

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>				
<p>Stakeholder organisation(s) (or your name if you are commenting as an individual):</p>		<p><u>Motor Neurone Disease Association</u></p>		
<p>Name of commentator (leave blank if you are commenting as an individual):</p>		<p><u>Chris James</u></p>		
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
<p>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.</p>				
1	short	3	11-12	The current physiological, social, spiritual and psychological needs of the person must also be assessed; without this, it is impossible to make meaningful assessments of changes in these needs.
2	short	4	22	This sentence should be strengthened: for many people, monitoring will need to be much more regular than every 24 hours; the current stipulation of 'at least every 24 hours' is inadequate and may give some professionals the impression that this is generally an acceptable minimum. Professionals should be encouraged to monitor for further changes much more regularly.
3	short	5		Section 1.2 should include a stipulation that the dying person be assured that someone will be available, though a specified route or point of contact, for these purposes at all times.

Comment [LD1]: Delete as appropriate

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4	short	6	19-22	We agree that the implementation of the dying person's care plan should be discussed with honesty and transparency, but urge that it should also be done with sensitivity; there is enormous potential for such discussions to become so honest as to be brutal. There may be a historical problem of dying people and those around them not being made aware of their position because care professionals over-prioritise sensitivity, and this is clearly undesirable; but it is not an either/or choice. Care professionals must be able to strike an appropriate balance between sensitivity and honesty – this is not easy, but it is precisely in order to assist with difficulties of this sort that guidance is needed.
5	short	9	13-14	The double negative in this statement makes its meaning highly obscure. If this item of guidance is to be retained, it must be re-written: we recommend removing the double negative, and casting it in the active voice rather than the passive (eg 'death may well occur at the same rate even if the dying person is given clinically assisted hydration'). We also query whether it is entirely correct to say that a lack of clinically assisted hydration is unlikely to hasten death – depending on why the person is dying and how quickly, a lack of hydration surely could accelerate the process.
6	short	12	23-25	We are pleased to see the guidance not to offer oxygen for breathlessness as a matter of routine; for people with MND, the administration of oxygen can be fatal.
7	short	17	10-11	Education in respect of communication at the end of life must be refreshed regularly for all clinicians and care professionals.
8	short	general		Although section 1.2.1 advises that the cognitive status and any possible speech, language or other communication needs should be taken into account when establishing the needs and expectations of people who may be entering the last days of their life, the guideline does not go on to offer advice on end of life care for people with cognitive impairments or communication needs. This should be addressed.
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Insert extra rows as needed

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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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