mnda
motor neurone disease
association

SUBMISSION TO THE COMMISSION ON THE FUNDING OF CARE AND SUPPORT

Executive summary

There is 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 remedy. 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. This requires high quality, timely and well-funded social care. The current situation does not deliver this.

Question 1

- The prevalence of MND will increase as the population ages, as MND disproportionately affects older people.
- All social care is provided for out of the private resources of individuals, whether by taxes or payments to providers or insurers; excessive reliance on a conceptual divide between the state and the individual risks obscuring this basic reality.
- Rising energy costs are an omission from the Commission's assessment.

Question 2

- The gravity of the crisis facing social care has not been fully recognised by the Commission.
- The current system is fundamentally under-funded; recent and forthcoming cuts are seriously compounding this pre-existing problem.
- This lack of funding manifests itself in multiple systemic problems, such as bureaucratic 'gaming' to delay assessments; this compromises the care delivered to service users.
- New funding must be brought into the system; any attempt to argue that the current settlement is adequate is unsupportable.
- There should be greater pooling of social care risk across the population, and consideration of greater use of tax funding to fund social care.
- The separate funding mechanisms for the NHS and social care create barriers to integration and therefore undermine the quality of care provided.

Question 3

- The outcome of the review must be an improvement on the current position; it must not simply be a modest increase in funding which keeps pace with the population challenges, but which leaves social services as under-funded as they currently are.

- A funding model that allowed the reliable provision of appropriate care, free at the point of need, would be attractive.
- We do not agree with the Commission that benefits and social care funding duplicate each other to any meaningful extent, and would not support a proposal to roll the two together.
- Social care funding should be ring-fenced within local authority budgets.
- There should be national eligibility criteria for social care.

Introduction: about MND and MND care

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 every day in the UK. It can leave people locked into a failing body, unable to move, speak or eat normally. Cognitive impairment and / or behavioural changes of varying severity can occur in up to 50% of cases. 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.

Care for people with MND is palliative in character from the outset, and can never be truly cheap: the rapid progression and gravely disabling effects of the disease make it a demanding condition to address. It can be shown, however, that poor care is ultimately much more expensive than high quality care: supporting a person with MND to live independently for as long as possible produces better outcomes. Failure to do so results in costly hospital admissions and emergency interventions to remedy the consequences of poor care.

The need for cost-effective services and the individual's need for high quality care are therefore aligned: it is not possible to provide the former without providing the latter. It follows from this that the funding of social care services is vitally important in MND: failures in social care will require earlier and more frequent recourse to the NHS, with increased costs for lengthy stays in hospital.

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.

Financial information: the cost of MND and care for MND

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.

The table below sets out a 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 £10,000 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, and annexed to this document, provide further illustration of this. In Case Study #1, 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 percutaneous endoscopic gastrostomy (PEG – a 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 shows 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.

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 remedy. 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.

Question 1: Do you agree with the Commission's description of the main challenges and opportunities facing the future funding of care and support?

We would make three observations, further to the Commission's overview.

Firstly, while predicting trends in the population overall is difficult, we can safely expect the prevalence of MND to increase: it is more common in older people, and as the population ages there will be more people with MND. Moreover, there is anecdotal evidence to suggest that improved care and treatment are allowing people with MND to live longer, which will further increase numbers with MND; any fall in care and treatment standards, for instance if the Government's current reform agenda were to misfire for people with MND, could reverse this phenomenon.

Secondly, we question the conceptual divide between individuals and the state in respect of paying for social care. This has been present in the policy discourse since at least the Green Paper of 2009, and something of a consensus seems to have emerged around the idea that any new funding settlement must consist of a combination of funding from taxation and contributions made directly from individuals. On a practical level, this is understandable enough.

Given the high-level nature of the Commission's terms of reference, however, we question whether it is appropriate to understand this distinction between tax and private funding in terms of a divide between the state and individuals. No professionally-provided care is provided for free: it has to be paid for; and similarly, tax funding is not free, but rather is paid for by all, compulsorily. All care, therefore, is provided from the resources of private individuals, whether via exactions by the state (tax), private payments at the point of use or to an insurance scheme, or through the giving of the time of private individuals (carers, volunteers).

The question, therefore, must be to what extend the resources for this provision should be provided from a collective pool. The more risk – and therefore resource – is pooled, the greater the role of the state must be; but the resources will still come from the time and wealth of individuals, even if channelled on their behalf by the state. While risk pooling is addressed by the Commission's discussion paper, we would like to see this fundamental conceptual issue take a more central place in the debate.

Finally, we feel that rising energy costs are an omission from the Commission's assessment of future challenges. Global competition for energy resources is increasing, and this competition seems unlikely to abate; fuel costs in the UK are highly likely to rise considerably over the medium to long term.

As well as obvious implications for supporting the vulnerable and funding their care, this has wider knock-on implications: an increasing need for remedial health treatment owing to people being unable to keep themselves warm would add costs to the NHS; and much of the new technology available for helping people with long-term conditions and improving the quality of their care relies on energy and the availability of commodities – if the affordability of either or both falls, these aids might not be available over the long term.

Question 2: Do you agree with the Commission's description of the strengths of the current funding system, and its potential shortcomings? Do you think there are any gaps?

We agree broadly with much of what the Commission says, but feel that the gravity of the crisis facing social care has not fully been recognised. The current system – prior to recent and planned cuts – has for some time been fundamentally under-funded: this lack of resources manifests itself in multiple systemic problems and gives rise to considerable unmet need (albeit that this is hard to quantify with confidence, for the reasons identified by the Commission). Our answer to this question will explore the systemic consequences of the current inadequate level of resources.

The lack of current funds in the system results in ‘gaming’ by social services and arbitrary decisions. There is an imperative to save money, such that a social worker who has taken a package of care to panel may be sent away to re-submit it on the pretext of spelling and punctuation errors, or be told to consider or re-consider care options already discounted: this has the advantage of saving a few weeks’ funding for the council. Such practices are a long-standing feature of social work, but intelligence from the MND Association’s regional staff suggest it is becoming ever-more pronounced; in some local authorities, social workers are being given clear messages not to provide any new packages. In others, local authorities are declining to provide care packages at all, on the grounds that the individual needs NHS continuing healthcare funding; this funding is, however, also becoming ever-harder to obtain, and more often than not the local authority will surely be aware that the individual has little chance of obtaining it – the result is blatant cost-shunting back and forth between the NHS and social services, while the person with MND is denied the care they need. By the time they do eventually start receiving care, probably from social services, the local authority has succeeded in saving a few weeks' funding.

The assessment of individuals can be similarly prone to manipulation. Vulnerable people might be visited several hours before they are due to arrive, before their carer and offspring is present to accompany them: the individual might then not fully put their difficulties across, and be assessed as needing less care than they actually do. Sometimes such occurrences are down to ineptitude, but sometimes they are deliberate. Assessment by phone, which can never give a clear picture of an individual’s circumstances, is similarly geared up to producing an assessment of the lowest need possible. Waiting times for assessments also appear to be on the rise: we are aware of one local authority in Yorkshire which only caters for substantial and critical needs, but which nonetheless has a waiting time for assessment of seven weeks.

Furthermore, the presence of a carer can lead to the individual being assessed as having no care needs, or very few, because the carer does everything that is needed. Carers assessments are seldom proactively offered to people, and even when they are conducted it is rare for any assistance to flow from them.

All of these extremely common shortcomings arise from a simple lack of cash in the system.

In this context, it is hard to feel optimistic of driving much-needed improvements in the quality of care. Many shortcomings in social care for people with MND arise from ignorance of the condition: there is little anticipatory assessment, so that when an individual's needs change the result is a crisis rather than a planned response; social workers routinely close cases, denying the person with MND continuity of care and putting them at the back of the queue for a new assessment when their condition changes; the overall experience of a person with MND depends on which part of social services responds to them (over-65s, disability and neurology teams all have different approaches), and whether there is an engaged and knowledgeable worker available. With the system unable to cope with existing demand, it is hard to feel optimistic about the prospects of the workforce being sufficiently trained and educated to remedy these problems – where would the necessary funding come from?

The way in which care is provided is also subject to worrying trends: social care is becoming increasingly task-based (for instance, helping the individual with a bath), with visits made to meet specified needs rather than to take a holistic view of the well-being of the individual. This is perhaps inevitable in a system governed by commercial contracts, which require precise definition of the work to be undertaken, but its implications are significant. Social workers can often decline to help with other simple tasks that the individual cannot accomplish, such as changing a lightbulb, and disputes can arise over whose responsibility such items of work are. The routine funding of domestic chores is of course a thing of the past, as councils no longer fund care of that sort for people with 'low' (in Fair Access to Care Services terms) needs. All of this militates against maintaining vulnerable people in an independent lifestyle.

We have a further related concern about the push for personalisation: we have received intelligence that some local authorities instruct social workers to use direct payments as a first resort, not because they are straightforwardly cheaper, but because the longer process of setting them up lets the council save a few weeks' funding. That said, if delivered without advice and brokerage support services, direct payments are indeed often cheaper than conventional delivery: unfortunately, those support services are essential for achieving good outcomes from direct payments. We have consistently said that personalised delivery is not right for everyone, and often deeply inappropriate for those with a fast-moving terminal condition: they should never be forced on people against their wishes, and certainly not simply to save money.

Finally, we feel that the lack of connectedness between health and social care merits further consideration. Ultimately this arises from the different funding mechanisms for the two: providing truly integrated care is a challenge when some elements are free at the point of use and others chargeable. The current climate of cuts is exacerbating this, with local authorities and the NHS already anticipating a need to shunt costs.

The overall picture of social care in England, and indeed elsewhere in the United Kingdom, is of an inadequately funded system, whose lack of resources manifests itself in multiple systemic problems, all driven by the need to save cash. The forthcoming cuts to local authority grants and freeze in council tax will compound this difficulty, and we are not convinced that the extra £2 billion announced at the Spending Review will compensate for this, not least because half of it is in the main local authority grant and councils are free to use it for other things (intelligence from various councils suggests that very few, if any, will direct it all towards social care).

In light of this bleak picture, we are deeply surprised to read the statement from the Government, in its 'vision' paper for social care, that, "[w]ith the solid basis provided in the Spending Review for social care, there is no reason for councils to restrict support to those with the most intensive needs." We call on the Commission to make it explicitly clear to the Government that new funding is desperately needed in adult social care, and any suggestion that current arrangements are adequate is wholly indefensible. Indeed, this is a truth that the very existence of the Commission implicitly acknowledges.

Current funding deficiencies point very strongly to significant volumes of unmet need. This need might be characterised as the need that would be met by councils if they provided care for people in all bands of care need, rather than just substantial and critical as most do at present; it can also be identified as existing for limited – but still unnecessarily prolonged – periods while people wait for assessments and while care packages are negotiated, with all the delays noted above. The pressures to underestimate need during assessment will also lead to unmet need. The circumstantial case for saying that there is considerable unmet need in England is therefore strong.

Identifying and quantifying this need is of course difficult: those with low or moderate needs will effectively be triaged away when they first make contact with local authorities, and we are not aware of data that quantify these contacts. For people with MND, as their illness progresses they will inevitably approach the council again, if they have been unsuccessful at first, with greater need; ultimately, they will in all likelihood receive a care package. This delay in meeting their needs is likely to generate costs in the NHS, however, as well as providing a poor care experience, for reasons outlined in the 'financial information' section. With health and social care funded separately, this is effectively another form of cost shunting: where is the incentive for social care to make earlier provision, if the benefit is felt only by the NHS? While we cannot quantify the ultimate cost of this unmet need, the Year of Care costings give an idea of the potential cost to the NHS.

Question 3: Given the problem we have articulated what are your suggestions for how the funding system should be reformed? How would these suggestions perform against our criteria that any system should be sustainable and resilient, fair, offer value for money, be easy to use and understand and offer choice? Please also take into account the impact that your suggestions will have on different groups.

We will begin our answer to this question by outlining characteristics that we feel a social care system must have in order to meet the needs of people with MND. These characteristics will of course hold good for many other conditions, though they particularly reflect the extreme nature of MND, in terms of its speed and its effects. We will then consider the implications of this for funding.

Characteristics of a successful social care service for people with MND would be as follows.

- The individual must be at the centre of care provision, being empowered and able to exercise choice; the concept of self-directed care in the health arena must be reproduced in the social care arena
- Services must be genuinely and meaningfully accountable to users; this accountability must be easy to access, and the system must be simple and easy to navigate
- Care must take a multidisciplinary and holistic approach
- Services must be seamless; a designated key worker who co-ordinates all services across health and social care is a proven way of achieving this
- Care must reflect the specific needs of the individual, and not follow a simplistic template pathway, which will inevitably be inadequate for a disease as complex and unpredictable as MND
- Care must be provided in partnership with carers, who must in turn be supported as an integral part of the care offering
- Care must include advice and support on accessing benefits and other legal entitlements
- Care must be anticipatory: expert knowledge of the possible future courses of an illness should be used to plan future care options
- Care and assessment must be timely: it is not acceptable for an individual to wait so long for services that their needs have changed, or the individual has died, by the time they are delivered
- There must be continuity of care.

We recommend numerous specific items of best practice:

- Cases must be banked by social workers, but not closed; the person with MND will inevitably need to contact social services again, and should be handled by someone who already knows the case and does not need to take duplicate information
- Referral to social services and initial assessment should be fast-tracked after diagnosis
- Sharing of data and information should be a central part of the designated key worker's role
- Local 'champions' for MND should be encouraged and cultivated: these are professionals with both an understanding of MND and a strong passion and 'feel' for providing the care it requires; their presence in an area can raise the quality of care available significantly, both by co-ordinating care and by disseminating vital knowledge to colleagues who would not otherwise know about MND
- Assessment should be undertaken on a multi-disciplinary basis; telephone assessment should not be used.

We also advise that personalised delivery models must be implemented with great care if they are to succeed for people with MND. Given the rapid progression of most cases of MND, many people do not wish to spend their remaining time making administrative arrangements; that said, some people with MND, particularly those with slower progression, do embrace and relish the opportunities offered by personalisation.

Personalised options that succeed for people with MND will therefore have the following characteristics.

- Strong advocates for people with MND will be an integral part of the personalised offering
- Advice on legal rights and benefits will be an integral part of the personalised offering
- The system will be easy to use
- Personalised options will always be available but never compulsory; delivery via traditional means will always be an option
- Risk, such as that arising from being an employer, will be minimised
- Direct payments will be available for carers
- There will be a good range of expert providers to choose from.

What, therefore, might a future funding settlement that allows these objectives to be met look like? It will be clear from the contrast between these aspirations and the systemic problems noted in response to question 2, which arise primarily from a lack of resources, that any such settlement must bring new funding into the system as a priority.

We agree with the Commission that increasing levels of resources will have to be devoted to social care as a result of increasing demand. In response to the question posed by the Commission of whether a further increase is necessary, to go beyond simply maintaining levels of provision in the face of increased demand, we reply clearly that it is. It cannot be right that the result of such a fundamental review of social care, at a time when it is best by such grave problems, does not produce recommendations that represent an improvement on the current position. Preserving and entrenching all of the current problems is not an acceptable outcome: a settlement that facilitates meaningful and lasting improvement must be the outcome of the current review.

Several key features of the debate so far will underline this. Firstly, although the Government has changed since the current wave of debate began in 2009, the position of the voluntary sector and services users has not. Of the funding options proposed in the 2009 Green Paper, the then Government opted for the ‘comprehensive’ one following the much-publicised (and somewhat politically contentious) ‘summit’ meeting of February 2010. While we do not necessarily advocate that this model be adopted wholesale under the current review, its key attractions must be understood: it allowed for reliable funding for care, which would be free at the point of need, and brought new funds into the system.

The sense of injustice felt by people who have amassed savings and are forced to run them down to pay for social care was rightly identified by the 2009 Green Paper, and again by the Commission. A funding model under which everyone receives at least some funding from taxation would alleviate this sense of grievance, and this was a further attraction of the ‘comprehensive’ option (though there may, of course, be other ways to remedy this grievance). This approach also had the effect of leaving care for working age adults effectively tax-funded: the peace of mind this would bring to people with MND would be invaluable and highly desirable.

We also note the strong consensus among the voluntary sector against rolling benefit funding into social care, and we question whether these streams of funding really do duplicate each other as the Commission suggests. Not only are they directed at different needs, but the eligibility criteria are so different that aligning them would either result in a considerable widening of eligibility for social care or an unacceptable tightening of eligibility for benefits. We do recommend, however, that advice on accessing benefits be made more readily available, and part of a joined-up package of health and social care for people with MND.

Finally, variations across different localities can also lead to a deep sense of unfairness, and proposals for national eligibility criteria were made by the previous Government. This is a policy that has already been implemented in Northern Ireland and is being considered in Wales: we recommend that it be adopted by the Commission. It will both ensure fairness and allow for better financial planning, control and accountability. One caveat to attach to this is that in Northern Ireland the effect of the criteria seems to have been to impose some kind of ceiling on what care can be made available, irrespective of need, with the only way to get past this ceiling being to move into residential care: this should not be allowed to happen in England, and we will make separate recommendations on this point to the devolved administrations in Wales and Northern Ireland as opportunity allows.

Recommendations

We make the following recommendations on the future funding of social care in England.

1. New funds must be brought into the system
    - This is necessary to ensure sustainability, fairness, choice and promotion of the wellbeing of individuals and families. The current funding arrangements are manifestly inadequate for present needs, and for the future: they leave individuals facing inadequate care and hard choices over how to use their own resources to cope with the consequences; they also make the levels of choice and quality that the Government wishes to see absolutely impossible to achieve.
2. There should be greater pooling of risk, and consideration should be given to increasing funding for social care from taxation
    - This is necessary to ensure fairness: it reduces the sense of grievance felt by those who have to deplete their assets to pay for vital care, and reduces the chance of people simply going without the care they need.
3. There should be no rolling up of benefits into social care
    - This is necessary to ensure fairness: any such merger of funding streams would inevitably reduce access to support currently available from benefits, which would be unfair for those receiving benefits but not social care.

4. Social care funding must be ring-fenced
    - This is necessary to achieve fairness and sustainability, and to recognise the contributions of everyone involved: if new funds are brought into the system, the corollary of this must be that they are spent on social care and not dispersed across local government, which would be deeply unfair on those who contributed the new funds. If the new funds are not available to be spent on social care, the settlement will of course immediately become unsustainable.
5. There must be national eligibility criteria for social care
    - This is necessary to achieve fairness and value for money: the Commission has rightly identified a deep sense of unfairness that arises when services are available for people in one area, but not another. National eligibility criteria will also allow for improved financial control and accountability, which will in turn drive down costs as councils understand their spending requirements better.

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