

# End of life care for people with life-limiting conditions

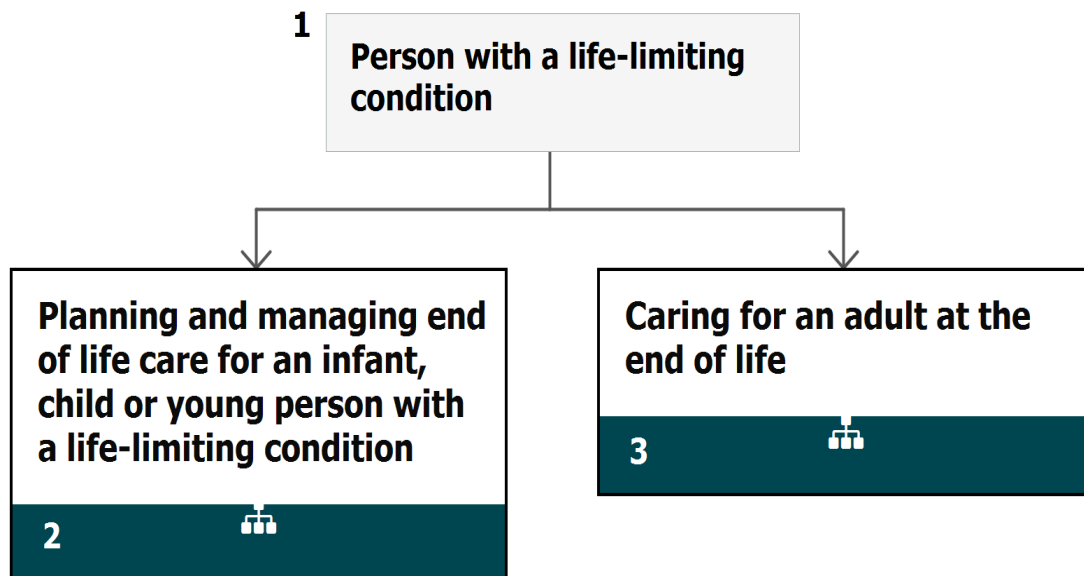
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/end-of-life-care-for-people-with-life-limiting-conditions>

NICE Pathway last updated: 11 September 2017

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



---

**1 Person with a life-limiting condition**

No additional information

**2 Planning and managing end of life care for an infant, child or young person with a life-limiting condition**

See [End of life care for people with life-limiting conditions / Planning and managing end of life care for a child or young person with a life-limiting condition](#)

**3 Caring for an adult at the end of life**

See [End of life care for people with life-limiting conditions / Caring for an adult at the end of life](#)

## **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

## **Approach 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

## **Chaplain**

an expert (with any or no religious beliefs) in religious, spiritual and or pastoral care for patients, families and staff, a chaplain also provides education and advice to organisations or trusts; chaplains work to a nationally recognised code of conduct and a set of standards and competencies

## **Chaplains**

experts (with any or no religious beliefs) in religious, spiritual and or pastoral care for patients, families and staff, chaplains also provide education and advice to organisations or trusts; they work to a nationally recognised code of conduct and a set of standards and competencies

## **Children**

aged 0-12 years – this includes neonates and infants

## **Child**

aged 0-12 years – this includes neonates and infants

## **Dying**

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

**End of life care**

in this interactive flowchart, end of life care for a child or young person includes the care and support given in the final days, weeks and months of life, and the planning and preparation for this

**Life-limiting condition**

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

**Life-limiting conditions**

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

**Neonate**

baby aged up to 28 days

**Paediatric palliative care**

an approach to care covering physical, emotional, social and spiritual support, which focuses on improving the quality of life for the child or young person and supporting their family members or carers, and includes managing distressing symptoms, providing respite care, and support with death and bereavement

**parallel planning**

planning for end of life care while taking account of the often unpredictable course of life limiting conditions; it involves making multiple plans for care, and using the one that best fits the child or young person's circumstances at the time

**Young people**

aged 13-17 years

## Young person

aged 13-17 years

## Your responsibility

### Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

### Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to

make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

### **Medical technologies guidance, diagnostics guidance and interventional procedures guidance**

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.