

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

SCOPE

1 Guideline title

End of life care for infants, children and young people: The planning and management of end of life care for infants, children and young people with life-limiting conditions

1.1 Short title

End of life care for infants, children and young people

2 The remit

The Department of Health has asked NICE: 'To prepare a clinical guideline on the End of life care for infants, children and young people'.

3 Need for the guideline

3.1 Epidemiology

- a) The death of an infant, child or young person has become an uncommon event in the UK.
- b) The infant mortality rate in 2012 in England and Wales was the lowest ever recorded, at 4 deaths per 1000 live births. As recently as 1982 the infant mortality rate was 10.8 deaths per 1000 live births. This change can partly be explained by improvements in health care, particularly in midwifery, obstetrics and neonatal intensive care.
- c) [Fair Society Healthy Lives: The Marmot review](#) noted factors that were independently associated with an increased risk of infant mortality, including births outside marriage, maternal age under 20

years, and deprivation. Complications of pre-term birth particularly respiratory and cardiovascular conditions, account for about half of infant deaths. Congenital anomalies account for about a third of infant deaths.

- d) Between 1982 and 2012 the age-specific mortality rate in England and Wales for children and young people aged 1 to 14 years fell by 62%, from 29 deaths to 11 deaths per 100,000 people. The age-specific mortality rate for children aged 1 to 4 years fell by 66% over the same period, from 47 deaths to 16 deaths per 100,000 people. Over the past 30 years child death rates from respiratory and circulatory conditions in England and Wales have been falling, as they have for the whole population. This reflects general advances in medical care and preventative measures. In 2012, congenital conditions and cancers were the most common cause of death for children and young people aged under 16 years.
- e) The 2014 report, [Why children die: death in infants, children and young people in the UK](#) noted that, despite improving mortality rates, more than 2000 children and young people aged between 1 and 19 years died in England and Wales in 2012. From 1 to 15 years cancer and neurodevelopmental, respiratory, cardiovascular and congenital conditions (all of which tend to be chronic and progressive) account for about 60% of deaths. For young people aged over 15 years external causes (such as accidents) are more common, accounting for 42% of deaths. The proportion of young people aged over 15 years who die from chronic conditions falls to about 30%, although cancer and neurodevelopmental conditions continue to be common causes of death.
- f) Despite declining mortality rates, it is estimated that almost 50,000 infants, children and young people aged 19 years or under in the UK (40,000 of these in England) are living with a life-limiting condition and may need palliative care. They may have widely varying needs, as there are over 300 conditions that could be

classed as life-limiting or life-threatening in infants, children and young people. Some of these infants, children and young people also have severe disabilities and multiple complex health and care needs in addition to palliative care.

3.2 Current practice

- a) In this guideline the term 'life-limiting condition' is used to refer to any condition which either generally or in a particular individual is thought likely to result in early death.
- b) In this guideline end of life care will include care of the infant, child or young person and of their family members or carers from first recognition of the life limiting condition through to their care in the last days and hours of life and after death.
- c) Children and young people and their family members or carers may have varied ideas about what, for them, would be good palliative and end of life care. However, most would place a high priority on being treated with dignity and respect and as an individual, and being involved in decision-making about their care. They would want to be without pain, or with as little pain or other distressing symptoms as possible. The Department of Health's [End of Life Care Strategy Fourth Annual Report \(2012\)](#) notes that 42.4% of people now die at home or in a care home.
- d) Infants, children and young people with life-limiting conditions, including those who are approaching the end of their life, need high-quality treatment and care that supports them to live as well as possible and to die with dignity. Providing such treatment and care often involves decisions that are complex and emotionally distressing, especially towards the end of their lives. The GMC guidance [Treatment and Care Towards the End of Life](#) considered that patients were 'approaching the end of life' when they were likely to die within the next 12 months. However, a more flexible approach defining this phase of care is adopted for infants, children

and young people in this NICE guideline, because they may have long-term life-limiting conditions. Together for Short Lives' [A guide to end of life care](#) states that most adults only need palliative care at the end of their lives, but many infants, children and young people with life-limiting conditions need palliative care over a much longer period. During this time their condition may fluctuate and there may even be times when it is difficult to determine if death is imminent.

- e) Palliative care combines a broad range of relevant health and other care services. Good palliative and end of life care depends on establishing good communication and care coordination and this requires effective networking arrangements between the relevant services. These include the hospital, hospice, primary care and community professionals, ambulance services, other support providers, and dedicated palliative care teams.
- f) Children's Palliative Care (CPC) aims to make infants, children and young people with a life-limiting condition as comfortable as possible by relieving pain and other distressing symptoms. It also provides them and their family members or carers with psychological care and social, spiritual and religious support as appropriate. CPC may be needed early in the course of an illness, together with other therapies to treat the condition. It may start from the antenatal stage, and may continue after the young person turns 18. It may be part of a plan for transition to adult care when appropriate.
- g) CPC is delivered by various providers, including primary, secondary and tertiary services, community services and hospices. CPC can be commissioned from the NHS providers working collaboratively. CPC is also provided by the voluntary sector (including children's hospices), although there is geographical variation in this provision.

- h) Some hospitals have specialist palliative care teams. Palliative care teams can provide care to infants, children and young people and their family members or carers (as appropriate) in hospitals, hospices and at home. However, not all palliative care teams currently provide care in all of these settings.
- i) There is variation in palliative care practice, particularly in how services are delivered. Together for Short Lives has recommended that locally available community-led CPC should be central to the arrangements and should be supported by specialist medical input, community nursing teams, children's hospice services, specialist palliative care providers, access to secondary and tertiary care, community paediatrics, primary care, emotional and psychological care and support, and local authority children's services (social care, spiritual and religious support, education, housing and leisure). In contrast, NHS England in its [2013/14 NHS Standard Contract for Palliative Care](#) recommends that multi-disciplinary palliative care teams led by clinical consultants should plan, deliver and evaluate palliative care services across a managed clinical network.

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

- a) Infants, children and young people aged up to 18 who have a life-limiting condition and their family members or carers (as appropriate).

Subgroups for consideration will include:

- Infants, children and young people with complex considerations that entail specific care needs, for example those with communication difficulties.
- Those with an antenatal diagnosis of a life-limiting condition.

4.1.2 Groups that will not be covered

- a) Adults aged 18 years and older.
- b) Infants, children and young people aged up to 18 years without a recognised life limiting condition who die unexpectedly (for example accidental death).

4.2 Setting

- a) All settings in which NHS-commissioned healthcare is provided.

4.3 Management

4.3.1 Key issues that will be covered

- a) Care of infants, children and young people with a life-limiting condition and their family members or carers (as appropriate) before death.
- b) Assessing needs and developing a personalised care plan, including parallel care planning. (Parallel planning refers to the development of plans that allow for unpredictability in the course of the condition.)

- c) Information and communication with children and young people and/or with the families and carers of infants, children and young people in relation to organ or tissue donation.
- d) Communicating and providing information, from recognition of a life-limiting condition until after death.
- e) Identifying the preferred place of care and the preferred place of death.
- f) The safe and effective management of distressing symptoms (such as pain and respiratory distress).
- g) The role of oral and medically assisted hydration and nutritional support during end of life care.
- h) The psychological and emotional needs of infants, children or young people with life-limiting conditions.
- i) The psychological and emotional needs of the family members or carers (as appropriate) of infants, children and young people with life-limiting conditions.
- j) The support needs of infants, children and young people and their family members or carers (as appropriate), including social, practical, spiritual or religious.
- k) Recognising when infants, children and young people are likely to die within a few days or hours.
- l) Decisions regarding life sustaining interventions, including cardiopulmonary resuscitation.
- m) The organisation of services providing the end of life care of infants, children and young people with life-limiting conditions.

- n) The needs of family members or carers after the death of an infant, child or young person and bereavement support before and after the death.
- o) Care of the infant, child or young person's body after death.

4.3.2 Issues that will not be covered

- a) The long-term specialist management of bereavement.
- b) Clinical management of the life-limiting condition.

4.4 *Main outcomes*

- a) Quality of life of the child or young person and their family members or carers (as appropriate)
- b) Satisfaction of the child or young person with their care.
- c) Satisfaction with care of the family members, carers (as appropriate) to the infant, child or young person.
- d) Whether children and young people are able to die in a place they or their family members or carers (as appropriate) choose.
- e) Psychological well-being, for example resilience, depression or anxiety in the child or young person and their family members or carers (as appropriate).
- f) Preventing and managing pain and other distressing symptoms, for example restlessness or agitation.

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 symptoms, signs, or combinations of symptoms or signs indicate that infants, children or young people are likely to die within a few hours or days?

- b) What preferences do children and young people with a life-limiting condition and their family members or carers (as appropriate) have for place of care and for place of death, and what determines those preferences?

- c) What is the clinical and cost effectiveness of a home-based programme of care, compared with care in other settings?

- d) What service delivery arrangements (including neonatal intensive care and rapid transfer from intensive care units) can best provide for the needs of infants, children and young people with life-limiting conditions, and for the needs of their family members and carers (as appropriate) during this time and after death?

- e) What is the clinical and cost effectiveness of a defined multi-disciplinary team (MDT) of a particular composition compared with one of a different composition and compared with care without a defined MDT?

- f) What psychological and psychopharmacological interventions are clinically and cost effective for children and young people with life-limiting conditions, especially during the end of life, and for the family members and carers (as appropriate) of infants, children and young people with a life-limiting condition?

- g) What interventions are safe, and clinically and cost effective for managing pain and other distressing symptoms associated with life-limiting conditions?
- h) What is the effectiveness of medically assisted hydration in infants, children and young people during end of life care?
- i) What is the effectiveness of medically assisted nutrition support in infants, children and young people during end of life care?
- j) What aspects of communication and information provision do infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) find helpful or unhelpful, especially as they approach the end of life?
- k) What assessments are helpful in developing and reviewing the personalised care plan for infants, children and young people with life-limiting conditions?
- l) What forms of social and practical support are helpful to infants, children and young people with life-limiting conditions and their family members or carers (as appropriate)?
- m) What forms of spiritual or religious support are helpful to infants, children and young people with life-limiting conditions and their family members or carers (as appropriate)?
- n) What information do infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) need in order to be involved in advanced care planning, including if appropriate decisions about stopping life-sustaining treatment and attempting cardiopulmonary resuscitation?
- o) Before and after an infant, child or young person dies, what considerations do their family members or carers (as appropriate) consider important (for example, communication, emotional,

spiritual and religious support, care of the body, and managing practical arrangements)?

- p) What aspects of communication and information provision help the family members or carers (as appropriate) of an infant, child or young person with a life-limiting condition to make decisions on organ or tissue donation?

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 always be an appropriate measure for some analyses in this guideline. 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 January 2015.

5 Related NICE guidance

5.1 Published guidance

5.1.1 Related NICE guidance

- Pressure ulcers (2014) NICE guideline CG179

- Neuropathic pain – pharmacological management (2013) NICE guideline CG173
- Opioids in palliative care (2012) NICE guideline CG140
- Patient experience in adult NHS services (2012) NICE guidance CG138
- Organ donation for transplantation (2011) NICE guideline CG135
- Acutely ill patients in hospital (2007) NICE guideline CG50
- Improving outcomes in children and young people with cancer (2005) NICE cancer service guidance
- Improving supportive and palliative care for adults with cancer (2004) NICE cancer service guidance

5.1.2 Published quality standards

- End of life care for adults (2013) NICE quality standard 13

5.2 *Guidance under development*

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

- Transition from children's to adult services. NICE guideline (publication expected January 2016)
- Care of the dying adult. NICE guideline (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](#)
- [The guidelines manual](#).

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