

RESPONSE TO THE WHITE PAPER 'EQUALITY AND EXCELLENCE: LIBERATING THE NHS'

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Executive summary

MND and the MND Association

We welcome the vision of the White Paper 'Liberating the NHS'. We have deep concerns, however, that it does not set out with any clarity a new settlement that will provide enhanced and more equitable care for people with motor neurone disease (MND).

MND is an extreme marker condition: it is always fatal, profoundly disabling and rapidly progressive. A system that can respond well to MND can respond well to more or less any condition.

The current NHS settlement has failed people with MND: access to services is deeply inequitable. Where improvements have been made, the work of the MND Association in driving change and co-ordinating it across institutional and professional boundaries has, almost without exception, been the decisive factor.

The MND Association already subsidises statutory services by over £3.5million. Demand on us is growing; as a voluntary organisation reliant on our own fundraising and volunteers, we cannot meet growing demand indefinitely.

We are very willing to continue to play a role in improving services for people with MND by: using our expertise to inform the current reform process; providing a platform by which health and social care services can be integrated and co-ordinated; continuing and developing our role in providing services and equipment; funding research; developing pathways and other tools.

The reform agenda

We are concerned at the pace and structure of the proposed changes. There are significant risks of increasing costs both in the short term, through upheaval, and the long term, through the proliferation of small institutions, a loss of economies of scale and the need to manage a highly complex nexus of commercial contracts. We believe that further reorganisation in the medium term is a likely consequence of these changes.

We have significant concerns regarding the conduct of the consultation exercise: ministers and officials have been inaccessible, and the consultation programme seemingly token.

GP commissioning and commissioning for MND

We strongly recommend that MND be commissioned at a higher population level than that of individual GP consortia: it involves relatively low numbers but high demand, and would expose GP consortia to significant insurance and systemic risk.

GPs typically, though not universally, lack knowledge of MND and it is not reasonable to expect them to acquire it. They should not be expected to commission for MND.

We present several possible alternative solutions:

- a dedicated commissioning network for MND and/or rarer neurological commissions under the aegis of the NHS Commissioning Board and possibly run by the MND Association
- commissioning by larger groups of GP consortia, with appropriate support

- a solution involving the Neurological Commissioning Support service.

Under the current proposals, MND will enter a ‘standards wilderness’ when the new arrangements come into force: it has no NICE guideline or quality standard, and the current National Service Framework for Long-Term Neurological Conditions will be defunct. New guidance must be commissioned to fill this gap – this can be adapted from existing MND Association tools such as the Year of Care pathway.

End of Life care is in danger of drifting into a similar ‘standards wilderness’ and greater priority must be attached to it within the Government’s proposals.

The vital role of specialist clinicians must be recognised, and their role in co-ordinating care safeguarded.

Providing MND care to a high standard is far less expensive than doing it poorly and then having to address the consequences. The White Paper reforms offer an opportunity to secure high quality care and to control costs at the same time.

Putting patients and the public first

Significant improvements are needed to both the information gathered on MND and the ability of the NHS to share it proactively with voluntary and community organisations, if the latter are to play the role envisaged in the new NHS settlements.

There is a significant risk that a vibrant market of providers of MND services will not emerge: numbers are low and the demands of the condition are high. The MND Association is willing to continue and expand its role in providing services, but cannot institute a full range of local markets on its own.

People with MND typically have only a short time remaining, and utilising accountability mechanisms will often not be attractive to them. Channels for voluntary and community organisations to assist in holding local services to account must be built into the new settlement.

Personalised care delivery models can bring great benefits to those who use them, but they are not right for everyone: nobody must be compelled to use them against their wishes.

While personalised models may be effective in integrating health and social care, more and bolder initiatives are needed: joint commissioning between health and social care, and co-commissioning in which the MND Association can play a role, should be explored and developed further.

Improving healthcare outcomes

Further clarity is needed about the impact of the proposals for value-based pricing on the only drug known to have any effect in MND, riluzole.

All domains in the Outcomes Framework must be applicable to MND, and significant work is needed before this is the case. End of Life care should be included within a top-level domain, and the concepts involved in reducing mortality, enhancing quality of life for people with long-term conditions and helping people recover from illness must be revised so that they can be made applicable.

The development of PROMs and other outcome measures, including measures that take the views of carers into account, will be welcome and should be proceeded with as quickly as possible.

Research

A clearer strategic focus on research within the NHS reforms is needed, although the references made to date within the proposals are positive.

Research should be included within the Outcomes Framework.

The role of voluntary and charitable organisations

The MND Association will continue to respond to need and shape the delivery of high quality care. The outcome of the current reforms must, however, be that statutory services provide high quality services that do not suffer from the current gaps and inequities.

The role of charitable organisations will continue to be broad, including information and signposting, funding of research, undertaking work to enhance individuals' quality of life and supporting volunteers. This is in addition to providing services through contracts with the NHS, which some charities will also wish to do.

Introduction (1): 'Liberating the NHS' – response to its vision

Overall, there is much to be welcomed, and applauded, in the vision and values of the White Paper - in particular its focus on patient voice and outcomes, and in shared decision making and personalisation of palliative and end-of-life care.

While the scale of change may be daunting, there is little value in clinging to existing structures for their own sake: any objective reflection on the performance of PCTs and the National Service Framework for Long Term Neurological Conditions (NSF) must conclude that they have failed to deliver for people with motor neurone disease (MND). Where there have been improvements in standards, equity and accessibility of care for people with MND, all too often they have been driven by the work, locally or nationally, of the MND Association.

It is worth reflecting on what the old system has failed to do, as the new system must be judged by the same yardstick: if it cannot deliver in these areas, it too will have been a failure. The failures are:

- to ensure equitable access to high quality care for all people with MND
- to develop any dedicated standards or guidelines for MND care
- to implement the National Service Framework for Long Term Neurological Conditions
- to ensure adequate levels of awareness of MND among GPs, nurses and other health and social care professionals
- to ensure diagnosis of MND is as swift and reliable as is medically possible, and communicated sensitively in all cases
- to deliver essential equipment, including wheelchairs, sufficiently quickly and to a sufficiently high standard to meet the needs of people with MND
- to provide continuing health care funding to people with MND when they need it
- to provide specialist palliative care early enough, or at all
- to support carers adequately
- to ensure services for people with MND are co-ordinated by specialists
- to provide respiratory management for people with MND
- to support clinical research adequately.

It must be emphasised that this failure is comprehensive: where services have been improved this has almost always been due to intervention by the MND Association, for instance by instituting our network of care centres, prior to which there were no centres of excellence in MND, driving the creation of pathways locally, organising training and education, raising awareness and providing vital equipment and finance. We are also one of the founders of the Neurological Commissioning Support service; this has proved a worthwhile and valuable venture, but it must not be overlooked that it arose from the total failure of existing commissioning structures to meet the challenges of MND and other neurological conditions. Through these initiatives we have worked with all types of institutions involved with MND care, on a co-production basis when appropriate, in response to the needs of people with MND as they have arisen, rather than institutional or contractual requirements or pressures.

As a consequence of this work, we subsidise statutory services significantly: local health and social care professionals come to us in the first instance often because they know the response of statutory services will be too slow or even entirely absent. Our expenditure on this subsidy, across our full range of care services, totaled over £3.5million in the year to January 31st 2010. Demand on our resources is growing as

first the recession and then in-year service reductions have started to bite, and our expenditure in this area is projected to have grown by over a fifth by January 2011. To give an example from one particular service, our direct financial support for people with MND stood at £79,408 (for 132 people) in the period May-July 2008; for the same period in 2010, it was £216,247 (for 367 people). We rely on our own fundraising and volunteer base to make this work possible, rather than state funding, and accordingly do not have the resources to meet this demand if it continues to rise at this rate for a significant period.

The reforms of the White Paper therefore offer an exciting and valuable opportunity to create a new and more successful settlement for people with MND. The consequences of failing to take this opportunity, or of making wrong decisions at this stage – in terms of quality of life for thousands of people, and ultimately the timing and manner of their deaths – do not bear thinking about. All sides must act decisively and in the interests of people with MND while there is a chance to make a significant difference for the better. We will be responding to all four consultations published following the White Paper, and seeking to engage further with the Government on these important issues.

This response will offer a frank assessment of the proposed reforms. Where we believe they will be of benefit we will say so, but equally where we believe they risk making things worse for vulnerable groups such as people with MND, we will make this clear: we have a duty to represent people with MND, and while we would be happy for our criticisms, where we make them, to be proved wrong, we would be neglecting our duty if we did not make such concerns as we have plain at this stage.

There is more at stake than the wellbeing of people with MND and their carers, although this should of course always be the over-riding concern. As will be shown, providing timely and appropriate care for MND is far less costly than providing care badly, which inevitably creates problems that need to be addressed by further care and interventions. If the wrong decisions are made at this stage, not only will services deteriorate, but the cost of MND to the state will increase.

In the context of these remarks the MND Association does however have considerable concerns over how the transition between the old and new regimes will operate, and the danger of people with MND falling through the net – reports are already reaching us of people with MND suffering problems as a result of service cuts or uncertainty over their future care, as are requests for financial and other assistance for the same reasons.

In addition the MND Association questions not that reform is needed but whether it is appropriate to introduce such fundamental reforms, with such haste, in the present climate of fiscal austerity. We also note that representative bodies for the medical professions have offered a very mixed response to the proposals, entailing both warm praise for some aspects and strong criticism for others. The prospect of a reform platform being implemented without the support of the professions is a worrying one. In connection with this, we raise below significant concerns regarding the conduct of the reform process and consultation on proposals to date. Moreover, in light of the extremely welcome emphasis within the proposals on an evidence-based approach, we would welcome the publication of the evidence upon which these proposals for reform are based, to help us, and all other interested parties, understand how the new mechanisms will work.

Introduction (2): About MND

MND is an extreme condition: it is always fatal and typically progresses with a rapidity that the care system struggles to respond to. Life expectancy from symptom onset is typically two to five years, although the lengthy diagnosis process means that many people are more than half-way through their illness before it is confirmed that they have MND – after diagnosis, the median survival time is just 14 months.

During this short span of time patients 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. Its profoundly disabling effects and speed of progression make MND an extreme marker condition: a system that can respond effectively to MND can respond effectively to more or less any other condition.

It must be emphasised, as this section of our response will show, that many of the orthodoxies of health policy cannot be readily applied to MND: a clear patient focus remains important when treating any illness, but this must always be within the context of MND. The single most important piece of information about any person with MND is that they have MND. The implications of this are so profound that, if they are fully understood and acted on appropriately, this in itself does much of the work of securing appropriate care.

MND can affect any adult at any age: most forms occur most commonly after the age of 40, although cases can occur as early as the mid-teens. As the condition is more common in older people, its prevalence will rise in coming years as the population ages.

The phrase ‘motor neurone disease’ is itself an umbrella term for a range of conditions that all involve the deterioration of the motor nerves or neurones in the brain and spinal cord, which pass messages to the muscles telling them what to do. The four main forms are:

- amyotrophic lateral sclerosis (ALS) – life expectancy two to five years from symptom onset; makes up approx. 65% of cases
- progressive bulbar palsy (PBP) – life expectancy six months to three years from symptom onset; makes up approx. 25% of cases
- progressive muscular atrophy (PMA) – life expectancy five years from symptom onset, most commonly in younger adults; makes up approx. 10% of cases
- primary lateral sclerosis (PLS) – onset is typically later in life, and life expectancy is not significantly less than normal; makes up only approx. 2% of cases.¹

Cases of MND are complex and unpredictable: all bodily movement can be affected, but there is no set order or predictable timeframe in which this will happen. The individual may lose one or more motor function quickly but retain others for some time.

Often the individual will remain mentally alert as they become trapped within a failing body. MND can affect areas of the brain beyond the motor system however, and fronto-temporal dementia affects up to 5% of patients, with a further 30% or perhaps more undergoing mild cognitive change which can, but does not always, intrude on daily life. Emotional lability – involuntary crying, laughing or other emotional displays, for no obvious reason – is also a feature of MND in many cases. Patients and carers may suffer profound depression following the diagnosis of MND, but it is not over-

¹ Figures are rounded and do not total 100%.

represented when compared to the general population.

In the UK in 2008, 1,956 people died of MND – equivalent to five people each day, and one death in every 296. The number of people known to be dying from MND is increasing year on year: in 2001, MND accounted for 1,595 deaths (one in 378 deaths). This increase is likely to be due, at least in part, to improved recording of MND on death certificates. As the population ages, however, this trend of increase is certain to continue.

There are approximately 5,000 people with MND in the UK at any one time. While this may superficially appear to be a low figure, the disease has an incidence, at 2 in 100,000, roughly similar to that of multiple sclerosis. The MS Society cites a figure of approximately 100,000 people with MS in the UK; the contrast between this and lower numbers for MND is largely a reflection of the rapidity with which most forms of MND usually prove fatal, as well as of its onset being, on average, later in life.

The current experiences of individual people with MND during the course of their illness vary enormously: some are cared for to a consistently high standard, many are subject to highly mixed standards of care, while others have distressingly poor experiences. Across the NHS in England as a whole – as well as wider institutions – the overall picture is one of significant variation and inequity.

Awareness of MND is low among health and social care professionals, the public as a whole and, indeed, among politicians. In September 2010 a minister of state gave an interview on national television in which he suggested that people with MND might regularly be expected to re-enter the jobs market: the profound error and inappropriateness of this comment would be apparent to anyone with a basic understanding of the nature of the illness.

This chronic low awareness extends, sadly, to neurological conditions generally, which so far have been conspicuous by their lack of prominence in the Government's discussion of its health reforms, just as they were an afterthought in the development of the previous regime of National Service Frameworks. It is vital that neurology is recognised: it is regarded as a specialism, but should not be. It is a disease area that affects eight million people in England: how much less 'specialist' do conditions have to be before they are recognised as a mainstream priority? Neurology must feature prominently in all aspects of the current reform process if it is to succeed: we cannot afford for neurological conditions to remain ghettoised as they have been under previous regimes.

1) GP commissioning and the reform agenda

a) GPs and people with MND

For the reforms to work for people with MND, they must:

- raise GP awareness of neurology
- ensure that GPs recognise neurological symptoms and refer people with MND to a neurologist much more quickly than at present
- ensure that commissioning for MND is undertaken by specialists, at an appropriate population level;
 - o ideally by a dedicated commissioning network for MND or rarer neurological conditions more broadly, under the NHS Commissioning Board, or

- by GP consortia working formally with MND Association care centres and other centres of excellence, or
 - by groups of GP consortia working together within a framework set out by the NHS Commissioning Board
 - ensure that whoever commissions MND uses the Year of Care Pathway, a tool developed by the MND Association and the only clear and comprehensive pathway available for all stages and aspects of the disease
 - take urgent action to provide interim guidance for MND to prevent it falling, in the absence of either the National Service Framework for Long-Term Neurological Conditions or a NICE guideline or Quality Standard, into a 'standards wilderness', by;
 - fast-tracking the production of a guideline and Quality Standard for MND by NICE, or
 - creating new forms of guidance for challenging conditions, such as the mooted 'quality threshold', National Strategy for MND or other form of quality marker.
 - Include a duty for any provider engaged by GP consortia to engage with the MND Association, whose work has, to date, driven the majority of improvements in commissioning and clinical practice for MND in England.
- i. Chapters two to four of this response will follow the structure of the White Paper: before that, however, it is necessary to explore and comment on the implications of the proposals in an over-arching way. The place to start must, inevitably, be the proposed shift to GP commissioning.
 - ii. The White Paper sets out the case for GP commissioning on the basis that GPs are, "best placed to coordinate the commissioning of care for their patients." Other things being equal, this stands to reason: however, for rare conditions such as MND, the benefits of the GP's close relationship with the patient will be more than outweighed by the very limited knowledge of MND that the GP is likely to possess. Commissioning for MND requires specialist expertise and general practitioners, by definition, often do not have it.
 - iii. It has traditionally been said that a typical GP will see only one case of MND in their career. With large shared patient lists this is perhaps no longer strictly the case, but MND remains a condition that GPs will very seldom encounter. The expertise in MND that most GPs are able to offer is therefore correspondingly low, with the result that they are not equipped to commission for MND.
 - iv. The condition's low prevalence would have significant implications for GP commissioning as envisaged in the White Paper, were it to become the responsibility of GP consortia. MND is not a cheap condition to treat, and responsibility for it would expose consortia to considerable insurance risk: the consultation on commissioning proposes that the exposure of consortia to such risk be minimised.
 - v. This risk cuts both ways: it extends to a risk of over-spending by GP consortia, which would in turn have serious consequences for people with MND. A likely scenario is that a GP, confronted with a patient with MND for the first or second time in their career, struggles to plan adequately to provide the level of care that the condition demands. Inappropriate care is commissioned, which then requires remedial action: considerable money has been wasted, and the consortium soon

risks overspending – and the White Paper and other consultations make clear that bail-outs will not be available. If exposed to the insurance risk posed by people with MND, many GP consortia will be in danger of running out of money – and when that happens, who will pay for the care of the person with MND?

- vi. So, for people with MND it is not often true to say that GPs and their practice teams are, “the healthcare professionals closest to patients.” There are of course exceptions to this: some GPs have a keen interest in neurology, and some undertake the vital care co-ordination roles referred to throughout this response; some might have half a dozen or so people with MND on their books at a time. These are, however, exceptional GPs and generalisations should not be drawn from them. The current initiative by Patrick Joyce, an artist now living with MND, to paint 100 portraits in the time he has left illustrates this, literally: Patrick's second portrait, after his wife, was of his neurologist, Dr Martin Turner. He has completed over a dozen paintings so far, including portraits of those conducting clinical trials and clinical research as well as those involved in his own care. He has yet to paint a portrait of his GP.
- vii. While we support the White Paper's pledge to empower professionals and allow them to exercise their judgment, it is clear that professionals other than GPs have an utterly crucial role to play and must be involved somehow in the commissioning process. We note that the British Medical Association has recommended that consultants and other specialists must be brought into the commissioning system alongside GPs, giving a system that embraces GPs and also secondary and tertiary care. We agree that an approach of this sort, that recognises the vital importance of all clinicians, and social care professionals,, is needed. Meeting this need is where there may be a role for charities and voluntary organisations such as the MND Association: we already work with clinicians and care professionals across all settings, and can provide a platform for a more integrated approach.
- viii. Nonetheless, even in the context of a more integrated and needs-led approach to commissioning GPs will retain a role. They will still be the first stop on the journey towards diagnosis, and here too higher awareness is needed: delay in referral to a neurologist is one of the major causes of delay in diagnosis with MND, and the most easily eliminated. This also presents an opportunity to control costs: inappropriate referrals to, for instance, ear, nose and throat specialists, or even for inappropriate surgery such as hip replacements – all true and not uncommon examples - can not only cost money, but leave a person's MND to deteriorate without any alleviation, which can necessitate intensive interventions when a diagnosis is finally made.
- ix. Here, a wider awareness of neurological issues more generally is the solution: there is no expectation that GPs should diagnose MND, but their role in making a referral to a neurologist is vital. A broader educative programme for GPs, focused on a simple 'think neurological' message is needed, rather than a specific programme of education about MND. There must be confidence in future that if, for example, a patient visits their GP with some weakness, wasting or loss of reflex in their lower leg, the GP will at least consider referring them to a neurologist, as well as referring them to an orthopaedic consultant for investigation of a potential trapped nerve – both are medically sound possibilities, but too often at present the former will be overlooked and accurate diagnosis delayed. The fact that this very basic difficulty can be stated in respect of GPs clearly indicates that commissioning for MND cannot be left straightforwardly to GPs; a more sophisticated solution is required.

- x. Let there be absolute clarity about this point: GPs cannot commission for MND. They are not equipped to do so without significant support, and it is both unrealistic and unfair to expect them to master the necessary specialisms.

b) Commissioning for MND

For the reforms to work for people with MND, they must:

- take urgent action to provide interim guidance for MND commissioning and provision to prevent it from deteriorating, in the absence of either the National Service Framework for Long-Term Neurological Conditions or a NICE guideline or Quality Standard, into a 'standards wilderness'
 - ensure that services for people with MND are commissioned at an appropriate population level
 - ensure that established features of high quality MND care are retained, particularly specialist nurses, other co-ordinating posts and multi-disciplinary teams
 - rectify current management failures whereby some good practice, such as multidisciplinary working, is discouraged
 - ensure that whoever commissions MND uses the Year of Care Pathway, a tool developed by the MND Association and the only clear and comprehensive pathway available for all stages and aspects of the disease.²
- i. What, therefore, will be the most effective approach to commissioning in order to ensure that the demands of MND are reliably met? This will be a significant challenge for the NHS, as MND is currently behind other neurological conditions in respect of the guidance and infrastructure available. It has no NICE guideline, and therefore will be without a Quality Standard for at least a time after the reforms come into operation – an application for a guideline has been made, but this process will take at least three years. It will take a further period of time for a Quality Standard to be developed from this, unless NICE is able to expedite the process. In the absence of either this or the National Service Framework, there is a significant danger that services for people with MND will be left in a dangerous state of drift: service re-design will focus on other conditions, existing institutions that currently possess expertise will be redesigned or restructured, the lack of guidance will lead to a failure to draw services together into more integrated ways of working and MND services will atrophy. Inequities in access to high quality care would deepen significantly.
 - ii. The first element of any successful approach must therefore be to acknowledge that MND is at risk of drifting into a 'standards wilderness' and that urgent action is required to prevent this. Further pressure has been added by the removal of the 18 week target from referral to treatment, which had been important in assuring swift treatment for such a rapidly degenerative disease; in MND delays in treatment tend to lead to the need for further remedial interventions. Low awareness, low numbers and a lack of NICE or other guidance threatens to create a 'perfect storm' – local care will become utterly dependent on local champions (a fragility in any care service at the best of times, and certainly in the current environment) and the postcode lottery will become the defining feature of MND care to an even greater extent than it already is. This urgent danger must be averted.

² The Year of Care is available from the [MND Association website](#), and has also been developed [into an online tool](#).

- iii. The MND Association has developed guidance and standards, and can work with Department of Health and the NHS Commissioning Board to roll these out nationally. As an example of this we append excerpts from our guidance on multidisciplinary care to this document: necessarily, it makes reference to outgoing NHS structures and initiatives, but could comfortably be adapted to offer guidance during the transition period.
- iv. In addition to the dangers posed by a loss of focus on MND and neurology, a similar danger pertains to end of life care. The failure of the End of Life Care Strategy to provide ring-fenced funding, and the failures in many areas to invest the funding that was made available in end of life care as intended, have left a need for further impetus to be given to efforts to improve end of life and palliative care. Instead, the lack of focus on this area in the White Paper and the lack of priority attached to it in the consultation on outcomes, which fails to include it in any of the top-level domains, is deeply concerning. End of life care is a vital consideration in cases of MND, and we recommend that a higher priority be attached to it within the new framework than is currently proposed.
- v. After this urgent difficulty has been addressed, attention to service design and commissioning for MND must be paid at the start of the process of developing a long-term settlement. MND is a challenging illness to commission for. It falls between neurology and palliative care: neurological services for people with MND will have strong palliative characteristics from the outset. Essential care cuts across boundaries of primary, tertiary and community services: whoever commissions for MND must be able to see and work across all of these boundaries and keep the care pathway intact. Moreover, as a rapidly progressing condition, MND requires dynamic care planning: an individual might require a small range of interventions early in their illness, but require a broad range just a couple of months later: care plans need to be responsive to this, and commissioning needs to take it into account in order to succeed.
- vi. Careful thought must therefore be given to the population level at which it is appropriate to commission for MND. Clearly the level of an individual GP consortium will be inappropriate, owing to issues of both GP expertise and insurance risk as outlined above. We will be happy to work with the Department of Health, and subsequently the NHS Commissioning Board, to arrive at an answer to this. In institutional terms, various options are clearly possible: the NCB may wish to institute a separate commissioning network for MND or rarer neurological condition; or it may wish to advise consortia to group together in order to commission MND services. The involvement of the Neurological Commissioning Support service in this solution must also be considered: it may be that its work should be built into the final settlement. Whatever the institutional arrangements eventually are, they must be settled by 2013.
- vii. A key feature of MND commissioning must be specialist nurses or other co-ordinating posts, to ensure that care is appropriately joined up. The evidence in favour of such an approach, both in terms of patient outcomes and cost savings, is strong, but specialist posts of this sort are vulnerable to cuts, and there is always a temptation for commissioners, particularly those without specialist knowledge, to rely on generalists or overlook the importance of co-ordinating roles altogether. In March 2005 the MND Association was assured that the gaps left by the withdrawal of the neuro nurse service in Norwich and Waveney at the end of 2004 would be

filled within six months, after we had raised concerns about a marked deterioration in services. We were ultimately obliged to work on this issue until the end of 2009, including involvement of the local MP, the media and the Secretary of State, until a firm commitment was made to new neuro nurse posts. This episode demonstrates clearly the risks associated with the loss of such services: the decline in quality is immediate, and reversing the error can be difficult.

- viii. It is because of the vital importance of co-ordinating care for people with MND that it has been a key focus of our work. An integral part of the best practice we recommend is that all people with MND should have a clearly-designated care co-ordinator. This will often be a specialist nurse, but may change between different professionals at different stages of the individual's illness, depending on their particular needs at a given point. Whoever undertakes this role, it is vital to ensuring that the person does not fall between gaps in services, with different institutions and professionals each assuming that another is meeting the patient's needs. Our work with community services, and via our care centres, puts great emphasis on the co-ordination of care by professionals who specialise in neurology and MND.
- ix. The importance of this type of role seems not to be widely understood, however. The Minister for Care Services recently stated that specialist nurses will be commissioned locally by GP consortia. We believe this would be a serious mistake, and are somewhat surprised that this decision has been taken. A significant obstacle to this will be the lack of awareness among the generalists who will undertake local commissioning about what specialisms exist: there are already far fewer specialist neurology nurses than, for instance, cancer nurses, and local commissioners will inevitably, in at least some instances, fail to recognise their importance and commission them. There is a significant danger that specialists will be frozen out of local commissioning: it is vital that structures exist to ensure specialist input into these decisions, and that they are not overlooked due to a simple lack of expertise. Such a failure would fly in the face of very welcome pledges regarding the involvement of clinicians in decision-making.
- x. It is also important to recognise that nurses will be employed by increasingly disparate organisations within the NHS, the private sector and the voluntary sector. There is a danger that some of these providers will not sufficiently understand the needs of the patient group they serve to ensure that the nurses they engage have the necessary specialist skills; inevitably, some providers will focus on cost rather than care in the first instance, engage generalist nurses and compromise the patient's care. This is of course a false economy, as costly remedial care will subsequently be required.
- xi. The report 'How to deliver high-quality, patient-centred, cost-effective care: Consensus solutions from the voluntary sector' rightly places strong emphasis on specialist co-ordinating roles, and as the Chair organisation of the Neurological Alliance, the MND Association endorses this. We also advocate the use of multi-disciplinary working and already facilitate it through our care centres and regional staff, although it still remains less widespread, and less supported by management, than it should be. Some managers in the NHS and local authorities discourage therapists and social workers from attending meetings of multi-disciplinary teams, to the point where many professionals either do not notify their managers of their attendance, or attend in their own time. Specialist expertise in commissioning is vital to ensure that this mis-management is not carried over into the new structures.

- xii. We envisage that support for commissioners from voluntary and charitable organisations will continue to be necessary, although ideally services will be commissioned at an appropriate population level by commissioners who have expertise already. However, if support for commissioners is needed, the voluntary sector has the expertise to provide it. Recently, charitable organisations have developed a role for themselves in supporting commissioners. The MND Association's Year of Care tool fulfils this function, while the Neurological Commissioning Support service – a joint initiative by the MND Association, the Multiple Sclerosis Society and Parkinson's UK – assists commissioners who may lack knowledge of neurological conditions. This service, like other voluntary and charitable organisations provision of advice, tools and capacity, is currently made available free of charge; however, if working with for-profit private providers or commissioning contractors, voluntary and charitable organisations will inevitably wish to reconsider this offering. This risks increasing costs relative to present models, which in turn may lead some organisations to opt to do without this advice. We recommend that further thought be given to how the new structures might engage with voluntary and charitable organisations, and how dilemmas such as this might be handled.

c) Costs

For the reforms to work for people with MND, they must:

- recognise and mitigate the inherent costs associated with the complex new structure proposed for the NHS
 - develop a robust budget-setting process that allows long-term decisions to be taken
 - avoid incentives for short-term cash-saving decisions to be made by individual providers that compromise care standards and consequently increase costs across the system as a whole.
- i. Turning away from the question of how services for MND should be commissioned, it must be asked more broadly what the impact of the proposed reforms as a whole might be. Will they work? Is it appropriate to introduce them now?
- ii. The reforms are being proposed in the context of significant fiscal austerity: while the Government has pledged to continue real-terms increases in the NHS budget, these will be modest, and certainly much smaller than those enjoyed in the past decade. Simply to keep pace with demand, therefore, the NHS will have to find efficiency savings of 4-6% each year, according to an estimate by the King's Fund – an enormous challenge on its own. Furthermore, a programme of finding £20 billion in efficiency savings has been undertaken and the Government has pledged to reduce NHS management costs by 45% over four years. Can the current proposals be expected to deliver these savings?
- iii. The NHS, when reformed in line with the current proposals, will be characterised by a proliferation of relatively small organisations, both in respect of GP consortia and the hoped-for development of a range of new providers. The potential for duplication of functions across these organisations is inevitably large. Moreover, the NHS will effectively be transformed into a complex nexus of commercial contracts: these will inevitably be challenging and expensive to administer. On the most basic theoretical level, therefore, there is good reason to fear that the new structures will be fundamentally more expensive and bureaucratic to operate than the present

ones. This leaves aside the costs of effecting the reorganisation itself, which Kieran Walshe, professor of health policy and management at Manchester Business School, writing in the British Medical Journal, suggested would cost £2-3billion.

- iv. There is further evidence to support concerns that GP consortia may not be able to manage their budgets effectively. Analysis by the Health Service Journal of spending by existing practice-based commissioning consortia has shown an average over-spend of 2.5%. This may not, however, be an entirely appropriate comparison: PBC consortia have their budgets set by PCTs and only handle them nominally; a GP consortium with total control over its budget might be expected to perform better than the PBC consortia have so far been able to. There is, however, no firm evidence to indicate that this is likely to be the case. It can, however, be noted that all specialist and complex commissioning has been handled by PCT and SHA structures – although much of this will remain with the NCB, some may become the responsibility of GPs – and we have no evidence at all about their likely abilities to handle it.
- v. Budget-setting will, this suggests, be crucial to managing resources effectively. Establishing a budget will be a significant challenge for a consortium, and will rely both on high quality data and effective budget-setting processes, including strong forecasting capabilities – a considerable challenge at small population levels for a low-prevalence but high-cost disease such as MND. Perverse phenomena such as higher spending towards the end of a financial year to ensure a budget is fully used, or indeed spending freezes early in the financial year to stretch a budget out, are already familiar within the NHS. Moreover, service re-design is likely to require significant investment, and possibly overspending, that is unlikely to be rewarded until future financial years. It may therefore be prudent for commissioning budgets to be allocated over periods of several years; strict in-year budgeting is likely to lead to difficulties. However, in a world of cost-cutting and fiscal constraint, too often cash is king; implementing this balanced policy that takes account of the medium term view may not be possible. The consequences for services of short-term prioritisation of budget considerations are likely to be a deeply harmful increase in inequities for patients, both of access to services and of outcomes.
- vi. The ability of consortia to take on all the functions currently handled by GPs has also been questioned. Work by consultancy Tribal has identified over 300 functions carried out by PCTs, and questions whether the consortia will have adequate administrative resource, based on the current projections of funding allowed to them for management costs, to take all of these over. Expertise from existing PCT managers and the private sector may meet this demand; it is less clear how much it will cost to buy this expertise in.
- vii. The danger to MND services from this scenario can be readily discerned: as is made clear in Appendix 2 to this response, short-term decisions to prioritise immediate costs at the expense of the quality of care inevitably lead to higher overall costs as the NHS has to deal with the consequences of these decisions. Costs of acute hospital admissions, surgery following falls or complications from the late or inappropriate provision of wheelchairs are all consequences of classic false economies. Without appropriate planning, short-term cash pressures arising from the reorganisation risk creating a vicious cycle of poorer care and higher costs.

d) Impact on performance

For the reforms to work for people with MND, they must:

- ensure a smooth transition from current arrangements to new ones, in which nobody's care is compromised or reduced
 - recognise and pre-empt the likelihood of a short-term drop in NHS performance due to process upheavals arising from reorganisation.
- i. As well as reducing costs, the reforms are intended to improve performance. Is it likely that this will be achieved in the short, medium or long term? Studies on institutional changes in the NHS and other organisations suggest that in the short term at least, the effects are likely to be deleterious.
 - ii. A recent report by the think tank Civitas, comparing the performances of PCTs that were subject to merger in the second half of the last decade to those that were not, found an absolute drop in performance on 'quality of service' and 'use of resources' lasting at least one year in PCTs that were merged. Non-merged PCTs, meanwhile, improved their performance. The relative performance of the merged PCTs took three years to match the pre-merger levels of those that were not. Moreover, a loss of capacity and organisational memory associated with one such merger were found by official enquiries to be contributing factors to the crisis in Mid Staffordshire. Irrespective of the merits of the design of the new system, therefore, a significant short-term drop in performance can be expected. This might manifest itself as rationing by waiting times or service reductions, which in turn are likely to lead to increased local variation and concomitant increases in health inequalities. The move away from process targets makes it less likely that steps will be taken to remedy these problems.
 - iii. Negative impacts from the transition process are already appearing, despite the reforms currently being subject to consultation and parliamentary approval. We have seen that commissioning posts are not being filled, and access to continuing health care funding is becoming increasingly hard to obtain, as the NHS guards against costs being shunted from adult social care services that are being subjected to in-year cuts. Clearer accountability in this transition period is needed: special effort must be made to ensure that those who are currently responsible for providing services do not neglect their responsibilities.

e) Specific potential difficulties

For the reforms to work for people with MND, they must:

- recognise the limited ability of GPs to act as 'gatekeeper' to emergency admissions
 - consider the risk of TUPE applying to staff redeployments, and arrange for a smooth transfer of staff from the old structures to the new in cases where this is a risk.
- i. There is reason to doubt that some of the hoped-for benefits of placing commissioning responsibility with GPs will emerge, apart from the concerns noted above regarding their specialist knowledge.
 - ii. One concern is that they may not be able to reduce costly emergency admissions as hoped. Analysis by healthcare information firm CHKS suggests that fewer than

one in five admissions is recorded as having visited their GP beforehand; this suggests that GPs' 'gatekeeper' function will apply to only a small number of emergency admissions.

- iii. A separate concern applies to the process of creating the new consortia: as the new bodies take on management staff to undertake commissioning, some of these personnel are likely to be drawn from the current ranks of PCT staff. Could the Transfer of Undertakings (Protection of Employment) Regulations apply to some of these roles? This would limit the flexibility available to consortia in recruitment. In practice, the scope of the new roles is likely to be much smaller than existing PCT roles, so this may be enough to avoid TUPE concerns. An exception to this may occur if the NCB instructs consortia to band together and commission some services jointly, at a higher population level; these commissioners could well be doing much the same as current PCT commissioners, and TUPE may require that they should therefore be the same people. Even if a very strict reading of the regulations leads consortia to believe they can avoid this, Cabinet Office guidance says that, "in circumstances where TUPE does not apply in strict legal terms, the principles of TUPE should be followed and the staff involved should be treated no less favourably than had the Regulations applied."³

f) Likely future

For the reforms to work for people with MND, they must:

- include provision for GP consortia to merge and de-merge quickly, smoothly and cheaply with minimal disruption to care services.
- i. The NHS's recent history of reform offers some indication of how the current programme might ultimately pan out in the medium to long term. The creation of GP consortia will produce bodies of a similar size to the previous Primary Care Groups. The comparison is not exact, as they will exercise greater responsibility and be constituted quite differently, but consideration of the experiences of PCGs may prove instructive.
- ii. It can immediately be noted that PCGs were obliged to band together into Primary Care Trusts within a matter of years. High back office costs, variable levels of expertise and a relative lack of commissioning purchase power made them expensive to operate and failed to guarantee high standards of care.
- iii. One possible future for the new consortia, therefore, is for them to merge together after their formation. It is possible that this will happen naturally, and a smaller number of larger consortia, perhaps of a similar size to current PCTs, will emerge. In this scenario, the MND Association would be very willing to advise on the restructuring of NHS organisations to create bodies that can respond more effectively to MND – there may be considerable opportunity here to arrive at innovative settlements designed around patient need rather than traditional institutional divides. The greater danger, however, is that political pressure will mount for the consortia to be forcibly integrated into larger groups if, for instance, the NHS experiences a significant short-term drop in performance and significant numbers of negative media stories emerge.
- iv. The White Paper states its intention to create structures that will not be susceptible

3 <http://archive.cabinetoffice.gov.uk/opsr/documents/pdf/copwm.pdf>

to ministerial intervention in the face of political pressure. This may, however, leave a future Secretary of State with no policy lever other than a further statutory re-ordering of the NHS. The recent history of the NHS, coupled with the significant dangers outlined above, create a significant risk that this will be the ultimate outcome of the current reform process.

g) System v. service

For the reforms to work for people with MND, they must:

- undertake a substantial policy comparison of the current proposals and previous public service reforms, in particular the changes to the railway network of the 1990s
- consider, as part of this review, whether substantial risk is likely to arise in relation to:
 - o increased managerial costs
 - o redeployment of personnel / loss of knowledge and organisational memory
 - o future capacity for strategic investment
 - o continued political interference.
- i. Comparisons with previous public sector reforms, beyond certain aspects of past NHS reorganisations as above, cannot easily be drawn. Perhaps the closest analogy is that of the reform of the railway network in the 1990s. The comparison is not exact – railway assets were sold to the private sector, which NHS assets will not be directly, although they will be removed from the public sector balance sheet – but there are also certain striking similarities. Just as the railways were, the NHS is to be transformed from an integrated service, albeit one encompassing many subdivisions, into a complicated nexus of commercial contracts between autonomous bodies – rather than a service, a system.
- ii. The success of the reform of the railways remains, after a decade and a half, a contentious subject – although the reforms have not been wholly reversed and certainly have their champions, the persistence of significant criticisms is itself of concern. The early period following the reforms was characterised by a drop in performance and an exodus of personnel from the industry; as new personnel entered, the expertise within the industry had to be rebuilt. Speed restrictions following the Hatfield crash and during the hot summer of 2003 were exacerbated by the lack of knowledge about the rail network that existed within the industry at that time. An equivalent failure in health could be catastrophic: if a procedure or service has to be suspended because of on high-profile failure, the lessons from which cannot be accurately applied due to a loss of expertise, the care of vulnerable patients could be compromised with tragic consequences.
- iii. Even now, the rail network attracts criticism for rapidly rising fares relative to those in other European countries and the high cost of the network to the taxpayer – greater than at any point under British Rail. Questions exist over the ability of franchise holders to plan strategically over the long term, the controlling of costs across the network, the efficiency of the procurement of new rolling stock, and the safety of fare-paying passengers (with several high-profile crashes caused by failures in track maintenance, a new phenomenon on the rail network which was not seen under British Rail). That said, a political consensus exists around the status quo: the reforms essentially survived thirteen years of a Labour government despite having been introduced by a Conservative one, and no political party is proposing a significantly new model of either ownership or regulation; by this yardstick, the

reforms can be judged a success.

- iv. It can further be observed, however, that a feature of the reforms has been political interference. The regulatory structure established when the reforms were instituted was comprehensively changed over the early years of the subsequent government, apparently due to a lack of political confidence in them rather than any clear evidence that they were ineffective. The revised settlement was itself changed further following the nationalisation of Railtrack and its replacement by Network Rail.
- v. While drawing firm conclusions from the experience of the railways about the future of the NHS is difficult, the comparison can be said to reinforce some of the concerns identified about the possible impact of the White Paper's proposals. Managing a complicated contractual nexus rather than an integrated service does seem to pose a risk of increased managerial costs and the duplication of functions between different organisations. A significant change in the deployment of personnel also appears to carry risks of expertise being lost and performance dropping accordingly in the short term. Effective strategic investment appears to be made more difficult in a more complicated and fragmented planning landscape. The risk also remains of continued political interference: with the direct levers of control removed, ministers only have the ability to change regulatory structures and the statutory settlement; in the absence of an ability to intervene directly, they may be more willing to make changes of this sort.
- vi. The MND Association does not have the resources to explore this comparison fully, but we recommend that serious consideration be given to undertaking a detailed independent study on the subject.

h) The process of reform

For the reforms to work for people with MND, they must:

- provide clear signposting to patient groups and other interested parties about who to engage with, and when
 - reflect carefully on the extent to which the consultation exercise has been appropriate for the scale of the proposed changes
- i. As the process of reform continues, the Government must give clear signposting to patient groups and other interested parties about what bodies will be taking decisions, and when they should be approached. If the reforms are to succeed, they must be delivered in partnership with expert groups: the MND Association possesses more expertise about MND than many parts of the NHS and DH, and the same will be true, *mutatis mutandis*, for representative groups of many other conditions. It is therefore essential that the Government clearly and transparently signposts opportunities for dialogue; a situation in which charities and other organisations are left unsure of who to talk to and when will result in vital intelligence and advice not being taken on board when needed, and services for the vulnerable compromised as a result.
 - ii. We must also express serious misgivings about the consultation process so far, which has been rushed, has seemed tokenistic at times, and has not offered an opportunity to engage meaningfully with the substance of the fundamental proposals. We are deeply concerned that such a profound change to such a major

part of our national life as the NHS is being treated as a routine consultation exercise, with a simple twelve-week window for responses, no pilot exercises, and none of the time for reflection usually allowed by the conventional sequence of green paper and white paper. We are also sceptical that the responses to the consultation can be meaningfully taken on board prior to the publication of the Health Bill this autumn – it seems probable that the proposals from the White Paper will be put directly in legislation with little or no heed paid to input from the consultation.

- iii. We have also been disappointed by the regional consultation events conducted by the Government. A representative sample of comments from our regional staff is presented in Appendix 4 to this response.
- iv. It is also our perception that ministers and, particularly, officials have not been as accessible as they might have been, and many organisations who are very willing to engage with this process have been left second-guessing it and at risk of missing vital opportunities despite their best efforts. This risks compromising the effectiveness of the reforms.
- v. We respond regularly to government consultation exercises and would not normally consider writing in such strong terms about the conduct of one. However, as this is arguably the most important consultation exercise on any subject for a generation, we feel we must express our profound disappointment and unease at the manner in which it has been conducted.

2. Putting patients and the public first

a) Shared decision-making

For the reforms to work for people with MND, they must:

- ensure that clinicians strike an appropriate balance between equipping the individual with enough information to make an informed decision about their care, and providing too much information too soon thereby causing avoidable distress
 - provide adequate funding to support the MND Association in a future information provision role if this is desired
- i. The recurring theme among the new proposals for health care of ‘no decision about me without me’ is an extremely welcome philosophy. Applying this to MND will require some consideration, however: there is a constant tension with a condition such as MND between providing too much information too early, which can be dangerously upsetting, and leaving the provision of information too late to allow the individual to make an informed decision. Different clinicians have different views about how best to strike this balance.
 - ii. An outcomes-based approach might stipulate that the patient has sufficient information to make informed choices about their care, which would leave clinicians some leeway, without allowing them to deny vital information to people with MND, even if with the best of intentions.
 - iii. Provision of information to support patient choice is something in which the White Paper proposes a 'range of third parties' should be involved. We see this as a key future role for the MND Association and are very willing to be involved: we can

provide information to people with MND, their carers and family members, health and social care professionals and others involved in a person's care. We envisage that this role could be part of our broader work to provide a platform to integrate services across traditional institutional divides, by making these services accessible to users. To do this on a formal, nationwide basis would, however, be a step beyond our current role and only feasible with public funding.

- iv. We note also that there is some debate over whether or not the proposed HealthWatch bodies will have a monopoly on signposting and 'citizen's advice bureau' functions. Greater clarity would be appreciated on how the Government envisages these bodies operating.

b) Information gathering and sharing

For the reforms to work for people with MND, they must:

- ensure that better data is gathered on MND, correcting the very basic omissions that currently exist
 - examine the quality of data already held
 - create mechanisms, and a supporting culture, for proactive data sharing by the NHS both internally and with other groups in social care, voluntary and charitable organisations and beyond
- i. The NHS has much improvement to do in the statistics it gathers on MND, although among statutory services it is not alone in this. The current approach of recording consultant episodes but not underlying diagnoses will make it very hard to plan services for people with MND, let alone assess them. For instance, the ONS and Public Health Observatories are not currently able to break down death statistics for people with MND by location – this sort of basic information-gathering must be put in place. We also have concerns about the quality of information available on NHS portals and the lack of a data set for MND. The recent announcement that the South West Public Health Observatory has had to revise its estimates of the number of deaths attributed to MND down by up to 15%, as these deaths should have been attributed to PSP, reinforces these concerns: it seems likely that we are the organisation with the most statistical information about MND in the UK. In this context, it must be made easier for voluntary and charitable organisations to work with the ONS and other bodies on statistical exercises.
 - ii. There is a second dimension to the information problem, however: accessing patient information is very difficult for patient groups. While there are privacy considerations attached to data sharing and a fine balance needs to be struck, if the Government wishes voluntary and charitable organisations to be more involved with providing services, access to data must be made easier.
 - iii. This is a major challenge, as it requires proactive information sharing by NHS bodies in a way that will go against the grain of a culture of confidentiality and data protection that has been in development for over a decade. Nonetheless, it is vital in order to ensure value for money: at present there are MND Care Centres that are under-utilised because they cannot legitimately contact some people with MND who would benefit from their services but have never been referred. Conversely, in some areas the care centre is well-utilised, but some of the people who go there are not in contact with MND Association branches, groups or regional staff who could provide them with a range of support services.

- iv. We will be able to provide information about people with MND, within the law, to appropriate bodies such as GP consortia and local authorities, and see this as an important element in drawing services together across the different professions and care spheres. Systemic improvements are needed, however, for this to be part of an effective system of data sharing that can properly involve the public sector. Improved data sharing must be an integral part of any initiative to involve local and voluntary groups in service provision – this is particularly relevant to lower-prevalence conditions where low numbers can make service provision especially difficult: numbers must not be artificially depressed on account of poor data sharing. A failure to share data adequately will result in inadequate planning locally, as the services for which the MND Association currently pays, in the absence of adequate statutory services, will not be factored in – currently, these represent unmet and unrecognised need.

c) choice of any willing provider

For the reforms to work for people with MND, they must:

- institute clear mechanisms for situations in which no market of willing providers emerges.
- i. While there may be benefits to securing a choice of willing provider, where MND is concerned there is a significant danger that there could be an absence of any willing provider. MND is, as we have seen, not a high prevalence condition, and it is certainly difficult to see many private sector providers choosing to specialise in it in preference to more lucrative markets – at least while those markets are not mature and there may be easy profit to be made. Commercial behaviour in the NHS marketplace to date bears out this concern: Independent Sector Treatment Centres have been observed to make a point of selecting low-risk patients, while being paid the same as NHS providers who are left to tackle the higher-risk cases.
- ii. Other than the private sector, there remain charitable organisations and former NHS providers: as we have seen, the NHS is already unable to provide effective services for MND in many areas, while there are few voluntary and charitable organisations beyond the MND Association who are likely to meet this need. We will be willing to play a role in developing further provision, building on our care centres, equipment provision and other work; we cannot make a vibrant market of providers on our own, however.
- iii. Furthermore, there is a fundamental lack of trained specialists in the UK: we have already seen in the social care sphere that the professional carers needed to meet the needs of people with MND are simply not there, and people with MND are unable to realise the benefits of personal budgets as a result.
- iv. The lack of specialists extends to palliative and end of life care. Hospice places for people with MND can be hard to obtain, owing both to the traditional focus of hospices on cancer and the highly demanding nature of MND – this picture does appear to be improving, but much work remains to be done. There remain too many extreme instances where specialist palliative care for people with MND is non-existent: we are currently working with NHS bodies, hospices and local authority services in Southampton to find a solution to once such long-standing problem.

- v. There must be clarity over what steps will be taken when there is no adequate market of providers.

d) Patient voice and accountability

For the reforms to work for people with MND, they must:

- recognise that lower prevalence conditions such as MND will never provide the loudest patient voice in any locality, and are at serious risk of being overlooked by local structures
 - institute channels to allow voluntary and charitable organisations to address with ease the proliferation of local decision-making bodies, to amplify the voices of patient groups for lower prevalence conditions
- i. The White Paper places a strong emphasis on accountability mechanisms to improve NHS performance. While we acknowledge the power of the theory behind this, that strong accountability will lead to proactive provision of high quality services and also for the correction of errors where they occur, we must question whether it will work in practice, particularly for low-prevalence and high-urgency diseases like MND.
 - ii. People with MND would generally prefer not to spend the short time they have left battling the system and attempting to obtain redress. Moreover, provision for MND is currently so patchy that almost every single person with MND will encounter at least one instance where a mistake or error is made for which redress ought to be available. Often there may not be much value in seeking this, however, as the person with MND and their carers will have other significant demands on their time.
 - iii. This problem is compounded by the low prevalence of MND: for less common conditions, there is unlikely to be the strength in numbers in any given locality to create a strong patient voice that will be listened to attentively by public bodies. It is the nature of local democracy that local politicians hear the loudest voices. MND is a condition of such low numbers that it will never provide the loudest voice in any locality. Indeed, local authorities have never been especially responsive to MND or neurological needs generally. We are not aware of any clear instances where local accountability mechanisms have been used straightforwardly to generate significant improvements in care for people with MND.
 - iv. Additionally, it is unclear where the voices of professionals will be heard, particularly if the professional in question happens to work in a commissioning area covered by one local authority, but personally be based in another.
 - v. Councillors will also need support on these issues: currently most councillors have no expert knowledge at all of any neurological condition and would not be able to make any useful contribution to the proposed new structures in respect of MND.
 - vi. We must not have a system where accountability is not clear: current lines of accountability are unclear and seem to reside in too many places. The new system, with its proliferation of new local structures, may be susceptible to repeating the significant mistakes of the past.
 - vii. We will develop these points further in our response to the consultation on local democratic legitimacy, and recommend that the Government considers further how

accountability can be made to work for low-prevalence, high-urgency diseases, and whether it is an appropriate mechanism for driving improvements.

- viii. We wish to make a further point about accountability and patient voice, however. A broad theme of the reform process is clearly to devolve responsibility to the localities, and correspondingly to oblige patients to address themselves to local decision-makers rather than national ones in order to secure change. The role of charities such as the MND Association is often vitally important when attempting to do this: as has been seen, people with MND often lack both the numbers, the literal voice, and the time to attempt it alone, and the MND Association has been active in pursuing change at local and national level (see the above example from Norwich) – it is a central part of our mission.
- ix. With decisions multiplied across hundreds of local authorities and other local bodies rather than a central department and smaller numbers of local organisations, we will increasingly lack the resources to assist people with MND in making their voices heard. Channels must be instituted for small to medium sized voluntary and charitable bodies to engage with this new proliferation of bodies. If this is not done, inevitably, MND will increasingly be overlooked. We regret that the Government has not seemed within this consultation to recognise the important contribution made by voluntary and charitable organisations to guaranteeing patients a voice.

e) Personalisation and integrated services

For the reforms to work for people with MND, they must:

- ensure that personal budgets cover both health and social care
 - ensure that the assessment of an individual for a personal budget is undertaken by someone who understand their condition
 - ensure that budgets and care plans are dynamic and capable of rapid change as the individual's needs develop
 - maintain the existing care provision models for those who do not wish to use personalised care, and not entail any compulsion to use personalised care where that is not the patient's wish
 - ensure that paperwork and processes for personalised care models are as simple to use as possible
 - avoid scenarios in which individual people with MND have to navigate cost-shunting between health and social care
 - ensure a smooth transition between self-tailored packages of social care, as can already be developed, and equivalent packages of health care when they become available
 - avoid scenarios in which people skimp on their own care due to a fall in their purchasing power under a personal budget relative to a centrally-commissioned care package.
- i. The concept of 'personalised' care, built around the needs of the individual, has become an orthodoxy in health policy, which is very much to be welcomed. Related to this, models of care built on 'personalisation' and in which the individual tailors their own care package have been developed for both health and social care. The White Paper makes a firm commitment to both; in this section, we address the latter in particular.
- ii. The NHS White Paper has re-affirmed governmental commitment to

personalisation, although some of the details of the schemes developed by the previous Government will clearly have to be re-worked to operate in the new landscape of NHS institutions.

- iii. The significance and appropriateness of personalisation for people with MND will need to be explored: while experience to date suggests that some people with MND find personalised care arrangements highly beneficial, for others the responsibility it brings can be a bewildering and unwelcome intrusion into the short time that remains to them. It must therefore be ensured that personalised arrangements are reliably available to those that want them, but that no person with MND is ever obliged to use them – traditional mechanisms must continue to be available. Even for those people with MND who use personalised solutions, forms and paperwork must be as simple, as short and as few as possible.
- iv. With this in mind, we were concerned to hear comments recently made by the Minister for Care Services, who suggested that while take-up rates for personal budgets are currently 15%, the aim should be to make them 100%. This would appear to imply compulsion and the withdrawal of existing delivery models, which we would oppose, and which appear to be in direct tension with the very welcome messaging in the white paper about listening to the patient's wishes.
- v. Broader difficulties associated with personalisation have been noted: as the Dartington Review of adult social care observes, the uptake of direct payments in social care has been very slow; and there are reports of concerns emerging from the pilot of Personal Health Budgets that the loss of economies of scale associated with more centralised commissioning is leading people to skimp on their own care, as their budget does not buy the same amount of care as they previously had.
- vi. We are also uneasy about the suggestion in the White Paper that personal budgets are an effective mechanism for integrating health and social care. In some cases they may have that effect, but there is also a serious risk that people with MND could be caught between the two, and obliged to navigate the cost-shunting that already occurs between them, or even mediate between them.
- vii. Greater consideration must be given to the interface between health and social care and how it can be made easier for people with MND. There may be some potential for achieving this through personalised delivery. At present, the availability of direct payments for social care, but their non-availability for health care creates a significant difficulty for some people with MND: when their condition reaches the point where they need NHS continuing health care, they lose the tailored package of support they have developed using social care direct payments. Even if personalised services are available on both sides of the divide, the fundamental disjoin of means-tested social care and free-at-the-point-of-need NHS care will remain. With such different financial settlements between the two, the problem of cost-shunting will persist. This is not an effective solution to the needs of people with MND, which span health and social care throughout their illness; the divide between the two does not align with their needs and creates a risk of unco-ordinated care.
- viii. Integrating health and social care requires bolder solutions. Joint commissioning has already proved valuable in some areas, and the work of the MND Association in bringing together and co-ordinating professionals across health and social care, has

already been set out; there is greater scope for co-commissioning in this area.

3. Improving healthcare outcomes

a) value-based pricing

For the reforms to work for people with MND, they must:

- guarantee the continued supply of riluzole both by agreeing an appropriate price with the manufacturer and mitigating any further increases in parallel exporting
- i. We would like to see greater detail on the White Paper's proposal for value-based pricing of drugs. There is only one drug available to treat MND, riluzole (trade name Rilutek), which has been shown to extend life for a matter of months.
- ii. Its effects are not immediately evident to the person with MND – it is difficult to assess how an individual's illness would have progressed in its absence – and it is relatively expensive (it is among the high value, in-patent drugs targeted for parallel export to the EU since the fall in the value of sterling). Nonetheless, it is the only drug available for MND, or any neurodegenerative disease, and as such is of great importance to the many people with MND who take it. Although its life-extending effects may appear quite modest, for those diagnosed with such a rapidly progressing conditions a few months can be extraordinarily valuable. Nor should it be overlooked that it has been approved by a NICE Technology Appraisal.
- iii. Given that its effects might arguably be seen as modest, would the NHS regard riluzole as offering only low value under the new price regime? If so, how would it reach an agreement with the manufacturer to continue to supply it to people with MND. Furthermore, how would it guarantee the security of this supply, given that a significant drop in the price paid for riluzole would instantly make it hugely profitable to export within the EU, even more so than at the time of writing? Banning such exports would not be permissible under EU trade laws. Clarification of the operation of this new policy would be greatly appreciated.

b) Outcomes

For the reforms to work for people with MND, they must:

- ensure that all aspects of the Outcomes Framework are applicable to people with MND
- use existing good practice such as the NSF and the MND Association's well-developed tools to develop outcome measures appropriate for people with MND
- develop PROMs for MND, and also mechanisms for capturing the views of carers.
- i. Measuring the efficacy of MND care in terms of its benefits for the patient is difficult: obvious measures such as reducing avoidable deaths do not apply, and the profound effects of the condition on the individual's quality of life make identifying positive outcomes challenging. In this respect, MND does not sit comfortably in the proposed domain of 'enhancing quality of life for people with long-term conditions' proposed in the consultation on the NHS Outcomes Framework; and the omission of end of life care from this domain, or the domain relating to reducing deaths, make this even more problematic. We will address this point further in the appropriate consultation response.

- ii. Nonetheless, it is important that the commissioning outcomes framework contains appropriate indicators relating to MND and that the Outcomes Framework contains adequate recognition of MND and neurology to facilitate this. Indeed, we recommend that every domain in the Outcomes Framework should be applicable to MND – it is too high-level and too sparse for some domains to be allowed not to apply to some conditions. It is unfortunate that a NICE guideline for MND does not already exist as the basis for developing these; this paper offers some areas for potential exploration as part of this process.
- iii. Much of the currently established good practice in relation to MND is process-driven. However it may be that some outcome measures can be derived from this work. For instance, the ability of people with MND to live in their own home might be an outcome measure derived from the NSF's Quality Requirements 5 and 7 (community rehabilitation and support; equipment and accommodation). The absence of secondary complications such as pressure sores may be another such measure. Minimising sleep-disordered breathing could perhaps be an outcome measure for the successful use of non-invasive ventilation, on which NICE issued guidance in 2010.
- iv. Patient Reported Outcome Measures for MND must also be developed. Again, this requires care in order to produce meaningful results: the nature of MND inevitably means that the patient will not be able to offer a perspective on the final stages of their care. For that reason, carers' views should be sought as part of the same exercise. It has been the experience of the MND Association in conducting its own surveys that carers can often be more critical of the care their loved one has received than the individual service-user might be. At times this may be a more acute assessment of the care offered; at others it could potentially be over-critical, albeit for the most understandable reasons. It is vital that PROMs for MND be developed, but the task poses particular methodological challenges.
- v. We broadly supported the move to a right to choose a GP proposed by the previous Government and are pleased to see that similar ideas are being put forward in the White Paper. The ability for people with MND to seek out MPs who have some expertise in MND could be extremely valuable to some although, as in our response to the past consultation on this subject, we doubt that in practice many people will do this, owing to lack of time and the practical difficulty of identifying an GP who has some expertise in MND.

4. Autonomy, accountability and democratic legitimacy

For the reforms to work for people with MND, they must:

- ensure that adult social care services are funded sustainably over the long term
- i. We will respond fully to the proposals on local democratic accountability in response to the appropriate consultation. The advent of new mechanisms for joining up services is in principle welcome, and if they have the effect of bridging the very difficult divide between health and social care, that will be very positive.
- ii. We must observe, however, that 'joined-up care services' is something of a platitude in this policy area: everyone pledges it or calls for it, and nobody disagrees with it as an ambition. A greater challenge will be to ensure that adult social care services are sustainable in the long term. Local authorities are already rationing care

services stringently in many areas, and with demographic pressures due to increase, the sustainability of the current settlement is highly doubtful. We will respond in full to the Government's proposals on social care when they are published, but wish to state here that a sustainable mechanism for bringing new funding into adult social care must be found.

5) Research

For the reforms to work for people with MND, they must:

- include a central and coherent strategic statement on how research is to be embedded in NHS processes
 - foster collaboration between the NHS and other research funders to maximise the value of funding.
- i. We welcome the commitment of the White Paper to, “innovation and to the promotion and conduct of research to improve the current and future health and care of the population,” in line with the NHS Constitution. We are concerned, however that the White Paper lacks a central and coherent statement on research; there are numerous welcome statements scattered through the document, but it is clear that a strategic focus on research is lacking. This lack of focus creates a danger that the various players in the new health system, both providers and commissioners, will fail to recognise research as a priority.
 - ii. Further work must therefore be undertaken, as a matter of urgency, to embed research as a priority within the new system as it is being designed, and to co-ordinate this work closely with a wider strategic approach to research funding – it is to be hoped that the Comprehensive Spending Review does not cut research point spending to the extent that a such a strategic approach cannot meaningfully be taken.
 - iii. Research must be included in the Outcomes Framework, and incentives for it built into the infrastructure relating to providers and commissioners. In particular, GPs have a poor track record of supporting clinical trials and encouraging patients to take part; clear incentives for this must be provided, and support will need to be provided to GPs to help them understand when and how to suggest patients should take part in research.
 - iv. Funding should also be addressed: the NHS should foster collaboration with other research funders to achieve clear research objectives, and co-ordinate its activity alongside that of other funders.
 - v. Clarification of the role of the Office for Strategic Coordination of Health Research (OSCHR) and the Office for Life Sciences (OLS) in the context of the NHS and medical research is also required to allow for future planning.
 - vi. It is vitally important that research is not only safeguarded for the long term, but bolstered: ultimately, disease is more expensive than research.

6) The role of voluntary and charitable organisations

For the reforms to work for people with MND, they must:

- provide clearer routes to voluntary and charitable organisations for working with and

- within the NHS
- end the current situation in which the MND Association provides a substantial subsidy to the care provided by statutory services
 - free voluntary and charitable organisations to adopt a more appropriate role, for instance involving information provision, signposting and providing support that enhances quality of life but may be beyond the reasonable scope of statutory services.
- i. The outcome of the current reforms must not be that charities end up subsidising statutory services that are unable to meet their obligations, or are able to decline to do so. While some voluntary and charitable organisations may wish to take on a provider role, and enter into contractual relationships accordingly, this is clearly distinct from charities being obliged to draw on funds raised from voluntary donations to fund care and other services that ought to be provided by statutory services. We do not accept any argument that the state should retreat from current levels of provision for people with MND: in one of the richest countries in the world, it is not appropriate for the most vulnerable, such as people with MND, to be obliged to fall back on charitable giving, which is neither sufficient nor sufficiently reliable to meet their needs in full.
 - ii. Currently the MND Association provides a significant subsidy, of more than £3.5 million, to MND care in England, Wales and Northern Ireland. It funds care centre co-ordinator posts, routinely provides key items of equipment (riser-recliner chairs, light writers, suction units), offers financial support to people with MND, provides communications devices through a partnership with AbilityNet and offers wide-ranging local support through its branches and groups, which are run entirely by volunteers. Many of these things should already be provided by statutory services. We also provide information, education and information and intelligence on the MND population to statutory bodies and others.
 - iii. We hope that, if the proposed reforms are well-implemented and take full account of the needs of people with MND, voluntary and charitable organisations will therefore be able to adopt a more appropriate role, which will still be multi-faceted. Prompting innovation and spreading best practice will be a key element of this: for instance, the recent short clinical guideline prepared by NICE on the use of non-invasive ventilation for MND arose directly from advice to NICE by the MND Association, which had become aware of research showing benefits from NIV and funded a clinical trial to demonstrate it conclusively. The Association also plays an active role in the neurological community, hosting events and facilitating information exchange. This type of activity should be continued, and will complement the proposed reforms.
 - iv. The role of MND Association trained volunteer Association Visitors, who are often the first port of call for people with MND after diagnosis and throughout their illness, should also be considered. Demand on them is likely to grow during the transition period and when the new arrangements are in place. How does this sit with the 'Big Society' push for increased volunteering in place of statutory services? Where will the new volunteers come from, and who will pay for their training, ongoing development, support, supervision and out of pocket expenses?
 - v. There will also continue to be a support role for voluntary and charitable bodies: they should continue with their support services and signposting of statutory support

for people with MND. Financial and other material support should continue, but in the realm of smaller items of provision that enhance the individual's quality of life but might nonetheless be slightly beyond what statutory services should be expected to provide. Such support should never be called on to provide essential items of equipment like riser-recliners and suction units.

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Appendix 1: overview of policy recommendations and the role of the MND Association

For the reforms to work for people with MND, they must:	To support this, the MND Association can:
<p>1) GP commissioning and the reform agenda a) GPs and people with MND</p>	
raise GP awareness of neurology	Continue and extend our training and awareness programme for GPs and other health and social care professionals.
ensure that GPs recognise neurological symptoms and refer people with MND to a neurologist much more quickly than at present (average time: seven months)	
<p>ensure that commissioning for MND is undertaken by specialists, at an appropriate population level;</p> <ul style="list-style-type: none"> - ideally by a dedicated commissioning network for MND or rarer neurological conditions more broadly, under the NHS Commissioning Board, or - by GP consortia working more formally with MND Association care centres and other centres of excellence, or - by groups of GP consortia working together within a framework set out by the NHS Commissioning Board 	<p>Take on responsibility for running the MND commissioning network, if this option is pursued.</p> <p>Share results of our work on identifying an optimum population level for MND commissioning, when complete.</p> <p>Make our network of care centres available to play a role in commissioning as required.</p>
ensure that whoever commissions MND uses the Year of Care Pathway, a tool developed by the MND Association and the only clear and comprehensive pathway available for all stages and aspects of the disease	<p>Provide our dedicated tools for commissioning MND including the Year of Care pathway, outcome measures and Standards of Care.</p> <p>Develop and extend the availability of our commissioning and delivery model for wheelchairs</p>
take urgent action to provide interim guidance for MND to prevent it falling, in the absence of either the National Service Framework for Long-Term Neurological Conditions or a NICE guideline or Quality Standard, into a 'standards wilderness'	Provide our dedicated tools for commissioning MND including the Year of Care pathway, outcome measures and Standards of Care.
fast-tracking the production of a guideline and Quality Standard for MND by NICE, or	Continue to press for the application to NICE that we have already made to be taken up and supporting its progression at all stages.
include a duty for any provider engaged by GP consortia to engage with the MND Association, whose work has, to date, driven the majority of improvements in commissioning and clinical practice for MND in England	
	Provide information and evidence to assist the formulation of new guidance.

creating new forms of guidance for challenging conditions, such as the mooted 'quality threshold' or other form of quality marker.	
b) Commissioning for MND	
ensure that established features of high quality MND are retained, particularly specialist nurses, other co-ordinating posts and multi-disciplinary teams	Continue to inform and influence local provision, including facilitating MDTs, through our Regional Care Development Advisers, care centres and volunteers.
rectify current management failures whereby some good practice, such as multidisciplinary working, is discouraged	Use these channels to continue to raise awareness of best practice.
c) Costs	
Recognise and mitigate the inherent costs associated with the complex new structure proposed for the NHS	Share our work on securing value for money in MND care, and the cost implications of providing care to a low standard.
develop a robust budget-setting process that allows long-term decisions to be taken	
avoid incentives for short-term cash-saving decisions to be made by individual providers that compromise care standards and consequently increase costs across the system as a whole.	
d) Impact on performance	
ensure a smooth transition from current arrangements to new ones, in which nobody's care is compromised or reduced	Continue to inform and influence local provision through our Regional Care Development Advisers, care centres and volunteers.
Recognise and pre-empt the likelihood of a short-term drop in NHS performance due to process upheavals arising from reorganisation.	Provide advice on service design and commissioning for MND, as above.
e) Specific potential difficulties	
recognise the limited ability of GPs to act as 'gatekeeper' to emergency admissions	Promote strategies to reduce emergency admissions to which GPs cannot act as 'gatekeeper' through promoting high quality care, as above.
consider the risk of TUPE applying to staff redeployments, and arrange for a smooth transfer of staff from the old structures to the new in cases where this is a risk.	We have already flagged this risk in our consultation responses.
f) Likely future	
include provision for GP consortia to merge and de-merge quickly, smoothly and cheaply with minimal disruption to care	Continue our regular monitoring of services available for people with MND, and share this data to inform institutional change.

services.	
g) System v. service	
undertake a substantial policy comparison of the current proposals and previous public service reforms, in particular the changes to the railway network of the 1990s	We have already suggested points of comparison that would reward examination.
consider, as part of this review, whether substantial risk is likely to arise in relation to: <ul style="list-style-type: none"> - increased managerial costs - redeployment of personnel / loss of knowledge and organisational memory - future capacity for strategic investment - continued political interference. 	Share our work on securing value for money in MND care, and the cost implications of providing care to a low standard. Continue to inform and influence local provision through our Regional Care Development Advisers, care centres and volunteers, to minimise the impact of loss of organisational memory.
h) The process of reform	
provide clear signposting to patient groups and other interested parties about who to engage with, and when	Provide policy input to the DH and NCB throughout the reform process.
reflect carefully on the extent to which the consultation exercise has been appropriate for the scale of the proposed changes	We append evidence to our White Paper response.
2) Putting patients and the public first	
a) Shared decision-making	
ensure that clinicians strike an appropriate balance between equipping the individual with enough information to make an informed decision about their care, and providing too much information too soon thereby causing avoidable distress	Provide guidance to clinicians on breaking the news of diagnosis appropriately.
provide adequate funding to support the MND Association in a future information provision role if this is desired	Provide information and signposting services to people with MND.
b) Information gathering and sharing	
ensure that better data is gathered on MND, correcting the very basic omissions that currently exist	Advise on information-gathering requirements for MND and the quality of data already held.
examine the quality of data already held	
create mechanisms, and a supporting culture, for proactive data sharing by the NHS both internally and with other groups in social care, voluntary and charitable organisations and beyond	Provide our data, within the law, on people with MND to NHS bodies and providers. Insist with dissemination of information locally through our RCDAs, branches, groups and volunteers.

c) choice of any willing provider	
institute clear mechanisms for situations in which no market of willing providers emerges.	Provide assistance of our care centre network if appropriate.
d) Patient voice and accountability	
recognise that lower prevalence conditions such as MND will never provide the loudest patient voice in any locality, and are at serious risk of being overlooked by local structures	Assist with providing patient voice as far as possible, via the new channels for lower prevalence conditions.
institute channels to allow voluntary and charitable organisations to address with ease the proliferation of local decision-making bodies, to amplify the voices of patient groups for lower prevalence conditions	
e) Personalisation	
ensure that personal budgets cover both health and social care	Continue and extend our training and awareness programme for health and social care professionals.
ensure that the assessment of an individual for a personal budget is undertaken by someone who understand their condition	
ensure that budgets and care plans are dynamic and capable of rapid change as the individual's needs develop	Provide guidance and support to health and social care professionals, and people with MND. Offer a brokering service to people with MND.
maintain the existing care provision models for those who do not wish to use personalised care, and not entail any compulsion to use personalised care where that is not the patient's wish	Advise people with MND on both models, to facilitate their choice.
ensure that paperwork and processes for personalised care models are as simple to use as possible	Advise on developing these mechanisms, by arranging focus groups and other input from people with MND and carers.
avoid scenarios in which individual people with MND have to navigate cost-shunting between health and social care	
ensure a smooth transition between self-tailored packages of social care, as can already be developed, and equivalent packages of health care when they become available	Provide support and facilitation to MDTs via our RCDA's.
avoid scenarios in which people skimp on their own care due to a fall in their purchasing power under a personal budget relative to a centrally-commissioned care package.	Provide financial support where absolutely necessary – our capacity for this is, however, extremely limited. Support commissioners and users of personal budgets in

	maximising the value of services purchased, in line with our current work as part of Neurological Commissioning Support
3) Improving healthcare outcomes	
a) value-based pricing	
guarantee the continued supply of riluzole both by agreeing an appropriate price with the manufacturer and mitigating any further increases in parallel exporting	Continue and build on our working relationship with the manufacturer, Sanofi Aventis.
b) Outcomes	
ensure that all aspects of the Outcomes Framework are applicable to people with MND	Suggest outcome indicators appropriate for people with MND.
develop PROMs for MND, and also mechanisms for capturing the views of carers.	Provide input to this process from people with MND, via focus groups and other mechanisms.
use existing good practice such as the NSF and the MND Association's well-developed tools to develop outcome measures appropriate for people with MND	
4) Autonomy, accountability and democratic legitimacy	
ensure that adult social care services are funded sustainably over the long term	Contribute to the work of the commission on social care, both individually and through our membership of the Care and Support Alliance.
5) Research	
include a central and coherent strategic statement on how research is to be embedded in NHS processes	Continue our role as a major funder of MND research, and our support for the wider research effort by our organisation of the annual International Symposium on MND.
foster collaboration between the NHS and other research funders to maximise the value of funding.	
6) The role of voluntary and charitable organisations	
provide clearer routes to voluntary and charitable organisations for working with and within the NHS	Assist with the design of these routes.
end the current situation in which the MND Association provides a substantial subsidy to the care provided by statutory services	Provide data and costs relating to our expenditure.
free voluntary and charitable organisations to adopt a more appropriate role, for instance involving information provision, signposting and providing support that enhances quality of life but may be beyond the reasonable scope of statutory services.	Take up a more appropriate role that does not involve providing essential services that are the responsibility of statutory services.

Appendix 2: information on MND care costs

Work commissioned by the MND Association has already identified some of the impacts of MND on both the economy and statutory services. The loss to the economy from MND – leaving aside care and treatment costs borne by the state – has been estimated at £500 million per annum. This figure arises from the most common age of onset, which is in or after the person's sixth decade: for those not yet retired, this is likely to be the time at which their earnings should be at their highest. The nature of MND also makes heavy demands of other family members: those who adopt the role of carer might well otherwise have been earners.

These economic costs can only be fully countered by the discovery of a cure for MND, which does not appear to be imminent. It is possible, however, that they can be mitigated to some extent by effective care and support, particularly to allow more carers to remain in the workforce or return to it.

The MND Association's Year of Care tool has allowed for the costs to statutory services during a 'year of care' for a person with MND to be calculated – this year may, of course, be the individual's last year of life. This process has led to an estimate of the average cost of care for someone with MND as £16,500 per month. This average does hide considerable variation between individual cases owing to the nature of the disease, but it must be remembered that the variability of the patient's individual condition should not mean variability in the quality of the care provided.

TABLE 1: simplified outline of where these costs arise.

Statutory service	Nature of services	£K per annum
NHS	Hospital services, medication, community services, specialist palliative care, transport	55
Adult social care	Social care packages, carer support	55
Equipment (sometimes jointly funded with MND Association)		83
Other		5.5
TOTAL		198.5

This equates to health and social care costs together accounting for around £10K per month, with additional costs for equipment depending on the patient's individual needs. Although the capital costs for equipment may appear expensive, often pieces of equipment can be loaned and returned, via the PCT's Community Equipment Service. Investment in the appropriate technology at the appropriate time will also save on community support costs – as additional staff would otherwise be needed at mealtimes, or to look after the patient's needs at morning or night. Further costs are also identified in the pathway, such as informal carer support or nursing home accommodation. This brings the total average cost to around £16,500 per month.

Case studies compiled as part of this work, provide further illustration of this. In one case study, the care of an 85-year-old man with MND featured duplication of effort by health and social care professionals, inappropriate referral to a nursing home, failure to provide a ventilator necessitating remedial respiratory care, and finally his death in hospital, where he had been admitted for the fitting of a PEG (feeding tube). The cost of this care was approximately £28,000 per month, compared to the Year of Care average of £16,500. Further case studies show similarly problematic care and unnecessarily high costs.

The Association’s work to date in relation to the Year of Care therefore strongly suggests that it is cheaper to provide effective care for people with MND than it is to provide poor care. Poorly-planned, inexpert and ill-coordinated care tends to lead to crisis situations, emergency admissions and prolonged hospital stays: these increase costs massively, and unnecessarily.

A similar study of wheelchair provision supports this. It found that NHS provision is inconsistent, prone to confusing and complex lines of accountability which compound delays for the patient, and drives some patients to make their own private provision. Delay leads to needless cost for the NHS and poorer care for the patient. The consequence of delay for people with MND is that, by the time of arrival of the originally-ordered wheelchair, it is likely that it will no longer be suitable for the patient, given that their physical needs are likely to have deteriorated further. So the cycle will need to begin again – with all the additional time (and cost) of OT assessment, delay in ordering, delay in delivery.

A format for costing the consequences of these delays – in other words, the likely experience of all wheelchair services across England – is set out in Table 1 below.

TABLE 2: projected capital and annual revenue cost of wheelchair supply

Capital cost of single wheelchair ⁴	Manual (tilt in space) – £1300	Power (tilt in space) – £3000		
	Initial Assessment	Return visit with wheelchair	Repeat assessment	TOTAL
Staffing cost				
Occupational therapist	785	78	78	234
Wheelchair engineer	1006	100	3207	520
Admin cost	20	20	20	60
			TOTAL staff cost	815
			Staff cost as % of wheelchair cost	
			Manual	>60%
			Power	>25%

Remember that this model assumes the purchase of new wheelchairs on each occasion – rather than, as is generally the case, the supply of an existing refurbished chair, in which case the staff costs would approach the value of the capital cost.

4 The NHS pays VAT on wheelchair purchases, but is able to negotiate volume discounts with manufacturers. While charitable agencies (such as the MND Association) are not liable for VAT, they also cannot access the volume discounts. This can result in a 20-50% surcharge to the charities.
5 Calculated on the basis of 2 assessments per day, with 230 working days. However, it is unlikely that many OTs in current pathways will achieve that level. Many PCTs will use private OT suppliers, or agency staff, whose charges will be higher
6 To cover adjustments at factory, required in wheelchair specification
7 Assuming twice yearly maintenance cost

An alternative ‘fast-track’ service is the service funded by the MND Association, and run from the Oxford Centre for Enablement by specialist OT Jenny Rolfe. The OT aims to see new referrals (i.e. patients with MND) within a week of referral. She applies no eligibility or assessment criteria, other than a diagnosis of MND, and she will take a wheelchair with her on her visit that can (if appropriate) be left with them immediately. She can then request specific adjustments to the chair from their supplier, which should be available within 3-4 weeks.

TABLE 3: projected costs of the ‘Oxford’ model

Capital cost of wheelchairs held⁸	Manual (tilt in space) – £2000	Power (tilt in space) – £6000		£126K
Storage				£2400
	Initial Assessment	Return visit with wheelchair	Repeat assessment	TOTAL
Staffing cost (per chair)				
Occupational therapist	100	100	50 ⁹	250
Wheelchair engineer	150 ¹⁰	Nil	320 ¹¹	470
Admin cost	10	Nil	10	20
			TOTAL staff cost	740
			Staff cost as % of wheelchair cost	
			Manual	c 35%
			Power	c 10%

Although the staffing costs, both in real terms and as a percentage of the capital cost, are lower in the Oxford model, the more significant feature of this example is that the time taken to supply a patient with a chair that they need is significantly shorter – a matter of weeks as against months. First use of a chair can happen within a week (rather than a month-plus), with delivery of a ‘tailored’ chair within around a month (not 18 weeks – by which time, of course, the chair may no longer still be suitable for the patient).

While individual experiences will vary, the benefits of prompt access to a wheelchair for patients with MND can be summarised as follows:

- Increased independence and quality of life (work and socially)
- Mobility in and outside the home

8 Including VAT. The Association is charged the dealer’s price without NHS discount. Storage is estimated at £40 per month per chair

9 Based on seeing patients in clinic

10 Based on £300 daily charge, and assuming 2 visits in a day

11 Assuming twice yearly maintenance cost

- Safety when manoeuvring roads or pavements
- Reduced pain, fatigue and muscle strain (obviously an important consideration for patients with MND)
- Reduced calls on carers (also reduction in carer fatigue)
- Greater ability to access health services as necessary – GP, MND Care Centre, day care etc

Independent mobility represents an opportunity for patients to continue work, as well as engagement in social and public life, for a longer period. There will also be immediate savings to the health service if patients can use their own transport to access care rather than NHS-funded transport. Furthermore, uncertain and unsteady mobility can result in a fall, requiring A & E attendance and potential treatments for fractures or head injuries. Patients without mobility are at risk of developing pressure sores, or other disability problems related to poor posture or body-use, and therefore incurring additional treatment costs.

Putting these issues in economic terms reveals that the £740 or so of staffing costs (Table 2, Oxford model) needed to equip a patient with a wheelchair, is an ‘enabler’ to **allow** people with MND longer participation in their social or economic lives and to **prevent** other avoidable or unnecessary costs to the NHS. This can be shown as follows:

TABLE 4: benefits and costs of timely provision

Cost of OT (MND Association)	‘Allows’ benefits	‘Prevents’ costs	Comments
£740		75	Average additional NHS cost (Table 1)
	2000		One extra month of employment (Table 3 estimate)
		150	1 visit a month (for 3 months) by paid carer
		300	3 months NHS transport costs
		500	Ongoing community-based treatment for pressure sores etc
		2800	Emergency admission following fall
	£2000	£3825	TOTAL

The ‘investment’ by MND Association therefore offers a ‘return to society’ – particularly the patient and the NHS – of between 5 and 8 times the initial staff cost. Even if the capital cost of the wheelchair is included, it will pay for itself through avoided costs and patient benefits - and most wheelchairs will be used several times over.

Further research supports the proposition that good care is cheaper than poor care. An evaluation of a specialist nurse post in Berkshire serving rarer neurological conditions, playing a vital role in co-ordinating the timely provision of care, found that the post paid for itself by proportions ranging from 165% to 274% of the post costs, depending on method

of calculation. This does not take account of any additional income to the hospital trust from freed capacity to increase the number of hospital admissions. The cost savings arose largely from a reduction in the average length of hospital stay (9.54 days, compared to 15.15 days the previous year).

There is therefore significant evidence that the costs of MND care and the quality of that care are strongly related. MND is a demanding condition, and cutting corners or making misjudgments about what care is required will inevitably create problems at a later stage: these problems will be expensive to correct. There is a clear opportunity to control the costs of MND care by ensuring it is provided to consistently high standards, and that good outcomes are secured for MND patients in the first instance.

Appendix 3: excerpts from the MND Association Guide to Multi-Disciplinary Team Working

Introduction

This Guide defines quality criteria for multidisciplinary working based on the MND Association's Standards of Care¹ and links these specifically with the National Service Framework (NSF) for Long Term Neurological Conditions². It will assist you in building and developing an integrated team covering assessment, care planning and review in line with the NSF. Finally there is a Standards of Care audit tool for use by teams as an aide to identifying areas where improvements could be made and achievements recognised. Some examples of good practice are also included and can be adapted as required. (These items are listed in the Annex and can be down loaded from our website www.mndassociation.org).

The outcome for you as a multidisciplinary team (MDT) is enhanced, cost effective, interdisciplinary working. Coupled with the ability to effectively measure performance, review membership and methodology and identify and address weaknesses.

The NSF states that "care planning requires an integrated multidisciplinary team of people who have the appropriate training, expertise and skills and who are able to cross-refer to provide co-ordinated care". The NSF aims to build on recent changes in NHS management and commissioning to bring about a structured and systematic approach to delivering treatment and care for people with long-term neurological conditions. Commissioners are encouraged to use the NSF in planning service developments. At the heart of the NSF are 11 Quality Requirements (QRs). These are drawn from and mapped against the core development standards in *National Standards, Local Action*³ and are expected to be fully implemented by 2015.

The QRs are based on currently available evidence, including the experience and needs of people with long-term neurological conditions. They are designed to put the individual at the heart of care and to provide a service that is efficient, supportive, and appropriate at every stage from diagnosis to end of life. Linked to each QR are 'evidence-based markers of good practice'. Each piece of evidence cited in the NSF has been reviewed and rated and reflects either expert (user/carer/professional) evidence or research based evidence.

The findings of a recent study into team working and effectiveness in health care delivered an important message to those concerned with health care organisation and delivery: "Good team work makes a critical contribution to effectiveness and innovation in health care delivery; and also contributes to team members' well being. Multidisciplinary working is a cost effective way of working reducing duplication, minimising gaps in service, enabling knowledge to be cascaded and enhancing knowledge and understanding of other disciplines."

The outcome for you as a professional is:

- A multidisciplinary team openness, with mutual respect of roles
- Increased cross boundary working and improved communication
- Development of support networks
- Development of multidisciplinary teaching and education
- Access to a wide range of services *For patients and carers there is:*
- Support from diagnosis
- Easy access to information
- An opportunity to discuss significant issues supportively and in a timely way

- Continuity of service provision
- Enhancement in the quality of the MND service
- Access to a wide range of services

Team Membership

Review representation regularly. Below is a table of key professionals who should be involved in your team, and a list of those whose specific skills may be involved from time to time.

An effective MDT will not rely solely on individual expertise and interest to sustain the group but will be able to absorb changes in personnel by developing a culture that ensures a balance of disciplines, agencies and skills.

Key Team Members

- Association Visitor
- Care Centre/Neurology Link
- Care Manager
- Dietitian
- Occupational Therapist
- Palliative Care
- Physiotherapist
- Respiratory Nurse
- RCDA
- Social Worker
- Speech and Language Therapist

Ideal/Co-options/Access to

- Benefits Adviser
- Care Agencies
- Carer support
- Community Nurse
- Continuing Care Assessor
- Gastroenterologist/PEG Team
- GP
- Housing
- Pharmacist
- Psychologist
- Rehab. Consultant
- Respiratory Physician
- Wheelchair Service
- Spiritual Support

Appendix 4: comments from MND Association regional staff following their attendance at regional consultation events on the White Paper

“At times the event felt a bit like a party political broadcast with much praise given to the coalition government and individual ministers. A positive spin was put on all concerns raised about changes to the NHS [...] Even though the purpose of the event was to consult with the voluntary sector on the changes it felt like it was a 'done deal'.

“I had hoped that there would have been more information on what the changes would be like at the ground level. Instead it was about asking us for solutions to problems, which is hard to do when you don't have all of the information.

“There was an encouragement for voluntary sector organisations to 'compete' for business in readiness for when GP's will take over commissioning - to become part of a 'market economy'. In my opinion this is moving away from the very essence of why many voluntary sector organisations exist in the first place - particularly the smaller ones!

“The proposals are about giving patients choice which is great if the patient is able and willing to do this. There appeared to be no recognition that potentially more burden will be placed on carers to manage services/support, only adding to their stress and workload.

“On a positive note it was a great opportunity to gather voluntary sector organisations together, to network and feel united!”

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“We were informed that 3rd Sector organisations should be out their touting for business too, and that the opportunities to be involved had never been so great. However how do smaller groups who hold vital local knowledge compete with corporate giants?

“Major discussion took place around the new social care white paper and Public Health consultations to be announced soon. It was felt that these three should all be looked at as one or at least at the same time so the whole picture could be seen in context.

“It was interesting that a patient gave a very passionate speech as the last question stating that so much knowledge was being lost from the PCT's and how people would be so much worse off from the destruction that is under way. The DH gent informed that the DH did not want to lose that expertise and that destruction would not happen. In this area one third of the PCT is to be made redundant in the next month so I am not sure in which part of the country their evidence is gained!

“After so much questioning and lack of clarity from such a massive number of people it was fascinating to hear the DH folks round up the day with such positivity and one can only imagine that they had not heard any of the conversation in the previous part of the day. Yes we have been consulted as for the purposes of ticking a box....however were we listened too at all?”

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“We were on tables with the workshop number and just left to our own devices, no comments no input. We were to feed back our thoughts which we did through someone else on the table but we felt that this was just an exercise and doubt if anyone would even

read them.

“I hope others had a better experience, I'd hoped that there would have been some facilitation. In the afternoon there was young man from DH at our table, he sat outside the circle, looked extremely bored and made no contribution at all, he left before the end of the discussion!”