



Cymru



**MS treatment in Wales:
is access still a lottery?**



Let's stop MS together

Foreword

MS is an unpredictable and incurable condition that affects people's nervous systems. It can attack suddenly or progress steadily, bringing a range of symptoms which can include sight loss, incontinence, fatigue and mobility problems. No-one with MS can be sure when or how it will affect them next. Around 4,900 people are living with MS in Wales.



The MS landscape has changed a great deal since the publication of the results of the last My MS My Needs survey, which were released in 2013. More disease modifying therapies (DMTs) for relapsing forms of MS are available. Public policy and guidance about how to treat and manage MS have been substantially revised. And, crucially, we now know that treatment with a DMT as close to diagnosis as possible improves long-term outcomes for people living with MS.

In the 2013 My MS My Needs survey, we discovered a postcode lottery of treatment, care and support, with apparent shortcomings and disparities in the services offered both across the UK and within Wales.

This year, we undertook a second survey to build on this research. This data provides an unparalleled insight into the challenges that still remain for people living with MS when accessing vital services and support to manage their condition.

Our research has shown us that, while some improvements have been made, we still have some way to go to ensure that people living with MS are able to access the right treatment at the right time, no matter where they live in Wales.

Results from the survey in Wales show that 49% of respondents who could potentially benefit from taking a DMT are doing so (an increase from 30% in 2013). While this increase is positive we still lag behind England (56%), Scotland (57%) and Northern Ireland (77%).

We must celebrate the improvements that have been made and maintain this momentum. We must work with decision makers at local and national levels to ensure that people with MS across Wales have equitable access to quality services, so they can be in control of their health and care and live full and independent lives.

Lynne Hughes
Director, MS Society Cymru

About MS

Over 100,000 of us in the UK have MS. It's unpredictable, and different for everyone.

It's often painful, exhausting and can cause problems with how we walk, move, see, think and feel. But it doesn't have to be this way. We're driving research into more – and better – treatments. For everyone.

Together, we are strong enough to stop MS.

Strength in numbers

We conducted a survey of 11,024 people across the UK with MS between February and April 2016, making this the largest collection of patient-reported data from the UK MS community to date.

75% of respondents completed a paper-based survey, sent out to MS Society members, and 25% responded through an email link via the MS Register and Shift MS. Because of age and gender bias in our sample, the data has been weighted to be representative of the UK MS population.

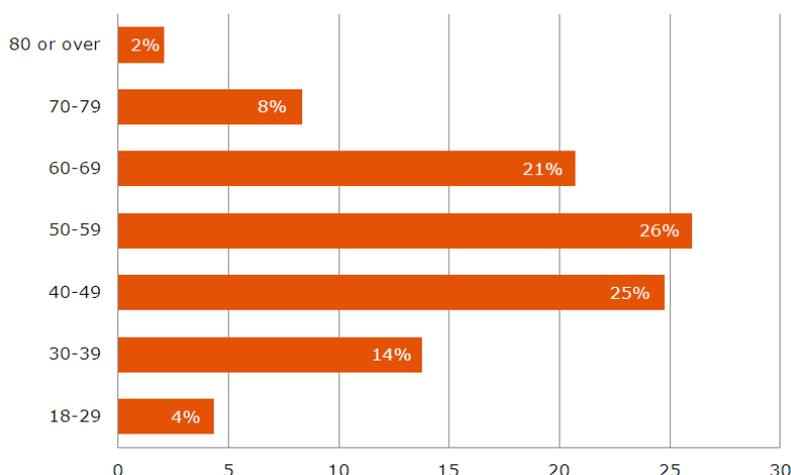
There are an estimated 4,900 people living with MS in Wales.ⁱ About 80-90% of people living with MS will initially have the relapsing remitting form of the disease (RRMS). The data presented here is from the 575 respondents who live in Wales.

74% of respondents were women, 26% men. Most were aged 50 to 59 years, and 55% were diagnosed more than 10 years ago. 45% of respondents had relapsing remitting MS.



3/4 of respondents were women

Figure 1: Age of respondents



This report focuses on the health and care aspects of the survey. Many of the figures cited are the proportion of people with a given need who said that this need was met, that is, the number of people who answered 'Yes' to a specific question, divided by the number of people who answered either 'Yes' or 'No, but I needed to'.

Key findings

- ▶ In Wales, 49% of respondents who could potentially benefit from taking a disease modifying therapy (DMT) are doing so (an increase from 30% in 2013). While this increase is positive we still lag behind the rest of the UK.
- ▶ Wales was the first UK nation to approve the symptom management treatment Sativex in 2014, yet only 1% of respondents are taking it.
- ▶ Recent access to health professionals and the right information are key to access to a DMT. 81% of people who had access to MS specialists and the right information in the past 12 months are taking a DMT. Only 20% of those who haven't accessed any of these services in the past 12 months are taking a DMT.
- ▶ 75% of respondents had their need for access to a neurologist met (an increase from 72% in 2013), but this is lower than the rest of the UK: 85% in Scotland, 86% in England and 89% in Northern Ireland.
- ▶ 81% of respondents saw an MS nurse within the past year. 87% of these people saw their MS nurse in a hospital setting
- ▶ 86% of respondents had not been offered a care plan or care plan review by their health professionals.
- ▶ 18% of respondents answered "not at all" when asked if they felt that the professionals who help plan their care worked well together.
- ▶ The most common key contact for health care and support in relation to MS was a MS nurse (59%) Only 16% of respondents listed their GP as their key contact for healthcare and support in relation to their MS.
- ▶ 29% of respondents required support to remain physically active in the last 12 months but had not received any support, or hadn't received enough.
- ▶ 28% of respondents said that they had needed emotional support in the past 12 months but hadn't received any help or support, or hadn't received enough.
- ▶ 43% of respondents have seen a specialist about continence advice in relation to their MS in the past 12 months.

Treat Me Right

Access to effective treatments is the top priority for people living with MS in Wales. It is our number one goal to ensure that people living with the MS have access to effective treatments to reduce relapses and slow disease progression, until the day we can stop MS.

Access to disease modifying therapies

There are now 11 disease modifying therapies (DMTs) licensed for relapsing forms of MS, all with different efficacies, side effects and methods of administration. They 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 outcomes. ⁱⁱ

All figures related to DMTs are calculated among those who could benefit from these treatments (i.e. those with relapsing remitting MS or secondary progressive with relapses).

The Association of British Neurologists guidelines for prescribing DMTs recommend that decisions about treatment should be jointly taken by the person with MS and their neurologist, with treatment starting as early as possible after diagnosis.

For people living with relapsing forms of MS, early and effective treatment presents the best chance of preserving brain and spinal cord tissue during the course of the condition.

The first DMTs made available for treating MS, beta interferons and glatiramer acetate, have been available through the Risk Sharing Scheme since 2002. The scheme was set up to assess the long-term effectiveness of these treatments, with results so far indicating that they reduce disability progression and are cost effective for the NHS. By preventing relapses and disability progression, people living with MS should be able to take greater control of their condition and their lives, directly and indirectly improving physical, economic, emotional and social outcomes.

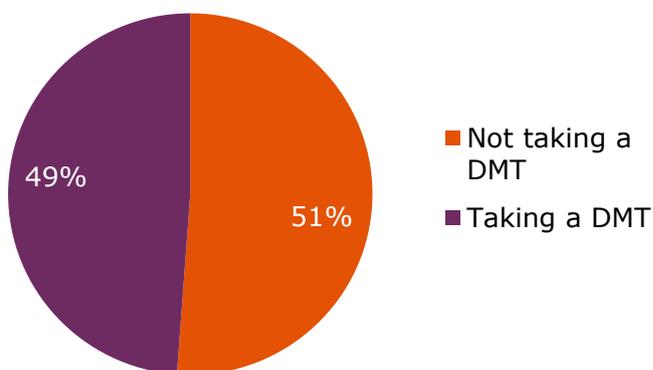
Access to treatment and services helps people living with MS manage their condition, identify early signs of complications and put in place prevention and treatment strategies to avoid unscheduled hospital admissions. ⁱⁱⁱ

With the increasing number of treatment options, it's more important than ever that people living with MS are supported to make choices about their treatment, and can access the best treatment for them, regardless of where in Wales they live.

In 2013, our survey found that access to DMTs for people with relapsing forms of MS in the UK was low (40% across the UK) with Wales having the lowest rate - just

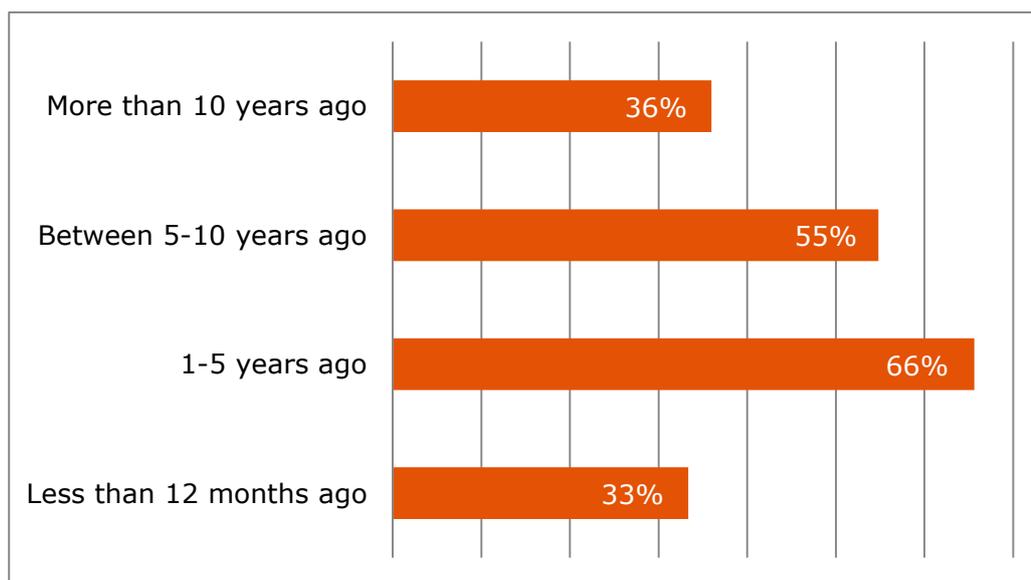
30%.^{iv} It is encouraging to see that the proportion of people receiving DMTs in Wales has risen to 49% in 2016.

Figure 2: Access to DMTs in Wales



This increase in DMT uptake reflects a significant positive improvement in MS healthcare in Wales. This is likely to be linked to the newer treatments that have become available on the NHS, which are judged to be more effective and easier to take. However, access to DMTs among those who could benefit in Wales remains the lowest in the UK (England 56%, Scotland (57%) and Northern Ireland (77%).

Figure 3: Access to DMTs by time since diagnosis



People diagnosed recently are more likely to be taking a DMT than those who were diagnosed some years ago. 66% of people diagnosed between 1 and 5 years ago are receiving a DMT, compared with just 36% of those diagnosed more than 10 years ago.

There are several drivers that make it more likely that a person will be taking a DMT. Access to health professionals and the right information are key; 81% of people who have access to MS specialists and the right information in the past 12 months are taking a DMT, whereas only 20% of those who haven't accessed any of these services in the past 12 months are.

Access to symptom management therapies

There are several symptom management therapies (SMTs) specifically licensed to treat MS, which can make a significant difference to the day-to-day lives of those living with MS. These treatments can help with problems such as spasticity and walking or an overactive bladder. Licensed SMTs for MS include Sativex, Fampyra and Botox.

Wales was the first UK nation to approve Sativex for routine use on the NHS in 2014. Speaking at the time, the then Health Minister Professor Drakeford said: "Following the appraisal of Sativex by the All Wales Medicines Strategy Group (AWMSG), I am pleased to announce we will be making the medicine available on the Welsh NHS to those who need it. "I hope this decision will help ease the suffering of some of those who have to live with the reality of MS everyday".^v

Yet, two years after its approval, our survey showed that only 1% of respondents are currently taking Sativex.

Recommendations

- ▶ Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis within six weeks and again within six months.
- ▶ Once medicines are approved by NICE or the AWMSG, Local Health Boards should make them readily through Local Health Board formularies without delay.
- ▶ People living with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.

Access to the right support

People living with MS 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.

Published earlier in 2016, the NICE Quality Standard for MS recommends 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 annually.^{vi} 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.

Respondents to our survey were asked to indicate their need for and access to support from various professionals over the past 12 months.

With an increasing number of treatments available, each with different support and monitoring requirements, it is vital that people with MS are fully supported to make an informed choice about their treatment. Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis with a specialist within six weeks and again within six months. However, anecdotal feedback from the MS community and clinicians in Wales suggest that timely follow up is becoming more and more difficult resulting in less time to assess people effectively, discuss treatment options and manage risks. With this added pressure on the case loads of MS neurologist and specialist nurses, people living with progressive MS tell us they feel they are being pushed further down the waiting lists with little or no support.

MS nurses

MS specialist nurses play a crucial role in the care and support of people with MS. Their role and responsibilities can be wide-ranging and varied. Typically, these include providing information and support on how to best manage MS and on DMTs, initiating and monitoring treatment for people with relapsing forms of MS, providing psychological support and co-ordinating care.



Over **1/2** identified their MS Nurse as their key contact for healthcare and support in relation to their MS.

88% of people who needed to see an MS nurse were able to in the past 12 months, which is much the same as the other nations of the UK. Given that Public Health Wales identify that there is an overall shortage in Wales of between seven and nine MS specialist nurses it's no surprise that 11% of respondents had not seen an MS nurse but felt they had needed to.

Given that people living with MS regularly cite their MS nurse as their key contact for treatment, care and support. (59% of respondents identified their MS nurse compared with 16% who listed their GP) it is vital that this shortfall is addressed urgently.

Neurologists

NICE recommends that all people living with MS have a comprehensive review of all aspects of their care at least once a year, and that this review is carried out by healthcare professionals with expertise in MS. This review can be led by a neurologist or an MS specialist nurse, but should draw on expertise from professionals across a multidisciplinary team. It should be tailored to the needs of the person living with MS and cover symptoms, the disease course and general health and provide an opportunity for the person with MS to discuss how they feel they are managing their condition. If a person is on a treatment, a comprehensive review could also be used to assess how it is working, typically including an MRI scan.

There are only four neurologists who specialise in MS in Wales and all four are based along the M4 corridor in South Wales. The only other provision comes from an MS specialist neurologist based at the Walton Centre in Liverpool who covers North Wales.

In 2013, 72% of respondents reported that they had their need to see their neurologist met. Our survey this year showed a 3% increase, with 75% of respondents saying that they had this need met. 17% had not seen a neurologist in the past 12 months but felt that they needed to. Our results show that the more recently a person with MS was diagnosed the more likely they are to have seen a neurologist in the 12 months. Unsurprisingly, those diagnosed within the past 12 months are the most likely to have seen a neurologist (92%), compared with only 44% of those diagnosed 10 years ago or more. This pattern though is not replicated with seeing an MS nurse.

Public Health Wales identify that there is a significant shortage of consultant neurologists in Wales and that some areas within Wales are not only poorly served by the number of consultants per head of population but have a non-existent specialist nurse input.^{vii}

We are aware that there is no short-term fix to boost the number of neurologists in the system. But given that there will be added pressure in an already stretched service as new treatments become available (including the first for progressive forms of MS), there is a need to urgently consider different service models and delivery in Wales.

In line with Welsh Government policy to provide more care in the community we would expect to see a shift of care from a hospital to community-based services^{viii}, yet overwhelmingly 87% of respondents who saw their MS nurse did so in a hospital setting, a 7% increase from 2013.

Professionals across the team

We also asked survey respondents about their access to other types of support including physiotherapists and continence professionals. Building capacity across a multidisciplinary team is another way of ensuring that people living with MS can access the support they need. This will become increasingly important as health and social care are further integrated, particularly if these services are moved from an acute to a community setting.

Continence advice and support

Many people living with MS experience bladder and urinary problems, including incontinence and infections. Continence advisers can provide people living with MS with information, for example about products and treatments for bladder problems, and confidential advice.

In Wales, 75% of respondents who had required specialist continence advice had received it. However, more than one in 10 (14%) people had not received this support despite needing to.

Physical wellbeing

48% of respondents had seen a physiotherapist in relation to their MS within the past year, but nearly one in five people (18%) had not seen a physiotherapist and felt that they needed to.

For those who did see a physiotherapist, the source of this support varied, with the largest number of people receiving support from the NHS (40% of respondents). 5% received physiotherapy through private health care, another 5% through a charity or voluntary organisation and 1% through another source.

Physiotherapy can have a significant impact on a person's rehabilitation after a relapse, or can improve movement and mobility for someone living with disability as a result of MS. Timely access to evidence-based and appropriate physiotherapy should be a basic entitlement, available for everyone living with MS in Wales who could benefit.

Other services that support people living with MS to remain physically active are important in helping them to remain healthy and independent in their day-to-day lives. Research suggests that support to remain physically active has resulted in a decrease in GP and hospital consultant visits and reduced hospital bed days for people living with MS.^{ix}

More than a quarter (29%) of respondents said that they needed support to remain physically active but had not received any. For those who had received support,

in the last 12 months
1/5 of respondents



required support to remain
physically active

...but had not received any

sources varied – 11% of all respondents received it from the NHS, 7% from their local council, 6% from a charity or voluntary organisation and 7% from somewhere else. This suggests that statutory services need to do more to support people with MS to remain physically active.

Emotional wellbeing

Half of people living with MS experience anxiety and half experience depression, with many experiencing both.^x Moreover, there is a strong link between mental and physical health – a study in England in 2012 found that, £1 in every £8 spent on long-term conditions was linked to poor mental health.^{xi} Ensuring people living with MS can access emotional support is vital, but 28% of respondents said that they had needed emotional support in the past 12 months but hadn't received any help or support, or hadn't received enough.

As with access to support to remain physically active, access to and the sources of emotional support from varied.

18% of respondents indicated they had received emotional support in the past 12 months; 13% of all respondents received it from the NHS, 2% from a charity or voluntary sector organisation, 2% through a private organisation and 3% from somewhere else.

Recommendations

- ▶ People living with MS should be offered a comprehensive review of their care at least once a year that draws on expertise from a multidisciplinary team.
- ▶ People living with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
- ▶ People living with MS should be offered support from a multidisciplinary team, including emotional support, continence advice and support to remain physically active.

Care planning

NICE guidelines state that people living with MS should have access to a single point of contact who coordinates access to care and treatment across a multi-disciplinary team.^{xii}

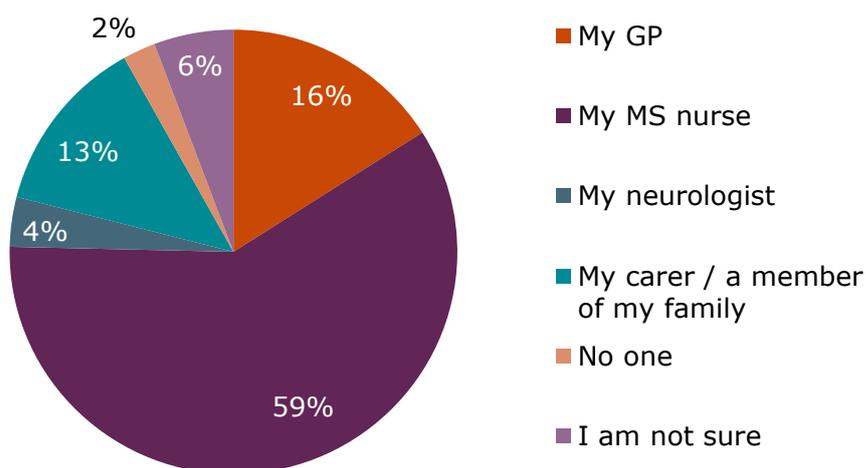
Care planning and care co-ordination has a vital role to play in ensuring that people living with MS can access all the support they need to best manage their condition.

The Welsh Government’s Neurological Delivery Plan^{xiii} recognises that this care planning process for people with long term neurological conditions is fundamental. It states: “The care planning process needs to be well co-ordinated to ensure the individual is receiving the right care at the right time in the most appropriate setting to enable them to live as independently as possible. This involves a multi-disciplinary and integrated approach, ensuring a person’s individual treatment and support needs, such as access to information, are assessed, recorded and met. Personalised care plans should be produced in collaboration with individuals.”

Care coordination

For our respondents, the most common key contact for health care and support in relation to MS was a specialist nurse (59%), perhaps unsurprisingly given the typical functions of their role, followed by a GP (16%).

Figure 4: Key contact for health care and support



People who listed their primary contact as a specialist nurse were most likely to feel they had their information needs met. This demonstrates the critical role that specialist nurses can play in helping people with MS make decisions about their care and treatment.

Despite this, our survey found that overwhelmingly people in Wales reported that they had not been offered a care plan or a review of their care plan by their health professional in the past 12 months (86%). For people to feel fully supported and empowered in their care, the MS multidisciplinary team must consist of health and social care professionals working with the person living with MS to achieve the best outcomes.

When asked if they felt that the professionals who help plan their care worked well together, 18% of our survey respondents answered “not at all”, while 15% responded “completely” and 34% “to some extent”.

Recommendations

- ▶ People living with MS should be offered a care plan or care plan review – this presents a key opportunity to involve people in their care.
- ▶ People living with MS should have a single point of contact for their care, who coordinates care across a wider multidisciplinary team.

Conclusions

Our research has shown us that while some improvement has been made, we still have some way to go to ensure that people living with MS are able to access the right treatment at the right time, no matter where they live in Wales.

It is encouraging to see that the number of people receiving DMTs in Wales has risen since 2013. However, access to DMTs among those who could benefit in Wales remains the lowest in the UK.

Following the election of the fifth National Assembly for Wales in May 2016, the Welsh Government pledged to develop a New Treatment Fund that will “support the early introduction of the most innovative, high-cost medicines recommended by the National Institute for Health and Care Excellence (NICE) and the All-Wales Medicines Strategy Group (AWMSG)”.^{xiv}

We welcome the development of the New Treatment Fund in particular given the commitment by the First Minister Carwyn Jones to ensure that it will benefit “not just cancer, but other conditions such as cystic fibrosis and multiple sclerosis”.^{xv}

People living with MS require access to treatment to manage their condition to improve their outcomes. There are now 11 DMTs licensed for relapsing forms of MS approved for use. But as we know only too well, they are not all equally available across Wales.

With an increasing number of treatments options, it’s more important than ever that people living with MS can access the best treatment for them, regardless of where in Wales they live. The unacceptable delays in accessing new treatments are caused by a variety of issues, including the under resourcing and lack of infrastructure to monitor a new treatment or drug and the process that Local Health Boards go through to add a new drug onto their formulary.

We will be working alongside the Welsh Government, MS teams, NHS managers and other associated stakeholders to make our recommendations a reality for everyone living with MS in Wales.

1. Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis within six weeks and again within six months.
2. Once medicines are approved by NICE or the AWMSG, Local Health Boards should make them readily available through Local Health Board formularies without delay.
3. People living with MS should be given the information, skills and confidence to play an equal role in making treatment decisions.

4. People living with MS should be offered a comprehensive review of their care at least once a year that draws on expertise from a multidisciplinary team.
5. People living with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
6. People living with MS should be offered support from a multidisciplinary team, including emotional support, continence advice and support to remain physically active.
7. People living with MS should be offered a care plan or care plan review - this presents a key opportunity to involve people in their care.
8. People living with MS should have a single point of contact for their care, who acts as coordinates care across a wider multi-disciplinary team.

Our commitment

We will use evidence and insight and work with others to support implementation of these recommendations by:

- ▶ Providing reliable information and support to enable people living with MS to take control of their lives.
- ▶ Supporting people living with MS to connect with other people with the condition.
- ▶ Funding the best, most relevant research to enable new treatments to reach people with living MS as quickly as possible.
- ▶ Campaigning for fair and appropriate access to treatment, care and support for every person living with MS.



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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.

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Contact us

MS National Centre 020 8438 0700
info@mssociety.org.uk

MS Helpline Freephone 0808 800 8000 (weekdays 9am-9pm)
helpline@mssociety.org.uk

Online

mssociety.org.uk www.facebook.com/MSSociety
twitter.com/mssocietyuk

MS Society Scotland

0131 335 4050
msscotland@mssociety.org.uk

MS Society Northern Ireland

028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru

mscymru@mssociety.org.uk

Multiple Sclerosis Society.
Registered charity nos. 1139257 / SC041990.
Registered as a limited company by guarantee
in England and Wales 07451571.

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