End of life care for infants, children and young adults

NICE quality standard

Draft for consultation

April 2017

This quality standard covers end of life care for infants, children and young people (from birth to 18 years) who have a life-limiting condition. Life-limiting conditions are those that are expected to result in an early death, either for everyone with the condition or for a specific person. It also covers support for family members and carers. It describes high-quality care in priority areas for improvement.

It is for commissioners, service providers, health, public health and social care practitioners, and the public.

This is the draft quality standard for consultation (from 18 April 2017 to 16 May 2017). The final quality standard is expected to publish in October 2017.

Quality statements

Statement 1 Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Statement 2 Infants, children and young people with a life-limiting condition have a named medical specialist who coordinates their care.

Statement 3 Children and young people with a life-limiting condition are given information about emotional and psychological support and how to access it.

Statement 4 Infants, children and young people approaching the end of life have any unresolved distressing symptoms assessed by the specialist paediatric palliative care team.

Statement 5 Parents or carers of infants, children and young people approaching the end of life are offered bereavement support when their child is nearing the end of their life and after their death.

Statement 6 Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care.

A full list of NICE quality standards is available from the quality standards topic library.

Questions for consultation

Questions about the quality standard

Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement?

Question 2 Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?

Question 3 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Questions about the individual quality statements

Question 4 For draft quality statement 2: Can stakeholders suggest who the medical specialist should be?

Question 5 For draft quality statement 4: Can stakeholders suggest how performance would be measured in practice? Are there specific symptoms or timescales that would be more suitable as the focus of quality improvement?

Local practice case studies

Question 6 Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to NICE local practice case studies on the NICE website. Examples of using NICE quality standards can also be submitted.

Quality statement 1: Advance care plan

Quality statement

Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Rationale

Advance care plans can help people with a life-limiting condition plan for and receive care at the end of their life that is in line with their wishes. Discussing an advance care plan provides an opportunity for the child or young person, and their parents or carers to talk directly and honestly with members of the multidisciplinary team about their wishes. This allows the child to influence the care that they receive, which improves their experience of care. If a life-limiting condition is diagnosed in a baby during pregnancy, it is important that an advance care plan is made before the birth to ensure that the right care is provided. The plan should be made with the full involvement of the parents.

Quality measures

Structure

a) Evidence of local arrangements to ensure that, when a life-limiting condition is diagnosed in a baby during pregnancy, the parents are involved in developing an advance care plan before the birth.

Data source: Local data collection.

b) Evidence of local arrangements to ensure that children and young people with life-limiting conditions are involved in developing an advance care plan.

Data source: Local data collection.

c) Evidence of local arrangements to ensure that the parents or carers of infants with life-limiting conditions are involved in developing an advance care plan.

Data source: Local data collection.

Process

a) Proportion of infants, children and young people with a life-limiting condition who have an advance care plan.

Numerator – the number in the denominator who have an advance care plan.

Denominator – the number of infants, children and young people with a life-limiting condition.

Data source: Local data collection.

b) Proportion of pregnancies with a diagnosis of a life-limiting condition in the baby in which an advance care plan is developed before birth.

Numerator – the number in the denominator in which an advance care plan is developed before birth.

Denominator – the number of pregnancies with a diagnosis of a life-limiting condition in the baby.

Data source: Local data collection.

Outcome

Experience of care of children and young people with a life-limiting condition.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as hospitals, hospices and GP practices) ensure that systems are in place for children and young people with a life-limiting condition to be involved in developing an advance care plan.

Health and social care practitioners (such as secondary care doctors, nurses, GPs and district nurses) involve children and young people with a life-limiting condition in developing their own advance care plan.

Commissioners (clinical commissioning groups) ensure that they commission services in which children and young people with a life-limiting condition are involved in the development of their own advance care plan.

Children and young people with a condition that may shorten their life help to develop their own advance care plan. This is involves talking about the person's wishes for how they are cared for at the end of their life. Parents and cares are also involved in developing advance care plans for their child. This may sometimes be done before a baby is born if the condition is diagnosed during pregnancy.

Source guidance

- End of life care for infants, children and young people: planning and management (2016) NICE guideline NG61, recommendations 1.2.5, 1.2.6 and 1.2.10

Definitions of terms used in this quality statement

Advance care plan

A plan that provides information about the child or young person's care. It typically covers the concerns and wishes of children and young people about their care, including what should be done, where, how, when and by whom. Advance care plans also consider what should not be done. [NICE's guideline on end of life care for infants, children and young people]

Quality statement 2: Named medical contact

Quality statement

Infants, children and young people with a life-limiting condition have a named medical specialist who coordinates their care.

Rationale

Assigning a named medical specialist to an infant, child or young person with a life-limiting condition can improve their experience of care. A named medical specialist can provide information and support, be a consistent contact and ensure that the child's needs are taken into account.

Quality measures

Structure

Evidence of local arrangements to ensure that infants, children and young people with a life-limiting condition have a named medical specialist who coordinates their care.

Data source: Local data collection.

Process

Proportion of infants, children and young people with a life-limiting condition who have a named medical specialist to coordinate their care.

Numerator – the number in the denominator who have a named medical specialist to coordinate their care.

Denominator – the number of infants, children and young people with a life-limiting condition.

Data source: Local data collection.

Outcome

Experience of care of children and young people with a life-limiting condition.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as hospitals, hospices, GP practices and district nursing services) ensure that systems are in place for infants, children and young people with a life-limiting condition to have a named medical specialist who coordinates their care.

Health and social care practitioners (such as secondary care doctors, nurses, GPs and district nurses) ensure that the care of infants, children and young people with a life-limiting condition is discussed and coordinated with their named medical specialist.

Commissioners (clinical commissioning groups) ensure that they commission services in which infants, children and young people with a life-limiting condition have a named medical specialist who coordinates their care.

Infants, children and young people with a condition that may shorten their life have a healthcare professional who is their main contact. This person coordinates their care and gives them information and support throughout their care.

Source guidance

End of life care for infants, children and young people: planning and management (2016) NICE guideline NG61, recommendation 1.2.2.

Question for consultation

Can stakeholders suggest who the named medical specialist should be?

Quality statement 3: Emotional and psychological support for children and young people

Quality statement

Children and young people with a life-limiting condition are given information about emotional and psychological support and how to access it.

Rationale

Children and young people with life-limiting conditions can face a wide range of stressful and distressing circumstances, particularly when they become aware that their life will be shortened. Emotional support can help children and young people to cope with their distress and build resilience. This can help reduce the risk of developing psychological problems and enhance quality of life.

Quality measures

Structure

Evidence of local arrangements to ensure that children and young people with a life-limiting condition can access emotional and psychological support services.

Data source: Local data collection.

Process

Proportion of children and young people with a life-limiting condition who are given information about emotional and psychological support and how to access it.

Numerator – the number in the denominator who are given information about emotional and psychological support and how to access it.

Denominator – the number of children and young people with a life-limiting condition.

Data source: Local data collection. Receipt of information can be measured at key points, for example, at diagnosis, during regular reviews, and at discharge from hospital.

Outcome

a) Incidence of psychological problems in children and young people.

Data source: Local data collection.

b) Experience of care of children and young people with a life-limiting condition.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as hospitals, hospices, GP practices and district nursing services) ensure that systems are in place for children and young people with a life-limiting condition to be given information about emotional and psychological support and how to access it.

Health and social care practitioners (such as secondary care doctors, nurses, GPs and district nurses) give children and young people with a life-limiting condition and their parents or carers information about emotional and psychological support and how to access it.

Commissioners (clinical commissioning groups) ensure that they commission psychological support services that are available for children and young people with a life-limiting condition.

Children and young people with a condition that may shorten their life and their parents or carers are given information about support that can help the child cope with their feelings. It explains the support available to them and how to arrange it.

Source guidance

- End of life care for infants, children and young people: planning and management (2016) NICE guideline NG61, recommendation 1.2.26

Equality and diversity considerations

Children and young people with life-limiting conditions who have a learning disability may have difficulties understanding information provided to them. Healthcare practitioners caring for children and young people with a life-limiting condition should establish if the person has a learning disability and tailor any information accordingly. All support provided should be accessible, as far as possible, to people with learning disabilities.

Quality statement 4: Managing distressing symptoms

Quality statement

Infants, children and young people approaching the end of life have any unresolved distressing symptoms assessed by the specialist paediatric palliative care team.

Rationale

It is important to manage distressing symptoms, in particular pain and agitation, to ensure that children and young people approaching the end of life have the best quality of life possible. If the child continues to have distressing symptoms, the specialist paediatric palliative care team should carry out an assessment and provide treatment to resolve them as quickly as possible.

Quality measures

Structure

Evidence of local arrangements to ensure a specialist paediatric palliative care team is available to assess and support infants, children and young people approaching the end of life with unresolved distressing symptoms.

Data source: Local data collection.

Process

Proportion of infants, children and young people approaching the end of life with unresolved distressing symptoms who are assessed by the specialist paediatric palliative care team.

Numerator – the number in the denominator assessed by the specialist paediatric palliative care team.

Denominator – the number of infants, children and young people approaching the end of life with unresolved distressing symptoms.

Data source: Local data collection.

Outcome

a) Rates of unresolved distressing symptoms

Data source: Local data collection.

b) Experience of care for children and young people at the end of life.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as hospitals, hospices, GP practices and district nursing services) ensure that protocols are in place for access to the specialist paediatric palliative care team when children and young people are approaching the end of life and have unresolved distressing symptoms.

Health and social care practitioners (such as secondary care doctors, nurses, GPs and district nurses) involve the specialist paediatric palliative care team when children and young people are approaching the end of life and have unresolved distressing symptoms.

Commissioners (clinical commissioning groups) ensure arrangements are in place to support infants, children and young people who are approaching the end of life to access the specialist paediatric palliative care team when and have unresolved distressing symptoms.

Children and young people who are nearing the end of their life and continue to have distressing symptoms are seen by a team that specialises in caring for children at the end of life, called a paediatric palliative care team. The team can provide treatment to help with the symptoms quickly and make sure the child is as comfortable as possible.

Source guidance

- End of life care for infants, children and young people: planning and management (2016) NICE guideline NG61, recommendation 1.3.20

Definitions of terms used in this quality statement

Unresolved symptoms

Symptoms not adequately managed by standard therapeutic approaches. [Expert consensus]

Specialist paediatric palliative care team

The specialist paediatric palliative care team should include at a minimum:

- a paediatric palliative care consultant
- a nurse with expertise in paediatric palliative care
- a pharmacist with expertise in specialist paediatric palliative care
- experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support).

[End of life care for infants, children and young people with life-limiting conditions: planning and management (NICE guideline CG61) recommendation 1.5.4]

Question for consultation

Can stakeholders suggest how performance would be measured in practice? Are there specific symptoms or timescales that would be more suitable as the focus of quality improvement?

Quality statement 5: Emotional and psychological support for parents or carers

Quality statement

Parents or carers of infants, children and young people approaching the end of life are offered bereavement support when their child is nearing the end of their life and after their death.

Rationale

Bereavement support can help parents or carers to cope before and after the death of their child. It can help with emotional and mental health problems, and relationship issues, and provide information on how to inform other family members about what has happened. Bereavement support can also provide advice on the aspects of care following death such as autopsy, genetic risk for family planning, and the cause of death.

Quality measures

Structure

Evidence of local arrangements to provide formal bereavement support to parents or carers when children and young people are approaching the end of life and after their death.

Data source: Local data collection.

Process

Proportion of parents or carers of children and young people approaching the end of life who have a bereavement support plan.

Numerator – the number in the denominator who have a bereavement support plan.

Denominator – the number of parents or carers of children and young people approaching the end of life.

Data source: Local data collection.

Outcome

Experience of bereavement support for parents or carers.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as hospitals, hospices, GP practices and district nursing services) ensure that systems are in place to offer bereavement support to parents or carers of children and young people approaching the end of life and after their death.

Health and social care practitioners (such as secondary care doctors, nurses, GPs and district nurses) are aware of referral pathways to services that offer bereavement support to parents or carers of children and young people approaching the end of life and after their death.

Commissioners (clinical commissioning groups) ensure that they commission services that include bereavement support for parents or carers of children and young people approaching the end of life and after their death.

Parents or carers are offered bereavement support when their child is nearing the end of their life and after their death.

Source guidance

- End of life care for infants, children and young people: planning and management (2016) NICE guideline NG61, recommendation 1.4.4.

Definitions of terms used in this quality statement

Bereavement support

Talking therapies aimed at supporting an individual anticipating or experiencing the loss of a loved one. [Expert consensus]

Equality and diversity considerations

Parents and carers of children and young people with a life-limiting conditions may have a learning disability that means they have difficulties understanding information given to them about bereavement support. Healthcare practitioners caring for children and young people with a life-limiting condition should establish if the child's parents or carers have any learning disabilities. All support provided should be accessible, as far as possible, to people with learning disabilities.

Quality statement 6: Home care

Quality statement

Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care.

Rationale

Home-based care for infants, children and young people approaching the end of life can be preferable to hospital care and has been linked with improved patient experience. However, to ensure they receive the right care and have the highest quality of life possible paediatric nursing care and advice from a consultant in paediatric palliative care should be available at all hours of the day and night, if needed.

Quality measures

Structure

a) Evidence of local arrangements to ensure that paediatric nursing care is available 24 hours a day for infants, children and young people approaching the end of life who are being cared for at home.

Data source: Local data collection.

b) Evidence of local arrangements to ensure that advice from a consultant in paediatric palliative care is available 24 hours a day for infants, children and young people approaching the end of life who are being cared for at home.

Data source: Local data collection.

Process

a) Proportion of infants, children and young people approaching the end of life and being cared for at home who have 24-hour access to paediatric nursing care.

Numerator – the number in the denominator who have 24-hour access to paediatric nursing care.

Denominator – the number of infants, children and young people approaching the end of life and being cared for at home.

Data source: Local data collection.

b) Proportion of infants, children and young people approaching the end of life and being cared for at home who have 24-hour access to advice from a consultant in paediatric palliative care.

Numerator – the number in the denominator who have 24-hour access to advice from a consultant in paediatric palliative care.

Denominator – the number of infants, children and young people approaching the end of life and being cared for at home.

Data source: Local data collection.

Outcome

Rates of home care for Infants, children and young people approaching the end of life.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as hospitals, hospices, GP practices and district nursing services) ensure that systems are in place for infants, children and young people approaching the end of life and being cared for at home to have 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care.

Health and social care practitioners (such as secondary care doctors, nurses, GPs and district nurses) ensure that infants, children and young people approaching the end of life and being cared for at home are given contact details for paediatric nursing care and advice from a consultant in paediatric palliative care, available 24 hours a day.

Commissioners (clinical commissioning groups) ensure that they commission services to provide 24-hour home care paediatric palliative care services for children and young people approaching the end of life that includes 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care.

Infants, children and young people who are nearing the end of their life and are being cared for at home can have nursing care or advice from a specialist at any time of day or night, if they need it.

Source guidance

- End of life care for infants, children and young people: planning and management (2016) NICE guideline, NG61 recommendation 1.5.9

Definitions of terms used in this quality statement

Paediatric nursing care

The paediatric nurse should be qualified to support parenteral drug administration, for example, continuous subcutaneous opioid or anticonvulsant infusions. [End of life care for infants, children and young people with life-limiting conditions: planning and management (NICE guideline CG61), recommendation 1.5.11]

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Information about how NICE quality standards are developed is available from the NICE website.

See quality standard advisory committees on the website for details of standing committee 2 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the quality standard's webpage

This quality standard has been incorporated into the NICE pathway on end of life care in infants, children and young people.

NICE has produced a quality standard service improvement template help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

health-related quality of life for parents and carers of infants, children and young people having end of life care

- experience of end of life care for infants, children and young people, and their families and carers.

It is also expected to support delivery of the Department of Health's NHS outcomes framework 2016–17.

Resource impact

- NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact tool for the NICE guideline on end of life care for infants, children and young people to help estimate local costs.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard 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 quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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