



House of Commons
Health Committee

End of Life Care

Fifth Report of Session 2014–15

*Report, together with formal minutes relating
to the report*

*Ordered by the House of Commons
to be printed 10 March 2015*

The Health Committee

The Health Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Department of Health and its associated bodies.

Current membership

[Dr Sarah Wollaston MP](#) (*Conservative, Totnes*) (Chair)

[Rosie Cooper MP](#) (*Labour, West Lancashire*)

[Andrew George MP](#) (*Liberal Democrat, St Ives*)

[Robert Jenrick MP](#) (*Conservative, Newark*)

[Barbara Keeley MP](#) (*Labour, Worsley and Eccles South*)

[Charlotte Leslie MP](#) (*Conservative, Bristol North West*)

[Grahame M. Morris MP](#) (*Labour, Easington*)

[Andrew Percy MP](#) (*Conservative, Brigg and Goole*)

[Mr Virendra Sharma MP](#) (*Labour, Ealing Southall*)

[David Tredinnick MP](#) (*Conservative, Bosworth*)

[Valerie Vaz MP](#) (*Labour, Walsall South*)

Powers

The committee is one of the departmental select committees, the powers of which are set out in House of Commons Standing Orders, principally in SO No 152. These are available on the internet via www.parliament.uk.

Publication

Committee reports are published on the Committee's website at www.parliament.uk/healthcom and by The Stationery Office by Order of the House.

Evidence relating to this report is published on the [inquiry page](#) of the Committee's website.

Committee staff

The current staff of the Committee are David Lloyd (Clerk), Sharon Maddix (Second Clerk), Laura Daniels (Senior Committee Specialist), Stephen Aldhouse (Committee Specialist), Daniel Moeller (Senior Committee Assistant), Nathan Hug (Committee Support Assistant), and Alex Paterson (Media Officer).

Contacts

All correspondence should be addressed to the Clerk of the Health Committee, House of Commons, 14 Tothill Street, London SW1H 9NB. The telephone number for general enquiries is 020 7219 6182; the Committee's email address is healthcom@parliament.uk

Contents

Report	<i>Page</i>
Summary	3
1 Overview	5
Beyond the Liverpool Care Pathway	7
2 Palliative and End of Life Care	13
Access to Palliative and End of Life Care	13
Quality of care in different settings	17
Preferred place of death	18
Competence of the workforce	20
Advance Care Planning	22
Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPR)	27
3 Resources, support and other issues	30
Community resourcing	30
Funding	30
Free social care at end of life	32
Bereavement support	36
Measuring quality of care	37
Research into Palliative and End of Life Care	39
Leadership	40
Acknowledgement	42
Conclusions and recommendations	43
Formal Minutes	47
Witnesses	48
Published written evidence	49
List of Report from the Committee during the current Parliament	51

Summary

The care that people receive at the end of their lives has a profound impact not only upon them but also upon their families and carers. At the most difficult of times, their experience will be made worse if they encounter poor communication and planning or inadequate professional expertise. The Health Committee has looked at the state of end of life care since the independent Review of the Liverpool Care Pathway, chaired by Baroness Neuberger, and found great variation in quality and practice across both acute and community settings.

All clinicians and providers who may care for people at the end of life should be aware of the Five Priorities of Care¹ but in light of the variation in practice we also recommend that a senior named person in each NHS Trust is given responsibility for monitoring how end of life care is being delivered within their organisation.

We welcome the focus on end of life care by the Care Quality Commission and recommend that they monitor both acute and community health care providers' move to the new approach in their inspections and as part of their thematic review.

Round-the-clock access to specialist palliative care in acute and community settings would greatly improve the way that people with life-limiting conditions and their families and carers are treated, especially if there were opportunities to share their expertise with other clinicians. Crucially their expertise should be more equitably available to people with a non-cancer diagnosis, older people and those with dementia, for whom early identification and sensitive discussion and documentation of their wishes is also important.

The situation is unlikely to improve unless clinicians feel confident to identify people who may be near the end of life and to start conversations with their patients about their wishes. Too often, however, staff feel that they lack the confidence, skills and training needed to raise end of life issues with patients, let alone understand the mechanisms available to patients and carers under the Mental Capacity Act 2005 which allow people to make their wishes clear. All staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning, including the different models and forms that are available and their legal status.

The use of Electronic Care Planning makes it easier to document and share people's wishes and care records between providers and also reduces the risk of an unwanted admission to hospital or failure to act on advance decisions to refuse treatment.

Most people who express a preference, would like to die at home but that is also made more difficult by the shortfall in community nurses and specialist outreach palliative care.

We strongly recommend that the Government provide free social care at the end of life to

¹ See paragraph 27

ensure that no one dies in hospital for want of a social care package of support.

Sustainable, long term funding for the hospice sector also needs to be addressed as part of the Government's response to the Palliative Care Funding Review as does full recognition of the importance of the voluntary sector.

Bereavement support for families should also be included as part of end of life care but availability is currently fragmented and inconsistent around the country. Family members and carers are too often left inadequately supported yet could be helped if there were greater awareness amongst health and social care staff of the impact of bereavement, as well as universal access to bereavement services.

We recommend further research into measuring the quality of end of life care and the priorities that matter most to people with terminal illnesses, their families and carers.

As is so often the case, we feel these important issues will not be addressed without clearly identified leadership to ensure that end of life care is prioritised and embedded in all future planning of services, based on the Five Priorities of Care, and delivered nationally to all those who could benefit.

1 Overview

1. Palliative and end of life care is provided to people who have an incurable and progressive illness. Good quality end of life care is seen as an essential component of modern health care services and in recent years a number of initiatives have been developed to improve the care people receive at this time.

2. There are many examples of good end of life care being provided in different settings. However, the experience that people approaching the end of life have varies and in too many cases is unacceptably poor. Of particular concern is the care that some people receive in acute hospitals, as has been highlighted in evidence from a number of sources.

3. In its evidence to this inquiry the National Council for Palliative Care remark:

“... successive governments have set high aspirations, saying that the way we look after dying people is a litmus test for health and care and should be core business for the NHS. Despite that, there is still unacceptable variation, which would not be tolerated in any other area of practice.”²

4. Each year around 500,000 people die in England and Wales. In 2013, approximately 80% of those who died were people aged over 65.³ One third of all deaths are people aged 85 and over, but only 15% of those who receive specialist palliative care are in this age group.⁴

5. The large majority of deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths (53%) occur in NHS hospitals, with around 21% occurring at home, 18% in care homes, 5% in hospices and 3% elsewhere.⁵ This is despite the fact that 63% of people say that they would prefer to die at home, while 29% would prefer to die in a hospice. Hospital was found to be the least preferred place of death in a study carried out by the Cicely Saunders Institute.⁶ Other sources put the figure for home as the preferred place of death even higher: ComRes polling for the Dying Matters Coalition in April 2014 showed that 72% of people would want to die at home.⁷ Macmillan Cancer Support cite evidence that shows that 85% of people who die in hospital would have preferred to die in another setting.⁸ People do change their minds however and the stated preferred place of death may change as death approaches.⁹

2 [ELC 47](#), page 2

3 Office for National Statistics (2013) [What are the top causes of death by age and gender?](#)

4 [ELC 77](#), para 1.2

5 Cicely Saunders Institute, [Local Preferences and Place of Death in Regions within England 2010](#)

6 [Ibid.](#),

7 [ELC 47](#), page 5

8 [ELC 42](#), para 2.3

9 [ELC 36](#), page 3

6. The demographics of death in relation to age profile, cause of death and place of death changed significantly during the 20th century. In 1900 most people died in their own homes. Acute infections were a much more common cause of death and a far higher proportion of all deaths occurred in childhood or early adult life. As a result of these changes, familiarity with death within society as a whole has decreased. Many people nowadays do not experience the death of someone close to them until they are well into midlife. Many have not seen a dead body and as a society we seldom discuss death and dying openly.¹⁰ Many people may lack the confidence to initiate discussions with medical staff about what should or shouldn't be done when someone is approaching the end of their life.¹¹

7. Following a review of end of life care services the Department of Health announced a new approach for those caring for dying people in England. The approach focuses on achieving Five Priorities for Care that should be applied whenever and wherever someone is dying, whether in hospital, a hospice, their own home or another location.

8. The Committee decided to examine the issues around palliative and end of life care, focusing on how different care sectors support people who are likely to die within 12 months, what opportunities exist for improving care quality, and the experience of those caring for people at the end of life.

9. The terminology which has grown up in this area is poorly understood and lacks clarity. Terms such as end of life care, palliative care, supportive care, specialist palliative care, general palliative care, hospice care, etc. are not always used clearly or consistently.¹² The General Medical Council and the National Council for Palliative Care say that people can be said to be 'approaching the end of life' when they appear likely to die within the next twelve months.^{13,14} This is the definition the Committee has used for its inquiry.

10. The World Health Organisation's definition of 'palliative care' is "an approach that improves the quality of life of patients and their families facing the problem 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."¹⁵

11. The National Council for Palliative Care (NCPC)'s guidance to doctors defines 'end of life care' as care that helps people with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into

10 Department of Health, [End of Life Care Strategy, 2008](#)

11 [ELC 49](#), para 8.1

12 Association for Palliative Medicine, December 2012, [Commissioning Guidance for Specialist Palliative Care: Helping to Deliver Commissioning Objectives](#)

13 General Medical Council, May 2010, [Treatment and Care Towards the End of Life: good practice in decision making](#)

14 National Council for Palliative Care and National End of Life Care Programme, June 2011, [Commissioning End of Life Care](#)

15 <http://www.who.int/cancer/palliative/definition/en/>

bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.¹⁶ In their written evidence, NCPC say:

We do note though that if end of life and palliative care were better and more widely understood, then this might enable better conversations between health and social care staff and people about death and dying, as well as services that meet their needs.¹⁷

12. Giving oral evidence to the inquiry, the Royal College of Physicians and Royal College of Nursing commented that end of life care is “everybody’s business” in every care setting; it is not provided solely by specialist staff.¹⁸ This view reiterates the National Institute for Health and Care Excellence (NICE)’s Quality Standard on End of Life Care which states that providing high quality end of life care and support should be an integral part of every health and social care worker’s role.

13. People with more complex needs may require ‘Specialist Palliative Care Services’ (SPC). SPC is the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support.¹⁹

14. It is worth noting that, while there is a continuing debate about legalising euthanasia and assisted suicide, these issues are outside the scope of this inquiry.

Beyond the Liverpool Care Pathway

15. The Government published its End of Life Care Strategy in 2008, and commented:

Many consider death to be the last great taboo in our society and ... most of us find it hard to engage in advance with the way in which we would like to be cared for at the end of life.

16. The Strategy recognised that many people did not have what could be described as a ‘good death’—being treated as an individual with dignity and respect, being without pain and other symptoms, being in familiar surroundings, and being in the company of close family and/or friends—and highlighted a number of issues to improve the situation:

- Government would work with the National Council for Palliative Care to raise the profile of end of life care and to change attitudes to death and dying in the wider society;

16 Association for Palliative Medicine, December 2012, [Commissioning Guidance for Specialist Palliative Care: Helping to Deliver Commissioning Objectives](#)

17 [ELC 47](#), page 3

18 [Qq106-107](#)

19 Association for Palliative Medicine, December 2012, [Commissioning Guidance for Specialist Palliative Care: Helping to Deliver Commissioning Objectives](#)

- there was a need for an integrated approach to planning, contracting and monitoring of service delivery across health and social care;
- all health and social care staff should be trained in communication for palliative care;
- end of life care should be included in training for all staff at all levels, to ensure that they have the necessary knowledge, skills and attitudes needed to care for people who were dying;
- everyone approaching the end of life should have their needs and preferences recorded in a care plan, including any advance decision to refuse treatment;
- families and carers of people approaching the end of life should be involved in decision making and provided with practical and emotional support both during the person's life and following bereavement;
- measurement of end of life care provision was necessary to monitor progress and facilitate change;
- better use should be made of end of life care financial resources across health and social care. The Government committed an additional £383 million to implement the strategy;
- the Liverpool Care Pathway, or an equivalent tool, was recommended for wider use than for patients with cancer—it should be used in hospitals, care homes, hospices and in people's homes.

17. The Strategy set out the key elements of an end of life care pathway and stressed that it was crucial that open discussions between health and social care staff, patients and their families and carers take place, to ensure the delivery of good end of life care. The Government recognised, however, that these discussions regularly failed to take place and that it would be a challenge to reverse that trend.²⁰

18. The Strategy described the Liverpool Care Pathway for the Dying Person (LCP) as “a multi-professional, outcome-driven document that provides an evidence-based framework for the delivery of care in the last days or hours of life.” This seemed to suggest that the LCP was a stand-alone document, rather than what it was intended to be: an approach to care in itself.

19. Until fairly recently, the LCP was widely used across the UK (excluding Wales) and commentators, including witnesses giving oral evidence to the inquiry,²¹ have acknowledged that where it was being used well it had a transformative effect on the way that end of life care services were delivered, supporting but not replacing clinical

20 Department of Health, [End of Life Care Strategy, 2008](#)

21 [Q28](#)

judgement. In a survey of clinicians carried out by the British Medical Journal, 97% of consultants said the LCP allowed patients to die with dignity when used correctly.²²

20. Giving oral evidence, Macmillan told us:

There were some aspects of it that were very positive. I remember being a district nurse before the Liverpool care pathway and after it, and I was very much involved in implementing it in Cheshire where I worked. It made a huge difference to things like anticipatory prescribing of medication, because we used to struggle to get GPs to get medication into somebody's home. If people were in the dying phase, we had the drugs prescribed and ready to use.

21. However, following media criticism and reports of poor treatment in acute hospitals at nights and weekends, lack of access to specialist palliative care teams out of hours and at weekends, and poor levels of care and communication an independent panel, chaired by Baroness Neuberger, was established in 2013 to review its use.

22. The review panel found evidence of both good and poor care delivered through use of the LCP. Use of the Pathway led, in some cases, to standardised treatment and care, carried out irrespective of whether that was right for the particular person in the particular circumstances, causing unnecessary distress and harm to dying people and those who were important to them. One of the submissions to the review reported: *"He was not given sufficient pain relief or sedation to ease his discomfort from what in effect was a slow death, attributable in part to dehydration and starvation."*²³

23. In their report the panel said:

The Review panel has reluctantly concluded that the term 'Liverpool Care Pathway' is most unhelpful: anxious and upset relatives cannot be expected to understand what an 'integrated care pathway is, let alone what it has to do with Liverpool. A 'pathway' suggests to most people a road that leading somewhere. When someone is 'put on' a pathway, it sounds like, as one carer put it, they are being placed on "a conveyor belt to death". In the context of the debate about assisted dying and euthanasia, some carers have formed the impression that "the pathway" represents a decision on the part of clinicians, in effect, to kill their dying patients, when that is clearly not the case.

24. The panel concluded that in too many cases, the LCP had come to be regarded as a generic protocol and used as a 'tick box' exercise, leading to problems with delivery of care.²⁴ As a consequence they recommended that use of the LCP should be phased out by July 2014 and replaced by an individual end of life care plan.

22 <http://www.bmj.com/content/346/bmj.f1303>

23 [More Care Less Pathway: A Review of the Liverpool Care Pathway](#)

24 Leadership Alliance for the Care of Dying People, June 2014, [One Chance to Get it Right](#)

25. Baroness Neuberger commented:

Ultimately it is the way the LCP has been misused and misunderstood that has led to such great problems, along with it being simply too generic in its approach for the needs of some. Sadly, it is just too late to turn the clock back to get it used properly by everybody. That is why we have recommended phasing out the LCP and replacing it with a more personalised and clinically sensitive approach.²⁵

26. The Leadership Alliance for the Care of Dying People (LACDP), set up after the independent review of the Liverpool Care Pathway, has developed a new approach to caring for dying people that is expected to be adopted by health and care providers. This approach focuses on the individual needs and wishes of the dying person and those closest to them, to both plan and deliver care. It centres around Five Priorities for Care which form a focus for care, as well as education and training, audit and research.²⁶

27. The Five Priorities for Care are that, when it is thought that a person may die within the next few days or hours–

- This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
- Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.²⁷

28. Macmillan Cancer Support were part of the LACDP that developed the Five Priorities for Care. In their written evidence they comment:

We understand the Department of Health will be conducting a review of progress in 2015. Anecdotally, however, there are problems with the implementation of these priorities as professionals report concerns that the picture is variable. Some areas have worked well across their locality and sectors to develop local guidance and documentation based on the

25 [More Care Less Pathway: A Review of the Liverpool Care Pathway](#)

26 House of Commons POST Note 481, [Palliative and End of Life Care, 2014](#)

27 Leadership Alliance for the Care of Dying People, June 2014, [One Chance to Get it Right](#)

recommendations of the Neuberger Review and, more recently, the Five Priorities for Care. Other areas, however, are still using the Liverpool Care Pathway by a different name.

29. The Department for Health has stressed however that the LCP is no longer valid and should not be used. Norman Lamb, giving evidence to the inquiry, explained:

It should not be used ... Absolutely not. We have been very clear about this. If clinicians and other health care workers, and indeed their employers, follow the principles, they will be on the right track. I commissioned the review by Baroness Neuberger and her team, and I wanted them to remain in place as a panel to monitor what happens over the first year of this new approach, so they are there ready to look at and monitor how things are going. It would be wholly wrong for a hospital, for example, just to re-badge their approach or their use of the Liverpool care pathway, call it something else, and carry on as before. It is not what everyone came together to achieve.²⁸

30. Dr Martin McShane from NHS England, told us:

We need to go back to the origins of the end of life care strategy from 2008, a 10-year strategy which set out some clear principles about addressing the key changes that were required. We have made quite a degree of progress in delivering that strategy...²⁹

We are thinking about trying to do it in the way we do things now, and we need to step outside that and ask what we need to change about our approach that would make this normal—which would make this the way we approach it.³⁰

31. The Royal College of Physicians has found that many Trusts are not sufficiently assessing or discussing the quality of care available to patients. For example, only 53% of Trusts have a named board member with responsibility for the care of the dying and it had only been discussed at a Board meeting in 42% of Trusts in the last year. Their written evidence states:

There is further evidence of low levels of assessment of delivery of end of life care. Only 56% of Trusts have conducted a formal audit of care in the previous year, despite recommendations that an audit into the delivery of care should be conducted annually. Trusts must recognise the importance of palliative care and ensure that the delivery of services are regularly assessed and discussed at board meetings so that patients' needs are sufficiently met.³¹

28 [Q175](#)

29 [Q177](#)

30 [Q189](#)

31 [ELC 16](#), para 8

32. Sir Mike Richards told us:

I have been to hospitals where it is very clear that those leading end of life care have direct access to the chief executive and the director of nursing, and others where that is not the case. Those where there is senior leadership and oversight tend to have made much more progress in moving on to what are now called the five priorities for care. Again, in that, as in everything else, there is wide variation.³²

33. The move by the Care Quality Commission (CQC) to prioritise end of life care in its new approach to inspections across all sectors is very welcome. We hope that it will go some way towards ensuring that poor end of life care is seen as a ‘never event’, as suggested by a witness to the inquiry.³³ The CQC has also begun a thematic review of the quality of end of life care, to understand the barriers that prevent people receiving good end of life care. They will report on their findings during 2015.³⁴

34. Every care provider should have a model in place based on the Five Priorities for Care that will deliver personal, bespoke care to people at the end of life. There should be no reason for any health or care organisation not to have introduced an appropriate alternative to the Liverpool Care Pathway.

35. We recommend that a senior named person in each NHS Trust and care provider is given responsibility for monitoring how end of life care is being delivered within their organisation.

36. We welcome the focus on end of life care by the Care Quality Commission and recommend that they monitor both acute and community health care providers’ move to the new approach in their inspections and as part of their thematic review.

32 [Q26](#)

33 [Q8](#)

34 [ELC 85](#), para 21

2 Palliative and End of Life Care

Access to Palliative and End of Life Care

37. The complexity of individual patients' palliative care needs should determine who receives specialist palliative care. Witnesses to this inquiry however have proposed that older people and those with non-cancer conditions are much less likely to have access to specialist palliative care services.^{35,36} One factor that has contributed to the current situation is that palliative care in the UK developed from the hospice movement, which traditionally focused on caring for people with cancer, where a terminal phase is more easily defined.³⁷ The British Medical Journal has described three distinct illness trajectories for people with progressive chronic illnesses:

- a trajectory with steady progression and usually a clear terminal phase; mostly cancer
- a trajectory with gradual decline, punctuated by episodes of acute deterioration and some recovery, with more sudden, seemingly unexpected death; for example, respiratory and heart failure
- and a trajectory with prolonged gradual decline; typical of frail elderly people or people with dementia.³⁸

38. The National Council for Palliative Care's written evidence suggests that people with cancer access over 75% of specialist palliative care services, although cancer causes around 30% of all deaths.³⁹

39. The NCPC also comment:

Dying does not make equals of us. There are still many inequalities and inconsistencies in people's experience and access to care. Reasons include age, gender, diagnosis, geography and deprivation. For example we know that you are more likely to die at home if you are a man; that you are much more likely to access specialist palliative care if you have cancer, and that you are more likely to die in a care home if you have dementia. The trajectories of some conditions, such as cancer, can be relatively predictable. However as more of us are living longer, and dying with a number of long term conditions, we need to ensure that everybody receives good care regardless of the complexity of their circumstances ... Dementia must be given equal parity

35 [Q3](#)

36 [ELC 47](#), page 8

37 [ELC 30](#), para 3.1

38 Murray, S.A., Kendall, M., Boyd, K., Sheikh, A., BMJ 2005, [Illness Trajectories and Palliative Care](#)

39 [ELC 47](#), page 14

of access to end of life care as is given to people dying of physical health issues.⁴⁰

40. In a recent debate, members of the House of Lords heard Baroness Bakewell quote from the report *Living and Dying with Dementia in England*: “people with dementia are not being appropriately identified for end of life care, and that they have less access to, and receive poorer quality care than people with other terminal illnesses.”^{41, 42}

41. Written evidence from the Alzheimer’s Society explains that it is particularly important that people with dementia have the opportunity to engage in end of life care discussions early in the course of their illness, while they still have the mental capacity and ability to communicate to express their wishes and preferences and agree in advance plans for their future care. By the time they reach the end of life phase of their illness they will lack the capacity to be involved. Most people with dementia reach the end of their lives in a care home. The Alzheimer’s Society have called for more palliative care services to be available to care homes with residents who have dementia, to avoid unnecessary admissions to hospital and to ensure that dementia patients at the end of their lives are treated with dignity and are free from pain.⁴³

42. The reasons for the variation in people’s ability to access specialist palliative care and end of life care are varied. Age UK’s written evidence draws attention to the fact that one third of all deaths are of people aged 85 and over but only around 15% of those who gain access to specialist palliative care are in this age group.⁴⁴ Despite the large number of older people who die each year,

The NHS continues to struggle to properly identify people who are in the last stages of life, unless they have a terminal or otherwise life-threatening condition ... This in turn means people are not able to plan properly or encouraged to discuss decisions about their future care ... A failure to understand multi-morbidity and frailty and the trajectory of people’s health living with either (or often both) means the NHS is not agile, failing to allow care and support to switch tracks quickly when someone is approaching the end of life.”⁴⁵

43. The Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care has also found that staff caring for frail and seriously ill older people have difficulty

40 [ELC 47](#), page 3

41 [Lords Hansard text for 12 Jan 2015](#)

42 Alzheimer’s Society and Marie Curie Cancer Care, Dec 2014, [Living and Dying with Dementia in England: Barriers to Care](#)

43 [ELC 40](#), paras 3.1, 4.2

44 [ELC 77](#), para 1.1

45 [ELC 77](#), paras 1.2 - 1.3

recognising the point at which a transition to a palliative care approach may be appropriate.⁴⁶

44. The British Heart Foundation in their written evidence highlight that even though heart failure survival rates are worse than for some cancers, unlike cancer patients, very few people with heart failure receive specialist end of life care. They note that GPs admit that introducing palliative care is fairly straightforward for people with cancer, who typically have a clear terminal decline, but much more difficult for patients with other life-threatening illnesses.⁴⁷

45. Whereas the majority of adults only need palliative care towards the end of their lives, the palliative care needs of children and young people are often protracted, frequently occurring prior to their last year and sometimes extending over several years.⁴⁸ It is common for children and young people's conditions to fluctuate and, as such, it is often much more difficult to identify when they are moving into their end of life phase.⁴⁹

46. Together for Short Lives explain that geography has a significant impact on the extent to which children and families are able to access 24/7 palliative care. Some families living in remote rural areas do not have access to the community children's nursing teams or paediatric services they need.⁵⁰ Their written evidence describes the situation:

Whether or not children are able to die at home or in their place of usual residence largely depends on whether they can access a sustainable local community children's nursing (CCN) service. A current shortfall in CCNs is affecting the choice which children and families currently have.⁵¹ The lack of availability of Community Children's Nursing teams has a detrimental impact on 24/7 children's palliative care support. The Royal College of Nursing (RCN) recommends that for an average-sized district with a child population of 50,000, a minimum of 20 whole time equivalent (WTE) community children's nurses are required to provide a holistic CCN service. This is in addition to any individual child-specific continuing care investment. However, only 17 community children's nurses are due to qualify in 2014/15 in the UK.⁵²

47. The National Survey of Bereaved People (VOICES) has found that care varies by level of deprivation. People living in the most deprived areas are less likely to experience outstanding or excellent care at the end of life than those in the wealthiest areas.⁵³

46 [ELC 30](#), para 4.2

47 [ELC 7](#), paras 11-12

48 [ELC 43](#), para 4

49 [ELC 71](#), para 3

50 [ELC 71](#), para 13

51 *ibid.*, para 7

52 *ibid.*, paras 15

53 [ELC47](#), page 9

48. We have heard from a number of witnesses that less than a quarter of hospitals have round-the-clock access to specialist palliative care teams throughout the week.⁵⁴ The Royal College of Physicians in their evidence state:

Patients' access to medical staff is a major issue in the palliative and end of life care pathway. In a recent audit conducted into palliative care the RCP found that only 21% of hospital sites provide face to face palliative care weekend services. 73% provide face to face palliative services on weekdays only ... The inconsistent availability of specialist palliative care seven days a week and poor uptake of training can dramatically impact on the quality of care available to patients.⁵⁵

49. The CQC told us that, having inspected over half of all the acute hospitals in England, they have seen a wide variation in the integration of the specialist palliative care teams with the acute medical wards.⁵⁶ Where the SPC team is well integrated with other hospital teams they are on hand to advise on the possibility that someone is approaching the end of life, particularly when a patient is admitted through A&E.⁵⁷

50. A member of the Royal College of Physician's patient and carer network has stated:

'From a patient and carer perspective the availability of and access to services by any provider will be highly variable in any given locality. It can be a matter of chance often linked to the recognition by clinician/professional/patient/family/carer of diagnosis which will enable access to whatever services exist or may be available subject to criteria.'⁵⁸

51. Generalist staff in acute settings must be competent in identifying people who are likely to be at the end of life, irrespective of their medical condition, so that they can offer specialist care where it will be beneficial. We recommend that NHS Trusts ensure that generalist staff are provided with opportunities to learn from specialist palliative care teams.

52. Round-the-clock access to specialist palliative care will greatly improve the way that people with life-limiting conditions and their families and carers are treated. This would also help to address the variation in the quality of end of life care within hospital and community settings. We also recognise the value of specialist outreach services. We recommend that the Government and NHS England set out how universal, seven-day access to palliative care could become available to all patients, including those with non-cancer diagnoses.

54 [Q15](#)

55 [ELC 16](#), para 7

56 [Q13](#)

57 [Q14](#)

58 [ELC 16](#), para 4

53. People with dementia should have equal access to end of life care as those dying as a result of other conditions. Particular attention should be paid to discussing and documenting their wishes as early as possible following diagnosis.

54. Commissioners should explicitly set out how they will provide specialist palliative care services for people from all backgrounds in their locality, including children and adolescents, people from ethnic minority backgrounds and those living in isolated or deprived communities and how they will ensure that those with a non-cancer diagnosis can also access specialist palliative care.

Quality of care in different settings

55. Staff attitudes towards, and communication with, dying people impact on the delivery of care. The National Survey of Bereaved People has found that staff in hospices are rated highest for treating patients with dignity and respect in the last three months of life; hospital staff received the lowest ratings, and nurses were rated lower than doctors.⁵⁹ The Committee notes that this may be affected by staffing ratios in different settings.⁶⁰

56. The Parliamentary and Health Service Ombudsman (PHSO) have told us that during the period 2011–2014 they investigated 220 complaints related to the treatment and care provided to individuals towards the end of their life and that the majority of those complaints related to care in hospital settings—182 out of 220 cases. They note that:

Whilst it is not clear why this might be the case, we believe the location of services and whether someone has support from friends and family for example, plays a significant role. What is perhaps more striking is that our case work contains virtually no complaints made about someone's experience of care within a hospice.⁶¹

57. PHSO are also quoted as reporting, “the reasonable expectation that an older person or their family may have of dignified, pain-free end of life care, in clean surroundings in hospital, is not being fulfilled,” following a detailed investigation of a number of serious complaints.⁶²

58. Half of all complaints that the Ombudsman deals with feature poor communication as a theme. PHSO's evidence goes on to say:

Communication failings appear at all levels; between clinicians and patients; between clinicians and family; within clinical teams; and finally, between the hospital and care in the community. Our case work has highlighted instances where people have only learned of their diagnosis through reading discharge summary information; families not being informed of the severity of a

59 ONS, July 2014, [National Survey of Bereaved People \(VOICES\) 2013](#)

60 [ELC 30](#), para 7.1

61 [ELC 90](#), para 3

62 [ELC 77](#), para 2.2

person's illness and therefore a lack of discussion has led to treatment not considered to be in the person's best interests. In other cases, relatives have learned of bad news over the telephone from GP practice managers.

What is clear ... is that healthcare professionals are not always having the open and honest conversations that are necessary in order for carers and family members to understand both the severity of the situation and also the choices that will need to be made.⁶³

59. Age UK's written evidence quotes the journal *Age and Ageing* which in 2011 examined the quality of care experienced by older people in acute hospitals and concluded that:

Many issues arose because of "attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources" as well as "uncertainty over the roles of specialist and generalist palliative care providers in acute hospitals."⁶⁴

Preferred place of death

60. There are many and complex reasons why people may not be able to die in their stated preferred place. Most people, when asked, say they would prefer to die at home. In spite of this, as a study by Gomes and Higginson, cited in the NCPC's written evidence has found, fewer people die at home each year. The findings suggest that should this trend continue, fewer than 1 in 10 people will die at home in 2030.⁶⁵ The NCPC's written evidence explains that polls consistently show that hospital is not where most people want to die and that more needs to be done to ensure that more people are cared for and die in their preferred place. They suggest that increased use of Advance Care Planning, better co-ordination and sharing of people's care plans, and round the clock access to specialist advice and pain relief are some of the actions that could facilitate a shift.⁶⁶

61. In both written and oral evidence to the inquiry we have been told that more could also be done to help those caring for people with dementia or frail elderly people in care homes. Care home staff face particular pressures: the rate of turnover in the workforce, the limited time available for staff training, the difficulty of maintaining staff numbers at weekends which leads to a reliance on agency staff, and the reduced level of medical support out of hours. The Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care report that care home nurses express anxieties about their responsibilities, particularly with regard to use of end of life care medications, often because of a lack of available support from NHS colleagues.⁶⁷ These pressures can lead to staff reactively sending their residents to hospital where there is a concern about their condition. Both the Royal College

63 [ELC 90](#), para 3.1

64 [ELC 77](#), para 2.3

65 Gomes, B, and Higginson, IJ, Jan 2008, "[Where people die \(1974-2030\): past trends, future projections and implications for care](#)" cited in [ELC 47](#), page 4

66 [ELC 47](#), page 5

67 [ELC 30](#), para 4.4

of Physicians and the Royal College of Nursing stressed that joint working between the NHS and the community sector can ensure that problems typically arising in the care home setting are anticipated and proper support made available, twenty-four hours a day, seven days a week.⁶⁸

62. The reverse situation was also discussed. Hospitals, on discharging patients who have dementia or are frail elderly, may send them to a care home rather than back to their own home without discussing their end of life care wishes. We were told:

They are sent to a care home, because they cannot put a package of care together to keep somebody in their own home ... It is iniquitous to send somebody to a care home from where their home has been for 60 or 70 years and they never see that home again. That is iniquitous, but it is happening.⁶⁹

63. Place of death is not always determined by the availability of services, however. Changing patient choice also plays a role. The Association for Palliative Medicine of Great Britain and Ireland have noted that as death approaches, people may change their previously stated preferred place of death from their home to an in-patient setting (hospital, palliative care unit or hospice). Some of the issues said to influence the decision include:

- the patient and family hold unrealistic expectations, despite efforts to communicate a poor prognosis, and therefore want a hospital admission for what they hope to be life-prolonging treatment;
- the patient is already in an acute care setting and their condition deteriorates more rapidly than a discharge home can be arranged (either through logistics with planning the discharge, transport home, or providing appropriate social care at home in a timely manner);
- the patient has potentially reversible clinical problems, justifying further hospital treatment;
- the patient knows their hospital medical team well and feels safer remaining under their care;
- the patient has insufficient practical support at home to accommodate their needs; some patients wish to refuse equipment such as a hospital bed being imposed on them.⁷⁰

64. On this last point, it is also important to be aware of the needs of family carers who will be required to look after the patient and to take account of their capacity to cope.

68 [Q132](#)

69 [Q132](#)

70 [ELC 36](#), page 3

65. When someone is dying they may simply be reluctant to see their home increasingly transformed into a ‘mini-hospital’.⁷¹

66. Data on preferred place of death refers largely to the preferences of adults rather than those of children and young people with life threatening illnesses and their families. Giving oral evidence to the Committee, Together for Short Lives commented on this, referring to a 2014 study by Professor Myra Bluebond-Langner which suggested that there is no clear evidence to support the inference that terminally ill children and their families would choose that they die at home. Families were found to change their minds about the place of death as their situations changed.^{72 73}

67. A specific issue that has been raised during the course of the inquiry is that people who do choose to die at home often want to be in their own bed but are told by staff that the recommendation is to have a hospital bed installed. Witnesses to the inquiry noted that while it was important to acknowledge that there are some risks to remaining in a standard bed, dying people and their families should be given the requisite information and allowed to make the decision themselves. The competence and confidence of staff who have these discussions is important in these situations, as the RCN explained:

As a district nurse you build up the confidence to be able to say, “Hang on a minute, we can take this person home. We don’t need a hospital bed. We can adapt their own bed.” They know the risks and we know the risks, and we are willing to take them.⁷⁴

Competence of the workforce

68. Many of those who provided written evidence to this inquiry expressed the opinion that health care staff need support to develop their competence in identifying, providing care to and communicating with people at the end of life and their families and carers.

69. The Parliamentary and Health Service Ombudsman’s evidence commented that their case work highlights particular difficulties relating to out of hours treatment and care. It was also clear that “healthcare professionals need to be supported to be better at having open discussions about care towards the end of life.” It went on to say:

Our case work has shown that there is a need to communicate in a way that is both sensitive but also makes clear the prognosis and what options there are for care based on the outcomes individuals may want for themselves. For this reason, it is vital that carers and family members and friends know who to speak to about any concerns they may wish to raise and that staff are

71 [Q145](#)

72 [Q85](#)

73 Bluebond-Langner, M et al, *Preferred place of death for children and young people with life limiting and life threatening conditions: A systematic review of the literature and recommendations for future inquiry and policy*, Palliative Medicine, 2013. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3808113/>

74 [Q145](#)

proactive and provide opportunities for concerns or fears to be raised and discussed. This is essential if the NHS is to plan for the care of people with complex needs in a way that helps achieve the best outcomes for the person and their family and carers.⁷⁵

70. We agree with Compassion in Dying when they say that staff training is needed to give clinicians the confidence to communicate positively with people about palliative and end of life care. Staff may need reassurance that, rather than causing alarm or distress to patients, having honest conversations about dying will in fact empower them to die in the manner of their choosing, in the place of their choosing and with less pain or loss of control both for themselves and their families or carers. “When patients are not informed about their prognosis and are not asked about their care and medical treatment preferences, they are denied the right to participate in decisions and might not have the death they want.”⁷⁶

71. The National Council for Palliative Care have commented in written evidence:

A well-trained and supported workforce is needed for these end of life conversations to take place. The Royal College of Nursing survey findings (2014) in which its members voiced serious concerns about their abilities to deliver high quality end of life care to dying people. The survey found that just 10.5% of nurses felt they were always able to deliver the right level of care to individuals, while almost 70% had experienced people being admitted to hospital at the end of their life due to a lack of resources to treat them in a community setting, despite this being against their wishes.

A 2012 survey for the Royal College of Physicians found only a third of respondents had attended any learning event on end of life care in the last five years. The survey also found that there is demand from doctors for continued professional development in end of life care. However, doctors reported a lack of support by their trusts to provide this type of training for them and other healthcare staff.

End of life care should be core business for the NHS, but is not being treated as such.⁷⁷

72. The Association of Ambulance Chief Executives, in their written evidence, highlight the role of ambulance staff in end of life care. They call for more specific education on end of life care that focuses on issues such as identifying the dying stage, the implications of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders and communication skills, and stress that it is not only front line staff who need additional training but also call centre and patient transfer staff. They suggest that higher education institutes should be

75 [ELC 90](#), para 6

76 [ELC 21](#), para 7

77 [ELC 47](#), pages 6-7

encouraged to increase the amount of time dedicated to end of life care in programmed leading to paramedic registration.⁷⁸

73. Giving oral evidence to the inquiry, NHS England’s Dr McShane said:

One thing we need, which is evidenced by the work that has been done on care planning, is a situation where professionals are instituting and refreshing care plans with patients, and involving carers and people important to the person much earlier on and engaging in that conversation: “If you are at the end of your life”—not “you are at the end of your life”—“what would matter most to you?” This is why I have taken the approach, certainly as the lead for long term conditions, that we need to get this right for any condition. Our approach should be driven not by a condition but by the needs of the person. That to me is about recognition, care planning, communication and working with people on what matters to them. That then will change the nature of the conversation.⁷⁹

74. It is essential that mandatory training and education is provided for generalist staff, whether qualified or unqualified, who care for patients nearing the end of life to ensure good end of life care in all settings. Appropriate skills and knowledge must be learnt and maintained. Employers must release staff for training, prioritising it in the same way as resuscitation training or infection control training, as suggested by the Association for Palliative Medicine of GB and Ireland.⁸⁰

75. We heard that too often staff lack confidence and training in raising end of life issues with their patients or delivering the right care. Training should be provided for all health and social care staff who are likely to provide care to people at the end of life, including training in communication skills. We recommend that NHS England works with care providers to identify and roll out tailored end of life care training.

Advance Care Planning

76. Most people die in hospital rather than in their stated preferred place of death. The lack of a care plan is a significant reason why people at the end of their lives do not benefit from specialist palliative care and are not able to die in their preferred place. The opportunity to create an individual’s advance care plan will be missed if clinical staff are reluctant to raise the issues of dying and death, especially if patients and their families are also reluctant to admit that someone is approaching the end of their life. And yet, as Sir Mike Richards of the Care Quality Commission told us: “There is a lot of evidence that care planning leads to better care.”⁸¹

78 [ELC 46](#), para 5

79 [Q187](#)

80 [ELC 36](#), page 4

81 [Q23](#)

77. It is helpful if patients and families are fully aware of the difference between the tools that are available to formally set out a person's wishes, including Advance Statements of Wishes and Advance Decisions to Refuse Treatment (ADRT). An ADRT is legally binding when it records in writing the informed decision of the person with capacity to refuse consent to treatment in specific situations, such as cardiopulmonary resuscitation or insertion of tube feeding. If the validity of an ADRT cannot be assured, for example because it is vague, the documents will be regarded as an Advance Statement of Wishes and must be considered when a decision must be made in the best interests of a person who has lost capacity. An Advance Statement of Wishes is not legally binding because a person cannot dictate in advance what interventions must be done to them.

78. Patients should also be made aware of the option to appoint and register one or several people to have Lasting Power of Attorney (LPA) for Financial decisions and separately to have LPA for Health and Welfare decisions. Those registered for Health and Welfare decisions can additionally be registered for enhanced decision-making, to include life-sustaining treatment decisions.

79. Dr McShane, giving evidence for NHS England, commented on the confusion that exists around advance care planning: "I must admit that I have been trying to work out the lexicon around this and I am not sure it is entirely helpful: an advance care plan could lead to an advance statement and an advance decision to refuse treatment, and I think we are confused."⁸²

80. The legal framework to support people's choices and preferences for their care is set out in the Mental Capacity Act 2005. Evidence received for this inquiry however suggests that it is not well understood. A recent House of Lords Select Committee report on the implementation of the core principles of the Act commented that "its implementation has not met the expectations that it rightly raised. The Act has suffered from a lack of awareness and a lack of understanding."⁸³ Norman Lamb also acknowledged, when giving evidence to the inquiry, that there is still some way to go to fully embed an understanding of the Mental Capacity Act and the mechanisms it has made available.⁸⁴

81. Compassion in Dying have found that while over 80% of people they asked said they would want to be able to decide which life-prolonging medical treatments they would have, in advance of losing mental capacity, only 4% have an Advance Decision to Refuse Treatment or have appointed a Lasting Power of Attorney for Health and Welfare to ensure that their medical treatment preferences are respected. Compassion in Dying say, "Work is needed to ensure that people can act on their preferences in order to have the death they want. More widely, we support that patients are involved in all decisions about their care, not just those on the refusal of life-prolonging treatments."⁸⁵

82 [Q225](#)

83 House of Lords, Feb 2014, [Select Committee on the Mental Capacity Act 2005—Report](#)

84 [Q225](#)

85 [ELC 21](#), para 3

82. In practice, most care plans are an Advance Statement of Wishes which must be taken into consideration if the patient loses mental capacity and a decision has to be made in their best interests. The requirements around taking a best interest decision are laid out in the Mental Capacity Act 2005.

83. Some of the witnesses we heard from suggested that the Government should do more to dispel the confusion:

There is no leadership being provided, as far as we can see, from the Department of Health in terms of policy directives around advanced care planning, which we would very much like to see, as well as engagement from NHS England in the implementation of advanced care planning. That will have a tremendous bearing.”⁸⁶

84. Earlier engagement with the tools available will enable patients with terminal or chronic diagnoses to record their end of life care preferences in advance of losing capacity.⁸⁷

85. The Parliamentary and Health Service Ombudsman’s written evidence comments:

The decisions made by healthcare professionals about a patient’s care are often made with the best intentions and to try to ensure the highest care quality. However, in cases where decisions are made without the opportunity for the patient and their family to have their preferences assessed fairly, the patient ends up feeling distressed by their lack of choice, and that they have received a poor service.⁸⁸

Their case work has highlighted a failure of GPs to liaise with hospitals to coordinate care, especially for those with complex multiple conditions.⁸⁹

86. Macmillan told us:

Advanced Care Planning (ACP) is an important means of understanding people’s wishes, needs and preferences at the end of life and then planning to meet them. Fundamentally, if people are not identified as approaching end of life and professionals do not initiate conversations to understand peoples’ needs and preferences, it is far less likely that plans can be put in place to meet those needs. There is evidence to suggest that the use of ACP to establish a person’s wishes around their care at the end of life can increase the likelihood of those wishes being met and that this impact is over and

86 [Q85](#)

87 [ELC 21](#), para 7

88 [ELC 90](#), para 3.1

89 [ELC 90](#), para 3.3

above the impact of specialist palliative care alone. However, anecdotally we know that uptake of the use of ACP across England is variable.⁹⁰

87. In its response to the House of Lords Select Committee Report on the Mental Capacity Act 2005 the Government committed to working with NHS England on developing guidance for front line clinicians, explaining the role of Lasting Power of Attorney for Health and Welfare and deputyships and how they should work with them.

88. We believe there is a role for the Government and NHS England to provide clarity and leadership with regards to the policy on advance care planning and its implementation. We recommend that the Government considers how it can further raise awareness of the mechanisms available to patients and carers under the Mental Capacity Act 2005 to make their wishes clear about end of life care. This should also include information about Advance Decisions to Refuse Treatment. The Department should provide an update to our successor Committee on the actions it has taken since publication of its response to the House of Lords Select Committee Report.

89. We recommend that all staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning, including the different models and forms that are available and the legal status of different options. Training should be developed in partnership with the National Council for Palliative Care and other non-government bodies with relevant expertise.

90. We have heard that Age UK and Compassion in Dying are jointly running a number of pilot projects with the aim of raising awareness of end of life rights and choices: the pilots focus on helping people to make advance decisions to refuse treatment and advance statements and care plans, and understanding the different options for making a Lasting Power of Attorney for Health and Welfare (LPA). The pilots have not been running long enough to be evaluated yet, but initial feedback has been positive and Age UK report a real demand for them. They hope to roll out the model more widely in the future.⁹¹

91. We recommend that the Government engage with Age UK to understand the outcome of their awareness raising pilots, learning lessons that can be applied to supporting other groups as well as older people to understand the options, and developing a strategy to promote advance care planning to patients in different settings.

92. Giving oral evidence, Norman Lamb acknowledged that the cost of making a LPA can act as a barrier to some people and he agreed that this was an area that the Government needed to review.⁹²

90 [ELC 42](#), para 4.2

91 [Q102](#)

92 [Q228](#)

93. We recommend that the Government carry out a review of the cost of making a Lasting Power of Attorney, including the impact on take up by people from different socioeconomic groups, with a view to identifying any financial barriers for those who have been unable to take out LPAs, and what support is available to those who cannot afford to use a legal route.

94. At present, should a person completing the LPA application form make any error, they are obliged to complete a new form and start the application process again, including paying a second time. We recommend that the Government review the LPA application process, with a view to making it simpler and cutting costs for applicants.

95. We have heard that electronic care plans and coordination systems can assist care staff to have conversations about end of life care with patients and make it more straightforward and likely staff in different settings will share information:

The third thing is around IT and communication. The only way we will get the sort of continuity of information that people are seeking in order to manage the complex needs that people have around end of life care, and complex care needs, is to make sure that the information can be shared between providers, preferably, I would say, between the individual and, with their permission, their carers if they so wish. End of life care is one of the key themes in the National Information Board priorities.⁹³

96. The Association of Ambulance Chief Executives (AACE) have stressed that it is vital for ambulance clinicians to be made aware when care plans are in place as they are often called in crisis situations. Without access to patient records and end of life care plans, staff are hindered in making difficult and time critical decisions such as whether to attempt resuscitation, transfer a patient to hospital, or ensure that they remain at home if that is their preferred choice. The AACE comment that enabling ambulance staff to view patients' resuscitation status and advance care plans en route to emergencies is only feasible with an integrated and electronic approach.⁹⁴ This point was echoed by the Minister in his oral evidence:

I do not want to sound like a record stuck in a groove, but where EPaCCS⁹⁵ are in place and the ambulance service shares the record and are able, as they travel to the location, to understand what that individual's wishes are, it enables them, for example, to take the person to the hospice rather than to the A and E department. Again, that sharing of information is critical to getting ambulance services understanding what the patient's priorities are.⁹⁶

93 [Q186](#)

94 [ELC 46](#), page 2

95 Electronic Palliative Care Coordination Systems

96 [Q240](#)

97. There is no systematic approach to recording patients' end of life care plans and preferences, however, so that they can be easily accessed by all health and social care staff who treat them. We have been told that clinicians are "often carrying information about patients 'in their heads' rather than relying on recorded notes to support the transfer of information between staff across organisational boundaries."⁹⁷ The Royal College of Nursing have suggested that concerns about Information Technology and confidential information sharing are a barrier to developing good record-keeping.⁹⁸

98. We recommend that the Government encourage and monitor the take up of electronic care planning and Electronic Palliative Care Coordination Systems (EPaCCS), to facilitate information sharing between providers, and that they review the best mechanisms to facilitate the understanding and take up of these plans. We also recommend that the Government explore options for a universal system for recording and filing advance care plans, with a standard template for use across England and a website dedicated to explaining the issues.

99. The Department of Health has notified the Committee that NHS England is working with Health Education England to develop a single accredited curriculum for paramedic training that will ensure that paramedics have the skills they need to resolve more calls on the phone (hear and treat) and at the scene (see and treat). We expect end of life care to feature in the new curriculum when the details are issued later in 2015.

Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPR)

100. Guidance issued by the NHS End of Life Care Programme (in 2012)⁹⁹ stresses that what can be considered a person's "best interests" are not decided solely by medical opinion; they are what the person would choose if capable. The assessment of best interests will be easier if someone has had an opportunity to discuss their future treatment ahead of time, through advance care planning, and where they or their carers are involved in treatment discussions should circumstances change.

101. People can lose mental or physical capacity when they become acutely ill or are approaching the end of their life. When someone has experienced a cardiac arrest, for instance, they will be unconscious and not in a position to consent to, or refuse, an attempt at cardiopulmonary resuscitation. It is therefore imperative that discussions about an individual's specific wishes for resuscitation should they suffer cardiac arrest should take place as soon as it appears that they may be approaching the end of their life.¹⁰⁰

102. Joint written evidence from the research teams at the University of Warwick Medical School and Cambridge University Hospitals raises concerns about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders. DNACPRs are put in place to ensure

97 [ELC 21](#), para 8

98 [Q135](#)

99 National End of Life Care Programme, Sept 2012, [DNACPR Decisions: Who decides and how?](#)

100 [Ibid.](#)

that no attempt is made to restart a patient's heart in the event of a cardiopulmonary arrest. They are written at a patient's request when a patient is dying from a terminal disease and is receiving palliative care, or when a patient is unlikely to survive an attempted resuscitation attempt due to their overall state of health.¹⁰¹

103. DNACPR decisions affect the majority of the population: two thirds of patients die in hospital and, of those, 80%-90% die with DNACPR decisions in place. We have heard evidence that staff are not always clear when 'resuscitation' should or shouldn't be attempted and that, while DNACPR only applies to restarting the heart and lungs in the event of a cardiac arrest, it is often misinterpreted to mean that other care should be withheld. The evidence suggests that people who have DNACPR orders receive poorer care than those with similar conditions and backgrounds who do not have such orders in place.

104. There is also known to be variability in the method of recording all types of resuscitation decisions and inconsistency around which recording methods are accepted in which regions. Some forms are not accepted by ambulance staff, with further documentation being required. Several regions have developed forms which are 'valid' across care boundaries, but examples still exist where patients in the community require multiple forms.¹⁰²

105. This is already being addressed in Wales where a unified DNACPR document and procedure has been developed for use in all settings.

106. The Association of Ambulance Chief Executives in their written evidence state that a unified approach to DNACPR documentation is crucial for paramedics and other ambulance clinicians when a swift and difficult decision needs to be taken to allow a person to have a dignified death. They comment:

Without a DNACPR form or information that establishes that a person is at the end of life, resuscitation may be the course of action decided upon by the clinician that may be later seen as unethical, inappropriate and most importantly not what the patient would have wished for.

As ambulance services we would strongly support, recommend and offer to assist with work to develop a universally recognised DNACPR form that can be electronically integrated into record systems across England and Wales.¹⁰³

107. We recognise that there will be emergency situations where no information is available on a patient's wishes or preferences. However, work should be taken forwards to minimise the number of such cases.

108. We recommend that the Government review the use of DNACPR orders in acute care settings, including whether resuscitation decisions should be considered in the

101 [ELC 49](#), para 3.1

102 [ELC 49](#), para 4.3

103 [ELC 46](#), page 3

context of overall treatment plans. This Committee believes there is a case for standardising the recording mechanisms for the NHS in England.

3 Resources, support and other issues

Community resourcing

109. In the Five Year Forward View, NHS England state:

Support and aftercare and end of life care—which improves patient experience and patient reported outcomes—will all increasingly be provided in community settings.¹⁰⁴

110. In their written evidence, however, the Royal College of Nursing suggest that while much public debate and attention has been given to the need to shift care from acute to community settings, not enough resources are being invested in the community to make this a reality for most patients. They cite district nursing, a specialism within community nursing which includes end of life nursing care in patients' homes, as one particular area of concern. Their figures show that there has been a 44% reduction in the number of qualified district nursing staff in England in the last decade; the district nursing workforce is ageing, with 60% aged 45 or over; and only five students took up graduate and post graduate district nursing training courses in London universities in 2012. The RCN call for a clear commitment from the Government to appropriately fund and resource community services if the savings that could be accrued from the acute to community shift are to be realised.¹⁰⁵

111. The NCPC's Specialist Palliative Care Workforce survey similarly reveals that specialist nursing workforce is ageing.¹⁰⁶ Avoiding a recruitment crisis will need proper planning at a national level.

112. Nursing homes with higher ratios of qualified nurses and care assistants to patients provide better care.¹⁰⁷

113. We recommend that Health Education England and NHS England set out how they plan to address the shortfalls in the staffing of community care services. The Committee sees this as essential to enabling people to die at home and in other community settings including care homes and nursing homes, where that is their preference rather than in hospital. This should involve their plans for the recruitment and training of district nurses.

Funding

114. The Nuffield Trust in its report 'Exploring the Cost of Care at the End of Life' proposed that given the finite resources available for health care, there should be some

104 NHS England, Oct 2014, [Five Year Forward View](#)

105 [ELC 28](#), page 3

106 [ELC 47](#), page 7

107 [ELC 30](#), para 7.1

understanding of the costs of end of life care, but “there is a stunning lack of good data surrounding costs for palliative care in England.” They have carried out several studies looking at this issue and found that the cost of end of life care provided in hospital is significantly higher than care delivered by GPs, community nurses, local authority funded social care and hospices. The bulk of the hospital costs is due to emergency hospital admissions.¹⁰⁸

115. In its written evidence to the inquiry the Cicely Saunders Institute supports this:

There is early evidence that provision of palliative care can lead to reductions in the overall cost of healthcare, largely through reduction in hospital admissions, and reduction in acute interventions near end of life. This is important, since the recent Nuffield Trust report on costs of last year of life shows that acute hospital admissions costs—largely unplanned admissions - represent about 70% of health care costs in the last three months of life.

116. One of the concerns raised by a number of witnesses is the serious funding challenge faced by hospices, which threatens their ability to provide a wide range of services. The Association for Palliative Medicine of Great Britain and Ireland refer in their written evidence to a report by Hospice UK published in 2014 which showed that half of hospices surveyed in England had had their NHS statutory funding either cut or frozen in that year, largely due to financial restrictions on NHS commissioners. Hospices still rely to a great extent on charitable funding.¹⁰⁹

117. Hospice care is not restricted to caring for people in a hospice building. As witnesses told us, it is also about providing specialist palliative care services to people in their own homes and providing respite support to the families and carers of terminally ill adults and children. The Rowcroft Hospice explained:

As a society, we need to get away from the impression that hospices are buildings and beds. We provide community based services, hospice at home services and in patient unit services, but we also provide education services that support the non hospice providers of palliative care and care homes, and, indeed, the hospital district nurses, that enable them to deliver end of life palliative care services better than they would otherwise.¹¹⁰

118. While Together for Short Lives said:

We hear from families that just using the local hospice for 15 or 16 hours to get a night’s sleep so that they can keep going is totally imperative to their daily lives. Families will break down and local authorities will find themselves in the position of having to take these children into care, and there are not

108 Nuffield Trust, Sept 2014 [Exploring the Cost of Care at the End of Life 2014](#)

109 [ELC 36](#), page 2

110 [Q70](#)

the resources available. It makes good economic sense to enable funding for short breaks.¹¹¹

119. The NCPC has said, “The Department of Health has not yet decided what should be included in a Palliative Care Funding currency. This is essential.”¹¹²

Free social care at end of life

120. We know that timely access to free social care is one of the barriers people at the end of life face when they would like to die at home. This is due to the complexity and length of the assessment and means-testing people have to go through prior to accessing either continuing healthcare or social care.¹¹³

121. The 2011 Palliative Care Funding Review, commissioned by the Secretary of State for Health, reported that 10-20% of the NHS budget is spent on people in the last year of their life, largely due to hospital admissions, and identified free social care at the end of life as ‘key’ to supporting people to die at home or in the community.¹¹⁴

122. Macmillan in their evidence state:

There are also issues accessing the social care support that is already available. The National Audit Office has highlighted that the process for accessing state-funded social care is complicated, lengthy, and is separate from the healthcare system. For people who may only have weeks to live this fragmentation leads to delays that can prevent them receiving the care they need to die in the place of their choice.¹¹⁵

123. NCPC said:

There is an evidence base for free, fast, social care at the end of life, which is likely to improve the rates of people dying at home. Some people at the end of life spend far too long in hospital waiting for a social care package, and in some case, even die in hospital, for want of social care support. People at the end of life and their families want to spend their last few weeks and days together, rather than phoning round for a social care package to be put in place. We work with five other national charities, Hospice UK, Macmillan Cancer Support, Marie Curie Cancer Care, the Motor Neurone Disease Association and Sue Ryder on this—our main call is that the financial assessment is removed for people at the end of life. This was recommended

111 [Q96](#)

112 [ELC 47](#), page 11

113 [ELC 47](#), page 12

114 Palliative Care Funding Review, July 2011, [Funding the Right Care and Support for Everyone](#)

115 [ELC 42](#), para 4.5

by the Palliative Care Funding Review, and endorsed by the Dilnot Commission and Barker Commission.”¹¹⁶

124. The National Audit Office in written evidence to the inquiry said:

Overall, we found that only limited information is available on the national and local costs of end of life care. Similarly, there is a lack of detail on how the proposed new funding arrangements will be applied.

Estimating the total cost of end of life care is difficult due, in part, to the complexity of the funding arrangements. The Department has not calculated the total costs of end of life care comprehensively.

The Department and other organisations have estimated the costs of some of the main elements of end of life care. While not providing a comprehensive total, in 2008 the Department estimated the costs of some of the main elements of end of life care. We uplifted these figures to account for inflation, which produced an estimate of £1.8 billion for 2013-14. The largest cost element is hospital admissions (estimated at some £800 million a year).

The current funding approach has been criticised for a lack of transparency and inconsistencies. The 2011 Palliative Care Funding Review commented that end of life care contracting is “overly complicated, difficult to navigate and not joined-up enough, leading to a lack of fairness and transparency for commissioners, providers and patients. The system is focused on providers and not patients. The review team [was] therefore convinced that changes must be made swiftly to the system.”¹¹⁷

125. Giving evidence, the Minister acknowledged that the Government is still trying to pin down a workable method for funding end of life care:

There is work under way to try to develop a tariff for end of life and palliative care. If we can get there and do it in a way that does not create new distortions, it would be an advance on where we are at the moment.¹¹⁸

While NHS England referred to:

Our inability to link data up and track outcomes across the whole system to how money is invested and what activity by people has taken place... Linking health and social care data is always very difficult and then, of course, because of the means-testing in social care there are different thresholds

116 [ELC 47](#), page 12

117 [ELC 93](#)

118 [Q198](#)

between different local authorities in how much money people might be personally spending.¹¹⁹

126. Notwithstanding the complexities, the Committee was disappointed by the lack of progress on developing a method to calculate the cost of free social care at the end of life and believes that developing this should be a priority.

127. In a letter to the inquiry Norman Lamb explained that a number of Palliative Care Funding Pilots were set up in April 2012 to collect data that would inform the development of a per-patient funding currency model for palliative care. Although the pilots collected data on the costs of care provided by the organisations who made up the pilot sites, they did not offer an estimate of the total spend across the NHS. From July 2013 the pilots also began collecting social care data. The aim of the additional data collection was to understand at per-patient level the costs of providing social care to people who were also in receipt of specialist palliative care.

128. Whilst the data has provided some material, further information outside the scope of the pilots is likely to be needed to properly cost a policy of free social care for people approaching the end of life. In particular, the pilots were unable to collect data on self-funded social care linked with periods of NHS specialist palliative care, partly because this data was not routinely collected by local authorities.

129. Many witnesses to this inquiry have also pointed out the inconsistency around health care being free at the end of life, so that a patient in a hospital or a hospice does not pay for his or her care; but because social care is not free, someone who spends time in a care home in their last days must find the money to pay for end of life care. This is at best confusing and inconsistent, at worst a barrier to people getting the care they need.

130. The NHS Continuing Healthcare Fast Track Pathway was developed to ensure that people with complex care needs, including a rapidly deteriorating condition that may be entering a terminal phase, are supported in their preferred place of care as quickly as possible. The Clinical Commissioning Group takes responsibility for commissioning and funding appropriate care, merging health and social care funding where appropriate. If the person receiving services through use of the Pathway is expected to die in the very near future, the CCG continues to fund their care package until they die.¹²⁰

131. In written evidence from the Association for Palliative Medicine of Great Britain and Ireland (APM) we have been told that access to services through the CHC Fast Track Pathway is inconsistent across the country. APM members report that seemingly appropriate applications are being rejected and people are being advised that the funding does not exist.¹²¹ A lack of clarity around who is eligible for access to services via the Fast Track Pathway could act as a barrier to many people who might wish to apply.

119 [Q207](#)

120 Department of Health, Nov 2012 (Revised), [Fast Track Pathway Tool for NHS Continuing Healthcare](#)

121 [ELC 36](#), page 4

132. We were disappointed that the Government was unable to provide our inquiry with the latest figures on how much money is spent annually on specialist palliative care. The most recent assessment was made in 2011 when the Palliative Care Funding Review. It is important to have this information, firstly, to be able to identify if hospices will be unable to provide services and need to turn seriously ill people away because they are unable to raise the necessary funding to support the needs of people in their communities; and secondly, to have an understanding of the likely cost of providing free social care at the end of life.

133. In correspondence to the Committee subsequent to his giving oral evidence, the Minister told us:

The Committee was also interested in the amount spent annually on specialist palliative care in England and requested an update on the 2011 figure of £450 million spent on specialist palliative care by primary care trusts.

Unfortunately, I am unable to provide you with an update on the quoted figure as the spend on specialist palliative care by Clinical Commissioning Groups is not collected centrally.

I understand from NHS England that although the Palliative Care Funding Pilots collected data on the costs of care provided by the organisations who made up the pilot sites, they do not offer an estimate of the total spend across the NHS.

However, I am aware that the Review of Choice in End of Life Care has considered costs of care as part of its work. The Review's advice to Government is due to be published shortly.

134. We recommend that the Government clarify the eligibility criteria for the NHS Continuing Healthcare Fast Track Pathway and phase out the social care means test (financial assessment) for people at the end of life.

135. This Committee strongly recommends that the Government provide free social care at the end of life to ensure that no one dies in hospital for want of a social care package of support.

136. We recommend that the Government set out what it intends to do to ensure sustainable, long term funding for the hospice sector as part of their response to the Palliative Care Funding Review.

137. We recommend that the Government ensure that their proposals for the future funding of palliative care fully recognises the importance of the voluntary sector.

Bereavement support

138. The ONS carries out the National Survey of Bereaved People, known as *VOICES* and commissioned by NHS England. The aims of the survey are to assess the quality of care delivered in the last three months of life for adults who died in England and to assess variations in the quality of care delivered in different parts of the country and to different groups of patients. The last survey found:

When asked whether they had talked to anyone from any support services since the death, most respondents reported that they had not, and did not want to (68%). However, 18% said that they had not, but would have liked to.¹²²

139. Evidence to the inquiry from Macmillan refers to the experience of the people who care for those who are dying and the impact it has on them:

Dying is rarely done in isolation and usually it involves families and friends. We are concerned, however, that across the wider UK, bereavement support is currently very fragmented and inequitable. Bereavement services and support is rarely a priority for service providers and there is little support in the system. It is not regarded as a health problem unless it manifests itself physically or mentally. There is a need, therefore, to raise awareness of the needs of the bereaved and issues related to pre-bereavement for individuals and families when someone knows they are dying. Specific barriers to improving bereavement support include:

- Professionals are unaware of the presence of their role in bereavement support and lack knowledge of other services.
- GPs are not informed of bereavement or may be unaware of how bereavement can affect individuals.
- There is a lack of services available around bereavement including specialist services.
- There is a lack of pastoral support in schools and in the workplace.
- Individuals do not identify their own needs and do not seek help. They are rarely identified and rarely signposted to support.¹²³

140. The Association for Palliative Medicine of Great Britain and Northern Ireland also told us that bereavement services are not consistently provided across the country and are often funded by charities. People who care for dying friends and relatives need support in the time before the person's death and afterwards, and special care may be required for

122 ONS, July 2014, [National Survey of Bereaved People \(VOICES\) 2013](#)

123 [ELC 42](#), para 11.4

those who experience particularly complicated grief, including children.¹²⁴ If carers witness poor care and themselves receive inadequate communication around a relative or friend's illness and death this can compound their loss and make it harder for them to come to terms with the death.¹²⁵

141. The first national strategy for children's palliative care—*Better Care, Better Lives*—was published in February 2008.

Whilst it is acknowledged that some parallels can be drawn between the principles applying to end of life care services for adults and those for children, it needs to be emphasised that there are also significant differences. For example, there are a wide variety of childhood conditions causing death before adulthood, many of which are rare. The time span of children's illnesses may also be different from adults, meaning that palliative care extends over many years. Moreover, children continue to develop physically, emotionally and cognitively, and this affects both their medical and social needs, as well as their understanding of disease and death. Above all, a child's death remains emotionally difficult, unnatural and unexpected for families and healthcare providers alike.¹²⁶

142. The National Bereavement Alliance's written evidence explains that children who are bereaved of a parent or sibling are more likely to have clinical rates of mental health difficulty, may underachieve at GCSE and have a greater risk of poor health behaviours.¹²⁷

143. Norman Lamb said, "The problem with all of this is that it is not just the dying person, but the person left behind, the loved one, who then lives with that awful experience for the rest of their life; we have a responsibility to them as well... making sure people have access to bereavement counselling is also very important."¹²⁸

144. Bereavement support provision is currently fragmented, with services not consistently provided around the country. Family members and carers are too often left inadequately supported. We recommend that the Government and NHS England raise awareness amongst health and social care staff of the impact of bereavement and provide for universal access to bereavement services in its funding plans for palliative care.

Measuring quality of care

145. The End of Life Care Strategy makes it clear that good information on palliative and end of life care is necessary for patients and carers to be able to make informed choices

124 [ELC 36](#), page 2

125 [ELC 90](#), page 5

126 Department of Health, Feb 2008, [Better Care, Better Lives](#)

127 [ELC 68](#), para 9

128 [Q242](#)

about their care.¹²⁹ This is also essential for clinicians, commissioners and policy makers to be able to plan services and assess the quality of care.

146. In order to drive improvement in end of life care there needs to be a validated set of measures which are directly related to patient outcomes. This will allow an assessment of the different models of care being developed around the country, particularly in light of the phasing out of the Liverpool Care Pathway, and proper evaluation of the difference that end of life and palliative care interventions are making. At present, while service providers may be recording data on use of palliative and end of life care, there is no mechanism for compiling the information and making it widely accessible.

147. Witnesses giving oral evidence to the Committee remarked:

There was one major difficulty with the Liverpool Care Pathway, which was that it was about measuring processes. It did not measure outcomes. What I mean by outcomes is the difference made to people's health or well-being... It is only if we show the difference made to pain management, breathlessness management and other difficult symptoms, and improvements in emotional well-being and family support, that we can show these things are making a difference.¹³⁰

If we were able to collect and measure data about the treatment or care that people receive through particular services, we would then be able much better to measure what the impact and effectiveness of those services is.¹³¹

148. We are aware that Public Health England (PHE) is consulting on options for introducing a new national collection of data from specialist palliative care, which they propose will be aligned with the information standard for electronic palliative care co-ordination systems (EPaCCS).¹³² PHE will establish a number of pilots to test the feasibility of the proposed dataset.

149. The CQC acknowledge that there is a role here for them as the sector regulator:

One of the things we need to be able to do is to raise the profile, measure what is good, publish what is good and then drive improvement through shining a spotlight. That is certainly what we at the Care Quality Commission are doing.¹³³

150. We recommend the development of outcome measures for palliative care. These must be properly evaluated and funded in order to improve the quality of care for people at the end of life.

129 Department of Health, [End of Life Care Strategy, 2008](#)

130 [Q28](#)

131 [Q24](#)

132 Public Health England, Mar 2015, [Individual-Level Data Collection From Specialist Palliative Care](#)

133 [Q9](#)

Research into Palliative and End of Life Care

151. Witnesses to the inquiry expressed concern that there is a lack of research evidence to inform the development of models for early identification of those people who would benefit from receiving palliative care and how to deliver palliative and end of life care services to non-cancer patients. We were told that just 10p in every £100 spent on health services research is devoted to palliative and end of life research.¹³⁴

152. In their evidence the Childhood Bereavement Network stress that better data collection is needed on the number of children who are bereaved of a parent, seriously hampering service development and planning. They estimate that approximately 33,000 dependent children (under 18 years old) are bereaved of a parent each year, bringing change and challenge into their lives which can be devastating.¹³⁵

153. The Government has provided information to the inquiry on the consultation carried out by the Palliative and End of Life Care Priority Setting Partnership, facilitated by the James Lind Alliance. This work has identified ten research priorities that matter most to people who are approaching the end of their life, their families and carers, and health and social care professionals:

- What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.
- How can access to palliative care services be improved for everyone regardless of where they are in the UK?
- What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?
- What information and training do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?
- How can it be ensured that staff, including healthcare assistants, are adequately trained to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?
- What are the best ways to determine a person's palliative care needs, then initiate and deliver this care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia, and stroke)?

134 [Q14](#)

135 [ELC 61](#), para 3

- What are the core palliative care services that should be provided no matter what the patients' diagnoses are?
- What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good coordination of services affect this?
- What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case coordinator improve this process?
- What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?

154. Norman Lamb said: "We recognise that it is a priority to do that work, and the fact that we have met and identified what the priorities for further research should be is indicative of that recognition. Of course, you also need good quality research proposals coming forward, but the fact that we have set out what the priorities need to be will, hopefully, encourage good, robust propositions to come forward."¹³⁶

155. We recommend that the Government pursue the research priorities that matter most to people with terminal illnesses, their families and carers and the staff providing care professionally to them, and set out what funding will be provided to ensure that future policy on palliative and end of life care is informed by a robust evidence base.

Leadership

156. Evidence provided to the Committee for this inquiry ventures that clear leadership on end of life care is lacking at the centre of Government, which suggests that it is not being treated as a priority. The NCPC commented:

Our experience is that end of life care is too easily forgotten by decision-makers. For example, it was only included in the NHS Mandate for 2014-15 as a result of concerted lobbying (it had not been mentioned at all in the draft Mandate). It has been only briefly mentioned in the recent Five Year Forward View for the NHS, in a case study, with no priority being given to it ... End of life care should be core business for the NHS, but is not being treated as such.¹³⁷

The thing we have consistently struggled with is lack of importance being attached to palliative and end of life care. It would be good if a poor

¹³⁶ [Q224](#)

¹³⁷ [ELC 47](#), pages 6-7

experience of care at the end of life could be seen as a never event within the NHS.¹³⁸

157. The Sue Ryder charity also express concern at the failure of the NHS's key document, which sets out its future direction, to provide leadership on end of life care:

End of Life has also been impacted by the loss of the End of Life Care Programme... Leadership now lies with the National Clinical Director for End of Life Care whose resources are much diminished in comparison. Despite much activity around end of life, it is still not being sufficiently acknowledged by government, with no end of life care direction being provided within the Five Year Forward View from NHS England.¹³⁹

158. We believe it is vitally important that the Government should provide clear leadership on care of the dying to ensure that models of best care are replicated around the country. In a Written Statement on 26 February 2015, responding to the Choice in End of Life Care Programme Board's Review of how the quality of end of life care could be improved by giving people greater choice,¹⁴⁰ the Minister for Care welcomed the Review's advice and noted that it is in line with the ambition set out in the Five Year Forward View.¹⁴¹ The advice from the Programme Board reflects many of the recommendations we have presented in this report.

159. The Five Year Forward View sets out a direction of travel for the NHS in England, covering all the major statutory bodies. The Department of Health and NHS England should ensure that end of life care is prioritised and embedded in future planning at all levels. They should identify named individuals who will be responsible for ensuring that the new approach to end of life care, based on the Five Priorities, is delivered nationally.

138 [Q8](#)

139 [ELC 44](#), para 2.2

140 Choice in End of Life Care Review Board, Feb 2015, [What's Important to me: A Review of Choice in End of Life Care](#)

141 House of Commons, [Written Statement \(HCWS301\)](#)

Acknowledgement

Exceptional palliative and end of life care is being provided in many different settings. The Committee particularly notes the dedication and support of family carers, voluntary organisations and health and care professionals in providing care for people who are at the end of their lives. The Committee would like to acknowledge their contribution and offer our thanks for the work that they do.

Conclusions and recommendations

Beyond the Liverpool Care Pathway

1. Every care provider should have a model in place based on the Five Priorities for Care that will deliver personal, bespoke care to people at the end of life. There should be no reason for any health or care organisation not to have introduced an appropriate alternative to the Liverpool Care Pathway. (Paragraph 34)
2. We recommend that a senior named person in each NHS Trust and care provider is given responsibility for monitoring how end of life care is being delivered within their organisation. (Paragraph 35)
3. We welcome the focus on end of life care by the Care Quality Commission and recommend that they monitor both acute and community health care providers' move to the new approach in their inspections and as part of their thematic review. (Paragraph 36)
4. Generalist staff in acute settings must be competent in identifying people who are likely to be at the end of life, irrespective of their medical condition, so that they can offer specialist care where it will be beneficial. We recommend that NHS Trusts ensure that generalist staff are provided with opportunities to learn from specialist palliative care teams. (Paragraph 51)

Access to Palliative and End of Life Care

5. Round-the-clock access to specialist palliative care will greatly improve the way that people with life-limiting conditions and their families and carers are treated. This would also help to address the variation in the quality of end of life care within hospital and community settings. We also recognise the value of specialist outreach services. We recommend that the Government and NHS England set out how universal, seven-day access to palliative care could become available to all patients, including those with non-cancer diagnoses. (Paragraph 52)
6. People with dementia should have equal access to end of life care as those dying as a result of other conditions. Particular attention should be paid to discussing and documenting their wishes as early as possible following diagnosis. (Paragraph 53)
7. Commissioners should explicitly set out how they will provide specialist palliative care services for people from all backgrounds in their locality, including children and adolescents, people from ethnic minority backgrounds and those living in isolated or deprived communities and how they will ensure that those with a non-cancer diagnosis can also access specialist palliative care. (Paragraph 54)

Competence of the workforce

8. We heard that too often staff lack confidence and training in raising end of life issues with their patients or delivering the right care. Training should be provided for all

health and social care staff who are likely to provide care to people at the end of life, including training in communication skills. We recommend that NHS England works with care providers to identify and roll out tailored end of life care training. (Paragraph 75)

Advance Care Planning

9. We believe there is a role for the Government and NHS England to provide clarity and leadership with regards to the policy on advance care planning and its implementation. We recommend that the Government considers how it can further raise awareness of the mechanisms available to patients and carers under the Mental Capacity Act 2005 to make their wishes clear about end of life care. This should also include information about Advance Decisions to Refuse Treatment. The Department should provide an update to our successor Committee on the actions it has taken since publication of its response to the House of Lords Select Committee Report. (Paragraph 88)
10. We recommend that all staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning, including the different models and forms that are available and the legal status of different options. Training should be developed in partnership with the National Council for Palliative Care and other non-government bodies with relevant expertise. (Paragraph 89)
11. We recommend that the Government engage with Age UK to understand the outcome of their awareness raising pilots, learning lessons that can be applied to supporting other groups as well as older people to understand the options, and developing a strategy to promote advance care planning to patients in different settings. (Paragraph 91)
12. We recommend that the Government carry out a review of the cost of making a Lasting Power of Attorney, including the impact on take up by people from different socioeconomic groups, with a view to identifying any financial barriers for those who have been unable to take out LPAs, and what support is available to those who cannot afford to use a legal **route**. (Paragraph 93)
13. At present, should a person completing the LPA application form make any error, they are obliged to complete a new form and start the application process again, including paying a second time. We recommend that the Government review the LPA application process, with a view to making it simpler and cutting costs for applicants. (Paragraph 94)
14. We recommend that the Government encourage and monitor the take up of electronic care planning and Electronic Palliative Care Coordination Systems (EPaCCS), to facilitate information sharing between providers, and that they review the best mechanisms to facilitate the understanding and take up of these plans. We also recommend that the Government explore options for a universal system for

recording and filing advance care plans, with a standard template for use across England and a website dedicated to explaining the issues. (Paragraph 98)

15. The Department of Health has notified the Committee that NHS England is working with Health Education England to develop a single accredited curriculum for paramedic training that will ensure that paramedics have the skills they need to resolve more calls on the phone (hear and treat) and at the scene (see and treat). We expect end of life care to feature in the new curriculum when the details are issued later in 2015. (Paragraph 99)

Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPR)

16. We recommend that the Government review the use of DNACPR orders in acute care settings, including whether resuscitation decisions should be considered in the context of overall treatment plans. This Committee believes there is a case for standardising the recording mechanisms for the NHS in England. (Paragraph 108)

Community resourcing

17. We recommend that Health Education England and NHS England set out how they plan to address the shortfalls in the staffing of community care services. The Committee sees this as essential to enabling people to die at home and in other community settings including care homes and nursing homes, where that is their preference rather than in hospital. This should involve their plans for the recruitment and training of district nurses. (Paragraph 113)

Free social care at end of life

18. We recommend that the Government clarify the eligibility criteria for the NHS Continuing Healthcare Fast Track Pathway and phase out the social care means test (financial assessment) for people at the end of life. (Paragraph 134)
19. This Committee strongly recommends that the Government provide free social care at the end of life to ensure that no one dies in hospital for want of a social care package of support. (Paragraph 135)
20. We recommend that the Government set out what it intends to do to ensure sustainable, long term funding for the hospice sector as part of their response to the Palliative Care Funding Review. (Paragraph 136)
21. We recommend that the Government ensure that their proposals for the future funding of palliative care fully recognises the importance of the voluntary sector. (Paragraph 137)

Bereavement support

22. Bereavement support provision is currently fragmented, with services not consistently provided around the country. Family members and carers are too often left inadequately supported. We recommend that the Government and NHS England raise awareness amongst health and social care staff of the impact of

bereavement and provide for universal access to bereavement services in its funding plans for palliative care. (Paragraph 144)

Measuring quality of care

23. We recommend the development of outcome measures for palliative care. These must be properly evaluated and funded in order to improve the quality of care for people at the end of life. (Paragraph 150)

Research into Palliative and End of Life Care

24. We recommend that the Government pursue the research priorities that matter most to people with terminal illnesses, their families and carers and the staff providing care professionally to them, and set out what funding will be provided to ensure that future policy on palliative and end of life care is informed by a robust evidence base. (Paragraph 155)

Leadership

25. The Five Year Forward View sets out a direction of travel for the NHS in England, covering all the major statutory bodies. The Department of Health and NHS England should ensure that end of life care is prioritised and embedded in future planning at all levels. They should identify named individuals who will be responsible for ensuring that the new approach to end of life care, based on the Five Priorities, is delivered nationally. (Paragraph 159)

Formal Minutes

Tuesday 10 March 2015

Members present:

Dr Sarah Wollaston, in the Chair, in the Chair

Rosie Cooper
Andrew George
Robert Jenrick
Barbara Keeley

Charlotte Leslie
Grahame M Morris
Andrew Percy
Valerie Vaz

Draft Report (*End of Life Care*), proposed by the Chair, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 159 read and agreed to.

Summary agreed to.

Resolved, That the Report be the Fifth Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

[Adjourned till tomorrow at 9 am

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the Committee's inquiry page at www.parliament.uk/healthcom.

Tuesday 20 January 2015

Question number

Simon Chapman, Director of Policy, Intelligence and Public Affairs, National Council for Palliative Care, **Dr Fliss Murtagh**, Cicely Saunders Institute, King's College London, and **Professor Sir Mike Richards**, Chief Inspector of Hospitals, Care Quality Commission

[Q1-68](#)

Giles Charnaud, Chief Executive, Rowcroft Hospice, **Barbara Gelb OBE**, Chief Executive, Together for Short Lives, **Stephen Lowe**, Social Care Policy Adviser, Age UK, and **Alison Penny**, National Bereavement Alliance and Childhood Bereavement Network

[Q69-103](#)

Wednesday 28 January 2015

Adrienne Betteley, Programme Lead, Macmillan Cancer Support, **Amanda Cheesley**, Long Term Conditions Nursing Adviser and **Carolyn Doyle**, Lead Nurse, End of Life Care, Royal College of Nursing, and **Dr Kevin Stewart**, Clinical Director, Royal College of Physicians

[Q104-166](#)

Rt Hon Norman Lamb MP, Minister of State for Care and Support, Department of Health, and **Dr Martin McShane**, Director for People with Long Term Conditions, NHS England

[Q167-242](#)

Published written evidence

The following written evidence was received and can be viewed on the Committee's inquiry web page at www.parliament.uk/healthcom. ELC numbers are generated by the evidence processing system and so may not be complete.

- 1 Age UK ([ELC0077](#))
- 2 Alzheimer's Society ([ELC0040](#))
- 3 Anscombe Bioethics Centre ([ELC0060](#))
- 4 Antonia Rolls ([ELC0015](#))
- 5 Association for Palliative Medicine of Great Britain and Ireland ([ELC0036](#))
- 6 Association of Ambulance Chief Executives ([ELC0046](#))
- 7 Association of Directors of Adult Social Services (Adass) ([ELC0045](#))
- 8 Breast Cancer Care ([ELC0017](#))
- 9 British Association for Counselling and Psychotherapy ([ELC0073](#))
- 10 British Geriatrics Society ([ELC0064](#))
- 11 British Heart Foundation ([ELC0007](#))
- 12 British Medical Association ([ELC0035](#))
- 13 Cambridge University Hospitals DNACPR/UFTO Research Team and Warwick University DNACPR Research Team ([ELC0049](#))
- 14 Care ([ELC0083](#))
- 15 Care Quality Commission ([ELC0085](#))
- 16 Celgene ([ELC0088](#))
- 17 Childhood Bereavement Network ([ELC0061](#))
- 18 Cicely Saunders Institute, King's College London ([ELC0043](#))
- 19 Clic Sargent ([ELC0054](#))
- 20 College of Paramedics ([ELC0091](#))
- 21 Compassion in Dying ([ELC0021](#))
- 22 Coordinate my Care ([ELC0031](#))
- 23 Deanna Tennancour ([ELC0029](#))
- 24 Department of Health ([ELC0087](#))
- 25 Dignity for the Aged, Dignity for the Dying ([ELC0078](#))
- 26 Douglas Macmillan Hospice ([ELC0081](#))
- 27 East Coast Hospice Ltd ([ELC0008](#))
- 28 Forest Holme Hospice ([ELC0062](#))
- 29 General Medical Council ([ELC0086](#))
- 30 Genetic Alliance UK ([ELC0048](#))
- 31 Gold Standards Framework Centre ([ELC0067](#))
- 32 Gold Standards Framework Centre ([ELC0069](#))
- 33 Hospice UK ([ELC0033](#))
- 34 International Observatory on End of Life Care ([ELC0051](#))
- 35 Kevin Sell ([ELC0037](#))
- 36 Macmillan Cancer Support ([ELC0042](#))
- 37 Mandy Preece ([ELC0014](#))
- 38 Marie Curie ([ELC0038](#))

- 39 MHA ([ELC0024](#))
- 40 Motor Neurone Disease Association ([ELC0065](#))
- 41 My Living Will ([ELC0089](#))
- 42 National Audit Office ([ELC0093](#))
- 43 National Bereavement Alliance ([ELC0068](#))
- 44 National Voices ([ELC0004](#))
- 45 Newlife Foundation for Disabled Children ([ELC0019](#))
- 46 Nuffield Trust ([ELC0084](#))
- 47 On Behalf of Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network ([ELC0032](#))
- 48 Parkinson's UK ([ELC0082](#))
- 49 Peter Hofschröder ([ELC0001](#))
- 50 PHSO ([ELC0090](#))
- 51 Picker Institute Europe ([ELC0041](#))
- 52 Plymouth University ([ELC0005](#))
- 53 Public Health England ([ELC0053](#))
- 54 Richard Von Abendorff ([ELC0012](#))
- 55 Rowcroft Hospice ([ELC0058](#))
- 56 Royal College of General Practitioners ([ELC0092](#))
- 57 Royal College of Nursing ([ELC0028](#))
- 58 Royal College of Physicians ([ELC0016](#))
- 59 Sebastian's Action Trust ([ELC0074](#))
- 60 Society of Homeopaths ([ELC0055](#))
- 61 Sonia Dalkin ([ELC0026](#))
- 62 Soul Midwives' School ([ELC0027](#))
- 63 St Christopher's Hospice ([ELC0076](#))
- 64 St Joseph's Hospice Association ([ELC0018](#))
- 65 St Mungo's Broadway ([ELC0050](#))
- 66 Sue Ryder ([ELC0044](#))
- 67 Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care ([ELC0030](#))
- 68 Tavistock And Portman NHS Foundation Trust ([ELC0010](#))
- 69 Teenage Cancer Trust ([ELC0006](#))
- 70 The British Psychological Society ([ELC0075](#))
- 71 The National Council for Palliative Care (NCPC) ([ELC0047](#))
- 72 The Royal College of Radiologists ([ELC0034](#))
- 73 Together for Short Lives ([ELC0071](#))
- 74 Transition Taskforce ([ELC0072](#))
- 75 Trinity Hospice ([ELC0023](#))
- 76 Urgent Health UK ([ELC0039](#))
- 77 Wales Palliative Care Strategy Group ([ELC0080](#))

List of Report from the Committee during the current Parliament

All publications from the Committee are available on the Committee's website at www.parliament.uk/healthcom.

The reference number of the Government's response to each Report is printed in brackets after the HC printing number.

Session 2014–15

First Report	2014 Accountability hearing with the Health and Care Professions Council	HC 339 (Cm 8916 and HC 731)
Second Report	Managing the care of people with long-term conditions	HC 401 (HC 660)
First Special Report	2013 accountability hearing with the General Medical Council: General Medical Council's response to the Committee's Ninth Report of Session 2013–14	HC 510
Second Special Report	2013 accountability hearing with Monitor: Monitor's response to the Committee's Ninth Report of Session 2013–14	HC 511
Third Report	Children's and adolescent's mental health and CAMHS	HC 342 (HC 1036)
Fourth Report	Complaints and Raising Concerns	HC 350

Session 2013–14

First Special Report	2012 accountability hearing with the Care Quality Commission: Government and Care Quality Commission Responses to the Committee's Seventh Report of Session 2012–13	HC 154
Second Special Report	2012 accountability hearing with Monitor: Government and Monitor Responses to the Committee's Tenth Report of Session 2012–13	HC 172
Third Special Report	2012 accountability hearing with the Nursing and Midwifery Council: Government and Nursing and Midwifery Council Responses to the Committee's Ninth Report of Session 2012–13	HC 581
First Report	Post-legislative scrutiny of the Mental Health Act 2007	HC 584 (Cm 8735)
Second Report	Urgent and emergency services	HC 171 (Cm 8708)
Third Report	After Francis: making a difference	HC 657
Fourth Report	Appointment of the Chair of Monitor	HC 744
Fifth Report	2013 accountability hearing with the Nursing and Midwifery Council	HC 699 (HC 1200)
Sixth Report	2013 accountability hearing with the Care Quality Commission	HC 761
Seventh Report	Public expenditure on health and social care	HC 793

Eighth Report	Public Health England	HC 840
Ninth Report	2013 accountability hearing with Monitor	HC 841
Tenth Report	2013 accountability hearing with the General Medical Council	HC 897

Session 2012–13

First Report	Education, training and workforce planning	HC 6-I (Cm 8435)
Second Report	PIP breast implants: web forum on patient experiences	HC 435
Third Report	Government's Alcohol Strategy	HC 132 (Cm 8439)
Fourth Report	2012 accountability hearing with the General Medical Council	HC 566 (Cm 8520)
Fifth Report	Appointment of the Chair of the Care Quality Commission	HC 807
Sixth Report	Appointment of the Chair of the National Institute for Health and Care Excellence	HC 831
Seventh Report	2012 accountability hearing with the Care Quality Commission	HC 592
Eighth Report	National Institute for Health and Clinical Excellence	HC 782
Ninth Report	2012 accountability hearing with the Nursing and Midwifery Council	HC 639
Tenth Report	2012 accountability hearing with Monitor	HC 652
Eleventh Report	Public expenditure on health and care services	HC 651 (Cm 8624)

Session 2010–12

First Report	Appointment of the Chair of the Care Quality Commission	HC 461-I
Second Report	Public Expenditure	HC 512 (Cm 8007)
Third Report	Commissioning	HC 513 (Cm 8009)
Fourth Report	Revalidation of Doctors	HC 557 (Cm 8028)
Fifth Report	Commissioning: further issues	HC 796 (Cm 8100)
First Special Report	Revalidation of Doctors: General Medical Council's Response to the Committee's Fourth Report of Session 2010–11	HC 1033
Sixth Report	Complaints and Litigation	HC 786 (Cm 8180)
Seventh Report	Annual accountability hearing with the Nursing and Midwifery Council	HC 1428 (HC 1699)
Eighth Report	Annual accountability hearing with the General Medical Council	HC 1429 (HC 1699)
Ninth Report	Annual accountability hearing with the Care Quality Commission	HC 1430 (HC 1699)
Tenth Report	Annual accountability hearing with Monitor	HC 1431 (HC 1699)
Eleventh Report	Appointment of the Chair of the NHS Commissioning Board	HC 1562-I
Twelfth Report	Public Health	HC 1048-I (Cm 8290)

Thirteenth Report	Public Expenditure	HC 1499 (Cm 8283)
Fourteenth Report	Social Care	HC 1583-I (Cm 8380)
Fifteenth Report	Annual accountability hearings: responses and further issues	HC 1699
Sixteenth Report	PIP Breast implants and regulation of cosmetic interventions	HC 1816 (Cm 8351)