

National Institute for Health and Clinical Excellence

Motor neurone disease – non-invasive ventilation
Stakeholder Comments

Please enter the name of your registered stakeholder organisation below.

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Stakeholder Organisation:	British Society of Rehabilitation Medicine (BSRM)
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Name of commentator:	Dr Margaret Phillips
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Order number <i>(For internal use only)</i>	Document	Page Number	Line Number	Comments
	Indicate if you are referring to the Full version or the Appendices	Number only (do not write the word 'page/pg') . Alternatively write 'general' if your comment relates to the whole document.	Number only (do not write the word 'line') . See example in cell below	Please insert each new comment in a new row. Please do not paste other tables into this table, as your comments could get lost – type directly into this table.

Example	Full	16	45	Our comments are as follows
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Proformas that are not correctly submitted as detailed in the line above may be returned to you

1	Full	4	3	Regarding patient centred care, we think the emphasis of this document should be that of use of NIV within the overall context of the patient and his/her respiratory management – at present overlapping issues such as end of life care and use of other modes of respiratory management are not fully integrated with the document.
2	Full	5	10	Suggest adding 'consultant in rehabilitation medicine' – could consider as an alternative to neurologist or as well as.
3	Full	6 and 16	30 1	Although this guideline is about NIV we would think there should be a place in it to specifically mention 'alternative palliative measures' and include them in the care pathway – e.g. vaccination, appropriate use of antibiotics, chest physiotherapy, breath stacking and use of cough assist in those who are able. This would also allow it to cross reference with BTS respiratory physiotherapy guidelines: 'Physiotherapy Management of the Adult, Medical, Spontaneously Breathing Patient'.
4	Full	6	10	Later discussion of monitoring of respiratory impairment suggests doing this every 3 months, or less for some. For the second monitoring this would be the same as 'soon after MND first diagnosed'. Would it be more straightforward to merge lines 10 and 11 as a post diagnosis visit to establish respiratory function and initiate discussion on future NIV?

5	Full	6	15	Consider stating 'provision of written information'.
6	Full	7	3	Suggest inability to or difficulty in completing a sentence as a sign of potential respiratory impairment, and patient self adoption of glossopharyngeal breathing.
7	Full	7	5	Emergency procedures to include written contact details and written plan for potential admissions.
8	Full	7	13	At end of section 1.1.5 consider equipment required if start to use NIV during day, e.g. fitting to and stability of wheelchair.
9	Full	9	2	Consider use of peak cough flow.
10	Full	12	17	When the paragraphs about those with dementia and those without are read they come to pretty much the same thing – a trial of NIV and see if beneficial due to symptom relief – so perhaps consider rephrasing.
11	Full	12	22	We wondered if the phrase 'patients ... with severe cognitive problems that may be related to respiratory impairment' was correct – are you meaning to not consider those with cognitive problems secondary to MND or should they have been included here as well?
12	Full	13	19	Consider discussions and plan for coming off NIV and end of life care plan to be instituted at this stage if not done before.
	Full	15	8	We wonder if consideration should be given to discussing end of life care being a norm before this stage, with it being routinely covered at institution of NIV, if it has not been done before (once people get to NIV they may well have been unwell with chest infections and required hospital admission), always remembering this will be very difficult with some patients.
	Full	16	1	Suggest 'end of life' care planning should be much further up care plan and included with wishes and plans regarding hospital admissions during intercurrent infections.
13	Full	75	14	As for point 2, suggest adding 'Consultant in Rehabilitation Medicine', either additional to or instead of neurologist.

Please add extra rows as needed

Please email this form to: MND@nice.org.uk

Closing date: 5pm on 22 March 2010

PLEASE NOTE: The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.