NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

SCOPE

1 Guideline title

Care of the dying adult: Clinical care of the dying adult in the last days of life.

2 The remit

The Department of Health 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, such as cancer or other forms of progressive illness, clinicians can become aware that death may be approaching fast, but there is time for clinical services to adapt the aims and level of care in the last days. 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 thought likely to be dying in a matter of days, and providing support to their families, or those of importance to them, at this time, is of profound importance. Death may take place in a variety of settings, depending on choice and individual needs. Recognising that someone is likely to be dying imminently 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 approaches, the clinical care provided should maximise the dying person's comfort and aim to reduce pain, anxiety and other symptoms and minimise disturbance and unnecessary intervention.

c) The likely time of death is often difficult to anticipate or predict, especially in people with chronic non-cancer conditions. Progressive weakness with no obviously reversible cause, altered breathing, increased periods of sleep and a general reduction in communication and participation in daily life may indicate that death is imminent.

d) Patient-centred multi-professional care provides the means to identify individual needs and make suitable care personalised 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 subtle. It is important that these decisions and any changes to the care plans are conveyed to all people involved. However, healthcare professionals, the people who are dying and their relatives and friends may all feel uncomfortable about having frank discussions and may therefore avoid them. This avoidance needs to be overcome in order to plan and share the individual's care.

e) Individualised care of people who are dying encompasses physical symptoms (such as pain, increasing fatigue and breathlessness), psychological symptoms (such as anxiety and depression), social and spiritual needs. Good communication and advance planning is necessary to ensure that people are appropriately involved in the decision-making process about the care they or their loved ones receive and that patients and families are treated with respect to maintain their dignity.

3.1 Epidemiology

Approximately 500,000 people die in England each year and, because of the increasing population, that number is predicted to rise. Most people want to die with family and others important to them nearby, to feel cared for, to be free from symptoms and to have 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. A variety of factors, including clinical needs, availability of family carers, local palliative care resources and cultural beliefs, may influence the choice of and actual place of dying and the level of support needed at the actual time of death.

3.1.1 Current practice

a) Until July 2014, 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) or its local derivatives. The LCP was intended to ensure that people thought to be in the last 2 or 3 days of life, regardless of their setting, died free of distressing symptoms and with dignity, by transferring the model of care as practised in hospices to other healthcare settings. However, there has been criticism about how some elements of the LCP have been implemented. These include issues about how patients were selected to be placed on the LCP; communication with patients and families; the appropriateness of withholding or withdrawing hydration, nutrition and some medication; injudicious use of pain-killers or tranquillisers leading to undue sedation; and the lack of research-based evidence. 'More care, less pathway', the report of an independent review panel on the use of the LCP recommended that it should be phased out of practice by July 2014 in the UK. The challenge for the NHS is to provide a framework and culture that ensures that care provided to people in the last days and hours of life is evidence-based, of high quality and is based on individual needs.

b) 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, although there are examples of excellent care, major improvements need to be made to ensure better care for people who are dying and better support for their families and others important to them.

c) A 'Leadership Alliance for the Care of Dying People' (LACDP) was set up following the 'More care, less pathway' report, with the aim of gathering consensus on the way forward after the withdrawal of the LCP. The LACDP published a report, 'One chance to get it right', in June 2014. It contained 5 new priorities for care to succeed the LCP as the new basis for caring for someone at the end of their life.

d) Recognising when a person is likely to be entering the last hours or days of their life is a challenge for even experienced clinicians in specialist palliative care. It is important to provide guidance that supports clinicians in all settings to make an assessment that death is likely within days and to communicate the prognosis sensitively, effectively and in a timely manner. 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, 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 less experience with these groups. Just as important as recognising when a person is likely to be dying is being able to monitor bodily and mental changes that may suggest the person is recovering and may need a different course of management to live for a longer time.

e) The provision of clinically assisted hydration, for some patients and those important to them, can be an important and comforting aspect of care in the last days of life. However, for some people, assisted hydration may be unnecessary or, if medical drips are applied without due care, harmful. The decision to initiate, continue, withhold or withdraw assisted hydration should be made on an individual basis, as the General Medical Council’s guidance for doctors advises. Apart from the clinical considerations, the ethical and cultural issues related to providing or withholding hydration remain controversial.

f) Managing symptoms such as pain, breathlessness, nausea and vomiting, troubling respiratory secretions, anxiety and agitation is key to a peaceful death. Current practice for managing these symptoms includes assessing for and treating any reversible causes. It is recognised that it is sometimes necessary to use sedative doses of medications such as opioids, benzodiazepines and major tranquillisers (antipsychotics or neuroleptics) to control refractory symptoms and 'terminal agitation'. However, the independent review of the LCP 'More care, less pathway', identified concern about injudicious use of such drugs, for example, starting them too early or using inappropriately high doses, leading to undue sedation. This may prevent communication in the final days and cause more distress for the person who is dying and their families or those important to them.

g) 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, nausea, vomiting, troublesome respiratory secretions and breathlessness or increasing anxiety, promptly without the additional delay of obtaining a new prescription and the dispensing of medication, especially out of hours. However, there has been some criticism of the arrangements for storing and disposing of such medication in the community. Furthermore, there have been reports that family members perceive that these drugs, if started too early or without good justification and communication, can hasten death.

h) 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 report also emphasised the importance of clear communication with patients, carers and families. Consideration of the timeliness and quality of multi-professional team clinical decision-making relating to the provision of care is vital and ideally this should involve both the person who is dying and those important to them.

i) It is recognised that for some people in the last days of life the ability to make decisions about their care may be limited because of reduced conscious level. The Mental Capacity Act is designed to protect people who can't make decisions for themselves or lack the mental capacity to do so and clinicians need to consider these issues when making decisions about care.

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 the Department of Health.

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

Adults (aged 18 years and over) in whom death is expected within a few days

4.1.2 Groups that will not be covered

Infants, children and young people aged under 18 years.

Young people over the age of 18 years who are cared for by paediatric services.

4.2 Setting

All settings where NHS funded care is received, including:

a) Care homes (with or without nursing).

b) Hospices.

c) Hospitals.

d) Private residences.

4.3 Management

4.3.1 Key issues that will be covered

a) How clinicians recognise whether or not people are likely to be in their final hours or days of life; and how they recognise that the patient may be improving and recovering. How uncertainties regarding both situations are managed and communicated.

b) Shared decision-making with the patient and carers about clinical care in the last days of life.

c) Anticipatory prescribing in the last days of life.

d) Clinical effectiveness of assisted hydration

e) Pharmacological management of pain, anxiety, breathlessness, terminal agitation, nausea, vomiting and respiratory secretions.

4.3.2 Issues that will not be covered

a) Service delivery (for example out-of-hours availability of staff or how services are structured).

b) Palliative care or end of life care before the last few days or hours of life.

c) Care after death (care of the body, certification and bereavement).

d) Case notes review for recognition of dying

e) The usefulness of laboratory and other biological evidence.

f) Multi-professional team structure.

g) Clinically assisted nutrition.

4.4 Main outcomes

a) Subjective rating of pain, breathlessness, anxiety, terminal agitation, nausea and vomiting and respiratory secretions.

b) Subjective and objective evidence of unwanted sedation, nausea or other side-effects as a result of pharmacological management of the symptoms above.

c) Family members' and carers’ views about the care that was provided.

d) Correct recognition of being in the last days and hours of life.

e) Length of wait for medication for symptom control to be administered after the reporting of symptoms.

f) Symptoms such as pain, breathlessness, anxiety, terminal agitation, nausea, vomiting and respiratory secretions.

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 likely to be entering the last days of life; or that they may be recovering? How should uncertainties about either situation be dealt with and communicated?

b) How are shared decisions about clinical care in the last days of life most effectively made between health care professionals, the dying person, their families, carers and others important to them?

c) What is the role of anticipatory prescribing in the clinical care of adults in the last days of life?

d) Is medically assisted hydration effective in improving quality of care for adults in the last days of life?

e) What is the role of pharmacological treatment in the management of pain, anxiety, terminal agitation, breathlessness, nausea, vomiting and respiratory secretions whilst minimising unwanted levels of sedation in adults who are in the last days of life?

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), although this may not be appropriate for the clinical context of this guideline. 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 final scope.

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).
- 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).
- Multiple sclerosis. NICE clinical guideline 186. (2014).

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):

- Bladder cancer. NICE clinical guideline. Publication expected February 2015.
- Motor neurone disease. NICE clinical guideline. Publication expected February 2016.
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs. Social Care guideline. Publication expected November 2015.
- Major trauma. NICE clinical guideline. Publication expected April 2016.
- Transition between inpatient mental health settings and community and care home settings for people with social care needs. Social care guideline. Publication expected August 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.