NICE National Institute for Health and Care Excellence

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.			
Stakeholder organisation(s) (or your name if you are commenting as an individual):	Marie Curie			
Name of commentator (leave blank if you are commenting as an individual):	Natasha Wynne, Policy and Public Affairs Manager			
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.

1	Full	General	General	Marie Curie is the UK's leading provider of care and support for people affected by terminal illness. We welcome the publication of the draft guidelines on the care of the dying adult as a resource to help healthcare professionals identify when someone is dying and improve care in the final days and hours of life. Research has shown that 110,000 people across the UK miss out on the palliative care they need [Dixon J et al. (2015) Equity in the Provision of Palliative Care in the UK]. Failing to identify that a person is approaching the end of their life and ineffective communication between healthcare professionals and dying people and their families at this time are clear barriers to appropriate care and support. The draft guidelines provide a good baseline for the skills that all healthcare professionals involved in the care of dying people should have. We welcome that the guidelines are aimed at healthcare professionals in primary care and care homes. This reflects the importance of strengthening care in the community to meet people's wishes to be cared for in their usual place of residence at the end of life and support the transfer of care out of hospitals where appropriate. However, guidelines will achieve little without sufficient community resources and effective implementation through training and embedding in continuing professional development. Results from an RCN (2014) survey of over 7,700 nurses found that almost half said they do not always have a chance to discuss with patients how they would like to be cared for in their final days, with problems with resources, time or training cited as the main reasons for this failure. We believe that investment in resources and effective workforce training across all relevant settings so professionals are empowered to deliver care in accordance with the guideline will significantly impact on practice. Not addressing these issues poses major challenges to implementation. This point is clearly made in the Leadership Alliance for the Care of Dying People's Five Priorities for Care (2014), which states, "Health and care staff will need the appropriate education and training to enable them to recognise and deliver these responsibilities in practice. Their employers and the system in which such staff work must support them in doing this."
2	Full	25	34-38	To clarify the comment above: Marie Curie realise that training, workforce planning and service delivery fall outside the scope of this guideline; however, we would like to emphasise that high quality care for all cannot become a reality without them. We look forward to working with NICE and sharing our experiences of best practice in the future to make sure the second guideline on improving supportive and palliative care, including service delivery, is as robust as possible and has wider applicability to the needs of people living with terminal conditions other than cancer.
3	Short	General	General	We welcome the person-centred approach taken in this guideline. The focus on shared decision-making and establishing the goals and wishes of both the dying person and those important to them is rightly placed at the core of developing an appropriate care plan for each individual. This is in line with the Leadership Alliance's five Priorities for Care. When done correctly, it can significantly improve the dying experience of both the dying person and their family.

4	Short	18-19	20…-2	The guideline rightly recognises that 'the process and timescale for dying varies widely'. It goes on to state those with progressive neurological disorders may spend weeks or month in general decline, such that 'many of the principles of communication, shared decision-making and pharmacological care can be initiated long before that time.' Although we recognise that the scope of this guideline is the last few days of a person's life, we believe this statement is misleading. For many people with a terminal illness, not just those with neurological conditions, good end of life care starts much earlier than the final few days. The principles outlined above, and in particular those relating to shared decision-making, good communication and early care planning (with the recognition that plans are likely to change as a person's condition changes) should ideally be adhered to from the point of someone's diagnosis or as soon as is acceptable to the patient and their family.
5	Short	4/ 12	26/ 1	The guideline encourages healthcare professionals to seek advice from those more experienced in providing end of life care. Clinical and practical experience is an important resource for spreading best practice and we are happy to see that a more collaborative approach is being encouraged. In relation to care homes, the Marie Curie care home support service in Hywel Dda Health Board in Wales is a good example of where adopting a collaborative, advisory model before a crisis occurs supports care home staff to deliver end of life care in a person's familiar surrounding (please see here for more details of the service). Although perhaps beyond the scope of this consultation, we think it important to flag up that this collaborative approach to learning, development and caring for those who support people at the end of life is effective. Opportunities to pursue these types of services should be encouraged more generally, not just in the final days, for high quality care to become the norm. However, we are concerned that a barrier to implementation here will be the availability of experienced professionals or specialist palliative care professionals to provide advice, particularly at weekends and out of hours. Only 7% of England's Trusts that responded to recent FOI requests had 24/7 face-to-face access with a palliative care specialist. In the absence of specialist support, people being cared for in the community may face inappropriate emergency admissions to hospital towards the end of their life because the emergency services are the only available support. A recent report by Marie Curie, Triggers for Palliative Care, also found that hospitals services were often not aware of how to involve their specialist palliative care team in the care of their patients. Although addressing these issues is beyond the scope of this consultation, we believe they should be raised as they will impact on implementation.
6	Short	5	29	It may be worth including, 'including supportive members such as a chaplain or social worker'.

7	Short	7	37-39	Marie Curie welcomes the guidance on producing individual care plans. We believe that further information could be included on the form this should take to encourage best practice in documenting people's wishes and facilitating ease of accessibility and use across different settings, e.g. when transitioning from community to hospital care or for providers of out of hours care. Encouraging the use of best practice would be helpful; for example, Electronic Palliative Care Coordination Systems (EPaCCS) is one method which is gaining traction in England. Universal coverage of EPaCCS was a key recommendation of the Choice in End of Life Care Programme Board's 2015 Review of Choice in End of Life Care.
8	Short	7	4	Marie Curie welcomes the inclusion of a named lead healthcare professional. We know that a lack of information, consistency, coordination of services and help to navigate the complex health system is a considerable problem and cause of stress for people who have a terminal illness and their carers and family [see Marie Curie (2014) Difficult Conversations, for more information]. Ensuring that people have the contact details of a relevant and appropriate out of hours service could help to reduce unnecessary and undesirable hospital admissions at the end of life. The Marie Curie Rapid Response service, which operates in various localities, is one example of a relevant service which the named professional should be aware of to help people being cared for in the community stay at home or in their care home throughout a crisis (for an example of how the service operates in Northern Ireland, please see here).
9	Short	8	19	It may be worth suggesting the possibility of referring to any local guidelines on mouthcare.
10	Short	18	8 …	Research into palliative and end of life care has historically been under-funded and there is a need for greater attention in this area. Marie Curie therefore welcomes the inclusion of recommendations for research in the guideline, which draws attention to important questions which require further research to answer. We would however like to draw attention to the work of Marie Curie and the James Lind Alliance on the Palliative and end of life care Priority Setting Partnership, which collated responses from people in the last year of life, their families and carers, and health and social care professionals regarding their priorities for end of life care research to find the top ten unanswered questions. Topics which are particularly relevant to the scope of this guideline and may warrant consideration or mention in this section of the guideline include: assessing and treating pain and discomfort for people with cognitive impairment or communication difficulties at the end of life; ensuring continuity for patients at the end of life, and how best to listen to and incorporate patient preferences in care planning.

Insert extra rows as needed

Checklist for submitting comments

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- 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.