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	The group felt that this was largely appropriate but did not think it was clear that 'end of life' was	No comments.
	section.	being considered.	
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	No comments.	The group felt	Group felt that
feel that there was a		that stating that	people at the

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

Is the setting appropriate?

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

guideline and that the setting should be expanded to include this area. care provided outside the NHS. 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. 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	be included in the	consider palliative	integrate with	standard
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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			continuation of	
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included as some also receive NHS funding as well. Suggest saying 'NHS funded				
included as some also receive NHS funding as well. Suggest saying 'NHS funded				
funding as well. Suggest saying 'NHS funded				
Suggest saying 'NHS funded			also receive NHS	
'NHS funded			funding as well.	
			Suggest saying	
services' would			'NHS funded	
1			services' would	

	cover these	
	rather than	
	stating 'where	
	NHS care is	
	provided'.	

Have we covered all the key clinical issues?

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

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

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

frantataran cual	oppuding the state	modical same	and
frontotemporal	coordination of	medical care	and
dementia) are	care may help to	should be	communication
separated from	prevent this.	highlighted here,	surrounding
anxiety and		in terms of 24	these areas.
depression.		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.).	
The group felt	The group		The group
that, despite	discussed the role		noted that there
enteral feeding	of the orthotist		was some
not being a	and noted that		communication
clinical issue	there was		around the use
covered, the	evidence to		of the term 'low
timeliness of	support early		technical
gastrostomy was	referral to the		equipment' and
an important issue	orthotist meaning		that this
that should be	that patients are		required
covered in this	able to maintain		clarification. For
section.	function at a		lower and upper
	higher level for		limb weakness
	longer.		there is specific
			equipment
			available such
			as mobile

		wheelchairs. The group noted that there were specific issues relating to access to this
		noted that there were specific issues relating
		were specific issues relating
		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.
	he group felt that	The group felt
	he guideline	that the section
	hould cover	on swallowing
	enteral feeding as	should be
prevention of th	he existing NICE	amended to
respiratory gu	juideline does not	'swallowing
infection as well co	cover frequency	difficulties and
as the early of	of assessment for	secretion
treatment of pe	eople with MND.	management'
respiratory		and this section
infections to		should be
prevent acute		amended to

nospital 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			
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	hospital		include oral
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			hygiene.
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	felt that		
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	respiratory		
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	complaints are the		
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	most common		
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	cause of		
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	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	admissions and		
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	that unplanned		
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	admissions		
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	represent a huge		
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	burden to both 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	patients and		
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	carers, and the		
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	healthcare		
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	system.		
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	Monitoring and		
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	interventions		
regular measurement of cough function and peak flow, use of cough assist devices, availability of community chest physiotherapy, access to home pulse oximetry	mentioned by the		
measurement of cough function and peak flow, use of cough assist devices, availability of community chest physiotherapy, access to home pulse oximetry	group included		
cough function and peak flow, use of cough assist devices, availability of community chest physiotherapy, access to home pulse oximetry	regular		
and peak flow, use of cough assist devices, availability of community chest physiotherapy, access to home pulse oximetry	measurement of		
use of cough assist devices, availability of community chest physiotherapy, access to home pulse oximetry	cough function		
assist devices, availability of community chest physiotherapy, access to home pulse oximetry	and peak flow,		
availability of community chest physiotherapy, access to home pulse oximetry	use of cough		
community chest physiotherapy, access to home pulse oximetry	assist devices,		
physiotherapy, access to home pulse oximetry	availability of		
access to home pulse oximetry	community chest		
pulse oximetry	physiotherapy,		
	access to home		
and rescue	pulse oximetry		
	and rescue		

medicines.		
The group again	The group noted	The group felt
highlighted that	that new genetic	that speech and
the integration	tests being	language
between clinical	discovered may	therapy should
and social care	aid diagnosis in	be considered.
was important	the future.	
here and		
suggested that		
provision of		
respite care (this		
overlaps with		
availability of		
social care		
network) should		
be considered.		
It was also		
suggested that		
advanced		
directives be		
specifically		
mentioned as part		
of 'preparation for		
end of life'.		
	The group felt that	There were
	patient	some
	information	discussions
	provided at	surrounding the
	diagnosis was	use of
	important and	gastrostomy
	should be	and positioning
		<u> </u>

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provided by an	and which
appropriate	should be used,
healthcare	what tube
professional with	should be used
relevant	and when/what
experience and	stage of disease
an understanding	it should be
of MND.	used at.
The group felt that	Nutrition should
the guideline	be considered
should cover	under a
gastrostomy and	separate
referral for	heading.
gastrostomy. This	
could include	
initial counselling	
and needs	
assessment.	
	The group falt
	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.
	TI (.)
	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	This was not covered.	The group felt that patient and carer satisfaction should be	The group felt that relevant outcomes would include the ALSFRS, access to
quality of life incorporated both patient and carer quality of life.		included. The group also wondered if inappropriate emergency	equipment and nutrition/gastrostomy effectiveness.

The group felt	admissions /	
that some	care could be an	
additional	outcome.	
relevant		
outcomes may		
include cognitive		
function, severity		
score, number of		
hospital		
admissions.		

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	As above.
		rapid referral	
		should be	
		covered. This	
		could state that	
		'how to diagnose	
		MND' would not	
		be covered.	
		T I	
		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 group felt	The group felt	None
the prevention of	that cough assist	that coordinating	identified.
unplanned	machines versus	care centres and	
admissions,	manually	inappropriate	
advanced decision	operated bag	hospital	
making and	systems and	admissions were	
multidisciplinary	avoiding	the most	
teams had the	emergency	important	
biggest cost	admission were	considerations.	
implication.	the most		
	important areas		
	to consider in		
	relation to costs.		

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

therapies,	home, in care	should this be
unplanned	facilities).	addressed in
admissions and		the guideline.
unlicensed		Gastrostomy
medications.		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.

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

evidence for MND	important for all.	assessment,
population with	Saliva and	and that
regards to breaking	secretion	nutrition
bad	management	should be
news/communication	was considered	included in the
of diagnosis and	important. It is	list of key
prognosis but that this	an area that isn't	clinical issues
could be extrapolated	done well at	that will be
from evidence in	present. From	covered
indirect populations	patient point of	
such as patients with	view	
cancer.	communication	
	is considered	
	important.	
The group agreed that		
the most important		
areas were:		
1. Communication of		
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		

monitoring.		

Any comments on GDG membership?

Group 1	Group 2	Group 3	Group 4
The following	The group felt that	The group felt that	The group felt
additions and	a dietitian,	the position of	that two
amendments	neurological	nurse may also be	additional co-
were suggested:	physiotherapist	for a care	optees should
O a martin a manaialiat	and respiratory	coordinator. The	be recruited,
-Genetic specialist	physician should	group also felt	namely an
specifically in	be included and	that a social	orthotist and a
MND	that an orthotist,	worker should be	psychologist.
-One of	respiratory	a full GDG	
neurologists	physiotherapist,	member.	
should be an	respiratory		
academic	physician could		
Descinatory	be co-opted.	The group also	
-Respiratory		felt that a	
physiotherapist		respiratory	
and respiratory		physiotherapist or	
physician should		nurse could be	
be co-opted re:		included as a co-	
secretion		opted member.	
management			
-Emergency			
Department		The group noted	
Consultant can be		that the specialist	
coopted		in palliative care	
		may be a	
-Association of		healthcare	
directors of social			

services representative	professional rather than a	
rather than social worker	nurse.	
-Representative of a patient group/association -Remove the psychologist and include in the coopted group and add someone from the MND association	The group felt that the GDG should include a member of the MND association.	

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	None.
		that hard to reach	
		ethnic groups	
		should be	
		considered.	

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.	