

Care of the Dying Adult

Consultation on draft guideline – deadline for comments 5pm on 09/09/2015 **email:** 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"> 1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) <p>See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.</p>				
Stakeholder organisation(s) (or your name if you are commenting as an individual):		<u>Together for Short Lives</u>		
Name of commentator (leave blank if you are commenting as an individual):		<u>Lizzie Chambers, Director of Development</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	Short	3	5	We are concerned that although the recommendation acknowledges that 'it is often difficult to be certain about whether a person is dying', there is no reference to the additional challenges faced when anticipating when young adults are entering their end of life phase - particularly when they are living with a

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				life-threatening or life-limiting condition and/or are cognitively impaired. Young people have a range of conditions with unpredictable trajectories, which may mean they have repeated 'end of life' episodes, any of which could be the final one. Palliative care services also have relatively little experience of caring for such individuals. The guideline should recognise these factors.
5	Short	5	17	We call for the guideline to emphasise the need for clear communication between children's and adults' services if a young person enters the end of life stage while in transition from children's to adults' services.
2	Short	9	15	This recommendation should acknowledge that some young adults will want their parents or guardians to be involved in decisions about withholding or withdrawing hydration. We ask that the Royal College of Paediatric and Child Health's document 'Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice' is used to inform the guideline.
4	Short	General	General	The needs of young adults at the end of their lives are different from older adults - and also from children. There is a wide range of conditions, from which young adults die and their condition often fluctuates. As they reach adulthood, young people will also have varying developmental needs. While some young adults may wish and be able to have more autonomy and express choice over their care, others may have profound cognitive impairment so decisions will need to be made in the context of their family unit. The clinical guideline should emphasise the need for age-appropriate end of life care to be provided to this unique group, in age-appropriate settings. Both of these groups will include young adults who will have lived with life-limiting conditions as children and young people - and in some instances from birth. They will have undergone transition from children's to adult's palliative care services. This group of young adults is growing in number due to improved medical treatments, information and support (Fraser LFK et al 2013, Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010). Adulthood is often the time when young people with life-limiting conditions (for example, Duchenne Muscular Dystrophy) experience a deterioration in their condition. This means that they are more likely to need end of life care once they have started to use adult services.
6	Short	10	24	This recommendation should address the fact that some adults will lack mental capacity to make decisions about their end of life care. In such cases, their family may be involved in making such decisions. This

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				should be addressed in any subsequent recommendations which are not covered in this clinical guideline. The extent to which young adults are regarded as having capacity to make decisions about their care should take into account the importance of the issue in question. The capacity needed by an individual to decide whether to refuse food and drink, for example, is different to that required to decide which clothes to wear.
8	Full	28	6	This section should include the upcoming NICE guidance 'Transition from children's to adult services'. This is expected to be published in February 2016.

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.
- 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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