

## Care of the Dying Adult

Consultation on draft guideline – deadline for comments 5pm on 09/09/2015 email: [CareofDyingAdult@nice.org.uk](mailto:CareofDyingAdult@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 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. 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>Stakeholder organisation(s)</b> (or your name if you are commenting as an individual):		<u>Childhood Bereavement Network</u>		
<b>Name of commentator</b> (leave blank if you are commenting as an individual):		<u>Alison Penny</u>		
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 2: 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	Long	87-107		In the section on <b>communication</b> , we were disappointed not to see a review of the evidence on the need for – and recommended ways of – supporting families to communicate specifically with children and young people when someone important to them is dying. We recognise that this section cross-references with Guideline CG138 on Patient

Commented [LD1]: Delete as appropriate

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			<p>experience in adult NHS services: improving the experience of care for people using adult NHS services but we are aware that this earlier guidance does not look at the specific information and support needs of patients' children.</p> <p>Each year in England and Wales, we estimate that 20,400 parents die, leaving dependent children (CBN, 2015). Many other children and young people are bereaved of someone else important in their lives each year.</p> <p>Children and young people facing the terminal illness of a parent have elevated levels of depression and anxiety: the most stressful time for them seems to be before the death (Seigel et al 1996). Their levels of anxiety are inversely correlated with the quality of communication in the family (Beale et al 2004) and with their perception of the well parent's general openness (Raveis et al 1999).</p> <p>Many children are not told when their parent is dying (Barnes et al 2000) and even families with open communication styles can struggle to communicate specifically about the parent's illness and impending death (Siegal et al 1996).</p> <p>Understandably, parents can struggle to have open supportive conversations with their children when they are facing the death of someone close: dealing with the complexities and disruptions of treatment and crisis can mean there is little time to talk about what is happening and to reassure children. There are emotional barriers to talking too: sometimes parents are worried about breaking down in front of their children or don't want to upset them with difficult news. The uncertainties of the illness or trauma can leave parents struggling to give children clear and consistent information. Young people themselves talk about their need to be kept informed, but say they find it difficult to open up conversations because they don't know how to, or because they are worried about upsetting people.</p> <p>Children and young people have specific information needs when preparing for the death of someone important in their lives. These may include reassurance on very specific concerns such as who will care for them after the person dies. They also need careful, age-appropriate explanations of specific terms and situations, including conditions, treatments and prognoses. Adults in the family can benefit from advice about how to talk to the children, and information about their children's reactions which may be disconcerting. Basic information can be helpful in itself, and can help parents support their children more effectively (Kennedy &amp; Lloyd-Williams, 2009).</p> <p>Clinical guidelines exist to support healthcare professionals help parents and carers to communicate with their children about the illness and death (Christ, 2000; Winston's Wish 2001; Fearnley 2012). A controlled study found that good quality support from healthcare professionals, including helping families communicate about the facts of the illness, treatment and death, reduced children's anxiety and improved their perception of their surviving parent's competence: outcomes with long term significance for how children learn to live with the loss (Christ et al 2005).</p>
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			<p><i>'Everyone was trying to stop telling me things, trying to hide stuff from me saying 'it will be better if you don't know these things' but I feel that if they'd have told me I'd have coped better. Because not knowing it was like, obviously it wasn't sudden because it was cancer but it was quite sudden because I didn't know how ill he was because nobody would tell me. Two days before he died I went to see him, and before I went everyone was telling me he was ok. And I went to see him and he was wired up to every machine possible and that just made me even more upset to feel that nobody could trust me to tell me. It felt to me as if they couldn't tell me, and I wanted to know.'</i> Bereaved young person.</p> <p><i>'He was in a big ward...the nurses didn't talk to me, they didn't help, they just walked about with needles and things. They could have told me what was happening and said what was going to happen, instead of just walking past me'.</i> Child bereaved of her father.</p> <p><u>References</u></p> <ul style="list-style-type: none"> <li>• Barnes J, Kroll L, Burke O, Jones A, Stein A (2000) Factors predicting communication about a diagnosis of maternal breast cancer to children Journal of Psychosomatic Research 52, 209-214</li> <li>• Beale EA, Sivesind D, Bruera E (2004) Parents dying of cancer and their children. Palliative and Supportive Care 2, 387-393</li> <li>• CBN (2015) Key Statistics on Childhood Bereavement <a href="http://www.childhoodbereavementnetwork.org.uk/research/key-statistics.aspx">http://www.childhoodbereavementnetwork.org.uk/research/key-statistics.aspx</a></li> <li>• Christ, G (2000) Healing Children's Grief New York: Oxford University Press</li> <li>• Christ G, Raveis V, Siegal K, Daniel K, Christ A (2005) Evaluation of a preventive intervention for bereaved children Journal of Social Work in End-of-Life and Palliative Care 1,3, 57-81</li> <li>• Fearnley R (2012) <i>Communicating with children when a parent is at the end of life</i> London: Jessica Kingsley Publishers</li> <li>• Kennedy, Vida L.; Lloyd-Williams, Mari Information and communication when a parent has advanced cancer. Journal of Affective Disorders. Vol 114(1-3), Apr 2009, 149-155.</li> <li>• Raveis V, Siegel K, Karus M, (1999) Children's psychological distress following the death of a parent Journal of Youth and Adolescence 28, 165-180</li> <li>• Siegal, K; Karus, D; Raveis, V (1996) 'Adjustment of children facing the death of a parent due to cancer' Journal of the American Academy of Child and Adolescent Psychiatry 35: 442-450</li> </ul>
2	Long	108	<p>Recommendation 9: After 'and those important to them' insert 'including children and young people OR Include new bullet point in list 'information about ways of talking to children and young people in the family about what is happening'</p>

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3	Long	134		Recommendation 17: After 'if any are specified' insert new bullet point: 'family and carers' (including children and young people's) support needs before and after the death'.
3	Short	5	22	After 'and those important to them' insert 'including children and young people OR Include new bullet point in list after line 29 'information about ways of talking to children and young people in the family about what is happening'
4	Short	7	26	After 'if any are specified' insert new bullet point: 'family and carers' (including children and young people's) support needs before and after the death'.
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Insert extra rows as needed

### Checklist for submitting comments

- Use this comment form and submit it as a Word document (not a PDF).
- 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.

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- 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.

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