Care of the Dying Adult

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

Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.

We would like to hear your views on these questions:

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.)

See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.

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<th>Stakeholder organisation(s) (or your name if you are commenting as an individual):</th>
<th>General Medical Council</th>
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<td>Name of commentator (leave blank if you are commenting as an individual):</td>
<td>Vibha Sharma</td>
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<td>Comment number</td>
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We would like to make an observation about recommendations 7 and 9. The introductory comments set the context for these recommendations, with the following opening statement: recognising and communicating that a person is in the last few days of life is essential for good end of life care. Ensuring good communication about this with the person and those important to them is a vital part of shared decisionmaking (lines 3-5). The draft guideline currently lays out the following recommendations in relation to patients not wishing to be informed about their prognosis:

- **Recommendation 7:** Discuss the dying person’s prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life and include those important to them in the discussion if the dying person wishes.
- **Recommendation 9:** Provide the dying person, and those important to them, with accurate information about their prognosis (unless they do not wish to be informed).

We would like to bring to your attention our guidance on *Treatment and care towards the end of life: good practice in decisionmaking*. This makes it clear that we expect doctors to take a series of steps when faced with these circumstances and highlights a doctor’s responsibility to attempt to discuss a patient’s prognosis with them if the patient has capacity, unless this will cause the patient harm. However, we also recognise the value of and sensitivity surrounding the last days of a patient’s life and the importance of doctors respecting the patient’s choice about how much they wish to know about their prognosis during this time period. The steps that we expect doctors to take are set out in paragraphs 56-59 of our guidance and you may wish to consider if there’s value in including a link to this guidance.

The draft guideline mentions that ‘The Guideline Development Group (GDC) felt that health and care professionals sometimes do not have, or may lose, their skills and confidence in delivering difficult news. Training programmes are available and health and care professionals should be encouraged to keep their skills updated’. Of course, as the professional regulator, we have set out general duties on doctors to keep their knowledge and skills up to date (paragraph 8 of our core guidance *Good medical practice*). There is also an obligation on doctors, through our revalidation process, to reflect on their practice; identify areas where they can improve; and ensure they have the necessary skills and competence to provide a good standard of care to their particular population of patients (see the revalidation guidance [here](#)). You might want to consider whether a reference to these professional obligations would strengthen the guideline.
The draft guideline states that the 'GDC noted in the evidence review that those important to the dying person may wish to try and withhold information regarding prognosis from the dying person. The GDC recognised this was a problem in their clinical experience and recommended that any requests be dealt with sensitively and respectfully, but clinicians should always act in the dying person’s best interest'. We suggest that the final guideline document should include a link to paragraph 59 of our guidance on Treatment and care towards the end of life: good practice in decisionmaking. In this, we state that ‘apart from circumstances in which a patient refuses information, you should not withhold information necessary for making decisions (including when asked by someone close to the patient), unless you believe that giving it would cause the patient serious harm. In this context ‘serious harm’ means more than that the patient might become upset or decide to refuse treatment’. It might also be helpful for the above section of the draft guideline to include a link to the Priorities of Care for the Dying Person resources (available at NHSIQ), since this framework has national support and underpins CQC inspections of end of life care provision in health and care services.

The draft guideline states that one particular issue that the GDG recognised is ‘when a dying person had expressed specific preferences or wishes regarding their care, but circumstances in their final illness indicate that their interests might be better served if these were not observed’. We note the scenario included in lines 15 to 24 of this section and would like to recommend that the following aspects of this are made clearer:

- Whether there was any discussion with the patient, while competent to make decisions, about the possible future course of her condition and the circumstances in which the question of whether to use a syringe driver might arise.
- Whether the patient and/or those close to the patient were/or could have been informed in advance about the consequences of opting not to have treatment by syringe driver and how it would impact on the patient’s death.
- Whether the patient made a competent decision against using a syringe driver or simply expressed a preference which left room for others to decide at the time whether complying with her wish was still in her best interests.

In the absence of the clarifications set out above, we believe you would need to provide a clearer explanation of the legal justification for not adhering to the patient’s wishes in relation to treatment, taking account of the requirements of the Mental Capacity Act (2005).
### 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](https://www.nice.org.uk/).  

**Note:** We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the
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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.