

National Institute for Health and Care Excellence

End of life care for infants, children and young people

Stakeholder Comments – Draft Scope

<u>NOTE:</u> NICE is unable to accept comments from non-registered organisations or individuals. If you wish your comments to be considered but are not a registered stakeholder, please register via the NICE website or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them. Please fill in both the ‘stakeholder organisation’ and ‘name of commentator’ fields below in order for your comments to be considered.		
Stakeholder organisation:		<u>Together for Short Lives</u>
Name of commentator:		<u>James Cooper, Public Affairs and Policy Manager</u>
Comment No.	Section number Indicate number or <u>‘general’</u> if your comment relates to the whole document	Comments Please insert each new comment in a new row. Please do not paste other tables into this table, as your comments could get lost – type directly into this table
Example	3.4.6	Our comments are as follows
Proformas that are not correctly submitted as detailed in the line above may be returned to you.		

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1	General	<p>Together for Short Lives welcomes the opportunity to comment on this draft scope. We wish to emphasise how important it is that the guideline advocates a holistic model which focuses on the wider social and spiritual elements of children's palliative care - and achieving outcomes which are important to children, young people and their families. This should be in addition to the clinical aspects of caring for children and young people with life-limiting conditions.</p> <p>Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices.</p> <p>Hospice UK, the national body for hospice care, also supports our comments on the draft scope.</p>
2	1	<p>We call for the title to be amended to 'Palliative care for infants, children and young people'. On the basis that the draft scope encompasses the period between a child being recognised as having a life-limiting condition and their death, the term 'palliative care' would be more appropriate. The term 'palliative care' incorporates end of life care.</p>
3	3.1 (f)	<p>The scope should refer to the fact that it is not unusual for siblings in a family with the same life-limiting condition. Witnessing a sibling dying from the same condition they have will have particular impact on these young people. Their needs should be considered in the guidelines.</p>

4	3.2 (a) and (b)	<p>In 2011, ACT and Children's Hospices UK (the two charities which went on to merge to form Together for Short Lives) held 37 'Square Table' events across England (http://www.togetherforshortlives.org.uk/professionals/resources/3962_square_table_-_local_learning_and_evaluation_report). These sought to deepen the level of shared understanding of children's palliative care. Each event brought together life-limited and life-threatened young people and their families, a range of health, education and social care professionals and providers as well as many other representatives from across the community including faith and business leaders.</p> <p>At these events, families of children who need palliative care gave us a vital insight into what is important to them. The most important themes they identified were as follows:</p> <ul style="list-style-type: none"> • Families want to be made aware of the breadth of children's palliative care services available to them - in language which they can understand. • As many children and young people as possible should be supported to die at home if that is their or their family's choice. • Families want to have to tell their story to as few professionals and agencies as possible across health, social care and education; they want a more joined-up approach. • The best outcomes for children are achieved when parents work in partnership with professionals and volunteers; key working is essential to this. • Training and skills should be improved among generalist professionals who come into contact with children with life-limiting and life-threatening conditions. • Young people and families want smoother and better planned transitions to adulthood - with a better range of opportunities for them. • Children's palliative care services need to be better prepared to respond to increasing numbers of premature babies with complex health needs who are surviving longer due to technological advances. • Better support is needed to enable children who need long-term ventilation to spend time outside of hospital. <p>Professor Myra Bluebond-Langner has conducted studies of end of life care and decision making in the families of children with life-limiting conditions. This has highlighted the complexity for children who may wish their parents as adults to be responsible for making this decision on their behalf. Parents may find it difficult to make an advanced care decision; it may not be possible for some to make a plan about preferred place of care for a child who may die suddenly. For others it may not also be possible to care for a child at home if there is insufficient space to provide care or store drugs and equipment. To address this complexity, health care professionals should support families to think through advanced care planning options. Training is needed to help professionals understand the systemic issues in family or group decision-making processes - and to help them communicate effectively.</p>
5	3.2 (c)	This section should specify that the effective networks should include community services (including community children's nurses and community paediatricians), social care services and education.
6	3.2 (d)	We ask that "Children's Palliative Care (CPC) aims to make infants, children and young people with an incurable condition as comfortable as possible" is altered to "Children's Palliative Care (CPC) aims to make sure that infants, children and young people with an incurable condition have the best quality of life possible."
7	3.2 (d)	We ask that this paragraph uses the term 'psychological care and support' in place of 'psychological support'.

8	3.2 (f)	We ask that the guideline uses terminology which makes clear the difference between 'special' and 'specialised' palliative care. We suggest that 'dedicated' may be a better term than 'special'. We also ask the guideline is clear whether the term 'home' includes usual place of residence.
9	3.2. (g)	We are concerned that the term "emotional and psychological support" does not fully represent the range of therapeutic mental health and relationship or family interventions that are needed and currently provided to children and their families by palliative care services. We advocate the term "emotional and psychological care and support".
10	3.2 (g)	Qualified health play specialists (HPSs) play a key role in hospital, hospice and community palliative care for infants, children and young people. However, the role of "play" and of this group of professionals has not been acknowledged in this section or the wider scope document. Given their often central role in helping a child to understand their condition, express themselves, memory making, infant attachment, preparation for medical procedures and quality of life at end of life, the guidelines should include recommendations relating to the role of HPSs.
11	4.1 (c)	We ask that the guideline makes clear whether the term "children who die unexpectedly without a prior known life-limiting condition" refers to those who have died as a result of an acute illness, injury or trauma - or those who are later found to have had a life-limiting condition on post mortem - or both.
12	4.1.1(a)	<p>We suggest that the subgroups are amended to reflect Together for Short Lives' definitions of life-limiting and life-threatening conditions. These are as follows:</p> <ol style="list-style-type: none"> 1. Life-threatening conditions for which curative treatment may be feasible but can fail - such as cancer or congenital heart disease. 2. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well - such as Duchenne muscular dystrophy. 3. Progressive conditions without curative treatment options, such as Batten disease. 4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.
13	4.1.1 (a)	The guidelines should address antenatal palliative care planning, therapeutic support and intervention needed by expectant parents who are hoping to carry a baby with a life-limiting condition to term. Parents who are not referred to palliative care services until the birth of their child state that it would have been more helpful to access these services during pregnancy to prepare them for parenting a child with complex needs.
14	4.2 (a)	<p>A significant proportion of children's palliative care across the UK is provided by the voluntary and community sector. While this is funded in part from statutory sources, some services receive no funding at all from their local health and social care commissioners. We call for this guideline to recognise this. A more effective way to specify the category of service settings to which the guideline should apply are those services which are registered with regulators of health and social care and which provide:</p> <ul style="list-style-type: none"> • Specialist medical input (for example, medical consultants with expertise in the child's condition). • Sustainable community children's nursing teams. • Children's hospice services. • Specialised children's palliative care. • Care in secondary or tertiary hospitals. • Emotional and psychological care and support. • Local authority children's services - social care (including services providing equipment to disabled children), education, housing and leisure. • Community paediatrics. • Primary care.
15	4.3.1 (b)	This key issue should incorporate advanced care planning and end of life planning.

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16	4.3.1 (f)	Pharmacological and non-pharmacological approaches should be considered as part of this key issue.
17	4.3.1 (h and i)	We believe that “addressing the psychological and emotional needs of the infant, child or young person with a life-limiting condition” is preferable to “the management of psychological issues”.
18	4.3.1 (j)	Short breaks (respite) are an integral part of children’s palliative care and should be considered as part of this key issue.
19	4.3.1 (j)	The support needs of infants, children and young people and their family members or carers (as appropriate) should include helping them to come to terms with a child’s change in behaviour, emotional state and/or loss of cognitive ability.
20	4.3.1 (l)	The guideline should address the ethical decisions that need to be made relating to acute interventions and withdrawing of treatment. For example, the guideline could usefully address long-term ventilation and resuscitation.
21	4.3.1 (p)	Care after death should incorporate verifying and certifying the death. It should also include caring for the body and helping families to plan a funeral and burial in ways consistent with their culture and faith.
	4.3.1 (o)	We ask that term ‘initial’ is defined.
22	4.3.1	<p>In addition to the key issues to be covered, we believe that the following should be included:</p> <ul style="list-style-type: none"> • Nursing care - including mouth care and preventing and managing pressure ulcers. • Care provided by Allied Health Professionals (AHPs) - including physiotherapy. • Equipment - including the use of syringe drivers, oxygen, suction devices and hoists. • Training for professionals providing children’s palliative care. • Effective organisational models for providing children’s palliative care. • Collaborative and integrated working between education, health and social care agencies caring for children with life-limiting and life-threatening conditions. • Transfers between care settings. • Helping children and young people to access education, through transport, equipment and support workers with appropriate knowledge and skills. • Providing support to children, young people and families in making choices about care, including end of life choices. • Communicating with children, young people and families, particularly: <ul style="list-style-type: none"> ○ children and young people with profound levels of learning disability and other specific learning difficulties ○ children and young people affected by neurodegenerative conditions who have experienced a loss of their cognitive ability ○ those for whom English is not their first language ○ those with different gendered parenting roles ○ parents who are separated. • Safeguarding. • Providing palliative care which is consistent with the culture and faith of the child, young person and their family - from the point at which a life-limiting condition is recognised or diagnosed and before, during and after death.

23	4.3.2 (a)	<p>We ask that the term “specialised management of bereavement” is made clearer in the scope. If this means that therapeutic work with bereaved families is not to be covered by the guideline, it would be helpful if an explanation could be provided as to why bereaved families have been excluded. Palliative care services often provide bereavement services ranging from remembrance day events to therapeutic groups and individual or family therapy sessions. Families often prefer to seek these services from providers who knew them and their child during their illness and end of life.</p> <p>Given the large and complex systems of care around infants, children and young people with life-limiting conditions, if palliative care services withdraw entirely after the child’s death this can represent another significant loss for the family. The circumstances of a child’s death are often highly traumatising; expecting families to engage with new services or therapists at this difficult time may further traumatise them - particularly for those families in greatest distress and for whom “specialised” or expert therapeutic intervention may be necessary. Additionally, many mental health services may decline to work with recently bereaved individuals. This may leave recently bereaved families unsupported at the time of highest need.</p>
24	4.4 (d)	<p>We believe that this should be amended to: “Whether children and young people are cared for and are able to die in the place of their choosing - or in the place chosen by family members, carers (as appropriate) and other people who are important to the infant, child or young person if the child or young person wants them to decide.”</p>
25	4.4 (d)	<p>Some children and young people may not be able to verbalise their preferences; it would be helpful if the guidance could address approaches to assessing choice and communicating with individuals who are non-verbal, either because they are too young or whose condition means they are unable to express themselves verbally.</p>
26	4.4	<p>In addition to the proposed outcomes, we also believe that the following should be included:</p> <ul style="list-style-type: none"> • Whether care provided is appropriate to the child or young person’s age. • Whether the child, young person and their family are able to achieve the outcomes they wish to before and after the child’s death; these might include: <ul style="list-style-type: none"> ○ accessing education or training ○ starting or maintaining a job ○ starting or maintaining a hobby ○ living independently ○ building and maintaining a social life and social networks ○ having relationships. • Whether children, young people and families can access a regular short break. • Whether children, young people and families can access the treatments and equipment they need. • Whether children, young people and families are aware of the children’s palliative care services available to them. • Whether children, young people and families are provided with information in language which they can understand. • The number of times that families have to tell their story to professionals and agencies across health, social care and education in order to secure the care and support they need. • Whether children, young people and families have access to a key worker. • Whether children, young people and families have access to generalist professionals who understand how to support and care for children with life-limiting and life-threatening conditions. • Whether young people experience a smooth and well-planned transition to adult services.
27	4.5 (b)	<p>We believe that the term “approaching the end of life” should be amended to “with life-limiting or life-threatening conditions”. This would better reflect the proposed population group in 4.1.1.</p>

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28	4.5 (e)	We believe that the term “approach the end of life” should be amended to “with life-limiting or life-threatening conditions”. This would better reflect the proposed population group in 4.1.1.
29	4.5 (g)	We would like the scope of psychological interventions considered to also include therapies based on play, music and art therapy. Group therapy and befriending models of support should also be included within the scope.
30	4.5 (g)	“What psychological and psychopharmacological interventions are clinically and cost-effective...” should be used in place of “What psychological interventions (including counselling and pharmacological interventions)”. This is on the basis that pharmacological interventions are not a subgroup of psychological interventions.
31	4.5 (l)	We ask that plans for families and carers are also included in this question.
32	4.5 (p)	We ask that this question also asks when these discussions should take place.
33	4.5	In addition to the review questions proposed, we also believe that the following should be included: <ul style="list-style-type: none"> • What is the clinical and cost-effectiveness of key working? • What is the clinical and cost-effectiveness of short breaks (respite)?
34	General	We note that all the epidemiology in the scope relates to child death. To make sure it takes account of all children who need palliative care, the guideline should consider data on children and families currently living with a life-limiting or life-threatening condition. A focus on quality of life, as well as quality of death, is crucial.

Please add extra rows as needed.

Please email this form to: EndOfLifeCareChildren@nice.org.uk

Closing date: 5pm on 18 November 2014