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House of Commons
Public Accounts Committee

End of life care

Nineteenth Report of Session
2008–09

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Public Accounts Committee

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**Nineteenth Report of Session
2008–09**

*Report, together with formal minutes, oral and
written evidence*

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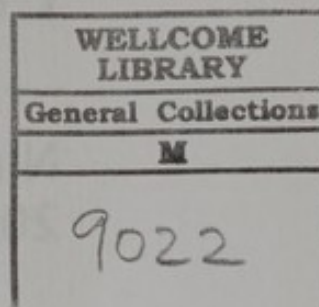
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Summary

In England approximately half a million people die each year. Around three quarters of deaths follow a period of chronic illness, such as cancer or heart disease, where people may need access to end of life care. End of life care services seek to support those with advanced, progressive, incurable illness to live as well as possible until they die.

The provision of end of life care is becoming increasingly complex, with people living longer and the incidence of frailty and multiple conditions in older people rising. People approaching the end of their life often require a complex mix of health and social care services provided in hospitals, care homes, hospices and their own home. End of life care is delivered by many people, including families and friends, specialist palliative care staff, and generalist staff such as doctors, nurses, and social workers, for whom end of life care represents a varying proportion of their role.

In 2006–07, primary care trusts estimated they spent £245 million on specialist palliative care, delivered by around 5,500 staff with specific training in the management of pain and other symptoms. There are no estimates of the full financial cost of end of life care, largely because of difficulties in identifying the proportion of time generalist staff spend with people approaching the end of life. The cost to NHS and social care services of providing care to cancer patients in the 12 months prior to death (27% of deaths) is, however, estimated to be £1.8 billion alone.

Most people would prefer not to die in hospital but a lack of NHS and social care support services means that many people do so when there is no clinical need for them to be there. There is a lack of training in basic end of life care amongst frontline staff, many of whom will at some stage come into contact with people nearing the end of their life. The Department of Health (the Department) has acknowledged that end of life care has not had the priority it should have had, and recognises the need to improve the provision of care for adults. In July 2008, it published its End of Life Care Strategy which commits additional funding of £286 million over two years, and aims to increase the availability of services in the community and develop the skills of health and social care staff.

On the basis of a report by the Comptroller and Auditor General,¹ we took evidence from witnesses from the Department and the NHS on the provision of end of life care. We examined the scale and quality of end of life care; the current and future approach to commissioning and funding of services; and the capability and capacity of NHS and social care staff to provide such care.

In January 1997, the Department of Health and Human Services (HHS) announced that it would be reviewing the effectiveness of the National Health Insurance Program (NHIP) and the National Health Insurance Trust (NHIT) in providing health insurance to low-income individuals. The review would focus on the program's financial stability, its ability to provide coverage to all eligible individuals, and the quality of care provided to enrollees.

The review would be conducted in three phases. The first phase would involve a review of the program's financial records and the NHIT's assets and liabilities. The second phase would involve a review of the program's enrollment data and the NHIT's ability to provide coverage to all eligible individuals. The third phase would involve a review of the program's quality of care and the NHIT's ability to provide services to enrollees.

The review would be completed by the end of the year. The results of the review would be used to inform the Department's decision on whether to continue the program and the NHIT. The review would also provide information on the program's financial stability, its ability to provide coverage to all eligible individuals, and the quality of care provided to enrollees.

The review would be conducted by a team of independent experts. The team would be led by the Inspector General for the Department of Health and Human Services. The team would also include representatives from the Department of Health and Human Services, the Social Security Administration, and the General Accounting Office. The review would be completed by the end of the year.

The review would be a major step in the Department's effort to reform the NHIP and the NHIT. The review would provide information on the program's financial stability, its ability to provide coverage to all eligible individuals, and the quality of care provided to enrollees. The review would also provide information on the program's ability to provide services to enrollees.

Conclusions and recommendations

1. **Most people express a preference to die at home but 60% die in an acute hospital, even when there is no clinical need for them to be there.** People should have the right to die in the place of their choice. The End of Life Care Programme team should work with Primary Care Trusts and Strategic Health Authorities to develop the means to share information on patient preferences. In line with the Department's strategy, Trusts should agree plans with their Strategic Health Authorities for increasing the availability of community services, such as 24 hour district nursing, and access to advice and medication out of hours to help reduce the number of unnecessary hospital admissions. People in care homes should have equal access to these services.
2. **People who die in hospital are not always afforded the end of life care they deserve, including effective pain management and being treated with dignity and respect.** Because someone is approaching the end of life it should not mean we abandon concern for their quality of life; end of life care should seek to sustain peoples' quality of life as a priority. Primary Care Trusts should seek assurance from the hospitals they commission services from that their staff have received sufficient education and training in end of life care. NHS hospitals that care for people who are approaching the end of their life, should employ a specialist palliative care team and promote the use of the Liverpool Care Pathway across relevant hospital wards.
3. **Lack of co-ordination between health and social care services mean that peoples' preferences for care are not always communicated effectively.** People nearing the end of their life should be allocated a single health or social care professional contact to improve the co-ordination of care between services and providers. Primary Care Trusts should require providers to develop care plans for all those who wish to have one. The Department's planned survey of bereaved relatives should also include consideration of how a patient's care is co-ordinated across settings and between providers.
4. **There is a lack of education and training in basic end of life care.** Improving the skills of health and social care staff should be a priority. In particular, the Department should work with the relevant professional bodies to put in place appropriate training. Primary Care Trusts and local authorities should commission hospices and voluntary groups to provide education for community and care home staff by, for example, building on the work already being undertaken by Marie Curie and St Christopher's Hospice. The new Care Quality Commission should provide assurance about the skills level of staff in health and social care organisations, as part of the new registration, inspection and monitoring regime.

5. **Primary Care Trusts have limited understanding of the local demand for and the cost-effectiveness of their commissioning of end of life care services.** Trusts should use the commissioning guidance provided by the End of Life Care Programme and benchmarking information provided by the National Audit Office, to assist them in allocating resources more effectively. Trusts should also consider whether work similar to that done in Sheffield for the National Audit Office would improve their understanding of demand and supply and accordingly their commissioning of end of life care services.
6. **There is a risk that the additional £286 million committed to improving end of life care will not be used as intended.** The Department should require Primary Care Trusts to account for how the additional funding is spent. Such information should be used to provide feedback to Trusts to allow them to benchmark their performance in improving service quality.
7. **There has been limited formal evaluation of the patient benefits associated with approaches intended to improve end of life care such as the Gold Standards Framework.** The Department should commission clinical evaluations to determine whether use of such approaches results directly in higher quality care. The planned survey of bereaved relatives may be appropriate in the evaluation of the Liverpool Care Pathway and aspects of the Gold Standards Framework and Preferred Priorities for Care. Other approaches need to be developed to evaluate the experience of the increasing number of elderly people who live alone.
8. **Some 70% of independent hospices have only one year contracts with the NHS and for 97% the funding they receive does not cover fully the costs of the NHS services they provide.** Primary Care Trusts should put in place three year rolling contracts to enable hospices to better plan their use of resources and develop their services. These contracts should cover the costs of the NHS services provided, including relevant overheads. Hospices should be commissioned to provide wider support, for example, training of care home staff and the provision of outreach services to improve the quality of care for more people in the last year of life.
9. **More people could be supported to die in their homes or in a care home if there was a more responsive system for providing the equipment and support services needed.** The Department should review how requests for equipment and other assistance that support people to remain in their homes are handled, and identify ways of improving the speed and flexibility of the provision of such services. Primary Care Trusts should check that residents in care homes are provided with the same access to GPs and other health professionals as they would have if they were living in their own homes.

1 The current place and quality of end of life care

1. End of life care services aim to support those with advanced, progressive, incurable illness to live as well as possible until they die. In England, approximately half a million people die each year, almost two-thirds of whom are aged over 75 years. Around three quarters of deaths are 'predictable' and follow a period of chronic illness, such as cancer or heart disease, where people may need access to end of life care.²

2. The majority of people (between 56% and 74%) express a preference to be cared for and die in their own home, which for some will be a care home, and to avoid dying in an acute hospital.³ The proportion of people expressing a preference to die at home has, however, been shown to change as death approaches. This can be because they require more extensive support, such as that provided by a hospice, and do not wish to be a burden to their family, or because they do not wish to die alone. Many people are admitted to hospital for emergency treatment of symptom management and, for some, hospital is their preferred place of care. Some people, however, remain on a medical or surgical ward when they no longer have a clinical need to be there. For those whose preference is not to return home or for whom home care is no longer feasible, an alternative is intermediate care, provided for example by a community hospital. Research evidence shows that people are generally very satisfied with the end of life care they receive in community hospitals.⁴

3. In 2006, only 35% of people died at home or in a care home and 58% of deaths occurred in an acute hospital, ranging from 46% to 77% across Primary Care Trusts.⁵ Place of death varies by age, with care home death rates highest for those over 85.⁶ There is also considerable variation by condition, with cancer patients more likely to die at home or in a hospice (Figure 1). The Department for Health (the Department) attributes this largely to the fact that specialist palliative care services and the modern hospice movement, started by Dame Cicely Saunders 40 years ago, has traditionally focused on cancer. More recently, however, there has been an increase in the proportion of patients accessing specialist palliative care services who have other conditions, such as renal diseases.⁷

4. Although the Department consulted a range of different representative groups to establish the impact of cultural factors on preferences for end of life care during the development its end of life care strategy, it found relatively few such cultural differences in people's preferences as they approach death. There are, however, considerable differences in how people or their relatives expect to be cared for immediately thereafter and the

2 C&AG's Report, para 1.1

3 Qq 4, 8, 40; C&AG's Report, para 2.3

4 Qq 4, 8, 37-40; C&AG's Report, para 2.3

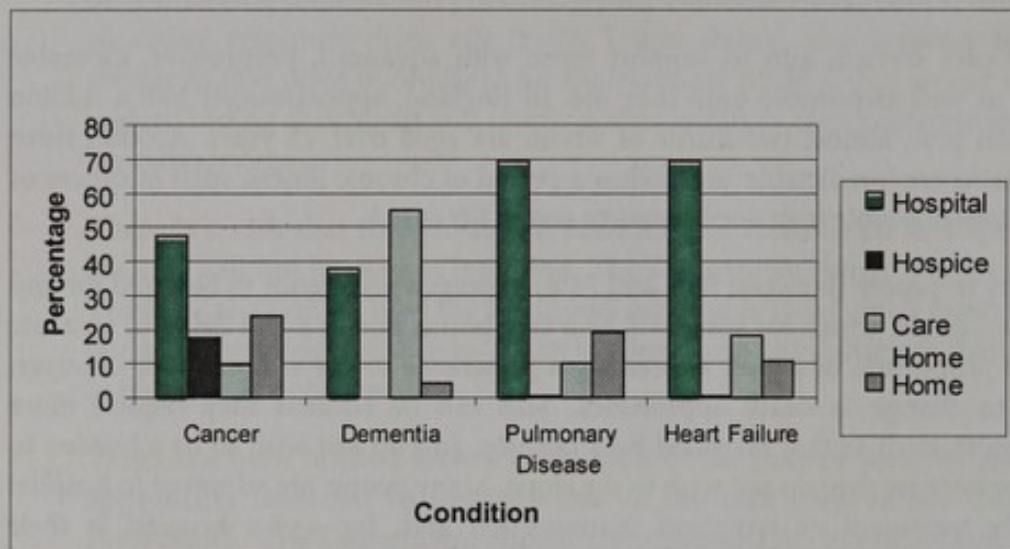
5 Q 4; C&AG's Report, paras 2.3-2.4; Figure 3

6 C&AG's Report, para 2.2

7 Q 11

Department acknowledged the importance of observing these differences and meeting the needs of patients and their families.⁸

Figure 1: Place of death varies by condition



Source: National Audit Office analysis of 2006 Mortality Statistics for England

5. As people approach the end of their life, they often require a complex mix of health and social care services.⁹ Co-ordination between health and social care services in relation to the planning, delivery and monitoring of end of life care is, however, generally poor and people approaching the end of their life often encounter problems, particularly when they are being transferred between health and social care providers. For example, residential homes, especially those without qualified nursing staff, often feel ill-equipped to care for people as they near the final stages of life and end up sending them to hospital or refuse to take residents back after a hospital admission, for example, if the patient is no longer weight-bearing.¹⁰

6. Current processes for securing home care in the community lack efficiency and flexibility, and there can be delays and difficulties in obtaining and completing the necessary forms at a time when people may have only days or weeks to live.¹¹ A lack of care planning and prompt access to services in the community can lead to some people approaching the end of their life being unnecessarily admitted to an acute hospital or to delays to the discharge of people who have no medical need to remain in hospital.¹² Information on patient preferences is also not always captured or shared effectively between the different agencies involved in delivering care.¹³ The Department acknowledged that end of life care requires good organisation and strategic planning, and

8 Qq 61, 76

9 Q 63

10 Qq 40, 65; C&AG's Report, para 18

11 Qq 69-71

12 Qq 4, 105-106

13 C&AG's Report, para 9

for Primary Care Trusts and local authorities and also the voluntary sector to work together in partnership, but that in many cases this has not been happening.¹⁴

7. Work carried out by the Healthcare Commission has identified that those people who die in acute hospitals are not always afforded the dignity and respect they deserve. Common issues include poor support for basic comfort; a lack of privacy for the patient and their family; poor communication by staff; and staff recognising too late that somebody is at the end of their life. Focus groups carried out for the National Audit Office identified examples where the standard of hospital care was below what had been expected, causing unnecessary stress for people approaching the end of their life and for those caring for them.¹⁵

8. The Department acknowledged the need to improve the standard of acute hospital care for people at the end of their life, but emphasised that it is possible for those who want, or have a medical need, to be in hospital at the end of their life to have a good death.¹⁶ It is seeking to improve the standard of acute hospital care for people at the end of their life by continuing to encourage uptake of the Liverpool Care Pathway tool.¹⁷ It is also promoting the development of specialist palliative care teams, and taking forward work to redevelop the hospital environment and improve patient privacy.¹⁸

9. The Department welcomed the findings of a review of patient records in Sheffield carried out for the National Audit Office, which explored the potential for changes in care pathways for people at the end of life and the alternatives to patients dying in hospital.¹⁹ The review found that the proportion of deaths in acute hospital could have been reduced from 50% to 31%, with a corresponding increase in deaths in other settings (Figure 2). It also found that the proportion of residents dying in care homes could have been increased from 61% to 80% if more support and advice had been provided to those homes.²⁰

10. Reducing unnecessary use of acute hospitals by people at the end of their life could make additional resources available for expenditure on end of life care. At least 40% of people who died in an acute hospital in the Sheffield in October 2007 did not have medical needs which required them to be admitted. These patients used 1,500 bed days, costing approximately £375,000, with nearly a quarter of them having been in hospital for over a month. Over the course of a full year, this could make around £4.5 million available for investment in community services.²¹

11. Economic modelling work by the National Audit Office estimates that, nationally, the cost of caring for cancer patients (who account for 27% of all deaths) in the 12 months

14 Qq 23, 65

15 Q 10; C&AG's Report, paras 12, 2.8

16 Qq 4, 38

17 The Liverpool Care Pathway is one of three tools recommended by the National Institute of Clinical Excellence to improve delivery of end of life care. The other two tools are the Gold Standard Framework and the Preferred Priorities of Care.

18 Q 10

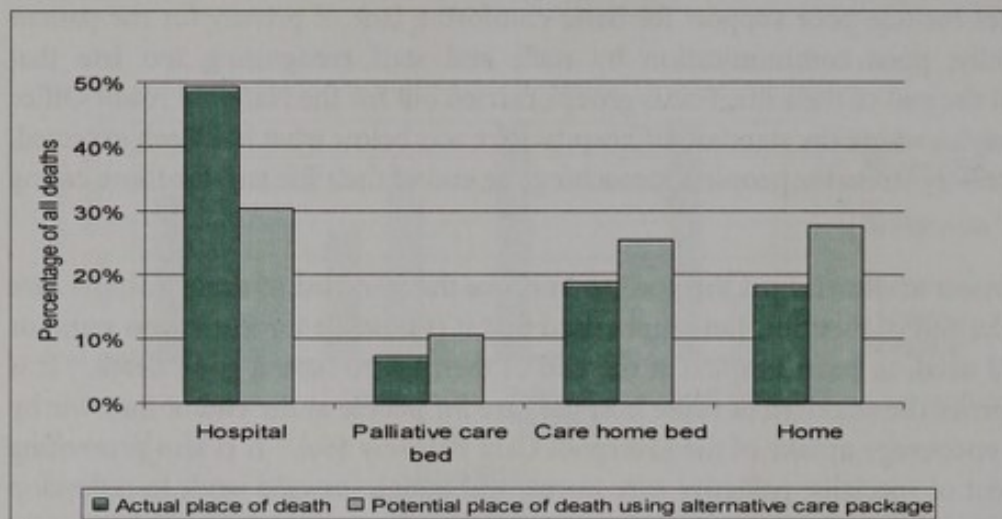
19 Qq 8-9; C&AG's Report; Appendix 2

20 Q 40; C&AG's Report, paras 3.12-3.13; Figures 14-15

21 Qq 8-9; C&AG's Report, para 3.14

prior to death was £1.8 billion and that a 10% reduction in the number of emergency admissions and a reduction of the average length of stay per admission of three days, would release £104 million for redistribution to other end of life care services.²²

Figure 2: Potential to increase the number of people who die outside of acute hospital



Source: Analysis by the Balance of Care Group on behalf of the National Audit Office

12. Work carried out by Marie Curie through its Delivering Choice Programme demonstrates that reductions of this kind are possible if appropriate community services for end of life care are put in place. For example, in Lincolnshire, the Programme helped avoid 500 admissions in a year, it showed that investment in community services can decrease the number of hospital deaths and reduce the number of admissions to hospital per patient as they approach the end of their life.²³ The Delivering Choice Programme is one of a number of examples of the modern hospice movement and the voluntary sector working with NHS and social care services to improve services in the community for people approaching the end of their life.²⁴

²² Qq 5, 107; C&AG's Report, paras 3.23–3.27; Appendix 3; Figures 24–25

²³ Qq 4, 107–109; C&AG's Report, Appendix 6; Example 5

²⁴ Qq 4, 65

2 The capacity and capability of staff

13. Much of end of life care is provided by a wide variety of generalist staff for whom end of life care represents a varying proportion of their role. As a result, these staff may not be trained in the identification, delivery and discussion of end of life care.²⁵ Such skills are essential to delivery of good end of life care as once patients are identified, their wishes can be discussed and care plans can be put in place.²⁶ The Department estimates that it needs to train hundreds of thousands of NHS and social care staff and is currently working with Skills for Health and Skills for Care to develop the competencies these staff will need. It is also developing an e-learning programme and a training programme which will focus on the improvement of communication skills.²⁷

14. A survey of doctors and nurses carried out by the National Audit Office found that only 29% of doctors and 18% of nurses had received any pre-registration training in end of life care. In addition, only 39% of doctors and 15% of nurses who responded to the survey stated that they had received pre-registration training in communicating with patients approaching the end of their life.²⁸ Evidence to the Committee by the Council of Deans of Health indicated that the level of pre-registration training provided to nurses (and other allied health professionals) who qualified in the last five years has improved and that all universities now provide some dedicated pre-registration training in end of life care. However, the proportion of respondents who had qualified in the last five years was small and a key issue is the need for post-registration training.²⁹

15. The Department has taken steps to improve the capability of NHS staff. In 2003, it allocated £12 million over three years to an NHS End of Life Care Programme. The Programme aimed to improve the quality of end of life care by working with Strategic Health Authorities to identify and spread good practice across the country. This included encouraging uptake of the Gold Standards Framework, Preferred Priorities for Care and Liverpool Care Pathway tools recommended by the National Institute for Health and Clinical Excellence.³⁰ These end of life care tools respectively seek to aid the identification of end of life care patients, record patients' preferences over the care they wish to receive and empower generalist clinicians to care for the dying and manage pain in the last days and hours of life.³¹

16. These tools are well regarded by a range of users and the limited research carried out has shown that they can lead to reductions in unnecessary hospital admissions and increase the likelihood of people dying in the place of their choice.³² A third of doctors and 54% of nurses who responded to the National Audit Office surveys reported being trained in at

25 C&AG's Report, para 2.24

26 Qq 10, 70

27 Qq 10, 26

28 C&AG's Report, para 2.25

29 Q 10; Ev 15–16

30 Qq 4, 20; C&AG's Report, para 1.7

31 Qq 10, 20, 55, 61

32 C&AG's Report, paras 16, 3.4

least one of the three tools and that this training had led to an increase in their confidence in delivering end of life care. Uptake of the tools by GP practices, however, varied with Primary Care Trusts reporting an average uptake by practices of 48% for the Liverpool Care Pathway and 60% for the Gold Standards Framework.³³

17. Little is known, however, about the direct patient benefits associated with their use due to difficulties in measuring outcomes for deceased patients. The Department is therefore seeking to measure the impact of the tools on patient care through the development of a programme of surveys of bereaved relatives, known as VOICES, which will be launched in 2009. Bereaved relatives will act as a proxy for the patient, providing detailed feedback on aspects of the quality of health and social care across the different care settings.³⁴

18. Primary Care Trusts rate education and training in care homes as the biggest challenge in delivering good quality end of life care.³⁵ There has been little end of life care training provided to staff working in care homes, and few staff have qualifications relevant to caring for people approaching the end of their life. Where training is provided, the nature of this training can vary widely. High staff turnover rates also mean that care homes are training fewer staff than they lose on an annual basis.³⁶

19. The Department, through its End of Life Care Programme, has also sought to address the lack of training in care homes and has worked with 1,300 care homes over the last three years to develop and implement e-learning programmes and to increase use of the Gold Standards Framework and Liverpool Care Pathway.³⁷ The Department have encountered little resistance to their staff being trained amongst the care homes it has worked with, but the homes often lacked the capacity to release staff to attend training courses or to develop in-house training materials themselves.³⁸ Although many care homes provide good quality care, there is still a significant amount of work to be done to develop the skills and training of staff in the 18,000 remaining care homes across England who have not yet had the benefit of the Department's training.³⁹

20. The care homes viewed e-learning as a flexible and cost-effective way of delivering training to their staff and reported that providing effective training can also have a positive impact on staff retention.⁴⁰

21. The Department does not propose to set a national target for increasing the number of care home staff with qualifications relevant to caring for people at the end of their life, but stated that Strategic Health Authorities or Primary Care Trusts may set themselves local targets.⁴¹ The Department also stated that over time it would expect to see an increase in

33 C&AG's Report, paras 3.7–3.9

34 Qq 43; 61–64

35 Q 103

36 Qq 40, 47–50, 102

37 Qq 40, 49–50, 54–55, 104

38 Qq 49–51

39 Qq 40, 45

40 Qq 49, 54, 104

41 Q 56

the number of care home residents able to die in care homes and that the levels identified by the review of patient records carried out in Sheffield for the National Audit Office, where the proportion of residents dying in care homes could have been increased from 61% to 80% was the sort of improvement that, it would like to see over time.⁴²

22. The Department considers that residents in care homes should have the same level of access to nursing and medical care as a person living in their own home and so is seeking to increase the level of support provided to care homes by specialist palliative care nurses.⁴³ Hospices can play a key role in providing this support through outreach services such as those developed for people with advanced dementia in care homes by St Christopher's Hospice. The Department considered that the work at St Christopher's provided a good example of partnership working where skills were being utilised across settings, thereby avoiding the need for patients to be transferred between institutions. In addition to disease specific approaches, the Department is also looking at ways in which the skills within the hospice movement can be used to improve patient care in different settings irrespective of the patient's diagnosis.⁴⁴

42 Q 40

43 Qq 40-41

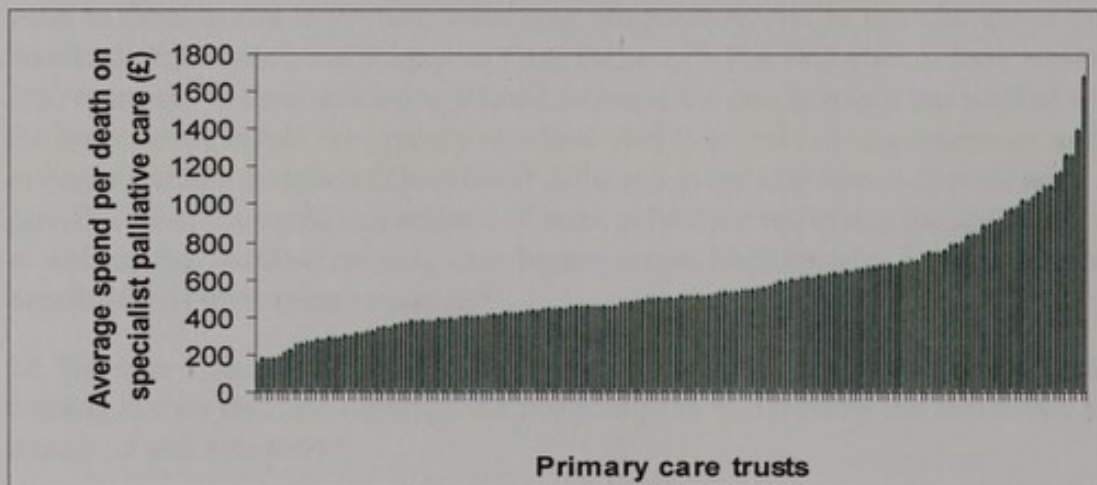
44 Qq 11, 20, 25, 41; C&AG's Report; Appendix 6; Example 2

3 Commissioning and funding of end of life care

23. Primary Care Trusts are unable to estimate the full financial cost of providing end of life care services due to difficulties in identifying the point at which end of life care begins and the proportion of time generalist staff spend with end of life care patients.⁴⁵ The National Audit Office estimates that the cost to NHS and social care services of providing care to cancer patients in the 12 months prior to death (27% of deaths) is £1.8 billion alone.⁴⁶

24. In 2006–07, Primary Care Trusts estimated that they spent an estimated £245 million on commissioning specialist palliative care, which is one aspect of end of life care delivered by around 5,500 staff with specific training in the management of pain and other symptoms.⁴⁷ There is, however, limited understanding of the local demand and supply of end of life care services, and the level of expenditure on specialist palliative care services varied widely between Primary Care Trusts, ranging from £154 to £1,684 per death (Figure 3).⁴⁸

Figure 3: Primary Care Trusts' average spend per death on specialist palliative care



Source: Department of Health survey of expenditure on specialist palliative care

25. Although the Office for National Statistics has data on the number of deaths and where people die, commissioning end of life care services is complex due to variability in patient needs and the resources required.⁴⁹ The Department acknowledged the need for better knowledge and understanding of end of life care across the NHS and reported that it has developed some initial commissioning guidance through its End of Life Care Programme.

45 Q 2; C&AG's Report, para 2.32

46 C&AG's Report, para 3.24

47 C&AG's Report, paras 2, 4

48 Qq 2, 99–100; C&AG's Report, para 2.36; Figure 11

49 Qq 57–60

It plans to refine this and develop it further as it obtains better information on the commissioning of end of life care services.⁵⁰

26. The voluntary sector has made, and continues to make, a huge contribution to end of life care.⁵¹ Some 70% of independent hospices, however, have contracts with Primary Care Trusts for one year only and, by May 2008, only 56% had agreed funding for 2008–09. Such contractual arrangements leave hospices with no firm, long-term base for developing and expanding their operations.⁵² The Department acknowledged that such short term arrangements are unacceptable but explained that one year contracts may have been offered due to Primary Care Trusts receiving one year allocations in 2008–09. As Primary Care Trusts now have two year funding allocations for 2009–10 and 2010–11, and an indication funding arrangement for the three subsequent years, the Department expect that they should now move to three year rolling contracts with hospices, as recommended by the Compact on Relations between Government and the Voluntary and Community Sector in England.⁵³

27. There are hospices and voluntary sector specialist palliative care services across most of England, although the number of beds is not necessarily equally distributed.⁵⁴ On average, independent hospices received funding of 31% of their net expenditure from Primary Care Trusts in 2006–07, with some hospices receiving nothing and others receiving up to 62% (Figure 4).⁵⁵ Although the proportion of funding received by hospices from the NHS fell from 34% in 2004, the Department stated that the NHS had doubled the amount of funding it provided to hospices between 2000 and 2008. The Department attributed the reduction in the proportion of funding received by hospices to hospices' expenditure increasing more rapidly than the level of funding provided by the NHS.⁵⁶

28. The hospice movement developed as a result of a gap in the services provided by the NHS and has traditionally raised significant funds each year to provide services to people nearing the end of their life. Hospices place a high value on their independence and neither the Department nor the hospice movement wish for them to be fully funded by the NHS.⁵⁷ In 2006–07, however, the funding received from the NHS by 97% of independent hospices did not fully cover the costs of the NHS services they provided, or the cost of relevant overheads. The Department acknowledged that this issue needed to be addressed and that Primary Care Trusts should fund their share of the overhead costs of hospices for the services that they buy from hospices.⁵⁸

50 Qq 99–100

51 Q 65

52 Qq 90–92

53 Qq 66, 94–95

54 Q 65

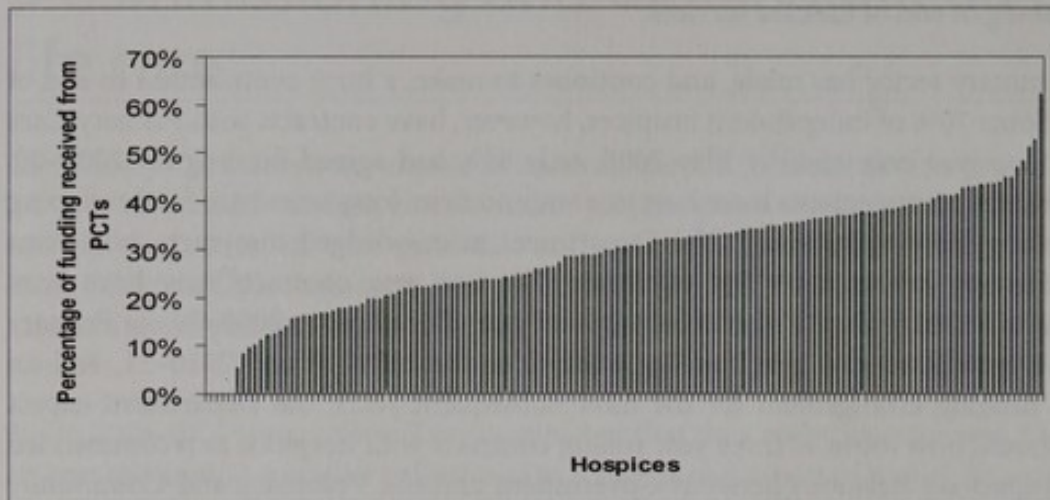
55 C&AG's Report, para 2.36

56 Qq 84–85

57 Qq 85–88; C&AG's Report, para 2.39

58 Qq 66–67

Figure 4: Proportion of hospices net expenditure provided by Primary Care Trusts in 2006–07



Source: Data provided to National Audit Office by Help the Hospices

29. The Department intended to introduce a national tariff for specialist palliative care which would allow full cost recovery by all palliative care providers by 2008–09. A number of factors, such as the lack of robust costing data and wide variations in spending patterns meant that this has not happened. The Department now consider that the development of a national tariff will not be possible over the next three years and that agreeing a local tariff, as has happened in North London, could be a better way forward.⁵⁹

4 The Department's plans for improving end of life care services

30. The **End of Life Care Strategy** (the Strategy), published in **July 2008**, builds on the End of Life Care Programme and sets out the Department's plans for improving the provision of end of life care for adults in England. Central to the Strategy are an increase in the availability of services in the community and the development of the skills of health and social care staff. The Department considers that investing in community services and staff training will improve the quality of care and, crucially, by reducing unnecessary admissions to acute hospital, improve the likelihood of patients being cared for in the place of their choice.⁶⁰

31. The Department's Strategy commits **additional funding of £286 million over 2009–10 and 2010–11**.⁶¹ This funding allocation is based on the Department's estimate of the cost of the key components required to deliver good end of life care. The largest of these components is **access to district nursing services 24 hours a day seven days a week**, which many places do not currently have. The Department considers that increasing access to such services is important if the number of unnecessary admissions to acute hospitals for patients at the end of their life is to be reduced.⁶² The Department expects to see significant improvements in end of life care over the next two to three years as Primary Care Trusts use this additional funding to increase capacity and develop services.⁶³ **The funding will not be ring-fenced**, but the Department expects Primary Care Trusts to account for how it is spent and will, through the SHAs, monitor whether it is used in the way that was envisaged by the Strategy.⁶⁴

32. As part of **Lord Darzi's NHS Next Stage Review**, each SHA was required to produce vision documents for **eight clinical pathways**, one of which was **end of life care**. As part of this process, Primary Care Trusts are currently working through their planning processes to identify and allocate resources over the next two years for end of life care. Each Primary Care Trust will produce a plan by February 2008 which will be reviewed and agreed by the Department on the basis of whether they meet the standards that have been set out in the Strategy, and an appropriate amount of money is being spent.⁶⁵

33. End of life care also features in the Department's Operating Framework for 2009–10, and the proportion of deaths occurring at home is one of the NHS Vital Signs indicators set out in the document.⁶⁶ There is, however, **no single outcome measure for evaluating the quality of end of life care**. Place of death is commonly used as a proxy measure since good data are available from the Office for National Statistics. The Department told us that other

60 Qq 4, 39

61 Qq 5, 14, 38

62 Q 39

63 Q 24

64 Qq 14–19, 96–97

65 Qq 12, 17, 21

66 Qq 7, 13

good markers could include whether a patient had a care plan in place, whether they were cared for on the Liverpool Care Pathway in the last days and hours of their life, and the findings of the planned programme of surveys of bereaved relatives.⁶⁷

34. In November 2008, the Department launched a consultation on a series of quality markers which set out what will be needed for high quality end of life care to be delivered by commissioners and providers. The quality markers are set out in nine parts and include specific markers for Primary Care Trusts, acute hospitals, care homes and a range of other care providers. Use of the markers will not be mandatory but, if they get general approval, the Department will discuss with the Care Quality Commission (which will have responsibility for regulating services across health and social care from April 2009) how it might choose to use them as part of its health and social care inspection regime.⁶⁸

67 Q 61

68 Qq 52, 45; Department of Health, *Quality Markers Consultation*, November 2008

Formal Minutes

Monday 30 March 2009

Members present:

Mr Edward Leigh, in the Chair

Mr Richard Bacon
Angela Browning

Rt Hon David Curry
Rt Hon Alan Williams

Draft Report (*End of life care*), proposed by the Chairman, brought up and read.

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

Paragraphs 1 to 34 read and agreed to.

Conclusions and recommendations read and agreed to.

Summary read and agreed to.

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

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

[Adjourned till Monday 27 April at 4.30 pm

Witnesses

Wednesday 17 December 2008

Page

Mr David Nicholson CBE, NHS Chief Executive, **Dame Christine Beasley DBE**,
Chief Nursing Officer for England, and **Professor Mike Richards CBE**,
National Clinical Director for Cancer, Department of Health

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5	The National Council for Palliative Care	Ev 22

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Annual Report 2007-08	HC 207	15 July 2008
Annual Report 2006-07	HC 206	15 July 2007
Annual Report 2005-06	HC 205	15 July 2006
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Oral evidence

Taken before the Committee of Public Accounts Committee

on Wednesday 17 December 2008

Members present:

Mr Edward Leigh, in the Chair

Mr Richard Bacon
Angela Browning
Mr David Curry
Nigel Griffiths

Keith Hill
Mr Austin Mitchell
Dr John Pugh

Mr Tim Burr CB, Comptroller & Auditor General, Mr Michael Whitehouse, Assistant Auditor General, and Ms Karen Taylor, Director, National Audit Office, were in attendance.

Ms Paula Diggle, Treasury Officer of Accounts, HM Treasury, was in attendance.

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL

END OF LIFE CARE

Witnesses: Mr David Nicholson CBE, NHS Chief Executive, Dame Christine Beasley DBE, Chief Nursing Officer for England, and Professor Mike Richards CBE, National Clinical Director for Cancer, Department of Health, gave evidence.

Q1 Chairman: Welcome to the Committee of Public Accounts. Today, we are considering the Comptroller and Auditor General's Report on End of Life Care. I actually asked the National Audit Office to look at this, and we all have personal experiences of our own of elderly relations. It is a subject which is always very close to our hearts obviously as individuals even more than as politicians, so it is a very important subject and perhaps has not up to now achieved the sort of front-line interest in politics that perhaps it should have done, so are very happy to have David Nicholson here, the Chief Executive of the NHS, to help us with our inquiry. Perhaps you could introduce your two colleagues, Mr Nicholson.

Mr Nicholson: Chris Beasley, the Chief Nursing Officer for England, and Mike Richards, the National Clinical Director for Cancer and End of Life Care.

Q2 Chairman: Well, the first problem that we can identify, and, if we look at the Summary, and we can see this particularly in paragraphs 4 and 17, it tries to delve into how much we spend because the PCTs do not seem to know how much they are spending on end of life care or indeed what are the needs of their population and, therefore, it is very difficult to know, I would have thought, how they can prioritise this subject.

Mr Nicholson: There is no doubt, when you look at the NHS as a whole, that the focus of the NHS over the last 20 or 30, or probably more, years of its existence has been around cure, and rehabilitation and end of life care has not always had the priority that either you might expect or it should have had. Indeed, a lot of the culture of the NHS around death is failure, death is kind of when everyone has given up, which of course is not what the real issue is, so

both the NAO Report, the work that Lord Darzi has done in the Next Stage Review and of course the End of Life Strategy Care have all shined a very big light on this set of issues, as no doubt we will talk about during this process. There is a significant amount of work to do.

Q3 Chairman: Well, of course, if death is failure, we all fail, so we do not want to perpetuate this attitude, do we?

Mr Nicholson: Absolutely, and death is not failure. There is absolutely such a thing as a good death.

Q4 Chairman: One of the things I am particularly anxious about and why I particularly wanted to encourage this inquiry is, I think, the importance of people being allowed to die at home if they want to, and this can be their own home or it can be a care home which, for many people, is their home. Now, three-quarters of people roughly want to die at home and in fact two-thirds of people die in hospital. That is a very sad state of affairs, is it not?

Mr Nicholson: Yes, it is, and all of the evidence that we have collected and the NAO have collected of course is that around two-thirds of all people, given the choice, want to die at home, but that is not to say it is not possible to have a good death in hospital, and there is a lot of work being done to take that forward, but absolutely central to the End of Life Care Strategy is giving people more choice and, to do that, you need to invest. You need to invest in community services, which is very important for us to do, to avoid emergency admissions towards the end of life, and there are lots of good examples around the country of working with Marie Curie and the hospice movement to improve services in the community. There is the work that is being done around the End of Life Care Strategy, the National

Department of Health

End of Life Care Programme which is going to spread good practice around the service, but we need to tackle this issue about emergency admissions and that is absolutely central to the Strategy.

Q5 Chairman: Because this is not a question of money, is it? If we look at paragraph 22, we can actually save money. If we change people's attitudes towards encouraging, or allowing, people to die at home if they want to, it would not actually cost the State more money, would it?

Mr Nicholson: Well, our calculations to get a comprehensive service out for end of life care for England as a whole would cost in the region of £286 million to do all of the things, all the various bits of the pathway that we need to do, which I am sure Mike will talk about, but it is absolutely true that, if you reduced the number of people who die in hospital, you could save up to £104 million to contribute to that.

Q6 Chairman: That is what the Report tells us.

Mr Nicholson: That is absolutely part of the arrangements we want to put into place, but, in order to do that, you do need to invest in the community upfront to avoid those—

Q7 Chairman: Now, as a result of this effort, this Report which we may be doing, is that going to be the focus of your attention now?

Mr Nicholson: Yes, it is and it is part of the Operating Framework. Mike will undoubtedly want to talk in a little more detail about that, but it is absolutely a part of that.

Q8 Chairman: Because, if we look at the detailed work on the ground, for instance, the Sheffield study, Appendix 2, paragraph 7, is it 40% of those who died in hospital could have been quite happily looked after at home?

Mr Nicholson: I think this study from Sheffield is one of the most important new findings that we have as a result of this Report, and I welcome it. What they have done is look at people who died in Sheffield in the month of October 2007, and I think there were 420 patients in total where around half of those patients died in hospital, but what they then went on to do was to look case-by-case by looking back at the case records to see who might have been able to die elsewhere, and they did identify the numbers that could have died either at home or in a care home which, for many, would have been their normal place of residence at that time. I think the overall finding is that potentially, rather than it having been 50% of people who did die in hospital, it could have come down to something around the 30% mark.

Q9 Chairman: Good, so it has been useful?

Mr Nicholson: Yes, indeed.

Q10 Chairman: But of course many people have to die in hospital, or will die in hospital, and we read that sometimes they do not get the respect that they deserve. This is in paragraph 2.8 on a report from the Healthcare Commission, that, "Common issues

included poor support for basic comfort, family and patient privacy, and spiritual, cultural and psychological needs. In many cases, poor communication . . .", so how are you going to try and change attitudes in our hospitals on that, particularly privacy? We have all had personal experience of this, where your loved one just has a curtain drawn around them and that is that really. It is not a great deal, is it?

Mr Nicholson: No, and there are three or four things which, I think, are important, and Mike will undoubtedly want to say something about it. Staff training is a key issue, and we are doing a lot of work in relation to that, there is the development of the Liverpool Care Pathway which helps to take this forward, there is the development of specialist palliative care teams and of course there is a whole set of work being done on redeveloping the environment in hospitals which will support and help this as we go forward.

Professor Richards: On all of those, I think one of the big steps forward that we have taken is focusing on the last few days of life with the Liverpool Care Pathway, which has been an enormously successful programme, but is not yet fully implemented across hospitals. I think it is now being used in about 85% of hospitals, at least on some wards, but we have got further to go to make sure it is being used on all appropriate wards, and that really does help staff know what they should be doing in the last few days of a patient's life. Equally, on top of that, one of the most important things is helping the staff, mainly clinicians, to actually identify that somebody is approaching the end of life and that they may be dying, and one of the things that came through from the Healthcare Commission Report was the fact that often that is not recognised until too late. That is a matter of training and we are putting a lot of effort into, first of all, developing the competencies that people need around end of life care, and we are working with Skills for Health and Skills for Care on that, and we are also then developing two major training programmes, one in communication skills around issues to do with the end of life care, and the second is to do with e-training, electronic learning. The important thing to recognise here is that, in order to get good end of life care, we really need to train hundreds of thousands of staff out of the 1.3 million who work for the Health Service.

Q11 Chairman: Now, if you are dying of cancer, you have got a much greater chance of dying at home, have you not, or in a hospice than other conditions? I think I know the answer, but why is that, and can you change it? I know that you will say that cancer is more predictable, but there are many conditions, such as dementia or chronic heart disease, where in fact the thing is very foreseeable, so there is no particular reason why you should not be in the long term successful in allowing people with other conditions to die at home as if they have got cancer.

Professor Richards: You are right about the predictability factor, but that is not the whole story. I think it is largely that specialist palliative care and the modern hospice movement started with cancer,

Department of Health

and that is what Dame Cicely Saunders really started just over 40 years ago with St Christopher's Hospice. Actually, in the latter years of her life, she too identified the need to spread that further and particularly to spread it to conditions like dementia, and there is now good work going on in that. I think we are taking two approaches on that, first of all, a disease-by-disease approach, for example, saying, "What can we do for people with dementia?", and there are some extremely good projects, for example, one run by St Christopher's Hospice on that which is providing outreach to patients with dementia from specialist palliative care. That is one approach. Equally, with people dying of renal diseases, there is a lot of interest at the moment from clinicians in the field of kidney disease in that, but we also need a systems approach which looks at what we can do with care homes and how, irrespective of the diagnosis that a patient may have, we can train up care home staff to provide better care, so I think all of those are important.

Chairman: Thank you very much. I have other questions, but I think my time has run out.

Q12 Nigel Griffiths: Chairman, I would like to pay tribute to the work of the Marie Curie Hospice in Falstone Road in my constituency, to the staff and the volunteers and the patients and the relatives for all that they do. How much of a priority is end of life care now?

Mr Nicholson: Over the last two years, we have obviously had the work going on around the NAO Report, but we have been working through something called 'the Next Stage Review' for the NHS as a whole, which was led by Lord Darzi, and that was based on eight pathways of care, so every single PCT in every part of the country and every region has been looking at these eight pathways of care. One of those pathways of care is end of life care, so, in that sense, it is one of the eight big pathways that are being considered by the NHS at the moment, and all of those regions have now produced their strategies and the PCTs are currently working through their planning processes to identify, and allocate, resources over the next two years for end of life care, so it is a significant priority for the NHS going forward. We of course also have had the End of Life Care Strategy which kind of overlays the national position on that.

Q13 Nigel Griffiths: Why then does it not figure more prominently in the new Operating Framework?

Mr Nicholson: Well, I think it does figure prominently in the Operating Framework and, if you look at the work that the PCTs have been doing up to now as part of their planning processes in the way that I have just described, it will be both a major mechanism for investment over the next two years, but also in improving services. If you look at the way in which we measure improvement around what we describe as the 'vital signs', death in home is a vital part of that and will be monitored over the next two years, as will the progress around the End of Life Care Report. We will expect the regulators to report

and inspect what progress has been made against PCTs and we expect PCTs to account to their local population about the progress they are making.

Q14 Nigel Griffiths: But, if it is so important and since the Department did announce, I understand, an additional £286 million to be spent on end of life care in the next two years, why is the funding not ring-fenced?

Mr Nicholson: We do not, as a matter of principle, ring-fence money in the NHS and have not done now for several years.

Q15 Nigel Griffiths: But you do for certain projects?

Mr Nicholson: As part of moving away from a position where you delivered big change by big national targets and big national budgets which we set out, we try to give as much money as we can this year, and next year, as you know, over 80% of the resource will be going out to PCTs, which is the highest amount ever, so we do not now ring-fence money in that way. Having said that, we are making a slight exception for end of life care and the reason we are doing that is because we think that end of life care is coming from so far back that perhaps you need some special arrangements, and we have arranged it so that, whilst the money is not ring-fenced, PCTs will have to account for the amount of money that they have got for the end of life care, and we will monitor that over the next two or three years to make sure that they are spending it in the way that we have described as part of the End of Life Care Strategy.

Q16 Nigel Griffiths: Is the Committee able to access how much is then going to each PCT?

Mr Nicholson: The allocations to PCTs are done on a needs and a per capita basis. They are not done around particular specialisms, so you cannot break it down in that sort of way. For example, we know from the variation work that the NAO have done that some PCTs have invested significantly in end of life care already and have got some of the things in place that are required and, therefore, they would not need to spend as much.

Q17 Nigel Griffiths: What are you going to do about the ones that have not, or what are you doing about the ones that have not?

Mr Nicholson: Well, they have got the Strategy, we have identified it in the Operating Framework, we have got the measures and they are now going through the planning process, they produce their detailed plans to us in February and we will look through each individual plan to see what they are going to do over the next two years to see whether they have come up to the standards that have been set out in the *End of Life Care Strategy* and that they are spending appropriate amounts of money, and we will not agree their plans unless they are.

Q18 Nigel Griffiths: Are we going to be able to see, as a committee, where the £286 million goes at the front-line service level?

Department of Health

Mr Nicholson: We will have that information in the Department of Health, so I am sure we will be happy to share it with you.

Q19 Nigel Griffiths: We may be able to extract it from you?

Mr Nicholson: We would be happy to share it.

Q20 Nigel Griffiths: What is your strategy for showcasing good practice and driving best practice down to front-line services in this area?

Mr Nicholson: I am sure Mike will want to say something about this, but fundamentally it is around the End of Life Care Programme.

Professor Richards: We have had a national End of Life Care Programme, a relatively small but nationally supported team, whose main remit is to spread good practice. Claire Henry, the Director of that Programme, works very closely with the ten different Strategic Health Authorities and the job really is to make sure that, where we are learning about things in one part of the country, we spread those to another, so, when we hear of a good programme happening in a care home or a good programme happening in a hospice, let us say, an outreach project for dementia, we will then make sure that that is widely known.

Q21 Nigel Griffiths: What happens if, in being widely known, they read it and put it in the bin? What do you do then?

Professor Richards: Well, as David Nicholson was saying, what we are doing is looking at the plans of each of the PCTs.

Q22 Nigel Griffiths: I know that, but what do you do? "Thanks very much. Actually I am a PCT, a crap PCT, but thanks for this", and it goes in the bin, what do you do? Anything?

Professor Richards: Yes, through the SHAs, the PCTs are performance-managed and we have set out what it is we think they need to do to achieve better quality of end of life care, and what I can say so far is that there is actually a lot of enthusiasm out there for doing it. I think up until now end of life care has had a very low profile and that is changing and, I think, through having a national strategy and having the Strategic Health Authority-level strategies, people are seeing that this is the vision of what can be achieved and my impression is that people are responding to that very positively.

Q23 Nigel Griffiths: You see, I would like to be as optimistic as you are, but I see a squeeze on NHS resources over the next decade and I see NHS costs escalating and generally escalating in areas that are designed to prolong life, not ensure that people have a dignified death. Therefore, I am keen to know what strategy the Department is going to adopt to ensure that your warm words and general sentiment are not squeezed out by other economic priorities within the NHS.

Professor Richards: Well, I think the first thing to say is that, although resources are important for this and that is why resources have been identified through

the End of Life Care Strategy, it is not only about resources. It is also about organisation, it is about good strategic planning, it is about getting PCTs working with local authorities, and we are getting them working together in partnership with the various providers and the voluntary sector, and that is what, in many cases, has been missing and, in many ways, if we can invest upfront in these services that do prevent people from having to come into hospital as emergencies, then actually over time there will be a netting off of one against the other, so I think the important thing is to crack on with this now.

Q24 Nigel Griffiths: When do you expect to see significant improvements?

Professor Richards: I am going to expect to see progress over the next two to three years.

Mr Nicholson: If you look at the way the allocations have been made, we have made allocations for two years, 5.5% growth for next year and the year after, and the information from the Pre-Budget Report shows that, after that, there is not going to be significant growth in the NHS with the economic circumstances. If you look at the Strategy, what we have said is that the £280-odd million that needs to be spent needs to be spent over the next two years, so certainly the capacity needs to be built over the next two years or it will not get built in the future, so we will be able to see the capacity going in, but I guess it will be three years before you see the real benefits of that capacity everywhere. You should see benefits straightaway in year one and year two, but certainly within three years we should be able to have a much better national picture.

Q25 Mr Bacon: Professor Richards, this may be best for you rather than Mr Nicholson, although, Mr Nicholson, please feel free to answer it too. I would like to refer you to page 53 of the Report, Appendix 6, where it is talking about a case study at St Christopher's Hospice concerning dementia. At the bottom there, it says, "Only a small number of patients had been referred for terminal care even though 40% died within six months of their referral. The project team felt that this was possibly due to an inability amongst professionals or care home staff to recognise the dying phase in patients with advanced dementia". As you will know, this Committee specifically looked at dementia and we found that two-thirds of people with dementia never receive a diagnosis. Now, I would be happy for both of you to comment on this, but where do things now stand in terms of the proposals for dementia?

Professor Richards: Well, I think I would be the first to acknowledge that we are at an early phase of the work on dementia. What I would say is that this particular project, and I am delighted that it has been included in this Report, is an extremely good example of partnership working between those who specialise in specialist palliative care, in other words, people like St Christopher's, and those who are good at looking after those with dementia wherever they may be, whether that is in care homes or whether that is in institutions for the elderly, mentally infirm,

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et cetera, and what they have found is that you need both sets of skills, those who know about dealing with dementia and those who know about end of life care. If you get the two working together, there is no doubt at all in my mind that you can get much better care without needing to transfer large numbers of patients from one institution to another, and a lot of it can be done in the institution they are in or at home, if that is where they happen to be, but without transfer.

Q26 Mr Bacon: Presumably, this is not mainly about money, it is about knowledge, about people being able to recognise the conditions?

Professor Richards: Knowledge and skills, yes.

Q27 Mr Bacon: Obviously, there is no training which has no cost, but you would not say it is primarily a question of money here?

Professor Richards: Not large-scale money, no.

Q28 Mr Bacon: Mr Nicholson, do you want to add anything?

Mr Nicholson: Only that there is a big connection between the End of Life Care Strategy and the Dementia Strategy which is to be published shortly.

Q29 Mr Bacon: When will it be published?

Mr Nicholson: Well, we are at the moment reviewing all of the strategies that are in the pipeline across the Department, as you might expect, against the financial output for the future. The issue is obviously making sure that, when we launch the Strategy, we have the resources to be able to implement it where resources are needed, but my expectation is in the early part of next year, and that Strategy will absolutely link up with what Mike says in terms of end of life care for people with dementia.

Q30 Mr Bacon: You will know that we had Professor Banerjee here with you in October last year, just 14 months ago, and I was talking about Professor Richards and you said, "He has made a fantastic impact on cancer services generally". We got into the discussion about having a National Dementia Director in the same way as Professor Richards is the National Cancer Director, and you said, "We have found that having a national clinical director is an enormously powerful way in which to focus", to which I replied, "But you do not have one at the moment", and you said, "No, not at the moment", and you then admitted that it was a possibility. You said, "We will think about the emerging findings at the end of November", that is November of last year, 13 months ago, "and the beginning of December as part of the Operating Framework, so theoretically we can consider it then". Then I said, and this is the point I wanted to come to, "You do not necessarily have to wait for the publication of the green and white versions of his Report before going ahead?", and you said, "No, and, if we are not careful, we will lose a whole year if we do not get something moving forward". Well, it is now 14 months later and you still have not got a National Dementia Director, have you?

Mr Nicholson: No, but nor did I say that we necessarily needed one.

Q31 Mr Bacon: Now you do not think we are going to have one?

Mr Nicholson: I will wait for the announcements, but that is not saying nothing has happened in relation to dementia since then because that is not the case.

Q32 Mr Bacon: No, but you were very clear that having a national clinical director is an enormously powerful way in which to focus. That is what you said.

Mr Nicholson: It certainly was for cancer, yes.

Q33 Mr Bacon: Why would it be different for dementia?

Mr Nicholson: Well, as I say, I do not really want to pre-announce what is going to happen as far as the development of the Strategy is concerned.

Q34 Mr Bacon: Well, I do not want you to pre-announce it either, but it is just that we were discussing this 14 months ago at which point you were saying not only that it was a powerful thing to have a national clinical director, but also that you certainly would not have to wait for the publication of the Report before going ahead because, if you did, you could end up losing a whole year. Well, have you not done just that?

Mr Nicholson: No, we have not lost a whole year. We have made, I think, significant progress, as is reported in the Operating Framework. As I said earlier, PCTs are currently working not only on their plans for end of life care, but also for dementia as part of that Strategy.

Q35 Mr Bacon: And the Strategy will be published when—in the new year?

Mr Nicholson: Early in the new year, yes.

Q36 Angela Browning: I wonder if I could just test a bit of the language we have been using so far in this debate. When we talk about people being in hospital, there is a world of difference between an elderly person being admitted to a trauma ward and somebody in their local cottage hospital at the end of their life, and my experience both of elderly relatives and of my constituents is that, for a great many, the small cottage hospital, with the attention and care they get there at the end of life, is actually something they appreciate and their relatives appreciate, whereas, as I think I may have quoted, Chairman, in a previous session, my late mother's admission at the age of 86 as a Parkinson's sufferer to a trauma ward with a fractured neck of femur was one of the most horrendous experiences of my life. There is a difference, is there not?

Mr Nicholson: Yes.

Q37 Angela Browning: So, when we say that people do not want to be in hospital, they want to die at home, these are shades of grey. Can I just put to you the question about people dying at home, and I

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suspect, if we went round the table, that is what we would all opt for today at the ages we are and in the state of health we are, but we know that things move on. We know that demographically there are going to be more and more people, particularly women, who are very elderly and who are living alone, and my worry is that, when we talk about people dying at home, it is not about providing the nursing care if they are incontinent and if they need fluids and care, it is actually about people dying alone. If there are no immediate relatives, which increasingly there will not be and all the demographics show us that, when we talk about dying at home, are we talking about providing functions or are we talking about what, I think, is very important when people die, actually having somebody there with them? When you gave us the costings, what did that include?

Mr Nicholson: I am sure Mike will talk about the detail of some of that, but in terms of the dying in hospital argument, I think you are absolutely right and one of the issues that we have struggled with, and I know the NAO did, was comparing countries with countries because, you are absolutely right, dying in an acute trauma ward and dying in your local community hospital is a completely different thing.

Q38 Angela Browning: Absolutely a different experience.

Mr Nicholson: So what we do not need to do is slavishly follow this idea that everybody has that it is a bad thing to die in hospital because it absolutely is perfectly possible to make that a decent experience for people, and I think that is absolutely right. In terms of the second part of your question about what other things you need, this £286 million is not about functions, it is about providing a whole package of care and support for the family and the individual, and Mike will talk about the elements of that because I think they are important.

Professor Richards: The first thing to say, taking this figure of half to three-quarters of people wanting to die at home, is that that is true if you do a survey of the healthy adult public.

Q39 Angela Browning: It is bound to be.

Professor Richards: That includes people who are in their 30s and 40s or whatever who are really hopefully a long way from death. If you ask older people, actually the picture changes and there is some good research work that has been done in London about looking at older people where actually they are saying, "I'm not so sure I do want to die at home and maybe I do want to die in some form of institution". Equally, as people get progressively frailer with illness, their views can change. Often, they do not want to be a burden to their family and they do not want to be on their own. Community hospitals, you are absolutely right, there is a research evidence base that shows that people are actually very satisfied with the care they get in community hospitals, and there was one study of six community hospitals where, I think, the only adverse comment was that the television was too loud, but, if that was the only thing that they could

find wrong, I thought that was rather good. In terms of the spend, we have estimated the spend based on looking at what key components, we thought, needed to be got into place and the single largest component was putting in place 24/7 community nursing because a lot of places have not got that, so we really felt that was important because that will then avoid unnecessary admissions to emergency departments and then to acute hospitals, but we should certainly use community hospitals wherever we can.

Q40 Angela Browning: Could I just bring you on to residential homes and, as the Chairman quite rightly pointed out, for many people towards the end of their life, it is their home, it is not an institution, it is their home. However, in practice, my experience is that, if, for example, somebody has a stroke or again a fractured neck of femur, which is quite common in the elderly, many residential homes are very reluctant to take a resident back unless they are weight-bearing and, all too often, particularly if these people are at the end of their life, they are never going to be weight-bearing again. So the idea that they can be retained or returned directly from hospital to a residential home, particularly if it has not got a nursing authorisation because, as we know, with the different categories of residential and nursing homes, some have a dual registration, but not that many, so, for those people who are residing in a residential home, again it is an additional worry that, when they discharged from a hospital, they do not actually go back to the residential home that has been their home and the relatives, or occasionally social services if there are no relatives, then have to hunt around for somewhere for them to go to. Now, we have had this discussion about discharge from hospital in more general terms, but let us just focus on those people who are genuinely at the end of their life. I thought, Professor Richards, the point you made right at the beginning about sometimes the difficulty or the reluctance or the sheer omission on the part of clinicians to actually identify that somebody is in the final stages of life was very telling because the reality is that people can take a very long time to die. Even if a clinician says, "This person is dying", it might be three days, but it could just as easily be another month, so the idea that at that stage you are then bussing them around or, as I have had in my constituency, very, very anxious relatives who feel their place is by the relative's bedside, having to hunt around for another home for them, and we know the problems there, some of my constituents have found the nearest bed 60 miles away, and this is the end of life. How are you going to resolve this shortage of capacity if people are going to go into nursing homes or residential homes?

Professor Richards: There are several points there, but I will try to deal with each briefly. Firstly, I think that the Sheffield study in this Report identified that around 60% of those who were residents at care homes died in the care homes, but they believed that that figure could go up to 80%, so that is the sort of improvement we would hope to see over time. I think there are a number of different things, firstly,

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providing a much better training in care homes and that has really started now. A few years ago, we were doing virtually no training related to end of life care in care homes and over the past three years, as a part of the Department of Health's End of Life Care Programme, we know that there is training going on in about 1,300 care homes. Now, there is a long way to go just before we get to the 18,000 care homes in the country, but that is a major element of this, skilling up the care homes so that they are able to look after the patients and making sure that they have got the support from a specialist palliative nurse. If it is a residential care home, they should have the same access to specialist palliative care nurses as a person would in their own home.

The Committee suspended from 4.06pm to 4.12pm for a division in the House

Q41 Angela Browning: Could I just pick up on this question of training of residential home staff which of course is very important, but of course the reality is that the resources needed to nurse somebody who is dying does put quite a strain on the home. I think, Professor Richards, you were just saying about people coming in from the hospice movement to assist with this into the home. Was that what I had understood you to say?

Professor Richards: If you are in a residential home, you should have the same access to nursing and medical care as you would if you were in your own home, and making sure, therefore, that you can get a community specialist palliative care nurse, and we have teams across the country, who can come in and advise the care home staff on how best to look after that patient, I think, is very important.

Q42 Angela Browning: When you talk about palliative care nurses, you are not just talking about cancer patients?

Professor Richards: Not a bit, no.

Q43 Angela Browning: Could I just quickly turn to page 8, "Further recommendations for the Department of Health" in the NAO Report, where it talks about the Gold Standards Framework, the Liverpool Care Pathway et al. I am rather surprised that the NAO, having looked at this, have concluded, "Little is known, however, about the direct patient benefits", and I wonder why that is, and we have talked about this quite a lot in the Chamber of the House of Commons. Why is so little known about the benefits?

Professor Richards: I suppose the simple answer to that is that it is very difficult to measure outcomes in end of life care because you cannot ask the patients afterwards, but one of the ways that we are tackling this is by developing a programme of surveys of bereaved relatives where they act as a proxy for the patients. This has been done in research by Professor Julia Addington-Hall for a long time. We know it works, it has been done with stroke patients, heart failure patients and cancer patients, and we are going to institute a national programme of surveys of bereaved relatives. I think that will give us the opportunity not only to know overall what people

are reporting about quality of care, but particularly we will be able to see, "Right, are those patients treated through the Gold Standards Framework and the Liverpool Care Pathway? Is the experience of care for them, as seen by the relatives, better for those patients?"

Q44 Angela Browning: Are you going to do that straightaway?

Professor Richards: Well, we are setting up this survey programme, but that will be set up during the course of 2009.

Q45 Keith Hill: I want to ask some questions about care homes and, if I ask the questions, I certainly do not want to suggest that many of these care homes do a poor job; on the contrary, I am sure that most of them do an extremely good job and I certainly want to pay tribute to Aigburth Methodist Residential Care Home in Leicester where my parents spent their final years. However, there are some questions about care homes. Can you tell me about the inspection regime for care homes?

Mr Nicholson: The inspection regime for care homes is just changing in the sense that it was the CSCI and it is now going to the Care Quality Commission which will be a combined regulator for both health and social care, which, certainly as far as services like this are concerned, will be much better because it will be able to look at the total care pathway both in terms of health and social care, and we have two separate regulators at the moment, so we think that is a big step forward and we think that will help improve the services.

Q46 Keith Hill: Well, you obviously already look, because we have data in the NAO Report, at the qualifications of staff in care homes. Do you look at things like conditions of work and pay and matters of that sort?

Dame Christine Beasley: The CSCI, which is the Commission for Social Care Inspection, which is the body that we talked about, they have a range of inspectors that look at a range of issues in care homes, as you say, their qualifications and staffing levels, so they tend to do it against those standards rather than go right down into the sort of nitty-gritty of it all, so that is the level that they inspect at, so it tends to be numbers and it tends to be qualifications and training.

Q47 Keith Hill: Why is there such a large turnover of staff in care homes, 25%, we learn in the NAO Report?

Dame Christine Beasley: I think the thing with care homes is that there is quite a lot of part-time staff and I think often people work for short periods of time in care homes when they are coming back into work and they often find that is acceptable. I think there is a bigger turnover of staff, as you would expect, in cities rather than in rural areas because there is a general turnover of work, and that is true in hospitals and in other areas, so it varies across the country, so there is a range of reasons why there is a large turnover, but you could equally find care

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homes where staff stay for a very, very long period of time and, just like other areas of work, it is often down to the leadership within the home and the sort of population that people come from.

Q48 Keith Hill: You do not think the relatively high turnover is anything to do with rates of pay in care homes? I ask the question bearing in mind of course that securing a place in a care home can be an enormously expensive business, and people pay £25,000 a year or more for such a place.

Dame Christine Beasley: You are talking about rates of pay for staff, and I think the really good care homes, increasingly we are seeing that the very small care homes that grew up in the 1980s and 1990s when a lot of the care was shifted are not viable businesses anymore and they are going out of business, so the bigger care homes, and there are many more of those, increasingly have to offer competitive rates with the NHS, otherwise they do not recruit, whether that is trained staff or whether it is healthcare assistant staff, so otherwise they will not recruit and they do not recruit.

Q49 Keith Hill: Presumably, this turnover accounts, in part at least, for the again relatively low level of training and qualifications amongst staff in care homes?

Dame Christine Beasley: Obviously, if staff turn over, you have got to keep the training going, absolutely. As Mike has said, I think the development of the e-learning is extremely useful for care homes because it is very difficult in relatively small places, which care homes are, to release staff to go off for training. They can do some of it, but it is hard to do that, so e-learning is a very attractive way of learning for both permanent staff and for staff that turn over for a variety of reasons.

Q50 Keith Hill: Fewer than half of the care homes at the moment provide any form of training, and actually the proportion of staff in care homes with the relevant qualifications is really extraordinarily low, is it not?

Dame Christine Beasley: Well, we inspect against the level that is set and it depends a little bit about how you are registered, but in a care home you need a registered nurse on duty for every shift and then you have to decide, just as you do in a hospital, and look at what your case mix is, what the level of your patients is or, in this case, your residents is and then you have to adjust your care. It is absolutely true that in care homes you will probably have a higher proportion of healthcare assistants as support workers because that is the level of care that most people in care homes need which is why, if people get really ill, you need to have specialist nurses able to go in and support some of those areas of work.

Mr Nicholson: I think it is just worth saying in relation to this, particularly the training issue, that we find no resistance or virtually no resistance amongst the people who own the homes to training and they desperately want training for their staff, and their staff certainly need it. We certainly find in the bigger chains now, which increasingly is the

landscape in care homes, that they are focusing quite heavily on training. The issue very often is having the capacity to develop the materials that are required and that is one of the things that we can do through the e-learning.

Q51 Keith Hill: Capacity on whose part?

Dame Christine Beasley: In the homes, so the bigger ones. For example, I visited a large care home of BUPA's in Birmingham about six months ago and, interestingly, the package of training they had put together meant retention, it helped them keep staff and it attracted staff to them because people came, saying, "Actually I want this training", but in places where they cannot do that, and obviously BUPA is quite a big organisation, our helping them with producing the training packages is very useful to them.

Q52 Keith Hill: Incidentally, what do you mean by a "bigger" care home? How many places would that be?

Dame Christine Beasley: I do not necessarily mean the home being bigger, but being part of a bigger organisation, so, for example, BUPA have lots of care homes.

Mr Nicholson: And the Methodists that you talked about and Anchor are big organisations now and have the capacity to build it, but also we are not just dealing with the inputs, the kind of staffing levels and all the rest of it in terms of inspection, but particularly in relation to end of life care we have launched a consultation on, what I think I would describe as, a series of 'quality markers' which people can look at, and Mike wants to say something on that.

Professor Richards: Just briefly on that, that was a commitment from the End of Life Care Strategy and something that we were really asked to do by the Strategic Health Authorities, and we have now launched the consultation on the quality markers and there are different quality markers for hospitals, for care homes, for communities, for PCTs and there are 11 different markers for care homes. Now, we are consulting on those, but, if they get general approval, obviously we will discuss with the Care Quality Commission how they might choose to use this in their inspection regime, but, just to reinforce the point, in the care homes where we have been observing training in end of life care, they are telling us that it aids retention of staff.

Q53 Keith Hill: It aids the retention of staff?

Professor Richards: Yes.

Q54 Keith Hill: But that is still on a relatively small scale, and my recollection is 1,300 out of the 18,500.

Professor Richards: Absolutely, but it does mean that there is an incentive for them to get involved in this training because it will help them with the retention of staff.

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Q55 Keith Hill: Very briefly, just describe some aspects of the training programme that you are doing to upskill people to be able to deal with the end of life situations that they have to deal with.

Professor Richards: Interestingly, the sorts of things we are doing in care homes are not dissimilar from the things we are doing in both general practice and in hospitals, the Gold Standards Framework, which is partly about actually identifying who might be approaching the end of life, having discussions with those patients, recording in advance what their preferences are, for example, "Would you choose to spend your last days in this care home or somewhere else?", and making sure that the care home staff know about the Liverpool Care Pathway and how to use it. All those sorts of things are part of the training that can go into a care home and can make a big difference.

Q56 Keith Hill: Do you have a target for the proportion of care home staff you would like to see with qualifications?

Professor Richards: I do not have a target because we are not in the business of setting national targets on this, but in their local developments then it is perfectly possible either for Strategic Health Authorities or, more likely, Primary Care Trusts to set themselves goals for seeing how they can get more training into care homes. I think it is now happening quite fast as people are beginning to see the advantages of so doing.

Q57 Dr Pugh: You would be perfectly happy, I guess, if you could point to a consistent standard of satisfactory end of life care throughout the country, saying it is all in place and everything is running pretty smoothly. I suppose for every PCT area, is it possible that an actuary or somebody like that could predict fairly accurately (a) how many people were going to die in any one given financial year and (b) more or less, broadly allowing for demographic factors, what they were probably going to die of?

Professor Richards: Yes, it is because you can look at trends over time and, through the Office of National Statistics, we have good data on numbers of death, where people die and, roughly speaking, what they die from as recorded on the death certificate.

Q58 Dr Pugh: So, in order to commission a satisfactory service, the PCT would have a fair inkling, and you would have a fair inkling too, of resources that would be required?

Professor Richards: That is of course more difficult because what an individual patient needs in terms of resources is much more variable.

Q59 Dr Pugh: Well, that is what I was coming to.

Professor Richards: Also, the biggest problem here is defining, if you like, where end of life care starts, so how long is that package of care for an individual patient.

Q60 Dr Pugh: Well, as I would have thought, it is rather hard to do it on a tariff basis because obviously, if you are dying of some fairly complex form of cancer as opposed to simply dying of heart failure in your late-90s or something like that, the costs are going to vary quite appreciably, are they not?

Professor Richards: There will be considerable variations patient to patient, yes. Whether it is cancer or heart failure, there will be variations patient-to-patient.

Q61 Dr Pugh: So, in terms of seeing how well you have done your job in order to sort of get a feeling of whether good levels of care have actually been developed, I was wondering whether it is that easy because you have talked about surveying the relatives and things like that, asking them what they thought of it, but is it not the case though that preferences can change culturally and within areas?

Professor Richards: Yes, indeed. There is no one single measure for end of life care and we have never pretended there is. Recording the place of death is the easiest one and one which we have data on already, but, for example, other good markers would be whether the patient had a care plan in place before they died, and whether they were cared for in the last phase of life on the Liverpool Care Pathway. As part of that care-planning, there is a tool called the 'Preferred Priorities for Care' tool where that helps staff to talk to patients about what their own priorities for care are and where they would like to die, but, equally, in that PPC tool we know that we have to repeat it and find out whether things have changed over time; things do not remain static.

Q62 Dr Pugh: It is worth saying that, for a very traditional community, I could imagine that the benchmark you might take is whether or not the death occurred without pain, without too much unnecessary intervention and so on, and maybe in an urban environment people are expecting a great deal of intervention and effort to be made on behalf of the dying relative and, therefore, actually trying to assess how well or how badly end of life care takes place is, to some extent, a subjective judgment, is it not?

Professor Richards: There are subjective elements to it, yes, but there is a lot more measurement that we can do and that we are planning to do, for example, with the survey of bereaved relatives, than we have been doing in the past.

Q63 Dr Pugh: When you do survey relatives, a person, particularly if they die of something like cancer, will be involved with a number of different agencies over and above the immediate hospital and health agencies, so, in order to assess how well the process has gone, if we can put it like that, are you looking at all the agencies and how they all mesh together or are you specifically just looking at how the health services do their side of it?

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Professor Richards: This programme is still in development. We know it can work because we have seen it working in a research setting, but our proposals at this stage are that we would ask specific questions, like, "Was your relative looked after in a care home?" and then to have a set of questions about the care home care, or, "Were they in an acute hospital?" and to have a set of questions about the acute hospital care, but also, importantly, to have questions about how well the relatives felt that care was co-ordinated across those different organisations.

Q64 Dr Pugh: Whose job is it to find out how the carers were treated, or is that not part of the remit?

Professor Richards: We will have questions about that as well in the survey programme.

Mr Nicholson: One of the important things here is that of course it is all based on a joint needs assessment with local government, so it is not just the Health Service doing this, but this covers both health and social care.

Q65 Dr Pugh: I would point out that most of the complaints I get actually are not about either the social services element or necessarily the hospital element, but it is often the transfer between the two sections which I get more complaints about than almost anything else really. In terms of delivering a consistent standard though, which is of course the aspiration, do you not have this problem that in this area, probably uniquely, you have an enormous effort made by the voluntary sector, hospices which are set up based on community subscription and so on, and they, to some extent, have their own mission statement and their own approach to it and some areas will be blessed with these organisations, whereas other areas will have fewer of them and, therefore, delivering a consistent standard is almost impossible without your actually evening out things, and that obviously militates against voluntary contribution in the first place.

Professor Richards: The first thing to say is that the voluntary sector has made, and continues to make, a huge contribution to end of life care. In fact, we are fortunate enough to have hospices and voluntary sector specialist palliative care services virtually across the whole country, and there has been some recent research which has shown that, even though the number of beds is not necessarily equal across the whole country, people are getting access to care, but yes, it is part of a PCT's job to make sure that their residents are getting good access to care, and that is part of the PCT planning process.

Q66 Dr Pugh: Why is it then that a large number of the hospices complain that, even when they deliver NHS services, they are under-funded, which is one of the facts in this Report?

Mr Nicholson: There are two issues, I think, in relation to our relationship with hospices. One of them is the views from hospices that many PCTs only contract for one year at a time, so that gives them significant issues to deal with, and the second

one is the one particularly that you described there which is that NHS organisations do not pay for full cost recovery, they do not cover the overheads of the hospices as well. We need to do something about both of those things and indeed we are because it is absolutely clear to us, and we have done this through the contract with the voluntary sector as a whole, and we have just had a Co-operation and Competition Panel which partly monitors this, that it is not acceptable for PCTs to contract on a yearly basis with the voluntary sector in this way, particularly hospices. They have been cautious, as you can imagine, in the past because of the financial difficulties in the NHS, they have been cautious because they only got a one-year allocation last time, and now they have a two-year allocation and a view about what the next five years are looking like, so it is our view now that PCTs should all move to three-year rolling contracts with hospices.

Q67 Dr Pugh: Well, that is one of the recommendations in the Report.

Mr Nicholson: That is exactly right, and that is what we are working through at the moment. In terms of full cost recovery, I do not think there are many people whom we fund services for who say that we would fully fund them. There is always a discussion and a debate about the resources and how they are used. We are clear though that NHS organisations should fund their share of the overhead costs of hospices for the services that they buy from hospices, and we are telling them that.

Q68 Dr Pugh: I am just suggesting that it is a difficult area to fund or a difficult area in which you can satisfy yourself that funding was evenly spread across the country to equal effect simply because it is an area where the health economy, as it were, interacts with the voluntary sector in a particularly effective way, I think, although, according to figures here, some meet 31% of hospice costs and others meet 62% and obviously there are some in between, and hospices are recipients of enormous bequests which can enormously enhance the provision in an area. Do you actually see a day coming when you could have a consistent standard that would be the same across the UK because I cannot?

Mr Nicholson: That is certainly the aspiration that we have behind the Strategy. That is why we have asked PCTs to plan it and that is why it is quite difficult in these circumstances to say how much each individual PCT should spend on end of life care services because, you are absolutely right, the mix is different in different parts of the country and some will spend more, some will spend less, but the service that the individual patient, the client, receives should be of a consistent standard. That is certainly what we want to do and that is why we have done the Strategy.

Q69 Mr Curry: I think of all subjects this is one where we ought to beware of trying to look for standard outcomes. We are all going to speak of personal circumstances, I suspect. When my

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mother died of cancer in her early seventies, my father was entirely vigorous, well and he took a huge part of the burden of looking after my mother until the very end when she wanted to go and, indeed, went and died in a hospice. It was a brain tumour and it was no longer possible for my father to cope. When my father died of a cancer, aged 90, a few months ago, he was by himself. He lived by himself in his own house, he was independent, but his needs could not be met by the family in the same sort of way. Therefore, the individual circumstances vary hugely. I understand if a patient has a life expectancy of no more than six months that can make available a much higher degree of support, social security welfare support in terms of aid for care because you need somebody who is going to look after their physical needs, probably cook or help a bit in the house, clean and generally make sure they are up in the morning, or alive in the morning if you like, because the family may not be able to attend on a daily basis. Are you satisfied that process of getting that aid rapidly works efficiently?

Mr Nicholson: No, it does not. The NAO Report reflects on that and our own experiences of life show us that does not always happen. There are some parts of the country where it works fantastically well but there are great bits of the country where it does not, and that is why we want the strategy.

Q70 Mr Curry: Macmillan nurses can fill those forms in for you, can they not? The pathways seem to be there.

Professor Richards: Going back to the point we made earlier, it is this first step in the care pathway of identifying that somebody is approaching the end of life and then once you have done that making sure there is a care plan developed so that we know what is appropriate for that individual, you are completely right, every individual will be different. It may be the same condition but at a different age or in a different circumstance they will need a different care plan.

Q71 Mr Curry: It needs to come quickly. My experience of phoning up was I had an extremely charming lady, who was extraordinarily helpful, on the other end of the phone but she said, "It will probably take three weeks to get the forms to you".

Professor Richards: That is the sort of thing we really do need to check.

Q72 Mr Curry: At that stage you need it quick. You are at the end of your tether, in a way. One should not forget that you have got to look after the relatives, the relatives need care as well at this stage because of the stresses involved.

Professor Richards: We make the point in the strategy that end of life care can be, and often is, urgent care. If you have got weeks to live days matter and if you have got days to live hours matter. We make that very point.

Q73 Mr Curry: How confident are you that support is flexible enough? For example, it may be that the family say, "We can look after mum, dad, at the weekend but during the week we have got a living to earn and family to look after ourselves. We need the care during the weekdays but we can cope at the weekend". If you then talk to one of the private companies which provide care, they come and clean and check, and they will say, "Please sign up saying we are doing it seven days a week because there is a higher rate of payment on that basis". It is actually quite difficult to come to an arrangement where you can do what you want to do without jeopardising the volume of care you can get when you are not able to help.

Professor Richards: I have to say I have not come across that particular circumstance, but the point you are making about the need for flexibility is a good one and that is what I would hope with good commissioning by primary care trusts working together with local authorities is exactly the sort of thing we are looking for.

Q74 Mr Curry: If I were to set up a business which was providing care, and it would not be medical care but perhaps cooking breakfast, cleaning, making sure people are all right, a lot of it just providing company for somebody frankly, what sort of licensing and inspection would I be subject to?

Dame Christine Beasley: I am wracking my brains back to my community days. Companies like that get licensed by their local authority. Much of what you are talking about in terms of support comes through the local authority or local authority commissioned services and they license people to provide some of those services that are often cleaning, shopping, visiting.

Q75 Mr Curry: Is there a correlation between the satisfaction in the service and whether you are urban or rural, whether or not you have an infrastructure of a GP's surgery which tends to be small? In metropolitan areas GPs' surgeries tend to be smaller, and in my experience less capable than some of the rural and suburban areas that have larger surgeries, more GPs, more on the ball in many ways. Is that just my prejudice or is there any truth in that?

Professor Richards: I do not think we have firm evidence at the moment on differences in satisfaction between urban and rural. We will, of course, have that when we have the survey programme of bereaved relatives because that will cover both urban and rural areas, so we will then be able to look at those sorts of things. I would not be able to put my hand on heart and say I know the answer to that at this stage.

Q76 Mr Curry: Are there cultural differences between people of different ethnic minorities in terms of the way they wish to be treated in end of life care?

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Professor Richards: Yes and no. We went into this in considerable detail during the development of the strategy and talked to people from a whole range of different faith groups, for example. In terms of care as people approach death, there are surprisingly few differences in how they want to be looked after. In terms of the rituals immediately after death, yes, there are considerable differences and it is important that we observe those differences and meet the needs and wishes of patients and their relatives.

Q77 Mr Curry: I suspect that most challenges are posed by people with dementia, perhaps. I say that because one sometimes has the impression, and I am very careful how I express myself, that people with dementia may be relatively serene in themselves but for the relatives it is an absolutely hellish disease because they see people becoming incapable, dependent, losing dignity, and sometimes for people nursing them it must be the most dedicated but also the most soulless activity you can imagine.

Professor Richards: I think we have some extremely dedicated carers of people with dementia. There are a lot of them who would say that it can be very satisfying to look after people with dementia, but to look after them well.

Q78 Mr Curry: I suspect in most cases it is not a practical proposition to look after them at home, is it, not in the same way as some of the other diseases?

Professor Richards: It depends on the level of impairment that they have.

Q79 Mr Curry: Can I put before you what struck me as rather surprising. My father, like many people, basically did not want to eat or drink and the only thing we could persuade him to drink were what I called astronaut juices, these concentrated fruit juices. His local GP prescribed a pantechnicon full of these things. Every cupboard in the house was stuffed full of these fruit juices and we kept telling him, "Go on, Dad, you have got to try and get four down a day because if you get nothing else you will be all right". He died and half a pantechnicon was still left in the house, so I took it back to the chemist and they said we had to throw the whole lot away, even though they were totally untampered with, they were still in their cardboard boxes. It is very difficult to get into them. They said, "You would be amazed how much stuff we throw away which is in perfect condition because we are not allowed to reuse it or reprocess it".

Professor Richards: I believe that is the case in terms of the regulations.

Q80 Mr Curry: There must be circumstances in which one can reuse at least some of these? These juices are in sealed containers and they are quite expensive.

Mr Nicholson: Yes.

Q81 Mr Curry: It costs the taxpayer quite a lot of money.

Mr Nicholson: All I can say is we can give you a note on that if you want, I have not got that information to hand on the regulations.

Q82 Mr Curry: I understand the concern about medicines but this is not really a medicine.

Mr Nicholson: I understand.

Professor Richards: The answer is we need to look into that and get back to you.

Chairman: Thank you very much, Mr Curry. Your last questioner is Austin Mitchell.

Mr Mitchell: I think as the oldest member of the Committee I am the one with the deepest personal interest in this subject.

Chairman: But the youngest at heart!

Q83 Mr Mitchell: That is true, which is why I had not thought about the problem until I read the Report. When I read the Report it was somewhat depressing, I thought. Let me start with the briefing we have had from Help the Hospices. Why do the hospices get such a shabby deal when they do such good service? We have a very good service of which we are very proud in Grimsby, St Andrew's, which does a marvellous job but what it can do is constrained by the lack of funding primarily because it gets so little funding from the NHS.

Mr Nicholson: I do not think the hospices are treated shabbily at all if you take the country as a whole.

Q84 Mr Mitchell: The share of funding has gone down according to this from 34% to—

Mr Nicholson: Between 2000 and 2008 the amount of money the NHS has spent in hospices has virtually doubled. What has happened in the figures that you are talking about there is the amount of money that hospices have been spending has gone up faster than the money they have been getting from the NHS. Every year since 2000 the NHS has spent more money with the hospice movement.

Q85 Mr Mitchell: They have had to spend a lot more on extra beds and increased real spend by £84,800,000 and income from government sourced funds, which was 31% of English adult hospice expenditure in the most recent year, has fallen from 34% in 2004.

Mr Nicholson: Yes, but it has doubled. They have been remarkably successful and they protect their independence.

Q86 Mr Mitchell: Yes, they have, but so much of their time is devoted to scrabbling around for money.

Mr Nicholson: The history of the hospice movement, of course, is the hospice movement came out of a gap in the services that were provided. They are independent, vibrant and they protect their independence very carefully.

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Q87 Mr Mitchell: They have taken a lot of weight off the shoulders of the Health Service.

Mr Nicholson: They work in partnership with the Health Service to provide fantastic services to patients. They do not want to be nationalised any more than we want to take them over.

Q88 Mr Mitchell: No, but they do want more money.

Mr Nicholson: Of course they want more money and we have given them more money and will continue to give them more money if they provide more services for NHS patients, particularly in line with the End of Life Care Strategy. Where they have got a reasonable position, as I said before, is operating on annual contracts with hospices is not acceptable, they need more consistency in the way that they are funded and we should cover those elements—

Q89 Mr Mitchell: You say this from a national point of view but what they get from the primary care trust does vary widely, and also the kind of deal they get varies.

Mr Nicholson: It does.

Q90 Mr Mitchell: The Report says that 70% of independent hospices have contracts with their PCTs for one year only.

Mr Nicholson: Yes.

Q91 Mr Mitchell: In other words, they have got no firm, long-term base for developing and expending their operations.

Mr Nicholson: Yes. That is not acceptable.

Q92 Mr Mitchell: In fact, by May 2008 only 56% had agreed funding for that year.

Mr Nicholson: Yes.

Q93 Mr Mitchell: Why was that?

Mr Nicholson: A whole series of reasons. PCTs have been very cautious about the way they have allocated money. This year they only had a one year allocation, so Government only allocated PCTs one year's money.

Q94 Mr Mitchell: It is our fault!

Mr Nicholson: No, I am not saying it is Government's fault at all. Now we have allocated two years' money and given them a view about what the three years after that might look like, so there is no excuse for PCTs not to—

Q95 Mr Mitchell: Can you not nationally impress on them the importance of doing more in this area and giving long-term support?

Mr Nicholson: Yes, we are doing, and we are going to monitor it and enforce it.

Q96 Mr Mitchell: Their briefing makes several suggestions. "Monitoring and investment and expenditure by the Department of Health would

help to ensure these funds are used to improve palliative end of life care services locally". Do you monitor it?

Mr Nicholson: We do not monitor it. What we said earlier was the extra money that is going into the service will be monitored from this year on.

Q97 Mr Mitchell: You will be sure that it goes to end of life care?

Mr Nicholson: Exactly, it is the end of life money that we are going to monitor.

Q98 Mr Mitchell: "Support for the development of tariffs and a timetable for implementation would help to remove some of the uncertainty in commissioning end of life care services".

Mr Nicholson: There are two issues here. There were plans to do a national tariff for this, a national price if you like, but it has proved incredibly difficult, not least of all for the kinds of conversations we have had around here about great variation in terms of the historic pattern of service and the choices of individual patients. It is proving almost impossible to do. Originally we said we would do it for 2008. It was obvious we could not do it for then and we tried to move it to 2009, but it is simply not going to be done over the next three or four years. Our view is in line with what happened in North London, for example, where they developed a local tariff, locally agreed what the funding arrangements should be and the transparency of that, we think that is a better option for people going forward.

Q99 Mr Mitchell: The third point is, "National guidance on commissioning these services", that is palliative end of life care among commissioners, "should be developed to support implementation of world class commissioning". Are you developing national guidance?

Mr Nicholson: There is a lot of work going on in this. There was absolutely a lack of knowledge and understanding in PCTs around end of life care which has been significantly improved by going through the work we have done as part of the Darzi review, so every PCT now has much more clarity about what is required in end of life care, but in our view that is not enough.

Q100 Mr Mitchell: You will be ironing out the differences which are shown in Table 11 on page 23 between the provisions by different primary care trusts?

Mr Nicholson: What we are saying is that as part of the End of Life Care Strategy we will look towards developing a guidance for commissioning end of life care by every PCT. I am not sure what the timetable of that is but that is certainly what we plan to do.

Professor Richards: We have already issued some guidance within the last couple of weeks and that is a first cut that has gone out from the National End of Life Care Programme but we will refine this and develop it further as time goes on as we get better information on end of life care services that

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we can then share with commissioners. The survey that you have been referring to, finding out exactly what PCTs are spending on specialist palliative care, we commissioned that survey, we undertook that survey as part of the development of the End of Life Care Strategy.

Q101 Mr Mitchell: I will trip back to Grimsby to St Andrew's Hospice and give them the good news and reserve my place! You are giving us good news, I hope. It says in the Report that more people die at home when they are in care homes, 70%, than die at home when they live at home. Why is that?

Professor Richards: I suppose the first and most obvious reason for that is that in a care home there are other staff around to look after them and provide for their basic needs. Some of those care homes are fully staffed nursing homes, others have residential care staff, so it is easier to support somebody in that environment.

Q102 Mr Mitchell: There are wide variations in the training of staff and the medical support that is provided. Why is that?

Dame Christine Beasley: There is variation. Some of it is acceptable variation, it depends on what sort of care home you are running and you need different training if you are working in a hospital or a nursing home than if you are in a care home. We have talked about what we are trying to do to make sure everybody gets the right level of training to support people who are dying in the variety of ways that people choose to die.

Q103 Mr Mitchell: PCTs rate education and training in care homes as the biggest challenge in delivering good quality care.

Dame Christine Beasley: Yes, it is.

Q104 Mr Mitchell: These places are underpaid, they find it difficult to attract staff of the right level and, while it is a question of inspection, the Health Service has to play its part in ensuring that staff are trained and people have decent support in their dying days.

Dame Christine Beasley: Absolutely. We mentioned before that e-learning is a really good way of doing it, that is what care staff have told us, it is easy to access. That is the work that we are doing as part of the End of Life Care Strategy that is free to care homes. Equally, because we have also done some work on it, we know that good training retains and attracts staff to care homes. Training all the way round is most important so that people get the best of end of life care.

Q105 Mr Mitchell: I was struck by something in the Report which I assume comes from Sheffield and you can tell me if it does not. A substantial

proportion of people died in hospital but there was no medical reason for them being admitted to hospital. Is not a slight touch of rigor mortis a medical reason for them being in hospital and dying in hospital? Why were these people in hospital who died there when you say there was no medical reason for them to be there?

Mr Nicholson: I think in many cases it is because we have not set up the community services to prevent them going into hospital in the first place.

Q106 Mr Mitchell: They do not get into hospital by just walking in.

Mr Nicholson: No, they get in because they phone 999, the ambulance goes to see them and takes them to an accident and emergency department, whereas if we have done the care planning properly and if we have the community nursing services in place then very often they can be managed in their own home so they would never have to go into hospital.

Q107 Mr Mitchell: All these calculations, you can save £100 million by reducing that proportion or seeing them stay a shorter period, these are all purely hypothetical.

Mr Nicholson: No. If you look at the experience of the Marie Curie Delivering Choice programme in Lincolnshire, over the course of a year by having these good community nursing services in place they estimate that over 500 admissions to hospital were avoided.

Q108 Mr Mitchell: That is from the Marie Curie in Lincolnshire, not from Sheffield?

Mr Nicholson: Yes. That is a programme that we have looked at in great detail that we believe is very good and one that we have recommended to other parts of the country.

Q109 Chairman: I can certainly echo those words about the Marie Curie programme in Lincolnshire, it is very good. Thank you, lady and gentlemen, for appearing before us on what is a very important subject. We are very proud on this Committee that we have managed to take up the NHS agenda in some areas which in the past were Cinderella areas—MRSA, dementia, stroke—and we hope that we can continue the fight on improving end of life care which is so important to the entire country. We are very grateful for the positive way in which you have answered our questions. This has been a very positive hearing.

Mr Nicholson: Can I wish you all a merry Christmas and a happy new year.

Q110 Chairman: A merry Christmas to you, Mr Nicholson, we so much love having you here!

Mr Nicholson: I love coming!

Chairman: Thank you very much.

1. Supplementary memorandum from the Department of Health

Questions 79–82 (Mr Curry): *Why are chemists not allowed to reuse or reprocess prescribed items, such as concentrated fruit juices, when they are brought back untampered with?*

The Department is concerned about wastage from unused medicines or liquid nutritional supplements, but cannot promote the reuse of returned medicines or supplements from patients and/or their families. The Royal Pharmaceutical Society of Great Britain's Code of Ethics states that, for reasons of hygiene and safety, medicines returned to a pharmacy from a patient's home, a nursing or residential home must not be supplied to any other patient. It is not possible to guarantee that any returned medicines will have been stored correctly, for example—ordinary tablets may deteriorate if left too close to a radiator or in direct sunlight. In addition, quality of returned medicines or supplements cannot be guaranteed on physical inspection alone.

Repeat dispensing makes it possible for patients to have their medicines dispensed in instalments for up to a year without having to contact their GP surgery. As each instalment is dispensed, the pharmacist checks that the medicines are still needed and being used appropriately by the patient. Repeat dispensing can make it easier for patients with long-term chronic conditions to obtain prescriptions, speeding up services and relieving pressure on GP surgeries. It is also an opportunity to make better use of pharmacists' skills by helping patients get the most out of their medicines and reducing waste. National repeat dispensing arrangements were established in 2005 as an essential service provided by all community pharmacies, although uptake of repeat dispensing around the country is variable.

Medicines use reviews and pharmacist-led full clinical medication reviews should also help to identify medicines that may no longer be required but they may also identify additional treatments that may be appropriate.

The Department is aware, however, that there has been little research done to evaluate the economic impact of non-adherence. The Department has therefore commissioned research on the scale, costs and causes of waste medicines. The research is expected to be completed by end 2009 and the outputs of this research will inform future policy in this area.

26 January 2009

2. Memorandum from the Council of Deans of Health

1. INTRODUCTION

This submission has been prepared by the Council of Deans of Health. The Council represents the deans and heads of UK university faculties for nursing, midwifery and the allied health professions. It has 86 member universities throughout the United Kingdom and is the principal source in higher education of collective views on education and research for nursing, midwifery and the allied health professions.

The National Audit Office (NAO) published its report *End of Life Care* on 24 November. The Council of Deans was concerned to see the following comment in the executive summary of the report (paragraph 14):

"Many healthcare professionals will come into contact with people approaching the end of their life, but our surveys found that only 29% of doctors and 18% of nurses had received any pre-registration training in end of life care. In addition only 39% of doctors and 15% of nurses had received pre-registration in communicating with patients approaching the end of their life".

The Council believed that this comment does not reflect the position now in pre-registration education and asked our members about current practice.

The evidence now available to us suggests that all pre-registration education in nursing and midwifery includes this subject area, as do many programmes in allied health profession education.

2. THE NAO REPORT AND ITS EVIDENCE

The comments on pre-registration education appear to be based on the results of a survey of nurses undertaken in May 2008 with the assistance of the Royal College of Nursing (RCN). 181 nurses responded to this survey. However, it is clear from Table 1 on page 8 of the survey report that only six respondents had been qualified for less than five years and only 12 respondents had been qualified between six and 10 years. Thus the survey was not able to capture in any significant volume respondents' experiences of recent pre-registration education programmes.

3. CURRENT PRACTICE IN PRE-REGISTRATION EDUCATION PROGRAMMES

The Council of Deans asked its members about the extent to which *end-of life care* features in their pre-registration programmes and for some examples of good practice. The Council has so far received responses from 30 member universities, all of whom report a significant role for end of life care within their programmes. Some examples of good practice reported are included in Appendix A with this submission.

Our attention has also been drawn to research which was published in *Nurse Education Today* in March 2008 (1), entitled *Palliative care and end of life issues in UK pre-registration, undergraduate nursing programmes*. This study, undertaken in 2006, surveyed the 66 undergraduate programmes and had a 79% response. It found that all the schools and faculties responding had some provision and the average number of teaching hours on end of life care was 45 hours. This was significantly greater than the study time shown by similar research undertaken in 1986 and 1994. The paper also highlighted the range of teaching methods used, including lectures, seminars, small group discussions and clinical case discussions. It notes that hospice visits occurred in three-fifths of the programmes. A table in the report showed the range and occurrence of topics covered in this part of the curriculum and this is attached in Appendix B.

4. CONCLUSIONS

- End of life care now features prominently in almost all pre-registration nursing programmes and in a number of allied health profession education programmes. The learning and teaching in this subject area in nursing will be the subject of further revision as universities develop new curricula following the forthcoming review of pre-registration education being undertaken by the Nursing and Midwifery Council.
- However, the NAO report shows that there are many experienced nurses, who did not benefit from this learning within their own pre-registration education. This indicates the need for significant investment into post-registration education in this area.
- Responses from healthcare professionals about their own experience of pre-registration programmes will provide very limited information about the curricula and efficacy of current pre-registration healthcare professional programmes, since programmes are reviewed and revised on a frequent basis. This observation will also apply to most discipline areas in higher education.
- The Council of Deans of Health is happy to assist the NAO in ascertaining the position as regards current education and training in healthcare, where this is relevant to their investigations.

REFERENCES

- (1) Dickinson *et al* (2008) *Palliative care and end of life issues in UK pre-registration undergraduate nursing programmes*, *Nursing Education Today* 28, 163–170.

Appendix A

GOOD PRACTICE IN “END OF LIFE CARE” EDUCATION WITHIN PRE-REGISTRATION PROGRAMMES, AS REPORTED RECENTLY TO THE COUNCIL OF DEANS OF HEALTH

Responses from members of the Council of Deans of Health showed a commitment to end of life care education in pre-registration programmes. Participation is innovative and through a diversity of methods. Below we have highlighted particular areas of good practice drawn to our attention in “end of life care” within pre-registration programmes:

BIRMINGHAM CITY UNIVERSITY

Birmingham provides modules on this area in the second and third year for Adult, Child and Learning Disability branches. There are interactive MOODLE sites (an online e-learning software, see www.moodle.org) on death and dying and end of life issues.

UNIVERSITY OF CENTRAL LANCASHIRE

End of life care features strongly in the pre-registration curriculum. For the Child branch, this includes a full study day (including visit with education input) at a local hospice and focuses on end of life issues in children. The teaching team is multi-professional and includes service users (both children and parents, including of those who have lost children). The study has run for more than three years and has evaluated really well.

UNIVERSITY OF EAST ANGLIA

End of life care is addressed in all four branches of the pre-registration course and the adult branch in particular.

Good practices regarding the teaching of end of life care include the following:

- An entire adult branch enquiry based learning package devoted to end of life care and incorporating "real world" documentation ie Macmillan nursing notes and the Liverpool Care Pathway record;
- Dying and bereavement as a feature of other enquiry-based learning packages used in all four branches;
- User representation in the form of video narratives of dying and bereaved people;
- A range of practitioners who contribute to the design and delivery of these learning packages;
- Clinical placements in areas where students can expect to gain experience of the care of the dying and the bereaved eg specialist palliative care units.

UNIVERSITY OF EAST LONDON

Physiotherapy and Podiatry students learn about end of life issues in an inter-professional module delivered in the second year of the programme. The end of life issues are covered in seminar and lecture format and involve input from a clinician who works in a hospice setting. In addition, some students have a placement in hospices located in London and Essex.

UNIVERSITY OF HUDDERSFIELD

Topics and themes on end of life care are included in the pre-registration curriculum in the first, second and third year.

Practice, both within the acute and primary care setting, is co-ordinated under the Gold Standards Framework (GSF), a systematic evidence based approach to optimising the care for patients nearing the end of life in the community originally developed by Dr Keri Thomas. For 3 years GSF has been part of the NHS End of life Care Programme.

We also have inter-professional learning workshops on 'breaking bad news' when students are in practice.

UNIVERSITY OF HULL

Hull introduces all students, regardless of branch, to issues surrounding end-of-life care within the first few weeks of their programme. Within the Adult Branch Nursing programmes, there is a particular focus on end-of-life issues at the end of year 2. An interactive workshop session is facilitated by lecturers who specialise in end-of-life care with the help of Macmillan nurses—this takes the students through the Liverpool CP stage by stage. Hull also provide an interactive session surrounding the breaking of bad news to patients who are terminally ill.

ISLE OF MAN DEPARTMENT OF HEALTH AND SOCIAL SECURITY EDUCATION AND TRAINING

We have a collaborative arrangement with the University of Chester and deliver their pre-registration programme on the Isle of Man—currently adult branch only. They have excellent specialist per capita palliative care provision.

They utilise the skills of our local hospice staff and Macmillan nurse specialists and palliative care CNSs whilst examining end of life care issues and use the local hospice for placements for some of their students.

Liverpool Care Pathway: used throughout the DHSS and currently being rolled out for use in nursing homes. Students are exposed to it from their first clinical placements, and are often fully aware of the implications and use of the LCP before this is addressed in the university setting. The use of the LCP in practice appears to enhance student nurses abilities to recognise and understand end of life situations.

End of life care is an issue that students never feel confident managing, and are always requesting more taught sessions to address the many issues they encounter.

Students who have placements at hospices have a far greater knowledge and confidence in managing end of life issues than their peers, and that they are able to utilise this knowledge in other areas of practice.

KING'S COLLEGE LONDON

End of life care education is very practice driven as King's involve both consultant and clinical specialist practitioners. They also involve academic staff with a psychology/ communication skill brief and increasingly staff from their Department of Palliative Care and Policy.

UNIVERSITY OF LEEDS

Within the third year students have the opportunity to work with simulated patients in exploring breaking bad news related to end of life and palliative care and communication skills in handling difficult situations.

LONDON SOUTH BANK UNIVERSITY

In the foundation department this issue is discussed and also the clinical skills of last offices is taught. In the adult programme, there is one half day session in the medical unit which the hospice undertakes regarding palliative care. There is also a 2 hour session on health promotion in palliative care. Some students choose to look at palliative care for their integrated study. Students have the opportunity to go to the hospice for placement from second year onwards. Primary care students get another session on symptom management and palliative care in the community.

MANCHESTER METROPOLITAN UNIVERSITY

The BSc (Hons) physiotherapy programme includes end of life care in year 2. This is covered via the use of a case study in which the patient is a young individual with cystic fibrosis who refuses to be put on the transplant list and is thus treated palliatively. Students assess the psychological impact of this together with the bereavement process taking into account all those involved with his care and his family.

MIDDLESEX UNIVERSITY

In Middlesex's adult nursing programme all students have end-of-life care as a key component of one of the core modules. Students are introduced to care planning at the end of life using the Liverpool Care Pathway, and an end-of-life care scenario is one of those used to examine students at their viva.

UNIVERSITY OF NORTHAMPTON

Northampton uses "Help the Hospices" current learning in their palliative care programme.

OXFORD BROOKES UNIVERSITY

End of life care is spread throughout three modules in first and second year for Children, Mental Health and Learning Disability branches.

UNIVERSITY OF STAFFORDSHIRE

Staffordshire has joint teaching appointment in Palliative care between the University Faculty of Health and Science and the Severn Hospice in Shropshire, England. He runs a range of palliative and cancer care modules for the university.

The member of staff also runs several online courses, including 'Introduction to Palliative Care Nursing', and he recommends students register free on these and study the course in their own time. See more at: <http://www.cancernursing.org/courses/currentcourses/full.asp?CourseID=34>.

UNIVERSITY OF SURREY

The Surrey University pre-registration curriculum (all branches) includes the Liverpool Care Pathway, including symptom management and palliative rehabilitation.

Appendix B

TABLE 5 FROM DICKINSON ET AL (2008) *Palliative care and end of life issues in UK pre-registration undergraduate nursing programmes*

TOPICS COVERED IN THE CURRICULUM ON END OF LIFE ISSUES (IN %)

Attitudes toward death and dying	100
Communication with terminally ill patients	98
Communication with family members	96
Pain and symptom management	94
Grief and bereavement	92
Spiritual care at the end of life	86
Psychological aspects of dying	84
Social contexts of dying	73
Euthanasia	71
Policy issues in palliative and end of life care	63
End of life nutrition	61
Advance directives	61
End of life hydration	59
Quality of life assessment	59
Research in palliative and end of life care	55
Relating to patients with AIDS	49
History of hospice/palliative care	49
Neonatal issues	27
Palliative and end of life care in the global context	22

3. Memorandum from Help the Hospices

ABOUT HELP THE HOSPICES

Help the Hospices is the national charity for the hospice movement supporting over 240 hospices across the UK. We work to help hospices deliver the very best care for patients and their families through education, training and support, as well as providing a national voice on issues that affect them.

ABOUT THIS BRIEFING

Help the Hospices welcomes the publication of the National Audit Office report, *End of Life Care*, which is the most in-depth study of its kind to look at this important issue.

The report follows the publication of the Government's first ever End of Life Care Strategy for England, and the inclusion of end of life care in Lord Darzi's NHS Next Stage Review, earlier this year.

This briefing provides the Public Accounts Committee with a perspective from the English charitable hospice sector on the current funding and commissioning challenges facing hospice care that we hope will be addressed through the implementation of the Government's End of Life Care Strategy.

KEY FACTS ABOUT THE DELIVERY OF HOSPICE CARE

- There are 157 charitable inpatient units for adults in the UK,¹ totalling 2,528 beds of which 2,189 (87%) are provided by independent local charitable hospices. This compares to 63 NHS units, with 675 beds.²
- Most hospice care is provided in the community, in or near to people's own homes. Around 140,000 patients were seen by home care teams and 31,000 patients attended day care services at specialist palliative care units including hospices during a one year period in 2006–07.³ The NAO report concluded that almost three times as many people were supported by hospices in their own homes than were cared for in inpatient facilities.⁴

¹ Sixteen of which are managed by national charities—10 by Marie Curie Cancer Care and six by Sue Ryder Care.

² Help the Hospices (HtH). *Hospice and Palliative Care Directory—UK and Ireland 2008*. London: HtH; 2008.

³ The National Council for Palliative Care (NCPC). *National Survey of Patient Activity Data for Specialist Palliative Care Services—MDS Full Report for the year 2006–07*. London: NCPC; 2007. (Figures relate to England, Wales and Northern Ireland but not Scotland.)

⁴ National Audit Office (2008) *End of Life Care*.

KEY FACTS ABOUT THE FUNDING OF HOSPICE CARE⁵

- Expenditure by independent charitable hospices in the UK was £484.4 million in 2007 (a rise of 8% from 2006) which equates to £1.2 million per day. Of this, £360,000 per day comes from the Government, leaving hospices to raise £840,000 per day.
- The average expenditure per hospice in 2007 was £2.6 million per year, an increase of 8% over the previous year and 19% over the previous two years.
- There is wide variation in the level of government funding that hospices receive. The highest level of government funding among adult independent charitable hospices in England in 2007 was 62%, while some hospices received nothing.
- On average, income from government sources funds 31% of English adult hospice expenditure. This proportion has fallen from 34% in 2004.
- During this time hospice expenditure has increased as more services are being provided. Hospices have increased their annual spend by £84,800,000, providing an additional 188 beds, 18 new hospice at home services and eight new day care facilities, alongside caring for an ever increasing number of patients.
- 70% of charitable hospices have funding agreements which last for one year only.⁶

APPLYING THE PRINCIPLES OF THE COMPACT WITH THE THIRD SECTOR

In October, the Commission for the Compact and Help the Hospices published new research looking at the relationship between charitable hospices and NHS Primary Care Trusts, and how well the Compact is being implemented in relation to supportive and palliative care.⁷

- The success of relationships between hospices and Primary Care Trusts relies upon effective personal relationships between key players rather than any external guidance. However, the Compact and its principles underpin good relationships and could be used as a useful tool in improving and developing them.
- Primary Care Trusts indicated that some kind of palliative care marketplace was likely to develop but in most places this was still embryonic. Some envisaged continuing to work with current providers whilst others were prepared to open up the market more widely.
- Hospices and PCTs agreed that national guidance on funding formulae would be very helpful as a basis for setting tariffs for hospice services, providing there was some flexibility to meet variations in local circumstances.
- Primary Care Trusts and hospices were generally content with the balance of risk in their relationship. However, Primary Care Trusts need to provide timely information about the level of hospice funding, in order to allow hospices to undertake robust financial planning, risk assessment and management.
- Further attention should be paid to the question of how the organisational independence of hospices can be maintained, and how this independence is managed within the terms of a contractual relationship.

HOSPICES SUPPORTING THE DELIVERY OF THE END OF LIFE CARE STRATEGY

The Government's End of Life Care Strategy describes hospices as "beacons of excellence", and envisages them having a "pivotal role within the new vision for end of life care".⁸

Hospices are well positioned to support the local health and social care system to deliver on the Government's strategy;

- Hospices provide integrated, co-ordinated services in line with Government's vision for patient-centred care at the end of life.
- They provide training, education and development of health and social care staff throughout the local health economy, helping to improve the skills, knowledge and competencies of care staff in all sectors.
- Hospices support and enable people to die in their preferred location, wherever possible
- They are developing innovative and creative partnerships with other providers, such as care homes.

⁵ Help the Hospices (2008) *Hospice Accounts: Analysis of the accounts of UK independent voluntary hospices 2005–07*.

⁶ National Audit Office (2008) *End of Life Care*.

⁷ Commission for the Compact and Help the Hospices (2008) *Positive Engagement, Future Practice: Learning for End of Life Care*.

⁸ Department of Health (2008) *End of Life Care Strategy—Promoting high quality of care for all adults*.

WHAT THE GOVERNMENT COULD DO TO HELP

The National Audit Office report has highlighted the wide variations in the level of expenditure by PCTs on end of life care. Information from our work also demonstrates the wide variation in the level of support given to local charitable hospices in the delivery of palliative and end of life care.

Help the Hospices has welcomed the publication of the End of Life Care Strategy, and the allocation of the additional resources to PCTs to support implementation.

There are a number of steps we believe that the Government and NHS could take to help ensure that the delivery of the Strategy is a success, and that the inequalities highlighted by the National Audit Office report are addressed. These include:

1. MONITORING THE INVESTMENT IN END OF LIFE CARE

The additional funding for PCTs to support implementation of the End of Life Care Strategy has been included in PCT baselines. Monitoring of investment and expenditure by SHAs and the Department of Health would help to ensure that these funds are used to improve palliative and end of life care services locally.

2. DEVELOPING A TIMETABLE FOR SUSTAINABLE AND EQUITABLE FUNDING OF HOSPICE CARE

The development and implementation of tariffs for palliative care services provided by the charitable sector was held up by the Government as the solution to the inequitable funding of hospice care. The timetable for implementation of tariffs was put back in 2007. Support for the development of tariffs, and a timetable for implementation, would help to remove some of the uncertainty in commissioning end of life care services from the voluntary sector within the context of World Class Commissioning.

3. PRODUCING GUIDANCE FOR COMMISSIONERS ON PALLIATIVE AND END OF LIFE CARE

The level of knowledge about palliative and end of life care among commissioners and PCTs is variable. National guidance on commissioning such services should be developed, to support the implementation of World Class Commissioning, and developed in partnership with key stakeholders and providers, drawing on local expertise.

4. RECOGNISING THE "REACH" OF HOSPICE CARE, AND THE NEED FOR A SPECTRUM OF LOCAL SERVICES TO MEET LOCAL NEEDS

It is often quoted that only 4% of deaths occur within a hospice. However, this underestimates the proportion of people supported by hospice care in other environments, such as care homes, hospitals, and people's own homes, as highlighted within the NAO report. Hospices aim to support people's wishes and preferences at the end of life, including over their preferred place of death, and a spectrum of services is needed to meet local needs for palliative care.

17 December 2008

4. Memorandum from Motor Neurone Disease Association

1. The Motor Neurone Disease (MND) Association welcomes the opportunity to submit this statement to the Committee of Public Accounts in advance of the Hearing on End of Life. The National Audit Office report references the MND Association *Year of Care Pathway* as a key tool to improve End of Life Care.

2. Few conditions are as devastating as MND. In the majority of cases it is rapidly progressive, always fatal and kills five people everyday in the UK. It leaves people locked into a failing body, unable to move, speak or eat normally. The intellect and senses usually remain unaffected. There are around 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no effective treatment.

3. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a World Free of MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

4. The MND Association agrees with the National Audit Office's findings that whilst most people wish to be cared for and die at home the vast majority of deaths occur in hospital. By reducing the amount of time people spend in hospital unnecessarily it could free hospital beds, and make resources available to support palliative care patients more effectively at home or in a hospice.

5. The Motor Neurone Disease (MND) Association believes that it is vital that people living with MND are able to remain in control of their care and that specialist palliative care is introduced from diagnosis. Five people a day die from MND and too many of them spend their final days in hospital contrary to their wishes.

6. In a survey carried out by the MND Association in 2005, only 39% of people with MND had been referred to specialist palliative care services. The National Council for Palliative Care (NCPC) states that over 90% of palliative care patients are those with cancer. However, around 375,000 people die each year from non-malignant diseases. This is a significant amount of unmet need.

7. The Association is concerned that many hospices give preferential access to people with cancer, with some only admitting one person with MND at a time. We recognise that people with MND place higher demands on staff time because of their complex care needs, but this should not prevent hospices from admitting them.

8. The Association believes that access to palliative care should be determined by clinical need not disease type.

9. Care for people approaching the end of their life is complex and requires a combination of health and social care services provided in the community, at home, hospitals, care homes or hospices. The MND Association believes that the coordination between health and social care services in relation to the planning, delivery and monitoring of end of life care is generally poor and hampered by different funding streams, leading to inefficiencies.

10. The urgent need for coordination of services has provided the impetus for the Association to create a Year of Care Pathway, an innovative new guide to commissioning aimed at helping the NHS and Social Services improve the commissioning and provision of services and equipment for people with MND.

11. The Year of Care Pathway was cited as an example in the report of a 'condition specific initiative' to improve end of life care. For the first time ever, the Year of Care pathway lists all the possible care and equipment needs that a person with MND may have over a 12 month period. By attaching a cost to each element, commissioners of services will be able to plan and deliver services more effectively for the benefit of people with MND.

12. The MND Association's Year of Care Pathway is an effective and easy-to-use tool for those commissioning health and social care, minimising inefficiencies and facilitating the provision of services as they are needed.

13. The MND Association would like to see the Year of Care Pathway adopted across the country to ensure that resources are used more efficiently and care is provided more effectively. Some of the learnings, method and principles underlying the Year of Care Pathway may be applied to other rapidly degenerative diseases.

December 2008

5. Memorandum from The National Council for Palliative Care

The National Council for Palliative Care is the umbrella organisation working to support all those involved in providing, commissioning and using palliative and end of life care services in England, Wales and Northern Ireland. We promote the extension and improvement of services for all people with life-threatening and life-limiting conditions wherever they are needed.

The National Council for Palliative Care (NCPC) welcomes the National Audit Office (NAO) report on End of Life Care. Its publication is timely and adds weight to improving end of life care and supporting the implementation of the National End of Life Care Strategy for England and the corresponding Strategic Health Authority (SHA) plans. NCPC will continue to play an active role in supporting its implementation.

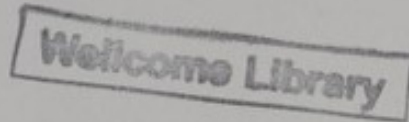
We hope that the Public Accounts Committee (PAC) ensures that good end of life care continues to be a key government priority in view of its importance to the nation and the people of United Kingdom. Specific issues that the PAC might wish to explore in relation to the findings of the NAO report include:

1. What action the Department of Health (DH) proposes to ensure that the NHS identifies patients who could benefit from end of life care so that their needs can be assessed and preferred place of care recorded. Improving the comprehensiveness of end of life care registers in primary care should be an early priority. Does the DH intend to investigate revisions to the Quality Outcomes Framework (QOF) to support this endeavor?

2. How does the Department of Health expect the NHS to address the End of Life Care needs of people with life limiting conditions other than cancer, in particular older people with multiple complex conditions (co-morbidity)? Many older people will also have dementia. How is it intended that there is a "read-across" between the new End of Life Care Strategy and with the soon to be published Dementia Strategy and other dementia and older people policies?

3. The NAO report highlighted the importance of workforce development and training for health and social care staff. Currently the arrangements for this are fragmented and *ad-hoc*. What plans does the DH have to ensure that standards for education and training are clearly defined and embedded in the NHS, in Social Services and in other sectors? For example, will it ensure that this is a core training requirement and assessed through NHS and other relevant appraisal systems?

11 December 2008



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