

Palliative and End of Life Care



Palliative and end of life care refer to the care of people who have an incurable and progressive illness. This POSTnote provides an overview of palliative care and its key components, approaches to managing and standardising care and key challenges to providing high quality care.

Background

There were over 500,000 deaths in England and Wales in 2013, of whom approximately 80% were people aged over 65 years.¹ Heart disease, lung cancer, and dementia were among the leading causes of death.² Annual numbers of deaths are predicted to increase by 17% from 2012 to 2030.³ Combined with this, more people are living with multiple long-term conditions and the period of ill-health at the end of life is growing. These factors are putting pressure on services and raise questions about how best to provide cost-effective care to enable people to live and die in the place and the manner of their choosing.³

Palliative and end of life care aim to provide holistic support to people who have any incurable or life-limiting progressive illness, to enable them to live as well as possible until they die. They include management of symptoms, and provision of psychological, social and spiritual support to the person and their friends and family. A 2013 national survey of bereaved people found that 76% of respondents rated the care that their friend or relative had received in the last three months of life as 'good' or better.⁴ However, the Care Quality Commission (CQC) states that there is evidence of 'huge variation' in the quality of palliative care that people receive.⁵ One framework for good practice, the Liverpool Care Pathway (LCP), was recently withdrawn following concerns about the quality of care provided to some people. In June 2014, the Department of Health (DH) announced a new approach to caring for people in the last days of life, based on the needs and wishes of the dying person and those close to them.⁶

Overview

- Palliative care includes management of physical symptoms such as pain, as well as social, psychological and spiritual support to the patient and their family and friends.
- About 75% of bereaved people rated the care that their friend or relative had received as 'good' or better; however, access to and quality of care varies.
- Effective communication between the dying person, their friends and family and professionals is key to high quality care.
- Early identification of people approaching the end of life, and supporting them to live and die in the manner and place of their choosing, could improve care quality.

This POSTnote focuses on palliative and end of life care for adults. It does not cover assisted dying, or issues specific to palliative care for children. The terms palliative and end of life care are used to mean different things. In this briefing, the term palliative care is used to refer to all care received by people with these conditions, including end of life care.

Palliative Care

The General Medical Council suggests that palliative care needs should be considered for people who are likely to die within the next 12 months.⁸ However, palliative care is provided on a needs-basis and can begin at any stage of an illness. In many cases it will be used alongside therapies to treat the illness. It may be provided to people with:

- late stage progressive and incurable diseases, including some cancers and dementias
- chronic conditions, if they are at risk of dying from a sudden crisis in their condition, for example heart failure
- general frailty and co-existing conditions
- life-threatening acute conditions caused by sudden events, such as an accident or a stroke.⁷

The Government has committed to ensuring that people can receive care in the setting of their choice.⁸ This includes specialist in-patient wards, hospices, acute hospitals or at home. However, although the majority of people in England report a preference to die at home (about 60%) or in a hospice (30%), currently the majority of deaths occur in hospital.⁹ Services provided within hospitals, by GPs and some community nursing is funded through the NHS, while hospice care and associated community services are largely funded by the charitable and voluntary sector.

Generalist and Specialist Care

Palliative care includes:

- **Generalist care.** Most palliative care is provided by people for whom care of the dying is not the major focus of their work. For example, care by GPs, district nurses, hospital consultants, nursing and care home staff. It focuses on day-to-day care and support.
- **Specialist Palliative Care (SPC).** This refers to services provided by multidisciplinary teams. Teams include specialists in palliative care, for example, consultants in palliative medicine and clinical nurse specialists in palliative care, as well as a range of other expertise. SPC teams provide in-patient facilities for people with complex needs, co-ordinate services, support generalists providing care, and provide bereavement support. About 160,000 people in England receive SPC annually.¹⁰

Key Components of UK Palliative Care

Management of Physical Symptoms

People's symptoms will vary depending on their condition(s), and any treatment they may be receiving, such as chemotherapy. Physical symptoms for a wide range of conditions can include nausea and vomiting, constipation, loss of appetite, and pain. Various drugs may be prescribed to manage symptoms and make the person as comfortable as possible, from laxatives for constipation to opioids to control pain.¹¹ Management requires regular monitoring of medications and their route of administration.^{12,13} This is because certain medicines can interact and cause side-effects or affect the activity of others.¹⁴ Further, some medicines may become redundant or burdensome at the end of life.¹⁵ For example, medication to decrease the patient's risk of future disease, such as statins for high cholesterol. However, for people whose prognosis is uncertain, the risks and benefits of continuing with such medicines can be less clear.

Social, Psychological and Spiritual Support

Social Care Services

The National Institute for Health and Care Excellence (NICE) has set a quality standard for palliative care for adults that includes social and practical support.¹⁶ Social care provision can include services such as home help and meals-on-wheels, as well as equipment to enable people to remain in their own home. A 2012 study by the Nuffield Trust found that about 30% of people used Local Authority-funded social care in the last year of life.¹⁷ A study for Macmillan Cancer Support in April 2014 reported that there were specific barriers to people accessing social care at the end of life due to inefficient bureaucracy, a lack of clarity between the health and social care systems, and the social care means-test.¹⁸ A review by the Social Care Institute for Excellence in 2013 suggested that poor access or late referral to social care services, or a lack of support for carers, can increase the likelihood of people at the end of their life being admitted to hospital, often as an emergency.¹⁹ Further, lack of support for carers may lead to them becoming socially isolated, which can continue after bereavement.²⁰

Psychological Services

Many people who are dying, as well as their family and friends, may experience depression or emotional difficulties.^{21,22} NICE recommends that lower levels of need should be met by health professionals providing the person's day-to-day care, and higher levels of need met through intensive services provided by specialists.²³ However, research indicates that there are gaps in access to specialist support for patients and staff.^{24,25} Further, there is debate as to the best way to detect and treat depression in palliative care settings, and a lack of evidence as to the relative efficacy of different types of therapy.²⁶ Projects are underway in the UK to facilitate better detection of depression among those approaching the end of life and the British Psychological Society is reviewing the role of psychology in palliative care.²⁷

Spiritual Support

Spiritual support encompasses both religious and non-religious support. Current provision ranges from formalised religious rituals to an informal sharing of ideas. A systematic review for DH in 2011 reported that there was a lack of literature about specific interventions designed to meet spiritual need.²⁸ Identifying and responding to spiritual need is seen as within the remit of all health and social care workers. NICE recommends that care teams should have access to suitably qualified spiritual care givers who act as a resource for patients, carers and staff.²⁹ However, research suggests that staff may not detect the need for spiritual support at key points of the person's care, or may be uncomfortable broaching spiritual issues with patients and that access to specialists varies.³⁰ The European Association for Palliative Care is reviewing the role and implementation of spiritual support in palliative care.³¹

Advance Care Planning and the MCA 2005

Advance care planning is a structured discussion between health and social care professionals with the dying person and their family and carers about their wishes, needs and preferences for future treatment and support. It is underpinned by the Mental Capacity Act (MCA) 2005 and its Code of Practice, which applies to all elements of care provided to adults (see POSTnote 381). There are a number of ways that a person over 18 who has mental capacity can make their preferences about future treatment and support known, in case they ever lose capacity to make such decisions themselves. These include advance statements about their general wishes and views, and legally binding advance decisions to refuse treatment or allow a family member or friend to make personal welfare decisions on their behalf (see Box 1).³²⁻³⁴ Advance care planning has been shown to improve palliative care by helping the person to live and die in the place and the manner of their choosing.³⁵ However, research indicates that the discussion of wishes and preferences about dying does not often occur in advance, or is discussed late. This may limit the ability of people to explore care options with their clinicians and family and to record their preferences.³⁶⁻³⁸

Box 1. Advance Care Planning

A person aged over 18, who has mental capacity, can make a(n):

- **Advance statement.** This is a statement, usually written, of the person's general wishes and views. A copy can be held in the person's medical notes. It is not legally binding, but must be taken into account by anyone making decisions about the person's care.
- **Advance Decision to Refuse Treatment.** This sets out the specific circumstances in which the person would not want certain treatments or would want a particular treatment to be stopped. It must be in writing if it is a decision to refuse life-sustaining treatment. It is legally binding if it is valid, acceptable and known.
- **Lasting Power of Attorney for personal welfare.** This allows a family member or friend to make personal welfare decisions on the person's behalf and in their best interests, if they ever lose capacity to make those decisions themselves. This can include decisions about life-sustaining treatments.

Managing and Standardising Care

Palliative care pathways or frameworks are used as tools to manage quality, co-ordinate services, and allow standard setting and monitoring of care processes. For example, the Gold Standards Framework was devised to improve the quality of care provided by generalists. It aims to support frontline staff to identify patients in the last year(s) of life, assess their needs, and co-ordinate care. It provides prompts to initiate advance care planning and allows GPs to include patients on a palliative care register.³⁹

Until recently, the Liverpool Care Pathway (LCP) for care in the final days of life was a widely used framework across the UK (excluding Wales). However, following media criticism, an independent panel was established to review the use of the LCP. Chaired by Baroness Neuberger, the panel reported that whilst the LCP could provide a model of good practice, it was frequently being used as a 'tick box' framework leading to problems with the delivery of care. It concluded that there was a lack of understanding among clinicians of existing guidance, and an unwillingness to discuss the prospect of death with the dying person and their family and carers. The panel recommended that the LCP be replaced over six to 12 months by an individual end of life care plan, supported by condition-specific good practice guidance.⁴⁰ Some experts have expressed concern that losing a standardised quality assurance tool will leave generalist staff without sufficient guidance and make it more difficult to monitor care.⁴¹⁻⁴³

New Approaches to Palliative Care

Following the publication of the Neuberger report, the Leadership Alliance for the Care Of Dying People (LACDP) was formed to develop a response to the recommendations (see Box 2 for the response of the devolved nations). The LACDP consulted patients, carers, the public and professionals on a set of draft outcomes and guiding principles for high quality care in the last days of life. In June 2014, the LACDP published a new approach that focuses on the individual needs and wishes of the dying person and those closest to them, to both plan and deliver care.⁴⁴ It centres around five priorities for care, which form a focus for care, as well as education and training, audit and research. It is now up to professionals, service providers and commissioners to implement these.

Box 2. Review of the LCP in the Devolved Nations

In Scotland, the Living and Dying Well National Advisory Group commissioned a review of the findings of the Neuberger report for Scotland. It recommended that the Liverpool Care Pathway (LCP) should be phased out in Scotland by December 2014. The Scottish Government has accepted the recommendation and issued interim guidance on caring for people in the last hours and days of life.⁴⁵ Northern Ireland has announced that the LCP will be phased out by October 2014. The Government in Northern Ireland has outlined five principles to underpin quality care in the final days and hours of life, based on its 2010 palliative and end of life care strategy.⁴⁶

The LCP was not used in Wales. Care is guided by Integrated Care Priorities (ICP) for the Last Days of Life. This approach was developed by the All Wales Palliative Care Implementation Group and seeks to ensure that the needs and wishes of the patient and their family are the central focus of decision-making, in partnership with professionals caring for the patient. The ICP audit report is published annually.⁴⁷

Challenges to Providing Quality Care

Challenges for clinicians and commissioners to providing high quality palliative care to all those who need it include difficulties in talking openly about dying, access to and quality of care, identifying people approaching the end of life, training, funding, co-ordinating services and monitoring.

Attitudes to Talking about Dying

Research suggests that in the UK a majority of the public want to be told if they are terminally ill, although exactly what information is desired will differ.⁴⁸ Effective communication by clinicians is generally seen as key to prevent misunderstanding and unnecessary distress and to ensure high quality palliative care.^{49,50} However, poor communication by clinicians is frequently a source of patient and carer dissatisfaction, particularly in acute hospital wards.⁵¹ The person dying, as well as their friends and family, may also find it difficult to talk about dying. This may be because many cultures avoid serious individual or collective consideration of death.^{52,53} In 2009, the National Council for Palliative Care set up the Dying Matters Coalition to promote public awareness of dying, death and bereavement. A survey it commissioned in 2012 found that the majority of people said that they felt comfortable talking about dying (70%). However, only a third reported having actually discussed their wishes about their own death with anyone. For those over 75 years, the main reason people had not discussed their wishes was a perception that other people did not want them to talk about their death.⁵⁴ The Neuberger report stressed that unless everyone is able to talk openly about death, the quality of care and range of services will remain inconsistent.⁴²

Access to and Quality of Care

Research suggests that there are disparities in access to and quality of palliative care depending on:

- **Condition.** For example, people with cancer are more likely to be referred to SPC and rate care more highly than people with cardiovascular disease.^{55,56} People with dementia are least likely to be referred to SPC.^{57,58}
- **Setting of care.** In a national survey, overall quality of care was rated highest in hospices and lowest in hospitals. It also found that relief of pain is managed least well at home.⁵

■ **Geographic area.** Compared with bereaved people in the most deprived areas, those in the least deprived areas are more likely to report that they felt they had a choice about where their friend or relative died and whether they were treated with dignity and respect.⁵

■ **Demographic characteristics.** These include ethnicity, disability, culture, sexuality and socio-economic status.⁵⁹⁻

⁶¹ For example, people from minority ethnic or lower socio-economic groups are less likely to die at home.⁶²

The CQC is reviewing variations in the provision of care, to identify actions needed to address any inequalities. It will report in spring 2015.⁶³

Identifying People Approaching the End of Life

Early identification of people approaching the end of life and their palliative care needs can enable advance care planning and the provision of effective support.⁶⁴⁻⁶⁶ This includes knowing when it is appropriate to refer someone to SPC, which can improve symptoms and patient satisfaction, and improve outcomes for the person's family and caregivers.⁶⁷⁻⁶⁹ However, identifying people who have a progressive or life-threatening condition and judging how long they have left to live can be difficult, especially in unpredictable illnesses such as organ failure, physical and cognitive frailty and for those who have several concurrent illnesses.^{70,71} Difficulties in determining prognosis may explain some of the disparity in access to SPC related to condition. Although some guidance exists⁷² the Neuberger report recommended the development and use of advanced prognostic tools, as well as more support for generalists in making a diagnosis and prognosis. Dying Matters is running a campaign to encourage GPs to identify their estimated 1% of patients in the last year of life.

Training

Palliative care is an established medical speciality. However, palliative care is often delivered by generalist staff, who are unlikely to have undertaken specialist palliative training. A report by the National Audit Office in 2008 found that providing training to generalists could increase their confidence in identifying people approaching the end of life, and improve their communication skills.⁷³ The DH 2008 End of Life Care Strategy stated that all health and social care staff should be trained in communication for palliative care.⁷⁴ However, training in palliative care may be lacking, for example where there is a lack of funding to release staff for training.^{75,76} A recent audit by the Royal College of Physicians found that although 82% of trusts provided training in the previous year, it was only mandatory in 19% of trusts. It recommended that training should be mandatory for all staff caring for dying patients, including communication skills training.⁷⁷ The Gold Standards Framework centre provides training to generalist providers.

Funding

Funding for palliative care has received increased attention in the past few years, with a number of reports urging change, including the 2010 Dilnot Commission.⁷⁸ In 2011,

the Palliative Care Funding Review in England set out proposals for developing a per-person funding mechanism, based on patient need rather than on age or disease.⁷⁹ It estimated that improved recognition of palliative care needs and services outside hospital could improve care and reduce hospital costs by £180 million per year. DH states that NHS funding for palliative care services is often poorly distributed and varies greatly around the country and is running pilots to collect data and refine proposals for a new funding system for palliative care.^{80,81} Other research has found that appropriate use of SPC, including supporting people to die at home, could save NHS money by reducing emergency hospital admissions.⁸²⁻⁸⁶ However, NHS savings may result in costs to other services. A report from the Commission on the Future of Health and Social Care in England in 2014 argued that a single, ring-fenced budget for health and social care would be more efficient and achieve better outcomes for people, but would cost more overall.⁸⁷

Co-ordination

Lack of co-ordination of care between different settings (such as GP surgeries, hospitals, and care homes) can result in patient and carer dissatisfaction with the quality of palliative care provided.⁸⁸ One particular issue is the co-ordination of care between the person's usual care team, and out-of-hours services, for example, during an emergency admission to A&E at night or over the weekend. Clinicians working in out-of-hours care are often unaware of the person's wishes and needs, especially if no advance care plan has been made, or if it has not been shared. National statistics indicate that for people dying at home, the quality of co-ordination of care was rated lower in 2013 compared to 2012.⁵ The DH is piloting Electronic Palliative Care Co-ordination Systems to increase co-ordination.⁸⁹ Early evaluation indicates that it might help people to die in their place of choice and may also save money.^{90,91}

Monitoring Standards of Care and Outcomes

CQC is introducing a new inspection approach in October 2014, and will include palliative care as one of eight core services when inspecting acute hospitals. Palliative care will also be included in inspections of community services and care homes, and a new approach to inspecting hospices will be introduced.⁹² Measuring patient and carer outcomes and experiences is also important to understand the impact of care. A number of tools have recently been developed to measure patient outcomes, such as the Palliative Care Outcome Scale and the Outcome Assessment and Complexity Collaborative suite of measures.^{93,94} In Wales, the iWantGreatCare programme is used to routinely capture patients' experience of SPC.⁹⁵ In England, the annual Voices survey provides data on the experiences of bereaved carers and relatives across all settings.⁵ NHS England and Public Health England are working together to establish a mechanism for routine collection of outcome data.

Endnotes

For references, please see overleaf.

Endnotes

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