



MS Society policy position statement

Care and support for people with MS and their carers

April 2017

Issue

The 2016 My MS My Needs survey found that 57% of respondents have care and support needs. People with MS need a wide variety of support with essential activities of everyday living and to help maintain their independence – from grab rails at home and a bit of assistance to do the weekly food shop, to help getting washed and dressed. Care and support can be provided by family and friends, voluntary organisations, private care agencies or local authorities. Unpaid carers of people with MS need practical and financial support too.

We know that too many people with MS are not getting the support they need. One third (33%) of My MS My Needs respondents in 2016 did not receive any or enough support. The quality and availability of local authority-funded social care is being adversely affected by significant underfunding of local government. Access to both private and publically-funded care and support services varies widely across the country.

The unpredictable, generally degenerative and incurable nature of MS make paying for care and support potentially expensive, difficult to manage, and hard to plan or save for. People with MS experience difficulties accessing information and advice about care and support and accessing local authority care. Those receiving care, and their carers, can experience a lack of coordination and communication between the health and social care professionals involved in their care

Social care professionals and paid carers do not always understand MS and the impact of the condition, especially fluctuating symptoms. People with MS consistently tell us that care and support services are too often inflexible, unreliable and unresponsive to their needs.

Improving access to responsive care and support is one of our strategic goals. The scope of this statement is England-only, given the divergent care systems in the UK. Although many of the issues faced by people affected by MS will be similar across the four nations, the policy response/recommendations will differ.

Evidence/Findings

It is worth noting that there is no official national data collected on social care needs and access amongst people with MS.

My MS My Needs survey (11,024 respondents across the UK with MS between February and April 2016. The initial survey was run in 2013):

- 57% of respondents in 2016 had care and support needs. Based on the latest prevalence data, that could mean more than 54,000 people with MS in England need care and support.
- Demand for support increased by over a fifth, from 35% to 57%, between 2013 and 2016.
- One third (33%) of respondents in 2016 did not receive any or enough support.
- More respondents fully funded their own support in 2016 than did in 2013 (16% to 39%).
- Fewer respondents received fully local authority-funded support in 2016 than 2013 (45% to 18%).
- Younger people with MS were less likely to be getting the support they need than older people in 2016. Only 32% of those aged 18-29 told us they had all of their needs met.
- Those with relapsing forms of MS were less likely to be getting the support they need than people with progressive forms in 2016. 12% of those with relapsing remitting MS said they received no support at all.
- A higher proportion of people received unpaid care, support or assistance from a friend or family member in 2016 than did in 2013 (71% to 85%).
- 36% of respondents in 2016 who needed support relied solely on unpaid care.
- 82% of those who felt comfortable on their income said they got the care they need, compared to just 39% of those who said they were really struggling (2016).
- Only 10% of people have been offered a care plan for their social care in 2016.
- 17% of 2016 respondents answered “not at all” when asked if they felt that the professionals who help plan their care worked well together.
- 15% of 2016 respondents identify a family member/their carer as their main contact for health and care support.

Qualitative evidence

- People with MS consistently tell us that it is difficult to understand how to access care and support. Focus groups conducted in 2014 with people with MS and their carers revealed a lack of awareness about what it is, who provides it and their entitlements.¹
- Focus group participants in 2014 also told us that they find themselves having to coordinate their care across a large network of disparate health and care professionals who don't always communicate themselves, which can be exhausting.
- Those who had a good relationship with a key person – often their MS nurse or MS Society support worker – felt more secure in where they could go if they needed further information and support, even if they knew this may be outside the remit of their role.
- People with MS consistently tell us that care and support services are too often inflexible, unreliable and don't understand MS/the impact of their symptoms. For people with fluctuating symptoms, inflexible care causes particular difficulty.
- Some social care focus group participants who received their personal budget as a direct payment tended to be more satisfied than those who had their care arranged for them by their local authority.² They found direct payments gave them more choice and flexibility. However, others, and their carers, found the oversight of a

¹ MS Society, Social Care Focus Groups Report, December 2015. Unpublished.

² Ibid

personal budget or direct payment an overwhelming task, which they did not receive enough support to manage.

External evidence

- Local authority social care budgets reduced by £5.5 billion between 2010 and 2015 at a time of growing demand.³
- Fewer people are receiving social care. Just over 1.1 million adults received social care support in 2015-16.⁴ In 2012-13, it was 1.3 million.⁵
- More than 1.2 million people don't receive the help they need with essential daily living activities. Among older people alone, the level of unmet need has increased 18% in the past year according to Age UK.⁶
- The National Institute for Health and Care Excellence (NICE) recommends that people with MS have a single point of contact to help coordinate their care.

Recommendations

National government

Funding

- Must deliver immediate investment in local authority adult social care to prevent its collapse; an estimated £2.5 billion at least is needed in 2019/20.⁷
- A long-term, sustainable funding settlement is needed to ensure people with MS can access the care and support they need in the future and retain financial security. People with MS must be protected from catastrophic care costs, including younger people with MS who have had little opportunity to save for care.

Local authorities and health professionals

Funding

- Local authorities with responsibility for adult social care should use opportunities available to them locally to raise funds to protect social care services and the people with MS who rely on them.

Information and advice

- People with MS require timely access to information and advice about the care and support services that may be available, regardless of whether or not they are eligible for social care at that time. Health professionals should regularly signpost people with MS in their care to such sources of information and support.

Co-ordinated care

³ ADASS, Autumn Statement Submission, 2016, <https://www.adass.org.uk/autumn-statement-2016-representation-by-adass>

⁴ NHS Digital, Community Care Statistics Social Services Activity, England, 2015-16

⁵ Health and Social Care Information Centre (2013), Fast Facts: Adults and carers receiving services. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366546/FactSheet_Social_care_adults_and_carers_receiving_services_FINAL.pdf (Accessed March 2017)

⁶ Age UK (February 2017), Briefing: Health and Care of Older People in England 2017. http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true (Accessed March 2017)

⁷ Kings Fund, Nuffield Trust and Health Foundation, November 2017, The Autumn Budget Joint statement on health and social care, <https://www.kingsfund.org.uk/publications/autumn-budget-2017>

- People with MS should have a single point of contact for their care who coordinates care across a wider multidisciplinary team. Who this point of contact is will vary depending on the person with MS and their needs.
- Everyone with MS should have the opportunity to co-produce a care plan covering the support they need from health and social care services.

Quality, person-centred care

- Care and support for people with MS must be person-centred, giving people with MS genuine choice and control over their care. That support must be reliable and adaptive to the fluctuating needs of the individual in order to enable people with MS to maintain their independence.
- Social care assessors should be supported to better understand the impact of MS and must take into account fluctuating needs when making eligibility decisions.
- People with MS should be offered a direct payment and crucially, support to manage it effectively.

Carers

- Carers' assessments must be offered on a routine and consistent basis, regardless of whether the person being cared for is in receipt of social care services.
- Carers' support services, like other areas of social care, need to be sustainably funded. That includes respite services that meet the needs of people with MS and their carers.