

**Submission by the MND Association to the inquiry on NHS
Continuing Healthcare by the All-Party Parliamentary Group on Parkinson's**

1. About MND and the MND Association

- i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure.
- ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a World Free of MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

2. Introduction: Continuing Healthcare and MND

- i. The availability of NHS Continuing Healthcare (CHC) for people with MND varies enormously, and unacceptably.
- ii. There is no doubt, however, that the support provided for a person living with MND by CHC when it is in place can make an enormous difference to their wellbeing and that of those around them: a CHC package can entail support as extensive as a live-in carer 24 hours a day plus additional support in the morning and evening.
- iii. People with MND will often move to CHC from a package of social care support. This can therefore be a step change in the level of support available. Some people with MND resist it, however, as accepting the CHC package may entail dismantling the tailored support they have build up using a social care direct payment. This is not a problem everywhere: in some areas, the NHS might use the same care agency as the local authority, or otherwise be able to continue and expand the existing package. The introduction of direct payments for CHC from 2014 should in principle remove this barrier.
- iv. Ultimately however, CHC often proves hard to get for people living with MND, and in some cases hard to retain. In some areas, people with MND seldom succeed in getting CHC on their first application, and access it only when they appeal against the refusal. In others, CHC can be withdrawn because the person

appears to have 'stabilised' or even, in some cases, because their need has actually increased – for instance, we have heard of a person living with MND who ceased to be considered at risk of falls because they had been confined to bed by their illness, and another for whom the fitting of a gastrostomy led to their being judged no longer to be at risk of malnutrition, both cases resulting in the withdrawal of CHC.

- v. This submission explores why CHC is so unfathomably hard to access for some people with MND, the perverse behaviours this can generate, and how the system appears from the perspective of someone living with MND. It also offers suggestions for future policy changes to correct the existing problems.

3. The CHC criteria

- i. The domains under which CHC assessments are carried out do not recognise the full impact of MND: looking at them individually, a person with MND will often not be awarded the top scores, even though the overall impact on the person of all the individual health problems together could be immense. This can give rise to perverse incentives and behaviours, both for professionals undertaking assessments and for applicants.
- ii. The timing of an assessment can be critical to success: a person whose needs are high and unstable, and who has not yet had adequate intervention by health and social care services, is most likely to score sufficiently under the domains to access CHC. A person who needs a wheelchair but has not yet been given one, for instance, might be assessed as needing CHC. Applying too early, when the person's needs are lower, or too late when they are better met, will result in low scores.
- iii. Another problem is that a person with MND can have their CHC reviewed, and be found to no longer to need it. This is a medical nonsense: the progressive and irreversible nature of MND means that once a need has been developed, it will remain for the rest of the person's life. If that need has been well managed, however, it can be counted in the assessment as no longer present.
- iv. Superficially this appears to be at odds with the instructions in the Decision Support Tool (DST), which state:

Needs should not be marginalised because they are successfully managed. Well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need will this have a bearing on NHS continuing healthcare eligibility.

- v. However, the DST goes on to state:

[W]here someone's skin condition is not aggravated by their incontinence because they are receiving good continence care, it would not be appropriate to weight the skin domain as if the continence care was not being provided.

- vi. No allowance is made for the fact that an existing CHC award may be the means by which a particular symptom is controlled. Hence the nonsense of the withdrawal of CHC from people with progressive conditions is permitted.
- vii. Ultimately, however, the criteria can be made to work for people living with MND, albeit with difficulty. This can be achieved not by focusing on the scores of the domains, but on the quality of care required: its nature, intensity, complexity and unpredictability, in the terminology used by the National CHC Framework. As part of every assessment, these four additional criteria should be considered: when this is done, the extreme nature of MND often allows the assessor to judge that they in effect give rise to a primary health need and render the person eligible for CHC.
- viii. This approach, however, relies to some extent on a high quality application, supported by care professionals who understand that this is the way to secure CHC for someone with MND. It also relies on the assessment being conducted properly, and due consideration being given to these four criteria. That people with MND often struggle to obtain CHC indicates that this is not done: while the criteria for CHC are problematic and warrant revision, an even greater problem is the sheer low quality of assessments.

4. Low quality assessments

- i. Use of the DST, and assessment for CHC in its wider sense, can both be effective in identifying the eligibility of people with MND when conducted by clinicians who have a sound knowledge of MND and who know the person being assessed. In many assessments, however, neither of these conditions is fulfilled. The professional undertaking the assessment can be ignorant of MND, and specialised clinicians and associated professionals such as occupational therapists go un-consulted.
- ii. Ignorance about MND on the part of a professional completing the DST can be particularly dangerous to the prospect of an accurate assessment. MND is not a fluctuating condition – once a motor function has deteriorated it does not recover – but people living with MND can experience ‘good days’ and ‘bad days’ mainly for reasons to do with fatigue. This does not mean that their medical symptoms fluctuate, but their practical ability may vary somewhat depending on how much energy they can muster. The difference between assessment on a ‘good day’ and assessment on a ‘bad day’ might well therefore be the difference between being awarded CHC and not being awarded it, if the professional completing the DST does not understand the effects of the disease.
- iii. The way in which DSTs are completed and used can compound these problems: we would agree with the widespread perception that the DST increasingly appears to be used as a tick-box assessment, rather than as a tool to support a subsequent assessment process. Badly used, as we have seen, it can lead to a total failure to assess the person’s needs as a whole, and instead look only at specific and very narrow criteria.
- iv. The presence of knowledgeable health and social care professionals who understand how to identify an individual’s needs within the framework of the

CHC criteria, and who have established a relationship of trust with decision-makers within the NHS, can often make a crucial difference to the success of a CHC application. Our regional staff report that in some areas CHC is accessible fairly reliably for this reason. This is, however, a symptom of a system that does not work: to be truly equitable, no system should be reliant on local relationships and the savoir-faire of specific individuals to such an extent.

5. Local variation

- i. With poorly functioning criteria and variable quality in assessments, it is inevitable that CHC will be subject to substantial variation in outcomes between localities.
- ii. Some people with MND can find that they are offered an extremely limited package of CHC, for instance covering, perhaps four nights a week. This is of no practical use, as the person's needs will remain unmet the rest of the time.
- iii. In some areas, the NHS has been known to fail to fund the care after agreeing to provide it. In one case a person's carer was sent a bill for care, and the situation resolved only with the involvement of the local MP and after enormous distress had been caused to the family.
- iv. Problems can also arise when the NHS attempts to shunt costs on to local authorities, for instance by disputing what is a health need and what is a social care need. This is especially common around issues related to eating and drinking and administering gastrostomy feeds.

6. The understanding and perspectives of people living with MND

- i. It is worthwhile to remember how CHC might appear from the perspective of a person living with MND, and their carer or close family members, who in practice will often support them with making applications and understanding their entitlements.
- ii. It can be hard for someone living with MND to understand and distinguish between the array of differing sources of financial and care support available to them. Broadly speaking the three main sources are the NHS, social care and welfare benefits, but very few people with MND can be expected to identify with total accuracy what support they are receiving, and from where.
- iii. Low general awareness of social care can often create an expectation that it is free (as part of the NHS or welfare state) and lead people to be shocked that it can be charged for. The introduction of direct payments has made social care appear more like a cash benefit. Even within the benefits system, there is low awareness and much confusion about what each individual benefit is for (never mind what the ever-changing array of acronyms like PIP, ESA, UC, WCA and so on actually stand for).
- iv. In this context, CHC is just another confusing entitlement to be applied for. It should not be underestimated just how hard it can be to keep across all of these sources of support while managing the draining day-to-day business of living

with MND, or supporting a loved one through their illness, where simply getting up and dressed in the morning can be a complex operation taking multiple hours.

- v. Clarity around CHC can be hard to come by for people in this position. There is abundant misinformation: some people may be told, or infer, that CHC is something to which someone with MND has an automatic right. The criteria by which it is assessed are hard to locate online, and even harder to understand. Meetings with people with MND to go through the DST can be run in an inappropriately clinical way, with a district nurse or similar going briskly through the questions and discussing the person's condition in blunt, insensitive terms; finding an opportunity to ask questions, or even identifying the right questions to ask, can be hard for the applicant and their carer.
- vi. Reassessments can also present serious problems: for someone with a progressive illness, it makes no sense that CHC funding might be reassessed and even removed; the prospect can seem to hang over a person. We strongly recommend that reassessments for people with progressive conditions be abandoned.
- vii. The problems identified above – criteria that work poorly for people with MND, low quality assessments and unwarranted local variation – can combine with the general nature of managing entitlements to care and support to make obtaining CHC a bewildering and, in the worse cases, distressing experience. This should not be the effect of any system or service intended to alleviate need.

7. Is CHC the right funding?

- i. It may be asked whether CHC is the correct source of funding to support people with progressive and terminal illnesses; it may be better suited to supporting people with long-term conditions or specific episodes of highly demanding care need. Nonetheless, it is the only source of funding for the care necessary to meet the high demands of MND once it has substantially compromised a person's health.
- ii. The expected tariff for palliative care may provide a more responsive and appropriate funding stream for people with MND. Combined with free social care for people nearing the end of life, which we also recommend be adopted, this could create a more accessible support system for people with MND. The mechanisms and criteria by which this would be accessed would still very likely be matters of contention unless extremely well-designed, however.
- iii. We would also recommend that assessment for CHC should be more anticipatory: while the existing Framework makes some reference to anticipating future need, this is often to the effect of scheduling a further review of need rather than awarding CHC on the basis that need will soon arise.
- iv. Finally, while we appreciate the reasoning behind eligibility to CHC being determined by primary health need and not diagnosis, we wonder if this broadly positive orthodoxy – looking at the individual, not the diagnosis – might have been adopted with unhelpful rigidity. Very often a diagnosis of MND will be the most important single piece of information about a person, from a health and

social care perspective: we recommend that for conditions whose impact is extreme and whose numbers are low, diagnosis ought to be taken into account to at least some extent. As a minimum this must include ending the practice of reassessing people with progressive conditions.

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