



Neurology now

The case for a new approach to neurology services



About MS

Multiple sclerosis (MS) is a neurological condition that affects more than 130,000 people in the UK. It's unpredictable and different for everyone. It's often painful, exhausting and can cause problems with how people walk, move, see, think and feel.

About the MS Society

We're the MS Society. We're here by your side through the highs, lows and everything in between. Together we fund world-leading research. We provide information and services so that everyone can live well with MS. We make our voices heard and campaign for everyone's rights. And we support one another so no one has to feel alone.

**Together we're a community
and together we'll stop MS.**

Contents

Introduction	4
About this report	6
Recommendations	7
1. The problem pre-pandemic	9
2. What's been done to improve neurology services?	14
3. The impact of the pandemic on people living with MS	17
4. How the pandemic compounded existing challenges	23
5. What does the future look like for people with MS if nothing is done?	28
6. Opportunities for change and our recommendations	33
7. Nation-specific recommendations	44
References	48

Introduction

Despite 1 in 6 people living with a neurological condition in the UK, neurology services have been stretched, underfunded and overlooked for years. This can't continue. Too many people with multiple sclerosis (MS) weren't getting the vital support they needed before the pandemic, now things are even worse.

MS can be relentless, painful and disabling. 1 in 2 people with the condition told us that not getting specialist support during the pandemic had contributed to their symptoms getting worse. Nearly a third experienced appointments with their MS service being cancelled or delayed.

In some areas people with MS get great care and feel supported by their team. But this isn't the case everywhere in the UK, especially when services are more stretched than ever. Healthcare professionals are doing their absolute best to support people with MS, but there are simply not enough of them.

In many ways the issues facing neurology are a microcosm of those facing the wider NHS. Waiting times continue to grow as the impact of the pandemic casts a lengthening shadow over the future, exhausted healthcare professionals try their best to catch-up, and unwarranted variation widens rather than narrows.

In other ways, the specifics of neurology can help develop some solutions to these seemingly unmanageable problems. It can show the value of thinking at speciality-level rather than simply lumping everything together under the umbrella of 'long-term conditions', which has sadly been the norm in major NHS policy documents of recent years.

“At one point, it became almost like my part time job just calling up and waiting for an answer, and being redirected from person to person trying to get an appointment”

Ayad, 24, living with progressive MS

With MS for example, people live with the condition for many years and good care can require up to a dozen services working together. It's the kind of condition that requires long-term, joined-up thinking across the NHS and other systems, offering a template for more integrated care across the whole population.

Getting neurology services right can help local NHS decision-makers meet many of their other targets. For example, we know that there are very high levels of unmet need for emotional and mental health support among people with neurological conditions. Good provision and referral pathways within neurology can go a long way to help local NHS regions deliver better in these areas overall.

Lastly, conditions like MS and Parkinson's are relatively stable over a number of years. Investment to support people to learn to self-manage their condition and take more control over their care (especially through technological innovation) is likely to be extremely good value for money. MS symptoms present relatively early in people's lives, and the condition has a long duration and a significant impact on employment. This is why MS is considered one of the costliest conditions in economic terms. And it's also why early, proactive intervention should be particularly attractive to Governments and policy makers.

With the right support and funding, there are huge opportunities for neurology services to innovate and deliver better care to people with neurological conditions.

Neurology services must be prioritised as the NHS rebuilds itself after the COVID-19 pandemic. We urgently need resourced plans to restore and improve neurology services in each UK nation, harnessing innovation, data and technology to ensure everyone with MS has access to the right professionals and treatment at the right time.

“The main problem locally is the lack of services - MS nurse access in particular. My GP is really good, but has gone on sabbatical as they aren't well, so I don't have that support now either. I have learnt a lot about how to manage my own MS over the years.”

Becky, 39, living with relapsing remitting MS

About this report

This report focuses on MS as an example of the issues facing people with neurological conditions more generally – before, during and after the pandemic.

We make use of our survey data from key points over the last three years:

- A major survey of people with MS from spring 2019.
- Snapshot surveys of both people living with MS and healthcare professionals in the summer of 2020 around the initial and second wave of the pandemic.
- Snapshot surveys of both people living with MS and healthcare professionals in August 2021, capturing views and experiences at this very different stage of the pandemic and beyond.

Using these findings and wider sources, the report paints a picture of the impact on people with neurological conditions of historic under-prioritisation of neurology services (Chapter 1). This is in spite of a number of improvement initiatives and underwhelming Government plans across the four UK nations (Chapter 2).

We go on to explore how these issues have been cruelly exacerbated by the pandemic (Chapters 3 and 4) and the shadow this is likely to cast over services and their patients into the future (Chapter 5).

Most importantly, Chapters 6 and 7 look at the key opportunities ahead, and ways UK Governments and the NHS can respond to this situation to create the better future that people living with neurological conditions deserve.

Recommendations

The recommendations outlined below are directed at all UK Governments and the NHS in all four nations. Nation-specific recommendations are outlined in Chapter 7.

Governments

1. All four nations must develop and resource national plans to restore and improve neurology services by working with neurological charities and patients. The plans should:
 - a. Ensure that people with neurological conditions aren't left behind in the wake of the pandemic.
 - b. Set out how the NHS will commission and deliver comprehensive, personalised and holistic physical and mental healthcare services for people with neurological conditions.
 - c. Build a thriving, sustainable health and care neurology workforce.
 - d. Address the current, unwarranted variations in treatment, care and support that people with neurological conditions still experience every day.
2. These plans should be accompanied by clear outcome measures agreed with clinicians and patients, and included in relevant accountability frameworks to ensure progress at both national and local level.
3. The 2021 Comprehensive Spending Review must include a multi-year funding envelope for training more neurology professionals.

NHS

The NHS in all four UK nations must:

1. Support providers to offer a range of self-management tools to help people with neurological conditions manage their condition and symptoms while they're waiting to be seen. This should utilise digital tools and aids, and targeted face-to-face support to reduce digital inequalities.
2. Commission appropriate community rehabilitation services for people with neurological conditions. And, in the longer-term, create an expanded right to rehabilitation on the NHS which allows people to access support to maintain their health and wellbeing and prevent deterioration.
3. Ensure that every patient with a neurological condition has access to a specialist nurse, working within a team of professionals, with the skills to meet their needs.
4. Explore opportunities to upskill lower-banded staff in neurology services to enable them to take on more clinical tasks along the pathway.
5. Ensure all MS teams have a sufficient number of administrative staff to free-up clinical staff to deliver clinical care.
6. Ensure neurologists provide timely advice to GPs to avoid referring people to neurology services if they don't need to be. This will free-up time for those services to support people who need it.
7. Develop data-driven regional plans for neurology services. This should include plans to encourage the adoption and spread of innovative models of care.

1. The problem pre-pandemic

NHS neurology services are usually the key gateway to the right support for people with MS: from the very start of their journey, being diagnosed by a consultant neurologist, to starting on therapies to slow the progression of disability or manage painful symptoms, to discussing self-management with a specialist healthcare professional, and more.

As the following chapters demonstrate, neurology services have been under-prioritised and under-funded for many years, despite 1 in 6 people across the UK living with a neurological condition.¹ The level of unmet need for treatment, care and support for people with neurological conditions is outlined in this report.

Access to services and treatment

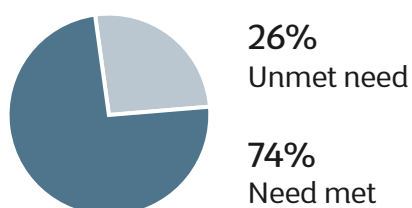
People with disabilities and long-term conditions like MS, face unequal access to, and benefit less from, health services, employment opportunities, and additional support.² Many people with disabilities live in poverty, which is associated with worse health outcomes and life expectancy.³ Scope's Extra Costs Commission estimated average weekly additional costs for people with neurological conditions are £200 per week, yet at that time (2015/16) the average award for disability benefits was around £360 a month.^{4,5}

Prior to the pandemic, there was high unmet need for therapies and treatments to manage debilitating symptoms of MS, and support to manage the emotional impact of the condition.

Figure 1 shows the findings of an MS Society survey of over 8,000 people with MS in the UK in 2019.⁶ This is supported by the recently published NHS England Getting It Right First Time (GIRFT) report which found significant unmet demand for neurology services from people with neurological conditions.⁷

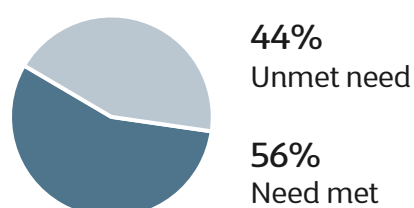
Figure 1: Access to services to manage MS symptoms when needed

Specialist continence support



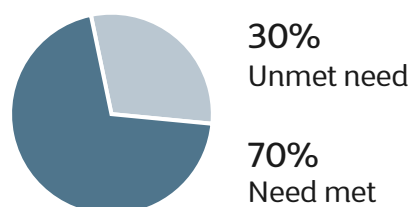
Answered by 3,862 respondents

Emotional support



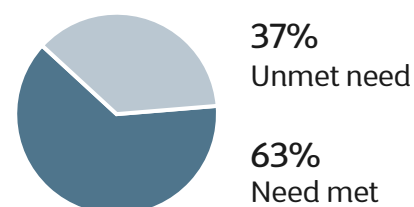
Answered by 3,565 respondents

Physiotherapy



Answered by 5,109 respondents

Support to stay physically active



Answered by 5,376 respondents

The same MS Society survey found the proportion of people on a Disease Modifying Treatment (DMT) to slow progression of disability, varied widely across the UK. There was a 28-percentage point gap between the nation with the best access and the nation with the worst. In Northern Ireland 81% of people eligible for treatment were on one, whereas in Wales this was 52%. There was also significant variation within nations: in England access to treatment varied from 52% to 67% in different regions.

The survey also found access to MS nurses and neurologists varied. 89% of respondents needed, and had been able to access, an MS nurse in the preceding 12 months. However, this varied across UK nations from 93% to 75%. This isn't explained by differing needs of people with MS across the country, but reflects unacceptable variation in access to services.

In recent years, DMTs have become available to some people with progressive forms of MS for the first time, and we expect more to become available over the coming years. This should be a cause for celebration. Yet, the evolution of treatments will place new demands on neurology services.⁸ Many MS professionals anecdotally tell us they're worried about how they'll provide access to a newly eligible population of people living with progressive MS when their services are already stretched.

Pre-pandemic, people with other neurological conditions were facing similar challenges accessing the neurological treatment and care they needed. The 2019 Neurological Alliance Patient Experience Survey found that 55% of respondents had experienced delays in accessing healthcare, and 29% of people who needed to see a neurologist had to wait more than 12 months for an appointment.⁹

“I can't access the services I need – I have to find and pay for services myself, like physiotherapy. It feels like there's just a lack of options for me due to my progression. Wiltshire doesn't seem to have anybody that specialises in MS at all, Swindon, Salisbury, no one appears to have a neurology department. People have to travel to Southampton to see a specialist – it's quite concerning.”

Caroline, 60,
living with MS

Workforce crisis

Across the UK, there's a workforce crisis in neurology.

The NHS England GIRFT report describes a shortage of MS-specialist neurologists in England, and adjusted for the population, France and Germany have over 7 neurologists for every 2 that the UK has.^{10,11} This shortage is reflected in neurologists' extremely large caseloads: an audit of 51 UK MS services in 2020 suggested a sensible caseload for a neurologist would be 615 people with MS, but found on average neurologists had caseloads of 1, 815 patients.¹²

For MS nurses, the same audit found average caseloads of 1,757 per nurse, far higher than the 315 per nurse ratio which is considered ideal by the MS Trust.¹³ GIRFT also found marked variation in access to neurology nurses between regions in England, ranging from 5 to 26 nurses per million people.¹⁴ Many MS nurses were recruited in the early 2000s when the Risk Sharing Scheme was established. Anecdotally, we understand that this demographic bulge means that many are now thinking about retirement, casting a shadow over the future sustainability of services. Estimates suggest at least 200 more MS nurses and over 100 more neurologists are needed in the UK for MS service caseloads to be manageable.¹⁵

Alongside a shortage of neurologists, there are limited opportunities to develop neurology specialists among trainees. In Northern Ireland, just 2 out of 138 core medical training places are attached to neurology each year – meaning addressing the workforce shortages will take many years.¹⁶

“... they obviously want to do the best job they can and not being able to see your patients is difficult and they're trying to do what they can do. [Staff] don't get paid enough, they don't have enough time, there's not enough staff, there's not enough things in place to help them do that job more efficiently. And [the government] need to create that.”

Roxy, 33, living with relapsing remitting MS

There's a shortage of physiotherapists in all parts of the UK. NHS England project the need for an additional 5,000 physiotherapists by 2023, alongside increased numbers of dieticians and occupational therapists.¹⁷ Anecdotally, neurology professionals tell us that there aren't enough allied healthcare professionals with neurology expertise to meet their patients' symptom management and rehabilitation needs.

While the workforce crisis is taking a heavy toll on people with neurological conditions, professionals are also struggling to cope with the rising demands of their caseloads. The 2020 audit of 51 UK MS services mentioned above, found 83% of services were very challenged or struggling to cope with their workload.¹⁸ More recently, our August 2021 survey of professionals supporting people with neurological conditions found 63% were finding it extremely or very challenging to provide a good service to everyone on their caseload.¹⁹

It's clear we need a long-term strategy to attract, recruit and retain the neurology and allied health professionals needed to deliver holistic care to everyone with MS on a sustainable basis, but that will take time. Chapter 6 of this report sets out opportunities to move to new workforce models now to manage the immediate capacity challenge services are facing and improve care for people with MS. Any long-term workforce strategy should be tailored around new workforce models, rather than simply continuing to do things as they've always been done.

83%

of services were very challenged or struggling to cope with their workload.

63%

were finding it extremely or very challenging to provide a good service to everyone on their caseload.

2. What's been done to improve neurology services?

England

We welcome NHS England's recognition of the need to improve care and services for people with neurological conditions. Their GIRFT report on neurology makes a series of recommended actions for themselves, hospital Trusts and others to help neurology services recover after the pandemic and become more sustainable in the long-term.

However, there remains a lack of prioritisation of neurological conditions at national level. These weren't mentioned, let alone prioritised, in the NHS Long-term Plan or the Interim People Plan.²⁰ Without national incentives or standards against which local health bodies are measured, neurology won't realistically see the benefit of other opportunities for change set out in this report (see Chapter 6).

There's been positive progress towards establishing agreed standards of care and best practice. NHS England RightCare published a toolkit for Clinical Commissioning Groups on improving care for progressive neurological conditions, in 2019. Since then, clinicians and patient groups have developed a series of Optimum Clinical Pathways for neurological conditions including MS, as part of NHS England's Neuroscience Transformation Programme. The MS pathway sets out what good care looks like from diagnosis through to advanced stages of the condition (and is due to be published soon).

Significant action now needs to be taken to test and roll-out that pathway, and implement the recommendations from all of the various initiatives above, in order to see benefit for people with neurological conditions.

Scotland

In 2020, the Scottish Government published a framework for improving neurology services. It includes addressing many of the issues people affected by MS have told us about; improving coordinated and personalised care, support for self-management, and timely access to care and support services. The framework detailed a series of high priority aims with a provisional deadline of March 2021. If these aims were met, they would provide the required infrastructure to underpin the entire framework. Achievement of these priorities will have been impacted by the pandemic, but it's unclear to what extent. At this time, there's been no progress report or revised implementation timetable.

Northern Ireland

A review of neurology services is underway to assess what's already in place and to identify priority areas for reform and development. This review has identified that new referrals outnumber outpatient appointment capacity (averaging 18,500 new or first appointments per year versus capacity to see 12,000 patients). The Review Team is identifying measures that will present solutions in the short-term, such as offering junior doctors additional speciality training places and creating more opportunities for joined-up working.²¹

The review is expected to deliver recommendations for change, an implementation and investment plan, and framework setting out the future of neurological services until 2035. This was expected in March 2020, but the review was halted due to the pandemic and recommenced in June 2021.

Wales

A decade ago, the Welsh Government published the Neurological Conditions Delivery Plan (updated in 2017). The aim was to provide direction for improving neurology services across Wales.²² However, an inquiry led by the National Assembly for Wales Cross Party Group on Neurological Conditions found progress towards this goal hasn't been at the required speed.

With the newly elected Government in May 2021, condition specific Delivery Plans are now being replaced by brief top-level Quality Statements sitting under the National Clinical Framework. The Wales Neurological Alliance is concerned that, without a comprehensive strategy, people with neurological conditions will have poorer and less personalised care. They're also concerned that the current model won't have the appropriate powers and authority to hold health boards and NHS Trusts to account. This may prevent clear and consistent pathways of care being available to all people living with neurological conditions in Wales.

3. The impact of the pandemic on people living with MS

The pandemic compounded existing challenges for neurology services and people with MS. It's underlined the need for urgent action to ensure a sustainable future. In May 2020, through the UK MS Register, we asked people living with MS how they were coping. Since the pandemic started, a third (32%) of respondents said they had healthcare appointments cancelled or delayed, and nearly half (45%) had appointments via phone or video call.²³

When the survey was repeated in August 2020, a third (34%) of people said their MS or symptoms had worsened since before lockdown. It's clear that not being able to access healthcare services was a key contributing factor. Just over half (51%) of those who said they had seen a deterioration in their MS or symptoms, thought the disruption to services they normally received had contributed to their worsening symptoms.²⁴

In a more recent survey of 746 people living with MS conducted in August 2021, of those (51%) who said their symptoms had worsened since the beginning of the pandemic, 53% said a reduction in specialist support contributed to their symptoms getting worse to some or great extent. The survey also found that a quarter of respondents who needed to see an MS nurse or neurologist in the past 12 months weren't able to.

“I was due to have another appointment in early August 2021, but it got postponed and now I've heard it will be end of September 2022, although I'm supposed to see someone on a yearly basis, there's obviously a really long delay due to COVID-19.”

Becky, 39, living with relapsing remitting MS

It's understandable that appointments with MS services were delayed or cancelled during the pandemic, with almost a third (29%) of respondents to our August 2021 survey reporting this. However, it's particularly worrying that over half (51%) of respondents who had experienced cancellations or delays hadn't received any information about how to self-manage their symptoms and/or condition even though they would have liked to. This represents a major missed opportunity given the potential of self-management approaches (set out in Chapter 6).

Disease modifying treatments (DMTs)

The pandemic has also affected access to DMTs, which are a vital form of MS care as they slow the progression of MS disease in eligible patients.

DMTs need to be started as soon as possible after diagnosis, and require regular assessment and monitoring by MS professionals to ensure any side effects are identified and managed. Prolonged delays between treatment doses, or abruptly stopping treatment, can be harmful.

Guidance on DMTs at the start of the pandemic

At the start of the pandemic, the Association of British Neurologist (ABN) issued guidance about the significantly increased risk of COVID-19 infection they thought was likely to be associated with certain DMTs namely, alemtuzumab, cladribine, ocrelizumab, and fingolimod.²⁵ They cautioned neurologists against starting patients on some of these treatments, and recommended that people already taking some of them delay their next dose/s while COVID-19 cases were high.

It is important to note that the ABN updated their guidance throughout the pandemic as new evidence emerged, so advice about specific DMTs changed across 2020.²⁶ We will look at what happened to prescribing levels in the years 2020 and 2021 (so far) below, but the picture will have been more dynamic on a month by month basis.

People on DMTs at the start of the pandemic

NHS prescribing data for England shows that overall access to DMTs for those already taking them was maintained quite well throughout the pandemic, with total levels of DMT prescribing falling only slightly from 2019 to 2020²⁷ (figures for Northern Ireland, Wales and Scotland are unavailable).

However, the pandemic did cause some delays to treatments. Responding to an MS Society survey in August 2021, 239 people with MS said they were taking a DMT. Of those, 31 (11%) said they had been told within the past 12 months that their MS treatment was delayed because of the impact of COVID-19 on their MS service.²⁸ We don't know whether these were delays in starting or continuing treatment.

People starting or switching DMTs during the pandemic

Available NHS data shows that the number of people starting a DMT in England in 2020 fell by 17% compared to 2019.²⁹ This data on the number of “new starts” includes both people switching from another DMT and those starting their first DMT. We are not able to distinguish between the two in the data available.

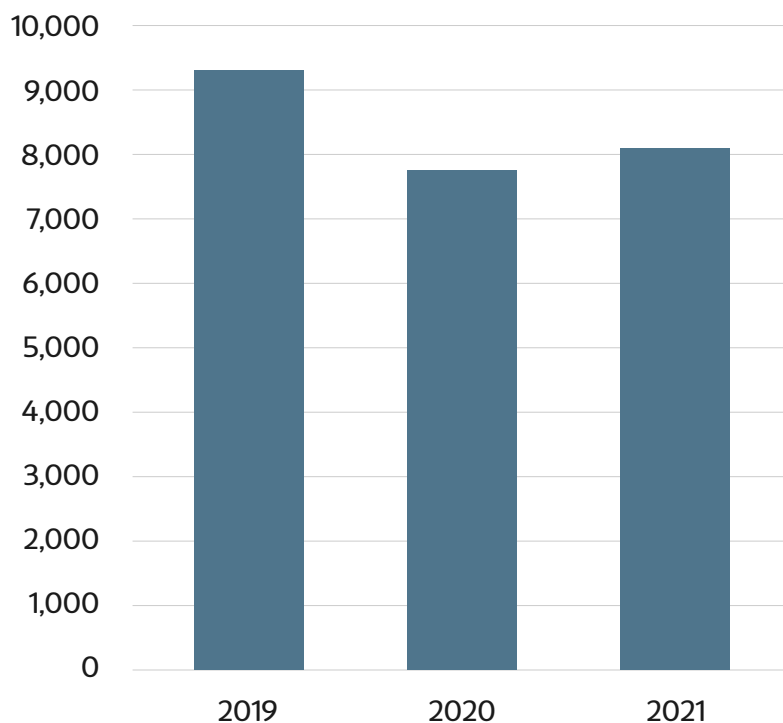
With regards people starting their first DMT, we think that in cases where neurologists would

normally have started a patient on one of the DMTs that the ABN initially advised may have an increased infection risk (see list above), most neurologists would have recommended an alternative, potentially safer DMT instead. Therefore, the 17% decrease in the number of new starts is not likely to be fully explained by people not being given an alternative option by their neurologist.

With regards people switching from one DMT to another, it is unclear what impact the pandemic had on overall numbers, if any. Some patients may have chosen to switch from one of the above DMTs to an alternative, safer DMT, in order to minimise their risk of catching COVID-19. One Europe-level study appears to show that most clinicians supported switching in general as a result of the pandemic.³⁰

If patients were being started on, or switching to, alternative treatments for the reasons outlined above, you would expect to see an increase in the number of those treatments being prescribed. NHS England data shows that the number of people starting the DMTs which the ABN issued cautions about (see list above) in 2020 fell by 31%, relative to 2019. However, the NHS data on new starts show that there was no corresponding increase in levels of the DMTs the ABN deemed safer to use in their March 2020 guidance. In fact, prescribing levels of these other DMTs fell by 5% in 2020, relative to 2019.

Given the above, it seems reasonable to conclude that the overall fall seen in the number of new starts could reflect a significant drop in people starting DMTs for the first time in 2020. Looking at the situation this year so far, available data on DMT prescribing shows new starts were still 13% lower in 2021 than in 2019 as seen in Figure 2.³¹ It is concerning that the figures have not significantly increased several months after COVID-19 restrictions ended, given how important DMTs are to slow progression of disability in eligible MS patients.

Figure 2: DMT “new starts” on the NHS in England 2019 - 21

Why might the number of people starting DMTs have fallen?

There are several likely factors behind this fall and it not possible to know for sure the relative impact of each factor. But we think it reflects a ‘perfect storm’ similarly seen in other conditions such as cancer during the pandemic. Firstly, capacity pressure on primary care meaning patients couldn’t be referred to neurology (indeed, there was a sharp decrease in neurology appointments between March and June 2020, compared to the same period in 2019.³² Secondly, similar issues in secondary care meaning those who were referred had to wait longer for a diagnosis and to start on a DMT where they were eligible. And these factors were combined with a

reluctance among some patients to seek medical advice, either due to a fear of COVID-19 infection in healthcare settings or putting increased pressure on the NHS.

People have to be 'in the system' in order to start treatment. Neurology services are now working through the backlog all of the above factors have created and we suspect there are a number of patients who have yet to present at services.

4. How the pandemic compounded existing challenges

The past year has been extremely difficult for those working in the health and care system. Neurology services have continued to provide the best care they can. But one survey in summer 2020 showed almost a quarter (23%) of MS professionals were redeployed away from their MS service, and another survey at that time found 69% of people living with MS were not able to speak with a specialist when they needed to.^{33,34}

During the peak of the pandemic in 2020 there was a sharp decrease in outpatient and inpatient neurology appointments in England (March-June) compared to the same period in 2019.³⁵ Tens of thousands additional people are now waiting to access these vital services compared to before the pandemic, and waiting times are shockingly high in some parts of the UK:

- In England, nearly 150,000 people were waiting to start treatment with a neurologist in July 2021, compared to just over 120,000 at the start of the lockdown (April 2020). Rather than decreasing as services start to normalise, the number has continued to increase month on month since May 2020.³⁶
- Waiting times vary hugely within England, from 46% of people being seen by a neurologist within 18 weeks of being referred in one region (the official national NHS target), to 93% in another.³⁷

23%

of MS professionals were redeployed away from their MS service.

69%

of people living with MS were not able to speak with a specialist when they needed to.

- In Northern Ireland as of June 2021, nearly 21,500 people were waiting for their first neurology outpatient appointment. Of those, nearly 15,500 had been waiting over a year for their first consultant-led appointment – that’s 72% waiting over a year.³⁸
- In Scotland, as of June 2021 there were over 15,500 people waiting for an outpatient neurology appointment – up from over 12,900 in December 2020.³⁹
- In Wales, in January 2020 there were over 8,000 people waiting to see a neurologist, with only 28 of those waiting over 36 weeks. At the height of the second wave (November 2020) this dramatically increased to 1,772 people waiting over 36 weeks. This number is slowly reducing, but is still significantly higher than pre-pandemic – at 875.⁴⁰

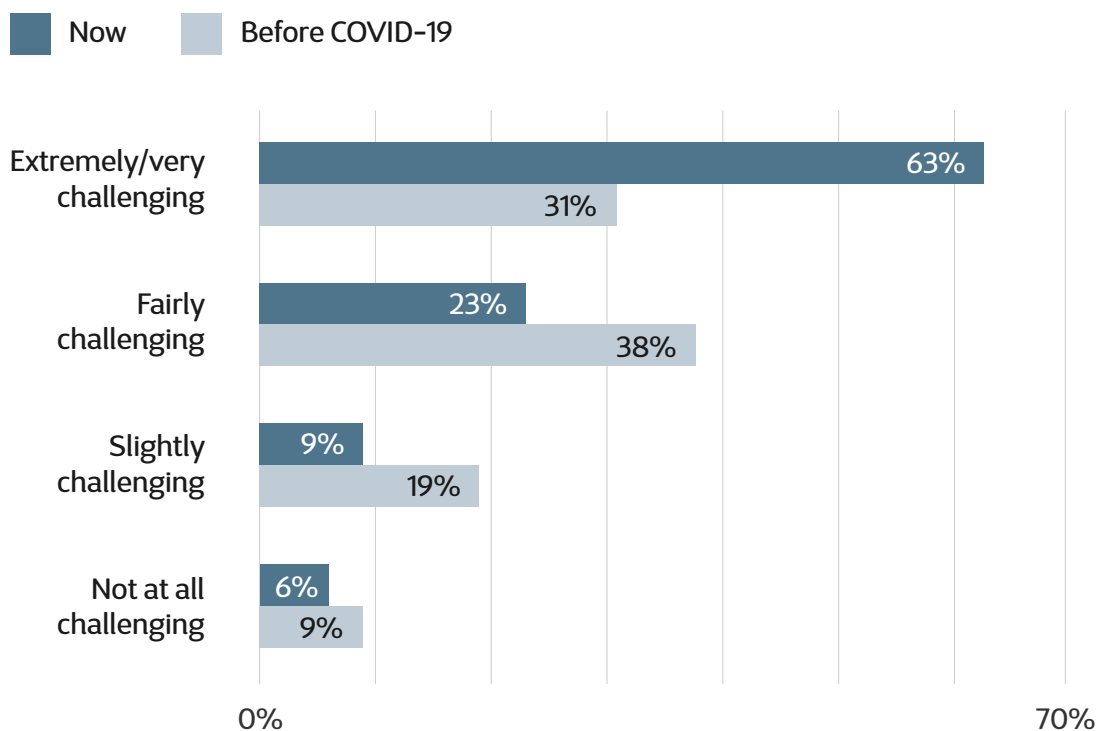
Many neurology services are now more worried than ever about their ability to provide a good service to everyone who needs it. This can be seen in figure 3, the results of a survey in which 196 neurology healthcare professionals were asked about how challenging they found it to provide a good service to everyone on their caseload now, compared to before the pandemic.⁴¹

“If I phone my MS nurse, I have to call more than once. You speak to the secretary who asks why you’re calling. You’ve got to explain yourself and make sure your reason is good enough to even be put through to your MS nurse. And if they don’t see it as a good enough reason then you’re not a priority.

And with the neurologist you’ve got to send two or three emails to chase that up. I understand they’re busy, but it can be frustrating and can be long.”

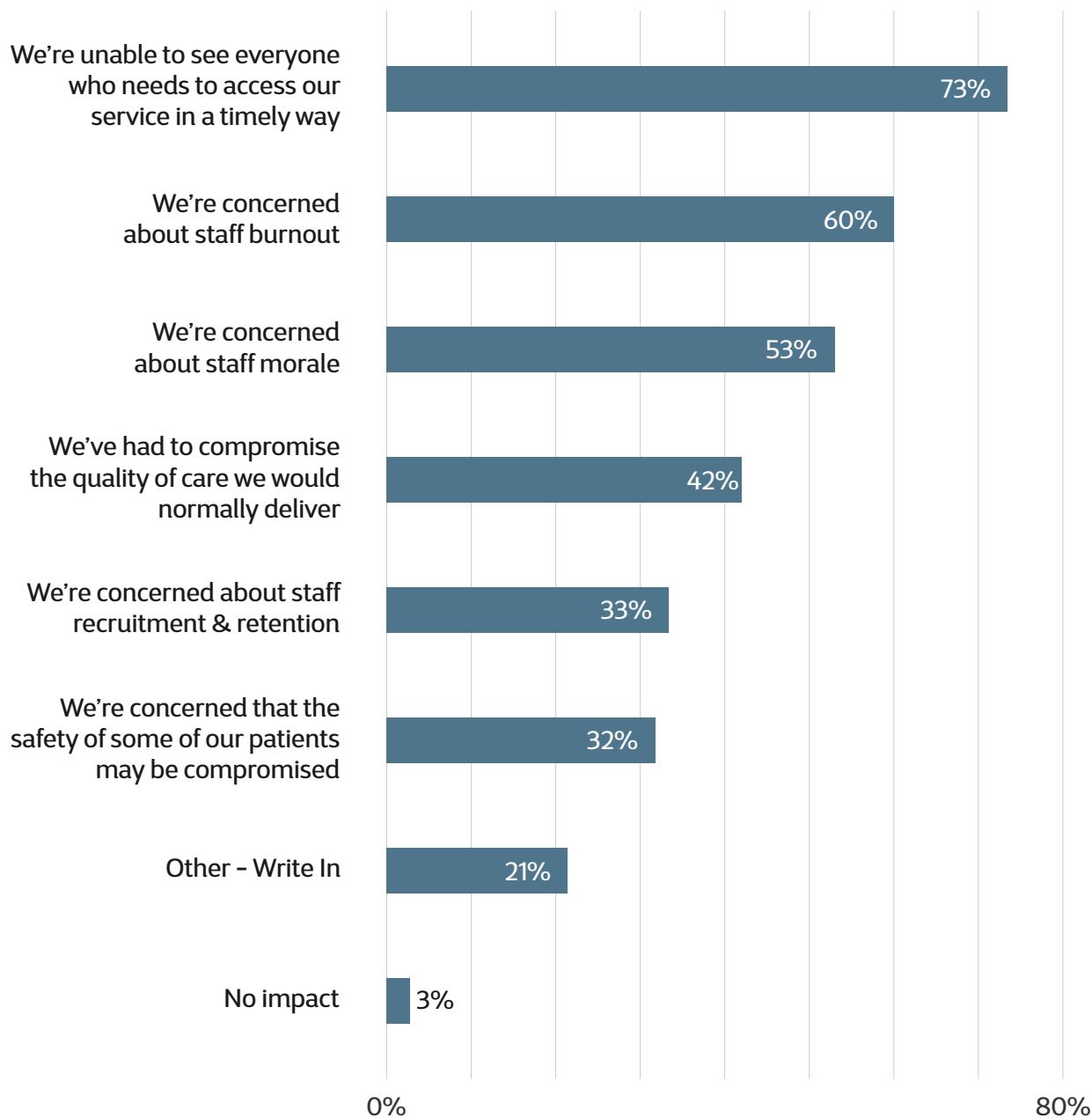
Roxy, 33, living with relapsing remitting MS

Figure 3: Professionals' responses to “how challenging do you find it to provide a good service for everyone on your caseload now and how challenging was it before COVID-19?”



Of those who found it extremely or very challenging to provide a good service to everyone on their caseload, figure 4 shows the impact this has on both professionals and patients.

Figure 4: Professionals' responses to “you said you find it challenging now, what is the impact of this on you and your colleagues? (Tick all that apply)”



In England, the Government have said that in July 2021, activity levels for neurology services had recovered to 75% compared to pre-pandemic levels, which is encouraging to hear. However, we found more than half of neurology professionals (53%) said waiting times have increased since March 2020. And of those, nearly a quarter (22%) think it could take 1-5 years to return to similar pre-pandemic waiting times.

The Office for National Statistics found disabled people are more likely than non-disabled people to say the pandemic affected their health and wellbeing, access to healthcare services, and medication.⁴² When the lockdown started and NHS services were restricted, people with existing health conditions were unable to receive their 'normal' levels of care or preventative services. We suspect there are 'hidden' patients who won't show up in waiting list figures yet. That's because they weren't referred to, or didn't seek, neurology services during the peak of the pandemic, either for fear of infection, increasing pressure on a stretched NHS, or inability to get a GP appointment. While neurology-specific data in this area are limited, we believe the situation is likely to be similar for people living with MS. We fear these patients will have deteriorated in the intervening time and may present at emergency services or on neurology waiting lists in the near future.

5. What does the future look like for people with MS if nothing is done?

The legacy of the pandemic could be devastating for people affected by progressive neurological conditions, like MS. 7 in 10 (72%) neurology healthcare professionals surveyed in August 2021, said the limitations to services during the pandemic will have a long-lasting impact on physical health for all or the majority of people with neurological conditions. In addition, over half (56%) of respondents felt all or the majority of people with progressive neurological conditions would also experience long-lasting impacts on their mental health and wellbeing (for example, increased anxiety or low mood).

The NHS in each nation has developed pandemic recovery plans. NHS Scotland estimate a 41% reduction in new outpatient activity in 2020/21 due to the impact of the pandemic. They've committed to increase funding and the number of diagnostic procedures, including an additional 24,000 MRI scans.⁴³ Anecdotally, radiology departments are struggling with increased demand which has a knock-on effect on diagnoses. However, by increasing capacity, people waiting for a neurology or MS diagnosis should benefit to some extent. However, the plan doesn't address the issues facing neurology services and it's unclear if the recovery plans can be achieved given the lack of definitive data outlining the extent of the backlog.

72%

of neurology healthcare professionals said the limitations to services during the pandemic will have a long-lasting impact on physical health for all or the majority of people with neurological conditions.

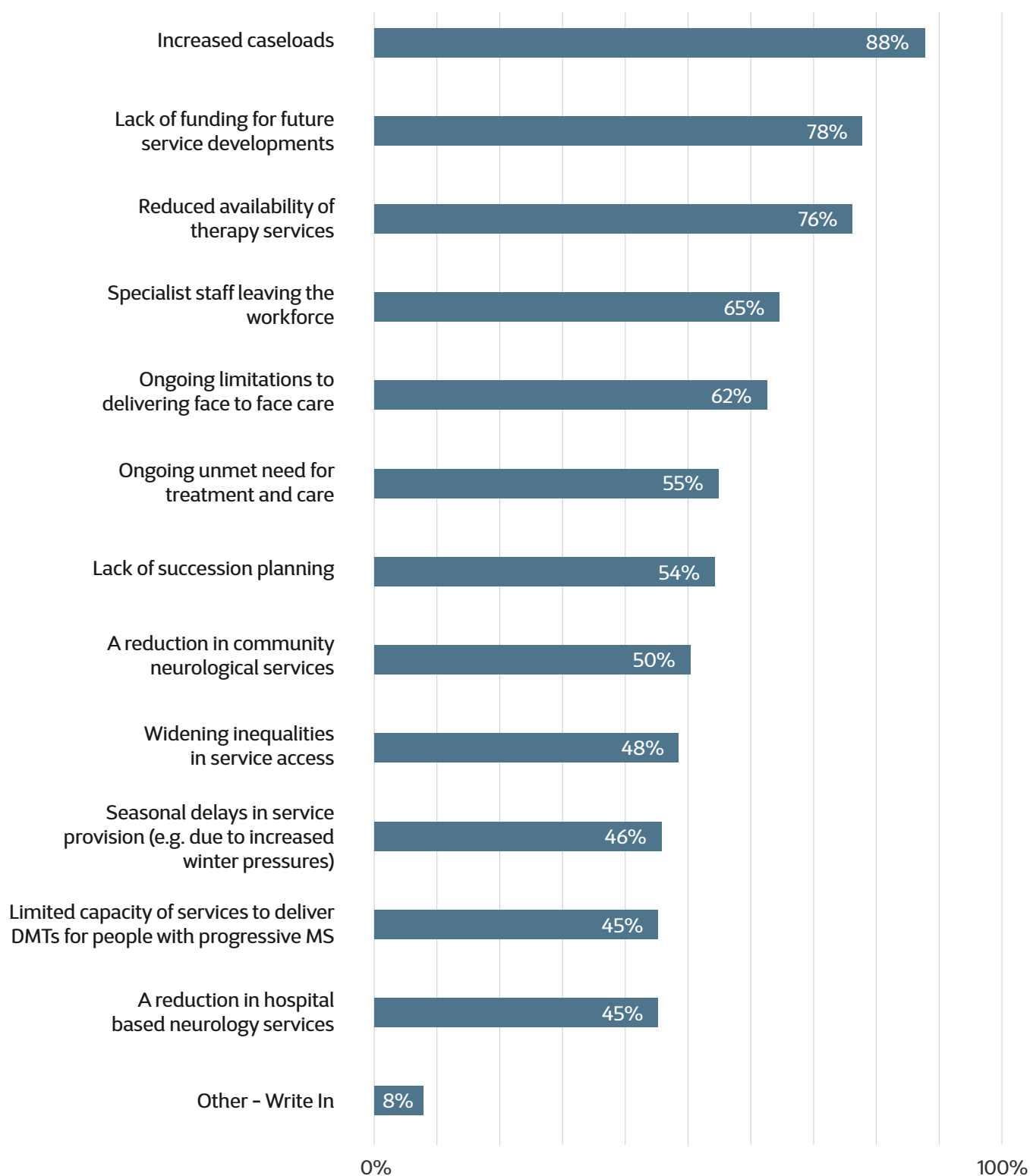
The reduction in outpatient activity, specifically the disruption to neurology and MS services, has translated to a 17% reduction in the number of MS diagnoses in 2020.⁴⁴

The recovery plans for Wales and Northern Ireland present a suite of recommendations aimed at reducing health inequalities, continuing new ways of working which emerged during the pandemic, and re-building the economy.^{45,46} However, concrete plans to reduce the backlogs in neurology services haven't yet been delivered.

In England, ICSs (responsible local health bodies) have been instructed by NHS England to prioritise neurology services in their COVID-19 recovery plans. However, as of March 2021, very few ICSs had developed plans for improving, or increasing access to, neurology services.⁴⁷

There are multiple challenges that will face neurology services over the next five years. In August 2021, we asked neurology healthcare professionals what they thought were the biggest challenges ahead. Figure 5 shows that increased caseloads and a lack of funding for future service developments were two of their key concerns. If nothing changes, these issues are likely to seriously impact standards of care for people with neurological conditions. The simple fact is that no service can indefinitely deal with increasing caseloads without additional resources, yet this is the future many health professionals see for their area.

Figure 5: Professionals' responses to “in the next 5 years, what do you think the challenges will be for services for people with progressive neurological conditions? (Tick all that apply)”



What we're doing to improve services

Below are two examples of the work we're doing in collaboration with professionals and NHS services at local level to try and improve care for people with MS. These examples demonstrate the kinds of challenges MS services face across England. Tackling such challenges effectively can take a long time, but achieving positive change is possible if services, clinicians, patients and the voluntary sector work together. In order to scale-up these approaches, NHS services need the capacity and right support to prioritise service development.

Creating more coordinated, sustainable MS services in the South West

The South West MS Network is a collaboration across 6 MS centres in Devon and Cornwall. As an active member of the Network's Steering Group, we're working with them on a range of activities to improve local services. These include:

1. Developing an MS Nurse training and mentoring programme to address gaps in workforce and put plans in place to manage when nurses retire/leave the service.
2. Piloting a patient activation hub – engaging people with MS in a 12-month pilot of a one-stop-shop for information and self-referrals to services.
3. Promoting and endorsing the Network's new regional research trials platform to increase access for people with MS to clinical trials.

Improving Coordination between MS and neurology services, and Primary Care in Cheshire and Merseyside

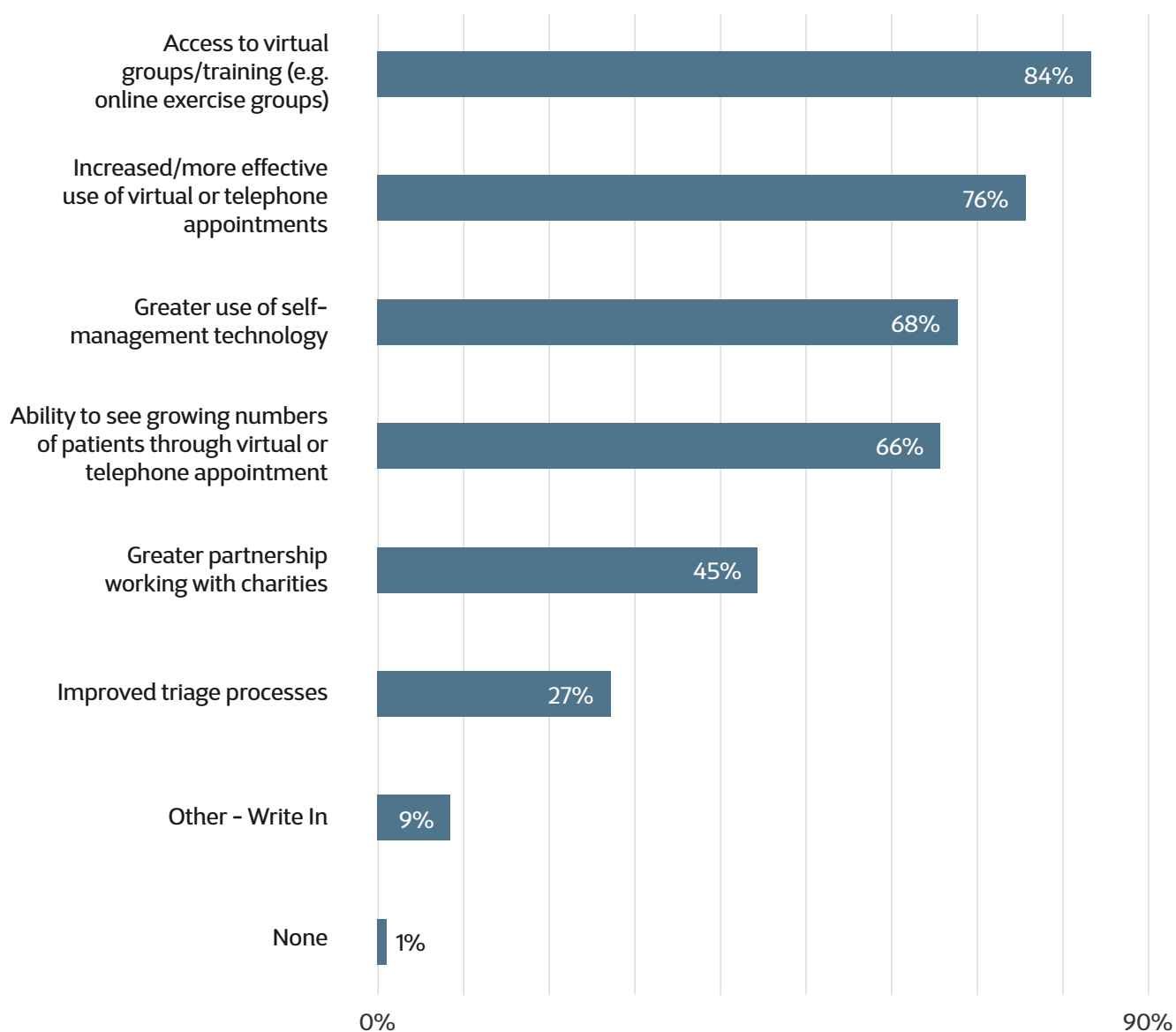
We're working across Cheshire and Merseyside to improve coordination between MS and neurology services, and primary care. This includes making a proposal to the NHS locally to fund a Neurological Wellbeing Coach operating within primary care (such as GP and pharmacy services). As part of a wider review of neuro-rehabilitation across the ICS, an occupational therapy and physiotherapy working group are developing closer links with primary care, alongside a leisure service offer to people living with neurological conditions. Accredited training for leisure centre staff enables them to effectively support people with neurological conditions to exercise and remain active.

6. Opportunities for change and our recommendations

As a necessity, health services across the UK have been operating very differently due to the pandemic. Many MS services were trialling and working in innovative ways before the pandemic and will need to continue to adapt if they are to be sustainable. There's huge opportunity to spread such innovation across the UK, with the right support and investment.

From a range of options, neurology healthcare professionals selected what they thought were the biggest opportunities within neurology services in the next five years (shown in figure 6). Access to virtual groups and training (such as online exercise groups), increased and more effective use of virtual or telephone appointments, and greater use of self-management technology were all identified as key opportunities.

Figure 6: Professionals' responses to “in the next 5 years, what do you think the opportunities will be for services for people with progressive neurological conditions? (Tick all that apply)”



Self-management

For the hundreds of thousands of people on waiting lists for neurology appointments, the NHS needs to proactively offer health prevention measures and self-management tools. This will take pressure off acute NHS services, as many hospital admissions can be avoided through timely out-of-hospital interventions. The Health Foundation found those who were able to self-manage their condition had 38% fewer emergency admissions. This could be reduced further if people were supported better in the community.⁴⁸

Our report with the Nuffield Trust, 'Improving care for people with MS: The potential of data and technology'⁴⁹, found people with MS can use digital tools to take more control of the management of their own symptoms, with the right support from healthcare professionals and others. While it won't get NHS waiting lists back under control alone, expanded information and support about self-management is a clear opportunity to help people with MS and other neurological conditions – both while they're waiting for appointments and throughout their lives.

Our August 2021 survey found half of respondents living with MS (51%) hadn't received information about how to self-manage their symptoms or condition in the preceding 12 months, even though they would have liked to. This could have been achieved through better use of digital tools and virtual services. We found, of those who had appointments via telephone or video, the vast majority received some or all (67%) of the support and information they needed.

The Royal College of Physicians found 51% of doctors who responded to their survey didn't have access to a webcam to carry out virtual consultations.⁵⁰ This highlights the need for neurology-specific guidance to be produced (working with people

“My MS nurses were great throughout everything. It was obvious they were stretched but they were great in coming back to you.

“If you phoned or emailed them, for instance, if it was something about symptom changes, they got back to you right away.

“The neurology side of it was good. The waiting list is quite long but a nurse prescriber was able to make a call and take advice to get me what was needed.”

Craig, 50, living with primary progressive MS

with neurological conditions) on how to effectively employ digital tools and appointments in neurology services in such a way that no one is left behind.

Recommendation for the NHS:

Support NHS providers to offer a range of self-management tools to help people with neurological conditions manage their condition and symptoms while they're waiting to be seen. This should utilise digital tools and aids, and targeted face-to-face support to reduce digital inequalities.

Rehabilitation

One of the services which has been hardest hit by the pandemic is rehabilitation. Three quarters (73%) of professionals who support people with progressive neurological conditions told us, in July 2020, that rehabilitation was the most common type of care that had been delayed, cancelled or limited as a result of the pandemic. Rehabilitation services can enable many people with MS to live independent lives less restricted by fatigue, incontinence, pain, immobility, cognitive fog and other debilitating symptoms. Professionals were concerned about the impact not receiving rehabilitation was having on those who needed it. Nearly 8 in 10 (76%) respondents wanted to see rehabilitation resume as soon as possible as a greater priority than any other type of service.⁵¹

There's strong evidence showing continued, co-ordinated multidisciplinary rehabilitation in the community improves long-term outcomes and can help to reduce hospital re-admissions.⁵² Self-management and preventative measures supported by trained healthcare professionals are invaluable to people with neurological conditions to prevent decline and ill-health.

76%

of professionals wanted to see rehabilitation resume as soon as possible as a greater priority than any other type of service.

Recommendation for the NHS:

Commission appropriate community rehabilitation services for people with neurological conditions. And in the longer-term, create an expanded right to rehabilitation on the NHS which allows people to access support to maintain their health and wellbeing and prevent deterioration.

Workforce

We support NHS England GIRFT's recommendations for how neurology services could make more effective use of the specialist staff they currently have, in order to free-up those professionals' time and improve care for patients. We think these recommendations have relevance across the UK.

GIRFT have a very important recommendation that all people with neurological conditions should have access to a specialist nurse. We regularly hear from people living with MS and their families about how important their MS nurse is to them. The MS Trust found that 90% of people with MS said they definitely had trust and confidence in their MS specialist nurse and 73% thought they had improved the coordination of their care.⁵³

Recommendation for the NHS:

Ensure that every patient with a neurological condition has access to a specialist nurse, working within a team of professionals, with the skills to meet their needs.

Unfortunately, this vision isn't currently a reality. As set out in previous Chapters, many MS nurses are struggling with unsustainable caseloads and access has been deteriorating. One recommendation from GIRFT to combat this is all specialist nurses

should be supported by an appropriate number of administrators, so their time can be better spent with patients instead of on paperwork and answering phones.

A lack of administrative support was a recurring theme in many of the services the GIRFT team spoke to. An earlier survey by the MS Trust found more than a quarter of MS specialist nurses had no administrative support at all, and three quarters felt they didn't have sufficient administrative support to enable them to focus on clinical tasks. They recommended that each full-time MS nurse needs administrative support for three days a week.⁵⁴

Administrative support is relatively easy to recruit and far less costly to the NHS than clinical staff, presenting an opportunity to unlock capacity of staff for more quickly – and cheaply – than training new highly specialised staff.

Recommendation for the NHS:

Ensure all MS teams have a sufficient number of administrative staff to free-up clinical staff to deliver clinical care.

GIRFT also recommends systems are set up for neurologists to provide timely advice to GPs. This means that GPs can avoid referring people to neurology services if they don't need to be, freeing up time for those services to support people who need it. An example of how this works in the Walton Centre in Liverpool is below.

Recommendation for the NHS:

Ensure neurologists provide timely advice to GPs to avoid referring people to neurology services if they don't need to be, freeing up time for those services to support people who need it.

Walton Centre – Liverpool

The Walton Centre in Liverpool created both a specialist nurse and consultant advice telephone service. In the former, patient calls are handled by trained, non-clinical staff and triaged to MS nurses as appropriate. This has meant MS nurse specialists can better manage their time and caseload of patients. The latter provides GPs with specialist neurology advice to manage neurology symptoms and provide care in the community.⁵⁵

Specialist Nurse Advice Line

The aim of the Nurse Advice Line is to provide people living with MS with specialist advice and information between their regular hospital appointments. The telephone service is operated by a trained call handler who can take caller's details and provide assistance with non-clinical tasks – such as booking appointments, chasing MRI scans and signposting people to information.

If a caller still needs to speak with a MS Nurse, they're booked into a telephone clinic or their call is returned within 2 days if urgent. This system allows MS nurses to effectively plan their workload, meet the needs of their service users, and speak to those who need it.

An audit of the service, conducted between April 2016 and December 2017, found only 70% of callers needed to speak with an MS nurse, and the trained call handler was able to effectively meet needs. 56% of callers needed telephone advice and guidance only, potentially avoiding callers needing to attend a follow-up appointment – saving an estimated £265,533.

Consultant Advice Line

The Consultant Advice Line provides GPs in primary care with specialist neurology advice and guidance by phone to support management of their patients with all neurological symptoms/conditions. This ensures patients are seen by the right services, avoids unnecessary appointments and hospital visits, and reduces the amount of people attending outpatient appointments inappropriately.

An evaluation of the service, conducted between April and December 2017, found that 43% of calls to the service received advice and guidance only, potentially avoiding an outpatient or specialist appointment – saving an estimated £37,303. Where GPs asked for, and subsequently received, specialist advice and guidance, only 33% of patients went on to be referred to secondary care.

The NHS England GIRFT report also suggests NHS Trusts develop certain skills and responsibilities among specialist nurses and other staff, which would have the effect of freeing up neurologists' time. Indeed, NHS RightCare's toolkit for progressive neurological conditions already recommends upskilling specialist nurses and pharmacists to take on aspects of DMT monitoring and management normally undertaken by neurologists.

Recommendation for the NHS:

Explore opportunities to upskill lower-banded staff in neurology services to enable them to take on more clinical tasks along the pathway.

Regional planning

Reforms to the NHS throughout the UK have recognised that a one-size-fits-all approach to service planning is rarely successful. We're keen that national level action isn't seen as a replacement for regional planning – but rather as a key enabler for it.

Regional and local planning are most powerful when combined with proper use of data. For example, the self-management approaches described above are more powerful if combined with patient-level data to help target interventions where they'll have the most benefit.

The UK MS Register holds data from over 15,700 people living with MS. The register links routine hospital data, clinical information and information provided by those who have 'opted-in' to the initiative, about their everyday experiences of living with MS. This data can be used to identify people who could benefit from prevention measures, such as a falls prevention programme for someone who has started to struggle with their mobility. And, target much needed services to areas of higher health inequalities.

Recommendation for the NHS:

Develop data-driven regional plans for neurology services. This should include plans to encourage the adoption and spread of innovative models of care.

Creation of national neurology plans

While there's much that local and regional decision-makers can do to prioritise neurology, true reform is unlikely and, in many cases, impossible without strong leadership at national level. Only articulating neurology as a clear priority and investing in areas that will make a true difference may lead to further reform.

Recommendations for UK Governments:

Our overarching recommendation is for all Governments of the four nations to develop and resource national plans to restore and improve neurology services by working with neurological charities and patients. The plans should:

- a. Ensure that people with neurological conditions aren't left behind in the wake of the pandemic.
- b. Set out how the NHS plans to commission and deliver comprehensive, personalised and holistic physical and mental health and care services for people with neurological conditions.
- c. Build a thriving, sustainable health and care neurology workforce.
- d. Address the current, unwarranted variations in treatment, care and support that people with neurological conditions still experience every day.

These plans should be accompanied by clear outcome measures agreed with clinicians and patients, and included in relevant accountability frameworks to ensure progress at both national and local level.

The 2021 Comprehensive Spending Review must also include a multi-year funding envelope for training increased numbers of neurology professionals.

In the short-term, by utilising innovative ways of working which have been developed through the pandemic and prior to it, by investing in virtual and digital self-management tools, and maximising effective use of existing and non-clinical staff, neurology services will be better able to meet the challenges they face and the needs of people with MS.

7. Nation-specific recommendations

The below recommendations are nation-specific.

England

1. England must follow the example of Wales, Northern Ireland and Scotland to publish a long-term workforce plan that quantifies the current and future workforce gap, how to meet current workforce challenges and plans to meet increasing demands within neurology as a specialty.
2. NHS England should work with the National Neurosciences Advisory Group and Neuro Intelligence Collaborative to establish outcome measures for neurology and mandate their collection in a national outcome framework, in order to drive up standards of care.
3. NHS bodies should explore opportunities to partner with charity and third sector organisations locally to offer truly joined-up care for people with neurological conditions.
4. Implement the recommendations of the Getting It Right First Time neurology report and resource a local implementation programme that targets support at services that need it most.
5. NHS England should resource several local pilots of the Optimum Clinical Pathway for MS which has been developed as part of the Neuroscience Transformation Programme.

6. Reform to specialised commissioning for neurology must ensure joined up specialist and community care, creating a comprehensive, personalised service focussed on the needs and priorities of each person with a neurological condition.

Scotland

1. As part of the NHS Recovery Plan the Government must acknowledge the need to focus on neurology services, including an increased focus on data collection for waiting times, expenditure, and prevalence and incidence figures to inform service planning, commissioning and delivery.
2. The Government should review and update the implementation for the Framework for Action in light of the additional pressures of the pandemic, including a new timeline for achieving the priorities detailed. There should be particular focus on workforce which underpins every aspect of service planning and delivery.
3. A national reporting framework should be considered to measure improvements in care and support, and partnering with Healthcare Improvement Scotland (HIS) to undertake self-evaluation of services.
4. HIS must review and update the condition specific standards to sit alongside the General Standards for Neurology. As part of this process a monitoring framework should be developed and rolled out.

Northern Ireland

1. The Department of Health must set out a funded delivery plan to support the implementation of recommendations made by the Neurology Review Team.
2. As a matter of urgency, the Department must take action to increase foundation level medical training places in neurology.
3. The Department must commit to retaining a specific focus on neurology services throughout any changes to the organisation of health and social care services and commissioning arrangements.
4. Future commissioning arrangements for neurology services must involve all stakeholders including community and voluntary organisations, patients and carers.
5. The Department of Health must ensure that new and review outpatient waiting times in neurology services are prioritised in waiting list initiatives.

Wales

1. Welsh Government should replace the Quality Statement with a comprehensive Neurological Conditions strategy and action plan with clearer outcomes and a stronger accountability structure.
2. Commit to workforce development and commission a strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with a neurological condition in a timely manner in a timely place.

3. Establish a national system for the collection, collation and publication of outcomes data on neurological services, working with the research community, people with neurological conditions and the third sector.
4. Ensure that the mechanism that replaces the Neurological Conditions Implementation Group (NICG) has the powers to hold Local Health Boards (LHBs) to account.
5. Create a new co-production and participation strategy that mandates and requires the replaced NCIG and LHBs to demonstrate the active participation of people with neurological conditions and carers in decisions about improvements to care and support at a national and local level.

References

- ¹ The Neurological Alliance, March 2019, Neuro Numbers 2019
- ² Joseph Roundtree Foundation, February 2020, UK Poverty 2019/20
- ³ Institute of Health Equity/The Health Foundation, February 2020, Health equity in England: The Marmot Review 10 years on
- ⁴ Scope Extra Costs Commission, June 2015, Driving down the extra costs disabled people face: final report
- ⁵ Scope, The Disability Price Tag, February 2019
- ⁶ MS Society, May 2020, My MS My Needs survey 2019: UK findings
- ⁷ NHS England/GIRFT, September 2021, Neurology: Programme National Specialty Report
- ⁸ Ibid
- ⁹ Neurological Alliance, July 2019, Neuro Patience: Still waiting for improvements in treatment and care
- ¹⁰ ABN, January 2020, UK Neurology Workforce Survey
- ¹¹ Royal College of Physicians, October 2019, Focus on physicians: 2018–19 census (UK consultants and higher specialty trainees)
- ¹² Hobart J, Rog D, Matthews J (2020) MS Audit Presentation at Raising the Bar for MS conference. November 2020
- ¹³ MS Trust, October 2018, MS Specialist Nursing in the UK 2018
- ¹⁴ NHS England/GIRFT, September 2021, Neurology: Programme National Specialty Report
- ¹⁵ Hobart J, Rog D, Matthews J (2020) MS Audit Presentation at Raising the Bar for MS conference. November 2020
- ¹⁶ Department of Health, October 2019, Neurology review - interim report

- ¹⁷ NHS England, June 2019, Interim people plan
- ¹⁸ Hobart J, Rog D, Matthews J (2020) MS Audit Presentation at Raising the Bar for MS conference. November 2020
- ¹⁹ MS Society, Ongoing impact of COVID-19 on services, August 2021
- ²⁰ MS Academy, February 2021, NHS Reset and Reform: A new direction for health and care in multiple sclerosis
- ²¹ Regional Review of Neurology Services, October 2019, Neurology review - interim report
- ²² NHS Wales, July 2017, Neurological Conditions Delivery Plan. High standard of care for everyone with a neurological condition
- ²³ MS Society, July 2020, Life in lockdown: experiences of living with MS during the coronavirus pandemic
- ²⁴ MS Society, August 2020, Life in lockdown 2: experiences of living with MS during the coronavirus pandemic. Findings from the UK MS Register 'Additional impacts of lockdown' survey.
- ²⁵ Association of British Neurologists (ABN), guidance on the use of disease-modifying therapies in multiple sclerosis in response to the COVID19 pandemic, March 2020
- ²⁶ See ABN guidance on the use of disease-modifying therapies in multiple sclerosis in response to the COVID19 pandemic, May 2020 and November 2020
- ²⁷ NHS Business Services Authority, Open Data Portal, Secondary Care Medicines Data and NHS England "Blueteq" data for DMT use, not publicly available
- ²⁸ MS Society Your experience of MS services survey, August 2021
- ²⁹ NHS England "Blueteq" data for DMT use
- ³⁰ Impact of COVID-19 on multiple sclerosis care and management: Results from the European Committee for Treatment and Research in Multiple Sclerosis survey, 25 March 2021

- ³¹ Figure 2 shows NHS England "Blueteq" data on the number of annual new starts on all DMTs where new starts are both people switching from another DMT and those starting their first DMT. We have used data for January - September 2021 to project overall annual total for 2021
- ³² Wilmington Healthcare and the Neurological Alliance, Impact of COVID-19 on neurology patients during wave 1, December 2020
- ³³ MS Society and MS Trust, July 2020, Findings of a survey of MS healthcare professionals on the impact of COVID-19 on MS services in the UK
- ³⁴ MS Society, August 2020, Life in lockdown 2: experiences of living with MS during the coronavirus pandemic
- ³⁵ Wilmington Healthcare, Impact of COVID-19 on neurology patients during wave 1, December 2020
- ³⁶ NHS England, Consultant-led Referral to Treatment Waiting Times, July 2021
- ³⁷ NHS England/GIRFT, Neurology: Programme National Specialty Report, September 2021
- ³⁸ Department of Health, August 2021, Northern Ireland waiting time statistics: outpatient waiting times quarter ending June 2021
- ³⁹ Public Health Scotland National Statistics, Inpatient, Day Case and Outpatient Stage of Treatment Waiting Times, Monthly and quarterly data to 30 June 2021.
- ⁴⁰ <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Referral-to-Treatment/patientpathwayswaitingtostarttreatment-by-month-groupedweeks-treatmentfunction>
- ⁴¹ MS Society, Ongoing impact of COVID-19 on services survey, August 2021
- ⁴² The Office for National Statistics, Coronavirus and the social impacts on disabled people in Great Britain: September 2020
- ⁴³ NHS Scotland, August 2021, NHS Recovery Plan 2021-2026

- ⁴⁴ The Scottish Multiple Sclerosis Register Report 2021, Public Health Scotland
- ⁴⁵ Welsh Parliament, Economy, Infrastructure and Skills Committee, Long-term recovery from COVID-19, March 2021
- ⁴⁶ <https://www.executiveoffice-ni.gov.uk/sites/default/files/publications/execoffice/consolidated-covid-19-recovery-plan.pdf>
- ⁴⁷ Novartis, Neurology Academy, MS Trust, Wilmington Healthcare, Neurological Alliance, March 2021, The future of MS commissioning
- ⁴⁸ The Health Foundation, August 2018, Reducing emergency admissions: Unlocking the potential of people to better manage their long-term conditions
- ⁴⁹ MS Society and Nuffield Trust, July 2018, Improving care for people with MS: the potential of data and technology
- ⁵⁰ Royal College of Physicians, 'Giant leaps for digital progress, but have we missed the small steps along the way?', 29 May 2020
- ⁵¹ MS Society, September 2020, Too much to lose: The importance of improving access to community rehabilitation for people with MS
- ⁵² NHS England, Service Specification for specialised rehabilitation for patients with highly complex needs, 2013
- ⁵³ MS Trust, Evidence for MS Specialist Services: Findings from the GEMSS MS specialist nurse evaluation project, November 2015
- ⁵⁴ MS Trust, November 2016, MS Forward View: a consensus for the future of MS services
- ⁵⁵ NHS RightCare, August 2019, Progressive Neurological Conditions Toolkit

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.

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

facebook.com/mssociety

twitter.com/mssocietyuk

MS Society Scotland

0131 335 4050

enquiries-scotland@mssociety.org.uk

MS Society Northern Ireland

028 9080 2802

nireception@mssociety.org.uk

MS Society Cymru

mscymru@mssociety.org.uk