motor neurone disease association

Response to the consultation on service specifications for specialised commissioning

Summary: four urgent points

We were very pleased to see the strong focus on MND in several of the service specifications, particularly the spec for neurosciences which contains a thorough, positive and ambitious description of a specialised MND service. This represents a step-change in the NHS's approach to commissioning MND services which we welcome.

This response addresses six of the draft service specifications (D1a-c, D2, D4c and A3D1). While we have a range of comments on each of them, we have four key points which, notwithstanding our positive overall view of the proposed approach, must be addressed urgently to ensure that serious problems do not arise with specialised services. They will be explored in full, but are presented in summary here:

1. Clarity is needed over how the commissioning model for adult neurosciences will work in respect of MND: while the firm commitment shown to MND is welcome, the proposed model either requires significant new resources in order to be realised, or risks imposing an inflexible regime that cannot be realised within current resources; either way, care must be taken when the new system comes in not to undermine strong provision where it currently exists.

2. The bar on referrals from non-neurologists appears to risk delaying access to treatments, albeit for a minority of patients. While most referrals to specialised MND centres come from neurologists, there are occasions when referrals are accepted from others professionals: putting an absolute bar on this would be both undesirable and, we suspect, unworkable.

3. The timescales proposed for equipment provision (D1a-c) are unacceptably long for patients with a rapidly degenerative condition such as MND. Much shorter timescales must be specified, and services must be designed to meet these timescales for MND patients. We are also concerned that the model proposed may be somewhat inflexible.

4. Input from neurologists into specialist respiratory support must be directly recognised within the service specification; the current draft does not take sufficient account of existing practice and NICE guidance.

Introduction

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.

iii. This response will take each of our four key concerns in turn, and then address further issues in each of the draft specifications on which we are commenting.

iv. We welcome the references to MND across multiple specifications, and in particular the extensive and thorough definition of an MND centre in the neurosciences spec. Historically MND has been somewhat overlooked (the Specialised Services National Definitions Set contained no detail on it at all, for instance), so it is important that these definitions and references are retained in the final specifications.

v. We will also be making the case to the NHS Commissioning Board that MND, and neurology more broadly, should feature prominently in its priorities when they are decided in the spring. A report by the National Audit Office in 2011 and subsequent report by the House of Commons Public Accounts Committee found that services for people with degenerative neurological conditions such as MND are unacceptably variable, and have not improved in proportion to increases in funding. It was also found the National Service Framework for Long-Term Neurological Conditions was not effectively implemented, though it was a worthwhile document and we are pleased to see it referenced in the neurosciences spec. There is therefore considerable scope for improving both patient experience and value for the NHS by addressing neurological services as a priority.

Section 1: Neurosciences – tiers, flexibility and how the new model works in practice

i. While we were very pleased to see such a comprehensive and positive description of specialised MND services in the neurosciences specification – and strongly urge that it be retained – we feel there is still much work to be done in mapping out how it will be applied to the tiered structure of provision proposed.

ii. Currently specialised MND services are provided mainly by the MND Association's network of care centres, which are not specifically commissioned, but rather provided by agreement with a neuroscience centre as part of that hospital's overall package of specialised neurology services.

iii. These centres operate in a variety of ways depending on local circumstances, but generally speaking use a much more lean and flexible approach than is proposed here, and certainly do not have the capacity to implement the new model in full without substantial new resources being made available.

iv. We will consider each tier in turn, starting with Tier 3, the specialist centre. This is the most straightforward element of the proposed new model, and aligns closely with most current provision. We would however like to see clarification of how much flexibility the proposed new model would allow, for instance in drawing together input from a range of disciplines – this is referenced in the spec, but it is unclear how far it might extend. For example, a specialist centre may be co-directed by a neurologist and a palliative care specialist. While the only current example of this arrangement is in Wales rather than England, we would not like to see the possibility ruled out if it is the most effective response to a region's needs, and it is not clear whether it would be possible under these proposals or not.

v. With regards to Tier 2, effective outreach into "main population centres" (which we take to mean district general hospitals, for practical purposes) will require significantly more resources, including extra training, than are currently dedicated to specialised MND services, and need to be built up over time. We would welcome this, as too often existing outreach arrangements, even at their most effective, can rely on good will and enthusiasm rather than being driven by the NHS's structures and processes.

vi. Within existing resources, more light-touch approaches can drive good results. Some existing centres have effective outreach, which may take the form of formal outreach clinics, or may consist of effective but less formal relationships entailing for instance second opinions, support with difficult cases and access to research programmes. Going beyond these approaches and delivering the model outlined in the specification would, while highly desirable and having the potential to improve services for people with MND significantly, require considerable extra resource.

vii. Similar, regarding Tier 1 we support the introduction of a duty on specialised centres to drive services out into community settings, providing appropriate resources are made available to do this. We caution, however, against the possibility of effective pre-existing relationships being needlessly swept away; sensitivity will be needed when introducing the new model in order to preserve existing good practice. Many existing centres already undertake highly effective outreach work into community settings: this can be by close liaison with the team in the specialist centre (which might include, for instance, a specialist nurse / coordinator, physio and OT), by using study days and special interest groups to enhance expertise within community services (which we take to be the intent behind the "virtual clinical network" mentioned in the specification), and / or by targeted visits to specific patients with complex needs, for instance delivering specialist physiotherapy and thus avoiding hospital admission.

viii. Overall, we would like to see, as a priority, more detail about how specialist centres will be resourced to implement this new model, particularly to provide community services. In other words, how will the "spokes" of the new model be established, given that current resources allow only for priority to be given to the "hub"? We hope that the above discussion of the three proposed tiers illustrates why this is such a pressing issue and we would hope that the strategic clinical networks, clinical senates and the Board's local area teams will be able to work together to provide the answers to these questions, and support seamless commissioning of both specialist centres and services in community settings.

ix. Bearing these points in mind, we are somewhat concerned that the NHSCB is negotiating contracts for 2013-14 now, with the service specifications still in draft form. While we appreciate that for many service areas, the specs represent a statement of the level that services should, in principle, already have attained, the description of an MND service is very different from the current situation. This may lead to NHSCB contracts for 2013-14 not implementing the specification, but also to CCGs also not commissioning appropriate MND services, in the belief that the Board will take care of everything (it is certainly the case that Joint Strategic Needs Assessments do not take appropriate account of MND – we are aware of only three that mention neurology at all). We are already aware of one locality where community MND services are falling into this gap, and expect there to be more.

x. Urgent action by the Board is required to ensure that appropriate services are in place: if the proposed model cannot be fully implemented in April (and there are good reasons for not doing so without amendment, as we have outlined), the Board must ensure that appropriate services have been commissioned to fill the gaps that will remain.

xi. Our final observation is that the general approach across all specifications focuses heavily on process. To some extent this is inevitable, as this is the first time that the make-up of all specialised services has been mapped out. The rationale underpinning the current NHS reforms as a whole, however, includes a clear focus on outcomes: while it is right that there should be a clear national standard that all specialised services should meet, outcomes for patients should be the ultimate focus, not the processes by which they are achieved. We have previously expressed our regret that the NHS Outcomes Framework has been framed in such a way as to minimise its relevance to MND. We would like to work closely with the Commissioning Board in developing outcome measures for specialised services that take proper account of the needs of people with MND, as well as working to refine the process and service specifications currently at issue.

Section 2: Referral

i. We have some concerns about the proposal to define a specialised neurology service as one that takes referrals only from other neurologists. While this is indeed how most referrals are made to MND specialists, we would not like to see this acting as an absolute bar on referrals from GPs and other healthcare professionals. The spec offers some examples of where non-neurologists may refer patients to specialists; it is unclear whether this point is included to extend this right only to the named professionals, or to illustrate that a wider range of non-neurologists, including GPs, may at times make such referrals.

ii. There are sound reasons for referral by a GP in some circumstances: a patient may be dissatisfied with their local neurology services, or feel that they cannot approach them, in which case they may wish their GP to refer them to a specialist. We have also seen some indications that referral from GPs direct to specialists for diagnosis may be increasing slightly in some areas, perhaps due to increased awareness of the availability of specialised services.

iii. There are also potential benefits to direct referrals: it may mean swifter diagnosis, which in turn will allow treatment such as riluzole (the only drug known to slow the progression of MND) to be started earlier. In a condition for which survival from symptom onset can typically be expected to be only two to five years, any delay to starting treatment is to be regretted.

iv. That said, we would not wish direct referral of cases of suspected MND by GPs to specialists to become the norm: the role of the specialist is to direct treatment once it has been confirmed, and perhaps give final confirmation of the diagnosis ahead of that, but not to investigate all suspected cases from scratch. Rather, we would not wish there to be an absolute bar on referrals by professionals other than neurologists, as they can at times be appropriate.

v. We are also uncertain how such a bar might operate, particularly given that such instances represent a small proportion of referrals. Differentiating between these and referrals from neurologists would not meaningfully affect what services are to be commissioned or on what basis, as far as we can see.

Section 3: Timescales

i. The timescales proposed for equipment provision are far too long for people with MND, and we are seriously concerned that new systems are being designed on the basis of the draft specification that will badly fail to meet the needs of this group.

ii. The proposed timescales we have in mind are:
   - D1a Complex Specialised Wheelchair and Seating Service: all patients to be “seen” within 18 weeks.

- D1b AAC / Communication Aids: patients to be seen within 6 weeks of acceptance of the referral, and equipment to be provided within 12 weeks of assessment or 18 weeks of referral
- D1c Environmental control equipment for patients with complex disability: all referrals acknowledged within 10 days of receipt, and equipment to be available for use (when required) within 18 weeks of accepting the referral.

iii. These timescales are far too long in respect of MND. For comparison, the Oxford MND wheelchair service aims to see all new referrals within one week and have an appropriate wheelchair supplied to the individual within three or four. While a slower service may result in some cash savings to the NHS, it comes at both an unacceptable personal cost to the person with MND, and a high risk of further cost to the NHS arising from the need for extra treatments to cope with pain or injury arising from unaddressed posture and mobility problems. It is currently not unknown for equipment to be provided only when the person's condition has changed so that it is no longer suitable, or even after the patient has died – this problem should be designed out of the new system, not deliberately designed into it. By every measure, the proposed approach is unacceptable.

iv. Many areas of statutory services have appropriate fast-track mechanisms for people with rapidly degenerative illnesses, including NHS Continuing Healthcare and some aspects of the benefits system. Even if faster timescales cannot be made available for all patients (although for all specialised provision we would expect this to be both feasible and self-financing), there should certainly be some form of fast-track provision for people with MND and other rapid illnesses.

v. Associated with this point, there may be a problem with the model outlined in the service specification. It is proposed to send the patient to a separate wheelchair service, which immediately introduces procedural barriers and the potential for delay and extra cost; as the Oxford MND wheelchair service model demonstrates, wheelchair provision can be most effectively handled by a specialised MND centre, provided it has an appropriately experienced and specialised occupational therapist. We will be rolling this model out two further centres, but it will not cover the whole of England, and we recommend the Board considers disseminating it.

vi. We will be happy to provide more information on the Oxford wheelchair model and put forward proposals for more effective supply of equipment of all types to people with MND.

Section 4: NIV

i. We were pleased to see the clear inclusion of NIV for people with MND in the draft specification on complex home ventilation. The document does, however, contain a significant omission: the input of neurologists to NIV support must be expressly acknowledged. The NICE clinical guideline recognises that skills from a broad range of professionals should be brought together in providing NIV, and the specification should reflect this. We suggest that sections 1.1 and 2.2 are places where neurology input could usefully be specified. Some existing and effective NIV provision is led by neurologists; the specification must allow scope for this provision to continue.

ii. The provision of a clinical guideline by NICE on the use of NIV for MND is still a recent development, and this opportunity should be taken to push for uptake of the treatment to be as wide as possible. It must always come with access to specialist respiratory physiotherapy and community outreach, as an effective way of avoiding unnecessary hospital admissions.

Section 5: Further issues

D4c Neurosciences

i. We have some concerns over the definition of a, "consultant neurologist with sub-specialist expertise." Neurologist numbers in England are low generally, and more specialists in MND are needed. We would not like to see the tight definition of a specialist neurologist exclude neurologists with significant expertise in MND – more than a general neurologist in a DGH can be expected to have – who see high numbers of cases and are on their way to meeting the criteria, but perhaps not quite there. Neurologists who specialise in MND must be allowed to develop within the NHS; if the definition as set out here is applied tightly, there may not be enough specialists neurologists to staff all the centres. Clarification of the acceptance and exclusion criteria may be a way to address these concerns.

ii. In section three, Applicable Service Standards, we are pleased to see the National Service Framework included. In the absence of a full guideline on MND, which is still at least two years away, the NICE technology appraisal on riluzole and short clinical guideline on NIV should also be included – both contain good general information on MND services as well as the specific topics they cover.

iii. Under section four, Key Service Outcomes, we recommend that falls and pressure ulcers should be mentioned under the 'safety' domain.

D1a Complex Specialised Wheelchair and Seating Service

i. In addition to our serious concerns about timescales, we have two further recommendations for this service specification.

ii. Firstly, it should be acknowledged within the spec that home adaptations can be crucial to using a wheelchair. Secondly, we recommend that work-based assessments are included, to enable people to stay in work when this is possible and in line with their preferences.

D1b AAC / Communication Aids

i. We have significant concerns about how deliverable this specification is, and how closely it reflects the current state of services.

ii. The local "spoke" service to provide a loan bank of "less expensive" and "more common" devices needs defining. Is it to be commissioned by CCGs, or as part of the specialised package? If the former, CCGs currently seem unaware of the costs to which they could be exposed: even a basic lightwriter costs £3,000 and is currently denied to some people with MND for lack of funds. We also strongly feel that local services also need to be upskilled: currently they often do not have basic knowledge such as what switching mechanisms or applications might be appropriate for people with MND.

iii. There also appears to be a danger that people could 'bounce' around the system, for instance between the specialist hub and local spoke services, when they need equipment urgently. Regarding referrals, we note that the target of assessing someone within six weeks applies only if the referral is accepted; if it is not, what happens to that person? How commonly might referrals be declined?

iv. The statement on page 11 regarding population size is opaque, and perhaps tautological. It should be clarified. The statement on page 12 regarding local funding arrangements is similarly unclear – could it lead to services being totally non-standardised, and delivered on basis of what is feasible locally, rather than on the basis of need? We are also unsure of the meaning of the statement about the, "trial and long term provision of low and high tech AAC systems," on page 12.

v. The exclusion criteria on page 11 appear to be too crude to meet the needs of people with MND: anticipatory assessment is essential given the rapid degeneration often seen in cases of MND, so excluding patients who have minimal upper limb impairment is not acceptable – what may be minimal impairment at one stage is highly likely to become significant impairment, perhaps very quickly.

D1c Environmental control equipment for patients with complex disability

i. The list of services outside the scope of specialised provision, and in some cases outside the scope of NHS provision, nonetheless contains services that are essential to allow people with MND to maintain any measure of independence. We would welcome a more direct acknowledgement of their significance, and of the importance of co-ordinating specialist provision with these other services.

ii. We must also note the current crisis of funding facing local government, which makes services such as home adaptations exceptionally difficult to obtain in some areas.

iii. In section 2.2, we are concerned at the statement that, “staffing will be determined by local requirements and the availability of skilled personnel.” Staffing should be determined by need alone, and the second part of the sentence should be struck out. If availability of staffing is a barrier to service provision, that would represent a failure in the NHS’s training policy; commissioning policy should not be formulated on the premise that such a failure is acceptable.

D2 Specialised rehabilitation for patients with highly complex needs

i. The inclusion of references to MND in this specification is welcome. It will be particularly applicable to people with MND who have survived longer from diagnosis, and have complex disabilities. Currently some specialised MND centres have strong links with neurorehabilitation units and can access parts of the service selectively, reflecting the degenerative nature of MND. We recommend that this cross-linking should be directly acknowledged within the specification.

ii. The list on page 10 of other services that patients must be able to access should also include housing services. As above, we must note that the funding crisis in local government is likely to impede the ability of some of those services to provide effective support.

iii. We are concerned at the footnote on page 15, which suggests that in some services, funding needs to be negotiated with CCGs once suitable equipment has been identified: firstly, it is unclear how this interacts with the proposal for all MND services to be specialised; and secondly, it is not acceptable to have people with MND being required to chase money around the system – all assessment of need should carry funding with it.

A3D1 Complex Home Ventilation

i. For completeness we will respond to the draft specification on complex home ventilation at this stage, although consultation runs until late February. We wish to reserve the right to send further feedback before then, if further points are drawn to our attention.

ii. As outlined in section 4 above, the input of neurologists to NIV should be acknowledged.

iii. We would also like to see clarification of the relationships between specialised centres, and local and regional networks outlined on page 7. Will NIV support for people with MND be available at local and regional level, with the specialised centres for weaning? Or will there be another arrangement, which may require greater travel for people with MND?

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