

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>Age UK</u></p>		
<p>Name of commentator (leave blank if you are commenting as an individual):</p>		<p><u>Tom Gentry</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	Full	General	General	<p>We are concerned the guideline is making generic recommendations across a highly disparate number of settings. Though the clinical factors may be the same, there are very different practical barriers to delivering effective end of life care in hospital, a care home, and a person's own home, for example. Availability of nursing support, particularly out of hours in the community is frequently cited as a factor in poor end of life care as is availability of pain relief. Poor skills in some care home staff, often the result of low wages and high staff turnover, means there may be an unreasonable expectation that certain tasks can be carried out. We therefore believe there should also be recommendations aimed at commissioners and providers. These should include guidance on appropriate skills mix and staff numbers as well as</p>

Please return to: CareofDyingAdult@nice.org.uk

Care of the Dying Adult

Consultation on draft guideline – deadline for comments 5pm on 09/09/2015 email: CareofDyingAdult@nice.org.uk

				the amount and type of commissioned services relevant to a local area, particularly where there are large concentrations of older people or care and nursing homes. Guaranteeing seven day palliative care services, regardless of setting, would be essential and is recommended by a number of recent reports (see for example, House of Common Health Select Committee (2015), PHSO <i>Dying without Dignity</i> (2015), <i>National care of the dying audit for hospitals, England</i> (2014).
2	Full	General	General	The guidance has an underlying assumption that the skills and training to carry out the recommendations exist in the range of settings described. The lack of education and training is cited not only in the reports mentioned above, but also in the Neuberger Review, the Francis Report (2013) and many others, in relation to poor standards of care at the end of life. This is equally the case with care of older people, a group for whom end of life care is most relevant as it represents 90% of all deaths. A significant skills gap also exists in recognising the transition from, for example, severe frailty to dying (see for example, Gardiner, C., et al, <i>Barriers to providing palliative care for older people in acute hospitals, Age and Ageing</i> , 2011). Indeed, there may be a long period where someone is living with multiple conditions and frailty for whom a sudden change can lead very quickly to entering the dying phase. This is even more challenging to recognise when their needs are non-specific, i.e. relating to general declining health rather than the symptoms of a condition, and an event like a fall is just as likely to precipitate dying as a stroke (an event this guidance appears to exclude under “major trauma”). Skills and training relating to end of life care and older people in general are still very poor and the recommendations to providers and commissioners (see above) must include having sufficient professionals with appropriate levels of training and ensuring that care of the dying is fully incorporated into the operations and pathways of any setting.
3	Full	General	General	The guidance does not sufficiently capture the need to record information, both clinical and relating to patient/family wishes, and to do so clearly and accurately. Handover of information about dying patients was cited in the Neuberger review as a factor in poor care, meaning a change of work shift could undermine the quality of care someone is receiving. The guidelines should place specific emphasis on accurately capturing and recording patient wishes, the outcomes of clinical assessment and any changes observed during reviews in a way that can be handed over to staff at the end of a shift or to out of hours staff. They should also include how this information should be communicated to family and carers if changes occur while they are not there – there is a general assumption in the guidance that there will always be a family member or carer available to discuss the care needs of a dying patient, which is unrealistic. Furthermore, the Neuberger review specifically highlighted the distress caused by family members arriving in a setting to learn that someone had been placed on an end of life pathway.
4	Full	General	General	There is no guidance around the nature of consent and application of the Mental Capacity Act. We believe this should be included as a headline recommendation, potentially after recommendation 10 (page 13) with sign-posting to relevant guidance included in the full document.
5	Full	General	General	There remains a huge amount of sensitivity around the topic of end of life care, as shown by the media reporting when this draft guidance was first published. We believe there should be clearer references to, and promotion of, high quality

Please return to: CareofDyingAdult@nice.org.uk

Care of the Dying Adult

Consultation on draft guideline – deadline for comments 5pm on 09/09/2015 email: CareofDyingAdult@nice.org.uk

				patient-facing information on this guidance and end of life care generally. Age UK has recently published a booklet on planning at the end of life (<i>Before you go, Age UK, 2015</i>) which could be promoted alongside this guidance. The Dying Matters Coalition and the National Council for Palliative Care also have a range of publications which could help people to understand the role of healthcare professionals and the decision-making process during the dying process. The guidance should recommend making such materials available, and NICE should highlight them as part of dissemination of this guidance.
6	Full	11	11	After “information”, add: “involving a multi-professional team”. We believe the current guidance risks giving the impression that a single professional can undertake this assessment.
7	Full	11	18	Additional bullet point: “Ensure this information is accurately recorded and can be easily found and understood by other professionals involved in their care”.
8	Full	12	1	This recommendation suggests reviewing patients at least every 24 hours. Though this may be appropriate with regards to a full review, the <i>National care of the dying audit for hospitals, England, RCP, 2014</i> , recommends that a person’s pain and symptoms be reviewed every four hours. This should be referenced here.
9	Full	12	7	At the end of this line, we recommend including: “For some older people, it may be appropriate to initiate comprehensive geriatric assessment or other similar evidence based intervention”.
10	Full	12	24	At the end of the line, we recommend including: “Staff should be confident to carry out these discussions sensitively and training should be made available for those that are not”.
11	Full	12	28	Additional bullet point: “while recognising that all staff should have basic competence in end of life discussions”.
12	Full	13	11	At the end of this line, we recommend including: “Any support and information they may need to engage in shared decision-making should be made available, including emotional and psychological support”.
13	Full	13	19	After “encouraging”, add: “and supporting”.
14	Full	13	40	After “care team”, add: “ensuring this can be easily communicated to professionals who may be involved in care at a future point and to out of hours teams”.
15	Full	14	6	The Neuberger Review was clear that with regards to hydration and comfort, the “default course of action should be that patients be supported with hydration and nutrition unless there is a strong reason not to do so”. The <i>Priorities of Care for the Dying Person (2014)</i> also recommends “If a dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected”. We do not believe the current wording on this point makes this sufficiently clear. After “are able to” on this line we recommend including: “recognising the default action should be that a person is helped to drink”.
16	Full	14	31	Additional bullet point: “This conversation must be handled sensitively, fully recognising this could be a particularly distressing moment for the individual, their family and carers”.
17	Full	15	7	Additional bullet point: “if there is any uncertainty, consider seeking advice from palliative care specialists”.

Insert extra rows as needed

Please return to: CareofDyingAdult@nice.org.uk

Consultation on draft guideline – deadline for comments 5pm on 09/09/2015 email: CareofDyingAdult@nice.org.uk

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 comment 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.