mnda
motor neurone disease
association

RESPONSE TO THE GREEN PAPER ON SOCIAL CARE

1. INTRODUCTION

1.1. Few conditions are as devastating as Motor Neurone Disease (MND). It is rapidly progressive in the majority of cases, it is always fatal and it kills five people everyday in the UK. It can leave people locked into a failing body, unable to move, speak or eat normally. The intellect and senses usually remain unaffected. There are around 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no effective curative treatment.

1.2. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a World Free of MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

1.3. We welcome the fact that the Green Paper has been published and that the Government is stimulating a significant debate about the future of social care. We also accept the Green Paper's case that the current system is unsustainable in the long term, and that change is required.

1.4. This response outlines several key areas of interest for the Association, and then addresses itself to the specific questions asked in the Green Paper. As an appendix, we attach a brief outline of the key features of a social care system that would meet the needs of people with MND.

2. NATIONAL CARE SERVICE

2.1. We welcome the proposed National Care Service and nationally-set levels of entitlement. MND is subject to very significant regional variations in the levels of care available in different areas, and we will be very pleased to see a situation in which there will be clearly-understood minimum entitlements that apply everywhere. We also welcome the proposal for assessments to be "portable" between different areas, which should also contribute to reducing the geographical inequities that affect care for people with MND.

2.2. Nationally-set entitlements will, however, still be limited by the differences that will always exist in spending power across different localities. The same amount of funding will always buy more services in some places than in others. To address this, as well as the question of whether the system should be wholly national or be partly local, we recommend that the national entitlements be set as a minimum, which local authorities may be entitled to ‘top up’. This may result in some areas spending more per head than others, but if the minimum funding is set at a reasonable level, there will still be a sound ‘baseline’ of provision that everyone can expect to receive, which will deliver greater equity than people with MND currently experience. (See also our answer to Question 3.)

2.3. The MND Association already supports the campaign for there to be a Constitution for social care equivalent to the NHS Constitution.[1] The creation of a National Care Service would seem to be the ideal opportunity to create such a Constitution, and we recommend that this be incorporated into the White Paper.

3. CARERS

3.1. Although valuable, much of the recent discussion around social care, including in the Green Paper, lacks an essential consideration of context, which we urge be developed in the White Paper. The discussion is framed very much by individuals and their needs: this is understandable, but an individual with care needs will almost always have family members whose lives are disrupted; the individual, their relations or their friends might all forsake their careers and interests as a result. This can have significant social and economic consequences.

3.2. We therefore agree with the argument that social care is not just a service for those people who have direct needs; it is a service that has a broader function in national life, and should be recognised as such. Shortages in childcare that prevent parents returning to work are, when they occur, acknowledged as damaging to the national interest; shortages in social care that have the same effect on other family members must be viewed in the same way.

3.3. At the very least, future work stemming from the Green Paper should, we feel, pay greater attention to the needs of carers. Carers’ needs are not currently well-served, or at least consistently addressed, and their quality of life can be seriously compromised by their caring role. Work is therefore needed to set out how the proposed National Care Service will improve their situation, and how it will dovetail with the existing Carers Strategy.

3.4. MND can progress extremely rapidly, and both individuals and their carers need timely access to support. For carers, the swiftness of the disease’s progress can make planned respite care utterly vital; notwithstanding that a separate Carers Strategy exists, we were disappointed to find that the Green Paper does not contain the word ‘respite’ at all. Another significant problem at present is the widespread failure of local authorities to offer carers the assessments of their needs to which they are entitled; very often the problem appears to be a pure lack of resource. When carers’ needs go unmet, the care of the individual they care for will inevitably be compromised; any new

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[1] http://www.socialcareconstitution.org.uk/introduction.htm

National Care Service must address this as an integral part of its approach.

4. ATTENDANCE ALLOWANCE

4.1. The Green Paper's proposal to divert funds from Attendance Allowance, and possibly other benefits, to social care has proved arguably its most controversial suggestion. While we acknowledge the thinking behind the Green Paper's case, we ultimately cannot accept it, and must recommend that the current Attendance Allowance arrangements are maintained.

4.2. Our submission to the consultation prior to the Green Paper stated clearly that we would not support any move to turn a rights-based benefit into a discretionary one. This remains our position. Accordingly, we cannot support Attendance Allowance being subsumed into the social care system.

4.3. Attendance Allowance is a universal entitlement for those aged over 65 with disabilities. By contrast, social care funding is means-tested; in addition, the eligibility criteria are generally tougher than those for Attendance Allowance (although social care funding decisions are made locally, so this can vary with location). Even under the proposed new system, where everyone who is eligible for social care will receive some state help, there may be people whose needs are not great enough to meet the social care eligibility criteria, but who would nonetheless currently receive Attendance Allowance. People in this position would therefore lose out under the new system. We cannot support any move that would bring this situation into being.

4.4. In practice, people with MND tend to have high needs, so they would not be the big losers under the proposed new system. As a matter of principle, however, we do not feel we can support the proposed new arrangements. In any case, we believe that the uncertainty that would arise from further attempts to pursue this reform would create extremely unwelcome anxiety for people with MND and other recipients of Attendance Allowance.

4.5. We may be able to reconsider our opposition to this change if two conditions are fulfilled. The first is that the White Paper is able to guarantee that social care eligibility criteria will be set at a level where everyone who currently receives Attendance Allowance will qualify for support from the new National Care Service .The second is that this support is guaranteed to be no lower than what Attendance Allowance currently provides,.

4.6. We understand, however, that the current proposals are modelled on care being provided to those with critical and substantial needs, and the “top third” of moderate needs. This means that the first criterion above cannot be met and it therefore seems clear that some future claimants who would receive Attendance Allowance under the current arrangements will not receive National Care Service support under the new ones. We do not see how this could be regarded as a forward step.

5. FUNDING MODELS

5.1. TAXATION

5.1.1. In the Green Paper, the Government argued that a wholly tax-funded National Care Service was not a viable option, and declined to offer it for consultation. The growing burden that this would place on the working-age population was cited as the justification for this. We regret that the detailed modelling on which the assessment of funding options was made has not been made available as was promised during the consultation period; in its absence, we cannot accept that the decision not to offer the tax-funded option is justified. We may feel able to revise our position once we have had sight of the modelling, but at the present time we must recommend that the tax-funded option be put back on the table.

5.1.2. Irrespective of whether the tax-funded option should be considered further, we recommend that the Government should reconsider its spending priorities and its financial commitment to social care. The Green Paper and the debate that has followed it has shown that social care is an issue of great importance to the public, and we do not see a justification for social care being anywhere other than very high on the Government's list of spending priorities. Particularly in light of our recommendation not to alter Attendance Allowance, we urge the Government to consider whether some of its 'big ticket' spending commitments should in fact be accorded a lower priority than social care, to bring new funds into the system without having to commit significant new tax revenues.

5.2. WORKING AGE ADULTS

5.2.1. The Green Paper focuses heavily on the challenges posed by an ageing population and the need to cater for increasing numbers of retired people. Discussion of working age adults and long-term conditions seems, by contrast, to be somewhat buried in the fine detail of the paper; indeed, the phrase "long-term conditions" appears only once in the whole of the document.

5.2.2. Although MND is age-related, and many people who develop it will be retired, many others will not. Although more common in older people, MND can affect any adult, and it is not unknown for it to develop in people in their mid to late teens.

5.2.3. MND is not generally, however, a condition that develops early in life with which the person then lives for a long time. People with other conditions that do develop in this way might be unable to work throughout their lives, and therefore be unable to build up savings, but this is not often the case for people with MND. Rather, those who develop MND in middle age may well have enjoyed full working lives up to that point, and have built up significant assets on which any means-tested solution would oblige them to draw. Others who develop MND, however, will not have significant assets, even if they have had a full working life.

5.2.4. This complex variety of circumstances must be borne in mind. The MND population contains more or less all scenarios of age and means with which the new system will have to contend, as well as a challenging diversity of needs: although it is often rapid, MND develops differently in different people – it can be said that no two cases of MND are the same. The challenge for any new system will therefore be to respond to rapid and long-term conditions that present a complex and unpredictable set of needs. The level of care that is appropriate to an individual's needs must be reliably and speedily accessible to them, irrespective of their means.

6. ANSWERS TO CONSULTATION QUESTIONS

1. We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- *prevention services*
- *national assessment*
- *a joined-up service*
- *information and advice*
- *personalised care and support*
- *fair funding.*

a) Is there anything missing from this approach?
b) How should this work?

We believe that one of the elements missing from the principles of the new system is timeliness: people should be able to expect to receive care services in a timely manner.

This is particularly important with MND, which can develop extremely rapidly and often does. A person's needs might therefore change quite suddenly, and it is not acceptable to have to wait several weeks or even months for a new assessment and then potentially longer for care to be arranged.

We recommend that a "fast track" should exist in all care and support provision for people with rapidly-changing needs, expert assessment of need should take place quickly, to enable people with MND to be placed on this fast track when appropriate (which will often be the case). This should apply to social care, NHS continuing health care, benefits (where a similar Special Rules system already operates, with mixed success) and other items of support such as the Disabled Facilities Grant.

Otherwise, we believe that the principles are sound.

2. We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.
a) Do you agree?
b) What would this look like in practice?
c) What are the barriers to making this happen?

We agree with this approach in principle, and are pleased that the Green Paper discusses this concept not only in relation to the divide between health and social care, but also in terms of the need for housing, benefits and other local authority services to be co-ordinated.

For a view of what this would look like in practice for someone with MND, the MND Association has produced a care pathway: the Year of Care gives a fully-costed outline of all the care services that a person with MND might need over the course of one year, and we are working to promote it to commissioners. We will be happy to share this with the team developing the White Paper.

The barriers to securing this joined-up experience are already well-documented. Departmental segregation is a major barrier, particularly if one or more department is short of funds, which leads to cost-shunting. The working practices of service providers and the mindsets of some health and social care professionals can also be barriers: at their best, providers and professionals work together, with the needs and desires of the service user at the centre of their attention; but this does not always happen.

3. The Government is suggesting three ways in which the National Care Service could be funded in the future:

- *Partnership – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.*
- *Insurance – As well as providing a quarter to a third of the cost of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.*
- *Comprehensive – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.*

a) Which of these options do you prefer, and why?

Although we wish to see the tax-funded option reconsidered, or a fully-modelled justification for its exclusion presented, we acknowledge that a 'partnership'-type approach as set out in the Green Paper has some merits. Everyone will receive some help from the state, which means that those who have been prudent and saved during their lives will not feel so strongly that they are being penalised by social care charges. It is also right that those who are least well-off should receive additional support from the state.

We will consider briefly how each variant of the 'partnership' model might affect people with MND. The simple 'partnership' option will work much as now, except that everyone will get some financial help from the state. After that, a means test will apply. In practice, many people with MND will receive significant help even after the means test: while some will have substantial assets, it may well be that their spouse or partner is still living in their house, for instance, and so it does not count under the means test. Ultimately the person with MND will almost always move from social care funding to NHS continuing health care funding. Such a model will therefore leave people with MND receiving more assistance than at present, but could in some circumstances still be very costly for the individual.

Under the ’insurance’ option, those who have taken out the insurance and are over 65 will have their social care needs met without further payment being required. Those who develop MND at a young age may, however, not have had chance to enrol in an insurance scheme, and may also have little in the way of savings; for them, taxpayer funding will be required. Those who develop MND before retirement – and therefore, presumably, before any insurance policy can mature – will likely find the insurance does not meet all of their needs, and will therefore be looking at a means-tested scenario as under the simple ’partnership’. The Green Paper lacks detail, however, on what would happen if a person developed care needs after paying into an insurance scheme for a relatively short length of time. While this option seems flexible, it does not appear to offer significant benefits for people with MND relative to the other two options.

Under the ‘comprehensive’ option, care costs beyond the state’s initial contribution will be met by insurance schemes for the over-65, and the state for the under-65. The certainty and peace of mind this would bring would be invaluable for people with MND, for whom clarity and certainty are at a premium. Overall, therefore, we favour this option of the three presented for consideration; it is the only one that will be effective for people with MND.

That said, we have some concerns over whether an insurance scheme, as required for the ‘insurance’ or ‘comprehensive’ options, can be made sustainable. In other countries, similar schemes have developed deficits as demand on them has grown, and the relevant government has had to step in, over and above its existing commitments. If this happens, it will leave us back in the current situation, with rising demand for social care that nobody has the financial resources to meet adequately, but where the Government has little choice but to meet the cost out of taxation.

We also understand that the private insurance sector does not yet have suitable products that can be used in this way. We recommend that the White Paper devotes attention to finding solutions to both of these problems.

A further difficulty we foresee with the idea of a ‘lump sum’ premium on retirement, or even after death, is that it might encourage parents to hand over assets to their children, so that they can claim not to be able to make such a payment. Disposing of assets in this way in order to avoid paying care home costs is already unlawful; the White Paper should consider to what extent avoidance of this sort might increase in the future, and how best it might be addressed.

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Our preference in principle, where there is a tension between national consistency and local flexibility, is for national consistency to receive greater priority.

That said, one way to resolve that tension may be for national entitlements to be set as a minimum, which local authorities would be entitled to ‘top up’. This may result in some areas spending more per head than others, but if the minimum funding is set at a reasonable level, there will still be a sound ‘baseline’ of provision that everyone can expect to receive. We would be interested to see this idea explored further in the White Paper.

We are conscious that this question leads to a further issue: will the new system be ‘cash-limited’ (like existing social care, where local authorities have a fixed amount of money and divide it as they see fit) or ‘demand-led’ (like existing benefits, where the individual entitlement is fixed and as many people receive it as apply and qualify for it – even at the cost of rising expenditure)?

We understand that the new National Care Service is intended to be cash-limited, which poses questions: if local authorities have a role to play, the allocation of resources is likely to work much as at present; but under a national system, how does cash-limiting fit with the idea of ‘national entitlements’? It is not at all clear from the Green Paper how the funds available under a cash-limited system will be divided up.

Under current arrangements, local authorities tend to use eligibility criteria to determine the allocation of resources: in most areas, therefore, people with low or even moderate needs do not receive funding, because the local authority lacks the resources to provide it. Any situation in which this practice is reproduced on a national level must be avoided: far from giving us an improved care system, it would represent a significant backward step. We are fundamentally unsure that a system of ‘national entitlements’ can meaningfully be run on a cash-limited basis.

For further information contact:

John Kell
Policy Manager
MND Association
David Niven House
10-15 Notre Dame Mews
Northampton
NN1 2BG

0208 3489703

john.kell@mndassociation.org

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APPENDIX: What should a social care system look like for people with MND?

Here we set out the key features of a social care system that will meet the needs of people with MND, by allowing for as high a quality of life as is possible, equitable access to services, and dignity in death. It must be noted that this is a particularly high-needs group: a system that responds well to them will inevitably provide a high quality of service to many other groups as well.

The Green Paper could, we believe, deliver a system that meets all of these criteria, if work is taken forward both with appropriate care, and with the necessary ambition.

Integrated care

From a service user's perspective, the joins between services should be seamless. This includes not just transitions between social care and health care, but also disability benefits and other entitlements such as the Disabled Facilities Grant. These services should work together in a co-ordinated way, so that each is alerted to needs that they must meet, and able to do so without interfering with other aspects of provision.

Integrated care provision also requires co-ordination of care, including the presence of designated key workers to co-ordinate multi-disciplinary teams, which is often necessary in cases of MND.

Appropriate provision

Care provision must meet the individual's needs by securing as high a quality of life for them as possible. This must entail more than ensuring they are simply dressed and fed, but instead must allow them to lead as full a life as is possible.

Service users and their carers must be able to offer meaningful input into deciding what provision is appropriate. This might mean allowing them to use direct payments or personal budgets to procure their own care; or it might mean them allowing a provider to put a care package together for them – both options must be available.

Timely provision

MND can progress with remarkable speed, and an individual's condition can deteriorate rapidly and unpredictably. Need must therefore be assessed and met quickly: it is not acceptable for services to take so long to be delivered that the intended user has either died, or endured a further change in their condition such that the service no longer meets their needs.

Expertise in MND

Care must be delivered to people with MND by professionals with expertise in neurological conditions and the management of their symptoms. Inexpert care can lead to necessary treatments not being delivered, and to preventable emergency hospital admissions.

Clarity and Simplicity

There must be clarity around what a person with MND is entitled to receive and, where necessary, around what providers are available to deliver it. There must be consistency regarding the levels of service offered throughout the country; people should know, broadly, what they can expect to receive irrespective of where they live at a particular time.

The system must also be simple to use. Current arrangements can add significant burdens and pressures to service users and their carers, at the worst possible time. This must be improved: administration must be simple, and information must be easily available.

Adequately funded

Statutory services must deliver what they should deliver, under the entitlements discussed above. It is not acceptable for statutory services to plead a lack of resources and therefore simply decline to deliver care.

Support beyond the needs of individual service users

There is a broader social context to social care, which meets the needs not just of the individuals with needs, but of their friends and family members who forsake their own interests to care for them. They must be supported to ensure they too have as high a quality of life as is possible, and can continue to play an active role in society during and after their time as a carer.

Improvement on current position

It would not be acceptable for any new system to offer lower levels of provision than the current one; unless our prosperity as a nation were to decrease significantly, there can be no excuse for a deterioration in social care provision. Any new system must be an improvement on the old.