Care of the Dying Adult

NICE National Institute for Health and Care Excellence

Consultation on draft guideline–deadline for comments5pm 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 ofDeveloping NICE guidance: how to get involved for suggestions of general points to think about when commenting.
Stakeholder organisation(s)(or your name if you are commenting as an individual):	**Christian medical Fellowship**
Name of commentator(leave blank if you are commenting as an individual):	Rick Thomas

Comment number	**Document**, **Short** version	**Page number** Or **'general'**for commentson the whole document	**Line number** Or **'general'**for commentson the whole document	**Comments** Insert each comment in a new row. Do not paste other tables into this table, becauseyour 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		General	General	CMF welcomes the new guidelines as an attempt to improve the care of those who are thought to be dying. The guidelines recognise that it can be very difficult, in practice, to determine when a dying patient is

Please return to:**CareofDyingAdult@nice.org.uk**

				entering the last few days (or weeks) of life. That uncertainty does not remove the need to continue to provide care but leads to the recognition that such care will necessarily be inimical to a programmatic approach. Care for those who may be dying will be relative to the individual circumstances of each case, and liable to constant adjustment in the light of ongoing review, including the possible need to revise the diagnosis of dying. Virtuous good sense must be the defining characteristic of such care, not slavish adherence to protocols. We welcome the guideline's commitment to research ways of reducing the impact on clinical care of the uncertainty surrounding the diagnosis of dying. At some points in the guidance, this uncertainty is well described, but at other points the language used fails to convey this uncertainty. We suggest that whenever the diagnosis of dying is described or implied, the 'uncertainty of certainty' be clearly admitted.
2		3-4	General	The list given of signs or changes that might suggest a patient is entering that final stage of care might be helpful, but will tend towards the notion of care during this final phase of life as a 'pathway'. The appearance of such signs or changes will be interpreted as the first step along this pathway leading to the implication that a protocol should now be followed. This was one of the criticisms of the Liverpool Care Pathway (LCP), and it is difficult to see how the present guidelines will avoid generating the same, heavily-criticised mind-set. ' Less pathway, more care' was the title of Baroness Neuberger's report, and we would suggest that greater emphasis is given in the guidelines to the recognition that such signs and changes can come *and go again*, and do not necessarily imply the final stages of life the first time they appear. It is essential that the new guidelines do not lend themselves to being interpreted as another pathway – compassionate care and kindness requires built-in flexibility, in the mind-sets of carers as well as in the guidelines themselves.
3		5	26-27	No explicit mention is made of the patient's spiritual needs in this section about communication. The GMC guidance states that discussion with patients who are dying should cover "the patient's needs for religious, spiritual or other personal support". We recommend that those who enjoy positions of trust, spiritual care and guidance in patients'

				lives, as well as those employed as hospital/hospice chaplains, be seen as part of the multiprofessional team. Quite often such a person will be the most appropriate person to explain prognosis and treatment options, and provide opportunity for the dying person to talk about their fears and anxieties, or prepare them for death. We would like to see specific reference made in the guidelines to the particular role such 'ministers' can fill, encouraging clinical staff to welcome and value their contribution. It should be recognised also that some healthcare professionals, especially those who have a personal faith, may well be competent to provide such spiritual support themselves. We also recommend that family members and carers be specifically offered or invited to have access to that sort of spiritual support.
4		9	General	Dehydration was a central concern of Baroness Neuberger's report, and was a recurring criticism of the LCP *as implemented.* The NICE guidelines fail to make any reference to supporting oral nutrition or to assessing the need for clinically assisted nutrition. Both the Review of the LCP and GMC guidance on *Treatment and Care towards the end of life* make clear that nutritional need must be assessed. Unless the NICE guideline specifically requires the assessment of nutritional needs, it is likely that reduced oral intake will be interpreted as a sign of dying, whereas it may be the result of nothing other than a sore mouth or ill-fitting dentures. Clearly, it is essential to distinguish those who are dying *of* dehydration from those who are dying and who may experience no sense of thirst. The guidelines recognise the limited nature of the current evidence base for assisted hydration but fail to propose further research in this area. In general, the guidelines appear to 'lean away' from hydration unless distressing symptoms or signs of dehydration, such as delirium, are clearly present. Even in that situation, it is more likely that sedation, not hydration, would be given to manage the delirium. We suggest that the guideline should lay greater emphasis upon the need for ongoing assessment of hydration. Monitoring urinary output is not mentioned but would be simple to do and would help avoid the need for monitoring frequent blood tests of renal function.

5		16	General	Our primary concern with this guidance lies in the area of anticipatory prescribing. This was another heavily criticised aspect of LCP, and we are concerned that the new NICE guidelines carry the same inherent weakness. When physicians write up sedatives and narcotics ahead of time, but are not called or present to confirm the appropriateness of their use at a particular moment, then the responsibility for decision-making falls to someone very junior. The fact that these medications have been written up in advance is too often interpreted as reason enough to use them, rather than making a careful assessment of the patient's needs at the time. What is intended as permission-giving can be interpreted as pathway protocol. We recognise that guidance has to apply across a range of care settings and that in some of those settings a doctor is not immediately available to assess and prescribe. Not to have medication prescribed in anticipation could, in these settings, lead to a delay in providing symptom relief. Where assessment would be quickly available, the practice of anticipatory prescribing should be discouraged to minimise the risk of overtreatment. Where there is no feasible alternative to anticipatory prescribing, assessment of patient needs by the most senior available care staff, and investment in training at all levels, would help ameliorate the risks of inappropriate use of pre-prescribed medication. In regard to anticipatory prescribing, the NICE guidance suggests future research on cost effectiveness but research also needs to focus on the dangers of overtreatment or undertreatment and how these could be offset.
6		16	27-28	The guidelines call for daily monitoring and assessment of side-effects by the lead healthcare professional. In care home or patient's home settings, it is very unlikely that daily visits by doctors will routinely happen, but in the final days of a dying person's life changes must be monitored by someone able to interpret those changes accurately and prescribe accordingly. Doctors cannot delegate that responsibility to others and the

				NICE guidelines, we suggest, should address this issue as it applies not only in hospitals but in primary care settings.
7		19-22	General	We applaud the commitment to further research into better management of delirium and agitation and respiratory 'noises' so that care can be as evidence-based as possible. Evidence concerning the place of hydration is conflicting, and there appears to be no plan for further research into this area. We question why this is excluded from the general commitment to further research and recommend including the need for more research into the issue of hydration in dying patients.
8		General	General	CMF welcomes the draft guidelines, the emphasis on evidence-based care, and the commitment to ongoing research. However, we believe that, in their present form they will lead to the same 'pathway' mentality, in practice, as was discredited in LCP.
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Insert extra rows as needed

Care of the Dying Adult

NICE National Institute for Health and Care Excellence

Consultation on draft guideline–deadline for comments5pm 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 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 checkingNICE 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.