



House of Commons
Public Administration
and Constitutional Affairs
Committee

**Follow-up to PHSO
Report: Dying without
dignity**

First Report of Session 2015–16



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the report*

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Public Administration and Constitutional Affairs Committee

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Contacts

All correspondence should be addressed to the Clerk of the Public Administration and Constitutional Affairs Committee, House of Commons, London SW1A 0AA. The telephone number for general enquiries is 020 7219 3268, the Committee's email address is pacac@parliament.uk.

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Summary

Failings in the care provided to people as they approach the end of their life can result in needless pain and suffering. In *Dying without dignity*, the Parliamentary and Health Service Ombudsman identified systemic issues affecting the quality and delivery of end of life care and used case studies to show how patients—and those close to them—had been affected by poor care. We welcome the report, which concluded that the NHS needed to improve in a number of areas and recommended that the report's findings be used to inform a new approach to end of life care.

Witnesses told us that they were aware of the issues raised in the report and that the focus must now be on implementing change. We agree. We want good quality, timely and compassionate care to be available to all those who need it at the end of their life. In this Report, we outline the key areas in which we expect to see significant and fast-paced improvements. These are:

- culture, behaviour and training;
- the provision of integrated, 24/7 palliative and End of Life Care (EOLC) services; and
- leadership and commissioning.

We also invite the Government to set out how it will ensure that the necessary improvements to end of life care provision are delivered.

We highlight the need to ensure that progress can be assessed objectively and suggest that clear targets for improvement are needed to enable such assessments. Comprehensive monitoring and reporting of progress against targets will also be required, and the Government must set out where responsibility for improving and monitoring end of life care lies.

1 Introduction

1. It is a function of the Public Administration and Constitutional Affairs Committee to scrutinise the work of the Parliamentary and Health Service Ombudsman (PHSO), which makes final decisions on complaints that have not been resolved by the NHS in England.¹ The post of Parliamentary and Health Service Ombudsman is currently held by Dame Julie Mellor DBE, who was appointed in 2012.² She is supported in this role by casework and corporate staff at the PHSO.

2. We undertake scrutiny of the PHSO's work principally through examination of her reports. This, our first Report of the 2015 Parliament, focuses on the PHSO's report of May 2015, *Dying without dignity*, which identified systemic issues affecting the quality and delivery of end of life care.³ We are grateful to all those who provided oral and written evidence in this inquiry—a full list of those who contributed can be found in the list of witnesses.

Definition of end of life care

3. NHS England has defined end of life care as care which is provided “in the last year of life”.⁴ It added that “the trajectory of different conditions mean that for some, ‘end of life care’ refers to the last few years of life, whereas for others, this could be a matter of months, weeks, days or hours. In the case of sudden unexpected death, the predominant focus of ‘end of life care’ may be on the period following death.”⁵

Overview of *Dying without dignity*

4. *Dying without dignity* highlighted recurrent themes seen in the Ombudsman's end of life care casework.⁶ The report used anonymised examples from real cases to show how patients—and those close to them—had been affected by poor care. We were dismayed to read accounts of people's suffering due to poor diagnoses, inappropriate treatment and poor communication. In one disturbing case, a mother watched her dying son spend more than 11 hours in pain because of delays in prescribing and setting up appropriate pain relief.⁷ In another case, junior doctors and an on-call anaesthetist tried 14 times to reinsert a patient's drip.⁸ They did not realise that his veins were shutting down because he was close to death.

1 The PHSO's responsibilities regarding NHS complaints are set out in the Health Service Commissioners Act 1993. Our scrutiny role in relation to the PHSO is set out in [Standing Order No 146](#) of the House of Commons. In the 2010–2015 Parliament, our predecessor Committee published the following reports in relation to our scrutiny of the PHSO: Public Administration Committee, Sixth Report of Session 2014–15, [Investigating clinical incidents in the NHS](#); March 2015; Public Administration Committee, Fourteenth Report of Session 2013–14, [Time for a People's Ombudsman Service](#), April 2014; Public Administration Committee, Twelfth Report of Session 2013–14, [More complaints please!](#), March 2014; Public Administration Committee, Tenth Report of 2010–12, [Remuneration of the Parliamentary and Health Service Ombudsman](#), July 2011; Public Administration Committee, Ninth Report of Session 2010–12, [Pre-appointment hearing for the post of Parliamentary and Health Service Ombudsman](#), July 2011. The Committee also took oral evidence annually on the work of the PHSO.

2 <http://www.ombudsman.org.uk/about-us/who-we-are/the-ombudsman>

3 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/8>

4 NHS England, *Actions for End of Life Care: 2014–16*, November 2014, p. 5

5 NHS England, *Actions for End of Life Care: 2014–16*, November 2014, p. 5

6 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/8>

7 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/3>

8 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/2>

5. Six key systemic failures in the provision of end of life care were identified in the PHSO's report, as follows:

Not recognising that people are dying, and not responding to their needs - if the needs of those who are close to death are not recognised, their care cannot be planned or co-ordinated, which means more crises and distress for the person and their family and carers.

Poor symptom control - people have watched their loved ones dying in pain or in an agitated state because their symptoms have been ineffectively or poorly managed.

Poor communication - healthcare professionals do not always have the open and honest conversations with family members and carers that are necessary for them to understand the severity of the situation, and the subsequent choices they will have to make.

Inadequate out-of-hours services - people who are dying and their carers suffer because of the difficulties in getting palliative care outside normal working hours.

Poor care planning - a failure to plan adequately often leads to the lack of co-ordinated care, for example, GPs and hospitals can fail to liaise.

Delays in diagnosis and referrals for treatment - this can mean that people are denied the chance to plan for the end of their life and for their final wishes to be met.⁹

6. The report concluded that the NHS needed to get better at: recognising that people are dying; making sure that symptoms are properly controlled; communicating with people, their families and other healthcare professionals; providing out-of-hours services; and making sure that service delivery and organisation help people to have a good death. It also supported several of the recommendations in the Health Committee's March 2015 Report on *End of Life Care*. The Health Committee looked at the state of end of life care and found "great variation in quality and practice across both acute and community settings" and made a number of recommendations.¹⁰ The PHSO noted its support for the Committee's recommendations on the need for more access to palliative care services, improved resources for support in the community, and better leadership.¹¹ We discuss the Health Committee's recommendations on leadership in more detail in chapter 4.

7. The National Palliative and End of Life Care Partnership is "a group of national organisations with experience of, and responsibility for, end of life care", and includes NHS England, the Association for Palliative Medicine, Marie Curie, the Care Quality Commission, Royal Colleges, Health Education England, Sue Ryder, the National Council for Palliative Care and many others.¹² *Dying without dignity* called on the National

9 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/1>

10 Select Committee on Health, Fifth Report of Session 2014–15, *End of Life Care*, March 2015, p. 3

11 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/8>

12 The partnership consists of the following: Association for Palliative Medicine, Association of Ambulance Chief Executives, Association of Directors of Adult Social Services, Association of Palliative Care Social Workers, Care Quality Commission, College of Health Care Chaplains, General Medical Council, Health Education England, Hospice UK, Macmillan Cancer Support, Marie Curie, Motor Neurone Disease Association, National Bereavement Alliance,

Palliative and End of Life Care Partnership to “use the learning identified in the report to underpin any new ambitions for end of life care, and upon the whole of the NHS to find the collective will to make those ambitions a reality.”¹³ This recommendation referred to the work that the partnership was then doing to agree a new framework for action on end of life care.¹⁴

8. In September 2015, the partnership published *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*.¹⁵ The framework sets out key aims and ambitions for improving the consistency and quality of end of life care, and the actions that should be taken at the national and local level—by leaders, commissioners and care providers—to achieve those aims and ambitions. We discuss the framework in more detail in the final chapter of this Report.

Reactions to the report

9. Witnesses broadly welcomed *Dying without dignity* and agreed that it highlighted key problems with end of life care provision.¹⁶ Hospice UK, Baroness Finlay of Llandaff and Dr Jane Collins, Chief Executive, Marie Curie, saw particular value in the very human and compassionate way that the report communicated the distress and suffering that can be caused by poor palliative and end of life care.¹⁷ Several witnesses also said that they were not surprised by the findings.¹⁸ Professor Irene Higginson, Head of Department, Head of Division and Director of the Cicely Saunders Institute, King’s College London, told us:

The report is very helpful but it does not tell us what we did not know already. It is very helpful to keep it in the public mind and the report has done that... But the issue now is to respond to the report and take some action and change things.¹⁹

10. The Association for Palliative Medicine agreed that the problem was “not lack of awareness of the issues, but rather a lack of implementation.”²⁰ Baroness Finlay addressed the issues highlighted in *Dying without dignity* in the Access to Palliative Care Bill 2015–16.²¹ She outlined how the Bill would require care commissioning groups to

National Care Forum, National Council for Palliative Care, National Palliative Care Nurse Consultants Group, National Voices, NHS England, NHS Improving Quality, Patients Association, Public Health England, Royal College of General Practitioners, Royal College of Nursing, Royal College of Physicians, Social Care Institute for Excellence, Sue Ryder, and Together for Short Lives. List of partners taken from the National Palliative and End of Life Care Partnership, *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*, September 2015, p. 3.

13 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/8>

14 National Palliative and End of Life Care Partnership, *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*, September 2015; [Media release from the National Palliative and End of Life Care Partnership](#)

15 National Palliative and End of Life Care Partnership, *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*, September 2015.

16 Q1 [Dr Jane Collins, Professor Irene J Higginson, and Professor Sir Mike Richards] Q56 [Ben Gummer, MP, and Dr Martin McShane] [Oral evidence 15.09.15](#); [DWD 01 \(Sue Ryder\)](#); [DWD 02 \(Baroness Finlay of Llandaff\)](#); [DWD 03 \(Marie Curie\)](#); [DWD 04 \(Hospice UK\)](#); [DWD 05 \(Association for Palliative Medicine\)](#); [DWD 06 \(Department of Health and NHS England\)](#)

17 Q1 [Dr Jane Collins, Chief Executive, Marie Curie] [Oral evidence 15.09.15](#); [DWD 02 \(Baroness Finlay of Llandaff\)](#); [DWD 04 \(Hospice UK\)](#);

18 Q1 [Dr Jane Collins, Professor Irene J Higginson, and Professor Sir Mike Richards] [Oral evidence 15.09.15](#); [DWD 02 \(Baroness Finlay of Llandaff\)](#); [DWD 05 \(Association for Palliative Medicine\)](#)

19 Q1 [Oral evidence 15.09.15](#)

20 [DWD 05 \(Association for Palliative Medicine\)](#)

21 [Access to Palliative Care Bill \(HL Bill 13\)](#) The Bill had its first reading in the House of Lords on 1st June 2015 and is due for its second reading on Friday 23rd October 2015.

“commission specific Specialist Palliative Care Services and improve research and education in this field.”²²

Priority areas for action

11. Ben Gummer, MP, the Parliamentary Under-Secretary of State for Care Quality, also accepted the report’s findings and agreed that the focus must now be on taking action. He said:

The whole report is an extremely welcome addition to what is now an overly-large library of criticism of palliative care and end of life care in this country. The six conclusions are apposite, correct and need to be adopted across the service. Our challenge is to make that happen.²³

12. We note the Minister’s point about the significant “library” of reports on these issues.²⁴ Accordingly, in this Report we avoid adding another lengthy list of recommendations. Instead, we focus on the key areas in which we expect to see significant improvements at pace. These are:

- culture, behaviour and training;
- the provision of integrated, 24/7 palliative and End of Life Care (EOLC) services; and
- leadership and commissioning.

13. We also invite the Government to set out how it will meet the challenge identified by the Minister of achieving the necessary improvements to end of life care provision.

²² DWD 02 (Baroness Finlay of Llandaff)

²³ Q56, [Oral evidence 15.09.15](#)

²⁴ Reports published in the past few years include: the Independent Review of the Liverpool Care Pathway, [More Care, Less Pathway - A Review of the Liverpool Care Pathway](#), July 2013; the Royal College of Physicians and Marie Curie Palliative Care Institute Liverpool, [National care of the dying audit for hospitals](#), England, May 2014; the Leadership Alliance for the Care of Dying People, [One Chance to Get it Right - Improving people’s experience of care in the last few days and hours of life](#), June 2014; the Choice in End of Life Care Programme Board, [What’s important to me. A Review of Choice in End of Life Care](#), February 2015; the Select Committee on Health, Fifth Report of Session 2014-15, [End of Life Care](#), March 2015; and the National Council for Palliative Care, [Time for Action](#), July 2015

2 Culture, behaviour and training

Skills and training

14. We have sought to probe why the care failings detailed in *Dying without dignity* were allowed to happen. Dr Collins outlined some of the causes of care failings and how they might be addressed:

Some of it [...] is that staff now no longer appear to feel confident in looking after people who are dying and obviously that is a significant training issue that you would think would be relatively easy to sort out, but a lot more work needs to be done on that, both at undergraduate and then postgraduate level. We need to link it obviously with some of the other issues that have perhaps come before this Committee in relation to compassion and care. I do think though that when people do not know quite what to do they tend to ignore it, and that is the very worst thing you can do, not only for the person who is dying, but also their family. We have to work out how we can best address this. It is very much down to NHS organisations, but the voluntary sector can undoubtedly play a part in that.²⁵

15. There was consensus among witnesses about the need for greater provision of end of life care training to generalist and specialist staff, including training on good communication.²⁶ This will be crucial to improving clinicians' skills and confidence so that they are better able to provide high-quality care to people who are dying.

Compassion under pressure

16. The question of how to ensure that all patients receive compassionate care is more complex. Dr Collins identified the importance of recruiting staff who are more likely to be compassionate.²⁷ We also heard from witnesses how compassion can be encouraged—even taught to some extent—and how it can be destroyed or suppressed by poor working conditions.²⁸ Professor Sir Mike Richards, Chief Inspector of Hospitals, Care Quality Commission, highlighted both the positive “power of example” from senior doctors and nurses, and the potential negative impact of reduced staffing levels, on levels of compassion. He said:

If one has seen compassion in action [from senior colleagues], that is much more likely to be modelled in the behaviour of the next generation. However, I also go back to the fact that it can be destroyed because we sometimes see that people who have been compassionate have compassion fatigue, if you like. But we have also seen in those same places that when we have taken the stress off them by saying to a hospital, for example, ‘You have to close a number of beds until you have more staff’, within 48 hours there is a change. It is not just me

²⁵ Q3 [Oral evidence 15.09.15](#)

²⁶ Qq2-4 [Professor Sir Mike Richards, Dr Jane Collins and Professor Irene Higginson] [Oral evidence 15.09.15](#); [DWD 01 \(Sue Ryder\)](#); [DWD 02 \(Baroness Finlay of Llandaff\)](#); [DWD 03 \(Marie Curie\)](#); [DWD 04 \(Hospice UK\)](#); [DWD 05 \(Association for Palliative Medicine\)](#); [DWD 06 \(Department of Health and NHS England\)](#);

²⁷ Q34 [Oral evidence 15.09.15](#)

²⁸ Qq34-38 [Dr Jane Collins, Professor Irene Higginson and Professor Sir Mike Richards] [Oral evidence 15.09.15](#)

saying you can see a change, the patients on the ward told us there had been a change.²⁹

17. Baroness Finlay suggested that “the core human attributes of caring, personal hygiene care and compassionate listening” had been devalued in the nursing profession, particularly since nurses’ training had become more focused on degree qualifications.³⁰ Dr Collins argued that having a degree does not make one less compassionate, but agreed that it would be beneficial to widen routes into nursing so as not to exclude people who “do not want to go down the degree route”.³¹ We agree that an increase in the diversity of access routes for nurses would go some way towards tackling problems with poor care provision, not least by reducing the pressure on nursing staff. We were therefore pleased to hear about forthcoming plans to “widen the ability for people to get into nursing”.³²

Culture and complaints

18. The importance of culture in hospitals and other care settings should not be underestimated. Hospice UK suggested that the “culture and organisation of hospitals are not well attuned to the needs of dying people”.³³ Sue Ryder highlighted how the culture in clinical settings is affected by clinicians’ attitudes to care, suggesting that there should be a more holistic approach to patient treatment.³⁴

19. Another key factor influencing the culture in care settings is the way in which complaints and reports about poor care are treated. As our predecessor Committee highlighted in its Reports, *Investigating clinical incidents in the NHS* (March 2015) and *More Complaints Please!* (March 2014), all too often within the NHS there is a culture of defensiveness, with complaints being dismissed and denied.³⁵ Instead, staff should be encouraged to report mistakes and near misses, and complaints should be used to drive service improvement. We were encouraged to hear from Professor Sir Mike Richards about hospitals that have fostered an open culture and how this has enabled them to learn from mistakes. He said:

The hospitals that are well led have an open culture, they encourage people to report when things go wrong. We see that they report more incidents than the hospitals that are less well led because they encourage that, so that they can learn from that. If you go to somewhere like Salford Royal or Frimley Park, they have this very open culture of saying when things go wrong so that they can be put right.³⁶

20. The link between good leadership and an open culture is well made. Culture change does not happen organically: senior leaders must set out the changes that are needed and communicate to staff and managers how they are to be achieved. Most importantly, they must follow up their words with actions and ensure that resources are organised in a way that supports those changes.

29 Q35 [Oral evidence 15.09.15](#)

30 DWD 02 (Baroness Finlay of Llandaff);

31 Qq50-51 [Oral evidence 15.09.15](#)

32 Q51 [Dr Collins] [Oral evidence 15.09.15](#)

33 DWD 04 (Hospice UK);

34 DWD 01 (Sue Ryder)

35 Public Administration Committee, Sixth Report of Session 2014-15, [Investigating clinical incidents in the NHS](#); March 2015; Public Administration Committee, Twelfth Report of Session 2013-14, [More complaints please!](#), March 2014

36 Q25 [Oral evidence 15.09.15](#)

21. We cannot overemphasise the importance of the right kind of leadership in achieving improvements in palliative and end of life care. Leaders must ensure that all staff receive the necessary training and support, and that compassionate care is valued and encouraged. This can be achieved only through leadership by example, with leaders demonstrating that care and compassion are valued at every level of the organisation. Systems should also be in place to enable organisations to learn from mistakes and complaints.

3 Provision of integrated, 24/7 palliative and end of life care services

Meeting end of life care needs at any time of day or night

22. Inadequate out-of-hours service was one of the six themes highlighted in *Dying without dignity*. It stated:

We [...] considered several cases where people who were dying had extremely poor experiences in getting support outside normal working hours. This can be because emergency medical services are often under pressure out of hours, and many specialist palliative care services are not able to provide round-the-clock availability.³⁷

It went on to detail the effect that the lack of access to palliative care expertise at night had on one dying patient, Mrs B, whose family watched her suffer “because the palliative care team were not available to help control [her] distressing symptoms in last hours of her life”.³⁸

23. The evidence we received was unanimous in agreeing the importance of seven-day access to specialist palliative care services.³⁹ It is clear that access to 24/7 specialist advice and services—ideally face-to-face—is central to ensuring that patients receive appropriate, high-quality care in good time. Professor Sir Mike Richards told us:

We need to consider specialist palliative care services as urgent services because, as the report illustrates, people need to be seen within a matter of minutes or very few hours, not waiting 11 hours or more, as in the report. We need to have these services available seven days a week and we need to have access to experts like Professor Higginson out of hours so that people can get the advice as well. We know from various studies that only about one in five hospitals is currently offering a seven-day specialist palliative care service.⁴⁰

24. Witnesses also highlighted the importance of co-ordination and integration between providers and services.⁴¹ The Association for Palliative Medicine said that many specialist palliative care services were not integrated across boundaries, having “discrete teams for hospitals, hospices and in the community”, and that they needed to “find ways to support the sharing of information about patients to provide seamless care”.⁴² On a similar note, the National Council for Palliative Care recently identified the development of “well-coordinated community-based care that will keep more people out of hospital” as a key priority for improving end of life care provision.⁴³

37 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/5>

38 <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/5>

39 Q8 [Professor Sir Mike Richards, Dr Jane Collins and Professor Irene Higginson] and Q62 [Ben Gummer] [Oral evidence 15.09.15](#); [DWD 01 \(Sue Ryder\)](#); [DWD 02 \(Baroness Finlay of Llandaff\)](#); [DWD 03 \(Marie Curie\)](#); [DWD 04 \(Hospice UK\)](#); [DWD 05 \(Association for Palliative Medicine\)](#); [DWD 06 \(Department of Health and NHS England\)](#);

40 Q8 [Oral evidence 15.09.15](#);

41 Q47 [Dr Collins] [Oral evidence 15.09.15](#); [DWD 01 \(Sue Ryder\)](#); [DWD 04 \(Hospice UK\)](#); [DWD 05 \(Association for Palliative Medicine\)](#);

42 [DWD 05 \(Association for Palliative Medicine\)](#);

43 National Council for Palliative Care, [Time for Action](#), July 2015, p. 4

25. The Department of Health and NHS England agreed that “expert palliative and EoLC [end of life care] services need to be available and their availability around the clock is key to building a system of high quality care. This is a necessary system-wide expectation and good EoLC cannot be achieved without it.”⁴⁴

Learning from good practice elsewhere

26. Baroness Finlay suggested that the development of palliative care services in Wales had been “largely successful compared to that of England, partly because of the focus in Wales on providing 24/7 services”.⁴⁵ Dr Collins agreed that the introduction of 24/7 cover from consultants and clinical nurse specialists in Wales had brought improvements.⁴⁶ She also highlighted the value of increased co-ordination between care providers in Wales:

Following the Sugar Report⁴⁷ there was the introduction of 24-hour, seven-day-a-week consultant cover, clinical nurse specialist cover, and much more co-ordination between the community and the independent charitable sector. That is something that we certainly in the charitable sector would love to have in England. It can be hard to work with the NHS, because we obviously sit outside it. That can make the delivery of services from the patient’s point of view as being seamless between hospital and then going into the hospice, for example, or going from the hospice into the NHS community services in the community sometimes a little bit more difficult. They seem to have cracked that there.⁴⁸

27. The Minister agreed that some of the best care examples around the country were based on a 24-hour service and highlighted the success of joint ventures with Macmillan, Marie Curie and Sue Ryder, where there was a “genuine working relationship with partners outside the NHS”.⁴⁹

28. The National Council for Palliative Care has suggested that “commissioners and providers should stop thinking in terms of ‘out of hours’ services and start designing services that meet people’s needs ‘at any time of day and night’”.⁵⁰ We agree. It is vital that good quality palliative and end of life care services are available wherever and whenever they are needed. Successful examples of integrated, round-the-clock services from across the UK must be replicated more widely so that all end of life care patients can receive the care they need when they need it.

44 DWD 06 (Department of Health and NHS England)

45 DWD 02 (Baroness Finlay of Llandaff)

46 Q8 Oral evidence 15.09.15;

47 The Sugar report is a 2008 report of the Palliative Care Planning Group Wales, led by Vivienne Sugar, to the Minister for Health and Social Services. The report is available here: <http://www.wales.nhs.uk/sites3/Documents/831/pcpg%20report%20final%20June%202008.pdf>

48 Q47 Oral evidence 15.09.15;

49 Q62 Oral evidence 15.09.15;

50 National Council for Palliative Care, *Time for Action*, July 2015, p. 6

4 Commissioning and leadership

How high a priority are end of life care services?

29. As outlined in chapters 2 and 3, the provision of robust, integrated, 24/7 services is crucial to providing consistent, high-quality end of life care in the most appropriate setting. We were therefore dismayed to hear from Professor Sir Mike Richards that these services have not been given “sufficiently high priority by the health service as a whole”.⁵¹ Professor Higginson told us that end of life care services and training have been chronically underfunded, with some commissioning groups spending as little as “£186 per person who died” and with others not funding any palliative care services in hospitals.⁵² This has not only affected the quality of care, but reduced the choices available to many patients. Hospice UK highlighted stark figures showing that less than a third of those who would prefer to die at home are supported in doing so.⁵³

30. Several witnesses flagged up the importance of good planning and commissioning in improving service quality and patient choice.⁵⁴ Dr Martin McShane, Director for Long Term Conditions, NHS England, gave an example of how effective commissioning and service planning in one area had improved care provision in the home and reduced the need for care in hospitals. He said:

One of the examples I would give you is from Midhurst where they have commissioned a community-based palliative care service and it serves 150,000 people across three counties. At the moment it receives 400 referrals a year and they have agreed care plans and 99% of patients are allowed to die at home. They have less frequent A&E attendances, decreased hospital admissions and a halving of in-hospital deaths for that cohort of patients who are receiving that care. We are starting to see that. One of the things that we have set out in the five-year forward view and with the new care models is a recognition that we need to use commissioning to support integrated care across the system, which will help exactly with this agenda.⁵⁵

Improving commissioning and leadership

31. The Minister, Dr McShane and Professor Sir Mike Richards all agreed that good commissioning depends partly on having access to the right information about local needs and services.⁵⁶ For example, Professor Sir Mike Richards told us that not every hospital chief executive knows how many deaths there were in their hospital in the past year, and questioned how they could effectively plan end of life care services without that basic information.⁵⁷ He went on to suggest that access to such information could be improved

⁵¹ Qq4–5, [Oral evidence 15.09.15](#)

⁵² Q2, [Oral evidence 15.09.15](#)

⁵³; DWD 04 (Hospice UK);

⁵⁴ DWD 01 (Sue Ryder); DWD 02 (Baroness Finlay of Llandaff); DWD 03 (Marie Curie); DWD 04 (Hospice UK); DWD 05 (Association for Palliative Medicine); National Council for Palliative Care, [Time for Action](#), July 2015

⁵⁵ Q71 [Oral evidence 15.09.15](#)

⁵⁶ Qq7 and 27 [Professor Sir Mike Richards], Q69 [Dr McShane], Q78 [Ben Gummer] [Oral evidence 15.09.15](#)

⁵⁷ Q7 [Oral evidence 15.09.15](#)

with better grouping and coding of complaints, so that potential issues with end of life care services could be more easily identified.⁵⁸

32. Both Professor Higginson and Professor Sir Mike Richards stressed that better commissioning need not mean increased spending.⁵⁹ Professor Higginson said:

In terms of commissioning the palliative care services, that definitely is an issue for the NHS and definitely it needs to be improved. Some community commissioning groups are supporting it and clearly some are not...[It] is not necessarily just a question of money because palliative care has an evidence base and is cost-effective. They could probably support palliative care at no additional cost to what they are doing by realigning their budgets in a better way.⁶⁰

This evidence that poor attitudes towards end of life care can be a barrier to improvement highlights the importance of leadership. **Senior leaders and commissioners must give end of life care provision greater priority and take the decisions and actions needed to improve services at a faster pace.**

33. We note the recommendations in the Health Committee's March 2015 Report, *End of Life Care*, on improving leadership, which were supported by the PHSO in *Dying without dignity*.⁶¹ The Committee called on the Department of Health and NHS England to "ensure that end of life care is prioritised and embedded in future planning at all levels", and recommended giving responsibility for end of life care delivery to senior named individuals at the national, NHS Trust and care provider level.⁶² Professor Sir Mike Richards told us that having that kind of accountability in the system was "vital".⁶³ However, he and Professor Higginson stressed that just naming individuals would not be sufficient, and that those people would have to understand the action that needed to be taken and be able to show what they had done.⁶⁴

34. The Government's response to the Health Committee Report, which was published on 15 October 2015, agreed that senior leadership within NHS trusts "is vital to the delivery of good end of life care."⁶⁵ It also noted that a key part of the Care Quality Commission inspection regime on end of life care focuses on "ensuring that services are well-led", including by asking about "whether the organisation has a named responsible clinical lead for end of life care, and a Board member with overall responsibility."⁶⁶ The Government response went on to identify the key figures at the Department of Health and NHS England who will have responsibility for driving forward improvements in end of life care.⁶⁷

58 Q27 [Oral evidence 15.09.15](#)

59 Q12 [Oral evidence 15.09.15](#)

60 Q12 [Oral evidence 15.09.15](#)

61 Select Committee on Health, Fifth Report of Session 2014-15, *End of Life Care*, March 2015, <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/8>;

62 Select Committee on Health, Fifth Report of Session 2014-15, *End of Life Care*, March 2015, paras. 35 and 159;

63 Q26 [Oral evidence 15.09.15](#)

64 Q26 [Oral evidence 15.09.15](#)

65 Government response to the House of Commons Health Select Committee Report on End of Life Care (Fifth Report of Session 2014-15), Cm 9143, October 2015, para. 4

66 Government response to the House of Commons Health Select Committee Report on End of Life Care (Fifth Report of Session 2014-15), Cm 9143, October 2015, para. 6

67 Government response to the House of Commons Health Select Committee Report on End of Life Care (Fifth Report of Session 2014-15), Cm 9143, October 2015, para. 75

35. We support the Health Committee's recommendations on leadership in its End of Life Care Report. We also highlight the role of commissioners in improving end of life care services, and stress the need to hold both commissioners and senior leaders to account regarding their actions to improve palliative and end of life care. We note the Government's response to the Health Committee's recommendations and its commitment to ensuring that services are well-led. We are pleased to note that the Government's response identifies key figures at the Department of Health and NHS England who will have responsibility for driving forward improvements in end of life care. However, we would like to see more detail on how the Government will ensure that senior leaders, commissioners, trusts and service providers are held to account.

5 Achieving measurable results

36. We want all those needing palliative and end of life care to receive good quality, timely and compassionate care, and we recognise the work that the National Palliative and End of Life Care Partnership has done to agree a framework to achieve this.⁶⁸

Overview of the Ambitions framework

37. The Ambitions for Palliative and End of Life Care framework is designed to encourage more collaborative and creative approaches to delivering better care. It sets out six ambitions for palliative and end of life care and advocates a partnership approach to achieving those ambitions. It states:

We need to break the cycle of reports asking for change. Our approach has to be different. We propose resetting our sights on six positive ambitions for palliative and end of life care. By setting out a framework for local action we want to create a new impetus for better care. We also identify the eight foundations that underpin and are required to bring about this improvement. Different individuals and organisations can lay these foundations, either on their own or collectively. These ambitions will guide us all on the next stage of our collective endeavour.⁶⁹

38. The six ambitions are outlined below.

(1) Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

(2) Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

(3) Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

(4) Care is coordinated

68 The partnership is "a group of national organisations with experience of, and responsibility for, end of life care", and includes NHS England, the Association for Palliative Medicine, Marie Curie, the Care Quality Commission, Royal Colleges, Health Education England, Sue Ryder, the National Council for Palliative Care and many others. In September 2015, the partnership published *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. As the title suggests, the framework sets out key aims and ambitions for improving the consistency and quality of end of life care, and the actions that should be taken at the national and local level—by leaders, commissioners and care providers—to achieve those aims and ambitions.

69 National Palliative and End of Life Care Partnership, *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*, September 2015, p. 9.

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

(5) All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

(6) Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.⁷⁰

The six ambitions are underpinned by eight foundations that need to be in place to achieve them. These are: personalised care planning, education and training, evidence and information, co-design, shared records, 24/7 access, those important to the dying person, and leadership.⁷¹

39. The framework emphasises the need for a collaborative approach at the local level and outlines the expectations on service providers and caregivers to take action. The framework document states:

We expect all those with influence over care for the dying and the bereaved, their families, their carers – both paid and unpaid, and their communities, to use our framework for local action to break the cycle of bad care highlighted in critical reports and recommendations...In a world characterised by less central direction and significantly more local collaboration, to achieve improvement we expect health and social care leaders to work together.⁷²

It goes on to ask care commissioning groups, local authorities and health and wellbeing boards to designate an organisation to lead on making the ambitions a reality. Similarly, commissioners, service providers and individuals who provide care are asked to use the framework to guide practice and behaviour. Within communities, people are asked to discuss death, dying, bereavement and their end of life wishes more openly, and to consider what they could do to help and support others.⁷³

Is the Ambitions framework enough?

40. We support the collaborative approach set out in the Ambitions framework and we hope that trusts, care providers and practitioners will be motivated to take action at

70 National Palliative and End of Life Care Partnership, [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#), September 2015, p. 11.

71 National Palliative and End of Life Care Partnership, [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#), September 2015, p. 17.

72 National Palliative and End of Life Care Partnership, [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#), September 2015, p. 36.

73 National Palliative and End of Life Care Partnership, [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#), September 2015, p. 36.

all levels to improve people's experience of healthcare in the last days of their life. The involvement of so many influential organisations in the Ambitions partnership suggests that there is sufficient will behind the framework to drive significant change, and we note the partnership's commitment to "hold ourselves to account as well as challenge others to show improvement".⁷⁴ However, we are also cognisant of the evidence we received about previous problems with implementing change in this area.⁷⁵

41. Baroness Finlay has suggested that legislation "would help to solve the failures in care highlighted in *Dying without Dignity*".⁷⁶ As we noted in the first chapter, her Access to Palliative Care Bill would require care commissioning groups to "commission specific Specialist Palliative Care Services and improve research and education in this field."⁷⁷ Dr Collins, Professor Higginson and Professor Sir Mike Richards all welcomed the Bill, with Professor Higginson calling it "a very important part of the potential solution to many of the issues" raised in *Dying without dignity*.⁷⁸ She suggested that it would help to increase access to palliative care, tackle inequality and encourage more research and development.⁷⁹ The support of Dr Collins in particular suggests that the Bill is compatible with the Ambitions framework, given that she is a co-chair of the Ambitions partnership.

42. The Minister had reservations about the Bill, particularly about "legislating for specific clinical areas". He said:

At the moment, we do not legislate for any clinical areas so we do not say that someone who has cancer should, by law, have oncological treatment. That is part of the commissioning process and part of the overall architecture of the NHS constitution. It would mean a radical shift in how we construct the NHS and I am nervous about going down that road because it slightly puts commissioners into a relationship with the law that I am not sure is where you want to put them. You want them to be thinking about how to provide great care to people wherever they are, whether they are going to live or die, not just because they are responding to a piece of legislation...⁸⁰

43. We understand that the Government is unwilling to use legislation to drive improvements in end of life care, but it must now set out how it will ensure that necessary improvements will be achieved.

44. We welcome the Ambitions framework and hope that the collaborative approach it advocates will bring significant improvements to end of life care. However, the slow

74 National Palliative and End of Life Care Partnership, [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#), September 2015, p. 36. The partnership consists of the following: Association for Palliative Medicine, Association of Ambulance Chief Executives, Association of Directors of Adult Social Services, Association of Palliative Care Social Workers, Care Quality Commission, College of Health Care Chaplains, General Medical Council, Health Education England, Hospice UK, Macmillan Cancer Support, Marie Curie, Motor Neurone Disease Association, National Bereavement Alliance, National Care Forum, National Council for Palliative Care, National Palliative Care Nurse Consultants Group, National Voices, NHS England, NHS Improving Quality, Patients Association, Public Health England, Royal College of General Practitioners, Royal College of Nursing, Royal College of Physicians, Social Care Institute for Excellence, Sue Ryder, and Together for Short Lives.

75 See paras 9-11, chapter 1.

76 [DWD 02 \(Baroness Finlay of Llandaff\)](#);

77 [DWD 02 \(Baroness Finlay of Llandaff\)](#); [Access to Palliative Care Bill \[HL\] 2015-16](#). The Bill had its first reading in the House of Lords on 1st June 2015 and is due for its second reading on Friday 23rd October 2015.

78 Qq 48-49 [Oral evidence 15.09.15](#)

79 Q48 [Oral evidence 15.09.15](#)

80 Q61 [Oral evidence 15.09.15](#)

pace at which improvements in end of life care have been achieved is not acceptable. We support the Ambitions framework and have identified specific areas in which we expect to see improvement at a faster pace, namely:

- culture, behaviour and training;
- the provision of integrated, 24/7 palliative and EoLC services; and
- leadership and commissioning.

45. We highlight the need to ensure that progress can be assessed objectively and suggest that clear targets for improvement are needed to enable such assessments. Comprehensive monitoring and reporting of progress against targets will also be required, and the Government must set out where responsibility for improving and monitoring end of life care lies.

46. *We recommend that, as a matter of priority, the Government should set out:*

- *how the effectiveness of measures to improve end of life care will be monitored and by whom, including key monitoring targets, time scales and indicators; and*
- *how any inconsistencies and sluggishness in implementing the framework will be remedied.*

Conclusions and recommendations

1. We cannot overemphasise the importance of the right kind of leadership in achieving improvements in palliative and end of life care. Leaders must ensure that all staff receive the necessary training and support, and that compassionate care is valued and encouraged. This can be achieved only through leadership by example, with leaders demonstrating that care and compassion are valued at every level of the organisation. Systems should also be in place to enable organisations to learn from mistakes and complaints. (Paragraph 21)
2. The National Council for Palliative Care has suggested that “commissioners and providers should stop thinking in terms of ‘out of hours’ services and start designing services that meet people’s needs ‘at any time of day and night’”. We agree. It is vital that good quality palliative and end of life care services are available wherever and whenever they are needed. Successful examples of integrated, round-the-clock services from across the UK must be replicated more widely so that all end of life care patients can receive the care they need when they need it. (Paragraph 28)
3. Senior leaders and commissioners must give end of life care provision greater priority and take the decisions and actions needed to improve services at a faster pace. (Paragraph 32)
4. We support the Health Committee’s recommendations on leadership in its End of Life Care Report. We also highlight the role of commissioners in improving end of life care services, and stress the need to hold both commissioners and senior leaders to account regarding their actions to improve palliative and end of life care. We note the Government’s response to the Health Committee’s recommendations and its commitment to ensuring that services are well-led. We are pleased to note that the Government’s response identifies key figures at the Department of Health and NHS England who will have responsibility for driving forward improvements in end of life care. However, we would like to see more detail on how the Government will ensure that senior leaders, commissioners, trusts and service providers are held to account. (Paragraph 35)
5. We understand that the Government is unwilling to use legislation to drive improvements in end of life care, but it must now set out how it will ensure that necessary improvements will be achieved. (Paragraph 43)
6. We welcome the Ambitions framework and hope that the collaborative approach it advocates will bring significant improvements to end of life care. However, the slow pace at which improvements in end of life care have been achieved is not acceptable. We support the Ambitions framework and have identified specific areas in which we expect to see improvement at a faster pace, namely:
 - culture, behaviour and training;
 - the provision of integrated, 24/7 palliative and EoLC services; and
 - leadership and commissioning. (Paragraph 44)

7. We highlight the need to ensure that progress can be assessed objectively and suggest that clear targets for improvement are needed to enable such assessments. Comprehensive monitoring and reporting of progress against targets will also be required, and the Government must set out where responsibility for improving and monitoring end of life care lies. (Paragraph 45)
8. We recommend that, as a matter of priority, the Government should set out:
 - how the effectiveness of measures to improve end of life care will be monitored and by whom, including key monitoring targets, time scales and indicators; and
 - how any inconsistencies and sluggishness in implementing the framework will be remedied. (Paragraph 46)

Formal Minutes

Tuesday 20 October 2015

Members present:

Mr Bernard Jenkin, in the Chair

Ronnie Cowan	Rt Hon David Jones
Oliver Dowden	Gerald Jones
Paul Flynn	Tom Tugendhat
Rt Hon Cheryl Gillan	Mr Andrew Turner
Kelvin Hopkins	

Draft Report (*Follow-up to PHSO Report: Dying without Dignity*), proposed by the Chair, brought up and read.

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

Paragraphs 1 to 46 read and agreed to.

Summary agreed to.

Resolved, That the Report be the First 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 Tuesday 27 October at 9.15 a.m.]

Witnesses

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

Tuesday 15 September 2015

Question number

Dr Jane Collins, Chief Executive, Marie Curie, **Professor Irene J Higginson**, Head of Department, Head of Division and Director of Cicely Saunders Institute, King's College London, and **Professor Sir Mike Richards**, Chief Inspector of Hospitals, Care Quality Commission

Q1–54

Ben Gummer, Parliamentary Under Secretary of State for Care Quality, Department of Health, and **Dr Martin McShane**, Director for Long Term Conditions, NHS England

Q55–95

Published written evidence

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

- 1 Association for Palliative Medicine ([DWD 05](#))
- 2 Department of Health ([DWD 07](#)); ([DWD 08](#))
- 3 Department of Health and NHS England ([DWD 06](#))
- 4 Hospice UK ([DWD 04](#))
- 5 Marie Curie ([DWD 03](#))
- 6 Professor the Baroness Finlay of Llandaff ([DWD 02](#))
- 7 Sue Ryder ([DWD 01](#))