NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

SCOPE

1 Guideline title

End of life care for infants, children and young people

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 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, and deprivation. Immaturity related disorders, particularly respiratory and cardiovascular disorders, 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 diseases 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 form 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. Complications from preterm birth accounted for two-thirds of infant deaths. 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 percent of deaths. External causes (such as accidents) are more common causes (42%) of death in young people aged over 15, and the proportion who die from chronic disorders falls to about 30 percent, although cancer and neurodevelopmental disorders continue to be important causes of death.

f) Despite declining mortality rates, it is estimated that almost 50,000 children and young people aged between 0–19 years in the UK (and 40,000 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 children and young people. Some of these children and young people also have severe disabilities and multiple complex healthcare needs in addition to palliative care.

3.2 Current practice

a) Children and young people and their family members or carers may have varied ideas about what, for them, would constitute 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. They would want to be without pain or with as little pain or other distressing symptoms as possible. As noted in the Department of Health's End of Life Care Strategy most people want to die in familiar surroundings and in the company of close family and/or friends.

b) 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 treatment and care to infants, children and young people with life-limiting conditions often involves decisions that are clinically 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. A more flexible approach to duration is adopted for infants, children and young people in this NICE guideline, taking account of the importance of long-term planning for people with life-limiting conditions. Infants, children and young people needing end of life care include those whose death is imminent (expected within hours or days), whether it is because of a life-limiting condition, a sudden acute crisis as a result of a pre-existing condition, or a sudden catastrophic event.

c) Life-limiting conditions are conditions for which there is no reasonable hope of cure and from which children and young people are expected to die. In this guideline these include infants, children and young people with conditions for which curative treatment may be feasible but can fail. Together for Short Lives' A guide to end of life care shows that most adults only need palliative care at the end of their lives, but infants, children and young people with life-limiting conditions frequently need palliative care over a much longer period, often from birth. During this time their health may fluctuate and it may be difficult to determine when they are dying and in need of end of life care. Palliative care combines a broad range of relevant health and other care services. Good palliative and end of life care depends on establishing effective networking arrangements between the relevant services. These include the hospital, hospice, primary care professionals, other support providers, and specialist palliative care teams.

d) Children's Palliative Care (CPC) aims to make infants, children and young people with an incurable condition as comfortable as possible by relieving pain and other distressing symptoms, while providing psychological, social and spiritual support for them and their family members or carers (as appropriate). It may be needed early in the course of an illness, together with other therapies to treat the condition (for example chemotherapy or radiotherapy). It may start from the antenatal stage, and may continue after the young person turns 18. It may constitute part of a plan for transition to adult care when appropriate.

e) CPC is delivered by a number of providers. Currently, general CPC may be commissioned from the statutory sector using collaborative commissioning arrangements. A significant part of CPC is provided by the voluntary sector, although there is geographical variation in this.

f) Some hospitals have special 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.

g) There is variation in practice especially with respect to the delivery of services. Together for Short Lives has recommended that commissioners ensure sustained and effective delivery of CPC. 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 support, and local authority children’s services (social care, education, housing and leisure). Support from social services and spiritual and faith leaders could also be sought.

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). The guideline will address care from the first recognition of the condition through to care in the final phase of the condition and after death. Subgroups to be considered are infants, children and young people with:

- complex health needs
- cancer
- an antenatal diagnosis of a life-limiting condition
- neonatal intensive care needs
- end-organ failure, including infants, children and young people eligible for organ replacement.

b) Adults aged between 18 and 25 who are in transition to adult care.[1]

c) Infants, children and young people aged up to 18 who die unexpectedly without a prior known life-limiting condition.

4.1.2 Groups that will not be covered

a) Adults aged 18 years and older, except for adults aged between 18 and 25 who are in transition to adult care.

4.2 Setting

a) All settings in which NHS-commissioned health care, and social care, 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.

c) How to make decisions on organ or tissue donation.

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[1] Adults aged 18 and over will be covered in the NICE guideline on care of the dying adult.

d) Communication and information provision from the 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 pain and other distressing symptoms.

g) The role of oral and medically assisted hydration and nutritional support during end of life care.

h) The management of psychological issues in the infant, child or young person with a life-limiting condition.

i) The management of psychological issues in family members, carers or other people who are important to infants, children and young people who have a life-limiting condition or a sudden or unexpected death.

j) The support needs of infants, children and young people and their family members or carers (as appropriate), including social, practical, emotional, spiritual or religious support.

k) Recognising when infants, children and young people are likely to die within a few days or hours.

l) How to make the decision to withhold or withdraw medical interventions, or to not provide cardiopulmonary resuscitation.

m) Planning and managing the transition to adult services for young people with life-limiting conditions.

n) Service delivery for infants, children and young people with life-limiting conditions.

o) Initial support and assessment of the needs of family members, carers and other people who are important to the infant, child or young person, after they have died.

p) Care of the infant, child or young person's family members or carers (as appropriate) after their death.

q) Care of the infant, child or young person's body after death.

4.3.2 Issues that will not be covered

a) Specialised management of bereavement.

4.4 Main outcomes

a) Quality of life.

b) Satisfaction of the child or young person with care.

c) Satisfaction of family members, carers (as appropriate) and other people who are important to the infant, child or young person, with care.

d) Whether children and young people are able to die in a place of their choosing.

e) Psychological well-being, for example resilience, depression or anxiety.

f) Preventing and managing pain and other distressing symptoms, including 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 approaching the end of life 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 are the key considerations to take account of when considering or arranging transition of a young person with a life-limiting condition to adult services?

e) What service arrangements can best provide for the needs of infants, children and young people as they approach the end of life, and for the needs of their family members and carers (as appropriate) during this time and after death?

f) 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?

g) What psychological interventions (including counselling and pharmacological 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 approaching the end of life?

h) What interventions are safe and clinically and cost-effective for managing pain and other distressing symptoms associated with life-limiting conditions?

i) What is the effectiveness of medically assisted hydration in infants, children and young people during end of life care?

j) What is the effectiveness of medically assisted nutrition support in infants, children and young people during end of life care?

k) 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?

l) What assessments are helpful in developing and reviewing the personalised care plan for infants, children and young people with life-limiting conditions?

m) What forms of social, practical, emotional, psychological, 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 aspects of communication and information provision help children and young people with life-limiting conditions, their family members or carers (as appropriate), and healthcare professionals to make decisions on advanced care planning, including the withdrawal of medical care?

o) When an infant, child or young person dies what considerations do their family members or carers (as appropriate) consider important (for example, communication, emotional and spiritual 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 who has died 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), 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 21 October to 18 November 2014.

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: 5th edition
- The guidelines manual.

Information on the progress of the guideline will also be available from the NICE website.