

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

SCOPE

1 Guideline title

Care of the dying adult

1.1 Short title

Care of the dying adult

2 The remit

NHS England has asked NICE: 'to develop a guideline on the care of the dying adult'.

3 Need for the guideline

- a) Death is a natural part of the life cycle. In some cases, cancer or other forms of progressive illness can make death imminent. Less frequently, sudden death occurs from rapid-onset illness or major trauma, such as road accidents, and the time to prepare for this event is limited.
- b) Caring for people who are in the final stages of dying, and providing support to their families or loved ones at this time, is of profound importance. Death may take place in a variety of settings, depending on choice and individual need. Recognising that someone is entering the last days and hours of life is vital to ensure that both dying people and their families or those important to them can prepare for death and make all relevant plans and preparations that they wish to. As death becomes imminent, the clinical care provided should maximise the dying person's comfort and aim to reduce pain, anxiety and other symptoms.
- c) The likely time of death is often difficult to anticipate or predict, especially in people with chronic non-cancer conditions. Progressive weakness, altered breathing, increased periods of

sleep and a general withdrawal from activities of daily living may indicate that death is imminent.

- d) Patient-centred multidisciplinary care provides the means to identify individual needs and make suitable care plans for dying people (and their families and carers), regardless of the underlying causes or the setting in which care is provided. The recognition and the assessment of factors that may indicate that the person is in the last days or hours of his or her life are complex and sensitive. Healthcare professionals may feel uncomfortable about having frank discussions and may therefore avoid them.
- e) Individualised care of dying people encompasses physical symptoms (such as pain, increasing fatigue and breathlessness), psychological symptoms (such as anxiety and depression), social and, for some people, spiritual needs. Good communication is necessary to ensure that people feel they are involved in the decision-making process about the care they or their loved ones receive, and this in turn helps to contribute to their perceptions of being treated with dignity and respect.

3.1 *Epidemiology*

- a) Approximately 500,000 people die in England each year and because of the ageing population that number is predicted to rise. Most people want to die with family and friends nearby, cared for, free from pain and with medical or nursing support available when it is needed. It is estimated that 70% of the population would prefer to die at home. Despite this, about 60% of people currently die in hospital and this figure is predicted to rise to approximately 65% by 2030. Cultural beliefs may also affect the choice of place of death and the support provided at the time of death.
- b) Until recently, NHS care in the last days of life was delivered and coordinated in many places by the use of end of life care pathways such as the Liverpool Care Pathway (LCP). The LCP was intended

to ensure that people thought to be dying within 2 or 3 days, whether they were in hospitals, nursing homes, or their own homes, died free of distressing symptoms and with dignity. The LCP was widely seen as a way of transferring the model of 'excellence' in care as practised in hospices to other healthcare settings such as hospitals and care homes. There has been criticism, however, about how some elements of the LCP have been implemented. Some families have complained that those dear to them were placed on the LCP without them being informed or without their consent. Others stated that medications and nutrition and hydration were automatically withdrawn from the dying person, and some dying people were over sedated by injudicious use of painkillers and tranquillisers. [More care, less pathway](#), the report of an independent review panel on the use of the LCP has recommended that, where used in the UK, it should be phased out of practice by July 2014. The challenge for the NHS is to provide a framework that ensures that care provided to people in the last days and hours of life is of high quality and is based on individual needs.

- c) The Royal College of Physicians (RCP) and the Marie Curie Palliative Care Institute published its [National care of the dying audit of hospitals](#) in May 2014. The audit found significant variations in care across hospitals in England. It showed that major improvements need to be made to ensure better care for dying people, and better support for their families, carers, and friends.

3.2 Current practice

- a) Recognising when a person is entering the last hours or days of their life is a challenge. Providing guidance that supports clinicians to make a prognosis of imminent death and communicate the prognosis sensitively, effectively and in a timely manner is important for both the person who is dying and their loved ones. Because of the long experience of palliative care in people with cancer, the approach of death in cancer is a relatively easier path

to predict. For those people dying as a result of chronic conditions such as chronic obstructive pulmonary disease or heart failure, from which temporary remissions occur, anticipating dying may be more difficult. More challenging still is anticipating dying in those with dementia or cognitive impairment or frailty because people in these circumstances may live for a long time, even with a reduced level of function; and because palliative care services have relatively less experience with these groups.

- b) The provision of assisted hydration can be an important and significant aspect of care in the last days of life. It is unclear whether the benefits of providing assisted hydration outweigh the burdens, with some studies showing positive effects on specific symptoms. The decision to give, withhold or withdraw assisted hydration has to be made on an individual basis, as the [General Medical Council's guidance](#) for doctors advises. The ethical and cultural issues related to withdrawal of this basic care element remain controversial.
- c) Managing pain, breathlessness, anxiety and distress is key to a peaceful death. Terminal restlessness is a distressing form of delirium that may occur in dying people. It is characterised by anguish (spiritual and/or emotional), restlessness, agitation, cognitive failure and variable levels of consciousness. Effective recognition and treatment of such restlessness is important. It is sometimes necessary to use sedative doses of medication such as opioids, benzodiazepines and major tranquillisers to control such forms of distress in the last few days of life. However, concern has been voiced about injudicious use of such drugs causing undue sedation, which may increase distress for the person who is dying and their families or carers.
- d) In the UK, a key approach to improving symptom control in end of life care in all settings (particularly the community) is the use of 'anticipatory' or 'just in case' prescriptions. This allows clinicians

such as district nurses to alleviate distressing symptoms of pain or anxiety in the dying person promptly without the additional delay of securing prescription and the dispensing of medication, especially out of hours. However, criticisms have been raised around storing and disposing of such medication in the community. Furthermore there have been reports that family members perceive these drugs, if started too early or without good justification and communication, to hasten death.

- e) The Neuberger review of the Liverpool Care Pathway ([More care, less pathway](#)) highlighted that frequently the decision that a person is dying is left to individual ‘out-of-hours’ clinicians without the support of an experienced team. The review also emphasised the importance of clear communication with patients, carers and families. Consideration of the timeliness and quality of multidisciplinary team clinical decision making relating to the provision of care is vital and it is believed that this should involve the dying person and those important to them.

4 The guideline

The guideline development process is described in detail on the NICE website (see section 6, ‘Further information’).

This scope defines what the guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from NHS England.

The areas that will be addressed by the guideline are described in the following sections.

4.1 Population

4.1.1 Groups that will be covered

Group	Rationale
Adults (aged 18 years and over) in whom death is expected within a few	NICE has commissioned a separate guideline on end of life care for infants, children and young people. More detail can be found on the NICE website .

days.	
<p>Special consideration will be given to people with:</p> <ul style="list-style-type: none"> • dementia • cancer • organ system failure (including heart disease). 	<p>More care, less pathway recommended 'condition-specific good practice guidance'. It is thought that patterns of clinical and functional decline differ in these 3 groups and may warrant special recommendations, if there is available evidence. Assessment of dying is less reliable in people with dementia than in people with cancer (as highlighted by Lorenz et al. 2008⁴ in a systematic review on evidence for improving palliative care at the end of life).</p> <p>In his announcement of the Care Quality Commission national review of end of life care, Professor Sir Mike Richards referred to 'inequalities' in care of the dying. This was related particularly to the subgroups of people with dementia, heart disease and cancer. Research indicates that relatives of people dying from cancer were more satisfied with the care that was received than relatives of people dying from other illnesses.</p> <p>The Alzheimer's Society has asked patients and carers about their priorities for research. One of the top five topics was end-of-life care for people with dementia.</p> <p>Dementia is included as a subgroup because it is a progressive and terminal disease (see for instance Mitchell et al., 2009⁵ and van der Steen et al., 2013⁷).</p> <p>People with communication, cognitive or learning difficulties are not included separately because these conditions do not have the same poor prognosis. If appropriate, separate recommendations may be made for people with these difficulties as part of NICE's responsibility to consider equalities. NICE's clinical guidance Patient experience in adult NHS services also makes recommendations for care for these groups.</p>

4.1.2 Groups that will not be covered

Group	Rationale
Infants, children and young people aged under 18 years.	Children's care needs at the end of life are different from the care needs of adults. NICE is developing a separate clinical guideline on end of life care for infants, children and young people.

4.2 **Setting**

All settings where NHS funded care is received, including:

- a) Hospitals.
- b) Hospices.
- c) Care homes (with or without nursing).
- d) Prisons.
- e) Private residences.
- f) Hostels.

4.3 **Management**

4.3.1 **Key clinical issues that will be covered**

- a) Signs and symptoms: recognising dying

Key clinical issues	Rationale
How do clinicians recognise that people are in their final hours or days of life?	<p>This issue was highlighted in More care, less pathway (recommendation 12) as being particularly complex and one in which clearer guidance for professionals (as well as further research by the National Institute for Health Research) is needed.</p> <p>A recent BMJ article (Kennedy et al. 2014³) and other systematic reviews summarise the evidence, but conclude that there is a need to work with and within the ‘uncertainty of recognising dying’.</p> <p>More care, less pathway also recommends that: ‘How any uncertainty about whether a patient is in the active process of dying should be taken into account in the clinical management of the patient, in different healthcare settings’.</p> <p>Recommendations on both issues may be developed based on an evidence review conducted in this area. It is anticipated that part of the evidence review will also look at how to manage uncertainty related to the active process of dying.</p>

- b) Multidisciplinary shared decision-making and communication

Key clinical issues	Rationale
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<p>Multidisciplinary shared decision-making about the possibility of dying, and communication</p>	<p>Although the forthcoming guideline on palliative care will address service delivery and the structure of the multidisciplinary team, it will not address multidisciplinary team decision-making.</p> <p>The Leadership Alliance for the Care of Dying People's One chance to get it right highlights communication about the possibility that someone is dying and shared decision-making in accordance with the person's needs and wishes as one of the top priorities.</p> <p>It also states that the needs of families and those identified as important to them should be actively explored in order to involve them in decisions about care.</p> <p>Where possible reference will be made to NICE's clinical guidance Patient experience in adult NHS services. However, communication issues specific to the last days of life are thought to require specific recommendations that may not be addressed in that guidance.</p>
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c) Principles and protocols for anticipatory prescribing

Key clinical issues	Rationale
<p>The role of anticipatory prescribing in the last days of life.</p>	<p>Anticipatory prescribing enables access to palliative care medicine out of hours, reducing distress for the dying person and their carers and the need for emergency admission to hospital. This may include 'just in case' medication provided in the community and anticipatory prescribing in hospitals.</p> <p>Currently only local protocols are in place and there is no national guidance for the NHS in England and Wales.</p> <p>How anticipatory prescribing is carried out and how it is communicated could benefit from guidance on a national level.</p> <p>There is variation in what is included (for instance inclusion of hyoscine).</p> <p>There are concerns about inappropriate administration, medication remaining in the community when not needed and perceptions of family/carers with regard to such medication leading to hastening of death. .</p>

d) Clinically assisted hydration

Key clinical issues	Rationale
Clinical effectiveness of assisted hydration	<p>This was highlighted as an issue in the Rapid evidence review carried out by the University of Nottingham (Parry et al., 2013⁶) as part of More care, less pathway (recommendations 17–22).</p> <p>People who are dying commonly experience a reduced need for food, but many retain thirst but may not be able to drink for various reasons. Withholding hydration from these people causes anxiety and distress for them and their families or carers. If fluids are stopped without a medical review it can result in progressive dehydration, which could accelerate the dying process or aggravate some symptoms such as delirium or pain.</p> <p>Evidence is available in a Cochrane systematic review (Good et al, 2014¹) of data from randomised controlled trials. However, the findings are inconclusive and there is variation in clinical practice, particularly in hospital settings, as identified in More care, less pathway.</p> <p>The General Medical Council provides general guidance in End of life care: meeting patients' nutrition and hydration needs. However, this guidance combines hydration with nutrition and is not specific to the last days and hours of life. More care, less pathway identified that guidance for nurses in particular is lacking.</p> <p>According to More care, less pathway, the LCP was not always followed correctly and the decision about clinically assisted hydration was not always communicated.</p> <p>This topic will include the decision-making and communication process surrounding clinically assisted hydration and the impact on the dying person, their family members and staff providing care.</p> <p>Some, but not all, of the issues related to route and method of administration may be covered by NICE guidance (CG174) on IV fluids therapy in adults in hospital.</p>

e) Pharmacological management

Key clinical issues	Rationale
The role of opioids, benzodiazepines and major tranquillisers in the management of pain, anxiety, breathlessness and terminal agitation and minimising	Palliative sedation is sometimes considered necessary to relieve distressing symptoms that are hard to control and to reduce anxiety, delirium and terminal agitation in dying adults. It is generally thought to be effective for this purpose. However, it is a

unwanted sedation	<p>treatment of last resort because of the risk of accelerating death (for example by respiratory depression and aspiration). It also frequently causes distress for families and carers because of the loss of ability to interact with the dying person, depending on the depth of sedation. Guidance is therefore needed on how to reduce symptoms of pain, anxiety, breathlessness and terminal agitation without causing undue sedation.</p> <p>Even though opioids relieve pain and distress, in some situations, such as kidney failure, the choice of opioid is critical. A review of the evidence on effectiveness could support the development of recommendations on key issues, such as when to start treatment, and take into account critical side effects (in particular respiratory depression).</p> <p>This has been highlighted as an issue in More care, less pathway (related to recommendation 23), which also notes that opioid painkillers and sedatives are often used inappropriately (for example, they may be used for agitation that is actually caused by dehydration or by opioids themselves).</p> <p>The impact of the pharmacological management of pain, anxiety, breathlessness and terminal agitation on families, carers and healthcare staff could also be covered in this section. More care, less pathway highlighted that there was often a perception that the use of strong painkillers had caused death. Communication about the use of these drugs is important.</p>
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4.3.2 Issues that will not be covered

Clinical issue	Rationale
Service delivery (for example out-of-hours availability of staff or how services are structured).	Service delivery guidance (for both palliative care and care of the dying adult) will be addressed in the proposed NICE guidance on palliative care for adults.
Social and spiritual needs of the dying person and their families and carers.	This may be addressed in the proposed NICE guideline on palliative care for adults.
Longer-term palliative care or end of life care	This may be addressed in the proposed NICE guideline on palliative care for adults.

outside of the last few days or hours of life.	
Care after death (care of the body, certification and bereavement).	This is not a priority for clinical guidance but should be guided by local protocols and respect cultural customs.
The use of prognostic tools to provide greater confidence in recognising that a person is dying.	<p>This was highlighted as a research topic that could be prioritised by the National Institute for Health Research in the context of traumatic bleeding. However, although prognostic tools may be informative about longer-term prognosis, the scoping group thought that current indices are unlikely to identify active dying in the last days or hours of life.</p> <p>This was confirmed by the rapid evidence review conducted by the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care⁶, which found research on prognostic indices that identify people at a higher risk of mortality (for time periods of 1–5 years of life expectancy), but not to indicate active dying.</p> <p>Therefore rather than prognostic tools, the identification of specific signs and symptoms was prioritised for this guideline.</p>

The importance of case notes review for recognition of dying	Links to recommendation 12 of the LCP review. This was not prioritised for this guideline but may feature in the proposed NICE guidance on palliative care for adults.
The usefulness or otherwise of laboratory and other biological evidence.	This clinical issue is linked to recommendation 12 of More care, less pathway . Although recognised as an important topic that includes the use of tests for blood sugar, calcium levels and renal function to guide treatment, the scoping group considered this to be an issue for specialist care rather than for people in their last days and hours of life more generally. It was therefore not prioritised for this guideline.
Multidisciplinary team structure.	This may be addressed in the proposed NICE guideline on palliative care for adults.
Clinically assisted nutrition.	<p>People in the last days or hours of their lives commonly experience a reduction in appetite and it might be more acceptable to them and their families and carers not to use, to reduce, or to withdraw assisted nutrition.</p> <p>Also, the clinical factors leading to the need for assisted nutrition and the technologies used to address these are different than those in related to assisted hydration.</p> <p>The evidence base is very small. There is a recent (last search March 2014) Cochrane review in which no studies were identified (Good et al., 2014a²). The scoping group thought that care in this area may be guided by clinical expertise because an evidence review would have little to add. Compared with other clinical issues, this was not considered a priority for this guideline</p>

4.4 Main outcomes

- a) Subjective rating of pain, breathlessness, anxiety, terminal agitation and undue sedation/drowsiness.
- b) Carers' and relatives' views about the care that was provided.
- c) Number of people correctly identified as being in the last days and hours of their lives.
- d) Length of wait for palliative care drugs.

- e) Adverse events including sedation, thirst, nausea, vomiting and delirium.

4.5 Review questions

Review questions guide a systematic review of the literature. They address only the key issues covered in the scope, and usually relate to interventions, diagnosis, prognosis, service delivery or patient experience. Please note that these review questions are draft versions and will be finalised with the Guideline Development Group.

- a) What signs and symptoms indicate that adults are in their final days of life?
- b) How are decisions about clinical care most effectively shared and communicated between health care professionals, adults in the last days of life, their relatives and those important to the person?
- c) What is the role of anticipatory prescribing in the clinical care of adults in the last days of life?
- d) For adults in the last days of life, is medically assisted hydration effective in improving quality of care?
- e) For adults who are in the last days of life, what is the most effective level of sedative medication (opioids, benzodiazepines and major tranquillisers) in the management of pain, anxiety, terminal agitation and breathlessness?

4.6 Economic aspects

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions. A review of the economic evidence will be conducted and analyses will be carried out as appropriate. The preferred unit of effectiveness is the quality-adjusted life year (QALY), and the costs considered will usually be only from an NHS and personal social services (PSS) perspective. Further detail on the methods can be found in [The guidelines manual](#).

4.7 Status

4.7.1 Scope

This is the consultation draft of the scope. The consultation dates are 2 August to 29 August 2014.

4.7.2 Timing

The development of the guideline recommendations will begin in October 2014.

5 Related NICE guidance

5.1.1 Published guidance

- [Prostate cancer](#). NICE clinical guideline 175 (2014).
- [Intravenous fluid therapy in adults in hospital](#). NICE clinical guideline 174 (2013).
- [Neuropathic pain – pharmacological management](#). NICE clinical guideline 173 (2013).
- [Idiopathic pulmonary fibrosis](#). NICE clinical guideline 163 (2013).
- [Neutropenic sepsis](#). NICE clinical guideline 151 (2012).
- [Opioids in palliative care](#). NICE clinical guideline 140 (2012).
- [Patient experience in adult NHS services](#). NICE clinical guidance 138 (2012).
- [Colorectal cancer](#). NICE clinical guideline 131 (2011).
- [Ovarian cancer](#). NICE clinical guideline 122 (2011).
- [Lung cancer](#). NICE clinical guideline 121 (2011).
- [Chronic heart failure](#). NICE clinical guideline 108 (2010).
- [Chronic obstructive pulmonary disease](#). NICE clinical guideline 101 (2010).
- [Motor neurone disease](#). NICE clinical guideline 105 (2010).
- [Metastatic malignant disease of unknown primary origin](#). NICE clinical guideline 104 (2010).
- [Advanced breast cancer](#). NICE clinical guideline 81 (2009).
- [Metastatic spinal cord compression](#). NICE clinical guideline 75 (2008).
- [Prophylaxis against infective endocarditis](#). NICE clinical guideline 64 (2008).
- [Acutely ill patients in hospital](#). NICE clinical guideline 50 (2007).

- [Dementia](#). NICE clinical guideline 42 (2006).
- [Service guidance for improving outcomes for people with brain and other central nervous system tumours](#). NICE cancer service guidance (2006).
- [Parkinson's disease](#). NICE clinical guideline 35 (2006).
- [Referral guidelines for suspected cancer](#). NICE clinical guideline 27 (2005).
- [Improving supportive and palliative care for adults with cancer](#). NICE cancer service guidance (2004).
- [Improving outcomes in haemato-oncology cancer](#). NICE cancer service guidance (2003).
- [Guidance on the use of gemcitabine for the treatment of pancreatic cancer](#). NICE technology appraisal guidance 25 (2001).

5.1.2 Published quality standards

- [Supporting people to live well with dementia](#). NICE quality standard 30 (2013).
- [End of life care for adults](#). NICE quality standard 13 (2011).
- [Breast cancer](#). NICE quality standard 12 (2011).
- [Chronic obstructive pulmonary disease](#). NICE quality standard 10 (2011).
- [Dementia](#). NICE quality standard 1 (2010).

5.2 Guidance under development

NICE is currently developing the following related guidance (details available from the [NICE website](#)):

- Multiple sclerosis. NICE clinical guideline. Publication expected October 2014.
- Bladder cancer. NICE clinical guideline. Publication expected February 2015.
- Suspected cancer. NICE clinical guideline. Publication expected May 2015.
- Motor neurone disease. NICE clinical guideline. Publication expected February 2016.
- Major trauma. NICE clinical guideline. Publication expected April 2016.
- Acute medical emergency. NICE clinical guideline. Publication date to be confirmed.

- End of life care for infants, children and young people. Publication date to be confirmed.

6 Further information

Information on the guideline development process is provided in the following documents, available from the NICE website:

- [How NICE clinical guidelines are developed: an overview for stakeholders the public and the NHS: 5th edition](#)
- [The guidelines manual](#).

Information on the progress of the guideline will also be available from the [NICE website](#).

7 References

- 1 Good P, Richard R, Syrmiss W, Jenkins-Marsh S, Stephens J. Medically assisted hydration for adult palliative care patients. Cochrane Database Syst Rev. 2014; 4:CD006273
- 2 Good P, Richard R, Syrmiss W, Jenkins-Marsh S, Stephens J. Medically assisted nutrition for adult palliative care patients. Cochrane Database Syst Rev. 2014; 4:CD006274
- 3 Kennedy C, Brooks-Young P, Brunton GC, Larkin P, Connolly M, Wilde-Larsson B et al. Diagnosing dying: an integrative literature review. BMJ Support Palliat Care. 2014;
- 4 Lorenz KA, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA et al. Evidence for improving palliative care at the end of life: a systematic review. Ann Intern Med. 2008; 148(2):147-159
- 5 Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG et al. The clinical course of advanced dementia. N Engl J Med. 2009; 361(16):1529-1538
- 6 Parry R. Evidence briefing pathways for the dying phase in end of life care. NHS National End of Life Care Programme, 2013
- 7 van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, Ribbe MW, Deliens L. Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study. BMC Med. 2013; 11:105