Response by the MND Association to the Community and Local Government Committee inquiry into the financial sustainability of local authority adult social care

About MND and the MND Association

i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop front-temporal dementia.

iii. There are up to 5,000 people living with MND in the UK at any one time. It can affect any adult, but is most commonly diagnosed between the ages of 55 and 79. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

iv. 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 groups, and 3,000 volunteers. The MND Association's vision is of a world free from 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.

Introduction

i. We welcome the Committee's focus on the financial sustainability and quality of adult social care. We strongly believe that this focus is justified and necessary, given the current crisis in funding for and provision of social care.

ii. Social care is a key part of good care and support for people with MND, their families and informal carers. The National Institute for Health and Clinical Excellence (NICE) clinical guideline on MND sets out what good care should look like. It states that social care professionals have an important role in ensuring that people with MND get the right support at the right time. They should be a part of multi-disciplinary care teams, work to secure appropriate equipment and adaptations and organise personal care, respite care and support for informal carers. Social care professionals should work with health professionals in an integrated way, and should offer continuity and a level of expertise to people affected by MND.

iii. However, we believe that social care is falling short on delivering this level of quality of care in a number of regards. We believe that this is as a result of historic and continuing underfunding of social care and the burden placed on local authorities to deliver more with less. We have seen the effect of this chronic underfunding on people with MND, a third of whom report that the cost of their care has increased over the last 12 months.[1]

iv. In particular, we have a considerable amount of evidence from informal carers about their experiences of care and support. We have recently submitted this evidence to the Department of Health as part of their consultation on improving support for carers, designed to inform the new cross-governmental carers strategy. Research with carers revealed both that they do not get the support they need, and that they do not feel the care their loved ones receive is good enough.

v. This submission is an extract from the report sent to Department of Health, and focusses on the following issue from the terms of reference of the inquiry:

> *The role of carers in providing adult social care, the relationship between local authorities and carers and whether the funding available is sufficient for local authorities to assess and meet their needs.*

The evidence in this submission, and in the full report, comes from a series of focus groups, telephone interviews and other evidence from current and former MND carers, along with the results of the MND Association's 2015 Carers Survey.[2] The Committee can read the full report, which includes a larger volume of evidence from carers and a full set of recommendations for Government, here.

Caring for carers of people with MND: how Government can help

i. Caring for someone with MND can be an extremely intense, exhausting and lonely experience. Over half (56%) of carers of people with MND provide over 100 hours of care per week.[3]

ii. Carers tell us that they often experience loneliness and isolation as a result of their caring role. They can also experience a sense of loss of identity, and some report that the relationship with the person they are caring for changes dramatically.

> *I ceased to be his wife – I was referred to as his carer all the time. It's the saddest way that people have to end their marriage.*
>
> Former carer

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[1] Amanda Attwood and Vivienne Gaulter-Carter, *The experiences and views of people living with Motor Neurone Disease (MND)* (MND Association: 2016)

[2] Sarah Fitzgerald, *Experiences and views of carers of people living with MND: Findings of the MND Association Carers Survey 2015* (MND Association: 2015)

[3] Ibid.

iii. Below is a summary of what carers told us, through focus groups, interviews and the 2015 MND Association Carers Survey, about their experience of care and support.

1. <u>Some MND Carers go without support</u>

i. Carers consistently told us that they did not get support or were not asked about their own health, wellbeing or support needs. Several also mentioned the sheer number of health and social care professionals involved in the care of the person with MND, but the lack of attention paid to their own needs.

> *No healthcare professional has ever in 6 years asked how I am doing.*
>
> Current carer

> *I am not sure if I have had an assessment or not. We have had a rush of people coming to the house in a short period of time, a little confusing.*
>
> MND Association Carers Survey 2015 respondent

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ii. For some former carers, this lack of focus on their own health and wellbeing meant that the extent of the care they were providing without support wasn't recognised at the time, or wasn't recognised quickly enough:

> *I was lifting a 15 stone man, by myself, and they would ask 'do you need any extra help?' and he would say 'no we're fine.' He didn't want to get help because it would be an indication that he was getting worse. If someone had asked me 'are you coping?' it might have been a different answer... [When he was admitted to hospital] they could see what was going on at home and that it wasn't safe. It had to be a crisis before anything changed. In hospital they required three people to move him. There was a discharge meeting, and they said they would only discharge him if he agreed to have extra carers in the house. I'll never forget, [my husband] capitulated as soon as it was put to him in a professional way.*
>
> Former carer

iii. Carers should not be expected to wait until crisis point before their needs and capability for caring is considered. This risks the health and wellbeing not only of the person with MND but of the carers themselves, which in turn can place unnecessary pressures on acute and emergency services. Health and social care professionals must ensure that carers are properly identified and their needs and ability to care appropriately and sensitively assessed.

2. <u>Problems with carers' assessments</u>

i. The MND Association Carers Survey found that only a third of carers of people with MND had received a carer's assessment. 38% were unaware of their right to one.

ii. In addition, research by Carers UK found that 39% of people caring for someone at the end of life waited 6 months or more for a carer's assessment.[4]

iii. Of those who reported that they had received a carer's assessment, 44% were offered equipment. Just under a third (31%) were offered information about funding sources, local services and emergency support. 19% were offered nothing. Many felt they weren't offered sufficient support through statutory services.

iv. Where carers' assessments work well, and result in appropriate support, they can make a significant difference to carers' lives. Some carers said they had received welcome support, in the form of small annual or one-off grants ranging from £75 to £200, respite care, and extra day and night care for the person with MND.

> *Carers' Assessments are a great way of sitting down and realising what you are doing. I appreciate mine. I have had two now and the opportunity to speak to someone about my worries, my caring role and what help there is for me is valued. Along with the small grant I receive to make sure I go and do something for myself. This year I went on a day's sewing course. It was lovely just sewing for a few hours.*
>
> Current carer

However, as discussed in more detail below, others felt what was offered was not sufficient to meet their needs and the evidence here strongly suggests that good practice is not consistent.

v. This situation is clearly not acceptable. The Care Act 2014 introduced some vital new rights for carers, but we are concerned that these are not being met consistently across the country. Research by Carers Trust supports this concern. It found that more than two thirds (69%) of respondents to its carers survey said they had noticed no difference since the Act came into force, and 'expressed frustration and anger at the lack of support they received in their caring role'. 65% were unaware of their rights and 65% had not received an assessment. 34% felt that their carer's assessment was not helpful, and 37% had not received a letter or support plan after assessment.[5]

vi. Local authorities saw £4.6 billion taken out of adult social care between 2010 and 2015.[6] Services, including those for carers, have suffered as a result. It is reassuring that research by the Association of Directors of Adult Social Services (ADASS) shows that, this year, only 1% of councils are targeting services for carers as an area for service reductions in 2016/17.[7] However, we have seen cuts to carers services, standstill budgets and extra charges introduced across local authorities in recent years. Without a sufficient and sustainable funding settlement for social care, local authorities will struggle to increase and improve on their practice in this area, and carers will continue to lose out as a result.

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[4] Carers UK, *State of Caring 2016* (2016)

[5] Carers Trust, *Care Act for carers: one year on* (2016)

[6] ADASS, *Budget Survey 2015: key messages* (2015)

[7] ADASS, *ADASS Budget Survey 2016* (2016)

3. Support and services don’t match needs

i. Some carers reported that support and services from both statutory and voluntary sources didn’t match their needs. This might be because of the type of activity available, or the carer’s ability to take advantage of what’s on offer. In some cases, there was a lack of awareness of what was on offer as well.

> *At one point when I was getting so little support I contacted the carers association, and got a heap of things about tea parties - I wasn’t able to leave the house let alone go to a tea party.*
>
> Former carer

ii. The overwhelming sense from participants is that support is occasional, ad hoc and often insufficient. There is often no follow-up at all after assessment and no sense of continuity in services for carers.

iii. Support for carers needs to be appropriate to their age, circumstances and interests. If a carer is unable to fulfil wellbeing outcomes as a result of providing 24-hour care, a grant or voucher will not offer them any support unless that carer feels able to leave the person they are caring for. Local services should work in partnership with carers to develop their offers and to ensure that they are appropriate and sufficient for carers needs.

4. Real problems with respite care

i. Carers of people with MND repeatedly highlighted problems with access to respite care.

ii. In some cases carers don’t feel able to access respite care because of concerns about quality and expertise in caring for someone with MND.

> *Respite care – it can be so distressing for the person with MND that the carer will never leave their side again.*
>
> Focus group participant

iii. For lots of carers there are systemic problems with accessing respite care, or accessing respite that is proportionate to the level of care they provide.

> *I have had to battle for 11 years with caring for my partner. I am mentally and physically tired, I have had one week’s respite and that was last year. I have been told by my social worker that there is no respite available.*
>
> MND Association Carers Survey 2015 respondent

iv. The MND Association Carers Survey 2015 showed that almost half (46%) of MND carers don’t take planned breaks from caring, but that 59% of these carers wish they could. Of those that are able to take planned breaks, 42% rely on friends and family members to do so.

v. Carers were asked their reasons for not taking planned breaks. A significant number said that they did not want to spend any time away from their loved one. For others, however, taking a break was not an option because the person they were caring for was not willing to be cared for by anyone else, because of availability of care or fears about the lack of expertise held by care professionals.

> *I wasn't able to leave my husband's side, particularly over the last 2.5 years of his life. He would have been so frightened, wouldn't have slept and in the long run would have been more work for me on return.*
>
> MND Association Carers Survey 2015 respondent

vi. Anecdotally, we hear about problems with availability of and access to respite care from across the country. We are extremely concerned that this service, which can be so important to supporting carers to continue their role, is not receiving sufficient funding to offer a real service to carers of people with MND.

vii. Respite care and carers' breaks must be available at the right time for carers. Respite must offer sufficient and regular support to carers providing substantial levels of care, and must be delivered by high quality services with the right expertise to care for people with complex diseases like MND. Where people with MND are unwilling or unable to receive respite in a residential setting, care must be available at home.

5. Support for carers after bereavement

i. Participants have told us that support for carers after the person they are caring for has died is often extremely limited, or even lacking completely. After fulfilling such a demanding caring role, this can have a profound impact on carers.

ii. Some carers told us they received no support after bereavement:

> *When she died I was dropped, left. No one asked about me.*
>
> Focus group participant

Others felt that support did not come at the right time, or was not sufficient:

> *There was Cruse, it took a while but I went there. But you only get 6 sessions – I don't think that's enough. It takes six sessions to get to know someone and feel like you can talk to them. He was very nice but they've got a queue of people waiting too.*
>
> Former carer

iii. Evidence from MND carers suggest that this is a significant gap in service provision, and one which needs addressing urgently. Services stop and often there is no follow-up from health and social care professionals. Carers reported difficulties in getting items of equipment collected after the person with MND had died, as well as concerns around finances which will be discussed in more detail in section 4.

iv. We back the call by Carers UK for a new programme of work around support for former carers, including pre- and post-bereavement and with finances and work.[8] It is vital that the experience of people caring for people with a terminal illness is recognised and valued, and that they are supported accordingly after the person dies. All health and social care professionals involved in the care of the person with a terminal illness have a role to play in supporting carers through this period to make the transition as easy as possible.

6. Conclusion

i. Carers contribute £132 billion worth of unpaid care each year.[9] Just one carer providing 100 hours of care per week to someone with MND saves the state more than £89,000 per year.[10] It is vital that they receive the right support to make sure they are able to continue their caring role.

ii. The MND Association's report on supporting carers of people with MND includes a full list of recommendations for Government on improving support, helping carers manage the financial impact of caring and valuing the work that carers do. We would like to highlight the following priorities to the Committee as areas where we believe it could call on the Government to make a real difference to the lives of carers of people with MND:

- Allocate sufficient and sustainable funding to the social care system to enable local authorities and partners to deliver a high-quality package of support to carers
- Conduct a review into the availability, quality and range of respite care and support available across the country, and establish a clear programme for improving access to this
- Create a new programme of work around support for bereaved carers, including young carers, and ensure that post-bereavement support is timely, sensitive and sufficient. It must take into account the impact of caring for a loved one with a progressive and terminal illness like MND
- Ensure that assessments are offered consistently across the country to all carers. A carer's assessment should take place in a timely manner, and must be repeated with follow-up assessments as needs change. Carers plans must take into account future as well as current needs
- Fast track assessments and provision of services for people who care for those with progressive and terminal illnesses

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[8] Carers UK, *National Carers Strategy: top dozen asks* (2016)

[9] Carers UK, *Value My Care* (2015)

[10] Calculated based on methodology from Carers UK, *Valuing carers 2015*: unit cost of replacement care (£17.20) x 100 hours x 52 weeks.

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