

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Guideline scope

### End of life care for adults in the last year of life: service delivery

#### *Topic*

NHS England has asked NICE to develop a service delivery guideline on the delivery of services for the dying adult in the last year of life.

This guideline will also be used to update the NICE quality standard for end of life care.

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the [context](#) section.

#### *Who the guideline is for*

- Generalist healthcare professionals in primary and secondary care.
- Specialist healthcare professionals in primary and secondary care.
- Commissioners of end of life care services.
- Providers of end of life care services.
- Other practitioners delivering end of life care services.
- People using end of life services, their families and carers, and the public.

It may also be relevant for:

- Organisations in the charitable sector delivering end of life care services.
- Providers of social care as part of end of life care services.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#).

## ***Equality considerations***

NICE has carried out an [equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to access to services for people with dementia, cognitive impairment or learning disabilities, and people who are homeless. It will take into account the specific needs of young carers and frail, elderly carers looking after people at the end of life.

## **1 What the guideline is about**

### ***1.1 Who is the focus?***

#### **Groups that will be covered**

- Adults (aged 18 or over) with progressive life-limiting conditions thought to be entering the last year of life.
- Health and social care professionals delivering end of life care services to NHS patients.
- Carers and/or those important to people accessing end of life care services.

#### **Groups that will not be covered**

- People not expected to die within the next 12 months.

### ***1.2 Settings***

#### **Settings that will be covered**

- All settings where care commissioned by the NHS for adults is provided.

#### **Settings that will not be covered**

- Settings where end of life care services are provided without any element of NHS funding.

### **1.3      *Activities, services or aspects of care***

We will look at evidence on the areas listed below when developing the guideline, but it may not be possible to make recommendations on all the areas.

#### **Key areas that will be covered**

- 1      Service organisation that supports the identification of people thought to be entering the last year of life.
- 2      Planning, coordinating and integrating the delivery of services, including sharing information between multidisciplinary teams.
- 3      Service delivery models for end of life care, including both acute, community and third-sector settings, covering:
  - types of services (supportive and palliative care) provided by generalists and specialists during the course of the last year of life
  - who delivers the services and how
  - multidisciplinary team composition
  - timing and review of service provision
  - location of services, for example, place of care
  - out-of-hours, weekend and 24/7 availability of services.
- 4      Service models that provide support for carers or those important to people accessing end of life services.
- 5      Adaptations to adult palliative and end of life services for young adults thought to be entering the last year of life.

#### **Areas that will not be covered**

- 1      Clinical management at the end of life.

### **1.4      *Economic aspects***

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic

analyses, using an NHS and personal social services (PSS) perspective, as appropriate.

## **1.5 Key issues and questions**

While writing this scope, we have identified the following key issues, and key questions related to them:

- 1 What are the best service models to support the identification of people who may be entering the last year of life?
- 2 What are the best service models to support advance care planning in the last year of life?
- 3 What are the best models for planning and delivering services for people who are in the last year of life?
  - 3.1 Who should be involved in providing end of life care services and how should these services be configured (for example, the organisation and composition of the multidisciplinary team)?
  - 3.2 What are the best models for coordinating, integrating and delivering services for people who are in the last year of life including the identification of barriers and facilitators to accessing end of life care services? Access for certain groups in particular will be considered, for example:
    - younger adults
    - people who are from disadvantaged socioeconomic groups
    - people who have protected characteristics under the Equalities Act
    - people with mental health problems and learning disabilities.
  - 3.3 When should services for people who are in the last year of life be provided and how should they be accessed?
  - 3.4 Where should end of life care services be delivered?
- 4 What are the best models of coordinating, integrating and delivering care for people entering the last year of life for whom disease-modifying treatments and life-prolonging therapies are still active options?
- 5 What types of end of life care services, including specialist services, should be available, and what is the minimum level needed to deliver unplanned 24/7 care?

- 6 What are the best ways to share information between multidisciplinary teams and services to ensure continuity of care for people who are in the last year of life?
- 7 What are the best service models to provide support for the carers or those important to the people accessing end of life services?

The key questions may be used to develop more detailed review questions, which guide the systematic review of the literature.

## **1.6 Main outcomes**

The main outcomes that will be considered when searching for and assessing the evidence are:

- 1 Patient-reported outcomes.
- 2 Views and satisfaction of those receiving end of life care; and of those important to them.
- 3 Health-related quality of life.
- 4 Preferred and actual place of care.
- 5 Preferred and actual place of death.
- 6 Staff satisfaction among providers of end of life care services.
- 7 Resource use and costs, including length of hospital stay, number of hospital visits and use of community-based services.

## **2 Links with other NICE guidance, NICE quality standards, and NICE Pathways**

### **2.1 NICE guidance**

#### **NICE guidance about the experience of people using NHS services**

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to end of life care:

- [Transition from children's to adults' services for young people using health or social care services](#) (2016) NICE guideline NG43

- [Motor neurone disease: assessment and management](#) (2016) NICE guideline NG42
- [Major trauma: assessment and initial management](#) (2016) NICE guideline NG39
- [Care of dying adults in the last days of life \(2015\)](#) NICE guideline NG31
- [Palliative care for adults: strong opioids for pain relief \(2012\) NICE guideline CG140](#)
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Service user experience in adult mental health](#) (2011) NICE guideline CG136
- [Medicines adherence](#) (2009) NICE guideline CG76

### **NICE guidance in development that is closely related to this guideline**

NICE is currently developing the following guidance that is closely related to this guideline:

- [Transition between inpatient mental health settings and community and care home settings for people with social care needs.](#) NICE guideline. Publication expected August 2016
- [Older people with social care needs and multiple long-term conditions.](#) NICE quality standard. Publication expected September 2016
- [Acute medical emergencies in adults and young people, service guidance.](#) NICE guideline. Publication expected November 2016
- [End of life care for infants, children and young people.](#) NICE guideline. Publication expected December 2016
- [Transition between children's and adults' services.](#) NICE quality standard. Publication expected December 2016

## **2.2 NICE quality standards**

**NICE quality standards that may need to be revised or updated when this guideline is published**

- [End of life care for adults.](#) (2011) NICE quality standard 13
- [Dementia: independence and wellbeing.](#) (2013) NICE quality standard 30

- [Breast cancer](#). (2011) NICE quality standard 12.
- [Chronic obstructive pulmonary disease](#). (2011) NICE quality standard 10
- [Dementia: support in health and social care](#). (2010) NICE quality standard 1

### **2.3 NICE Pathways**

When this guideline is published, the recommendations will be added to [NICE Pathways](#). NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive, topic-based flow chart.

The NICE Pathway will also include links to:

- [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31
- [End of life care for adults \(2011\)](#) NICE quality standard 13
- [Palliative care for adults: strong opioids for pain relief \(2012\) NICE guideline CG140](#)
- [Improving supportive and palliative care for adults with cancer](#) (2004) NICE guideline CSG4

## **3 Context**

End of life care is defined by NHS England as care that is provided in the 'last year of life'. After the Liverpool Care Pathway was withdrawn in 2014, a number of national reports and policy documents began to describe the changes needed for a new approach to end of life care services identifying that high-quality, timely, compassionate and individualised care should be accessible to all those who need it. There is now a clear need to progress this intention by describing the models of care and the service delivery arrangements that need to be put in place for people as they approach the end of their life.

Care in the last year of life may be delivered by disease-specific specialists and their associated teams; by generalists such as primary care teams or hospital-based generalists (for example, elderly care); or by palliative care specialists. Care that is given alongside, and to enhance, disease-modifying

and potentially life-prolonging therapies, often for years, is called 'supportive care'. Giving this type of care in the last year of life can also ensure that people live well until they die. Care that is aimed primarily at giving comfort and maintaining quality of life in the last months of life is commonly referred to as palliative care. Palliative care particularly aims to provide relief from pain and other distressing symptoms, integrate the psychological, social and spiritual aspects of the person's care, and continue to offer a support system to help people to live as actively as possible until their death. This care can be provided by generalists and by disease-specific specialists, within their remit for ensuring comfort and dignity during long-term management and for acute episodes. It can also be provided by specialists in palliative care, working alongside generalists and disease-specific specialists, for patients and families with complex needs or in specialised in-patient settings.

This guideline aims to describe end of life (in the last year of life) care services for all conditions and diseases. It will review service models provided in the acute setting by disease-specific specialists and their supportive services, or by primary care or specialists in palliative care.

### **3.1 Key facts and figures**

Approximately 470,000 people die in England every year and projections suggest this number will rise by 17% between 2012 and 2030. Approximately 171,000 people receive specialist palliative care. This is mostly delivered in the last 3–6 months of life, although, specialist palliative care sometimes starts earlier in the course of a progressive life-limiting disease; usually in larger acute hospitals delivered as a supportive care service alongside treatments aimed at modifying diseases and to help prolong life. In addition, some people who are still receiving disease-modifying treatment may attend hospices for specialist day care and rehabilitation services.

For people aged 50 and over, long-term diseases and conditions are the leading causes of death. Currently, 15 million people in England live with one or more long-term condition. The changing demographic structure of England and the growing number of older people with degenerative diseases and dementia will mean that the balance of disease-modifying options compared

with palliative treatments (aimed at relieving suffering and maintaining quality of life), will need to change.

### **3.2 Current practice**

Although the 2004 NICE guidance on [Improving supportive and palliative care for adults with cancer](#) was clearly focused on the support of people diagnosed with malignant diseases, it was used as a template and has increasingly been applied in practice to other selected diagnostic groups, especially those in which specialist palliative care services, such as hospices, already had significant engagement. These groups included advanced neurological conditions such as motor neurone disease and multiple sclerosis; end stage pulmonary, cardiac and renal disease. However, it is recognised that supportive and palliative care are much less established for some diagnostic groups, for example, dementia, Parkinson's disease and frail elderly people with palliative care needs.

The provision of supportive care for people with life-limiting illnesses who are still receiving active treatments aimed at modifying disease and prolonging life, and for those important to them, is still very variable on a geographical basis, being mainly confined to a few large teaching hospital trusts where hospital-based palliative care teams have had the opportunity to become more integrated with oncology and other specialist services. The equity of service delivery and organisation of supportive care for conditions other than cancer is worse. Transitions between disease-specific services and those aimed at providing supportive and palliative care are still often unclear.

Specialist palliative care in England largely emanated in the 1970s-1990s from independent hospices. As these have become more integrated with the NHS, and with the growth of hospital-based specialist care teams, specialist palliative care professionals now reach into the acute and community sectors. However, their coverage in independent care and nursing homes is less well developed. Hospices provide day care and out-patient facilities, as well as in-patient beds, and they also provide outreach into the community. With the multiplicity of agencies - NHS, charitable and social care providers – that can

provide palliative care for people in the last year of life, the role of primary care is not always clear.

The changing health and social care environment in England needs clear guidance on how to provide more equitable and consistent supportive and palliative care for all people who have chronic and progressive diseases, not just those with cancer, who are entering the last year of life. There is a need to define, where possible, who should provide these services wherever NHS funding is received, including the availability of services outside of normal working hours.

### **3.3 Policy, legislation, regulation and commissioning**

#### **Commissioning**

[Commissioning guidance for specialist palliative care](#) (National Council for Palliative Care 2012) sets out the factors that commissioners need to consider when commissioning specialist palliative care and includes useful sources of information and data, information on starting to measure value and impact, and some early evidence of the potential for cost reduction and cost avoidance. The NICE guideline, where appropriate, will use sources of data and models for commissioning services outlined in this document.

The National Palliative and End of Life Care Partnership has published a [National framework for local action 2015-2020](#) outlining their ambitions for palliative and end of life care

The National End of Life Care Programme has also teamed up with partners to bring together a suite of tools to support [end of life care commissioning](#) and planning.

## **4 Further information**

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in January 2018.

You can follow progress of the guideline.

<http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799>

Our website has information about how NICE guidelines are developed.