



MS Society policy position statement – social care funding

This position statement sets out the principles that the MS Society believes must underpin the social care funding system in England so people with MS and their carers of all ages can access the support they need, whether they fund their own care or are local-authority funded. 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.

Context

We know that responsive care and support can make all the difference to people affected by MS, supporting them to live independently and participate in society. More than 90,000 people with MS live in England, and 4,000 are newly diagnosed each year. Many people experience their first symptoms in their 20s and 30s, and many people retire early as a result of the condition. MS is also expensive – on average, people with a neurological condition such as MS experience £200 per week in an extra costs associated with their condition¹ and recent MS Society research indicates that people who self-fund their care could face lifetime social care costs of over £110,000.² MS Society research suggests that as many as 50,000 people with MS could need care and support in England, and this number is expected to rise in line with the ageing population.³

However, over the course of several years, it has become evident that the current social care funding system in England is no longer fit for purpose. Local authorities have been consistently underfunded in the midst of heightened demand caused by an ageing population and people with disabilities living longer. Consequently, over time, local authorities have increasingly struggled to provide the responsive care and support many people affected by MS need, while people who self-fund their care often struggle with high costs and accessing the care they need in a fragile care market with often very limited choice. With the number of people receiving care decreasing by 24% between 2009/2010 and 2013/14 alone and increasing numbers of Directors of Adult Social Services coming forward with concerns about the future viability of the social care system, it is undeniable that the system needs to change.

These problems are very much reflected in the experiences of people with MS: we know that too many people with MS are not getting the support they need. Despite the introduction of national eligibility criteria in 2015 under the Care Act, people with MS describe variation in what is available in different local authority areas, even between two neighbouring authorities. In 2016, MS Society's My MS My Needs survey of people affected by MS in England showed that one in

¹ Extra Costs Commission, <https://www.scope.org.uk/get-involved/campaigns/extra-costs-commission/full-report>

² MS Society research, 2018

³ MS Society, My MS My Needs, 2016

three (33%) did not receive any or enough support.⁴ The social care system has been chronically underfunded for years and it is widely acknowledged that the difficulties people with care and support needs face will only be resolved if long-term funding reform is implemented that is sufficient to deliver improvements in care.

There is also perceived unfairness in the current social care charging system, as people who self-fund and need care over a long period of time are likely to be liable for high care costs for which there is currently no state protection (except when assets are nearly depleted). In addition, working-age disabled adults and older people are subjected to the same charging system in spite of the former generally having fewer assets and savings to draw on to pay for care, with many also forced to retire much earlier than average due to poor health. This inequity in the charging system disproportionately touches people affected by MS as our research showed that 60% of respondents who identified they had needed social care in the last year (in 2016) were aged 18 to 60.⁵

In 2017, the UK Government committed to bringing forward proposals for how to fund social care in the long-term and create a more sustainable system in its Green Paper on social care. This paper is expected to be published in late 2018. Over the last twenty years, there have been twelve consultations, including commissions, Green Papers and White Papers, but in spite of these efforts successive governments have been unable to successfully reform the system.

The MS Society's vision for a social care funding system that works for people affected by MS

We will strive for and call on the Government to implement a system that truly works for people affected by MS. However, given this issue remains unresolved after two decades of debate, we recognise we are unlikely to see all the changes we need at once. Given the urgency of the immediate funding challenge, we advocate that it would be better to make incremental improvements to the system than see no change at all for people affected by MS who require care and support and risk the collapse of the system.

MS Society's key priorities for reform

The three recommendations below are our key priorities for reform of the social care funding system, and reflect the views and experiences of people affected by MS. If implemented, we are confident these priorities would unlock the greatest change for people affected by MS:

- **Immediate investment** in local authority adult social care is a prerequisite to any calls for long-term change in adult social care funding.⁶ Simply put, investment is needed to prevent the social care system from collapse in the interim of a long-term funding settlement being implemented. As such, the Government should put in place the funding required to cover this period. The Government will need to invest at least £1.5bn in 2019/20 (rising to £3.6bn in 2025) to stabilise the social care system, and must also ensure adequate funding is invested beyond that, should proposed reforms not be implemented by then.⁷

⁴ MS Society, My MS My Needs, 2016

⁵ Ibid.

⁶ Note: Working-age adults account for 49% of local authorities' total spend on social care and PSSRU projections on future costs highlights that public expenditure on social services for younger adults is projected to rise from around £8.4bn (0.53% of GDP) in 2015 to £18.4bn (0.73%) in 2035 (at constant 2015 prices). The latter shows the pressure on local authority social care budgets will only continue to increase over the coming years, and therefore must be addressed as a matter of urgency.

⁷ LGA

- Government must implement **long-term sustainable funding** for social care to ensure people with MS can access the care and support they need and retain financial security. Any long-term funding solution for social care should be based on society as a whole contributing towards the cost of social care, with increased funding being raised through increases in general taxation.⁸
- The Government should do more than only investing the funding required to maintain the system as it stands today. It must guarantee that enough funding is raised and invested to **expand eligibility** and therefore enable more people to access the care they need, including preventative care.

More broadly, the MS Society are committed to the Care and Support Alliance's (of which we are a member) seven tests for what social care funding reform should look like and deliver.⁹

- ✓ The investment of short-term funding required to keep the social care system afloat until long-term reforms are implemented
- ✓ A sustainable long-term funding solution that shares the costs of social care fairly across society and delivers an improved system.
- ✓ A commitment to putting an end to unmet need for all (regardless of age); ensuring better provision of lower level care and support, as well as preventative care.
- ✓ Improving the quality of care and enabling the provision of person-centred care for all people, regardless of their age, underpinned by a sustainable workforce and technology.
- ✓ A system that works for everyone who needs care, including working-age adults, older people and informal carers of all ages.
- ✓ Making social care more affordable and protecting working-age adults, older people and carers from high costs they cannot predict.
- ✓ A long-term plan to put the care market on a sustainable footing.

In addition to the Care and Support Alliance's 7 tests, MS Society is calling on the UK Government to make the following specific commitments relating to social care funding to ensure the latter works for people affected by MS (see [here](#) for more information on how the current social care system is funded and charged). If delivered, these would help to improve peoples' experiences and the accessibility of care:

- **Affordability.** Whichever charging system the Government chooses to implement, the Government must make social care more affordable for everyone affected by MS. People with MS already pay enough for their care among the many other extra costs associated with having a disability. The Government's reform of the social care funding system should not demand people affected by MS who need care take responsibility for a greater proportion of their care costs than they currently do, without guaranteeing significant improvements in the quality of care or expanded access to care (i.e. expanding eligibility). Older people and working age adults should be treated fairly by the charging system, relative to their differing circumstances. Both voluntary insurance and taking more of

⁸ Note: We do not have a view on the specific form of revenue. While we discussed different types of taxation, including income tax and national insurance during the focus groups, there was no clear consensus on which method of taxation should be employed, although 2 out of 6 of the original focus groups specifically advocated for an increase in National Insurance contributions.

⁹ Note: These 7 tests for social care funding reform have been developed in collaboration with over 80 other charities. The latter have agreed that each of the 7 tests set out below must be delivered in order for the care system to work for everyone who needs care and support, including people affected by MS.

peoples' assets to pay for care (for instance by taking housing into account in the domiciliary care means-test) are unlikely to be sufficient to fund the social care system in isolation.

- **Integration.** The Government should ensure that legislation and financial incentives in both health and social care enable integrated ways of working between the two systems. Fully integrated ways of working between social care and health need to become embedded equitably across England and communicated clearly to patients. This is vital so that people with MS understand the support available to them across both systems, how to access it and have a coordinated experience of care.
- **Awareness.** However social care is funded, the Government must lead the delivery of an information and awareness campaign about social care working with local authorities. This should be targeted at promoting information and having conversations about care and the potential cost of care at key points of interaction with public services. This should take place in appointments with healthcare professionals, benefits advisors and employers, as well as any other relevant services. This awareness and these conversations should be targeted at relevant points of life, including retirement planning, care planning and financial planning.
- **Transparency.** The Government must put mechanisms in place to assure the public that funding intended to be spent on social care is used for that purpose, and must also ensure greater transparency as to how the money is spent by improving the standardisation of data collection about social care funding (both at the local and national levels) and the accessibility of this data to the public and stakeholders.

Evidence

We have developed our evidence base over the course of 2018 to understand:

- What people affected by MS understand about the current social care system and what they think about it
- How people affected with MS want to see the social care system funded and how much responsibility they think individuals and the state should take for care costs respectively
- What improvements people affected by MS want to see in the social care system, building on our existing evidence base (see position on [care and support](#).)

MS Society My MS My Needs survey

9,008 respondents across England with MS between February and April 2016 responded to a survey that found that:

- 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%).
- Those respondents who felt they were struggling on their income were less likely to feel their needs were being met than those who felt they were comfortable on their income (82% compared to just 39% of those who said they were really struggling).
- Self-funders are less likely to feel that their care needs are being met than those who are local authority funded (36% compared to 23% and 30% for part-funders).
- 9% of self-funders report struggling or really struggling on their income.

The more the person contributes the less likely they are to feel that their needs are met. This suggests that people who are funding their own care may not be purchasing all the care they need because the cost is a deterrent. Charging structures should not deter people from seeking help when they need it. That means they are more likely to access care when their needs have

increased, potentially missing the opportunity for preventative support. The results could also point to the fact that the financial threshold at which an individual has to pay for their own care costs in their entirety is relatively low at £23,250, close to the minimum income standard according to The Joseph Roundtree Foundation (JRF). The fact that almost 1 in 10 self-funders reported struggling or really struggling on their income could be related to the extra costs associated with living with a disability.¹⁰

MS Society focus groups on social care funding

In 2018, MS Society convened focus groups across England to explore how people with MS want to see social care funded, and what the state and the individual's responsibility should be for paying for social care. 60 people with MS and their carers were involved in 7 focus groups from a variety of regions and age groups.¹¹ Attendees were asked to reflect on various different proposals for how social care is funded.

Across the focus groups, there was wide agreement that central Government should increase investment in social care and that the state should take on more responsibility for paying for care. There was also a clear perception that social care should be funded through a risk-pooling approach, in which everyone contributes more collectively into the system. Therefore, there was clear consensus that **some form of increase in taxation would be the preferred way of funding** the social care system in the long-term.

The focus groups also found:

- Varied understanding of social care, and how it was funded – with many people unaware that it was distinct from healthcare
- The cost of social care was a disincentive to access for many people.
- All groups agreed it is not fair or realistic to expect people with MS to save towards their care costs, given the unpredictability of the condition and the fact that many struggle financially as a result of not being able to work or having to rely on benefits.
- People with MS felt that they are/have already contributed to social care and the NHS through their taxes, and particularly National Insurance contributions. Once it became clear that social care is not free at the point of use, which many were not aware of, some felt betrayed by the system.
- All groups wanted to see a greater integration between the health and social care systems, and a move towards a social care system that was funded and charged in the same way as the NHS.
- There was an overall negative view of social care, with lack of integration and poor information in a confusing system being consistently highlighted as issues.

It is worth noting that the results from our focus groups were mirrored in both the Care & Support Alliance's Big Social Care Survey¹² and the King's Fund and Health Foundation's recent deliberative work with the general public.¹³

¹⁰ Extra Costs Commission, <https://www.scope.org.uk/get-involved/campaigns/extra-costs-commission/full-report>

¹¹ Note: In total, we engaged with 60 people affected by MS in our focus groups during 2018. The first six focus groups took place between February and April 2018, and involved 51 people affected by MS. Our focus groups were held in Manchester, Staffordshire, East Sussex, Islington, Barnet, and online; they included both people who had first-hand experiences of the social care system and those who did not, as well as people who funded their care themselves and people who received support through their local authority. The focus groups engaged with men and women from different age groups from rural, sub-urban and urban areas. The seventh focus group was held in September 2018 in Winchester and included 9 people affected by MS, as well as two people with dementia and six carers from a local voluntary organisation (as this was a meeting with the Minister for Social Care). While the majority of the content mirrored previous focus groups, timing was condensed and therefore not all questions were the same.

¹² Note: The Care and Support Alliance is a coalition of more than 80 of the country's leading charities who are calling for a properly funded care system. See [here](#) for more information.

¹³ King's Fund, Health Foundation, "A Fork in the Road: Next steps for social care funding reform", 2018