

Submission to the Commission on the Future of Health and Social Care in England

Introduction

- i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure.
- ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a World Free of MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.
- iii. The demanding nature of MND makes it an extreme marker condition: a system that can respond well to MND can respond well to more or less anything. Unfortunately, the current system often struggles: while excellent care can be found within it, so too can distressingly poor experiences.
- iv. The challenges that MND, and age-related neurodegenerative disease more broadly, poses to our society and care system will increase over the coming years. As progress is made in fighting the traditional 'big killers' and as the population ages, more people will live long enough to develop MND, who might otherwise have died of something else before their symptoms emerged (by the time symptoms become apparent, a person's motor neurones have been dying for an unknown period of time, possibly years or even decades). Moreover, while we are some distance away from curing MND, we have developed and are developing interventions and therapies to prolong survival. In twenty years' time, although it is difficult to say by how much, we would expect the MND population to be appreciably larger than it is today as a proportion of the general population.
- v. People with MND are generally best cared for in the home: other than in a crisis or at the initiation of a new treatment or intervention, there is little that an inpatient hospital stay can achieve for them. When it goes wrong, MND care can be characterised by long waits for social care assessments, NHS equipment being delivered so slowly that the person can no longer use it either because their condition has progressed further or because they have died, hospices refusing to

admit people with MND if they are using non-invasive ventilation, or even at all, a lack of care to provide respite for carers, unplanned admissions following respiratory crises, choking episodes or falls, all usually preventable, and of course the same horror stories of poor treatment during inpatient stays that have become prominent in the health discourse in recent years.

What in your experience are the most significant problems that the current arrangements cause?

- i. In respect of social care, people with MND can suffer from delayed assessments, further subsequent delays in agreeing packages of care, arbitrary cuts in the amount of their direct payments, and generally interacting with the system in a crisis, rather than obtaining anticipatory support. It should be understood that a person with MND will progress through all of the old social care eligibility bands, from low needs through to critical, and their eligibility for social care is, not withstanding the means test, therefore a matter of 'when' not 'if'.
- ii. Beyond social care, the NHS and the two systems together can inflict badly co-ordinated services on people with MND – in extreme cases with two teams operating in parallel, each oblivious to the other's existence and providing overlapping care to the same person. Attempts to shunt costs between the NHS and social care, or within the NHS, are common, and the system overall is poor at preventing unplanned admissions to hospital. These problems are outlined in the National Audit Office report 'Services for People with Neurological Conditions' (December 2011).

Does the boundary between health and social care need to be redrawn to ensure that people can receive good-quality well-co-ordinated treatment, care and support that meets their needs in a timely, safe and dignified way?

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What are the barriers to achieving better co-ordinated and integrated care? Why have they not been overcome in the past? What would be needed to surmount them?

- i. The budgetary divide between health and social care is probably the largest structural barrier to better co-ordinated and integrated care. The highly demanding nature of MND, and the requirement for both health and social care support throughout a person's illness, makes this a particularly serious problem for people with MND.
- ii. With both health and social care in England operated along market lines, there is a clear incentive for providers in both systems to minimise costs and maximise revenue. Any activity carrying an up-front cost, irrespective of the potential longer term savings, is therefore likely to be subject to cost-shunting, either between the NHS and social care or within the NHS, for instance between CCGs and specialised commissioners. This is particularly problematic where the activity carrying the up-front cost will be charged to one budget, but the savings arising from it (for instance, preventive measures to minimise unplanned hospital admissions) accrue to another budget.
- iii. Furthermore, the logic of planning NHS services by commissioning is that all the key activities necessary for care must generate revenue for the provider. Yet in

practice it is very hard to align monetary rewards with clinical need exactly, particularly for complex conditions such as MND, where well over a dozen, sometimes close to two dozen professionals will be involved in a person's care at any one time, not all of them from the NHS. The result can be a failure to provide vital support, not least work to co-ordinate services. Care co-ordination activity does not generate revenue under the tariff. Some providers therefore officially discourage or even forbid it.

- iv. These problems are particularly acute in respect of social care due to the current crisis of funding it faces, but are becoming ever-more problematic in the NHS too, in response to tightening budgets and the need for new institutions to establish their responsibilities. A shift to a funding mechanism based on outcomes or a 'year of care' might eliminate the problem of intra-NHS cost shunting and of providers actively declining to undertake co-ordinating work.
- v. It can also be observed that when effective service redesign takes place, it is not always, or even often, driven by commissioning processes. The existence of MND care centres – specialised MND clinics – in England is entirely down to providers and neurologists working with the MND Association to institute them; they have never been formally commissioned by the NHS. There are other examples beyond MND, for instance the reconfiguration of stroke services in London.
- vi. One further barrier that might be identified relates to personnel working in the health and social care systems: while the silos into which the two disciplines, and specialisms within them, are divided may be institutional, they have the effect of encouraging health and social care professionals to think first and foremost in terms of their own area. So, it may be an overly broad generalisation to suggest that GPs lack a full understanding of social care and what it can achieve or that social workers might not have a strong grasp of the benefits that a particular specialised health intervention might bring, but there will be some truth in them. Any institutional shift must be accompanied, and followed for a prolonged period, by a sustained drive to change cultures and mindsets to work more effectively in an integrated way.

Is there a better way of defining health and care needs? Could this be done without changing current funding arrangements? If not, what kind of changes would be needed?

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Should the entitlements and criteria used to decide who can access health and care be aligned? If so, who should be entitled to what and on what grounds? Is it possible to balance national consistency with different local needs?

- i. Access to care, whether health or social care, should be determined by need. That said, the strict eligibility criteria for social care under both existing arrangements and the Care Bill going through Parliament, stipulate much more stringent criteria than apply to NHS care; in the former case, a nationwide threshold approximating to the old 'substantial' needs threshold is about to be set; in the latter any perceived need, however minor, is sufficient to trigger NHS attention.

- ii. The prospects for aligning these thresholds seem slim: relaxing social care criteria would require an expansion of public spending every bit as politically unpalatable as restricting NHS access to align with social care would be. We certainly would not support any move to introduce a new barrier to NHS access for apparently minor complaints, such as the refundable fee for an appointment recently proposed by a group of GPs: the first symptoms of MND can often be apparently minor problems, such as a foot dragging slightly or a scarcely perceptible slurring of the speech; anything that would slow or discourage investigation of these symptoms would delay diagnosis and treatment unacceptably.
- iii. One more fruitful avenue for exploration might be aligning assessments: using primary care as a more streamlined gateway to social care, with quick referral and as much assessment as possible done in the first consultation, could have the effect of making access appear more equitable, even if tougher criteria for social care remained in force. A significant educational push and culture change among GPs, who are by no means always aware of the significance or benefits of social care, would be essential for this to succeed.

What is the right balance between the individual and the state in paying for services? Could this be made more consistent between the NHS and social care?

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What values and principles do you think should be used to guide our thinking about how health and care should be funded?

- i. As we wrote in our submission to the Dilnot Commission, the dichotomy between the individual and the state in respect of paying for health or social care services is a false one: the services are not free and must be paid for, either by the individual at the point of use or via taxation or some other collective mechanism.
- ii. The question is, rather, one of how much risk should be pooled, and across how large a population. If none at all, then the individual pays for services when they need them – or rather, lucky individuals who do not develop care needs pay nothing, and unlucky individuals who develop substantial needs face catastrophic costs, with most people somewhere between these two extremes over the course of their lifetime. People with MND are, however, at the most costly end of this spectrum: if they had to pay all costs of health and social care at the point of use, most would quickly be financially ruined and die squalid and impoverished deaths.
- iii. Even looked at through the lens of pooling risk, however, the current NHS and social care arrangements are almost polar opposites: in health, essentially all risk is pooled across the entire population; in social care, almost no risk is pooled, with only the poorest offered any firm protection, and many people liable to ruinous costs if they develop significant care needs. As Dilnot observed, social care need is unique among the major lifetime risks we face, in that there is no effective scheme of private or public insurance against such costs.
- iv. We recommend that the Commission approaches the issue as one of risk and how it is to be shared, rather than as a matter of the unhelpful dichotomy between the individual and the state.

Other views

- i. In the introduction to this submission, we outlined the future challenge of age-related neurodegenerative disease. In terms of finding cures and effective treatments, age-related neurodegenerative disease is proving a much more difficult area of biomedical research than the traditional 'big killers' have: unlike in cancer for instance, where the aim is to kill unwanted cells, combating neurodegenerative disease requires keeping cells alive – unsurprisingly, this is proving a much harder challenge.
- ii. Any re-design of the health and social care system should take full account of the future disease challenges that will be faced by the population. Research must be made integral to the delivery of care and support, and investment made now to head off the greatly increased burden of neurodegenerative illness that we can expect to face in twenty years' time.

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