



My MS My Needs 2016 - A Summary



Foreword

The number of people with MS in the UK is increasing, the number of treatment options available has been expanding and the research agenda for MS has never been more exciting.

At the same time, increasing demand and reducing resources mean that it is becoming more difficult to deliver responsive treatment, care and support to people with MS across the UK.



Against this backdrop, this report provides a crucial insight into the needs of people with MS across the UK. And while improvements have been made since the first My MS My Needs survey in 2013, people with MS continue to face significant variation in the treatment, care and support they receive based on where they live, when they were diagnosed, their financial situation or the information they are able to access.

No two people with MS experience the condition the same way. But every person with MS should be able to receive the right treatment, care and support when they need it.

Yet, more than 1 in 4 people with MS who need support to maintain their physical wellbeing don't get it. 1 in 5 doesn't get emotional support when they need it. A higher proportion of people with MS report needing care and support than in 2013, but a smaller proportion of people report they are getting the care they need. 60% of people leave work early as a result of having MS.

There are signs of progress too, though – more people with relapsing forms of MS are accessing a disease modifying therapy (DMT), and a higher proportion of people with MS report having enough information about MS and drugs compared to 2013.

This report is for you, the MS community, to delve deeper into the collective needs of people with MS across the UK. Let us work together to build on these successes, learn from areas that are delivering excellent treatment, care and support, and reduce the variation in services that exists across the UK. Together, let's use this evidence to make sure that every person with MS is able to access the right treatment, care and support for them, until together, we stop MS.

Introduction

Effective treatments, responsive care & support and independent lives are three of the goals from the MS Society 2015-2019 strategy. For the MS Society to achieve these goals it is vital that we understand the experiences of people with MS. That way we can make sure we focus our attention and resources in the right places.

That's why in 2016 we conducted our second My MS My Needs survey. The survey aims were to:

- Gather up to date information on the health and social care needs of people affected by MS across the UK; on a national and local level.
- Find out whether people's experiences of MS treatments and the health and social care landscape in the UK has changed since 2013.
- Understand the current experiences of people with MS in relation to employment and welfare.

Almost 11,000 people across the UK with MS completed the survey between February and April 2016, making this the largest survey of people with MS to date.

Our first My MS, My Needs survey was run in 2013. While the 2016 questionnaire was broadly similar to the original 2013 version, some questions were changed, removed or added, meaning that comparisons cannot always be made.

In 2016, 75% of respondents completed a paper-based survey, sent out to MS Society members, and 25% completed the survey through an email link, via the MS Register and Shift MS. Because of age and gender bias in our sample, the 2016 data has been weighted to be representative of the UK MS population. This was a change in the sampling method from the 2013 survey when all respondents completed a paper-based survey sent to MS Society members. We cannot determine what effect this may have had on our results but it is important to bear this difference in mind when looking at comparisons between 2013 and 2016.

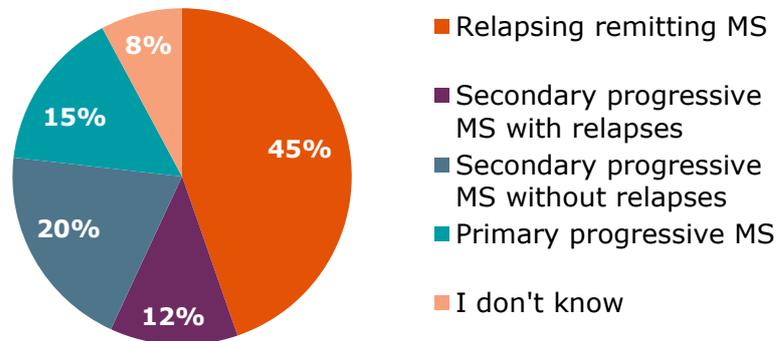
The data presented in this report is from 10,888 people who completed the questionnaire. It presents some of the key findings from My MS My Needs 2016 and, where possible, trends using the 2013 and 2016 data have been highlighted.

Since the survey completed in 2016, we have published several major reports looking in depth at different aspects of the experiences people with MS had told us about (see page 15 for more details) and the survey responses have allowed us to quote up-to-date information about the lived experience of MS in a wide range of policy positions, responses to Government consultations and less formal conversations with decision-makers – as well strategic decisions within the MS Society about what areas of work to prioritise within our different goals.

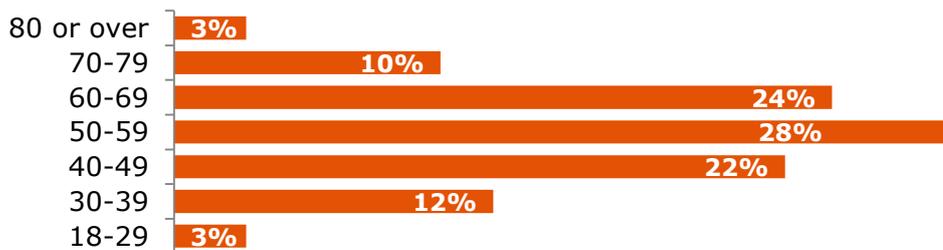
In addition to these specific reports and uses, we feel it is important to publish the key findings in a single summary report, so that people with MS have an easy way to look at how their experiences compare to those of others across all the aspects of life with MS covered in the survey.

The following outline the demographics of those responding to the survey.

Type of MS of respondents



Age of respondents



Gender of respondents



3/4 of respondents were women

A view on My MS My Needs 2016, from Carole

"I am a volunteer with the MS Society's Research Network. I have had MS for many years and I was also a young carer for my mum, who had primary progressive MS. Everyone's MS is different. Sadly not all of us seem to get the care that we need, whether it be with access to treatments, finances, social care and support etc. This survey has highlighted where some of the many gaps in services lie.

I was so pleased to be asked to be involved with something as important as the My MS, My Needs survey and also to be able to fill it in myself about my own needs. It is vital that the MS Society involves people actually living with MS, both themselves or as carers/friends, to find out what we really need.

It was very disappointing to find that some things haven't changed much in some areas since the previous My MS, My Needs survey back in 2013, such as access to DMTs, inadequate Mental Health help and inadequate access to healthcare professionals.

It will be great to see how future Campaigns run by the MS Society will help to address these issues and to enable us just to get on with our lives more easily, alongside the reality of living with MS."

Carole, MS Society Volunteer

Disease Modifying Therapies (DMTs)

The MS Society believes that every person with MS should have access to the right treatment at the right time, no matter where they live. In recent years, several new disease modifying therapies (DMTs) for MS have become available on the NHS. These treatments can decrease the number and severity of relapses and slow the progression of disability. Added to this, there is now consensus among the MS and clinical community that early treatment with a DMT can improve long term outcomes¹. Our results show that there has been some improvement in the proportion of people taking DMT's.

- The proportion of people taking DMTs has increased from 40% in 2013 to 56% in 2016.
- Access to health professionals and the right information remains key to accessing DMTs.
- 82% of people who have seen an MS nurse, seen a neurologist and received the right information reported taking a DMT. This compares to just 11% of people who did not see either of these key professionals or receive the right information.
- This trend was also evident in 2013, where 69% of those who accessed both professionals and the right information reported taking a DMT, compared with only 7% of people who did not access any of these.
- Those diagnosed within the last 5 years are most likely to be taking DMTs. 76% of eligible people diagnosed 1-5 years ago are taking a DMT, compared to 44% of those diagnosed more than 10 years ago.

All figures relating to DMTs are calculated only out of those who could potentially benefit from these treatments (that is, those with relapsing remitting MS or secondary progressive MS with relapses).

For more information see our main policy reports on access to treatment at:

<https://www.mssociety.org.uk/accesslottery>

¹ MS Society (2015) Time to Act - a consensus on early treatment, London, MS Society

Health care

People with MS often require access to professionals from all parts of the health and social care systems to best manage their condition. We believe that people with MS should have timely access to professionals and be at the centre of decision-making about their care. In 2016, the NICE Quality Standard for MS recommended that people with MS have access to care from a multidisciplinary team with expertise in MS, and access to a comprehensive review of their treatment and care annually². This team should consist of a range of professionals including neurologists, MS specialist nurses, physiotherapists and occupational therapists, speech and language therapists, psychologists, dietitians, social care, continence specialists and GPs.

Access to health professionals

- The proportion of people who reported seeing a neurologist when they needed to increased from 83% in 2013 to 86% in 2016.
- The proportion of people who reported seeing a MS nurse when they needed to also increased from 83% in 2013 to 86% in 2016.
- Overall 63% of respondents reported seeing a neurologist in the past 12 months and 68% reported seeing a MS nurse in the past 12 months. For both questions approximately 11% of people said they did not see a nurse or neurologist despite needing to.
- Of those with a need 73% of respondents were able to see a specialist continence advisor when they needed to in 2016. This compares to 71% of those with a need in 2013.

Physical wellbeing

- In 2016 over a quarter of respondents (26%) required support to remain physically active in past 12 months but had not received any.
- In 2016 28% of respondents reported receiving support to remain physically active, which is a slight increase on 2013 when 26% of respondents reported receiving support to stay physically active.
- 17% of people in 2016 had not seen a physiotherapist within the last 12 months but felt they needed to.
- About the same proportion of people had seen a physiotherapist in relation to their MS (43% in 2016 and 44% in 2013).

² NICE (2016) Quality Standard: Multiple Sclerosis. <https://www.nice.org.uk/guidance/qs108> (Accessed July 2016)

Emotional support

- Only 23% of respondents received support for mood or emotional issues in 2016 and 21% reported they needed support/more support.

Health care planning in 2016

- The most common key contact for health care and support in relation to MS was a specialist nurse (46%), followed by a GP (21%).
- People who listed their primary contact as a specialist nurse are most likely to feel they had their information needs about MS drugs met.
- Worryingly 5% said that no one currently co-ordinates their care, while 14% said it was a carer or member of their family - in this case, the degree to which that carer or family member has support from NHS professionals is unknown.
- Overwhelmingly, people living with MS in the UK reported not being offered a health care plan or health care plan review in the past 12 months (83%). Only 7% of respondents reported being offered a health care plan and 5% a review of their health care plan.

A word on treatment and access to healthcare, from Andy

“Questionnaires and advice from the MS Society give people with MS the information they need. It gives people the information they need to make informed choices.

At my centre they work together for me. When I had a bad relapse, I had an issue with a cancelled MRI. Even out of hours my MS nurse sorted it out, called the neurologist and the next day I was booked in for one. The nurse, neurologist and physio together are a great team, even though I share them with so many other patients they feel like my team.

It's a shame other people feel they don't have joined up support. Going to a specialist MS centre has made a huge difference to me. But not everyone has that, or even knows how to access them. There are people in my town that live 12 miles away who don't know the local centre exists. They are supported in the community, but those MS nurses have huge workloads, the options they have a different.

It's a lottery; your life can be so different depending on where you live and who you're referred to. When I meet people with MS, I make sure they know what's out there; the MS Society groups are my forum for this. Giving people the information you need to make the choice.”

Care and support (social care)

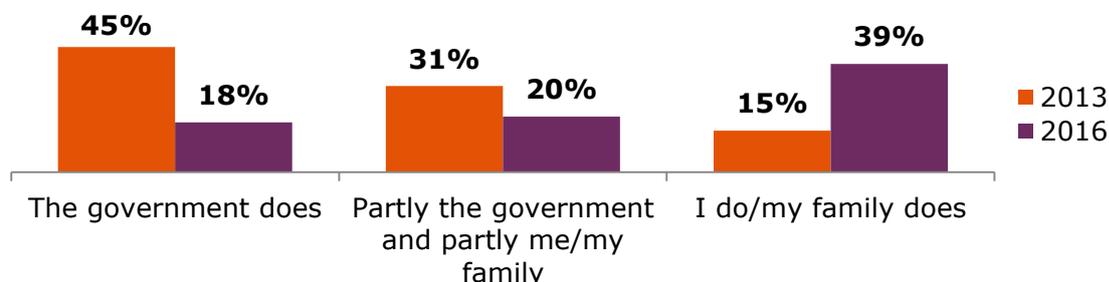
Many people with MS, at some point, will need care and support to live their daily lives. That might be support from family and friends, voluntary organisations, private care agencies or social care arranged by local authorities. Social care offers a wide variety of support that people need to maintain their independence – from grab rails at home and assistance to do the weekly food shop, to help getting washed and dressed.

What is the level of need for care and support?

- In 2016, 66% reported they are getting all the care and support they need. In 2013, 74% of those who needed it reported they received social care support³.
- The proportion of people reporting they require support has increased, from 35% to 58%, since 2013.⁴
- As MS is a progressive condition, it is not surprising that older people with MS were more likely to need support than younger people with the condition.
- However, younger people with MS are less likely to be getting the support they need than older people. Only 36% of those aged 18-29 told us they have all their needs met, compared to 75% of those aged 70-79. Although only 220 people aged 18-29 completed the survey, it is concerning that they were much less likely to report having their needs met than any other age group.
- Only 11% of respondents said they had been offered a social care plan, while 6% had been offered a social care plan review.

Sources of support and how support is funded

Comparison between how people pay for their social care (2013-2016)



³ The question wording relating to receiving care and support was different in the 2013 and 2016 surveys. In particular, in 2016 people were asked to say whether they received all or some of the support they needed, whilst in 2013 they were not asked to state whether support they received was enough. Please see the appendices from the 2013 and 2016 reports for the question wording.

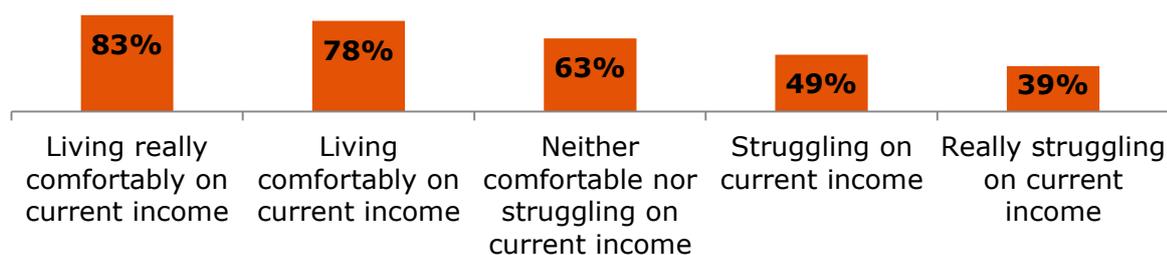
⁴ A definition of social care was included in the 2016 survey, whereas in 2013 no definition was provided so respondents understanding of the term 'social care' may have differed.

- In 2016 39% reported that they or their family pay for all of their care and support, while 20% said that the government part fund their care. 18% of people said that the government paid for all of their support. Self-funders are less likely to feel their care needs have been met. This is worrying given a greater proportion of people are paying for their own care than in 2013. 76% of people who reported that the government paid for all of their support felt that they had received all of the social care support that they needed. Whereas 64% of people who said that they or their family paid for all of their care felt their needs had been met.
- A higher proportion of people receive unpaid care and support from a friend or family member than did in 2013 (increased from 71% in 2013 to 86% in 2016)⁵. 39% of people who need support told us they rely solely on unpaid care.

Feelings about income

- Those who report feeling more comfortable on their household income are more likely to feel that their needs for care and support have been met.

Those who had their care and support needs met by feelings about current household income (2016)



A word on social care, from Doug

"I feel that there is a problem in adult social care, with so many people suffering so many different afflictions, each needing representation.

Pre-armed with the maximum available data on the subject, speaking for a large portion of the community - one coordinated voice for MS sufferers instead of 100,000 individual users of social care can have the impact we need.

This seems to me to be the only way to address the issue and initiate the debate the country so badly needs."

Doug, Living with MS

For more information see our main policy report on social care at:

<https://www.mssociety.org.uk/ms-resources/social-care-and-ms-community>

⁵ The question relating to receiving unpaid care and support was different in the 2013 and 2016 surveys. In particular, in 2016 the definition of care and support specified that this was for practical tasks whilst in 2013 it did not. Please see the appendices from the 2013 and 2016 reports for the question wording.

Employment and welfare in 2016

People with MS are less likely to be in employment than the general population or the wider population of people living with long term conditions⁶. Finding and remaining in employment has many benefits for individuals, their family, community and wider economy. It can provide someone with the money they need, but jobs are also valued beyond financial benefits. There is a strong evidence base to show the links between employment and good health and wellbeing⁷. While some people with MS and other progressive conditions could potentially gain financially and socially from working, others are simply unable to work due to their symptoms.

- Only 44% of working age (under 60⁸) respondents reported being in full or part time employment.
- More people feel that they need support to remain in employment than support with finding employment. Only 6% of people either in work, looking for work or a student felt that they needed support to find employment in the past 12 months. 11% reported needing support to remain in employment.

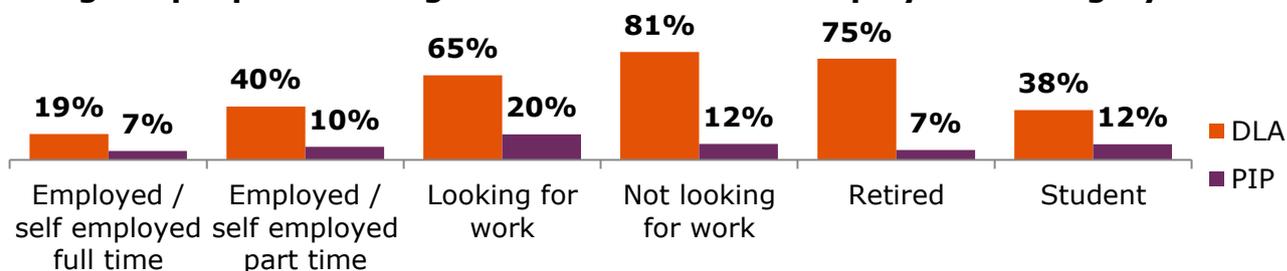
Employment Support Allowance (ESA): people who find it difficult to work due to a health condition or disability may be eligible to access ESA

Personal Independence Payment (PIP): can help cover the extra costs that could be faced if people need support doing everyday tasks or find it difficult to get around outside

Disability Living Allowance (DLA): PIP is replacing DLA for people of working age

- 23% of respondents were receiving Employment Support Allowance. 51% of people not in employment (looking for work, not looking for work or a student) were receiving ESA.
- The below figure indicates that one in five people who reported that they were looking for work were receiving PIP.

Percentage of people receiving PIP and DLA in each employment category



⁶ NHS Outcomes framework, employment of people with long-term conditions. Available here: <http://content.digital.nhs.uk/catalogue/PUB20722/nhs-out-framind-may-16-comm2.pdf>

Bajorek, Z., Hind, A. & Bevan, S., 2016. The impact of long term conditions on employment and the wider UK economy

⁷ Waddell, G. & Burton, A.K., 2006. Is working good for your health and well-being?

⁸ Ten year age bands were used within the questionnaire, meaning that statistics for those under 65 years of age cannot be provided.

- 60% of respondents had either retired early or left work entirely as a result of their MS.
- Only 13% respondents had not made any changes in relation to their work because of their MS.

For more information see our report on Employment at:

<https://www.mssociety.org.uk/ms-resources/exploring-employment-support-needs>

A word on work, from a healthcare professional⁹

“Many [people with MS] appear to have been forced to leave work as the disease has progressed and their symptoms have worsened...

Particular symptoms such as high levels of fatigue, reduced mobility, visual or bladder problems, cognitive changes may have impacted on their abilities/roles at work.

Some people highlight that they have become increasingly overwhelmed prior to either reducing hours and or finally deciding to leave paid employment.”

Anonymous, a health & social care professional

⁹ Employment that works. Supporting people with MS in the workplace:
<https://www.mssociety.org.uk/ms-resources/employment-works-people-ms-appg-report>

Summary of key findings

In summary our survey suggests

- ▶ The proportion of people taking DMTs has increased since 2013 and those more recently diagnosed are more likely to be taking them.
- ▶ One in five people are not getting the emotional support they feel they need and one in four are not getting support they feel they need to remain physically active.
- ▶ MS nurses are the most common key contact for people about health care and support in relation to MS.
- ▶ The vast majority of people with MS have not been offered a care plan or care plan review for their health care within the last year.
- ▶ A smaller proportion of people report getting the social care support they feel that they need compared to 2013 and more report needing support.
- ▶ Younger people with MS are less likely to get the social care support they need (though this is based on a relatively small sample).
- ▶ People who pay for their own social care support are less likely to feel that their care needs have been met.
- ▶ A greater proportion of people are paying for their own care than in 2013.
- ▶ A higher proportion of people report receiving unpaid care and support from a friend or family member than did in 2013.
- ▶ 39% of people who need care and support rely solely on unpaid care.
- ▶ 60% of people leave work early as a result of having MS.
- ▶ More people feel that they need support to remain in employment than support with finding employment.

This survey has given us a real insight into the lives of real people living with MS. Whilst we have seen some positive changes since the 2013 survey, it is clear that there is still more that needs to be done.

We believe these insights are vital in helping us to achieve a better world for people affected by MS.

A final word, from Andy

“It’s important to me that the MS society finds out about peoples experiences. Looking at the results, it’s really interesting; it gives me an idea of what’s going on out there.

What other people go through and their experiences. The MS Society can use this to campaign for change.”

Further Reports

Unless specified all data has been taken from the 2016 My MS My Need Survey. Data tables can be found in the appendices to this report.

For further information on specific topics please see the reports below:

Access to treatment and healthcare

This report was created to enable our local and national influencing on access to services and treatments.

Our reports for access to treatment were broken down by nation and can be found at <https://www.mssociety.org.uk/accesslottery>

Social Care

This report was developed in collaboration with the Nuffield Trust to support our social care campaigning.

Our report on Social Care can be found at <https://www.mssociety.org.uk/ms-resources/social-care-and-ms-community>

Employment

Our analysis on employment was used to support the All Party Parliamentary Group for MS (APPG on MS) Report. An additional report was produced with the Nuffield Trust was used for wider policy influencing around employment.

Our report on Employment can be found at <https://www.mssociety.org.uk/ms-resources/exploring-employment-support-needs>

APPG report can be found at: <https://www.mssociety.org.uk/ms-resources/employment-works-people-ms-appg-report>

We're the MS Society.

Our community is here for you through the highs, lows and everything in between.

We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk



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 **Let's stop MS together**