



National Audit Office

End of Life Care

LONDON: The Stationery Office
£14.35

Ordered by the
House of Commons
to be printed on 24 November 2008



SUMMARY

1 People are generally living longer and, of the half a million people who die each year in England, two-thirds are over 75 years old. The majority of deaths occur in an acute hospital (hospital) and do so following a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most people wish to be cared for and die in their home but the number of people who are able to do so varies with age, geographical area and, most significantly, by condition.

2 End of life care services aim to support people approaching the end of their life to live as well as possible until they die. End of life care is often delivered by a large number and wide variety of generalist staff such as doctors, nurses, allied health professionals and social workers, although the exact number of people

involved in delivering this care is not known. Specialist palliative care is an aspect of end of life care delivered by health and social care staff with specific training in the management of pain and other symptoms and the provision of psychological, social and spiritual support. Around 5,500 staff work in specialist palliative care.

3 The provision of end of life care services has become increasingly complex: people are living longer and the incidence of frailty and multiple conditions in older people is increasing. As a result, people approaching the end of their life require a combination of health and social care services provided in the community, hospitals, care homes, or hospices. Care is also provided by informal carers such as family members, close friends or volunteers.

4 Primary care trusts (PCTs) spent an estimated £245 million on specialist palliative care services in 2006-07. The Department of Health (the Department) estimates that the overall annual cost of end of life care to NHS and social care services is measured in billions of pounds. We estimate that the annual cost to NHS and social care services of providing care to cancer patients in the 12 months prior to death (27 per cent of deaths) is £1.8 billion.

5 The Department has acknowledged that the priority given to end of life care within NHS and social care services has been relatively low, and has worked to raise its profile in recent years. In July 2008, following consultation over two years, the Department published its *End of Life Care Strategy* (the Strategy) which aims to improve the provision of care for all adults approaching the end of their life, including support for their families and carers. The Strategy centres on:

- improving the provision of community services by, for example, making rapid response community nursing services available in all areas 24 hours a day seven days a week, and improving coordination of care between local authorities and PCTs;
- equipping health and social care staff at all levels with the necessary skills to communicate with, and deliver care to people approaching the end of life, and their carers; and
- developing specialist palliative care outreach services by encouraging PCTs and hospices to work together to provide appropriate support to all adults in the community, regardless of their condition.

6 The Department considers that the implementation of its Strategy should reduce inappropriate admissions to hospital and enable more people approaching the end of their life to live and die in the place of their choice. To this end the Department has committed additional funding of £286 million over 2009-10 and 2010-11. Against this background, this report considers the scope for improving the pattern of care in light of the available evidence on the impact and appropriateness of existing provision.

7 In preparing this report, we drew on the knowledge and experiences of a wide range of health and social care staff involved in the delivery of end of life care and, most importantly, people approaching the end of their life and those caring for them. In addition to our censuses of PCTs and independent and NHS hospices and our survey of care homes, three unique features of our methodology (Appendix 1) include a detailed examination of the

patient records of 348 people who died in Sheffield in October 2007 to identify the potential for people to die in their preferred place of care (Appendix 2); modelling of the provision of end of life care services to identify whether the quality of such services can be improved within existing resources (Appendix 3); and detailed reviews of end of life care services provided by three PCTs (Appendix 4).

Findings

Place of care

8 Research suggests that the majority of people (between 56 and 74 per cent) express a preference to die at home, although this proportion may decline as death becomes more imminent and people want access to more extensive support, such as from a hospice. Mortality statistics for 2006 show, however, that 35 per cent of people die at home or in a care home.

Fifty eight per cent of all deaths occur in a hospital, although this figure varies from 46 per cent to 77 per cent between PCTs. Place of death also varies by condition, and cancer patients are more likely than others to die at home or in a hospice; the majority of deaths from dementia occur in care homes; and the vast majority of deaths from heart disease and pulmonary disease occur in hospital. For some people approaching the end of their life, however, there will be clinical reasons for admission to hospital, and for some it is their preferred place of care.

9 A lack of prompt access to services in the community leads to people approaching the end of their life being unnecessarily admitted to hospital. The absence of 24 hour response services and timely access to advice and medication leads to unplanned admissions. In addition, information on patients is not always captured or shared effectively between the different agencies involved in delivering care. This can lead to Do Not Attempt Resuscitation orders not being known or recognised to providers such as out of hours GPs and the ambulance service, resulting in inappropriate admissions to hospitals.

10 The proportion of care home residents who die in hospital could be reduced. Our survey found that a quarter of care home resident deaths occur in a hospital. There were also wide variations between care homes in the number of residents who die in hospital, ranging from none to all residents. In one PCT, the proportion of residents dying in care homes could have been increased from 61 per cent to 80 per cent, if greater support and advice had been provided to those care homes.

11 Independent hospices have an important role in the delivery of end of life care services, both in inpatient care and increasingly in day care and in services in care homes and peoples' homes. Independent hospices currently provide around 2,150 inpatient beds, compared to 450 provided by NHS hospices. Although traditionally focused on cancer, hospices are also increasingly offering services to people with other conditions. Whilst the proportion of non-cancer patients receiving hospice services is low, it is growing.

Meeting the needs of patients and carers

12 NHS and social care services are not meeting the basic needs of many people approaching the end of their life. The findings of published research and work carried out by the Healthcare Commission were that people approaching the end of their life are not always afforded the dignity and respect they deserve. Our focus groups identified a similar picture, where the standard of hospital care and social service provision was below what had been expected and care plans for patients had not been drawn up and agreed. These issues had unnecessarily caused stress for people approaching the end of their life and those caring for them.

13 Despite all carers being entitled to an assessment of their health and social care needs, our census of PCTs found that only 29 per cent provided such assessments as standard. PCTs also do not routinely record whether carers have received an assessment. Caring for a person approaching the end of their life can place a heavy burden on the physical, emotional and mental wellbeing of carers but only 24 per cent of PCTs stated that they offer respite care to all who need it.

The skills and training of health and social care staff

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

15 Ninety care homes responding to our survey (74 per cent) stated that they provide specific training on end of life care, but in less than half of cases was this training compulsory. Data collected by Skills for Care in 2007 show that as few as seven per cent of care home workers and five per cent of nursing care home workers have an NVQ level 3 qualification which includes

optional training in supporting people at the end of life. Staff turnover rates also suggest that care homes are training fewer staff than they lose on an annual basis.

Approaches to improving the delivery of end of life care

16 Fifty four per cent of general nurses and a third of doctors reported being trained in the use of at least one of the three National Institute for Health and Clinical Excellence (NICE) recommended approaches to end of life care (Gold Standards Framework, Liverpool Care Pathway or Preferred Priorities for Care). For those specialising in palliative care, the figures were 91 per cent of nurses and 95 per cent of doctors. These approaches, rolled out as part of the End of Life Care Programme between 2003 and 2007, are well regarded by a range of users and both doctors and nurses reported that their use had improved their confidence in delivering end of life care. There has, however, been little measurement of the benefits for patients of using these approaches and the direct benefit to patient care associated with their use has yet to be fully demonstrated. What research has been done has shown that their use can decrease unnecessary hospital utilisation and increase the likelihood of people dying in their preferred place of care.

Commissioning services

17 PCTs' expenditure on specialist palliative care services does not reflect the pattern of need. Although there is likely to be some variation in expenditure depending on need and the delivery models used, our census of PCTs and data collected by the Department found large variations in the average amount spent on specialist palliative care services for individuals approaching the end of their life (£154 to £1,684 per death). There is also variation in the availability of palliative care beds, and in the number of staff within hospital and community specialist palliative care teams. The provision of care home places and hospice services is also in many cases not proportional to need.

18 Coordination between health and social care services in relation to the planning, delivery and monitoring of end of life care is generally poor and is hampered by different funding streams. It can be difficult to determine what proportion of patients' needs are medical and fall under the NHS budget, or non-medical (social care) and are funded, in part, by local authorities and by the patient based on a needs assessment. A lack of integrated services and an absence of a single point of contact to coordinate care can lead to particular frustration.

19 In 2006-07, hospices provided inpatient services to over 38,000 people and supported over 112,000 people in the community, yet current contractual arrangements with PCTs limit their ability to plan and develop services.

Seventy per cent of hospices have only one year contracts with PCTs. On average, independent hospices received funding of some 31 per cent of their net expenditure (approximately £130 million) from PCTs in 2006-07, though some received as much as 62 per cent.

20 The Department has not yet implemented a national tariff to underpin commissioning of palliative care for NHS and voluntary sector providers.

In its response to the House of Commons Health Committee's 2004 report on palliative care, the Department stated that it was on course to implement a national tariff which would allow full cost recovery by all palliative care providers by 2008-09. A number of factors (for example, the lack of robust costing data) mean that it has not been possible for the Department to deliver a national tariff to this timescale. Whilst the Department continues to work towards delivery of a national tariff for specialist palliative care, there is no specific timetable.

The potential for improving end of life care services within existing resources

21 Our detailed examination of patient records in one PCT found that 40 per cent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month.

Alternative places of care for these patients identified by our work were equally split between home based alternatives (in a patient's own home or a care home) and bed based care in a hospice. Local data suggest there was sufficient inpatient palliative care capacity to take many of the patients who died in hospital.

22 Reducing the amount of time people approaching the end of their life spend in hospital could make resources available which could be used to better support people in their preferred place of care.

We estimate that caring for cancer patients in the last year of their life costs some £1.8 billion, and that £104 million could be redistributed to meet people's preferences for place of care by reducing emergency hospital admissions by ten per cent and the average length of stay following admission by three days (a reduction of around 25 per cent in the current average length of stay). The lack of robust data on the cost of delivering end of life care to people with conditions other than cancer limits our

ability to extend this analysis to other conditions. People with other chronic conditions typically spend a greater proportion of their last year of life in hospital following emergency admissions, so there is likely to be scope for further redistribution of resources.

Overall conclusion

23 The majority of people would prefer not to die in hospital, but a lack of NHS and social care support services mean that many people do so when there is no clinical reason for them to be there. There is scope for more people to die in their home, care home, or a hospice by improving training of all NHS and social care staff in understanding and awareness of end of life care needs, and extending specialist palliative care services for those that need them, regardless of their condition. Improved delivery of these services will require more effective commissioning and partnership working between the NHS, social services and the voluntary sector. The skills in end of life care which have been developed in the hospice movement, primarily in working with cancer patients, could be extended to patients with other terminal conditions, and to the care home sector through outreach services and training.

24 Given the potential to redistribute resources identified in our work, there is scope for PCTs to improve services in all settings by deploying existing and future resources more efficiently and effectively in supporting people in their preferred place of care. To achieve this improvement, there will be a continuing need for the Department to support PCTs as they reconfigure services and redeploy resources to better meet the needs of their local population. The following recommendations set out the actions required to address the problems we have identified and are in line with the aims and recommendations of the Department's Strategy.

Recommendations

For the Department of Health aimed at supporting implementation of its Strategy

- a** **The wishes of people approaching the end of their life are not always conveyed to those who need to know.** Such data should ideally be captured in the Summary Care Record; but until it is fully operational, the Department through the national End of Life Care Programme should support PCTs and strategic health authorities to develop protocols to help capture, document, and share accurate patient information on preferences. This information should be regularly updated and shared with all providers across the health, social care, independent and voluntary sectors who influence decisions concerning where and how patients receive care.
- b** **There are significant gaps in the education and training curricula for health and social care professionals.** The Department should work with the relevant professional bodies to ensure that all trainee doctors, nurses, allied health professionals, and registered social care staff receive an appropriate level of training in the delivery of end of life care.
- c** **Few care home staff have sufficient training in providing end of life care.** The Department should strengthen the existing standards against which care homes are assessed to include a requirement to demonstrate that staff have received such training, including: communication skills; how to avoid unplanned emergency admissions; the provision of adequate pain management; and treating all residents with dignity and respect.

Further recommendations for the Department of Health

- d** **The Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care provide a framework for improving the delivery of end of life care, including identifying the point at which it should begin. Little is known, however, about the direct patient benefits associated with their use.** The Department should commission clinical evaluations to determine whether their use results directly in better quality care for patients. For example, the planned survey of bereaved carers may be appropriate in the evaluation of the Liverpool Care Pathway and aspects of the Gold Standards Framework and Preferred Priorities for Care.

- e** **Commissioning end of life care services is complex and there is a limited understanding of the national picture of demand and supply of end of life care services.** The Department should provide more information and, as appropriate, guidance to assist PCTs to meet end of life care needs and allocate resources more efficiently and effectively by building on the evidence from our work. The guidance should apply the World Class Commissioning Framework which was launched in December 2007 and aims to improve the way health and social care services are commissioned.

For PCTs as commissioners of end of life care services in implementing the Strategy

- f** **Advance care plans seek to make clear a person's wishes in anticipation of a gradual deterioration in their condition, which may result in a loss of capacity to make decisions or to communicate their wishes to others.** PCTs should encourage providers to develop care plans, including advance care plans, for those who wish to have one, and review and update them as necessary.
- g** **A lack of coordination between services or a single point of contact can lead to frustration for patients and carers.** PCTs should commission effective coordination of end of life care services through a single point of contact for patients and carers, including access to advice and Carers' Assessments.
- h** **PCTs generally contract with independent hospices on an annual basis leading to uncertainty in planning and sometimes financial pressures.** PCTs should work with independent hospices to develop three year contracts, based on commissioned services and levels of activity, to enable hospices to better plan the use of resources. These contracts should be in accordance with the existing guidance on how the Government and the voluntary sector should work together.
- i** **Hospitals will continue to have an important role to play in end of life care but these services do not always meet the needs of patients and carers.** PCTs should use the World Class Commissioning Framework to commission end of life care services from hospitals to meet the needs of patients and carers. They should obtain assurance from hospitals on whether staff have received sufficient training; there is suitable inpatient accommodation including private, dedicated space for consultations for patients, their relatives and carers; and there are timely and effective discharge planning arrangements.

Further recommendations for PCTs

- j** **There is considerable variation between PCTs in how specialist palliative care services are commissioned and in the availability of such services to the local population.** When working with local authorities in carrying out Joint Strategic Needs Assessments and developing priorities for Local Area Agreements, directors of public health should monitor whether the current provision of end of life care services and the needs of the local population are fully assessed and gaps addressed. PCTs should use our feedback reports on the results of our PCT census to compare and contrast the extent of their services.
- k** **People's preferences for place of care are generally not being met and access to hospice services is primarily for people with cancer.** PCTs should explore the possibility of commissioning more services from hospices to support patients with conditions other than cancer. Such services could include the coordination of care in the locality, providing training to generalist staff working in other settings, and working in partnership with care homes to enhance the care that they provide.

For the General Medical Council and the Nursing and Midwifery Council

- l** **The current reviews of medical and nursing education present an opportunity to improve the level of basic training which doctors and nurses receive in end of life care.** The General Medical Council's Education Committee in its review of Tomorrow's Doctors should address how to improve skills in identification, delivery, and awareness of end of life care. The review by the Nursing and Midwifery Council of pre-registration nursing education should address similar issues.