

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Notes from stakeholder workshop discussion: Motor Neurone Disease (MND)

These following questions formed part of the discussion of the breakout groups at the stakeholder workshop.

-Is the population appropriate?

Group 1	Group 2	Group 3	Group 4
The group suggested that 15 years might be a better cut off.	End of life should not be included as a stratum as this needs to be considered throughout every section.	The group felt that this was largely appropriate but did not think it was clear that 'end of life' was being considered.	No comments.
It was also suggested that diagnostic criteria for MND should be included here.			

Are there any specific subgroups that have not been mentioned?

Group 1	Group 2	Group 3	
The group did not feel that there was a	No comments.	The group felt that stating that	Group felt that people at the

benefit to including people receiving end of life care as a patient subgroup.		people at the end of life would be considered a separate subgroup indicated that it would be covered separately elsewhere, not within this guidance.	end of life as a should be omitted as a separate patient subgroup because end of life care should take place throughout the patient journey.
The group felt that people with frontal temporal dementia may be a subgroup who would receive different management and this would be an appropriate patient subgroup.		The group suggested that frontal temporal dementia should be specifically stated as a group that would not be covered. This group should be covered within the NICE dementia guideline.	Fronto-temporal dementia should be included as a subgroup as these patients are treated differently.

Is the setting appropriate?

Group 1	Group 2	Group 3	Group 4
The group highlighted that social care should	The group felt that it was important to	It was highlighted that much of this scope should	The group noted that this was the

<p>be included in the guideline and that the setting should be expanded to include this area.</p>	<p>consider palliative care provided outside the NHS.</p>	<p>integrate with social care services. With the new government agenda to integrate these services better, the group suggested that it should be recognised within the scope and the interface should be highlighted, specifically around the coordination and continuation of care.</p> <p>Hospices were queried. It was noted that not all were NHS funded, some were 3rd sector funded. Would these also be included as some also receive NHS funding as well. Suggest saying 'NHS funded services' would</p>	<p>standard setting for NICE guidelines.</p>
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		cover these rather than stating 'where NHS care is provided'.	
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Have we covered all the key clinical issues?

Group 1	Group 2	Group 3	Group 4
<p>The group was in agreement that the use of tele-health (including smartphone apps) in monitoring of symptoms was particularly important to include here as it is increasingly common practice. It was noted that there is need for an integration or compatibility of telehealth systems to ensure communication between organisations.</p>	<p>The group felt that timely and accurate diagnosis was important as people with MND are often misclassified. The group also felt that timely and appropriate service delivery was important as every case of MND is individual and care is highly variable.</p>	<p>The group felt strongly that diagnosis should be included. It is a hugely important topic. They agreed that the issue was not how to diagnoses, but ensuring that there is rapid referral to the right person (similar to cancer diagnosis and referral). They suggested that the scope should include the diagnostic pathway – getting into the system.</p>	<p>The group felt that the use of a multidisciplinary team for assessment and the frequency of assessment should be considered. In particular, the group felt that the guideline should consider communication of the multidisciplinary team.</p>

		Communication should not just be limited to diagnosis. It should be throughout the care pathway.	
It was noted that coordination of care process vary significantly with geographical location. Shared care (a collaboration between tertiary specialist MND centre and local neurologist) was highlighted here as an important issue.	The group agreed that the use of a multidisciplinary team was important to consider as many patients are currently not receiving this and it is difficult to identify who should be part of the MDT.	The group queried what 'low technical equipment' was. Would this exclude electric wheelchairs? It was thought that these should be included and wheelchairs specifically stated in the scope. It was suggested this could state just 'equipment including environmental control systems' or 'low and high tech equipment' if there was a need to recognise the difference between the two.	The group discussed relevant staging and assessment tools which may be considered.

<p>It was suggested that flaccidity e.g. foot-drop should be added to 'muscle stiffness and cramp'.</p>	<p>The group felt that the guideline should consider cough clearing technologies as these services are variable at present.</p>	<p>Suggested that secretions in general should be stated, tenacious secretions, saliva management, drooling etc.</p>	<p>The group felt that for commissioners, it would be useful for the guideline to consider time to referral.</p>
<p>'Low technical equipment' was found to be confusing terminology and the group preferred to specify 'wheelchairs or mobility systems'. The group felt that this point on lower limb weakness should be expanded to include the neck.</p>	<p>The group felt that the guideline should consider the education of patients and carers, for example, the importance of taking up flu vaccinations.</p>	<p>The group highlighted that depression and anxiety aren't cognitive changes. This should state 'psychological conditions including depression' and then 'cognitive changes' as a separate point.</p>	<p>The group felt communication of diagnosis was particularly important and should include both communication to patients and carers. This should include the communication of uncertainty and ongoing communication throughout the condition.</p>
<p>The group felt that it should be made clear that cognitive changes due to dementia (particularly</p>	<p>The group consider the avoidance of crisis admissions to hospital. It was felt that better</p>	<p>Under point c the group suggested that respite should be mentioned. Integration of social and</p>	<p>The group noted that there was some uncertainty around the use of genetic tests</p>

<p>frontotemporal dementia) are separated from anxiety and depression.</p>	<p>coordination of care may help to prevent this.</p>	<p>medical care should be highlighted here, in terms of 24 hour continuing care. Reassessment after 1 year is unreasonable as people with MND don't get better. Group would also like to include patient and carer education (using equipment etc.).</p>	<p>and communication surrounding these areas.</p>
<p>The group felt that, despite enteral feeding not being a clinical issue covered, the timeliness of gastrostomy was an important issue that should be covered in this section.</p>	<p>The group discussed the role of the orthotist and noted that there was evidence to support early referral to the orthotist meaning that patients are able to maintain function at a higher level for longer.</p>		<p>The group noted that there was some communication around the use of the term 'low technical equipment' and that this required clarification. For lower and upper limb weakness there is specific equipment available such as mobile</p>

			<p>phones and wheelchairs.</p> <p>The group noted that there were specific issues relating to access to this equipment and physiotherapy services. The group also noted that education relating to this equipment was important so that people with MND are aware what the equipment can be used for.</p>
<p>There was much discussion around secretion management for prevention of respiratory infection as well as the early treatment of respiratory infections to prevent acute</p>	<p>The group felt that the guideline should cover enteral feeding as the existing NICE guideline does not cover frequency of assessment for people with MND.</p>		<p>The group felt that the section on swallowing should be amended to 'swallowing difficulties and secretion management' and this section should be amended to</p>

<p>hospital admission. It was felt that respiratory complaints are the most common cause of unplanned admissions and that unplanned admissions represent a huge burden to both the patients and carers, and the healthcare system. Monitoring and interventions mentioned by the group included regular measurement of cough function and peak flow, use of cough assist devices, availability of community chest physiotherapy, access to home pulse oximetry and rescue</p>			<p>include oral hygiene.</p>
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medicines.			
<p>The group again highlighted that the integration between clinical and social care was important here and suggested that provision of respite care (this overlaps with availability of social care network) should be considered.</p> <p>It was also suggested that advanced directives be specifically mentioned as part of 'preparation for end of life'.</p>	<p>The group noted that new genetic tests being discovered may aid diagnosis in the future.</p>		<p>The group felt that speech and language therapy should be considered.</p>
	<p>The group felt that patient information provided at diagnosis was important and should be</p>		<p>There were some discussions surrounding the use of gastrostomy and positioning</p>

	provided by an appropriate healthcare professional with relevant experience and an understanding of MND.		and which should be used, what tube should be used and when/what stage of disease it should be used at.
	The group felt that the guideline should cover gastrostomy and referral for gastrostomy. This could include initial counselling and needs assessment.		Nutrition should be considered under a separate heading.
			The group felt that breathing difficulties should be considered and specifically, this should cover the management of breathlessness and managing respiratory secretions with cough-assist

			mechanisms.
			The group felt that posture and pressure relief should be considered, as well as the use of occupational therapy.
			The group felt that the section considering cognitive changes should be renamed 'behavioural management'. The group did not feel that there was necessarily any differences in the treatment of depression and anxiety in people with MND although it was likely that treatment would vary depending upon the stage

			of the disease.
			The group felt that the guideline should consider the support needs of carers as well as people with MND.

Have we captured the relevant outcomes?

Group 1	Group 2	Group 3	Group 4
The group agreed that it was important to ensure that quality of life incorporated both patient and carer quality of life.	This was not covered.	The group felt that patient and carer satisfaction should be included. The group also wondered if inappropriate emergency	The group felt that relevant outcomes would include the ALSFRS, access to equipment and nutrition/gastrostomy effectiveness.

The group felt that some additional relevant outcomes may include cognitive function, severity score, number of hospital admissions.		admissions / care could be an outcome.	
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Are there any critical clinical issues that have been missed by the scope?

Group 1	Group 2	Group 3	Group 4
As above	As above	Rapid access and rapid referral should be covered. This could state that 'how to diagnose MND' would not be covered.	As above.
		The group queried whether the enteral feeding guideline had an MND subgroup. They suggested that although they agree it is	

		covered elsewhere, this guideline should make a specific mention of that and signpost to it.	
		Diagnostic pathway and the use of mobility aids (for example, wheelchairs) may have a large impact on quality of life.	

Are there any areas in the scope which are irrelevant and should be deleted?

Group 1	Group 2	Group 3	Group 4
None identified.	None identified.	None identified.	None identified.

Which practices have the biggest cost implication for the NHS?

Group 1	Group 2	Group 3	Group 4

The group felt that the prevention of unplanned admissions, advanced decision making and multidisciplinary teams had the biggest cost implication.	The group felt that cough assist machines versus manually operated bag systems and avoiding emergency admission were the most important areas to consider in relation to costs.	The group felt that coordinating care centres and inappropriate hospital admissions were the most important considerations.	None identified.
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If you had to delete or deprioritise two areas from the scope which would it be?

Group 1	Group 2	Group 3	Group 4
Pain management.	None identified.	None identified.	None identified.

Are there are any of diverse or unsafe practice or uncertainty that need to be addressed that aren't currently covered?

Group 1	Group 2	Group 3	Group 4
The group felt that the biggest areas of unsafe practice included complementary	None identified.	The use of oxygen for breathing and the provision of care packages (at	The group felt that there was uncertainty in the genetics of MND and how

therapies, unplanned admissions and unlicensed medications.		home, in care facilities).	should this be addressed in the guideline. Gastrostomy was a concern, especially timing (when gastrostomy should be applicable, safety, and what the best method is?). Communication of diagnosis by healthcare professionals was also highlighted.
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As a group, if you had to rank the areas of the scope in terms of importance, what would your areas be?

Group 1	Group 2	Group 3	Group 4
The group agreed that the communication of diagnosis is critical and suggested that this topic should come first in the list. It was acknowledged that there may be a lack of	None identified.	There would be different priorities for different groups of people although the diagnostic pathway is	The group felt that communication of diagnosis should be above monitoring and on-going

<p>evidence for MND population with regards to breaking bad news/communication of diagnosis and prognosis but that this could be extrapolated from evidence in indirect populations such as patients with cancer.</p> <p>The group agreed that the most important areas were:</p> <ol style="list-style-type: none"> 1. Communication of diagnosis and subsequent prognosis and discussion of advanced directives at this point. 2. Acute care and the unplanned admission (appropriate and timely respiratory management). 3. Monitoring including frequency of and use of telehealth in 		<p>important for all. Saliva and secretion management was considered important. It is an area that isn't done well at present. From patient point of view communication is considered important.</p>	<p>assessment, and that nutrition should be included in the list of key clinical issues that will be covered</p>
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monitoring.			
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Any comments on GDG membership?

Group 1	Group 2	Group 3	Group 4
<p>The following additions and amendments were suggested:</p> <ul style="list-style-type: none"> -Genetic specialist specifically in MND -One of neurologists should be an academic -Respiratory physiotherapist and respiratory physician should be co-opted re: secretion management -Emergency Department Consultant can be coopted -Association of directors of social 	<p>The group felt that a dietitian, neurological physiotherapist and respiratory physician should be included and that an orthotist, respiratory physiotherapist, respiratory physician could be co-opted.</p>	<p>The group felt that the position of nurse may also be for a care coordinator. The group also felt that a social worker should be a full GDG member.</p> <p>The group also felt that a respiratory physiotherapist or nurse could be included as a co-opted member.</p> <p>The group noted that the specialist in palliative care may be a healthcare</p>	<p>The group felt that two additional co-optees should be recruited, namely an orthotist and a psychologist.</p>

<p>services representative rather than social worker</p> <p>-Representative of a patient group/association</p> <p>-Remove the psychologist and include in the co-opted group and add someone from the MND association</p>		<p>professional rather than a nurse.</p> <p>The group felt that the GDG should include a member of the MND association.</p>	
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Any specific equalities issues relevant to motor neurone disease that have not already been discussed?

Group 1	Group 2	Group 3	Group 4
None.	None.	The group noted that hard to reach ethnic groups should be considered.	None.

Other issues raised during subgroup discussion.

Group 1	Group 2	Group 3	Group 4
None.	The group felt that	None.	None

	any consideration of communication of diagnosis should cover both the patient and the carer.		
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