes up the principle of autonomy into a more commanding position than it would have with the gentleman on the Westminster Bridge. The same sort of consideration arises in connection with the general attitude to the care of people who may be in distressing circumstances as, for example, when they go to prison, to protect them against committing suicide. I would find it useful to analyse a little further the concept that you have brought forward there, Professor Tallis, as to what it is that elevates the principle of autonomy and takes the decision out of the kind of range that would apply

to people going to prison or somebody just standing on Westminster Bridge.

Professor Tallis: I suppose the fundamental concept behind autonomy is that you respect the person’s wishes, or the wishes that you believe they have. It seems to me that in the case of terminal illness, where you have tried absolutely everything to alleviate the suffering and the outcome is pretty certain, you have a pretty good idea of what the person’s wishes are if they express the desire to have assistance in death. The chances of getting it wrong seem to be less. When it comes to the chap jumping over the bridge, clearly this might be a moment of sadness and he would regret it (or not live to regret it) subsequently, and, there, you have so much that is uncertain, you set default to being paternalistic and say, “Well, it is probably not in this chap’s best interests and I am going to save him.” So it is a different situation. It is partly a difference about knowledge. With a patient who has reached the stage of being considered for assisted dying, one knows an awful lot about the person themselves—what they have been through, what they can stand, what mental science can offer—so you have much more knowledge—which one does not have, of course, for the chap jumping over the bridge.

Q1967 Chairman: In Oregon—I think you mentioned this yourself in your earlier narrative to us—quite a high proportion of the people who are given the medicine (if that is the right word for it) or the drug, in order to end their lives, do not in fact use it. In a sense, that focuses on the fact that even the decision that they are making to request it—because the doctor has to be pretty sure that they really do want it—is qualified somewhat by the possibility that they may reconsider and in fact not use the medication. It was put to us rather eloquently by one of those who were helping us in Oregon that the idea of having this medicine gives people a kind of insurance that if matters get really bad they will not have to continue, and in fact the experience has been in quite a number of cases that it never gets that bad that they want to use the medication. Is that an important factor, in your view, in considering what is a wise proposal to make here?

Professor Tallis: It is, because it is not as if they have boarded a train they cannot get off. Obviously it is built into the Bill that you have a minimum period of consideration. It also relates to what the Bishop of St Albans was saying—I think it was about collateral—and it seems to me that this is a good example of collateral. Many more people are helped by having access to assisted dying than actually avail themselves of this particular facility. So the knowledge that there is a way out if you need it may

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make unbearable suffering—at least temporarily, anyway—more bearable.

Q1968 Baroness Hayman: Could I come back like a terrier to this 38 per cent or 41 per cent of people in Oregon who feel a burden and quote that as one of the reasons for dying. Do you feel that it is possible in your experience of seeing patients for people to have very strong distaste for needing help, completely divorced from any pressure from others to give them a sense that they are being a burden? Obviously none of us would want people to undertake the important decision because others have made them feel that they should no longer continue. However, in observation—the Bishop has sanctioned the use of personal illustration—my husband had a slipped disc two years ago. He hated, absolutely hated, the situation and considered himself to be a burden. I really do not believe I was making him feel that way. I hope not! I use this as an illustration because of evidence we have had about personality type. Have you experienced, with other patients, a phenomenon of people who, without even the burdens of society making them feel that way, or relatives pressurising them to feel that way—indeed, relatives not wanting them to feel that way—still find that part of their personal makeup is a strong distaste for being in a situation where they need carers?

Professor Tallis: I think that is a very good point. Being a burden is not always internalising external pressure, which I think is the essence of what you are saying.

Q1969 Baroness Hayman: Much more eloquently than I did.

Professor Tallis: It is absolutely right that one may not wish to feel a burden. Obviously, in your husband's case he did not mind feeling a burden, in the sense he knew there was some way out, and the suffering that was unbearable ultimately was going to end up all okay. It just seemed to me that in the

context of an illness that has only one outcome, a multiplicity of unpleasant, unalleviated symptoms, then your own decision that you do not want to be a burden is not actually, as I say, internalising external pressures. Having said that, I thought I responded very badly to what Lord McColl said about the paper because I was racking my brain to remember the data which I half remembered. If I recall correctly, and I may have got this wrong—I think this is the Ganzini paper—the feeling of burden, although it may have affected X per cent, was, first of all, not the sole feeling or motivator for people who took assisted dying, even where they felt a burden. I may be wrong on that and it may have to be corrected.

Q1970 Lord Joffe: You are right on that. Indeed what the report said and the Department of Health in Oregon also said was that it was one of several reasons. In rating the reasons, burden came a lot lower than loss of control, autonomy and independence.

Professor Tallis: Yes. I thought that.

Dr Dacombe: I would like to endorse Professor Tallis's remarks about this definition of burden not necessarily being an internalisation of external pressures. I do think people do define what being a burden is for themselves. Certainly I have encountered patients who would perceive their life and the prospect of living their life to the end to be a burden, whether it is a burden to them or a burden to others, and that is based on their definition, perhaps despite a very loving and supportive family, friends and all the services being available to them.

Baroness Hayman: Thank you.

Chairman: Thank you very much indeed. As I said, you will get a chance to review the transcript in due course in order to ensure that it says what you did say. We are very grateful to you for your help. I am sorry this session has run on rather longer than we had anticipated. That is a measure of the help you have been able to give us. Thank you very much.

TUESDAY 18 JANUARY 2005

Present	Arran, E Finlay of Llandaff, B Hayman, B Jay of Paddington, B Joffe, L	Mackay of Clashfern, L (Chairman) McColl of Dulwich, L Patel, L Thomas of Walliswood, B
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Examination of Witnesses

Witnesses: Ms MICHELE WATES, DR JIM GILBERT, PROFESSOR JOHN FINNIS and DR FIONA RANDALL, examined.

Q1971 Chairman: Thank you very much for coming to help us this afternoon. I think that, possibly, the name plates we have provided for you do not have your correct titles. I think I am right in saying that both Mr Gilbert and Ms Fiona Randall are qualified medical practitioners?

Q1971 Chairman: *Dr Randall:* Yes.

Q1972 Chairman: First of all, I should explain that the evidence that you help us with will be taken down and you will get a chance to look at the transcript to see whether it accords with what you thought you said. In due course, the corrected transcript will be appended to our report and will become public as a document when that report is published. I would invite you, in what order you think appropriate, to give a short introduction of yourselves and your points of view, and then the Members of the Committee will wish to ask you questions about particular matters in your area that they would like further help on. Dr Gilbert?

Dr Gilbert: My name is Jim Gilbert and, as you say, I am a qualified medical practitioner, consultant and medical director of a palliative care service in Devon since 1992, during which time, as a service, we have looked after approaching 10,000 patients with advanced, incurable, progressive diseases, and, importantly, the families and those close to them. I have served on the Association for Palliative Medicine, which is the Hospice Doctors' National Association Ethics Committee. I have published on end-of-life care and ethics over the years and currently chair the Royal Devon and Exeter Hospital Clinical Ethics Reference Group. For the Association for Palliative Medicine Executive Committee, together with my colleague Dr David Oliver, I conducted a survey of UK palliative care doctors in 2003 regarding attitudes to euthanasia and physician-assisted suicide.

Q1973 Chairman: You are using the same definition as I am inclined to use: physician-assisted suicide is where the patient himself or herself self-administers the prescription whereas euthanasia is where the

doctor acting on a request performs the necessary action to bring the patient's life to an end?

Dr Gilbert: Exactly. This survey was referred to briefly this morning, and I have a copy, in case you have not got it for the record here, of both the questionnaire and all the responses. We sent out 726 of these to all those on our database of UK practising hospice doctors and it was interesting that we received, despite all the busyness of those individuals, over 600 replies without any prompting over the course of just a few weeks. Briefly, the results of this survey showed over 90 per cent opposition to legislation permitting euthanasia or physician-assisted suicide. Both options were put in the survey. I have got full details of the numerical results and the comments that came with that for the Committee to look at later. It seems to me that with this Bill there is a clear expectation that assisted dying is to be offered in the context of palliative care and that, therefore, the overwhelming opposition of hospice doctors as evidenced by this survey seems an important consideration. I would like to comment briefly on why I think this might be. Firstly, I would certainly not suggest that palliative care can in all circumstances relieve all suffering. I know that has been an important question for the Committee to have answered. Within existing law, doctors do seem confident, however, that physical symptoms can be treated fully in the last few weeks of life, and I know that in previous sessions of this Committee it has been recognised that existential suffering and the fear of dependence may be much more relevant to requests for assisted dying than uncontrolled symptoms. In these circumstances, my belief is that doctors wish to reassure people unequivocally who believe themselves to be a burden and to emphasise the value of their continued living rather than giving them a psychological if not physical push from the bridge by agreeing to help them end their lives. Finally, from me, a word if I may about prognosis and prognosticating—the art of so doing—because it is far from a science. It is clearly envisaged that an important safeguard has been included in this Bill by restricting assistance in dying to people with a short prognosis. Much reassurance seems to have

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been taken from this restriction. I believe that doctors working in palliative care are uniquely well positioned to see the fallacy of this apparent safeguard. Paul Glare's earlier evidence to this Committee demonstrated great inaccuracies in doctors' honestly estimated prognoses, and given the injustice that will be perceived by those in favour of assisted dying in denying such assistance to those people who deem themselves to be suffering unbearably as a result of chronic rather than terminal illness, there seems good reason to believe that an estimate of a short prognosis will be easily obtainable from a well-intentioned but perhaps misguided pair of doctors willing to stretch a point in order to comply with what they perceive to be patients' wishes. In summary then, from me, palliative care doctors are overwhelmingly opposed to the provisions of this Bill. It seems both unjust and unworkable to me to restrict assisted dying to those with a short prognosis, and the major relevant suffering (existential suffering and the fear of dependence) may lie out-with the remit of health care and the competence of doctors to judge.

Professor Finnis: I am John Finnis, Professor of Law and Legal Philosophy at the University of Oxford and a Fellow of the British Academy. I have worked quite a lot on moral and even theological matters, but my academic work at Oxford is on public policy and law, in which matters private morality and belief are not the issue but, rather, the interplay between legal principles and social consequences. It is in that capacity that I want to give evidence today. At present, there is a clear principle: never intend to kill the patient; never try to help patients to intentionally kill themselves. That is the law, it is the long-established common morality, it is the ethic of the health care profession and it is Article 2 of the European Convention on Human Rights, and so forth. There is a "bright" line, and though like other laws and principles it is not invariably respected it is not in the least artificial or brittle; it rests on a rational principle that a person's life is the very reality of the person, and whatever your feelings of compassion you cannot intentionally try precisely to eliminate the person's reality and existence without disrespect to the person and their basic equality of worth with others. I think that that principle underlying the clear line is sound and right, though I am not here primarily to ask you to agree with it. Rather I am here to compare the present situation with the situation once any form of euthanasia or legalised assistance in suicide is admitted. In the new situation, any attempt to draw the line is necessarily artificial. The principles on which any attempted line would be based undermine each other and subvert the attempt to hold a line. If autonomy is the principal or main concern, why is the lawful

killing restricted to terminal illness and unbearable suffering? If suffering is the principle or concern, why is the lawful killing restricted to terminal illness? Why must the suffering be unbearable if there is real and persistent discomfort? If suffering is unbearable, why should one have to wait for 14 days? If suffering and terminal prognosis are the concern, why is relief restricted to those who are capable of asking for it? Each of those questions is not simply a reason for doubting the rationality of any proposed line alternative to the present principled lines, each of the questions is also a reason why there will be much more abuse and secrecy and underground killing than at present, because each of those questions can and will be asked by any doctor faced with a patient demanding euthanasia or assistance in suicide or with a patient not demanding it but suffering or confronting an early death. Patient autonomy pushes the doctor to accede to requests that do not meet the legal criteria of terminality or suffering. Suffering, or terminality, and medical responsibility each push the doctor to set aside the requirement of voluntariness. All this will cause eternally reinforced and profound changes in medical and professional ethics, so that intentional death-dealing becomes a clinical option and, of course, also a hospital management option and a nursing home option. Now, you as a Committee have been to the Netherlands and read the government-sponsored and government-commissioned reports in 1991, 1996 and 2003 investigating the practice of euthanasia in that country. You may have in mind the figures that can be found in the tables in these reports but they are known to extremely few people in this country, and I would like to put them in evidence publicly today. The latest figures can be found extracted from the reports and set out in scholarly fashion by the Dutch medical practitioner Dr Richard Fenigsen in the journal *Issues in Law & Medicine*, volume 20, summer of 2004. The two earlier surveys are analysed in depth by Professor John Keown in his Cambridge University Press 2002 book, *Euthanasia, Ethics and Public Policy*, Chapters 9-13. I will restrict myself generally to the 2001 figures published in 2003, after Keown's book. The population of the United Kingdom is a bit less than four times that in Holland, but the death rate here is a bit more than four times the size, so it is reasonable to multiply the Dutch figures for euthanasia by four to get a sense of the Dutch picture if it were replicated here. Taking the Dutch 2001 figures, based on their own government-sponsored, ministry-commissioned tables, generated by confidential interviews with hundreds of Dutch medical practitioners and questionnaires to many thousands of medical practitioners who had signed

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death certificates, there would be here in the United Kingdom nearly 15,000 deaths per annum by active, voluntary euthanasia and nearly half of these would be done without the legally required procedures. There would be over 1,000 assisted suicides, at best about half of them in accordance with legal procedures. But then there would also be nearly 4,000 cases of active, involuntary euthanasia; that is, lethal injection without the request of the patient, all totally illegal and uncertified. There would additionally be over 11,000 cases of lethal overdose of painkillers with intent to cause death, and none of these would be certified. These figures are so embarrassing that the authors of the 2001/03 report omitted a line of inquiry they had pursued in their own previous reports, which had revealed in 1991 that over 70 per cent of the deaths caused by lethal overdoses of painkillers with intent to cause death were without the patient's request or knowledge. In other words, there would be, in the United Kingdom, over 30,000 cases per annum of death intentionally and actively caused by physicians, of which only about 7,500 would be in accordance with the law's procedure. Of these 30,000, over 12,000 would be without the patient's knowledge or consent—not to mention at least a dozen cases a year when newborn babies are actively euthanised without the consent or knowledge of their parents out of a total of about 400 euthanised newborns killed by lethal injection. Besides all that, there would be over 70,000 cases where life-sustaining treatment is withheld or withdrawn with the explicit intention to cause death. That is 70,000 plus out of about 110,000 cases where life-sustaining treatment is deliberately withdrawn or withheld where otherwise it might have been given. So we are looking at well over 100,000 cases of active or, so-called, passive euthanasia in the full sense of an intent to bring about death, and of these only about 7,000 or 8,000 are in accordance with the law's requirements—projected future euthanasia law in assistance in dying—while tens, if not scores, of thousands of these are not voluntary. Those are the figures scientifically estimated by the Dutch government's appointed experts simply multiplied by four to get a rough UK figure. The authors gloss over these figures in their soothing commentaries. I can imagine that they may even have glossed over them in their discussions with you, possibly, though their 2003 report repeats the eye-opening assertion that they made in 1996: namely, it is the patient who is now responsible in the Netherlands for avoiding termination of his life; if he does not wish to be killed by his doctor then he must state it clearly orally and in writing, well in advance. So the public policy point I want to make is that none of this is accidental or can reasonably be assumed to be

peculiar to Holland. The interplay between patient autonomy, suffering, prognosis, patient embarrassment, medical autonomy and the hidden influence of relatives and carers with their own autonomy and interests, in the context of an officially sanctioned devaluation of human life under conditions of disease, disability and disablement is, inevitably, I should say, a web of forces making it impossible to establish and hold an effective line once the present clear line and principles are abandoned. The violation of the right not to be killed, the right not to be put in vivid fear of being killed and the violation of the right not to be pressed into suicidal decisions would therefore become, I am confident, more widespread and more burdensome—I suspect enormously more burdensome—than the present violation of the autonomy rights of a relatively few that is alleged (I think fallaciously) by supporters of the Bill you are considering.

Dr Randall: I am a consultant in palliative medicine and I have been since 1982. I have served on the BMA Ethics Committee and I have a Philosophy PhD in health care ethics. More recently I have been involved in working with the Department for Constitutional Affairs on the Mental Capacity Bill; I was asked to attend that from the Association of Palliative Medicine and that has been fascinating and worthwhile. I would like to take two sets of things. The first is about the overall impact on patients of legalising assisted suicide and euthanasia through this sort of Bill, and the second is about the role of doctors in this Bill. The first set of points to do with the overall effect on our patients. I think my overwhelming anxiety about the legalisation of PAS and euthanasia through this Bill is that it will, I think, increase the suffering of the terminally ill and not decrease it. My reasons for thinking that are as follows: that increasingly in recent years I have found that patients perceive they are a burden; that they are valueless because they can no longer do things; that they need care. A lot of their distress, after most physical symptoms have been alleviated, is emotional; that they feel useless and a burden. My worry is that if this Bill were to go through assisted suicide and euthanasia would become a treatment option, so the option would have to be presented to all terminally ill people who were believed to be in the last months of life. So for the rest of their natural life they would be faced with this enduring choice: as to whether they should “go for” assisted suicide and euthanasia on the grounds that they have become a burden to their families because they perceive that they are useless. We live in an environment where autonomy—the ability to make your own choices, be yourself, do your own thing, be independent—is so highly valued now that

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patients who have lost their independence so easily feel valueless and a burden, and being faced with a constant choice for the last months of your life as to whether you ought to opt for assisted suicide and euthanasia, I think, would be a very distressing condition to put patients in. So many of them would feel all the time: "Should I do this? Is this now too much for my relatives? Is the nursing home eating up my money?" (That is a more minor issue—it should not be an issue but is still often an issue.) So I think that considering that a small minority of patients would be expected to actually choose assisted suicide and euthanasia, the collateral effect on the great majority who would not, in the end, choose it but would be presented constantly with "Ought I to choose it?", I think, would be an increase in suffering because of the agonising choice which they are constantly presented with. Going on from the general effects, I think there are logical consequences of this proposed legislation which would follow which I, as a citizen, feel are undesirable. There are two logical consequences which follow, which I think go on from what John was saying. The first is, if we are saying that the entitlement to assisted suicide and euthanasia—and that is what this Bill is about; it is about giving these people an entitlement if they meet certain criteria to assisted suicide and euthanasia—is thought to be a benefit for those who are terminally ill, logically, it must be extended to others who feel they are suffering unbearably but are not in the last few months of their life, because otherwise it appears very unjust that this apparent benefit can be gained only when it is believed that you are in the last months of your life, and not for instance earlier when you might be in the earlier stages of Huntington's career, the earlier stages of motor neurone disease, or the earlier stages of diseases which may have a very long process of increasing disability. So the entitlement would logically have to be extended outside the terminal period of life because otherwise it is inequitable if you think it is a benefit. That is a logical consequence, so I think it would be followed—not because people are bad and people are nasty but because it logically follows by reason. The other logical consequence that I think is a bad thing for society is if this benefit of an entitlement to assisted suicide and euthanasia for unbearable suffering is to be there for competent patients how are you logically going to deny this to incompetent patients who you believe are suffering because of distress due to Alzheimer's disease? Some Alzheimer's disease patients actually appear very distressed and it is difficult to know what they are feeling, but if people judge that they really were suffering then why should they be denied the benefit, if you think that is what it is, of having their life

ended? So, logically, there will be this extension, as John has said has happened in the Netherlands, towards this for the incompetent patient, and that is not because people are nasty people, it is because it would be the way that your thinking would go. So I think the logical consequence of this sort of Bill is extension to non-terminal illness and extension to incompetent patients. Both of those extensions would actually concern me for society overall. The second thing I would like to say is to do with the role of doctors in this Bill. Doctors have a huge role in this Bill. On the one hand you may say they have power and with that goes a tremendous responsibility in this Bill. If we look at the so-called doctor-patient relationship, and what the effect might be on that of legalising assisted suicide by your doctor or euthanasia by your doctor, doctors are really expected not to harm their patients. It is a very strong principle for us. Society normally thinks that intentionally killing another person is a harm. I really think there is a threat to the doctor-patient relationship and the fundamental trust in this if your doctor is expected to be the person who assists you to commit suicide or give you a lethal injection. Quite often, at the end of life, when patients have had what has turned out to be the last injection, relatives erroneously think you have bumped them off and you have not. If this becomes legalised, how many more people are going to think that when you are in care somebody is going to come and end your life? Once that thought gets hold it will be enormously difficult to eradicate it. So my worry is towards the trust in the doctor-patient relationship—it is a big problem. In the country at the moment there is terrific anxiety about doctors misusing their powers in the ability to shorten life—terrific anxiety about this—so I think legalising this manoeuvre towards allowing doctors to give lethal injections is very bad for the confidence of patients and their doctors. Lastly, looking at it from the doctor's point of view: this Bill expects us to decide whether the patient is suffering unbearably. I cannot decide whether a patient is suffering unbearably because only the patient can say that. I cannot be expected to judge what for this particular individual is unbearable suffering. Then, as a doctor, I am expected to judge whether this patient is in the last few months of their life. It is enormously difficult to do that. Paul Glare's evidence I know you have had, of some studies that have been done which show that however hard you try our ability to guess how long someone is going to live is very limited, and yet that is what we are supposed to do in this Bill. After we have made these extremely difficult judgments, one of which, in fact (the judgment of suffering unbearably), I think is impossible, on which is based an extremely serious consequence—the ending of a

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patient's life—somebody will come after us and will judge whether we did the right thing or not. So we are asked to make judgments that, I think, are extraordinarily difficult and then judged by somebody else, the Commissioner, and if they think our judgment was flawed in any way it goes before the coroner, and then goodness knows what else happens. So I think there may be an enormous reluctance on behalf of doctors to get themselves into that position. I find myself wondering why on earth is the Commission scrutinising this after the patient is dead? Why not before the patient is dead? In summary, I would say I think legalising physician-assisted suicide, euthanasia, by means of this Bill has more adverse consequences for the whole of society than it does benefits. Thank you.

Ms Wates: My name is Michele Wates, I am an independent researcher and writer and mainly my work has been around the relationship between disability and family life. I am speaking today as a person with a progressive illness. As long as our society has had written laws the central tenant has been to protect people, especially those who may be physically and/or mentally vulnerable, from being intentionally—or for that matter unintentionally—killed. I believe that this law would turn that principle on its head and establish in its place the principle that a person may invite others to kill them. I think this would represent a central shift in the mores of our society. Media attention has been overwhelmingly focused on a small number of exceptional cases of people who are not in a position physically to take their own lives, insisting that they should have a legal right to be assisted in committing suicide. It is extremely important that lawmakers do not overlook the much larger numbers of people who feel that their existence and their right to support would be put at risk in the climate established by any such change in the law. In my opinion the legislation that we currently have is both necessary and adequate to deal with the complexities of individual situations. A relative, a friend or a care-giver who claims to have killed someone on compassionate grounds should be able to satisfy the courts that this is indeed the case and I believe that the law as it stands is flexible enough and that those who administer justice are astute enough to cope with exceptional circumstances, as recent judgments have demonstrated. The proposed legislation draws a line that I find quite disturbing between those who “qualify” to be assisted in killing themselves and those whom society would seek to prevent from committing suicide. Some will be seen as clearly qualifying, in other cases it would, I believe, be unclear as to whether people qualified or not, while others definitely will not be seen as qualifying. Whether or not a person is deemed to

qualify will deem how the medical profession is required to respond to their needs. So take the following scenario: imagine that a husband and wife have serious financial problems and lose their home as a result. Both of them become depressed and the husband goes to the doctor to say he is suffering unbearably and feels suicidal. That doctor is bound to seek to help him recover from his depression and should also point him in the right direction to get help with finding somewhere to live. Imagine that the wife is also depressed as a result of the same circumstances that have caused her husband's depression, and she too feels suicidal. She approaches a doctor and a solicitor who is known as a supporter of assisted suicide and informs her that she is suffering unbearably. Because she is also able to show that, unlike her husband, she has a terminal illness, she is not treated for depression but two weeks later is lawfully killed. Her husband, at her request, is not informed until after her death that that is her intention. I think we would do well to be extremely cautious about the language of anti-discrimination practice, choice and human rights of the individual that are frequently used by many of those who support assisted killing. To see where this might lead we need look no further than the example of the Netherlands. “Over the past two decades the Netherlands has moved” (I am quoting now from an article by Marilyn Golden, who is an American author) “from assisted suicide to euthanasia, from euthanasia for the terminally ill to euthanasia for the chronically ill; from euthanasia for physical illness to euthanasia for psychological distress and from voluntary euthanasia to non-voluntary and to involuntary euthanasia. Once the Dutch accepted assisted suicide it was not possible legally or morally to deny more active medical assistance to die—ie euthanasia—to those who could not effect their own death. Nor could they deny assisted suicide or euthanasia to chronically ill who have longer to suffer than the terminally ill, or to those who have psychological pain not associated with physical disease. To do this would be a form of discrimination. Involuntary euthanasia has been justified as necessitated by the need to make decisions for patients not medically competent to choose for themselves.” This is quoted from an author called Hendin¹ in 1996 who describes, also, how for a substantial number of people in the Netherlands physicians have ended their lives without consultation with the patients. As a disabled person I have lived for many years with the knowledge that society's view of the value and acceptability of a disabled person's experience may

¹ The paragraph as worded appears in Hendin, Herbert, et al .1997. “Physician-assisted suicide and euthanasia in the Netherlands: lessons from the Dutch”, JAMA (Journal of the American Medical Association) 1997; 277: 1720-1722

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be quite different from my own. A person who wishes to die because they have come to regard their life as valueless and lacking in dignity as a result of disability or illness may find that they have the acquiescent agreement of those around them, including people who may be their medical professionals. It is widely assumed that it is impairment and illness even of themselves rather than the social and physical environment in which impairment and illness are experienced that leads to suffering and loss of human dignity. I know from personal experience that the quality of my life is not determined by the progress of my illness and extent of my impairment so much as by the access that I have at that particular time to assistance, to equipment, to appropriate environments, to accessible transport, etc. I think it is also important to acknowledge the changing social context within which this debate is taking place and to be open about the fact that with an ageing population society has a vested interest in not having to pay to support increasing numbers of people who are disabled and/or sick. It is insufficiently acknowledged that there is at least a perception of competing and conflicting interests in this matter. We should not be naïve about this. Carers and terminally ill and disabled people may have different perceptions and different interests. This is not to make judgments, it is to face facts. The Bill, in effect, I believe, wishes these complexities away, saying merely that the physician should have satisfied himself that the request is made voluntarily. I believe that a pressure on those who find themselves “qualifying” (and that is a term I, personally, find chilling in the terms of the Bill), whether this pressure came from outside themselves or whether the pressure had been internalised, would, in some cases, be an intolerable pressure and that people who did not want to die would feel that it was incumbent upon them to seek death. It is not enough that the Bill says that the physician should have satisfied themselves that the request is made voluntary; the pressures that people are under will in many cases be internalised and, therefore, no longer open to scrutiny. I think it is significant that the Disability Rights Commission in the UK is unanimous in its opposition to the passage of this Bill. So that if we are talking of the recognition of rights that must weigh for a lot. Members of the Committee may also be aware of similar opposition by disabled people in other countries. I think that the proposed legislation would erode that most fundamental principle that human beings value the lives of friend and stranger. One of the most distinctive and heart-warming features of human society is the value placed on another human life and the steps that people will take to reduce

suffering and to preserve the life of a fellow human being. To erode that principle, as I believe the proposed legislation would do, is to make the world a bleaker and more dangerous place for all of us.

Chairman: Thank you very much.

Q1974 Earl of Arran: I have a question for Dr Gilbert. I will ask this not in an accusatory way but more of a rhetorical way. Would you not accept that in spite of the most expert delivery of palliative care man can offer at the moment, there is still, nevertheless, a small group of people whose intractable distress or unacceptable suffering cannot be alleviated?

Dr Gilbert: I would accept that. I think, however, my general medical experience would make me also observe that this is by no means confined to palliative care or to people within a few months of the end of their lives. For instance, there are people with arthritis, for instance, who find it unbearable that their lives are restricted by the pain that they have to endure chronically, perhaps, for many, many years. I would not claim for a moment that palliative care has the answer to all that, nor indeed that medicine has the answer to all that. In the end, I think it is inescapable that unbearable suffering lies in the mind of the individual concerned and so no palliative care, nor medicine, can alleviate all suffering.

Q1975 Earl of Arran: What do you suggest should happen to that small group of people? Surely it must be genuine, unacceptable suffering.

Dr Gilbert: Absolutely. I would raise no question about the validity or the genuineness of that suffering. What I would expect to do and I would expect other health care professionals and social care professionals to do, and collectively be supported by society in doing, is our utmost to help alleviate that suffering and to continue to help alleviate that suffering and make it plain to people that collectively we will not stop attempting to relieve that suffering as much as we are able to do. However, to eradicate suffering in the human condition seems too big a task for medicine.

Q1976 Baroness Hayman: I wanted, with some trepidation, to discuss with Professor Finnis the clarity of the line that at present exists. While he explained very clearly how from some viewpoints there is clarity, could I ask him whether he would accept that from a patient’s perspective, more than a doctor or a lawyer’s perspective, the clarity is perhaps not as focused as he suggests? I am thinking of the patient whose end-of-life circumstances take them on to a life support machine, a patient whose end-of-life circumstances take them on to

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dependence on medication which, if not taken, will end their life, or the patient who is at home and has a knowledge of pharmacology at its most basic and has the ability to squirrel away, if you like, an appropriate amount of medication, or the patient who can swallow. In all those circumstances, that patient's autonomy is respected by our legal system if they wish to end their own life. Would you accept that for some patients, whose fate is such that they cannot swallow, they are in different circumstances but they may feel that they want exactly the same end in exactly the same context—and let us leave aside whether it is logical to have this end-of-life situation—and they would feel they were very much at the same point on the spectrum as the other patients who have the ability to exercise their autonomy?

Professor Finnis: Yes. It seems to me not quite adequate to say that the present law respects the autonomy of the person who can commit suicide. It does and it does not. A few years ago in the *Bland* case some Members of the House of Lords sitting in judgment on it said that the decriminalisation of suicide was to respect autonomy. More recently, when the whole House looked at it again in a judicial capacity, in the *Pretty* case, they said it is not about a right—autonomy in that sense—it was decriminalised because of the evils of seeking to pursue, by the instruments of the criminal law, these people in their desperate circumstances. I would not myself articulate it as an autonomy.

Q1977 Baroness Hayman: Perhaps if I articulated it in terms of the right to refuse treatment and the inappropriateness of a doctor administering treatment when there is no consent to it.

Professor Finnis: That is a second and different scenario, and a very important one. Can I just finish off the point about “I haven't got the same advantage as others in being able to commit suicide”? That is a difference between persons, but the law takes care not to give public support to those who wish to act on an evaluation of their own life which the law cannot safely admit. If I decide to kill myself, I declare myself to have a life not worth living. We all have a very strong interest in that evaluation not being one that we accept. Of course, we commiserate deeply with the person who makes that mistaken evaluation of their own existence but we seek to preserve society from the judgment running wild that, in a certain condition, “You have got nothing left to live for and you would be better off dead, and, of course, we would be better off if you were dead”. We have a huge interest in that judgment not being ratified and that is why—

Q1978 Baroness Hayman: The *Miss B* judgment did not ratify that.

Professor Finnis: Which judgment?

Q1979 Baroness Hayman: Miss B.

Professor Finnis: In which circumstance?

Q1980 Baroness Hayman: About the right to have a life support machine turned off.

Professor Finnis: That judgment, as I understand it, never came to any definite view on whether she was acting suicidally or simply exercising the other right which you have rightly introduced into the discussion, which is the right to refuse treatment. Society has a very strong interest, of course, in upholding the right of anyone to refuse physical intervention on their own body if they do not consent to it. Society accepts there is then going to be a grey area in which people use their absolutely legitimate and valuable right of keeping others at bay from one's own body, and there is going to be a grey area in which some people misuse that or mistakenly use it to commit suicide. However, society has a strong interest in not coming down on the right to refuse interventions on one's body for the sake of finding a line that is indeed a secret line, one in the privacy of one's own heart. There will be some people who are making this decision to refuse treatment because they are suicidal, and we have an interest in not trying to seek too scrupulously to find that. On the other hand, we have a strong interest in giving them incentives to value their life. On the general question of whether we have an interest in respecting people's autonomy, and its bearing on this Bill, I would say all questions of intention are, in the end, questions of interiority. We have an enormous interest in doctors not forming the intention to kill us. There are many circumstances when it is just as ambiguous, from the outside, whether a doctor has the intention to kill us or whether the doctor has made a judgment that this treatment would be too burdensome or would be futile for us. So there we want a clear line but we have to recognise that a clear line is one that runs, so to speak, through the soul and mind and intentionality of the doctor, and we are never going to be able, with the instruments of criminal law, to seek out and find every case where doctors have abused their position by forming and acting on an intention of the forbidden kind. That is part of the basic reason why, I think, any breach of the principle “never try to kill”, “never intend to kill” is one we have a huge interest in avoiding.

Q1981 Baroness Hayman: Thank you. Just one other question: you have given us figures for what would happen in this country extrapolated from the

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Dutch experience. Have you done the same figures extrapolated from the last Oregon health service report?

Professor Finnis: No, I have not, but I would like to say that I regard Oregon as two things: a very intermediate stage and a very curious, isolated bubble. The law in Oregon is the result of campaigns that have been run in a large number of states—a considerable number of states—in the United States, which have always failed in other states but have succeeded narrowly in Oregon. These campaigns have been highly skilled and dedicated campaigns by people who make no secret in their own publications, although it is not generally publicised, that they regard assisted suicide as simply one stage in a progressive liberation of society from its present taboo. So they carefully restricted the Oregon law that they sought and gained to assisted suicide. It is a state which exists in a rather special set of circumstances, very advantageous, well-off, isolated in many respects from the rest of the country. I have no doubt whatsoever that if the Oregon experiment or regime were to be adopted in the wider United States it would soon prove impracticable to hold the line in the way that it has been held in the few years since Oregon's law has been in force, and we would have a movement towards the Dutch experience, extensively—perhaps not as rapidly as in Holland because in certain respects American culture retains a bulwark against cynicism, a bulwark that may conceivably not exist in Holland.

Q1982 Baroness Hayman: I am very interested in that response, if I may say, my Lord Chairman, about the intention of those who support the Bill to take this further, because when we were in Oregon I did ask and probe about this on several occasions, about physician administration rather than physician-assisted, and got very clear statements, which were on the record, that they not only were not pressing for it but they did not believe it would be achievable. I am interested in your view that this would inevitably follow.

Professor Finnis: I think there is no doubt that the national campaign which was successful in Oregon, but not elsewhere, has these much wider objectives. We heard this morning that in Switzerland they take no interest in terminality, they take no interest in unbearable suffering, but they do take an interest in the line between assisted suicide and euthanasia, but they then fudge that so that any movement of the patient counts as making an assisted suicide and not euthanasia. I imagine that in Switzerland, too, that line, which results from the old law about assisted suicide in Switzerland, will eventually crumble.

Q1983 Chairman: Dr Randall, I think you wanted to make some comment on the answers that have been given to Lady Hayman's question.

Dr Randall: I think it was about what autonomy means and the difference between a positive right and a negative right.

Q1984 Baroness Hayman: It was not, although that was the way in which it was answered. It was about whether this clarity of where the line is, is really there from the patient's point of view.

Dr Randall: Patients on the whole can distinguish between refusing a line of treatment that they do not want and what this Bill is proposing, which is a right to assistance by the doctor in directly ending your life. I think to most common people there is a difference between the right not to have treatment forced upon you, which is almost a negative right, and a positive right to have the doctor give you a lethal injection. I think most people could see that those were two different scenarios.

Q1985 Baroness Hayman: And turning off a life support machine?

Dr Randall: We have to draw some distinctions. I think the distinction we have, which is that a patient does not have to undergo a treatment that they do not want, is one which everybody would wish to uphold. It is interesting that there is a Health of the Nation target to reduce the suicide rate. One of the Health of the Nation targets—and for doctors this has been brought home to us—is that we are supposed to be reducing the suicide rate, so we are supposed to be reducing the suicide rate generally and yet this Bill would propose that there is a particular group of people who we should assist to commit suicide. That is actually a bit inconsistent.

Professor Finnis: The one piece of behaviour, ie switching off a life support machine, can be two or three totally different acts, even though physically from the outside it is exactly the same piece of behaviour.

Q1986 Chairman: There is a distinction between these cases about whether or not the person, subject to the life support machine, is able to give a decision or not.

Professor Finnis: That is one of the contexts in which you get two different acts.

Q1987 Chairman: Where a person can give a decision the decision rules. Where a person cannot give a decision, normally these days anyway, it is ultimately a question for the court unless there is complete agreement. Is that not so?

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Professor Finnis: The court's criterion would be to take as a base line that the doctor must not be doing it in order to end the life because he does not think the life is worth living.

Q1988 Baroness Jay of Paddington: You spoke earlier about this idea of the "safely admitted" legal position in which I thought you were talking about the way in which the courts would proceed. Where do you see the tipping point on safely admitted law? If we look, for example, at the evidence of case law in recent judgments, Miss B is one and that is what you have just been discussing with Lady Hayman, the withdrawal of treatment, and if we look at the case last week in the courts about someone who assisted their wife to die, he was then regarded as having undertaken a merciful act. At which point do you think that society would say the number of cases of this kind which has received that response from the judiciary and from the courts is such that the safely admitted area of law has been crossed into something which you would regard as unsafe?

Professor Finnis: I think it becomes unsafe the moment you start to admit that an omission done with the precise intention to end life is okay.

Q1989 Baroness Jay of Paddington: So you would regard the decision last week as unsafe?

Professor Finnis: The decision last week was that he should be convicted and given a suspended sentence to signify that this is the line.

Chairman: It was a conviction. The question was what the sentence should be and obviously the discussion was about whether the sentence was appropriate. There was a conviction underlying the sentence. I think the question is whether, if the sentences are seen as very light—

Baroness Jay of Paddington: Or non-existent.

Chairman: If a conviction has been recorded by the court they have to dispose of the case somehow. If the case is seen as disposed of in an awfully light way people will say the line is being eroded. I think that is the point.

Q1990 Baroness Jay of Paddington: My Lord Chairman has put it more precisely.

Professor Finnis: The court could have given an absolute discharge but it did not. He was given a suspended prison sentence. We can argue about whether that is too light or not. I think it is dangerous for the law to go down this route, but it is a danger that people can reasonably hold different views on. The Bill goes far beyond this. In the Bill there is not a universal principle of never intending to kill.

Q1991 Baroness Jay of Paddington: In practice, in the common sense normal understanding of this, would you feel there was absolutely no future in the discussion that given this lack of clarity, as I have just demonstrated in terms of my reaction to what I thought had been reported, it would be better for there to be a clear statutory provision which enabled that sort of procedure to be undertaken which did not depend on the lightness of the response to a conviction or the discharge of a particular case?

Professor Finnis: We have a clear statutory procedure, i.e. it is murder and you should be convicted of murder if you do that sort of thing and then it is for the Court of Appeal to deal with it. That is the only safe line.

Chairman: This Bill would not have covered that case either, but that is another matter.

Q1992 Lord McColl of Dulwich: There is no doubt that there are elderly people who are worried about whether the doctor is coming to help them or to do something else. It may not be a large number of people, but certainly there are such people in Holland and some of them are moving out to Germany, which is an interesting movement. If the European Union were to introduce a Bill which precluded doctors and nurses from taking any part in an assisted suicide or euthanasia that would certainly clarify the particular issue. I wonder what you would feel about that. Obviously it would not apply to Switzerland but it would to the others.

Professor Finnis: If the European Union constitution were to be adopted it might well cover this sort of thing, although those who defend the constitution often say that it does not include this kind of national matter. That is neither here nor there. In the Council of Europe you have the so-called Marty Report and initiative (which has not yet been adopted). A lot of my remarks earlier this afternoon were directed at the line of thought which has got a regrettable momentum to it in the Marty Report, which is that there is all this abuse in countries with outdated laws like ours and the way forward is to go into the clear open world of the Netherlands and Belgium where there is not abuse because it is all above board. What I was pointing out was that there is massively more abuse in the Netherlands and no doubt in Belgium, although we do not have the figures for that, than there is elsewhere or in countries like ours with "outdated laws". Public discussion in Europe is at least as confused and to some extent lacking in serious information as it is in this country.

Chairman: We are busy trying to remedy that at least to some extent.

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Q1993 Lord Joffe: Dr Gilbert, you referred to the Glare work on prognosis. I have here an article which was either in *The Lancet*, the *British Medical Journal* or possibly the *New England Law Journal*, but it is a review of prognoses across a whole range of different areas and it provides a summary which says, "Symptoms like anorexia, breathlessness or confusion are important predictors that an individual is rapidly approaching the end of life", and then he goes on to say, "Simple, reliable and valid prognostic models that combine these factors have been developed and can be readily used at the bedside of terminally ill cancer patients." Would you accept that?

Dr Gilbert: I would not accept that. I think that is an assertion that is not grounded in good evidence. I do not know of any evidence that that approach has been applied and shown to be robust. It is interesting that it is in the conclusion of the report rather than the main body. I know of no evidence, although I know of many attempts to make some sort of standardised conglomerate scale that would then be robust in predicting prognoses.

Q1994 Lord Joffe: This is of cancer deaths only that this is referring to.

Dr Gilbert: Even among cancer deaths only.

Q1995 Lord Joffe: Basically the same doctor, Mr Glare, also wrote a subsequent letter to *The Lancet* in which he repeated this. You quoted him as being supportive of the view that you expressed about the complexity and difficulty.

Dr Gilbert: I wonder if he did indeed show any evidence of that view indeed to show that he had applied such a conglomerate measure because it would be a very easy study to do. There is no shortage of cancer patients to which one could apply a scale. The absence of that published evidence seems to me to make that highly questionable.

Q1996 Lord Joffe: All I can say is that the articles are there, the evidence is there and presumably he based it on statistics and facts. Let us leave that. We cannot take it further than you and Mr Glare.

Dr Gilbert: I would add to that the effect of a very clear incentive in the mind of a well-intentioned doctor asked to assess prognosis on the basis of knowing that if he assesses it in a particular way that results in an entitlement for that patient to have what they are seeking. That seems to me to be an extremely important factor.

Q1997 Lord Joffe: But that turns on the integrity of the doctor and his ability to make sound judgments.

Dr Gilbert: I am not sure I agree with that. I think we are talking about a doctor wanting to provide for the patient who tells him he is suffering unbearably, perhaps that doctor is known to be a doctor who is sympathetic to the whole business of physician assisted suicide, not compromising their integrity, simply wishing to bend the rules in order to provide the patient with what they seek because it believes it to be the best for them.

Lord Joffe: We must leave over the question of integrity and bending rules and maintaining integrity to another time.

Chairman: I want to be clear before you leave this. Lord Joffe has read out a portion from an article about models under which the length of life still remaining to people can be predicted. We have heard today that the World Health Organisation model was nought to five and we have heard from somebody with considerable experience in actually looking at these matters about how one would proceed and how reliable it is. Do you know of any other model? There is another one that was mentioned today of which the doctor that gave evidence said he did not really use it.

Lord Joffe: Karnovsky's model.

Q1998 Chairman: The impression I had from him was that perhaps he would not be inclined to rely on it either to any great extent. I do not know whether you know of that model.

Dr Gilbert: I know of that model. I know of no published evidence to show that this has been used and shown to be a reliable predictor any more than the suggestion from Lord Joffe.

Q1999 Chairman: Do you know of any other models other than these two?

Dr Gilbert: No, and yet I know the name Christakis was mentioned earlier on. Nicholas Christakis is another prominent researcher in this area, and I know of very great efforts that have been made for purposes other than assisted dying to arrive at accurate, valid prognoses and so far as I am aware none of them has proved successful.

Q2000 Chairman: Obviously when you are predicting it is a matter of probability and I suppose it may be possible to draw curves showing one's experience over a time. We have heard it said that if you do that the standard deviation in these is very large. Are you able to comment on that one way or the other?

Dr Gilbert: Yes, I agree with that. I think the standard deviations are very large. Those figures are for populations of people, 100 or perhaps even 1,000 patients with similar stage disease and similar clinical features. We are talking about extrapolating

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from that with the wide standard deviations that you mentioned to one individual together with the incentive that I mentioned, which hangs on the response.

Q2001 Lord Joffe: The doctors in expressing their view have said that they had taken into account the circumstances of that particular patient. We are talking about the end stage of life lost, the last one, two or three months. So they are not blindly applying the statistics table.

Dr Gilbert: And yet if we were to get down to the last one or two months it seems to me we would be coming a good deal away from the major burden that it seems to me this Bill is attempting to alleviate, ie the recognition that the greater problem is with existential suffering and dependence rather than the last few weeks of people's lives often in hospices which, based on the evidence I have, can be satisfactorily dealt with within existing law.

Q2002 Lord Joffe: I am not sure. The purpose of the Bill is to cover the end of life and the most pertinent part of the end of life must be the closer you get to it, the end. Let us perhaps move on to Professor Finnis. Professor, putting aside for the moment your extrapolations from what you say was the report of Professor Van der Wal—we will come back to that because I think there would be grave disagreement about your interpretation of those figures—the evidence that we received in the Netherlands was that the society as a whole was very supportive of what was happening in the Netherlands and the doctors, by a considerable majority, were also very supportive of it and everyone was very satisfied with the way things were proceeding apart from a small group of people mainly motivated by religious beliefs. Would that surprise you bearing in mind the view you have expressed of the terrible dangers if this law were enacted in this country?

Professor Finnis: It does not surprise me in one major respect and that is this: I have known the general attitude that is expressed by people in the Netherlands has been from the outset, from the late 1980s, accepting or complacent or however you want to put it. My former student, John Keown, started to go over to the Netherlands in the late 1980s and got a wonderful frank reception from doctors, lawyers, public prosecutors, everyone involved in the whole business, and they laid out the kinds of facts which he subsequently wrote up and which were then amply confirmed in these government sponsored studies which I have referred to this afternoon. So in that sense I have known well, since 1989, that this kind of practice was widely accepted. On the other hand, he says it goes along

with a great deal of ignorance on the part of the general population of the parameters and extent to which the law is not being complied with, and of the things that are happening which are simply outside the law and are not disclosed to the prosecutors. His explanation of the extent to which the Dutch continue to trust their doctors and so on would be, to a considerable degree, that they are still not aware of the facts, these facts have to be dug out of the tables, they are not really discussed in the commentary, they are there objectively in the figures. Beyond that, I am not really in a position to comment, although I hinted at a comment earlier on when I gave a sort of amateur's explanation of the different psychology, the cultural formation etcetera that you have in the United States, which I visit a lot, and the Netherlands, which I have hardly ever been to. I am sure there is a difference in attitudes there.

Q2003 Lord Joffe: Are you suggesting there is some sort of cover up which has misled the Dutch population as a whole? My interpretation of all the evidence that we received in the Netherlands was that nowhere is there more discussion about the issues in depth at all levels of society.

Professor Finnis: Cover up is not the right word. An absence of commentary certainly exists in relation to the report that I mentioned. One only has to read the commentary and compare it with the facts in the tables that they are commenting on to see that there is an inattention to certain of the facts that are there in the figures. I do not doubt that there is a widespread discussion of the fact that you can have these facilities or experience these forms of release or extinction. I have looked at books by Dutch doctors in which is graphically laid out the extent to which they discuss amongst themselves and with the patients the prospect. All I can say is that the state of mind that comes across in anecdotal accounts of that sort is one that I would deeply regret seeing amongst my own friends and the population in this country.

Q2004 Lord Joffe: But you have hardly ever been there, did you say?

Professor Finnis: I make no secret of the fact. I have spent a day or two in Holland. I am speaking of vivid accounts by Dutch practitioners who are masters of English and who have translated their own works. Bert Keizer's book, published in the mid-1990s,² is extremely graphic. It gives a kind of diary of his conversations with his colleagues and with his patients whom he had killed, the patients whose death he has overseen in other ways. It is gripping. It is extremely disturbing if the kind of

² [Bert Keizer, *Dancing with Mister D* (1996)]

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attitude displayed and reported by him were to become widespread in this country. I think it would be a huge change for the worse.

Q2005 Chairman: I think it would be useful certainly for me to have specific references to the Government report to which you referred because we have had some but my recollections are not sufficiently clear to be sure that they have the same figures as yours and I would like to be sure that we get a chance to look at the documents that you are referring to. We may well have them already, but I am not absolutely certain of that as I sit here at the moment. Therefore, it would be very useful for me and my colleagues to have specific references so that we can look at these for ourselves and see whether they are included in the documents we got from the Dutch government when we were there.

Professor Finnis: I will supply the Committee with the article of Richard Fenigsen that I referred to, which annotates in depth the precise reports that he is referring to. Those are in Dutch, but the earlier two, the 1991 and 1995/96 studies, have been extensively discussed in the English literature.

Q2006 Lord Joffe: I suppose the figures will be intelligible.

Professor Finnis: And the figures should be intelligible.

Q2007 Lord Joffe: The 2001 one has not yet been translated, although we have summaries of that, but that is the most recent experience of the last five years and obviously experience changes. Many of the statistics that you refer to are contained in a submission prepared by the Linacre Centre of which you are a vice president or member, which is a Catholic think-tank, is it not?

Professor Finnis: That is correct, although I had no part in the preparation of this last submission. I have not seen it.

Q2008 Lord Joffe: Perhaps you could take back, when you are producing this, a statement which you have made and repeated over here, which is that most striking of all in both the 1995 study and the 2001 study the authors suggest that it is the patient who is responsible for avoiding termination of his life. "If he does not wish euthanasia he should say so clearly orally and in writing well in advance." That was your statement, was it not?

Professor Finnis: Yes. I was reading from Fenigsen's article.

Q2009 Lord Joffe: We took this back and referred it back to the people who prepared the report and they said they had never stated this and on page 201

I cannot find anything like this. So perhaps you could explore that as well when you produce the tie-up which the Lord Chairman has asked for.

Professor Finnis: I will certainly investigate that.

Q2010 Lord Joffe: Let us just come back to the statistics. You say all these statistics are based exactly on the statistics provided in the 2001 report. You have extrapolated from those figures to get the figures for the UK, have you?

Professor Finnis: I have extrapolated from Fenigsen's account and summary of what is in the report.

Q2011 Lord Joffe: So if Fenigsen got things wrong you will have got them wrong as well, will you not?

Professor Finnis: Yes.

Q2012 Lord Joffe: We could go on for a long time talking about individual statistics which you have quoted and the interpretation of those statistics. I think we should leave that and move on to Oregon. You said Oregon was "a remarkable exception" and that you are absolutely certain that if this assisted dying were extended to the USA there would be dire results for the USA. Is that not what you said or what you conveyed?

Professor Finnis: Yes. I took it in several stages. What I said is that if this were to be applied in other states, the first thing that would happen is that the restriction to assisted suicide and the exclusion of euthanasia would crumble and fall away. I predict this with high confidence having read, for example, the judgments of the courts that have commented on these issues running up to the decision of the United States Supreme Court which reversed several courts and upheld the line that there is not a right to suicide or euthanasia in the United States. But the attitudes of the judges (which I have in fact debated with Professor Ronald Dworkin, who came before this Committee in 1994 to support this Bill,³ in front of one or more of the authors of those judgments) show that although the terms of the discussion were officially limited to assisted suicide, the principles on which they were reasoning were ones which immediately extend beyond assisted suicide to euthanasia. So that would be the first thing. Beyond that, I simply rely on a common sense judgment, which everyone is entitled to contest or support, that the kind of developments which I showed the reason for in Holland, not just the fact of, would extend in the United States as they have extended in The Netherlands, though I think more slowly in the United States than in The Netherlands.

³ [It was in fact 1993: see H.L. Paper 91-vii of 1992-93 (29 June 1993) e.g. p. 162, Q. 452.]

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Q2013 Lord Joffe: What you are saying is two things. One is that there would be a change from a patient assisted dying to active euthanasia and this would pervade the whole of the USA. What possible evidence or justification have you for saying that because the position in six or seven years of Oregon is that no one has actually sought to change the law there to move it from assisted dying to active euthanasia? The people who you referred to who have run these campaigns were emphatic in their evidence to us that there was no chance that the law would be extended in that way. Why are you so certain?

Professor Finnis: Their principles and the content of their general propaganda go far beyond suicide and certainly extend to euthanasia. They have made a perfectly realistic and absolutely correct judgment that at the moment it is politically impossible to go beyond assisted suicide in the United States. Even amongst what you might call the “sophisticated elites” in the United States there is a kind of assumption (entirely naïve) that there is some big difference between assisted suicide and doctor-administered euthanasia. I think this is a way station, which would be rapidly gone through once they had moved into assisted suicide. Politically euthanasia is certainly off the map at the moment, only assisted suicide is on the map and so the campaigners who succeeded in Oregon have got a huge incentive to say to you what they evidently did say to you, namely we have no further territorial ambitions.

Q2014 Lord Joffe: So you can predict the future with great confidence?

Professor Finnis: It is for everyone to judge. These facts are available to all.

Q2015 Lord Joffe: May I just ask a question or two of Dr Randall. I am just looking for an article which you wrote which I thought was an admirable article. What you did point out in this article, which is published, it is a Danish publication, I cannot pronounce the name but I can show it to you—

Dr Randall: Is it “Acta Anaesthesia Scandinavia”

Q2016 Lord Joffe: That is the one.

Dr Randall: That helps me to work out which article it is.

Q2017 Lord Joffe: Effectively what I understood the article to say is that it covers “double effect”. You point out that when determining intention in relation to “double effect” there is great reliance on the doctors and the integrity of the doctors. I think the wording was “the public acceptance of the moral and legal distinction between intending and foreseeing effects of treatment is based on the trust and integrity

of doctors. In return doctors have to be worthy of that trust.” I am wondering why much of the opposition to this Bill has come from palliative care doctors and others who say they do not trust other doctors and wonder whether that would perhaps undermine to some extent your views on the importance of integrity in differentiating between intention and not.

Dr Randall: I have not said I do not trust other doctors.

Q2018 Lord Joffe: I am not saying that you have. I said other doctors who have come here to give evidence have referred to their concern that other doctors will simply wave patients through. They would take a very liberal view and would not actually effectively enforce the safeguards that are proposed in this Bill.

Dr Randall: I would not say that I do not trust other doctors. What I would say is that doctors under this Bill, as I described earlier, are being put in an exceedingly difficult position by this Bill in the judgments that they are being asked to make. I think it would be better, if society wants assisted suicide and euthanasia to be legalised, to take doctors out of it apart from establishing the diagnosis, the prognosis and the treatment options for the prolongation of life and the relief of suffering. I do not think it would be a good thing if society legalised this. However, if society does want to legalise this, I think it would be better to take doctors out of this altogether, as in other countries they have taken nurses out of it. I would take the doctors out of it apart from our medical role in the diagnosis and treatment of the condition. That way you would not have collateral effects on your doctor/patient relationship. You would not have this problem of the elderly vulnerable people worrying about what would happen to them when they were in care. Also, I think this Bill, based on the figures Jim has given us, would be difficult to enact because of the number of doctors who might conscientiously object to taking part in it. It then becomes very complicated because you have to find another consultant physician and the other consultant physician has to be in the same speciality. One wonders how this would work in practice. It would not be up to the doctors who conscientiously object to make it work. I think that the adverse effects of involving doctors outweigh any benefits. It is not that I do not trust doctors. I think that it has an adverse impact on the doctor/patient relationship. You do not need us to do this.

Q2019 Lord Joffe: We went into this quite carefully in Oregon where there was also considerable opposition from many doctors, but it works over there because the law was passed and doctors

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normally obey the law subject to their conscience. Does it surprise you that it works in Oregon?

Dr Randall: I have not been to Oregon. I do not know the people of Oregon. I have not lived in the culture of Oregon and so I would not be able to say anything about what I would expect or not expect of the people living in that culture because unless I knew that culture I could not possibly comment as to whether I was surprised or not.

Q2020 Lord Joffe: But there are doctors here who support this Bill and who would be prepared to implement it.

Dr Randall: I would assume that there are. What I am saying to you is that it becomes complicated if the doctor that is the patient's attending physician wants to conscientiously object and then the patient has to be passed to another doctor who then becomes the attending physician, so the patient's care by the definition of the Bill then has to be passed to another doctor and then you have to find a consultant physician in the right speciality who is happy to do it. It could become rather an onerous process. My main concern about the Bill is the effect of the doctor/patient relationship and the position it puts doctors in, which I think is unnecessary if society in the end decides that it is in the interests of the majority of its members to legalise these processes.

Dr Gilbert: Could I add one further reason why it seems to me that many doctors at and arguably those doctors most closely up against these clinical scenarios particularly do not want to be involved in this process and it is this. Agreeing with a patient that it would be best for them to end their lives has been referred to as a psychological push from the bridge. I recognise not all doctors see it that way, but I think that is a useful concept. The mixture of roles and the moral judgment that is expected of doctors perhaps gives that push from the bridge psychologically greater force than were it to be a technician in such a role, clearly defined as purely doing that and making no moral judgment about whether it was the right thing for the patient.

Q2021 Lord Joffe: There were doctors who appeared before us this morning who actually said that in their view many doctors would see it as important to remain involved with their patient's right to the end and not to abandon them.

Dr Gilbert: I was impressed by the question asked by Lord McColl about on what grounds a doctor might object to being excluded from the actual process of administering medication and I did not hear an answer to that.

Q2022 Lord Joffe: Are you taking a different view from Dr Randall who does not want doctors involved at all?

Dr Gilbert: No.

Q2023 Chairman: Not involved in the actual process of assisting the suicide or the dying.

Dr Gilbert: Indeed. I am taking precisely the same view. I do not know where the misunderstanding has arisen.

Q2024 Lord Joffe: Let us get it clear. Do you accept that the doctor could give the prescription for the drugs?

Dr Gilbert: Certainly the doctor could, although I think that would be wrong as well. I think in doing so it entails a moral judgment that agrees with the patient that their life is no longer worth living. I think that may be one of the reasons why we see this disparity between those people who profess that they wish their lives to be ended and the very few people who actively take steps to commit suicide despite the availability of medication. I think they need that psychological "push from the bridge" and that moral judgment, which is often expected of doctors, to agree with them that the best thing overall would be for them to end their lives. We could achieve clarity about that by excluding doctors from the process.

Q2025 Lord Joffe: I think there is a misunderstanding as to the role of the doctor. The role of the doctor is to ensure that the various safeguards in the Bill have been complied with. It is not to form a judgment on whether it is a wise decision or an unwise decision of the patient.

Dr Gilbert: If you will forgive me, that seems to run counter to me to much of the evidence this morning which seemed to include doctors looking after patients towards the end of life as the final thing that they could do for the patient. I think that was positively described. What are they doing there? Simply a legalistic assessment of whether the safeguards have been met.

Q2026 Chairman: It is perfectly plain that what the Bill envisages is not only that the doctor will see that the safeguards are in place but also, assuming the safeguards are in place, he or she will either, as in the case figured in the preamble, actually do the necessary procedure to end a patient's life or will provide the necessary medication for the patient to end his or her life.

Dr Gilbert: Yes. It seems to me there could not be a clearer enactment of agreement that that would be the best thing for that patient than co-operating in that process.

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Q2027 Chairman: That might not be so because if a doctor says to me that I should have a life prolonging treatment and I do not want to have it and I say no, the doctor is then precluded from giving me the treatment, although he or she does not believe that my decision is the right one and thinks I should have accepted their advice. The mere fact is that the doctor who does carry out the patient's wishes in this particular case would not necessarily imply that the doctor agrees with the patient's view of the matter. He or she would be simply complying with the patient's request made in accordance with the rules and so on.

Dr Gilbert: But actively doing so.

Q2028 Chairman: Yes, actively agreeing or actively accepting the patient's request. You may say that no doctor would want to do that unless he or she agreed and the doctor cannot be obliged to do it, the doctor may have objections to doing it. I think you are saying that for the doctor to do it would imply in your judgment that the doctor had agreed that it was the best course open to the patient in the circumstances. All I am saying to you is that it does not necessarily follow, although it might be a difficult position for the doctor to be in if he was injecting somebody to end their lives at a time when he thought it was not a good thing to do.

Dr Gilbert: Indeed.

Dr Randall: There is a parallel distinction here in other parts of health care. A patient can always refuse treatment if the patient does not want it. I know there is legal argument about it at the moment, but currently patients cannot require a doctor to perform a treatment that the doctor really feels is going to result in overwhelming harm and not benefit. So the parallel is with, say, a patient requesting a surgeon to do an operation where the surgeon says the risks of it far outweigh any possible benefits. The surgeon has the power to refuse and the responsibility to refuse.

Q2029 Chairman: He would not incur the responsibility of carrying out the operation unless he thought in the circumstances it was the right thing for him to do.

Dr Randall: Yes. What this Bill is about is doctors being asked to do something at the request of the patient. It is not being asked for doctors to stand away and refrain from treating the patient, it is asking the doctors to do something. So it is about the patient having a positive right to require that from the health care profession who then have a duty. If the patient has a right to physician assisted suicide or euthanasia some part of society has a duty to provide it and this Bill gives the duty to doctors.

Q2030 Chairman: I think I am right in understanding Dr Gilbert to say that he would assume that a doctor would not carry out one of these procedures unless the doctor agreed that it was appropriate in the circumstance.

Dr Gilbert: That is exactly my position. Otherwise, while providing a patient with a lethal prescription or indeed administering that lethal prescription, he would be at one and the same time saying, "This is something that I think is wrong. I still value your life; I think you should still value your life."

Q2031 Chairman: If the doctor has made a conscientious objection it would not be happening in any case with that doctor. But the case that you are figuring is the case of a doctor who has not got a conscientious objection against doing it at all but who in the particular circumstances of the case thought it was not an appropriate request from the patient for various reasons. Although the legal background and the legal safeguards had been fulfilled, the doctor still thought that it was not an appropriate course to take in that situation. You say that if he then carries it out it is to be assumed that he agrees that it is the appropriate course in the circumstance. Is that right?

Dr Gilbert: That is right.

Professor Finnis: It might help to inject the concept which is right through the Mental Capacity Bill and through the medical law which underlies that. When a doctor does anything it has to be in the patient's best interest. Rather than the word "appropriate", wrong or right, I think what Jim Gilbert is saying is that by doing something the doctor is ratifying that as "in my judgment it is in the patient's best interest".

Q2032 Chairman: There is nothing in this Bill about the patient's best interest.

Dr Gilbert: I accept that. I think that is what he is saying.

Q2033 Chairman: I think it is possible to put it more generally, as Dr Gilbert has done, and say that if a doctor is doing something on account of the patient asking the doctor, he thinks it is at least a reasonable thing to do in the circumstances and if he disagrees with a patient's assessment of the situation he ought not to do it. I think that is what you were saying.

Dr Gilbert: That is right. Can I just come back once more from the perspective of the patient in this because it may well be that the patient is still uncertain and is still in some sense testing out whether this is right, this jumble of views, one of which is that I am being a burden, one of which is that I am suffering and so on. If a doctor is prepared to enforce or ratify that view then that is what is perhaps clumsily referred to as the psychological push from

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the bridge. If it comes from a doctor it carries a different weight in my estimation, particularly a doctor with long association, than it would if it came from a technician.

Q2034 Chairman: Ms Wates, I think you wanted to add something. You have been extremely patient in listening to others. You must have a chance to give your point of view on these matters.

Ms Wates: It seems to me there are several places in the Bill where it really is very subjective from the way that the Bill is worded what is meant, and there is the whole question of whether the patient's judgment is impaired. The doctor must make a decision about that because if he considers it is wrong then he should bring in a psychiatric opinion.

Q2035 Chairman: The assumption of the Bill is that it only applies in the case of a fully competent patient and if there is any doubt about that it has to be investigated. I think that is the basis on which the Bill proceeds.

Ms Wates: Yes, but a sound judgment is a well-informed judgment. I suppose he might judge that the patient was competent but not well informed.

Q2036 Chairman: As I understand the rules, the doctor is not supposed to indulge in any procedures or accept a decision not to proceed with procedures without giving full information to the patient of the various options available and the consequences in the doctor's view of the various options that are open. It is part of the doctor's informed concept which is fundamental to the doctor/patient relationship in this country now. The doctor would be obliged to explain in some detail exactly what the situation was if the patient did ask for this particular treatment.

Ms Wates: Surely the doctor's point of view on the patient's situation would make a huge difference to the information that he presented and the weight that he put on the information. You cannot get away from that.

Q2037 Lord McColl of Dulwich: Professor Finnis, vis-à-vis the question in Oregon of this leading to euthanasia, is it your understanding that the Euthanasia Society does see this Bill as a precursor to euthanasia?

Professor Finnis: You mean in this country?

Q2038 Lord McColl of Dulwich: Yes. The other question is dealing with the question of excluding doctors and nurses from taking part in this oral euthanasia. Some of us found it quite a chilling experience when we visited Holland during the last Select Committee on euthanasia because we were particularly anxious to know how the doctors felt

about doing euthanasia and we asked one particular doctor and he said, "It was terrible. We agonised all day." But he said the second case was much easier and the third was "a piece of cake". We found that rather chilling.

Professor Finnis: I have not investigated the present attitudes of the Voluntary Euthanasia Society in this country. I have made no attempt whatsoever to keep track of its policies. I do know that in the past prominent members of it have said more or less openly that they regarded assisted suicide as a step on the way to euthanasia, and that is certainly the case in the United States as well, though again I have not made a study of particular policies of particular groups. I have discussed these matters extensively with leading supporters of the general movement such as Professor Ronald Dworkin with whom I have given seminars for 20 years and debated the matter in public as I have described. There is no ambiguity about the reluctance to take it all in one bite and so Professor Dworkin's books only speak about assisted suicide and leave in shadow what all the principles and arguments in the book move towards, which is also euthanasia for the competent and to some extent for the incompetent. I think it would be very surprising to me if it could be established that the policies of the Voluntary Euthanasia Society did not extend to euthanasia as a next step in a process which they regard as one of liberation—and I understand their arguments.

Q2039 Baroness Finlay of Llandaff: This morning we heard from a doctor, who is not a consultant in palliative medicine and therefore not on the specialist register, her view of her role in providing the palliative care. She also spoke about the questionnaire that you referred to, Dr Gilbert, and in it she outlined that indeed in palliative medicine many doctors have discussions with patients about a desire to die and sometimes those discussions go on and they may be discussions that persist, and yet we heard from Baroness Greengross that she felt that there was a need to campaign very strongly for open communication with patients. I wonder how you marry up the openness of the questions that are on the questionnaire with the fairly solid block of resistance from those dealing with these patients all the time that put a doctor, such as Dr Dacombe, in a very small minority in welcoming any moves in this direction.

Dr Gilbert: I think that is very interesting. There is a clear basis from the survey for recognising that these sorts of issues about wishing for an earlier death are not terribly uncommon in palliative care practice. Certainly my own experience and that of my colleagues in the south-west that I know well would be that such matters do have an opportunity to be

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openly discussed and that one tries to concentrate on what are the distressing issues for that patient and those close to them at that time. One of the things that might puzzle outsiders as a result of the data is how could one understand a position where there is such overwhelming opposition to such permissive legislation as we are discussing today and yet this openness in discussing issues around death and dying. All I can do is extrapolate from my own experience that although many people want to talk about the timing and the nature of their death, my experience is that it does not put me as a clinical practitioner in a difficult position at all to have people discuss these issues and I do not feel disempowered in a way that you might expect me to feel, or restricted by the current laws of this country.

Dr Randall: My experience is of patients expressing the fact that they are fed up with this existence, they feel a burden and wish it was all over and that does give you the opportunity to ask if there is anything in particular that is the source of this distress and, where possible, to address that. I think a lot of the satisfaction one gets from one's job is what can we alleviate from this knowing that it is part of the human condition and there is no way one is going to be able to alleviate all ills. It is very interesting that so many of the people caring for dying patients are opposed to legalising assisted suicide and euthanasia given that we are the people who will be having most of these discussions with patients.

Q2040 Baroness Finlay of Llandaff: The Bill before us requires that the unbearable suffering that we are referring to is related to the terminal illness that the patient has. I wonder, based on your own experience of patients who have been extremely distressed, when you have had these complex conversations, what the nature of that suffering originated from and how much it was related to the life experience and how much it was related to the illness experience.

Dr Gilbert: I can give one illustrative though not typical example of something which you might want to be uncovered here of a man whose profound wish was for his life to be over, a man who described in graphic terms how guilty and worthless he felt. As a result of sensitive discussions over quite some period of time it emerged that he felt this guilt as a result of terrible acts, by his own admission, of child abuse in the context of terminal illness. He was not alone in reviewing his life and coming to some sort of summary as to how worthwhile it had been. That is not a typical example but an illustrative example of ways in which people reviewing their lives might well be distressed by previous behaviours or activities or experiences that are producing apparently unbearable suffering but where the relationship to the terminal illness is at best a tenuous one.

Dr Randall: To take more every day examples of this sort of occurrence of patients saying, "I'm fed up and will be glad when it's all over". I think the clause in the Bill where you have to decide that the patient is suffering unbearably as a result of the terminal illness is clinically quite difficult because you often have one surviving spouse who is ill. The person who was their source of company and comfort is dead. When they say they are fed up and they wish it was all over are they asking to be out of this because of their illness, is it the loss of their key relationship or are they suffering unbearably as a result of the terminal illness? What is one meant to judge out of all of this? I think that clause makes it very, very difficult to disentangle what counts as being as a result of the terminal illness and what counts as part of your social circumstances, your previous life, self-esteem, total life experience. I find that clause very difficult to imagine working with as a doctor.

Ms Wates: Another example might be an elderly couple where they still had each other and they had a loving and romantic relationship and then one of them becomes doubly incontinent and the thought that her husband will be changing her incontinence pads every day makes life seem unbearable and so she may actually seek death. It is not trivial because to that individual it is huge. For a reason as non-life threatening as that in actual fact there are things that can be done to preserve the dignity of both partners and with the right assistance that relationship can go on thriving and those people can go on supporting each other. English people have the expression "die of embarrassment". This is a country where we are prepared to die of embarrassment. These are things that have to be recognised. They should not be a cause of death.

Dr Gilbert: Could I add one thing about being a burden which if I leave the room without having said I shall be disappointed? If people, as they do, recognise that at times in their lives they are being a burden then we could respond to that by agreeing with them and agreeing with them that that is producing unbearable suffering and then behaving consistently with that and helping them to end their lives or we could take the view and express to them that, without denying that they are being a burden at some stage of life, we are all a burden, most obviously in infancy, but that it is a burden that collectively we wish to shoulder, and behave in a way that is consistent with that, ie not acknowledge that they should end their lives and help them do so.

Q2041 Baroness Finlay of Llandaff: I just wonder if Ms Wates would agree that the way that the doctor responds or the carer or whoever gives the patient very powerful messages about themselves and where things are going and whether one of the fundamental

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tenets of our society as it is at the moment is to provide care and support to those who are possibly the most vulnerable. We have heard about the lack of resources that there are for people and a speculation that resources for palliative care would follow the enactment of this Bill, although we know from the Dutch experience that there was no palliative care. The Bill came in, there was a block of money, but then the Dutch decided not to recognise specialist palliative care and indeed we heard in Holland that the flow of money is now drying up. So there was a peak and then it did not go on. I wonder, based on your discussions with people who have a disability, how you feel that the resource allocation would potentially be improved or not and how such decisions would be made when resources may be used in another area of health.

Ms Wates: I think it was said earlier on that the Bill is about the end of life. The Bill talks about unbearable suffering in the context of terminal illness. It does not actually say that it is focused on the end of life and I think that I and many other disabled people feel that this Bill would have huge implications in terms of palliative care and people who need assistance to live. The whole principle of choice and the promotion of

independence I think would be subtly undermined by the passing of this Bill and I think that is a very grave fear for a lot of disabled people in this country as this law is being discussed. I would urge your Lordships to realise just how much people feel threatened in life by this potential legislation which, looking to the Dutch experience, could really erode society's commitment to providing care and promoting independence. Actually, the gloss is fairly chilling because what is unbearable suffering? What is terminal illness? Do I qualify? It really is scary. Please understand that I am speaking personally. It does need to be addressed and it does need to be realised that the Bill has huge implications in terms of the living of disabled and ill people.

Q2042 *Chairman:* Thank you all very much for the help you have given us. We are very grateful to you for the help you have given and the way you have answered our questions. You will get a chance to review the transcript in due course. Perhaps in the meantime you would give us these references because I would personally like to see the situation in relation to the reports that we have seen. Thank you very much.

 THURSDAY 20 JANUARY 2005

Present	Arran, E	McColl of Dulwich, L
	Finlay of Llandaff, B	Patel, L
	Hayman, B	Taverne, L
	Jay of Paddington, B	Thomas of Walliswood, B
	Joffe, L	
	Mackay of Clashfern, L	
	(Chairman)	

Examination of Witness

Witness: LORD WALTON OF DETCHANT, a Member of the House of Lords, examined.

Q2043 Chairman: Good morning, Lord Walton. We have invited you to come. You were the chairman of a committee some 10 years ago that dealt with some at least of the issues with which we are concerned.. It was not a committee dealing with a particular bill, in the way that we are, and so there are distinctions, but with your background and experience the Committee felt it would be useful for you to have an opportunity to come along and give us such help as you feel able to do. As you know, the help will be transcribed and you will get an opportunity of correcting the transcript. The duly corrected transcript will be appended to our report and become public property, in the full sense, at that stage. Would you like to say something yourself to start with Lord Walton and then members of the Committee may have questions on which they would like your help.

Lord Walton of Detchant: Yes. Thank you, my Lord Chairman. First of all, may I say at once that I wholly appreciate and understand the sincere and compassionate reasons why Lord Joffe has introduced this Bill. Of course I appreciate that it is likely to receive, in certain quarters, a great deal of support. I think the Bill itself has been very thoughtfully and very carefully drafted, incorporating a large number of safeguards which I believe are very important. Having said that, at the end of the day I feel I cannot support the Bill, if only because of a number of issues which we did handle in detail in the select committee I chaired (1993-1994). In particular, I would turn to clause 1, paragraph (2) of the Bill, in which it says, “‘assisted dying’ means the attending physician, at the patient’s request, either providing the patient with the means to end the patient’s life or if the patient is physically unable to do so ending the patient’s life”—and I stress those last few words because, in my view, that can only be construed as deliberate, intentional killing. In other words, it does mean that in those circumstances it is, in my opinion, voluntary euthanasia. Having said that, of course I warmly endorse what is said in clause 15 of the Bill, that: “A patient suffering from a terminal illness

shall be entitled to request and receive such medication as may be necessary to keep him free as far as possible from pain and distress.” That, after all, is the motivation of the hospice movement in the UK, which is increasingly influential in the treatment of individuals with terminal illness of all kinds. Hospice care is not just delivered in the buildings called hospices, but it is a kind of philosophy of care which extends out into the community and which is practised by many general practitioners—perhaps not as widespread or effectively as it might be, but I believe that is increasing. Of course organisations such as Marie Curie Cancer Care and Macmillan Cancer Care make a major contribution in that field. Having made those points about the Bill, I would like briefly to quote one or two things which were said in the report of the committee which I chaired in 1994. First, we totally accepted the concept of informed consent to medical treatment but, equally, we endorsed the right of a competent patient to refuse consent to any medical treatment, even if that ultimately resulted in death. We went on to say, however, that the right to refuse medical treatment is far removed from the right to request assistance in dying. We spent a long time considering the very strongly held and sincerely expressed views of those witnesses who have advocated voluntary euthanasia. Many of us, including myself, had experience of relatives or friends whose dying days or weeks were less than peaceful or uplifting or whose final stages of life were so disfigured that the loved ones seemed already lost to us and were simply weary of life. We made a number of other points of that type but went on to say that, ultimately, we did not believe that these arguments were sufficient reason to weaken society’s prohibition of intentional killing, a prohibition which is the cornerstone of law and of social relationships. It protects each one of us impartially, embodying the belief that all are equal. We did not wish that protection to be diminished and therefore recommended that there should be no change in the law to permit euthanasia or physician-assisted

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suicide. One of our reasons was because we did not think it was possible to set secure limits on voluntary euthanasia, because to legalise it was a discreet step which need have, in the view of certain witnesses, no other consequences, but in fact it would be next to impossible to ensure that all acts of euthanasia were truly voluntarily and that any liberalisation of the law would not be abused. We were concerned over the possible erosion of any such legislation, whether by design or inadvertence, or by the human tendency to test the limits of any regulation—as has clearly happened for example, in relation to the Abortion Act. There are some of the things we dealt with. We went on to discuss the concept of double effect, upon which I would be very happy to expand at a little later stage should your lordships so wish. I would like to add at this stage a number of other important points. First, when, I understand, the former Chairman of the Ethical Committee of the Royal College of Physicians gave evidence, I believe he, in a personal capacity, is supportive of the Bill, but I feel I ought to make the point that the President of the Royal College spoke to me only a couple of days ago and made it clear that the college is totally neutral on this issue: it is not expressing a view but leaves it to Parliament to decide. I would also add that I and the members of my committee were gravely concerned, in the great majority, by what we found in Holland. In Holland, when we visited there, we found that more than 1,200 individuals were subjected to voluntary euthanasia each year at their consent, under certain conditions, but over 1,000 were subjected to non-voluntary euthanasia because they were neither competent to withhold or to give consent. There were a number of cases which seemed to me to stretch credence far beyond what was reasonable: the *Chabot* case, in particular, where a lady in her fifties who was physically fit, whose son had died from leukaemia and whose daughter had committed suicide, claimed to be intolerably depressed and not to have responded to medication. She requested euthanasia and it was granted. In the *British Medical Journal* of just a few days ago, 8 January, there is quite an important article. Of course the Dutch did strengthen their law and, indeed, convicted a general practitioner in 2002 of helping his 86-year old patient to die, even though the patient was not technically ill but was obsessed with his physical decline and hopeless existence; however, the Royal Dutch Medical Association say that doctors can help patients who ask for help to die, even though they may not be ill but suffering through living. This is following a three-year inquiry that they have conducted. I think they are in a situation which is going far beyond what I would regard as being acceptable. Of course, you are aware, my lords, of the case in the Northern

Territories of Australia, where an individual patient suffering from cancer, believing that she had terminal cancer, was subjected to euthanasia, though the post-mortem showed that her cancer had been effectively treated. I am wholly aware that public opinion and the view of certain members of the committee which I chaired has changed over the years. I know full well that Lady Warnock, for instance, has expressed, a totally different view, as have Lady Jay and Lady Flather. Having said that, I was frankly surprised by Lady Warnock's comments to the effect that if she became "a major burden upon her family"—and I am quoting what she has said publicly—she might well consider requesting assisted suicide because of feeling that she was a burden. That is, in my view, not a very valid argument—and I have told her this, so I am not quoting anything which is contrary to what I have said to her personally—because we in my select committee in 1994 were concerned that vulnerable people, the elderly, lonely, sick or distressed, would feel pressure, whether real or imagined, to request early death. That was one of the things that did give us considerable concern. I know there are many people who criticise the concept of a slippery slope, but I, as I said before, believe that, if this Bill were to be passed, it would in the first instance set down very strict criteria but I think those criteria might well be progressively eroded with the passage of time, leading the widespread practice of voluntary euthanasia. I would only add that there is of course quite an important article in this morning's *Times* by the Archbishop of Canterbury on this issue. He does in fact express the view on behalf of the Church that the Church would not wish to see deliberate killing, whether by euthanasia or whether by assisted suicide, and he goes on not only to promote the concept of double effect but to endorse it by saying, as we did in our report, that in those who are in terminal illness and who are being offered the principles of palliative care, it is perfectly reasonable for a doctor, in order to relieve pain, distress and suffering, to give such doses of medication to relieve those symptoms which may have—not invariably but may have—the secondary consequence of shortening life. This is totally acceptable, in my opinion, and has been accepted for years in medical practice and within the law. I admit certain philosophers regard this as being a hypocritical concept but I believe it has been practised for years sensibly and effectively. Those, my lords, are the preliminary comments I would like you to make.

Q2044 Chairman: Before I invite my colleagues to ask you questions, you mentioned the two branches of the central section of this Bill, one making it legal for a doctor to provide the means for a person to end their own life, and the second—although it

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happens, I think, to be first—the possibility of a doctor, in the case where the patient could not self-administer, doing the necessary procedure himself or herself to bring the patient's life to an end. Do you distinguish in any way between these?

Lord Walton of Detchant: Yes, I do. I would not be as bitterly opposed to the first concept as I am to the second. I am totally opposed to the concept of deliberate and intentional killing.

Q2045 Baroness Jay of Paddington: Thank you, Chairman. I am grateful to you, Lord Walton, for my membership of your committee 10 years ago. As you rightly say, I have slightly moved my opinions, as a result, I think, of what has happened in the last 10 years. I wonder if I could ask you about some of the things which have happened, which are not to do with personal experience, in the way you have described Lady Warnock's shift in her views, but are about the evidence that we now see of the way in which some laws which are related to the proposals which Lord Joffe has made have worked effectively and within the context, as you say, of secure limits, in, for example, Oregon, which we have very recently visited. And also what you feel about the fact that, although I was one of those who were a little concerned about the adamant position we took on this even 10 years ago about advanced directives or advanced directions (as we now call them)—and I spoke about that in the debate we had on our report—it has now become government policy during this last period to adopt a position in which an advanced direction is part of a bill, which we hope will become a statute, which is now before us. Thirdly, I think one of the things we spoke about and which we were very concerned about was the nature of any proposal in this area on the doctor/patient relationship—and this was something which I remember you feeling very concerned about from your own clinical practice. Again, I think one of the things which has been, shall I say, “reassuring” about the evidence which people have given to us, both of their own experience and of their study of what has happened in other countries, has been that, contrary to what one might expect, the doctor/patient relationship is often said to have improved as a result of these changes in the law, because of the openness of discussion which can take place, etcetera. I wonder what your reflections are on those things which have changed in those particular ways.

Lord Walton of Detchant: I think that last point is extraordinarily valid because the days of “Doctor's orders” are long past and the practice of medicine is a partnership between the doctor and the patient, in which it is the doctor's responsibility and duty to indicate to the patient what he or she regards as being the best course of action to follow in the management of their condition, but it is up to the

patient to decide whether or not to accept that advice. Now, of course, that only can apply to the competent patient. In relation to the incompetent patient, of course, this issue is being considered now by this House in relation to the Mental Capacity Bill, so I do not think I need expand on that, except to say that, as you remember, we in our committee strongly supported the concept of advanced directives but did not at that time wish to make them legally binding.

Q2046 Baroness Jay of Paddington: Exactly.

Lord Walton of Detchant: The reason why we did not wish to do so was because we recognised that someone might sign an advanced directive—and I have done so personally and it is lodged with my GP—but then might forget or not take steps to update its terms and that might not take account of developments in medical science, in medical practice, which had taken place since the advanced directive was originally signed and that therefore the position might have changed. That was one of the reasons why we did not wish to make them legally binding but, of course, since that time they have become virtually binding in common law and there have been a number of notable cases reported where in common law the advanced directive has been regarded as being binding. So I think that position has changed. Does that answer your questions?

Q2047 Baroness Jay of Paddington: I was only going to ask, slightly more generally—and it may not be a specific enough question for you to want to respond—whether you do feel that some of the broader experience we have seen empirically in the last 10 years from other countries has in any way altered your view, as it certainly, I have to say, has altered mine?

Lord Walton of Detchant: I understand that. I appreciate that entirely. No, I am not reassured by what I have seen happening in Holland. I have no personal experience of what has happened in Oregon but I am concerned, as I have said, about some of the cases that have been dealt with in the Northern Territories in Australia. Whether it happened or not, I do not know, but I am told that the federal authorities in Australia were thinking of overturning that Bill. But it has not, so far as I know, been overturned.

Q2048 Baroness Finlay of Llandaff: May I say for the record, from those involved in palliative care, that we owe a great deal to your report, where you commended the development of services, although we recognise in the evidence that we have had on this Committee that services are still dramatically under-developed in many parts of the country. I

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wonder if I could ask you a little bit about the doctor/patient relationship?

Lord Walton of Detchant: Yes.

Q2049 Baroness Finlay of Llandaff: I wonder if you feel it is true that we have seen an improvement in communication between doctors and patients in this country in the last 10 years, in terms of information about their diagnosis, prognosis, what to expect, possible side-effects and so on, where of course we have not had any change in the law, and, therefore, perhaps globally, or in the western European world, certainly in the northern countries, there has been an improvement in communication skills which is not related to a change in the law but has been for other pressures from within medicine.

Lord Walton of Detchant: There is no doubt at all, in my view, that that has happened. I now speak as a former chairman of the Education Committee of the General Medical Council and subsequently its president. Twenty-five years ago we made it clear that one of the most important things that had to be raised in the education of medical students was the development of communication skills and an increased understanding of the wishes and needs of their patients, including skills in counselling. I believe that the doctor/patient relationship has, in consequence of that, improved very greatly in the UK. Vocational training for general practitioners has helped and post-graduate training for people working in other specialities has also helped. A great deal of effort has been put into that over the years. So I agree. And I think it is salutary that whenever questionnaires have been put to the public about the individuals in society whom they trust, doctors and nurses have always come at the head of the list—certainly much higher in the list than lawyers and certainly a great deal higher than politicians.

Q2050 Baroness Finlay of Llandaff: We have heard from the Association of Palliative Medicine that the consultants in palliative medicine are very strongly opposed to any change in the law, with 93 per cent opposing a change in the law towards euthanasia—92.6 per cent in fact—but three-quarters of them have had discussions with patients who have asked for euthanasia. I wonder whether you feel it is fair to conclude that this openness in communication means that patients are now able to discuss the future and how it may lie, and can use that question as an opener—indeed, we have heard as well that in Oregon people would use questions about whether they should consider euthanasia or whatever as a way of flagging up their distress—and that one of the things that specialist palliative care has been able to do is to help patients unravel the different components of their distress to try to improve their quality of life for however long they have it.

Lord Walton of Detchant: I think that is, again, an important development. I have had personal experience, though not recently, of being in a position to discuss the whole question of euthanasia with patients suffering from terminal illnesses, particularly in the field of neuro-muscular disease; for example, motor-neurone disease. I know full well that the Bill includes a provision for someone who may have requested assisted suicide to retract that request. Interestingly, in the correspondence that I have received on the Mental Capacity Bill, I have had three or four quite moving letters, one from a lady, whom I shall not name but who gave evidence to our select committee and whom I have met on many other occasions, who some years ago requested assisted suicide (she was not capable of killing herself) because she felt her life was so infinitely distressing that she did not wish to continue, and now she is absolutely delighted that that did not happen. Hard cases make bad law, so I do not think that is an invariable experience, but I believe it is right that some people do think about it very seriously but are then persuaded that there are satisfactory alternatives.

Q2051 Baroness Finlay of Llandaff: I should say, as a clinician, that I completely concur. I myself have had patients who have lived not only unexpectedly long in terms of months but even in terms of years after having initially been asking quite clearly for euthanasia, who then have been subsequently extremely glad. Particularly younger people who were young parents. The last matter I would like to address with you is the issue of double effect, which in your report you helpfully mapped out and that established a definition for people. I wonder if you would agree that it has perhaps been misinterpreted at times because, whatever you give to a patient, if the patient is dying there will always be a last dose of drugs, just as there may have been a last cup of tea or a last breakfast, but it is difficult to prove that that last dose of drugs did not kill the patient, just as it would seem absurd to try to prove that a cup of tea, unless the patient choked on it, killed the patient. But it is distressing for professionals, if they go to give a patient an additional dose of analgesia, turn the patient, and the patient has died half an hour later, and it is easy for a family and others to misinterpret that as having been “assistance” to die.

Lord Walton of Detchant: I appreciate that this concept is a very controversial one. As I say, some philosophers regard it as being hypocritical, but we said in our report that the adequate relief of pain and suffering in terminally ill patients depends on doctors being able to do all that is necessary and possible. In many cases this would mean the use of opiates or sedative drugs in increasing doses. In some cases patients may in consequence die sooner

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than they otherwise would have done, but this is not, in our view—and that is in our report—a reason for withholding treatment that would give relief, as long as the doctor acts in accordance with responsible medical practice with the objective of relieving pain or distress and with no intention to kill. One other thing which I think I ought to say is that there have been a number of cases or examples in the press of doctors saying that they have practised euthanasia. In my opinion, the very great majority of them have been practising double effect and not euthanasia. I think this is something which has been widely misconstrued. As we, again, say in our report, if this intention is the relief of pain and distress and the treatment given is appropriate, then the possible double effect should be no obstacle to such treatment being given. Some may suggest that intention is not readily ascertainable, but juries are asked every day to assess intention in all kinds of cases and could do so in respect of double effect if, in a particular instance, there was any reason to suspect that the doctor's primary intention was to kill the patient rather than to relieve pain and suffering. In our report we quoted the notable case of Dr Bodkin Adams, who was accused of murder. A distinguished physician called to testify in that case asserted that a particular dose of morphine must certainly kill, only to be told that the patient had on several occasions had the same dose before and had survived. That was the reason why that case collapsed. It was clear evidence that Dr Bodkin Adams was practising double effect.

Baroness Finlay of Llandaff: Today's experience lays that out. I would like to follow it up, for the record. We now, in the light of recent research, do not have any evidence that giving opioids at doses to relieve pain does kill patients but the myths perpetuate. Thank you.

Q2052 Baroness Hayman: Perhaps I could follow that up, my Lord Chairman, because I know that this issue of double effect is very controversial, and take one example and ask Lord Walton about where he sees distinctions arising. He was talking, in relation to double effect, about intent and the intent in the doctor's mind and the significance of that. I think you said earlier that the provision of assistance in suicide was "far removed" from accepting a patient's refusal to take life-saving treatment. I can absolutely understand that is true from a doctor's point of view; I have difficulty with the patient's perspective. If you have a patient who is terminally ill and perhaps—and we know the difficulties of predicting length of life—assumed to be within the last couple of months on a doctor's prognosis, I wrestle with the difficulty of whether there is a clear distinction between the patient who happens to be on a life support machine and able

to make their views known, who happens to need medication which maintains their life, who, it is clear, both in case law and in medical ethics has the right to take a decision which speeds the end of their life, and the patient who, because their individual medical circumstances are different (they cannot swallow, they are not on a life support machine, they are not in receipt of medicine which they can refuse), is left with, as I understand it, the only alternative being to starve themselves to death. Which is not a happy scenario for many people. I just ask whether, from the patient's perspective, in these areas there is such a clear distinction? Now, that is quite separate from the wider effects that there be in other areas.

Lord Walton of Detchant: So far as that last issue is concerned, we in the select committee were set up because of two notable cases. The first was the case of a Dr Cox. He was a Guildford rheumatologist who had a patient who was in the terminal stages of rheumatoid arthritis who was crying out in intolerable pain and was asking the doctor continually to help her to end her life. He claimed that massive doses of morphine and other opiates had failed to relieve her pain and, in the end, I think almost in panic, he gave an injection of potassium chloride into her intravenous drip, which stopped her heart instantly. Of course, he was accused of murder, but the charge was ultimately amended to one of attempted murder. Dr Cox had not fully understood nor used the principle of double effect because the patient had not been adequately sedated. If adequate sedation had been given in addition to the opiates, then I believe the situation might well not have arisen. The second case, of course, was that of Tony Bland, the boy who was crushed in the Hillsborough Stadium disaster, who entered for four years a persistent or permanent vegetative state: his heart was working, he was breathing spontaneously, but all the evidence showed that he had no brain cortical activity. He was unable to swallow and was being fed by a gastric tube. He was not sentient. I would totally oppose any suggestion that any patient who, however demented, still had some sentient capacity could ever be starved to death. I think that is intolerable and quite contrary to medical practice. But for a patient in the permanent vegetative state the issue is different. We had a conflict of opinion between the doctors and nurses on the issue of whether tube feeding was medical treatment. The doctors believed that any treatment which required invasion of the human body by, for instance, inserting a gastric tube, was medical treatment, but the nurses said that food and fluid, however given, was an absolute human right. In the end, we concluded that the same outcome in Tony Bland's case would have occurred if the antibiotics had been

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stopped because we said there was no obligation upon the medical team to continue with any form of treatment which added nothing to the wellbeing of the individual as a person. In the end, of course, the case went to the High Court, as you are aware, and eventually up to the House of Lords, and his feeding tube was removed and he died peacefully about three weeks later. I hope that answers your questions.

Q2053 Baroness Hayman: It does and it does not. It is tremendously helpful in some areas. But I am trying to get to the quintessential case, where we are not talking about someone who is in a persistent vegetative state, we are not talking about someone who could have been helped by better palliative care, and trying to deal with the case where the palliative care has been of the highest standard. Indeed, in Oregon, a lot of the evidence was that pain in itself was not the major issue for a lot of people. It is the individual who assesses their own situation as being intolerably painful, distressing for them. It is the individual who has had the optimum palliative care, who is completely sentient, who knows exactly what they want, who by one throw of the dice (in terms of their medical condition) is able to influence the time they are there, so that they speed it up because they refuse treatment, and the other one who, by circumstances of their medical situation, would need assistance from a physician and does not get it.

Lord Walton of Detchant: I totally sympathise with your view on the second case. In relation to the first case, as I said before, any patient who is competent is wholly entitled to refuse treatment of any kind, even if that results in death. That is perfectly acceptable and something with which I would totally agree. In the second case, I sympathise with the view that that patient should be given assistance to kill themselves, but, on the other hand, I cannot accept the view that in that situation a doctor would be required, if necessary, to give a lethal injection. That, in my view, stretches the principles of medical care and medical treatment beyond what is, in my opinion, reasonable, and I am concerned that, if that were to be accepted under law, if this Bill became law, inevitably we would see the same continual erosion as has happened, for instance, in the Abortion Act and certain other pieces of legislation. That is my personal concern. I appreciate that others may take a different view.

Q2054 Lord Patel: Your comment about the shift in the medical profession I too find rather interesting. On a personal basis, a member of the Ethics Committee of the Royal College of Physicians of London expressed a view in support, but the college has come out as a neutral stand.

Lord Walton of Detchant: Yes.

Q2055 Lord Patel: A stand that is backed also by the Academy of Medical Oncologists.

Lord Walton of Detchant: Yes.

Q2056 Lord Patel: And the Royal College of General Practitioners.

Lord Walton of Detchant: Yes.

Q2057 Lord Patel: And in fact the GMC also has a neutral stand.

Lord Walton of Detchant: Yes.

Q2058 Lord Patel: Does that surprise you?

Lord Walton of Detchant: No, it does not. Let's take the Royal College of Physicians first, because I had quite a discussion with the President on this issue. She said, if they were going to have to produce a formal opinion on the Bill, they would be required by their statutes to undertake an extensive inquiry to involve fellows of the college, members of the college, and this was a process that would take some considerable period of time. After careful consideration, the council of the college decided to express a neutral opinion, leaving it to the good sense of Parliament to come to a decision.

Q2059 Lord Patel: You do not think this demonstrated the recognition that there might be a shift in the profession?

Lord Walton of Detchant: I think it does demonstrate the view that there has been in parts of the profession a shift in opinion. But I still believe myself that, if there were to be a properly designed questionnaire which set out the various options to the profession as a whole, the majority would not wish to see this Bill implemented. Many of the questionnaire exercises that have been undertaken in the past have really been, in my view, extremely flawed. One questionnaire some years ago asked: "Would you wish to request help to have a gentle easy death?" Well, who wouldn't? That was taken by certain people to imply that people were supporting euthanasia. Well, that was not the intention of the great majority who answered that questionnaire.

Q2060 Lord Joffe: Lord Walton, first of all I would like to thank you very much for you opening comments on the humanitarian principles behind this Bill. It is much appreciated. If I could start off by clearing up the position in the Northern Territories. In fact in the Northern Territories of Australia there were only somewhere between four or it might have been six cases before the legislation was over-ruled by the Federal State which actually had the jurisdiction, because the Northern

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Territories was, as it were, a territory and not a state.

Lord Walton of Detchant: Thank you.

Q2061 Lord Joffe: So I do not think many conclusions can be drawn from the experience in the Northern Territories.

Lord Walton of Detchant: No.

Q2062 Lord Joffe: I would like to come back to this point which has been raised by Lady Jay and Lord Patel about the change in public opinion—an opinion in parts of an opinion, I think—which you have clearly recognised. It is extraordinary if one looks at that change and starts to list it. We have the Royal College of Physicians, the Royal College of General Practitioners and the Academy all moving from outright opposition to a position, as you point out in the case of the physicians, of neutrality. Internationally, we have had evidence from Oregon, Belgium, The Netherlands, all of whom have introduced legislation since your committee reported—

Lord Walton of Detchant: Yes.

Q2063 Lord Joffe: -- legalising assisted dying. In addition, we have Switzerland, where in evidence we have heard that assisted dying has been in place there for something like 100 years without any known abuse or abuse or without vulnerable people being put at risk, and then, of course, public opinion has remained at 80 per cent or more in favour of patients just having an option. I wonder whether, with all this mass of opinion, even though you have clearly made your position clear, has it given you cause for thought? Has it influenced your thinking in any way?

Lord Walton of Detchant: That is a very valid question and the answer is that of course it has given me pause to thought. I have considered this extremely carefully. Having looked at much of the evidence that has come from public surveys and from professional sources, and, indeed, from Oregon and Holland and Belgium and Switzerland, I have nevertheless, after agonising over this issue, stayed with the view which I have expressed today and which I expressed in our report of '94.

Q2064 Lord Joffe: Thank you. I think it is clear from what you say that the borderline between supporting assisted dying and not supporting assisted dying is a very fine one.

Lord Walton of Detchant: It is a very fine one. As I said in answer to the Lord Chairman's question, I am aware of circumstances—even, Lady Findlay, in hospices—where on a couple of occasions I know full well that someone carefully left some tablets next to the bed of a patient who was in terminal

illness, which they subsequently took and it terminated their life. I have heard of one or two such cases. Very rare. Very occasionally. I nevertheless do not condone that but I know that it has happened on occasions. I accept that there is a distinction between helping an individual to commit suicide—I do not approve of it—and a doctor giving a lethal injection which is deliberate and intentional killing—which I still cannot condone under any circumstances.

Q2065 Earl of Arran: Lord Walton, could I say straight away that I fully respect and, indeed, understand your very principled objections to this Bill. You mentioned in your opening remarks safeguards, and words to the effect that you are pleased that they are as they are at the moment. From a physician's point of view, if this Bill were to become law, are there any additional safeguards you would like to see therein?

Lord Walton of Detchant: I have read it carefully several times and if it were to become law I cannot readily see any additional safeguards which I would wish to see introduced.

Q2066 Baroness Thomas of Walliswood: Lord Walton, we have had in evidence quite a lot of discussion about the length of time which is a suitable length of time at which you can determine when a patient might die. In effect, the Bill says that that length of time is six months.

Lord Walton of Detchant: Yes.

Q2067 Baroness Thomas of Walliswood: That is what the effect of the Bill would be. I think other doctors have said to us that they feel that at two to three months you could be pretty certain what the prognosis of death is but in a longer period it is much more uncertain. Do you have any comments, as a physician, on that distinction?

Lord Walton of Detchant: In a lifetime of medical practice I have been enormously surprised by a number of things which have happened. I remember the wife of a friend, a physician, who was suffering from what was regarded as terminal cancer, a malignant melanoma with multiple metastases across the body, in the liver and in the lungs and so on, to such an extent—and this was years ago—that her husband who was abroad was brought home from services in the armed forces to be with her when she died. Within a period of two to three months the metastases disappeared and she lived for another 30 years. That is an exceptional example.

Q2068 Baroness Thomas of Walliswood: It is on the outside edge, as it were?

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Lord Walton of Detchant: Well, I think it was probably the body's immune response beginning to work very much more effectively. These things are very unpredictable. There are patients in whom one says on the basis of clinical experience that the patient is likely to die within three or four weeks. There are others where you say, "I think the patient has six months, maybe nine months" etcetera, and time proves you to be quite wrong, because they either live longer or die earlier than you had anticipated on the basis of your experience. So it is not an exact science. Clinical medicine never is and never will be an exact science. For that reason, I think six months, if the Bill did become law, would be a reasonable period of time. I would not wish to shorten it.

Q2069 Chairman: Lord Walton, just to follow a little bit further that line you have just been discussing, my impression of the evidence is that those who deal primarily with malignant conditions, cancerous conditions, on the whole are more able to predict with some precision, particularly in the closing months, perhaps two months, of life, when the end will come than those dealing with a number of other illnesses which ultimately are expected to end in death. It is said, I think, that in that case it is more problematic. Is that in accordance with your experience?

Lord Walton of Detchant: Absolutely. So far as the cancer cases are concerned, I think the prediction is more easy but by no means precise. In people, for example, with motor neurone disease or other neurological conditions, with which I am very familiar from my clinical practice, it is very difficult indeed to predict what is going to happen. A patient with motor neurone disease does not die as a consequence of the paralysis of the muscles, which are progressively lost, unless of course the respiratory muscles are badly affected—and, even with some of them, when they are sentient and capable of intelligent decisions they are helped by artificial respiration and a number of other techniques—and of course it is very difficult to predict how long people with motor neurone disease are going to live. The same is true, of course, of people with many dementing processes and other progressive neurological disorders, where it is not the dementia which kills but the secondary consequences of the dementia which usually will eventually kill the individual. As I said at the outset, I recall very well—forgive me for mentioning this—the case of my own mother, who died eventually at the age of 93. She had a series of six strokes and for the last year of her life was unaware of her surroundings. On several occasions, in discussion with the GP, the family said that if she developed another attack of pneumonia we would not wish her

to be given antibiotics. In fact, she developed two more attacks of pneumonia but recovered spontaneously each time. So these are very difficult issues to consider.

Q2070 Lord McColl of Dulwich: You mentioned the failure of the Abortion Act. It was very carefully framed by very sincere people who thought they had put in place very secure limits and yet the moment it was passed it did not do what it was meant to do and abortion on demand became the norm. Furthermore, the clause in the Bill to protect those who did not want to take part, again that failed, although it was carefully worded. I am sure you had many friends, as I did, who were obliged to emigrate because they could not secure jobs in a surgical role. My worry is that if that bill was carefully phrased but failed to do what was intended, why would this Bill not also fail in a similar way? That is one question. The second is this: We hear that in Holland old people are genuinely worried because they are not quite sure what the doctor is coming for: Is he coming to help or to despatch them? We have also heard that the role of the doctor might be compromised. What would you think to an amendment which is being tabled which would preclude members of the medical and nursing professions, and professions allied to medicine, taking any part in this whatsoever? You would have to have a different group of people or professions who would do this job, so that there would be absolute clarity and no confusion of the roles.

Lord Walton of Detchant: The first point I would make is that you should forgive me, I think, for disagreeing with the point you made at the outset, but I turn to the noble and learned lord, the Chairman: I do not believe that the Abortion Act has been significantly amended in relation to its provisions but those provisions have been widely ignored, leading virtually to abortion on demand. That is one of the major arguments which concerns me about this Bill, that, if it were to be enacted, then I believe, as I have said, that it would lead progressively to the practice of voluntary euthanasia. That is my concern. As to the second provision you have suggested, I feel uncomfortable. I cannot comfortably feel that it would be possible to find a group of individuals, who are sufficiently well trained and sufficiently capable of taking into account all of the circumstances, who are outside the medical and nursing professions, who would be willing and able to do this. I think that is a dangerous possibility and I would not wish to support it.

Q2071 Baroness Finlay of Llandaff: I wonder if I could ask you one further question which has just come to mind as a result of your response on your

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experience of communication and communication training and the impact of what the doctor says on what the patient perceives. If this Bill, in any form, not necessarily its current form, were to proceed, whether it should have a clause in it whereby it is an offence for a clinician to instigate and offer euthanasia—as opposed to the question being raised by the patient initially—because of the inference to the patient that, if a doctor says, “Have you considered euthanasia?” or “Have you considered assisted suicide?” there is a subtext, a subliminal message, that what lies ahead of them is so terrible that the doctor dare not spell it out and that there is an inference that their life is either not worth living now or may not be in the future.

Lord Walton of Detchant: I think that is a very thoughtful suggestion and one which deserves very serious consideration. Having said that, of course, I said at the outset that medical schools have been teaching students communication skills now for well over 25 years, but, even so, every doctor has had the experience, after a lengthy consultation, a time which for a patient I understand can be a very

sensitive and difficult time, of asking the patient at a later stage what was said on that first occasion, and the inaccurate recollections are sometimes stunning and very disturbing. In our medical school and in the vocational training programme for general practitioners we had a regular procedure at Newcastle of asking students to videotape a consultation with a patient and then to have the videotape played back with their colleagues/peers in the same class criticising their competency and then subsequently asking some of those patients to come back and to explain what they had been told in the consultation. And it is extremely difficult, because sometimes they have misinterpreted what seemed to the students and to some of the doctors to be very simple concepts. So it is a complicated issue but, you are right, it needs to be something which is vigorously pursued.

Chairman: Thank you very much indeed, Lord Walton. I refrained from taking up with you the relative position of trust of doctors and lawyers since I think it may not be directly relevant to our discussions. Thank you very much indeed.

Memorandum from the Attorney General

ASSISTED DYING FOR THE TERMINALLY ILL BILL

THE SELECT COMMITTEE

1. I have agreed to provide assistance to the Committee on the current legal position in relation to assisted suicide and euthanasia, and the meaning and effect of the proposed legislation, in accordance with my role of giving legal advice to Parliament. My evidence will be limited to advice on the legal questions and will not include any views on the merits of the proposal and will not give any indication of government policy in this regard.

2. The clerk to the Select Committee has made it clear that the Committee would welcome assistance on the following matters:

- (i) The current statutory position in the UK in respect of attempted suicide, assisted suicide and voluntary euthanasia.
- (ii) The current practice in relation to the prosecution of people who are believed to have participated in any of the above, including the position of people who go abroad in order to procure assisted suicide or euthanasia.
- (iii) The current state of the law in respect of a patient's right to refuse life-prolonging treatment and to the withholding or withdrawal of life-prolonging treatment without a patient's consent, and the status in law of current medical guidelines on these acts.
- (iv) Interpretation of recent judgements, under both national and international law, on cases involving assisted suicide or euthanasia.
- (v) Whether the enactment of legislation allowing assistance with suicide for terminally ill people who are suffering unbearably would be likely to have any implications in law for the obligations placed on authorities, such as (for example) prisons, to protect those in their charge (some of whom might be deemed to be suffering unbearably) from self-harm.

- (vi) The Bill before the committee provides, *inter alia*, that a doctor who carries out assisted suicide or euthanasia “shall be deemed not to be in breach of any professional oath or affirmation” (Section 10(3)). The Committee seeks assistance on whether a change in the law could affect professional oaths or affirmations in this way.

I will respond to these questions at the Select Committee, but provide this background paper on the current law in advance for the assistance of Committee members.

THE CURRENT LAW OF HOMICIDE

3. There are three relevant offences: murder, manslaughter and complicity in suicide.

Murder

4. Murder is defined as “unlawful killing with malice aforethought”. This is to be contrasted with those forms of manslaughter which consist of killing without “malice aforethought”. The principal distinguishing feature between murder and manslaughter is that murder requires an intention to kill or to cause grievous bodily harm. The penalty for murder is life imprisonment. In summary, deliberately taking the life of another person, whether that person is dying or not, constitutes the crime of murder. Accordingly, any doctor who practises mercy killing can be charged with murder if the facts can be clearly established.

5. The only exception is where the doctor acts to do all that is proper and necessary to relieve pain with the incidental effect that this will shorten the patient’s life. This was explained by Devlin J. in *R v Adams* [1957] Crim L R 773. Doctor Adams was charged with the murder of a patient. It was alleged that he had prescribed and administered such large quantities of drugs that he must have known that death would result. In his summing up to the jury, Devlin J. stated:

“If her life was cut short by weeks or months it was just as much murder as if it was cut short by years. There has been much discussion as to when doctors might be justified in administering drugs which would shorten life. Cases of severe pain were suggested and also cases of helpless misery. The law knows no special defence in this category . . .”

However he went on to say:

“. . . but that does not mean that a doctor who was aiding the sick and dying had to calculate in minutes, or even hours, perhaps, not in days or weeks, the effect on a patient’s life of the medicines which he could administer. If the first purpose of medicine—the restoration of health—could no longer be achieved there was still much for the doctor to do and he was entitled to do all that was proper and necessary to relieve pain and suffering even if the measures he took might incidentally shorten life by hours or perhaps even longer. The doctor who decided whether or not to administer the drugs could not do his job, if he were thinking in terms of hours or months of life. Dr Adams’s defence was that the treatment was designed to promote comfort and if it was the right and proper treatment the fact that it shortened life did not convict him of murder.”

This introduced into English law the “double-effect” principle, that is if an act has two consequences, one good and one bad, the bad consequence may nevertheless be acceptable depending upon the circumstances.

Manslaughter

6. Manslaughter is usually classified as either voluntary or involuntary. Voluntary manslaughter consists of those killings that would be murder, because the accused has the relevant *mens rea*, but which are reduced to manslaughter because of one of the three special defences provided for by the Homicide Act 1957. These special defences are diminished responsibility (section 2 of the Homicide Act 1957), provocation (section 3 of the Homicide Act 1957), and killing in pursuance of a suicide pact (section 4 of the Homicide Act 1957). Involuntary manslaughter refers to those types of manslaughter where the accused lacks the *mens rea* for murder. It encompasses killing by an unlawful act likely to cause bodily harm and killing by gross negligence.

Killing in pursuance of a suicide pact

7. Section 4(1) of the Homicide Act 1957 provides: “it shall be manslaughter, and shall not be murder, for a person acting in pursuance of a suicide pact between him and another to kill the other or be a party to the other being killed by a third person.”

8. A suicide pact is defined in section 4(3) as: “a common agreement between two or more persons having for its object the death of all of them, whether or not each is to take his own life, but nothing done by a person who enters into a suicide pact shall be treated as done by him in pursuance of the pact unless it is done while he has the settled intention of dying in pursuance of the pact.”

9. The burden of proving that he was acting in pursuance of a suicide pact is placed on the accused. He must prove not only that there was in fact a suicide pact, but also that at the time of the killing he had the intention of dying himself.

10. Killing in pursuance of a suicide pact is closely related to the offence of aiding and abetting suicide under the Suicide Act 1961 (see below).

Abetting suicide

11. The traditional attitude of the common law was to condemn suicide and it was regarded as a criminal offence until the law was changed by the Suicide Act 1961 (“the 1961 Act”). The 1961 Act provided: “the rule of law whereby it is a crime for a person to commit suicide is hereby abrogated.” One result of the 1961 Act is that it is no longer a crime to attempt suicide. However, the 1961 Act continues to impose a considerable measure of responsibility upon persons other than the suicide or would be suicide. The 1961 Act makes it a statutory crime to aid, abet, counsel or procure a suicide or attempted suicide and the offence carries a penalty of up to 14 years’ imprisonment.

12. The consent of the Director of Public Prosecutions (“the DPP”) is required to initiate proceedings for the offence (Suicide Act 1961, section 2(4)). In *R v Hough* (1984) 6 Cr. App. R. (S) 406, Lord Lane C.J. commented that the crime of abetting suicide could range “from the borders of cold blooded murder down to the shadowy area of mercy killing or common humanity.” In that case a 60 year old woman was sentenced to nine months’ imprisonment for aiding and abetting the suicide of an eighty four year old woman who was partly blind, partly deaf and suffered from arthritis. The accused had provided the woman with tablets and, when the 84 year old woman became unconscious, placed a plastic bag over her head.

13. In *Wallace* (1983) 5 Cr. App. R. (S) 342, a sentence of 12 months’ imprisonment was described by the Court of Appeal as “at the extreme of leniency” in a case where the offender pleaded guilty to aiding the suicide of a 17 year old by buying her tablets and alcohol.

Elements of the offence

14. The offence is governed by the ordinary rules which apply to aiding and abetting crime. “Aid” and “abet” are generally considered to cover assistance and encouragement given at the time of the offence, whereas “counsel” and “procure” are more aptly used to describe advice and assistance at an earlier stage. To procure is generally taken to mean to produce by endeavour and the word covers the provision of help to a person who wishes to commit suicide: *R v Reed* (1982) Crim L R 189. In *Reed* the accused was convicted of a conspiracy to aid and abet suicide and the Court of Appeal stated that a person procures a thing by setting out to see that it happens and taking the appropriate steps to produce that happening.

15. As a general rule aiding and abetting requires proof of *mens rea*, and this is usually taken to mean an intention to aid as well as a knowledge of the relevant circumstances. For the purposes of the section 2 offence, the accused must intend that someone commit or attempt to commit suicide. This is made clear by the decision in *Attorney-General v Able* [1984] 1 QB 795. In that case the accused, who were members of the voluntary euthanasia society, published a booklet entitled “a guide to self deliverance” for distribution to members of the society. The booklet set out both the purpose of the society, namely that it was to overcome the fear of the process of dying and five separate methods of suicide. On the Attorney-General’s application for a declaration

that the supply of the booklet involved the commission of the offence, Woolf J. held that before an offence can be established to have been committed, it must at least have been proved:

- “(a) that the alleged offender had the necessary intent, that is, he intended the booklet to be used by someone contemplating suicide and intended that person would be assisted by the booklet’s contents, or otherwise encouraged to attempt to take or to take his own life;
- (b) that while he still had that intention he distributed the booklet to such a person who read it; and,
- (c) in addition . . . that such a person was assisted or encouraged by so reading the booklet to attempt to take or to take his own life.”

Jurisdiction

16. The general rule is that the English courts do not accept jurisdiction over offences committed outside England and Wales, even if the accused is a British subject. In *Treacy v Director of Public Prosecution* [1971] AC 537, Lord Morris stated: “the general rule as expressed by Lord Halsbury L. C. in *MacLeod v Attorney-General for New South Wales* [1891] AC 455 at 458, is that “all crime is local” and that jurisdiction over a crime belongs to the country where it is committed. Unless, therefore, there is some provision pointing to a different conclusion, a statute which makes some act (or omission) an offence will relate to some act (or omission) in the United Kingdom.”

17. In *Re Z* [2004] EWHC 2817 (Fam), Headley J. expressed the view that the making of arrangements in England to assist a person to commit suicide abroad fell within section 2(1) of the 1961 Act. This was clearly correct. In that case Mrs Z was suffering from an incurable and irreversible illness. She had become increasingly disabled by her condition and would in due course die as a result of it. In late 2003 she began to express strong views about seeking assistance to commit suicide. She knew that this could be arranged in Switzerland, where it is not unlawful to assist suicide. Mr Z proposed to make all the necessary arrangements and to accompany his wife for the assisted suicide. The Local Authority sought to restrain Mr Z from removing Mrs Z from England and Wales. The critical issue in the case was the extent of the duty owed by a Local Authority when the welfare of a vulnerable person in their area was threatened by the criminal or other wrongful act of another. It was held that although the Local Authority was under an obligation to investigate the position of a vulnerable adult and to consider whether she was legally competent to make and to carry out her decision and her intention, there was no obligation to seek the continuation of an injunction to prevent Mr and Mrs Z from travelling to Switzerland. Although the acts of Mr Z could amount to an offence of aiding and abetting suicide this was a matter for the police and the DPP to consider once they had been informed of the facts. Headley J. noted that Parliament “has committed to the DPP the discretion as to whether to permit a prosecution” and that this militated strongly against the intervention of the civil remedy of an injunction. He went on to state: “This case affords no basis for trying to ascertain the court’s views about the rights and wrongs of suicide assisted or otherwise. This case simply illustrates that a competent person is entitled to take their own decisions on these matters and that that person alone bears responsibility for any decision so taken. That is the essence of what some will regard as God-given free will and what others will describe as the innate right of self-autonomy. It illustrates too that the civil court, and in this context, especially the Family court will be slow to restrain behaviour consistent with the rights of others simply because it is unlawful where adequate powers are vested in the criminal justice agencies.”

The Pretty Case

18. In *R (Pretty) v Director of Public Prosecutions* [2002] 1 AC 800, it was held that a terminally ill Claimant could not require the DPP to undertake not to consent to the prosecution of her husband for assisting her proposed suicide. It was further held that section 2(1) of the Suicide Act 1961 was compatible with Articles 2, 3, 8, 9 and 14 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (“the European Convention”).

19. In *Pretty v United Kingdom* 29 April 2002, the Strasbourg Court held that there had been no violation of the Convention in Mrs Pretty’s case. The Court did not consider that the blanket nature of the ban on assisted suicide was disproportionate. It accepted the Government’s argument that flexibility is provided for by the fact that consent is needed from the DPP to bring a prosecution and by the fact that a maximum sentence is provided allowing lesser penalties to be imposed as appropriate.

Refusing Treatment

20. In *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, the Court of Appeal made it clear that an adult, mentally competent patient enjoys an absolute right to refuse medical treatment even where refusing treatment means certain death. The legal position in England and Wales is often stated adopting the words of Cardozo J. in *Schloendorff v Society of New York Hospital* (1914) 211 NY 125: “every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent commits an assault, for which he is liable in damages.”

21. This principle was recognised by the Strasbourg Court in *Pretty v United Kingdom*: in the sphere of medical treatment, the refusal to accept a particular medical treatment might, inevitably, lead to a fatal outcome, but the imposition of medical treatment, without the consent of a medically competent adult, would interfere with a person’s physical integrity in a manner capable of engaging the rights protected under Article 8(1) of the Convention.

22. The essential principle in English law is that a doctor may only carry out a medical treatment or procedure which involves contact with a patient if there exists a valid consent by the patient or another person authorised by law to consent on his behalf.

23. The exceptions to the general principle are:

- (a) children, where a parent or the court may override the patient’s refusal if that is in his best interests;
- (b) here the treatment is for the mental disorder of a patient detained under the Mental Health Act 1983;
- (c) here the treatment is justified to the extent that it is reasonable in the circumstances and where the competence of the individual is unknown. For example, faced with a patient in a casualty department who has taken a drugs overdose a doctor would be entitled to entertain doubts as to the patient’s competence and so act out of necessity to save his or her life;
- (d) as a matter of public policy the common law may justify interventions against a competent person’s wishes in wholly exceptional circumstances. For example a patient may not refuse measures designed to maintain basic hygiene in a hospital ward where those measures are considered necessary in the interests of other patients.

24. Consistent with the principle that a competent adult patient has an absolute right to refuse consent to any medical treatment, a patient’s anticipatory refusal of consent (a so called “advance directive” or “living will”) remains binding and effective notwithstanding that the patient has subsequently become and remains incompetent.

25. In *Miss B v An NHS Hospital Trust* [2002] EWHC 429 (Fam), a tetraplegic patient was found competent to refuse life sustaining treatment (artificial ventilation) and the court made a declaration that continued treatment was unlawful. Dame Elizabeth Butler Sloss P, stated “*The treating clinicians and the hospital should always have in mind that a seriously physically disabled patient who is mentally competent has the same right to personal autonomy and to make decisions as any other person with mental capacity.*”

The Bland Case

26. In *Airedale NHS Trust v Bland* [1993] AC 789, it was held that where a patient was incapable of deciding for himself whether to continue treatment, what could lawfully be done to him depended upon whether the treatment was in his best interests. The patient, aged seventeen was in a persistent vegetative state. The medical opinion was that there was no hope of any improvement in his condition or recovery. With the concurrence of the patient’s family, the authority responsible for the hospital where he was being treated sought a declaration that they might lawfully discontinue all life sustaining treatment and all medical support measures designed to keep the patient alive. The House of Lords held that the object of medical treatment and care was to benefit the patient. Since a large body of informed and responsible medical opinion was of the view that existence in the persistent vegetative state was not to the benefit of the patient, the principle of the sanctity of life was not violated by the ceasing of giving medical treatment and, therefore, withdrawing the treatment was lawful. The House of Lords went on to advise that before treatment was discontinued in any other case, a declaration should be sought from the Family Division to the effect that continued treatment and care no longer conferred any benefit upon the patient. Details of the procedure to be adopted in applications to the court are set out in the Official Solicitors Practice Note [2001] 2 FLR 158. Where a patient is diagnosed as being in a persistent vegetative state, the court, after careful consideration of the patient’s best interests, may authorise the withdrawal of artificial nutrition and hydration on the basis that this constitutes medical treatment and that such treatment is futile: the patient has no further interest in being kept alive. The function of the court is to verify the diagnosis of the patient as being in a persistent vegetative state. The views of the

patient's relatives or of others close to the patient will be taken into account by the court but cannot act as a veto. The question of the withdrawal of artificial nutrition and hydration from a patient whose condition falls significantly short of the persistent vegetative state has been left open for future decision. The courts are unlikely to grant declarations to permit or to sanction the withdrawal of treatment where there is any real possibility of meaningful life continuing to exist (*Re D (Medical Treatment)* [1998] 1 FLR 411).

The Burke Case

27. In *R (on the application of Oliver Leslie Burke) v The General Medical Council* [2004] EWHC 1879, the Claimant suffered from cerebellar ataxia. He wished to establish that he would receive food and water by artificial means when the need arose. He contended that the relevant guidance issued by the General Medical Council ("the GMC") on the withholding and withdrawing of life prolonging treatments was incompatible with his rights under Articles 2, 3, 6, 8 and 14 of the European Convention. In the course of his judgement Munby J. stated at paragraph 213: "*A failure to provide life prolonging treatment in circumstances exposing the patient to inhumane or degrading treatment will in principle involve a breach of Article 3. Where the NHS has assumed responsibility for treating a terminally ill patient's condition and he has become reliant on the medical care he is receiving, there will prima facie be a breach of Article 3 if that care is removed in circumstances where this will reduce him to acute mental and physical suffering and lead to him dying in avoidably distressing circumstances. Moreover, even if the patient's suffering does not reach the severity required to breach Article 3, a withdrawal of treatment in such circumstances may nonetheless breach Article 8 if there are sufficiently adverse effects on his physical or moral integrity or mental stability.*"

28. If the patient is competent, his decision as to where his best interests lie and what life prolonging treatment he should have is, in principle, determinative. If the patient is incompetent, the test is whether the treatment is in the patient's best interests. If the patient is competent or where incompetent, and has made a valid advance directive, his decision to require artificial nutrition and hydration is in principle determinative and the withdrawal of such treatment before the patient finally lapses into a coma would involve a breach of both Articles 3 and 8. Once the patient has finally lapsed into a coma there will no breach of Articles 2, 3 or 8 if artificial nutrition or hydration is withdrawn in circumstances where it is serving absolutely no purpose other than the very short prolongation of the life of a dying patient who lacks all awareness of what is happening. In these circumstances it can properly be said that the continuation of the treatment would be bereft of any benefit and would be futile.

29. Where it is proposed to withhold or withdraw artificial nutrition and hydration and there is an issue as to the capacity of the patient or the patient's best interests, the prior authorisation of the court is required as a matter of law.

30. This case is subject to appeal and the Department of Health has now applied to join that appeal. There is therefore a question mark over its effect on the right of patients to demand any life prolonging treatment they wish, no matter how untested, expensive or inappropriate. However, that does not affect the issue before this Committee.

Medical Guidelines

31. The GMC has issued guidance entitled "Withholding and Withdrawing Life Prolonging Treatments: Good Practice In Decision Making." It was published in August 2002. The GMC believes that the guidance reflects, as so far established, the broad consensus within the council, the professions and the public as to what can be regarded as good practice in this area of decision making. The status of this guidance was considered by Munby J. in the *Burke* case, who stated "the guidance is not a legal textbook or statement of legal principles. It consists primarily of professional and ethical guidance for doctors provided for them by the professional body which is responsible for such matters."

The Position Of Detained Persons

32. In *Reeves v The Commissioner of Police for the Metropolis* [2000] 1 AC 360, the House of Lords held that where police officers were aware that a prisoner was a suicide risk they had a duty to take reasonable care not to allow a prisoner to kill himself. Respect for personal autonomy did not preclude the taking of steps to "control a prisoner's environment in non-invasive ways calculated to make suicide more difficult".

33. In *Keenan v The United Kingdom* (3 April 2001) 33 EHRR 38, the applicant's mentally ill son committed suicide in Exeter prison where he was serving a sentence of four months' imprisonment for assaulting his girlfriend. Nine days before his expected release date he had been given a disciplinary punishment consisting

of seven days in segregation in the punishment block and an additional 28 days' imprisonment. Relying on Articles 2, 3 and 13 of the Convention, the applicant complained that the prison authorities had failed to protect her son's right to life and that he had been subjected to inhuman and/or degrading treatment in the period before his death. The Court found that there had been no violation of Article 2 but that there had been a violation of Articles 3 and 13. In relation to Article 3, the Court held that the lack of effective monitoring of Keenan's condition and the lack of informed psychiatric input into his assessment and treatment disclosed significant defects in the medical care provided to a mentally ill person known to be a suicide risk.

34. An adult prisoner of sound mind and capacity has a specific right of self-determination which entitles him to refuse nutrition and hydration: *Secretary of State for the Home Department v Robb* [1995] Fam 127. In that case an adult prisoner began to refuse all nutrition. Medical experts agreed that he was of sound mind and fully understood the consequences of his decision to refuse food and that death would result. The Home Secretary sought a declaration that the physicians and nursing staff responsible for the prisoners might lawfully observe and abide by the prisoner's refusal to receive nutrition and might lawfully abstain from providing him with hydration and nutrition for as long as he retained capacity to continue to maintain his refusal. In the course of his judgement Thorpe J. stated that the state interest in preventing suicide had no application in such a case where the refusal of nutrition and medical treatment in the exercise of the right of self-determination did not constitute an act of suicide.

Examination of Witnesses

Witnesses: RT HON LORD GOLDSMITH QC, a Member of the House of Lords, Attorney General, and MR DAVID PERRY, Treasury Counsel, examined.

Q2072 Chairman: Attorney General, we are extremely obliged to you for coming along this morning to help the Committee on the legal issues which are at the base of our consideration of Lord Joffe's bill. We are grateful for the draft paper that you have given us on the background legal issues. We understand that that paper is subject to possible refinement in the light of the discussion that we may have in the course of the morning. As you know, the evidence that you give will be transcribed. You will have an opportunity of correcting it, and, ultimately, it will become part of our report and be duly published. I also want to make it clear that what we have invited you to come to help us with is the legal position and any matters of prosecutorial policy, if there are any, that may be relevant to that, but there is no question of anyone wishing to ask you about the general policy of the Government in relation to this particular bill. If that is to be expressed, it will be expressed by others at an appropriate time, but, so far as you are concerned, we do not expect you to comment on that in any way whatsoever. You have a colleague with you whom you would like to introduce?

Lord Goldsmith: Thank you very much indeed. Yes, I would. I have with me Mr David Perry, who is senior Treasury Counsel and an extremely experienced advocate in criminal and human rights fields. He has assisted me in preparing the draft paper to which you, Lord Chairman, have referred, and I will at appropriate moments invite him perhaps to answer or to supplement answers that I give, if that is satisfactory to the Committee. Before that, could I simply acknowledge my gratitude for what you have said about why I am here? I am here as part of my traditional role of seeking to give legal advice to Parliament, to assist where I can. I am not here in any

sense to express any policy view on my own behalf, let alone on the Government's behalf, on Lord Joffe's bill, and, as you say, such views on the policy of the bill will be stated by others at an appropriate moment, no doubt, but they will not be from me this morning.

Q2073 Chairman: Would you like to give us a brief introduction or would you prefer to go to questions immediately? Your paper is before us, but it might be useful, if you felt it would be helpful, if you would give us a brief summary of the relative position?

Lord Goldsmith: I will happily do that. What it seemed to us may be helpful to the Committee was to deal with the current state of the law, firstly in relation to homicide, defining the different offences of murder, manslaughter and complicity in suicide, and drawing attention to an aspect which is important, that deliberately taking the life of another person, whatever the motives may be, constitutes the crime of murder unless there is a defence which reduces to it manslaughter. So a doctor who practises "mercy killing" could be charged with murder if the facts could clearly be established. I also draw attention in the draft paper to the fact that where a doctor acts to do all that is proper and necessary to relieve pain with the incidental effect that this will shorten a patient's life, that will not be murder. We take that from the ruling given by Mr Justice Devlin in the *Adams* case, and it introduces what is termed "the double effect principle", which means that if an act has two consequences, one good and one bad, the bad consequences may, nevertheless, be acceptable depending upon the circumstances. We draw attention also to the different sorts of manslaughter, to killing in pursuance of a suicide pact and to the provision in the Suicide Act 1961. It is probably

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worth pausing for a moment on that. The traditional attitude of the common law was to condemn suicide, and it was regarded as a criminal offence until that was changed by the Suicide Act 1961. That abrogated, in terms, the rule of law under which it was a crime for a person to commit suicide; so it follows that it is also no longer a crime to attempt to commit suicide. That was a consequence of the 1961 Act, but the Act continues to place a high degree of responsibility on other people who assist the suicide or would-be suicide; so it is a statutory crime to aid, abet, counsel or procure a suicide or attempted suicide. It is an offence which carries a penalty of up to 14 years' imprisonment. The consent of the Director of Public Prosecutions is required to initiate those proceedings, but they are brought from time to time. In the draft paper we seek to define the elements of what is meant by "aiding and abetting". For present purposes it is probably sufficient to say that "aid and abet" generally is considered to refer to assistance and encouragement given at the time of the offence, in this case at the time of the suicide or attempted suicide, and "counsel or procure" usually refers more to advice and assistance given at an earlier stage. It will be necessary to demonstrate the requisite intent on the part of the person who is said to have aided or abetted, counselled or procured, and the draft paper sets out particularly one of the implications of that when it comes to publications which provide information or offer more in relation to ways to assist suicide. The other matter dealt with in the draft paper is an analysis of those cases in which the courts have had to deal with the issue of people who have either wanted themselves to decline full treatment, albeit in the knowledge that that will induce or result in their own death, and those cases of doctors who are faced with a difficult issue of whether to continue to provide treatment to people and whether they are obliged to do so; whether they are right to insist upon giving treatment to people who do not wish it to be provided. We are happy to seek to explain, as best we can, the cases in relation to that. Fundamentally, it is very important to draw a distinction between the case of people who are competent, who have the mental capacity to reach a decision, and someone who has not. Someone who has the mental capacity to reach a decision is entitled, as part of the right of autonomy or self-determination, to refuse further treatment even if that is irrational, or unreasonable, by anybody else's standards. Different considerations apply where the person is not competent to reach a decision. Then doctors generally would not be entitled unilaterally to refuse to continue treatment, but there are cases where they may do so, as the jurisprudence shows, where it is in the best interests of the patient and in accordance with a body of medical opinion to fail to continue to provide treatment. We go through a

number of the cases which touch on those issues. The draft paper makes the point that the right of self-determination, as it were, that I refer to applies to people in institutions as well and applies to people who are in prison, and that has been so determined by the courts. That may be a sufficient general statement, I hope, to be of assistance.

Chairman: Thank you very much.

Q2074 Baroness Hayman: Perhaps I could I kick off with two questions, one of which is quite specific. You will forgive me, but I have only just read your paper. The very last sentence in it I did not quite understand. The judgment was that there was a state interest in preventing suicide but that the refusal of nutrition was not suicide. Is that correct?

Lord Goldsmith: Yes. It is perhaps right to say, firstly, that what the law says is that if somebody refuses treatment in the knowledge that that will lead to death—the intention of that will lead to death—that is not suicide; and so it differs, in that respect, from the taking of a positive act.

Q2075 Baroness Hayman: That nutrition and hydration were not considered treatment. This is what I am interested in, whether in those circumstances the refusal by an individual to take nutrition or hydration constitutes suicide. It just struck me as strange?

Lord Goldsmith: It does not constitute, in the law's eyes, suicide to refuse treatment, or nutrition or hydration.

Q2076 Baroness Hayman: Thank you. The broader point I wanted to ask you was that we have had a lot of discussion in the Committee about whether it is possible to prevent drift in an area like this if you have legislation on the statute book. There are some who are concerned that, although this bill or another bill might be extremely tightly drawn in the first instance, there would be an inevitability of it being more widely applied. I wanted to ask you whether, in general terms, that risk could be mitigated best by legislation that was permissive of specific acts, as Lord Joffe's bill would be, or whether there is any advantage in what I presume would be a potential other legal approach, which would be to provide a specific defence to the offences under the Suicide Act of aiding and abetting in particular circumstances, much the same circumstances as those contained in Lord Joffe's bill, for example, where the person was terminally ill, competent, had requested this in a sustained manner; whether there is a view about whether one legal approach or the other is easier to enforce, because one provides the possibility of *ex post facto* scrutiny by the DPP and the courts on this?

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Lord Goldsmith: A couple of observations, if I may. First of all, of course, the effect of Lord Joffe's bill, were it to become law, is not limited to affecting the provisions under the Suicide Act. The Suicide Act creates a statutory offence of aiding and abetting, counselling or procuring suicide, but, in fact, the act of someone who actually does the act which brings about the death is murder or some other form of homicide; so it goes beyond that. That is the first point. The second point is that I would not want to comment, as it were, more generally on the risk of drift, because that, I think, in itself is drifting into the policy areas, and I do not know where this would lead and I want to avoid that, for reasons that have been given. The final point is that any set of provisions, however they are put together, which identify the circumstances in which acts which otherwise would be unlawful are lawful—and that would be the effect of Lord Joffe's bill that an act which otherwise would be unlawful, indeed murder, would be lawful—obviously always poses issues for the law enforcement authorities as to how effectively they can be policed, but I am not sure that turns on the precise vehicle which is used in order to do it as opposed to the contents of the conditions which are laid down having seen how difficult it is to verify that those conditions have applied.

Q2077 Chairman: To make sure that I have understood exactly what the position is, Attorney General—we summarised it a little bit with Lord Joffe earlier on, but I want to be sure that my grasp of it is as complete as it can be, because it is quite important—there is the general law of murder and there is the statutory offence, to which you have referred, under the Suicide Act.

Lord Goldsmith: Yes.

Q2078 Chairman: These are general offences. If Lord Joffe's bill became law and activities under it were otherwise covered by these provisions, either of murder or of the section in the Suicide Act, it would be a defence to show that what you had done, although within these provisions, was within the law as laid down in Lord Joffe's bill, provided the conditions which are set out for the lawfulness of the process were properly complied with. Is that correct?

Lord Goldsmith: The effect of the bill would make lawful that which would currently constitute the offence of murder or aiding and abetting suicide. If a person acted inconsistently with the provisions of the Act, he or she would remain liable to criminal penalties for that Act. The only hesitation I have in giving an unqualified "Yes" to your question is that you put it in terms of "who would have to prove that the conditions were met". My hesitation was—and I would ask Mr Perry to add to it—upon whom would lay the burden of either showing, proving or

disproving that the conditions have applied? Of course, the general rule is that if the Crown brings a claim, brings a charge, normally all the elements of that charge have to be proved beyond reasonable doubt by the prosecution. I am not sure—it is not clear in the bill—whether, in fact, the intention is that it should be some sort of burden on the doctor to prove that the conditions applied or whether it would be for the prosecution to disprove the availability of the defence.

Q2079 Lord Taverne: I have two questions. The first is one of clarification. The evidence we received in The Netherlands was that many of the cases which fell outside the Dutch euthanasia legislation—what might be called cases of involuntary euthanasia—were those that involved babies who had no prospect of survival and were judged to be in considerable pain where they were killed, or allowed to be killed, but there could be no question of coming within the Bill because there was no consent. However, in those cases where there was a prosecution the defence advanced was one of necessity, which was often successful in the sense that it led to an acquittal. I want to be clear that, although there is the concept of necessity in English law, it could not possibly apply in our law to a case like that. That is correct, is it not?
Mr Perry: Yes.

Lord Goldsmith: Yes. I looked to Mr Perry for some confirmation there. The law has been subject to some comment and the precise boundaries of the defence of necessity have been under comment by the courts and, indeed, there are cases before the courts, not at all in the context that you raise but in other contexts, but I would certainly agree with Mr Perry that your proposition is right. It would not be a defence.

Lord Taverne: The second question is a completely different one; a difficult one, I think. There are cases where people are not prosecuted. There was recently a lot of publicity about a policeman who had assisted his wife to die and he was told that he would not be prosecuted?

Lord McColl of Dulwich: He was prosecuted.

Lord Taverne: He was prosecuted?

Q2080 Chairman: If it is the same case—there may be more than one case—but there was a case last week which was reported in which a former policeman, I think I am right in saying, was involved in a suicide pact effectively. The wife died, but he did not, and he was, in fact, prosecuted and I think there was a conviction. I think it must have been on a plea.
Lord Goldsmith: He pleaded guilty.

Q2081 Chairman: The sentence was what was in issue.

Lord Goldsmith: He received a nine-month suspended sentence.

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Q2082 Lord Taverne: But there are cases, I understand, where it is sometimes decided not to prosecute. Are there any guidelines on that slightly grey area where sometimes it is not quite clear whether it is a case of assisted suicide?

Lord Goldsmith: The Crown Prosecution Service would be responsible in England and Wales for deciding, once a file is provided to them by the police, if it is, whether there should be a prosecution. There is no offence-specific policy for offences under the Suicide Act particularly. Each case would be reviewed on its merits to look to see whether the evidence supported the charge and where the public interest was in favour of charge a prosecution would be brought. The case that Lord Taverne has just referred to is one of them. There was another recent case where, in fact, the wife was acquitted of assisted suicide. It was alleged that she had helped her husband to try and commit suicide by purchasing paracetamol for him and assisting him to take it. She was acquitted of that, but the prosecution took place. I think there may be another one in the wings as well. There is no policy of not prosecuting these. Each case would be looked at on its own merits and, if appropriate, a prosecution would presently be brought.

Q2083 Chairman: The prosecution system would apply the ordinary rule of needing sufficient evidence and then a judgment on whether or not public interest required the prosecution to go ahead?

Lord Goldsmith: Yes.

Q2084 Chairman: There might be specific provisions for some other types of offence, but not in this particular case?

Lord Goldsmith: No, that is right.

Q2085 Baroness Jay of Paddington: I was not intending to make the point at this moment, but I do think this is interesting to ask as non-lawyers. I have found it enormously helpful that you have set out these various cases in the way that you have, and the conversations you have brought to bear reflect a conversation which we have had in other sessions about people reading these cases and how they are reported, etcetera, which, of course, has nothing to do with the law in itself. For example, picking up the point at the top of page seven—and this is something, again, we have discussed a great deal—about people going to other countries to assist their suicide, what is rather colloquially called “death tourism”, the general rule is that the English courts do not accept jurisdiction for offences committed outside England and Wales. You may say that this is drifting into the policy area and beyond the legal area, but do you think there is a growing perception that there is a muddle about all of this in relation to these different

types of cases, the one that Lord Taverne has raised with you, which we have discussed here before, the questions, as you say, of individual cases being looked at on the basis of the object of the prosecution and issues, as I say, about “death tourism” not being legitimately prosecuted under English law? Is there a sense in which the common law is building up a series of cases which are not enormously clear, because often the justices, as you have quoted and we have seen in other places, say that this is ultimately for Parliament to decide or for society to consider?

Lord Goldsmith: I think there are two principles. The first is that it is for the prosecuting authorities to apply the law as Parliament lays it down. It is not for the prosecuting authorities to decide that a particular law is or is not a good idea, and therefore it would be wrong in principle for a prosecuting authority to decide that it was on some wholesale basis not going to apply the law because it thought that it would be better if it were not there. Firstly, it is for the prosecuting authority to apply it, and that is what the prosecuting authority seeks to do: it looks at all the circumstances of the case—it does not need a prosecution in every single case, as it does not in relation to any area if one looks at the evidence or the circumstances—but the second is a clear principle that, save in exceptional circumstances, the courts in this country do not prosecute, do not accept jurisdiction, do not prosecute people for things that they do abroad. There are exceptions. We have made exceptions in relation to war crimes and hostage taking, very serious offences of that sort, and occasionally in relation to murder as well, but, generally speaking, what people do in other countries, if it is lawful by the laws of those other countries, we would not think it right, or we do not prosecute, and we cannot. In those cases where a suicide has taken place abroad, it would be appropriate to look at the events which have taken place in this country, because those might themselves amount to an offence. They might not, but, if the events which have actually happened in this country do not amount to an offence, then there will not be an offence to prosecute.

Q2086 Baroness Jay of Paddington: You think the consistency is absolutely there both in practice and in principle?

Lord Goldsmith: I have no reason to think that the prosecuting authorities are not acting consistently in those areas. I understand, on a more general basis, and it is true in other fields as well, that different countries adopt different rules, given the ease of travel. It may sometimes give the impression that, providing you go somewhere else, you can do something you cannot do here and is that right? I think it is a bigger policy question whether that should happen. One of the recent cases involved the

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question of whether the local authority should try and stop somebody from travelling abroad in order to commit suicide.

Q2087 Baroness Finlay of Llandaff: I wonder if I might ask you a little bit more about events surrounding suicide. One of the issues that came to my mind was coercion, where somebody may be given inconsistent messages saying that they should commit suicide in whatever form, and whether persistent coercion has ever been viewed as an offence where they are not practically aiding and abetting the act of the suicide but may have been aiding and abetting the thought processes that led to it and where that stands in law?

Lord Goldsmith: The consent, of course, would not be a defence to murder—the fact that the person wants to be killed is not a defence to murder—and, equally, consent is not a defence to aiding and abetting suicide. That obviously is the very essence of the offence. When one is in the field of refusal of medical treatment and things of that sort, if one is looking for whether or not that is the consent of a person who is wanting to do that, we will be looking to see whether, in fact, it was genuinely consent or whether it was not consent. I will ask Mr Perry if he want to anything to this which would be helpful in answer to that question.

Mr Perry: Only this, that if the person subject to coercion does not attempt to commit suicide or, in fact, commits suicide, the offence contrary to section 2 would nevertheless be established, because it is a statutory form of counselling or procuring and, therefore, in accordance with ordinary principles, if you encourage the commission of an offence, it does not actually matter if what would have been the offence in fact takes place, it is a statutory form of inchoate offence, so that would nevertheless be something that the criminal law could involve itself with.

Q2088 Baroness Finlay of Llandaff: That is very helpful, but I wonder if I might ask you another question. We have heard from the estimate, Lord Joffe suggested that between, I think, three and seven per cent of people who would be potentially eligible under the bill proposed would be people who would avail themselves of it. I have tried to do some rough sums and make that about 15,000 deaths a year potentially, given the number of deaths in the UK where we have over 600,000 deaths a year. If I have got my maths wrong I hope you will forgive me. I wondered how the Crown Prosecution Service or the Coroner's Service could potentially cope with that number and whether there is a precedent anywhere other than in the Abortion Act for pre-event reporting: because the Bill that we have been considering is post-event reporting and the criminal

justice system obviously acts on post-event reporting, but with the Abortion Act we do have pre-event reporting occurring. I wonder if that does provide any safeguards in law or whether that is a procedural auditing and monitoring process only but does not help within the law?

Lord Goldsmith: I do not know about the numbers. I cannot comment either on the maths or on the underlying figures. Just pausing over the issue of pre-event reporting, I cannot think of any area in which, as far as the law enforcement authorities are concerned, there is some pre-event reporting, and, indeed, on the whole, we are rather against being asked in advance to sanction whether something will or will not be an offence if it is done, because one really wants to see what all the circumstances are rather than hear somebody's account of what they might be.

Q2089 Baroness Finlay of Llandaff: Because with abortion the forms have to be signed prior to the abortion occurring, and the abortion would be deemed to be illegal if those forms have not been signed prior, and those forms are notified through. Admittedly it is within the Health Services. It is not notified to a court of law, but I wondered what the legal status was around that?

Lord Goldsmith: They are not notified, as far as I am aware, to the law enforcement authorities, so the police and the prosecuting authorities have no idea that a particular abortion is about to take place and are not, therefore, involved in any way in the predetermination of that.

Q2090 Baroness Finlay of Llandaff: I wonder if there is any attempt in law of the assessment of capacity? I know that we are dealing with this in relation to the Mental Capacity Bill, but it is recognised in practice that the amount of capacity that you need for a decision depends on the size of that decision, and I wondered if there is any precedent in law over assessing capacity?

Lord Goldsmith: The courts, and particularly the family courts, are faced from time to time with having to determine, sometimes on disputed medical evidence, whether a particular person does or does not have capacity, and one of those is the decision of the President, Dame Elizabeth Butler-Sloss, in the *Miss B* case. There is a long analysis in that case of the competing medical evidence and the conclusion which the President reached as to whether there was capacity or not. That may well be of interest for you to look at, but I do not think there is a simple answer I can give. It is an examination of all the circumstances in the case and the evidence from competent medical people, and others, of the individual themselves and the court's assessment which leads to the conclusion.

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Q2091 Chairman: I think I would be right in saying that the main content in that case was whether or not the lady in question had capacity. The doctors were refusing to accept her statement of what she wished because they thought she did not have capacity, and one of the bases on which they suggested that was to them the somewhat irrational looking appearance of her requirement, and I think the President had to analyse the concept very fully. Perhaps that is the best analysis, which is easily attainable in the Law Reports, of this particular problem.

Lord Goldsmith: Yes, that is why I referred to it.

Q2092 Lord Joffe: Firstly, to come to a point which was raised about the onus of proof, I think clause 10 actually deals with that in the Bill and it specifically refers to a physician acting in good faith. I wondered whether, in your view, that would have an effect on the onus as it was intended.

Lord Goldsmith: I am not at all sure that it does do that. It says "acting in good faith", but it says nothing about who has the burden of proving that he was acting in good faith or was not acting in good faith, and it would not be at all unusual to have a statute which would say a person doing X, Y or Z or being X, Y and Z shall not be guilty of an offence, but the onus may still remain on the prosecution, at least if the person who raises the possibility that it is a fact that is proven. This is partly a drafting issue, but it is also an issue about what is known in law as reverse burdens of proof, where there are statutes which appear to have imposed on an individual the burden of proving something such as that he was not driving at the time, or whatever it may be, and the courts have said that sometimes that has to be read as still leaving the fundamental burden of proof on the prosecution to disprove that fact beyond a reasonable doubt. It is quite a well travelled area of jurisprudence, which Mr Perry is very familiar with, but I am not sure that there is anything else to add on that.

Q2093 Chairman: Do you want to add anything, Mr Perry.

Mr Perry: No thank you.

Q2094 Lord Joffe: The only other question I want to ask, and it is building on the questions raised by Lord Taverne and Lady Jay but with a view to putting some context into it: according to evidence submitted to the Committee, 22 British citizens have been assisted to die in Zurich by an organisation called Dignitas. Happily none of their families or friends who accompanied them to Zurich appear to have been prosecuted. As British membership of Dignitas has rocketed from 90 in 2002 to 557 last month, it is clear that there will be many more assisted deaths in Zurich. The public, I think, are confused about what the law is in the light of these facts. Would it not be

in the interests of justice for the Director of Public Prosecutions to publish the criteria he uses in deciding in such cases whether to bring a prosecution under clause 2 of the Suicide Act, so that members of the families who wish to accompany their families or friends on what is a sad last journey could make a decision as to whether or not they are in breach of the law?

Lord Goldsmith: The question was raised in the very sad case of Dianne Pretty whether or not the Director of Public Prosecutions could and should produce advance guidance as to the criteria that he would apply, but the view has been taken by the Director that he ought not to attempt to do that, that he should continue with the policy that he presently has, which is of reviewing the circumstances of any case presented to him after a police investigation, deciding, on the circumstances of the case, whether a prosecution should be brought or not. Part of the reasoning for that, as I understand it, is that it would be inappropriate—because this is really what was being put him—for him to issue a policy the effect of which was to say that, "I the Director of Public Prosecutions have decided to suspend or not to apply part of the law which Parliament has put in place and has not removed." The only footnote I would add is that Lord Joffe referred to cases where it is understood people have committed suicide with assistance at the premises of Dignitas in Zurich. I understand that investigation at least into certain cases there have not been completed, so I do not think one should draw from the fact that there have not been any prosecutions at this stage, that there may not be.

Baroness Jay of Paddington: I thought you said to me categorically that because these cases were without the jurisdiction of the English and Welsh law that it would not be appropriate at this stage—I think the phrase you used in the papers it was "generally accepted that they would not be prosecuted" anyway?

Chairman: That is in respect of offences committed solely abroad.

Baroness Jay of Paddington: I thought we were talking about solely abroad?

Chairman: I think that is the point.

Q2095 Baroness Jay of Paddington: I am so sorry, I misunderstood what you said.

Lord Goldsmith: What I would seek to say is that in relation to what happens abroad there cannot be a prosecution. In relation to what happens here there can be, and at least in theory there is the question as to whether what is done prior to leaving the country in order to go to Zurich amounts to aiding and abetting, counselling or procuring.

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Q2096 Baroness Jay of Paddington: So that a case like the one of *Z v the Local Authority*, not necessarily that one, but those kinds of circumstances could be looked at again?

Lord Goldsmith: Yes.

Q2097 Chairman: I think paragraph 17 deals with this point expressly at the first sentence there, and so the question in any such case is whether arrangements were made in England or whether the arrangements were made only abroad. If they are made only abroad, there would be no question of prosecution. If they are made to some extent in England, there might be, and the Attorney has said there are some investigations, without specifying which cases, still going ahead, and therefore one cannot say for sure, but the jurisdictional position is reasonably plain. Whether or not in any particular case there were arrangements sufficient to breach the law made in England already would be perhaps more difficult to determine, but it would require investigation.

Lord Goldsmith: Absolutely.

Q2098 Chairman: I think I am right in saying that your evidence earlier would cover this, that the Director of Public Prosecutions has no specific policy relating to that type of offence. It was general criteria which are used for deciding whether or not prosecutions should be brought that apply to this as it would apply to the vast majority of other offences?

Lord Goldsmith: Yes.

Q2099 Baroness Thomas of Walliswood: I am not a lawyer, and I hope you will forgive me if I ask a question which does not make sense in your terms, but I am going to try my best to ask it all the same. As I understand it, and we see it in the *Bland* case, the courts make law in the sense that a serious judgment delivered in a court of law becomes a precedent for later cases in which the same circumstances arise. I hope I have got that more or less right. At same time there are pressures upon the courts which come from what you may broadly call society as a whole. People's attitudes change, and the law perhaps does not change as quickly as the attitudes change, and that is probably quite sensible. The possibilities which are open to medicine, and this more relevant for this particular circumstance we are talking about, also change. People can be preserved in life for longer than was possible years ago with similar conditions. What I would like to know is whether there is any sense in which this series of cases, which we have discussed in various contexts, actually amounts to any perceptible shift in the way that the courts are handling these extremely difficult, contentious and controversial cases. I wonder if you could throw any light on that area for us?

Lord Goldsmith: The traditional lawyer's view is that courts do not make law, they simply declare law which has always been there, but I think that is no longer regarded as a realistic approach in what takes place. I say this with some diffidence in the presence of the Lord Chairman.

Q2100 Baroness Thomas of Walliswood: I also am aware of that.

Lord Goldsmith: I think the whole issue of how far the courts can go is a very interesting and important jurisprudential and political question as well. The courts plainly do take account in different ways of changing conditions, social, medical, scientific conditions in different ways, but the courts also operate within the primacy of the law which is laid down by Parliament, and whilst the courts have had to grapple with, so it seems to me, the issues of refusal of treatment as medical technology and facilities become more and more advanced, they have sought to do it always by reference to clear existing principles, such as the right of self-determination and the issues in relation to capacity of the individual. I think to some extent I would probably leave it to others to say whether you can discern a trend of movement by the courts generally one way or another. For the purposes of the Bill, it seems to me important just to recognise that the law which Parliament has laid down in the Suicide Act will still remain the law, however medical conditions change, and the law which the courts will need to apply.

Q2101 Lord McColl of Dulwich: Does the last page, paragraph 34, of your very helpful written evidence mean that the state has an obligation to prevent suicide of a prisoner by some act of a process like hanging but no obligation to prevent him committing suicide by refusing nutrition and hydration?

Lord Goldsmith: I will ask Mr Perry to answer that.

Mr Perry: That is correct. The position is that the provision of treatment involves an invasion of the individual's bodily integrity, and the law respects self-determination in that respect. If it were not to respect it, then the provision of treatment would amount to an assault or trespass. However, where there is an individual in prison who would seek to commit suicide, the state is under an obligation to ensure that they are not permitted to take steps to do an act whereby they take their own life.

Q2102 Lord McColl of Dulwich: So nutrition and hydration is regarded as treatment?

Mr Perry: Yes.

Lord McColl of Dulwich: So he can commit suicide in a prolonged painful and uncomfortable way but not in a quick way?

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Q2103 Chairman: Is it right to say that a prisoner is entitled to refuse food or drink?

Mr Perry: Yes.

Q2104 Chairman: But the authorities are under a responsibility to take all reasonable care to ensure that there are no means presented to a person in custody by which he or she would be able to kill themselves. I have a feeling that, in fact, I was a party to the case you referred to in paragraph 32. I am not absolutely certain of that, but I am very familiar with that line of authority. I think it is the case that there is a general rule of that kind in relation to people in the care of the state, that, for example, a thing on which it would be easy to hang a rope, or providing a rope, or something of that sort, would be regarded as a breach of duty, whereas the state is not obliged to force a person to eat or drink if they decide that they do not want it?

Lord Goldsmith: May I add one point, because I know Lord McColl used the expression "commit suicide". It goes back to what I said before, that the law would not regard somebody who refuses to do something as committing suicide and, therefore, someone who does not take steps to force them to eat or force them to take treatment is not regarded as aiding or abetting suicide. If somebody takes a positive act by hanging himself or whatever else it may be, then that would be a suicide and people who assist with that by an act would be in a different category. The law has a tight definition.

Q2105 Lord Taverne: How far has the law changed in one respect? It used to be the practice for Home Secretary's to force the prisoners who went on hunger strike, and it was the Home Secretary at the time who decided that that should no longer be done. The Bobby Sands case is an obvious one. Would the Home secretary now be in breach of the law if they went for force feeding?

Lord Goldsmith: Yes, unless the person who was refusing food was not competent to take that decision. There is certainly at least one court decision where the court has authorised force feeding in circumstances where the view was taken by a judge that the individual was not competent to take a decision because of the medical condition from which he was suffering, to be fair, evidenced, I think, to some extent by what he was doing in relation to force feeding. This was Ian Brady.

Q2106 Baroness Hayman: It is in a sense a circular argument, is it not?

Lord Goldsmith: Yes. The court reached a conclusion on all the evidence that he was not competent.

Q2107 Baroness Hayman: But he was not sectioned under the Mental Health Act?

Mr Perry: He was detained as a convicted murderer, but he was being detained in a secure psychiatric hospital.

Q2108 Chairman: It is probably not a very fair question for me to ask, but what is the underlying principle that requires due care to be taken, as, for example, in Reeves' case?

Lord Goldsmith: It is not a fair question.

Q2109 Chairman: I readily acknowledge that?

Lord Goldsmith: With diffidence, I would suggest that the way we would put it is to say that, once the state has taken responsibility for an individual by taking him under their charge, then the state comes under an obligation to exercise reasonable care in relation to the welfare and well-being of that individual.

Q2110 Baroness Finlay of Llandaff: I am sorry; this is going to be a terribly badly worded question. You referred earlier on to the principle of best interest. It has been suggested to us that if this Bill became law then the possibility of physician assisted suicide and euthanasia would be a therapeutic option, because it would be part of the therapeutic armamentaria of the doctor, and once something is a therapeutic option, then it has the potential to fall into the patient's best interests because it would not be a therapeutic option if it were never in somebody best interests. At the moment we do not consider killing as within the realm of best interest, so it is never a therapeutic option as defined and in the law. I wonder whether there would be a position in law whereby it could be deemed to be an obligation on physicians to offer assisted suicide or euthanasia to all patients to whom it might potentially pertain because it could potentially be deemed to be in their best interests, linking into them being informed of all of the therapeutic options available to them?

Lord Goldsmith: I am just considering the circumstances in which this question actually arises. The context in which I referred to best interests, and which the cases refer to, are circumstances where the individual is not competent to make a decision. As the *Bland* case shows, there are circumstances in which the individual, not being competent, is therefore not in a position to say, "I do not want any further treatment". Notwithstanding that, are the medical officers under a duty or are they entitled to decline to provide further treatment because they regard it as in that person's best interests because they are in a vegetative state or whatever it may be? Where the person is competent, that is not a question which arises; and my understanding of the bill is that one of the key conditions under which it would apply would be that the person was competent to make that decision and was competent, as I have said, right down to the moment of death.

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Q2111 Baroness Finlay of Llandaff: So what would be the position in law if a doctor who had a patient in front of him and decided to not offer something to that patient which other doctors would consider was a therapeutic option for that patient? For example, a person with a malignant disease where the doctor took a decision to withhold the information that radiotherapy and chemotherapy were available, whereas if that patient were being treated by somebody else, he would have been offered that therapeutic option. Is it an offence in law to withhold that information or not?

Lord Goldsmith: I do not see why it would be an offence in law. I am focusing upon the criminal offences in law and not touching in any way—it would be right outside my field of expertise—upon what the standards of professional ethics required by the relevant professional bodies would be. I put that out of my mind. I do not think that declining to invite a patient to consider the possibility of suicide would be a criminal offence.

Q2112 Chairman: Thank you very much indeed for taking the time to come along, Attorney General, and to Mr Perry also for coming along and helping to eliminate an area which has certain difficulties in it

for us to fully understand. So far as the draft paper is concerned that you have given us, we would perhaps invite you to let us know if you want any changes to be made in it. Otherwise we would be likely to use it as part of the evidence. I do not myself notice anything that has come up in the course of the discussion which modifies it, but you may want to let us know.

Lord Goldsmith: I will do that, and I will do that very shortly.

Q2113 Chairman: It may be just a little helpful to slightly extend the passage that we were dealing with earlier about the form making the distinction as plainly as possible to make it between the two possible cases, a case where there is no arrangement made in this country, all the arrangements are made abroad, and cases where the arrangements are started being made in this country and continue abroad.

Lord Goldsmith: Yes.

Q2114 Chairman: As far as I am concerned, I think what you have put is quite clear, but it may be possible to make it even clearer. Thank you very much.

Lord Goldsmith: We will do that.

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Present	Arran, E	McColl of Dulwich, L
	Finlay of Llandaff, B	Patel, L
	Hayman, B	St Albans, Bp
	Jay of Paddington, B	Thomas of Walliswood, B
	Joffe, L	Turnberg, L.
	Mackay of Clashfern, L	
	(Chairman)	

Examination of Witnesses

Witnesses: PROFESSOR KATHLEEN FOLEY and PROFESSOR TIMOTHY QUILL, examined.

Q2115 Chairman: We want to thank you both for joining us, one from New York and the other from New Orleans. The system is that what you say is taken down by a shorthandwriter and the transcript will be available for you to check to ensure that what is narrated is what you thought you said. The draft will then be put on our report as part of their report which will become public when our report is published, so your evidence as corrected will be part of that report and become public property at that time. I think it would be useful if each of you were to give a short introduction on the subject matter of our Bill, and then I will invite my colleagues here to ask you questions on matters on which they think you could be of further help. Let us begin with New York.

Professor Foley: Thank you for the opportunity to meet with you. In this brief five minutes I will introduce myself, and then speak about my concerns about the Bill. I am Kathy Foley; I am an attending neurologist at Memorial Sloan-Kettering Cancer Centre. This is a 380-bed cancer research centre in New York City. I have worked here for about the last 30 years and have developed an internationally recognised clinical and research programme in cancer pain. I have also chaired three WHO expert panels which have published the really leading monographs on pain and palliative care in cancer patients, in children, and focusing on cancer pain, again with many of my British colleagues who have helped foster that work. I have been a director for the last nine years of the US project to approve the care of the dying, sponsored by the Open Society Institute. That project has ended and I am currently the director of an international effort to improve end of life care, and I am the current president of the International Association for Hospice and Palliative Care. As I want to focus on the Bill, I think I am particularly respectful of the work of the Committee and their commitment to try to improve the care of the dying. However, my sense is that this Bill does not really address the major problems of the dying in Britain nor in the world. The WHO in developing its initiatives in palliative care has asked governments not to consider such legislation for physician assisted

suicide and euthanasia until the needs of their citizens had been met with pain and palliative care services, and clearly Britain is a leader in advocacy for hospice and palliative care yet the full penetration of services in your own country is not available, as in mine, and especially is not available for those of our ageing population with non cancer diagnoses. Not all of your citizens have access to palliative care units, as occurs in my own country, or to full home care and hospice services, but more importantly these programmes as funded by your country and your government, particularly your hospice programmes, require anywhere from 30-50 per cent of philanthropic support to survive, so the government is only paying half in some areas and perhaps higher in others, but with limited resources and a lack of 100 per cent funding my concern is such services are at enormous risk, are not fully penetrated, and even not met as my own country has not met the criteria of the WHO that such services are available to 100 per cent of people 100 per cent of the time. I think more importantly it will be a very strong statement that Britain makes to the world that its way to focus on caring for the sufferer is to kill the sufferer, and legalising physician assisted suicide and euthanasia does that. It would make the physician the agent of death, it medicalises killing really at a time when our resources for care are limited, when physicians in their daily practice are under enormous pressures in your country and in my own, and perhaps it will take 10, 20, or 30 years for all of these issues to be resolved and for care to be provided to all, and perhaps at that point in time this legalisation might be reconsidered, but at this point in time it is I do not think economically feasible or socially or politically appropriate to do so for the implications and damage that it might do, both to the profession of medicine, to the trust of a patient-physician relationship and, most importantly, to the care of the dying. I have some specific issues about the Bill and will try to rapidly address those but I am happy if you wish to cut me off in what I am saying. The Bill is named in a way to really deceive the public. As you know, advocacy groups in my own country as well as yours

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have done focus groups and public relations campaigns and learned that assisted dying is a much more acceptable way to talk about physician assisted suicide and euthanasia. I think the Bill should be more transparent for the public so that the public understands that it is about physicians assisting patients in their death by allowing the patient to commit suicide or actually killing the patient, and although this language is charged I think is important for the public to participate in that kind of an open discussion and to hear it in that way. As the Bill is written it is rather subtle, a little bit hidden, and I do not think it is as transparent as other British Bills typically are, so I would appreciate to see that the Bill's name be changed and there be more openness about the issues. The Bill outlines medical therapy for the dying but does not give any definitions of either terminal illness or of suffering. Like The Netherlands, but in contrast to Oregon, the Bill states that patients have to have unbearable suffering to enjoy this medical treatment, but what is seen as unbearable to one clinician and one patient is seen as highly treatable to another and clearly my 30 years' experience in this centre has taught me that patients who were thought to be untreatable, whose pain was uncontrollable and unbearable, are readily controlled with super expertise provided to them, and like your country and like mine such expertise is not widely available to everyone in our society. The patient is to be informed of alternatives but that is not enough. They really I think, if you are to move forward with this Bill, really have to have a trial of those alternatives. Both studies now from The Netherlands and some studies about patients in Oregon suggested that in both countries up to 46-50 per cent of patients have not received palliative care services that they might benefit from, and when offered to them choose that rather than physician assisted suicide in Oregon or even physician assisted suicide or euthanasia in The Netherlands. They also need rather sophisticated psycho social support. I guess the question will be asked will the patient who requests assisted dying, if they say "Will you replace my hip", be able to jump the queue in your country for hip replacement or for a ventricular defibrillator because they said that otherwise they want physician assisted dying? These are issues that have to be addressed. Will the ALS patient in your country receive C-path or have home perenteral feedings as another choice in their unbearable suffering of living in a nursing home where they wish not to be? Will they receive 24 or even 12-hour nursing home, or will they receive the support and care of their children? Will the disabled be dealt with differently under these regulations? We know several things from The Netherlands—that the practice cannot be regulated; that there is significant under reporting from The Netherlands in a country where tolerance and

openness has been fostered, so that one is creating a law and regulating something that appears to be unregulatable in the country where we have the greatest experience. We know little about Oregon because of the secrecy surrounding the Bill, and we also know little about those individuals both in The Netherlands or in Oregon that have requested physician assisted suicide but have been rejected by the health care establishment, and we know little about the care that they are receiving, so that we are at a loss to help predict what would happen and what safeguards should be in place for those whose requests are rejected and how we might provide appropriate care, and this moves me to the broader construct which is the important issue is how we care for the huge large majority of people, the 99 per cent of people who need good care, and to what extent have we met their needs and met the WHO recommendations? Lastly, I think the point that I would like to make in summing up is that there is, as I said, new data coming forth from The Netherlands and some from Oregon that suggest two things: that the physician-patient relationship does not exist; that patients aided in death know their doctors less than three weeks in Oregon, and the prescriptions are written by those physicians. In The Netherlands it is common for physicians to reject the request for patients, and yet we know little about the care. In a very interesting study published by Doctors Pearlman and Back they interviewed family members of individuals who were aided in death through an underground network in Oregon in Washington, so they were not within the legal system within the US, and what was apparent about those patients is that for 15 years, for 14 years, for 12 years, these patients had always said that they would commit suicide if they developed a serious illness, and this was a very fixed belief on their parts, and I think understanding that and knowing that suggests that there is a population of individuals who are not necessarily suffering unbearably, not necessarily being undermanaged or undertreated, who choose this approach, and so I think the question that we need to ask and that you need to ask is are we then attempting to cater to a very small population of patients who want control over the end of their life and want physicians to provide that control, and that this Bill is not about compassionate care to a population of individuals but about facilitating the needs of a group of people who would wish this, and I think that is a very important issue that now, again, data from The Netherlands and data from Oregon is helping us begin to assess. In closing, then, I think Britain has been the leader in advancing palliative care; it has a long way to go like the rest of the world; for those of us who work in resource poor countries where you have been the leader I daily see patients who have no access to morphine, no access to antiretrovirals,

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inappropriate care, and the message they will receive from you will be that "We do not have treatments for suffering except to kill the sufferer", and I think that for a society at this point in time would be a serious implication for the professionalism of medicine and for the care of the most vulnerable in our society of the dying.

Q2116 Chairman: Thank you very much. Now I think we will ask Professor Quill if he would be kind enough to give us his introduction.

Professor Quill: Thank you, and thank you for giving me the privilege of speaking with you here today to give you another perspective on this subject. My perspective comes from my work as a primary care physician for 25 years. I am also a professor of medicine, psychiatry and medical humanities at the University of Rochester in Rochester New York where I direct our palliative care programs, and I was also a hospice medical director here in the US for 10 years. I am in New Orleans right now because of the national hospice and palliative care meetings here. I have written about the doctor/patient relationship, about doctor/patient communication, medical decision-making and end of life decision-making; those have been my areas of study during my career. Like Dr. Foley, I too advocate improving palliative and hospice care everywhere I go, and agree with her that services can be improved. We do not have perfect systems of end of life care or palliative care here in the United States or in the United Kingdom, as we do not have a perfect system in many other aspects of medical care in both of our countries. I also advocate for better last resort choices for terminally ill patients whose suffering becomes intolerable to them despite excellent palliative care. Most such patients have undertaken long battles against their underlying diseases, and most accept hospice reluctantly only when that battle has been lost. Although palliative care should be part of the treatment plan for all such patients while they are receiving active, disease-directed treatment, palliative care becomes the predominant focus toward the end of life. Both of our countries have excellent systems of care to address the needs of those who accept that they are dying, and these systems can generally relieve most, but not all suffering. It is for the latter patients, whose suffering becomes intolerable despite our best efforts to provide relief, that the question of a physician-assisted dying emerges. I found myself in the center of this debate when I published a narrative in the *New England Journal of Medicine* in 1991 describing my providing this possibility to a patient named Diane. Diane had acute leukaemia, and initially turned down aggressive treatment that had a small chance of cure. She wanted to make the most of her remaining time to be with her family and to complete some "unfinished business." She hoped to live as long as

possible, provided her life was meaningful to her and she could interact comfortably with those around her, but when and if her quality of life was irreparably lost, she wanted to die quickly and painlessly. What is not well understood about her story was that Diane then spent over 3 months on a home hospice program. During that time, she took several life-prolonging treatments such as transfusions and antibiotics. Because I was willing to give her access to medication that could end her life, she was able to live that time without fear that she would have to suffer in a condition that would be unacceptable to her. She only took her life at the very end of this process when she had an uncontrollable infection and accelerating symptoms and her life would have been measured in hours to days which would have been, to her, unacceptable. I have subsequently met many people who were like Diane for whom this is a very fundamental issue, and it is for these people that this question about legal access to a physician-assisted death comes up. These are people who want a loud voice in how they die. They are often people who have been through long struggles in the medical system, trying to live longer and those struggles have ended. Now, excellent hospice care in this country is the standard of care for people who are dying and palliative care should be part of the care plan for everybody with a severe illness. Assisted death should only be thought about for those infrequent cases when suffering becomes unacceptable despite our best efforts. If such a person is on a life support we give a very different message as palliative care physicians. The message we give when a person on life support says they want to stop is "listen to the patient, they generally know what they are talking about", it is very critical to listen to them at this juncture. If someone does not have a life support to stop and their suffering is the same or much more severe, the message we give is very different—there "must be something wrong with the patient; all they really need is more palliative care." In fact what we should do in both circumstances is listen attentively to the patient, carefully evaluate them for depression, and make sure their access to palliative care is sufficient. If they have looked at every alternative and are still suffering intolerably, then we try to find the best way to respond to them. If we are considering stopping life sustaining therapy, you will see if you look into a medical record that we get our best minds together. We document very carefully what we are doing, and we are very cautious about doing this even though it is medically permissible because it is subject to all the same risks that physician assisted suicide would be. If the patient receives a physician assisted suicide chances are there are no second opinions; the process goes underground. Because of this secrecy, physician-assisted suicide can be much more idiosyncratic than the process of stopping life

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supports; so one of the key questions in this process is do we better protect and respond to patients with a secret system like in the United States outside of Oregon, or with an open process? We now have empirical data from Oregon about what an open process might look like; and we have learned that physician assisted suicide accounts for one in 1,000 deaths; it is not a frequent occurrence. But one in 50 people who are dying talk to their doctors about physician assisted suicide, so the process of discussion is much more open. One in six talk to their families about this, so this taboo topic that was occurring underground is much more out in the open. We also know that 85 per cent of people who have died from physician assisted suicide in Oregon are participants in home hospice programs. Also, in Oregon, compared to the rest of the nation, palliative care has really improved. There are more deaths at home than in other parts of the country; morphine prescriptions per capita are among the highest in the country; physicians attend pain and medical communications workshops more than in the rest of the country, and that the study of this process when you open it up becomes much more intensive. Most of my work is done doing standard palliative care consultations right now. I help patients and families achieve excellent pain and symptom management and try to understand their goals in light of their medical condition. Our palliative care teams provide support and try to help patients and families make the most out of the time they have. It is inspiring work, and it is something that I genuinely love to do. I have also become a safe person for people to talk to who are considering these last resort options because I have been willing to talk openly about the practice of physician assisted suicide and other last resort options, so I see cancer patients and ALS patients who are wondering about these options. Most want ideas and support as they are considering what their choices might be at the end of their life; they do not have the kind of choices they would like—they would all choose to get better if that was within their grasp. All would like to live as long as possible as long as their life has meaning, but many of these patients also want information about what choices they could have. Armed with this information most people choose to keep living and they live in a way that feels less trapped to them, so the possibility of an escape is extraordinarily important to many people. A few will end up wanting some kind of assistance in dying and, again, this is where we need to have a much more open process, a predictable process, a process where we can get our best minds together to try to find a way to respond to these patients. Such open response is a core part of what we ought to be offering in palliative care; because it is infrequent does not mean it is unimportant. Thank you.

Chairman: Now it is open to members of the Committee to ask questions of one or other of these contributors from the other side of the Atlantic.

Baroness Finlay of Llandaff: Thank you both for being with us today by link. I have a question for Kathy Foley. Could explain the difference between a patient who decides to stop their treatment in the example that we have just been given and a patient who asks for physician assisted suicide or euthanasia, and the difference for the caring team but also where there are differences for the patient themselves in that? Although the outcome for both is that there will be death, I wonder if you could explain if you see there being differences in the route to that death.

Professor Foley: I think that is an important question because probably Dr Quill and I disagree on this construct of making distinctions between withholding and withdrawing care, and assisting patients in death. As you well know probably, our Supreme Court made the distinctions between withholding and withdrawing care, and physician assisted suicide and euthanasia from a legal perspective and withdrawing care, if we use the example of life support that Dr Quill gave, is an example where really what patients are exercising is their right not to have their bodies invaded by a respiratory support, by a bronchial tube, by a variety of devices that are viewed as external to them invading their body, and that they have control and permission to give up and not to use that type of support. Again, the attempt to conflate withholding and withdrawing life support to physician assisted suicide has been a very strong movement, making them appear that they are the same as opposed to being different. So let me give you some aspects of how they may be different. If we talk about withdrawing a patient from life support, in this country life support typically occurs in patients who are institutionalised. We have very few patients at home on life support, so therefore life support occurs in a very regulated transparent environment where, when patients wish to have their life support removed, they typically will request it of their physician, they often will request and have discussions by an ethics committee, the hospital administration may be involved in it as well, a lawyer may well be involved in it—there are a variety of aspects that make it quite open, quite transparent, and therefore highly and fully regulated. Those patients commonly in hospitals are assessed by a psychiatrist, so that the common approach is that the patient is asked, a psychiatrist is asked to comment on the patient, and a variety of open transparency occurs. In physician assisted suicide, if we use the US example, it occurs in the secrecy of the home with no psychiatric consultation and with no discussion but with, more importantly, the recognition that we are not asked to provide treatments to patients in that setting and no patient is invaded except by a disease over which the physician and the health care establishment has little or no control except to help

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improve it for the patient. So the settings in which this occurs, the transparency and the ability to regulate, are really quite different and there is a belief, both ethically and philosophically, that these are different but there is a movement to try to conflate all of these. The use of high doses of opioids, withholding and withdrawing all end of life procedures all have the same aspects, yet our philosophers and ethicists see them as distinct and our legal system has seen them as very clearly distinct. Our constitution has given people a constitutional right for withholding and withdrawing of care and yet there is no such thing as a constitutional right to physician assisted suicide and euthanasia.

Professor Quill: Can I comment on that? I do not disagree that there may be ethical, legal, and perhaps moral differences between them—I do not disagree with that. I also try to look at these acts from the point of view of the patient who is faced with being ready to die, and we clinicians are often racking our brains for something that can be stopped to help them die so that we are within what is legally acceptable to do. Many patients do not see any significant differences between dying from voluntarily stopping a life-sustaining therapy and dying from taking an overdose of legally prescribed medication. In my opinion, the patient's and their family's views and values in the circumstance are often the most important as we think about these acts and are trying to respond to a particular patient, so we are very often trying to find a way to respond and if we can find a life support to be stopped then we would stop that life support. In my view, all of these "last resort" acts that result in a patient's death should be subject to very similar kinds of regulation: in fact there is very little formal regulation about what is required to stop a life support, so even in the absence of regulation there is good documentation. Many of these cases are, however, at home as well. Feeding tubes can be stopped as a life-prolonging therapy; some patients on ventilators are at home, but still you see very good documentation about what is going on because it is an open process. If you did any of these acts without a patient's will then you would be into a very troubling moral conundrum, so they all depend very heavily on trying to act according to the patient's will and wishes.

Q2117 Lord Turnberg: It has been very helpful listening to your experience. We have been teasing away at some of the issues and one of them has been defining "terminal illness". We have been talking about terminal illness being within six months of a person dying, as far as one can tell. I wonder if you have any comments on this?

Professor Foley: I would be glad to start. There are probably two references that might add to your confusion about this issue, that is work by Joanne

Lynn and the data from the support study and what Dr Lynn showed in a group of seriously ill patients, over 10,000, admitted to five leading centres in the country who were studied with interventions that were focussed on improving their end of life care, was that on any one day those very seriously patients had a 50 per cent chance of living for a year or longer. Nicholas Christakis has written a very lengthy text as part of a PhD thesis on prognosticating and has again attempted to come to some definition of how one would identify a terminal illness. As you know our Medicare healthcare policy requires that patients be given a diagnosis prognosis of less than six months, yet we see many patients living quite beyond that and see the deficits in the prognosis. What Dr Christakis has identified is that for the most part physicians are poor at prognosticating about their patients and, again, can be wrong as often as 50 per cent of the time using a six month criteria. Dr Lynn has suggested that if one uses a criteria of one year you might be a little bit better and increase the statistical validity of using one year, but again it is not this reliable and she has argued that really the way that we should decide how we provide care financially, economically and otherwise, to people at the end of life, should be on their functional status and their burden of disease and not based on the idea of a terminal illness. There are others much more famous than I who have said that life is a terminal illness, so we could argue that this could be available to people from the moment of birth.

Professor Quill: The definition of terminal illness is something we are used to doing. To go on to a hospice programme in this country you have to have a prognosis of six months or less. We had a fairly stringent criteria in the past of six month prognosis and what ended up happening is people generally lived a very short period of time because we had to be so sure they were likely to die in six months, and if you were not that sure, if your programme was a little more liberal but it was just likely they would die in six months then your programme might be cited so we really for a while moved that prognosis very short. The six month prognosis has now been liberalised for hospice purposes so you have about 80 per cent chance of dying in the next six months and length of stay has gotten a little bit longer. We clinicians are used to prognosticating all the time, and in doing so we are making statistical statements of probability. The patient is likely to die in six months. When a person goes to an acute hospice unit, we prognosticate that they are very likely to die within the next two weeks. There are some times when we can be quite sure of that; there are other times where it is less certain. Heart failure is a good example of where there is a lot of uncertainty about how quickly a person would die, but some of that uncertainty depends on continuing very aggressive treatment. If

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we continue all of those treatments that a person is on, then it is very uncertain how long they will live. If we are going to stop all those treatments, they are highly likely to die in the near future. The reason why we continue these medications even when a patient is prepared to die is that the symptoms when you stop the treatments can end up being very difficult to deal with. One of the other things we have learned about physicians prognosticating is that, in fact, they tend to be overly optimistic rather than pessimistic, so when a doctor says the patient might live a month the average patient is probably going to live much shorter than that. Physicians tend to be overly optimistic when they prognosticate.

Q2118 Chairman: I think we were told that in the hospice conditions you are required to opt for having comfort care only, is that right?

Professor Quill: That is correct, but take as an example a heart failure patient. Treating their heart failure is a comfort measure—in other words, treating their disease keeps them comfortable, so it does not mean they are stopping all their heart failure treatments. Those are generally only stopped when they are imminently dying and we use other measures to manage their final symptoms, so even in hospice care we try to keep people alive and going as long as possible as long as their life is meaningful to them. Many disease treatment measures are comfort measures as well.

Professor Foley: I would like to respond to that, if I may, because I do not fully agree with Dr Quill. The way that legislation is written is that patients do have to give up concurrent care, that is aggressive chemotherapy; they are not candidates for phase two or phase three clinical trials; that is not covered in the Medicare benefit at the present time; and patients who have significant cardiac failure could not then become candidates for heart transplants or ventricular defibrillators and receive concurrent hospice care. The financing of Medicare is established in that way. There are hospice programmes around the country who because of their philanthropic support and added monies provide some of those services to patients that are not necessarily provided, so in contrast to the American hospice system as compared to the British we are not fully integrated, as you are; concurrent care is not possible; and patients do have to make this choice of giving up aggressive cancer therapies for hospice care. This is a policy issue that is under great debate and of great concern but it is quite different from your system where concurrent care is available.

Q2119 Lord McColl of Dulwich: I am a practising surgeon and I would like to ask two questions. What is the evidence that, outside Oregon, physician assisted suicide is happening underground?

Secondly, is the specialty of palliative medicine recognised as a distinct specialty in the United States, Holland, Belgium or Switzerland, as it is in the United Kingdom?

Professor Quill: Let me go first on this question. In terms of the secret practice in the United States, Diane Meier, myself and several others have done a nationwide study on this subject and found that the secret practice seems to be about the same rate as in Oregon, somewhere in the two-three per cent range, as best you can tell. (Meier et. Al. A national survey of physician assisted suicide and euthanasia in the United States. *New England Journal of Medicine*; 338:1193-1201) The techniques you have to use to study these secret practices are very challenging; we spoke with researchers who conduct nationwide studies on child abuse and other illegal activities to try to get a sense of how we can protect the respondents and still get true data about this, so it is not the strongest data in the world. The Oregon data are much more reliable because of people openly responding for themselves about a legally accepted practice. Palliative medicine in the United States is a growing medical field that is on the verge of being a formally recognised specialty; there is a certification process here in the States that a growing number of people are obtaining. We still have many more job openings for palliative care clinicians and researchers than there are people to fill them, but I think it is a specialty that is growing here in the States.

Q2120 Lord McColl of Dulwich: Would it be possible for you to let us have the published papers showing this evidence, please?

Professor Quill: Yes. I would be glad to send that to you.

Professor Foley: There are I think two published papers, one in press and one in review by Doctors Back and Pearlman who interviewed 60 family members of 35 patients who had been aided in death or who had themselves had committed suicide in the setting of a terminal illness, and these are patients who for the most part had had, as I mentioned previously, longstanding beliefs that this is what they would do, and this is an analysis through very detailed family interviews of what made them do this, "What the physician/doctor relationships were" is the name of one paper, "What the timing of death was" is the title of another, and I can provide you with those references, but what they do provide us in contrast to other data that we have is the sense of a group of individuals who do not see that they need doctors for any part of this and really do not wish to involve doctors with this, although they would have benefited by speaking with doctors and who have had long committed views on this sense of control, and I think it is important for us to recognise that and also I totally agree with Dr Quill that physicians should be

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able to have detailed discussions about the concerns of patients for hastening their death and what the meaning of that is. I will gladly send you a series of papers written by one of our leading palliative care nurses, who did a phenomenal logic inquiry with patients who asked for a hastened death, and to hear the compelling conversations of these patients who felt in such a power relationship with the physician, who felt that they were afraid to say to the physician that they were in pain because it might obscure their further treatments, who felt that hastened death was the only option because of poor communication with their physicians, but most importantly their significant vulnerability. So I think we are beginning to have a much better understanding, and clearly every physician needs to know how to talk with patients about these issues, and how to evaluate patients and to provide them with options and what those options are. There is such a range of options from dignity conserving therapy that Dr Chochinov has advised for such patients and demonstrated improvement, and now the data from The Netherlands and Oregon suggesting that when patients are given such options they choose them for their care; he is beginning to open up in a much broader sense our understanding of how to care for such patients and their requests.

Professor Quill: Additionally, this is one of the fundamental questions I think you need to think about, and we all do; whether these kinds of conversation that both Dr Foley and I believe should occur are facilitated by an open process or not. Currently if you want a physician assisted suicide outside of Oregon this exact conversation goes underground; it becomes dangerous to get a second opinion because it might undermine an illegal practice, so in fact these are very complex conversations. One of the good things about an open process such as is being considered in the United Kingdom is that the patient is evaluated by his or her own doctor, and also a specialist in their illness and a specialist in palliative care. These are very complicated questions and the vast majority of people raising them simply want to explore them, they want to know there could be options, and they probably will not act on them.

Professor Foley: But I would argue that an open process does not really add to it because I can tell you that in our hospital-based consultation service this is a very common question for patients who are expressing their desires for a hastened death, their willingness to be open and talk about it. They are enormously relieved, and here in New York State where neither physician assisted suicide or euthanasia is legalised, these are very open discussions with patients who understand this is an illegal practice yet want very much to talk with them, and our psychiatry service here has enormous

expertise in looking at these issues of hastened death. Dr Bill Breitbart has published a series of studies from our population and an AIDS population he cared for where this has been very open, so Americans and particularly those in New York have no question they wish to talk about this, want to talk about it, need to talk about it, and there is expertise to provide that conversation, and it does not necessarily mean you have to provide that to the patient and the open discussion does not require an open legalisation policy.

Q2121 Lord Joffe: I want to ask three brief questions which I will roll together in relation to prognosis. We have had evidence that prognosticating in relation to cancer cases in particular and the end stage of life can be reliably done. Secondly, that it is much easier and much more reliable to prognosticate in relation to the very last months of a terminally ill patient's life and, thirdly, have you statistics on the average length of stay of terminally ill patients in hospices?

Professor Foley: I can begin with the last question, and this is published data that the National Hospice and Palliative Care Organisation will gladly provide to you, but the average length of the stay of patients in hospices—and it is important to recognise that our hospice programmes are different from yours—eighty per cent of patients in the US who receive hospice care receive that care at home and 80 per cent of the care has to be provided at home, so we do not have in any way the number of freestanding in-patient hospice programmes as do you. The length of stay is 14-16 days, and this has been reduced rather dramatically over the last several years for many different factors. The data for cancer—I do not want to say that it can be reliably done but because we have the best of the survival curves for cancer treatment we can use those to be predictive but we have little to no data on patients with congestive heart failure, on patients with Alzheimers, on patients with chronic neurological degenerative diseases. Those are the areas where we lack the most, and recognise in the US that only 20 per cent of our population receives hospice care so 80 per cent of people die in the US without ever receiving hospice care, yet 60 per cent of cancer patients receive hospice care. Do we know the last months and days of life? We do and we do not and I think this is often the dilemma and, as I will reiterate, this is why we have tried to argue that in social policy and government policy the language of terminal illness is one that is not definable well enough except in a very arbitrary way which one can accept, and why is a patient's life with six months different from a year, and why are we making a decision here of terminal illness and not serious illness?

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Professor Quill: Certainly, if our median length of stay in a hospice is two to three weeks, that suggests we have some accurate, conservative definition in terms of what constitutes terminality. You can make an argument that is way too short for that particular decision and, certainly, I would advocate longer stays for people on hospice programs. Some of the reasons that so few people die in hospices has to do with the reasons which Dr Foley was talking about, that our hospice programs restrict the most aggressive disease directed therapy and do not pay for it. Many times, when we are trying to prognosticate in heart failure or in chronic lung disease, particularly heart failure, the uncertainty comes because we are still continuing a good amount of disease directed therapy. If we stop those therapies people will die much sooner, but the challenge is that they will then die much more symptomatically if we stop those therapies. Again, we tend to only stop them only when patients are literally dying. It does illustrate some of the complexity of prognosticating. With people who are ready to die, they would be ready to stop all of their treatments, but then that might lead to a very symptomatic death and that is the challenge those patients present to us.

Q2122 Bishop of St Albans: My name is Christopher Herbert, and I am the Bishop of St Albans. I would like to raise a question with Dr Quill. I am assuming if a patient asked you for euthanasia simply because they were tired of life, you would not meet that request, but you would advocate euthanasia, therefore, only for those patients who were suffering unbearably. It follows that if appropriate pain control was available, would you be still advocating euthanasia?

Professor Quill: I am not an advocate of euthanasia, I am probably much more of an advocate of physician assisted suicide because it has the safeguard built into it of having a patient finally having to act by his or her own hand. That is an important piece of the puzzle. On the other hand, you still have to have a way of responding to people suffering the same or greater who cannot take the medication. Again, in this country, the way we respond to such cases would be with the possibility of terminal sedation or stopping eating and drinking. There are possibilities that patients have which are not euthanasia. With regard to how much and what kind of suffering, I think we have very good answers for almost all pain problems. Pain is very rarely the sole reason a person is asking for an assisted death. The data in Oregon support this very much and all of the other studies I have seen support this also. When a person says to me they are ready to die because they have a lot of pain, I breathe a huge sigh of relief because I have learned from Dr Foley and others about good pain relief measures and if I cannot do it myself I can find other experts

who can help. More commonly, people want to die because they are tired of living, they have been going on a long time with their illness, they have many, many symptoms in addition to pain such as: debility; fatigue; anorexia; open wounds; they cannot get up; they cannot sleep, all kinds of symptoms which simply they are exhausted with, and they are frequently symptoms which we have less good answers for than we do for pain. Generally, when a person says they want to die, and they are asking for euthanasia or assisted suicide, this is the beginning of a serious conversation and intense evaluation where we look for and try to understand the nature of their suffering and try to respond in other ways. Only for those cases where we can really understand the suffering, understand why it is unbearable to the particular person and do not have other ways which are acceptable of responding, are we then looking at “last resort” options. I would include in these “last resort” options interventions like terminal sedation, stopping life support, and assisted suicide as the last, last resort.

Q2123 Earl of Arran: This is a question to both Dr Quill and Dr Foley, and it is a very obvious question. When we were in Oregon, we understood from the Oregon authorities that other neighbouring states had come, seen and had, indeed, flirted with the idea of assisted suicide with a formula for it in Oregon, but they had not been conquered by it, indeed, they have shied away. I would be very interested to know why this is? Do you think that other neighbouring states, after seven years of assisted suicide in Oregon, in the next few years will embrace what Oregon performs?

Professor Foley: We have written a rather critical argument with Dr Hendon against the Oregon health division and the fact that they have lacked transparency in presenting information. I would gladly provide the series of articles as well as an edited text we discussed. I do not think one can easily speak to the other states except to recognise that after the Oregon passage of the law—Remember it was passed in Oregon with a 51:49 per cent vote through a referendum which is a relatively usual system of creating a bill such as it was, but again, it is unique to Oregon. Oregon was also a state which had developed priorities for healthcare and, in a way, was leading the nation until the government went bankrupt trying to provide a more socialised system of healthcare. It was seen as a model in that perspective. The Oregon governor was an emergency room physician and very much an advocate. Oregon is different from the surrounding states in that since about 1993, well before the passage of the law and consideration of the law, there were discussions about prioritising end of life care. There was a development of a policy on life sustaining therapy which was advocated by Dr Susan Tolle, the group

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there, early on and way before the legislation. Then the Medicare data suggested that in Oregon only 31 per cent of people die in hospitals; if you go to California, upwards of about 55 per cent die in hospitals; and if you go to the state of Washington about 52 per cent of people die in hospitals. There is something uniquely different about where people die in Oregon along with a history of a small state focusing on socialised medicine. The other states have not embraced it. After the passage of the law in Oregon, states such as Michigan, Maine, California, all turned down votes after significant debate and discussion. In the US 10 states further enforced their laws on physician assisted suicide and euthanasia. In a Supreme Court decision, which Dr Quill was involved in, between the different appellate courts in the West Coast and the East Coast, the Supreme Court decided it was not a constitutional right. These states are quite different, California being a state with a broad immigrant population, a very diffuse population, no priorities set in healthcare for end of life care, inadequate pain and palliative care services and the report card, which has been done recently by the Robert Wood Johnson Foundation, demonstrates that it does not provide particularly overwhelmingly great palliative care to its citizens. They have different states, different populations, different make-up, different use of Medicare and we think these are very, very important differences which do not resonate with states like my own.

Professor Quill: An additional word about Oregon, Susan Tolle has written a paper about the “silver lining” that comes from the passage of physician-assisted dying legislation and more open discussion around these issues. One of the good things which has come out of this, in addition to more choice, is the concomitant improvements in palliative care and hospice care in the state of Oregon. There is much more open discussion about the real intensive look by ethicists and palliative care physicians about improving the general baseline care which everyone receives there in terms of palliation. I think there is growing public acceptance of the practice by Oregonians if you look at public opinion surveys. Why have other states not taken this on? Right now in our country it is very hard to have discussions which are not dominated by the edges, so we end up with very polarised discussions around potentially contentious issues. It is very hard to find the middle ground. I believe the next state which is likely to have a referendum which has a good chance of passing will be the state of Washington. Washington almost passed a referendum which included both assisted suicide and euthanasia in 1991. There was an unfortunate incident of Dr Kevorkian doing something very provocative right at the eleventh hour during that last referendum process in Washington, and it was narrowly defeated. Most of

these referendums come down right about 50:50 plus or minus a few percentage points. Again, this is a challenge on how we establish policy where there are significant differences of opinion amongst the population.

Professor Foley: I would like to comment on the Susan Tolle article. As much as that article has been described as what is called, the Silver Lining, Dr Tolle published a second paper in 1999, and it was a study we have supported through our project on that in America. That study analysed pain management throughout the state of Oregon and demonstrated significant complaints by family members of inadequate pain management, and this was in 1999. Moreover, Dr Quill outlined the good things about Oregon which made it, perhaps, an improved place for end of life care suggesting that it has the largest morphine availability of any state in the country. Again, it has had that since 1994 and it has led in that. We do not fully understand it except there are a large number of major pharmaceutical distribution companies there that may account for morphine being sent outside the state and not used within the state of Oregon. The aspect of physicians and patients attending many, many workshops, these were widely available around the state, I participated in several. They were predominately attended by nurses and predominately by nurses who had already expertise in pain and palliative care. Today, similarly with other states, Oregon gets a very poor grade, we call it an “E”, a the number of palliative care units within their hospitals; the number of certified palliative care physicians or the number of nurses who are certified by the Hospice and Palliative Care Nursing Association. I do not want to be critical of Oregon because many other states are similar to Oregon, but I want to point out that when you begin to look at the hard numbers—as was done in this Robert Wood Johnson report card of states around the country—the only good thing which Oregon led on was the number of deaths at home as it may be a positive indicator.

Q2124 Lord Joffe: This question is to Professor Foley. I wonder whether, when you distribute your article and send it to us, you can send us also a copy of the article by Dr Peter Goodwin, headed *The Distortion of Cases in Oregon*, who had rather more, perhaps, actual experience of what happened in Oregon than yourself?

Professor Foley: I am very respectful that Dr Goodwin may have it, but it would seem to me that—and I think something which your Committee should consider—it should not be the advocate who has these details about the patients, but that a system should be open and transparent and a health division should have this information. We are terribly dependent on advocates telling us about patient

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information which the health division will not provide to us. In any type of open, transparent society where we are trying to better understand the needs of patients and their need for assistance at the end of their life, it would seem to me the Oregon Health Division should be repository of such information, not individual advocates. I cannot send you that article because I do not think I know which one you are referring to, but if you send me which one that is I will be glad to try and find it for you.

Professor Quill: If you want to get a view from the lens of an advocate and an opponent about these issues, Dr Foley and Dr Hendon have written a book on this entire subject and, Peggy Battin and I have written a book covering some of the same issues. It can give you two different lenses to look at Oregon and other issues from each of our perspectives. If you have not had the opportunity to read those two perspectives, I think it can be helpful to try to understand our differing views on these complex issues.

Q2125 Chairman: Is there any neutral person who has written a book?

Professor Foley: I think you have raised a really important question and, as you deliberate and address this issue, it is so critical for there to be a neutral position. Because of the way the law was developed, it has constrained the Oregon Health Division from making this an open and transparent process. The data is not available, physicians who refuse to participate in physician assisted suicide are not asked to comment, their concerns are not in any way accumulated, interviewed or prioritised by the Oregon Health Division. At the same time, patients in advance are not asked to define why they want this, but rather six or nine months later their physicians are asked about this. In fairness to understanding how we can improve the care of the dying, any government which wants to support such a process needs to make it like any other medical therapy which is open, transparent, can allow for judgment of other clinicians, where there is no suppression of disagreement and where there is an openness which allows for this kind of discussion and debate rather than newspaper articles and articles written by

advocates who have lots of information but no way for verifying that information because of the lack of access and confidentiality on the concern of patients. Such patients do not want such confidentiality, often they want good care and we need to be able to regulate that care as we regulate any other care. Therefore, creating such closed systems puts those patients at risk and puts physicians at risk and does not teach us how we can better improve the care for such patients.

Professor Quill: There are genuine ethical issues involved in making some of this data available, partly because of the politically charged environment. People's privacy is violated on a regular basis outside of their choice. I agree with Dr Foley, we need to understand these issues, and Oregon is the laboratory where we have this opportunity to understand an open process. But we have to be very respectful of these vulnerable patients and their families, and how much potential there is to distort and misuse very personal information. We are also getting more and more reliable data out of Oregon from responsible researchers. For example, Linda Ganzini—who I think you may have met when you were out in Oregon—has interviewed many patients who are contemplating this possibility in real time. She is an experienced psychiatrist—one I believe who is quite neutral on this subject of legalisation—who found these patients did have the capacity to make decisions for themselves, they were not clinically depressed. In an incremental way, we are getting more and more meaningful data out of Oregon. It is at such a different level than the data we are getting from any other place in the country, that we need to let that continue to unfold and learn from it. The openness of the law has made this look possible, you simply cannot look at these issues anywhere else in our country at the same level.

Chairman: On behalf of the whole Committee, I would like to thank you very much for your assistance in helping us to understand these issues. As you have both said, these are complex issues and it is sometimes hard to know where one has got reliable neutral data on which to proceed. Thank you very much, indeed.

WEDNESDAY 2 FEBRUARY 2005

Present	Arran, E. Finlay of Llandaff, B. Hayman, B. Jay of Paddington, B.	Joffe, L. Mackay of Clashfern, L. (Chairman) St Albans, Bp.
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Examination of Witnesses

Witnesses: MR BERNARDO STADELMANN, Vice-Director, MR DANIEL FRANK and MRS CHANTAL FAVRE, Federal Ministry of Justice, Switzerland, examined.

Q2126 Chairman: Thank you very much indeed for agreeing to see us. We take a note of the proceedings and you will get a chance to see the transcript of what we think you said. You will be able to correct it if any corrections are needed and in due course it will be appended to our report. At that stage it will become public as part of our report. It would be helpful if you could give us to start with a rundown of your situation in relation to the matters that we are concerned with. As you know, our task is to examine the factual background to Lord Joffe's Bill which is proposing a certain change in the law of England and Wales relating to assisted dying. The situation in Switzerland is relevant to that and we would be glad to have your perspective on it. When you have given us a short account of the situation as you see it my colleagues would like to ask you some questions on matters of particular concern to them in this inquiry.

Mr Stadelmann: Honourable Lord Mackay of Clashfern, my Lords, my Ladies, ladies and gentlemen, I am very honoured to welcome you in the name of the Federal Office of Justice. The British Embassy has forwarded us your wish to be briefed about the legal situation in our country in matters of euthanasia and assisted suicide. We have also taken note of the basis on which you would like to conduct this meeting and we agree to have a record of our conversation by your shorthand writer. We appreciate being given the opportunity to review the transcript of our conversation before the publication of the record. [I will also be able to give you the notes of my short introduction.] The Federal Office of Justice is an agency of the Federal Department of Justice and Police; it is the Justice Ministry of Switzerland. It is responsible for key legislative matters pertaining to the constitutional and administrative law, private law as well as criminal law. It functions as an adviser to the rest of the Swiss Government in all legislative matters and drafts advisory opinions. Mrs Chantal Favre on my left and Mr Daniel Frank on my right are two of my collaborators in charge of the preparation of penal legislation. We work in the Penal Division of the Federal Office of Justice. The subject of today's conversation has often been discussed in the past in Switzerland and it is at present occupying our

Criminal Law Division, but in terms of legislative drafts it does not represent one of the Federal Council of Government's priorities during the current legislation. The legal situation in Switzerland is that euthanasia has a bearing on life—the greatest legal interest of all. That is why it is not the medical sciences but the democratically authorised legislator who determines the boundaries between permissible and impermissible killing. Indirect active euthanasia, which is defined as the use of means the secondary effects of which may shorten life, and passive euthanasia, that is, a renunciation or discontinuation of life-prolonging measures, are permissible. It has still not yet been decided whether both forms of euthanasia should explicitly be regulated by law. However, it is clear that direct active euthanasia, that is, a deliberate killing in order to shorten the suffering of another person, will remain a punishable offence. Finally, the possibilities offered by palliative medicine and care must be fully exhausted in order to ease the suffering of terminally ill patients in the last stages of life. The Federal Council of Government will have to debate in the next two years a motion on "Euthanasia and Palliative Medicine", which has been forwarded by Parliament, and examine the extent to which legislation on passive and indirect active euthanasia is necessary. It will also discuss promoting palliative medicine and the problem of so-called death tourism. First of all I would like to outline some definitions of the various forms of euthanasia and their position in Swiss law. I was talking about direct active euthanasia. It is the deliberate killing of a person in order to shorten the suffering of this person. The doctor or a third party deliberately administers an injection to the patient which results directly in their death. At present this form of euthanasia is punishable under Article 111 of the Swiss Penal Code, that is, intentional killing. I can give you a sheet showing the most important legal provisions.

Q2127 Chairman: Thank you very much.

Mr Stadelmann: This form of euthanasia is punishable under Article 111 (intentional killing), Article 114 (mercy killing on request), or Article 113 (manslaughter), of the Swiss Penal Code. Indirect

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active euthanasia is defined as the use of means to relieve suffering, for instance, morphine, which may have the secondary effect of shortening life. The possibility that death might occur earlier than it would otherwise have done is taken into account. While not covered explicitly by the Penal Code this type of euthanasia is generally regarded as permissible. This perspective is also reflected in the guidelines of the Swiss Academy of Medical Sciences about Care of patients at the end of life (the SAMS guidelines). I think you are going to meet somebody from the Swiss Academy of Medical Sciences. What about passive euthanasia? This is simply the renunciation or discontinuation of life-prolonging measures, for example when a life support machine is switched off. There are no specific provisions governing this form of euthanasia either, although it is regarded as permitted. The guidelines of the Swiss Academy of Medical Sciences also define passive euthanasia in the same terms. In respect of assisted suicide, according to Article 115 of the Swiss Penal Code, only a person motivated by self-serving ends who helps another to commit suicide, for instance, by obtaining a lethal substance, can be punished by a strict regime of imprisonment for up to five years or by ordinary imprisonment. Assisted suicide involves enabling the patient to obtain the lethal substance which the persons wishing to commit suicide then takes themselves without any external assistance. Organisations such as EXIT offer assisted suicide within the framework of the law. Provided they cannot be accused of having any self-serving motive they are not punishable. According to the guidelines of the Swiss Academy of Medical Sciences assisted suicide is not considered part of the physician's activity. Palliative medical treatment and care describe not only medical treatment and physical care, but also psychological, social and pastoral support to the patient and his family. It can significantly increase the quality of life of the seriously and terminally ill and thus also avoid a situation in which they express a wish to die. I would like to brief you now about the political discussion in Switzerland surrounding the problem of euthanasia. In the wider sense this discussion touches upon various aspects of the end of life, as we have already seen. It includes all the different forms of euthanasia which I have just mentioned—active direct euthanasia, active indirect euthanasia, and what is known as passive euthanasia, as well as palliative medicine and assisted suicide with its attendant phenomenon of death tourism. Patient rights must also be included in this discussion. In the context of active direct euthanasia both the Federal Council, our Government, in its July 2000 report on the Ruffy postulate (that is, the parliamentary postulate), and the Parliament have rejected the possibility of easing the legislation that makes killing another person a

criminal offence (most recently in December 2001 when considering the parliamentary initiative put forward by Cavalli, a Member of Parliament). This means that direct active euthanasia remains a criminal offence in Switzerland. There is a motion of the Legal Committee of the Council of States entitled *Euthanasia and Palliative Medicine* that calls for indirect active euthanasia, passive euthanasia and measures to promote palliative medicine to be regulated. This motion was referred to the Federal Council in March 2004. Our intention is to examine whether and how possibly revised regulations could be implemented; that is our task. Today it has not been decided how these new regulations would be enacted. It could either be done in a specific bill or in a revision of our Penal Code. The result of our work is still open. We are examining different possibilities to give an answer to the problems that are signalled by our parliamentarians. It should also be noted that in the specific area of assisted suicide three other parliamentary proposals dating from 2001 and 2002 (a parliamentary initiative by Vallender, another motion by Vallender and a motion by Baumann) have called for Article 115 of the Penal Code, incitement to and assistance in committing suicide, to be revised in order to combat the so-called death tourism, which allegedly is developing in Switzerland because of the country's liberal approach to assisted suicide. These three initiatives have been rejected or abandoned. They are no longer being considered by Parliament. The Members of Parliament who proposed these initiatives and proposals have either left Parliament or abandoned their proposals. After two years, these proposals can no longer be considered by Parliament. However, it is interesting to note which kinds of negative situations they were highlighting. In particular attention was drawn to the fact that mentally ill people are assisted in committing suicide without their situation having been examined thoroughly beforehand, that there is no clear delineation between Articles 115, that is, inducement to commit and assistance in committing suicide, and Article 114, killing on request, of the Penal Code, and that an increasing number of people from other countries in which right-to-die organisations and assisted suicide are illegal want to come to Switzerland to commit suicide. In this connection the papers published by the Swiss Academy of Medical Sciences as well as by the National Ethics Commission should be noted. These are papers were published last year and they deal in detail with the problem of assisted suicide and to some extent also with the phenomenon of death tourism. I think you are going to meet representatives of both organisations. In addition, a current and complete revision of the guardianship legislation in Switzerland will provide an opportunity to the legislator to put forward a proposal for the federal

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regulation of the patient's living will. That is a new possibility and in this way, by revision of the guardianship legislation, there will be a way of dealing with this problem of the patient's living will. With regard to information about the current practice in Switzerland I think you will have the possibility to meet the Attorney General of Zurich, Dr Andreas Brunner. He is First Public Prosecutor and he will talk to you in detail about the problems he is confronted with. We can come back to this point later. The Swiss authorities are aware of the problems that exist today relating to this increasing practice of assisted suicide and also increasing death tourism, that is, people from other countries coming to Switzerland just to die. The aim is now for the Swiss Government to ascertain whether there is a danger of the situation in Switzerland being exploited and, if so, to take appropriate steps to remedy the problem. As you can see, we have in Switzerland a clear legal framework which sets a limit to misusing practices and violations of legal provisions. These questions lie primarily in the specific purview of the competent judicial bodies in those cantons which encounter suicides, especially involving people from other countries. It is primarily not a problem of legislation, but of application of existing legislation and the existing legal framework. It may be interesting for you to know in this connection that in the past 40 years only nine people have been convicted in Switzerland of inciting to suicide and assisted suicide. However, this should not prevent the federal authorities from examining the possibility of creating a legal basis for regulating the activities of right-to-die organisations. This is the point we are now discussing with the involved organisations, the prosecutors and the medical organisations. This is my introduction to this matter and now I think you would like to formulate your questions.

Q2128 Chairman: Thank you very much indeed. That is extremely helpful. Are you able to give us figures here for the number of people who have come to Switzerland, non-residents that is, who have been assisted to die in the last two or three years? Do you have such figures?

Mr Stadelmann: We have some information. It is not very easy to get this information because organisations involved in assisted suicide and especially with respect to people from other countries do not have an obligation to give official information. EXIT does publish these figures and we know that EXIT has a very limited practice with regard to people from other countries. I will give you the figures for EXIT. These are mostly Swiss citizens or people residing in Switzerland. Until 1993 there were about 30 cases a year. We have no information for 1994/1995 and since 1996 we know there have been about 100 cases per year. In 2003/2004 there was an

increase to between 130 and 150 cases for EXIT. DIGNITAS is another organisation. We know they deal mostly with people coming from foreign countries. They declared three cases in 2000, 37 cases in 2001, about 55 cases in 2002 (and eventually some more cases in other cantons but they were operating mainly in Zurich) and 91 cases in 2003 there is an increasing tendency.

Q2129 Baroness Hayman: As I understand it every death from suicide has to be reported, so there would be a responsibility on EXIT and DIGNITAS fully to report every case with which they were involved. Would there be penalties if they did not report cases? Do you have any feeling that there is under-reporting going on?

Mr Stadelmann: Every single case of a non-natural death has to be reported to the criminal investigation authorities. We make a difference between administrative authorities, health authorities and criminal authorities. We do not have an administrative regulation for this kind of activity, for right-to-die organisations, so they do not have to report, and there is no control over their activity, but they have to report every case of unnatural death. You should know that in Switzerland criminal investigation is cantonal. It is not regulated on a federal basis. Each canton is responsible for the procedures and for the prosecution, but every single case has to be reported.

Q2130 Chairman: To the cantonal criminal authorities?

Ms Favre: Yes.

Mr Stadelmann: The authority concerned will open a criminal investigation in every case, the initial purpose of which is to determine whether the death is the result of suicide or criminal action by a third party. They have to establish if there was really suicide, if the person acted herself, or if the action of a third person assisted who must be qualified as a perpetrator. This is the problem of establishing the boundary between Article 115 and Article 114. In this sense Article 115 of our Penal Code is fundamental in making this distinction between the legal assisted suicide and the illegal killing. In the case of assisted suicide the authority will have to determine whether the person who has killed himself committed the act under his own control and on his own responsibility. That means it must be ensured that he was under no pressure to act and that he acted independently in the knowledge of the meaning and full significance of his behaviour. This is the current practice and the practice of our tribunals to establish those criteria for establishing the boundaries. The person has himself to carry out the action that finally resulted in death. It may be the last action. It may be taking the lethal substance herself or activating the pump for receiving

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the lethal substance in the body. If there is coercion or threat or if there is no sound judgement of the person concerned, then death cannot be considered as suicide by our tribunals and it has to be judged under one of the other Articles, 111-114.

Q2131 Baroness Hayman: Is there not a big problem of evidential issues if you can only examine those questions for a potential prosecution after the event? How do you establish the mental state of the person, the issues of coercion and so on, when it is *ex post facto* and your witness is not there?

Mr Stadelmann: This is a problem of judicial prosecution. It is one of the great problems the Zurich authorities are encountering. The problems are known. They have some problems in establishing conviction and obtaining information from the foreign country of which the person comes from in the case of death tourism. In the Swiss cases they do not have the same problem, because the physicians are known, the clinical history of the person is well known and the prosecutor can obtain the information about the case.

Q2132 Baroness Hayman: So the clinic would know? EXIT would have developed an evidentiary base that was then available for the criminal authorities to look at and that would be in a standard form? They would have ways of showing that mental health had been assessed or lack of pressure from other people? Would there be some sort of code of practice developed?

Mr Frank: Please correct me, but I think you have to enter into a contract with EXIT in the days when you are still healthy, when you have no lethal illness and on the day before you die you still have to be in a position to fully understand what you do so that EXIT in the process of assisted suicide can present to the prosecution the consent of the victim as established in the documents.

Q2133 Baroness Hayman: It is always the independent assessment that is difficult. A signed piece of paper is one thing when you are talking about an individual's state of mind. You tend to need some external validation of that.

Mr Frank: In general with many criminal cases it often happens that there is a big mystery surrounding a criminal act, and with regard to assisted suicide it cannot be excluded that maybe there were other reasons also present with the doctor helping the person or within the organisation. You can never exclude it, but as a general rule it is in the interests of all these organisations to have all these documents at hand to show to the prosecution that it was a legal activity that occurred. I think this might be one of the problems the cantons are encountering when they deal with these questions and maybe it is also that

families ask the same question: was it really the free will of the person who died? It is in the interests of EXIT to provide the prosecution with as much evidence as possible that it was a legal activity.

Q2134 Chairman: Can you help us a little bit further on the mental aspect of the matter? Is it normal in your understanding for some kind of certificate to be available either from the ordinary practitioner or from some specialist on the mental capacity of the person who has died around about the time at which the assisted suicide took place?

Mr Stadelmann: It is quite difficult for us to comment on single cases. If you take Article 115, it is quite short. It is "Whoever, motivated by self-serving ends, incites another person to commit suicide or assists him in it, shall be liable to confinement" etc. It means that the person who commits suicide cannot be punished and the person who makes an attempt to commit suicide cannot be punished. A person who incites another person to commit or attempt suicide can be punished if there are selfish motives as well as a person who helps or assists somebody else to commit suicide. It is all we know from the legislation. If the single elements are given and you have to establish evidence in these cases, you have to know whether the person committing suicide could have acted in his full responsibility, in full knowledge of the circumstances and of the meaning of the act he is going to accomplish. If this is not given the judge will have to establish if the action of the third person must be qualified as having a preponderant importance for the death of this person. If you cannot establish that the person acted herself there might be an important action for a third person and this person could be pursued for his participation, for his intervention. The aspect of mental capacity and sound mind is important for the criminal prosecutor to establish. How can he acquire this evidence? Dr Brunner will explain his difficulties to you. There are great difficulties. If this person comes from another country and stays one or two days in Switzerland, he will have great difficulty establishing the elements that should permit him to judge the case. As he said, there are some organisations who are aware of this problem and they have begun to collaborate with the criminal prosecution so that when they report the case they can also establish the important elements of it because they want to prove that their activity does not cause major problems to the prosecution authorities or to the political authorities of a given place.

Q2135 Baroness Jay of Paddington: On Article 115, obviously this is translated but you have spoken about the self-serving ends of people involved in assisting people. We find it is a very different system in terms of private medical insurance, etc, that you

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have here from the system in the UK. Do people pay the organisations for this service directly or are they just members of EXIT, for example? How do you establish the understanding legally that they are not self-serving in terms of their own business activity? I know it is using “self-serving” in a slightly tendentious way, but if they are making a business out of running this organisation that in itself is self-serving, is it not?

Mr Stadelmann: I agree with you that this aspect of selfish or self-serving ends is an important element of this Article. The prosecutor will have to ascertain whether the person who assisted the suicide had any personal interest. Our tribunals have established some criteria for that—if the person who has acted can be considered to have acted out of such selfish motives, if his intention was primarily to satisfy his own material or emotional needs, maybe he is very close to the person or there may be the possibility of eliminating some major problem for the family, or other motives such as gaining an inheritance, relieving himself of the burden of supporting the individual if there is an obligation to do so, or eliminating a person he hated, for instance, but also fulfilling a need for emotional attention. This has been developing in recent times because of the publicity about such cases you could also have such kinds of motives which are selfish motives. With regard to your question, we do not know more about these organisations than what is published or what these organisations declare themselves. You will have the opportunity to talk with them. You will see what they declare. We do not know everything. It would be interesting also to know from the public prosecutor if he has other information. We are not aware of this kind of practice. We know that people pay an annual fee.

Q2136 Baroness Jay of Paddington: They have a membership.

Mr Stadelmann: Yes. They pay first a membership fee and then an annual fee, which is not very important, I think. It would be difficult for the criminal prosecutor to establish based on this annual fee that there is any selfish or commercial interest but we do not know if there is something else.

Q2137 Baroness Jay of Paddington: You do not know whether they charge something beyond that?

Mr Stadelmann: We do not know if the people coming here pass on other payments to these organisations.

Q2138 Baroness Jay of Paddington: You do not know that? Nobody has ever asked formally?

Mr Stadelmann: It would be very difficult to establish.

Q2139 Chairman: That kind of investigation would not be undertaken by this department.

Mr Stadelmann: No.

Q2140 Chairman: It would be a cantonal matter. We are hoping to see the gentleman in Zurich who would have had responsibility for these investigations there. So far as the general law is concerned, I understood you to say (but I may have misunderstood), it would be necessary for the person who did participate in a suicide to know that the person committing the suicide, the patient, was of a mental capacity to understand what he or she was doing. Am I right in that?

Mr Frank: Yes, you are right. If the person even knew that this person was incapacitated, it is a crime, because then he commits an intentional killing. He is using the person who commits the suicide as a means to his own ends, so this is one of the most important aspects to establish capacity. This will be duly examined by the prosecution.

Q2141 Baroness Finlay of Llandaff: I apologise; I may have missed the beginning if you said when historically these articles were written. I wondered what the date of them was?

Mr Stadelmann: This is a very interesting question. This article was introduced with the creation of the Swiss Penal Code in 1942. It was written in 1937 and introduced in 1942. It was not created as a euthanasia law in Switzerland. It was just introduced in the context of killing within the law. It simply confirmed a legal situation that existed before in the cantons but in 1937 there was a codification, a unification, of canton laws.

Q2142 Chairman: For the Federation?

Mr Stadelmann: For the whole Federation. The criminal law was unified, but the prosecution law was left to the cantons and at this moment in 1937 they took over already known dispositions, the provisions from cantonal law, and integrated them in a new federal law. It was not something revolutionary or new and it was not intended to facilitate the killing of hopelessly sick individuals. It did not have anything to do with euthanasia and with right-to-die organisations. This phenomenon has been developing since the eighties.

Q2143 Baroness Finlay of Llandaff: The history then is that it was pre-the antibiotic era, pre-the modern technology era when this law was written and so, as medical technology has evolved, perhaps I am wrong but it seems that you have had to define and interpret this law much more precisely because of things like antibiotics, surgery, resuscitation techniques and so on, and I wonder whether you have in law a duty to try to prevent suicide. Here you are talking about

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assisting but is there a duty whereby somebody should try to stop a suicide and do you have any national policy to try to decrease the number of suicides within the country?

Ms Favre: Suicide is allowed for everybody, as we know. We do not try to be restrictive. We know there are some projects for helping some organisations, who care about suicide, and we try to make now a unified regulation about this subject, but it is still in the beginning stages. They are mostly private organisations who try to do something to decrease it. I think the number of suicides, for people who are very ill, mostly in the terminal phase of life, is a small number. The suicides of young people are increasing much more. This fact gives more importance to suicides generally.

Q2144 Chairman: For the young people there is no question of assistance? The young people are able to commit suicide without help?

Ms Favre: Yes.

Q2145 Chairman: So that assisting suicide does not come into that?

Ms Favre: Young people do it very violently. Other people could do that also but they do not like to do that. They like to do that in a slow form.

Q2146 Baroness Finlay of Llandaff: The proposals that you have very helpfully described to us sound very similar to our attempts to codify end-of-life decisions, particularly advance refusal of treatment with advance decisions and possibly statements of what people would want beforehand, but it also sounds as if you are drawing a distinction between rational suicide and depression related suicide. I return to the question as to how you make that distinction when the evidence from the clinical field is that there is a very high incidence of clinical depression in people who have physical illness.

Ms Favre: I think that is a point. If the person is fully conscious of his will, “I will die now and I am very conscious; I am not sick by thinking about that”, this is the point.

Q2147 Baroness Finlay of Llandaff: But there are people who are profoundly depressed and will repeatedly attempt suicide and they seem to be absolutely determined to kill themselves by whatever means.

Ms Favre: This is also a question you could discuss with EXIT, because they have some of their own rules. They do not practise assisted suicide with depressive people. They had some cases which caused a lot of trouble—it is ten years ago—and then they had a moratorium. They did not accept assisting depressive people.

Q2148 Baroness Finlay of Llandaff: So they are assessing for psychiatric disease?

Ms Favre: Yes, and now they make a study about these cases because they have got more demand for such cases. They are providing an opinion about that and will, but with very strict conditions, be open again to such cases.

Q2149 Baroness Finlay of Llandaff: Could I ask you about the role of the physicians in relation to your Penal Code and whether physicians are completely outside: they are practising medicine and then you have a separate acceptance of suicide within your legal framework, or whether you have a perception that you have doctors ending patients’ lives illegally but that never comes to light?

Mr Stadelmann: The Penal Code and all these dispositions apply to everyone, also to doctors. If there are criminal activities that never come to light, it is a problem of criminal prosecution. You have to know the cases and you have to examine them and establish the evidence, but the criminal code applies to everybody, including doctors. The problem, which you pointed out before regarding psychiatric diseases, was a central point of this Article when we were talking about soundness of judgement, because the person who is not capable will not be recognised as committing suicide. You will perhaps have to conclude that there has been the intervention of a third person, and see if this third person has acted himself or has had a major influence on this death. You have the same problem again of the boundaries between Articles 114, 111 and 115. The point is that for our legal terms it is the same problem. If you look at the suicide rates in Switzerland you will see that they are quite high in the European tables. There are some federal authorities looking for the causes of this and we have some figures which could be of interest to you. The research about this evolution is beginning and there are not yet definitive conclusions that have been taken in this matter. One difficulty is that the health system is again a cantonal system and a cantonal responsibility. Each canton should do research and look at the causes of suicide in their territory. At the federal level we can assemble this information, and the measures we can take at the federal level are only incentivising measures, programmes for incentivising organisations or for working with private associations that are caring for this problem of suicide. One of the conclusions of the suicide research—and you may be able to talk about that also with the physicians you are going to meet—is that suicide is in most cases, almost without any exception, caused by psychological disease, by a depressive situation. For the legal situation we are again confronted with this problem of soundness of judgement. Physicians are examining suicide and they say in most cases it is very closely related with

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diminished mental capacity or limits of your will, so a legal problem exists in almost each case. I have just one bit of information about the guidelines of the Swiss Academy of Medical Sciences. They say, for instance, that they work very much with the respect of patients' wishes but they say that respect for patients' wishes reaches its limit if the patient asks for measures to be taken that are ineffective or to no purpose or that are not compatible with the personal moral conscience of the doctor, the rules of medical practice or applicable laws. One limit is the Penal Code, for instance.

Q2150 Baroness Finlay of Llandaff: And that is guidance which provides a conscience clause to doctors?

Mr Stadelmann: These are the guidelines of an association. It is not the law. You were also talking about the obligation to protect people, the duty of care. This duty of care exists. It is the first duty of a physician who is in front of such a person, especially when you consider that the cause of the wish for suicide is conditioned by a depressive situation.

Q2151 Earl of Arran: This is perhaps a slightly unfair question because you deal primarily in facts but you also have views. Is it your view that DIGNITAS is here to stay and will continue in Switzerland but with ever-increasing regulations and restrictions, or can you not give a view on that?

Mr Stadelmann: I agree with you, and I think that criminal prosecution will develop and will establish some new limits and precise jurisprudence in this sense and maybe also with increased work because one of the problems of the prosecution authorities is that this death tourism will occasion for them greater work and expense. This is the price but I think if the authorities do this work and give the possibility of jurisdiction to establish more precise limits to the interpretation of this Article it should automatically reduce the activity of an organisation like DIGNITAS because in DIGNITAS we have certainly the problem of the difficulty of establishing criminal evidence. One of the problems, as I told you at the beginning, is that we are also dealing with the possibility of making a new administrative law to regulate the activities of these organisations. The action of criminal prosecutors can only come afterwards, as my Lady said. It comes after the death has occurred. If you can regulate these organisations you have maybe one disadvantage, for you will legalise an organisation which has not been legalised yet in Switzerland. You give them a legal framework, but at the same time you can have a preventive effect by establishing those limits, so we have both possibilities: either the criminal authorities establish these limits with their jurisprudence or the legislator does it at an administrative level with a new law that

gives guidelines for the activity: the registration duty, the control of the activities of those organisations. Then you could, have with such a law established, some minimal deadlines for establishing the will of the person who has a persisting wish to die.

Q2152 Baroness Hayman: You have inspection.

Mr Stadelmann: You have inspections, so you can act to prevent misuse.

Q2153 Baroness Jay of Paddington: When you spoke in your introduction about the possibility of some different approach being taken up by the Federal Council this was what you envisaged, was it? This is what you think the Federal Council may be moving towards?

Mr Stadelmann: It might be, yes. It is one of the possibilities we are dealing with now, because we have been charged to examine the whole problem and we have to report to Parliament within the next two years with an analysis of the problem and the possibility of intervention at a federal legislative level.

Q2154 Lord Joffe: I might have misunderstood what you said but in answer to Baroness Finlay's question about many people who commit suicide suffering from depression I thought you said that most people suffer from depression and I wondered whether you were referring to the younger people who commit suicide or the people who were being assisted to die.

Mr Stadelmann: I was just referring to the first researches that have been done in Switzerland about the causes of suicide. One of the conclusions is that the most expressed wish to suicide is in connection with a kind of psychological psychiatric prognosis. It is not necessarily depression but psychosis. It is quite an exception to find a fully healthy person that looks at his life and says, "Okay; now I will commit suicide because I have reached the aims I have fixed for my life". These are the results of research about suicide and suicide causes in Switzerland.

Q2155 Chairman: Suicide generally?

Mr Stadelmann: Yes, generally, young and old.

Q2156 Baroness Jay of Paddington: So that I can be clear about this, you are talking about healthy physically as well as mentally?

Mr Stadelmann: Yes.

Q2157 Baroness Jay of Paddington: Because otherwise that evidence would be counter to some we have heard, for example, in Oregon where there is assisted suicide in very particular circumstances where people are terminally ill with a physical illness. The evidence seems to be from there that this is not people who are mentally ill as well, whereas I hope I

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understand you to say that if someone is perfectly healthy physically and has a long expectation of physical life there has to be something out of kilter mentally for them to decide to commit suicide.

Mr Stadelmann: It seems to be so. If you look at article 115, it does not define suicide in relation to a disease. Article 115 is about the suicide of every patient from every age, every personal situation and every health situation. We do not have any difference in Article 115. That is why this Article is so wide. It gives so many possibilities to act. All these other reflections, all these other works that are being done now, are dealing with restrictions at the administrative level, at the medical level, the guidelines of the Academy itself. It reduces this large possibility to some cases in which they could agree a situation that could justify the action of the doctor. All these other attempts to establish guidelines are in effect limiting the meaning of the scope of 115.

Q2158 Chairman: Can you help me on a more general level? The Swiss Penal Code that was initiated in 1937 and then came into force in 1942 I think was a codification of the criminal law of the whole of Switzerland. Previously there had been some differences between the cantons on criminal law but has that now all disappeared in favour of a common Penal Code that operates in the whole of Switzerland, as far as the law is concerned the responsibility for prosecution under that code being left with the cantons. Is that correct?

Mr Stadelmann: Yes.

Q2159 Chairman: And so nowadays a canton would not be able—or would it be able?—to introduce a new criminal provision of its own. It would be a matter solely for the federal authorities to change the criminal law in the country. Is that right?

Mr Stadelmann: That is right.

Q2160 Chairman: So far as duties of care and so on are concerned, they are not criminal law duties generally speaking. You may have criminal law duties in relation to health and safety at work and that kind of thing. I am not sure whether you have that, but there will be a civil law as well with duties of care. Am I right so far, that there are civil duties of care such as you mentioned the doctor has?

Mr Stadelmann: Yes.

Q2161 Chairman: In relation to that type of law, for example, if you have someone in prison, is there any duty of care in the Swiss civil law to impose on the person in charge of the prison a duty of care to prevent someone who may be liable because of their imprisonment to contemplate suicide, in other words to protect them against carrying it out? Do you follow me?

Mr Stadelmann: Yes. In the civil law you can, in order to protect a person from herself, put this person in detention. If this person is in prison or in hospital or at liberty, but you or a physician are aware of this risk, in order to protect her from herself, this person can be put in protective care in a hospital or in a medical institution.

Q2162 Chairman: You explained to me that the criminal law is now federal.

Mr Stadelmann: Yes.

Q2163 Chairman: Is the civil law of that kind also federal?

Mr Stadelmann: Yes.

Q2164 Chairman: So it is the same in all the cantons, but again different administrations may exist for the different cantonal authorities?

Mr Frank: Yes.

Q2165 Baroness Hayman: You said earlier that the health departments of the cantons had no responsibilities for information gathering around the activities of EXIT, that the only reporting responsibilities were to the criminal justice organisations. Have the health departments decided to undertake any investigations in research into the sorts of people who are coming forward and asking for help with assisted suicide? Has there been anything done by an independent government body to look at those things? The other thing I want to ask is that we have talked very much as if the assisted suicide provisions or non-provisions were only used by organisations. Switzerland has many rural areas where presumably access to an organisation is not easy and I wondered whether this was a specialist facility or whether individual GPs were acting in accordance with the Penal Code and assisting where they had no self-serving ends and whether anything had been written about that?

Mr Stadelmann: To answer your first question, the cantonal health authorities have responsibilities. They have the responsibility also to gather information. They do not have a responsibility vis-à-vis of the federal government. They do not have to necessarily gather information at the federal level, but at their field of responsibility in the cantons they have responsibility for investigation, for gathering information about the practice in relation to the sort of people who are coming from other countries.

Q2166 Baroness Hayman: Do they publish that?

Mr Stadelmann: I do not know if they publish this. This is another problem, publication of information, but they are concerned by this problem. They are concerned by the control of medical activity, physicians are controlled, the pharmacies are

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controlled, the prescription of lethal substances is controlled at cantonal level. When DIGNITAS opened a new apartment, a new clinic, as you may want to call it that, in another canton, Aargau, which is not far from Zurich, the authorities immediately acted and were concerned about this problem. They were looking at the activity of these physicians who were giving prescriptions for lethal substances and so forth. It is the responsibility of each local government. This is the first question. We have difficulties with the intervention from federal government in these matters which are in the competence of the local government. Your second question concerned the individual doctors rather than the organisations. As we said before, individual doctors are concerned about the criminal law as everybody else is. They also have to report every case of assisted suicide. The guidelines of the Swiss Academy of Medical Sciences establishes the same responsibilities. They have to report in a very precise way. They have to document the whole procedure.

Q2167 Baroness Hayman: If one wanted to find the figures how would one do that?

Mr Stadelmann: The figures exist, certainly. We had some reports in the press where doctors reported their activity, their involvement with terminally ill people, and the possibilities they have to deal with that. They say, "One of the possibilities, active euthanasia, I cannot give to this person, but I can say to that person, 'You may commit suicide if you want'", and a doctor has also the possibility to prescribe the substance, if he is not in violation of any legal provisions concerning the activity of medical persons, hospitals and physicians.

Baroness Hayman: And presumably we would need to go to the health department of the relevant canton to see whether their reports—

Baroness Jay of Paddington: Every canton.

Q2168 Baroness Finlay of Llandaff: How is that recorded on the death certificate and is there a standard system of recording across Switzerland or does each canton keep its own register and record with different categories determined by the canton?

Mr Stadelmann: I do not know. It should be cantonal, but I do not know if the death record specifies the kind of death. The civil record does not.

Q2169 Baroness Finlay of Llandaff: It does not record the cause of death?

Mr Stadelmann: If you mean the civil record, that is federal.

Q2170 Baroness Finlay of Llandaff: They certify that the person is dead but they do not certify the cause of death?

Mr Stadelmann: No, but if you mean the criminal records or the health authority records, the hospitals, clinics and physicians, there you will certainly find those specifications, but that is again cantonal.

Q2171 Baroness Finlay of Llandaff: In the UK we record that somebody is dead and then we write what we believe to be the cause of death, the primary cause and possibly the secondary causes of death, contributory factors, and that data is all collected centrally.

Mr Stadelmann: In the civil record, or is it health?

Baroness Finlay of Llandaff: The health department.

Baroness Jay of Paddington: It is because of the National Health Service legislation though, is it not? It has nothing to do with the criminal law.

Baroness Finlay of Llandaff: No, but it is interesting.

Chairman: Death recording in the United Kingdom is part of the registration system. You have to register a death as part of the system which has existed for a long time, long before there was a health service. The cause has to be on the death certificate.

Baroness Jay of Paddington: But the collation centrally is a Department of Health thing, is it not?

Baroness Finlay of Llandaff: It is the ONS, the Office of National Statistics.

Baroness Hayman: Every country, in order to be able to have WHO information, has its centralised figures. We will know how many cancer deaths there are. You will know how many cancer deaths there are in Switzerland somehow and that will have to be on the same basis of the cantons.

Q2172 Chairman: There is a record of the total number of deaths in Switzerland per annum. It is held by somebody. In Switzerland there will be a record of each death in a certificate that is held centrally.

Ms Favre: Yes.

Q2173 Chairman: And somebody will be able to tell how many deaths there have been in Switzerland in a particular year.

Ms Favre: Yes.

Q2174 Chairman: Is that in the federal government?

Ms Favre: Yes.

Mr Stadelmann: There is a Federal Office of Statistics which will collect information from federal authorities as well as from cantonal authorities. In some matters you have information from both and in other cases you have information only from cantonal authorities. That information is collected and published by the Federal Office of Statistics.

Q2175 Chairman: And that will distinguish between deaths from natural causes and all other deaths?

Mr Stadelmann: Exactly.

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Q2176 Chairman: So we could get that if we wanted to?

Mr Stadelmann: Yes.

Q2177 Baroness Finlay of Llandaff: The difficulty is, who decides that it is a suicide? Is it the doctor who decides it is a suicide and writes down “suicide” or is it that the doctor says, “This was not natural causes” and it therefore goes to a legal authority which then will hear all the evidence and decide whether it was a suicide or an accidental death or, we have a term, “death by misadventure”?

Mr Stadelmann: This would be a question maybe for the prosecutor who knows exactly how the procedure is going. The doctor certainly fills in a form and declares what he has established and, if there is a different finding afterwards because the criminal prosecution comes to another conclusion, it might be corrected. We have had these nine condemnations in 40 years and that means that mostly the declaration of the doctor will be right.

Chairman: I think we have used our opportunity very fully to ask questions and be helped by you. I would like very much on behalf of the committee to thank all three of you for your help to us. As I say, you will see the transcript in due course and be able to review it and see that it accurately records what you thought you had said. Thank you very much.

WEDNESDAY 2 FEBRUARY 2005

Present	Arran, E. Finlay of Llandaff, B. Hayman, B.	Jay of Paddington, B. Joffe, L. Mackay of Clashfern, L. (Chairman)
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Examination of Witnesses

Witnesses: DR CHRISTOPH REHMANN-SUTTER, President of the National Advisory Commission on Biomedical Ethics, and DR MARGRIT LEUTHOLD, Secretary General of the Swiss Academy of Medical Sciences, examined.

Q2178 Chairman: Thank you both very much for coming this afternoon to help us in our investigations into the background circumstances in Switzerland that relate to the Bill that Lord Joffe has proposed for consideration in the House of Lords to alter the law of England and Wales in relation to matters of which you are informed. Our system is that a shorthand note will be taken of what you say. We invite you this session together because although you are representing different institutions there is a good deal of common information between you about these matters. Would you please first of all introduce your view of these matters from the Swiss point of understanding in order that we may have a general overview of where you see these problems, and then members of the committee will want to ask you questions about their particular concerns? You will get a chance to review the transcript to make sure that it is what you thought you said and then that transcript will become public property when it is corrected and appended to the report and the report is published.

Dr Leuthold: I am Margrit Leuthold. I am Secretary General of the Swiss Academy of Medical Sciences. It is a foundation which has existed for 60 years and one of our main tasks is to establish medical ethical guidelines in all fields of medicine. There are critical issues to consider and we would like to give practitioners and the nurses advice on how to deal with these issues in practice by the patient's bed. The process of dying and what to do is a big issue in our Academy. Before I go into a bit more detail it is good to give you a general background about the history of the whole subject in Switzerland. I do not know whether Christoph would like to say anything.

Dr Rehmann-Sutter: No. I would appreciate it if you could do that.

Dr Leuthold: Please correct me or give additional information if I forget something important. Under Swiss law there is this paragraph in the Penal Code, paragraph 115, which says that assisted suicide is not forbidden in Switzerland so a legal case cannot be made out of it if the person assisting is doing it out of pity or high moral attitude, but if you want to get the house of your neighbour and try to do it that would not be according to the Penal Code. That is how it has been fixed for many decades under Swiss law. What

is also important to realise is that it is not restricted to medicine or to physicians or to a special group of people. The Penal Code is for everybody. Because we have this Swiss law it has never been forbidden to assist in suicide, whether it is a physician, a nurse or anybody else. This is the background to it. The Swiss Academy of Medical Sciences established guidelines in this field ten or 15 years ago, saying very clearly that physician-assisted suicide is not a part of medical practice. It is outside what a medical doctor has to do. Also, we refer to the moral tradition in medicine in Switzerland, but it does not explicitly say that it is forbidden for a doctor. It is regulated like that. In 2003—and I am sure you are familiar with this study—Switzerland was one of six European countries taking part in a study and it became for the first time very clear from the figures that in Switzerland there is quite a high number of physician-assisted deaths of any sort, active euthanasia and also physician-assisted suicide. It is one per cent out of all death cases and of that 0.7 per cent is euthanasia and 0.4 per cent is physician-assisted suicide. It became clear that it is a reality in Switzerland as well as in other countries in this regard, and also because there are cases which are recognised by the Swiss Academy of Medical Sciences where patients can be in a situation where a doctor cannot just step away from the bed and say, “This is no longer my business”. This was the initial point from which to revise our guidelines. This was a long process which took us two years. We established a committee which was put together from all kinds of disciplines—nurses, theologians, medical doctors of course, and also a lawyer was in there. These people tried to set up these new guidelines. Last year they underwent a long process of consultation so that everybody in this country had the right to give their comments or recommendations on these guidelines. They went over them once again and added some points and left out some others, and this is the final version which was printed and translated at the beginning of this year, so this is very new. Coming to the point of physician-assisted suicide, it is on page 6. I do not want to go into every detail but the most important point is that we changed the formulation we had in the former guidelines and now it says, “In this borderline situation a very difficult conflict of

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interests can arise for the doctor". If a patient is terminally ill (I have to add this because it is important) these guidelines refer only to the last few weeks of a patient's life. This conflict of interest is described as follows: "On the one hand assisted suicide is not part of a doctor's task, because this contradicts the aims of medicine. On the other hand, consideration of the patient's wishes is fundamental for the doctor-patient relationship. This dilemma requires a personal decision of conscience on the part of the doctor. The decision to provide assistance in suicide must be respected as such." This is one of the key sentences because in the old version it only said that assisted suicide was not part of a doctor's task, full stop. We added this, "In any case, the doctor has a right to refuse help in committing suicide", which is also important. "If he decides to assist a person to commit suicide, it is his responsibility to check the following preconditions", and there are three of them. One is, "The patient's disease justifies the assumption that he is approaching the end of life". The second one is, "Alternative possibilities for providing assistance have been discussed and, if desired, have been implemented", which refers to palliative care and other matters. The third point is, "The patient is capable of making the decision, his wish has been well thought out, without external pressure, and he persists in this wish. This has been checked by a third person, who is not necessarily a doctor". These are the three conditions and then the final sentence of this paragraph is very important: "The final action in the process leading to death must always be taken by the patient himself". As you may be aware, active euthanasia is forbidden also by the Penal Code, Article 114. This is referring to this Penal Code, so that the last act has always to be done by the patient himself or herself. These guidelines, as you can imagine, have been discussed quite heavily also in the press but the large majority of our physicians and nurses agree with this change towards a slight opening of the possibilities at the end of life. I am happy to give you copies of this.

Q2179 Chairman: Thank you very much. Would you like to follow now, Dr Rehmann-Sutter?

Dr Rehmann-Sutter: I have to start with an apology. We do not have an English translation of our ten pieces which our committee published in September last year, but I am sure you have a German version. I can try to express some of the key elements of it orally.

Q2180 Chairman: The interpreter can translate it for you.

Dr Rehmann-Sutter: Thank you. It is a very short text. I am the President of the Swiss National Advisory Commission on Biomedical Ethics. When we started our work on end-of-life issues we saw that

the Academy already was in this field of discussion and had started a revision, which we have just heard about from Margrit, and we tried to add a more societal perspective because we are a counselling body to the parliament and to the government.

Q2181 Chairman: That is the Federal Government?

Dr Rehmann-Sutter: Yes. Compared with you Switzerland started the discussions from the opposite direction. As you have heard, we have this situation where assisted suicide is permitted except if the person who assists has selfish motives. The law does not say which kinds of motives he or she should have, only which kinds of motives are not allowed. In the case of self-interest it is banned but otherwise it is not. At the time when this legal provision was introduced in the 1940s—

Q2182 Chairman: 1942, we are told.

Dr Rehmann-Sutter:— there were no organised offers of assisted suicide. I hear you have met EXIT.

Q2183 Chairman: We are going to meet them tomorrow.

Dr Rehmann-Sutter: These organisations are a product of the 1980s and 1990s. That was one of the key things that introduced in the view of our Commission a new element into the discussion from the point of view of society as a whole. It changes the moral quality of assisted suicide in some way and our main question was, in what way shall we introduce the moral quality of assisted suicide? Perhaps I should start with where we ended. We ended up supporting the principles of this legal provision but we were concerned with the impossibility of the state having legal oversight of the practice of these organisations. That was the main concern at the end. Perhaps I should mention a few points which were important in our procedure. We consider suicide as always a tragedy which involves a kind of violence against oneself and sometimes also against others. We see also that the law has a role in suicide prevention. Swiss law, like other legal systems, sees the appropriate answer by society to a person who makes an attempt at suicide not in punishment but in help and support first of all in order to make a second try less probable. That was the second point. The third was that we saw not only a legal difference between assisted suicide and euthanasia but also a moral and ethical difference. More precisely, active direct euthanasia is where another person has to bring somebody to death on demand. The main difference is that control over the act is in the hands of the person who decides to try. That makes it an action of a different moral quality because the actor is a different person. The second aspect (which is also important in my view) is that the person who has to help or who decides to help is not killing. It makes a

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difference for him or her too also from a retrospective perspective, seen afterwards, because for the conscience of that person it does not include an act of killing and the person who wants to die does not have to get somebody in to kill him or her. It is not necessary to bring a friend or relative into this position of having somebody else killed. These were the main aspects that made us think that assistance in suicide is from an ethical perspective something different which allows us to have different social norms around it. Then the question is, of course, what is the morally appropriate answer of the legal community to society, to somebody who is ready to do such assistance, and we saw that there are two deep-rooted values which are key in this field. One is respect and the other is care, respect in the way that Margrit Leuthold has expressed it, as a decision which is well made, which is considered, either the decision by somebody who wants to help or by somebody who sees no alternative other than to go into death. The other value, which is equally important, is care in the sense of responsibility for the person who is in such a dreadful circumstance that they see no other way out than to go into death. In the direction of keeping somebody in life it is not a responsibility or a care in the sense of doing the best for him to do what he or she wants to do efficiently but also to keep him here, to change perhaps the situation in such a way that life gets meaningful again or gets attractive again or less dreadful. This includes also medical assistance, which has a high value in our society, so we see it as a moral value of care and responsibility for those who are in danger of getting suicidal. A further point was the psychiatric evidence, that this autonomy of a person who says, "I want to kill myself" is not only something which is a matter of fact, that somebody has this decision and that is the end of the story. It has a history and it has a history which is ongoing. It is a process and it has its ambivalences in it. Psychiatrists have told us (and we have one on our Commission) that this autonomy in the case of persons with a wish to commit suicide or a wish for death is not just a free and informed decision like, for example, participating in a set of study or filling out a form but a decision of somebody who is under circumstances of distress, of fear, of lost hope, therefore also something that could in principle change again. Given this evidence, this does not mean that we have to consider every person as a psychiatric case or every decision as a decision which cannot be turned round in the other direction. There is also the respect necessary but perhaps not blindly. These elements made us say that the state has this duty to provide an oversight of the activity of those organisations offering help for suicides to make sure that they follow minimum requirements of assessment, that they do the technical thing well. We believe that they perhaps do not put enough weight

on the lengthy process of evaluation and assessment of the person or on giving support to the person to make him or her possibly change their mind again, to see what in his or her circumstances could be changed in order to make things better. That is the main thing. In terms of medicine we followed the recommendation made by the Academy that in principle it is not an action that can be deduced from the roles of medicine. It is in this way not normatively spoken of as part of medical practice. Medical doctors are whole persons, citizens, and they should also have the right to make a decision by their conscience. The state should not tell them under which circumstances it is ethically legitimate to provide assistance to suicide. The state could perhaps say under those circumstances it is not legitimate but in the end the decision about legitimacy has to be made by the person himself or herself. That was very important in our recommendation. Perhaps the most controversial recommendation (which is in our TG6) is about the activity of hospitals, and perhaps we will have another round of discussion about this. We said in short that every hospital or institution of long term care should be explicit about their policy on whether or not to allow organisations to come in to provide this help, so that somebody who makes a choice of in which hospital or in which institution he or she wants to go can take that into consideration. On the other side it means that our National Ethics Committee does not say that hospitals should never do it and that is the controversial point.

Q2184 Chairman: Thank you both very much indeed. I wonder if I could ask Dr Leuthold about the practice of medicine in Switzerland. The ordinary person will have a doctor to whom they go from time to time and that relationship will last for quite a long period of years. Would that be the ordinary arrangement?

Dr Leuthold: In the countryside it still is like that: you have a long term established relationship with the family doctor, sometimes going over decades, but when you enter hospital this liaison is no longer as strong as it might be in the countryside. You enter a different system and sometimes the family doctor is still close and can have contact and give his experience of a long term relationship to the hospital doctors but this is now the exception rather than the rule. In this regard the system is different compared to Holland. They are also in the process of physician-assisted death. I think their family doctor has a different role.

Q2185 Chairman: You say that in the country districts the situation would be for the person to have a long-standing relationship with his general practitioner. In the cities is it more in the nature of partnerships now?

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Dr Leuthold: There specialisation is much more common so you go usually directly to a specialist, an oncologist or a gynaecologist or whatever. In the big cities not many citizens have a family doctor in the traditional sense.

Q2186 Baroness Jay of Paddington: Can I ask a question which follows on from that in relation to the question of assisted suicide? This is probably my failure to appreciate the complexities of the situation in Switzerland, but if you want to take advantage of the law around assisted suicide do you always have to be part one of these organisations like EXIT or DIGNITAS in what you have just discussed with Lord Mackay? If you lived in the countryside could you ask your general doctor to do this for you or could you approach someone who you were involved with or, as you say, on a more casual basis in a city? How does the system work?

Dr Leuthold: It has not been outspoken so far really. This one per cent which is in that table is the grey zone. We know that it happens but we do not know exactly how it happens.

Q2187 Baroness Jay of Paddington: You mean you know it happens apart from the people who are recorded by the organisations?

Dr Leuthold: Yes.

Q2188 Baroness Jay of Paddington: So if I lived in a small village without access to one of these well-known organisations it would be much more difficult? Is that the point?

Dr Leuthold: It really depends on the relationship you have with your doctor and also his or her moral attitude. I could imagine, but this is, as I said, in this grey zone and this whole investigation has been made on an anonymous basis. The doctors filled out all these forms and sent them in anonymously so you could not follow up who it was and who did what in the practice. I could imagine that that corresponds to the reality in that, for example, an oncologist has a relationship with a patient for a couple of years and then the terminal phase begins and the patient asks, "I just cannot support life any more. Could you help me?", and in this kind of contract of mutual trust the doctor does not just abandon the patient in the last phase of his or her life. With this respect of the autonomy of the patient in this grey zone it then happens. I know myself only very few doctors who would stand up and say, "I have assisted in suicide with some of my patients".

Q2189 Baroness Jay of Paddington: Even though this has been something which has officially been part of the system for a very long time?

Dr Leuthold: It is in a sense not allowed but it is not forbidden, as Christoph Rehmann described, if there are no selfish motives, but also in Switzerland it is not a subject which is treated openly and frankly. It is, as I said, in this grey zone.

Q2190 Baroness Jay of Paddington: That is interesting, is it not? For example, and I am sorry to persist but as we are discussing this, when we visited the state of Oregon in the United States they said that because the people we heard evidence from (and of course we did not speak to everybody) felt that because there was this availability of assisted suicide the discussions about end-of-life practice and so forth had become much more open.

Dr Rehmann-Sutter: We could observe this also as an effect, that the discussion becomes more open, in that we have at least these numbers now. For example, we know about the range of magnitude per year done by EXIT and from there we can also have an idea of how many are done by medical doctors privately or which involve medical doctors. It does not necessarily involve a doctor.

Q2191 Baroness Hayman: That was what I wanted to ask you about because in the recommendations about putting in place a framework where there would be reporting and there would be a code of practice, perhaps based on what the Academy of Medical Sciences have put forward, were you recommending that that should apply to non-physicians as well? As I read the legislation (or the lack of legislation), if a partner or a child of someone who was suicidal and asked for help, which was not from prescription drugs but it could be a pillow over the head,—

Dr Rehmann-Sutter: A pillow? I am sorry to interrupt you but a pillow over the head would not be considered as a suicide.

Q2192 Baroness Hayman: "Help me keep the plastic bag on".

Dr Rehmann-Sutter: That is a margin case perhaps. Providing a pistol, yes.

Q2193 Chairman: In other words the patient has to do the final act in assisted suicide?

Dr Rehmann-Sutter: Right.

Q2194 Chairman: The assister can go quite a long distance but the ultimate decision and act for assisted suicide has to be with the patient? Am I understanding it right?

Dr Leuthold: Yes.

Q2195 Baroness Hayman: The final act, if someone is crushing some tablets, putting them into a mug for someone else, spoon-feeding them, but the

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swallowing is done by the patient—this can go very near.

Dr Leuthold: Right.

Q2196 Baroness Hayman: My question is again back to the individual who is not a doctor. Would you be suggesting the same sort of framework for that person as for a physician? I am sorry; I was not listening as closely as I should have been. You talked about four conditions, one of which was a terminal illness. The law as it is does not talk about terminal illness at all. Were you recommending that this should be within the framework only of terminal illness?

Dr Rehmann-Sutter: No, we did not do that. We did not have a recommendation that it should be done also in other circumstances but neither did we recommend that the law should be changed or narrowed to a condition of terminal illness. The law allows that anybody can provide this help, not only medical doctors, to persons in whatever phase of their lives, given that they are competent.

Q2197 Baroness Hayman: Did you have any discussion about a difference between competence and depression, for example, because there are levels of depression which would not make someone incompetent for a range of decisions but which might make people very uncomfortable about assisting, carrying through a decision for suicide? Psychiatric assessment is really what I am asking about.

Dr Leuthold: This is one of the crucial issues, that you should be able to exclude depression or any other mental illness if you want to check whether it is a patient's free will which leads him to this final wish. Our psychiatrists gave us the idea, at least this was my impression, that this can be done rather accurately so you can as a trained psychiatrist say whether this is depression or not. We rely on this expertise but, of course, in practice it is absolutely crucial that you can exclude that.

Q2198 Baroness Hayman: You talked about the very clear ethical difference between administration and assistance so that the last act had to be that of the patient themselves and the fact that the actor was a different person made a big ethical difference. Could you explain to me how one applies that to another end-of-life decision, a competent patient who wants to discontinue life-saving treatment, a patient who is currently on life support who is able to express their wishes—I realise it is very few but it happens—for life support to be turned off? They cannot do that act themselves and yet this is something that we accept because we define it as refusal of treatment. I wonder where the clear division is on who is the actor on this one.

Dr Rehmann-Sutter: That is a good question. If you disconnect somebody from a life-saving machine then you let nature take its course, but nevertheless you have least the negative responsibility of not continuing. If you have the clear wish, the clear desire, of the ill person, I think that also makes a moral difference to active euthanasia. We did not have from our committee a recommendation on this and I think this will be one of our next topics of discussion. I see there is a difference but clearly not the same one as there is between active direct euthanasia and assistance to suicide.

Q2199 Chairman: Of course, in many of these treatments that are covered by the general description that Lady Hayman gave some degree of maintenance to keep the system going has to be put into it. There is an active ingredient to continue the treatment and the discontinuance of the treatment may involve more or less activity. The thing may just die off if you do not continue the ventilating system so that there are grades of interference required. The crucial point from your point of view, I understood, Dr Rehmann-Sutter, was that in the case of the turning off of invasive life-prolonging treatment the crucial distinction is that in that case when that treatment is turned off it is nature taking its course that causes the person's death and that is not suicide, whereas suicide, according to the Swiss view of it, must be a killing by the person themselves. If you are going to have what I might call the benefit of Article 115 of the Code it has to be a decision by the patient and an act by the patient that finishes the patient's life and that involves a competence to take such a decision. A patient who is not capable of deciding, because of mental illness or something of that kind, is not committing suicide because they have not got the capacity to make the decision to kill themselves. Is that right?

Dr Leuthold: That is right, yes, and you are not allowed to assist in this, so this is the most important prerequisite. I would agree; I see the difference as you describe it. It is a very good question. In the first situation you take away something which has artificially prolonged life with some help from technical support, which determines how long you live on. In the other case you add phenobarbital to the system, the human being, and this is where the killing occurs.

Q2200 Baroness Hayman: I can grasp this intellectually and see it very much from the position of the observer or indeed the doctor. I think from the patient's point of view, the patient who is terminally ill, the patient whose desire is to end their life as soon as possible, the distinction between how that desire is enacted and with what assistance depends on the lottery of what their disease is rather than to my mind

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an easy-to-understand ethical difference. These are the issues with which we are all grappling.

Dr Rehmann-Sutter: I perfectly agree with this. I find it very important to differentiate between different perspectives. You consider now the perspective of the patient as rather different from that of a doctor standing by or an observer or society which sets up norms. Let us go back to the difference between assisted suicide and direct euthanasia. You mentioned before that in practice those two might come very close. You mentioned key actions like swallowing which are minor things. We discussed that also in our committee and we ended this discussion in clarifying that from a descriptive perspective those actions might indeed be very close and perhaps nearly indistinguishable, but from the perspective of the subject who interprets his or her actions (and we need to consider both participants as moral subjects interpreting their own actions) it makes a great deal of difference, even if it is a minor step, if the patient knows this is the decisive step, “If I don’t do that I will live on. If I do it I will die”, and if the helper also knows that all he or she does, as the situation provides, is not by itself an automatic causation that leads to death but that the other partner knows that he or she can or cannot do this decisive last step. It depends on the understanding of those participating that even minor steps are really in an ethically important way decisive.

Baroness Jay of Paddington: And they may also be legally important. That really is the difficulty, is it not?

Chairman: Yes.

Q2201 Earl of Arran: What about motor neurone disease, for instance? What would happen there, because the patient presumably is not capable of committing the final act himself or herself? The patient would have to have assistance there, would they not?

Dr Leuthold: We have discussed these cases as well. If you take, for example, an ALS patient, or two of them and one is still able to release the trigger and the other not, of course in practice then you have maybe a big difference because one can commit so-called suicide and the other not. The other has no more the possibility to commit suicide so he or she would have to live on because he or she cannot do the last act by himself or herself. In practice this could be a real dilemma and maybe an injustice because the one result is possible and the other not. Of course, we have also discussed this exact situation when everything is prepared, so you are as a patient deciding to commit suicide and everything is prepared and let us say everybody is waiting until you do the last triggering, and then of course there is the question, is there really free will? Is there a pressure to do it now?

Q2202 Chairman: When everything is ready?

Dr Leuthold: Yes. It is very difficult for each individual case to have a fair, just system. I think it is almost impossible.

Q2203 Chairman: So far as the system here is concerned at the present time the two cases that you have just referred to would be treated differently. The case in which the person with ALS or motor neurone disease can press the trigger and give the lethal dose would be suicide whereas the other one would not?

Dr Leuthold: That is the theory.

Baroness Jay of Paddington: I was going to ask how much you thought the legal theory was so in practice.

Q2204 Baroness Finlay of Llandaff: Can I return for a moment—and thank you for your very useful presentations—to the psychiatric and psychological evidence that you took in relation to suicide? You referred to the anger associated with a suicide both within the person and also towards those around and their ambivalence, which one sees clinically with patients who will attempt suicide with very major serious attempts but then if they have not died they may express gratitude later on that they did not die even though their attempt was certainly life-threatening. I wonder whether, in the evidence you took, you considered, if we think about the two patients with ALS, the fluctuating ability of patients as well because their deterioration is not fixed, so a patient may be unable to do something one day but another day appear to have superhuman strength or willpower, sometimes even to sit up to greet relatives, and that burst of energy often towards the end is misinterpreted by family as a sign that they are getting better or improving whereas a clinician will recognise that it may be, if you like, the rise before the fall. They have a final burst of energy in life before they die and succumb to their disease and, as you said, die naturally. I wonder whether you considered the fluctuating clinical state in the way that you wrote your guidelines and considered formal assessment of competence, advising on a tool for depression for GPs rather than to psychiatric services always.

Dr Leuthold: We made our own task easier because we restricted ourselves to the last weeks of a person’s life. The condition is formulated in such a way that this wish has to be stable over a certain period of time. We wanted to prevent or take out these few hours when the patient is desperate and then the next day he is better and the wish disappears, so this is part of the pre-condition, that his wish is stable not just over two days but over a period of time, which of course cannot be fixed to a certain number of days or weeks. It depends on the illness and it depends on the patient.

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Q2205 Lord Joffe: What was the rationale behind your decision to limit the recommendation in the guidelines to terminally ill patients? Was there anything in addition to the question of competence which made you arrive at that recommendation?

Dr Leuthold: These recommendations have the title “Care of patient at the end of life” and this part, physician-assisted suicide, is only a small part. The main focus is on palliative care, on helping a human being to die in a decent way. This is the focus of our guidelines. In the National Ethics Committee, where I am also a member, of course we treat the subject in its whole breadth, including psychiatric patients who are not at all at the end of their life, and all kinds of aspects, but this would have been far over the goal of these guidelines. We are very much aware that with this restriction we leave out huge questions around the whole issue which have now been picked up by the National Ethics Committee.

Dr Rehmann-Sutter: The guideline does not include a formal restriction to those cases?

Dr Leuthold: No.

Dr Rehmann-Sutter: But it has from the start had only these cases under consideration?

Dr Leuthold: Yes, because it is an end-of-life guideline generally.

Q2206 Lord Joffe: So a doctor who, for reasons of conscience, helped somebody who was not terminally ill to die would not be acting illegally or contrary to the views of your Academy or your committee?

Dr Leuthold: I think your formulation is correct.

Q2207 Lord Joffe: In framing your approach to the guidelines did you consider the possible effect of the legislation as it stands on vulnerable people like the elderly or the disabled?

Dr Rehmann-Sutter: Yes, this was also a concern, but it looked not so dangerous because it is already the situation in Switzerland that we have this Article 115 which allows it and it did not end in a huge number of assisted suicides. It was a concern, especially with regard to the circumstances in the near future when elderly people are a larger sub-population in our society when perhaps money is more restricted for a person, when more persons come into situations with restricted support, restricted medical and nursing aid and so on and perhaps come under a sort of pressure, also financially, not to depend on the family.

Dr Leuthold: I would say it still is a big concern and we have to observe very carefully the development and the effect on society as a whole of the values of a society such as Switzerland. What we can say from the experiences in Zürich, and I am sure you will learn more about it tomorrow, is that we introduced in 2000, I think, the legalisation that these organisations have access to homes for elderly persons who are chronically ill. Since then we have not observed a

change in the numbers of people who would like to commit suicide, which is a sign that this practice did not really change behaviour or put pressure on or anything. This is also a very short observation period but I think everybody in this country is aware that this is a very delicate issue, that the value of the life of an old, ill person could deteriorate, not only because of the possibility of physician-assisted suicide but because of other more general tendencies in our society.

Q2208 Lord Joffe: Presumably that is why one wants to produce a legal framework so that there are safeguards.

Dr Leuthold: Yes.

Q2209 Earl of Arran: Does this make doctors very nervous about whether they are behaving legally or illegally?

Dr Leuthold: Maybe less nervous than in the United States or in other countries. So far we have never had such a case. We have had one or two where doctors clearly wanted to get rich and offered active euthanasia, I think, to some patients. However, in general, since we are a very liberal society and we have this liberal regulation by law, so far it has not been a matter for or against law. I think their own standards set up by the doctors' community was more in the direction of not getting involved in assisted suicide.

Q2210 Baroness Finlay of Llandaff: The medical profession self-regulates, does it? The death certificate, of which I have been fortunate to be shown a copy, simply certifies that the person is dead. It does not state on the certificate why they died.

Dr Rehmann-Sutter: From the canton of Zürich?

Q2211 Baroness Finlay of Llandaff: This is from Zürich, yes.

Dr Leuthold: In our guidelines—can I just have a copy for a second?—we have here also that the death of a patient as a result of assisted suicide must be reported to the examining authorities as an unnatural death for investigation.

Q2212 Baroness Finlay of Llandaff: So they are reported?

Dr Leuthold: Yes.

Q2213 Baroness Finlay of Llandaff: But if you had a lot of euthanasia or physician-assisted suicide happening and the doctor did not self-report, is there any way that you would know about it?

Dr Rehmann-Sutter: Probably not.

Dr Leuthold: No.

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Q2214 Baroness Finlay of Llandaff: The death certificate does not state—

Dr Leuthold: It is a self-declaration.

Q2215 Baroness Finlay of Llandaff: On our death certificates you have to write the cause of death and if your cause of death is not very precise or looks strange, for instance, if you have an awful lot with the same thing written on, then you may be investigated separately. How do you record the cause of death and where do you record it?

Dr Rehmann-Sutter: I do not know.

Q2216 Baroness Hayman: Can I return to the issue of ALS patients and the problem of those who may have mental capacity but do not have the physical capacity to administer for themselves? Are they excluded by these guidelines?

Dr Leuthold: They would be excluded whether it is fair or not.

Q2217 Chairman: You were making the point before about the total numbers of deaths in Switzerland and the total number in this area, which I got the impression was rather small.

Dr Leuthold: Yes. What I am talking about is 700 persons per year who either have physician-assisted suicide or euthanasia and out of those 700 I would say—and this is just a guess—that not even a handful would fall into that category. We are talking about a few individuals and, of course, for those individuals this is essential. Out of the vast majority of those who even consider committing suicide at the end of life I am talking about those only.

Q2218 Baroness Hayman: We have had evidence that it is the patients with exactly these sorts of degenerative disease who have the most acute problem because they know that a lot of means that would be open to other people, for instance, to squirrel away their own tablets and wait until they have enough to attempt suicide in other ways, are not possible for them and in some ways they make the most emotionally powerful case for needing physician assistance, so there is some irony that they are the ones who cannot avail themselves of a liberal regime as you describe it.

Dr Leuthold: I agree with you. Even if you take these guidelines I would start with these patients to be included because if you have ALS patients you do not really know whether they will still go on for half a year or a year or if the end is quite close. If you take our guidelines in the very strictest sense we would not say that this is a terminal phase of life, and they could not be considered anyway.

Q2219 Chairman: If you take the situation of the critical point about the person who has passed the ability to do it themselves, even the last impression of the tap or pump, it is not the guidelines that intrude on that; it is the law that says it has to be assisted suicide and suicide means killing yourself, so there must be sufficient physical and mental capacity left to enable a person to kill themselves before Article 115 comes into the picture. If you are not under 115 you are under one of the earlier clauses and these are penal clauses.

Dr Leuthold: There is, of course, a gap between theory, law and practice and if you look at these numbers it is one per cent for euthanasia and physician-assisted suicide in total and out of this one per cent 0.7 per cent are euthanasia, active or direct or indirect. The larger fraction is actually euthanasia in Switzerland despite this law.

Q2220 Baroness Finlay of Llandaff: The question in that study was about the intention with which an action was taken. It did not look at what was actually done.

Dr Leuthold: No, no. They looked at what was actually done.

Q2221 Baroness Finlay of Llandaff: But did they actually look at the final dose of drug given? I thought they asked the physician what the intention was behind the last dose of drug given, but in some of those you cannot be sure that it was the drug that killed the patient or whether the patient was dying of their disease anyway and they had a dose of drug but it was not the drug that killed them, because to kill people you are talking about nine grams or so of barbiturate and in those sometimes it was milligrams of an opioid, if I remember. I may have remembered it wrongly.

Dr Leuthold: You are correct. I would not rely too much on these figures but nevertheless they give us some evidence about the real situation. Even these numbers might be different or need interpretation.

Q2222 Baroness Finlay of Llandaff: Or they give you evidence of ignorance amongst the physicians about the pharmacology of the drugs that they have prescribed.

Dr Leuthold: But the study set up would not have been very good. It is self-declaration, of course. It is a way of interpreting a situation at the end of life to mark here or there.

Chairman: Which study is that? Is that one of the van der Wal studies?

Q2223 Baroness Finlay of Llandaff: No, it is not. It was another one.

Dr Rehmann-Sutter: Van der Heide in *The Lancet*.

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Baroness Finlay of Llandaff: Yes, it was in *The Lancet*, one of six nations. We have got that.

Q2224 Chairman: That is the same one as we had in Holland, is it?

Dr Leuthold: Holland, Belgium, Switzerland, Denmark, Sweden, Spain.

Q2225 Chairman: It is just that I want to be sure we have the right one if there is any doubt about what the specific facts were.

Dr Rehmann-Sutter: It was in *The Lancet*, Agnes van der Heide.

Q2226 Baroness Finlay of Llandaff: Just now when you were talking I think you said 700 physician-assisted suicides.

Dr Leuthold: No 700 cases of, let us say, physician-assisted death. I refer to this number—one per cent out of the 70,000 death cases in Switzerland.

Q2227 Baroness Finlay of Llandaff: These figures, which I have only just been given, and perhaps I am misunderstanding them, suggest that there are 30,000 deaths. This was in the year 2000 with a total of 900 suicides, and 713 were under the age of 65.

Dr Leuthold: That is only male.

Baroness Finlay of Llandaff: Oh, sorry, and then I have got to add in females.

Chairman: Some females died as well apparently.

Baroness Finlay of Llandaff: Yes, but with fewer suicides.

Baroness Hayman: They do not come on the statistics, Chair.

Baroness Jay of Paddington: If you do not work you do not die!

Q2228 Baroness Finlay of Llandaff: These were ordinary suicides?

Dr Leuthold: Yes.

Q2229 Baroness Finlay of Llandaff: But in the others they were end-of-life decisions. The figure you are talking about is for end-of-life decisions, is it not?

Dr Leuthold: Yes.

Baroness Jay of Paddington: We are all talking about papers which most of us have not seen.

Chairman: Exactly. Are we going to see the paper you are talking about, Lady Finlay?

Baroness Finlay of Llandaff: You are welcome to have it. It is the Federal Statistics Office's publication in 2004, and the figures are from the year 2000.

Q2230 Baroness Jay of Paddington: Could I go back to the general point, and I know this is a very delicate area and I am not asking you to make any specific comment, but in the area that you have described where the theory or the practice may be different

from the guidelines or the law, have there been any cases that you know of, in which assisted suicide has been conducted in the sorts of circumstances that Lady Hayman has been describing of someone in the very advanced stage of ALS and not quite able to push the pump themselves, where anyone has been prosecuted for appearing to help them end their life?

Dr Leuthold: To my knowledge such a case never came to the court. I cannot think of any. The only cases we remember are those where there were selfish motives.

Q2231 Baroness Jay of Paddington: So they were different “wrong motives”?

Dr Leuthold: Yes.

Q2232 Baroness Hayman: What about the disciplinary consequences for physicians who act? These are guidelines. I wanted to ask what force the guidelines had. You said earlier that if a physician assisted suicide under the terms of Article 115, even if it was not an end-of-life case, would not be a criminal offence.

Dr Leuthold: No.

Q2233 Baroness Hayman: It would not be a disciplinary offence?

Dr Leuthold: These guidelines are a kind of code of conduct for physicians.

Q2234 Baroness Hayman: What happens when someone breaks the code of conduct?

Dr Leuthold: Most of our guidelines are part of the code of practice of the Association of Medical Doctors in Switzerland, so if you do something against this code of practice then in the worst case you can be excluded from this Association. It is more a moral code of conduct in that the medical doctors know what is the ethically approved standard.

Q2235 Baroness Hayman: We have the same system in the United Kingdom and the General Medical Council is almost in continuous session with complaints against doctors for more serious or less serious breaches of the codes. It may be relationships with patients or all sorts of things. You are saying that there have been no disciplinary hearings around assisted suicide because that presumably would mean that there have not been complaints by families about the behaviour of physicians.

Dr Rehmann-Sutter: I do not know.

Q2236 Chairman: Where would these complaints go to in your system? Who is in charge of the regulation of doctors? If a doctor breaches a part of the code is it the Association that deals with it?

Dr Leuthold: It is the Federal Association of Medical Doctors.

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Q2237 Chairman: That is not the same as yours?**Dr Leuthold:** No. We are kind of the ethical consciousness. The Association is one of our founders. We have a very strong link and the President is always a member of our board.**Q2238 Chairman:** I just wanted to be absolutely right, but I think I am right in saying that these guidelines are for the care of the terminally ill and that is why it is assumed that you are terminally ill if you are seeking assisted suicide in the subject that that guideline deals with, but it would not, of course, be a breach of the guideline if you dealt with an assisted suicide in a situation with which the guideline does not deal, namely, where you have not reached the stage of terminal illness but there is some other condition that has produced a desire to die and the physician has assisted it. Is that right?**Dr Leuthold:** That is right.**Q2239 Baroness Hayman:** I would be very interested, Lord Chairman, if it was possible to make some inquiries of the disciplinary body, to know if there was any data about complaints against physicians in relation to assisted suicide.**Dr Leuthold:** I am sure that there are no such cases but I do not know really.**Earl of Arran:** One is left believing, therefore, that the interpretation of the law is very liberal.**Chairman:** Why do you say that? I have no information so far to suggest that the law has ever actually been broken.**Baroness Jay of Paddington:** Or has never been invoked.**Q2240 Chairman:** We do not know. It is one thing to say there have been no prosecutions and therefore the law must be liberally interpreted if you know in fact that there have been infringements of the law, but if you do not know whether there have been infringements or not you cannot make that deduction. Are you able to help us on that point?**Dr Rehmann-Sutter:** I remember one case at least where it was not an issue of selfish interest but of lack of competence. It was a case in Basle when EXIT tried to help a depressive patient to die and the official—**Q2241 Baroness Finlay of Llandaff:** Chief Medical Officer of the canton?**Dr Rehmann-Sutter:** That must be it. He intervened and prevented this assistance from being provided by reference to this law. Otherwise it would have been broken in some interpretation because the law does not say explicitly whether in any cases of depression it means directly that there is lack of competence.**Q2242 Chairman:** So he intervened to suggest that the interpretation should cover that particular circumstance?**Dr Rehmann-Sutter:** Yes. There is now a big discussion within EXIT, and I am sure you have heard about that, about finding special cases of depressive patients or patients with other kinds of psychiatric diseases in a state of clarity where they cannot be excluded formally from the position of being competent. What we have said in our recommendation is very general. The law should follow the rule that whenever the desire to die is a symptom of the disease then the person needs care and treatment and not assistance for suicide, but in practice, of course, the question is how to decide in a particular case at a particular time whether this is a symptom of the disease.**Q2243 Chairman:** There might be situations in which there was some mental condition affecting the patient but which did not in fact result in the patient not being competent to take a decision that they wanted to have suicide; is that right?**Dr Rehmann-Sutter:** This is the case under discussion. In the discussions in the Commission we think that these cases can happen, that the fact of the presence of a psychiatric disease, depression for example, is not in each case an exclusive condition for enough competence. This term “competence” needs interpretation relative to what people in psychiatric conditions can experience. That was also an important point for us. It needs a long term caring relationship between the one who assesses the capacity and the patient himself. Merely a formal encounter resulting in expertise will probably not be enough evidence for that.**Q2244 Chairman:** Can you tell us a little bit more about the Commission that you head up and which you have been speaking for this afternoon? When was it first set up?**Dr Rehmann-Sutter:** In 2001, so it is very young.**Q2245 Chairman:** Vigorous therefore; it has the vigour of youth. It was set up by the Federal Parliament?**Dr Rehmann-Sutter:** Indirectly, yes. The Parliament made a law which asked the government to install such a committee.**Q2246 Chairman:** And then the ministers appointed the members of the Commission?**Dr Rehmann-Sutter:** Right.**Q2247 Chairman:** What period of office do you hold?**Dr Rehmann-Sutter:** It has an upper limit of 12 years.**Dr Leuthold:** With re-election after three years.

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Dr Rehmann-Sutter: There is a maximum of three re-elections and we are about one third medical professions, one third ethical professions, theologians and philosophers—I myself am a philosopher—and one third additional experts who are needed, for example, in law, biology, psychology, etc.

Q2248 Chairman: The function is to advise on biomedical ethics but does that relate solely to the ethics of the medical and associated professions or does it include ethical issues that might be of a biomedical character but related, for example, to participation by non-medics in assisted suicide?

Dr Rehmann-Sutter: I would say the latter, the more general.

Baroness Jay of Paddington: I am sorry to return to this question about ALS and assisted suicide but Lord Joffe has shown me, and I have read it before and I had forgotten, a reference to a case which must have been quite familiar to you about a woman in this country who was almost completely paralysed after a severe brain haemorrhage and she was in care for four years and then signed up with EXIT, but obviously was in a situation where it would have been very difficult for her to administer a lethal dose. Her husband created—and there is a drawing of it—a rather extraordinary contraption by which she was enabled through a kind of catheter arrangement—and I knew I had seen something like this, which is what reminded me, and Lord Joffe with his brilliant filing system had it—which enabled her with this process technically to administer the dose. This case was reported in the normal way through the official EXIT procedures because it was EXIT she was involved with, was considered and was agreed to be the kind of assisted suicide which was, I suppose one should say, technically at least within the law as described, but frankly, to the common-sense person looking from the outside does seem to have been verging on active support and active euthanasia but was regarded as being within the guidelines. There must presumably be quite a lot of cases of this kind, and this is where perhaps I am not parting company with you, Chairman, but am concerned about

whether, if they have not been prosecuted, this means that they are or are not happening.

Chairman: The truth about that case is that it was held to be within the strict letter of the law because they constructed this apparatus and he would not have found it necessary to do that if they were going to interpret the law more generously.

Baroness Jay of Paddington: Quite, but what we are discussing is the grey area which you referred to much earlier in our discussion. I think the grey area must have become quite extensive.

Chairman: My point is the simple one, that unless we know that the law has been broken we cannot make any deduction from the fact that there have not been prosecutions. That is the only point I was trying to make, although I was perhaps making it rather at length. I understand that it is possible to have a borderline, which is quite difficult, and ingenuity was apparently required to get over the borderline into the lawful area in that particular case.

Lord Joffe: I spoke to Dr Bosshard who gave evidence to us and who wrote this article, and he said that there was really no need for the husband of the patient who took it, who was a technician and liked constructing ingenious devices, but that there are other medically approved devices which would have served the purpose just as well.

Baroness Jay of Paddington: This does look quite bizarre.

Q2249 Chairman: He wanted to demonstrate his ingenuity. Who knows, he may patent his device. Thank you very much indeed for your help in an area of very considerable interest and difficulty. You have given us a very clear picture of the situation as it exists here, although of course, obviously there are areas of great difficulty in applying a law of this kind in the many varied circumstances which the law may have to address. Thank you both very much and, as I say, when you read the transcript of the evidence I hope it will be clear and you will realise how wonderful the account was that you gave to us all.

Dr Leuthold: Thank you.

Dr Rehmann-Sutter: Thank you. It has been a privilege to have these discussions.

 THURSDAY 3 FEBRUARY 2005

Present	Arran, E. Finlay of Llandaff, B. Hayman, B. Jay of Paddington, B.	Joffe, L. Mackay of Clashfern, L. (Chairman) St Albans, Bp.
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Examination of Witnesses

Witnesses: DR ANDREAS BRUNNER, Attorney General for the Canton of Zürich, and MR BEAT SOMMERHALDER, Prosecutor, Canton of Aargau, examined.

Q2250 Chairman: Thank you very much indeed for having us here and being willing to give us some time to help us in our inquiry into Lord Joffe's Bill which seeks to change the law of England and Wales in relation to end of life and assisted dying. We know that you have considerable experience in this area in Zürich and perhaps also more generally and we thought it would be very helpful to have your experience as part of the evidence that we collect. The shorthand writer will take a note of the evidence. We will submit the transcript to you for review before it is published and then it will be appended to our report and become general public property when the report is published. If it is convenient for you what I thought might be good would be for you to give us a shortish introduction on your view on the matters relating to your experience of the area we are concerned with and then my colleagues might wish to ask questions of particular concern to them.

Dr Brunner: My Ladies, my Lords, welcome to Zürich. After the Second World War Sir Winston Churchill was here in Zürich and had his famous speech with the even more famous sentence, "Let Europe arise". Perhaps this meeting serves also on another subject to make Europe arise once more because in this case of assisted suicide we would be grateful to have not just our regulation but also some regulation in other countries on this subject. With me today is the Prosecutor from the canton of Aargau, Mr Sommerhalder. Aargau is between Berne and Zürich. You have travelled through the canton of Aargau to get here and Mr Sommerhalder is here because the organisation DIGNITAS, which you will visit this afternoon, rented a house in Aargau to make assisted suicide available there also, I think because they had too many problems with us. They are now staying there and I am quite glad of this because you were also at the Government yesterday and you saw Mr Stadelmann. They thought at the Government that assisted suicide questions were more or less the problem of the canton of Zürich which has 1.2 million inhabitants rather than the problem of the whole country. Now it has gone also to the canton of Aargau it has moved up a little bit in importance to them. I am sorry I have invited you to this room because we are reconstructing this 18th

century building and the other rooms are not perfect at the moment. My English is not very good. Our interpreter is here if necessary and we have to be very clear about what we mean on each word because the terms are quite difficult and there could be some misunderstandings which I hope will not occur. If I say something impolite to you it is not impoliteness, just that I cannot do it better. I read Lord Joffe's very interesting proposal for the Bill and also the statements of Baroness Finlay, which make another point, and those of the church. In our country it is mostly the Roman Catholic Church which is totally against assisted suicide. I think a lot of the proposals in Lord Joffe's Bill would be very important if they were regulated in Switzerland also. If it is convenient to you I thought we would stay about an hour here and then I shall invite you to have a business lunch in the house across the road, which is also a little bit related to our subject in a historical grove, where we can speak together informally further on the subject.

Q2251 Chairman: That sounds very convenient.

Dr Brunner: I will start by giving you the development of the Swiss law but I do not wish to go over the same things you heard yesterday from Mr Stadelmann.

Q2252 Chairman: You can take your own line. You will have a way of putting it which will be your own and I am sure we will listen with great interest.

Dr Brunner: In Switzerland we have had a very liberal law since we made our penal law in 1934. Under our Penal Code we have two Articles concerning this subject. One is "homicide on request" and that says that anyone killing a human being at his serious and urgent request shall be sentenced with imprisonment for up to three years. That is important in connection with suicide. When you are at the limit from suicide it might make the difference to have assist in suicide, that is to say that the man is doing the killing, which was asked also in the case of Diane Pretty which everybody knows about. The next one is assisted suicide, Article 115 of our penal law, that is, that anyone, who for a selfish motive shall help someone to commit suicide, shall be sentenced in a penitentiary for up to five years if the suicide has been

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completed or attempted. Those is the only law prescriptions we have; we have no other prescriptions on suicide in any other law. When the law was made in Switzerland we did not have any suicide organisations. The meaning of assisted suicide was, for example, as a last duty of friendship to help a person to die. In the late 1980s there was the first suicide organisation was established here in Switzerland. That was EXIT, and initially they had a couple of assisted suicides. Now we have five or six organisations and some splinter organisations also. They are people who worked in an organisation but who had perhaps some problem with the organisation and have now set up their own little organisation. Until the year 2000 there were no big problems with that. In the early 1980s we made some processes and we described that as murder and that was not at all, and then that was quiet on the whole problem. Then in about 2000 suicides of people from England started. We had out of the whole of Switzerland in the canton of Zürich 26 Swiss people. I can give you those afterwards. DIGNITAS started then with German people. I do not want to go through all the years but the highest figure was in 2003 when EXIT was about the same and DIGNITAS now had a lot of people, 93, only two from Switzerland, the most from foreign countries such as Great Britain. Our police do not make a difference between England and Great Britain; I am sorry.

Q2253 Chairman: You are not unique in that particular respect!

Dr Brunner: Last year the numbers were a little bit deeper because we have now the canton of Aargau where they are also going, and in Aargau last year there were about 20 assisted suicides. Of British people we have seven. In EXIT most of the assisted suicides are for Swiss people. That is very important. They have from time to time one from Germany, for example, but this person had acquired in his life a close relationship to Switzerland or has his children here or something like that. DIGNITAS went up from five (in 1999 there were zero) to 93, so we have in total about 100 in Switzerland. This year has started with a lot of assisted suicides. The normal way of proceeding in assisted suicides in our country is that the person who wants to have suicide will be a member of one of these organisations. In the past it was important that the organisations only gave help to dying persons. I make a difference between helping a person to die and helping a person to suicide. Helping to die refers to people who are incurably ill and very near the end of life. That process would start quickly. Helping to suicide refers to all other persons. That means the killing or homicide or help to suicide of a person in whom this state of being near to death is not yet reached. That means that with treatment

their lives can go on for months or even years, perhaps even more than ten years. The third section in this category is the killing of people who are old, who are afraid to be mentally ill or who have the first beginnings of mental illness; they would receive help from the organisation. That is all allowed in Switzerland. It is not necessary that it is the first category, that is, the helping to die. It is also free for persons who live longer but the doctor has got to have a reason for that because people in our country are taking a barbiturate and then they have to go a doctor who gives a prescription. Also, concerning Lord Joffe's Bill, it is important to see that you have very few doctors who want to give those prescriptions. Normally they are doctors who have ended their professional career who are doing that. For young doctors it is quite difficult because the understanding for doctors is to help people to stay alive. That is quite a big problem and every organisation has a couple of these doctors. You see one or two today, to help them, a doctor of confidence of the organisation. That is quite difficult. For me the doctor should be quite neutral. There have to be two doctors, not just the doctor of the organisation. They speak with this doctor. Then they get the prescription. Afterwards they are going to homes for elderly people in Zürich. That is allowed; it is two years ago but there were only six persons. There was no problem. Or mostly they are foreigners in one of the apartments of the organisation. You will hear about the process this afternoon, that they are coming in, they are speaking once more and then after a couple of times they are drinking that barbiturate and finally, when they are dead, the people have to inform the police because it is not a normal death. We have that as a control and the police come with the forensic physician and the public prosecutor. That is not a normal penal procedure. We are coming only afterwards and that makes quite a lot of problems. They show us a couple of documents, like the suicide declaration, the medical diagnosis and all that. We want also now to have from the medical that they have capacity of judgement. That is very important. They make also a processing record of that. Now perhaps what we have most problems with are the people who are paralysed who have to have some infusion or stomach catheter. That is concerning the Article on homicide on request because it is very important in our country that the human being committing suicide is doing the last act himself or herself. Normally they drink the cup or with the infusion and they have to be capable of turning around here and doing a little bit of other things, which is quite difficult because they are really ill people sometimes. Another really difficult case is mentally ill persons, normally mentally ill or more than starting with Alzheimer's disease. There are three positions of Alzheimer's disease. Now we are

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making a process for when Alzheimer's disease is too advanced so that the person is no longer conscious of what he is doing. That is quite a difficult section. On the other side we have to see also that there can be mentally diseased persons who can be from time to time for a period in a good condition, and then we say lastly that it can be possible that this person can be assisted to suicide. Another problem is double suicides. We get from time to time double suicides, say, a couple who have lived 50 years together or a sister and brother. Here you have big problems because if I am in a couple or in a relationship and I ask him, "Shall we go to the cinema today?", and he says, "Oh, no, I prefer to go to the opera", and I say, "Come on, let us go to the cinema", it is a discussion and one person has more influence than the other. I was once in my profession doing a little bit of politics also and we had a letter from a couple who announced that they were going to have assisted death a few days later. When they wrote that I thought, "I have to visit them". I visited them. It was a couple in their eighties. He had cancer of the prostate and I saw that the lady had spent 50 years doing what her husband wanted. When her husband said, "Come on, darling, let's go", she said, "Yes". I tried to tell her that I knew a couple of widows who were quite happy afterwards. There is a restart of life for someone like that. I only want to show that the double suicides are a big problem. Then we have problems with foreigners. The normal way is that they come from other countries. They have some written contact with the organisations and they arrive one day by plane or by car or train in Zürich or Aargau and the same day or the day afterwards they are committing suicide with assistance. For me it seems they had pressure first from the journey to come here, and also they came on several occasions with television teams or writers or whatever, but also, if they come alone when they are in this room they feel a pressure to go. That is quite a problem. For me that means that the explicit wish to die has to continue over some time. If I may make this remark, those 14 days you have in your proposal, Lord Joffe, is a very short time and it would be good to think that over once more perhaps, because it is very important to say that apart from mental problems people have dips in their lives. One day you want your life, the next day not. My mother is 85. She is in good condition but there are periods when she says, "I want to die. My husband is dead. I do not have anything to do". Two days afterwards she has a great concert and she is happy". In old people it is like that. You have got phases. You are in a dip, you are low, and then you go up and life is beautiful. We have that also and it is very important that we do not get persons to suicide who are in a phase like that in my opinion. Perhaps now you can ask some questions and then I will show you what I think we have to do

as law in the canton of Zürich because I have prepared the law a little bit to have some regulations and if Switzerland does not do this we will prepare in the canton of Zürich such a law, we will make such a law to put some pressure on the country. It is stupid when we make a law. We need to make a law in all Switzerland but to put some political pressure on we will make a law.

Q2254 Chairman: That is quite an interesting and important point to explore. I think I am right in saying that the criminal law is now federal Swiss law?

Dr Brunner: Yes.

Q2255 Chairman: And the Articles you referred to are from the Swiss Penal Code which rules in Aargau and in Zürich and everywhere else?

Dr Brunner: Yes.

Q2256 Chairman: What I am not clear about from what you have just been saying is this. You can have pressure from Zürich or from Aargau or from other cantons on the Federation to change the criminal law for the Federation but if you cannot persuade the Federation to act are you still able in the canton of Zürich itself to promote a criminal law which will govern what takes place in Zürich?

Dr Brunner: Yes. I understand your question quite well. I do not want to change the criminal law. We cannot do that. The criminal law has to be changed by the Confederation but we can have a law of authorisation and monitoring of those organisations. That is not criminal law.

Q2257 Chairman: That is administrative law, would you say?

Dr Brunner: Yes.

Q2258 Chairman: You can make administrative law arrangements and there are administrative law tribunals, are there not, in Switzerland distinct from the criminal court?

Dr Brunner: That is right.

Q2259 Chairman: And these tribunals could, for example, administer a registration or regulation system for a given organisation like EXIT or DIGNITAS?

Dr Brunner: Yes. Every canton could do that also.

Q2260 Chairman: I just wanted to be clear. I thought from what we heard yesterday that the criminal law is now in the Federation and in the Federation only.

Dr Brunner: We do not change anything in the criminal law. That is because we have big discussions also on these questions of helping suicide, of helping to death. Also, in the hospitals there are quite a lot of discussions and I do not think we will find a way

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forward in the next few years but perhaps I can make some remarks not on the criminal law, the liberal point of the suicide rules in the criminal law, but on the organisation and structure and financial points.

Q2261 Chairman: You explained to us that when a death occurs other than for natural causes the police are informed and a level lower than the ordinary criminal level of investigation goes ahead. Is the report sent to you?

Dr Brunner: Yes. The normal criminal report but if the report is not clear then we open a normal criminal procedure. We have every year two or three of them.

Q2262 Chairman: In that case what you are seeking to establish is whether or not the criminal law has been observed and followed in what was done.

Dr Brunner: Yes.

Q2263 Chairman: There was a question we raised yesterday and perhaps this is a good time to ask you to deal with it please. That is that under Article 115 in your code a person who assists must have no selfish motive. We were wondering about the situation of an organisation that provides these services and helps, whether, for example, there is any financial consideration for their service and, if so, whether that has any effect on the rule that the person assisting must have no selfish interest in the suicide.

Dr Brunner: This is a very important point. That is also something in the law which has to be done. This organisation now in Switzerland can be an association without any control by the state or anyone. One of the points is that we want to have that in our regulations, that the organisations' financial transactions, each franc, each pound, that comes in and where from, have to be open, because that is a problem also. How much can you take for assisted suicide? I hear rumours from time to time that they take a lot of money but I have no proof of that. We are looking but at the moment we have no proof on that. I think that is very important. It is also very important to have in these organisations a good approved selection of people who are doing these assisted suicides because there is a danger from so-called angels of death. From time to time you have in hospitals, and I am sure you have had that also, persons who are killing a lot of people for pity or something like that. I think that is quite a danger and we have had persons in this for whom it becomes a little bit not only financially a business but also a mission to help people die and that is not good. They have to have a clear distance from that. I also mean that in our regulation it should say, for instance, that you must not have more than five to ten cases of assisted dying per year or something like that, to have it on a very low base so that in each case you help it is a very individual case and not, "Oh, where is the next

case?". What you said on selfish points, I mention now too financial points. You have to open up all that, you have to make some regulations about what they are allowed to know. There are also people, when they are being helped, who make big donations to those societies. Should those societies be allowed to take donations like that? I can imagine that a man or a woman who wants to die might give quite a lot but also on the other side it is quite dangerous to have too much money for that. I think it is very important to have some regulations in this case.

Q2264 Chairman: You have not made such regulations yet?

Dr Brunner: Nothing.

Q2265 Baroness Jay of Paddington: I was going to ask you a general question before you get into the detail. As Lord Mackay said, that is very important to us in terms of framing regulations. I hope this does not sound negative. It sounds as though the concern about this has been stimulated by the increasing numbers, which are obviously of concern, of people coming to this country in order to take advantage of these organisations that exist here. Why has it taken people in the position that you are in, as it were, so long to see the necessity for regulation in this area?

Dr Brunner: Because I think it is not my problem. You did not shoot on me. I told that but it is a problem of the politician.

Q2266 Baroness Jay of Paddington: No, but as you said to Lord Mackay, individual cantons can make regulations.

Dr Brunner: Yes. We have a parliament also in our country.

Q2267 Chairman: These are the politicians?

Dr Brunner: Yes.

Q2268 Chairman: Of whom you do not count yourself one?

Dr Brunner: And this has to pass the politicians also. Here you have the same spectrum of meanings as in the parliament of the country. It is quite difficult to make legislation in this case, to find a way where you can go.

Q2269 Baroness Jay of Paddington: But is it right to say that the concern about this has been stimulated by the increase in the numbers of foreign people coming? For example, we had an informal discussion over dinner last night with some doctors who said that they felt that it was appropriate that this should be offered to foreigners because in Switzerland everyone was equal in terms of the kind of treatment they would receive, but from what I hear from you (and we have heard other people say this) it has really

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been the influx of people from other countries that has caused people here to look at the regulations.

Dr Brunner: Yes. Foreigners coming in the last few years have made the whole problem come up in discussions. That was one point. I am not against the foreigners coming and I think it would be not correct to put it like that. For me it is the procedure that this person comes today and dies the same day. Then I say that is also in Lord Joffe's Bill, to have to stay. That is not because it is a foreigner. Foreigners can die if they live in Switzerland or in Zürich also.

Q2270 Baroness Jay of Paddington: But you would get over that problem if you legislated for it, for example, in the way that the other countries who offer this have done, which excludes people except if they are resident because then the concerns about people having a long term relationship with people and being—

Dr Brunner: I think that is very important.

Q2271 Baroness Jay of Paddington: Exactly. My basic question is, is that what really concerns you?

Dr Brunner: It sums up the whole problem. Before we had 20, 30 a year. It was "normal business" and we had quite a good relationship also with EXIT. They make really good things. They also send the persons to psychological institutes to control them and things like that. They are making that, what we need to have the law, but the new ones who have come up have made most of the problems for us. Under the new ones there is DIGNITAS which takes foreigners but there are little groups also; it is quite difficult.

Q2272 Chairman: Little groups as well as DIGNITAS operating in Zürich?

Dr Brunner: Yes, but only a few, two or three. Even then they leave before the police come. They give the people the barbiturate and then they go and then a couple of days later the person is dead. That is also a problem that we have that could be one reason, that certain doctors give quite quickly the prescription for the barbiturate and then they do not care about people. They take it when they want.

Q2273 Baroness Hayman: Can I just follow up that point because I have always found it slightly confusing? The law that does not prevent the assisting of suicide is a national law under the Penal Code, yet most of the conversations we have are around organisations involved in this. What I was trying to find out was whether there was practice going on that was between an individual doctor and an individual patient, perhaps in a country area where they are not involved with EXIT or one of the big organisations, and whether you feel there is unreported assistance that goes on as part of a physician/patient relationship separate from the

organisations that, if you like, specialise in offering the service.

Dr Brunner: I am sure you are right and I am sure also that there is no demand for police in something like that. They make this as quite a normal death. That is a little bit the same problem we have also got in hospitals. I am sure that we have quite a lot of them who are doing that. I know that from friends of mine who are doctors. If there is a patient they discuss that together. I think that is the same in each country. I know also in Germany you do not have the possibility to do like here but I know from German doctors also that they are practising that. You make a very important point there.

Q2274 Chairman: Here in this country it would be perfectly lawful for a doctor to assist in the suicide of his or her patient?

Dr Brunner: It depends.

Mr Sommerhalder: In most of the cases it is okay, yes.

Dr Brunner: Also, for example, if a man has Alzheimer's or something like that and they speak together and he says, "Come on, doc, now. It is time for me", I think that arises but I think also, as I said at the beginning, that very few doctors want to give the barbiturate because it is against the doctor's ethical position.

Q2275 Chairman: It would be lawful for them to do it under the federal criminal law?

Dr Brunner: Yes.

Q2276 Chairman: But you think that generally speaking anyway in Switzerland there is reluctance on the part of ordinary doctors, the GPs, to become involved in this process because they think it is outside the ordinary range of medical care? Is that right?

Dr Brunner: That is right.

Q2277 Chairman: But there may be some who do it nevertheless.

Dr Brunner: There may be some, yes.

Q2278 Chairman: I am right in thinking that where it happens it ought to be certified to the police, whether it is a doctor that does it or someone other than a doctor, but when a doctor does it he is supposed to certify—

Dr Brunner: Also, yes, because it is not a normal death. You have to certify each not normal death.

Q2279 Baroness Hayman: But the figures that you gave us were the figures for the organisations?

Dr Brunner: Yes.

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Q2280 Baroness Hayman: In the last five years have there been no certifications for individual doctors outside those organisations?

Dr Brunner: I cannot tell you that. I do not know. I know that we have several persons who died with barbiturate on their own and in one case we could follow the way back to where the barbiturate came from and we found the doctor, an elderly doctor who is quite a difficult man. He comes from the canton of Aargau, but we made it that he cannot make any prescriptions now.

Q2281 Baroness Hayman: So it was a disciplinary process, that he cannot give prescriptions now?

Dr Brunner: Yes.

Q2282 Baroness Hayman: Has there been any research on complaints to the disciplinary body for doctors by families about this?

Dr Brunner: Yes.

Q2283 Baroness Hayman: Because this is how you would expect unreported cases to come to light. If a family member was unhappy about something they would perhaps complain either to the police or to the medical authorities.

Dr Brunner: Yes, that is absolutely true. That makes another point which I want to tell you. We had also quite a lot of problems with family members. There are cases of persons wanting suicide. They speak together in the whole family. It is a family decision. You can also ask if there is some pressure or not. If your old auntie who has got millions is in a mood where she has to pay a lot—I do not know, but you have to mention that also. In most cases a family goes, “Okay”, but there are also people who do not advise their families. We have had also British people who did not advise their family. For the family there is a big shock. That is quite a big problem also. How can the family be involved in a process like that or even not be involved, because if you take the family together you can say that is a pressure? I do not know.

Q2284 Chairman: I am right in thinking that there will be cases—and you do not happen to have the numbers—where a doctor who agrees to give the prescription will report that in the ordinary way as an unnatural death. That would be, as far as one can understand, perfectly lawful and so there would be no complaint from that source in respect of any illegality but there might be other cases where a doctor who does that does not report and that would certainly be a cause for disciplinary action, I would think. Do we know whether there have been reports of that kind to the disciplinary authorities for doctors?

Dr Brunner: That we have also, yes.

Q2285 Earl of Arran: When a person is very poor and wants to take advantage of assisted suicide does the gathering together of the money come from friends and family or is there any village funding or canton funding for doing this?

Dr Brunner: No, we have no canton funding, no village funding for that. Normally, if the person is living in Switzerland it is not expensive at all.

Q2286 Earl of Arran: I meant a Swiss national.

Dr Brunner: Then it is not expensive at all. They take 50 or 60 francs, the organisation and the doctor, for the prescriptions. That is not a problem of money there. It could be a problem of money for the foreigners who are coming, if it is from Japan or something like that. If you come from Britain you can do it for a couple of hundred pounds, I think, not on the train but by aeroplane.

Q2287 Chairman: I know—Ryanair.

Dr Brunner: That is not a problem.

Mr Sommerhalder: We heard that they paid the organisation here about £500 to £1,000 for the costs for documents here. Foreigners pay about £500 or £1,000 maybe.

Q2288 Baroness Jay of Paddington: No, but the Swiss person does not?

Mr Sommerhalder: No.

Q2289 Chairman: The Swiss person wanting to have this assistance would pay something less?

Mr Sommerhalder: Fifty francs maybe.

Dr Brunner: I did not hear this number. The organisations have to pay for the burial, the cremation, going back. We have also now a new problem. There was a man who came from Hong Kong last year and he died and he wanted to be buried in Zürich. We had to do that also according to our laws. Normally they go back to their own country but they had not got too much money to take him back but they rented here 25 years ago.

Q2290 Earl of Arran: Does not either EXIT or DIGNITAS have to file annual audited accounts to some central authority? They are a limited company presumably, or a trading company.

Dr Brunner: As I have tried to say, there is no surveillance, they are associations without any state control. I think that should change.

Q2291 Chairman: That would be a matter for legislation in the canton.

Dr Brunner: Yes, as well as in the country.

Q2292 Chairman: And that would require the legislative will of the Parliament to be used for that purpose. Would it be possible as part of the

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administrative arrangement to require some time to elapse between the first request for suicide and it actually happening? Could that be done apart from the criminal law as a matter of regulation, do you think?

Dr Brunner: I will do that, yes. That is for me quite important, that you have the constant deep wish for suicide. That is the most important thing because there are also medical and scientific works from doctors which say that from 100 per cent of elderly ill persons who have a wish to die and explain this wish to die, two months or three months afterwards only 50 per cent stay at this wish. That is not important for the cases, just for the help to die which I said at the beginning makes a difference. There this can be quite short, I think. Perhaps you will speak with EXIT also on that. They say also that there are people who go from time to time really a long way in illness. They have tried everything. They also wanted to do everything, also the family did, and then comes the decision on the day and then they want to go really. The discussion was before but that is really for people only at the end of the final phase, two weeks or something like that.

Baroness Jay of Paddington: I think it would be very helpful when you come to describe in detail what your proposals are if you would be kind enough—I think I am probably being a little stupid about this—to say what it is that you can effect through regulation because you just replied to Lord Mackay that you could regulate on the time frame for decisions and yet you said to Lord Arran and to me that when there were other types of regulation, such as the audited accounts and my more general concern about a regulatory framework, this would all have to be a legislative decision.

Chairman: My concern as well. It would all be legislative.

Q2293 Baroness Jay of Paddington: But when you said that you can do that yourself I thought—

Dr Brunner: Not myself, no. Sorry.

Q2294 Baroness Jay of Paddington: That means I have misunderstood.

Dr Brunner: I can in the canton and I can put that in our—

Q2295 Baroness Jay of Paddington: All right, but the audited regulation has to be federal, does it?

Dr Brunner: Yes. I can put it in a statement what should in my opinion be in such a regulation of the country. First, that is the obligatory authorisation and monitoring of the organisations which are working in the canton of Zürich. They have, as I said, to disclose each point of funds. Also we have here problems of barbiturate control and they have to show us which internal control of the association they

are doing with their organisation structure. You will see EXIT this afternoon. They are quite a big organisation. They have their own ethic commission. They have their own control commission. They are really an organisation which tries also in an ethical way to make sure that everything is okay. On the other side DIGNITAS—do not tell him that I said that, although he knows that I am saying that—is a one-man show with a couple of pupils who are around him. That is quite difficult because then we have to look at different meanings, different points of view, internal controls. The second point is assistance to suicide. There has been a clear selection of that. I think it should be obligatory to go to a good institute for psychological tests on what you have so that you are clear that those people are really good people and not on the way to having a mission to kill people. They have to be regulated, with education and also further education on the supervision of this assistance to suicide. With EXIT it is very high, sure. It came clear, not more than five or ten cases a year. It is also for me important to have no business connections. What I said on selection, education, further education, supervision and treated cases has to go under assistance to suicide but also to the doctors who are in the organisations. They also have to make a full, conscious decision, not under their own proposal, to help people to die though their prescriptions. Then we have to put up some standards for the cases. In the section of help to die, the two-week cases, I say that you have the prescription not of the doctor of the organisation but of your own doctor or hospital doctor that this person is terminally ill and wants certainly to die. You have to have a medical certificate for your constant wish to die and on the capacity of understanding and how the barbiturate has been taken. These prescriptions cannot be older than one month. There are also prescriptions we have now which are two or three years old and people have not seen them any more; we have to regulate that. On the second point, help to suicide, you have to have really good medical witnesses over the illness and how it happened. Then I think we should put down also (and we will) that all other options, such as palliative medicine, this person did not want or had it or it did not help, and then you have to have two medical diagnoses to say that the wish is well considered and constant and long. That is very important and here we should discuss the political discussions. Those have to be normally between two and three or six months, so longer than 14 days, much longer. That is only for people who can live longer than a couple of weeks. We are here in the category of help to suicide. Then we have to make also clear standards for the mentally ill person, psychiatrically ill persons, if the organisations are allowed and under what conditions with an obligation to co-operate with the official

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persons because some of the organisations do not want to co-operate at all. That is not good. Then we have regulations on costs to pay because normally assisted suicide for the canton of Zürich costs altogether about 2,000-3,000 euros. That has also to have some sanctions for the doctors, for the organisations, for everyone. We will try but I do not think we will get that in these regulations, that is the point. I think when we have those rules at least there will be better control. That is all I tell you now. That is all we can do in the canton, this regulation, and at the same level not changing the criminal law, but it is not a good solution to have it in a canton. We have to do that all over the country.

Q2296 Chairman: The Federation could do it?

Dr Brunner: Yes.

Q2297 Chairman: But, failing the Federation, the cantons could do it?

Dr Brunner: There will be a little bit more pressure and they will do it. It takes two more years, I think. We have, for instance, federal regulations for marriage, making connections between people, standards also. We rule everything in our countries and one of the most important points, also with liberal law, is the final decision. We do not have any rules because we are discussing and discussing and we do not find any rules but we practise in the dark quite a lot. That we have to see also.

Q2298 Bishop of St Albans: I want to move to a more general point. When I was a parish priest I had the sad duty to take numbers of funerals of people who had committed suicide, not assisted suicide, just suicide. The impact upon those families was, of course, in many cases absolutely dreadful. It left the family feeling broken and in a terrible state and that did not seem ever to go away. Is there any evidence in your canton of the long term impact of legally assisted suicide upon the family and upon the wider community?

Dr Brunner: There is not, as I told you before, but I think that you have to speak about that also with the organisations. For me that is not the point we follow. For me it is very important that it can be that a person says, "No, I do not want anything to be said to the family", for different reasons, but to say what you mentioned now, just in those words, also to this person who does not want to take the family in, I think is very important.

Mr Sommerhalder: In most cases the family is involved in assisted suicide. They build the will together.

Bishop of St Albans: I can only report a broadcast I heard on the BBC about two weeks ago about an American man who had been in a case of assisted suicide which he was absolutely fine about, he

thought, and then just found it absolutely devastating and could not cope afterwards at all with the loss of his mother. That could be for all sorts of reasons and I do not want to do a straightforward cause and effect, but the impression gained from that programme, which was not about assisted suicide; it was a biographical programme about a writer, was that the impact on him had been absolutely terrible. I do not know whether there is any evidence and, as you say, it is outside your particular brief.

Q2299 Baroness Finlay of Llandaff: I wonder if I could return for a moment to some aspects of regulation. Has this 115 part of your law been used for anything other than this assisted suicide with barbiturates? Is there another incidence of suicide where you invoke that part of your federal law?

Dr Brunner: Yes, it can. We have got some different cases also out of these organisations. I told you at the beginning but today most of them we have got on this case.

Q2300 Baroness Finlay of Llandaff: So they are always in the context of somebody being ill and having their death brought forward as a suicide?

Dr Brunner: Yes, but we have to make a difference, perhaps not so clearly. For criminal law it is no problem but for the doctor it is a problem to make the prescription if the person is not really very ill. That is the second control.

Q2301 Baroness Finlay of Llandaff: How long is the prescription valid for if a doctor writes a prescription?

Dr Brunner: Now it is for ever, or you take—I am not so sure but I think the validation of prescriptions is one year, but if you take the barbiturate and you take it at home you can have it for a long time. I think there we have to look also that there is control and that is why we do it.

Q2302 Baroness Finlay of Llandaff: That was my next question, whether you have control of barbiturate prescriptions.

Dr Brunner: Not any more, nothing.

Q2303 Baroness Finlay of Llandaff: So they would be like antibiotic prescriptions?

Dr Brunner: Yes.

Q2304 Baroness Finlay of Llandaff: You did say during your presentation that there were problems with reporting after the event and you outlined some. In your proposals have you thought of putting in a system of pre-event reporting so that at the time the request is made there would be some reporting so you could monitor the whole process?

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Dr Brunner: No, and we are clearly against this way to get it. I will tell you why. You will never find out if you put the state before that point. You will have too many questions which are open, too many meanings which are open. That is not good if you take the state before the organisation. I will take an example I know quite well. In the little infant hospital they have the neonatal cases and they made in the big hospital in Zürich an arrangement so that it is quite difficult to make the decision to turn off the things in the really big cases.

Q2305 Baroness Finlay of Llandaff: Switching off the ventilator?

Dr Brunner: Yes, and in the hospital they talked together, the chief, everyone, that is five persons, had to say yes, including the parents. If one person does not, they do not do it. I think that is a way but if you take the state to this you will never find a solution for

that.
Q2306 Lord Joffe: I was very interested in your proposals in the legislation that you thought you might like to bring in. I would like to touch on a couple of the points you made. You talked about a maximum of four or five. Was it per organisation or per doctor?

Dr Brunner: Per person, not to assist more than about five assisted suicides per year.

Q2307 Lord Joffe: So it was not an organisation?

Dr Brunner: No, it was not an organisation.

Q2308 Chairman: One person?

Dr Brunner: One person.

Q2309 Chairman: To guard against the idea of a person having a mission to kill people?

Dr Brunner: That is it.

Q2310 Lord Joffe: I think you distinguished between two groups of people who are interested, at the one end, in getting assistance to die where they are in the process of dying, and the other was long term. I think you said something about more or less two weeks would cover the first case but it seems very low to me.

Dr Brunner: No. If I said that, it is only for an example. A couple of weeks I say. I want to make the difference. A couple of weeks, also one or two months. It is quite difficult to make here a clear measure but I want to have the distinction between those ways when the natural death is really very near and those when we do not speak for a couple of months or years. I say one or two weeks. It can be a little bit more and the other is months and years.

Q2311 Lord Joffe: I see. You mentioned about the ethical code and about it being against the doctor's code of ethics. That does not refer to assisted dying in the case of terminally ill patients?

Dr Brunner: Yes, it can also have that because most of the doctors also in our country go with the patients still to the end and there is no abbreviation of the end.

Q2312 Lord Joffe: Perhaps I am misunderstanding something. In the new guidelines which the Swiss Academy of Medical Sciences have produced it refers to terminally ill patients and that if a doctor's conscience influences him to make a decision to assist a patient to die that is appropriate.

Dr Brunner: Yes, but they do not make the division that I make between those two groups of cases.

Q2313 Lord Joffe: So you are referring to the second group?

Dr Brunner: I am referring to the first group also and then to the second group.

Q2314 Lord Joffe: Oh, I see. Again, perhaps I am not making myself clear. Bearing in mind that the Swiss Academy of Medical Sciences make this recommendation that a doctor who feels from a conscience point of view that it is correct to assist a patient to die, they specifically cover that in their recommendations, that seems to me to be in accordance with the code.

Dr Brunner: Now I understand what you mean. That is okay but it is very low and I know many doctors will say, "That is not for me". Before it was not ethical at any point and now only in the terminal illness they say in the ethic rules it could be in certain circumstances and I think that is quite a big path for the doctors.

Q2315 Lord Joffe: Finally, you have read the Bill that we have prepared. It only relates to terminally patients and I wondered if that Bill with safeguards included in it covered the concerns that you have expressed and you want to incorporate in any future legislation.

Dr Brunner: Perhaps it would be good to make the difference between these two groups as I told you before. Then you have to make the decision: do you take only the first group to make your regulation or do you take also the second group which can also be very helpful, I think? The big problem is that your way is not going on the way of organisations, more on the medical way. I also mentioned that it would be quite difficult. I do not know the problem in Britain but you have to speak with a lot of doctors. If you find also good doctors to do this work there will be in Great Britain, I think, a big change and it could be quite difficult. That is my opinion. It is very clear. I can speak afterwards on two or three points if you

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want because our time is now running out. We can discuss it further over lunch.

Q2316 Earl of Arran: Can I just ask very quickly, how long might it be before your regulations become law?

Dr Brunner: That depends. Now in the Confederation Mr Stadelmann told them that they have made a report on that and they will speak with the Minister of Justice and then he will decide if he wants to make a bill for the country for that.

Baroness Jay of Paddington: That is about two years.

Q2317 Earl of Arran: It is quite a long time.

Dr Brunner: You wait two years but the decision is now made in the next two months and if they do not say, "We made it now quickly", we will start in the canton of Zürich.

Q2318 Earl of Arran: Does it have to be approved by others before it can become effective? Does it have to meet with anyone else's approval or voting or a referendum?

Dr Brunner: That is possible, yes. The way it goes now is from the cantonal government to the cantonal parliament and if it is approved at the cantonal parliament then it is okay, but it is possible that there will be a referendum. We have a lot of referenda. We are voting people.

Q2319 Chairman: There is a good turnout as well. I just want to make clear the passage in the medical ethical guidelines of the Academy. It says in 4.1 under the heading of "Assisted suicide", "In this borderline situation a very difficult conflict of interest can arise for the doctor. On the one hand assisted suicide is not part of a doctor's task, because this contradicts the aims of medicine. On the other hand, consideration of the patient's wishes is fundamental for the doctor-patient relationship". Then it provides for a conscientious decision on the part of the doctor which must be respected. I think that is really what you were referring to, that on the one hand it is not

part of a doctor's task but on the other hand a doctor may do it whereas in fact I think I picked you up as saying that generally speaking in this country, at least in this canton, and probably also in Aargau as well, it is more through the organisations rather than through individual doctors that this assisted suicide occurs.

Dr Brunner: Yes.

Q2320 Baroness Hayman: And within the organisations the reason why it is doctors that are involved is simply because of the need for a physician to write the prescription.

Dr Brunner: Yes.

Q2321 Baroness Hayman: It could be anybody who was assisting if it was another method of suicide?

Dr Brunner: Yes. The doctors are not assisting in the organisations. There are members of the organisations who are assisting. There are some cases but normally the doctors make the prescriptions and that is it.

Q2322 Baroness Hayman: Is the doctor present though?

Dr Brunner: No. There is present in the act of dying someone from the organisation.

Q2323 Baroness Jay of Paddington: Can nurses write prescriptions in Switzerland?

Dr Brunner: No.

Q2324 Chairman: Thank you very much indeed. I am not sure whether our colleague from Aargau wants to add anything.

Mr Sommerhalder: No. Dr Brunner has told you about the old doctor who made these prescriptions, and the administrative tribunal had a session because of this case about two weeks ago but we never heard the result. We hope the Bill will confirm forbidding those prescriptions.

Chairman: Thank you very much.

Memorandum by Dignitas

1. We thank you for your invitation of 14 July 2004, to present written evidence in connection with the project of the Right Honourable Lord Joffe.
2. Dignitas is an association based on Section 60 ff of the Civil Code of Switzerland. It has been established on 17 May, 1998. Its purposes are:
 - 2.1. To help people to establish a living will (in German: Patientenver-fügung) for the case that an individual would no longer be able to communicate. In this living will, the member has the possibility to accept or to strike-out several paragraphs;
 - 2.2. To assist people to obtain a pain-free suicide, following Section 115 of the Criminal Code of Switzerland; a service which is given also to members living outside of Switzerland and which has lead to considerable discussions as well as in Switzerland as abroad;

2.3. To help its members in institutions for elder people in case of difficulties, especially with the staff of the institution or with physicians which have not been choosen freely by the member.

3. Dignitas is counting actually about 4,300 members in not less than 52 states of the world; about 560 of them (13 per cent) are residents in the UK. British members are interested mainly to be a member of Dignitas in order to have the opportunity to get an assisted suicide on Swiss soil in case they should want to end their lives for a valuable reason.

4. Between 10 October 2002, and 4 April 2004, 22 British residents have choosen this way and have been accompanied to suicide by Dignitas in Zurich. Their birth years have been from 1925 to 1965.

5. They and their family members have all deplored that the work Dignitas is doing in Switzerland is, for the time being, not possible in the United Kingdom, and that this situation is responsible for the fact that even terminally ill subjects of Her Majesty have to leave their bed, their home, their town, their county, their country, and to travel to Switzerland, just in order to make it possible to end their lives in a dignified, risk-free and pain-free manner. And, indeed, this awful feeling to be forced to leave their own country in this respect is also what does make us feel very unhappy in every single case. We would prefer by far to make a visit to our members in the UK in order to accompany them to suicide at their homes, or to know that similar organisations as Dignitas in Switzerland would work in the UK.

6. Dignitas' work starts from the ideas which have been characterised by the European Court for Human Rights in Strasbourg in its Dianne Pretty decision of 29 April 2002.

6.1 In paragraph 61, the Court has said:

“Although no previous case has established as such any right to self-determination as being contained in Article 8 of the Convention, the Court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees.”

6.2 In paragraph 65, the Court has said:

“The very essence of the Convention is respect for human dignity and human freedom. Without in any way negating the principle of sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.”

6.3 And in paragraph 67, the Court has said:

“The applicant in this case is prevented by law from exercising her choice to avoid what she considers will be an undignified and distressing end to her life. The Court is not prepared to exclude that this constitutes an interference with her right to respect for private life as guaranteed under Article 8 § 1 of the Convention.”

7. Nevertheless, the Court did reject the application of Mrs Dianne Pretty who had asked the British authorities to grant to her husband in advance not to prosecute him in case he would assist her planned suicide.

8. This decision is understandable as long as we have a look only to the individual situation in the case of Dianne Pretty. If her lawyers would have presentend facts about the general suicide situation in the UK and its consequences, it is at least thinkable that the Court would have decided in an other manner. Cf later points 10 ss.

9. Dignitas had tried to establish itself in the case of Dianne Pretty as *amicus curiae*. It had presented a memorandum to the Court, but as it had got knowledge of the case only after the public hearing of Mrs Pretty in February 2002, and as the Court's work after that hearing had been speeded up to the maximum in order to render its decision in any case prior to the foreseeable death of Mrs Pretty, the presentation of the memorandum came too late. We do add this memorandum in the annex.

10. During the more than six year's work of Dignitas, we have learned that the discussion about the item of euthanasia is, in any case, misleading as long as not a far broader view on facts of life and death are also taken into consideration.

11. In this respect, we do have the impression that the public discussion of euthanasia is influenced mainly by two very different groups, but both do have the tendency to focus only on the fact that the result of euthanasia is just death. The two groups are (a) the press, especially the tabloid one, and (b) the Pro Life organisations and/or some churches.

12. With respect to the said press, we should just look what George Bernard Shaw tells the public about newspaper men in his play "The Doctor's Dilemma", act IV:

"Walpole returns with The Newspaper Man, a cheerful, affable young man who is disabled for ordinary business pursuits by a congenital erroneousness which renders him incapable of describing accurately anything he sees, or understanding or reporting accurately anything he hears. As the only employment in which these defects do not matter is journalism (for a newspaper, not having to act on its descriptions and reports, but only to sell them to idly curious people, has nothing but honour to lose by inaccuracy and inveracity), he has perforce become a journalist, and has to keep up an air of high spirits through a daily struggle with his own illiteracy and the precariousness of his employment. He has a note-book, and occasionally attempts to make a note; but as he cannot write short-hand, and does not write with ease in any hand, he generally gives it up as a bad job before he succeeds in finishing a sentence."

13. With respect to the pro life organisations, we should point out that Dignitas does consider them nearly all as to be hypocrites.

14. They are arguing just dogmatically and not at all reasonable. What Arthur Schopenhauer, the well known German philosopher, has said about dogma might apply to them:

"The power of early imprinted religious dogma is so enormous that they are apt to suffocate the conscience and, at last, all compassion and all humanity. If you would like to see with your own eyes and at short distance what early imprinted religion may cause, do observe the Englishmen. Look at this nation which has been favoured first of all other nations by nature and which is endowed with reasonableness, esprit, faculty of judgement and firmness of character; look at them, deep beneath all others disparaged, even run down by their stupid church belief which makes the impression, among their remaining capabilities, of a fixed religious mania, a monomania. They do owe all that only to the fact that their education lies in the hands of the clergy which does see that all articles of faith are imprinted yet in the earliest youth in a way which goes even to a sort of partial brain palsy and is manifested a life long in that imbecile bigotry by which even most intelligent and sophisticated people among them do accept to be de-graded and what takes us any possibility to understand them."

15. The Swiss Government had told Swiss Parliament in an official answer of 9 January 2002, to a question of Andreas Gross, MP, that in Switzerland every year about 1,350 people are dying by suicide, and that up to about 67,000 people every year do suffer from missed suicide attempts.

16. Sarah Payne and Rachel Lart (<http://www.radstats.org.uk/noO70/notes>) have shown that in the UK, every year more than 5,000 people do commit suicide, and that about 50,000 to 100,000 people will attempt suicide (their paper arises from a project carried out by Rachel Lart, Lesley Doyal and Sarah Payne, School for Policy Studies, and David Gunnell, Department of Social Medicine, University of Bristol. The project was funded by the NHS Research and Development Programme). Whilst those authors do calculate the rate of suicide attempts in relation to committed suicides between 10 and 20 times, the Swiss Government had pointed out that the rate might be even 50 times, which would lead to a number of about 250,000 attempts per annum in the UK. It is unknown if newspapers or pro life groups pay any attention to these facts, and nobody until today in the UK seems to have made estimations of the costs which are caused by the suicidal situation for the National Health System and/or for public economy or even by what means these terrific numbers and costs might be reduced.

17. If we compare the number of more than 5,000 deaths by suicide every year in the UK and the number of 22 UK residents having come to Switzerland in order to have an assisted suicide with Dignitas in a period of 18 months, we do see a complete disproportion in relation to the public interest for the two different facts. It is a clear indicator for the fact that even enlightened people do have difficulties to consider these facts under an angle of reasonableness instead of an angle of emotion. Reasonableness is an item related to the cerebrum; emotion instead is related to the brain stem.

18. There has been, in former decades (or, for Switzerland, years) a similar problem which had caused analogous discussions: the item of abortion. We do remember here in Switzerland how happy Swiss women were who had the opportunity to make a trip to the Netherlands or the UK in order to get an abortion, whilst in Switzerland abortion had been, in principle, illegal until 2002. Where abortion has been illegal, clandestine abortions took place, at high risks for the mothers health. Since there is a legal possibility to get abortion, these risks do no longer exist. And as the problem of abortion can be discussed openly, there is also a lot of information about contraception. The result: The number of illegal abortions is tending to zero, the number of legal abortions has a clear tendency to be reduced. Such a solution will, of course, not lead to an ideal situation but to an optimum.

19. Human societies do face the same problems with euthanasia. Euthanasia has been and is a primordial human need *vis-à-vis* a situation of illnesses which do have a dignity-affecting effect on human beings in their own view and feeling. Do listen again the European Court for Human Rights:

“In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.”

20. This means, that also for the problem of ending the lives of human beings by suicide the society should look for an optimum.

21. The Swiss Society for the European Convention on Human Rights (SGEMKO) has published on 11 September 2003, a study, compiled by Peter Holenstein, one of the best Swiss investigating journalists, in order to get an estimation of the costs of the suicidal situation of Switzerland. He showed that these costs are as high as at least 2.4 milliard Swiss Francs (about 1.1 milliard GBP) every year. In order to get the equivalent in the UK, this sum might be multiplied by a factor between 3.7 (relation between 1,350 Swiss suicides and 5,000 UK suicides) up to 8 (7.2 million Swiss people to 59.1 million UK people). The respective sums would be between 2.4 and 8.8 milliard GBP. Even only a slight reduction of the terrific numbers of suicide attempts would bring considerable relief also in public economy. And not to forget: every suicide and every suicide attempt does affect normally first the members of rescue and police bodies and a whole family. We should never forget the people around the one who has suicidal ideas.

22. SGEMKO had proposed in its media conference of 11 September 2003, to establish a programme in order to reduce the number of suicides and of suicide attempts. For SGEMKO, such a programme should be composed of at least the following elements:

22.1 A permanent information campaign which informs the public about the risks of past suicide methods with today high risks to harm body and mind (told in details);

22.2 The establishment of a broad network in order to give people with suicidal ideas the opportunity to get advice in any direction; first of course in order to look at the principal problem which has induced the suicidal idea and whether this problem could be solved; importance is required in order to give the individual the possibility to speak frankly and without fear about his ideas and problems. So there should be no coercion in order to put a person to a psychiatric institution, if the person is looking for help.

22.3 The possibility to grant an assisted suicide without risks and without pains in cases where an individual, after serious information and counselling, still wants to end their own life (as long as the individual has capacity of decision in this respect).

23. As the European Convention on Human Rights (ECHR) does guarantee the Human Right to risk-free and pain-free suicide, there will be no possibility to reduce this right only to terminally ill people—an idea which is frequently discussed in British newspapers but would violate article 14 of the ECHR which prescribes that the rights and freedoms enshrined in the Convention have to be granted to every-body without any discrimination. Why should politics or paternalistic law reduce the autonomy of human beings in this respect and for what legal purpose?

24. It might be of some interest that section 115 of the Swiss Criminal Code has the following wording:

“*Abetting and assisting suicide.* Is punished with heavy prison up to five years who is abetting or assisting someone else to suicide by selfish motives, if suicide has been committed or attempted.”

25. Therefore, abetting and assisting suicide without selfish motives is not a crime and legal.

26. On the other hand, section 114 of the Swiss Criminal Code punishes with prison between three days and three years a person which has committed a mercy killing.

27. So, in Switzerland, euthanasia in the form of the new laws in the Netherlands or Belgium allowing physician to kill patients would not be possible. It is always the persons themselves who wants do end their own lives who have to do the last act themselves.

28. This has the consequence that misuses are nearly totally excludable. And this Swiss pattern has also the effect that the world wide working taboo against killing a person by an other person is not violated.

29. There are clear indications that the “slippery slope argument” has no reasonable background. After that the City Council (executive) of the City of Zurich has decided in October 2000 not to exclude any longer assisted suicide organisations from visits in old people’s homes or nursing homes, the number of assisted suicides in those institutions of the City of Zurich did not raise at all. It has been stable within the range of less than five cases per year.

30. Dignitas has made the experience that less than 20 per cent of its members which have been given the “green light” by a Swiss physician in order to get an assisted suicide do really commit suicide. More than 80 per cent do live on after that Dignitas has opened for them the door of the emergency exit and will die the natural way. They are always telling Dignitas what a big relief the “green light” has been for them: they have been delivered from their dilemma either to be forced to follow the path through the hell of their suffering or to intend a high risk suicide attempt at their own.

31. Therefore, Dignitas would be grateful if the British legislator would approach the Swiss model.

32. Dignitas is, in this respect, very near to one of the most brilliant British state philosophers of all the times, Thomas More, who, in his famous “Utopia”, has said as early as in 1517:

“I have already told you with what care they look after their sick, so that nothing is left undone that can contribute either to their ease or health: and for those who are taken with fixed and incurable diseases, they use all possible ways to cherish them, and to make their lives as comfortable as possible. They visit them often, and take great pains to make their time pass off easily: but when any is taken with a torturing and lingering pain, so that there is no hope, either of recovery or ease, the priests and magistrates come and exhort them, that since they are now unable to go on with the business of life, are become a burden to themselves and to all about them, and they have really outlived themselves, they should no longer nourish such a rooted distemper, but choose rather to die, since they cannot live but in much misery: being assured, that if they thus deliver themselves from torture, or are willing that others should do it, they shall be happy after death. Since by their acting thus, they lose none of the pleasures but only the troubles of life, they think they behave not only reasonably, but in a manner consistent with religion and piety; because they follow the advice given them by their priests, who are the expounders of the will of God. Such as are wrought on by these persuasions, either starve themselves of their own accord, or take opium, and by that means die without pain. But no man is forced on this way of ending his life; and if they cannot be persuaded to it, this does not induce them to fail in their attendance and care of them; but as they believe that a voluntary death, when it is chosen upon such an authority, is very honourable.”

28 August 2004

REFERENCES

- Memorandum of Dignitas to the European Court of Human Rights, Strasbourg, in the case of Dianne Pretty vs the United Kingdom (original in English).
- Lecture of Ludwig A Minelli to the Giessen Congress on Physician Assisted Suicide (original in English).
- Article of Ludwig A Minelli (in German) “Die EMRK garantiert das Recht auf Suizid”, published in “Aktuelle Juristische Praxis”, May 2004.
- Study about annual costs of suicide situation in Switzerland (in German) “Der Preis der Verzweiflung”, of 11 September 2003.

Examination of Witnesses

Witnesses: PROFESSOR WOLFGANG HOPFF, DR HANS-R NÄGELI, MR LUDWIG MINELLI, MRS SORAYA WERNLI, MR SILVAN LULEY and DR PETER REINHARDT, DIGNITAS, examined.

Q2325 Chairman: Thank you for agreeing to give evidence to us in our inquiry. What you say will be taken down by the shorthand writer. You will have a chance to review the transcript before it is published. It will then become part of our report and become public when our report is submitted. Do you want to make any short statement to begin with to show how your organisation works and what the position is of the various people who are here?

Q2325 Mr Minelli: We have sent you a memorandum and all that is necessary to say is in this memorandum and so I can shorten this part. Professor Hopff is President of our counselling

board. If we have special questions we ask him or the lawyer, Felix Egli, who has today an assembly so he cannot assist here. Professor Hopff is a physician and pharmacist. Dr Nägeli has been one of our collaborating physicians. He also has worked for EXIT in the German part of Switzerland for many years and he has great experience. Dr Reinhardt is one of our newest collaborating physicians. He has seen recently English people who have come to us in order to die and he can give you information about these cases. Mrs Wernli will speak in German or French and Mr Luley will do the translation if necessary. She is the head of the part where the accompaniments are organised. She is in touch by

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Mrs Soraya Wernli, Mr Silvan Luley and Dr Peter Reinhardt

phone with the members who want to come to Switzerland and who have got a green light from one of our physicians. Mr Luley is the head of our office. He has a lot of phone calls from all over the world. We have about 4,500 members in 52 countries around the globe. He speaks German, French, English and Spanish. I am the founder and Secretary General of this organisation. I have been the legal adviser of two directors of EXIT in the German part of Switzerland, Dr Zeik and later Mr Hollenstein. They have had in their organisation power struggles and after the second power struggle I decided to found DIGNITAS which is an organisation where power struggle is not possible.

Chairman: Thank you very much. We will go straight to questions in that situation.

Q2326 Lord Joffe: Could you perhaps outline the procedure once somebody wants to become a member and then exactly how the process works if they ask for assistance to die? If you could take us through that it would be very helpful.

Mr Minelli: We have phone calls, we have e-mails, we have faxes, where people are asking us whether we can help them. Then we ask their postal address and we send them our documentation in German, French, English or Italian. After that they will send us a membership declaration and when we have got that we send them a letter telling them that they are now a member. We tell them to pay the fees. We tell them how they can ask in order to prepare an assisted suicide, and then we are waiting. If somebody is eager to have our help very soon then they phone us and we tell them, "Please send us a personal request for preparing an assisted suicide together with medical documents". Sometimes, especially from the United Kingdom, people have difficulty getting copies of their medical records. I do not know why. I do not know whether this is legal or whether the UK physician says, "I will not give you copies of your records", but there is sometimes a difficulty. When we have the personal request and the medical documents we send them to one of the physicians who collaborates with us and ask him whether he would be prepared to write a prescription for pentobarbital of sodium for this person, always under the condition that he will see the person first, speak to the person and decide definitely after this interview. If he tells us yes we tell the member that the member has now the provisional green light and from this point on we may discuss the date to come to Switzerland. We prefer it if people come twice to Switzerland, firstly in order to see the physician, to have the definite green light and to go back, and then to come perhaps later, but if somebody is terminally ill we cannot ask that they come twice and so they come once. They see the physician, the physician writes a prescription and

almost immediately after the assisted suicide will happen. If a physician has seen from the medical file that there are perhaps some possibilities to help our client's life he tells us and we are always in correspondence or phone contact with the member and we tell the member that there will be possibilities. Sometimes, if people with multiple sclerosis ask for help from the United Kingdom then our physicians tell us, "Why has this person until now not had the newest medicine, interferon?", and then if we discuss it with the member, the members tell us, "I cannot get interferon. It is too expensive for the National Health Service". In Switzerland there is no restriction. If somebody has multiple sclerosis they will get interferon in order to see whether the situation can be improved. Sometimes also people come to see our physician and our physician tells them during the interview, "You should still try another alternative", and we have seen several times that a physician has told them, "You should try morphine", if they have not tried that, and sometimes they return and try morphine and 14 days later they are back and they are telling us the side effects and pains are worse. If then we discuss a date in order for them to come to Switzerland for assisted suicide we discuss how they will come: by aeroplane, by railway, by car, even by ambulance or mobile home, and then we make arrangements to meet the person at the railway station or the airport and then we go with the person, after we have got the prescription, to our apartment and in the apartment there is waiting one of our collaborators who makes the accompaniment. At least three times we tell people when they come to us, "Listen: the fact that you have come to Zurich does not mean that you have said A and now you are obliged to say B. You are completely free to leave this apartment and to go back if you would like. That is no problem for us", and several times we have seen that people say, "Yes, I will go back and perhaps I will come later but I know now how it works. I have seen your apartment. I will go back". About one year ago we had a 27-year old Irishman, Martin Barry, and I can name him because he went to the radio station in Ireland and told his story. He had multiple sclerosis and I looked for him at his hotel in Zürich and made the transfer from the hotel to our apartment. He was in a wheelchair and a physician came to the apartment. He discussed it with Mr Barry and Mr Barry was quite firm that he would have the assisted suicide. The physician left and I told Mr Barry the second or third time, "I tell you again: you are completely free to leave this room, to go back and to come later if you wish". "No, no. I will die now", he told us, and then I said, "Okay. I will take with me your wheelchair but if you decide to go back a phone call in half an hour and I will be back in this room". I went to my house and I had not been here for half

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an hour and there came the phone call: Mr Barry wanted to go back to Ireland. This was a Friday. I went immediately back to town. I put my hand on his shoulder and said, "I congratulate you for your decision. You do not have to look now for a hotel room. You will be my guest until Monday when you have your return flight", and I had Mr Barry here in this house, in my guest room. On Saturday I discussed it with him. On Sunday my partner, Miss Schultler, and I went with him to the cemetery of Zürich Fluntern where James Joyce is buried and we visited the grave of James Joyce. After that we went to the zoological garden and passed three hours there. My partner told him, "Listen: you are a journalist. You could write a book", and I think he has now written the book and is looking for an editor. Recently he mailed to me, "I never expected that my 30th year would be possible for me. Now it is one year since this experience". Overall, about 80 per cent of the members who have got the provisional green light never call again. This green light is something so relaxing for them, they have been in such a heavy dilemma first about whether they will have to linger on through this illness until a so-called natural end or whether they should try to kill themselves by one of the common methods (which nearly always will fail), that when they have the green light this dilemma is destroyed and they can live better. We have put in for you a copy of a letter from the husband of a lady who has died with DIGNITAS and you may see what this husband has told us.

Q2327 Baroness Jay of Paddington: You also included, Mr Minelli, which I thought was interesting, a letter to somebody who was suffering from Parkinson's Disease. This is the English letter. You say that he obviously has not tried some of the conventional therapies for Parkinson's, like Madopar. It seems from the point in the letter that he is somebody who does not like to take drugs. Is that correct?

Mr Minelli: Yes. Mr Luley has written this letter and he can answer directly.

Q2328 Baroness Jay of Paddington: What would happen to this man if, following your advice, which is for him to get treatment for his Parkinson's Disease and to use the Madopar, or whatever it may be, he came back to you and said, "I still insist that I do not want to take drugs and I want to go through with the procedures at DIGNITAS"?

Mr Minelli: Then we would accept him. On the basis of my article, of which I have given you an English translation by Professor Eckstein at Cambridge, we think the right to suicide is guaranteed by Article 8 of the European Convention on Human Rights without any pre-condition, so even if a person comes and tells

us, "I have no illness at all but I would like to end my life", I would think that the person has a right to make this decision and even has a claim against the state in order to get help because trying one of the common methods is so cruel because of the risk of failure that this treatment would not be practical and effective but rather illusionary and the European Convention has no illusionary rights and treatments which are practical and effective.

Q2329 Baroness Jay of Paddington: That is the overriding thing? Mr Luley, you say in the letter, "Your decision about not taking drugs does appear a very irrational decision which cannot be supported and therefore does not allow a doctor to give his agreement to an assisted suicide for which, after all, he will have to carry the responsibility". In a sense you are saying to this man that there is a wider ethic, beyond the legal permission to commit suicide or have assisted suicide, which is important. Is that what the letter is saying? I am just trying to get to the bottom of the advice you give.

Mr Luley: You might have seen that our motto in DIGNITAS is "Live with dignity, die with dignity". "Live with dignity" comes before "die with dignity". In a case where there is no evidence that the patient has tried to improve his situation, it sounds irrational to a doctor who will look at his request and thus he would say, "This person could improve his present state of health, his present quality of life, with a little effort". If the patient does not give any indication of that effort there must be, from a rational point of view, some doubt. Any doctor, looking at the request of such a person, would probably ask, "Why did he not do anything to improve his situation?". In this particular case I wrote this letter to give the patient something to think about, to clearly express that an organisation like ours, even though we say everybody has a guaranteed right, as Mr Minelli has just explained, we cannot by morals and ethics just blindly follow a request when there is not a clear reason. I think, at least, a person has to make a little bit of effort. They have to show that they have tried at least one treatment to improve the situation. That is why I wrote this gentleman the letter, as we have done in other cases too, to explain to them, "Try to improve the situation. We would like to help you. On the other hand, if at the end of the day the normal treatments do not improve the situation and you really want to go, there will be a door open for you".

Q2330 Chairman: Can you give us some numbers, Mr Minelli, over the last few years? Can you tell us (a) the number of people who have approached you and (b) the total number of actual suicides that you have assisted as an organisation in these years?

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Mr Minelli: Since we have started we have had up to yesterday 362 people who have died with DIGNITAS. We have had about the same number of members who have died naturally within this time. I have no detailed statistics besides those that are published in our annual report but I have them in my head. The biggest group of members comes to us come from Germany and the second biggest group from the United Kingdom.

Q2331 Chairman: When somebody applies for membership that is the only thing they are applying for in the first instance, is it?

Mr Minelli: Yes, they apply for membership first.

Q2332 Chairman: Is there a fee for membership?

Mr Minelli: There is a registration fee, which is 100 Swiss francs, and an annual minimal fee of 50 Swiss francs. If somebody joins between October 1 and December 31 there is no annual fee for that year, only the registration fee of 100 Swiss francs.

Q2333 Chairman: That makes them members of the association?

Mr Minelli: Yes.

Q2334 Chairman: You mentioned the total membership. That is for all countries, is that right?

Mr Minelli: 4,500.

Q2335 Chairman: That is the total for the whole world?

Mr Minelli: Yes.

Q2336 Chairman: How many of these are in Switzerland roughly?

Mr Minelli: About 600 or 700.

Q2337 Chairman: That is the first stage; you become a member. If somebody is not a member they would have to become a member in order to get any help from you?

Mr Minelli: Of course.

Q2338 Chairman: The next stage you have described is if somebody wants help. What sort of financial arrangements are there at that point?

Mr Minelli: We have been forced to adjust our membership fees for special services at the beginning of this year because last year we did not have enough income to pay all our costs and so we decided at our last general assembly in December 2004 to introduce a fee for preparing an assisted suicide of 1,000 Swiss francs, and if we have to manage afterwards all the works with the authorities in relation to burial, another 1,000 Swiss francs.

Q2339 Chairman: Is your organisation responsible when an assisted suicide takes place in your apartment for informing the public authority of the canton that that has happened?

Mr Minelli: When a member has died in our apartment our collaborator has to phone the police, an emergency phone call, and he announces a DIGNITAS assisted suicide. After that a police officer, a sort of coroner and a legal physician will arrive and they have to make an instruction to look to see whether there is a crime or not. Up to now they have never found a crime.

Q2340 Chairman: Your collaborator is there?

Mr Minelli: Yes, and also relatives normally.

Q2341 Chairman: Is the collaborator a person with any particular qualifications?

Mr Minelli: The qualification must be that he has a lot of empathy with other people, that he is on the same line as we are, first to help towards life if it is possible, and therefore also our collaborator tells the person, "You have the liberty to leave if you would like", and he must be very reliable. He must do his work exactly like we have instructed him. These are the main qualifications we need.

Q2342 Chairman: Is he paid for that?

Mr Minelli: He is paid 500 Swiss francs for every accompaniment.

Q2343 Chairman: You do not normally have a doctor present at that stage?

Mr Minelli: The doctor is not present. The doctor is perhaps there or in his office but in the apartment the only assistant is the accompanier. The doctor is not present.

Q2344 Chairman: The doctor makes a prescription for the barbiturates?

Mr Minelli: He makes a prescription for 15 grams of pentobarbital of sodium.

Q2345 Chairman: Has the doctor seen the patient before?

Mr Minelli: Of course.

Q2346 Chairman: He comes to the apartment to see the patient?

Mr Minelli: To the apartment or the patient goes to the doctor.

Q2347 Chairman: And it is at that stage that the prescription is given?

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Mr Minelli: Yes.

Q2348 Chairman: What happens next? Does the collaborator come and collect the prescription? How does it work?

Mr Minelli: Sometimes we have prescriptions with the addendum “Primopraxi” and with this we can get the pentobarbital, so we have a reserved portion. We take this reserved portion and afterwards with the prescription we go to the pharmacy and look for a new one.

Q2349 Chairman: I see. You have got a kind of reserve that you keep up to date with the prescription if you have to take some out for a particular patient? Is that right?

Mr Minelli: Yes, normally we have a reserve.

Q2350 Chairman: Do you keep that at the apartment?

Mr Minelli: No. The companion or collaborator will have the reserve. We never hand out the pentobarbital. We always prepare it in a glass of water. We give it to the member. If the member leaves it is put away. If the powder is not yet dissolved we take it back. We never hand it out because we have to guarantee to the state that there is no misuse with pentobarbital. On the other hand, we have to guarantee to our member that we may help him.

Q2351 Chairman: And then, as you mentioned, it may be that your organisation will be responsible for the arrangements following the death and if you are there is an additional arrangement for that?

Mr Minelli: Yes.

Q2352 Chairman: That will include the return of the body to the home or to have cremation or whatever?

Mr Minelli: Following the instruction we get from the patient.

Q2353 Chairman: All that is in documentation before the assistance takes place?

Mr Minelli: Yes.

Q2354 Chairman: Can you tell us a little bit more about the nature of your organisation? What is the structure of the organisation?

Mr Minelli: The structure is very simple. We have different categories of members. We have two active members and therefore no power struggle is possible. We have always to agree. One of the active members is the husband of Mrs Wernli, an old friend of mine, and the other is myself. We two are the General Assembly. We take the basic decisions and as the General Secretary I have to execute these decisions. Our members from all over the world have no

member rights, no voting rights, because we have seen that the voting rights of other members may come to a power struggle in a general assembly of 700 or 800 people and we wanted to avoid such a situation. Then we have the board of Professor Hopff and the lawyer Dr Egli. They counsel the General Secretary. If I have a specific question where I cannot find the solution myself I will ask the members of the counselling board.

Q2355 Chairman: Can you give us an example of where you have sought their advice?

Mr Minelli: At the beginning of our activity we discussed the question whether or not it would be possible to help mentally ill people.

Q2356 Chairman: What was the conclusion?

Mr Minelli: The conclusion was that if somebody with mental illness has capacity of decision he has the right to an assisted suicide, but of course we would never hasten the death of a mentally ill person. We will try to be sure that there is no other solution possible, so normally if somebody with a mental illness is helped he has been ill for 10 or 15 years before and has tried a lot of different therapies and had no positive effect.

Q2357 Chairman: So if a member from your ordinary membership comes along and he sees the doctor with a view to having a prescription but the doctor considers that his mental state is at least doubtful, what happens then?

Mr Minelli: Then we will ask a second doctor, perhaps a specialist, a psychiatric physician, because we would in any case avoid helping a person who has no capacity of decision or where capacity of decision is doubtful.

Q2358 Chairman: Are the doctors that give the prescription or to whom such a reference is made, part of your organisation? What is the connection between your organisation as you have described it so far and the doctors who do the prescribing or who may be asked to examine a patient from the point of view of that patient's competence?

Mr Minelli: The doctor is completely independent from us. We are always looking to see if we can find physicians willing to collaborate with us and fortunately we find sometimes a physician who accepts the responsibility of the back side of the medal of modern medicine and tells us, “Yes, I will help because I know that modern medicine, modern hygiene, are causing a lot of pains when people are in old age”.

Q2359 Chairman: If a member is applying for help do you refer them to one or other of these doctors?

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Mr Minelli: Yes.

Q2360 Chairman: And you arrange the doctor for them? How many doctors have you got altogether collaborating with you at the moment, roughly?

Mr Minelli: Six to eight.

Q2361 Chairman: They are all in Zürich, I suppose, are they?

Mr Minelli: Not all, no. We have some in Zürich, and we have some in the canton of Aargau and in the canton of Lucerne.

Q2362 Chairman: Is it only in Zürich and Aargau that you give assistance?

Mr Minelli: We have an apartment in Zürich. We have a little house in Aargau, and, of course, if we have Swiss members we go to their homes.

Q2363 Chairman: And that could be anywhere in Switzerland?

Mr Minelli: Of course.

Q2364 Chairman: In that case are the doctors who assist you or collaborate with you all over the Federation as well? I had understood they were in Zürich but I may be wrong about that.

Mr Minelli: Sometimes, if the member is able to travel, we ask the member to come to see the doctor but sometimes also I have travelled with the doctor to see a member at his home.

Q2365 Chairman: The doctor presumably is also paid when he gives the prescription.

Mr Minelli: We have doctors collaborating without payment. We have doctors who are paid. This is very individual.

Q2366 Chairman: Are the accounts of your organisation published?

Mr Minelli: We publish not accounts but information about the finances.

Q2367 Chairman: That is a subtle difference.

Mr Minelli: Yes. We publish balances or income and outgoings, but also a lot of information about what we have got as fees from our members and our expenses.

Q2368 Chairman: Would it be possible for us to get a copy of just one of these? We do not need a whole lot of different years.

Mr Minelli: This is the report of the year 2003, the latest report which has been printed.

Chairman: That would be very good if we could have that as part of our record.

Q2369 Baroness Finlay of Llandaff: Could I ask a little bit about the assessment process? You said that if you can get the medical records of people you will go through them and then a doctor will see the patient. Can you explain what that assessment process is and what the qualifications are of the doctor who is seeing the patient?

Mr Minelli: Our members first send us a personal request and their medical documents. Then we send a copy of the request and a copy of the documents to one of our physicians and the physician studies this documentation and tells us on the basis of this documentation whether or not he will be able to write a prescription, and only when he gives the green light do we discuss with the member when to come. Then the doctor sees the member, has a discussion with the member and also with relatives, and then makes the definite decision. Every doctor collaborating with us is an experienced doctor, sometimes retired but in any case has broad experience and in most cases is also a specialist in one or other field.

Q2370 Baroness Finlay of Llandaff: You said that you assess capacity for people's ability to make a decision and I wondered how you assess capacity.

Mr Minelli: In order to see whether somebody has capacity of decision or not you need not be a doctor. You can ask a simple pattern of questions in order to know whether the person is orientated in time and in locality and whether they can express themselves so that you understand them. We have had recently a publication of the magazine of the Swiss doctors in which there was an article by doctors from the cantonal hospital of Lausanne discussing the capacity of decision of patients and there you may find a pattern of about nine questions which are very simple and which do not need any medical information. Also, the Swiss Academy of Medical Sciences in one of its last regulations says that capacity of decision may be certified by persons who are not doctors.

Q2371 Baroness Finlay of Llandaff: Do you have any psychiatrists amongst the group of doctors that you refer to?

Mr Minelli: Not until now but we are looking for some because until now we have been very reluctant to have mentally ill people because there is one procedure in court in the canton of Aargau where this question has been raised. We had last week a hearing at the court and we are expecting the court's decision within the next three or four months and if the decision is favourable then I think we will have more possibilities to help mentally ill people, but because of this case I am looking for a psychiatrist because always when we have mentally ill people we would like to have at least two doctors and at least one

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psychiatrist telling us that capacity of decision is not in doubt.

Q2372 Baroness Finlay of Llandaff: I was wondering because there is a high incidence of depression in physical disease which often will respond to treatment but can be difficult to diagnose, and therefore it is not easy to diagnose depression in people who have advanced physical illness.

Mr Minelli: We know that and if somebody is asking us to prepare an assisted suicide but there is no terminally ill situation we are very slow and we wait until the member calls us again. We never call the member, "Would you now make your decision?". We tell them we are looking to see whether we are able to find a physician. Sometimes the physician tells us the medical documents are not sufficient; we need more information, and sometimes when we have the impression that there is a depression which could be related to the illness we even phone the member and tell them, "You could try this, you could try that". We try always to help them towards life. Sometimes we see that by this method the intention to put an end to their lives goes away. I had a 77-year old man. He visited me about three years ago and he told me, "I have no illness at all but I think it is time to go. I would like to end my life. I have been separated from my wife, not in court but in reality, and I think it is time for me to go". Then I told him, "I do not think that I will find a Swiss physician to write a prescription for you in this situation because doctors have difficulty writing a prescription for a person who is not ill, but I suggest that you could write to the cantonal physician, the authority who controls the physicians, and ask him whether he would grant such a decision so that you can get pentobarbital". The cantonal physician answered immediately, "I will not give this permission and if you would like to have a decision in order to be attacked at court you must ask it specially and that will cause costs". Then he asked for this special decision and the cantonal physician did not reply any more. I heard nothing of our member for two years. After two years I got a message from him that he has a new address and that he is again together with his wife and then I wrote a letter to him in order to ask, "Should we ask now the cantonal physician to render his decision?", and he told me, "I do not need it any longer". He had been in a dilemma and with this possibility I opened the way out of the dilemma. I had in mind that it could have been a depression of old age and perhaps it has been.

Q2373 Baroness Finlay of Llandaff: When you talk to people do you ask them whether they have informed all of their family and their close friends and whether they have thought through the

implications of their action for other people in the family?

Mr Minelli: We have even printed in our documentation, "You should speak with your family, with your friends, as soon as possible in order to give them the possibility to get acquainted with the idea of assisted suicide". For instance, I have a member, a German professor, living both in California and in Germany. He is now 96 years old. Four years ago he told me, "I will come to Zürich and have my assisted suicide and then you can inform my wife". I told him, "Listen: that is not our way of doing it. It is not fair on your wife and it is not fair on DIGNITAS because if we proceed this way your wife could be very angry and this anger would have just one object—DIGNITAS, so I think you should be fair with your wife and fair with us". After that he informed his wife and also his daughter. Later on he made the journey to Switzerland together with his daughter. He has been here and seen the physician. The physician has written a prescription and then he left for Germany and now he is again in California and two weeks ago he wrote a letter that his cancer of the prostate has become worse and that he intends to come within two or three months. We are always telling our members, "You should speak with your relatives, with your family, with your friends because it is important not only that they know it, not only that they have the opportunity to get acquainted with the idea, but also in order to come with you to Zürich. Do not come alone to Zürich. If relatives are coming with you, if possible bring at least two persons so that after your death a single person does not have to go back alone to their country".

Q2374 Earl of Arran: I am sure you are well aware that in the future it is possible that certain restrictions and regulations might be imposed upon organisations such as yours. To what extent do you worry about this?

Mr Minelli: Not at all. I do not worry about it.

Q2375 Earl of Arran: They give you no anxiety?

Mr Minelli: No, because we had the other problem of the public prosecutor, Dr Brunner. He wanted to make a cantonal law and after that I published my article about the European Convention on Human Rights with assisted suicide. After that we reopened our house in the canton of Aargau. He has no more the intention of making this law. He is now thinking that perhaps a federal law could be made but the Director of Justice in Berne, Mr Koller, has said publicly that if you want to make a law you should first know a lot of things and they do not know anything. Swiss authorities have never visited us and therefore we are very grateful that you make this visit

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to us. Perhaps this is the problem of the prophet in his own land.

Chairman: That is an appropriate moment to ask the Bishop if he has any questions.

Q2376 Bishop of St Albans: I would like to go back to try to understand the organisation itself because you began by saying there are no power struggles and it seemed from your description that the reason there are no power struggles is that there appears to be absolute power between you and your colleague. Is that the case? Who could, for example, say to you, "Sorry, Mr Minelli, but it is time for you to step down as the leader of this organisation"?

Mr Minelli: If Mr Wernli has the impression that I am doing something the wrong way he will tell me and then we will discuss it.

Q2377 Bishop of St Albans: But nobody has the authority to say to you, "Actually, it is time for you to hand the chair over to somebody else"?

Mr Minelli: No. I have been told very early in my life by a German author who has written about human rights and about justice, "Whenever you are setting up a philanthropic organisation you must exclude power struggles because I have lived in Germany and in an organisation for human rights one member of the board sued the others in court and they have no longer been able to do any real work to help people in the field of human rights". This lesson I learned.

Q2378 Chairman: So you did that. You carried that doctrine into practice in having yourself and your colleague, the two of you? You consider that outlaws any form of power struggle? Would you be able to give us, because I think it would be useful to have it, your documentation suggesting to the member that they should consult their relatives and if possible bring at least two with them if they came to Zürich?

Mr Minelli: This is not printed. This we tell them over the phone.

Q2379 Chairman: But the print says to consult their relatives?

Mr Minelli: We will give you our documentation, the German and the English and, if you would like it also, the French.

Q2380 Chairman: So far as I am concerned at least it will be sufficient to have it in English. That would be very useful because obviously, as you are asked questions, some other aspects of the written documentation will become apparent and it will be useful to have that.

Mr Luley: Most of the physicians who look at the requests of members of DIGNITAS also ask, "What about the consent of the husband or the wife? What

about the children?". They usually ask before they make their decision. For example, Dr Reinhardt, looking at the requests, always says, "What about family? What about friends? How does the family see the situation?". Most of us want to know in advance.

Q2381 Chairman: Supposing that the member said, "I do not wish the family to know anything about it".

Mr Luley: We have to respect that because at the end of the day it is a personal decision. In the German documentation, which is more up to date, it is already printed that the family members should be involved in the whole discussion.

Q2382 Chairman: Perhaps we do need the German copy if the basic text has changed.

Mr Luley: In the English documentation, and I will leave everything with you, there is mention that family members should accompany members to Switzerland once they wish to come for an accompaniment. Also, all the phone calls and ongoing communication that we have with members are in our office. We have e-mails, letters, telephone calls.

Q2383 Chairman: Once the member puts in an application to have help then you have this correspondence with them?

Mr Luley: Absolutely.

Q2384 Chairman: And before they leave home?

Mr Luley: Absolutely. Everything has to be set up and prepared in advance. All these matters are discussed before they come here.

Q2385 Baroness Jay of Paddington: You mentioned, Mr Minelli, that you try to encourage people to come more than once, maybe to come for a preliminary visit. Do you have any idea how many do that?

Mr Minelli: I have no statistics for that.

Q2386 Lord Joffe: Dr Reinhardt, your colleague mentioned that you do some of these examinations of patients. Could you tell us how you go about it and how long an examination would take on average?

Dr Reinhardt: I cannot give you a clear period of time. It depends normally on the records we have from the doctors. Normally we have 10 or 20 documents. The situation is so clear that you speak for 20 or 30 minutes. Sometimes it is an hour. It depends so much on the situation of the illness and the family situation so that I cannot give you an average time.

Q2387 Lord Joffe: The range is from half an hour to an hour or more?

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Dr Reinhardt: Yes, about that.

Q2388 Chairman: What is it you are looking for? What is the examination directed to?

Dr Reinhardt: I cannot understand you.

Professor Hopff: It would be a general examination and he will get all the information from the university hospital or where the patient comes from or from the first doctor who had the treatment under control and he will see all the diagnoses. He will just prove whether this diagnosis is correct. He will be the so-called second opinion so that any crime is excluded. That is why we ask for a second opinion from another doctor.

Q2389 Chairman: On whether or not the patient is suffering from some physical condition that makes it appropriate that he should be helped? Is that right?

Professor Hopff: Yes. May I give you a life example? I have felt healthy all my life and last August I passed the pilot's examination of our Swiss aerial office and it is very careful. They examine you hard. My doctor said, "You are very healthy and if you continue, you are now 75, you will keep your pilot's licence up to 80". At the beginning of last December I still felt very healthy but the first week of December my right salivary gland began to swell and after some days I had a pulmonary embolism and we cured this and then we looked for the secondary one and this was a very fast-growing cancer so we started chemotherapy and just last Saturday I came out of hospital. Now for me it is the same. I gave all the diagnoses to DIGNITAS from the hospital that it is a very malignant, fast-growing cancer but still we have to go to a second doctor and he can decide whether an accompanied death will be possible. I can tell you from my experience when I was a long time ago Vice President of EXIT that we very often saw, when people had the so-called green light that they would be accompanied if the pain was unbearable, that, as Mr Minelli has said, about 50 per cent of our patients could relax and some days later when we said, "We will be there; we will help you; we will accompany you", the husband called and said, "My wife peacefully died last night". This was in about 50 per cent of cases, and I can tell you how glad I am that I have the guarantee that when the situation is unbearable I can come here and Ludwig Minelli has been to my place and discussed this problem with my wife, with my son and with my daughter. They said, "We will be very sorry but anyway you do not have to suffer. If you decide to die we will agree". That is a life example.

Q2390 Chairman: I understand. Thank you very much indeed.

Professor Hopff: But now I am very grateful that I have found a very collaborative oncologist and he knows my opinions. Therefore, we went a little deeper and he said, "You are the pharmacologist. You tell me just before dying", and so he could get me again at the last moment.

Q2391 Baroness Hayman: Could I just explore a little more what the second opinion is for? It is obviously there to verify the physical disease but you were talking earlier about the importance of competence and of knowing that someone is not, for example, suffering from a severe clinical depression which would stop them being competent. Could I understand a little more who assesses for competence? Having just heard you speak it would not be necessary for you, I completely understand you there, but for some patients obviously it is a matter of concern for the organisation and from what you were describing of the initial interview for the doctor is that screening for competence and mental illness as well as verifying medical records?

Professor Hopff: The second opinion more or less is for us never to get in trouble with the police authorities. When you have a different doctor and he says the same, the authorities will be quiet.

Q2392 Baroness Hayman: But if a patient came from England, for example, where there is not the legal provision for this, it might well be that the medical records showed the extent of the cancer but would not say, "And this patient has spoken to me and expressed the desire to end their life and they are competent to express that desire", because that conversation might not have taken place in England, so it is not verifying the second opinion. You would have to start from the beginning with that issue.

Professor Hopff: Yes, it is very difficult to answer your question because first of all it is an elementary human right of the patient and the doctors give the signal, "It is true what the patient says and we can accompany him".

Mr Minelli: We have no other way to get pentobarbital of sodium than with a prescription from the doctor. I would prefer another system. I would prefer that a doctor makes a certificate telling us that the patient has been instructed about possible alternatives, that he has not accepted alternatives, that he is sound of mind, and that with this certificate I can go to the canton pharmacist in order to get a decision that I can go to the pharmacy to get pentobarbital of sodium. If we had this system the doctor would not have the problem of writing a little prescription which is normally against what doctors have learned.

3 February 2005 Professor Wolfgang Hopff, Dr Hans-R Näegeli, Mr Ludwig Minelli,
Mrs Soraya Wernli, Mr Silvan Luley and Dr Peter Reinhardt

Q2393 Baroness Finlay of Llandaff: Can I ask Mrs Wernli what the accompanying person does while they are there?

Mrs Wernli: First of all, our collaborator who is present during the accompaniment will check all the documents, the personal request and so on. The next step is a short conversation between the collaborator and the physician who has written the prescription. Quite often it is between Mrs Wernli herself, the physician and the person being accompanied, the three together. They review the request once again. The people requesting accompaniments will have sent all the documents beforehand, so we have their personal request and letter in which they describe everything. We have the physician's report, so in that respect the interview between the physician and the person wanting the accompaniment will have taken place already, so we know what the situation is and who wants the accompaniment. If we all have the same opinion and if the doctor says, "Yes, this person has this possibility; I have written a prescription", and the collaborator and everyone else agrees upon it, then the collaborator talks to the member and the relatives present. Everybody is different. Some people would like to sit down and have a conversation with the person present during the accompaniment. Others are in a lot of pain. They do not want to wait. They want to go ahead. We talk to them, whether they want to have candlelight, classical music. Whatever their wishes are we try to accommodate them and, most importantly, the people who come are always being told at all times that they may leave and go home. They do not have to take the medicine. They can leave whenever they want. Even in the last minute they can say, "I do not

think this is the right way for me", and walk away. There is another very important thing too, that if the person from DIGNITAS who is there during the accompaniment feels there is something wrong (it is the thing about empathy that Mr Minelli mentioned), "I do not think this person really wants to go or maybe he is pressured by his relatives", or whatever, they may say, "No, I am not doing this accompaniment; I am sorry".

Q2394 Chairman: But then ultimately it happens.

Mrs Wernli: It has happened, yes. If somebody comes up here and says, "I wish to go", put yourself into the situation that you are the person helping this very ill person to have the accompaniment. If you personally feel within you that there is something wrong here, that this person does not really want to go, would it not be your moral and ethical responsibility to say, "No, I cannot help you with this accompaniment"?

Q2395 Chairman: But it is the accompanying person, the helper, that ultimately hands over the prescription for the patient to take?

Mr Luley: No, he does not hand over the prescription.

Q2396 Chairman: He hands over the medicine, I mean.

Mr Luley: Yes.

Q2397 Chairman: That is what I mean—not the paper but the actual material.

Mr Luley: Yes indeed. He puts it within reach of the person who wants to go.

Chairman: Our time has passed rather quickly. We have to move on. Thank you very much indeed.

THURSDAY 3 FEBRUARY 2005

Present	Arran, E. Finlay of Llandaff, B. Hayman, B. Jay of Paddington, B.	Joffe, L. Mackay of Clashfern, L. (Chairman) St Albans, Bp.
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Examination of Witnesses

Witnesses: DR KLAUS HOTZ, **Dr Klaus Peter Rippe**, DR GIANCARLO ZUCCO, PROFESSOR CHRISTIAN SCHWARZENEGGER and Ms SARAH J SUMMERS LLB, EXIT, examined.

Q2398 Chairman: Good afternoon. It would be very helpful if you could give us a description of the structure of EXIT. I think I am right in saying that EXIT has different organisations in the different parts of the Federation, depending on whether it is the German area or the French area. Is that right so far?

Dr Hotz: Mainly we have EXIT in the German-speaking part. There Dr Zucco and I are members. Then we have in the French-speaking part an EXIT organisation and that was the first EXIT organisation in Switzerland. Now we have a new organisation, DIGNITAS, which is probably the one you know in England because people who travel from England to Switzerland to commit assisted suicide come to DIGNITAS.

Q2399 Chairman: We have just come from DIGNITAS.

Dr Hotz: Of course we are rather critical of DIGNITAS. EXIT thinks it is working more seriously and we are not making suicide tourists because we think that is the wrong thing to do.

Q2400 Chairman: The people you deal with are residents of Switzerland?

Dr Zucco: They are residents. It does not matter if they are foreigners or Swiss.

Q2401 Chairman: Could you give us a short rundown on the nature of the organisation and what the system is?

Dr Hotz: EXIT is an association according to Swiss law. That is the easiest form to organise in Switzerland, an association, which you know also in England. EXIT has about 50,000 members, so it is a relatively large association. A board is elected from the General Assembly each year and the board has now five persons. These five persons are leading EXIT. Then we have two additional organisations. We have the Ethical Commission where two people are members which decides difficult cases. Then we have the Compliance Commission which is controlling what has been done and I am a member of the Compliance Commission.

Q2402 Chairman: That is to see that what is being done is complying with the rules?

Dr Hotz: The rules within the association.

Q2403 Chairman: We have had described to us the general law and particularly Article 115 of the Swiss Penal Code and the earlier Articles which have a bearing on this, so we have that kind of criminal law background already. In EXIT I gather you have regulations that you have made in the association yourselves for the way in which you carry out your activities.

Dr Hotz: We have our statutes which are much stronger and where the conditions for assisted suicide are much higher than the penal law, which is of course very open. We must firstly have a poor medical prognosis, unbearable pain or substantial impairment. The full discretion of the person committing suicide is the second part. It is these two with which we work within EXIT.

Q2404 Chairman: Is there any time frame in relation to natural death? In some places a time within which natural death is expected is set out as a requirement for assisted suicide. Do you have that or not?

Dr Hotz: No, we do not have that. For us the autonomy of the person is in a way our first point of view. We are rather liberal on this medical prognosis. If you have, for instance, a person who is over 90 and is fed up with life, has different pains but is not before death, then we help. We interpret our rules. Of course, we look at each case. With a 70-year old person we would not do that. With a 90-year old we are more liberal to consider the autonomy of a person.

Q2405 Chairman: We have understood that general structure. I think it would be useful for us to know in a particular case what the procedure is for the actual patient and what happens, how you apply the conditions in a practical example. Would that be possible?

Dr Hotz: Yes, of course. **Dr Zucco:** As a rule we agree to assist people who are members of our organisation. If somebody who is not a member wishes to be accompanied then he has to become a

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member. We have about 50,000 members in Switzerland. When one of these members wants to be assisted in suicide then he has to apply specifically. There is a first visit which we conduct with this person, and based on this first meeting we decide if this is a case for EXIT or not.

Q2406 Chairman: Who does the person see on the first visit?

Dr Zucco: We have a team of about ten people who do this assisted suicide and it is one of this team. The first thing that we try to assess is the capability of the person to make such a decision. If we are satisfied with that—and, of course, this is not a permanent decision; it is just a decision at first glance and there will be more opportunities of confirming this assessment—then we try to establish the seriousness of the wish. We try to do this over a certain period of time because there are people who want to die today and tomorrow they want to live, so we try to postpone the execution of the suicide as much as possible. If finally the decision is made that the person can qualify then we have to ask this person to provide us with two documents. One document is a sort of diagnosis that he is supposed to get from his surgeon or consultant and the doctor is supposed to do that. He cannot refuse to provide that.

Q2407 Chairman: That is the person's own doctor?

Dr Zucco: Generally speaking, yes. He has to testify to the diagnosis and then say if the disease would carry the person to death; in other words if it is a terminal patient or not. The third point, which is extremely important, is the confirmation of the capability of the person to decide on this specific question. The second document that we need is a prescription because all assisted suicides which we practise at EXIT are done by using a barbiturate which, being a narcotic, cannot be provided in a pharmacy just like that. You need a prescription. This is a little bit of a stumbling block because you need a doctor who is willing to do that, and of course there is no forcing him to do that. It is his autonomous decision. We are very happy if the family doctor does that because he is the one who has known the patient for the longest time. If he is not willing to do that because of ethical considerations or religious considerations or whatever, there are a number of doctors who work very closely with EXIT because they think in the same way as we do, so normally we would resort to one of those. Once we have the document from the family doctor and this prescription then it is up to the patient to decide if and when he wants to die. Then he just has to call the person who has been assigned to him or her.

Q2408 Chairman: That is the same person as he saw at the first visit?

Dr Zucco: It is the same person. The patient has the possibility of refusing the person. If the chemistry between two people is not okay then this can be done. We have had such cases. However, generally speaking the same person accompanies the patient all through this process. We have found that generally speaking only one third of the people for whom we open a case will also die with EXIT. The rest will die a natural death or we lose contact with them. When the day comes that has been fixed for the accompaniment we bring the barbiturate with us and the procedure is exactly the same as you heard from DIGNITAS. If you want I can repeat it but to save your time maybe it is not necessary.

Q2409 Chairman: Could I just say what I understand it to be, that is to say, once the patient comes and the barbiturates are there with the person from EXIT then, after confirming the situation is the same as it was before and the patient still wants to have the barbiturates, the EXIT person makes them available to the patient and the patient has them within his or her reach and can use them if they are going to proceed. Is that a reasonable summary?

Dr Zucco: Yes, that is right, and the person who brings the barbiturate stays until the end, until also all the formalities have been completed with the authorities.

Q2410 Chairman: He telephones or sends a message to the police authorities because it is an unnatural death?

Dr Zucco: Exactly.

Q2411 Chairman: And then the police come. Do you normally have an arrangement with the patient about what is to happen thereafter in the way of disposal of the body and so on? That is all arranged beforehand?

Dr Zucco: For a certain part, yes, but the relatives of the person who dies have the possibility of discussing this with the policeman that comes because Switzerland is a very decentralised country.

Q2412 Chairman: Yes, very much so. We have realised that.

Dr Zucco: In every canton there are different rules. For instance, in Basel the corpse of the person who has died has generally to go to a medical institute for an autopsy. In all other cantons this is not a rule. This is only done in cases where this is requested by the coroner.

Q2413 Baroness Jay of Paddington: Could I just ask you a question about the issue of people who cannot or find it very difficult physically to administer the

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medicine themselves? Lord Mackay described, and you did not contradict him, that you leave the barbiturates within reach of the person. What happens with people who are very physically disabled?

Dr Zucco: Generally speaking this medicine is administered orally, so we prepare the solution that the patient has to drink and we put it on the table and he or she is supposed to take the glass into his or her hands. This is the normal way. If somebody is disabled and cannot do that for some reason or, for instance, cannot drink because he is paralysed or the stomach does not function properly, then there is an alternative way of administering this medicine. This is by infusion in the veins. The principle stays the same. The last action has to be done by the person who dies, so this means in this case opening a valve. This is done not very frequently but in several cases. These are the two different options.

Q2414 Chairman: The valve is constructed in such a way that, so long as you have the will to open it, it is quite easy to open?

Dr Zucco: Exactly.

Q2415 Chairman: Like taking the top off a bottle, for example?

Dr Zucco: It is like a tap.

Q2416 Chairman: But very easy to turn? Some taps are more difficult than others.

Dr Zucco: Yes.

Q2417 Chairman: The last act is the patient's?

Dr Zucco: Yes. As a matter of fact today there is no longer a tap in most cases. There is a small wheel that they have to push.

Q2418 Chairman: We have heard it said in some other places that it is something that you can squeeze; you can open the thing by squeezing a valve.

Dr Zucco: No. Many people are working at developing systems which allow people who are very disabled to be able to commit suicide which would not otherwise be possible. This is because several people who are, for instance, tetraplegic are discriminated against because even if their wish is very clear and very understandable they cannot be assisted because they cannot move.

Q2419 Chairman: They do not have any movement at all?

Dr Hotz: We try in these cases to have two people, that the assistant from EXIT has a witness, and there have been cases also where a video has been made to prove afterwards that the person opened the valve, which is of course a delicate action.

Professor Schwarzenegger: We had a meeting with the prosecutor of the canton of Zürich to discuss several methods by which tetraplegics and others could commit suicide. Several technical measures have been proposed and the public prosecutor has expressed doubts about the methods. It is something which is decided in accordance with the authorities.

Q2420 Baroness Hayman: Have there been very difficult cases with tetraplegics or people with advanced ALS where you have not been able to help them despite their express wish because they did not have the physical capacity to take the last act?

Dr Zucco: In my experience I never had any case like that. I cannot speak for other people. I never heard that we had such a case, maybe because we try to clarify the whole process from the very beginning.

Q2421 Chairman: So the prosecutor is quite happy with a large degree of assistance, if I can put it that way, in terms of getting the infusion ready and everything else, as long as there is a discernible last act that is the patient's?

Dr Zucco: There was some concern some time ago concerning this infusion and the reason was that the prosecutor of Zürich thought that an infusion required more preparation so that the patient might be impressed by these preparations and might decide that now he has to die because everything has got so far. Now it has been accepted because what we do is keep asking until the last second, "Do you really want it?". We try to make it easy for the patient to say no.

Q2422 Chairman: If there was a big assembly of preparation required would that be thought possibly to put pressure on the patient, "Having gone this far I cannot return", as it were, so that until the very last minute when the patient's action of some kind is required, you keep telling them, "You need not do this"?

Dr Zucco: Yes.

Q2423 Baroness Hayman: In terms of your concern with the monitoring and the keeping to the rules and the conditions, how do you verify that each of the people who works as an accompanist is abiding by these rules and how does the state do that? Is their view only retrospective, after the event, or do they have any knowledge of your procedures or checks or random checks and procedures?

Dr Zucco: We have very frequent and strong supervision where cases, especially difficult cases, are discussed and we from the team are supposed to follow certain courses for improving our capabilities and for making sure that we abide by the law. I must say that during all these years, and EXIT was founded 23 years ago, there have been very few cases

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where there were problems with justice, for instance. It was mainly related to a company assisting people who had psychiatric problems. This is several years back. The possibility for the authorities to verify what has happened later on is almost impossible. The only way is to have an autopsy of the corpse, but this can only establish if the barbiturate was used, not much more than that. Also, the clearness of the will cannot be established post mortem.

Q2424 Chairman: Do you normally have a writing from the patient at the beginning if the patient is able to authenticate a document? Do you get that at the initial stage when they see your official in the first instance?

Dr Zucco: This is not required but we are very glad if we get something like this. There are patients who like to keep a sort of diary on the disease so if we get copies of this, especially if it is handwritten, we are very glad.

Q2425 Chairman: The authentication afterwards that the law has been fulfilled depends, I suppose, on seeing what sort of equipment there was there and whether there was one of these things and then on the integrity of the relatives, if they are there, and of your representative who is there?

Dr Zucco: Right.

Q2426 Chairman: It is normally just one person from EXIT, is it?

Dr Zucco: Yes. Dr Hotz mentioned that in special cases there would be a second person. Generally speaking the second person who is always there is not from EXIT. It is generally speaking a relative or a friend or whoever. He or she has the function of a witness.

Q2427 Bishop of St Albans: I think I may have missed something, which is the place where all this happens. Is it usually in the patient's home? Where do most of the assisted suicides happen?

Dr Zucco: In most cases by far the patient dies at home. There are cases where the patient does not have a home any more because they are in a public institution. Zürich is different from the rest of Switzerland because in old people's homes in Switzerland it is possible for EXIT to become active, but for all the rest of Switzerland this is generally speaking not allowed. In these cases it is difficult because the person has no home. Actually, the old people's home is his home. If he or she wants to die with EXIT he will have to leave this home and then the only alternative is that EXIT has a room in Zürich and one in Berne where these people can come to die.

Q2428 Bishop of St Albans: Can I follow up on a different subject which is about the exercise of power by those who control the barbiturate? You were saying earlier that personal autonomy is the key and yet, if I am 70 years of age and I wish to exercise personal autonomy that you think I should not, I cannot, so there appears to be a kind of exercise of power by someone other than the patient over their own autonomy. Have I misunderstood that?

Dr Zucco: There are two aspects. One is EXIT and the other one is the doctors who are supposed to write the prescription. There may be cases where EXIT agrees to assist somebody but where no doctor is prepared to make the prescription. Because we only use this barbiturate then in these cases we have to stop. There is no way that we can assist somebody. This is why other organisations have been looking for different ways of assisting people who want to commit suicide which would not require a prescription. There was one such organisation in Switzerland, very small, and they had problems with justice, so at present they cannot continue to practise. As far as EXIT is concerned there has been some time ago a change of philosophy because in the beginning EXIT was only prepared to assist people who were terminally ill or had very strong pains or were disabled, for instance, they had to spend their life in bed, and recently it has been decided that we would also assist elderly people who simply decide that they do not see any meaning in their life any more. They have different problems, for instance, they do not see well any more or they cannot leave their room or whatever, but they would not die of this. These people we are now prepared to assist. There is no opposition, let us say, from the authorities.

Q2429 Bishop of St Albans: Suppose it was a 17-year old young person who was suffering from depression or just wanted to die. Would you think that was an acceptable thing for them to do?

Dr Zucco: You say depression?

Q2430 Bishop of St Albans: Or whatever.

Dr Zucco: For depression this makes a difference because this is what you can consider a psychiatric disturbance and because this is a very controversial subject EXIT decided about five years ago to stop assisting such people even if, according to the law, this would have been completely possible. Very recently there has been again a decision in the other direction, that in selected cases where people who have a psychiatric disturbance are very clear in their will they can again be assisted.

Q2431 Bishop of St Albans: Could you say on what moral grounds as opposed to legal grounds you make these distinctions?

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Dr Rippe: There are two principles. It is not only the principle that follows autonomy but also on the other hand we have the principle of care or of benevolence and to make a responsible choice of the person there has to be some evidence that it is their autonomous will. For example, for the 17-year old person who has depression we have to believe that he has tried all possible therapies. There is a long dialogue with the person to make it clear that it is his autonomous will, that he has considered all the facts and all the options of his life and if his decision is well considered with all necessary information and so on. Therefore we have always two principles—care and autonomy.

Q2432 Chairman: In such a case you would still need to get a doctor's prescription?

Dr Rippe: In all cases there will be a doctor's prescription.

Q2433 Chairman: So the doctor's guidelines will apply and in the 17-year old person's case the doctor might take a different view of whether it was advisable and whether in conscience he could decide to assist by granting a prescription?

Dr Rippe: I think for a 17-year old boy or young lady with depression no doctor will do it because they can be cured.

Professor Schwarzenegger: That is a legal question also and you can find in the documentation that our medical legislation also prohibits doctors from prescribing barbiturates in such cases. There must be an analysis of the case and it must be well documented and only under these circumstances is a doctor allowed to hand out a prescription. That is like a third filter in the system which is a control mechanism beyond the reach of autonomy. It is the medical legislation field which could lead to punishment against the doctor and also to disciplinary measures like revoking his licence. That is why this does not happen.

Q2434 Chairman: It would be useful to get a little bit more detail. This is medical legislation that controls the barbiturate prescription?

Professor Schwarzenegger: That is right.

Q2435 Chairman: We have not actually been referred to that unless it is in this document.

Professor Schwarzenegger: It is in this document. We have translated the provisions from the law on pharmaceutical products where this is contained and because it is a narcotic it also falls under the narcotics law. This, in combination with the health law of the cantons, prohibits doctors from issuing a prescription in such cases as you mentioned before. This is like the third filter level after one has controlled the legal capacity of the person and the

second problem area is whether the person is committing suicide and taking the last action by himself or herself. This is a second important filter in our system and the third one is the control over the narcotics. You will find the details in the document.

Q2436 Chairman: I have just been looking at them. On pharmaceutical products it says, "Prescribing and dispensing of pharmaceutical products must be carried out in accordance with the acknowledged rules of medical and pharmaceutical science". Is it your view that in the case that the Bishop has mentioned, of a 17-year old person suffering from depression, the acknowledged rules of medical and pharmaceutical science would not permit the prescribing of barbiturates in that situation?

Professor Schwarzenegger: That is right. They would indicate to treat the depression.

Q2437 Chairman: And you have given us the narcotics law you immediately underneath and again it is the acknowledged rules, this time of medical science, pharmaceutical being missed out?

Professor Schwarzenegger: That is right.

Q2438 Baroness Hayman: Would there also be an issue under Article 16 about legal capacity?

Professor Schwarzenegger: That is the first filter. That is what EXIT is taking a lot of attention to filter out right from the start, that this is done in the first contact.

Q2439 Baroness Hayman: The depression could be a reason for saying that someone did not have capacity and therefore did not get over the first hurdle?

Professor Schwarzenegger: That is absolutely right.

Dr Rippe: In the case of depression no people from EXIT will prove that they have the capacity to act autonomously, so there is a fourth filter for these persons.

Dr Zucco: If there is a case where depression is involved or psychosis or whatever, then we request a certificate from a psychiatrist that this person, in spite of that, is capable of deciding whether to live or to die, and if the psychiatrist does not issue this document we have to refuse the case.

Q2440 Chairman: On the initial visit of the patient he or she is seeing one of your people that work in this area and the certificate that they have to get from the doctor will normally bring out, will it, if there is any psychological or psychiatric problem, because it might be difficult on a single visit for somebody who was not a fairly well trained psychiatrist to notice that there was something deficient about the person's capacity? You rely to some extent anyway on the

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medical certificate which at that stage you ask the patient to produce?

Dr Zucco: Right. Anyway, if there is the slightest suspicion that somebody may be psychologically ill it will be a long process. Even if the case is accepted it is not going to happen very soon because there will be more steps to go through to make it really very clear that this is finally the will of the person.

Q2441 Chairman: As you have explained before, people have cycles of ups and downs and you have to ensure in the ordinary case even that it is a properly fixed determination that is at the basis of the request?

Dr Zucco: Yes, you are right.

Q2442 Baroness Finlay of Llandaff: Moving away from competence for the moment, how do you determine whether a person has been subject to coercion?

Dr Zucco: That is a very good question. It is very difficult because it is very difficult to know exactly what the family situation of a person is. You can ask as many questions as you want but finally some people are not even very willing to answer your questions on this subject. I have already seen many people say, "This is none of your business. This is our family affair". The best way to make sure that we are accompanying the right persons is to try to stay in touch with them over a longer period and have contacts with them, for instance, even by telephone, and many things will develop that you do not see during the first visit.

Q2443 Baroness Finlay of Llandaff: I was wondering about the situation of an old person who is in care, where the family are having to pay for the care and the financial pressures are mounting. What do you do about those cases?

Dr Zucco: These are from our point of view very difficult cases because sometimes you can assume that there is pressure from the relatives but sometimes it is the person himself or herself who wants to die, maybe because he or she feels that he is putting pressure on the relatives. These cases are extremely difficult to decide. What we have to do finally is to make sure 100 per cent by talking repeatedly to the person that this is really his or her wish to die. There may be cases where we make the wrong decision. I cannot exclude that. This is typical of every activity.

Dr Hotz: Maybe in reality you have to realise that people who come to EXIT in large part have terrible health problems, cancer mostly, these people are in a terrible state and they want to die. You see relatively quickly that they mean it and that there is not pressure from the family. They are suffering, they have a terrible life. We have about 150 cases per year

and out of these 150 probably 100 are also urgent cases where we have to act quickly, so this problem is probably not such a large problem. Then you have others maybe who are not so sick but in my experience the people who decide to come to EXIT and make an assisted suicide have a very strong character. You need a strong character to fix a date and say, "Saturday next week: that is the day I go". You just do not do that out of pressure. These are very minimal exclusive cases and I think even in these cases there would be a remark in these talks, maybe even at the last moment. I think it is not such a big problem. You have to see it in proportion. We have about 150 cases in EXIT per year. That is not so many cases.

Q2444 Baroness Finlay of Llandaff: And you said about 100 of those are cancer patients?

Dr Hotz: About two-thirds, that is about right.

Dr Zucco: This changes, of course, every year. Last year was the year when we had the most cases. I will give you the exact figures. Last year we had 154, the year before 121, and in the previous years it was about 100. I still think that there are certain borderline cases where you have to make a decision that maybe is not the correct decision. This is a risk that perhaps we cannot avoid.

Q2445 Baroness Finlay of Llandaff: I want to ask you about the cancer patients specifically if I may. What are the symptoms that you are judging as requiring urgent suicide?

Dr Hotz: Suffocating, for instance.

Q2446 Baroness Finlay of Llandaff: Breathlessness?

Dr Zucco: It depends on the disease. If it is cancer it depends what type of cancer.

Q2447 Baroness Finlay of Llandaff: Oh, sure, but what I was wondering was what interventions are you making sure these patients have had to relieve their symptoms before you give them their dose of barbiturate? Do you have a procedure to make sure that they have had palliative care according to one of the European protocols, that you are using the European Association for Palliative Care pain control protocol, the protocol for dyspnoea? Are you using consultants in palliative medicine to see these patients for symptom relief to be sure that it is their will, not the symptom, which has driven them to despair?

Dr Zucco: It is very important to consider that. We are not the only interlocutors of these people. They are in touch with their surgeons, with their families, and these questions are being discussed back and forth.

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Q2448 Baroness Finlay of Llandaff: But we know that palliative care in Switzerland, with all due respect, is not well developed.

Dr Zucco: It is not very well developed. I have an example. In Basel there is what we call a hospice. This is a place where people go to die. When somebody who is an EXIT member goes to die there we are not allowed to accompany him in that clinic. What normally happens is that we have a three-party discussion: the patient, somebody from the hospice and somebody from EXIT, and we offer the patient two different approaches. One is the EXIT approach and the other one is the palliative care approach which in Switzerland maybe is not very well developed but it goes very far. When I say it goes very far I mean that the doctors are prepared to give the patient very high amounts of morphine, for instance, to control their pain and by doing this very often the death process is accelerated. What happens in fact is that the patient can say, "I take the EXIT approach, which means I have to go home again and then I have to drink this barbiturate so it will be a matter of minutes to die", or he can accept the alternative offered by the hospice, which is that in two or three weeks he does not get any food any more, he gets high doses of morphine and finally he is going to die that way. It is up to the patient to decide. What is always very important in our opinion is that the patient sees the different alternatives that he has and by having these meetings with all the people involved you are very sure that the patient finally decides what he thinks is good for him.

Q2449 Lord Joffe: You have written guidelines and principles which set out your policy and how you go about it. Could we have copies of these documents?

Dr Zucco: We have our statutes and then we also have guidelines, recommendations.

Q2450 Lord Joffe: Could we get copies of these documents?

Dr Hotz: Those are our internal documents which we are not handing out except to the police authorities. The police authorities have these guidelines but we do not give them to everybody. That is an internal paper which is restricting us and we want to keep certain literature. There are always exceptional cases and we do not want that suddenly somebody comes and says, "Oh, this is against the recommendation you have". We sometimes have very unusual cases. We have the Ethical Commission which decides about these very unusual cases and we do not want to be too much restricted with those patients. We also have the Compliance Commission. We check on every case where there has been a going and in other cases where we were not active. We check every person together with these recommendations.

Q2451 Chairman: You gave us numbers, 151, I think.
Dr Zucco: 154 last year.

Q2452 Chairman: Is that for EXIT in one area of Switzerland or is it for the whole country?

Dr Hotz: That is EXIT in the German speaking part and the Italian speaking part.

Dr Zucco: I do not know if you have been informed about that. There are two EXIT organisations. They are separate. They just happen to have the same name because they were founded by the same person. There is one EXIT for the Swiss alone, which is the French speaking part of Switzerland. Our EXIT is responsible for the German speaking part and the Italian-speaking part. The figure of 154 covers the German speaking part and Ticino.

Chairman: Can you give us the population and the total number of deaths in the area covered by your EXIT, that is, the Italian and the German speaking parts? I just want to get an idea of the proportion of assisted deaths in your organisation in relation to the total number of deaths and the total population of that area.

Q2453 Baroness Hayman: Perhaps the total number of suicides as well.

Dr Zucco: A study has been done in the past covering about ten years. During these ten years, which was up to the year 2000, it used to be that the people who died with EXIT were about five per cent of people who committed suicide. It was about 0.1 per cent of the total people who died during that time. Recently, because the number of accompaniments has increased, it is approaching ten per cent of suicides.

Professor Schwarzenegger: You can give us an address and we can send you the study because it is available in English. That is one point. The second point is that I was never informed that the palliative care in Switzerland is at such a low level. That is a new thing for me. Legally I think it is assured that the autonomous decision by the patient is kept up, so that means either he can select palliative care and then he enters into this indirect active euthanasia debate, which is allowed according to Swiss criminal law, or he takes the EXIT way which was described before, which means assisted suicide where it must be an autonomous act by the person himself. It is not that people are under pressure to select EXIT or commit suicide, at least according to my studies.

Q2454 Chairman: I think the point is that obviously, as Dr Zucco and Dr Hotz said, perhaps Dr Hotz particularly, some of these people are very ill and so there is no question about particular types of pressure. It is a pressure of the illness that is so obvious, but the pressure of the illness can be affected by the extent to which good palliative care is

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available and I think that is probably the relevance of palliative care to what we are concerned with.

Professor Schwarzenegger: Of course.

Dr Rippe: There is no contradiction between these two ways. In EXIT there is general agreement that it would be better to have more palliative care in Switzerland. Switzerland has its own foundation which puts money into the palliative care field. The most important point is to see if the person is autonomous or forced by the disease and then the possibility to choose between these two options, but we fully agree that there should be more palliative care in Switzerland. It is not so bad but it is bad enough.

Chairman: It is not an uncommon situation the world over.

Q2455 Baroness Hayman: I have a very quick question about residence qualifications. You explained to us that you disagree with DIGNITAS about non-residents. I think I saw some figures that it is not nationality that you work on; it is the issue of residence.

Dr Zucco: Yes.

Q2456 Baroness Hayman: Could you tell me what the qualifying period for residence is to be a member of EXIT?

Dr Zucco: There are no rules from the side of EXIT but to become a resident in Switzerland is not an easy thing. It is excluded that somebody can become resident because he wants to die in Switzerland. This would be a very long term thing that would be required.

Q2457 Chairman: It is the general legislation that determines when you can become a resident.

Dr Zucco: Yes.

Q2458 Baroness Hayman: So if I were an expatriate working here and the first week I was working here I wanted to join EXIT I could not?

Ms Summers: Probably if you were working here you would have a resident permit as an expat.

Dr Rippe: I think that is two questions.

Q2459 Baroness Hayman: It is the definition of residency that is the key point.

Dr Rippe: The other question is whether EXIT will do it. That is an open question.

Dr Zucco: We handle that from case to case. We also have cases of people coming from abroad to die here. We want to be flexible on this subject. We do not want to promote this suicide tourism but on the other hand if somebody in the UK has relatives in Switzerland, for instance, the mother lives in Switzerland and the son is in the UK, and the son wants to die with EXIT, in such a case we may decide that we accept the case. It depends very much on the circumstances. There was a case recently of a German citizen who had lived in Switzerland for 20 years and then he went back to Germany. He is still a member and if he should decide that he wants to die with EXIT we would accept the case. That is why we do not have very strict rules of residency.

Q2460 Baroness Hayman: It is not the minimum three months, six months? You do not have a rule like that?

Dr Zucco: No.

Chairman: Can I thank you very much indeed, all of you, for your help. Sarah, you have not had a chance to contribute but I know you contributed to the paper. Thank you very much indeed.

Written Evidence

TAKEN BEFORE THE SELECT COMMITTEE ON THE ASSISTED DYING FOR THE TERMINALLY ILL BILL [HL]

Memorandum by Affinity

AFFINITY (formerly the British Evangelical Council, which was founded in 1952) is a network of evangelical Christian denominations, church groupings and independent causes. It is probably the largest association of exclusively Bible-centred churches in the United Kingdom, representing approximately 1,200 congregations.

1. OUR INITIAL RESPONSE

We are disappointed to see the reappearance of this Bill, an earlier version of which, as the Patient (Assisted Dying) Bill, was defeated in the House of Lords in June 2003.

Nevertheless, we recognise that there is a minority of people, plus a few organisations, who are persistently seeking to change the current legal safeguards and introduce some forms of euthanasia into the United Kingdom.

2. OUR BIOETHICAL PRINCIPLES

The best responses to any bioethical issue are based upon robust principles. Without such principles, responses inevitably degenerate into feeble subjectivity and utilitarianism. In the context of this Submission, our response is based on five principles,

- 2.1 All human beings are made in the image of God (Genesis 1:27). Therefore, all human beings have intrinsic dignity and value.
- 2.2 It is God who gives (Ecclesiastes 5:18), sustains (Psalm 54:4), and takes human life (1 Samuel 2:6). Therefore, to choose, or engineer, or bring about death, whether our own, or someone else's, without divine sanction, is to usurp God's prerogative (Psalm 104:29).
- 2.3 Since human life is a gift it involves stewardship, not ownership (Romans 14:12; 1 Peter 3:7). Therefore, sentiments such as, "It's my body, I shall do as I please with it", display excesses of personal autonomy that are entirely misplaced and unacceptable.
- 2.4 Innocent human life is not to be taken (Genesis 9:6). The Sixth Commandment (Exodus 20:13) reinforces this principle. Therefore, to destroy innocent human life is an offence against God's holy law.
- 2.5 All human life demands special care (Matthew 7:12), particularly those who are weak and vulnerable (James 1:27; Zechariah 7:8-10). Therefore, such innocent lives are to be protected, not plundered.

3. OUR BIOETHICAL CONSEQUENCES

Based upon these principles of historic, orthodox, biblical Christianity, which are undeniably honourable, wholesome and beneficial, we,

- 3.1 Seek to uphold and promote the utmost respect for all human life, from fertilisation until natural death.
- 3.2 Are opposed to the deliberate taking of innocent human life, at any of its stages.
- 3.3 Are opposed to all forms of euthanasia, whether it is carried out on the newborn because of some genetic disorder, whether the patient is elderly and judged to have a life not worthy to be lived, or whether it is defined in terms of deliberate acts or deliberate omissions. If the intent is to kill the patient, it is wrong. Such actions are callous and unworthy of any decent society.
- 3.4 Are especially concerned by the current pressure to legalise some forms of euthanasia, particularly for the elderly, who are seriously or terminally ill. We regard this as a perilous slippery slope—voluntary euthanasia will undoubtedly open the door to involuntary euthanasia, as has

occurred in the Netherlands (see, John Keown (1995). *Euthanasia Examined*, Cambridge University Press, pp. 261-296).

3.5 Are also concerned about other issues associated with euthanasia, such as, the use of “quality of life” assessments and “living wills”. The former tend to be too subjective and hedonistic, while the latter are inappropriate and only serve to encourage a climate of medically-assisted suicide.

4. OUR OPPOSITION TO THIS BILL

This Bill is a truly awful piece of proposed legislation. We are totally opposed to it, in both principle and in consequence. Some of our more important observations and objections are listed here:

4.1 The Bill is shocking to read—it sends a chill through the reader. Its ethos is contrary to all good medical ethics and practice. In particular, it is contrary to Hippocratic-Christian medicine, which, for over 2000 years, has specifically forbidden doctors to assist in deliberately bringing about the death of patients—“do the patient no harm” has been its enduring maxim. Noncompliant doctors have rightly, throughout the ages, been regarded as renegades.

4.2 If the Bill were to become law it would forever redefine, and hence, destroy the historic role of doctors and the whole healthcare profession as compassionate carers and life preservers. It would undoubtedly lead to the greater corruption of medicine. Not only would the illustrious record of medicine be abrogated, but also the crucial doctor-patient relationship of trust would be eroded, and the vulnerable would become fearful of even entering healthcare facilities.

4.3 The legalisation of any form of euthanasia, including assisted suicide, as envisaged in this Bill, would require that such procedures become “management options”, to be discussed with all seriously-ill and terminally-ill patients, who, because of their very vulnerability, could easily be pressurised into making inappropriate decisions. The subtle power of doctors should not be underestimated. Patients would become anxious and fearful of being burdensome, and thus “a duty to die” would be engendered.

4.4 The Bill would be unworkable. Some of the safeguards, such as definitions of “terminal illness”, “within a few months” (p. 2, lines 23, 27) and “made voluntarily” (p. 3, line 8) are notoriously impossible to define and predict. They are subjective. Pro-euthanasia healthcare workers will simply ride roughshod over such supposedly protective measures. Furthermore, the history of medical bioethics demonstrates that once a permissive law has been enacted, its originally tight boundaries are soon expanded—consider, for example, the initial provisions and expectations of the 1967 Abortion Act.

4.5 The wording of the Bill provides huge scope for confusion. For example, the stark phrase, “. . . the patient wishes to be assisted to die” (p. 2, lines 43-44), could be interpreted as helping the patient to die well, as in good palliative care (of which we would approve), but we fear that its intended meaning is that of bringing about death prematurely (of which we disapprove). Similarly, the term “suffering unbearably” (p. 2, line 48) may be true of a patient on one day, or week, or month, but may not apply at a later day or period. It is well known that news of a poor prognosis can have a significantly depressing effect upon a patient (and relatives and carers), yet this can be temporary and often, maybe, weeks later, buoyancy can return.

4.6 The Bill states that the patient must be informed of “the alternatives” (p. 3, line 5), including palliative care. This is insufficient and belittles the ways in which palliative care has transformed dying and death in recent years. Palliative care, which is simply the application of good medicine at the end of life, needs to be experienced, not merely discussed.

4.7 In addition to corrupting the medical profession, the Bill also insists that members of the legal profession are to be drafted in as collaborators (p. 3, line 38). Furthermore, the involvement and potential trauma for those who act as the “other witness” (p. 4, line 1), in terms of future regrets, doubts and mistakes, will be too great a burden for most people to bear.

4.8 The Bill allows (p. 4, lines 25-29) for the so-called declarations to be revoked. But once signed, patients are sending a signal, albeit, perhaps unintentionally, to the healthcare team that they are requesting less than the best future medical care and treatment—a psychological barrier will have been irrevocably breached. And with what urgency will doctors inform their patients of their rights of revocation? A pro-euthanasia doctor would inevitably be lax in this area. And how will patients,

judged to be on the borders of incompetence and therefore frequently confused, revoke their declarations? These alleged safeguards are illusory.

4.9 The Bill allows for conscientious objection (p. 4, lines 30-43), but what is the point of such a waiver, if the morally-sensitive doctor has to refer the patient “without delay” (p. 4, line 37) to a pro-euthanasia doctor? And what if the ethos of the hospital is anti-euthanasia and one cannot be found? And will some hospitals become centres of excellence for the training and implementation of euthanasia to which patients will be transported? Perish the thought!

4.10 The Bill asserts that any healthcare professional who assists a patient to die will not have breached “any professional oath or affirmation” (p. 5, line 22). This is rank hypocrisy. What about the Hippocratic Oath, or the Declaration of Geneva? Twenty-five years ago, Thomas Beauchamp and James Childress (1979) warned in their seminal book, *Principles of Biomedical Ethics* (Oxford University Press, p. 113), that, “Rules against killing in a moral code are not isolated moral principles; they are threads in a fabric of rules that support respect for human life. The more threads we remove, the weaker the fabric becomes.” This Bill would shred that fabric.

4.11 The Bill describes the lethal chemical(s) used to bring about the death of the patient as “medication” (p. 6, line 19). This is a deplorable misnomer and only fuels the argument that the Bill, and indeed, the whole issue of euthanasia, is unnatural, deceitful and offensive.

4.12 The Bill seeks to establish a monitoring commission in the hope that all cases of euthanasia will be documented and filed (p. 6, line 20). This, on the evidence from the Netherlands, will be a vain hope. There, such reporting increased from 30 per cent to 41 per cent by 1996 but, based on the latest 2001 figures, is still only 54 per cent. In other words, the administration and monitoring of Dutch euthanasia, in spite of their professed “strict” and “precise” guidelines, remains a shambles.

4.13 The Bill includes (p. 6, line 22) the phrase “an attempt” to assist to die. Is this a tacit recognition that assisted suicides are neither always successful, nor what are purported to be “deaths with dignity”? The Select Committee will no doubt be aware of the shocking account of the Dutch experience, reported by Groenewoud et al. (*New England Journal of Medicine* (2000) 342: 551-6), which showed that a quarter of doctor-assisted suicides in the Netherlands were botched, and that instead of merely “assisting”, nearly 20 per cent of doctors had to act decisively to actually kill their patients. When such disasters occur, would the Bill allow doctors to cut the throats of their patients? And if not, why not, because the doctor’s intention would have consistently been to kill the patient? It is so obvious—the practice of assisted suicide always leads to full-blown euthanasia.

4.14 Section 15 of the Bill (p. 7, lines 3-6) is wholly unnecessary and disingenuous. It merely serves to unnerve the general public about end-of-life issues. Any good doctor will already be prescribing and administering the appropriate drugs, such as analgesics and sedatives, to relieve pain and distress—no change in the current law is required.

4.15 We recognise that the “greying” of the population has increased the financial and personal costs of caring for the elderly. The economic arguments in favour of euthanasia are unassailable. The utilitarian says, “Why should we care, when it’s cheaper to kill?” If euthanasia were to become public policy, the financial savings, and the freeing up of other resources within the NHS, would be huge. But so would the moral cost. The Bill would have a profoundly negative effect upon research and development into proper care—legalised euthanasia drives out palliative medicine. Instead of regarding the elderly and terminally ill as costly “bed-blockers”, and therefore expendable, we should be investigating and funding procedures and facilities to ensure that “their last days are not lost days”. No person has a life unworthy to be lived. To enable such patients to die well is not only the application of good Hippocratic-Christian medicine, but it is the fitting end of a person’s life, and a proper closure for the bereaved family. Euthanasia, of any sort, is counter to these civilized and important end-of-life events.

5. OUR CONCLUSIONS

5.1 The Christian gospel is the message of hope. We believe that in this life all human beings have the opportunity to be reconciled to their God and so live and die well. The people of God are entrusted with this gospel to demonstrate to all people how to live well and how to die well. Christians must therefore be in the vanguard by showing compassion towards all those who suffer, including the disabled and the dying.

5.2 We call upon all those in authority to oppose every form of euthanasia and instead to encourage legislation, resources and action that will support and cherish human physical, mental and spiritual life, at all its stages.

5.3 We are glad to learn that the Bill is opposed by many groupings within the medical profession, including the BMA and the Royal College of Nursing, and many disability rights groups, such as Disability Awareness in Action, and other organisations like, Age Concern and Help the Aged. We join them in our steadfast opposition to this Bill.

5.4 The end of life is always a complex and difficult time for patient, carers and families. It is the last of life's great endeavours. The dying deserve the best care and attention. Medical treatment should be provided when it will be beneficial, and palliative care when it will not. Euthanasia must never be regarded as proper medical treatment. Killing the patient can never, ever be the right answer.

We welcome this opportunity to submit this response to the Select Committee on behalf of our constituency.

We sincerely hope that the Select Committee will conclude, as its forerunner, the Select Committee on Medical Ethics, did in 1994, not "... to weaken society's prohibition of intentional killing." And that this Committee will again recognise that, "It would be next to impossible to ensure that all acts of euthanasia were truly voluntary, and that any liberalisation of the law was not abused."

We trust that the Select Committee will resolutely oppose this Bill, and any other attempts to relax our current laws regarding the issues of dying and death.

20 August 2004.

Memorandum by ALERT

ALERT is an organisation funded only by donations from people in this country. The newsletter is circulated to about 700 people. It was founded in December 1991 to provide well-documented information on, and to warn people of, the dangers of euthanasia legislation and pro-death initiatives, and to defend the lives and rights of the medically vulnerable, recognising that all human beings are of equal value.

1. PURPOSE OF THE BILL

"To enable a competent adult . . . to receive medical assistance to die . . ." "Assistance to die" is explained in Section 1, paragraph (2) as meaning providing the patient with the means to end the patient's life or ending the patient's life . . .

Providing the patient with the means to end his/her life is formal co-operation in suicide, or indirect killing. Ending the patient's life is direct killing of a person. To kill, breaks the most basic principle or morality. To authorise killing of the innocent would be brutal, barbaric and uncivilised, and no supposed subsidiary good effect could possibly justify it. Medicine is the science and art dealing with the maintenance of health and the prevention, alleviation, or cure of disease (Webster's Medical Desk Dictionary 1986). Causing death is the antithesis of medicine. The phrase "*Medical* assistance to die" is therefore contradictory and meaningless. Section 1, paragraphs (1) and (2), however, state that it shall be lawful for a physician to "assist a patient. . . to die." The wrong would be aggravated by the fact that that it was carried out by a *physician*—one who has dedicated himself to the service of the life and health of his patients. The Bill would specifically destroy the security of the doctor/patient relationship and corrupt the profession of medicine.

2. QUALIFYING CONDITIONS

It is futile to discuss qualifying conditions, since there can be no safeguards against permitting an act which is intrinsically wrong and contrary to the duties of the caring professions. No amount of legislation can change the evil nature of the act. Medicine is an inexact science, and unless life is deliberately ended, the prognosis remains uncertain.

3. OFFER OF PALLIATIVE CARE

Under this heading may be included the second section in the introductory paragraph of the Bill: "to make provision for a person suffering from a terminal illness to receive pain medication". Palliative care is a part of good medicine and all patients have a right to it. Free health care is available to all. It is already lawful for a doctor to give whatever medication is needed to control pain, even at the risk of shortening the life of the patient. We wonder why this superfluous clause has been inserted, and sees it as a red herring, to divert attention from the real issue.

4. DECLARATION (SECTIONS 4, 5 & 6)

Any such declaration, as all suicidal intent, should be seen as a cry for help and not taken at face value and acted upon, since it is as intrinsically wrong. At present assisting suicide is a felony and rightly so, for although suicide itself is not punishable in British law, suicide can never be a right. It remains a gravely wrong and inhuman way of dealing with problems of life. For the House of Lords to ever suggest the opposite is a derogation of its duty to protect the rights of all citizens especially the vulnerable.

5. DUTIES OF PHYSICIANS AND CONSCIENTIOUS OBJECTION (SECTION 7)

This section in effect adds a compulsory aspect to the legislation in overriding a physician's conscience. To follow his conscience is the first duty of any moral individual and a good conscience is essential to the practice of medicine. If laws are immoral it becomes a duty to disobey them. Such a clause makes the Bill all the more harmful, in presenting as a duty what is by nature reprehensible. Dr Shipman's actions were universally condemned, and to suggest that doctors may act in this manner, albeit with the consent of the patient, will change forever the face of British medicine.

6. SECTIONS 8 TO 14

We did not see any point in discussing these proposed regulations since, as stated above, no amount of legislation can change the evil nature of the act.

7. ADMINISTRATION OF DRUGS TO PATIENTS SUFFERING SEVERE DISTRESS (SECTION 15)

The concept of assisted suicide is abhorrent. We would rather see the House of Lords discussing the development of care services for the aged and the seriously ill.

8. POWER TO MAKE REGULATIONS (SECTION 16)

We quote William L. Shirer, who interviewed a Nazi judge condemned to death at the Nuremberg trials. The judge broke down and cried saying "How could it have come to this?" William Shirer responded: "Herr Judge, it came to this the first time you authorised the killing of an innocent life."

9. TITLE AND EXTENT (SECTION 17)

ALERT is astounded that 10 years after the Select Committee on Medical Ethics of the House of Lords decided that euthanasia was unacceptable, such a Bill should have serious consideration.

10. FURTHER EVIDENCE

We would be pleased to be invited to give oral evidence to the Select Committee.

We attach a paper on the case of Michael P Freeland demonstrating the confusion in evaluating suicidal patients with serious medical illnesses in the climate of the legislation in Oregon.

27 August 2004

Supplementary evidence from the Chair of the Ethics Committee of the APM

Thank you for listening to the Association for Palliative Medicine of Great Britain & Ireland's evidence on 21 October 2004. As requested by your chairman, Lord Mackay of Clashfern, I have sent the reference Glare P, Christakis N *Predicting survival in patients with advanced disease*. Oxford Textbook of Palliative Medicine Edited by Doyle D, Hanks G W, Cherry N and Calman K, Oxford University Press 2004 pp 29–40 to the Clerk to the Select Committee.

I would like to take this opportunity to clarify some points in the APM's evidence:

1. "Doctors (and other healthcare professionals) are not very accurate when making temporal estimates in individual patients, although this may be improving" (Summary in article cited above).
2. The House of Commons Health Committee (July 2004) received evidence on the current patchy provision of palliative care and recommended an expansion of consultant numbers.

3. Palliative care professionals cannot function as gatekeepers to euthanasia or physician assisted suicide. To contemplate this is to misunderstand the close trusting relationship which must exist with a patient if intimate issues such as concerns about death and dying are to be discussed.
4. The assessment process as outlined in the Bill is fraught with practical difficulties:
 - What is to be done if the doctors disagree?
 - Patients may be informed that palliative care exists but this is quite different from experiencing this care. Many patients are initially reluctant to be referred to specialist palliative care but once they receive this care they wish that they had come earlier.
 - In view of the acknowledged difficulties in diagnosing depression, particularly in the elderly, a psychiatric assessment should be mandatory not optional.
5. There is nothing in the Bill about the practicalities of administration of euthanasia and physician assisted suicide. May I draw your attention to Groenewoud J H *et al*, *Clinical problems with the performance of euthanasia and physician assisted suicide in the Netherlands*. *New England Journal of Medicine* 2000; 342: 551–6. This paper highlights the fact that there may be suffering associated with euthanasia and physician-assisted suicide.
6. The retrospective monitoring is an inadequate safeguard for doctors. Why are requests not assessed prospectively?
7. Implementation of this legislation may undermine the high standards of the care of the dying which have been achieved in this country. Improvements in care can only result from rigorous research and provision of appropriate levels of resources. This issue is far too important to be influenced by existing poor market research based on opinion polls and postal questionnaires. Proper studies with rigorous, unbiased methodologies need to be conducted and published in peer reviewed journals.
8. I am aware that the Select Committee are planning visits to the Netherlands and to Oregon. The APM would be delighted to arrange a visit to a specialist palliative care unit in this country, so that Committee members can see at first hand the reality of current practice. Please let me know if the Committee wishes to take up this invitation.

Dr David Jeffrey MA, FRCP(Edin), FRCP (Lond)

Chair of Ethics Committee Association for Palliative Medicine

Memorandum by the Association of Catholic Nurses for England and Wales

As an organisation we are grateful for the opportunity to comment on the above Bill, and hope our thoughts will assist the committee to produce a balanced conclusion whilst ensuring the continued sanctity and dignity of all human life.

We had hoped to engage the views of all of our members, but as time is short we were not able to do this as fully as we would have liked. The attached views are therefore those of the executive committee of our association with the assistance of our Ecclesiastical Advisor Rev J B Hurley. Our comments will be shared fully with our members at the next Annual General Meeting in October 2004.

1. INTRODUCTION

The Association of Catholic Nurses for England and Wales (formally the Catholic nurses Guild) has been established for over 100 years and is a member of the International Committee of Catholic nurses and Midwives (CICIAMS). As an organisation it is concerned with the professional life of nurses on a spiritual and ethical level, dedicated to the care and respect of human life.

The Catholic Church teaches us that life is given to us by God and is to be respected and cherished by all, from conception to death, and that only God has the right to take that life away.

2. BELIEF AND CONCERN

The Association agrees all attempts should be made to relieve the suffering and distress of those experiencing terminal illness, to receive the expert help and advice of palliative care experts, hospice care and given appropriate pain relief and alternative therapy. This care should be ongoing and in agreement with the patient.

Our concern is raised when measures beyond those of adequate pain relief are considered in full knowledge that the measures considered would end life.

3. INDIVIDUAL REQUEST

Individuals expressing a desire for assisted death due to terminal illness have the right to expect analgesia for the purpose of pain relief, so they may be kept comfortable. The same as they have the right to be cared for with compassion and love by professionals, trained to deliver that care. However it is believed measures that go beyond the accepted level of analgesia with the purpose of ending life is wrong in the eyes of the Catholic Church. This is a belief shared by many Christian and non-Christian beliefs; we therefore do not stand alone in our aim to preserve life.

4. COMPETENT ADULT

Competent adults should, and currently are, able to decide on whether to accept treatment extending their life through the direct intervention of healthcare professionals. This would include the right to have, or not to have further tests, artificial ventilation or feeding. There are currently many cases whereby professionals, because of the patient's distress, weakness or the disease process, question the competence of the adult. With the assistance of the psychiatrist these decisions often remain unclear, and professionals are left battling with their conscience. It is feared this could be the case with those wishing to take part in the assisted death of the terminally ill and may leave some questioning their professional knowledge and moral integrity.

5. PROTECTION FOR THE PHYSICIAN AND OTHER MEDICAL PERSONNEL

Concern is raised over pressure that may be put upon the consultant physician from professional colleagues, or relatives to support the action should they feel it is in the best interest to assist them to die. This pressure could easily be exerted on other health professionals, who work closely with the patient, and we see nurses very much in this group, to persuade the physician on behalf of the family. It is understood all physicians will be clear about their right to refuse to participate in this, however in emotive situations they may become vulnerable and open to persuasion.

You will be aware nursing staff are often questioned on ethical issues, and these questions, with increasing frequency, relate to whether something had been "done" to the patient to speed the death because of service pressures. This we know is not the case, but the question will become more common place should this bill be passed.

6. CONCLUSION

It is the belief of the Association of Catholic Nurses this Bill should not be passed in order to protect the vulnerable and preserve the sanctity of all life. It is believed God gives life and should only be taken by God at His Choosing. The terminally ill should be treated with dignity and respect, with all aspects of care attended to, to the highest standard, but no one has the right to choose the time of their dying.

Memorandum by The Association of Catholic Women

INTRODUCTION

1. The Association of Catholic Women is an organisation of women and men "supporters"; it is listed in the Catholic Directory, but is independent as an organisation of the Catholic Bishops' Conference of England and Wales.
2. The membership of the Association numbers more than 1,000. The coincidence of the consultation period with the summer holiday period has made it impossible to undertake a consultation exercise amongst the membership at large. This response represents the corporate view of the Association's Steering Committee.
3. Many of the Association's members have experienced the work of hospices, both in the United Kingdom and abroad; through this experience we have direct knowledge of people of all faiths and none whose last weeks of life have been transformed from times of fear, anxiety and pain to peaceful and virtually pain-free acceptance.

THE BILL IN THE CONTEXT OF THE NATURAL ORDER

4. The drive to give and to preserve life is one of the most powerful of animal instincts. Mothers of all species fight ferociously to protect the lives of their offspring. Babies born in the most adverse conditions of war, disease and famine cling to life and respond remarkably well to only minimal standards of care.
5. Medical practitioners accept that seriously ill and injured people often defy unfavourable prognoses through sheer determination to survive.
6. Our society has rightly held the conscious giving of one's own life to save that of another, or in defence of one's beliefs, to be an act of supreme heroism and sacrifice.
7. By contrast, when we speak of "losing the will to live", we are describing a condition of despair, a departure from the natural order. A decision to seek to end one's life, or to seek to have it ended, results from a sense of hopelessness, a belief that death must be preferable to the physical pain or loss of personal independence (both of which are recognised triggering factors in clinical depression) presently being endured.
8. In such circumstances, our clear duty to a fellow human being, rather than to collude with the person's despair, is to do whatever is possible to alleviate the pain, both physical and psychological, that has led him or her to seek assistance to die. This is the underlying principle of palliative care, which is the hallmark of, but is not exclusive to, the hospice movement.
9. The first duty of medical practitioners is to do no harm. The alleviation of pain is at the heart of medical practice; the administration of pain-relieving medication is held to be a licit and positive practice, even in circumstances in which the medication will itself shorten life.
10. To ask a doctor or other medical practitioner to assist a person in ending his or her life is to move beyond the aim of pain alleviation; it goes against the principle of non nocere. The compassion doctors and nurses rightly feel for the patients in their care should not be used a lever of persuasion to set aside that principle.

THE BILL IN THE CONTEXT OF EXISTING LEGISLATION

11. The intrinsic value of human life has, for many centuries, been the underlying principle of the rule of law. Crimes against the life of the person rightly attract the most severe penalties. Even in time of war, the taking of human life outside of recognised rules of engagement attracts the opprobrium of the international community and is punishable in international law as a war crime.
12. If enacted, the provisions of this Bill would directly contradict Section 58 of the Mental Capacity Bill. For the government to give time to a Private Member's Bill, the effect of which would be to render inoperative safeguards built into its own legislation, as recently amended, is irrational.

THE PRACTICAL IMPLICATIONS OF THE BILL

13. The dual purpose for which this Bill is proposed to be enacted is twofold: "... to enable a competent adult who is suffering unbearably as a result of a terminal illness to receive medical assistance to die . . . ; and to make provision for a person suffering from a terminal illness to receive pain relief medication."
14. The latter provision, as described in Section 15 of the Bill already exists. It is difficult to see what purpose this provision serves, either in the title of this Bill or in Section 15, other than to draw attention to the one universally acceptable proposal; this might, in fact, mislead members of Parliament and the public, who may not be aware that this is already an entitlement exercised under the oversight of doctors but, more often than not, nurse managed. To include this provision could soften opposition to the more contentious proposals in the Bill.
15. Sections 2 and 3 enumerate a comprehensive list of "qualifying conditions" which must be met before the patient may proceed to execute a declaration that he or she wishes to be assisted to die.
16. The gradual erosion of these safeguards may be envisaged. The Bill as it stands only applies to competent adults who are suffering unbearably. How soon will it be before a campaign begins to extend its provisions to relieve the unbearable suffering of terminally ill children? Obviously, minor children could not be competent to make the declaration; therefore parents or guardians would be permitted to do so on their behalf. Once the principle was conceded that a responsible adult could make the declaration on behalf of a suffering, but incompetent minor, it would be only a short step to permitting an adult child to make the declaration on behalf of an elderly, incompetent parent. It would come to be seen to be unfair for a suffering, terminally ill but incompetent person to be left unassisted for the lack of an appropriate adult relative; another competent adult could be appointed to make the declaration. Thus, carefully constructed safeguards could be set aside with relative ease, apparently for the best of motives.

17. Both the solicitor witness and the lay witness to the advance declaration, as provided for in Section 4, are required by sub-sections (3)(b) and (4)(b) to make an assessment as to the patient's soundness of mind, which neither is likely to be professionally competent to make. Solicitors, as far as we are aware, are not trained to assess competence in a matter of life and death.

18. There is an implicit assumption in the requirement in Section 7 for an attending physician or a consulting physician who has a conscientious objection to assisting a patient's death to refer the patient to another physician who has no such conscientious objection, that such a conscientious objection will be the exception, rather than the rule.

19. Moreover, the requirement to refer to a physician who has no such conscientious objection renders the objecting physician complicit in an outcome to which he or she has a conscientious objection.

20. The provisions of Section 7(1) and of Section 10(1-3) relating to protection for physicians and other medical personnel are silent with regard to discrimination in career progression.

21. The establishment of various monitoring commissions, to cover either countries or regions at the discretion of the Secretary of State, is a potential cause for concern about lack of consistency of application; there is scope for considerable variation between commissions in the application of the qualifying conditions for making an advance declaration.

22. The requirement for the attending physician to send the file of documentation to the monitoring commission only after the assisted death (or attempted assisted death) has taken place, and for the monitoring commission to determine at that stage whether the qualifying conditions have been met is hard to understand. A determination that the qualifying conditions have not been met can no longer protect the patient.

23. On every day in the year, throughout the United Kingdom, in hospitals, hospices, care homes and in their own homes, terminally ill patients request and receive medication for the relief of pain and distress, as described in Section 15. At least one member of this Steering Committee has direct personal experience of the administration of such palliative treatment to a close family member in hospital. There is no need, legal or ethical, for this Bill to be enacted to guarantee this entitlement.

24. The power given to the Secretary of State in Section 16, to make regulations by statutory instrument, gives him or her power to go beyond the intentions of Parliament; the requirement for such statutory instruments to be approved by resolutions of both Houses of Parliament is not a realistic safeguard (as the examples in paragraph 16 illustrate).

25. None of the safeguards in the Bill will (or, indeed, could) protect the patient from psychological pressure (perhaps self-imposed) to decline palliative care in favour of assisted suicide, in order to avoid being a burden to family or medical staff, to free up resources of staff, beds or medication. The Bill, if enacted, could in fact exacerbate a desire for self-harm in vulnerable people. It is possible to envisage hard-pressed medical staff not seeking to deter such patients.

CONCLUSION

26. There is a well-established and commonly understood principle that "hard cases make bad law". There can be few "harder cases" than the prospect of terminally ill patients suffering pain and distress that is capable of relief, and the compassionate desire to relieve that suffering is laudable.

27. We believe that the capabilities of modern medicine render the ending of life to prevent such suffering unnecessary. Good nursing care provides the opportunity for the patient to live the final stages of his or her life, initially approached with dread and fear, as a time for reconciliation, final family contacts and peace.

28. We believe that there is intrinsic value in all human life, at whatever stage. Respect for human life is not, however, an exclusively Catholic, Christian or even religious concept. We have sought to demonstrate that respect for life is enshrined in both the natural order and the British legal system.

29. This Bill would, if enacted, remove a vital safeguard only recently inserted by amendment to the government's own legislation, and is therefore misconceived. We are convinced that it also represents a significant departure from an underlying principle of British law and would be the likely precursor of legislation to permit the wider use of euthanasia.

30. The Association of Catholic Women strongly urges members of this Select Committee to recommend that this Bill should not proceed.

SUMMARY

1. INTRODUCTION (PARAGRAPHS 1-3)

- The Association of Catholic Women, listed in the Catholic Directory but independent of the Bishops' Conference of England and Wales, is an organisation of more than 1,000 women and men "supporters", many of whom have direct experience of the work of hospices at home and abroad.
- This response, from the Association's Steering Committee, is informed by this experience.

2. THE BILL IN THE CONTEXT OF THE NATURAL ORDER (PARAGRAPHS 4-10)

- The drive to give, preserve and cling to life is powerful; examples abound of the expectations of both medical science and common sense being defied.
- The desire to choose death is an aberration, motivated by despair, the response to which should be to seek to alleviate the pain (physical or psychological) which gives rise to it.
- To ask doctors or nurses to comply with a patient's wish to end his or her life is to ask them to deny their principal duty to the patient and to collude with the patient's despair, rather than try to treat the symptoms giving rise to it.

3. THE BILL IN THE CONTEXT OF EXISTING LEGISLATION (PARAGRAPHS 11 AND 12)

- The intrinsic value of human life has been the underlying principle of the rule of law since earliest times.
- The provisions of this Bill contravene this principle and contradict provisions recently inserted into the government's own legislation.

4. THE PRACTICAL IMPLICATIONS OF THE BILL (PARAGRAPHS 13-25)

- The provision in the title of the Bill and in Section 15, to enable a person suffering from terminal illness to receive pain relief medication, is unnecessary, in that such medication is already routinely administered to terminally ill patients whether in hospital or not.
- The "qualifying conditions" outlined in the Bill, while apparently tightly drawn, are vulnerable to gradual erosion over time, especially in view of the provision to give power to the Secretary of State to make regulations by statutory instrument.
- There is an inherent assumption in the qualifying conditions that doctors who hold a conscientious objection to assisting a patient's death will be few in number, and the requirement that they refer to another doctor who does not object makes them complicit in the action to which they hold a conscientious objection.
- The patient is not protected by the proposed monitoring arrangements; neither is the patient protected from psychological pressure to cease being a burden and to release medical and care resources.

5. CONCLUSION (PARAGRAPHS 26-30)

- The desire to alleviate the pain and suffering of terminally ill patients is laudable.
- The capabilities of modern medicine render the taking of life to prevent such suffering unnecessary; skilled nursing and palliative care can enable patients and their families to experience their final days and weeks as a positive and peaceful ending.
- The Bill represents a significant departure from an underlying principle of British law and medical ethics, and is misconceived in that it would remove a vital safeguard recently inserted by amendment to the government's own legislation.
- The Association of Catholic Women strongly urges members of this Select Committee to recommend that this Bill should not proceed.

Memorandum by the Association of Hospice and Palliative Care Chaplains

The Association of Hospice Chaplains and Palliative Care Chaplains and the College of Health Care Chaplains recently held meetings at which the Assisted Dying for the Terminally Ill Bill was discussed. Both groups felt it important to respond to the Bill.

The Assisted Dying for the Terminally Ill Bill, is an attempt to address the experience of patients living with pain and distress. As chaplains working in hospitals and hospices we have much experience of patients and families living with very real and genuine pain and distress. As members of the multi-professional team we know that many staff also experience pain and distress in caring for patients and their families.

We are unable to support this Bill because:

- Whilst we acknowledge that the Bill is based on the experience of patients it is based on the experience of a limited number of patients. A number of patients are greatly helped in their pain by the provision of holistic palliative care, which can so often enable people to re-evaluate their feelings and give hope for the life that they are still able to live.
- Many patients living with an irremediable condition feel extremely vulnerable because they are facing death and can feel they have little or no control over what happens to them. We feel that this sense of vulnerability could lead to patients making ill-informed decisions under a perceived pressure to relieve the stress of those close to them, and not to be a burden to the team of health care workers looking after them.
- The criteria and words used in the Bill are too subjective and will lead to a variety of interpretation that will be impossible to check and verify. Given that the unbearable suffering depends upon the patient self-reporting the way could be open for assisted death on demand.
- It is unacceptable that physicians or any profession should be given the power to assist anyone to actively end their life. This would be an unacceptable change of role for those working as health care providers.
- We believe that patients who consider they are experiencing unbearable suffering should experience holistic palliative care in order to give them the best quality of care that can be given to them and their families and those close to them.
- The Bill seems to indicate that palliative care is an only an alternative and not as many of use believe integral part of the National Health Service. It surely is the right of all patients with a life limiting disease to be provided with proper palliative care.
- If some physicians in hospices and hospitals were legally able to assist patients in dying it would fundamentally change the purpose of both institutions.
- If physicians can choose to not take part in assisted dying, the Bill places a duty on the physician to find someone who will assist the patient, surely this is an impossible burden on them?
- The whole notion that physicians can estimate how long before a terminal illness is likely to result in death is one fraught with difficulty. Most physicians are most reluctant to put a time frame on any terminal illness.

The Assisted Dying for the Terminally Ill Bill raises for us the following issues:

- The Bill states that patients, following a process outlined in the Bill, will be able to request the assistance of a physician in order to die (clause 1:1). However, many patients living with an irremediable condition will have been cared for—not just by a physician—but by a multi-professional team within a hospice or hospital unit. The knowledge that the physician and other members of the team (Clause 10:2) may assist a patient to die could compromise their relationship with the rest of the team who do not agree that a patient should be assisted to die. The relationship of the team with other patients could also be compromised, as patients could be anxious or confused as to the nature of care being offered. Patients and families frequently talk with each other about their illness and the care they are receiving.
- A number of words and phrases within the Bill are open to subjective interpretation such as “unbearable suffering.” (clause 2:2,d) and “terminal illness” The interpretation of “unbearable suffering” could vary from physician to physician and case to case. Patients may suffer unbearably in ways other than physical pain. The term “terminal illness” is used in the Bill for when a physician has given a prognosis of death within a few months. We know that so often such time scales prove to be wrong and more physicians seem reluctant to give them.

- Physicians may not be the appropriate people to make decisions on the criteria of suffering unbearably. It is our experience that patients, due to a number of factors, can frequently change their views as to how they feel; this can happen on a daily basis or even hour by hour.
- Physical pain is implied as a major criterion (clause 2:2,d) contributing to a patient qualifying to request assistance to die. However, patients can experience emotional, social and spiritual pain. As the concept of “pain” is open to interpretation this criterion could change.
- Active employment of physical pain control and palliative care is only mentioned as an “alternative” (clause 2:3,e) or that patients are “entitled to request . . . such medication” (clause 15). Patients should be strongly encouraged to experience the range of pain control and palliative care available to them and which should not be seen as alternative care, or something a patient has to request.
- The process set out in the Bill in order for a patient to “qualify” for assistance in dying has several stages: ensuring that a patient has made an informed decision, alternatives have been discussed and the patient’s wishes to revoke their decision. This will be a lengthy process that physicians may feel they do not have adequate time to fully resource.
- The patient is recommend to inform their next of kin if they have taken a decision to be assisted in their death (clause 9). Next of kin and families could experience many strong emotions when they know that such a decision has been taken. The family could need support from the multi-professional team. This would require a team who supported assisting patients in dying and who will have time to spend with families and friends.

We would wish the following to be considered:

- Physicians who are prepared to assist patients to die could find that the relationship of trust that they have developed with both patients and other professionals may be compromised due to the “power” that they could be seen to have in assisting a patient to choose to die.
- A patient who considers that they are a burden to their family may feel under pressure to request assistance in dying.
- When a patient has taken a decision to request assistance in dying they may find it difficult to revoke the decision for a variety of reasons.
- The decision of what is and what is not unbearable suffering is too complex for any professional to judge. The Bill does not sufficiently address how this is to be interpreted.
- There is no acknowledgement as to the impact on family and friends, and the effects on other staff and units as a whole.
- There is little research into patients’ decision making at the end of their life. Before this Bill was to become law more research in this area would be required.
- There is a need for a robust debate in regard to physician assisted suicide and euthanasia. There exists a great deal of interest in these matters and society as a whole needs an opportunity to debate these matters.

Memorandum by the British Association of Social Workers

1. The British Association of Social Workers (BASW) is the largest professional association for social workers and social care staff in the UK. The Association has 10,000 members employed in frontline, management, academic and research positions in all social work settings who share a commitment to ethical practice and the best possible standard of service for all those who require social care support.
2. The Association shares the concern expressed by the Voluntary Euthanasia Society that present UK law concerning assisted dying does not effectively serve the interests of persons challenged by terminal illness and their relatives and informal carers or those providing health, social or pastoral care to such individuals. We therefore welcome this Bill and the constructive debate it is likely to give rise to. We are pleased that the Bill embodies a statutory right to pain relief and palliative care and promotes choice. Everything possible must be done to alleviate avoidable pain and suffering.
3. This is a complex issue and debate within the Association suggests that the views of social workers mirror those found elsewhere in Britain reflecting our diverse perspectives on the sanctity of life, religion and other influences. Essentially there are three main groups, those who believe that our right to control how and where we end our lives should be paramount, those who consider that to enshrine such a right in law would give rise to unacceptable pressure on some of us to seek assistance to die prematurely when faced with terminal illness and unbearable pain and those who have not really thought through the issues. We are glad that the Bill

acknowledges that some people will remain strongly opposed to assistance to die and makes provision for conscientious objectors.

4. However, as social workers we believe that one of the most important issues is the right of all individuals to be informed and consulted about the likely course of their illness, the implications of any treatment decision and their place and manner of dying. Existing UK law militates against such dialogue with the result that significant decisions may be made by health professionals and well meaning relatives and not shared with those concerned.

5. Such occurrences and the spectre of desperate individuals either suffering in silence or traveling a distance to another jurisdiction are wholly unacceptable and therefore on balance we are inclined to support this Bill subject to rigorous testing of the proposed safeguards to minimise the possibility of unacceptable pressure being placed on any individual to opt for assistance to die when they might not otherwise have done so.

SPECIFIC COMMENTS ON THE CONTENT OF THE DRAFT BILL

Qualifying Conditions

6. We consider that the Qualifying Conditions afford reasonable safeguards to persons wishing to be assisted to die. However, we would suggest that Para. 2(2) should be reworded as follows:

“Having been informed by the patient that they wish to be assisted to die the attending physician shall:—”

Delete Paragraph (a) and (b) then becomes the new (a).

Offer of Palliative Care

7. We consider that Paragraph 3 might be extended to exclude the attending and consulting physicians from providing the specialist advice and palliative care even if they are qualified to do so.

Declaration made in Advance

8. Paragraph 4(6). We are more than a little concerned that an actively involved social worker or other social care worker may not be a member of the medical care team and despite similar considerations arising would be competent to witness the declaration. Very significant practical difficulties will arise for some terminally ill individuals in securing individuals to witness their declaration if the proposed legislation precludes those family members and professionals working most closely with them. Whilst we can appreciate that the draft legislation seeks to eliminate the possibility of conflicts of interest we do not consider such an arrangement to be unduly onerous for professional care staff or relatives. Indeed in situations where such individuals have been very actively involved in arriving at a decision it would seem logical for one of them to witness the declaration rather than somebody more independent.

9. We would suggest that the Bill should make provision for a right of appeal against a decision by the Attending or Consultant Physician that the qualifying conditions are not met.

We hope that these brief comments are helpful to the Select Committee and would be pleased to provide any additional information that may be required.

British Association of Social Workers

September 2004

Memorandum by the Catholic Union of Great Britain and the Guild of Catholic Doctors

The Joint Ethico-Medical Committee is composed of members drawn from the two parent bodies. The Catholic Union is an organisation of the Catholic laity which is not affiliated to the hierarchy but which represents the Catholic viewpoint, where relevant, in Parliamentary and legislative matters. The Guild of Catholic Doctors represents Catholic Medical Practitioners in the United Kingdom.

GENERAL COMMENTS

Euthanasia, as understood by the Catholic Church, is an act or omission which of itself or intention causes death with the purpose of eliminating suffering. Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used. Assisted suicide is included in the definition of euthanasia.

It is noteworthy that the definition of "assisted dying" given in clause 1(2) includes direct killing, ie direct euthanasia, of those unable to commit suicide. It is dishonest to give the bill a title of "assisted dying", when it is intended to allow direct euthanasia.

It is a reality that we will all die. Modern medicine has allowed most of us to live into old age, but there will come a point, whether by direct illness or by the frailty due to the degenerative process of old age, when death will be inevitable. Many accuse those who feel strongly about the sanctity of life of requiring that everything must be done to keep patients alive at all costs. This has never been a position adopted by the Catholic Church. We accept that medical procedures, which are disproportionate to any expected results or which impose an excessive burden on the patient and his family, can be refused or withdrawn so long as the normal care due to the sick person is not interrupted.

The Church has always taught that man has free will; that is the freedom to choose between what is right and what is wrong. In secular understanding free will is frequently translated as personal autonomy. However personal autonomy is not absolute. The nature of man is that we live in relationships with one another. Our actions and choices in many ways have an effect on others. Suicide by an individual affects others in many ways. This fact was recognised by the Supreme Court of America, in its memorable and rare unanimous decision of 26 June 1997, where it held that the US Constitution did not protect the right to suicide. It manifested a particular sensitivity to the fact that rarely are all those facing disability or terminal illness in equivalent situations. It said "*The State's interest goes beyond protecting the vulnerable from coercion; it extends to protecting disabled and terminally ill people from prejudice, negative and inaccurate stereotypes, and sociological indifference*".

This Bill implies we are totally autonomous individuals and that our real value lies in our ability to act and choose. By contrast, the Christian understanding assumes we are essentially not isolated individuals but persons in relationships. Indeed we are persons only in and through our relationships with other persons. Our ability to relate to and act in support of others is part of our very humanity. Appropriate medical care, supported by the moral teaching of the Christian churches, urges that life does not have to be prolonged at all costs. Individuals who competently choose to commit suicide are not legally prohibited from doing so. In respecting the freedom of an individual to commit suicide the physician has no duty to assist them. To do so would destroy the solidarity which the medical profession should have with its patients, offering them care and support during their times of difficulty.

Some years ago the Roman Catholic and Anglican Churches submitted a joint statement to the House of Lords Select Committee on this subject; "*Neither of our churches insists that a dying or seriously ill patient should be kept alive by all possible means for as long as possible. On the other hand, we don't believe that the right to personal autonomy is absolute. It is valid only when it recognises other moral values, especially the respect to human life as such whether someone else's or not.*"

There is little evidence of demand from doctors for legalisation of euthanasia. The most recent large survey was done by Doctors.net, regarded as the foremost medical Internet company in the UK. 986 medical practitioners completed it over a two-week period from 26 March to 9 April 2003. A total of 9,000 doctors were approached over this period, selected at random, and the company was assured that an 11 per cent response rate was typical of this type of Internet study. It revealed that a majority of doctors are not in favour of either euthanasia (61 per cent) or assisted suicide (60 per cent). Only 22 per cent of doctors were in favour of euthanasia and only 25 per cent were in favour of assisted suicide. A significant number (13 per cent) were undecided, mainly because they were not directly involved in the decision-making process. Most doctors would refuse to perform either euthanasia (76 per cent) or assisted suicide (74 per cent) if it were legalised.

The case for the decriminalisation of euthanasia has been reduced by the success of the hospice movement. 98 per cent of terminal pain can now be relieved. The emphasis of the proponents of euthanasia and assisted suicide has therefore shifted to the other forms of suffering experienced by some at the end of life. Surveys have shown that most people who request assisted suicide are lonely and not always terminally ill. (*New England Journal of Medicine* 1999: 340; 577-583.)

We have seen in the *Dianne Pretty* judgement in 2003, that there is no "right to die", least of all at the hand of another. All the judges were unanimous, at appeal, in the House of Lords and in Strasbourg, in denying the applicant's request that her husband be not prosecuted for assisting her suicide. Their reasons are voluminous and we trust that the Select Committee will review them.

SPECIFIC COMMENTS*Opening paragraph*

This includes the phrase “... and to make provision for a person suffering from a terminal illness to receive pain relief medication.” Symptom relief is part of normal medical care, and has been since medicine was first practised in ancient times. Its inclusion in this Bill implies that doctors are being negligent in not providing adequate care. There is absolutely no need for such a phrase to appear in any new legislation, and especially not in any legislation relating to euthanasia.

Clause 2 (Qualifying conditions)

Prognosis is not an exact science and there can be no such certainty regarding prognosis as the Bill presumes. Even diagnosis can be uncertain, as has been shown repeatedly in post mortem studies worldwide, where the cause of death given on the death certificate was found to be incorrect in around 25 per cent of cases.

Unbearable suffering cannot be objectively assessed and is therefore a subjective assessment. Furthermore acceptance by a physician that suffering is unbearable and sufficient to warrant euthanasia is tacit recognition that a patient's life is no longer of value. Such value judgements of the worthiness of an individual's life will do great harm to the relationship of trust and caring that must exist between patients and their doctors.

Clause 3 (Offer of palliative care)

We are not persuaded that *bona fide* professionals in the field of palliative care would undertake the tasks envisioned, given that one outcome is the antithesis of their ethic. Last year the World Medical Association in its Washington conference advised all doctors to avoid co-operating with euthanasia, even in jurisdictions where it is legal.

Clause 4 (Declarations made in advance)

Despite the conditions, there is no way to ascertain that the patient is making the request freely and that they are not being coerced to do so by relatives or others. The medical profession can experience difficulty assessing a patient's mental state, so how is a solicitor to determine that a patient is of sound mind?

Clause 7 (Duties of physicians, and conscientious objection)

This clause, despite its wording, does not grant conscientious objection. It is recognised in law that a person who commissions another to commit a crime is not innocent but guilty by their complicity. So it is morally. A person who cannot perform an act, but passes the patient onto others in the knowledge that they will perform the act is morally equally culpable of that act. Those who hold convictions about the immorality of euthanasia will be unable to comply with this Act as they will not be able, in conscience, to refer the patient onto other willing physicians. To refer a patient to another physician for euthanasia would be acting against one's conscience. The right to practise in accordance with one's conscience or religious belief is protected under article 9 of the Human Rights Act.

Clause 8 (Psychiatric referral)

A single psychiatrist cannot resolve the question of competence, in the manner suggested. The *Mental Capacity Bill* makes this abundantly clear. Capacity varies with time and the nature of decision under consideration.

Clause 10 (Protection for physicians and other medical personnel)

We read this whole section with great anxiety as it seeks to protect medical teams and doctors rather than the patient. It is the complete reverse of current good practice. It would in many ways put the doctor outside legal control. We fear that this is one of the purposes of the whole Bill, to protect the doctor and not the patient.

Clause 11 (Offences)

Given the other weaknesses in the Bill, we are not convinced that these provisions are as protective as they seem, for example diagnosis and prognosis are notoriously difficult, and assessment of the unbearability of suffering is subjective. What are the criteria to be used for judging that a declaration was false? As we have seen with the 1967 Abortion Act doctors “acting in good faith” can lead to almost any falsification. Who really believes that the 180,000 women who annually have abortions on psychiatric grounds were suffering from the stated depression or neurotic illness given as the medical reason for their abortions?

Clause 15 (Administration of drugs to patients suffering severe distress)

This clause is completely unnecessary. Not only is this practice lawful, it is standard medical practice for doctors to ask their patients about pain and distress, and give appropriate medication.

Clause 16

The powers given to the Secretary of State to make regulations would give scope for far reaching variations, well beyond the intentions of Parliament. As the outcome of changes to such regulations will control the outcome of death for individuals, it is inappropriate that any such changes should be exercised by Statutory Instrument. The reality is that any changes would be recommendations of an appointed unelected commission, all of whom would favour euthanasia.

CONCLUSION

We sincerely hope that the Committee will examine the reasons put forward, by the House of Lords Select Committee on Medical Ethics in 1994, against euthanasia and reach the same conclusion. The conclusions of the 1994 report of the House of Lord Select Committee on Medical Ethics are equally valid today as then.

2 September 2004

Memorandum by the Christian Medical Fellowship

INTRODUCTION

The Christian Medical Fellowship (CMF) is an interdenominational organisation with more than 4,500 members. The membership comprises British doctors who are Christians and who desire their professional and personal lives to be governed by the Christian faith as revealed in the Bible. Members practise in all branches of the profession, and through the International Christian Medical and Dental Association are linked with like-minded colleagues in over 100 other countries.

CMF regularly makes submissions on ethical matters to Government committees and submitted evidence to the 1993 Lords Select Committee on Medical Ethics.¹ We have also published widely on the subjects of euthanasia and assisted suicide (please see our website at www.cmf.org.uk and our CMF Files on *Euthanasia*² and *Assisted Suicide*³). We are grateful for this opportunity to comment on the difficult issues raised by the Assisted Dying for the Terminally Ill Bill and would be very willing to give oral evidence to the Select Committee if invited.

Our submission is divided into two sections. The first addresses our general concerns about the legalisation of assisted dying. The second addresses specific elements of the Assisted Dying for the Terminally Ill Bill. Our conclusion is that euthanasia and assisted suicide should not be legalised and that this bill should not proceed.

SECTION ONE

General concerns about the legalisation of assisted dying

In the terms of the bill assisted dying means the attending physician either providing the means to end the patient's life, or if the patient is physically unable to do so ending the patient's life. This bill if passed would

¹ www.cmf.org.uk/ethics/submissions/euth_sub.htm

² www.cmf.org.uk/cmffiles/euthanasia.htm

³ www.cmf.org.uk/cmffiles/pas.htm

therefore legalise both assisted suicide and euthanasia. The arguments against euthanasia and assisted suicide are essentially the same. We have used the term “assisted dying” to encompass both practices, and have outlined below our objections to the major arguments in their favour.

1. THE ARGUMENT FOR ASSISTED DYING FROM AUTONOMY

One of the major arguments in favour of assisted dying is that of autonomy, the so-called “right to die”. We all value living in a free society but for society to function there must be limits on individual autonomy. Rights need protection, but must be balanced against responsibilities and the rights of others. No person chooses assisted dying in isolation. Friends, relatives, healthcare staff and society are affected by the wider ramifications of the process. The effects of individual decisions on others now living and on future generations must be considered. Autonomy is never as uncomplicated as “my right to die”. Therefore although we recognise the importance of autonomy we have the following concerns in relation to this bill.

1.1 *The “right to die” will change the role and vision of the medical profession*

Legalisation of assisted dying will present legalised killing as a potential good rather than a fundamental harm for the first time. It will establish killing as a viable “therapeutic option” that, if deemed valid in some cases, will need to be considered in all cases. This will fundamentally change the whole ethos of medicine. As a profession, and as a society, we have always seen the wish to die, for example in the suicidal person, as a cry for help, an indication that something is wrong that needs to be addressed. The medical profession has been built on seeking ways to relieve suffering, treat illness and preserve life; to restore dignity and hope. This bill changes the role of doctors and the doctor-patient relationship by introducing the option of doctors killing their patients.

Calls for assisted dying have been encouraged either by the failure of doctors to provide adequate symptom control, or by their provision of inappropriate interventions which neither lengthen life nor improve its quality. This has understandably provoked distrust of doctors by patients. However, legalising assisted dying is not the answer to this problem. Patients’ fears of being kept alive by futile medicine will be replaced by the fear of being killed prematurely without their consent.⁴ Rather what is needed is a relationship of trust, where the role of the doctor is to assist the patient in being in control of what happens. Patients want above all a doctor who will listen to them, take their concerns seriously, explain the options clearly and respect their wishes; a doctor who will strive to offer the best care available. This is what lies at the heart of the doctor-patient relationship. This is the way to calm patients’ fears, and restore autonomy.

1.2 *The “right to die” will in reality be the right to be killed and will increase the power of the medical profession not the autonomy of the patient*

In the Netherlands, some 30 per cent of euthanasia requests are rejected by doctors on the basis that the patient’s suffering is not sufficiently severe.⁵ Conversely, approximately 1,000 deaths (0.8 per cent of the total) are due to patients being killed against their wishes or without explicit consent.⁶ The bill requires a doctor to make a judgement about the patient’s request. Ultimately it is the doctor’s assessment of diagnosis, treatment options, prognosis and the anticipated degree of future suffering that is the decisive factor, not the patient’s autonomy.

Assisted dying legislation makes doctors less accountable and more powerful. Patients decide on the basis of information given to them by doctors. However it can be difficult to be certain in these areas; diagnoses may be mistaken,⁷ prognoses misjudged, there may be new treatments of which the doctor is unaware, the doctor may not be up-to-date in symptom control. Furthermore, doctors are human and subject to temptation. Sometimes their own decision-making may be affected, consciously or unconsciously, by extrinsic pressures and influences, such as their own emotional state, discussion with family members and the views of other health care professionals.

⁴ For example: *Burke, R (on the application of) v The General Medical Council* Rev 1 [2004] EWHC 1879 (Admin) (30 July 2004).

⁵ Jochemson H and Keown J. Voluntary euthanasia under control? Further empirical evidence from the Netherlands. *JME* 1999;25:16-21.

⁶ Onwuteaka-Philipsen BD *et al.* Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995 and 2001. *Lancet* 2003; 362: 395-9.

⁷ Rees W *et al.* “Patients with Terminal Cancer” who have neither terminal illness nor cancer. *BMJ* 1987;295:318-9.

1.3 *The “right to die” puts vulnerable patients at risk*

The law is always concerned to protect vulnerable groups in our society. The Select Committee on Medical Ethics, in its 1994 report, unanimously ruled that there should be no change in the law.⁸ Lord Walton reflected on this in a speech to the House of Lords on 9 May 1994:

“We concluded that it was virtually impossible to ensure that all acts of euthanasia were truly voluntary and that any liberalisation of the law in the United Kingdom could not be abused. We were also concerned that vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death.”

This conclusion still holds.

1.4 *The “right to die” simplifies the difficulties in ensuring a decision is truly autonomous*

Many patients with a terminal illness are vulnerable and lack the knowledge and skills to alleviate their own symptoms. They may well be fearful about the future and anxious about the effect their illness is having on others. Their decision-making may also be affected by depression, confusion, and dementia. There are many anecdotal accounts of patients who, on admission to a hospice, say “let me die”, but are grateful that their request was not acceded to once they have received effective symptom relief.

Many elderly people already feel a burden to family, carers and a society which is cost conscious and short of resources. They may feel pressure, real or imagined, to request assisted dying. As has been noted elsewhere, “A sense of a duty to die is all too easy to create and all too difficult to detect.”⁹ These patients need to hear that they are valued and loved. They need to know that we, as doctors and as a society, are committed to their well-being, even if this does involve expenditure of time and money.

In the 2002 study by Kelly *et al*¹⁰ there is an acknowledgment that “the wish to hasten death has been shown to be temporally unstable, raising concerns about assisting a patient’s request for suicide at any particular point in their illness.” Poor communication, lack of emotional support from doctors and a concern that the patient was a burden to others were associated with a greater desire for a hastened death. Where these factors were absent there was a low likelihood of a patient expressing an interest in an accelerated death.

The desire for death is most significantly correlated with measures of depression in terminally ill patients.¹¹ Yet nearly 80 per cent of psychological and psychiatric morbidity in patients with cancer goes unrecognised and untreated.¹² It is important that efforts are focussed on addressing these issues in patients. The debate about assisted dying must recognise the importance of psychiatric conditions—which are potentially treatable—and that a patient’s desire to die will often decrease over time. While we recognise that certain mental stresses are not treatable—existential angst, loss of dignity, fear of the dying process—these factors are not medical as such, and do not warrant a “medical” solution in the form of assisted dying. The spiritual and emotional nature of these issues may require the input of people from outside the medical profession. Doctors cannot be expected to be pastors and counsellors; they are not necessarily equipped to address the many needs behind a patient’s expressed wish to die. Allowing them to kill patients is not the answer to that problem.

1.5 *The “right to die” is the “choice” mainly of those who are well not those who are terminally ill*

In Emanuel *et al*.¹³ 60 per cent of the terminally ill respondents supported euthanasia in a hypothetical situation involving others, but only 10 per cent seriously considered euthanasia for themselves. Less than 4 per cent had discussed these interventions with a physician or hoarded drugs for suicide and a very small minority of patients took concrete action such as requesting assistance to die. The paper concludes that patients’ personal interest in assisted dying is not a stable preference but may shift over time.

Interest in assisted dying is far less in the terminally ill than in the general population (if surveys that cite 81 per cent support for it amongst the public are to be believed¹⁴) and it cannot be assumed that a desire for assisted dying at one point in time will remain as death actually approaches.

⁸ Select Committee on Medical Ethics. Report. London: HMSO, 1994. (House of Lords paper 21-I).

⁹ Baroness Finlay of Llandaff. Hansard[HL]; 6 June 2003 at 1599.

¹⁰ Kelly B *et al*. Terminally ill cancer patients’ wish to hasten death. *Pall Med* 2002;16: 339–345. Lord Joffe referred to this research in his 2003 House of Lords briefing paper.

¹¹ Chochinov HM *et al*. Desire for death in the terminally ill. *Am J Psychiatry* 1995;152: 1185–1191.

¹² Maguire P. Improving the detection of psychiatric problems in cancer patients. *Soc Sci Med* 1985;20: 819–23.

¹³ Emanuel EJ *et al*. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000;284: 2460–2468.

¹⁴ See for example www.ves.org.uk/publicopinion.html

1.6 *The “right to die” of the few may open the door to a slippery slope that puts the vulnerable at risk*

The “slippery slope” is a contentious issue, but we believe a real one. Human nature seems such that it will push beyond what lawmakers originally intend. For example, those who framed the 1967 Abortion Act did not envisage the abortion on demand practices of the 21st century. Would a similar slippery slope follow the legalisation of assisted dying? There is no evidence to prove it would not. Without entering the philosophical debate, we are greatly concerned by aspects of the Dutch practice of euthanasia.

Philosophically it is hard to limit assisted dying to just those who are terminally ill. If relief of unbearable suffering is the aim then why not extend it to other patient groups who are suffering unbearably? To refuse assisted dying for patients who are not terminally ill but with similar symptoms could be seen as discriminatory. And why just limit it to patients who can request assisted dying? Surely it would be “bad practice” and “uncompassionate” to see someone suffering unbearably but not to offer them assisted dying because they were unable to request it themselves.

The Royal Dutch Medical Association (KNMG) and the Dutch Commission for the Acceptability of Life Terminating Action have recommended that active termination of the lives of patients suffering from dementia is morally acceptable under certain conditions. Two earlier reports from the commission affirmed the acceptability of similar action for severely handicapped neonates and comatose patients.^{15,16} A study of Dutch neonatal doctors showed that just under half had assisted the death of a handicapped newborn child, despite this situation being outside the euthanasia legislation.¹⁷ Case reports include a child killed for no other reason than it possessed abnormal genitalia and a woman killed at her own request for reasons of “mental suffering”.¹⁸

Involuntary euthanasia will happen, regardless of the intentions of the legislators. According to the first Rummelink Report,¹⁹ there were over 3,000 deaths from euthanasia in the Netherlands in 1990. More than 1,000 of these (0.8 per cent of all deaths) were without an explicit request from the patient. The most recent figures show that the problem persists.^{20,21} Furthermore, the lack of full reporting indicated in the third “Rummelink” report is a major cause for concern and would invalidate the reliability of any monitoring commission that might be set up.²²

1.7 *Autonomy is not the real question—it is the issue of compassion*

If patient autonomy were the only yardstick by which decisions are measured, assisted dying would effectively be on demand. Furthermore we would agree that anyone who wanted to die, for whatever reason, has the right to do so. Clearly it is not just the desire to die but the suffering of the terminally ill that is driving this debate—the argument is that it is compassionate to end the patient’s life if their suffering is severe. This is no longer an argument from autonomy but from compassion.

2. THE ARGUMENT FOR ASSISTED DYING FROM COMPASSION

This argument accepts that killing can be compassionate and thus changes fundamentally the values of our society and the medical profession. In the UK we have had up to now a different definition, based in the Judeo-Christian tradition, of what it means to be compassionate: “to suffer with” (com-passion). Our nation has prided itself on developing ways to care for the terminally ill that have been envied the world over. Hundreds of doctors from abroad every year come to see how British palliative care has developed new and creative ways of relieving suffering, restoring dignity and hope to the dying. This bill would undermine the efforts of so many dedicated NHS and Hospice staff to continue to provide the personally costly service of caring for the dying.

Advances in palliative medicine mean that many of the unpleasant symptoms experienced during terminal illness can be relieved or substantially alleviated. We acknowledge that palliative care doesn’t work for every patient. Experience in the hospice movement has shown, however, that restoration of dignity through creative care is possible for the vast majority.

¹⁵ Hellema H. Dutch doctors support life termination in dementia. *BMJ* 1993; 306:1364.

¹⁶ Sheldon T. Judges make historic ruling on euthanasia. *BMJ* 1994; 309:7-8.

¹⁷ van der Heide A *et al.* Medical end-of-life decisions made for neonates and infants in the Netherlands. *Lancet* 1997; 350(9073):251-5.

¹⁸ Dutch doctors pushed on to “slippery slope” over euthanasia. *Independent* 1993; Wednesday 17 February p 8.

¹⁹ van der Maas PJ *et al.* Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991; 338:669-74.

²⁰ Onwuteaka-Philipsen BD *et al.* Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995 and 2001. *Lancet* 2003; 362:395-9.

²¹ Hendin H *et al.* Physician-assisted suicide and euthanasia in the Netherlands. *JAMA* 1997; 277:1720-2.

²² Sheldon T. Only half of Dutch doctors report euthanasia, study says. *BMJ* 2003; 326:1164.

Regrettably such a standard of care is not yet available to every dying patient. The recent report of the Commons Health Committee on palliative care recommended that more should be done to develop palliative care and improve accessibility. The disparities in regional distribution of services also need to be addressed and effective training made more widely available.

A study of over 1,000 doctors, nurses and social workers showed a negative correlation between willingness to endorse assisted suicide and knowledge of symptom management.²³ If assisted dying is legalised, the incentive for creative caring will decrease. Additionally, where doctors do not have good knowledge of symptom management, there will be an increased tendency to see death as the “treatment” of choice.

The European Association for Palliative Care has re-affirmed its opposition to the legalisation of euthanasia.²⁴ If care is aimed at achieving “the best possible quality of life for patients and their families” by focusing on a patient’s physical, psychosocial, and spiritual suffering, requests for assisted dying are extremely uncommon. The answer is not to change the law, but rather to improve our standards of care.

SECTION TWO

Specific critique of the bill

1. The definition of “terminal illness” in section 1(2)²⁵—does it include only illness that despite treatment would result inevitably in the patient’s death within a few months (eg. disseminated cancer, motor neurone disease etc), or does it include illness that would result inevitably in the patient’s death within a few months if not treated (eg severe asthma, COPD, diabetes, many infections, congestive heart failure, peritonitis, severe psychoses, some chronic inflammatory conditions, anorexia etc)? A patient with one of these latter conditions might argue that they did not want to be treated, and that by virtue of then having a “terminal condition” might request assisted dying.

The state of Idaho in 1977 passed a law defining a terminal condition as “an incurable physical condition caused by disease or illness which . . . shortens the life of the patient.” This could include almost any medical condition. Dr Jack Kevorkian’s definition was “any disease that curtails life even for a day.”

2. The definition of “unbearable suffering”²⁶ is not objectively defined. Some patients find symptoms that most consider tolerable to be unacceptable.

3. Section 7 introduces a legal obligation for doctors with a conscientious objection to refer any patient requesting assisted dying to doctors with no conscientious objection. This amounts to forced complicity, and presumably those who refuse to comply are thereby committing an offence under the Act?

4. Section 7(2), whereby an attending physician who conscientiously objects, is obliged to refer the patient to another attending physician makes a mockery of the definition of attending physician given in the bill as the doctor who has “primary responsibility for the care of the patient”.

5. The fact that assisted dying can be carried out on the authority of two doctors without any further review or appeal until after the patient is dead (section 13(2)) virtually ensures that anyone requesting assisted dying persistently enough will eventually receive it.

6. Under the bill there is no need for the four people involved in the assisted suicide process to have met the patient before and only the solicitor and witness have to satisfy themselves of his/her identity. The laxity of these provisions will encourage the foundation of special clinics to streamline the process, providing the requisite personnel and allowing completion of the declaration in a single visit, with a further visit two weeks later for the assisted dying procedure.

7. Psychiatric referrals (section 8) to assess whether the patient is suffering from a psychiatric or psychological condition causing impaired judgement are only required under the Act if in the opinion of the attending or consultant physician the patient may not be competent. But the attending or consultant physician may lack the skill to assess competence or impaired judgement, especially if the latter is secondary to depression.

²³ Portenoy RK *et al.* Determinants of the willingness to endorse assisted suicide. A survey of physicians, nurses and social workers. *Psychosomatics* 1997; 38:277-87.

²⁴ Materstvedt LJ. Palliative care on the “slippery slope” towards euthanasia? *Pall Med* 2003; 17:387-92.

²⁵ “terminal illness” means an illness which in the opinion of the consulting physician is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will be likely to result in the patient’s death within a few months at most.

²⁶ “unbearable suffering” means suffering whether by reason of pain or otherwise which the patient finds so severe as to be unacceptable and results from the patient’s terminal illness.

8. Doctors are protected from prosecution under the Act (section 10(1-2)) if they are acting in “good faith”. In other words, if the doctor believes that he/she is right in deciding that the patient fulfils the statutory criteria, they cannot be prosecuted. This makes nonsense of basic legal principles where the clinical or legal judgement of any doctor must be subject to objective independent assessment and scrutiny.

9. All historical ethical codes (eg Hippocratic Oath, Declaration of Geneva, International Code of Medical Ethics, WMA Statement of Marbella) declare euthanasia and assisted suicide to be unethical. It follows logically that all doctors who perform or assist in either euthanasia or assisted suicide are in breach of those oaths and declarations. Section 10(3) is therefore nonsense. It also undermines the medical profession’s right and responsibility to regulate the behaviour of its own members in this matter.

10. Wilful falsification or forgery of a declaration made with the intent of causing a patient’s death (section 11(1)) will in the main prove impossible to establish because the key witness, the patient, will be dead. The same holds for witness statements.

11. Section 12 will encourage patients choosing assisted suicide or euthanasia in order to benefit their immediate families. It will also place huge pressure on patients to request early death in order that their families might benefit from insurance money, rather than being faced with medical fees for ongoing care.

12. Sending a copy of the file to the monitoring committee after euthanasia has been performed means that suspicious cases cannot be investigated prior to the death of the patient. Furthermore, section 16(1) gives the Secretary of State authority to dispense with record keeping about euthanasia altogether.

13. The declaration form contains no place for the signatures of attending and consulting physician.

14. Although this bill only seeks to establish euthanasia or assisted suicide as a right for competent adult patients, that may prove unsustainable. Once the Mental Capacity Bill comes into law there will be nothing to stop a patient enacting an advance directive for this “treatment option” should they become incompetent and develop “unbearable suffering” according to their own definition.

CONCLUSION

The above facts and arguments lead to the conclusion that:

1. Euthanasia and assisted suicide should not be legalised.
2. The proposed bill is fundamentally flawed and would substantially change the way medicine is practised in this country.
3. The bill should not proceed.

August 2004

Memorandum by The End-of-Life Care Research Group, Vrije Universiteit Brussels

1. THE END-OF-LIFE CARE RESEARCH GROUP

- The research programme of the End-of-life Care Research Group of the Vrije Universiteit Brussel consists of two inter-related research areas. The first is the needs and quality of palliative terminal care (PTC). The second is medical end-of-life decisions (ELDs) that effectively or potentially shorten the life of patients (eg voluntary euthanasia, physician-assisted suicide, alleviation of pain and symptoms with a potential life shortening effect, withholding or withdrawing of life prolonging treatment, etc).
- The programme includes clinical and epidemiological studies involving the interdisciplinary study of PTC and ELDs. The programme builds on a line of research on end-of-life decisions that has been carried out over the past six years and resulted in many publications in eg *Bioethics*, *Palliative Medicine* and *The Lancet*.
- Main topics of the research programme are medical practice at the end of life in Flanders, Belgium; the involvement of different caregivers; the decisions making process; and international comparative studies.
- I can provide a full CV of all my work and publications on request.

2. THE IMPORTANCE OF THE END-OF-LIFE CARE RESEARCH GROUP

- Over the past decades, more than ever, end-of-life care has attracted the interest of the public, policy makers, and healthcare professionals. Many factors have contributed to this. In all developed

countries, ageing of the population has resulted in a growing need for geriatric care in general and specifically end-of-life care, since this groups accounts for the vast majority of decedents. In addition there has been a growing recognition in many countries that end of life care is less than optimal.

- Many dying patients still experience pain and other symptoms, considerably limiting the quality of their remaining lifetime. Because of for example, “morphinofobia”, there are indications that all too often physicians withhold sufficient pain medication for dying patients.³⁶
- There is a sense that the health care systems have failed to educate health care professionals to provided the adequate services to ensure good care for the dying.
- Moreover, the intensive discussion about voluntary euthanasia and physician-assisted death has focused attention on the care of the dying and the factors that might spur a patient to request administration of drugs to hasten death.
- In Belgium, uniquely in the world, the regulation of voluntary euthanasia and the expansion of palliative care were intimately connected, and co-evolved synergistically.

3. TWO IMPORTANT STUDIES FOR THE SELECT COMMITTEE TO CONSIDER

- As an experienced researcher in the area of palliative terminal care (PTC) and end of life decisions (ELDs), I am a privileged observer of the relevant societal and legal developments on the issue.
- For this submission there are two research studies I have been involved in that I would like to highlight. I attach both these research papers to this memorandum for your attention.

4. STUDY 1: END OF LIFE DECISIONS IN MEDICAL PRACTICE IN FLANDERS, BELGIUM: A NATIONWIDE STUDY (DELIENS *et al* 2000)³⁷

- This study examined death certificates relating to about 2,000 deaths in Flanders, Belgium—before legislation for voluntary euthanasia came into force.
- We found that the estimated incidence of voluntary euthanasia in medical practice in Flanders at this time was 1.1 per cent of all yearly deaths.
- We concluded from this study that despite voluntary euthanasia being considered murder under criminal law, it did exist.
- There is some concern about the pressures that vulnerable people would be exposed to if voluntary euthanasia were to be legalised. Netherlands data shows that there is no evidence for this argument.³⁸
- In addition, our study found that voluntary euthanasia was practiced significantly more often among higher educated patients than among lower educated ones. This data suggests that contrary to concerns about the so called “slippery slope”, social inequalities of the traditional sense also exist within voluntary euthanasia practice.
- The rate of termination of life without explicit request was far higher in this study (3.2 per cent) than in the Netherlands (0.7 per cent).³⁹
- In this study we concluded that if anything, regulation of voluntary euthanasia appears to be associated with a reduction of ethically dubious practices of life termination. This is perhaps because less attention is given to those requirements of careful end of life practice in a society with a restrictive approach than in one with an open approach that tolerates and regulates voluntary euthanasia and physician-assisted suicide.

5. STUDY 2: END OF LIFE DECISION-MAKING IN SIX EUROPEAN COUNTRIES: DESCRIPTIVE STUDY (VAN DER HEIDE *et al* 2003)⁴⁰

- This study involved a European comparison of ELDs across six countries: the Netherlands, Belgium, Switzerland, Italy, Sweden and Denmark.

³⁶ Deliens L, Ganzini L, Vander Stichele R, The use of drugs to hasten death. *Pharmacoepidemiology and Drug Safety* 2004; 13, 113–115.

³⁷ Deliens L, Mortier F, Bilson J, Cosyns M, Vander Stichele R, Vanoverloop J, Ingels K, End-of-life decisions in medical practice in Flanders, Belgium: A nationwide survey. *The Lancet* 2000; 356: 1806–1811.

³⁸ Onwuteaka-Philipsen BD, van der Heide A, Koper D, Keij-Deerenberg I, Rietjens JA, Rurup ML, Vrakking AM, Georges JJ, Muller MT, van der Wal G, van der Maas PJ, Voluntary euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995 and 2001. *The Lancet* 2003; 362: 395–399.

³⁹ Onwuteaka-Philipsen BD *et al Lancet* 2003.

⁴⁰ van der Heide A, Deliens L, Faisst K, Nilstun T, Norup M, Paci E, van der Wal G, van der Maas PJ, End-of-life decision-making in six European countries: descriptive study. *The Lancet* 2003; 362: 345–350.

- Data showed that the Netherlands (followed by Belgium and Switzerland) consistently had the best communication between physicians and their patients and families concerning ELDs. This highlights the benefits of an open and transparent system with regards to ELDs.
- In this study, 92 per cent of ELDs in the Netherlands were discussed with competent patients; followed by 78 per cent in Switzerland and 67 per cent in Belgium. This is compared to Denmark (58 per cent), Italy (42 per cent) and Sweden (38 per cent)—countries that have a restrictive approach to voluntary euthanasia and physician-assisted suicide.
- Where a patient was incompetent, 85 per cent of physicians in the Netherlands. (77 per cent in Belgium) discussed end of life decisions (including but not exclusive to life termination without explicit request) with relatives. This compares to only 39 per cent of cases in Sweden and Italy and 52 per cent of cases in Denmark.
- This study also serves to show, again, that the slippery slope has not occurred in the Netherlands. In this study, in all countries—except the Netherlands—termination of life without explicit request happened more frequently than voluntary euthanasia and physician-assisted suicide.

6. TO CONCLUDE

- One of the important motivations for legally regulating voluntary euthanasia in Belgium was the high ratio between rates of life termination without explicit request and voluntary euthanasia (3.2 per cent of all deaths compared to 1.1 per cent for voluntary euthanasia).
- It is my conclusion that the question should be not whether voluntary euthanasia is to be part of end-of-life care (for, whether the practice is legislated for or not, it already is), but how it is practiced and integrated into end-of-life care.
- In Belgium, where voluntary euthanasia now has legislation, the focus of the debate has moved from an ethical and ideological debate towards the development of requirements of prudent practice and of guidelines for good medical practice at the end of life.
- Should you wish to discuss these issues with me further, please contact me at the above postal or email address.

August 2004

Memorandum by Friends at The End

1. THE FACTS OF DEATH

1.1 The dying process often means a lot of pain and distress to ourselves and to those around us. This escapes general attention not only because death today tends to be a very private matter, but because in popular films and conventional literature people are depicted as dying serenely in bed surrounded by their loved ones, or suddenly as if felled by a blow.

1.2 The reality is often very different. Unless a massive stroke or other sudden event carries us off, we are most likely to suffer from a variety of extremely unpleasant symptoms which are repellent to ourselves and to others.

1.3 Within a medical framework death is often seen as a failure by medical practitioners and a struggle goes on to postpone death as long as possible whatever the embarrassment and suffering.

1.4 Often sedation is used instead of painkillers and even hospices do not always understand that the patient would prefer not to endure the last hours, days, weeks, or even months provided by modern medicine.

1.5 Accounts of the deaths of Jo Shearer and Shirley Nolan are provided in Appendix 1.

2. FRIENDS AT THE END

Friends at the End is an organisation committed to promoting knowledge about the facts of death and end-of-life choices. It is an educational and caring society which maintains that each of us is entitled to personal choice and its members range in age from as young as 22 to some over 90 years old.

2.1 *Its purposes*

2.1.1 In terms of its Constitution (Appendix 2) its principal purposes are:—

- (a) to promote knowledge about end-of-life choices and dignified death; and
- (b) to support those concerned about end-of-life choices and dignified death and to support those suffering from distress, especially that associated with the end of life; and
- (c) to advance medical education relevant to the processes of death and terminal illnesses; and
- (d) in furtherance thereof to fund research into the causes, cures and prevention of distress in the dying and those caring for them and to publicly disseminate the outcome of such research; and
- (e) to act along with others in pursuit of the above, and its subsidiary purposes are all things reasonably conceived to bring about or advance the foregoing.

2.2 *Its activities*

2.2.1 Friends at the End meet in Glasgow on Saturday afternoons three times a year with a wide variety of speakers, sometimes doctors, nurses, health care professionals, sometimes speakers with a personal experience to relate. The gatherings are very friendly and relaxed, and question-time is always lively. We have a Newsletter full of topical information of interest and full reports of our meetings and activities. Readers are welcome to write about any issues surrounding a good and peaceful death.

2.2.2 We provide speakers for secondary school classes in ethics and for any other gatherings.

2.2.3 Information is provided on many topics including

- 2.2.3.1 Living Wills (also called Advance Directives) with sample forms (See Appendix 3).
- 2.2.3.2 Scottish Welfare Powers of Attorney (See Appendix 4).
- 2.2.3.3 Sample Do Not Attempt Resuscitation forms.
- 2.2.3.4 NHS Trusts' policies on Living Wills and Do Not Attempt Resuscitation instructions.

2.2.4 We provide an advice and counselling service for those suffering distress caring for the dying.

3. ASSISTED SUICIDE AND VOLUNTARY EUTHANASIA: ARGUMENTS AGAINST AND FOR IT

3.1 *Background*

3.1.1 Suicide has never been illegal in Scotland and has been allowed in the rest of the UK since 1961, but it is a crime for anyone else to be involved. This means that if you are too ill or disabled to take your own life, the person who helps you can be charged with murder.

3.1.2 Some people suffer greatly before the end comes. Care for the dying has improved a lot in recent years, but medical technology has also enabled life to be extended even when the person is past being able to enjoy it. We believe that we should be able to ask for help when we feel we have suffered enough.

3.1.3 Opposition to voluntary euthanasia comes mainly from those with religious convictions who say they believe life is a gift from God and is therefore sacred. Other arguments are used to support these views but the fundamental one is the “sanctity of life”.

3.2 *Arguments against assisted suicide and voluntary euthanasia*

3.2.1 **THE SANCTITY OF LIFE** This phrase has little meaning unless both “sanctity” and “life” are defined. Sanctity means “sacredness”, something that must not be interfered with, but to us life is a continuum. It starts with the egg and the sperm which are biologically programmed to be lost in their hundreds and millions throughout the lifetime of the individual; on to the embryo; the foetus; the infant; the child; the man and woman, to the “lean and slippered pantaloons, sans eyes, sans teeth, sans everything”; as Shakespeare so graphically put it. Brainless old age is what we all fear but it is possible to lose one’s “biographical life”, one’s individual personality, in childhood or adolescence as Tony Bland did. He lay in a Persistent Vegetative State (his brain was so damaged that he was always in a coma) as a result of the Hillsborough football disaster. The House of Lords decided that his biological life could be ended—four years after the tragedy.

- 3.2.2 **UNNECESSARY AND UNNATURAL** Palliative care is so good that life can end “naturally” with the minimum of suffering. This is not true as will be shown in the “Arguments For”. Some people die in intensive care, being fed intravenously, attached to a ventilator with tubes coming out of every orifice. How can this be regarded as natural?
- 3.2.3 **THE SLIPPERY SLOPE** Once euthanasia is legalised it will open the door to abuse and will allow unscrupulous relatives to put the elderly and infirm to death, like Hitler did. Old people will feel pressurised to ask for euthanasia so that they are not a burden. Evidence for this view is often misquoted: a survey of deaths in the Netherlands in 1991 (the Rummelink Report) showed that 2.5 per cent of all deaths were by euthanasia; a second (1996) and third Report (2001) came up with the same 2.5 per cent figure.
- 3.2.4 **DOCTORS MUST PRESERVE LIFE** They have sworn the Hippocratic oath—the trust between them and their patients would be destroyed if they were allowed to perform euthanasia or Physician-Assisted-Suicide (PAS). Few doctors practising today have been asked to swear this ancient Greek oath, but they do have a professional duty to care for their patients to the best of their ability with compassion and skill.

3.3 *Arguments for assisted suicide and voluntary euthanasia*

- 3.3.1 **CHOICE** We can now choose our partner, when to have a child, and whether to continue with an unplanned pregnancy. We have the right to accept, or refuse, medical treatment. We should have the same right to decide when and where to die. The present law is based on traditional beliefs which are no longer held by many UK citizens and should not be imposed on those who do not share them.
- 3.3.2 **TERMINAL SUFFERING** Even with the best palliative care, between 5 per cent and 10 per cent of those dying cannot have their suffering adequately relieved. Pain is often a major problem, but not the only one—nausea, vomiting, coughing, breathlessness, incontinence, and other horrible symptoms which can be difficult to treat. Severe weakness and total dependence on others are inevitable and many people find this the most distressing thing to bear. The final stages are often treated by increasing the dosage of pain-killers such as morphine and heroin and also by giving sedatives which induce sleep which slides into coma and death. This is known as “terminal sedation” and in most cases the patient takes no part in the decision to use it.
- 3.3.3 **DOCTORS’ DUTY OF CARE** Those who truly want to do their best for their patients by responding to a request to end their suffering are forbidden by law from doing so. Many surveys of British doctors have shown that some already help their patients to die and risk their professional career by doing so. Doctors are also able to give pain-killers in such high doses that people die more quickly. This is known as the “double effect”—if the intention is to relieve suffering, but the side effect is death.
- 3.3.4 **PUBLIC OPINION** Eight-one per cent of the public think that a person suffering unbearably from a terminal illness should be allowed by law to have medical help to die if that is what he or she wants (National Opinion Poll 2002).
- 3.3.5 **WORLD OPINION** Euthanasia has been accepted in the Netherlands for over 20 years and a law was passed in 2000 to regulate this. Belgium passed a similar law in 2001. In the US, one State, Oregon, has had a Physician Assisted Suicide law since 1998.

4. SCOTTISH LEGISLATION

4.1 **LEGAL BACKGROUND** Neither suicide nor attempted suicide are crimes in Scotland and the society believes that a person will only be criminally liable if he did something to encourage another person to put his or her intention into effect. Nevertheless, it is possible that a person who urges another to commit suicide or furnishes the means to do so could be guilty at common law of recklessly providing the means of self destruction unless the act of the victim him or herself in taking the final step is considered to break the chain of causation.

4.2 **POWERS OF ATTORNEY** have a long history of use in Scotland. Until comparatively recently, such mandates fell if their granters became incapax, and until the implementation of the Law Reform (Miscellaneous Provisions) (Scotland) Act 1990 Scots law recognised no concept of an “enduring Power of Attorney” (to use a term of English law) and if you, as the granter of a Power of Attorney, reached the stage where you could no longer understand the management of your affairs, the authority which you had granted

to other people to assist you fell on the grounds that the authority could only subsist while you actively wished it to be in place.

- 4.2.1 The 1990 Act enabled attorneyships to be exercised notwithstanding the subsequent incapacity of the granter, and at that point people began to confer upon their attorneys powers to deal with their welfare in the event of them losing capacity.
- 4.2.2 The Adults with Incapacity (Scotland) Act 2000 significantly revised the law relating to Powers of Attorney and created a new form of mandate (available from April 2001) known as a Welfare Power of Attorney. It also created a new public authority called the Office of the Public Guardian to supervise (among other things) the exercise of Welfare Powers of Attorney created by the Act and the Continuing Powers of Attorney which the Act also created, in the process ending the possibility of granting Powers of Attorney intended to remain in force notwithstanding subsequent incapacity, which now can only be granted in terms of the Act. All Powers of Attorney governed by the Act must be registered with the Public Guardian in order to become effective.
- 4.2.3 Those acting as attorneys for adults with incapacity are required to do so in accordance with the following principles:—
 - (i) The intervention must benefit the incapax and not reasonably be achievable without the intervention.
 - (ii) The intervention must represent the least restrictive option available, given the condition of the incapax.
 - (iii) Account must be taken of the following views:—
 - (a) The past and present feelings of the incapax.
 - (b) The nearest relative and primary carer of the incapax, so far as reasonable and practical.
 - (c) Any attorney or other person who has powers relating to the act proposed.
 - (d) Anyone whom the Sheriff (the English equivalent might be the County Court Judge) directs should be consulted.
 - (e) Any other person who appears to the person seeking to intervene to have an interest.
- 4.2.4 There is a code of practice for Welfare and Continuing Attorneys issued under the authority of Section 13 of the Act.
- 4.2.5 Apart from granting, withholding, and withholding consent to medical and dental treatment, areas commonly covered by a Welfare Power of Attorney would include:—
 - (a) Acting to ensure the comfort, privacy, heating and adequate ventilation of the granter's accommodation.
 - (b) Ensuring that carers assisted the granter to dress independently.
 - (c) To take decisions over the adequacy and dietary requirements of the granter's meals, cleaning arrangements etc.
 - (d) The activities which the granter could carry out at a day-centre or elsewhere, what hobbies or interests could continue to be provided for the granter, and the possibility of holidays.
 - (e) Provision for visits by families and friends.
 - (f) Assessing and reacting to the diagnosis, likely development and longer term prognosis of any illnesses.
 - (g) Ensuring that the granter has reasonable amounts of personal dignity and privacy.
 - (h) Authority to liaise with whoever has financial authority to act for the granter.
 - (i) Authority to liaise with the local authority and others in connection with services such as community care.
- 4.2.6 The legislation clearly recognises that a person who has granted a Welfare Power of Attorney is entitled to be able to rely upon those to whom the power has been granted to exercise it, which includes the refusal and withholding of medical treatment.
- 4.2.7 A Welfare Attorney is in a much stronger position to enforce the granter's wishes than a health care proxy or other mandatory.

4.3 PROSPECTIVE LEGISLATION—*The Assisted Suicide Bill*

- 4.3.1 More or less contemporaneously with the studies which gave birth to the Adults with Incapacity (Scotland) Act 2000 Professor Sheila McLean of the Institute of Law & Ethics in Medicine and Professor Joseph Thomson of the Faculty at Law in the University at Glasgow carried out a study into the possibility of legislation, in the course of which was prepared the outline provisions for legislation contained in Appendix 6 as the Assisted Suicide Bill.
- 4.3.2 The Bill provides immunity from prosecution for a registered medical practitioner who assists a person to die after that person has made an oral or written request (which may be included in an advance directive or “Living Will”), when the person concerned is
 - (a) “terminally ill; or
 - (b) in extreme physical or mental suffering.”
- 4.3.3 The authors of the draft Bill (Appendix 6) and Professor McLean in particular, have an international reputation and the Bill is masterfully laconic; it recognises that Parliament will wish to debate the fine details, outcome and safeguards—at the time it was produced, Welfare Powers of Attorney were not yet available.

5. GUIDELINES IN THE NETHERLANDS

The Society understands that the following guidelines have been followed in the Netherlands for over 20 years:—

- (i) There must be unbearable physical or mental suffering.
- (ii) Those suffering unbearably do not require to be terminally ill in order to benefit.
- (iii) The suffering and the desire to die must be lasting.
- (iv) It must be the patient’s own decision.
- (v) The patient must have a clear understanding of his or her condition and prognosis, be capable of assessing the options, and have done so.
- (vi) There must be no other acceptable solution.
- (vii) The time and way the patient dies must not cause avoidable misery to others (eg close relatives should be informed and the patient’s affairs be put in order).
- (viii) The practitioner involved must consult another professional.
- (ix) A medical practitioner must be involved in prescribing the right drugs.
- (x) The decision process and the actual treatment must be carried out with the utmost care.

6. SUPPORT FOR THE BILL

The Society welcomes the introduction of a humanitarian measure addressing the express wishes of over 4/5ths of the United Kingdom’s population. Dr Michael Irwin, a member of the Society, helped draft the original Bill when Chairman of the Voluntary Euthanasia Society of England and Wales.

It wishes to draw the attention of the Committee to the following points:—

- (1) The current Bill requires the patient to be terminally ill—this seems inhumanely narrow when compared to the Dutch guidelines.
- (2) Only competent adults will benefit from the proposed legislation. This raises interesting questions in relation to the treatment of young people. It also would appear to disenfranchise those who have granted advance directives or *Living Wills* in order to provide against such an eventuality as their losing the capacity to make informed decisions, and also those who have granted Welfare Powers of Attorney under the Law of Scotland.
- (3) The detailed formalities surrounding the type of declaration proposed in the Bill are complicated and could easily be inadvertently infringed.
- (4) Although common in some jurisdictions, such as Spain, it may be felt in this country that a solicitor (or indeed, any other lay person) is not an appropriate judge of medical competence.
- (5) It may be difficult to obtain witnesses.

- (6) There are varying degrees of mental capacity and mental competence. For instance, a person may in general be incapable of giving instructions for the management of his or her quotidian affairs, but know perfectly well that a particular child or adviser is the person whom he or she would wish to conduct them, and, similarly, may be in no doubt of his or her desire to bring terminal closure to a period of unbearable suffering. The Society would therefore suggest that wherever the concept of mental competency is introduced, it be qualified as competency to take a decision of this type.

It is suggested that the Bill take account of the Scottish Ministers as well as the Secretary of State in areas where it is proposed that Regulations will be made.

APPENDIX 1

ACCOUNTS OF THE DEATHS OF JO SHEARER AND SHIRLEY NOLAN CONTAINED IN A PRESENTATION TO FRIENDS AT THE END BY LIBBY DRAKE IN MARCH 2004

Two Strong Women

A Talk by Libby Drake of South Australia Voluntary Euthanasia Society (SAVES)

These two women, the victims of disease, were hopelessly but not terminally ill and were in excruciating and unrelievable pain.

Jo Shearer was a journalist who died aged 56. She had suffered scoliosis, S-shaped spinal curvature, from age 34, moderate at first but deteriorating rapidly at age 54. Her vertebrae protruded through to her stomach, and some of the vertebrae rotated. Apart from the spinal pain, which prevented her from standing, from lying except on hot water bottles, she had Sjogren's syndrome which took moisture from her eyes, mouth and lungs, and meant that she had to apply eye gel every 20 minutes to prevent sight-threatening ulceration. She had pain on breathing, painful tenosynovitis of the hands, and calcium deposits on the knees which grated when she walked. Jo managed to write a diary of her condition and its progression. In desperation, after no effective medical help, she decided to take her life, as was her right, in February 2000. She drank a sedative mixture and pulled a custom-made bag over her head but, unfortunately, while asleep, she pulled this bag up to her forehead, so denying herself suffocation. On waking she was taken away forcibly and detained in hospital for two weeks, apparently under the Mental Health Act. Her time there was even more hellish than before. The medical staff disbelieved her pain, dismissing it as "in her head". On release, Jo was experimented on with a large number and variety of drugs for four months without useful effect. In August 2002, lacking any alternative course, she succeeded in taking her life by a drug overdose.

Jo died alone, in unrelievable pain and in terror lest her second attempt might fail. Before her death Jo gave her journal to SAVES in the hope that it would be published and used to help others and to assist change.

The other example of desperate illness was Shirley Nolan, who died aged 60. Shirley was UK born. She and her husband emigrated to Australia in 1971. Her son Anthony was born with Wiscott Aldrich syndrome, an incurable bone marrow condition that leaves the immune system unable to fight infection. Attempts towards a marrow transplant failed, partly because there was no register of donors. In desperation to save her son, Shirley set up the Anthony Nolan Bone Marrow Trust. She worked tirelessly to publicise the tragedy of all those suffering from immune system deficiency and related diseases.

Anthony suffered a short life of isolation and monotony in a sealed and sterilised unit. He died in 1979 aged 7. Shirley continued her efforts in support of the Trust, which now has world-wide renown, with a network of donor registers and seven million potential donors as well as a research branch. In 2000 Shirley was awarded an OBE in recognition of her charitable work.

But two years after Anthony's death, Shirley began to have symptoms of Parkinson's disease. She gradually developed distressing symptoms, her self-confidence eroded.

After an unsuccessful attempt on her life in December 2001, Shirley succeeded four months later by injecting herself with a cocktail of drugs and maximising the time before she would be found. This woman, who was such an advocate of life and who had done so much for others had been forced to die alone, frightened, and by her own hand. In her suicide note, she briefly reviewed her life, especially her work with the Trust that carries her son's name. She wrote that when life no longer has any quality but is reduced to intolerably cruel days and nights of suffering, there should be THE RIGHT TO DIE WITH DIGNITY.

Both women had been strong and intelligent, had a passion for life, were achievers, became hopelessly ill and suffering greatly, tried every form of medical help available and died alone and afraid. Current laws reduced these great women to a horrendous end.

Yet in Australia public opinion polls have shown an 80 per cent support for VE.

APPENDIX 2

THE CONSTITUTION OF FRIENDS AT THE END

Adopted 28 October 2000

PURPOSES

The principal purposes for which this Society is established are:—

- (a) to promote knowledge about end-of-life choices and dignified death; and
- (b) to support those concerned about end-of-life choices and dignified death and to support those suffering from distress, especially that associated with the end of life; and
- (c) to advance medical education relevant to the processes of death and terminal illnesses; and
- (d) in furtherance thereof to fund research into the causes, cures and prevention of distress in the dying and those caring for them and to publicly disseminate the outcome of such research; and
- (e) to act along with others in pursuit of the above

and its subsidiary purposes are all things reasonably conceived to bring about or advance the foregoing.

MEMBERSHIP

Any person accepting the above purposes and who is approved by the Council, shall be entitled to join.

Resignation may be effected on reasonable notice.

The Council may on good cause shown (which prima facie includes non-payment of any subscription for more than six months) terminate any person's membership, but, while taking immediate effect, this will be open to appeal to a general meeting of the members.

MEETINGS AND COUNCIL

- (a) At least six weeks' notice will be given of any general meeting.
- (b) Once in each calendar year the members will hold a general meeting:—
 - (i) to receive and consider report from the Council on the year's activities;
 - (ii) to receive and approve the annual accounts;
 - (iii) to elect a Convener, a Secretary and a Treasurer (whose offices shall not normally be combined) together with three other members who together shall form the Council and hold office until the conclusion of the next Annual General Meeting. Casual vacancies in any of these offices and in the Council itself shall be filled by the remaining members of the Council in whatever manner they deem fit. The Council shall have power to co-opt up to three additional members;

No person elected to the office of Convener, Secretary or Treasurer shall hold the same office for more than three years consecutively, nor may any member of the Council serve for more than six years consecutively. Three members of the Council (one of whom must be the Convener, Secretary or Treasurer) shall be a quorum at its meetings;
 - (iv) to appoint an external examiner of the accounts (who shall not be a member of the Council) which shall be prepared and examined as envisaged in the Charities Accounts (Scotland) Regulations 1992 or such substitute statutory provisions as may be enacted from time to time. Funds may be invested in habile and repute responsible nominee names.
- (c) A special general meeting may be called when appropriate and shall be called upon the written requisition of at least 20 members submitted to the Secretary specifying the business concerned and the resolutions proposed. These will appear in the notice calling the members to the meeting, which will be called to take place not more than eight weeks from the delivery (which may be vouched by certificate of first class recorded delivery) of the requisition to the Convener or the Secretary.
- (d) Motions affecting the constitution once adopted at general meetings shall then be subject to a postal ballot of all members conducted within seven working days of the meeting. Unless subject (in the opinion of the Council) to bona fide error or force majeure, no postal vote shall be counted which is returned more than three weeks from the date of despatch of the ballot papers.
- (e) Simple majorities will suffice except where amendment of the constitution is concerned, when a majority of two thirds of those voting is required.

- (f) No person at any meeting or by postal ballot shall have a casting as well as a deliberative vote and in the event of any motion failing to achieve the necessary majority the motion will fail.
- (g) No proxy may be constituted except in writing duly intimated to the Secretary.

DISSOLUTION

In the event of dissolution any funds remaining will be distributed to such charities as the Council may deem appropriate.

APPENDIX 3 EXAMPLES OF LIVING WILLS - A**PRO-CHOICE LIVING WILL**

Living Will - Friends Style (11 June 2004)

Important Notes	To the maker of this <i>Living Will</i>	To treating doctors
	This is an important document. It is an Advance Directive about how you wish to be treated should you suffer a loss of mental capacity to make decisions about your future medical treatment. Please complete it clearly. You should discuss your <i>Living Will</i> with your doctor and with those who are closest to you so they are aware of your wishes.	<p>This <i>Living Will</i> is the below named person's Advance Directive which sets out his/her decision(s) to accept/refuse certain forms of medical treatment should he/she lose the capacity to consent, or lose the ability effectively to communicate his/her consent to, or refusal of, medical treatment.</p> <p>This <i>Living Will</i> should be brought to the attention of all treating clinicians and nurses.</p> <p>This <i>Living Will</i> was signed at a time when the person named below had the necessary capacity to consent to or refuse the treatments here described.</p> <p>Knowingly to treat the person named below contrary to a clearly expressed advance refusal set out in this <i>Living Will</i> is likely to be a criminal assault.</p> <p>If you are in any doubt as to the binding nature of the decisions set out in this <i>Living Will</i> you should seek independent legal advice.</p>
	<i>Living Wills</i> are recognised as being legally enforceable by:	<ul style="list-style-type: none"> ❖ the General Medical Council ❖ the British Medical Association ❖ the Royal College of Nursing ❖ the Nursing and Midwifery Council ❖ the Law Society of England and Wales

TEXT OF LIVING WILL**Personal Details**

I, name _____

of address _____

am of sound mind and not suffering from any physical or mental condition which impairs my capacity to make the medical treatment decision(s) set out in this document.

I have carefully considered how I would wish to be treated if through accident, illness, or injury I lose the capacity to consent to medical treatment or the ability effectively to communicate my consent or refusal.

A

Imminently life threatening physical illness from which there is little or no prospect of recovery

(please tick the box you wish to apply)

I, name _____

☐

(i) I wish to be kept alive for as long as reasonably possible and consent to all appropriate medical treatment.

or☐

(ii) I refuse medical treatment aimed at prolonging or artificially sustaining my life. I consent only to medical treatment whose aim is to keep me comfortable and, so far as possible, free from pain. I refuse all other medical treatment.

declare that my medical treatment wishes are as follows:

If I suffer from physical injury or illness which in the opinion of two or more independent doctors (one a consultant), is imminently life threatening and from which there is less than a ten per cent likelihood of recovery.

Examples of an imminently life threatening condition are the last stages of MND, AIDS, extensive stroke, severe head injury, or widespread cancer where the incapacity is due to physical reasons. Please note this list is not exhaustive and is for illustrative purposes only.

Page 2

Welfare Attorney

(In Scotland, all Welfare Powers of Attorney must be drawn up by a lawyer, signed and witnessed as a full legal document. You may appoint an adult as your Welfare Attorney to act for you legally in all decisions concerning your health and welfare if you become unable to make decisions for yourself.)

The following person has been appointed my Welfare Attorney to take part in discussions about my medical care on my behalf if I am unable to make my wishes known for myself. I have discussed my views about my future medical treatment with him/her and given him/her a copy of this document. This person is to be consulted about and involved in those decisions by the health care team when considering what my intentions would have been in any uncertain situation. I require anyone who is caring for me to respect the views expressed by my Welfare Attorney on my behalf.

Name

Address

Daytime telephone number

Evening telephone number

Health Care Proxy

In the event of my not having a Welfare Attorney who is able to give instructions, or in the event of that person not being available, I have asked the following person to take part in discussions about my medical care on my behalf if I am unable to make my wishes known for myself. I have discussed my views about my future medical treatment with him/her and given him/her a copy of this document. I would like this person to be consulted about and involved in those decisions by the health care team when considering what my intentions would have been in any uncertain situation. I want anyone who is caring for me to respect the views expressed by my Health Care Proxy on my behalf.

Name

Address

Daytime telephone number

Evening telephone number

Presence of relative or friend

If my life is in imminent danger I wish the following person to be contacted to give him/her the chance to be with me. I accept that it may not be possible to contact the person named and for him/her to arrive in time

Name

Address

Daytime telephone number

Evening telephone number

GP details (optional)

My General Practitioner is

GP's address

GP's telephone number

GP's declaration

I have discussed the matters contained in this *Living Will* with

I am satisfied that he/she has the capacity to make the decisions contained in this document and satisfied that he/she understands the consequences of those decisions.

GP's signature

Date of signature

Signatures <i>In Scotland the Living Will should be witnessed by a witness who should not be a relative, your Welfare Attorney, your Health Care Proxy or anyone who stands to gain from your death. They should sign at the same time as yourself and should then print their name and address in the spaces provided.</i> <i>If this deed is granted in or to be used in England and Wales a second witness is required. They should sign at the same time as yourself, and write 'witness' after their signature, and should then print their name and address in the spaces provided.</i>	My signature Signed _____ Date _____	
	Witness one Signature _____ Full name of witness _____ Address of witness _____ _____ _____	Witness two Signature _____ Full name of witness _____ Address of witness _____ _____ _____
	Where to deposit your completed Living Will I have given copies of this Living Will to:	
	A Name e.g. your GP _____ Address _____ _____ Telephone _____	C Name any other person, e.g. your solicitor or Health Care Proxy _____ Address _____ _____ Telephone _____
	B Name e.g. Welfare Attorney _____ Address _____ _____ Telephone number _____	D Name e.g. your local hospital _____ Address _____ _____ Telephone number _____
	Review dates This <i>Living Will</i> was reviewed and confirmed by me as not requiring any change on the following dates:	
	Date _____	Signature _____
	Date _____	Signature _____
	Date _____	Signature _____
	Date _____	Signature _____
Date _____	Signature _____	
<i>This document remains effective unless I have made it clear above that my wishes have changed and that a new version has superseded it</i>		

APPENDIX 3

EXAMPLES OF LIVING WILLS—B

LIVING WILL ALLOWING FOR REFUSAL OF UNWANTED TREATMENT

TO MY FAMILY, MY PHYSICIAN AND MY SOLICITOR

This declaration is made by me, _____ residing at _____
at a time when I am of sound mind and after careful consideration.

I, the said _____

in the event of my being unable to take part in decisions concerning my medical care due to my physical or mental incapacity, and in the event that I develop one or more of the medical conditions listed in clause (3) below and in the event that two independent physicians conclude that there is no reasonable prospect of my making a substantial recovery, do hereby DECLARE that my wishes are as follows, viz:—

- (1) I request that my life should not be sustained by artificial means such as life support systems, intravenous fluids and/or drugs or tube feeding.
- (2) I request that distressing symptoms caused either by illness or by lack of food or fluid should be controlled by appropriate sedative treatment, even though such treatment may have the incidental and secondary effect of shortening my life.
- (3) The said medical conditions are:—
 1. Severe and lasting brain damage sustained as a result of an accident or injury.
 2. Advanced disseminated malignant disease.
 3. Advanced degenerative disease of the nervous and/or muscular systems with severe limitations of independent mobility, and no satisfactory response to treatment.
 4. Stroke with extensive persisting paralysis.
 5. Pre-senile, senile or Alzheimer type dementia.
 6. Other conditions of comparable gravity.
- (4) I request that, in the event of my becoming incapable of giving or withholding consent to any medical treatment or procedures proposed to me, the Court be petitioned to appoint as my Welfare Guardian, _____
residing at _____
whom failing _____
residing at _____
whom again failing _____
whom all failing _____
such other person as may be deemed by the Court to be a fit person. It is my specific request that in exercising his or her powers to consent or withhold consent on my behalf to any medical treatment or procedures, my guardian shall take into account, in any determination of what is in my best interests, the requests which I solemnly make in clauses (1) and (2) of this document.

And I declare that I hereby absolve my medical attendants of all legal liability arising from action taken in response to and in terms of this declaration.

I reserve the right to revoke this declaration at any time, before a witness, in writing or orally.

SIGNED by me at _____
on the _____
day of _____
Two thousand _____
in the presence of:—

Witness

Full Name

Address

(In Scotland only one witness is required)

APPENDIX 4

APPOINTING AND ACTING AS WELFARE ATTORNEY

Background

It has been settled law since Roman times that if you know what you are doing you can give someone a mandate to carry out certain acts on your behalf—the problem was that up until about 10 years ago if you reached the stage where you could no longer understand the management of your affairs, the authority which you had granted to other people to assist you fell, the rationale being that the authority to act could only subsist while you actively wished it to be in place.

On 31 January 1991, the law changed to allow powers of attorney to continue in existence notwithstanding the supervening incapacity of their grantors, and at that point people began to confer upon their attorneys powers to deal with their welfare in the event of them losing mental capacity. Under the current regime set up by the Adults with Incapacity (Scotland) Act 2000 these powers of attorney count only as so-called continuing powers of attorney, which basically deal with your property and financial affairs only. New powers of attorney which are intended to continue after supervening incapacity are governed by this Act. The Act set up a new form of mandate, called welfare powers of attorney dealing with welfare matters and created a new public authority to supervise the use (among other things) of both the new types of Power, called the Office of the Public Guardian.

It has to be borne in mind that you need to have full capacity to understand what you are doing when you grant a power of attorney. However, a decline or partial loss of capacity does not mean that it is completely impossible to grant the power, because the law accepts that people can have periods of lucidity. Having said that, however, anyone granting a welfare or continuing power of attorney has to be certified by someone such as a solicitor, advocate or registered medical practitioner as understanding the nature and extent of the document in question, and the person so certifying cannot be one of the attorneys. It is open to the person making the certificate to say what other people he or she has consulted in coming to their views.

Needless to say, it is probably wise to ensure that your attorney's powers are as wide as possible. If the attorney is not acting within the terms of the power, there could be a range of problems with members of the family and other people, including the possibility of action taken after the death of the granter.

Welfare powers of attorney, as we say in the law, are “creatures of statute” and accordingly in order to be effective they need to comply with all the statutory requirements, including a meticulous adherence to the forms of certificate laid down under subordinate legislation. This means that the certificates cannot be amended except in the areas and in the manner laid down, sections you might feel are irrelevant cannot be omitted, they have to occur at the end of the document and you will need two certificates if the same document is to serve as both a continuing and a welfare power of attorney. Some other bureaucratic points arise with regard to the registration forms, being sure not to omit dates of birth, postal codes, relationships (if any) to the attorneys and so on. You should also know that there is a statutory obligation on executors to inform the Public Guardian if an attorney dies.

One of the things to bear in mind is that it is not legally possible for people other than named individuals to be appointed as welfare attorneys. Another is that while you might want to name a number of people as potential attorneys acting on a joint and several basis it might be prudent to say whose view is to prevail in the event of disagreement.

Action areas for Welfare Attorneys

Examples of areas which might be covered by a welfare power of attorney include:—

- Assessing your accommodation and facilities as being suitable for your current conditions. Is your accommodation comfortable, private, warm and adequately ventilated?
- What would make it easier for you to dress independently?
- How are you supplied with meals, are they adequate, and do they meet your dietary requirements?
- Are the cleaning arrangements adequate?

- What activities could or should you engage in at a day centre or otherwise, what hobbies or interests are catered for, and do friends or relatives call?
- What about holidays?
- Religious considerations.
- What is the diagnosis, likely development, and longer term prognosis of any illnesses?
- What about reasonable amounts of personal dignity and privacy?

It will be necessary for a welfare attorney to liaise with whoever has financial authority to act for the granter. It will also be necessary to liaise with the local authority in relation particularly to community care services, and while the local authority normally has no supervisory duty over welfare attorneys they do have if the attorney does not have a sufficient authority to act and a welfare guardian is appointed.

Registration with the Public Guardian

The Public Guardian is likely to be an increasingly-important official and his office has already produced a huge quantity of material. This is available on CD-rom by telephoning 01324 678300, or faxing 01324 678301, e-mailing him at 'opg@scotcourts.gov.uk', or writing to The Office of the Public Guardian, Hadrian House, Callendar Business Park, Callendar Road, Falkirk, FK1 1XR or visiting the website at 'www.publicguardian-scotland.gov.uk'. The Public Guardian's Office can assist in difficult cases and investigate complaints.

In order to come into effect, welfare powers of attorney and continuing powers of attorney need to be registered with the Public Guardian and it is one of his requirements that any person called to act as an attorney should signify agreement to act by signing an official form to that effect. Examples of the form are available on the internet, and copies can be provided. You are, inter alia, supposed to put your and the attorneys' dates of birth, post codes, and ethnic origins on the form.

The Act also allows for other people to seek appointment as so-called "welfare interveners", but it is surely much better to decide for yourself whom you would wish to act for you.

Modern government is obsessed with bureaucracy and you should be aware that once the welfare power of attorney has been registered (which it has to be in order to become effective), the Public Guardian will send copies of the power to yourself and the attorneys (if requested), and all of you are supposed to notify any changes of address to the Public Guardian's Office.

Because of the bureaucracy involved, many people would say that unless you already have in place a pre-Act Power of Attorney, it would make a lot of sense in financial matters to have a non-Act power of attorney (operative only while the granter has mental capacity) as well as a welfare power of attorney and continuing power of attorney which would take effect once or if the grantor has become incapax. The non-Act powers of attorney do not need to be registered with the Public Guardian and there is a strong school of thought that the continuing and welfare powers of attorney should not be registered until they are required, simply being kept in a safe place or registered in the Books of Council and Session until the need arises.

However, if registration is delayed until then, the requirements for registration may have changed and the forms which you have signed under the current regime or whichever one is in force at the time the powers of attorney is granted may have been changed. In that case, it may not be possible to register the power of attorney, and without registration, it is worthless. This is an argument which the Public Guardian puts forward in favour of early registration, and if there are errors in the power of attorney or application form, it will be too late to do anything about them. Registration is covered by Section 19 of the Act, and the cost of doing so is currently £35.

If you have given instructions that the welfare power of attorney is only to be registered in the event of you actually becoming incapax, the fact of this incapacity will need to be proved to the Public Guardian.

Whether or not a Power of Attorney is to be registered with the Public Guardian at the time of granting of when it is needed is up to the granter. It can be registered in the Books of Council and Session for preservation as an interim measure, and the Public Guardian would need to accept an official Extract (including the certificate) if that was the course of action decided upon.

The principles to be employed

A fundamental point of the 2000 Act is that if you are actually acting as an attorney for an adult with incapacity you are required to do so in accordance with the following principles:—

1. The intervention will benefit the incapable person (whom we shall hereafter refer to by the shorter technical Latin description of incapax) and the benefit cannot reasonably be achieved without the intervention.
2. The intervention needs to be the least restrictive option available, given the condition of the incapax.
3. Account has to be taken of the following views:—
 - (a) the past and present feelings of the incapax;
 - (b) the nearest relative and primary carer, so far as reasonable and practical;
 - (c) any attorney or other person who has powers relating to the act proposed;
 - (d) anyone whom the Sheriff directs should be consulted;
 - (e) any other person who appears to the person effecting the intervention to have an interest.
4. The incapax is to be encouraged to exercise whatever skills remain concerning the management of property, financial affairs or personal welfare.

Some of these principles may at times be in conflict and if you are the attorney, it will be your primary job to strike the right balance.

The code of practice

There are a lot of codes of practice issued under the 2000 Act, and there is a code of practice for continuing and welfare attorneys brought into force under Section 13. The Code of Practice is 76 pages long and anyone acting as an attorney might find it appropriate to read this and/or ask their solicitor for a synopsis.

Meetings

The code of practice is voluminous and full of advice, not all of which may be practical. It advises, on an attorney becoming aware of the adult's incapacity, that a meeting take place between the adult, the nearest relative, anyone nominated by the Sheriff to act in place of the nearest relative, the primary carer, any other attorneys and "any other person with an interest in the welfare of the adult or an assistant adult to express his or her views", while any one of those not attending the meeting should be written to explaining the position to all affected.

The purpose of the meeting is said to be to explain the scope of the powers, and to discuss how you as attorney will go about your job (such as clarifying whether you would like regular meetings and if so with what frequency).

Record keeping

Section 22 of the Act provides that attorneys appointed under it require to keep records of the exercise of the powers. Such record keeping will not automatically be examined as a matter of course but the maintenance of a good file is said to be a useful prophylactic against all kinds of unwelcome attention in the future.

The file might contain, for instance, a note of the name, address and other contact details of doctors and social workers providing care services to the adult and also details of any professional advisers you will be dealing with such as accountants and solicitors. Apart from correspondence and notes of meetings and phone calls, full financial and accounting records should be maintained.

Views taken account of

If decisions are taken, you should record the adult's present feelings and wishes and how these have been indicated. You are also supposed to encourage the adult to exercise whatever skills he or she has and any intervention must be the minimum necessary. This will depend upon the circumstances of the case.

Acting in good faith

Concerns have been expressed that it would be unethical or even illegal to involve the full range of persons mentioned in the code with regard to the administration of someone's affairs—that may well be so, but it still illustrates the need to take prudent precautions when acting, especially as a welfare attorney.

Nevertheless, Section 82 of the Act provides protection for breaches of duty if an attorney has acted “reasonably and in good faith” and in accordance with the general principles derived from Section 1, as mentioned earlier.

Obtaining confidential information

It would be prudent to include in your welfare power of attorney authority for your attorney to obtain confidential information, such as details of the treatment which you have been receiving. If the attorney cannot obtain the information because inadequate powers have been conferred on him/her, the attorney might refer the matter to the Public Guardian or seek an intervention order under the Act.

Coping with disagreement

If you are acting as an attorney and find people in disagreement with you, the code suggests that you should direct them to your statutory responsibilities as attorney, to the powers that the grantor has conferred, and that the grantor has chosen to confer these powers on you.

It will assist you if you can show that you have applied the general principles systematically, that you have balanced one principle against another, that you have taken account of the past and present wishes and feelings of the incapax and, if necessary, that you have taken legal advice—nevertheless you may find in the end that you simply have to insist. The code says that “if you are confident in your judgement, do not back down. You would be letting the adult down if you gave in for the sake of peace, or stood down, leaving the adult with no-one (or someone other than you, whom the adult chose) to take care of their affairs. Also, you can exercise your own right to apply to the Sheriff for directions under Section 3(3)”.

Resignation

Unlike traditional Powers of Attorney, which could be hard to relinquish, the power granted under the 2000 Act can be resigned.

Where a Welfare Attorney wishes to resign and the document conferring the Power of Attorney has been registered, this must be done in writing and intimated to the granter, the Public Guardian, any guardian or, where there is no guardian, the granter's primary carer and the Local Authority where they are supervising the Welfare Attorney. Resignation will not take effect until the expiry of 28 days from intimation to the Public Guardian. If a joint Attorney is willing, however, to continue to act or any substitute Attorney is willing to act, resignation will be effective upon submission of evidence to that effect.

Termination

Another feature of the 2000 Act Powers of Attorney is that the Act provides for them to be terminated in a number of circumstances. Basically, these are:—

- Where the Granter and Attorney are married to each other, upon the granting of a decree of separation or divorce to either party or a declaration of nullity of marriage, unless the Power of Attorney deed states otherwise,
- On the appointment of a guardian with powers relating to those conferred in the Power of Attorney.

Further advice

You may feel that the above comments are sufficient for your present needs, but if you wish further information and advice our Private Client Team at Biggart Baillie will try to answer any questions you may have.

APPENDIX 5

EXAMPLE WELFARE POWER OF ATTORNEY

EXAMPLE

WELFARE POWER OF ATTORNEY

by

SOMEONE

in favour of

SPOUSE AND CHILDREN

jointly and severally

2002

BIGGART BAILLIE

Solicitors

Edinburgh & Glasgow

FAS 0434

GMW2/NAME.WPOA

I, *[Someone]*,residing at *[Address]*;

CONSIDERING that I am desirous of appointing a proper person to act as my Welfare Attorney in the event of my becoming incapable of making personal decisions about my general care and welfare

* * * * *

DO HEREBY in this Deed Nominate and APPOINT *[full names and addresses of someone's spouse and children]*

and each of them alone and the survivor of them all jointly and severally to be my Welfare Attorneys and Attorney (all of whom without regard to number or to gender being hereinafter referred to as "my Attorney")

DECLARING that the appointment of any one or more of them shall terminate upon him, her or them becoming unwilling or unable to act and the same shall be satisfactorily evidenced for the purposes of these presents

- (a) by written resignation signed before a witness to the effect that such resigning Attorney is unwilling to act or to continue to act as my Attorney, and/or
- (b) by Medical certificates granted by two registered medical practitioners to effect that the said Attorney is or has become mentally incapacitated, * * *

WITH FULL POWER, warrant and commission to make such decisions or give or withhold such consents in relation to my welfare as I would be able to make or give or withhold were I capable of so doing, and in particular without prejudice to the foregoing generality,

I CONFER upon my Attorney the following powers all to be exercised or not, and if exercised, then my Attorney shall have regard to (a) my feelings on the matter in question in so far as I am able to communicate my views, (b) the feelings and views of my primary carer, (c) the feelings and views of my nearest relative, and (d) where appropriate the views or opinions of the relevant health care professionals, videlicet:—

- (One) To make decisions about my general physical and mental well-being and to consent to any medical or dental health care or course of treatment and/or research which is necessary to my general physical or mental well-being or to which I would have, in the absence of evidence to the contrary, consented had I been capable of so doing, subject to the safeguards set out in

- Part 5 of the Adults with Incapacity (Scotland) Act 2000 or any statutory modification or re-enactment thereof from time to time in force, and to withhold the said consent if not so satisfied, all as my Attorney considers to be in my best interest, subject to the said safeguards,
- (Two) To arrange that I receive such services as are essential to or in the opinion of my Attorney desirable for my physical health and safety, and assistance or training intended to develop or enhance my capacity to take advantage of such services or to meet my essential health and safety requirements,
- (Three) To apply for free personal and nursing care or any other type of financial assistance available to me in relation to my health or overall welfare,
- (Four) To decide where and with whom I should live, whether temporarily or permanently, and if it becomes apparent to my Attorney that I am no longer capable of living safely in my usual home then my Attorney shall have power, in consultation with my family, primary carer and health care professionals, to make alternative accommodation arrangements believed to be acceptable to me,
- (Five) To make normal day-to-day decisions on my behalf including but not restricted to my diet, dress and personal appearance,
- (Six) To decide whether I should participate in any educational vocational or other training and, if so, the nature and extent thereof and matters relating thereto,
- (Seven) To decide on the level of my participation in religious, social, sporting or cultural activity and prevent or restrict my participation, if, in the opinion of my Attorney, such activity would be injurious to my general welfare, and to decide with whom I should or should not consort,
- (Eight) To commence, defend, compromise, continue, appeal or settle any legal proceedings that relate not to my estate but to my personal welfare,
- (Nine) To exercise any rights afforded me by legislation, contract or otherwise in relation to the maintenance of or access to my confidential and other personal data including but not restricted to access to my medical records or to personal files held by social work services,
- (Ten) To take me on holiday or authorise some other individual or individuals to do so, and make or consent to all such arrangements as are necessary in connection therewith, and to claim either in advance or arrears the costs or out-of-pocket expenses incurred by my Attorney or, with his consent, such other individual or individuals, in relation to or in connection with such holiday and arrangements,
- (Eleven) To assist my Attorney in making decisions which affect me, and having given careful thought to the implications, I record my current wishes on treatment as follows:—
- (a) I desire to have such treatment as might be necessary to maintain comfort or relieve suffering and regard this as an overwhelming priority even if life is thereby threatened or truncated;
 - (b) I desire to have such treatment (including major surgery) intended, and likely, to secure that I shall be able to lead an independent life within my home environment and to enjoy a quality of life similar to or better than that which I enjoyed before the condition, illness, accident or other trauma the onset or occurrence of which gave rise to consideration of such treatment;
 - (c) I record that a condition of high dependency and intensive care is acceptable to me in the context of planned treatment but not otherwise; and
 - (d) I do not agree to the use of life support equipment being used to keep me alive except on a short term basis and where there is realistic hope that upon the termination thereof I shall enjoy a quality of life similar to or better than that which I enjoyed before the condition, illness, accident, surgery or trauma the onset or occurrence of which gave rise to consideration for such treatment and DECLARE that my family are aware of my wish to die with dignity;
 - (e) I desire to be a registered organ donor and agree that in the event of my medical attendants reasonably being satisfied that I am in no danger of experiencing any mental or physical pain or distress or being conscious of the action or actions of removal taking

place, my Attorney may consent to the removal of any suitable part or parts of my body for the purposes thereof;

I understand that my Attorney will seek to elicit my wishes at the time any such treatment is in contemplation, and in the absence of clear indication to the contrary, will have regard to my wishes as recorded above:

AND I FURTHER PROVIDE AND DECLARE

- (Primo) that my Attorney shall be entitled (a) to reclaim the costs or out-of-pocket expenses incurred by him in relation to the exercise of any of the foregoing powers, and (b) to be remunerated on the appropriate scale for any professional services rendered by him,
- (Secundo) that my Attorney shall be entitled to resign by witnessed instrument in writing,
- (Tertio) that the supervening incapacity of my Attorney evidenced by an appropriate certificate by two or more registered medical practitioners shall terminate my Attorney's appointment,
- (Quarto) that a copy certified as true by a Solicitor shall have the same force as an original document referred to in (Secundo) and (Tertio) above, and
- (Quinto) that this Welfare Power of Attorney shall remain valid and of full force and effect notwithstanding my supervening mental incapacity, unless first recalled by me in writing, and that a copy of the registration document is to be sent to my Attorney if this Welfare Power of Attorney is registered with the Public Guardian by someone other than him.

SIGNED and DELIVERED by me as a Deed

at

on the

day of

Two thousand and

in the presence of

Witness

Full Name

Address

This certificate is incorporated in the document subscribed by the within designed [*someone*] ("the granter") on the _____ day of _____ Two thousand and that confers a Welfare Power of Attorney on the also-within-designed [*Names of someone's spouse and children*] and the survivor of them all jointly and severally

I certify that:

A. I interviewed the granted on the _____ day of _____ Two thousand and immediately before he subscribed this Welfare Power of Attorney

AND B. I am satisfied that, at the time this Welfare Power of Attorney was granted, the granter understood its nature and extent

I have satisfied myself of this: (a) because of my own knowledge of the granter; (b) because I have consulted the following persons, who have knowledge of the granter on the matter:

AND C. I have no reason to believe that the granter was acting under undue influence or that any other factor vitiates the granting of this Welfare Power of Attorney.

Signed Date

Print Name

Profession

Address

.....

Note: Any person signing this certificate should not be the person to whom this Welfare Power of Attorney has been granted.

APPENDIX 6

DRAFT ASSISTED SUICIDE BILL

Prepared by Professor Sheila A M McLean of the Institute of Law and Ethics in Medicine,
University of Glasgow

- s.1(1)** It shall not be an offence for a registered medical practitioner to assist in the death of a person if the following conditions are satisfied:
- (i) a person has made a request to die;
 - (ii) in the opinion of a registered medical practitioner and a qualified legal practitioner, the person is competent to make such a request;
 - (iii) in the opinion of two registered medical practitioners, one of whom has not been involved in the care of the person, that person is
 - (a) terminally ill; or
 - (b) in extreme physical or mental suffering.
- s.1(2)** A request for assistance in dying for the purposes of s.1(1) may be made verbally or in writing.
- s.1(3)** For the purposes of s.1(2) a written request may be incorporated into an advance directive.
- s.1(4)** The immunity provided by s.1(1) extends to any person supplying the means for assisted suicide and any person acting under the direction of the registered medical practitioner.
- s.2(1)** A person over the age of 16 shall be presumed to be competent for the purposes of s.1, unless in the opinion of a registered medical practitioner and a qualified legal practitioner that person is not competent.
- s.2(2)** For the avoidance of doubt, a request for assistance in dying is not per se evidence of incompetence.
- s.3** No registered medical practitioner or any person acting under his or her direction shall be obliged to assist in the death of any person.

1. SCHEDULE

1. When a person has died as a result of an act authorised by this statute, the death shall not be treated as a material breach of any contract.
2. When a person has died as a result of an act authorised by this statute, that person shall not be treated as having died as a result of personal injuries for the purposes of the law of tort or delict.
3. When a person does not die as a result of an act authorised by this statute, unless the person is competent and withdraws the request, a registered medical practitioner remains obliged to assist in that person's death.
4. When a person does not die as a result of an act authorised by this statute owing to the negligence of a registered medical practitioner, that person retains title to sue for compensation under the law of tort or delict.
5. When a person does not die as a result of an act authorised by this statute owing to the negligence of a registered medical practitioner, any relative of that person has title to sue under the law of tort or delict for any distress occasioned thereby.

APPENDICES

1. Accounts of the deaths of Jo Shearer and Shirley Nolan contained in presentation to FATE by Libby Drake in March 2004.
2. Constitution of Friends at the End.
3. Examples of Living Wills.
4. Information on Scottish Welfare Powers of Attorney.
5. Example Welfare Power of Attorney.
6. The Assisted Suicide Bill.

Memorandum by The George House Trust

We are the largest HIV care and support charity in the North West of England and work with around 1400 people living with and affected by HIV across the region.

Although the death rate from HIV is less than one third of the level eight years ago because of the high level of effectiveness of the latest combination drug treatments (in 2003 deaths among people with HIV in the North West were 30 as opposed to 98 in 1995), some of our service users do have concerns around their own deaths.

One concern is around pain control and we therefore welcome the proposed right to pain relief from a palliative care specialist contained in sections 3 and 15 of the draft Bill.

The Bill's fundamental purpose, to provide a right for terminally ill people who are suffering unbearably to have medical assistance to die if they persistently request this, is one that some of our service users would appreciate. We therefore support this Bill to provide people with this choice, should they so wish.

21 July 2004

Memorandum by Help the Hospices

SUMMARY

1. Help the Hospices solicited views from 69 hospice staff during a six-month consultation period. The sample was not scientifically selected and conclusions regarding the frequency of views in independent hospices as a whole should not be extrapolated from the data to which the submission refers. The submission and summary use the term euthanasia to refer to all forms of assisted dying.
2. About two thirds of respondents identified it as unethical for health care professionals to assist death whilst about one third of respondents would treat it as an ethical obligation.
3. Respondents were divided on whether the introduction of euthanasia would undermine or promote the exercise of patient autonomy in terminal care.
4. Many respondents argued the introduction of euthanasia would deny patients the sense of sanctuary that hospice care currently offers, and would compromise the relationship of trust between professional carers and patients. However, a minority argued that better communication between professionals and patients would result from implementing the Bill.
5. A minority of respondents indicated they would find euthanasia more acceptable if the physician assisting death were not the attending physician and/or if assisted deaths took place outside hospices.
6. The majority of respondents did not consider that palliative care could provide relief in all circumstances. However, many respondents did not regard the efficacy of palliative care as determinative of the moral status of euthanasia.
7. The following were seen as significant problems in implementing the Bill:
 - patient competence throughout the process;
 - the requirement that patients be fully informed;
 - physician and psychiatric referrals;
 - the 14 day waiting period;
 - continuing care for those seeking assisted death, particularly symptom control;
 - the capability of legal and lay witnesses in carrying out their duties; and
 - accountability of the physician attending death.
8. The Bill was seen to require further clarification in respect of:
 - the rights of competent terminally ill minors;
 - the definition of unbearable suffering;
 - the capacity of hospice volunteers to act as lay witnesses;
 - the apparent absence of a requirement that the patient be competent in order to understand that they possess a right to revoke; and
 - ability to defer the date of death without revoking a valid declaration.
9. The Bill's focus on physician decision-making was regarded as inconsistent with good practice in multi-disciplinary team working.

INTRODUCTION

1. Help the Hospices supports hospices in the UK through grant-aid; education; training; information and advice. It is the national voice for the 188 adults' and children's hospices run by local charities (known as "independent" hospices). These provide 72 per cent of UK specialist inpatient palliative care, as well as many community and day care services.

METHODOLOGY

2. In his memorandum of 22 October 2003 Lord Joffé requested that a Select Committee give consideration to seven key issues. Help the Hospices focused its consultation around those aspects that staff in independent hospices are, through experience, uniquely well qualified to address:

- (i) Whether palliative care can in all cases provide the care that will enable terminally ill patients to die with dignity, and free of unnecessary suffering.
- (ii) Whether the safeguards in the Bill, intended to protect vulnerable members of society, are adequate.
- (iii) The effect on patients, health staff and the families of patients were the Bill to become law.
- (iv) The different views within the professions involved in providing palliative care.

3. Using convenience and purposive sampling, Help the Hospices consulted 69 specialist palliative care staff via interviews and regional focus groups (Scotland, Wales, South East of England and North of England). The interviews were conducted at the outset of the consultation to inform research design and supply qualitative data. Many staff attending focus groups elicited colleagues' views and presented these on their behalf.

4. The focus group sample included 10 specialist palliative care physicians, 34 specialist nursing staff including community nurse specialists, two physiotherapists, one occupational therapist, five social workers, six chaplains, one volunteer, one counsellor and two management professionals drawn from 29 independent hospices. About half of staff in the sample currently occupy leadership roles: of this fraction three were chief executives or equivalent, 11 were directors of services (clinical, medical or nursing) and the remainder were multi-disciplinary team leaders or team leaders in their specialty.

5. Focus groups used a modified nominal group technique. Participants identified all likely opinions of those working in and using hospices. Respondents subsequently recorded their own views in writing. It was thus possible to survey the totality of views and also to permit minority opinions to be expressed in confidence without fear of conflict.

6. Within the timeframe set by the Committee, it was not possible to elicit hospice users' views.

7. *It is emphasised that focus groups were not scientifically selected but, of necessity, consisted of hospice staff able to attend. Help the Hospices is confident it has captured the range of views held by hospice staff and some indication of their prevalence. However, the frequency with which views are held across independent hospices cannot reliably be extrapolated from these data. In order to discourage undue weight being placed upon frequency indicators, data are reported below using approximate fractions rather than percentages.*

HOSPICE VALUES AND EUTHANASIA

8. The independent hospice movement pioneered specialist palliative care and continues to lead its development. Respondents emphasised hospice care's holistic principles: respecting the physical, emotional, and spiritual needs of whole persons. They also emphasised respect for autonomy. However, consideration of patient needs alongside respect for autonomy generated differing assessments of the impact of euthanasia on the exercise of autonomy (see below).

Approaches to moral reasoning

9. About one half of respondents cited Christian belief as relevant to their view on euthanasia.

10. Many respondents urged attention to the moral distinction between factual and normative propositions. Regarding euthanasia as morally wrong, they argued that the extent to which palliative care could relieve suffering was not relevant to the moral status of euthanasia.

11. Those indicating support for the introduction of euthanasia cited respect for autonomy as a foundational rationale and/or indicated they believed euthanasia to be right by reason of unbearable suffering.

12. Respondents differentiated between moral and ethical beliefs. About one half indicated they believed euthanasia to be morally wrong, with the remainder indicating it was either not a moral issue or morally right. However, two thirds of respondents indicated they believed it unethical for health care professionals to provide assistance to die. One third of respondents indicated they would treat assisting death as an ethical obligation.

Respecting autonomy

13. For some respondents, respecting autonomy in the context of holistic care entailed accepting euthanasia. They reasoned that where patients concluded that euthanasia was in their best interests, they were entitled to seek others' assistance to die.

14. For other respondents, respecting autonomy in caring for the terminally ill entailed rejecting euthanasia. They viewed autonomy as context-dependent, arguing that some decisions are meaningful only if social structures facilitate their implementation. They reasoned that introducing euthanasia would change the landscape of palliative care in ways that denied patients resources and choices. For instance they anticipate that the availability of euthanasia would reinforce in elderly patients the belief that they are less deserving of care than the young; that patients may choose euthanasia in order to not to impose emotional or financial burdens on carers; and generally, as euthanasia became more socially acceptable, lingering death would become less so. Respecting the autonomy of those seeking euthanasia may thus ultimately inhibit the exercise of autonomy in others.

Moral rights and duties

15. Questionnaire responses implied three views on the relationship between patients' desire to die and others' duty to assist. About one third regarded the creation of a patient's right to euthanasia as entailing a corollary duty on health care professionals to assist. About one third treated euthanasia as a freedom independent of corollary duty, so although a patient might seek euthanasia it would remain unethical for medical professionals to provide it. About one third of respondents viewed euthanasia as an impermissible moral choice that society should neither permit nor assist.

16. Respondents noted that the Bill does not create a duty in organisations to provide euthanasia, and that some hospices might decline to do so.

Multi-disciplinary care

17. The high standard of hospice care is founded on integrated multi-disciplinary working. Irrespective of moral belief, almost all respondents expressed considerable concern about the impact on multi-disciplinary working of introducing euthanasia. They feared patient care could be compromised, and the hospice movement weakened, through conflict arising from differing ethical beliefs and the exercise by some professionals of their right of conscientious objection.

18. Some respondents argued that the Bill's focus on physician decisions was inappropriate. Staff in multi-disciplinary teams may possess more knowledge and expertise than attending or consulting physicians. (Where palliative care is provided in the home, for example, attending physicians may be General Practitioners with limited knowledge of palliative care, whilst "attending nurses" would be palliative care specialists.) Moreover, patients and families often develop more intimate relationships with nursing and other staff.

A safe haven?

19. Many respondents suggested the introduction of euthanasia would deny patients the sense of sanctuary hospice care currently offers and compromise the relationship of trust between physicians and patients. However, a minority argued that better communication between professionals and patients would result from implementing the Bill.

20. One fifth of respondents indicated they would find euthanasia more acceptable if the physician assisting death were not the attending physician. One fifth of respondents indicated euthanasia would be more acceptable if assisted deaths took place outside hospices, for example in patients' homes.

21. Anxieties remain that should hospices carry out euthanasia this will have a significant negative effect on fundraising. At present hospices provide 72 per cent of in patient palliative care, levying no charge on patients and receiving less than 50 per cent of their income from public funds.

CAN PALLIATIVE CARE ENABLE TERMINALLY ILL PATIENTS TO DIE WITH DIGNITY AND FREE OF UNNECESSARY SUFFERING?

22. Respondents selected from five answers to the question: “In your professional experience can palliative care in all cases provide the care which will enable terminally ill patients to die with dignity and free of unnecessary suffering?” The alternative answers expressed the range of views derived from interviews with hospice staff:

- (i) No respondent selected the unqualified “Yes”.
- (ii) Just over one third of respondents selected EITHER “Yes in principle, but good palliative care is not universally available” OR “Yes, but only using deep sedation”.
- (iii) The remainder, just under two thirds of respondents, selected EITHER “No, because we cannot fully control pain and/or the terminal stages can be undignified” OR “No, because some patients wish to control the time and manner of death and this is not a medical issue”.
- (iv) Because the “no” answer rationales are logically inconsistent with a “yes” response to the question, checking both “yes” and “no” alternatives was recorded as a “no” response.

23. Of the two thirds of respondents who indicated that palliative care could NOT supply relief a majority (about two thirds) ALSO checked a box indicating they believed providing assistance to die was inconsistent with their ethical obligations. For the one third of respondents who believed palliative care COULD provide relief it was not axiomatic that euthanasia was therefore wrong. Of these respondents, about one half identified assisted dying as either morally neutral or morally right, although a clear majority also believed it would be unethical to themselves supply assistance.

24. About three quarters of respondents had experienced a patient request to die. Data do not indicate whether these were persistent requests or statements of distress.

IMPLEMENTING THE BILL

25. Respondents gave detailed consideration to the practical implications of the Bill’s implementation.

The hospice context and issues of competence

26. Most hospice in-patients are in terminal stages of cancer. Average length of stay is 13 days, with implications for the Bill’s operation in hospices.

27. Many of the decisional stages envisaged in the Bill raise problems regarding competence in terminally ill patients:

- (i) Anxiety, depression, and cognitive deterioration can make determining competence in terminally ill patients particularly difficult.
- (ii) Competence often fluctuates during terminal stages, so patients may be competent for one stage in the process the Bill provides, but not another.
- (iii) Symptom control (eg use of psychotropics) often adversely affects competence.
- (iv) Patients may be competent but unable to communicate their wishes.

Requesting euthanasia

28. Whilst the Bill anticipates it will be patients who initiate requests to die, some respondents reasoned it would become an ethical obligation to inform patients of their right to euthanasia. The average length of hospice stay, together with the required waiting period, would mean discussion of euthanasia would have to be initiated promptly. Respondents expressed concern that distressed patients and families would be compelled to consider euthanasia early in admission; but feared that if this was not done, some would object they had been denied information.

Respondents pointed out that many patients enter hospice fearful that death may be hastened by medical intervention. If hospices were required to initiate discussion of euthanasia these patients would cease to perceive them as safe havens.

29. Respondents envisaged difficulty in determining what constituted a request to die such that the 14 day waiting period clearly “started to run”. Patients raise euthanasia for varied reasons, including acknowledging impending death, encountering a setting where they may voice fears, or seeking reassurance. There was concern that such statements would have to be treated by staff as the first stage in a legal process rather than

a trigger for psychological support; and that patients might feel inhibited from expressing their feelings in case this was interpreted as a request for euthanasia.

30. Respondents pointed to patients' complex responses to the experience of terminal illness. Patients frequently experience feelings of hopelessness, when desire for death may be expressed; but these feelings are accompanied or superseded by unanticipated enjoyment of remaining periods of life.

Determinations of attending and consulting physicians

31. Difficulties in assessing competence have been set out above. It was argued that further clarification was required in relation to the rights of competent, terminally ill teenagers.

32. Informed decision making presents several problems:

- (i) Respondents urged attention to the lived experience of pain. They argued that experience of effective pain control is radically different from the promise of pain control, and cessation of pain almost unimaginable if symptom control has been poor. On this view, patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed.
- (ii) Respondents were concerned that the most vulnerable patients—very elderly, very ill or from deprived backgrounds—may have limited capability to process complex information about the course of their illness and treatment options.
- (iii) Terminal illnesses have differing trajectories, with some less predictable than others. As the course of a terminal illness decreases in predictability, increasingly complex information about symptoms, their management, and possible side effects, is required. Respondents argued it thus becomes correspondingly problematic to assess a patient as fully informed about treatment options.
- (iv) Respondents acknowledged that medical staff intentionally or inadvertently exert influence on decision-making through the way information is presented. It was emphasised that to make informed choices, patients will require clear, neutral communication from carers, and ready access to intelligible information.
- (v) The influence of family members and the availability of social support were regarded by many respondents as significant in determining how truly voluntary a request could be.

33. Respondents indicated potential confusion around physicians' roles in determining unbearable suffering. The Bill appears to define it as a subjective assessment by the patient. However, Ss 2(2)(d) and 2(3)(d) require that two physicians concur in finding that the patient is suffering unbearably. Some respondents concluded the Bill accorded precedence to the patient's view alone. Others concluded that if the physician was required to consider the patient's point of view, s/he may reasonably disagree with it.

34. Some respondents argued that where a physician is to conclude that a patient is suffering unbearably "as a result of that terminal illness" all palliative care options must first be exhausted. Further to this, a minority proposed that where patients are fully sedated, suffering is not unbearable. On this view, euthanasia as a "treatment of last resort" is never necessary.

35. To the extent that unbearable suffering is determined by clinical staff, respondents argued that multi-disciplinary teams are better placed to assess this than physicians alone.

36. Many respondents were concerned about the loose definition of terminal illness, contending that physician's prognoses are frequently over-optimistic.⁴¹

37. Respondents expressed concern that the consulting physician may not necessarily have expertise in palliative care. As with an attending physician who is not a palliative care specialist, s/he may not be qualified to conclude the patient was well-informed about palliative care options as the Bill requires (Ss 2(2)(e)(iv), 2(2)(f), 2(3)(e) and 2(3)(f)) or to give the patient information.

38. To the extent that referral to the consulting physician was intended as a safeguard there was anxiety around the scope for collusion, with patients referred to colleagues known either to favour or disfavour euthanasia. Conversely, it was unclear what would happen where the consulting and attending physicians disagreed, and whether this might lead to "opinion shopping".

39. Many respondents, irrespective of their own moral views, commented that if a patient were suffering unbearably, and euthanasia were a treatment option, the 14-day waiting period was excessive.

⁴¹ Paul Glare, Kiran Virik, Mark Jones, Malcolm Hudson, Steffen Eychmuller, John Simes and Nicholas Christakis "A systematic review of physicians' survival predictions in terminally ill cancer patients" *BMJ*, Jul 2003; 327: 195–0.

Psychiatric referral

40. Respondents argued that only a psychiatrist with specialist knowledge of mental states in terminal illness would be qualified to determine the issue of competence.

Continuing care

41. Respondents expressed concern that once a patient was on the “assisted dying track”, attention would be deflected from seeking and providing the best palliative care. Were it necessary to maintain patient competence throughout the process, symptom control could be compromised through excluding treatments adversely affecting competence.

Legal and lay witnesses

42. Respondents questioned whether—in anything but straightforward cases—a solicitor or lay witness could affirm that patients were of “sound mind”. Terminally ill patients’ fluctuating competence, and the impact of medication, again raised concern.

43. Doubt arose whether legal or lay witnesses could determine that decisions were truly voluntary, particularly where patients saw themselves as burdens on carers and family.

44. Given the restricted classes, finding suitable lay witnesses was thought to present difficulty. It was argued that lay witnesses were expected to discharge an onerous task particularly where there may be differences among family members.

45. On current wording, it is unclear whether hospice volunteers could act as lay witnesses.

46. It is unclear what consequences would flow should witnesses revise their view on whether patients were of sound mind, or their decisions voluntary, subsequent to signing the declaration.

Procuring death

47. Respondents expressed concern that the Bill does not stipulate that patients be competent when advised of the right to revoke. As S 2 and S 3 operate as qualifying conditions for S 4, assistance to die may apparently be provided where a patient becomes incompetent after completion of the declaration; and is therefore incapable of understanding, or exercising, their right to revoke.

48. Respondents suggested that patients may find it difficult to assert a change of mind at this stage, in the face of the emotional and practical investments made by carers and family.

49. Some respondents expressed concern that revocation appears to be “once and for all”. They wondered how flexible patients could be in choosing the moment of death or whether a request to postpone the time of death would be deemed a revocation. Some speculated that if the declaration operated flexibly it might function as an “insurance policy” for patients. Patients might be supported to die naturally because they had the “reassurance” of being able to seek assistance should they need it.

50. Respondents suggested that permitting the attending physician to act alone at the final stage, with no witnesses present to observe dealings with the patient, raised problems of accountability.

51. Difficulties may arise where euthanasia is inconsistent with hospice charitable objects, and memoranda and articles of association.

August 2004

Memorandum by the Linacre Centre for Healthcare Ethics

RESUME

Euthanasia is standardly defended by reference to one or both of two considerations: autonomy and welfare. Either consideration can lead to much more widespread euthanasia than defenders of its legalisation had originally envisaged. If euthanasia is about patient choice, why should the patient need to be terminally—or physically—ill to receive it? If euthanasia is about benefiting the patient, why should patients who cannot request it be deprived of this benefit? Thus we see in the Netherlands an extension of euthanasia to those who are mentally ill or “tired of life”, and also to significant numbers of patients who have not consented to it—including patients who could have consented but in fact have not. In this submission, we argue that respect for the patient’s life is part of respect for the patient’s human dignity, and that palliative care, not euthanasia,

is the morally appropriate response to terminal suffering. The law should continue to uphold human dignity and equality by prohibiting homicide/assisted suicide for disabled and able-bodied alike. Suicidal people should not be confirmed in their own estimate of their lives' value; instead, they should be supported and protected, whatever their physical condition.

1. INTRODUCTION

The Linacre Centre for Healthcare Ethics⁴² is a research institute under the trusteeship of the Catholic Trust for England and Wales. We publish material, run conferences and provide speakers on a range of bioethical issues, and also offer advice and information to individual health professionals and patients. We welcome the opportunity to contribute evidence to the Committee on the Assisted Dying for the Terminally Ill Bill, and would be pleased to respond to any questions the Committee may wish to raise on this evidence, or on related issues.

2. RESPECT FOR LIFE

The Catholic Church holds—in common with other faiths—that human life is a gift from God, to be cherished and protected. In the Jewish and Christian understanding, human beings are created in the image and likeness of God, and God's loving care extends not only to the strong and well but to those who are suffering in body and mind. We do not have absolute dominion over our lives, but hold them in stewardship from God. The appropriate response to human suffering is solidarity with, and care for, the sufferer; it is not deliberate killing of that person, with or without request. Respect for a human being cannot be divorced from a valuing of, and respect for, that person's presence in the world.

The Church teaches that the fundamental moral principles of Christianity are accessible to human reason, without reliance on revelation. Thus the secular belief in human equality, enshrined in the Universal Declaration of Human Rights of December 1948 (since recognized by the European Convention on the Protection of Human Rights and Fundamental Freedoms) squares well with the teaching of the Church on the basic equality of human beings. Human beings are "equal" at a deeper level than their varying mental or physical condition might suggest: they are equal in their nature and basic dignity as human beings. An essential part of respect for human dignity is respect for the value of human existence: human bodily life. A valuing of each person's life, and a refusal to attack that life as "worthless" or "unwanted" by that person or others, is integral to a society in which all are valued and protected.

2.1 *Suicide Act 1961*

Thus the Suicide Act 1961 protects all members of society equally from assistance in suicide. The Act does not discriminate between disabled and non-disabled suicidal people: there is no suggestion that disabled people, unlike other suicidal people, have lives of doubtful worth which may therefore be curtailed. Many disabled people welcome the protection the Act provides from pressures to ask for "help in dying" which they themselves might feel at times of pain or despair. While decriminalizing suicide itself, out of concern for the survivor of a failed suicide attempt, the Act nonetheless treats suicide as contrary to the wider public policy of upholding human dignity and equality by excluding participation in intentional killing.⁴³ In its prohibition of assisting suicide, the Act is a central component in the network of laws protecting the vulnerable.

3. DEFENCES OF EUTHANASIA

What are the ways in which voluntary euthanasia (and assisted suicide, which is not significantly different) are standardly defended? Euthanasia is normally defended by reference to one or both of two considerations: autonomy and welfare—the latter assumed to include the timely ending of a life thought "worthless" or "undignified." These two considerations pull in different directions, and each in its own way can encourage a widespread practice of euthanasia, not limited to the cases permitted by the Assisted Dying for the Terminally Ill Bill. In the Bill itself, this tension between autonomy and welfare, and logical pressure to expand the grounds for euthanasia, are very much in evidence.

⁴² This submission has been prepared by Dr Helen Watt, the Director of the Centre, in consultation with Professor Luke Gormally, Senior Research Fellow at the Centre, Anthony McCarthy, the Centre's Research Fellow, Professor John Finnis of Oxford University and Professor John Keown of the Kennedy Institute of Ethics. Professor Gormally has also made a personal submission to the Committee.

⁴³ After the decriminalization of suicide itself by the Suicide Act, "the policy of the law remained firmly adverse to suicide, as section 2 (1) [of the 1961 Act] makes clear". The 1961 Act "conferred no right on anyone [to commit or attempt to commit suicide]" (Lord Bingham in *Regina (Pretty) v. Director of Public Prosecutions* (2001), para 35).

3.1 *Autonomy*

The stress on the patient's autonomy, and subjective assessment of the value of his or her life, can be seen in the way "unbearable suffering" is given a purely subjective definition in the Bill: suffering, whether mental or physical, which the patient him or herself finds unacceptable. While the Bill requires the patient to be informed on alternative responses to his or her suffering, such as palliative care, a patient who rejects such alternatives, and states that the suffering is unbearable, may then be "helped to die". Although doctors conscientiously opposed to euthanasia will not be required to perform it, they will be required by the Bill to refer the patient to a more compliant colleague. Thus doctors will not be permitted to respect what they reasonably regard as the patient's best interests, but will be required to transfer the patient to someone they think will act in a way directly contrary to those interests. There is a negation here of the doctor's right to protect (or at least, not to threaten) the patient's interest in life, in favour of the patient's presumed right to secure an end to his or her existence. Even a patient who is suffering "unbearably" can, the Act assumes, make a free choice to die which is not unduly influenced by depression or lack of knowledge of alternatives.

However, this emphasis on the patient's wish to die (rather than receive, for example, palliative care) is combined in the Bill with a requirement that the patient be terminally ill for euthanasia to be performed. It is difficult to see why this should be required: if the patient's suffering, whether mental or physical, is unacceptable to the patient, why is it relevant what the source of the suffering is? Why introduce this one "objective" criterion of the patient's closeness to death, given that the suffering caused by a non-terminal illness, mental or physical, may be no more acceptable to a patient than that caused by a terminal illness?

3.2 *Welfare*

There is, in short, a wish to set some limits on patient autonomy and the presumed right to die.⁴⁴ Most supporters of euthanasia would not defend it in cases where the patient was suffering from some purely temporary condition. This is because they see euthanasia as defensible not simply as something wished for by the patient, but as something which is in the patient's interests, objectively defined. Life, they think, has no value in some situations, though not in every case in which death might be sought; in particular, life has no value if the patient cannot look forward to any improvement in a serious and distressing illness.

However, once a "welfare" view of euthanasia is adopted, there is once again a "slippery slope" to other forms of euthanasia than those involving terminal illness, or indeed a voluntary request. The very existence of some human beings is seen as a bad or worthless thing, so that death is in such people's interests. But if this is true, why should euthanasia not be given to the chronically ill? And why should it not be given to children and the mentally incapacitated, who will also "benefit" from it, but are unable to request it?

4. THE NETHERLANDS

The position of euthanasia advocates who stress both "autonomy" and "welfare" considerations is inherently unstable. There is not just a "logical" but a "practical" instability: either consideration can lead in practice to much more widespread euthanasia than was originally envisaged in official guidelines. Thus in the Netherlands we see both an extension of euthanasia to those who are mentally ill or "tired of life"⁴⁵ and its extension to those who are unable to consent, such as infants and young children.⁴⁶ Indeed, there is now official toleration of non-voluntary euthanasia, in that (for example) euthanasia of children is required to be reported. In 2001, 100 out of 1,088 deaths of babies under one year of age involved the giving of drugs with the explicit purpose of ending life.⁴⁷

Three major Government-ordered studies of euthanasia and other end-of-life decisions have been carried out in the Netherlands, where euthanasia was accommodated for many years by court decisions before being legalized by statute. These studies show a far from reassuring picture with regard to observance of guidelines,

⁴⁴ Few would argue that patient autonomy should be an overriding consideration in medicine generally. A doctor would not normally amputate a finger, or assist a patient in self-amputation, merely because this was requested.

⁴⁵ With regard to grounds for euthanasia, 3 per cent of doctors say that they have themselves assisted suicides of people "tired of life" who did not have any serious somatic or psychiatric ailment (G van der Wal, A van der Heide, BD Onwuteaka-Philipsen & PJ van der Maas, *Medische Besluitvorming aan het einde van het leven: De praktijk en de toetsing procedure [Medical Decisionmaking at the End of Life: The Practice and the Review and Verification Procedure]* (Utrecht, 2003), p 104, Table 10.2). 29 per cent of doctors consider this an acceptable motive for assisted suicide (*Ibid.*, p 107).

⁴⁶ In Belgium, too, where euthanasia has recently been legalized, a member of the Belgian House of Representatives, Madame Avontroot, claims that many cases of non-voluntary euthanasia are performed, without even the family's consent, and that the number of cases registered after a year (2003) is far below the real number (see the electronic briefing of the Institut Européen de Bioéthique *Quality of Life—Spécial Belgique* January–June 2004, p 8). The president of a commission evaluating the law on euthanasia, Dr Distelmans, recently called for the law to be extended to minors and those with degenerative conditions such as Alzheimers who had made an advance request (*Ibid.*, p 2).

⁴⁷ Van der Wal, van der Heide *et al.*, p 121.

including the requirement that the patient give consent.⁴⁸ In the studies, the term “euthanasia” is used in the official Dutch sense of “active voluntary euthanasia”; moreover, not all deliberate life-terminating acts—let alone deliberate life-terminating omissions—are classed as “euthanasia”, “assisted suicide” or “life terminating acts without request”. To arrive at a more realistic, though still conservative, figure for euthanasia in the Netherlands, it is necessary to count all acts—and if possible, omissions⁴⁹—on the part of doctors which are chosen with the “explicit intention” (or “explicit purpose”) of ending life. These figures are available for 1990 and 1995; however, the data for 2001 make it impossible to determine the exact level of (for example) non-voluntary active killing, since doctors who gave intentional overdoses of painkillers with the intention of hastening death were not asked, as in previous years, if the patient had consented.

4.1 Compliance with guidelines

When we read that 900 patients were deliberately killed without their request in 1995 (a figure which rose to 980 in 2001) we should remember that this figure, alarming as it is, does not include 1,537 cases where palliative drugs were given with the explicit, unrequested aim of hastening death.⁵⁰ If we include this group of cases, it becomes clear that more than a third of those actively killed were killed non-voluntarily. Even excluding this group of cases of active non-voluntary euthanasia, one in five of those actively killed were killed without their request.⁵¹ If we turn to euthanasia by omission, there were as many as 18,000 such cases in 1995,⁵² of which 14,200—a substantial majority—were without the patient’s request. It is worth noting that by no means all the patients killed without request, whether by act or by omission, were incompetent at the time.⁵³

4.1.1 Reporting

It is often said that euthanasia will be better controlled where it can be freely reported.⁵⁴ In fact the Dutch experience shows widespread underreporting, in addition to widespread disregard of other guidelines. About half the cases of “euthanasia” and “assisted suicide” revealed by the 2001 survey went unreported, as did 99 per cent of cases of termination of life without the patient’s request, 100 per cent of cases of intentional lethal overdose of painkillers (whether requested or unrequested), and a huge majority of cases where the patient killed was a child.⁵⁵

This is in line with earlier research, which found that between 15 per cent and 20 per cent of doctors said they would not report their euthanasia cases under any circumstances, and that 20 per cent of doctors’ most recent unreported cases involved ending life without consent.⁵⁶ Such cases, both the 1990 and 1995 studies revealed, were virtually never reported.⁵⁷ Even where euthanasia takes place “with consent”, there is a real possibility

⁴⁸ For an in-depth analysis of the first two studies, together with much other useful material, see J Keown, *Euthanasia, Ethics and Public Policy* (Cambridge, 2002). For a summary statement of striking results of these studies which come into view when the terminological ambiguities are clarified, see J Finnis, “Euthanasia, Morality, and the Law”, *Loyola University of Los Angeles Law Review* 1998, Vol 31, pp 1123–45 at pp 1125–8.

⁴⁹ As John Keown comments on the 1995 study, “A note to the relevant questions [on withholding/withdrawing treatment with the explicit intention/purpose of hastening death] states that an intention to ‘hasten the end of life’ could also be understood as an intention ‘not to prolong life’. This creates an unfortunate ambiguity . . . An intention not to prolong life is not the same as an intention to end it. In many of these cases doctors may have intended to withhold/withdraw treatment not to end the patient’s life, but because the treatment was futile or too burdensome” (*op cit*, pp 129–130).

⁵⁰ PJ van der Maas *et al*, “Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands”, *New England Journal of Medicine* 1996, Vol 355, p 1704.

⁵¹ Keown, *op cit*, p 128. The larger figure includes assisted suicide.

⁵² See note 8.

⁵³ Indeed, of those killed without their request, between 25 per cent and 40 per cent (depending on the series studied) were capable of making a request, but did not do so. See Finnis, *op cit*, at p 1126; Loes Pijnenborg *et al*, “Life-Terminating Acts Without Explicit Request”, *Lancet* 1993, Vol 341, pp 1165, 1197; The New York State Task Force on Life and the Law, *When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context* (1994), p 134 n 31; J Keown, “Euthanasia in the Netherlands: Sliding Down the Slippery Slope”, in J Keown (ed), *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (Cambridge, 1995), at p 292 n 104.

⁵⁴ A comparative study of six European countries (A van der Heide *et al*, “End-of-life decision-making in six European countries: descriptive study”, *Lancet* 17 June 2003, published online at <http://image.thelancet.com/extras/03art3298web.pdf>) shows a high rate of euthanasia in the Netherlands, and a relatively high, if not the highest, rate of non-voluntary life termination. (It is worth stressing that not all cases of active non-voluntary killing—much less non-voluntary killing by omission—will be included in these figures.)

⁵⁵ R Fenigsen, “Dutch Euthanasia: The New Government Ordered Study”, *Issues in Law and Medicine* 2004, Vol 20, No 1, p 77. It is striking to note that in 3 per cent of these cases, the baby was euthanised without the consent or knowledge of the parents (Van der Wal, van der Heide *et al*, Table 12.2) and that similarly in three cases older children were euthanised without the request of either the child or the parents (Table 13.2).

⁵⁶ Van der Wal *et al*, “Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands”, *New England Journal of Medicine* 1996, Vol 335, p 1708.

⁵⁷ H. Hendin, “The Dutch Experience”, *Issues in Law and Medicine* 2002, Vol 17, No 3, p 230.

of pressure being brought to bear by doctors and/or relatives. It is startling to note that more than 50 per cent of doctors surveyed thought it appropriate to suggest euthanasia to patients.⁵⁸

As one researcher comments, “When, as the 1990 and 1995 studies document, 59 per cent of Dutch physicians do not report their cases of assisted suicide and euthanasia, when more than 50 per cent feel free to suggest euthanasia to their patients, and when 25 per cent admit to ending patients’ lives without the patient’s consent, it is clear that terminally ill patients are not adequately protected.”⁵⁹ Most striking of all, in both the 1995 study⁶⁰ and the 2001 study,⁶¹ the authors suggest that it is the patient who is responsible for avoiding termination of his life: if he does not wish euthanasia, he should say so clearly, orally and in writing, well in advance.

5. PALLIATIVE CARE

What then, should the terminally ill patient be offered in place of euthanasia, which the Dutch experience over many years has shown to be impossible to contain? Euthanasia in the Netherlands has been linked to poor palliative care, though such care is improving. Thankfully, the hospice movement in the UK is particularly strong; however, efforts must certainly continue to extend high quality care to all who need it.⁶²

We warmly endorse the holistic care provided, in particular, in the hospice setting: care responding to the patient’s physical, social, psychological and spiritual needs. It is worth remembering that drugs are not the sole response to the emotional distress a terminally ill person may experience. For this reason, we would question the wording of Clause 15 in the Assisted Dying for the Terminally Ill Bill, which gives the patient a right to “request and receive” drugs which “may be necessary to keep him free as far as possible from pain and distress”. Without denying that drugs are sometimes needed to treat mental, as well as physical, suffering, it is the experience of those working in palliative care that patients can often be otherwise assisted to a point where they are fully reconciled with their situation, and able to use their last days to the full. Drugs are often not the best response to mental distress, and it wrong to require that such distress be removed “as far as possible” by such drastic measures as making the patient unconscious throughout the dying period. It should be for the palliative care team to determine when there is no better response than sedation to mental suffering, though this option must be kept in mind.⁶³

We would emphasise the moral importance of intention in regard to palliative care (and indeed, human action generally). It is often permissible to accept a foreseen but unintended side-effect such as the shortening of life, or the patient’s inability, due to sedation, to engage in social or spiritual activities. While it is normally the case that palliative drugs are more likely to extend than to shorten the patient’s life, where the reverse is true, their use can still be justified, if the life-shortening side-effect is balanced by the intended effect of treating pain. The same can be said of the side-effect of shortening life as a result of stopping treatment which is burdensome to the patient. There is a significant difference between continuing to value the patient’s life, while foreseeing that it will be shortened by giving or omitting treatment, and seeing life as having no value, and thus to be deliberately curtailed.

6. CONCLUSION

To conclude: a doctor’s willingness to kill some patients—whether because this is their “choice” and/or because the doctor thinks their lives have no value—undermines a commitment to the patient’s true welfare which is basic to medicine. Voluntary euthanasia is not a “private” choice: it very much affects (among other things) the character of doctors, and their treatment of other patients. Once legalized, euthanasia would become a “quick fix” for disposing of “difficult” patients in response to the demands they make on care. Medicine would be robbed of the incentive to find genuinely compassionate solutions to the difficulties presented by such patients. The kind of humane impulses which have sustained the development of hospice medicine and care would be undermined, because too many would think euthanasia a cheaper and less

⁵⁸ PJ van der Maas, JJM van Delden and L Pijnenborg, *Euthanasia and Other Medical Decisions Concerning the End of Life* (1992), pp 101–2.

⁵⁹ Hendin, *op cit*, p 234.

⁶⁰ G van der Wal and PJ van der Maas, “Euthanasie en andere medische beslissingen rond het levenseinde: De Praktijk en de Meldingsprocedure [Euthanasia and Other Medical Decisions Concerning the End of Life: The Practice and the Notification Procedure] (The Hague, 1996), p 237.

⁶¹ Van der Wal, van der Heide *et al*, p 201.

⁶² It is also important to safeguard the hospice movement itself from any euthanasiast influences. To avoid the deliberate hastening of death—as opposed to the acceptance that death will occur—is central to the hospice ethos.

⁶³ We are assuming here that there is no intention to hasten death. In fact, “terminal sedation” is sometimes carried out with precisely this intention: the patient is sedated and feeding is withheld, not simply as futile or burdensome, but with the aim of ending life. Such euthanasia by omission is, in our view, morally comparable to active euthanasia.

personally demanding solution.⁶⁴ Doctors would be mistrusted by patients, who would die in an atmosphere of suspicion. Many patients would be killed without request, even if this remained illegal. The suicidal would be confirmed in their estimate of their lives' value, while the non-suicidal would be, at least, disheartened by the public view of lives such as theirs. For all these reasons, it is vitally important that society continue to value the lives of all its members, including those who, in pain or distress, do not see their own lives as worthwhile. Euthanasia betrays the suicidal by accepting their own view of their lives: suicidal people, whatever their physical condition, need protection and support.

Memorandum by Macmillan Cancer Relief

1. Macmillan Cancer Relief is a national charity that works to provide people who have cancer, and their families, with expert nursing and medical care as well as emotional and practical support. Macmillan Cancer Relief has been closely concerned with the development, quality and monitoring of palliative care since the charity was established at the beginning of the last century.

2. Macmillan has taken the position that, given our present state of knowledge and the existing legal situation, we will not take a stance on assisted suicide. Our decision is influenced by a number of key principles which we believe should govern an end-of-life policies and services:

- Patients should be enabled to exercise choice and make personal decisions.
- To exercise choice, patients and families need access to information about options.
- Health and social care professionals need to be sensitive to patients' personal circumstances and beliefs.
- Healthcare professionals need to be supported and trained to openly discuss end of life issues with colleagues, patients and their families.
- There should be access to supportive and palliative care for all to enable people to die in the place of their choice, including their home, if they so wish.
- There is a need for research into patient and carer views at end of life.

3. Macmillan Cancer Relief believes that greater access to high quality supportive and palliative care is vital for cancer patients. We believe that everything possible should be done to alleviate a patient's pain and distress by managing their symptoms and also by providing appropriate psychological and emotional support to patients. However, we recognise that a small number of people who are terminally ill have symptoms which cannot be relieved by palliative measures.

4. Macmillan believes that the debate around end of life issues has been dominated by the medical and legal professions and the media, but that the views and wishes of patients and carers have been absent. More robust research needs to be undertaken to understand these views.

3 September 2004

Memorandum by CARE

1. INTRODUCTION

1.1 CARE is a supporter-based Christian charity incorporating more than 160 pregnancy crisis centres, fostering and remand fostering initiatives and day care for people with learning disabilities. In addition to social care and educational programmes, CARE undertakes research and lobbying on associated issues in the parliaments and assemblies of the United Kingdom, European Union and United Nations.

1.2 CARE welcomes this opportunity to make a contribution to the work of the Select Committee on the Assisted Dying for the Terminally Ill Bill ("the Committee"), and is grateful for the time given by the Committee to consultation with the public and other interested groups.

1.3 CARE's 100,000 supporters have been interested in the issue of terminal care management for over 20 years and on their behalf, CARE's Public Policy team has submitted evidence to a large number of committees considering the issue. These included the House of Lords Select Committee on Medical Ethics and inquiries by the Law Commission into Mental Incapacity.

1.4 CARE has regularly tested its members' views on key issues such as the withholding and withdrawal of treatment and the use of "advance declarations". Their views remain strongly opposed to any change in law that would weaken the prohibition of intentional killing or permit doctors and nurses to assist in shortening the life of patients.

⁶⁴ See the Linacre Centre's 1993 *Submission to the Select Committee of the House of Lords on Medical Ethics*, 6.1.3 (5), published in L Gormally (ed), *Euthanasia, Clinical Practice and the Law* (London, 1994), pp 154–5.

1.5 The wider issues surrounding euthanasia have been debated at length in a variety of contexts, including the House of Lords Select Committee on Medical Ethics. We take it as axiomatic that the legalisation of euthanasia or assisted suicide would fundamentally alter the ethos of medical care, undermine the trust that elderly, disabled and terminally ill patients can vest in medical professionals and lead to pressure on vulnerable patients to consider ending their lives when they would otherwise take advantage of legitimate healthcare options. We do not intend to rehearse those arguments at length, but will limit our comments to the provisions of the Assisted Dying for the Terminally Ill Bill itself.

2. GENERAL COMMENTS

2.1 CARE is opposed to the Assisted Dying for the Terminally Ill Bill as it permits voluntary euthanasia, that is the intentional killing of a patient by act or omission as part of their medical care.

2.2 CARE holds that no new evidence has been brought forward which should undermine the work, report and considered conclusions of the House of Lords Select Committee on Medical Ethics. Their findings included the following:⁶⁵

- There should be no change in law to permit euthanasia (Recommendation 278).
- We strongly endorse the right of the competent patient to refuse any medical treatment (Recommendation 279).
- We do not recommend the creation of a new offence of mercy killing (Recommendation 293).
- We recommend no change in law on assisted suicide (Recommendation 295).

2.3 CARE recommends that the Committee reject the Bill, which is flawed in principle, drafting and practice. Nor do we consider that the legislation could be so improved as to make it either desirable or safe for the terminally ill, disabled or mentally incapacitated.

2.4 We observe that current legislation provides an effective framework for handling end of life issues.

3. COMMENTS ON CLAUSES OF THE BILL

The long title of the Bill

The long title of the Bill suggests that it is intended to “*enable a competent adult who is suffering unbearably as a result of terminal illness to receive medical assistance to die at his own considered and persistent request; and to make provision for a person suffering from a terminal illness to receive pain relief medication.*”

CARE believes that the phrase, “to make provision for a person suffering from a terminal illness to receive pain relief medication” is misleading. Although Clause 3 requires that a specialist in palliative care has attended the patient to discuss the option, the Bill establishes nothing in this regard that is not already common medical practice in the United Kingdom.

CARE holds that the phrase “medical assistance to die” is also disingenuous. Under the definitions of the Bill, “assisted dying” can and would include the actual killing of a patient as opposed to assisted suicide or assisted death. While the Bill and its language seek to give the impression that the aim of the legislation is to allow clinicians to help patients through the natural process of death, it is clear that the Bill deals with the assisting of suicide or purposefully killing.

Clause 1 (Authorisation of Assisted Dying)

Clause 1 of the Bill provides that “subject to the provisions of this Act, it shall be lawful for a physician to assist a patient who is a qualifying patient, and who has made a declaration in accordance with this Act that is for the time being in force, to die.”⁶⁶

CARE contends that the Bill establishes an exception to the offence of intentional killing. Under the Bill, a doctor can end the life of his or her patient, albeit under specific circumstances, and not be prosecuted for that action.

With this in mind, CARE refers the committee to the report of the Medical Ethics Select Committee 1994 and their findings relating to the legal prohibition on intentional killing:

⁶⁵ Page 58, House of Lords Report of the Select Committee on Medical Ethics, Vol 1.

⁶⁶ Assisted dying is defined as providing the patient with the means to end the patient’s life or, if the patient is physically unable to do so, ending the patient’s life.

- (a) Belief in the special worth of human life is at the heart of civilised society. It is the fundamental value on which all others are based, and it is the foundation of both law and medical practice. The intentional taking of human life is therefore the offence which society condemns most strongly. (Paragraph 34)
- (b) The prohibition [of intentional killing] is the cornerstone of the law and social relationships. It protects each of us impartially, embodying the belief that all are equal. We do not wish that protection to be diminished and we therefore recommend that there should be no change in the law to permit euthanasia. We acknowledge that there are individual cases in which euthanasia may be seen by some to be appropriate. But individual cases cannot reasonably establish the foundation of a policy which would have serious and widespread repercussions. Moreover, dying is not only a personal or individual affair. The death of a person affects the lives of others, often in ways and to an extent which cannot be foreseen. We believe that the issue of euthanasia is one in which the interests of the individual cannot be separated from the interest of society as a whole. (Paragraph 237)
- (c) . . . issues of life and death do not lend themselves to clear definition, and without that it would not be possible to frame adequate safeguards against non-voluntary euthanasia if voluntary euthanasia were to be legalised. (Paragraph 238)
- (d) As far as assisted suicide is concerned, we see no reason to recommend any change in the law. We identify no circumstances in which assisted suicide should be permitted, nor do we see any reason to distinguish between the act of a doctor or any other person in this connection. (Paragraph 262)

CARE argues, in line with the findings of the Medical Ethics Select Committee and of other previous select committees, that the prohibition on intentional killing should not be weakened by the legalisation of assisted suicide. It would be impossible to establish sufficient checks for it to be safe to allow doctors to be treated differently in this connection.

Clause 2 (Qualifying Conditions)

Clause 2 establishes a number of conditions that must be met before the attending physicians should be able to allow the patient to die. It is CARE's view that the clause represents a number of potential difficulties.

Clause 2 (2a) requires that the patient shall have informed the attending physician that he or she wishes to die. The clause does not stipulate what should constitute a request to be assisted to die, thereby beginning the process given under the Bill. Presumably, a request made when the patient is suffering from pain or distress that could be relieved through appropriate palliative care would qualify.

CARE believes that this would potentially set the patient on a course resulting in euthanasia and limit the potential for legitimate health care options.

Clause 2 (2b) stipulates that the attending physician consider the patient's medical records and establish that there is no reason to believe that the patient is incompetent, where "incompetent" means not having the capacity to make an informed decision. CARE believes that there are a variety of problems with this condition:

- The definition of incompetence is vague. CARE does not believe that the clause is fit for any objective criteria for establishing competence and, moreover, would argue that the desire to end one's own life could potentially be an indication of mental incompetence.
- The physician, who must only be a registered medical practitioner, may not have the aptitude or expertise to establish that the patient is or is not competent.
- This provision creates a clear potential for "doctor shopping" where patients who are denied a request on the grounds on mental incompetence would seek to be treated by a doctor more likely to agree to his request.
- CARE suggests that the Committee should seriously consider the implications of the Bill that establishes euthanasia as a normal part of medical treatment if the Mental Capacity Bill should become law, particularly if proxy decision makers would be able to request the active commission of euthanasia on behalf of a patient without capacity, and whether this could be considered to be in the patient's best interests.⁶⁷

⁶⁷ Clause 1(5) of the Mental Incapacity Bill establishes that "an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests. Clause 4(1) of that Bill states that the person making the determination on best interests must consider "all the circumstances appearing to him to be relevant", while Clause 4(2)–(6) establish a number of particular factors, such as "beliefs and values" that would influence decisions, or "past and present wishes or feelings".

Clause 2 (2c) states that the attending physician should have made the determination that the patient has a terminal illness, where terminal illness means an illness which in the opinion of the consulting physician is inevitably progressive and which will result in the patient's death within a few months at the most.

CARE believes that the definition of terminal illness, which relies on the opinion of the consulting physician of death within a few months, is unavoidably subjective and indefinite. Given the wilfully imprecise nature of this definition, it would be very difficult to determine which patients would not meet the qualifying conditions.

Clause 2 (2d) stipulates that the attending physician must have concluded that the patient is suffering unbearably, where unbearable suffering means suffering by reason of pain or otherwise which the patient finds so severe as to be unacceptable and results from the patient's terminal illness.

Again, CARE holds that this provision would be impossible to apply in practice—does it relate to physical suffering or mental and emotional suffering also? Does it apply when appropriate palliative care is in place or when it is withheld? Clearly, the Clause would not preclude “perceived” suffering, such as frustration over the loss of movement.

Indeed, “suffering” and “pain” are complex terms, subjectively felt within a network of different factors—not all are physical but some are social, mental, or spiritual. The decision cannot be made by the attending physician, or perhaps even by the patient. The decision can also change over time, stages of illness and depending on the treatment available.

Clause 2 (2e) requires that the attending physician inform the patient of his medical diagnosis, prognosis, the process of being assisted to die and the alternatives to assisted dying.

CARE argues that the patient's continuing decision will depend much on how the patient is informed of these factors, not just that they are informed. The process then is open to considerable abuse, and patients may be given information or medical advice that is “leading” or unsympathetic to their values.

Clause 3 (Offer of palliative care)

Clause 3 is superfluous, and seems to be intended to divert attention from the genuine objective of the Bill.

CARE is also concerned that the Bill in general takes a tick-box approach to palliative care. Patients may be made aware of its availability, but may not be aware of its potential in relieving pain and maintaining quality of life.

Clause 4 (Declaration made in advance)

CARE believes that there are considerable problems, particularly with the witnessing provisions of the Clause. For example, the solicitor must ascertain that the patient is of sound mind and has made the decision voluntarily—again, it is questionable that he or she would be able to make this judgement.

Furthermore, it is unclear who will be able to perform as the second witness. Neither the attending physician, consulting physician, psychiatrist, member of the medical care team, relative or partner may serve as the second witness.

CARE recognises that this is intended to reduce the potential of abuse, but argue that it is ineffective. Indeed, it seems that the second witness would provide no check against abuse, given that it would potentially be someone who is not familiar with the patient or his or her illness and would, again, be unqualified to judge whether the patient is competent, understands the implication of his or her decision and, furthermore, has made the decision voluntarily.

No provision is made in the Bill for witnessing third parties (ie, consulting physicians, witnesses) to actively prevent the process of euthanasia if they believe that the patient's request for assisted death is involuntary.

Clause 5 (Further duties of attending physician)

Clause 5 sets out further duties for the attending physician, including the need to inform the patient of his right to revoke the declaration. However, the Bill does not deal with the question of what status the declaration should have should the patient lose his or her ability to revoke the declaration or his become mentally incapacitated or unable to communicate their a desire to revoke the declaration during that time. Indeed, it seems that it would remain in force. Clause 5, therefore, represents an inadequate safeguard against abuse.

Clause 6 (Revocation of declaration)

Clause 6 stipulates that a patient may revoke a declaration without regard to physical or mental state.

Again, CARE argues that the clause offers insufficient safeguards, as a patient may well lose the actual physical capacity to revoke a declaration and to communicate that decision effectively (a definition of capacity within the Mental Capacity Bill). Moreover, that patient may be able to revoke the declaration without regard to his mental state, but he may become unaware of his previous decision and of its significance.⁶⁸

Clause 7 (Duties of physicians, and conscientious objections)

Clause 7 provides that no person is under a duty to, whether by contract or by any statutory or other legal requirement, to participate in any diagnosis, treatment or other action authorised by the Bill to which he has a conscientious objection.

CARE argues that the clause is ineffective, since there is an obligation to become materially involved in a process of referral. It is both illogical and unreasonable to conclude that a physician whose conscience would be violated by performing or participating in assisted dying or voluntary euthanasia would then be content with passing his patient to a doctor who will commit euthanasia.

Clause 8 (Psychiatric referral)

Clause 8 provides that physicians who believe that the patient may be incompetent must make a referral to a psychiatrist.

CARE is concerned about the limited nature of the provision and that a referral to a psychiatrist is not an integral part of establishing competency on the part of the patient. It is also unclear why the attending and consulting physician can take the view that a patient is not incompetent (as in Clause 2 (2b)) but is deemed incapable, and must seek the psychiatric referral, if finding the patient incompetent. In other words, a higher standard of evidence is required to establish that the patient should not receive assistance to die than to establish that he meets the qualifying conditions. We fear that this may create a situation where it is easier for a doctor to carry out euthanasia than it is to withhold it.

Furthermore, the psychiatrist may only give a narrow determination (that the patient is not suffering from a psychiatric or psychological disorder causing impaired judgement) and thus presents a very low hurdle taking no account a variety of subtle judgements that a psychiatrist could make.

This clause, like others, would leave no room for objective definition. What can be considered a psychiatric or psychological disorder causing impaired judgement?

Clause 9 (Notification of next of kin)

Clause 9 establishes that the attending physician shall recommend that the patient informs his or her next of kin of the request for assistance to die.

CARE expresses surprise that there is only a requirement to recommend that the patient informs his or her next of kin, and that there is not an absolute requirement that the next of kin be notified.

The implications for third parties are clearly worrying. Firstly, it may be the case that third parties such as family members hold information relating to specific qualifying conditions which the attending and consulting physicians do not (ie, evidence of mental incapacity). Secondly, a close relative or carer may, for instance, return from holiday to discover that a terminally ill loved one had received assistance to die.

Again, CARE draws the attention of the committee to the conclusions of the Medical Ethics Select Committee, which found that “dying is not only a personal or individual affair”. CARE is surprised at the extent to which absolute autonomy is placed at the heart of the Bill, and while there is a clear need to respect and defend the principle patient autonomy we argue that we must also establish limits where choice affects and impacts upon third parties and society at large.

⁶⁸ The ability to retain information is another possible criteria for mental capacity, given under Clause 3 of the Mental Capacity Bill.

Clause 10 (Protection for physicians and other medical personnel)

Clause 10 establishes protection for physicians and other medical personnel who have acted in good faith in accordance with the Act.

We are concerned that the clause establishes a “good faith” defence where euthanasia has been committed outside the conditions of the Bill, increasing the potential for abuse.

Clause 12 (Insurance)

Clause 12 requires that no insurance policy that has been in force for 12 months or more shall be invalidated by reason of a doctor having assisted a qualifying patient die in accordance with the Act.

CARE argues that the clause provides further opportunity for abuse of the patient. His or her death presents potential for pecuniary gain for third parties.

Even if third parties do not seek to persuade the patient to request assistance to die the potential to benefit third parties may convince a patient to request assisted suicide where they would not in other circumstances.

Clause 14

Clause 14 establishes a monitoring commission that will monitor the workings of the Act and all medical practitioners who have assisted a patient to die will forward all medical records for consideration by the three Commissioners.

The commission shall receive the medical files and consider if the qualifying conditions have been met. If they believe that they have not, they shall refer the matter to the coroner (or procurator fiscal in Scotland) for further investigation.

CARE notes that the requirement to report to the monitoring commission in the Netherlands, where doctors complained that they were forced to criminalize themselves by reporting to the Commission, created an impetus towards full legalization of euthanasia.

Clause 15 (Administration of drugs to patients suffering severe distress)

Clause 15 gives that a patient suffering from a terminal illness shall be entitled to request and receive such medical treatment as may be necessary to keep him as far as possible from pain and distress.

Again, CARE argues that the clause is superfluous and establishes nothing that is not already an accepted part of medical practice. For instance, in the so-called “Lindsell Case” of 1997 the legal principle that patients are entitled to medical relief from pain and distress under existing legislation was established.

4. CONCLUDING REMARKS

4.1 CARE is grateful for the time given by the Committee to consultation with the public and other interested groups.

4.2 CARE would be opposed to the introduction of assisted suicide or euthanasia. It would threaten legal and clinical safeguards for vulnerable patients such as the terminally ill, mentally incapacitated and disabled.

4.3 We see no reason why the considered conclusions of the Medical Ethics Select Committee of 1994 should be challenged. No new evidence or factors have come to light that would substantially dispute their findings and the law has been periodically tested in the courts.

4.4 We consider that the problems presented by the clauses of the Assisted Dying for the Terminally Ill Bill are indicative of the dangers of weakening the law on intentional killing and of the clinical risks that would accrue to such changes. We do not believe that it is possible to improve or amend the Bill to make it either ethically acceptable or safe for patients.

4.5 Of particular concern to us is the interplay between such a Bill as the Assisted Dying for the Terminally Ill Bill and the upcoming Mental Capacity Bill. We strongly suggest that the Committee consider the impact of the Bills in tandem.

4.6 We urge the committee to reject the Bill and to prevent its progress to further stages.

August 2004

Letter from Marie Curie Cancer Care

Marie Curie Cancer Care is grateful for the opportunity to respond to the call for evidence from the Select Committee on the Assisted Dying for the Terminally Ill Bill.

1. Marie Curie Cancer Care was founded more than 50 years ago and provides palliative care services to patients in both community and hospice settings across the United Kingdom. The Charity also conducts scientific and palliative care research and delivers palliative care education to healthcare professionals. It is the largest provider of hospice beds and specialist palliative care outside the NHS and this year will serve more than 23,000 cancer patients and around 1,000 people with other life-limiting illnesses such as motor neurone disease, multiple sclerosis and HIV/Aids.

2. Marie Curie Cancer Care has been opposed for some time to any change in United Kingdom legislation relating to euthanasia or physician assisted suicide (PAS). The Charity endorsed the statement on voluntary Euthanasia published in 1997 by the National Council for Hospice and Specialist Palliative Care Services (National Council).

3. Marie Curie Cancer Care has not recently sought the opinions of its approximately 3,000 clinical staff on these issues. The Charity is aware that recent consultations by the National Council and others have revealed that a complete spectrum of opinion may be held by healthcare professionals who specialise in palliative care. This diversity of view probably reflects the range of opinion which is found in society in general.

4. The recent report of the House of Commons Health Committee on Palliative Care identified that the “taboo nature of the subject of death was a recurrent theme of the inquiry. A general reluctance to discuss the topic informs much of society and perhaps accounts in part for the problems people encounter in negotiating choices in this area.” The Charity believes that it is vitally important that issues concerning how society cares for those who are approaching the end of life are considered and discussed in a public forum. Currently, debate is largely based on opinion poll findings and influenced by very fervently held and expressed opposing views. Marie Curie Cancer Care strongly supports the call from the National Council and others for a delay in legislation until the results of robust research into all aspects of euthanasia and PAD are available and have been widely debated in society.

5. There are some aspects of the current Bill on which the Charity would wish to comment specifically.

6. Clause 15 on pain relief is wholly unnecessary. The right to the administration of pain relief is acknowledged and well established in clinical practice and should have no bearing on the consideration of PAD. There is absolutely no need for a conscientious objection clause 7(2) in relation to the administration of pain relief. It would be unprecedented that a therapeutic course of action required an act of legislation. The Committee might wish to consider whether a comment on the need for all health care professionals to have more education in the use of analgesics would be helpful.

7. Marie Curie Cancer Care is concerned about some definitions of terms within Section 1.2. These are either inconsistent with current common usage, for example, a distinction is usually drawn between euthanasia, an act committed by one individual upon another, and PAD, when a physician assists a person to die, or risk being inconsistent with other legislation, for example the definition of competence.

8. The Bill places emphasis on the need to inform the patient of the availability of palliative care, although it is not clear about how this should be done. The inference that palliative care is an alternative to PAD is misleading and inappropriate. It risks reinforcing the erroneous belief that palliative care is only concerned with the process of dying instead of recognising that involvement with palliative care practitioners throughout the course of an illness could prevent or reduce any suffering produced by that illness.

9. The Bill places an enormous potential burden on palliative care practitioners, and doctors in particular, in requiring that they respond to a request for PAD within a two week timeframe. This demand on specialist time and facilities risks disadvantaging other patients who may be in greater immediate need of these services and is ethically unjust and inequitable. Marie Curie Cancer Care supports the call of the National Council for Hospice and Specialist Palliative Care Services for a greater investment in all forms of palliative care services which could benefit a far larger number of people than those who are likely to pursue a request for physician assisted dying.

2 September 2004

Memorandum by The Medical Ethics Alliance

1. The Medical Ethics Alliance is a coalition of medical and nursing associations of Hippocratic and World Faith medical bodies. It seeks to promote debate within and without the profession on health care matters. The following reflects our collective view formed over some time. Some of our constituent bodies will be making their own submissions. Thank you for giving us the chance to contribute.

2. Our remarks may be more wide ranging than the Bill before the Committee, but we consider that on the evidence published from other countries, it is never possible to consider only one aspect. For example, there is evidence that attempted suicides fail even when there is medical assistance. The commonest reason for this being vomiting. Thus assisted suicide also overlaps with euthanasia. The Bill acknowledges this at 1(2) where it is stated;

“Assisted dying means the attending physician, at the patient’s request, either providing the patient with the means to end the patient’s life or if the patient is physically unable to do so ending the patient’s life”

3. Autonomy;

We share a desire to see an increase in patient autonomy. This must be balanced against the protection of the vulnerable. Paradoxically medical involvement in euthanasia and assisted suicide increases the power of those who have the medical knowledge of diagnosis, prognosis, and the means to end life. They should not be indemnified against error, intended or otherwise. This Bill would make doctors bedside judges and executioners.

4. Medical errors are common at the end of life and there have been many studies comparing pre mortem and post mortem diagnoses. These can show major discrepancies especially where the patient died of multiple pathologies. A common mistake being the cause of breathlessness wrongly attributed to malignancy or heart failure, when it is actually due to treatable conditions such as infection or pulmonary embolus.

5. Quality of Life;

What underpins euthanasia killings are judgements on the worthwhileness of certain human lives. Though it may be at request it implies that the doctor shares the patient’s evaluation of their quality of life. Consciously, or sub consciously, the doctor must believe that the patient does not have a worthwhile life. Thus the doctor is making a distinction between the worth of one life over another, a position that is in conflict with the principle that all are equal before the law. It effectively removes the protection of the homicide law from some people. How can this outlook be limited, after all many patients in similar or worse states will not ask for death? How can medical teams hold such contrasting views at the same time on different patients?

6. Definitions of “terminal, serious, progressive physical illness”

Despite the distinctions made, and conditions applied, these terms raise insurmountable difficulties for clinicians. Prognosis can be extremely difficult and many conditions could fall within these terms such as chronic arthritis, Parkinsonism or even diabetes. The term “unbearable suffering”, is subjective and no doubt influenced by many factors. We are extremely doubtful that this can be satisfactorily defined in law and practise has convinced us that the patients’ experience of suffering is very variable. For example, the appearance of a loved one at a dying person’s bedside, can transform their desire to live. Many of us will attest to the fact that the last few days of a person’s life may be the most important in their lives.

7. The claimed unmet need for euthanasia;

In last year’s introduction of this Bill, Lord Joffe cited a number of surveys which seem to support the conclusion that there is an unmet need for euthanasia and that, in fact, the incidence is higher in countries where it is illegal. In Holland it was said that “only” 0.7 per cent of deaths were a result of ending the lives of patients without their request.

8. The Rummelink report from Holland [Committee to Investigate Medical Practice Concerning Euthanasia. The Hague; Ministry of Justice and Ministry of Welfare, Public Health and Culture 1991] also looked at withholding treatment such as tube feeding, [1] and the intensification of pain control with the explicit purpose of accelerating the end of life and further cases of partially intending to shortening life. The total rises to a 24,500 deaths or 19 per cent of all deaths. [2] The overwhelming majority were not requested and shows a frightening attitude by doctors.

9. The other thing which the Rummelink report shows, is the strict system of safeguards required by Dutch law is frequently breached with non notification or false certification as to the cause of death, being commonplace. The legal correspondent of the BMJ reported as recently as the 17 July 2004 at page 127, that;

“New penalties proposed for Dutch Doctors who flout euthanasia laws”.

It seems that the Dutch government is concerned that only a half of euthanasia deaths are being reported. This, of course, implies that half are incorrectly being reported as due to natural causes.

10. More recently there has been a drift to more physician assisted suicide, from and euthanasia for the terminally ill, and to euthanasia for the chronically ill, from euthanasia for the physical illness, to euthanasia for psychological distress and from voluntary euthanasia to non voluntary euthanasia. as Hendrin says, “every guideline set up by the Dutch . . . has been modified and violated.”[3]

11. Seriously Flawed Australian Studies

Three ardent supporters of euthanasia in Australia [Kuhse, Singer & Baume], claim that euthanasia is more common in countries where it is illegal [4]. But they conflated the categories of “not prolonging life”, and “hastening death” and fail to distinguish between foresight and intended consequences. They have added in the figures from good palliative care, where palliative care doctors did not prolong the dying process, thus artificially inflating their figures. Their survey, supposedly repeated the questions in the Rummelink investigation, but mistranslated the Dutch questions. [4]. Their paper has been strongly criticised in Australia.

12. It has been seriously questioned by the Council of Australia and New Zealand Society of Palliative Medicine, and was criticised by the leading Australian oncologist Professor Alex Crandon, who also said that none of the directors of gynaecological cancer services had heard of a single doctor practising secret euthanasia.

13. Euthanasia and assisted suicide rates in Holland, Belgium, Switzerland, Sweden, Denmark and Italy were compared on the basis of an anonymous questionnaire sent to doctors, and over 20,000 deaths were studied. [5] Euthanasia deaths were 65 times commoner in Holland than Italy, and none were reported from Sweden. This study corrects the misleading conclusions of the flawed Australian study.

14. The Logic of Euthanasia;

If euthanasia is a good thing for those asking for it, why is it not also a good thing for those who are as ill, or even more ill, but who have not asked for it?

15. Financial Considerations

Anyone with direct experience of the NHS, will know there is a relentless pressure to comply with protocols, especially where resources are concerned. There is always a downward pressure on doctors to be thrifty.

16. The Slippery Slope;

Though Lord Joffe last year denied this occurs, there has already been a progression for euthanasia from physical to mental illness in Holland. There has also been discussion of euthanasia for “existential reasons”, though this has not been made legal so far.

17. “It is already happening here”;

Studies purporting to show a significant percentage of doctors have taken active steps to end patients’ lives, need to be interpreted with caution. In this day of medical teams and colleague oversight, why has there been no reporting of this to statutory bodies? The absence of reporting to the GMC speaks for itself, and criminal prosecutions are exceedingly rare, and the chances of falsifying death certificates will be substantially reduced if the recommendations outlined in the Shipman enquiry, are implemented.

18. Again there is scope for misunderstanding given the principle of double effect, and the legitimate administration of sedation or analgesia, and its possible foreseen, but not intended effects. Reference to the appropriate dosages recommended by palliative care authorities or the Royal College of Anaesthetists, should be the standard. Surveys which do not refer clearly to double effect, or the recognised treatment regimes, are very likely to be misleading.

19. Attitudes to Euthanasia and Assisted Suicide taken by those in health and the ill;

There is ample evidence that what people want for themselves when illness is a distant possibility, is very different from that when illness comes. The sick do not choose the same as the well. National polls amongst the well, should therefore be treated very cautiously. It is interesting that the terminally ill can almost always be trusted to manage their own drugs, often having in their possession a potentially lethal dose.

20. Nor should we project upon the sick our own feelings as carers, doctors or nurses. Retrospective studies such as that quoted by Seale and Addington-Hall [6] reflect the views of relatives and carers not the patients themselves. There are studies showing that the terminally ill predominantly wish to live on.

21. There have also been studies showing that depression may lead to a desire to hasten death, as well as feeling a burden to others. Where these are absent there is little likelihood of patients wanting death hastened. There is no evidence that people with motor neurone disease commit suicide when they still can.

22. The case of Dianne Pretty which went to the European Court of Human Rights, demonstrates this, as well as clarifying the legal position, that there is no such thing as the so called “right to die”, let alone at the hand of another.

SUMMARY

- The interests of the individual cannot be separated from the interests of society as a whole.
- Euthanasia is out of control in Holland where it was first legalised.
- Economic interests of health providers exert a pressure towards the least costly management of the dying.
- Attempts to define “severe suffering” will soon be extended to more and more categories of the sick and this is why the disabled fear a change in the law.
- There is no logical reason why if euthanasia is “good” for some, it is not also “good” for others, thus creating a pressure for voluntary euthanasia to become non voluntary.
- Paradoxically assisted suicide and euthanasia increases medical paternalism, rather than patient autonomy.
- It will lead to a dangerous change in the attitude of doctors towards the very sick and dying.

20 July 2004

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Memorandum by the Methodist Church

Thank you for the opportunity to respond to the call for written evidence to the Select Committee on the Assisted Dying for the Terminally Ill Bill.

1. The Methodist Church in Britain has about 330,000 members and 6,000 churches. As in wider society, within the Church there is diversity of opinion on this issue. This response is based upon debate that has taken place at the Methodist Conference, the overall governance body of the Methodist Church, in committees and working groups.
2. Christians have much to offer to this debate, including theological, moral and philosophical clarity and insight but also the spiritual dimension of our lives as individuals and communities. The Methodist Church opposes Euthanasia but recognises that this does not lessen the complex moral problems integral to the final stages of some terminal illnesses.
3. The Christian tradition insists on the infinite respect owed to every individual human being. This respect is not proportional to their level of well-being, not to any assessment of how seriously ill, injured or disabled they are. This is often referred to as the “sanctity” of human life. In the instance of someone seeking assistance in dying there is a difficult and ongoing, as yet unresolved, debate as to whether allowing such a process shows such respect. It is for this reason that the Methodist Church would want to draw particular emphasis to condition 2(e)(iv) in the Bill the alternatives, including, but not limited to, palliative care, care in a hospice and the control of pain;
4. The Methodist Church has made the following statement regarding legally binding Advance Directives:

- (i) They may not give sufficient opportunity for a patient to change their mind in situations whose emotional and/or physical character were not accurately foreseen.
- (ii) They may not have sufficient safeguards to inhibit the desired medical action/inaction before a distressing situation goes into remission (if only temporarily).
- (iii) Vulnerable people may be exposed to undue pressure in construing their Advance Directives (swayed by emotional arguments about “quality of life” or political arguments about insufficient resources to sustain lives).
- (iv) No Advance Directive can cover all conceivable circumstances to which a patient may come; so a binding living will might prove to be prone to inconclusive interpretations, leading to distraction from professional medical care.

There is some reassurance that the Bill refers specifically to assisted dying being requested due to the current condition of the person seeking such a process, removing some of the anxieties about being able to cover all “conceivable circumstances”. We also recognise that the individual would have to be considered competent to make such a decision. We would still state, however, that the above concerns would continue to apply to protect vulnerable people in the controls and processes outlined in the Bill. We are not sure they are sufficient to enable people to make appropriate choices.

5. The Methodist Church will continue to engage its members in this debate, recognising that there are some divergent views within its membership. We would be pleased to be further consulted regarding this important issue.

Sources: *Methodist Conference Statement on Euthanasia*, 1974

Methodist Conference Issues related to Euthanasia, 1993

“*Shadows—a Study Pack on Euthanasia*”, 1994 (Methodist Church Baptist Union)

7 September 2004

Memorandum by the Modern Churchpeople’s Union

INTRODUCTION TO THE ORGANISATION AND TO THE AUTHOR

(A) The Modern Churchpeople’s Union (The MCU) was founded in 1898 to encourage and protect exponents of liberal theological and ethical thought within the Church of England. Since the 1920s it has campaigned for the Churches to support the legalisation of euthanasia in the context of terminal illness. The MCU has asked Professor Badham (a Vice-President of the Union) to present evidence to the Select Committee along the lines of his articles in *Studies in Christian Ethics*. Conscious that the Committee will receive submissions from Christian bodies opposed to any relaxation of the present laws against euthanasia, the MCU is concerned that the Select Committee should be aware that there are also strong Christian arguments in favour of euthanasia, and that these arguments are supported by 66 per cent of those members of the Church of England who worship on a weekly basis.⁶⁹

(B) Paul Badham has been Professor of Theology and Religious Studies in the University of Wales, Lampeter since 1991. Religious and ethical beliefs concerning life, death and immortality have been his major research area, and he has published six books relating to Christian beliefs about death, dying and immortality. The articles referred to by the MCU are:

Should Christians Accept the Validity of Voluntary Euthanasia? *Studies in Christian Ethics* October 1995. Reprinted in Robin Gill, *The Churches and Euthanasia* Cassells, 1998.

Euthanasia and the Christian Doctrine of God in *Studies in Christian Ethics* June 1998.

A comparable chapter, *A Theological Examination of the Case for Euthanasia* was published in Paul Badham and Paul Ballard *Facing Death* University of Wales Press 1996.

MEMORANDUM OF EVIDENCE

1. *Why people support the legalisation of assisted suicide*

The reason most people give for joining a voluntary euthanasia society is that they do not like what they see ahead of them. They do not themselves wish to endure the protracted dying process they have watched their parents go through.⁷⁰ Clive Seale’s research has shown that 28 per cent of all relatives believe that it would

⁶⁹ Robin Gill, *The Churches and Euthanasia* Cassells 1998 p 21.

⁷⁰ P Nowell Smith in Paul Badham, *Ethics on the Frontiers of Human Existence* New York 1992 p 211.

have been better if their loved one had died earlier than they actually did. When asked if their loved one had expressed a wish to die 24 per cent said “yes”. Of these 36 per cent had explicitly asked for medical help to die.⁷¹

2. *The lack of consistency in Christian opposition to euthanasia*

The primary theological argument against permitting assisted suicide is that issues of life and death are for God alone to determine. However there is a serious inconsistency in applying this principle when the question of shortening the dying process is discussed, and not applying the same principle when questions about the extension of the dying process arise. Almost all Christians today accept the desirability of vaccination, even though in 1829 Pope Leo XII ruled that anyone who accepted, or practised, vaccination was, “no longer a child of God”. This was because vaccination infringed on God’s sovereignty over life and death.⁷²

3. *Why Christian acceptance of birth control may foreshadow acceptance of euthanasia*

The closest parallel for the likelihood that most Churches will come to accept the morality of assisted suicide is the change in their attitude to birth control. Historically almost all Christians were opposed to birth control on the grounds that it challenged God’s unique authority over issues of life and death. This stance has since been abandoned by almost all Church leaders in the protestant traditions as well as, in practice, by Roman Catholic laity. Hans Kung has shown that very similar arguments were used in the papal encyclical against euthanasia, *Evangelium Vitae*, as in the papal encyclical against birth control, *Humanae Vitae*.⁷³ The Pope’s position is consistent. What is not consistent is the position of other Christians and their leaders. Most now accept that it is good for couples to consult together, and to obtain medical advice and help to plan their families, and to decide when it would be best for a new human life to begin. Yet many of the same people are opposed to such consultation and help being sought to determine when the battle against terminal illness should be abandoned, and the person be given help to die as painlessly as possible. However just as the practice of the Christian laity led to acceptance of birth control, so the views of the laity may ultimately change Church thinking on euthanasia. Professor Robin Gill has shown that 84 per cent of Christians of all denominations who worship once a month support euthanasia, as do 66 per cent of weekly Church-going Anglicans.⁷⁴

4. *Jesus’ Golden Rule and the case for legalising assisted suicide*

The heart of Jesus’ ethical teaching was the primacy of the law of love. Throughout his ministry, the main source of conflict between Jesus and the religious authorities of his day was Jesus’ insistence that loving response to human need must always outweigh the detailed requirements of the Old Testament Law. Jesus believed that the essence of religious law was summed up in the maxim, “love your neighbour as yourself”. His own Golden rule was, “Always treat others as you would like them to treat you.”⁷⁵ This rule could be relevant to the case of a doctor wishing to help a terminally ill person to die. The suicide rate is higher for doctors than for almost all others. No doubt many factors contribute to this, but at least one is the fact that they know the implications of terminal illness, and have the means to release themselves from it. Dr. Michael Irwin claims that “many physicians and nurses have private arrangements that they will hasten each other’s deaths should they ever be unfortunate enough to resemble the condition of some of their patients”.⁷⁶ For doctors who have made such “arrangements”, the legalising of assisted suicide would not only protect their colleagues from possible serious repercussions, it would also enable such doctors to give to their patients the treatment they wish for themselves. In behaving thus they would literally be following Jesus’ golden rule.

5. *Is suicide the ultimate sin?*

One objection to legalising assisted suicide is the belief that suicide itself is the ultimate sin of despair against God. It is generally assumed that “The Everlasting . . . has fixed his canon ‘gainst self-slaughter”, and that “the calamity of so long life” must be endured. But this is Shakespeare speaking through Hamlet.⁷⁷ It is not the case that the canonical scriptures forbid suicide. Indeed those Biblical figures who chose “death before dishonour” received the praise of their contemporaries.⁷⁸ It is interesting that, though historically Jesus died a cruel death

⁷¹ Article by Clive Seale in *The Times Higher* 6 January 1995 p 16.

⁷² Derek Holnes, *The Triumph of the Holy See* Burns & Oates 1978, p 82.

⁷³ Hans Kung and Walter Jens, *A Dignified Dying* SCM 1995 p 119.

⁷⁴ Robin Gill, *The Churches and Euthanasia* Cassells 1998 p 21.

⁷⁵ Matthew 7:12.

⁷⁶ *Sunday Times* 20 July 1997.

⁷⁷ Hamlet Act 1. Scene 2. lines 129ff; Act iii, Scene 1 lines 56ff.

⁷⁸ Judges 17: 28–30; 1 Samuel 31: 3–6; 2 Samuel 1: 11–27; 1 Maccabees 6: 44; 2 Maccabees 14: 41–42.

at the hands of his enemies, the fourth Gospel presents it as his own choice: “No one takes it from me. I lay it down of my own accord.”⁷⁹ From a Christian perspective death is not viewed as a disaster, but as gateway to fuller life. In the early Church this was very firmly believed. According to St Athanasius in the fourth century, the best evidence for the resurrection of Jesus is the way Christians, “treat death as nothing . . . they go eagerly to meet it . . . rather than remain in this present life.”⁸⁰ Two-thirds of the early Christian martyrs were not sought out, but handed themselves in to the Roman authorities for execution.⁸¹ Arthur Droge and James Tabor argue that before St Augustine changed Christian attitudes to this question, many of the early Christians continued to hold the stoic understanding of suicide as, “a noble death”.⁸² The beliefs of the early Christians provide an interesting counter balance to those of their successors today who give priority to the prolongation of life at all costs.

6. *The naturalness of death*

The general biblical perspective is that there is a natural time for everything: “A time to live and a time to die”.⁸³ In this context while premature death is seen as a tragedy, death in the fullness of time is something to be accepted. Ecclesiasticus 30:17 says “Death is better than a miserable life, and eternal rest than chronic sickness.” This could be a motto for those who support euthanasia. One of the oldest Christian prayers, often attributed to St Ambrose, is a prayer to God for a good death:

“Grant to life’s day , a calm unclouded ending,
An eve untouched by shadows of decay.”⁸⁴

If this is something that Christian tradition has seen as appropriate to ask God for, should it not also be legitimate to ask this from one’s fellow human beings?

7. *Does palliative care remove the need for legalising assisted suicide?*

It is often claimed that with the advance of palliative care the case for euthanasia is no longer as strong as it used to be. In some respects this is true. In comparison with death columns in newspapers 30 years ago, newspapers are now more likely to report that a person died “peacefully”, than that the person died, “after much suffering bravely borne.” However the fact that support for euthanasia has also grown over the same period indicates that pain is not the sole consideration. Many people find the inevitable indignities and limitations consequent on terminal illness “burdensome” and would wish to be spared from having to endure them. Now that intensive therapy facilities enable death to be kept at bay for longer, these factors have become increasingly significant.

8. *How legalising assisted suicide could help the helpless*

It is sometimes claimed that that if assisted suicide were legalised this would put pressure on the terminally ill at their weakest point. However the well-known theologian Hans Kung counters this. He argues that it is the present situation, where people are denied assistance to die, which really puts pressure on the terminally ill. He claims that very often terminally ill people are “exposed to intolerable suffering at the very point when their helplessness is at its greatest”. He urges that “it is precisely the most vulnerable who should be allowed the means to ensure that their lives are not dragged out endlessly”. Kung believes that if assisted suicide were allowed it would enable people to die, not in lonely isolation, but “supported by true friends and with the help of an understanding doctor, in composure and confidence, in gratitude and in tranquil expectation.”⁸⁵

9. *The evidence from the Netherlands*

In reflecting on the likely impact of any bill legalising assisted suicide the evidence from the Netherlands needs to be carefully evaluated. Abuses consequent on permitting euthanasia in the Netherlands have been widely reported by British opponents of Euthanasia. However according to the Royal Dutch Medical Association, and the Dutch Society for Health Law, such opponents of euthanasia have conveyed, “a very inaccurate and unreliable impression about the extent and nature of the practice of voluntary euthanasia in that country”.

⁷⁹ John 10:18.

⁸⁰ St Athanasius, *On the Incarnation* Mowbrays 1963, pp 57–59.

⁸¹ A Droge and J Tabor, *A Noble Death* San Francisco 1992, p 154

⁸² Droge and Tabor, *A Noble Death*.

⁸³ Ecclesiastes 3:2.

⁸⁴ *Hymns Ancient and Modern Revised* number 17.

⁸⁵ Hans Kung and Walter Jens, *A Dignified Dying* SCM 1995 pp 34, 38, 119–121.

This conclusion is supported both by the findings of the Rummelink Commission, and by the encyclopaedic survey of the Dutch situation by Margaret Otlowski. The findings of the Rummelink Commission established that “voluntary euthanasia is in fact performed much less frequently than had earlier been thought.”⁸⁶ What their figures showed was that “a large number of patients seek assurance from their doctors that active voluntary euthanasia will be available if the suffering becomes intolerable”,⁸⁷ but relatively few go on to take advantage of this. According to Ruurd Veldhuis, in 1995, 34,500 people took the precaution of going through the necessary legal procedures to enable them to receive euthanasia “when time would come”. But of these only 3,200, fewer than 10 per cent of those who had obtained approval, ultimately did go ahead with it.⁸⁸ Margaret Otlowski concludes that “there is no indication that active euthanasia on request is practiced more often in The Netherlands than elsewhere.”⁸⁹ Helga Kuhse and Peter Singer think that the primary benefit of the legalisation of euthanasia in the Netherlands is that it has enabled doctor and patient to talk freely through all the options available. This has had the valuable consequence that “the open practice of voluntary euthanasia may have reduced the incidence of doctors acting without the consent of the patient in ways that the doctor foresees will result in the patient’s death.”⁹⁰

10. *Is the present position in the UK sustainable?*

Hitherto it has been recognised in British medicine that in the pursuit of controlling pain, caring doctors may prescribe medication that they “foresee” but do not “intend” will shorten the lives of their patients. This way of “helping out” suffering patients is legal, but because death cannot be “intended” there can be no open discussion of the doctor’s plans with either the patient or their relatives. No patient can know whether or not their doctor will actually help them out in this way. No doctor who acts in this way can now be wholly confident that their professional judgement will not be called into question by a “whistle-blower” who queries the need for the dosages being prescribed. Ever-increasing knowledge about the minimum dosages needed for controlling pain may make this way of helping people out in the final stage of illness hazardous for the doctor. The ruling in the Burke case has raised further problems. It is now significantly more difficult for doctors to choose to bring to an end life-sustaining treatment for terminally ill patients. In all questions of doubt, the issue must henceforth be resolved “in favour of the preservation of life”.⁹¹ All these factors suggest that the traditional understanding of how doctors may legitimately ease their patients out of terminal suffering are being increasingly called into question. In the light of this new situation the proposed careful legislation to allow physician-assisted suicide would bring peace of mind to both patient and doctor. In the increasing complexity of modern medical advances, such legislation would now seem necessary to enable good medical practice to continue.

11. *A recommended amendment to the proposed legislation*

Clause 4 section 8 says that the declaration shall remain in force for six months. This may put pressure on a patient to ask for implementation of assisted suicide before that date, rather than lose their authorisation for it, and face the hassle of going through the whole legal procedure again. This would seem unfortunate. Hence it would seem sensible to remove a time limit.

12. *The opportunity this legislation offers for a Christian death*

Historically it used to be the practice of all believers to summon a priest when death was thought near, so that the patient could be given the last rites, and die surrounded by an atmosphere of prayer and worship, as well as in the presence of family and friends. Modern technology has largely taken away that option. Most die alone in a hospital bed so attached to saline drips and other support systems that the older death-bed scene ceases to be possible. Yet if one were allowed and assisted to face the reality of the inevitable it would be possible for death to become an affirmation. One could imagine a situation where a Christian could say goodbye to family and friends, a Holy Communion service could be celebrated at the believer’s bedside, and he or she could be given the last rites in preparation for the journey through death to the life immortal. In a context of faith this would seem a more Christian way of death than the present lonely extension of the dying process.

⁸⁶ Margaret Otlowski, *Voluntary Euthanasia and the Common Law* Oxford 1997, p 437.

⁸⁷ Otlowski, 441.

⁸⁸ Ruurd Veldhuis, “Tired of Living, Afraid of Dying: reflections on the practice of euthanasia in The Netherlands” *Studies in Christian Ethics* Volume 11 Number 1.

⁸⁹ Otlowski 437.

⁹⁰ H Kuhse and P Singer, Editorial in *Bioethics* 3, 1992 p 4 Cited in Otlowski p .439.

⁹¹ *The Times* 31 July. *The Sunday Times* 1 August.

SUMMARY OF EVIDENCE

Knowing that the Select Committee is likely to receive submissions from Christian bodies opposed to euthanasia, the MCU is anxious that the Christian case for euthanasia should also be heard. Euthanasia is supported by 66 per cent of members of the Church of England who worship each week. Most people want assisted suicide to be legalised so that they don't have to suffer as they saw the generation above them suffer. 28 per cent believe that it would have been better if their loved one had died sooner than they did.

Christian opposition to euthanasia is based on the idea that God alone should determine issues of life and death. Yet all Christians accept the legitimacy of keeping death at bay. Most also accept the legitimacy of family planning and choosing when a baby should be born. The papal encyclical against euthanasia used similar arguments to the encyclical against birth control. Christians who think it right to seek medical help in the timing of birth should think it equally right to seek medical help in the timing of death.

Jesus' maxim "always treat others as you would like them to treat you" is relevant to assisted suicide. More doctors commit suicide than any other profession. In at least some cases such suicides are in response to knowledge of terminal illness. Some doctors and nurses have pacts to help each other out if they face suffering in terminal illness. Such doctors should treat their patients as they themselves wish to be treated.

Christians who lived before St. Augustine did not see suicide as intrinsically wrong. Old Testament heroes who committed suicide were praised for doing so. Christians have often seen Jesus as choosing to lay down his life. Death at the end of a long life should be seen as natural, not as something to be feared. If it is moral to pray to God for an easy death, it should be equally moral to ask for a doctor's help for it.

Although good palliative care will encourage many not to ask for assisted suicide it will not cover all cases. "Suffering" goes much wider than pain. Hans Kung believes that it is the weakest and most vulnerable who suffer most under the present system. They would have the most to gain if assisted suicide were legalised. Most of the terminally ill people in the Netherlands who go through the legal procedures necessary for euthanasia do so, because they want the assurance of knowing, that if their suffering becomes intolerable, they will be released from it. But fewer than one in ten of these will ultimately go ahead with euthanasia. The main benefit of the Dutch legislation is that it enables doctors and patients freely to explore all possibilities.

We need assisted suicide to be made legal because the traditional understanding of good medical practice is breaking down. The giving of medication to control pain "foreseeing" but not "intending" the shortening of life is becoming hazardous for the doctor. The legalising of assisted suicide would also enable the revival of the Christian death-bed, with its opportunities for final farewells, and for commending the person to God.

Memorandum by the Nursing and Midwifery Council

The Nursing and Midwifery Council (NMC) is an organisation set up by Parliament to protect the public by ensuring that nurses and midwives provide high standards of care to their patients and clients. As a regulatory body for nursing and midwifery, the primary function of the NMC is public protection through professional standards. One of the most important ways of serving the public interest is by the provision of advice and guidance to our registrants on professional issues.

The Council has 23 voting members, of which 12 are practitioner members and 11 are lay members. Meeting quarterly, they set Council policy.

The Nursing and Midwifery Council would like to submit evidence on the Assisted Dying for the Terminally Ill Bill [HL] by:

- Commenting on the relationship of the bill to the field of palliative care that nurses practise in both generalist and specialist roles.
- Commenting on the role of the nurse as defined in the bill.

1. The Nursing and Midwifery Council is aware that there has been an identification of inconsistencies in palliative care services in the report *Palliative Care Fourth Report of Session 2003–2004* (House of Commons Health Committee 2004). The report recognises that there exists inequity by geographical area, by patient group and by disease group. This report also recommends that the skills of healthcare staff are raised and that training in palliative care becomes part of continuing professional development. Recurrent themes run throughout the report regarding issues of patient choice, equity of care, communication, recognition of cultural beliefs, workforce issues and quality assurance. Palliative care is defined by the World Health Organisation as an approach "that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of an early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". The WHO declares that palliative care "provides relief from pain and other

distressing symptoms; affirms life and regards dying as a normal process” and it “intends neither to hasten or postpone death”. The NMC welcome the recognition within this Bill that the main concern is to relieve suffering. However, the Nursing and Midwifery Council is concerned that there is potential conflict for the role of the nurse working within palliative care. Specifically paragraph 3(1) which states that “the attending physician shall ensure that a specialist in palliative care who shall be a physician or nurse has attended the patient to discuss the option of palliative care” and the definition of “unbearable suffering” [paragraph 2:2(d)] defined as “suffering whether by reason of pain or otherwise which the patient finds so severe to be unacceptable and results from the patient’s terminal illness”. The NMC is concerned that due to the aforementioned report of inequalities around the provision of palliative care and the recognised need to improve the education of health professionals that nurses may be placed in challenging professional and ethical positions should a patient request assisted dying which might actually be a direct consequence of inequity of local service provision.

2. There is no comprehensive definition of the nurse within the Bill. The NMC is concerned that paragraph 2, provides clear definitions of the roles of the attending physician and the consulting physician but only identifies nurses as a member of the medical care team “assisting the attending physician”. A diverse group of roles are practised within the specialty of palliative care by nurses with varying degrees of responsibility and autonomy. Nurses are more often than not the principal professional for patients who are in the end stages of life. This has not been adequately addressed by the Bill.

3. The NMC recommend that conscientious objection in paragraph 7(2) should not just be identified for medical staff and should include nursing staff. Although medication will be prescribed by the physician nurses may be ultimately responsible for the administration and titration of the medications to keep the patient free from pain and distress as stated in paragraph 15.

4. Paragraph 13 sets out the requirements for documentation. The NMC is concerned that there is no consideration of nursing documentation. The Nursing and Midwifery Council believes that record keeping is a fundamental part of nursing and midwifery practice and it is recommended that this is incorporated into the Bill.

5. Paragraph 14 sets out the monitoring commission and reporting requirements. The NMC is disappointed that there is no recommended nursing member on the monitoring commission. The NMC acknowledges that palliative care is undertaken within a broad multiprofessional framework, however, the role of the nurse within the speciality is a fundamental one and there are distinct regulatory and professional issues to be monitored.

SUMMARY

The Nursing and Midwifery Council recognises that there are strong views within the nursing profession regarding end-of-life issues.

The NMC Code of Professional Conduct: standards for conduct, performance and ethics (2004) states that nurses must protect and support the health of individual patients and clients. The Code also clearly directs that nurses must respect the rights of the individual and the patient/client’s role in planning their own care. Nurses are advocates for the patient/client and have a legal, moral and professional duty to care recognising the patient/client’s right to individual choice at all times.

The NMC welcomes the recognition within the Bill that the main concern is to relieve dying. However the conclusion of this organisation is that there requires to be more detailed consideration of the highly valued nursing roles that practise within this domain of care.

REFERENCES:

House of Commons Health Committee (2004) *Palliative Care Fourth Report of Session 2003-2004*, Volume One, London: The Stationary Office Ltd.
Nursing and Midwifery Council (2004) *The NMC Code of Professional Conduct: standards for conduct, performance and ethics*, Nursing and Midwifery Council. www.nmc.org

20 August 2004

Memorandum by the Prince Leopold Institute of Tropical Medicine

1. With this memorandum we would like to submit evidence-based information to the Select Committee on the Assisted Dying for the Terminally Ill Bill.

The information derives from a study conducted in 11 Western European countries (including the UK) on the perspective of persons living with HIV (PLWH) in Europe on the issue of euthanasia.

This international study was co-ordinated at the Institute of Tropical Medicine in Antwerp (Belgium), one of the leading academic institutions in Europe in HIV/Aids-related medical and social research, with a strong societal mission and impact.

2. The above-mentioned study was carried out within the framework of EUROSUPPORT, a European research initiative and support network for PLWH, funded by the European Commission (SANCO/Public Health). EUROSUPPORT aims at gaining scientific insight into newly emerging and rapidly changing HIV-related problems by using a multidisciplinary approach. The European Commission has continuously financially supported this initiative since 1996, now being in its fourth phase.

The research and support network includes HIV-treatment centres and patient organisations in 11 European member states, carrying out targeted empirical research on the needs of PLWH.

3. The study on euthanasia was conducted as an essential part of the first EUROSUPPORT project (1996–98). The study involved a cross-sectional data collection on issues relevant to the quality of lives of PLWH. It is important to mention that at that point in time, effective HIV treatment such as antiretroviral combination therapy had just started to become available on a large scale in Western European countries.

4. In what is to follow we summarise the main findings from this study:

- The total number of respondents was 1,341 and 194 self-reported questionnaire were from the UK. Patients from the UK, the Netherlands, and Belgium most strongly supported assisted dying (euthanasia) legislation: In the UK 77 per cent of the respondents supported legislation when the physician administered the medication and 61 per cent when the patient self-administered the medication.
- 61 per cent of UK respondents also viewed that assisted dying legislation would severely decrease their anxiety in relation to their disease and the uncertainty of their personal future (this was the highest percentage following the Netherlands).

However, only 16 per cent of UK respondents had discussed assisted dying with their physicians, compared to 45 per cent of respondents in the Netherlands. In the UK 60 per cent of respondents had discussed this with “someone else” (other than the physician), compared with 82 per cent of respondents in the Netherlands.

5. In what is to follow we summarise the main conclusions from the study:

- Despite the methodological limitations of the study, our findings indicate that across Europe and in the UK, a considerable interest does exist in assisted dying (euthanasia), irrespective of the fact of whether the patients involved are actually prepared to pursue this avenue for themselves.
- Due to the availability of more effective and better tolerated HIV-treatments, the issue of euthanasia may become less relevant in the future for PLWH. However, it must be borne in mind that there are an increasing number of HIV-infected patients who cannot be treated with these therapies, due to development of resistance or other side effects. Thus, as for any other patient suffering from a chronic disease that is treatable but not curable, the option of patient assisted dying will remain extremely relevant. For patients with an incurable disease who choose not to continue with palliative care but who continue to suffer, assisted dying should be an available option.

6. Reference of the referred article:

Andraghetti R, Foran S, Colebunders R, Tomlinson D, Vyras P, Borleffs CJ, Fleerackers Y, Schrooten W, Borchert M. (2001). Euthanasia: from the perspective of HIV infected persons in Europe. *HIV Med*, 2001; 2(1): 3–10.

19 July 2004

Copy of a letter to the Select Committee from Dr Fiona Randall

At the Select Committee meeting on the afternoon of 18 January 2005 I gave evidence and would like to submit this written answer to one of Baroness Hayman’s questions as supplementary evidence. At the time I did respond to this question but have subsequently considered that I did not give it the detailed response which it requires and deserves. I would like to rectify that omission by way of this letter.

I recall that Baroness Hayman noted the apparent similarity between on the one hand allowing patients to refuse life-prolonging treatment, such as ventilation, together with allowing people (unaided) to commit suicide, and on the other hand providing physician assisted suicide and euthanasia. Baroness Hayman asked why, if the law respects the patient's autonomy in the case of refusal of life-prolonging treatment and permitting (unassisted) suicide, it should not also respect the patient's autonomy in providing physician assisted suicide (PAS) and euthanasia when the patient requests it.

In particular, Baroness Hayman explained that it is difficult to see a difference between a doctor switching off a ventilator when the patient is refusing that treatment, and the doctor assisting suicide or giving the patient a lethal injection. One could argue that if these two acts are morally indistinguishable, they ought not to be treated differently by the law.

This is an important argument and could be presented logically as follows:

Major premise: Morally indistinguishable cases should not be treated differently by law.

Minor premise: Respecting a patient's refusal of life-prolonging treatment is morally indistinguishable from respecting the patient's request for PAS and euthanasia.

Conclusion: The law should not treat a patient's refusal of life-prolonging treatment differently from a patient's request for PAS or euthanasia.

The conclusion does follow logically from the premises. The conclusion would mean that if a patient's autonomous refusal of life-prolonging treatment such as ventilation was to be respected and thus the ventilator turned off, then a patient's autonomous request for PAS and euthanasia should also be respected and the patient given a lethal prescription or lethal injection. In both situations it could be said that the patient's autonomous choice is being respected.

Whilst the conclusion does follow logically from the premises, I will argue that the minor premise is actually false and the major premise is seriously flawed. Consequently the conclusion based on these premises should be rejected. I will begin by examining the minor premise to explain why it is false.

MINOR PREMISE

The premise states that respecting a patient's refusal of life-prolonging treatment, and thus withholding or withdrawing that treatment, is morally indistinguishable from respecting a patient's request for PAS or euthanasia, and thus providing a lethal prescription or lethal injection (in the Committee the legal situation whereby suicide is not a crime was also noted). I would argue that there are important moral distinctions between these two acts/decisions, and they are based on the issues of:

1. the cause of the patient's death; and
2. the intention of the doctor.

I will discuss these in turn.

1. *The cause of the patient's death*

It is sometimes argued that the withholding or withdrawal of a life-prolonging treatment causes the patient's death. Thus if artificial hydration and nutrition are withdrawn or withheld from patients who cannot eat or drink by mouth and have refused tube feeding and hydration, then since it is overwhelmingly likely that the patient will die without sustenance, the withholding or withdrawal of the tube feeding and hydration causes the patient's death. The same argument applies to the situation Baroness Hayman mentioned when a patient who is unable to breathe without a ventilator refuses the ventilation which is then withdrawn, and the patient's death is overwhelmingly likely to follow. If one agrees with this view, then one concludes that the withholding or withdrawal of the treatment should, both legally and morally, be considered to be the cause of the patient's death.

I would argue that the patient's death is caused by the underlying failure of essential organ function which renders the patient incapable of survival without constant life-prolonging treatment. The fundamental cause of the patient's death is the patient's condition, not the withholding or withdrawal of the treatment.

Death would have been caused by the pathological conditions of inability to take in nourishment or inability to breathe.

The life-prolonging treatment merely prevents death from occurring so long as it continues and other causes of death do not intervene. When the treatment is withheld or withdrawn, it could be said that "the body's own causality" results in death.

If my line of reasoning is rejected and instead it is considered that doctors cause the death of their patient's when they withhold or withdraw life-prolonging treatment, then it must follow that in all cases where doctors withhold or withdraw life-prolonging treatment they have caused the patient's death.

Since the available array of life-prolonging treatment is so extensive, and since the precise timing of so many patients' deaths is now influenced by patients' decisions to forgo some possible life-prolonging technology, one would have to conclude that doctors actually cause the death of many of their terminally ill patients. Such a conclusion is deeply counterintuitive. Neither patients nor doctors consider that the doctor causes the death of the patient when the doctor agrees to withhold or withdraw a treatment which the patient is refusing.

Moreover, if one reached this conclusion then every death which followed the patient's refusal of life-prolonging treatment and subsequent withholding/withdrawing of that treatment would have to be examined legally as a possible case of murder or manslaughter. This is because one of the conditions for murder and manslaughter is causing the person's death, and in this case the doctor would be seen as having caused the patient's death. This would be completely unmanageable legally and also intuitively wrong.

Alternatively, it might be argued that patients refusing a potentially life-prolonging treatment, for example when they think that for them its harms and risks exceed its expected benefits, are committing suicide. This conclusion is also deeply counterintuitive and likely to be offensive to patients who are competent and have judged that for them the benefit of extended life is outweighed by the burdens and risks of the ongoing treatment, especially in the context of terminal illness which is the context of the current Bill.

In fact, the law does not regard the withholding/withdrawal of the treatment as the cause of the patient's death in these situations. I would argue that it does not make sense to regard it as morally the cause of the patient's death.

Thus I would conclude that the cause of the patient's death, following the withholding/withdrawal of life-prolonging treatment which the patient has refused, is the underlying illness. This conclusion concurs with current practice when writing death certificates.

In contrast, the cause of death following PAS or euthanasia is the lethal medication, whether taken by the patient himself/herself or administered by the doctor.

In respect of the cause of death, the act/decision of withholding/withdrawing life-prolonging treatment which the patient refuses is clearly distinguishable both morally and legally from PAS and euthanasia. These two situations are not morally the same, and are not currently treated as legally the same.

2. The intention of the doctor

The moral distinction between intending and foreseeing the death of a patient following withholding or withdrawal of life-prolonging treatment may appear finely drawn. It can be argued that a doctor who switches off a ventilator when a competent patient refuses to remain on it is intending to cause the patient's death. Those who take this position assert that the doctor must inevitably intend the patient's death since he or she knows that it is overwhelmingly likely that death will follow. The contrary position, which I would support instead, is that the doctor intends to withhold or withdraw a treatment which the patient is refusing, and that the doctor foresees but does not intend the patient's death.

There are two aspects to intention in this case. The first is to do with what the doctor wants, desires or seeks as the outcome of the act/decision. Some people who maintain that the doctor intends the patient's death seem to believe that the doctor wants, seeks or desires that patient's death. Yet this is surely not the most accurate representation of the case. The representation which I think most accurately describes the case is that the doctor neither desires nor seeks the patient's death, but rather intends only to withhold or withdraw a treatment which the patient does not want because its burdens and risks outweigh its benefits in that patient's view. Similarly, when doctors carry out a treatment with known harms and risks, even risks of death, we do not conclude that they intend those harms and risks, but rather that they foresee them. Nor do we believe that patients who consent to the treatment intend or choose to undergo those harms and risks, but rather that they foresee them as adverse consequences of a treatment which has expected benefits.

The second aspect of intention relates to the fact that it is intention to cause the death of the patient which is being considered. Those who believe that the doctor who withdraws or withholds a life-prolonging treatment intends the patient's death must believe that the doctor intends to cause the patient's death. I would argue that since doctors quite reasonably do not consider that the withholding or withdrawal of life-prolonging treatment is the fundamental cause of the patient's death, they cannot logically intend to cause death by withholding and withdrawing the treatment.

It simply makes no sense to say that doctors intend to cause death when they do not think that their decision

is the cause of the death. In parallel with this moral reasoning, the law does not take the line that they intend to cause the patient's death.

In contrast, when a doctor prescribes a lethal prescription to provide PAS, or administers a lethal injection in euthanasia, the doctor knows that the lethal medication will cause that patient's death and intends that it will cause the death when taken into the body.

In summary, I would conclude that respecting a patient's refusal of life-prolonging treatment is morally distinguishable from respecting the patient's request for PAS and euthanasia, since the cause of death and the doctor's intention are different. The two situations are definitely not the same. Indeed the differences are so significant as to make the two situations not even similar.

MAJOR PREMISE

I will turn now to the major premise, that morally indistinguishable cases should not be treated differently by the law. In this particular case it is being argued that if patients' autonomy is being respected in one case, it should be respected in the other case (if that case is regarded as substantially the same). This premise raises issues about the function of the law and its relationship to morality. Three essential points should be considered.

Firstly, it is a central function of the law to safeguard the interests of everyone in the community, and not just the interests of a minority or an individual, however deserving, against those of the majority. For example, patients cannot legally require provision of a particular treatment which is not available on the NHS due to nationally agreed criteria based on a just distribution of scarce resources. It is relevant that in the case of PAS and euthanasia it is believed that only a small minority of terminally ill patients would choose these measures, whilst all terminally ill patients would be faced with this difficult choice as a medical treatment option.

Secondly, morality is much more complicated than the law could ever be. An enforceable, consistent, and comprehensible law is necessarily a "blunt instrument" compared with the great complexity of moral judgements. Yet the law is the blunt instrument which must uphold the good of the community. So the law has to make distinctions which are unambiguous and comprehensible to ordinary folk, and it cannot possibly follow all the intricacies and nuances of thought and feeling which exist in morality, and which judges can take into account when applying the law in individual cases.

Thirdly, in treating cases of respecting refusal of treatment differently from requests for PAS and euthanasia, the law does not say that there is always a clear moral difference between the two. It is saying only that for legal purposes, based on the best outcome for the whole community, it is necessary to make this distinction. It is not the purpose of the law to dictate which particular acts are, or are not, morally indistinguishable. Although it might be possible to imagine a scenario where respecting a patient's refusal of treatment appears morally indistinguishable from PAS and euthanasia (I have tried and failed to do this), it does not follow that the law should treat them as though they are indistinguishable, particularly as in the vast majority of cases there will be obvious and significant moral differences.

I have argued that the minor premise is false, and that the major premise is simplistic and seriously flawed. Therefore the conclusion which follows from them should be rejected. Thus it is not necessarily unreasonable, and not illogical, for the law to treat a patient's refusal of life-prolonging treatment differently from a patient's request for PAS or euthanasia. The law currently does this by dictating that the patient's choice to refuse treatment must be respected by withholding or withdrawing the treatment, whilst the patient's request for PAS or euthanasia should not be granted by provision of these procedures. So it is not necessarily unreasonable or illogical legally to require doctors to withhold or withdraw a life-prolonging treatment which a competent patient is refusing, and thus respect the patient's autonomous choice, whilst at the same time refusing to provide PAS and euthanasia which the patient is requesting.

Those of us who gave evidence on the afternoon of 18 January 2005, and argued against the legalisation of PAS and euthanasia both in general and in particular via this Bill, were arguing that the law would best serve the interests of the majority of terminally ill patients if it continued to prohibit assisted suicide and euthanasia, especially by doctors. It is clearly the function of the law to say that people cannot have some of the things that they would autonomously choose, on the grounds that the availability of that choice, or the exercise of that choice, would harm the interests of others. As a group we were arguing that making PAS and euthanasia available, especially as a medical treatment option (as proposed in the Bill), would harm the interests of patients overall more than it would benefit them. In terms of autonomy, we were arguing that the range of autonomous choice available to patients must be limited in order to safeguard the welfare of all in the community, in the same way that the law restricts so many potential choices to safeguard the welfare of others. We were arguing that it is morally preferable and justifiable, and the best legal policy, to avoid making PAS

and euthanasia available to the minority of patients who would choose it, in order to safeguard the welfare of the majority of patients and the underlying values of the community in which we all live.

There is no short and simple answer to the question which Baroness Hayman raised in the Committee. It is a question of such importance that I am grateful to Baroness Hayman for having raised it. I hope you will forgive such a lengthy explanation and that it may be helpful to the Committee. I contacted Judy Phillips who advised me that I should submit this supplementary evidence to yourself so that it is available to the Committee.

21 January 2005

Memorandum by the Royal College of Anaesthetists

The Royal College of Anaesthetists is pleased to have the opportunity to comment on the Assisted Dying for the Terminally Ill Bill although, having only received a formal request to do so on 6 August 2004, we have been unable to discuss this as fully as we would wish. Although we were not directly involved in the consultation process, and in advance of these recent deliberations, the Bill was discussed in Council in May. At that time Council determined the following minuted statement. "After considerable discussion, although it was realised that palliative care verged on the pain management activities of the College and indeed some aspects of intensive care did also, this was not thought to be very relevant to the work of anaesthetists. Moreover members of Council were very clear that they felt it inappropriate to support a bill which emphasised medical roles in ending lives."

Following your formal invitation to comment, I have conducted a consultation process over the summer with members of Council to try to obtain a more detailed response. Although a number of the comments inevitably result from personal experience either during medical care with which the respondent has been involved or, indeed, from personal family circumstances, there is, nevertheless, no doubt that virtually every respondent would re-emphasise the minuted decision from our May Council meeting.

Some of us also had the opportunity to discuss the Bill with Ms Deborah Annetts from the Voluntary Euthanasia Society who was involved with the drafting of the Bill. She clearly emphasised that the intentions of the Bill were not a substitute for inadequate pain relief or inadequate palliative care but it was intended to be specifically directed at independently minded people for whom no palliative care was available and who perceived their future life to be futile. The problem for anaesthesia as a specialty is that our work includes responsibility for critical and intensive care and also pain management services. Palliative care, on the other hand, is largely the province of physicians specifically trained in this key area, although anaesthetists with pain management expertise do become involved. We have anxiety that, because anaesthetists are so close to a number of terminally ill patients, the implications of the Assisted Dying Bill may impinge on our current practice and management of patients both in intensive care and in pain clinics.

Although we feel unable to support the Bill in its current form, we would urge that specific discussion centres around the implications of it to these key areas of our activity. The discontinuation of treatment in critically ill patients when the outlook has become futile is something which many of our colleagues have wrestled with over many years. The decisions that are taken are difficult enough as they are without potential added complications of misinterpretation of the Assisted Dying Bill. In the pain management situation, particularly in acute situations in hospital where our consultants have specific responsibility for acute pain services, again there could easily be a fine line to draw between the relief of pain and assisting death. We are very concerned as a specialty that a Bill which is designed to help a very small group of people with specific conditions and personal circumstances should, as a result of the legislation involved, inadvertently detrimentally affect the care which we as anaesthetists, intensive care and pain management specialists are trying to provide for our patients. We appreciate that the Bill tries to be specific in these key areas and do not wish to muddle the situation, but nevertheless we feel that these issues, together with those surrounding anaesthesia and surgery in terminally ill patients, need to be carefully thought through if the Bill is to achieve its aims without impeding care for others.

We are particularly concerned that the second stated purpose of the Bill is "to make provision for a person suffering from a terminal illness to receive pain relief medication" because we feel it has been included when there is already a legal framework and understanding for this and those specialised in the area believe that this is always possible to achieve. We would hope that the key effect of any such Bill would be to promote effective and funded pain relief and palliative care to eliminate the need for assisted dying apart from in a very small and specific group of chronically ill patients, usually with neurological disease. The provision of adequate pain relief and palliative care is not only the view of the Voluntary Euthanasia Society, but also that of the College.

We believe that in parts of the UK, the failure to provide adequate pain relief (whether as medication or alternative strategies) is a consequence of (a) poor training of doctors and nurses in pain management, (b) reluctance to prescribe and/or administer opioids appropriately for terminally ill patients, (c) fear and misunderstanding by patients and their relatives about opioids, (d) wide variation in the provision of specialist pain management services (see CSAG report, Dr Foster report etc.) (e) wide variation in the provision of the expert palliative care services in hospitals, hospices and the community and (f) some PCTs fail to purchase any or sufficient services for their patients. Despite a recent single injection of Government money it is our understanding that the majority of hospice and community based palliative care is still provided by charitable bodies such as McMillan Nurses and not by the NHS.

Terms such as “assisted dying” and “good death” appear to have been used to promote all aspects and definitions of euthanasia whereas these terms can quite legitimately be used to describe a death that enables the last weeks, days and hours of someone’s life to be as painless and peaceful as possible. Although it is claimed that doctors are already actively assisting people to die, even those not well informed and knowledgeable about pain management know that, if strong pain relieving drugs are given, the result may also hasten death. It is not the intention to end life and cause death, however, it is a means of trying to provide a more comfortable life near and up to the time of death. This Bill on the other hand describes something quite different which is actually, within closely confined limits, assisting somebody to die.

We would caution against the claims that the Bill supports the rights of the autonomous person. The care of a person with capacity and someone without should be of the same high standard. The Bill quite rightly excludes those who do not have capacity but in this case no capacity will then result in no rights for such people. However, the Mental Incapacity Bill that is presently following a similar route will allow another to consent on a person’s behalf. It is not difficult to see how confusing and open to abuse these issues may become in the future.

One Council member wrote the following “I have always understood the medical principle of do no harm, a basic ethical standard that any doctor should strive to avoid at all costs and at this simple level appears to me to encompass all that medical care is about. The distinct conflict between this and that of actively making someone die seems to me to be one that cannot be resolved. Does our society’s failure to provide any patient with compassionate (and as far as possible) pain free care at the end of their life have to result in the futility resulting from the enactment of this Bill.”

Bills to facilitate assisted dying are not the answer to the deficiencies listed above and should not be contemplated until the NHS can guarantee expert pain management and palliative care services throughout the UK. The twofold purpose of the Bill is potentially misleading when the highly commendable provision of adequate pain relief medication is somehow linked to the highly contentious business of assisted dying. In addition, this link will serve to reinforce the belief of many patients, relatives, nurses and doctors that strong pain relief (ie opioid medication) is only suitable for use when death is very imminent. Cecily Saunders and all who followed after her battled for decades to destroy this misconception and it would be a retrograde step to reforge such a link.

Looking at the assisted dying aspects of the Bill, there is a world of difference between the withdrawal of life sustaining support (or its initial implementation) and the deliberate decision to actively terminate life. The assertion that assisted dying is happening already is, we believe, exaggerated. While very few clinicians would actively administer a substance to kill a patient, they may decide not to administer a drug such as an antibiotic when it might in other circumstances be indicated, or they might not treat an abnormal pathological finding, but very few, if any, would decide to administer something to actively terminate life. Although one might argue that the end result might be the same, while one is covered within the doctor’s accepted role in making a treatment decision based on all the information, the other is not.

CONCLUSION

It is quite apparent from all the discussions I have had with members of Council of the Royal College of Anaesthetists that they would not support the Bill in its current form. Although there are a number of concerns centred around the inadvertent effects that the Bill might have on the way in which we treat patients in specific acute care situations, the overwhelming concern is with the adequate provision of pain relief and palliative care. We are of the unanimous view that the linking of the assisted dying elements of the Bill to those concerned with absent or inadequate provision of pain management and palliative care services is inappropriate and that this will do much to impede the current development of these services in today’s NHS. We would urge that in the future, if aspects of the Bill are to be discussed which impinge upon the activities of anaesthesia, critical care and pain management, this is done at an early stage of drafting to ensure the relevance of such a Bill in

today's NHS and to avoid potential conflict with the dedicated practice of those clinicians involved in these areas of patient care.

10 September 2004

Memorandum by the Royal Collage of Paediatrics and Child Health

This sets out the conditions, need for second opinions, safeguards and penalties that apply in situations where a competent adult seeks the help of a medical practitioner in ending their own life because of their terminal illness and the unbearable suffering it imposes.

We consider that there are a number of ways in which the interests of children might be involved, as set out below:

1. *A competent adult may have dependent and incompetent children*

Presumably there needs to be some mechanism to safeguard the interests of such children if their parent chooses to exercise their rights under the Bill. It could be argued that this would be an issue anyway for a terminally ill parent, but the Bill does need to consider the possible impact of an earlier/accelerated death on the child including the means by which this is achieved.

2. *Competent children with terminal illnesses*

A child is legally competent to consent to medical treatment at 16 years and earlier than this if they are deemed competent to understand the nature and purpose of that treatment and its impact on their family. Some children with terminal illness may express a wish to die, especially if they have a long experience of illness and its consequences for them. In fact children in these circumstances may be just as competent as adults to express their views and know what their implementation means. Given the safeguards the Bill proposes it might be felt unjust to exclude them from its humanitarian provision unless there were public policy or best interests reasons for doing so.

3. *Incompetent children with terminal illness*

Whilst only the courts can make decisions about medical treatments on behalf of incompetent adults, parents can and do make decisions and provide consent for their incompetent children. Faced with the terminal illness and unbearable suffering of their child what action is open to parents who wish to relieve that suffering by bringing about the death of their child. The RCPCH position has been against euthanasia in practice because of its illegality as well as concerns about whether it creates a slippery slope and is open to abuse. However a situation in which assisted dying becomes legal for adults will inevitably create circumstances in which the position with respect to children will need to be re-examined.

Although the Bill excludes children there do seem to be moral reasons based on fairness and rights as to why the situation with respect to provision for both competent and incompetent children, their parents and the health care teams who provide treatment for them might be reconsidered.

September 2004

Memorandum by The Royal College of Pathologists

1. The Royal College of Pathologists supports the comments submitted by the Academy of Medical Royal Colleges, on which the College is represented. However, the College wishes to draw attention to some specific issues relating to the practice of pathology. The Bill has been discussed by the Executive of the College and is due to be considered at the meeting of the College's Council on 9 September.

2. Clause 2(2)(c) requires the attending physician to make "a determination that the patient has a terminal illness". Post-mortem research and clinical audit studies performed in the UK, Europe, USA and many other countries consistently show a c. 30 per cent error rate in the medically certified cause of death. Significant errors (ie misdiagnosis of the terminal illness resulting in inappropriate treatment) occurs in c. five per cent of cases. Therefore, the procedure of making "a determination that the patient has a terminal illness" is not as reliable as the Bill implies. Almost all histopathologists (doctors who perform postmortem examinations) have experience of cases deemed to have died from an untreatable terminal illness, but postmortem examination discloses another condition—that would have been treatable—for the patient's death.

3. Clause 2(2)(e) requires the attending physician to inform the patient of his medical diagnosis and prognosis. In view of the above comments about the limited reliability of determinations of diagnosis and prognosis, the patient might also be sensitively apprised of the possible risk of error in making these determinations.

4. The College suggests that the Bill deals in a general way with the methods available for assisted dying under this legislation. Clearly the methods should be “humane”.

5. The Bill does not mention what should be done by way of certification of the cause of death. Since the immediate cause of death would be unnatural (administration of a drug), the death would presumably have to be reported to a Coroner (or, in Scotland, a Procurator Fiscal). Doctors participating in assisted dying should be apprised of the possibility that the Coroner might subject the death to medicolegal scrutiny.

3 September 2004

Memorandum by the Royal College of Physicians of Edinburgh

The Royal College of Physicians of Edinburgh is pleased to respond to the House of Lords Select Committee on its *Call for Evidence on the Assisted Dying for the Terminally-Ill Bill*.

The College recognises the intention of the Bill to protect individual autonomy and understands the risk of encouraging illegal practices (as happened with abortion) if people in extreme distress are not supported. The needs of a few tragic but rare cases must be balanced against the dangers for society as a whole, and the College has major concerns about the legislation as proposed. However, the College also recognises that the principles of assisted dying are a matter for individual conscience and accepts that there are Fellows of the College who are supportive of the principle, if concerned about the practicalities of implementation.

Specifically the College is concerned about:

- the impact of such legislation on the doctor-patient relationship and the harm it might do to the trust in doctors;
- the ability and willingness of doctors to act as the “attending” or “consulting” physician;
- the difficulty in defining clearly many critical aspects of the Bill;
- the potential for misinterpretation by and for vulnerable groups such as older people, those with disabilities and those with degenerative diseases and their families;
- the implication in the draft Bill that those with needs for pain relief are not already served well when the profession has put such great store on effective pain relief and palliative care as a whole.

The College offers the following information and observations to the House of Lords Select Committee as it considers the draft Bill:

1. ETHICAL CONSIDERATIONS

(a) Have ethical considerations changed over the years?

The present Bill is a further attempt to succeed where previous Parliamentary attempts to legalise voluntary euthanasia failed. It has been persuasively argued that the ethical case for legalising is no stronger now than in the past. In an influential paper [“The History of Euthanasia Debates in the United States and Britain” *Annals of Internal Medicine* 1994: 121:10;793–802], E J Emanuel observes that the “arguments propounded for and against euthanasia in the 19th century are identical to contemporary arguments”. Then and now, he suggests, the typical arguments for, are:

- “(1) it is a human right of self-determination;
- (2) it would produce more good than harm, mainly through pain relief;
- (3) there is no substantive distinction between active euthanasia and the withdrawal of life-sustaining medical interventions; and
- (4) its legalisation would not produce deleterious consequences”.

Against these are typical counter-arguments:

- “(1) challenging the assumption that most deaths were painful;
- (2) emphasising the willingness of practitioners to stop treatments and use pain medications;
- (3) maintaining the distinction between active and passive euthanasia; and
- (4) enumerating the adverse consequences of legalising euthanasia.”

Examining the historical contexts in which interest in euthanasia has waxed and waned, Emanuel concludes that:

Public interest in euthanasia

- (1) is not linked with advances in biomedical technology;
- (2) it flourishes in times of economic recession . . . ;
- (3) it arises when physician authority over medical decision making is challenged; and
- (4) it occurs when terminating life-sustaining medical interventions become standard medical practice and interest develops in extending such practices to include euthanasia.

The third and fourth of Emanuel's conclusions are particularly relevant to the present Bill. The argument for "a human right of self-determination" has been strengthened by current challenges to "physician authority over medical decision making"; and the argument that "there is no substantive distinction between active euthanasia and the withdrawal of life-sustaining interventions" has been strengthened by growing medical and public acceptance of the latter. The distinction may also have been blurred by palliative medicine's increasing ability to support a prolonged period of dying that is relatively pain free but may be psychologically burdensome to the patient or their family. So, although the essential arguments for and against legalising euthanasia may not have changed, the social and medical context of the present Bill may have added weight to the arguments for legalising it, as may the precedent of legalised euthanasia in a growing number of other countries, including the Netherlands, Belgium and some American states. UK opinion polls moreover suggest that while only a small minority of doctors would be willing to administer voluntary euthanasia, a larger minority is in favour of legalising it, and a majority of the British public is supportive of legalisation.

(b) *Improving patient autonomy*

Current challenges to "physician authority over medical decision making" are not necessarily supportive of legalising euthanasia. The English High Court's recent decision on the judicial review of the GMC's guidance on *Withholding and Withdrawing Life-Prolonging Treatment* supports the competent patient's right not only to refuse but also to require treatment. The implications of this (including the resource implications) have yet to be clarified, but the decision has been welcomed by disability rights advocates strongly opposed to physician assisted suicide: in their view, disabled people's quality of life is all-too-often subjectively undervalued by doctors considering whether to withhold or withdraw treatment [<http://news.bbc.co.uk/1/hi/uk/3682473.stm>]. In the shadow of Shipman, this may add weight to arguments warning against "the adverse consequences of legalising euthanasia". Alongside this, many doctors, all-too-aware of this shadow, remain unpersuaded by consequentialist philosophical arguments which deny any "substantive distinction between active euthanasia and the withdrawal of life-sustaining medical interventions": to their medical conscience, the distinction between active and passive euthanasia, or perhaps the principle of double effect, is a saving foothold on a morally treacherous slippery slope.

(c) *Are there adequate safeguards?*

The present Bill offers safeguards of a different kind, publicly ascertainable rather than appealing to the individual or collective conscience of physicians. In a modern democratic society, it is necessary that safeguards against medical malpractice should be publicly ascertainable, not least if society decides that voluntary euthanasia or physician assisted suicide should be legalised. But it is less clear that the purely procedural safeguards proposed in the present Bill are sufficient to achieve respect for the person as well as the rights of patients who would be subject to its provisions. The Bill accords "a competent adult who is suffering unbearably as a result of a terminal illness" the right "to receive medical assistance to die at his own considered and persistent request" provided that certain "qualifying conditions" are met. But it offers no assurance that assistance will be provided respectfully, with due consideration for the vulnerability as well as the technical competence of the patient suffering from a terminal illness. Indeed the strict "qualifying conditions" required by the Bill may actually encourage an impersonal approach to the patient as someone whose case for euthanasia has to be bureaucratically proved, lest the doctor commits a punishable offence. This raises the question of whether the present Bill is addressing what for most dying patients and their doctors are the essential issues.

(d) *Tragic dilemmas*

There are occasions on which even the most skilled palliative care is unable to relieve what the Bill calls "unbearable suffering". Morally, it seems wrong that in circumstances when all else has been tried and failed, patients should be denied the right to medical assistance to die. But occasions when all else that modern palliative care and patient-centred professionalism have to offer have actually been tried and failed are now

rare; and where there is failure it is more likely to be failure to achieve appropriate standards of care, treatment or respect for persons.

This is not to deny that there are “hard cases” when it is difficult if not impossible to achieve the outcome desired by patients and doctors alike. The present Bill offers a possible way of achieving that outcome. But it does so at the risk of bureaucratising and depersonalising doctor-patient communication, and also of the broader deleterious social consequences feared by opponents of euthanasia. Whether these hard cases can be resolved in a better way than at present, by the proposed Bill or by some other means, is ultimately for Parliament or the courts to decide. But, in principle, it is difficult to envisage any statutory or legal solution which can meet all the different and sometimes conflicting moral and ethical demands arising in this context. Indeed, it may have to be accepted that some of these hard cases are genuinely tragic dilemmas.

Such dilemmas can be outlined in terms suggested by Ricoeur [*vide* Ricoeur P *The Just* Chicago: University of Chicago Press 2000]. We begin with the ethically desirable aim of a good death. But morality requires us to respect the universal rule: it is wrong to kill except to save a life. This, however, conflicts with the moral and especially medical rule to relieve suffering wherever possible. Thus we can recognise, in the cases for which the present Bill is designed, a tragic dilemma which the Bill’s purely procedural approach masks. If public opinion is so swayed by hard cases that the pressure for legalisation of euthanasia becomes irresistible, the tragic dilemma will not be removed: it will simply reappear in a different form. But whether euthanasia is legalised or remains illegal, what the tragic dilemma involved in hard cases essentially calls for is practical wisdom, or as Ricoeur puts it “wisdom in judging” which “consists in elaborating fragile compromises where it is a matter less of deciding between good and evil, between black and white, than between gray and gray, or, in the highly tragic case, between bad and worse”.

The business of “elaborating” such “fragile compromises”, Ricoeur suggests, is exemplified by “the model of the small circle bringing together relatives, doctors, psychologists, and religious leaders at the bed of someone who is dying. Wisdom in judging and the pronouncement of wise judgement”, he writes, “must always involve more than one person” [*op cit* 155]. Those involved in this scenario (with the exception of religious leaders) are not unlike those whom the present Bill envisages as involved in the process of determining whether a patient is “qualified” “to receive medical assistance to die”. But, again, the bureaucratic procedures prescribed in the Bill may obstruct the spirit of the “wisdom in judging” needed to achieve “fragile compromises”.

It could be observed that, in the context of this draft Bill, society is on the one hand criticising doctors for denying autonomy but, on the other hand, would now wish doctors to facilitate what many would consider quite abhorrent decisions for the patient and for society. It might therefore be reasonable to challenge why doctors and not a wider group should not share this moral burden.

(e) *Improving patient autonomy*

“Wisdom in judging” involving “more than one person” is very close to the ideal of patient-centred professionalism to which medicine in the UK is now increasingly committed [*vide* Irvine D *Patient Centred Professionalism—Decision Time* 2003 Duncan Memorial lecture, Royal Society of Medicine]. This ideal respects not just the formal rights of patients, but the substance of those rights: it respects the autonomy of patients as partners in their own health care, but also recognises that patients often are also vulnerable individuals who may need medical assistance to maximise their autonomy. In this respect, patient-centred professionalism offers a less medically-dominated way of achieving the “fragile compromises” required to resolve “hard cases” than does the present Bill, which makes the doctors involved the ultimate judges (under a “monitoring commission”) of the patient’s qualifications for the right to assisted death.

Doing all that can be done to achieve the ideal of patient-centred professionalism, through medical education and by maintaining standards of clinical practice, is currently a major priority of the British medical profession. With this in mind, the medical profession may reasonably ask whether enactment of the present Bill will not distract attention from, and in fact present new obstacles to, the real task of respecting and enabling patient autonomy. Many doctors, moreover, are likely to have strong reservations about carrying out what is required by the terms of the Bill and may choose to avail themselves of the Bill’s provisions for conscientious objection. Those who are willing to carry out euthanasia therefore may have a larger number of cases of this kind referred to them than is conducive to optimal patient-centred care.

(f) *Parliamentary authority with regard to medical professionalism*

More generally, the medical profession may seriously question whether Parliament has the moral authority to declare in clause 10(3) of the Bill that “A physician to whom subsection (1) applies . . . shall be deemed not to be in breach of any professional oath or affirmation”. Whether a “professional oath or affirmation”, which is as analogous to a religious as to a civil commitment, can be abrogated by Act of Parliament in this way may raise sufficiently serious constitutional issues as to make Parliament very wary of enacting this clause.

2. PRACTICAL CONSIDERATIONS

(a) *Difficult definitions*

(i) The definition of “terminal illness” is too broad and by implication for a period of up to six months, excluding those in the last two weeks of life. Difficulty judging prognosis is well documented in the literature.

(ii) “Competence” is determined more by the nature of the patient’s illness and the medication/treatment used than time before death. It will be difficult for doctors to assess the competence of patients with communication problems due to the nature of their illness eg aphasic stroke patients, although there are reasonable safeguards within the draft Bill.

(iii) The distress described in this Bill as “unbearable suffering” is almost never due solely to uncontrolled physical symptoms such as pain or breathlessness. Depression is common but poorly diagnosed and often untreated in the medically ill and in palliative care populations. Even patients without psychiatric illness can be extremely distressed by concerns such as loss of autonomy/independence, the indignation of loss of control of bodily functions, burdening family or friends and existential distress. Psychosocial and spiritual care services are under-resourced and the recent NICE guidance on supportive care for cancer patients recognises this. Non-cancer patients with advanced, progressive neurological, respiratory or cardiovascular disease are a growing population in an ageing society and have access to even fewer services, particularly in the community. The prospect of struggling to cope over a prolonged period of physical and mental decline is acknowledged to be a potent driver for patients wishing to avoid suffering themselves or burdening their informal carers. These fears can be particularly pronounced at the time of diagnosis or when there is clear illness progression, and may resolve when support mechanisms are in place. In short, “unbearable suffering” can be improved with good access to high quality palliative support.

(iv) Patients must make “persistent and considered” requests but this requires amplification to determine qualifying status.

(v) In the draft Bill the “visiting physician” must be an NHS consultant and the College questions why employment status rather than professional qualifications and competence should be used within the qualifying criteria. In addition, should this visiting physician require complete independence from the “attending physician” and work in a different unit or region? This could be difficult to achieve in practice, particularly in remote and rural areas.

(b) *Scope of the Bill*

The College recognises the importance of introducing such legislation across the UK consistently and understands that the Scottish dimension has been identified by their Lordships at the second reading.

(c) *Notifying relatives*

The College is very concerned that it may be impossible for doctors to proceed to treat in the face of outright opposition from distressed relatives. Doctors already face the moral dilemma posed in balancing their duty to do what is in their patients’ best interests as required by the GMC’s Good Medical Practice, against opposing the wishes of well-intentioned relatives. The draft Bill, if enacted, will place, on some, an intolerable burden where patients have not informed and do not wish to inform their relatives. This, again, poses a real danger to the general perception of the profession’s trustworthiness and such a burden may lead to individual doctors invoking the right to conscientious objection.

If assisted dying becomes a legal option for terminally ill patients in extreme circumstances, there may be an obligation on doctors to ensure this is made known. This could also damage the doctor-patient relationship and be alarming and distressing to patients and their families.

8 September 2004

Memorandum by the Royal Marsden School of Cancer Nursing and Rehabilitation

1. BACKGROUND

The Royal Marsden School of Cancer Nursing and Rehabilitation, part of The Royal Marsden Hospital, is a provider of specialist post registration cancer and palliative care education to nurses and allied health professionals. The hospital has a staff of 10 teachers all of whom have a nursing or rehabilitation professional registration. All programmes are developed and delivered in close collaboration with clinical colleagues within the trust. This submission has been prepared by the Assistant Chief Nurse/Head of School, Sara Lister and Lecturer Practitioner Palliative Care Patricia Hunt, following discussion with Consultant in Palliative Care Dr Julia Riley and the Chief Nurse/Deputy Chief Executive Dr Dickon Weir Hughes. This submission has been reviewed by the staff of the School and represents the majority of their views.

2. APPROACH TAKEN IN RESPONSE

This response will focus on what we consider are the implications of the Bill from the perspective of post registration nurse education:

3. ISSUES AND CONCERNS

3.1. If this became legislation all nurses working in environments where the powers of this bill maybe enacted would need to undertake education about the implications for nursing practice and the role of the nurse if this circumstance arose. This would obviously have considerable manpower and resource implications in an environment where staffing is already very stretched and the education and training agenda to meet the requirements of clinical governance is already extensive. As a minimum a programme would need to include the following content:

- Exploration of the philosophy underpinning the Assisted Dying Bill because this is in significant contrast to the holistic approach underpinning palliative care. Currently palliative nurse education programmes are designed around the principles underpinning palliative care, which are defined by the WHO (2004) as an approach that improves the quality of life for patients with life-threatening illnesses and their families by early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems. The WHO (2004) principles continue by expressing that palliative care affirms life and regards dying as a normal process and intends neither to hasten nor postpone death. In essence, the current palliative care philosophy taught in palliative care programmes would need to be reviewed as it is contradictory to the legislation within the bill.
- A structured framework to enable practitioners to explore their own values and beliefs in respect of assisted dying and to be able to make a conscious decision about the extent they would be involved if the situation arose.
- Details of the alternative palliative care provision available. If a patient has developed a therapeutic relationship with the nurse directly involved in their care we suggest that they may first explore these issues with that nurse. Although specialists in palliative care are increasing in number through out the country and will be available to attend a patient to discuss palliative care, it is expected that the patient may want to further discuss this with the nurses directly involved in their care.
- Legal background and standing of the Bill.
- Implications for their professional practice of the Bill.
- Spiritual perspectives of assisted dying.
- The practicalities of how a patient will be assisted to die. (The Bill does not make this explicit) If it is going to be through the administration of a drug, the mode of delivery, the action of the drug, potential side effects must be included. This will be necessary; as a patient will want to know what will happen.
- How to respond to a patient who expresses a wish to die, the questions to ask and areas to explore.

3.2. It is estimated that as a minimum two days would be required to cover the content.

3.3. If this legislation was introduced a considerable amount of time in existing palliative care programmes would need to be dedicated to this area of practice. This would detract from the content dedicated to the holistic care of the patient and family including symptom management, pain relief, spiritual and psychosocial issues.

3.4. This Bill includes legislation to make provision for pain relief for a person who is terminally ill. Currently there are no legal restrictions to the prescription of appropriate pain relief by a medical practitioner to a person who needs it, so we don't know why this has been included. The restriction to appropriate pain relief is often due to poor access to appropriate palliative care facilities or lack of healthcare professionals with the expertise to prescribe appropriately. We suggest that the funding is increased to improve education for pain management in the terminally ill. Appropriate education with adequate funding is essential.

3.5. Section 3 suggests a choice between Palliative care and assisted dying. The approach to palliative care is a holistic one and begins at the point of diagnosis. It is not a treatment option when the pain or symptoms get unbearable. The philosophy of Palliative care is to be involved early in the course of the disease, involving the patient and family so symptoms and pain never become unbearable. Palliative care should be available to an individual who chooses assisted death. This should not be an either/or situation. From the education perspective it is essential that the bill doesn't suggest this.

4. CONCLUSION

We oppose this legislation. We suggest that the interests of dying patients and their families would be better served by increasing the funding available for palliative care, specifically improving the opportunities for healthcare professionals to access appropriate education to enable them to develop the competencies required to give patients effective palliative care.

5. REFERENCES

WHO (2004) WHO Definition of Palliative Care (Electronic Version) retrieved 20 August 2004 from <http://www.who.int/cancer/palliative/definition/en/print.html>

August 2004

Letter from the Scottish Partnership for Palliative Care

Thank you for inviting the Scottish Partnership for Palliative Care to submit written evidence to the Select Committee on the Assisted Dying for the Terminally Ill Bill. The Scottish Partnership for Palliative Care is the umbrella and representative body for palliative care in Scotland. Our members include NHS, voluntary and professional organisations engaged in the commissioning, delivery and development of palliative care.

Many of our member representatives have participated in the UK wide consultations carried out by Help the Hospices and by the Association for Palliative Medicine of Great Britain and Ireland, and we have not therefore felt it appropriate to conduct our own additional consultation in response to the Select Committee's call for evidence.

However, the Scottish Partnership for Palliative Care would take a general view that the Bill is contrary to the ethos of palliative care which, in the World Health Organisation 2002 definition "intends neither to hasten nor postpone death".

We would therefore broadly support the position taken by the Association for Palliative Medicine of Great Britain and Ireland in opposition to this legislation.

The text of this letter above has been circulated to all our member representatives (total 92) inviting them to register any objection to a response in these terms from the Scottish Partnership for Palliative Care. We received no objections, one statement that a full consultation should have been carried out by ourselves and 29 unsolicited statements of support. I trust this will be of use to the Select Committee.

August 2004

Memorandum by the Terrence Higgins Trust

1. The Terrence Higgins Trust (THT) is the UK's largest and longest established charity for people living with and affected by HIV/AIDS. THT regularly consults with our members and those who use our services. A majority of our Trustees are elected by the membership.

2. THT and the Centre of Medical Law and Ethics, Kings College London, produced the first widely available *Living Will* in October 1992. Research was undertaken to test the acceptability of the *Living Will*. This showed that it was mainly being used by men between the ages of 30 and 40 with a diagnosis of HIV or AIDS and that it was simple to complete and highly valued.

3. Over 20,000 copies of the *Living Will* were distributed between 1992 and 1994. Currently, THT receives 80-90 requests for the *Living Will* each month.
4. Since the introduction of highly effective combination drug therapy in 1996, the number of HIV related deaths has reduced by 70 per cent and many people living with HIV now view their condition as a long term, manageable illness. However, HIV treatments are complex, life long and often result in severe side effects. Over 400 people die of HIV related causes in the UK each year. Many people living with HIV want to guarantee that their decisions about their care at the end of their life are respected.
5. THT supports the aims and objectives of the Assisted Dying for the Terminally Ill Bill. The current use of the criminal law, in particular the Suicide Act of 1961, does not help either a terminally ill person or the health care professionals supporting them.
6. People living with HIV take many difficult, complex decisions about their care and treatment over many years. The provision of a safe and regulated option of assisted dying for competent, terminally ill adults would extend their choice to be able to make decisions throughout their life with HIV.
7. THT believes that the Bill provides careful safeguards, including the obligatory consideration of all the alternatives, in particular the option of palliative care, the provision of pain control and the revocation of decision at any time, and will create a robust legal framework for end of life decision making.

27 August 2004

ISBN 0-10-400649-8



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