

## End of life care for infants, children and young people

Consultation on draft guideline – deadline for comments 5pm on 12/08/16 email: [EndOfLifeCareChildren@nice.org.uk](mailto:EndOfLifeCareChildren@nice.org.uk)

	<p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on the draft recommendations presented in the short version and any comments you may have on the evidence presented in the full version. We would also welcome views on the Equality Impact Assessment.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none"><li>1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.</li><li>2. Would implementation of any of the draft recommendations have significant cost implications?</li><li>3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)</li></ol> <p>See section 3.9 of <a href="#">Developing NICE guidance: how to get involved</a> for suggestions of general points to think about when commenting.</p>
<b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):	Christian Medical Fellowship
<b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	
<b>Name of commentator person completing form:</b>	Rick Thomas
<b>Type</b>	[office use only]

Please return to: [EndOfLifeCareChildren@nice.org.uk](mailto:EndOfLifeCareChildren@nice.org.uk)

## End of life care for infants, children and young people

Consultation on draft guideline – deadline for comments 5pm on 12/08/16 email: [EndOfLifeCareChildren@nice.org.uk](mailto:EndOfLifeCareChildren@nice.org.uk)

Comment number	Document (full version, short version or the appendices)	Page number Or 'general' for comments on the whole document	Line number Or 'general' for comments on the whole document	Comments
Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.				
Example 1	Full	16	45	We are concerned that this recommendation may imply that .....
Example 2	Full	16	45	Question 1: This recommendation will be a challenging change in practice because .....
Example 3	Full	16	45	Question 3: Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact.....
1	Short	General		CMF welcomes these guidelines and supports the general tone and balance of the content. In particular, we welcome the absence of any reference to a 'pathway' of care, but the repeated emphasis given to the need for ongoing communication and continuous review.
2	Short	General		<p>We would like to see the scope of the guidelines extended to include <b>unborn</b> children with severe, life-threatening conditions. Development of screening techniques means that more women and their partners will be able to know earlier in pregnancy that their child has a life-threatening disorder. The availability of perinatal hospice care has been shown to reduce the number of women opting for abortion at this stage. Continuing support through the pregnancy and after birth has meant that some of these parents have been able to hold their babies after birth, if only for a matter of hours.</p> <p>A British Parliamentary Inquiry into abortion on the grounds of disability <sup>1</sup>concluded that: <i>'...the studies have all found that around 20% of women, between one and two years after an abortion for fetal abnormality, have a psychiatric condition, usually a complicated grief reaction, a depressive disorder or post-traumatic stress disorder.'</i> The availability of perinatal palliative care would encourage a higher proportion of pregnant women carrying a baby with a life-threatening disorder to continue their pregnancies and avoid many of the mental disorders associated with regret. In one British study, when parents were offered perinatal hospice as an option, 40% chose to continue with their pregnancies.<sup>2</sup></p> <p>Parents need and deserve best-practices care. Britain has a unique programme of children and baby hospices. These</p>

<sup>1</sup> <http://abortionanddisability.uk/assets/Abortion-and-Disability-Report-17-7-13.pdf>

<sup>2</sup> Breeze AC et al. Palliative care for prenatally diagnosed lethal fetal abnormality. Arch Dis Child Fetal Neonatal Ed. 2007 Jan;92(1):F56-8.

Please return to: [EndOfLifeCareChildren@nice.org.uk](mailto:EndOfLifeCareChildren@nice.org.uk)

## End of life care for infants, children and young people

Consultation on draft guideline – deadline for comments 5pm on 12/08/16 email: [EndOfLifeCareChildren@nice.org.uk](mailto:EndOfLifeCareChildren@nice.org.uk)

				<p>offer a positive, civilised response to the challenge of disability. Examples of hospices providing perinatal hospice/palliative care programs and support include The Maypole Project<sup>3</sup> which offers emotional psychosocial support, including prenatal support, integrated with children's hospices and children's hospitals in southeast London and Kent to ensure a holistic package of care. They support children diagnosed with a complex life-threatening or life-shortening illness and/or disability between birth and 18 years of age. Also Zoe's Place baby hospice which offers palliative, respite and terminal care for babies/infants aged from birth to five years old.<sup>4</sup></p> <p>Whenever possible, we recommend that every parent who receives a prenatal diagnosis should be given information written by individuals who have received the same news, and experienced the same disability in their child.</p>
3	Short	4	11-13	<p>The guidelines are careful to avoid the use of the term 'consent'. Clearly, the capacity to consent to treatment is dependent on age, maturity and cultural background - consent can only occur if the child fully understands and agrees. The notion of 'assent' might be useful to introduce - assent can occur if the parent/carer fully understands and the child assents by agreeing to trust the parent/carer.</p> <p>Occasionally a child may be too afraid, confused, or ignored to refuse assent, in which case the term assent may be misused to cover a child's refusal.</p> <p>In some cultures, children's rights are not emphasised – rather it is the rights of a parent or community leader that are emphasised. We suggest it is important in the model of shared decision-making, outlined in the guidelines, that the child's rights are respected at all times, even when these are counter-cultural.</p>
4	Short	6	7	<p>As well as being accurate and truthful, the language employed by health professionals should be in lay terms, neutral, compassionate and person-centred. Many families facing complex and frightening problems seek wise counsel, advice and support from professionals, not just the communication of percentages and clinical facts.</p> <p>Health professionals should signpost families to a wide range of sources of information, including information leaflets covering all their options, and telephone and online helplines manned by trained professional counsellors.</p>
5				
6				

Insert extra rows as needed

### Checklist for submitting comments

<sup>3</sup> <http://www.themaypoleproject.co.uk/>

<sup>4</sup> <http://www.zoes-place.org.uk>

Please return to: [EndOfLifeCareChildren@nice.org.uk](mailto:EndOfLifeCareChildren@nice.org.uk)

## End of life care for infants, children and young people

**Consultation on draft guideline – deadline for comments** 5pm on 12/08/16 **email:** [EndOfLifeCareChildren@nice.org.uk](mailto:EndOfLifeCareChildren@nice.org.uk)

- Use this comment form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include page and line number (not section number) of the text each comment is about.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, comment forms do not include attachments such as research articles, letters or leaflets (for copyright reasons).  
We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.

You can see any guidance that we have produced on topics related to this guideline by checking [NICE Pathways](#).

**Note:** We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.