

Improving supportive and palliative care (update)

NICE National Institute for
Health and Care Excellence

Consultation on draft scope – deadline for comments 17.00 on 29/01/2016

email: Supportivepalliativecare@nice.org.uk

Please note:		Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline. Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope.	
Stakeholder organisation (if you are responding as an individual rather than a registered stakeholder please state name here):		<u>Childhood Bereavement Network</u>	
Name of commentator (if you are responding as an individual rather than a registered stakeholder please leave blank):		<u>Alison Penny</u>	
Comment No.	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, as your comments could get lost – type directly into this table.
Example	3	55	The draft scope currently excludes people who have already been diagnosed. We feel this group should be included because...

1			<p>We understand the rationale for excluding children with long-term and life-limiting conditions, as they are covered in the separate forthcoming guideline for the care of children at the end of life. This guideline will also cover the needs of siblings of these children</p> <p>However, a separate group of children are affected when their parent or carer (or someone else important) has palliative care needs. This group has specific support needs before and after their parent's death, yet are often overlooked in policy and practice issues. We believe the EIA (and the scope) should make specific reference to this group, in line with the 2004 guidance p24: <i>'The Guidance concentrates on services for adults, but the needs of children who may be affected by an adult carer or relative with cancer are acknowledged'</i>.</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>Children bereaved of a parent are at increased risk of poor mental and physical health. Compared to their non-bereaved peers they are:</p> <ul style="list-style-type: none"> a) are at increased risk of early mortality, being 50% more likely to die before middle age (Li et al 2014) and more likely to die early once over the age of 65 (indicating a persistent association with early mortality) (Smith et al, 2014). b) are 3 times more likely to have physical health symptoms in the clinical range, more likely to have a serious illness or accident, or to have been hospitalised (Worden 1996)
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			<p>c) are more likely to do things that risk their health including smoking, drinking (Sweeting et al 1998), not wearing a seat belt, being in a car with a driver who has been drinking, carrying a weapon, being in a physical fight (Hamdan et al, 2012), being hospitalised for drug or alcohol use (Wilcox et al 2010). Those bereaved suddenly are more likely to have substance or alcohol abuse disorders (Brent et al 2009).</p> <p>d) are 1.5 times as likely to have a mental disorder (Fauth et al, 2009); more likely to report depressive symptoms at the age of 30 (women) (Parsons 2011); 1.71 times more likely to attempt suicide in young adulthood (Jakobsen and Christiansen 2011); more likely to be hospitalised for a psychiatric disorder (Wilcox et al 2010)</p> <p>This group merits specific inclusion.</p>
2	6	139	<p>We would like to see specific mention here of children and young people included in the group that may be important to the person with life-limiting conditions. In our experience, if this group is not explicitly included, they are often overlooked.</p> <p>Alternatively, an addendum could be added to line 148:</p>
3	6	148	<p>1.7 should also include identification of these people: eg</p> <p>‘When and how often should supportive care needs be reviewed in carers and those (including children and young people) who are important to people with life-limiting conditions? How should these people best be identified?’</p>
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Checklist for submitting comments

- Use this 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.

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- 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, do not include attachments such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments.

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