

### Contents

<u>Definition</u>	2
<u>Incidence and place of death</u>	3
<u>Signs and symptoms</u>	3
<u>Support</u>	3
<u>Further resources</u>	7
<u>External websites</u>	7
<u>References</u>	8

### Definition

The World Health Organization (WHO) defines palliative care as *'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'*.<sup>1</sup>

End of life care is part of palliative care and describes care offered to people who are nearing the end of their life, regardless of diagnosis.<sup>2</sup> It is often defined as care during the last year of life.<sup>3,4</sup>

The National Council for Palliative Care (NCPC) offers the following as a definition for end of life care: *'end of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support'*.<sup>2</sup>

The following Social Care Institute for Excellence (SCIE) [video](#) explores the importance of clear communication when speaking to people about death and dying.



SCIE. *End of life and palliative care: thinking about the words we use*. 12 December 2014.

More information about these two different terms can be found on the [Marie Curie website](#).

e-Learning for Healthcare offers the [End of Life Care for All \(e-ELCA\)](#) e-learning programme, which can be accessed in full via CPPE's website under [e-Learning for Healthcare learning modules](#). This programme contains over 170 learning modules. The 'Introduction to e-learning for End of Life Care' module covers why e-ELCA was developed and the 'Relationship between palliative care and end of life care' module offers more information about what is meant by end of life care and its relationship to palliative care. There is also a 'Communication skills' module which explores the challenges associated with end of life care in practice.

[Return to contents](#)

### Incidence and place of death

Around 500,000 people die in England each year. Up to 74 percent of people say they would prefer to die at home, but currently 58 percent of people die in hospital, with considerable geographical variation.<sup>5</sup> The annual number of deaths in England is expected to rise by 17 percent from 2012 to 2030. The percentage of deaths occurring in the group of people aged 85 years or more is expected to rise from 32 percent in 2003 to 44 percent in 2030.<sup>6</sup>

The [Variations in place of death in England](#) report and follow-up [Deprivation and death: Variation in place and cause of death](#) report summarise how many people die per year nationally and regionally, and the pattern of death by age, gender, socioeconomic deprivation, cause and place of death.

[Return to contents](#)

### Signs and symptoms

The way that people experience end of life is personal and often unpredictable, although in the last few weeks and days, there are several changes that can take place.

- Physical changes
  - changes to appearance
  - weakness and fatigue
  - inability to control temperature
  - changes in appetite
  - bowel and bladder problems
  - breathlessness
  - noisy breathing
  - [pain](#)
  - nausea and vomiting.<sup>7</sup>
- Emotional changes
  - appearing calm or detached
  - confusion
  - restlessness or agitation
  - delirium
  - spiritual and emotional pain.<sup>7,8</sup>

More information about these changes can be found on the [Marie Curie website](#). Marie's Curie's [Final moments of life](#) webpage talks about what to expect during a person's last hours and moments.

[Return to contents](#)

### Support

The National Institute of Health and Care Excellence (NICE) [End of life care](#) guidance includes relevant NICE guidelines, NICE Pathways and quality standards related to end of life care.

Specifically, NICE has two quality standards (QS) and two guidelines (NG) which set out markers of high-quality care in this area:

- [End of life care for adults \[QS13\]](#)
- [Care of dying adults in the last days of life \[QS144\]](#)
- [Care of dying adults in the last days of life \[NG31\]](#)
- [End of life care for adults: service delivery \[NG142\]](#)

### Patient choices

Some resources which consider a person's choices around end of life include:

- [End of Life Care and Human Rights: A Practitioner's Guide](#)
- [Sue Ryder training: Human Rights and End of Life Care workshops](#)
- [The ReSPECT process](#)
- NHS England's [Resources for end of life care](#)

The following SCIE [video](#) explores the importance of person-centred and holistic care at the end of life.



SCIE, *What matters to the person who's dying*. 12 December 2014.

### Advance care planning

Advance care planning (ACP) is a key part of end of life care. A panel of multidisciplinary, international ACP experts achieved an agreed definition of ACP: '*Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness*'.<sup>9</sup>

The National Gold Standards Framework (GSF) Centre offer information on ACP on their [website](#), where you can find the following [video](#), which outlines five simple steps to ACP.



GSF Centre. *GSF Advanced care planning*. 2017.

The [ReSPECT process](#) can be complementary to a wider process of advance or anticipatory care planning.

More information can be found in NICE's [A quick guide for registered managers of care homes and home care services](#) and on Marie Curie's [website](#).

The [End of Life Care for All \(e-ELCA\)](#) e-Learning for Healthcare, which can be accessed in full via CPPE's website under [e-Learning for Healthcare learning modules](#), offers an 'Advance Care Planning' module that will help you understand the principles and purpose of ACP, its benefits and limitations, and how to carry out ACP in practice.

### Management of symptoms

NICE guideline [NG31]: [Care of dying adults in the last days of life](#) outlines recommendations on how to communicate with those who are at the end of life (Section 1.2 *Communication*), how to ensure that a person is supported to participate in shared decision making where possible (Section 1.3 *Shared decision-making*), maintaining hydration (Section 1.4 *Maintaining hydration*), pharmacological interventions, including treatment options (Section 1.5 *Pharmacological interventions*), and anticipatory prescribing (Section 1.6 *Anticipatory prescribing*).

Pharmacological interventions are focused on managing:

- pain
- breathlessness
- nausea and vomiting
- anxiety, delirium and agitation
- respiratory secretions.<sup>10</sup>

The British National Formulary (BNF) offers a [Prescribing in palliative care](#) treatment summary, which also outlines treatment options and links to individual monographs.

The [Scottish Palliative Care Guidelines](#) offer recommendations on pain management, symptom control, palliative emergencies, end of life care (including syringe pumps and medicine compatibility data) and general medicine information.

The following resource requires a subscription, which your organisation may hold:

- The [Palliative Care Formulary](#) (PCF) via MedicinesComplete. The PCF gives details on the use of medicines outside of their product license and information on symptom management.

There are several NICE clinical knowledge summaries relating to management in palliative care that discuss both pharmacological and non-pharmacological treatment options for those who are in palliative care, as well as for those who are approaching end of life:

- [Palliative care – general issues](#)
- [Palliative care – oral](#)
- [Palliative care – cough](#)
- [Palliative care – dyspnoea](#)
- [Palliative care – constipation](#)

- [Palliative care – nausea and vomiting](#)
- [Palliative cancer care – pain](#)
- [Palliative care – secretions](#)
- [Palliative care – malignant skin ulcer](#)

The [End of Life Care for All \(e-ELCA\)](#) e-Learning for Healthcare, which can be accessed in full via CPPE's website under [e-Learning for Healthcare learning modules](#), offers a *Symptom management* module which will help you to understand the principles of symptom management and management of some commonly occurring symptoms in end of life care. This includes pain, breathlessness, nausea and vomiting, constipation, and assessment and management of anxiety and other psychological conditions.

### Multidisciplinary teamwork

NHS England's [Specialist Level Palliative Care: Information for commissioners](#) has been prepared to describe what should be provided in terms of specialist-level palliative care for people with progressive, life-limiting illness who have complex needs, and/or those whose usual care teams require the expert advice, guidance and support of those with specialist knowledge and skills in palliative care.<sup>11</sup>

Marie Curie's [Professionals who provide care](#) outlines the healthcare professionals involved in palliative and end of life care, and their roles.

### End of life care in care homes

England is now classified as an aged society and, by 2035, will be classified as a super-aged society. Care homes play a critical role in the delivery of care for those who are at the end of their life.

The SCIE's [Person-centred care for older people in care homes](#) resources require free registration to the SCIE website. The SCIE also have a [video](#) that focuses on how care homes can support their staff after the death of a resident.



SCIE, *End of life care: Supporting staff in care homes*. 12 February 2014.

My Home Life has also produced [Supporting a good end of life](#), a step-by-step guide to good practice in end of life care.

[Return to contents](#)

### Further resources

#### Charities and patient support

- Age UK: [End of life planning](#), with practical information and emotional support.
- Macmillan Cancer Support: [At the end of life](#).
- The Alzheimer's Society: [End of life care](#) factsheet.
- Dying Matters's [Information](#) page is primarily for people approaching the end of their life and their carers, relatives and friends.
- NHS Choices: [End of life care](#).

#### Publications and policy

The [National End of Life Care Intelligence Network \(NEoLCIN\)](#) is part of Public Health England, an executive agency of the Department of Health. NEoLCIN offer a range of resources, including:

- [The role of care homes in end of life care](#)
- Electronic Palliative Care Co-ordination Systems (EPaCCS) in England: [Survey of clinical commissioning groups \(2013\)](#)

Ambitions Partnership hosts [Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026](#) and a [knowledge hub](#) where you can find resources, such as assessment tools, useful information, best practice examples and case studies.

The Department of Health and Social Care's [End of Life Care Strategy: promoting high quality care for adults at the end of their life](#) publication sets out a vision for giving people approaching the end of life more choice about where they would like to live and die.

The Institute for Public Policy Research has released [End of life care in England: A briefing paper](#), which looks at the current policy and data around end of life care in England.

The Department of Health and Social Care released [One chance to get it right](#), which is an independent report responding to the recommendations in the Liverpool Care Pathway review.

#### International organisations

The World Health Organization has information on [Palliative care](#).

The [European Association for Palliative Care](#) is a membership organisation dedicated to the promotion and development of palliative care throughout Europe.

[Return to contents](#)

#### External websites

CPPE is not responsible for the content of any non-CPPE websites mentioned on this page or for the accuracy of any information to be found there.

All web links were accessed in September 2023.

[Return to contents](#)

### References

1. World Health Organization. [Palliative care](#). [No date].
2. Addicott R. [End-of-life care](#). *The King's Fund*. 2010.
3. National Institute for Health and Care Excellence. Quality standard [QS144]: [Care of dying adults in the last days of life](#). March 2017.
4. Marie Curie. [What is palliative care?](#) August 2022.
5. National Institute for Health and Care Excellence. Quality standard [QS13]: [End of life care for adults](#). November 2011. Updated September 2021.
6. NHS England. [Actions for end of life care: 2014-16](#). 2014.
7. Marie Curie. [What to expect in the last weeks and days](#). November 2022.
8. Marie Curie. [Providing spiritual care](#). March 2022.
9. Sudore R L, Lum H D, You J J, et al. [Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel](#). *Journal of Pain and Symptom Management*. 2017; 53(5): 821-832.
10. National Institute for Health and Care Excellence. NICE guideline [NG31]: [Care of dying adults in the last days of life](#). December 2015.
11. NHS England. [NHS England Specialist Level Palliative Care: Information for commissioners](#). April 2016.

[Return to contents](#)

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