



leading edge

3rd in a series of papers on community health and care

NOVEMBER 2005

ISSUE 12

Improving end-of-life care

Key points

- Some 56 per cent of people would prefer to die at home, but only 20 per cent do so. As many as 56 per cent of people die in hospital although it is an unsuitable environment for most dying patients.
- By 2020, the over 50s will comprise half the adult population – it is essential we rethink current service provision and end-of-life care to ensure it can meet the demands an ageing population will make in the next 20 years.
- Palliative care services will need to be kept fit for purpose – more ‘terminally ill’ patients may need to be admitted to hospices in the final stages than is currently possible.
- Advanced care plans need to be adopted as standard and based on a full assessment of patient needs and preferences.
- All people at the end of life need to have choice over the place in which they die. The hospice system may need to be extended so that high-quality specialist end-of-life care is available for more people, with all diagnoses.

End-of-life care is a part of the much wider area of palliative care and people can live with a life-threatening condition for years. Palliative care services need to be designed so they are integrated with other services and are able to meet the wide range of needs of service users, their families and their carers throughout the palliative phase and into end-of-life care.

This *Leading edge* briefing examines the current state of end-of-life care in the NHS and the opportunities for improvement offered by the consultation, *Your health, your care, your say* and the recent Department of Health initiative on dignity.

This is one of a series of NHS Confederation briefings designed to influence the debate on improving community health and care. These papers are aimed at informing Government policy on care outside hospitals. However, the intention is that this briefing should also support members in the planning of services.

Introduction

“Better care of the dying should become a touchstone for success in modernising the NHS. This is one of the really big issues – we must make it happen.”

NHS chief executive Sir Nigel Crisp, 2003

and eventually fatal illness, or an advanced or irreversible disease, need high-quality well-organised end-of-life care. This group of patients includes patients with organ failure such as heart disease and chronic obstructive pulmonary disease (COPD), stroke, general frailty, dementia and other neurological conditions as well as people with cancer.

Defining end-of-life care

Although attention tends to have been given to cancer care, all patients with a chronic, progressive

Although some conditions such as cancer have a relatively predictable trajectory of illness and decline, others may involve a slower decline over a period of years,

“Reducing emergency admissions by increasing community care would allow more patients to “die well””

followed by sudden admission to hospital and then death. End-of-life and palliative care therefore overlaps with care for patients with long-term conditions.

End-of-life care complements supportive and palliative care, which the National Institute for Clinical Excellence (NICE) says should:

- treat the patient as an individual
- show patients respect and preserve their dignity
- help with control of symptoms particularly pain
- offer psychological, social and spiritual support
- reassure patients that their families and carers will receive support during their illness.

There is a well recognized definition of palliative care:

“Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.”
(NICE, 2004)

The current picture

Of the 530,000 people who die in England every year, just over half die in hospital – although few choose hospital as their preferred place of death. Most would like to die at home, but only about a fifth currently do so. Whether patients’ and carers’ needs and choices are met is too often down to the historical pattern of service delivery.

Currently, a majority of people with chronic conditions die in hospital, for example:

- 58 per cent of those with heart failure
- 78 per cent of those with renal failure
- 61 per cent of those with COPD.

Most people who die in hospital do so in the first week after admission. The mismatch between patients’ preference and reality has a number of possible causes. One important reason may be that it is difficult in an acute hospital to diagnose whether a patient has entered the dying phase. Shifting focus from fighting disease to controlling symptoms and giving support in the last days or weeks of life can be a challenging time for ward teams.

Patients may be given treatment they no longer need or want. Typically

they are admitted as emergencies, and many are transferred from care homes in their last week of life. Death may come as a shock, with neither the patient nor their family prepared, able to access supportive care or experience any proper sense of closure. Reducing such admissions by increasing community and social care would enable more patients to ‘die well’ in the place and manner of their choosing. It would also bring cost savings.

A second reason for the mismatch between patients’ wishes and reality may lie in the availability of services. While much excellent care exists, in many places appropriate services – such as 24-hour, seven-days-a-week nursing – may not be available. Or professionals may be unaware of what does exist and fail to refer patients to appropriate services. In our death-denying culture, some professionals are reluctant to address the topic with patients or their families and so do not find out their problems and concerns.

Poor communication among professionals and ineffective co-ordination between day and out-of-hours services can also hamper palliative and end-of-life care. Inconsistent community provision, inadequate equipment, ageing carers or poor family support

	Home	Hospital	Hospice	Care home
Preferred place of death	56	11	24	4
Actual place of death	20	56	4	20

Source: National Council for Palliative Care

mean some patients are unable to choose where they die. The Health Service Ombudsman has identified care of the dying as a cause of repeated complaints.

Recent studies have highlighted the high incidence and prevalence of depression among those reaching the end of their life. Physical ill health, living in chronic pain and a loss of capacity to function often impacts on the patient’s mental health well-being. Depression is difficult to diagnose and often goes untreated. Pain is unmanaged at a time when quality of life is of paramount importance.

Models

Most end-of-life care is weighted towards cancer patients, yet more people die of heart failure and COPD (see table 2). While 95 per cent of patients using hospice or palliative care have cancer, 300,000 with other life-threatening conditions might benefit but are excluded by reason of their diagnosis, according to the National Council for Palliative Care.

There has been a great deal of work on the palliative care needs of people with cancer, which has been widely used by cancer networks and is now being adapted to the needs of people with other conditions. This work needs to be considered in determining needs and services.

There are also some innovative models being used to address the

needs of people with other conditions and these are being discussed by NCPC policy groups. For organ failure patients particularly, palliative care specialists are beginning to collaborate with disease specific specialists such as heart failure nurses, but more work is needed.

Although there are excellent models of specialist palliative care, some services are overstretched or used inappropriately. The Commons Health Select Committee found in 2004 that inequities in palliative care existed by reason of diagnosis, geography, age and ethnicity.

Most end-of-life care is provided by generalist staff in hospital wards, primary care or care homes. Quality varies, with some services understaffed and others not working to their full potential. Vital moves include:

- enablement of generalists, especially within the community, with enhanced workforce
- better use of guidelines and protocols
- greater access to support as needed

Table 2: Causes of death in England 2003 (per cent)

Cancer	25
Heart disease	19
Respiratory disease	14
Strokes and related disorders	11
Other	31

Source: Office for National Statistics

‘Most end-of-life care is weighted towards cancer patients’

- ensuring ongoing education in key competencies.

Pressure for change

Demographic ‘timebomb’

The proportion of the population aged over 65 is projected to increase from 16 per cent in 2004 to 21 per cent by 2024. The result is that in 2024 those aged 75 or over will form 10.7 per cent of the population. The number of people over 80 will increase by half, and those over 90 will double. Currently people over 65 account for 84 per cent of deaths and those over 80 for 51 per cent. Many older people will need support and care, but they will have very different individual needs.

The ratio of people of working age to retired people will fall from 7:1 to 4:1. On current trends, people will be more likely to live alone due to family fragmentation and divorce. Already 14.4 per cent of households consist of pensioners living alone, and 50 per cent of women over 75 live alone. They will have less access to informal care from family members.

While people can expect to live longer, some can also expect longer periods of ill-health at the end-of-life. As medical advances convert many acute life-threatening episodes into chronic, life-limiting conditions, some people may live with different combinations of cancer, heart disease, dementia, diabetes and arthritis. Many

'Different cultural attitudes to dying will give rise to different service needs'

live for 8 to 12 years with serious ill health within the community, whereas previously they might have died sooner or lived in institutions.

Increasing numbers of people will be living with organ failure and frailty and dementia, and fewer with the cancer-based trajectory (see diagram) on which much of hospice, specialist palliative care,

hospital acute care and end-of-life care has previously been based. There needs to be a shift towards end-of-life care that incorporates the organ failure and frailty and dementia trajectories.

This shift should involve many health and social care providers. Increasing integration of the health and social agendas would reduce the disassociation between these disciplines on the ground. This disassociation particularly occurs in areas such as night-sitting and personal care assistance, thereby

contributing to the breakdown in home care. The number of children with life-limiting illnesses who survive into adulthood will also grow.

Consumerism

People are used to exercising choice in every area of their lives, and expect to be able to do so in health and social care. The articulate and demanding 'baby boom' generation is likely to assert more actively 'pensioner power' than previous generations. They will expect to be kept informed and involved in their treatment and care and to have their choices met.

Workforce changes

As the population grows older, fewer people of working age will be available to provide services to an increasing number of elderly people. Demands on people of working age will increase and work and career patterns will therefore change.

Cultural and ethnic diversity

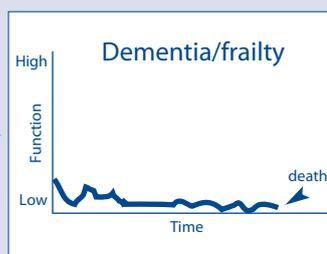
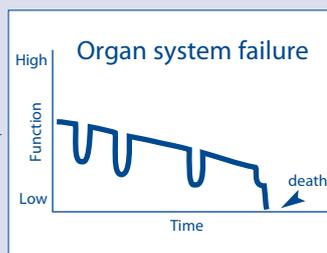
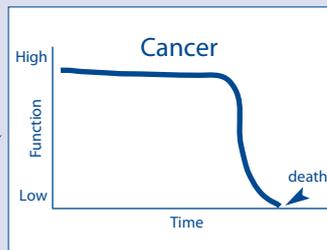
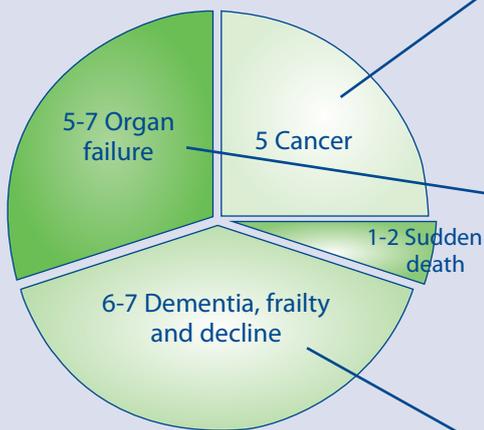
Cultural and ethnic diversity is a key issue in planning service provision. Different cultural attitudes to disease, care, dying and death will give rise to different service needs and affect how services are designed and made accessible. For instance, many ethnic minority patients may wish to return to their country of origin to die, or to die in hospital rather than at home or in a hospice.

Policy responses

A momentum for change has been gathering. A range of policy initiatives in recent years have sought to improve end-of-life care, including:

Illness trajectories

GP's workload – causes of death
Context – 20 deaths/GP/Year



Three trajectories of illness after Lynn.J et al WHO Palliative care; The Solid Facts.

- the NHS Cancer Plan (2000), which promised “the care of the dying must improve to the level of the best”
- the Government’s decision to spend an extra £50 million a year on specialist palliative care services (2001)
- National Service Frameworks, especially those for older people (2001) and long-term conditions (2005), which aimed to put the individual at the heart of care and provide supportive and appropriate care from diagnosis to end-of-life
- the Department of Health strategy paper, *Building on the best* (2003), which emphasised patient choice – consultation showed that patients and carers wanted choice over care at the end-of-life
- NICE guidance on improving supportive and palliative care (2004)
- the Health Select Committee inquiry into palliative care (2004) identified inequities and called for greater integration between health and social care
- the new General Medical Services contract (2004) which offers incentives for GPs to specialise in end-of-life care
- the Coronary Heart Disease Collaborative’s report (2004) recommending ways to implement the NICE guidance
- the social care green paper *Independence, well-being and choice* (2005) which focuses on improved quality of life, personal dignity, choice and control as well as on

preventing problems and developing the workforce

- development of new models-of-care tools to ensure high-quality end-of-life care
- management of depression in primary and secondary care (NICE, 2004).

NHS end-of-life care programme

The NHS’s end-of-life care programme was set up in 2004 to help healthcare professionals in England improve end-of-life care for patients regardless of their disease and to widen the pool of staff trained in palliative care. By helping to build local capacity, capability and clinical leadership, the programme’s objectives are:

- greater choice for patients of place of care and place of death
- fewer emergency admissions of patients who wish to die at home
- fewer patients transferred from a care home to hospital in the last week of life
- improved skills among generalist staff in the provision of end-of-life care.

The Government is funding the programme with £12 million over three years. The programme is co-ordinated by a national director, and two national clinical leads, and all strategic health authorities have appointed an end-of-life care lead and steering groups to implement the programme in their area.

‘Only when everyone’s involvement is recognised can there be joined-up planning’

Envisaging the future

How can end-of-life and palliative care be improved? To meet patients’ expectations and provide optimum care, the NHS, working with the voluntary sector, needs to ensure future provision for end-of-life care includes:

End-of-life care strategic plans that incorporate all health, social and voluntary providers involved in the delivery of care for people in the last stages of life. Other specialist teams need to be included such as cardiologists and care of the elderly and ambulance staff. Only when everyone’s involvement and contribution are recognised can there be effective joined-up comprehensive planning and best supportive care for those in the final stage of life.

Advanced care plans that are discussed with the patient and based on a full assessment of their symptomatic, psychological and social needs. Discussion should cover issues such as having a proxy to speak on the patient’s behalf, resuscitation decisions and preferences for care. These advanced care plans indicating preferences for management differ but are in addition to advanced directives, which indicate preference for refusal of treatments or management. In the light of the new Mental Capacity Act these plans will become increasingly

'Depression may be a co-morbidity but the value of treatment must not be ignored'

important. The plans should enable the patient to choose where they live during their illness and where they die. Community-based services will need to respond to the choices patients make.

Planned pathways and frameworks of care that are reliable, anticipate need and offer clear options. To achieve this better communication is needed including co-ordination between services, sectors and professionals. Planned care pathways will reduce fear and anxiety for patients and carers, as well as limit sudden crises that result in hospital admission.

Use of generic quality of life indicators that are available to assist in the evaluation of quality of life and monitor effectiveness of treatment. Depression may be a co-morbidity in this group but the perception that it is understandable must not lead to ignoring the value of treatment. Considering depression in this group of patients who otherwise may not broach the subject, would be beneficial.

Future planning needs to cover the following areas:

Community care – a focus is needed on increasing capacity of home/community care so more care can be outside hospital; preventing unnecessary hospital admissions and thereby increasing

hospitals' capacity to deal with more appropriate acute treatments (and reducing the Standard Hospital Mortality Ratio as a consequence); and delivering reliable high quality home care at each stage including the final days.

Emergency Care – those involved in emergency care such as out-of-hours providers need to be incorporated into all planning.

Pain Control – work by the Picker Institute and the Patients' Survey strongly suggests pain control is a major issue in many services and an area where the UK seems to compare poorly with practice in other countries.

Support for carers – this kind of support includes information and advice on matters such as bereavement and finances. Social and voluntary care should provide respite and night-sitters. Carers should have access to training and 24-hour advice to enable them to cope better and respond appropriately during crises. They should be treated as members of the team.

Support for staff – the aim is to ensure generalist staff in hospitals, primary and community care – including care homes – can provide most end-of-life care and have access to specialist support when necessary.

Improved means of communication across boundaries – communication using IT transfer, patient-held records and so on needs to be improved to enable better transfer of factual information on advanced care plans and assessment tools.

Promoting best practice

The NHS has developed three tools that exemplify best practice in end-of-life care. These tools are complementary with many overlapping aspects.

Gold Standards Framework for community palliative care (GSF)

GSF was developed in primary care to provide a framework for GPs, district nurses and their colleagues to improve the organisation and quality of care in the community for patients in their last year of life. The framework was intended initially for cancer patients, but is now being used for any patients with a life-limiting illness, in any community setting including home, care home, community hospital and prison.

Some areas are using GSF in the community to collaborate across the hospital setting and develop complementary inpatient initiatives such as a supportive care pathway. In England GSF is currently used in all SHAs, two-thirds of PCTs and almost a third of practices. It is also widely used in Scotland and Northern Ireland and is being introduced in Wales.

Across the UK there are over 200 local GSF facilitators responsible for the programme. There are four levels of adoption each taking about 6 to 12 months to achieve each practice team. Many PCTs have 100 per cent coverage and can integrate GSF into clinical governance agendas, locally enhanced services and PCT-wide protocols and referral criteria. Practices tend to adapt GSF

to their own needs and use it as a springboard to further developments.

GSF embodies three processes:

- identifying patients in the palliative phase of their disease and near the end-of-life
- assessing patient care needs and preferences
- developing a proactive care plan.

The aim is to help control patients' symptoms, enable them to die well where they choose, provide security and support to carers and promote confidence, team working, satisfaction and communication among staff. A separate GSF programme currently includes over 100 care homes.

GSF is being evaluated by Birmingham and Warwick universities. Findings show increased numbers of patients dying where they choose, more advanced care planning and improved co-ordination and communication.

Liverpool Care Pathway (LCP)

The LCP document helps generalist staff care for dying patients in the last 48 hours of their lives. The document is multi-professional and provides an evidence-based framework for end-of-life care. For example, the pathway includes the assessment of the dying patient's medication so that non-essential medication and other inappropriate interventions can be discontinued.

LCP was developed at the Royal Liverpool University Hospitals and the Marie Curie Centre Liverpool for use in hospitals, but can also be used in primary care and care homes. The aim was to translate hospice care into the acute sector and develop outcome measures for end-of-life care. LCP improves multi-professional communication and documentation, integrating national guidelines into clinical practice. It involves a 10-step programme that can be implemented in six to 12 months. It is now being used in 135 acute trusts – though not in every ward – as well as care homes and hospices across the UK.

Preferred Place of Care (PPC)

Lancashire and South Cumbria Cancer Services Network developed the preferred place of care concept. The PPC is a patient-held record that helps patients and carers discuss and agree the care they would like and where the patient would like to be cared for at the end of their life. It records the patient's thoughts about their illness and the choices available to them. In particular, it allows them to express what they do not want to happen. Recording wishes in this way can form the basis of care planning for multi-professional teams. Out of 99 patients who completed PPCs, 90 died in the place of their choice, including 78 at home. PPC is currently used in 50 clinical settings in both primary and secondary care.

Policy implications

- All people at the end-of-life need to have choice over the place in

'Evaluation of the Gold Standards Framework found more patients were dying where they chose'

which they die and be able to access reliable, consistent, high quality community care, emergency care and inpatient care. This may require the development and extension of the existing hospice system so that high quality specialist end-of-life care is available for more people with all diagnoses not just cancer. It will also need better collaboration between disease specialists, palliative care generalists and primary care.

- Commissioners will need to keep palliative care services under review to make them fit for purpose as the population's demography changes. This might mean ensuring that more 'terminally ill' patients can be admitted to hospices in the final stages than are currently able to do so.
- The existing programmes extending palliative care skills to a wider range of health professionals need to be continued and expanded. The work of palliative care specialists to include non-cancer patients care needs to be evolved. Support is also needed so that generalist staff in all settings can provide most end-of-life care with access to specialist support when necessary.
- Advanced care plans need to be adopted as standard, discussed with the patient and based on a full assessment of their needs and

'Support for carers is important and their needs should be separately assessed'

preferences and communicated to all others involved in their care. To support these and other improvements, we need planned pathways, frameworks and protocols of care that are reliable, anticipate need and offer clear options.

- Support for carers is an important part of any strategy. Their needs have to be separately assessed, which includes the need for information and advice on matters such as bereavement and finances.
- Payment by results and other systems may need to be adapted to support changes in the configuration of services and the location of care.

Further information

NHS End-of-Life Programme: www.endoflifecare.nhs.uk

Gold Standards Framework: www.goldstandardsframework.nhs.uk

Liverpool Care Pathway: www.lcp-mariecurie.org.uk

Preferred Place of Care: www.cancerlancashire.org.uk

National Council for Palliative Care: www.ncpc.org.uk

Range of policy initiatives:

www.dh.gov.uk

www.nice.org.uk

www.parliament.uk

Commissioning a patient led NHS:

www.dh.gov.uk/assetRoot/04/11/67/17/04116717.pdf

Your health, your care, your say public consultation:

www.dh.gov.uk/NewsHome/YourHealthYourCareYourSay/fs/en

Further reading/related links

National Council for Palliative Care: www.ncpc.org.uk

NHS End-of-life Care initiative:

www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/EndOfLifeCare/EndOfLifeCareArticle/fs/en?CONTENT_ID=4106262&chk=lpWBHL

Speech by Liam Byrne to the National Care Association (1 November 2005)

www.dh.gov.uk/NewsHome/Speeches/SpeechesList/SpeechesArticle/fs/en?CONTENT_ID=4122525&chk=T8KSkI

This series of briefings forms part of the NHS Confederation's work on community health and social care. For more information, visit www.nhsconfed.org where copies of briefings are downloadable or contact Elaine Cohen at elaine.cohen@nhsconfed.org

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