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

NICE guideline: short version

Draft for consultation, 1 July 2016

If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.

This guideline covers the planning and management of end of life care for infants, children and young people.

There is wide regional variation in paediatric palliative and end of life care practice, particularly in how services are delivered. Children, young people and their parents or carers have varied ideas about what represents good care and what is a priority for them at different stages.

This guideline covers the physical, emotional, social and spiritual elements of end of life care, and focuses on improving the child's or young person's quality of life and supporting their family. There are, for instance, recommendations on managing distressing symptoms and providing care and bereavement support after death as well as on how services should be delivered.

Who is it for?

- Professionals who provide end of life care for children and young people
- Commissioners of end of life care services for children and young people
- All children and young people with life-limiting conditions (conditions that are expected to result in an early death, either for everyone with the condition or for a specific person)

- Families, carers and other people who are important to children and young people with life-limiting conditions

This version of the guideline contains the recommendations, context and recommendations for research. The Guideline Committee's discussion and the evidence reviews are in the full guideline.

Other information about how the guideline was developed is on the project page . This includes the scope, and details of the Committee and any declarations of interest.

Contents

1. Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in Your care.

Making decisions using NICE guidelines explains how we use words to show the strength of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

In this guideline:

- ‘Children and young people’ refers to everyone under 18 years old. This includes neonates and infants when applicable.
- ‘Parents or carers’ refers to the people with parental responsibility for a child or young person. If the child or young person or their parents or carers (as appropriate) wish, other family members or people important to them should also be given information and be involved in discussions about care.

1.1 General principles

1.1.1 Recognise that children and young people with life-limiting conditions and their parents or carers have a central role in decision-making and care planning.

1.1.2 Regularly ask children and young people and their parents or carers how they want to be involved in making decisions about their care, because this varies between individuals, at different times, and depending on what decisions are being made.

1.1.3 Explain to children and young people and to their parents or carers that their contribution to decisions about their care is very important, but that they do not have to make decisions alone and the multidisciplinary team will be involved as well.

1.1.4 When difficult decisions must be made about end of life care, give children and young people and their parents or carers enough time and opportunities for discussions.

1.1.5 Be aware that continuity of care is important to children and young people and their parents or carers. If possible, avoid frequent changes to the healthcare professionals caring for them.

Communication

1.1.6 Think about how to provide information for children and young people with life-limiting conditions, taking into account their age and level of understanding. When appropriate, use formats such as:

- one-to-one discussion
- play, art and music activities
- written materials and pictures
- digital media, for example social media.

1.1.7 When deciding how best to communicate with the individual child or young person and their parents or carers, focus on their views and take account of:

- their personal and family situation
- their religious, spiritual and cultural beliefs and values
- any special needs, such as communication aids or the need for interpreters.

1.1.8 Ask children and young people with life-limiting conditions and their parents or carers:

- if there are other people important to them (such as friends, boyfriends or girlfriends, teachers, or foster parents) who they would like to be involved, **and if so**
- how they would like those people to provide a supporting role.

1.1.9 Think about how best to communicate with each child or young person and their parents or carers:

- when the life-limiting condition is first recognised
- when reviewing the Advance Care Plan
- if their condition worsens
- when they are approaching the end of life.

1.1.10 Ensure that all parents or carers are given the information and opportunities for discussion that they need.

1.1.11 When deciding which healthcare professional should lead on communication at a particular stage in a child or young person's illness, take account of:

- their expertise and ability to discuss the topics that are important at that time
- their availability, for example if frequent discussions are needed during an acute illness or near the end of life
- the views of the child or young person and their parents or carers.

Providing information

1.1.12 Be aware that most children and young people with life-limiting conditions and their parents or carers want to be fully informed about the condition and its management, and they value information that is:

- specific to the child's or young person's individual circumstances
- clearly explained and understandable
- consistent
- up-to-date
- provided orally and in writing.

1.1.13 Be aware that some children and young people and parents or carers may be anxious about receiving information about their condition.

1.1.14 Ask how children and young people and their parents or carers would like to discuss the life-limiting condition. For example:

- Ask which topics they feel are important and would particularly want information on.
- Ask whether there are topics they don't want detailed information on, and discuss their concerns.
- If appropriate ask parents or carers whether they think their child understands their condition and its management, and which professional their child would like to talk to about it.
- If appropriate, ask parents or carers what they think their child should be told about their condition.
- Discuss with the child or young person and their parents or carers their right to confidentiality and how information about their condition will be shared.
- Review these issues with them regularly, because their feelings and need for information may change over time or if their circumstances change.

1.1.15 When talking to children and young people and their parents or carers:

- be sensitive, honest and realistic
- give reassurance when appropriate
- discuss any uncertainties about the condition and treatment.

1.1.16 Be alert for signs or situations that the child or young person or their parents or carers need more information or discussions, for example if:

- they are more anxious or concerned
- the child or young person's condition deteriorates

- a significant change to the treatment plan is needed.

1.1.17 Provide children and young people and their parents and carers with the information they need on:

- their role and participation in Advance Care Planning (see Advance Care Planning)
- the membership of their multidisciplinary team and the responsibilities of each professional (see Multidisciplinary team)
- the care options available to them, including specific treatments, preferred place of care and place of death (see Preferred place of care and place of death)
- any relevant resources or support available to them.

1.2 Care planning and support throughout the child or young person's life

1.2.1 When a life-limiting condition is diagnosed, tell the child or young person (if appropriate) and their parents or carers about the condition and what it may mean for them.

1.2.2 Manage transition from children's to adult's services in line with the NICE guideline on transition from children's to adult's services.

1.2.3 In all discussions with children and young people and their parents or carers explore with them whether, based on their beliefs and values, there are any aspects of care about which they have particular views or feelings.

Advance Care Planning

1.2.4 Develop and record an Advance Care Plan for the current and future care of each child or young person with a life-limiting condition. The Advance Care Plan should include:

- demographic information about the child or young person and their family

- up-to-date contact information for:
  - the child or young person's parents or carers **and**
  - the key professionals involved in care
- a statement about who has responsibility for giving consent
- a summary of the life-limiting condition
- an agreed approach to communicating with and providing information to the child or young person and their parents or carers
- a statement covering what information about the child or young person and their parents or carers will be shared, and with whom
- an outline of the child or young person's life ambitions and wishes, for example on:
  - family and other relationships
  - social activities and participation
  - education
  - how to incorporate their religious, spiritual, and cultural beliefs and values into their care
- a record of significant discussions with the child or young person and their parents or carers
- agreed treatment plans and objectives
- education plans, if relevant
- a record of any discussions and decisions on
  - parallel planning of end of life care and medical care that is specifically for the underlying condition
  - the preferred place of care or place of death
  - organ and tissue donation (see recommendation 1.1.16)
  - management of life-threatening events, including plans for resuscitation or life support
  - specific wishes, for example on funeral arrangements and care of the body
- a distribution list for the Advance Care Plan.

1.2.5 Begin discussing an Advance Care Plan with parents during the pregnancy if there is an antenatal diagnosis of a life-limiting condition.

1.2.6 Develop and regularly review Advance Care Plans:

- with relevant members of the multidisciplinary team **and**
- in discussion with the child or young person and their parents or carers.

1.2.7 Advance Care Plans should take account of the child's or young person's life as a whole.

1.2.8 When developing the Advance Care Plan, take account of the beliefs and values of the child or young person and their parents or carers.

1.2.9 Explain to children and young people and their parents or carers that Advance Care Planning should:

- help them be involved in planning their care and give them time to think about their views carefully
- help them to understand the life-limiting condition and its management
- ensure that relevant professionals can plan, develop and implement a management plan for now and the future
- help to prepare for possible future difficulties or complications
- support continuity of care, for example if there are changes in the professionals involved or in the care setting (such as a hospital admission or discharge).

1.2.10 Share the Advance Care Plan with the child or young person and their parents or carers, and with relevant professionals and services involved in their care, such as:

- GPs

- hospital consultants
- hospices
- respite centres
- community nursing services
- their school and other education services
- ambulance services.

1.2.11 Update the advance care plan when needed, for example if:

- new professionals become involved
- the care setting changes (for example, hospital admission or discharge)
- the child or young person and their parents or carers move home.

Discuss the changes with the child or young person (if appropriate) and their parents or carers.

1.2.12 Share the Advance Care Plan with everyone involved each time it is updated.

1.2.13 When making an Advance Care Plan, discuss with the child or young person and their parents or carers:

- the nature of their life-limiting condition, its likely consequences and its prognosis
- the expected benefits and possible harms of the management options.

1.2.14 Be aware that all children and young people with life-limiting conditions should have an Advance Care Plan in their medical record, and that this should not be confused with a do-not-resuscitate plan.

1.2.15 Be aware that any existing resuscitation plan for a child or young person may need to be changed in some circumstances, for example if they are undergoing general anaesthesia.

Organ and tissue donation

1.2.16 Discuss with the child or young person and their parents or carers whether or not they are eligible to donate organs or tissue.

1.2.17 Involve the organ donation service if needed. If organ or tissue donation is not possible, explain why.

1.2.18 If the child or young person is eligible to donate organs or tissue, discuss this with them and their parents or carers when they are ready and as part of Advance Care Planning, and:

- provide written information leaflets if needed
- discuss how deciding to donate could affect their care, for example by changing their place of care and place of death
- explain the practical policies and procedures involved.

1.2.19 If the child or young person does not have the capacity to decide about organ and tissue donation, ask their parents or carers to make the decision.

1.2.20 For further information on organ donation, including donor identification and consent, see the NICE guideline on organ donation for transplantation.

Emotional and psychological support and interventions

1.2.21 Be aware that children and young people with life-limiting conditions and their parents or carers may have:

- emotional and psychological distress and crises
- relationship difficulties
- mental health problems.

1.2.22 Be aware that children and young people and their parents or carers may need support, and sometimes expert psychological intervention, to help with distress, coping, and building resilience.

1.2.23 Be aware that children and young people may experience rapid changes in their condition and so might need emergency interventions and urgent access to psychological services.

1.2.24 Be aware of the specific emotional and psychological difficulties that may affect children and young people who have learning difficulties or problems with communication.

1.2.25 Provide information to children and young people and their parents or carers about the emotional and psychological support available and how to access it.

1.2.26 Regularly discuss emotional and psychological wellbeing with children and young people and their parents or carers, particularly at times of change such as:

- when the life-limiting condition is diagnosed
- if their clinical condition deteriorates
- if their personal circumstances change
- if there are changes to their nursery care, school or college arrangements, or their employment
- if there are changes to their clinical care, for example if their care changes focus from treating the condition to end of life care.

Social and practical support

1.2.27 Be aware that children and young people with life-limiting conditions and their parents or carers have varied social and practical support needs, and that those needs may change during the course of their condition. This may include:

- material support, for example housing or adaptations to their home, or equipment for home drug infusions

- practical support, such as access to respite care
- technical support, such as training and help with administration of drug infusions at home
- education support, for example from hospital school services
- financial support.

Religious, spiritual and cultural support

1.2.28 Ask children and young people with life-limiting conditions and their parents or carers if they want to discuss the beliefs and values (for example religious, spiritual or cultural) that are important to them, and how these should influence their care. Be aware that they may need to discuss their beliefs and values more than once.

1.2.29 Take account of the beliefs and values of children and young people and of their parents and carers in all discussions with them and when making decisions about their care.

1.2.30 Be aware that:

- some children and young people and their parents or carers find discussions about their beliefs and values difficult or upsetting
- others find these discussions reassuring and helpful.

1.2.31 Be aware that children and young people may feel differently to their parents, carers, or healthcare professionals about how their beliefs and values should influence their care. If there is disagreement, try to make a mutually acceptable care plan, and if necessary involve the chaplaincy service or another facilitator.

1.3 Care of the child or young person who is approaching the end of life

1.3.1 Never assume that there is a do-not-resuscitate plan in place for a child or young person unless this is explicitly stated in their record.

1.3.2 Be aware that discussing the Advance Care Plan can be distressing for children and young people who are approaching the end of life and their parents or carers, and they may:

- be reluctant to think about end of life care
- have difficulties discussing end of life care with the professionals or with one another
- have differences of opinion about the care plan.

1.3.3 When making or reviewing the Advance Care Plan for a child or young person approaching the end of life, talk to the parents or carers about the care and support they can expect when the child or young person dies. Discuss their personal needs and feelings about this.

1.3.4 When a child or young person is approaching the end of life, think about and discuss with them and their parents or carers their specific support needs. Review these needs regularly.

1.3.5 When thinking about the possibility of treatment withdrawal for a child or young person who is approaching the end of life, take into account their beliefs and values and those of their parents or carers.

1.3.6 Be aware of the importance of talking about dying, and if appropriate discuss with children and young people:

- whether they want and are able to talk about dying
- whether they or their parents or carers would like support in talking to each other about this.

1.3.7 Take account of the beliefs and values of children and young people and their parents or carers when thinking about funeral arrangements and the care of the child or young person's body after death.

1.3.8 When a child or young person is approaching the end of life, discuss with their parents or carers what would help them, for example:

- important rituals
- recording or preserving memories (for example with photographs, hair locks or hand prints).

Preferred place of care and place of death

1.3.9 Discuss with children and young people with life-limiting conditions and their parents or carers where they would prefer to be cared for and where they would prefer to die.

1.3.10 Agree the preferred place of care and place of death with children and young people and their parents or carers, taking into account:

- their wishes, which are personal and individual
- their religious, spiritual and cultural values
- the views of relevant and experienced healthcare professionals
- safety and practicality.

1.3.11 If possible, services should ensure that children and young people can be cared for at their preferred place of care and die at their preferred place of death.

1.3.12 Explain that the place of care or place of death may change, for example:

- if the child or young person and their parents or carers change their minds **or**
- for clinical reasons **or**
- due to problems with service provision.

1.3.13 When discussing possible places of care or places of death with children and young people and their parents or carers, provide information about:

- the various care settings (for example home, hospice or hospital care)
- the care and support available in each setting
- practical and safety issues.

1.3.14 If the child or young person and their parents or carers prefer home care, take into account and discuss the practical considerations with them, such as the possible need for:

- home adaptations
- changes to living arrangements
- equipment and support.

1.3.15 If it is suspected that a child or young person may die soon and they are not in their preferred place of death, think about whether rapid transfer is possible and in their best interest. Discuss this with them and their parents or carers.

1.3.16 When planning rapid transfer to the preferred place of death, review and if necessary update the Advance Care Plan in discussion with the child or young person and their parents or carers and with the healthcare professionals who will be involved following the transfer. The updated Advance Care Plan should include a record of:

- any intended changes to care and when they should happen
- care plans that cover:
  - the final hours or days of life
  - what will happen if the child or young person lives longer than expected
  - support for the family after the child or young person dies
  - care of the child's or young person's body after death
- the professionals who will be involved and their responsibilities
- the professionals who will help with the practical and administrative arrangements after the death.

1.3.17 When planning rapid transfer of a child or young person to their intended place of death:

- be aware that the course of their condition may be unpredictable, and that they may die sooner or later than expected
- discuss any uncertainties about the course of their condition and how this could affect their care with them and their parents or carers
- ensure that relevant changes to the Advance Care Plan are implemented.

1.3.18 Think about using the rapid transfer service to allow the child or young person to be in their preferred place of death when withdrawing life-sustaining treatments, such as ventilation.

1.3.19 Before rapid transfer, agree with the parents or carers where the child's or young person's body will be cared for after their death.

Managing distressing symptoms

Managing pain

1.3.20 When assessing and managing pain, be aware that various factors can contribute to it, including:

- causative factors, for example musculoskeletal disorders or constipation
- environmental factors, such as an uncomfortable or noisy care setting
- psychological factors, such as anxiety and depression
- social, emotional, religious, spiritual or cultural considerations.

1.3.21 When assessing pain in children and young people:

- use an age-appropriate approach that takes account of their stage of development and ability to communicate

- try to identify what is causing or contributing to their pain, and be aware that this may not relate to the life-limiting condition
- take into account the following causes of pain and distress that might have been overlooked, particularly in children and young people who cannot communicate:
  - neuropathic pain (which can be associated with cancer)
  - gastrointestinal pain (which can be associated with diarrhoea or constipation)
  - bladder pain (which can be caused by urinary retention)
  - bone pain (which can be associated with metabolic diseases)
  - pressure ulcers
  - headache (which can be caused by raised intracranial pressure)
  - musculoskeletal pain (particularly if they have neurological disabilities)
  - dental pain.

1.3.22 Be aware that pain, discomfort and distress may be caused by a combination of factors, which will need an individualised management approach.

1.3.23 For children and young people who have pain or have had it before, regularly reassess for its presence and severity even if they are not having treatment for it.

1.3.24 Think about non-pharmacological interventions for pain management, such as:

- changes that may help them to relax, for example:
  - environmental adjustments (reducing noise)
  - music
  - physical contact such as touch, holding or massage
- local hot or cold applications to the site of pain
- comfort measures, such as sucrose for neonates.

1.3.25 When tailoring pain treatment for an individual child or young person, take into account their views and those of their parents or carers on:

- the benefits of pain treatment
- the following possible side effects of analgesia for moderate to severe pain (such as opioids):
  - unwanted sedation
  - reduced mobility
  - constipation.

1.3.26 Consider using a stepwise approach to analgesia in children and young people, based on pain severity and persistence:

- For mild pain, consider paracetamol[1] or ibuprofen[2] sequentially, and then in combination if needed
- For moderate to severe pain, consider one of the following options:
  - paracetamol[1] or ibuprofen[2] sequentially, and then in combination if needed **or**
  - low-dose oral opioids (such as morphine[3,4]), **or**

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[1] At the time of publication (2016) paracetamol did not have a UK marketing authorisation for use in children under 2 months of age by mouth, pre-term infants by IV infusion, children under 3 months rectally, children under 16 years as a concentrated liquid (500 mg/5 ml) for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[2] At the time of publication (2016) ibuprofen did not have a UK marketing authorisation for use in children under 3 months of age or weight less than 5 kg for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[3] At the time of publication (2016) oramorph liquid did not have a UK marketing authorisation for use in children under 1 year for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[4] At the time of publication (2016) sevredol tablets did not have a UK marketing authorisation for use in children under 6 years for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

  - transmucosal opioids **or**
  - subcutaneous opioids **or**
  - intravenously infused opioids (if a central venous catheter is in place).

1.3.27 If treatment with a specific opioid does not give adequate pain relief or if it causes unacceptable side effects, think about trying an alternative opioid preparation.

1.3.28 When using opioids, titrate treatment to find the minimal effective dose that will relieve and prevent pain.

1.3.29 Titrate treatment to provide continuous background analgesia, and prescribe additional doses for breakthrough pain if this occurs.

1.3.30 In addition to background analgesia, consider giving anticipatory doses of analgesia for children and young people who have pain at predictable times (for example when changing dressings, or when moving and handling). Do not include anticipatory doses when calculating the required daily background dose of analgesia.

1.3.31 Calculate opioid dosages for children and young people who are approaching the end of life using weight rather than age, because they may be underweight for their age.

1.3.32 If you suspect neuropathic pain and standard analgesia is not helping, consider a trial with other medicines, such as:

- gabapentin[5] **or**
- a low-dose tricyclic antidepressant (for example amitriptyline[6]) **or**

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[5] At the time of publication (2016) gabapentin did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[6] At the time of publication (2016) amitriptyline did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

- an anti-NMDA agent (for example ketamine[7] or methadone[8]), used under guidance from a specialist.

Managing agitation

1.3.33 Be aware that as children and young people with life-limiting conditions approach the end of life they may:

- become agitated, shown by restlessness, irritability, aggressive behaviour, crying or other distress
- show signs of delirium, such as confusion, disrupted attention, disordered speech, hallucinations and agitation.

1.3.34 If a child or young person who is approaching the end of life becomes agitated or delirious, make sure that they are safe from physical injury.

1.3.35 If a child or young person becomes agitated as they are approaching the end of life, look for causes and factors that may be contributing to this, including:

- medical disorders and conditions such as pain, hypoxia, anaemia, dehydration, urinary retention or constipation
- psychological factors such as fear, anxiety or depression
- adverse effects from medication.

1.3.36 For children and young people with a neurological disability who are approaching the end of life, be aware that the symptoms and signs of agitation or delirium can be mistaken for the signs and symptoms of seizures or dystonia.

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[7] At the time of publication (2016) ketamine did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[8] At the time of publication (2016) methadone did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

1.3.37 If a child or young person who is approaching the end of life needs treatment for agitation:

- identify and if possible treat any medical or psychological conditions that may be contributing to it
- think about non-pharmacological interventions, such as:
  - calm speaking, reassurance, distraction, and physical contact such as holding and touch
  - changes to the environment to make it more comfortable, calm and reassuring, to reduce noise and lighting, to maintain a comfortable room temperature, and to provide familiar objects and people and relaxing music
  - religious and spiritual support if this is wanted and helpful
- think about pharmacological interventions (beginning with low doses and increasing if necessary). Drugs to think about using include:
  - benzodiazepines, such as midazolam[9], diazepam[10] or lorazepam[11]
  - neuroleptics, such as haloperidol[12] or levomepromazine.

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[9] At the time of publication (2016) midazolam injection did not have a UK marketing authorisation for use in children and buccolam did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[10] At the time of publication (2016) diazepam rectal tubes did not have a UK marketing authorisation for use in children under 1 year of age for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[11] At the time of publication (2016) lorazepam did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[12] At the time of publication (2016) haloperidol did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

Managing seizures

1.3.38 If a child or young person is approaching the end of life and has a seizure, look for and if possible treat or remove any potential causes, triggers or contributing factors, for example:

- fever
- electrolyte disturbances
- drug reactions
- sleep deprivation
- pain
- excessive environmental stimulation.

1.3.39 If a child or young person is thought to be at increased risk of seizures, include seizure management in their Advance Care Plan. Think about the benefits and drawbacks of specific seizure treatments and:

- take into account how any decisions could affect the choices available for place of care and place of death **and**
- discuss this with the child or young person and their parents or carers.

1.3.40 For children and young people who are approaching the end of life, be aware that abnormal movements (such as dystonic spasms) might be mistaken for seizures. If in doubt seek specialist advice.

1.3.41 If a child or young person is approaching the end of life and is thought to be at increased risk of seizures (for example because they have had seizures before or because of an existing brain disorder), explain to them and their parents or carers:

- how likely it is that they may have a seizure
- what they might notice if a seizure happens
- that seizures can be frightening or upsetting

- what parents or carers should do if a seizure happens at home (for example, placing the child or young person in a safe position).

1.3.42 Ensure that parents or carers who have been provided with anticonvulsive therapy (such as buccal midazolam) know how and when to use it if the child or young person has a seizure at home.

Managing respiratory distress

1.3.43 If a child or young person is approaching the end of life and has respiratory distress, breathlessness or noisy breathing, think about and if possible treat the likely causes or contributing factors. If it is likely to be caused by:

- Anxiety:
  - discuss why they are anxious
  - reassure them and manage the anxiety accordingly
  - consider breathing techniques and guided imagery
- Physical discomfort – think about what could be causing the discomfort (for example their position) and help them with it if possible
- Environmental factors – think about environmental changes such as changing the temperature
- Accumulated airway secretions – think about repositioning, airway suctioning, physiotherapy or anti-secretory drugs
- Medical disorders (for example pneumonia, heart failure, sepsis or acidosis) – use appropriate interventions (according to their Advance Care Plan) such as:
  - anti-secretory agents
  - bronchodilators
  - nebulised saline
  - sedatives or anxiolytic agents
  - opioids
  - oxygen.

1.3.44 For children and young people who are approaching the end of life and have respiratory distress, breathlessness or noisy breathing that needs further assessment, consider referral to an appropriate specialist (for example, a respiratory or cardiac specialist).

1.3.45 If a child or young person is approaching the end of life and has respiratory distress, breathlessness or noisy breathing:

- explain to them and to their parents or carers that these symptoms are common
- discuss the likely causes or contributing factors
- discuss any treatments that may help.

Managing hydration

1.3.46 If a child or young person with a life-limiting condition is approaching the end of life or is dying, discuss how to manage their fluid needs with them and their parents or carers.

1.3.47 If a child or young person is dying, encourage and support them to drink if they want to and are able.

1.3.48 If a child or young person is dying, continue to provide them with lip and mouth care.

1.3.49 If a child or young person is dying and cannot drink, discuss with them (as appropriate) and their parents or carers whether starting or continuing enteral tube or intravenous fluids is in their best interests.

1.3.50 Be aware that enteral tube and intravenous fluids may have a significant effect on care, may be a burden for children and young people, and may mean the place of care and place of death need to be changed.

1.3.51 If a child or young person is given enteral or intravenous fluids, review this decision regularly to make sure it continues to be in their best interests.

Managing nutrition

1.3.52 If a child or young person is approaching the end of life or is dying, discuss how to manage their nutritional needs with them and their parents or carers.

1.3.53 If a child or young person with a life-limiting condition is dying, encourage and support them to eat if they want to and are able.

1.3.54 If a child or young person is dying and they are receiving enteral tube feeding or intravenous nutrition:

- discuss with them (as appropriate) or their parents or carers whether continuing this is in their best interest **and**
- review this decision regularly.

Recognising that a child or young person is likely to die within hours or days

1.3.55 For children and young people with life-limiting conditions, be aware that:

- there are various symptoms and signs (individually or in combination) that indicate they may be likely to die within hours or days **and**
- the wider clinical context is also relevant **and**
- there is often some uncertainty about this.

1.3.56 When assessing whether a child or young person is likely to die within hours or days, be aware that the following signs are common in the last hours or days of life, and monitor these non-invasively as far as possible:

- a change of breathing pattern (for example noisy, laboured or irregular breathing)
- impaired peripheral perfusion (which can be indicated by a pale or grey appearance, or a prolonged capillary refill time), including temperature instability

- loss of interest in or ability to tolerate drinks or food
- a marked and unexplained fall in urine output
- an altered level of awareness (for example reduced consciousness, alertness or responsiveness, excessive sleeping, or confusion)
- intractable seizures that keep occurring even with optimal management
- new onset of profound weakness
- increasing pain and need for analgesia.

1.3.57 When assessing symptoms and signs to decide whether a child or young person is likely to die within hours or days, take into account the wider clinical context, including:

- their normal clinical baseline
- past clinical events (such as previous episodes of temporary deterioration)
- the overall progression of their condition.

1.3.58 When assessing whether a child or young person is likely to die within hours or days, take into account the clinical judgement of healthcare professionals experienced in end of life care.

1.3.59 If the child or young person or their parents or carers feel that they are likely to die within hours or days:

- be aware that they may be correct
- discuss their concerns with them.

1.3.60 When a child or young person is likely to die within hours or days, support them and their parents or carers by:

- listening to any fears or anxieties they have **and**
- showing empathy and compassion.

1.3.61 When a child or young person is likely to die within hours or days:

- be aware that they or their parents or carers may not express their feelings openly, and may:
  - have intense and varied feelings such as fear, hopelessness or anger **or**
  - become more accepting of the inevitability of death
- give them and their parents or carers opportunities to talk.

1.3.62 If a child or young person is likely to die within hours or days, explain to them and their parents or carers:

- why you think this is likely, and any uncertainties
- what clinical changes can be expected
- whether you think the treatment plan should be changed.

1.3.63 When children and young people become seriously ill and are likely to die within hours or days, provide care as specified in their Advance Care Plan and review if needed.

1.3.64 Be aware that children and young people may have difficulty asking directly if they are going to die or are dying. Explore and discuss their concerns if you think they want to talk about this.

1.3.65 Be aware that parents or carers may have difficulty asking directly if a child or young person is dying. Explore and discuss their concerns if you think they want to talk about this.

1.3.66 If a child or young person may be approaching the end of life and they or their parents or carers want to be involved in making decisions about their care, discuss and review their Advance Care Plan with them.

1.3.67 When a child or young person is approaching the end of life, discuss with them and their parents or carers and with relevant healthcare professionals:

- any available invasive treatments that might be in their best interest
- any interventions they are currently receiving that may no longer be in their best interest.

1.3.68 If withdrawing a treatment for a child or young person who is dying, explain to them and to their parents or carers that it is often difficult to tell if or how this may affect them, or when they will die.

1.3.69 When a child or young person is likely to die within hours or days, ensure that they can have private time with their parents or carers.

1.4 Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person

1.4.1 Discuss with parents or carers the practical arrangements that will be needed after the death of their child, and provide this information in writing. This should cover matters such as:

- the care of the body
- relevant legal considerations, including
  - the involvement of the child death overview panel
  - the involvement of the coroner
  - registration of the death
- funeral arrangements
- post-mortem examination (if this is to be performed).

1.4.2 When a child or young person is approaching the end of life, discuss the bereavement support available with their parents or carers and provide them with written information.

1.4.3 When a child or young person is approaching the end of life, talk to their parents or carers about available psychological bereavement support groups.

1.4.4 Offer bereavement support to the parents or carers both before and after the death of a child or young person.

1.4.5 When planning bereavement support for parents or carers:

- talk to them about the support that is available and explore with them what they would find helpful and acceptable
- think about what support different professionals could provide, for example:
  - their GP
  - healthcare professionals who know the child or young person and are involved in their care
- think about the role of individual healthcare professionals in providing specific aspects of support
- inform the multidisciplinary team about the support plan.

1.4.6 When making a bereavement support plan with parents or carers, discuss possible options with them such as:

- opportunities to talk to the professionals caring for the child or young person, to:
  - discuss memories and events
  - answer any concerns or questions they may have
- home visits from the healthcare professionals caring for the child or young person
- bereavement support groups.

1.4.7 Give professionals involved in the care of the child or young person opportunities to talk about and explore their thoughts and feelings:

- when the child or young person is approaching the end of life **and**
- after the child or young person has died.

1.4.8 Following the death of a child or young person, ensure that relevant healthcare and other professionals are informed in a timely manner.

1.4.9 Update relevant documents and databases after the death of a child or young person (to avoid, for example, clinical appointments being offered by mistake).

1.4.10 Ensure that healthcare professionals providing bereavement support have the necessary expertise.

1.5 Service delivery

Multidisciplinary team

1.5.1 Children and young people with life-limiting conditions should be cared for by a defined multidisciplinary team.

1.5.2 As the child or young person’s circumstances change (for example if they change from having care primarily to manage their condition to having end of life care), the membership of the multidisciplinary team should be adjusted accordingly.

1.5.3 Depending on the needs of the child or young person, the multidisciplinary team may include:

- healthcare professionals from primary, secondary or tertiary services, including those with specialist expertise in palliative care
- social care practitioners
- education professionals
- spiritual or religious advisors
- hospice professionals.

1.5.4 Explain to children and young people and their parents or carers:

- who the multidisciplinary team members are and how they are involved in their care

- how the multidisciplinary team membership will change if the care that is needed or the care setting changes.

1.5.5 Think about involving children and young people and their parents or carers in multidisciplinary team meetings (when appropriate).

1.5.6 Think about having a named individual from the multidisciplinary team to act as a first point of contact and coordinate care for the child or young person and their parents or carers.

Rapid transfer arrangements

1.5.7 In collaboration with local hospitals, hospices, and community, primary care and ambulance services, establish a rapid transfer service for children and young people with life limiting conditions to allow urgent transfer to the preferred place of death (for example from the intensive care unit to their home, or other locations [such as a children's hospice]).

Home care

1.5.8 For children and young people with life-limiting conditions who are approaching the end of life and are having home care, services should provide (when needed):

- specialist medical advice at any time (day and night), for example telephone advice
- paediatric nursing care at any time (day and night)
- home visits by a healthcare professional with expertise in palliative care, for symptom management
- practical support and equipment for interventions including oxygen, enteral nutrition, and subcutaneous and intravenous therapies
- anticipatory prescribing for children and young people who are likely to develop symptoms.

1.5.9 Services should have agreed strategies and processes to support children and young people who are approaching the end of life and are having home care. These services should be based on established clinical networks, and should collaborate on care planning and service delivery.

1.5.10 Services for children and young people who are approaching the end of life and are being cared for at home should be able to support parenteral drug administration (for example, continuous subcutaneous opioid or anticonvulsant infusions).

Terms used in this guideline

Advance care plan

A formal care plan that includes details about the child or young person's condition, decisions made with them and their parents or carers (for example about managing symptoms), and their wishes and ambitions. This plan is a core element of their palliative care.

Approaching the end of life

The phase of illness after a change in the person's condition that means they are likely to die within weeks.

Children

Aged 0–12 years. This includes neonates and infants when applicable.

Dying

When the child or young person is likely to die in hours or days.

End of life care

Care throughout life for children and young people with life-limiting conditions. It includes symptom management and psychological, social, spiritual and practical support.

Life-limiting condition

Conditions that are expected to result in an early death, either for everyone with the condition or for a specific person.

Neonates

Babies aged up to 28 days.

Young people

Aged 13–17 years.

Implementation: getting started

This section will be completed in the final guideline using information provided by stakeholders during consultation.

To help us complete this section, please use the stakeholder comments form to give us your views on these questions:

1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.

2. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)

Context

The 2014 report Why children die: death in infants, children and young people in the UK noted that, despite improving mortality rates, in 2012 more than 2,000 children and young people aged between 1 and 19 died in England and Wales. In addition, it is estimated that almost 50,000 children and young people aged 19 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 this age group (Fraser 2012). Some of these children and young people also have severe disabilities and multiple complex health and social care needs.

End of life care combines a broad range of health and other care services, including hospitals, hospices, primary care and community professionals, ambulance services, dedicated palliative care teams, and other support providers. Services span the public sector and charities. Because of this, good communication, care coordination, and effective networking are essential. Children and young people are likely to need different services at different stages of their illness and they will get the best care possible when services communicate with and support each other.

Palliative care for adults is a well-established discipline, with evidence that if it starts early it can both enhance and even prolong life. Paediatric palliative and end of life care generally lasts longer and is for a wider range of life-limiting conditions than for adults (Spathis 2012). It begins when a life-limiting condition is diagnosed (which could be diagnosed at the antenatal period), and continues even if a child is having treatment for the underlying condition (World Health Organization 1998). Young people may continue to have palliative care after they turn 18, and it may be part of the transition to adult care (see the NICE guideline on transition from children's to adult's' services).

Children, young people and their parents or carers can have varied ideas about what represents good palliative and end of life care, and they may have differences of opinion with each other. They may also have different priorities at different stages in their lives.

This guideline covers the physical, emotional, social and spiritual elements of end of life care, and focuses on improving the child's or young person's quality of life and supporting their family. There are for instance recommendations on managing distressing symptoms and providing care and bereavement support after death. It also includes recommendations on how services should be delivered. The guideline is aimed at all providers of paediatric palliative and end of life care (whatever their level of practise), as well as children and young people with life-limiting conditions and their parents and carers.

The guideline covers children and young people with life-limiting conditions. It does not make recommendations for children or young people who die suddenly and unexpectedly (for example accidental death).

More information

To find out what NICE has said on topics related to this guideline, see our web page on end of life care.

Recommendations for research

The Guideline Committee has made the following recommendations for research. The Committee's full set of research recommendations is detailed in the full guideline.

1 Preferred place of care and place of death

When planning and managing end of life care, what factors help children and young people with life-limiting conditions and their parents or carers to decide where they would like end of life care to be provided and where they prefer to die?

Why this is important

When deciding the place of care and place of death, paediatric palliative care services sometimes assume that the main concern of parents and carers is that their child is able to die at home. However, the Guideline Committee's experience suggests that there are other significant factors for children and young people as well as their parents and carers (in particular, treatment of distressing symptoms) that may affect their choice of care setting. No research has been done to identify these factors, but it is important to recognise any reasons why a care setting might not be suitable. Understanding this would allow services to provide more personalised care, improve planning, and reduce waste and the cost of care.

2 Rapid transfer protocols

Do protocols for rapid transfer of children and young people with life-limiting conditions help ensure that they are able to die in their preferred place of death?

Why this is important

There are currently large regional differences in the availability and speed of rapid transfer to the preferred place of death for children and young people who are likely to die within hours or days. A number of local rapid transfer protocols and guidelines exist, but there is no evidence on what type of protocol would be useful to staff or would improve rapid transfer services. Research in this area could improve patient and family experience, as well as potentially reducing the cost of rapid transfer.

3 Emotional and psychological support and interventions

What emotional support do children and young people with life-limiting conditions and their parents or carers need, and how would they like these needs to be addressed?

Why this is important

Previous UK studies, such as The Big Study for Life-Limited Children and their Families from Together for Short Lives, have explored broad themes of psychological support needs. However, no studies have tried to understand psychological difficulties using standardised measures of psychological and relationship distress, or looked at what families want from psychological therapies.

Before research into effective interventions can be carried out, the following aspects of psychological difficulties need to be better understood:

- their range (for example low mood, worry, stigma, conflict in family relationships, avoidance, and distress about medical procedures)
- their severity (from mild long-term low mood to severe depression with suicidal thoughts)

- their context (for example socioeconomic status, and communication or mobility needs).

4 Managing breakthrough pain

What is the acceptability, safety, and effectiveness of different types of opioid analgesia for breakthrough pain in children and young people with life-limiting conditions who are having end of life care in the community?

Why this is important

Opioids (with morphine the most common first-line agent) are effective as background analgesia for children and young people who are having end of life care. However, no evidence was identified on how to provide safe and effective breakthrough analgesia (particularly in community settings). This potentially exposes children and young people who are having end of life care in the community to untreated pain or significant side effects. Studies should aim to provide evidence-based options to help manage breakthrough pain in the community. This would improve the safety and effectiveness of care for breakthrough pain, and would be likely to reduce emergency hospital admissions.

5 Recognising that a child or young person may be dying

What signs and symptoms indicate that a child or young person with a life-limiting condition is likely to die within hours or days?

Why this is important

Healthcare professionals are often asked to estimate how close a child or young person may be to death. There is very little evidence on which to base any such estimate. To help predict when a child or young person is in the last hours or days of life, a clearer understanding is needed of which groups of signs and symptoms indicate this most clearly. This would improve healthcare planning, but importantly would also allow families to realistically address their ‘hopes and wishes’ for their child's care while preparing themselves for the child’s last hours and days of life.