Motor Neurone Disease

NICE National Institute for Health and Care Excellence

Consultation on draft guideline – deadline for comments 5pm on 13/10/2015 **email:** MND@nice.org.uk

Stakeholder organisation(s) (or your name if you are commenting as an individual):		**Motor Neurone Disease Association**		
Name of commentator (leave blank if you are commenting as an individual):		**Alison Railton**		
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**
1	All	general	General	The MND Association welcomes this draft guideline. We are confident that it will be a highly useful tool in raising standards of MND care, and intend it to be a central element in our work with statutory services and other stakeholders from 2016 onwards. We feel that the draft guideline is predominantly a helpful statement of best practice, and there is far more of it that we are happy with than we would wish to see changed. Inevitably, this response will focus mainly on aspects we would like to see improved, but we would not want this to disguise our general satisfaction with the draft. We are grateful to NICE and the members of the Guideline Development Group for producing it.
2	All	general	general	In some instances, we feel that the summary guideline has omitted helpful content from the full guideline that it would be better for it to include. We appreciate the tension between the need for brevity and the need to offer full and rounded guidance, but we will highlight a few respects in which we strongly believe the summary guideline – as the version to which health and social care professionals will turn most frequently – should be expanded.
3	All	general	general	People living with and affected by MND are not permitted to respond directly to this consultation; instead, we are the stakeholder with whom they are required to register their views in England, Wales, Northern Ireland, the Channel Islands and the Isle of Man. In order to facilitate this, we constructed an online survey which went live on September 8th and closed on September 30th. There were 390 respondents, among whom were people with MND, carers, former carers, and some health and social care professionals (although generally we expect their professional bodies to represent their views). A representative selection of free text answers to this survey is included at appropriate points in this response.

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				This response is informed by the evidence gathered through that survey, and also by comment from expert staff within the MND Association, who have considerable experience of working with people with MND.
4	All	general	general	Additionally, this response is informed by a piece of research commissioned by the MND Association to investigate different configurations of MND care. The Models of Care project is being run by the independent consultancy OPM, and will deliver its final report by the end of 2015. An interim report, which outlines findings to date from a literature review, an online call for evidence and telephone interviews with clinicians and other practitioners, has already been delivered. We will be happy to share the interim report, and full report if time permits, with NICE on request. The findings to date of the Models of Care work confirm that MND care is arranged in a multiplicity of ways. Identifying or generalising about individual models and their effectiveness is an extremely challenging task, but it can be safely observed that multidisciplinary care is often delivered to a high standard by community-based services. The emphasis placed by the draft guideline on multidisciplinary care is extremely welcome, as are the findings regarding its cost-effectiveness. We are concerned, however, that the characterisation of multidisciplinary care in the draft guideline is not representative of how at least some, and probably much, care occurs in the real world. While formally organised teams based in hospital clinics are undeniably an important part of the MND care mix, multidisciplinary care can be, and often is, delivered in the community, by professionals working in sometimes much looser arrangements. These latter instances are almost entirely absent from the draft guideline. This is therefore the single biggest aspect of the draft guideline about which we have concerns, and we strongly urge the GDG to look again at this area, very carefully. If the final version does not address this issue, there is a significant risk that many health and social care professionals may simply not recognise the world it describes, and accordingly not understand how to apply its recommendations to their work, or even not feel any obligation to. We outline this concern in more detail, with specific reference to the draft guideline, in our comments 31 to 39 below.
5	All	general	general	Timeliness of delivery is a key theme that runs through the guideline, and we welcome its prominence. In our survey, 96% of respondents agreed this is important. We recommend, however, that the wording used in the guideline be reconsidered. Phrases such as 'without delay' or 'without unnecessary delay' were felt by many respondents not to capture the urgency required when addressing a rapidly progressing illness. Some respondents suggested that timescales should be specified, often in terms - at most - of a small number of weeks. We would support this approach being introduced at appropriate points in the guideline.

				Respondents commonly reported that provision of home adaptations, wheelchairs and other equipment was notably slow. A further theme that emerged from responses was services or equipment being delivered so slowly that they were no longer appropriate for the person's needs: - *New services were often delivered well after they were needed by my father as the disease progressed rapidly in the final 18 months.* - *My mum passed away within 8 months of diagnosis, and many assessments were done too late for equipment and facilities that would be beneficial to be put into place due to rapidly changing needs.*
6	All	general	general	While the guideline's emphasis on timeliness is welcome, albeit that it would benefit from being made sharper, we feel that greater emphasis could usefully be placed on the need to assess and provide in an anticipatory manner. In our survey, 71% of respondents felt the guideline could give more prominence to anticipatory assessment. A further 26% gave free text answers, which provide powerful insight into both the importance of informed anticipation of progression, and some of the complexities that arise from it. Numerous respondents effectively summarised the importance of anticipation, and how things can go wrong without it. - *Things happen and then it's thought about. It should be the other way round.* - *Dad went through a horrendous phase without proper communication devices, which meant his other care suffered as he couldn't explain what he needed. He also had difficulty getting on top of a saliva issue which meant he would spasm and then not be able communicate or swallow, this then led to more issues. Speed is everything when getting on top of a new development in the disease.* - *I don't think any normal practitioner would understand that 'urgent' means 'before symptoms arise'. Every practitioner dealing with MND should be considering what will happen next and get that step in place even if it's slightly early. If you are dealing with something urgently then really you are too late because the patient will already be suffering. The day my dad was diagnosed he applied for planning permission to build a carer's wing. When the first carer was needed the extension wasn't ready. When he got a hospital bed he was already sleeping downstairs, when he got a wheelchair he was already using a borrowed scooter, when he got eye gaze he was already using software he had found himself.* Other respondents provided examples of effective good practice, which usually rely on at least one of the patient and a care professional being alert to the need for anticipation. - *Failure to plan ahead has not really affected me so far because I am fairly clued up on what I need, what is available and where and from whom I can get it. My neurologist always comments that I am ahead of the game.* - *We have been fortunate that our OT has anticipated our needs. There is often no time to jump through*

				bureaucratic hoops when aids are urgently required. However, some respondents highlighted that if done insensitively or inappropriately, anticipatory assessment and provision can cause distress to the person with MND, by alerting them to the likely future course of the disease. Individual preferences about how much they wish to know in advance vary from person to person. - *My concern in anticipatory assessment is the worry in waiting for awful symptoms to occur. I was asked five years ago what hospice I wanted to go in - this is not helpful. My solution would be to give someone a pack on diagnosis with sealed envelopes with specific symptoms that MAY occur written on the front - when ready (at the first onset of the symptom) they open the package and see the help / advice / equipment is available.* - *Needs must be met quickly when they arise but too much anticipation is frightening. I don't know how my mother would have got through it if she had known everything that might happen.*
7	All	general	general	The use of riluzole to treat MND is covered by a separate technology appraisal (NICE TA20). While it is right that the technology appraisal remains separate from this guideline and is therefore outside its scope, we would like to see signposting from the short version in particular to TA20. Given that riluzole is the only drug known to slow progression of MND and currently licensed for use in the NHS, some signposting to it would be appropriate. In our survey, 90% of respondents felt a statement about riluzole should be including; only 3% felt it unnecessary, and the remainder had no opinion or were unsure.
8	All	general	general	As the guideline is intended to provide guidance on health and social care, it is right that it does not go into detail about matters such as welfare benefits and the financial implications of a diagnosis of MND. Nonetheless, the financial implications can be significant, and an individual's or family's economic circumstances can have an enormous bearing on their day-to-day experience of the disease (for instance, some may be able to self-fund equipment; others may be unable to move home or adapt their existing one; others still may struggle to make ends meet and suffer from anxiety arising from this). One point at which clinical practice and financial considerations meet is in the provision of evidence to support welfare benefit claims. We recommend that a statement be included advising clinicians to provide evidence in a timely manner when requested, and to support their patients to access fast-track claims processes whenever possible. It may not be appropriate to go into details about specific mechanisms such as DS1500 forms, not least because they are liable to change by the Government, but it may be worth reassuring clinicians that there is no prospect of any professional sanction in the event that, for instance, a person with MND lives somewhat longer than a clinician had judged that they might, earlier in their illness and at the time of a welfare benefits application. This statement should be included in both versions of the guideline.

9	Appendices	404-412	general	We welcome the recommendations for research, and would be grateful for clarification from NICE of whether it will take any steps to instigate these research projects, or if that will be a matter for stakeholders such as ourselves. Our most substantial recommendation for a further research priority is multidisciplinary care, specifically how it is arranged and the cost-effectiveness of different models. Our Models of Care report will provide a start in answering this question, but as the issue is a highly complex one, and changing as the NHS develops, we anticipate that further research may be necessary.
10	Full	32	1-11	We recommend that the figures given for the proportions of MND cases made up of different sub-types are presented more clearly. The figures given in the guideline appear to be prevalence figures, but the differing rates of progression among the sub-types of the disease mean that the equivalent incidence figures may look very different: if 25% of people living with MND at any one time have progressive bulbar palsy, for instance, the proportion of diagnoses with this type must necessarily be somewhat higher than 25%, as survival times are shorter than the average for MND as a whole. The guideline should clarify that the figures presented are indeed prevalence (if that is the case), and set out the contrast with incidence clearly, in order to ensure that clinicians and practitioners have accurate expectations of the proportions of different types they may encounter.
11	Short	33-34	17-23, 1-3	These lines also use the slightly ambiguous figures for different types of MND.
12	Full	32	23	The guideline cites figures of ‘about 5,000’ people living with MND in the UK at any one time, and around 1,100 people diagnosed per year. We would be interested to see the source of the ‘about 5,000’ figure as, although we believe it is plausible, we have only been able to identify firm evidence for a population of up to about 4,500. The diagnosis figure by contrast seems low: death certificate figures for MND from 2004-8 ranged between 1,361 and 1,508 per year. Given that the MND population is not appreciably shrinking, the rate of diagnosis must be approximately the same as the rate of deaths; indeed, we believe that the ageing demographic profile of the population as a whole may be causing the MND population to grow somewhat, in which case the diagnosis rate should be slightly higher than the death rate. An authoritative exploration of these issues by NICE would be welcome; at the very least, the number of diagnoses should be re-examined, or a comparable figure for deaths presented. If the 1,100 figure is a reference to cases in England only, this should be clarified, as the context suggests very strongly it is intended to refer to the UK as a whole.
13	Full	32	31-32	We question the use of the term ‘care centres’ in the guideline. While the term is in common use among professionals familiar with MND, its meaning is not self-evident. The ‘care centres’ established and funded by the MND Association’s care centre programme, which we believe is what the guideline intends to refer to, might more formally be described as

				specialist multidisciplinary MND outpatient clinics – for instance, in the relevant NHS England specialised service specification. Those unfamiliar with their operation may infer that the 'centres' are more extensive in their offering than is the case; their status as services not currently formally commissioned within the NHS, or fully funded by the NHS, complicates matters further. In some regions, networks rather than single centres have been established, which makes the term even more difficult. We therefore recommend that the informal term 'care centres' is avoided in this formal guidance, or alternatively is referenced and a definition given (the term currently goes undefined), and more formal terminology used thereafter.
14	Full	60	Table	The discussion of possible costs arising from the practices in respect of referral outlined here suggests that no additional costs would arise from them compared to other current practice. In England, we do not believe this is strictly true: under identification rules for specialised commissioning, neurology services only count as specialised, and therefore only attract an uplift in tariff, if the referral is made from one neurologist to another. Referral direct from a GP, for instance, to a specialist in a designated neuroscience centre would not be classified as specialised; it can of course still happen, but could generate a reduced level of income for the hospital. These identification rules may in future be revised: if the coding of NHS activity can be made more accurate in respect of neurology, specialised activity can be identified by code and not referral route. We await confirmation from NHS England of when this might prove possible.
15	Full	61	Table	The same point applies to the discussion of referral pathways in the table on page 61 as in comment 14 above: diagnosis by a neurologist expert in MND would generally fall under NHS England's specialised commissioning regime, but the design of that system does not intersect well at present with the recommendation to refer directly to a specialist neurologist. We welcome the reference to the Association's Red Flags tool.
16	Full	68	15	References to the Association throughout the guideline variously use the terms 'MND Association' and 'MNDA'. We would be grateful if the term 'MND Association' could be used consistently; we do not refer to ourselves as 'MNDA'.
17	Full	70	40	References to the Association throughout the guideline variously use the terms 'MND Association' and 'MNDA'. We would be grateful if the term 'MND Association' could be used consistently; we do not refer to ourselves as 'MNDA'.
18	Short	5	6-8	It is not clear which clinicians this paragraph is addressing; it could apply equally to a GP or to a non-specialist neurologist, but the wording in its second sentence seems to rule out the latter. We recommend clarifying that this is

				sound advice for both groups of clinician.
19	Short	6	2-4	We support the recommendation for a clearly named coordinator of care, and single point of contact that a person with MND can contact in an emergency. However, we recommend that more thought is given to, and guidance offered on, how this works in practice. In particular, is the single point of contact intended to be a care coordinator? The nature of the care coordinator role is discussed further in point 31. In context, this wording in the draft guideline appears to imply, but not explicitly state, that this single point of contact should be in the hospital where the person was diagnosed. This may or may not be the intended meaning, but it is not representative of how MND care is arranged in practice. We asked about this in our survey, and respondents fed back as follows: - 24% have a single point of contact in the hospital where they were diagnosed - 10% have a single point of contact in another hospital - 18% have a single point of contact not based in a hospital - 21% do not have one and feel it has been a problem for their care - 7% do not have one and feel it has not been a problem for their care. We also asked respondents to indicate how satisfied they were with their care overall: those who had a single point of contact, in whatever setting, were more likely to indicate that they were satisfied. The Models of Care project also sheds some light on this aspect of care. Among respondents to its call for evidence, fewer than half identified a key worker or coordinator for people with MND in their area (although this is not quite the same role); some noted that the first member of the multidisciplinary team (however constituted) to make contact with the patient assumes the key worker role, which in the majority of cases is maintained throughout the patients' disease progression. Overall therefore, we support the recommendation for a single point of contact, but believe that how it should work in practice requires further exploration.
20	Short	6	8-12	As part of this process to ascertain the preferences of people with MND for receiving information and involving their family members in their care, it should be recommended that these preferences be included in all letters of referral to other agencies. This will help to avoid the inappropriate omission, or inclusion, of carers and other family members at later stages.
21	Short	7	17-23	We recommend that the guideline suggest a follow-up appointment be offered for a couple of weeks after diagnosis, to

				allow for questions to be asked and care planning to be developed once the person with MND has had a chance to take in the news.
22	Short	7	17-19	The formulation 'many people with MND may not have informal care available' is potentially somewhat misleading. While it is certainly possible for someone to have no informal care available, for instance if they live alone or are themselves caring for a spouse or other relative with their own care needs, it is probably a step too far to describe this group as 'many'. The same wording occurs in the table on page 74 of the full guideline. The current wording could also be taken to mean that this phenomenon is distinct to MND, although there is no reason to believe it is. That said, our recent survey of carers benchmarked the experience of caring for someone with MND against the National Carers Survey, and found that the burden on an MND carer, in terms of the time commitment required of them, is greater than the average in the carer population as a whole. The guideline may wish to take this into account when discussing issues pertaining to carers; we will be happy to supply the MND Carers Survey to NICE on request.
23	Full	71	4-8	We agree with the suggestion that it is important to connect a person with MND to a palliative care centre, to provide a framework for proactive care planning, tailored to the individual's care needs. However, it is not clearly made in the guideline's recommendations, and indeed is slightly cut across by the suggestion that early referral to palliative care should be reserved for complex cases (see our comment 53). We recommend that this advice be clearly added to the guideline's recommendations.
24	Full	71	Table	We agree that the diagnosis and information on prognosis and management should be given by a neurologist with current expertise in MND. In our survey, 98% of respondents agreed that diagnosis should be given by a neurologist expert in MND whenever possible
25	Full	74	Table	We note that in the short version of the guideline, the advice in guideline CG138 is not signposted. The result is that certainly in the short guideline, and also in the full version if the reader is not familiar with CG138, numerous crucial considerations in how to give a diagnosis of MND, which have a significant bearing on the experience of the patient, are not addressed. In particular, we strongly recommend that the following are expressly included, along with reference to CG138 if appropriate, but not using the reference as a substitute: – The diagnosis must be given in a private place (as in CG138) – The patient should be given the opportunity to bring someone with them (as in CG138); ideally, to avoid this

				invitation causing anxiety by alerting the patient to the likelihood of bad news, the invitation to have a friend or relative present should be extended for all appointments from the start of any investigation into suspected MND (not covered in CG138) – After the diagnosis has been given and the appointment is over, the person with MND and whoever is with them should have time in a private room in order to compose themselves (not covered in CG138). In our survey, 79% of respondents felt it should specify that diagnosis should be given in a private place, and the person should be invited to bring someone with them; a further 20% felt this was so obvious as not to need stating. The qualitative evidence generated by our survey on this issue was among the most powerful we received, and strongly suggests that these recommendations are indeed not too obvious to need stating, and should be spelled out. Numerous respondents reported that they or their relative were given the news alone, without the opportunity to bring someone with them. – *My father was given his diagnosis alone and had to drive himself home afterwards. I was surprised at the time that this was considered appropriate.* – *We had no idea that my husband was going to be given life changing news - I dropped him off at the hospital and he was given no support once he'd been told, nor was I contacted to pick him up. He then had to find his way home on the bus in a state of shock and find the words to tell me. I think this was extremely cruel and could have been handled a lot better.* – *My mum was given the diagnosis on her own and it distressed her terribly, if a phone call had been made prior to the appointment somebody would have gone with her.* One respondent noted that even those who might not feel inclined to bring someone with them could come to feel it was a mistake – people should not be obliged to bring someone, but it should perhaps be recommended, even if only gently. – *In my case, because I am so independent I chose to go alone, however that was not the wisest move I have made.* Some respondents gave examples of the diagnosis not being given in private, which often seem to go hand-in-hand with a delivery lacking compassion and empathy. - *My sister's diagnosis was done on the ward for everyone to see and hear, after confusion about whether we could have a room or not – the left hand in the ward didn't know what the right hand was doing. Some of the distress caused that day could have been [avoided if things had been] better planned and managed between doctors and the ward sister.* - *My husband was given his diagnosis in an open ward by a consultant who had several students with him. No*

				compassion was shown and my husband was lucky I was with him. - *The consultant who gave me the definitive diagnosis at Morriston Hospital did so on the ward and in a very downbeat way. He would have made a good undertaker.* A failure to provide adequate information about the significance of the diagnosis was another theme among the responses. - *I hear from patients about their diagnosis being given in private but without family members or any support / information at the consultation. The most recent case I'm thinking of was on a Friday afternoon, the gentleman had never heard of MND but was told he would die from it, and soon... He was advised to 'go home' and talk to his wife about it. Not having any knowledge of MND he did not know what he was supposed to be talking with his wife about! They spent entire weekend without support / advice, didn't sleep or eat, literally 'worried sick'.* - *As an allied health professional I recently found myself in a home visit realising that my patient's diagnosis had amounted to medical jargon in a copy letter and neither she nor her husband understood what she had or what MND is. It fell to me to try to inform, which was similar to giving the diagnosis, something which is not part of my job and for which I was not prepared.* - *My dad was given his diagnosis by his doctor who then just gave him some leaflets and left him to it. My dad was handed an agonising death sentence by someone who couldn't answer his questions.* Many respondents reported that after being given the diagnosis they would have benefited from some time in a quiet and private place to gather their thoughts and compose themselves before beginning the journey home, but that this was not an option for them. This added to the trauma of receiving the diagnosis, and was sometimes compounded by professionals beginning care planning procedures with insensitivity and inappropriate haste. - *My mum was told and then we were asked to sit back in a corridor and wait to see MND nurses and fill in a questionnaire which indicated how the illness would progress. We were shell shocked by the news and time would have been appreciated in a private room to recover from the shock. The questionnaire etc and meeting the support team was inappropriate at the time. I will never forget wanting to burst into tears in a busy corridor.* - *My late husband and I had just been told the devastating news that he had MND; we were then sent into a crowded waiting room to wait to book another appointment, my husband was sobbing and the whole room went quiet with everyone staring at us. It was a very difficult moment.* - *My diagnosis was given to me at the end of the consultation, when my husband and I were sitting at opposite sides of the room. We were clearly expected just to get up and go, which we did. Both of us were in tears we walked the length of the corridor, as staff just stared at us, no one offered comfort or a private corner. It was the most horrendous experience.* - *Total shock when diagnosis given - we had a horrific experience by a physio who outlined all we would require, this was within ten minutes of being told the devastating news. We were in shock and speechless.*

				A further recurring theme was people having to drive home after receiving such a devastating piece of news. – *Our experience was far from ideal, my husband was given his diagnosis and then asked to leave. He was given no chance to sit and recover from the shock and was not asked how he intended to get home. He had a 45 min drive along busy A-roads whilst in a distressed state - hardly the best time to be in charge of a car.* – *When I was told I had MND I was alone, drove home alone and the house was empty. I was a danger to myself and other road users as all I knew about MND was that it was bad.* Numerous examples of good practice also emerged from the survey, but even in these the devastating nature of the news is clear. - *My father was shocked when he received the news and very grateful I was there with him, to discuss with the neurologist and to drive him home. It is important to have someone with them. I was asked to pass the news on to family as my dad was so shocked after.* - *I believe my brother was given the weekend to think about it and then return with any questions. At that time I thought this was very generous and caring. The shock would have meant he wasn't listening so a weekend with family and friends gave him a short moment to catch his breath and return to receive more information.* - *I accompanied my mum to every appointment, including pre diagnosis. It is such a devastating moment, it's very challenging to retain much information at all in such circumstances and patients absolutely need support of family / friends, both emotional and practical.*
26	Short	7	25-26	This section notes the possible implications of frontotemporal dementia (FTD) for the individual's mental capacity. Overall, we feel the guideline does a good job of recognising the significance of FTD, and welcome the emphasis placed on it throughout. In our survey, 77% of respondents agreed that recognising FTD in the guideline was important; 21% were unsure, and 2% felt it wasn't important. It is possible, however, that when MND occurs in older people in particular, they may also already have, or go on to develop, another type of dementia such as Alzheimer's instead of, or even as well as, FTD. This too will have implications for mental capacity and consent, similar to those identified throughout the guideline in respect of FTD. The possibility should be included in both versions of the guideline – an inexpert reader might otherwise draw the conclusion that non-FTD dementias do not occur in people with MND.
27	Short	34	9-12	This paragraph contains a mistake in presenting the statistics on dementia and cognitive change: it refers to 10-15% of people with MND developing FTD, and a further 50% showing signs of mild cognitive change. This suggests a total of up to 65%.

				Page 75, line 3 of the full guideline states that up to 50% of people with MND experience cognitive change, and that this includes those who develop FTD. We believe the latter to be correct, and recommend that the wording on page 34 of the short guideline be corrected.
28	Full	32	17-21	This text is the same as page 34 of the short guideline, and presents incorrect statistics as per our comment 27 above. It should be corrected.
29	Short	5	1-5	We believe that the wording in this section unhelpfully conflates emotional lability with FTD, which risks misleading the reader. Emotional lability is a motor response symptom and often temporary, and therefore quite distinct from cognitive change. At worst, an inexpert clinician or practitioner might currently take emotional lability to mean that there has been cognitive change and the individual lacks mental capacity, even though this may not be the case at all; as it stands, the guideline will not save the reader from such an error. We recommend that emotional lability is addressed separately, and at greater length, in the guideline: for those who develop it, it can be one of the most distressing symptoms of MND, and should be given greater consideration. If evidence to support more extensive coverage in the guideline does not exist, a new research recommendation should be added. There is however one respect in which the guideline could say more on cognitive change: it does not say anything on the risk of a person with FTD becoming aggressive or undergoing other serious behavioural change. This may generate a need for greater support for the carer, or even put the safety of children in the household at risk. We recommend that these aspects should be addressed, or a research recommendation made if there is insufficient evidence.
30	Short	7	25-27	This text rightly states that someone with FTD may lack capacity. However, there is no balancing statement to emphasise that people with milder cognitive change may still be able to reason: although they may struggle to take new information on board, with appropriate help and support to do so they may still be able to process it rationally. In short, reasoning may still be intact even if the ability to take information on board has become impaired. Discussion in the table on page 77 of the full guideline ventures into this territory; it would be desirable to reflect some of this content in the summary version,
31	Full	101	10-18	This point addresses a characterisation of multidisciplinary care that runs through the guideline, and a contrasting characterisation of 'general care'. We will use this comment to set out our broad concerns in relation to this issue, and

				recommendations for how the guideline might better address it. Subsequent comments will address the same issue in relation to specific items in the guideline. We must emphasise that we strongly support the guideline's emphasis on multidisciplinary care and welcome its findings in relation to cost-effectiveness – our concerns relate only to the detail, albeit crucial, of how this care is characterised. The contrast between 'general care' and 'MDT care' presented in both the guideline and the assessment of economic evidence is an overly simplistic binary divide that does not represent the complex and varied reality of MND care in the UK. The 'general care' comparator describes a situation that is probably not terribly representative: how many people are really diagnosed with no input from an MND specialist, and their care then managed in a general clinic with two reviews per year? Surely a small and shrinking number, if only because of the MND Association's care centre programme. The description also fails to take any account of the involvement of community services in this 'general' model, which could themselves supply a substantial element of multidisciplinary care for some people. The description of multidisciplinary care is also problematic, as it assumes that the care is delivered by a formally constituted team, based in a hospital. Community-based services, network models and less formal arrangements are considered only seldom, for instance in reference to 'an extended outreach team' clearly envisaged as 'on top of' the costs of the clinic-based MDT. Again, this risks making the comparator unrepresentative of MND care as it occurs in the real world. A further risk is that developments in health policy will make this approach seem increasingly remote from real-world practice: the NHS in England, and to an extent elsewhere, is embarking on a clear shift of focus out of hospital and into the community, for instance with the development of new care models following NHS England's Five Year Forward View. The guideline should therefore take full account of community services and care network models, without which some health professionals may read it and find it describes a world that simply does not correspond with the one they work in. It will be harder to incorporate them into the economic analysis, as the necessary evidence appears not to exist. For this reason, we suggest adding a research recommendation on this subject. Additionally, while it is often implicit that effective multidisciplinary care must be well coordinated, this is not consistently stated in the guideline, and the nature of coordinator roles is not explored. At times there even seems to be an inference that a coordinator is a specialist nurse, when the two roles are distinct: providing nursing care to a person is not the same as coordinating their care, and while the latter might ideally entail a fully resourced role in its own right, professionals from a range of disciplines can in principle take that role on. From the discussion and evidence below it will be clear that coordination can take place within the community or in hospital, but that there must be clarity among all professionals about who is responsible for it, and that there must be effective coordination when necessary between services in different settings.

				Input from people living with MND supports the view that multidisciplinary care is highly desirable, but that the reality is more complicated than the guideline suggests. In our survey, 97% of respondents approved of the strong advocacy of multidisciplinary care, but only a minority of respondents recognised multidisciplinary care as involving a formal, clinic-based team: - 29% said their care was organised exactly like that - 56% said their care was partly or very different - 15% weren't sure. Differences observed between real life care and the description in the guideline were as follows: - 20% of respondents said there doesn't seem to be a formal team - 17% of respondents said the professionals who support them are based in the community, not a hospital clinic - 67% of respondents said the professionals who support them are based in a mix of the community and a hospital clinic - 14% of respondents said they don't receive support from professionals from a wide range of disciplines - 30% of respondents said the professionals who help them aren't well coordinated with each other. When we asked respondents to indicate their satisfaction with the care they received, those who received multidisciplinary care of whatever sort were more likely to express satisfaction; those who expressed dissatisfaction were more likely to note that care was not multidisciplinary or well coordinated. These responses did not, however, reveal any clear relationship between satisfaction with care and different types of multidisciplinary care (hospital or community-based, or in formal or informal teams). More research is needed to show some different models of multidisciplinary care are more effective than others. Respondents to our survey, ranging from people living with MND to carers and to health and social care professionals, outlined an array of multidisciplinary care arrangements with involvement by, variously, hospitals, hospices and community services. - *In the absence of a care centre in West Dorset, coordinated care is offered via Joseph Weld Hospice where all the professionals have an MDT each month and there are joint clinics attended by a neurologist every three months.* - *The core multi-disciplinary team were based in the hospital, there was some evidence of them working as a team - but it was by no means always evident Counselling was never offered to my husband. Social care was arranged by me in the first instance, I never managed to get a formal carer's assessment. It was only through the MNDA [*sic*] that I knew of Continuing Healthcare, and it was only because I asked for my husband to be*

				assessed for CHC that it eventually happened[. ...] It worries me that if I had not spoken with our RCDA and hassled the professionals this might not have been offered. - *Not everybody will be fit enough to continue to travel to clinics. Care centres may be difficult to access and parking can be a nightmare. We have had to arrange taxis to take people to and from clinic appointments at care centres due to the lack of parking and arduous journey. Ultimately all of the patients I see can't make it to the care centre. Some patients prefer to stay with local neuro hosts. In my area our MDT is community based and includes the palliative care team.* - *We are quite geographically isolated so care was often coordinated by our GP, and district nurses.* - *MDT is hospice based under palliative care plus the option of hospital MND care centre clinic. This works really well.* - *None of the MDTs in NE London are attended by a neurologist - they are fundamentally community based with input from the Care Centre Coordinator.* - *My husband's care was originally clinic based but as he deteriorated it was an ordeal to get to the clinic and wait approx 3 hours, so care was passed to the neurological community care team.* Some respondents highlighted problems with coordination of care. - *The MND coordinator is excellent and always fully informed. Other members of the virtual team don't seem to be aware of each other's involvement.* - *The multidisciplinary team meets but never asks for updates prior to discussing my husband. Key individuals leave without us knowing. As my husband has a more slowly progressive form we notice these things getting worse over time*. It was common for respondents to note that community-based professionals were key to their care. - *Because I live at a distance from my main hospital clinic it is a great help to have some support nearer at hand. This includes speech and occupational therapists and physiotherapist. They all keep in close touch with my co-ordinator.* - *Before the local MDT was formed 5 years ago my care was haphazard. Now it is excellent.* - *Worked wonderfully for us. One foot in the hospital system and one foot in the community where most care actually took place. Couldn't fault it.* The interim Models of Care report reinforces this picture of a varied landscape of multidisciplinary care – and in some cases, less obviously multidisciplinary, more general care. A common situation identified by the Models of Care work is of a community-based multidisciplinary team (MDT) with

				which a specialised MND clinic has strong links. Respondents to the call for evidence outlined this scenario: - *In between clinic appointments there is often frequent discussion with the local health community as issues/problems arise. We do also have regular MND MDTs in each area so information can be discussed and shared then* (Bristol) - *The MND Coordinator attends local MND MDT's where possible and links in with the [MND Association] Regional Care Development Advisers to help facilitate seamless care over into the community and good communication.* (London) One neurologist indicated that the central clinic is actively building this local, community-based capacity: - *We are building a network of local teams - I think the time for large (often distant) 'Centres' is passing and Networks linking local teams is the way forward.* (Neurologist who specialises in MND) Many of the in-depth interviews generated evidence of the importance of delivering care in the community, and in the homes of people with MND. It was not uncommon for interviewees to articulate that MND care should lean towards community services as opposed to acute care, and that the majority of care occurs in the community. Among these responses, the value of MND clinics, including care centres organised along the traditional Association model, was still recognised: they provide access to procedures that cannot be performed in the community, and they are a valuable source of advice and support for those in the community. Outreach clinics organised from the central clinic can avoid patients travelling long distances. Differing attitudes and preferences on this issue were observed among different clinicians and practitioners: some neurologists and other hospital-based staff were characterised by respondents as firm advocates of hospital-based clinics, perhaps at the expense of looking beyond the acute setting and being willing to get advice or support from community services. Equally, general neurologists were sometimes characterised as reluctant to refer 'their' patients to a specialist clinic, or as being unaware of the full range of MND services available. A further reported observation was that MND Association staff appeared more likely to be invited to clinics and meetings in hospices and the community than in the acute sector. While the draft guideline advocates that coordinated assessments should be undertaken at the multidisciplinary clinic, and implies that the team should therefore meet, in hospital, in the presence of the person with MND, evidence of current practice and views on best practice identified by the Models of Care project do not entirely support this. Among respondents to the call for evidence, 46% said the MDT meets as a group without the patients, 19% said the MDT initially meets as a group with the patient, and 12% said the MDT subsequently meets with the patient.

				One respondent questioned the value of large meetings with the patient present: *All multidisciplinary team members may not be required from the outset. Many professionals seeing together may be frightening for the patient. Additionally, it would be waste of time and resources of the professionals if they are not needed. A tailored approach of seeing patients in the community with quick response time is most suitable for this group of patients.* A respondent to our September 2015 survey voiced similar reservations about large meetings with patients present, drawing on experience in Scotland: - *A monthly or bimonthly 'clinic' based in Aberdeen where patients are 'rolled out' in front of a group who then 'observe' and then debate each others opinions in front of the patient. MND nurse not in attendance (neurologist did not work with MND Scotland nurse at all).* There was also evidence of considerable variation in MDT arrangements, in respect of the size and composition of the team, and frequency and nature of meetings. Many have good input and attendance from community teams, hospitals, and hospices; however a few reported little input from hospitals or, in some cases, neurologists. Others were noted as having excellent input from, and close working with, MND clinics including care centres. Another variation apparent in the evidence was the presence or absence of neurological care coordinators based in the community. Some were noted, for instance in Greenwich, Hertfordshire and Milton Keynes. In other areas, such dedicated roles appear to be absent. It can also be noted that multidisciplinary teams and clinics are seldom, if ever, formally commissioned or planned by the NHS in any territory covered by the Association.
32	Full	65-9	general	This review of evidence suggests that there is an absence of evidence on multidisciplinary care outside hospital clinics. This supports the case for a research recommendation on the topic.
33	Full	103	16-18	This description of an outreach team arising from the hospital-based MDT is an example of the hospital-oriented focus of the guideline; it appears not to take into account the possibility of support from community-based multidisciplinary care.
34	Full	104	1-4	We feel this is a problematic characterisation of ‘general’ care. If someone is assessed only twice a year, it seems unlikely that needs such as for communication support will be reliably or promptly picked up as assumed here.

35	Full	109	Table	The lack of evidence in respect of community-based services and additional coordinators is a substantial problem, and contributes to the guideline's relative weakness on community-based care. The nature and value of coordinator roles in different settings must be included in any new research recommendation.
36	Full	112	Table	We particularly welcome this recommendation against inappropriate case closure, which is often reported to us as a problem. A similar conclusion is drawn in the Models of Care interim report.
37	Short	8-9	21-28, 1-2	Assumptions about the nature of a multidisciplinary team hinder this section somewhat. To avoid this problem without exploring the nature of MDTs at inappropriate length for the summary document (and bearing in mind the relative lack of evidence), the use of the phrase 'coordinated multidisciplinary care', which avoids assumptions about the nature of teams, may be more appropriate.
38	Short	9-10	24-30, 1-10	We recommend that an MDT – whether based in hospital or the community – should involve the GP of the person with MND. Ideally this would be as a core member, although bearing in mind practicalities such as the need to attend MDT meetings, strong communication and information sharing between MDT and GP is perhaps the best recommendation. In our survey, 82% of respondents felt GPs should be included in the core team. Respondents reported that their GP's involvement in their care varied: - 18% said their GP was heavily involved - 27% said their GP was somewhat involved - 40% said their GP was only very occasionally involved - 15% said their GP was not involved. GP involvement correlated positively with the respondent's satisfaction with their care, which suggests that more research may be needed to test the proposition that GP involvement in MND care has a beneficial effect. We also recommend that palliative care should be in the core team: in our survey, 95% of respondents believed that specialist palliative care should be part of the core team. Speech and language therapy should be available on an 'access' basis at least, and benefits advice should be available as well – 96% of respondents wanted to see benefits advice added to the list. Although the draft guideline recommends that a specialist nurse should be a core member of the team, this role is not defined or explored. In different settings, such a role might be dedicated to MND, or might cover a range of rarer neurological conditions. The Models of Care interim report identified a variety of views about to what extent, and how, specialism should be brought into multidisciplinary teams: some saw great benefit in having an MND specialist nurse,

				both in terms of care provided and the ability to up-skill other members of the team; others saw more need for specialism in care coordination, and even argued that this would be more valuable than a specialist nurse as such. See point 31 above for further discussion of coordinator roles.
39	Short	34	29-29	These lines use the problematic generalisation about 'care centres' versus 'general care' already discussed. We recommend that they are amended to reflect the variety and complexity of MND care available.
40	Appendices	389	24-28	We welcome this observation that the measures of quality of life in EQ-5D may not be adequate for capturing the experiences of people with MND. It accords with our own research, for instance on attitudes towards the end of life, which indicate that people with MND can become accustomed to, and value, a quality of life that they might previously have felt would be unacceptable. We will be happy to supply this research on request. One respondent to our survey captured how views of what constitutes an acceptable quality of life can change as someone adapts to living with MND: - *Patients choices may change during the course of the illness. After becoming accustomed to living with MND I rescinded my Do Not Resuscitate [Order].*
41	Appendices	393	6-9	In stating that 'palliative care costs are only occurred once in the last phase of the individual's life' we believe that the guideline is confusing palliative care with end of life care. Palliative care can be delivered at any phase of the person's illness.
42	Appendices	393	19-21	The inability to factor costs and benefits associated with equipment into an analysis of multidisciplinary care is a significant problem, and this must be factored in to any future research. Qualitative evidence submitted to the inquiry into communication support run by the All Party Parliamentary Group on MND in 2014-15 indicated that the scope for communication devices to improve quality of life is, in some cases, enormous. The benefits and costs associated with this must be factored in to any authoritative analysis of the value of MND care.
43	Full	157	Table	The wording in this paragraph is unclear, or possibly problematic: as written, it states that social services provide assistance with motoring, the blue badge scheme, Motability and car adaptations, home adaptations, wheelchairs and AAC. It may be the intended meaning that social services provide assistance with applying for these services; but they are not, themselves, social services (the blue badge scheme and some provision for home adaptations are administered by local authorities, but do not count as social care; wheelchairs and AAC are NHS responsibilities).
44	Full	157	Table	We agree that the advice given here about case closure is particularly relevant for social care, and welcome its

				inclusion. Discussion in the same table also notes that assumptions should not be made about the ability or willingness of family members to undertake caring responsibilities; we agree.
45	Short	12	9-25	Social care can be a difficult aspect of MND care if not delivered to a high standard; it would be helpful for the guideline to include advice to address the potential problems associated with it. Care workers can lack expertise in MND, and can also rotate very quickly, providing little continuity; the resulting care can feel like a parade of strangers visiting someone's home. Some respondents to our survey identified this as a significant problem in their care. - *Untrained, unskilled carers, with no knowledge or understanding of MND, caused more problems than they solved.* - *My main bone of contention is the carers. I appreciate they are on zero hours and minimum wage (and that until caring becomes a profession alongside nursing things probably won't change). But an awful lot of heartache and misunderstanding could have been prevented if they had some understanding of the condition. I often ask them if they know anything about MND, and to go and google it - especially the emotional side effects including anxiety.*
46	Full	170-1	Table	The helpful discussion in this table about having conversations at key junctures about legal mechanisms and control later in the illness could be sharpened and included in the short version of the guideline. In particular, we would like to see clearer guidance about making counselling available prior to starting NIV, to alert people to the possibility that it might give them a measure of control over the timing of the end of life. In our survey, 80% felt that the guideline should specify that counselling be available when NIV is being considered, to ensure the possible implications for end of life are understood; 9% felt the current approach sufficient. Respondents gave examples of how early discussion of end of life considerations before commencing NIV can be important, but also difficult. We would be happy to see the guideline include a statement clarifying that withdrawal of a treatment is legally distinct from euthanasia, as this seems to be a common area of confusion and uncertainty for some professionals. - *There was an out of the blue end of life discussion at the initial consultation about the NIV machine which was horrific. We were told that when he was dying the NIV machine would have to be taken off. This sounded to me, the carer, almost like euthanasia. Very shocking at a fairly early stage of his illness.* - *I think an additional statement should be included regarding discussions and counselling at the start and end of treatment. Professionals working in respiratory teams frequently have differing opinions on when or if NIV*

				withdrawal should be discussed. - *Would it be appropriate to include a statement which clarifies the distinction between the withdrawal of an intervention such as non-invasive ventilation and assisted suicide? For a number of healthcare professionals I have come across who have been involved in the process of withdrawal of ventilation, this has been difficult to resolve.* - *This happened to us my husband he had been using a Bipap for 6 years. When my husband became very ill in hospital he became totally dependent on his Bipap, Whereas before he only used it at night, he was very anxious because he knew he didn't want to live if he had to have ventilation 24 hours a day. I raised this concern with the respiratory nurse and she said you have choices – we can gradually take it away and give medication enough to relax you through it. My husband took great comfort from this as he didn't realise this could be done as no one had mentioned it before. This ended up being the decision he made. So most definitely this should be explained at the beginning.* - *People are not always aware of implications when started on NIV.* Respondents identified instances both where people with MND did not wish to consider the issue, and where this reluctance caused difficulties later. - *Difficult this one. I accept the final outcome. I do not want to be given all this information at the outset. Let me have a bit of peace and quiet, gather my own thoughts.* - *With reservations - my husband did not want to know what the future held - he very much wanted to live for the day. At one point one of the doctors did speak to him about a DNACPR order - he was adamant that he should never be subject to one - though did say he didn't know how he might feel at the time one became necessary, yet when the FTD had developed to the point where he could not communicate a DNACPR was put in place. My husband did not want to think about Lasting Power of Attorney when we updated our wills and he was still able to understand what was involved - I wish I had known of the possibility of FTD developing. It was expensive, time consuming (at a difficult time) and distressing to have to apply to the Court of Protection just to enable me to file his tax return and sign on his behalf! Somewhere there needs to be a relaxed discussion at least with the partner, where one exists as to the possible problems that might occur.* Advice must also be given on potential problems that can arise with the use of NIV. - *Constant explanation of what non invasive therapy can mean. Ultimately my partner commenced and became reliant on the respiratory machine and the deterioration was rapid and additional problems with facial abrasion, nose and mouth discomfort through dryness occurred which was unexpected and very distressing.*
47	Full	171	Table	The evidence in this table about misunderstanding of when palliative care might be available suggests that referral to

				specialist palliative care at a reasonably early stage should be a matter of routine.
48	Full	272	Table	This discussion further supports our recommendation that there should be early discussion of the possible issues around withdrawing NIV at the end of life.
49	Full	281	Table	This discussion further supports our recommendation that there should be early discussion of the possible issues around withdrawing NIV at the end of life.
50	Short	24	13-15	This discussion further supports our recommendation that there should be early discussion of the possible issues around withdrawing NIV at the end of life.
51	Short	13	2-12	This section should be clarified, to emphasise that all health and social care professionals in an MDT should be prepared to have conversations about end of life issues, and should not close them down when the person with MND initiates them – this could be at any time, not necessarily when a professional might expect it, and people with MND tell us that they place importance on being able to discuss this when they feel ready. This responsibility should not be assumed to rest only with palliative care teams. Many respondents identified the need for such discussions, and even expressed annoyance at some professionals' apparent reluctance to engage in them. - *Depends on the person...in our case my wife happened to be very open and exploratory...eg she wanted to give her remains for study...the clinician always had difficulty in dealing with such strident honesty* - *We were caught out by the speed of the disease. So end of life discussions were left to family members. Wills and power of attorney were discussed early on but not considered at that point and therefore not completed before respiratory and physical condition deteriorated to such a debilitating extent. It should be insisted upon early with a knowledgeable professional to avoid problems later.* - *Even professionals from the specialist team at the MND Centre shy away from discussion about end of life issues. It would not be considered 'up beat' enough!!* - *What are clinicians waiting for. Why are they waiting? Until that conversation can't be had with a voice. It's barbaric.* - *I made it quite clear that if I had lost my mental capacity or was for other reasons not able to communicate I did not want to be resuscitated. Once I had done this I was able to get on with my life without worrying so much about the assumed progression of my illness* - *The ability to discuss end of life is often more difficult for the carers / family of the sufferer and medical staff should be sensitive to that and allow discussion when raised.*

				- *We would have both welcomed counselling at the beginning and at the end. We didn't know the end was so close when it did come.* - *I think there should also be a sentence emphasising that people can change their mind at any time.* The consequences of failing to address wishes about the end of life early enough were recounted by some respondents. - *An advance care plan is so important. It wasn't done in our case and led to all sorts of problems in trying to fulfil end of life wishes. For example, being in a hospice instead of dying in hospital - the question was never asked by professionals until it was too late and the death was in hospital, not the preferred place which was hospice.* - *My husband couldn't discuss his end of life choices, he'd lost his voice and couldn't type, it was too late for him.* There are however obvious problems with raising end of life issues insensitively, as numerous respondents identified. - *I have been quite blown away by how an MND nurse brings up an end of life plan - like it's just another treatment. Even receiving a phone call 'out of the blue' asking me if I want one. I do believe the patient should be the one to instigate it, I object to having it rammed down my throat!* - *On one visit to the neurologist my husband was asked, 'where would you like to die?' There was no preamble, no explanation that his condition had not suddenly deteriorated and that he was simply being asked about his wishes in line with guidelines that seemed to have been updated just prior to the consultation. My husband was unable to respond, he was by then too slow with the Lightwriter - and was distressed by the question - this should have been delegated to the neurological nurse specialist as a question to be asked in the home setting, or at the very least there should have been some explanation of why he was being asked.* - *It should not be discussed though at diagnosis! This is a devastating time and patients and family need time to digest this first, not try and talk end of life care. Totally wrong timing and insensitive.* - *This in particular is a very private and personal business, done too quickly it would be very distressing. Left too late especially if the bulbar issues become especially challenging and psychological factors develop and it is essentially too late. Very tricky one.*
52	Short	13	10-12	This recommendation could usefully be strengthened: nearly all people with MND will find one or more of their communication ability, cognitive ability or mental capacity impaired during their illness, so this should simply be a recommendation to start advance care planning at an early stage, once the person with MND is ready to face it (which will vary considerably). In our survey, 88% of respondents agreed that the guideline should recommend that advance care planning be started early in a person's illness, to ensure it is not hindered by, say, communication difficulties later on; 4% disagreed. We also recommend that lasting power of attorney (LPA) should be added here; to discuss it under circumstances of 1.7.5 (when considering NIV or gastrostomy) is too late.

53	Short	13	13-14	We recommend that early referral to specialist palliative care should be routine for all people with MND, not just complex cases. The analysis in the full guideline and views expressed by people with MND as discussed in our points 46 and 51 above bear this out. In our survey, 82% of respondents felt there should be early referral to specialist palliative care for everyone; 16% felt the guideline was correct to reserve this for people with significant or complex needs.
54	Short	14	3-5	Although tracheostomy is out of scope of this guideline, similar considerations may pertain to it as to gastrostomy and NIV, as referenced here. Given that this discussion is focused on planning for the end of life, there is a case for referring to tracheostomy – if it is not covered in an ADRT or other legal instrument, there is the possibility of it being introduced in an emergency situation.
55	Short	17	15	We would like to see the references to assistive technology expanded to include computer access, to ensure that people are still able to use online services and communication channels as outlined earlier on page 12. In England and some other territories, computer access is dealt with by environmental control services, but this is not always widely understood by professionals or service users; a clear statement would help set appropriate expectations on all sides. In particular, the ability to communicate should be preserved, rather than assistive technology being restricted to specific purposes such as environmental control. In our survey, 86% felt that there should be a statement that the person's ability to communicate should be maintained for its own sake; 14% felt the current approach sufficient
56	Short	17	24-25	We recommend that more detail be provided on the characteristics of wheelchairs for people with MND, such as the need for wider arms, a head support, a tilt function and so on. In our survey, 81% of respondents felt the wording should be expanded to give more details of the MND specifics of appropriate wheelchairs; 19% felt the current approach to be sufficient.
57	Full	239	table	The content on AAC in this table is mostly a good match with NHS England's service specification, although it does not directly address the funding divide between communication support (AAC) and computer access for those who can still speak (the responsibility of EC services). Addressing the importance of maintaining social interaction and a role in society is helpful. However, the service specification makes very clear that referral for AAC assessment can be made on an anticipatory basis; we would like to see the guideline offer similar clarity, in order to be consistent. In our survey, 78% of respondents wanted to see a separate statement making clear that referral for AAC could be on an anticipatory basis; 22% felt the current approach sufficient.

				One respondent to our survey highlighted that early understanding and anticipation of cognitive change can also be crucial to securing effective ongoing communication, as well as avoiding the pitfall of concentrating on swallowing function at the expense of speech. - *My husband developed FTD, by this stage it was too late for him to learn how to use a communication device suitable for his physical abilities at that stage. I had signposted spelling difficulties that had not been present before the onset of MND, and changes in empathy - yet although the neurologist tested for FTD this information did not feed through to the SaLT - who when she did come really didn't seem to have an up to date grasp of what equipment was available. Her appointments were always too long and too distressing for my husband with a concentration on swallowing rather than communicating - this led him to express what I assume to have been extreme frustration - a wordless howl that I can still hear three and a half years after his death.*
58	Short	20	23-4	We recommend that this provision should specify that the speech and language therapist should have appropriate knowledge of MND.
59	Short	21	6-8	As with the equivalent section in the full guideline, this should specify that referral for assessment can be anticipatory, in line with NHS England's service specification. It should also clarify the meaning of 'complex' in this instance, which is quite specific: here, 'complex' need means that in addition to impairment of the voice, the person is also losing hand function (and therefore cannot use more basic text-to-speech communication aids). Accordingly, the guideline should also clarify that in non-complex cases, assuming no anticipatory referral, local speech and language services should meet the person's needs, not an AAC hub (in England). In some areas of the country, a timeframe for anticipatory assessment of 18 weeks is starting to be used: so, if the person might be expected to develop 'complex' needs within 18 weeks, an anticipatory referral is appropriate, even if the need is only just starting to develop. This will ensure that by the time the need is clear-cut, provision should be in place. We would be content to see this timescale proposed (though this does not mean we would support a general timescale of 18 weeks from referral to provision for any MND service – for too many people, this would be unacceptably slow).
60	Short	12	20-30	This section does not address the substantial impact of isolation and shrinking social networks as a result of MND, for both the person living with MND and their carer or carers. We are, however, pleased to see the value of wider communication such as email, as well as face-to-face communication, acknowledged: this engagement with the wider world can be hugely important to a person with MND.

61	Short	14	20-21	This stipulation regarding bereavement support is welcome, but could offer more specifics about what this support should involve, and what is meant by 'as appropriate'. The full guideline offers no further detail, although the finding in the evidence review that support from health and care services seems to carers to 'disappear' immediately after bereavement rings true.
62	Short	16	9-14	Reference to neck control and support should be included in these paragraphs on saliva management.
63	Short	18	17-22	We recommend the inclusion of advice on training and support for carers, both on technical matters such as feeding using a tube and keeping the tube clean, and on issues such as addressing potential awkwardness or more complex issues, such as feelings of guilt if eating solid food in front of someone who is tube fed.
64	Short	17	7-16	Daily living needs such as shopping, housework and food preparation should be added here; these are all within scope of social care as defined in England by the Care Act 2014.
65	Short	19	20	We advise against the use of the word 'normally' here; in this context, it may appear to have a loaded meaning. Neutral language such as 'without assistance' should be used.
66	Short	20	1-2	This text notes that some people choose not to have a gastrostomy, but no further guidance is offered on what the implications of this might be, or what support should be made available to them. We recommend that the guideline offers further clarity on this point.
67	Short	20	8	This stipulation should offer greater clarity about what is meant by 'unnecessary delay' (for instance, waiting until a patient is clinically able to undergo the procedure might be a necessary delay, but having to wait because a hospital cannot roster an anaesthetist would not be), or alternatively use more direct wording such as 'urgently'.
68	Short	22	17-22	These paragraphs are arguably unclear in what decisions they are asking clinicians to make: what conclusions should they draw in respect of the route of administration and cost of the medicine? Although part of the role of NICE guidance is to evaluate cost-effectiveness, this is the only point in the guideline at which the reader is advised to make a judgement on cost. We recommend that this text should either be much clearer about what it expects from clinicians, or remove reference to cost in particular. In our survey, 80% of respondents felt these paragraphs were clear, but 68% felt they should not advise clinicians to consider cost.
69	Short	22	14-15	While it may be strictly true that the decision to offer a treatment rests with clinicians, we would prefer to see a

				reference here to the person with MND, to acknowledge that this decision will be made with knowledge of their circumstances and, when possible, preferences.
70	Short	22	1-3	When mechanical cough support is used, ongoing professional support must be in place. This has been known to cause difficulties for people with MND, so it should be stipulated in the guideline.
71	Short	24	6-12	This recommendation should be expanded to stipulate that the person with MND must understand the possible interaction between NIV and other equipment – in particular, that it can sometimes be incompatible with eye gaze devices.
72	Short	33	10-11	The MND Association has a range of information and support available for professionals caring for people with MND, which in many cases go into greater detail than the short guideline, and in some cases than the full one. We also suggest that the MND Association Red Flags tool, already mentioned in the guideline, and Outcomes Standards framework as tools that might assist users of the guideline. Our award-winning Guide to End of Life, although written primarily for people with MND, is directly relevant to the guideline's content on planning ahead and is already used by professionals. We will be happy to supply these to NICE, and discuss whether and how they can be promoted alongside the guideline.
73	Short	34	16	We feel it is misleading to state that MND 'mainly affects people aged 50 to 65 years'. While this may be the age group in which incidence is highest, MND can affect any adult. The current wording may create misleading expectations among clinicians and professionals not already familiar with MND. We recommend that the guideline states that MND can affect any adult, but is most common between the ages of 50 and 65.
74	Full	194	Table	While clear guidance on exercise is very welcome, we recommend that there should also be guidance on fatigue. While the aim of exercise is to maintain function and quality of life, over-exercise or competitive exercise may be ill-advised, and lead to fatigue that outweighs any other benefit. Without guidance on this subject, less experienced professionals may recommend inappropriately intensive rehab-style exercises.
75	Appendices	409	Table	The study design for this research recommendation proposes to collect information from the existing AAC hubs in England in order to identify a baseline of AAC use among people with MND. This approach will not, however, capture the full MND population: before a person's needs become 'complex' (see comment 59) they will be met by local speech and language therapy services, not the specialised hubs. Most people with MND in England can expect to be referred to a hub at some point in their illness, but at any one time a substantial portion of the MND population using AAC will not be on the hubs' caseloads. The current proposed study therefore cannot meet its stated objectives using the

				proposed methodology; we recommend this be revisited. Additionally, we recommend that the scope of the study specifically include the use of high tech AAC, notably eye gaze, at or near the end of life. Evidence to the APPG inquiry on communication support exhibited a divide among professionals: palliative and end of life care professionals tended to promote advance care planning and argue that communication at the end of life when the person has speech problems is often unsuccessful; SLTs expert in AAC, by contrast, reported seeing eye gaze and other approaches used to good effect at the end of life. More robust research on this topic is required in order to identify best practice.
76	Full	173	4-11	We would like to see a greater prominence given to pain in its own right, rather than being bundled in with other symptoms. In the full version of the guideline it is mentioned in the context of muscle problems (as here, although often only in parentheses) and end of life. It is also included in the list of things an MDT should review, although in the short version of the guideline it attracts no mention beyond this. Although the development of MND – that is, the process of the motor neurones dying within the body – is not itself painful, pain is in practice a major element of the problems presented by MND for those who develop it, whether from muscle problems such as cramps or posture-related issues. The notion of 'painless progression', while technically accurate, is one that gets challenged by people with MND at Association events. If insufficient evidence can be found to expand the guideline's content on pain, a research recommendation should be added.
77	All	General	General	Dry mouth can be a troubling symptom of MND; we recommend that the guideline offer some guidance on it.
78	All	General	General	A few respondents to our survey made reference to their wish, or the wish of the person they cared for, to leave their bodies or specified organs and tissues to medical research. Advice on this appears not to be offered routinely by clinicians; we recommend the GDG considers whether to include advice on this. - *I feel organ donation, brain and spine should be talked about as I only found out through an MND Thumb Print [magazine] as my consultant isn't allowed to mention the subject. It seemed to me a worthwhile thing to do from a research point of view so something good might come out of this most inconvenient of diseases.* - *My mother has recently died, nearly five years since diagnosis. She regularly updated her advance directive (ADRT) with the help of the MND nurse. But when the time came, much of it was ignored. She also wanted to leave her body or 'tissue' for research but, again, was not properly advised. The university research team told me that the MND clinicians did not think this was a suitable subject to raise with their patients. I have since spoken to the consultant and he has written to say they will look at amending their practices in future.*
79	All	General	General	There is no reference in the guideline to genetic testing for MND, or to genetic counselling. Although, as the guideline

				notes, genetic influences are only part of the explanation for MND and the full range of mutations involved has not yet been identified (notwithstanding that 5-10% of cases involve the clear transmission of the disease down the generations), there may still be some diagnostic benefit in genetic testing, and there may more often be a benefit in terms of informing family members about possible risks to future generations. For people with MND who are considering starting a family this may influence their decisions; when possible, they may wish to access pre-implantation genetic screening in order to ensure that any children are born without a specific mutation. We recommend that these points are addressed in both versions of the guideline.

Insert extra rows as needed

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