

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

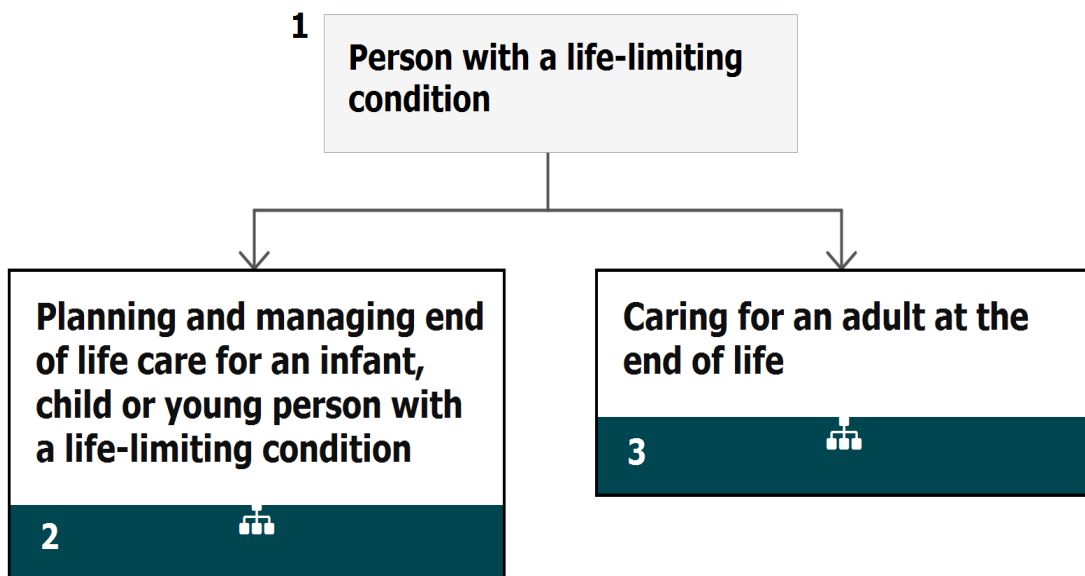
NICE Pathways bring together all NICE guidance, quality standards and other NICE information on a specific topic.

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 pathway see:

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

Pathway last updated: 13 March 2017

This document contains a single pathway diagram 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

The guidance in this pathway represents the view of NICE, which was arrived at after careful consideration of the evidence available. Those working in the NHS, local authorities, the wider public, voluntary and community sectors and the private sector should take it into account when carrying out their professional, managerial or voluntary duties. Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way which would be inconsistent with compliance with those duties.

## Copyright

Copyright © National Institute for Health and Care Excellence 2017. All rights reserved. NICE copyright material can be downloaded for private research and study, and may be reproduced for educational and not-for-profit purposes. No reproduction by or for commercial organisations, or for commercial purposes, is allowed without the written permission of NICE.

## Contact NICE

National Institute for Health and Care Excellence  
Level 1A, City Tower  
Piccadilly Plaza  
Manchester  
M1 4BT

[www.nice.org.uk](http://www.nice.org.uk)

[nice@nice.org.uk](mailto:nice@nice.org.uk)

0845 003 7781