

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>Together for Short Lives</u>	
Name of commentator (if you are responding as an individual rather than a registered stakeholder please leave blank):			
Comment No.	Page number or ' <u>general</u> ' for comments on the whole document	Line number or ' <u>general</u> ' 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	1	26	This should be changed to 'It <i>will</i> also be relevant for' as the new guidelines should be used by all services providing palliative care, including children's hospices that support young people over the age of 18.
2	3	52	The draft scope currently includes only adults with life-limiting conditions and we feel that this should include adults with life-threatening conditions. Life-threatening conditions or episodes are those for which curative treatment may be feasible but can fail. The trajectory of their illness may be unclear, and it is therefore vital that they are able to access supportive and palliative care.
3	4	69-70	We support the inclusion of 'carers and those important to them' in the holistic needs assessment as the needs of families and loved ones are often overlooked in care planning. This support for families is vital as families of young people with life-shortening conditions are usually the primary carers and face huge pressures in providing around the clock care - most relationships will suffer, with 36% experiencing a breakdown of the family.
4	4	71-76	We support this holistic definition of needs but ask that it includes bereavement support for 'carers and those important to them'.

5	4	75	We support the inclusion of 'sexual functioning (and/or 'wellbeing')' as part of the holistic needs assessment. The sexual needs of young people with life-shortening conditions are often overlooked and so Together for Short Lives, in partnership with the Open University, has produced a guide which aims to help break down taboos and enable professionals to gain skills and confidence in exploring sexuality for these young people safely and legally – "Talking about Sex, Sexuality and Relationships: Guidance and Standards". This guide should be referenced in the guidelines as a resource for professionals working with young people.
6	4	81, 87	We support the recognition that palliative care requires care 24/7. Around the clock care, provided by families and supported by professionals and services, can improve outcomes for children and young people and reduce unplanned, unnecessary and expensive emergency hospital admissions.
7	7	179, 216	Question 3.8 is of vital importance for young people. Due to advances in medicine and care, more young people are living into adulthood. However, many young people describe transition as a 'cliff-edge' as the support they previously received is taken away. It is crucial, therefore, that these guidelines relate to the forthcoming 'Transition from children's to adults' services' guidelines and we welcome the inclusion of this document in the 'Links with other NICE guidance' section.
8			

Add extra rows if needed

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.
- 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.

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.

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