DH Department of Health

End of Life Care Strategy

Promoting high quality care for all adults at the end of life

Executive Summary

July 2008

NHS

Executive Summary

Background

1. Around half a million people die in England each year, of whom almost two thirds are aged over 75. The large majority of deaths at the start of the 21st century follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere.

2. The demographics of death in relation to age profile, cause of death and place of death have changed radically over the course of the past century. Around 1900 most people died in their own homes. At that time acute infections were a much more common cause of death and a far higher proportion of all deaths occurred in childhood or early adult life.

3. With these changes, familiarity with death within society as a whole has decreased. Many people nowadays do not experience the death of someone close to them until they are well into midlife. Many have not seen a dead body, except on television. As a society we do not discuss death and dying openly.

4. Although every individual may have a different idea about what would, for them, constitute a 'good death', for many this would involve:

    *   Being treated as an individual, with dignity and respect;

    *   Being without pain and other symptoms;

    *   Being in familiar surroundings; and

    *   Being in the company of close family and/or friends.

5. Some people do indeed die as they would have wished, but many others do not. Some people experience excellent care in hospitals, hospices, care homes and in their own homes. But the reality is that many do not. Many people experience unnecessary pain and other symptoms. There are distressing reports of people not being treated with dignity and respect and many people do not die where they would choose to.

6.   How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.

7.   In the past, the profile of end of life care within the NHS and social care services has been relatively low. Reflecting this, the quality of care delivered has been very variable. Implementation of this strategy will make a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.

Context

8.   The themes set out in the strategy have built on the best available research evidence and on existing experience from:

*   Voluntary hospices, many of which have been beacons of excellence in end of life care since the foundation of the modern hospice movement by Dame Cicely Saunders at St Christopher's Hospice in 1967.

*   The NHS End of Life Care Programme (2004–2007), which has contributed significantly to the rollout of programmes such as the Gold Standards Framework (GSF), Liverpool Care Pathway for the Dying Patient (LCP) and the Preferred Priorities for Care (PPC).

*   The Delivering Choice Programme currently being run by Marie Curie Cancer Care. This has highlighted the benefits of taking a whole systems approach to the delivery of end of life care.

*   Numerous examples of innovative practice, which have been provided during consultation on the strategy.

Whole systems and care pathway approaches

9.   The strategy was developed over a period of a year by an advisory board and six working groups and over 300 stakeholders were consulted. From this process a consistent message has emerged that a whole systems approach is needed. Within this, a care pathway approach both for commissioning services and for delivery of integrated care for individuals has been strongly recommended. The care pathway involves the following steps:

* Identification of people approaching the end of life and initiating discussions about preferences for end of life care;

* Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly;

* Coordination of care;

* Delivery of high quality services in all locations;

* Management of the last days of life;

* Care after death; and

* Support for carers, both during a person's illness and after their death.

Key areas addressed by the strategy

10. The strategy sets out key areas, with the related actions and recommendations highlighted in bold throughout. These key areas can be summarised as follows.

Raising the profile

11. Improving end of life care will involve Primary Care Trusts (PCTs) and Local Authorities (LAs) working in partnership to consider how best to engage with their local communities to raise the profile of end of life care. This may involve engagement with schools, faith groups, funeral directors, care homes, hospices, independent and voluntary sector providers and employers amongst others. **At a national level, the Department of Health will work with the National Council for Palliative Care to develop a national coalition to raise the profile of end of life care and to change attitudes to death and dying in society.**

Strategic commissioning

12. As the services required by people approaching the end of life span different sectors and settings, it is vital that an integrated approach to planning, contracting and monitoring of service delivery should be taken across health and social care. A strategic approach to commissioning led by PCTs and LAs is vital and commissioners are reminded of the requirement to conduct equality impact assessments of any planned changes to services. All relevant provider organisations should be involved in the commissioning process.

Identifying people approaching the end of life

13.   Caring for those approaching the end of life is one of the most important and rewarding areas of care. Although it is challenging and emotionally demanding, if staff have the necessary knowledge, skills and attitudes, it can also be immensely satisfying. However, many health and social care staff have had insufficient training in identifying those who are approaching the end of life, in communicating with them or in delivering optimal care. To address this, a major workforce development initiative is now needed, with particular emphasis on staff for whom end of life care is only one aspect of their work. This will include the provision of communications skills training programmes and other programmes based on the competences needed by different staff groups. Professional regulatory bodies and higher educational institutions will need to be engaged in this endeavour.

Care planning

14.   All people approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in a care plan. In some cases people may want to make an advance decision to refuse treatment, should they lack capacity to make such a decision in the future. Others may want to set out more general wishes and preferences about how they are cared for and where they would wish to die. These should all be incorporated into the care plan. The care plan should be subject to review by the multidisciplinary team, the patient and carers as and when a person's condition, or wishes, change. For greater effectiveness, the care plan should be available to all who have a legitimate reason to access it (e.g. out of hours and emergency services).

Coordination of care

15.   Within each local health economy mechanisms need to be established to ensure that each person approaching the end of life receives coordinated care, in accordance with the care plan, across sectors and at all times of day and night. PCTs will wish to consider the work from the Marie Curie Cancer Care Delivering Choice Programme. This demonstrates the effectiveness of establishing a central coordinating facility providing a single point of access through which all services can be coordinated. In addition, it is recommended that PCTs create locality-wide registers for people approaching the end of life, so that they can receive priority care. Currently there is a pilot testing this in Leeds.

Rapid access to care

16. As the condition of a person may change rapidly, it is essential that services are marshalled without delay. If a person is likely to live for only a matter of weeks, days matter. If the prognosis is measured in days, hours matter. Therefore, PCTs and LAs will wish to consider how to ensure that medical, nursing and personal care and carers' support services can be made available in the community 24/7, including in care homes, sheltered and extra care housing and can be accessed without delay. From the emerging data from Marie Curie Cancer Care and others, it is evident that provision of 24/7 services can avoid unnecessary emergency admissions to hospital and can enable more people at the end of their life to live and die in the place of their choice.

Delivery of high quality services in all locations

17. Commissioners will wish to review the availability and quality of end of life care services in different settings. These will include services provided in hospitals, in the community, and in care homes, sheltered and extra care housing, hospices and ambulance services. We expect PCTs to build upon current guidance, their baseline review of service provision and findings from their local reviews of end of life care carried out as part of Professor the Lord Darzi's NHS Next Stage Review. Also, commissioners will wish to refer to the quality standards, being developed in collaboration with Strategic Health Authorities (SHAs) End of Life Care Pathway Chairs, which set out what is needed to deliver high quality care at the end of life, adopting a care pathway approach. Consultation on these will commence shortly.

Last days of life and care after death

18. Increasingly, the LCP, or an equivalent tool, is being adopted by those providing end of life services. The LCP, which was first developed for use with cancer patients, has now been successfully modified for use for people with other conditions. It can be used in hospitals, care homes, hospices and in people's own homes. For people who die suddenly, the care after death module is appropriate. The adoption of this tool is further supported by those hospitals who have participated in the National Care of the Dying Audit – Hospitals (NCDAH) based on the LCP.

Involving and supporting carers

19.   The family, including children, close friends and informal carers of people approaching the end of life, have a vital role in the provision of care. They need to be closely involved in decision making, with the recognition that they also have their own needs. For many this will have been the first time they have cared for someone who is dying. They need information about the likely progress of the person's condition and information about services which are available. They may well also need practical and emotional support both during the person's life and after bereavement. Carers already have the right to have their own needs assessed and reviewed and to have a carer's care plan.

Education and training and continuing professional development

20.   Ensuring that health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care for the dying will be critical to the success of improving end of life care. For this to happen, end of life care needs to be embedded in training curricula at all levels and for all staff groups. End of life care should be included in induction programmes, in continuing professional development and in appraisal systems.

21.   The health and social care workforce can be segmented into three broad groups in relation to end of life care. Staff who spend the whole of their time caring for those at the end of life, those who frequently deal with end of life care as part of their role and those who care for people at the end of life infrequently. Developing core competences for each of these groups is work best led by organisations such as Skills for Care and Skills for Health, in collaboration with the Academy of Medical Royal Colleges. **SHAs will wish to consider how training can best be commissioned and provided to ensure that relevant staff have the necessary competences.**

Measurement and research

22.   Good information on end of life care is needed by patients, carers, commissioners, clinicians, service providers, researchers and policy makers. Each group will have somewhat different questions to ask and therefore different priorities for information. The NHS Choices website contains information which may be helpful.

23.   Measurement of end of life care provision is a key lever for change and is essential if we are to monitor progress. This will require measurement of structure, process and outcomes of care. Structures and processes will largely

be measured through self assessment by organisations against the quality standards, on which consultation will commence shortly.

24. In addition to information on place of death, which is available through the Office for National Statistics (ONS), outcomes of end of life care will in future be monitored through surveys of bereaved relatives, national audits and regular reviews of complaints.

25. Development of this strategy has, wherever possible, taken account of the best available evidence, but has also revealed deficiencies in the evidence base. Working with charities and with other statutory funders, the Department of Health now wishes to enhance research into end of life care, especially for those with conditions other than cancer. A new one off initiative will build on the good foundations laid through the National Cancer Research Institute's supportive and palliative care research collaborative.

Funding

26. It is difficult, if not impossible, to calculate the cost of end of life care in this country. This is partly because of the difficulty in defining exactly when end of life care starts. However, the key elements of expenditure can be identified. These are:

   * Hospital admissions;

   * Hospices and specialist palliative care services;

   * Community nursing services; and

   * Care homes.

27. Across health and social care, the overall cost of end of life care is large (measured in billions of pounds) and there is widespread agreement that these resources are not all being used as well as they might be. In addition, there are costs met by other government departments, such as the Attendance Allowance and Disability Living Allowance. There are also costs to unpaid carers.

28. As promised in the manifesto commitment, the government is committing increased resources to implement the strategy amounting to:

   * £88m in 2009/10

   * £198m in 2010/11

29.   However, many of the improvements envisioned can be achieved by better use of existing health and social care resources. It is likely, for example, that at least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay. Further work on the cost impact of new end of life care service models, developed through the Marie Curie Cancer Care Delivering Choice Programme, is encouraging, showing a reduction in hospital admissions and increase in home deaths with stable overall costs.

30.   However, in reviewing local areas, commissioners will need to consider the financial implications of:

★   Establishment of coordination centres/facilities;

★   Provision of 24/7 home care services;

★   Improved ambulance transport services for people near the end of life;

★   Additional specialist palliative care outreach services to provide advice and care for non-cancer patients and to increase input into care homes and community hospitals; and

★   Improved education and training of existing staff in care homes, hospitals and the community.

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