A different path: Rethinking MS hospital care

September 2025

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About MS

MS is a neurological condition that affects more than 150,000 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 us

We're the UK's largest charity for people living with multiple sclerosis (MS). We're here for everyone living with MS — to provide practical help today, and the hope of a cure tomorrow. We play a leading role in research. We fight for better treatment and care. We let people with MS know they're not alone and offer advice and support to help them.

Acknowledgements

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Foreword

Life with MS is different for everyone. But one thing many people share is the challenge of getting the right care at the right time. When symptoms change suddenly or support isn't there early enough, it often leads to hospital stays. These admissions aren't always avoidable. But many happen because of problems that could have been dealt with sooner.

We used Hospital Episodes Statistics data to take a close look at how people with MS in England interact with hospital care. The report focuses on areas that have a major impact on people with MS. These are delays in getting a first neurology appointment and barriers to accessing ongoing treatment. And what happens when care breaks down and people end up in hospital unexpectedly.

What we found shows just how much variation there is across the country. In some areas, services are working together, and people get the help they need before their health gets worse. In others, there are gaps that leave people without answers or support. These differences have real consequences, both for individuals and for the wider health and care system.

But this isn't just about systems. At the heart of all of this are people trying to live their lives while managing a long-term condition. Many of those we heard from told us that what they want isn't complicated.

They want care that makes sense. They want to be able to plan ahead and live independently. They want to feel that someone is listening when they say things aren't working.

To make that happen, we need implementation of the Optimum Clinical Pathway for MS. We also need stronger leadership and accountability, investment in the workforce that supports people every day, and better use of data.

We're sharing this report with one clear purpose: to help drive change. We need those in charge of planning and delivering care to listen to what people with MS are telling them. That will give us a real chance to do things differently. We can reduce the number of hospital stays that never needed to happen. And make care more consistent, more responsive, and more person-centred.

Nick Moberly
CEO, MS Society

Executive summary

Hospital care plays a vital role in supporting people with MS. In the April 2023 to March 2024 financial year one in three people with MS were admitted at least once. And almost half had a neurology outpatient appointment.

But our report shows a system under increasing strain. People are waiting longer for first neurology appointments and don't have equal access to treatment. At the same time, preventable emergencies continue to drive admissions and rising costs.

These issues are connected. When care is missing earlier on, the consequences are felt later in hospital. For people with MS, this often means deteriorating health, added stress, and loss of independence. This doesn't have to happen.

These challenges come at a time of major change. The NHS in England is undergoing some of the biggest reforms in a generation. These will shape how services are organised, where care is delivered, and who should provide it.

Our report gives a fuller view of hospital care for people with MS in England. It draws on hospital activity data, a survey of 600 people with MS, and conversations with clinicians. Together, these sources help to show what care looks like in practice. Including where it's falling short, and why we need a rethink of how services are delivered. It makes the case for a different path, one that better meets the needs of people with MS.

Planned care

- **Planned hospital care remains vital for people with MS**. In the 2023 to 2024 financial year, over 27,900 people with MS had planned hospital admissions. These include overnight stays and day cases, where treatments like infusions were given. Overall, these amounted to more than 84,000 planned admissions of people with MS. In addition, 52,700 attended over 152,000 neurology outpatient appointments. These numbers show how important ongoing outpatient care is.
- **Experiences of planned care vary**. Planned care aims to provide reliable and supportive treatment. But over a quarter of people surveyed weren't satisfied with the hospital care they received. They highlighted concerns about the consistency and continuity of both inpatient and outpatient services.

Delays in first neurology appointments and impact on diagnosis

- **People are waiting longer for their first neurology appointment**. In the 2023 to 2024 financial year, people with MS waited 22 weeks on average for a first neurology appointment. In the 2019 to 2020 financial year, people waited 13 weeks on average. That's a 65% increase. These delays put people at risk of worsening symptoms, growing anxiety and delayed diagnosis and treatment.

- **Rising demand and a stretched workforce are driving delays.** Neurology services are under pressure. Too few consultant neurologists and MS nurses are available to meet growing demand. Referral pathways also vary widely. In most areas, people with MS have to go through several stages before reaching a specialist. This shows the need to streamline the process and use triage effectively.

Barriers to accessing treatment and care

- **Where you live still shapes access to care.** Almost half of planned MS admissions are in specialist neuroscience centres. These aren't evenly distributed in the country. Of the 15 sites with highest planned admissions, 13 are specialist centres. This set up can help deliver expert care. But it also means many people aren't treated at their nearest hospital. Longer journeys and higher costs put a greater strain on people already managing MS symptoms.
- **Travel remains a real barrier for many.** Many people must travel beyond their nearest hospital to access specialist care. Our survey found that nearly one in five people with MS were travelling more than 20 miles for their planned appointments.

Unplanned care

- **In the 2023 to 2024 financial year, one in seven people with MS had at least one unplanned hospital admission.** These admissions cost £113.5 million. For people without MS, the figure was one in sixteen[1].
- **Unplanned admissions of people with MS totalled almost 30,000 in the 2023 to 2024 financial year, similar to pre-pandemic levels.** Unplanned admissions were growing year on year until the COVID-19 pandemic when they reduced in line with the national trend. Admissions of people with MS have now increased again.
- **MS is a complex condition and attending hospital unexpectedly can be distressing.** People told us their MS isn't always understood in A and E or as an inpatient, which means their needs aren't always met.
- **Some Integrated Care Boards (ICBs) had over three times the rate of unplanned admissions of others.** These ranged from 23 to 77 unplanned admissions of people with MS per 100,000 people. The median[A] was 50.

Reducing avoidable admissions

- **Many people's admissions could be avoided.** In the 2023 to 2024 financial year, one in seven unplanned admissions of people with MS were caused by bladder or bowel issues. This includes urinary tract infections. In addition, almost one in eight admissions of people with MS were due to respiratory infections including COVID-19.

A The median is the middle value in a range of figures. This means 50% of the values are above and 50% are below.

Together, these issues cost the NHS over £28 million. With the right support in the community, many of these unplanned hospital stays could be prevented. People with progressive and advanced MS are more likely to be admitted, but often their care falls short. For example, they're less likely to have annual reviews with an MS specialist.

- **Repeat admissions could highlight missed opportunities**. A third of people admitted unexpectedly in the 2023 to 2024 financial year had more than one unplanned admission. The readmission rate within 30 days is higher for people with MS than the England average. Over five years, people admitted five times or more made up over 40% of unplanned admissions, costing over £220 million.

Improving unplanned care

- **Long stays increase the risk of deterioration**. The average unplanned hospital stay for someone with MS was 9.3 days in the 2023 to 2024 financial year, well over a week. Extended hospital stays can increase the risk of greater disability and loss of independence.
- **People often describe poor experiences of unplanned care**. Six out of 10 survey respondents who had an unplanned hospital stay in the last two years weren't satisfied with their care. People spoke of poor understanding of MS among staff and limited access to inpatient rehabilitation such as physiotherapy or occupational therapy.
- **Access to specialists in hospital varies hugely**. More than 5,000 unplanned admissions of people with MS were to hospitals without a neurology service or visiting neurologist in the 2023 to 2024 financial year. Specialist advice can reduce admissions, length of stay and improve outcomes.

Recommendations

Delays to first appointments, pressures on planned care, and high unplanned admissions show that changes need to be made. The system that isn't working well enough for people with MS. These challenges are connected and so are the solutions. The following recommendations outline the necessary steps to improve care for people with MS:

- **Adopt the MS Optimum Clinical Pathway** — NHS England should formally endorse and fund the MS Optimum Clinical Pathway. This approach provides a consistent structure for MS care from diagnosis to advanced MS and can help reduce avoidable hospital care.
- **Strengthen leadership and accountability** — Every Integrated Care Board (ICB) should have a named lead for neurology who's responsible for MS services and hospital pathways. Nationally, the Department of Health and Social Care must keep senior neurology leadership through upcoming structural changes.
- **Use data to support improvement** — Integrated Care Boards should be using neurology dashboard data to understand why unplanned admissions are high. And to identify population needs and drive service improvement. NHS England should make this data public so that progress can be tracked and wider organisations can support improvement.
- **Invest in the workforce** — The NHS Long Term Workforce Plan must address staffing shortages across neurology, MS nursing and allied health professions. This means investing in MS specialist nurses and their development. And recruiting more consultant neurologists to reduce pressure on overstretched teams.
- **Develop a Modern Service Framework for neurological conditions** — One in six people live with a neurological condition but they've been neglected for too long. Like cardiovascular disease and mental health, neurological conditions need dedicated national attention and the right investment. This will help to reduce variation and improve outcomes.

1. Introduction

In England, over 123,000 people live with multiple sclerosis[2]. It's a lifelong condition with complex needs that change over time.

Treatment, care and support are vital to people with MS. It allows them to live well, do what's important to them and live as independently as possible. Hospitals can form a big part of this care. From getting a diagnosis, receiving treatment, having follow ups, managing symptoms to accessing urgent care when needed.

This report draws on hospital data, insight from people with MS and from key stakeholders. It provides an overview of how people with MS interact with hospital services. It highlights the demands, costs and opportunities.

The evidence shows a system that's often stretched thin. As for other neurological conditions, hospital care for MS is falling short. There are rising costs and stark differences in access to care depending on location. Behind these trends are people trying to find their way through a system that can feel disjointed and reactive. Instead of supportive and preventative.

Sub-optimal care impacts people with MS physically, emotionally and financially. Without timely access to diagnosis and disease modifying therapies, people are at a higher risk of relapses and irreversible disability. For those unexpectedly admitted, hospital stays can be distressing.

They can increase the risk of acquiring infections, deconditioning and a stepwise increase in disability. Poor care can have long-term impacts on someone's quality of life, independence and employment.

In this report, we start by outlining what good MS care should involve. This sets the standard against which today's services can be judged. We analyse the policy context. And we then address the overall patterns and four key areas in planned and unplanned care:

- Delays in first neurology appointments and impact on diagnosis
- Barriers to accessing treatments
- High avoidable unplanned admissions
- Improving unplanned care

Finally, we present a set of national recommendations aimed at improving care, addressing variation, and reducing pressure on hospital services. These are drawn from the evidence. If implemented they offer a chance to create care that's more reliable, responsive and focused on what people with MS need. The next step is to take a different path and turn this opportunity into real change.

2. Methodology

This report brings together various sources to provide a clearer picture of hospital care for people with MS in England. We worked with HSJ Information (formerly Wilmington Healthcare) to analyse Hospital Episode Statistics (HES). We focused on inpatient care and outpatient neurology services data from 2019 to 2024. This included looking at admissions and lengths of stay. And the types of care people with MS received in both planned and unplanned settings.

It's important to note some limitations. Firstly, HES data relies on clinical coding, which may not be consistent. And GIRFT neurology classifications may be out of date. Without accompanying demographic data, we're unable to make conclusions about who's receiving care and possible inequities.

In autumn 2024 we conducted a survey with 600 people living with MS in England. The survey explored recent experiences of hospital care. This report includes direct quotes from people who completed the survey. The views expressed and terminology used are theirs. They were informed about how their responses would be used and their identities have been protected.

We also followed up with a small number of people to understand their experiences in greater detail. Their pseudonymised experiences are included in the report, with their permission.

We also spoke with a range of professionals working in the neurological space. Including MS nurses, neurologists, service managers and representatives from national charities and public sector organisations. These conversations helped us understand how services are delivered on the ground and the challenges faced by teams.

We engaged our Equality, Diversity, and Inclusion (EDI) Reference Group of people with MS on the findings. And people with MS reviewed the report. These added valuable perspectives and helped ensure the report reflects real experiences. Alongside insights from our everyday work with the MS community. Together, these shaped a fuller understanding of variations in access and experience that may not be covered by the data alone.

By combining these perspectives, the report offers a fuller understanding of hospital care for people with MS. And highlights areas where improvements are needed.

3. What should care look like for people with MS?

People with MS should be able to expect well-coordinated, personalised care at every stage. From first symptoms through to advanced MS care. The MS Optimum Clinical Pathway[3] (Figure 1) sets out what that should look like. It's based on the experiences of people living with MS and the expertise of those who support them.

It shows how care can work well when services are joined up and responsive. But we know that's not always the reality. At each stage, there are gaps that can leave people waiting too long or without the right support. The pathway helps highlight where care needs to improve:

Recognition and diagnosis — People experiencing possible MS symptoms should get quick access to primary care. They should get prompt specialist referral and diagnostic tests, with a diagnosis provided within 12 weeks where possible. They should get clear communication, emotional support and connection to an MS specialist nurse and multidisciplinary team (MDT) from the start.

Treatment initiation and care planning — After diagnosis, people should meet their specialist MS team to discuss treatment options. They should start therapy within 12 weeks of a decision to treat. There should be flexible delivery settings and personalised care plans reflecting individual needs.

Ongoing monitoring and support — People with MS should have regular reviews, including neurological assessments, MRI scans and local safety monitoring. They should have timely access to multidisciplinary services coordinated by a named professional. People with MS must be able to access rapid support during relapses to help maintain independence and quality of life.

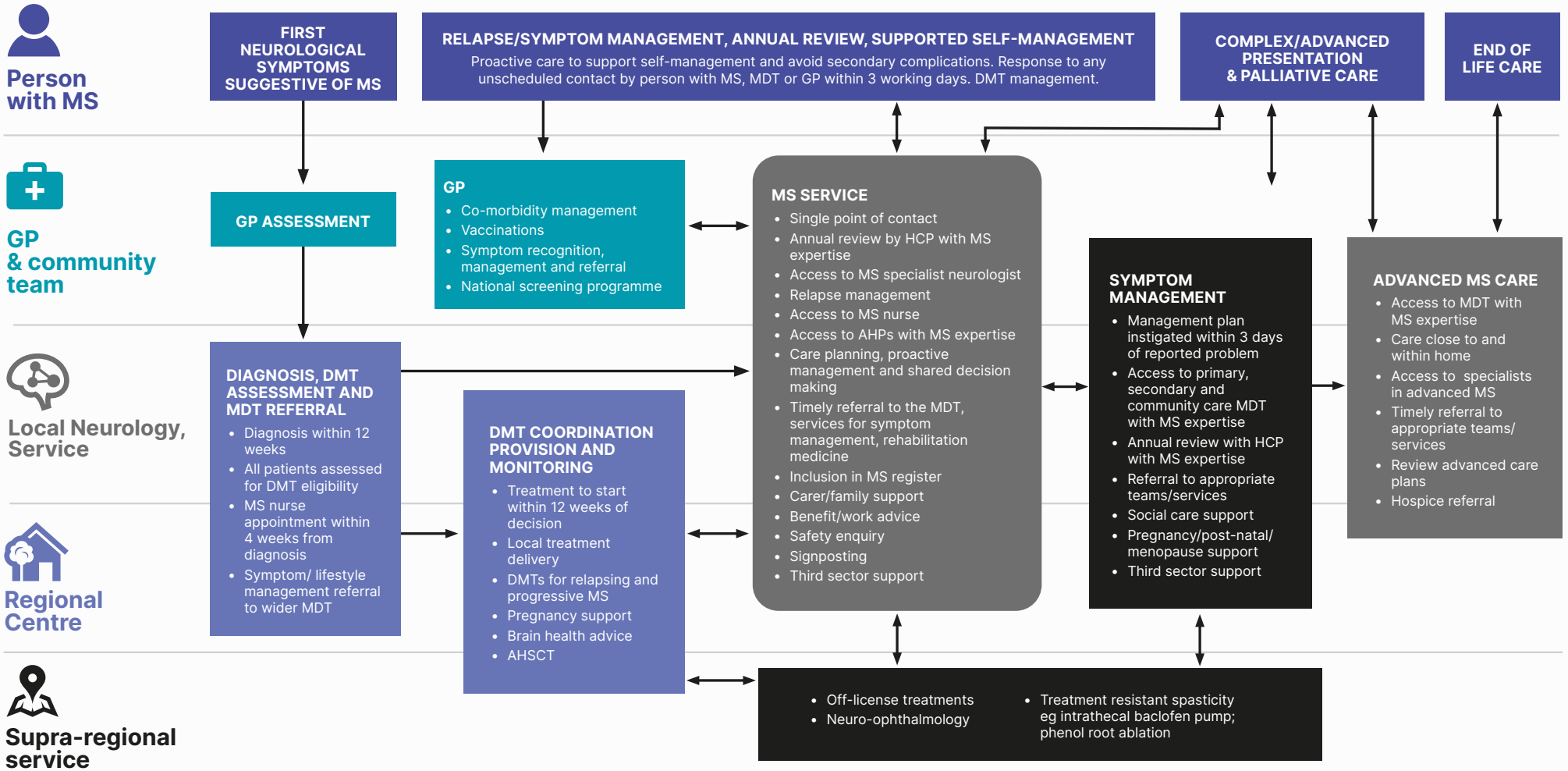
Preventing unplanned admissions and supporting recovery — Care for people with MS should focus on reducing crisis and unplanned hospital admissions. Work between MS teams and community services should be coordinated, with early discharge planning and accessible rehabilitation after hospital stays.

Care for people with advanced MS — People with advanced MS should have regular multidisciplinary reviews. These should address a wide range of needs, supported by community care, home visits and rehabilitation. Including, where appropriate, integrated end of life care.

Figure 1: The Multiple Sclerosis Optimum Clinical Pathway

GOAL: Appropriate, timely, proactive, quality care at every stage
ON-GOING: Patient and carer information, education, shared decision-making, supported self-management, lifestyle advice, opportunity to participate in research

Multiple Sclerosis Optimum Pathway



4. Policy context

The NHS in England is undergoing some of the biggest changes in a generation. These reforms are wide-reaching, and they matter for people with MS. They will influence where care is delivered, how services are organised, and who should commission and provide them. At their heart is a shift in approach. It aims to move away from hospital-based care and support more people in their own communities.

The 10 Year Health Plan[4] sets out a vision where local neighbourhood teams deliver more of the care people need day to day. This could make a real difference for people with MS. Many people struggle with long or frequent journeys to access care, support and treatment.

Care closer to home is something people have asked for time and again and has been promised. But making it a reality will depend on getting the right services in place. That includes access to timely diagnosis, neurorehabilitation and support with symptoms. It must also be clear how local services will link with specialist teams so that care is properly joined up.

Alongside this, Modern Service Frameworks have been introduced to tackle the wide variation in treatment across the country. These aim to improve coordination, reduce hospital admissions and make sure people are treated in the right setting.

But, save for dementia, neurological conditions have been left out of this process so far. This is despite neurological conditions affecting one in six people in the UK. Without a dedicated framework, the chance to improve outcomes and avoid emergency admissions for people with MS could be missed.

More changes are also underway alongside this. NHS England has delegated the responsibility for commissioning many specialised services to local Integrated Care Boards (ICBs)[5]. For neurological conditions including MS, there's an opportunity to commission across the whole pathway. And in doing so, better meet population health needs.

But this must not lead to a postcode lottery. Specialised commissioning budgets aren't ringfenced. This means that essential care could vary depending on ICBs' financial position. Alongside this ICBs have been asked to cut running costs by a further 50% and are subject to mergers. Restructuring has led to the loss of specialist knowledge and longstanding relationships.

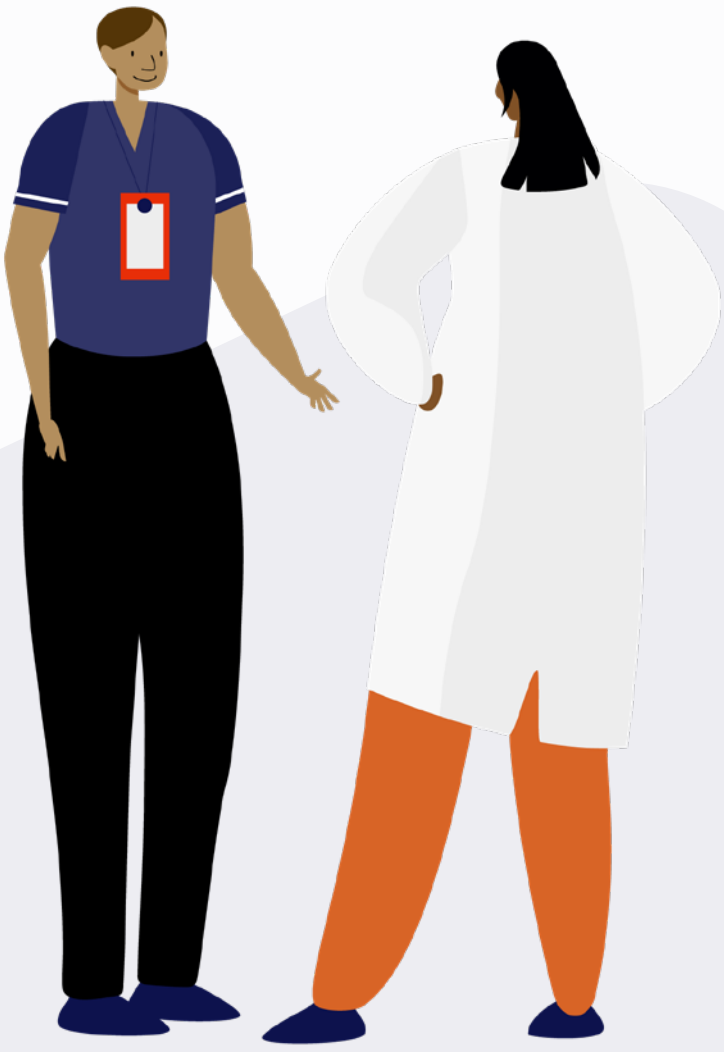
At the same time, local teams are under increasing pressure to deliver complex services with fewer resources and less direct support. Capacity to engage in service development activity is impacted.

Wider challenges

These changes are happening at a time of wider uncertainty. The merger of NHS England into the Department of Health and Social Care was announced in March 2025. This raises questions about future leadership. People with MS need to know that there will still be national oversight of neurology services with a programme for improvement. And that specialist expertise will not be lost as structures are redrawn.

The Long-Term Workforce Plan will set out how the NHS will grow and support its staff in the years ahead. This is vital. The NHS needs enough trained professionals in neurology, rehabilitation, mental health and MS nursing to deliver these reforms.

These reforms present an opportunity to do things differently. But we need strong leadership, proper resourcing, and a clear focus on neurological conditions. Without them, there's a risk that people with MS will once again be left behind.



5. Planned care

Planned hospital care is a crucial part of managing MS. It gives people access to the treatments, assessments and follow-up they need to stay well and adjust as their condition changes. In the 2023 and 2024 financial year, 27,900 people had at least one scheduled inpatient visit, with over 84,000 admissions in total. These visits can involve a range of care and tests, including infusions, MRI scans and symptom management.

Alongside inpatient care, outpatient support plays a vital role. In the 2023 to 2024 financial year 52,700 people with MS attended over 152,000 outpatient appointments[B]. Of these, nearly 71,000 were delivered remotely via telemedicine. These appointments help ensure people are regularly reviewed. They help ensure that their treatment plans remain appropriate and any changes in their condition are picked up early.

We need to deliver this care on time to help people avoid health crises and maintain their independence. But the sheer volume of outpatient appointments places considerable demand on services. This underlines the need to find new approaches that better meet people's needs.

Planned care in the 2023 to 2024 financial year for people with MS:

27,900 people had **84,100** planned admissions

52,700 people attended **152,600+** outpatient appointments Including nearly **71,000** via telemedicine

9,150 people attended first neurology appointments

Almost **one in five** people travelled more than **20 miles** for their planned hospital care

Hospital Episode Statistics and MS Society survey

Planned care should feel structured and supportive, but people's experiences vary. Some described their appointments as efficient and helpful, and many people were grateful for the high quality specialised care they receive.

But over a quarter of survey respondents who had a planned visit to hospital in the last two years weren't satisfied with their care. Particular issues were a poor understanding of MS, delayed care, difficulty getting to appointments, and lack of continuity of care.

B The outpatient data only includes people with MS who have been an inpatient since diagnosis. This means the outpatient figures could be higher than we report.

This section explores two key points in the planned care pathway where people face barriers to care. First, we look at the delays many face to see a neurologist after being referred. Then we focus on the challenges people encounter when trying to access treatment after diagnosis. These can make a lasting difference to how people experience their MS and the support they receive.

Delays in first neurology appointments and impact on diagnosis

The first neurology appointment is a key milestone in the MS diagnostic pathway. In the 2023 to 2024 financial year, 9,150 people with MS had one. It typically follows a referral from a GP. It's often the first time a person meets a neurologist to begin investigations and discuss their symptoms in detail.

This appointment helps shape the course of future care. It's the first step towards referral to an MS specialist neurologist, who usually confirms diagnosis. This usually includes type of MS. Then they can prescribe treatment with the oversight of an MDT.

In the 2023 to 2024 financial year, the average waiting time for a first neurology appointment for people with MS reached nearly 22 weeks. This is up from 13 weeks in 2019 and 2020, marking an increase of 65% (see chart 1)[C]. It's unacceptable for people with suspected MS to wait for five months for this appointment. People with MS need early diagnosis and timely treatment to manage the condition and improve long-term outcomes.

This reflects longer waiting times across all types of neurology appointment. According to the Neurological Alliance's 2024 My Neuro Survey, 32% of people with MS waited between one and two years for a neurologist appointment. And another 24% waited over two years. This means that more than half faced waiting times of more than a year to see a neurologist[6].

Chart 1. Average waiting time (days) for first neurology appointments for people with MS in England

Year	Average waiting time for first neurology appointment (days)
2019/20	92
2020/21	96
2021/22	102
2022/23	128
2023/24	152

C Note that this varies by ICB, with the average being skewed by an outlier in 2023/24. However, there has still been an upward trend over the years.

These extended waiting times have a significant impact on people with MS:

- Without timely diagnosis and access to specialist care, people are more likely to face delays in starting treatment and managing symptoms. This can increase the risk of experiencing a relapse, worsening symptoms, and irreversible disability. In some cases, these lead to unplanned admissions before diagnosis.
- Anxiety and depression are more common among people with MS than in the general population. Some people may experience these symptoms before a formal diagnosis. This can be either as part of the condition or in response to the uncertainty of waiting. Long waiting times and limited support after diagnosis often make mental health challenges worse. These difficulties can have a significant impact on motivation, coping and overall wellbeing. This adds to the considerable burden of living with MS[7].
- Delays in getting a clear diagnosis or treatment plan can disrupt work and daily life. This hinders access to workplace adjustments, social care, or financial support. Access to social care is based on individual need rather than diagnosis alone. But having a confirmed diagnosis can help speed up the assessment process. Delays in clinical appointments may also affect the accuracy of disability measures, which can influence the support provided.

What's driving this?

There are several reasons for these extended waiting times.

- **Workforce shortages** and uneven distribution of specialists — We don't have enough consultant neurologists and MS specialist nurses to meet demand. The UK ranks 44 out of 45 European nations for the number of neurologists per person[8]. Many work part-time and cover large areas which limits capacity further. They're also unevenly distributed in England. Trusts can't offer timely new appointments without enough staff. This contributes to long waits for diagnosis and early support. This was recently flagged in early findings from the DIMES study. This research project focused on improving how care is provided for people living with MS. It identified delays at multiple points along the MS pathway, with shortages in both neurology and radiology contributing to slower progress[9]. It's important to note that neurology is a broad specialty covering a wide range of conditions beyond MS. So there are many competing demands for first appointments and limited availability.
- **Diagnostic imaging delays** — MRI is essential for confirming MS. But national figures among all specialities show that around 20% of people referred for diagnostics in January 2025 waited over six weeks. This missed NHS targets which will include people with MS. Although the average wait is around 2.4 weeks, variation is wide. And some regions report waits of six to 18 weeks for non-urgent scans[10].

- **Referral pathway delays** — Referral systems can add delays to neurology access. Stakeholders told us that triage is often inconsistent or lacks the support needed. This means some people with suspected MS wait longer than necessary before seeing a neurologist. This inconsistency contributes to wide variations in waiting times and unequal experiences for people living with MS. The data shows differences in access but it doesn't fully explain why these happen. Still, the triage process is probably an important factor affecting how quickly people reach specialist care.

Solutions

To tackle these challenges and reduce delays for first appointments, care pathways must adapt:

Right specialist, right time — It's important that people get to see the specialist who can best meet their needs. This means consultant neurologists should focus primarily on supporting people with new diagnoses to make best use of their time. And those who need urgent reviews. See the Rapid Access Neurology Assessment Service for an example of making sure that people see the right person quickly. People with MS can be supported through routine follow-ups by MS nurses and other members of the team. This way, professional skills are used where they're needed most, and people with MS see the right person. People with MS value talking openly with skilled professionals who understand their concerns. And are best placed to support or refer them.

'I no longer seem to have planned appointments for my MS — I assume due to availability of staff and that I am stable. When I do attend, I generally don't have any issues and any questions I have are always answered. My most recent visit (about 18 months ago) was purely due to the DVLA wanting me to be seen…'
Woman with relapsing remitting MS

- **Strengthening primary care awareness and links with neurology** — Improving awareness in general practice is also an important part of reducing delays to diagnosis[11]. Practice nurses and other primary care staff need training to recognise people with early neurological symptoms. This would help staff to understand when specialist input is needed. Better links between neurologists and primary care could reduce time to assessment, diagnosis, and treatment. This could include using existing platforms such as 'Advice and Guidance'.
- **Pre-appointment preparation** — This needs to be a core part of how MS services are organised. One of the most effective ways to do this is by arranging an MRI scan before the person sees a consultant. A UK audit found where MRI was performed ahead of the first clinic visit, diagnosis was much quicker. Cases were much more likely to achieve diagnosis within six weeks[12]. Over 90% of MS diagnoses are confirmed with MRI[13]. So having imaging in place avoids delays and makes better use of specialist time. This simple step can help reduce repeat appointments and ease pressure on services.

- **Well implemented Patient Initiated Follow Up** — With resources under pressure, Patient Initiated Follow Up (PIFU) can help services manage demand. People with MS request follow-up appointments when they need them, rather than attending routine ones. If well implemented, this approach can free up more space for new referrals and urgent cases. Clear communication with people with MS is important so they understand how and when to use PIFU. Careful monitoring is also needed to ensure that PIFU doesn't worsen health inequalities. When done properly, it can reduce waits for first appointments and make better use of available clinical time.

All of these challenges come in the context of the upcoming updates to the McDonald diagnostic criteria. The changes should be a step forward in diagnosing MS earlier and more accurately. This is positive for people with suspected MS. But it could increase demand on already stretched services.

Partnering with charities for post-diagnosis support — Diagnosis Connect

Poor experiences of diagnosis aren't limited to long waiting times. An MS diagnosis can be scary and people often feel uncertain about the future. They can be left feeling they have too much or not enough information.

The NHS is improving this by working more closely with charities. Charities can offer practical advice, emotional support, and tailored guidance from the moment someone is diagnosed.

Being connected directly to trusted organisations helps people feel more confident managing their condition day to day. This kind of early support can help people understand and manage their condition. And get the most out of their healthcare.

The Diagnosis Connect programme[14], backed by £10 million in government funding, is an important step towards expanding this approach. People with long-term conditions will benefit from personalised support that complements NHS care.

New digital referral systems will make the process easier. Healthcare teams will be able to connect patients quickly to a wide range of voluntary and community organisations. Patients will also receive information through NHS digital channels like the NHS App. This will make it simpler to find and use available support.

The government will start by developing Diagnosis Connect for conditions diagnosed in primary care. We need it to expand to include complex neurological conditions like MS, which are diagnosed in secondary and tertiary care.

Rapid Access Neurology Assessment (RANA) — The Walton Centre

The Rapid Access to Neurology Assessment (RANA) service was developed by clinicians at The Walton Centre in February 2021. It offers a practical way to ease pressure on urgent care for people with neurological symptoms. RANA gives Emergency Department clinicians direct access to specialist input when patients present with a neurological, sign or symptom.

Patients referred into the service are seen as a priority. It helps to avoid unnecessary admissions and reduces the number of people waiting for a routine neurology appointment. This supports faster diagnosis and earlier treatment planning for those with time-sensitive symptoms.

The service runs Monday to Friday, 9am to 5pm, with access to scans and neurophysiology testing on the same day. RANA is available to Trusts across Cheshire and Merseyside. Referrals can only be made by clinical teams to ensure referral criteria is met.

RANA has created a clear route for urgent assessment outside the traditional outpatient pathway. It's helped improve access to neurology care and reduced demand on first appointments.

Barriers to accessing planned treatment

The state of planned treatment

The MS treatment landscape has changed considerably in recent years. Around 20 DMTs for MS are being made available on the NHS. Many people take oral DMTs or receive or self-administer subcutaneous injections at home. But others have to go to hospital to get their treatment.

Most DMT delivery in hospital is via infusion. But a smaller number have subcutaneous injections or autologous hematopoietic stem cell transplantation (AHSCT). HES data shows that therapeutic infusions make up the majority of all planned admissions of people with MS. In the 2023 and 2024 financial year around 13,000 people received over 45,000 therapeutic infusions.

The growing use of infusion-based therapies has increased pressure on services. Infusion units are shared across specialties including rheumatology and oncology. New treatments for other neurological conditions, such as headache disorders, are also starting to rely on this form of delivery. This means that there's growing competition for chairs and space[15].

Where services are located adds to the pressure. Almost half of planned MS admissions are in specialist neuroscience centres rather than spread in line with population need. Of the 15 hospital sites with the highest planned admissions of people with MS, 13 are N1-designated specialised centres. These centres have developed around existing infrastructure and clinical expertise. This means that many people must travel long distances for routine treatment.

Analysis of data on DMT prescribing and delivery is needed to understand how services are performing and meeting people's needs. But much of it is underused by health systems and isn't publicly available. Making better use of data and increasing transparency are essential. It will help improve care and ensure people with MS get the treatment they need.

The issues and their impacts

Variable waiting times

The Optimum Clinical Pathway for MS states that people should start DMTs within 12 weeks of a decision. But we don't have national standards on MS. So we know that this is not being actively measured or met by all prescribing centres. And it isn't a consistent priority for service improvement.

Without publicly available data on waiting times, we rely on insight from people with MS and healthcare professionals. We regularly get calls to our MS Helpline from people who are waiting to start treatment. Some have been waiting for a year or more. People tell us they don't understand why they're waiting and that they're worried about the impact of the delay. We know that we don't always hear the positive stories. But everyone should be able to start treatment promptly and be informed about any delays.

It's important to note that not all treatment delays are avoidable. For example, some will be due to the person with MS's commitments or preference.

Or they could be waiting for other treatment to finish.

But other barriers to starting people on treatment quickly can be addressed by services. These include low capacity of neurologists and MDTs. As well as the need to access tests ahead of DMT initiation and physical space for administering DMTs. The example in Box B demonstrates what one trust has done to make their service more efficient and reduce waiting times.

Pharmacy-led clinics reducing DMT waits at Imperial College Healthcare NHS Trust

Imperial College Healthcare NHS Trust cares for over 4,000 people living with MS. Despite this large patient group, specialist staff are limited. The trust has five part-time neurologists and three MS nurses covering more than 1,800 people on DMTs. Neurologists were responsible for about 1,400 patients each, far beyond what is considered manageable. Waiting times to start treatment often stretched to several months.

To meet these challenges, the trust developed a pharmacy-led approach to managing DMTs. The service began in 2006 with basic pharmacy support and has grown steadily. Now it includes specialist prescribing pharmacists and homecare technicians, with a consultant pharmacist in place since 2025. Pharmacists handle patient discussions about treatment, manage prescribing, and oversee monitoring. They work closely with the neurology and nursing teams.

The introduction of pharmacy-led clinics has led to a real shift in how quickly people can start treatment. **Patients once faced waits of one to two months before even meeting a nurse to discuss therapy. Now treatment discussion begins within two to four weeks following the decision by the multidisciplinary team. The average time to start treatment is less than two months.**

This faster access applies both to infused therapies, such as ocrelizumab, and self-administered treatments like ofatumumab. Overall, these changes have cut the waiting period by about half or more. This represents a 50 to 75% reduction in delay before treatment starts.

Pharmacists complete assessments and prepare patients in advance. This has eased pressure on infusion services. And reduces cancellations and delays. The success relies on clear roles, agreed procedures, and fully funded pharmacy positions. Imperial plans to expand pharmacy and nurse-led clinics and involve patients more in their care. This shows how changing who delivers treatment can cut waiting times and support specialist teams, without affecting care quality.

Travelling for planned care

Planned care is concentrated in specialised neurocentres, which aren't evenly distributed across the country. 19 ICBs don't currently have one. This means many people must travel beyond their nearest hospital to access specialist care.

Our survey asked people about all their planned care, including outpatient appointments. It found that nearly one in five people with MS were travelling more than 20 miles for their care. Some also described how they were travelling far for their DMTs and disease monitoring.

Travelling has real consequences for people with MS:

- For people with MS, travelling can be incredibly tough. Fatigue and mobility problems amongst other symptoms can make even short journeys difficult. When appointments are in different places or are needed regularly, managing them becomes harder. This can increase the chance of missed treatments or delays. Many also face poor access to suitable hospital or public transport. This can mean relying on taxis to get to and from appointments, which comes at a significant cost.
- A two-tier system may be forming. Those close to specialist centres can access more services. But others experience delays or reduced treatment options. This can impact disease management, progression, and overall quality of life. Studies involving adults with relapsing-remitting MS have shown how uneven DMT provision is. People living in more deprived areas are less likely to receive any DMT at all[16].

  Stakeholders told us that the DMT they take isn't always based on efficacy. Sometimes people are prioritising choice of DMT based on time and cost of travel.
- Centralising services can lead to fragmented care. Often people with MS are treated in a hospital far from home. But they rely on local services for monitoring and everyday symptom management and emergency admissions. Without effective communication between teams and shared records, this can create inconsistent care and confusion for the person[17].

'It's a long way to travel, 75 mile round trip. I even have to travel that distance every 6 months just for a blood test.'
Person with relapsing remitting MS, living in East of England

Emily's experience

Emily has lived with relapsing remitting MS for around 20 years and been on three different DMTs in that time. She receives her current DMT at the specialised neurocentre in her region. It takes 2.5 to 3 hours at the hospital every four weeks, with additional travel time each way. 'I live literally next door to a hospital but have to travel 20 miles instead to go for my infusion. It would be ideal if I could attend the hospital closer.'

She drives herself to the appointment. But this has meant making some changes. 'I've changed my times of my infusion because there's this one motorway that just gets so backed up, and it would take me like an hour to get home after my infusion. I feel dreadful, so I want to just get home as quick as possible. So now I go in the morning… I'm not a morning person.'

The long journeys back also started to feel dangerous as her disability progressed. So, she got her car adapted through Motability so she could remain independent. 'Because I don't have much sensation in my feet and my lower limbs, I was really, really struggling to get home. I've now had my car adapted, so it's all hand controls… [It] was a lot to get my head around. It was also really difficult to do at first.'

Emily accepts the frequent travel because she sees treatment as a lifeline and trusts the care at the neurocentre. 'The hospital that I go to is very well known and it's very well regulated and wonderful… So you just do it, don't you?'

Accessing high efficacy DMTs

High efficacy DMTs are very effective at reducing relapses and slowing disability progression. It's now widely accepted that early treatment with these is more effective than an escalation approach. This approach delays high-efficacy therapies until disease activity worsens. People with MS should receive timely and effective treatments, if they want to. It's essential for better long-term health and quality of life[18].

But access to these treatments varies significantly across England. This is shown from NHS England's Getting It Right First Time (GIRFT) report in 2021[19]. It found that the money spent on high efficacy DMTs varies by region. In some regions around two thirds of their total MS drug spend is on high efficacy DMTs. But for other regions it's barely more than a quarter of their total DMT spend.

This means access to high efficacy DMTs for MS patients varies regionally. Stakeholders told us that in some cases it can take two months just for high efficacy DMT options to be approved at MDT level.

Solutions and enablers

Using data more effectively

Specialised neurology centres and ICBs need to use the data available on the DMT and inequalities dashboards to

better meet their populations' needs. This includes looking at variation in prescribing of high efficacy DMTs and how far people travel for care.

Bringing planned care closer to home
The NHS 10-Year Health Plan sets out plans for neighbourhood health centres. These centres offer a real chance to reduce the travel burden for people with neurological conditions, including MS. They aim to bring more services into local communities. For people with MS, journeys to access planned care at neuroscience centres and district general hospitals can be long and difficult. This could help them to avoid unnecessary travel.

People with MS need access to multidisciplinary clinics including MS nurses at these centres. They should also provide DMT monitoring closer to home. Neighbourhood teams should be integrated with neurologists, MS nurses, and other specialists. This will be vital to managing complex symptoms and relapses closer to home.

We need clear and well-defined pathways between neighbourhood centres and secondary and tertiary care. This will allow people with MS to receive routine care locally. And they will still be able to access specialist treatments and expertise when needed.

Neighbourhood centres could transform planned MS care by making it more accessible and coordinated. But delivering this level of care needs investment in staff training and enough workforce capacity. It's important that the centres have enough resources. Without it they might only provide partial support.

This could mean that people with MS to continue travelling long distances for planned care.

Using District General Hospitals (DGHs)
District General Hospitals (DGHs) could take on a bigger role in prescribing, administering and monitoring DMTs. This could significantly reduce travel for people with MS. Many people must make frequent long journeys that can be challenging and costly because treatment is largely limited to specialist centres. DGHs can safely manage these treatments closer to where people live by developing local services with the right support. This should include clear shared-care arrangements and service level agreements.

This approach is in line with the new Service Specification for Adult Specialised Neurology[20]. The specification highlights the need for networked care. Stakeholders have also mentioned the growing use of virtual MDT meetings between specialists and local teams. This would allow DMT prescription closer to home.

6. Unplanned care

Unplanned care is essential for people with MS when things go wrong. But unexpected hospital stays can be distressing for people with MS. People sometimes stay longer than clinically necessary and experience long term impacts. We need to improve inpatient care for people with MS and provide access to high quality support after discharge.

Preventing avoidable admissions is essential. With the right care before reaching crisis, many shouldn't need urgent hospital care. We need national and local action to address why MS-related unplanned admissions are happening. And to start doing things differently.

In the 2023 to 2024 financial year:

- **More than one in seven people (14.9%) with MS had at least one unplanned admission**. This means they are 2.4 times more likely to have an unplanned admission than average in England compared to people who do not have MS[21].
- **Unplanned admissions totalled 29,335**. Unplanned admissions dropped during the pandemic in line with the national trend. But they have since increased. Before the pandemic they were rising so data must be monitored to see if this trend continues.
- **Unplanned admissions cost commissioners £113.5 million**. This doesn't include the wider cost of other services and support post-discharge. Including rehabilitation, social care and welfare. The mean cost per person with MS admitted unexpectedly was £6,165, 68% more than people without MS (£3,666)[22].
- **One in three of people with MS with an unplanned admission were admitted more than once in the year**. People with MS who have had an unplanned admission are likely to be admitted again within the next 30 days. 22.4% of unplanned admissions occurred within 30 days of a previous one. The rate for England as a whole was much lower at 14.8%[23]. This is likely to be as a result of various factors including inadequate recovery and ineffective discharge. More should be done to identify those at highest risk of readmission. And make sure they get the support they need to prevent readmission.
- **Some ICBs had over three times the rate of unplanned admissions of others**. These ranged from 23 to 77 unplanned admissions of people with MS per 100,000 people with a median of 50. The five London ICBs had the lowest unplanned admissions for their population size. Some variation may reflect the exact number and demographics of people with MS in each ICS. But stakeholders told us that variable provision and quality of care has an effect.

Unplanned admissions of people with MS in England in 2023/24:

29,335 unplanned admissions

Over **1 in 7** people with MS with an unplanned admission vs **1 in 16** people without MS

Total cost **£113.5 million**

Mean cost per person admitted unexpectedly was **£6,165**, 68% more than people without MS (£3,666)

Average length of stay was **9.3 days**

Hospital Episode Statistics and MS Society survey

Reducing avoidable admissions

People with MS experience too many avoidable admissions. They're largely admitted to hospital unexpectedly for reasons related to their MS. But many of these complications and conditions can be prevented or treated without the need for hospital admission. We can reduce avoidable admissions and support people better with disease management, early detection, early intervention and rapid access to neurology. And robust urgent care closer to home.

Of our survey respondents, over a quarter thought their unplanned admission could have been avoided.

The HES data tells a similar story. In the 2023 to 2024 financial year, one in seven (14.3%) unplanned admissions were due to a urinary or bowel issue. Such as a urinary tract infection, complications with a urinary catheter or constipation. These cost the system £12.8 million. Over one in ten (10.6%) were due to a lower respiratory tract infection, not including COVID-19, which came to a total of £14.6 million. This rises to one in eight when COVID-19 is included.

These findings are not new and have been well documented in previous reports using HES data[24, 25]. As the Optimum Clinical Pathway sets out, people with MS should have access to coordinated proactive care. This would reduce the need for unplanned care.

Table 1. Top 10 reasons for unplanned admission for people with MS in 2023/24 by primary diagnosis

Primary diagnosis	Number of unplanned admissions
Multiple sclerosis	2,650
Urinary tract infection	2,385
Sepsis	1,435
Lobar pneumonia	1,330
Pneumonitis due to food and vomit	1,240
Pneumonia	915
Unspecified acute lower respiratory infection	860
Infection and inflammatory reaction due to prosthetic device, implant and graft in urinary system	760
Tendency to fall	675
COVID-19	675

The issues

Many of the top ten reasons for unplanned admissions can be prevented with the right care and treatment at the right time. For example:

- DMTs reduce relapses, particularly high efficacy DMTs
- Good support from bladder and bowel services reduces urinary tract infections and constipation
- Support from speech and language therapists helps prevent aspiration pneumonia and pneumonitis
- Exercise reduces risk of pneumonia
- Falls prevention services, including physiotherapy, reduce falls
- Proactive management of cases by MS nurses reduces unplanned admissions and days in hospital[26]
- Support to self-manage is an important part of all these services and of living well with MS.

But not everyone has what they need. Survey respondents were asked to select what could have prevented their admission.

- The GP or health professional having greater knowledge of MS and linked health issues (64%)
- Seeing a GP or other healthcare professional earlier (29%)
- A different medication being prescribed (29%)
- Knowing how to better self-manage some MS related health issue (24%).

Over one in three survey respondents reported not having enough information and support from healthcare professionals on MS. As well as treatments, and symptom management. This group were more likely to have had a recent unplanned admission than those who report having enough (52.3% versus 35.5%).

Our 2022 'My MS My Needs' survey showed the extent of unmet need and how it has grown. For example, of respondents reporting needing specialist continence support in the last 12 months, 40% hadn't received it. For physiotherapy, it was 38%[27].

'Both my wife and I were unaware of the serious effects of the bladder and bowel issues associated with MS. Had we known more we may have spotted the problem and got it sorted earlier before it became so serious.' Man with secondary progressive MS, aged between 45 and 54

Available services and capacity vary across the country. This explains part of the unmet need. This is particularly true of services that have neurological expertise, such as neurophysiotherapy and neuropsychology.

But getting the right care also relies on people's needs being identified in the first place. Primary healthcare professionals and MS specialists, particularly MS nurses, are key to this. But many people don't get a review with a professional with MS expertise once a year, as recommended by NICE[28].

MS professionals are dedicated to their work, but they're overstretched and under resourced. Almost 80% of MS patients live in areas where MS nurses have unsustainable caseloads[29]. The MS Trust determined that 1 full time specialist nurse needs 60% WTE (work-time equivalent) administrative and coordinating support.

This ratio would optimise productivity[30]. But less than 17% of MS teams in England meet this.

Navigating a challenging health system as someone with a long term health condition has multiple risks. Particularly if care is not coordinated. These include deterioration, missed appointments and delays to care. It can lead to more intense treatment needed and longer stays in hospital[31].

People with progressive and advanced MS are more likely to have unplanned admissions, but they're less likely to see specialists. It's well understood that people with progressive and advanced MS are more likely to be admitted to hospital unexpectedly. They're more likely to stay in hospital for longer and be admitted repeatedly than others with MS[32]. But they're also less likely to have annual reviews[33].

This can mean missed opportunities to prevent hospital admissions. MS teams have had to shift their resources to those eligible for, or already on DMTs. This is because of initiation and monitoring requirements. Only one in three MS teams offer home visits[35], excluding some from face-to-face contact with an MS nurse.

'When initially diagnosed, I was assigned an MS nurse who came to the house to advise on support etc. Soon after, I moved to [a city in England] where home visit MS nurses were not a thing. Once all treatment options had been explored, I was basically left to get on with things. The only reason I get good support now is because I am in the drug trial. More could be done to support MS patients in encouraging them to keep moving and do what they can.' Man with secondary progressive MS

Jane's experience

Jane is in her 70s and lives with her husband. She was diagnosed with primary progressive MS almost four decades ago. In that time, she's never seen an MS nurse but sees a neurologist every few years. She feels she 'dropped off the list' because she's 'been around too long.'

For years, she's had an indwelling catheter. This is changed every six weeks by a community nurse.

The only other healthcare professional she sees is her GP, though it's hard to make an appointment. Since getting a catheter, she's had three UTIs that have caused severe delirium and required hospitalisation. On one occasion, doctors arrived by air ambulance to see her at home.

After a recent chance meeting with an MS nurse, she hopes to start being seen by the local team.

Urgent neurological care and expertise isn't available everywhere. In the 2023 to 2024 financial year only 19% A and E attendances by people with MS met the 4 hour standard. This is compared to 72% nationally[36]. After their long wait, people with MS are more likely to be admitted than average in England. In the 2023 to 2024 financial year 54% people with MS were admitted compared to 28% nationally[37]. Stakeholders put this down to poor understanding of MS and poor access to neurological expertise. This can lead to overcaution in emergency departments. In fact, around a quarter of people with neurological conditions presenting at A and E don't need to be admitted[38]. The RANA case study demonstrates that they could be seen elsewhere. **But there are clear routes to addressing these challenges.**

1. **National funding to implement the Optimum Clinical Pathway**. This would help to coordinate care, organise annual reviews and allow access to appropriate symptom management and rehabilitation. People with MS would get the care and support in the community they need. And it would prevent deterioration to the point of hospitalisation.
2. **Using neighbourhood health centres to meet the needs of the one in six people with neurological conditions**. At multidisciplinary clinics for neurological conditions, people can access integrated care more easily. But demand outstrips capacity, and they aren't mainstream, particularly in community settings. Neighbourhood health centres and a single electronic patient record could support people with integrated care close to home and prevent avoidable admissions.
3. **Investment in roles across MS teams and allied health professionals to provide the services that people need**. More funding for coordination and administrative support in MS teams means that clinical nurses can use their time more effectively.
4. **Better proactive support for people with advanced or progressive MS**, including identifying people not on caseloads and lost to follow up. The Optimum Clinical Pathway sets out the need for a named advanced MS lead in each MS team. The MS Trust is supporting Advanced MS Champions to better meet people's needs. The pilot saw an average reduction of 52 emergency admissions of people with MS per site, per year. This accounts for 403 bed days per site every year[39].
5. **Providing urgent neurological care without hospitalisation**. Acute neurology clinics can allow people to see specialists urgently and reduce waiting times and admissions. The ten year plan commits to 'expand same day emergency care services and co-located urgent treatment centres'. This is part of the shift from hospital to community. We need access to urgent neurological expertise to be included. As well as robust plans to support capacity and distribution of neurologists.

A spotlight on urinary tract infections

UTIs are classed as urgent care sensitive conditions. This means they should be treated at home or in the community, without hospital admission, as much as possible. Despite this, they've been a leading cause of unplanned admissions of people with MS for a long time[40]. In the 2023 to 2024 financial year, for cases where UTI was the primary diagnosis:

- 2015 people with MS were admitted 2,385 times. This means that, while one in 450 people in England has MS, they account for one in 67 UTI admissions[41].
- average length of stay was 9.7 days, over 50% longer than the England average of 6 days for a UTI[42].
- UTI admissions cost £8.5 million and accounted for over 23,000 bed days.
- rates varied significantly between ICBs. They ranged from one UTI admission for every five patients with an unplanned admission, to one for every 19 patients.

Secondary diagnoses of UTIs are recorded when someone developed a UTI after unplanned admission or already had one when they came in. Amongst people with MS, secondary diagnoses of UTIs are even higher admissions due to UTI. We need substantial improvement in bladder care in hospital, as well as prevention. In the 2023 to 2024 financial year:

- there were 3,290 admissions of people with MS with a secondary diagnosis of UTI. This is over one in ten unplanned admissions amongst people with MS.
- people with a secondary diagnosis of UTI had longer stays with an average length of 17.6 days. Together these stays cost £20.2 million.

The consequences of UTIs can be significant. For people with MS, they often cause symptoms to worsen and can trigger relapses, both impacting quality of life. Occasionally they can cause sepsis or death. There are longer term risks too. Repeated UTI infections are associated with antibiotic resistance[43], a major public health threat.

High UTI incidence and hospital admissions aren't unique to MS. Many neurological conditions cause bladder dysfunction, known as 'neurogenic bladder', which increases risk of UTI. ICBs should look at improving preventative care and early intervention for people with neurological conditions. They would better meet their population's needs, reduce unplanned admissions and save money. Adopting best practice and innovative interventions is essential. These include the expert consensus guidance for bladder management in MS[44].

Unplanned admissions of people with MS in 2023/24: urinary tract infections

2,385 unplanned admissions due to UTIs

Mean length of stay was **9.7 days**, over **50% longer** than the England average of 6 days

These admissions cost over **£8.5** million

And accounted for over **23,000** bed days

Another **3,290** unplanned admissions included secondary diagnoses of UTIs

Hospital Episode Statistics and MS Society survey

Reducing avoidable UTI admissions: unavailable innovation

NeuroResponse is an innovative service that improves the care of people with MS when they get a UTI. It improves quality of life, reduces unplanned admissions and ensures appropriate use of antibiotics. It uses technology to streamline UTI detection and treatment outside of hospital.

NeuroResponse has evolved over the last 7 years in response to high unplanned UTI admissions for people with MS. Healthcare professionals and people living with MS co-designed the service to make sure it met people's needs.

How it works

Sample pots with personalised QR codes are sent to everyone who signs up to the service. If they notice symptoms of a UTI, they can ring a direct line number or, more recently, use the NeUro App.

This will connect them to a clinician who is integrated into urgent care (IUC) and can view their personal UTI care plan.

The clinician completes an assessment. If a person needs urgent care, they will be directed to A and E, but most people are supported to manage at home.

The clinician sends a courier to pick up a urine sample from their home. This is taken to the laboratory, where the QR-label speeds up the analysis process.

If the person has a UTI, the same clinician prescribes appropriate antibiotics to be picked up at a local pharmacy. If a UTI is not present, they may refer to other health services for review, if required.

Implementation

A pilot in North Central London was successful. This was followed by an Innovation Champion commissioning the service, which built the evidence base.

The NeuroResponse team were also awarded a NHS Small Business Research (SBRI) grant to create an app. The team worked closely with people living with MS and health professionals to design and test the 'NeUro App'. Their aim was to offer a 'UTI care plan in your pocket'.

But in April 2025, during ICB reconfigurations, the service was decommissioned. This means it currently isn't available anywhere for people with MS.

Making unplanned care work better for people with MS

For someone with MS, staying in hospital can be distressing, disruptive and hinder their long term outcomes and quality of life. People tell us that the staff in hospital often don't fully understand their MS — and how it affects and is affected by other illness. This means their needs often aren't met.

In the 2023 to 2024 financial year, people with MS spent an average of 9.3 days in hospital when admitted unexpectedly. Many spend 10 days or more. This risks serious deconditioning, loss of muscle mass and a stepwise increase in disability. These increase the need for rehabilitation and support, and come at significant cost to the system.

Neurological expertise during an inpatient stay, improved knowledge of MS, effective discharge and support after discharge should reduce these risks. But unequal distribution of neurological services and expertise around the country are major barriers. As well as patchy availability of post-discharge support, including neurorehabilitation, and continuing pressures on general and neurology workforce.

'I had a half-hip replacement and was bed-bound for seven days. Because MS was indicated on the board above my bed, ward nurses would not get me out of bed for exercises, saying their physiotherapists had to do that. I did not see a physiotherapist at all while admitted, and as a result lost strength in my legs which worsened my overall condition permanently.' Woman with secondary progressive MS

The issues

Not everywhere has access to acute and liaison neurology. People with neurological conditions including MS often attend, and are admitted to, their nearest hospital. Most people with neurological conditions are treated on general wards[45].

But the neurological capability and access to liaison neurology varies enormously between sites. Inpatient neurology consultations have a positive impact on management of people's conditions and shorten their stay[46]. So any variability in access can lead to variation in outcomes. Roshana's story shows what seeing a neurologist in hospital can mean to people with MS.

Based on the original GIRFT categorisations, HES data shows that over 5,000 people with MS were admitted unexpectedly to sites without acute neurology or visiting neurologists in the 2023 to 2024 financial year. There have been some successful local efforts to improve the availability of acute and liaison neurology since the GIRFT report was published. But this hasn't been consistent. And even where there's a level of neurology service provision, patients aren't always seen by a neurologist.

'I was admitted… when I had my first major relapse. It was awful. I spent five nights there. I kept being told a neurologist would be coming to see me and then the day would pass and no one came. In the end I discharged myself.' Woman with relapsing remitting MS

A major issue is that liaison neurology is largely invisible. It isn't directly commissioned and the number of people seen isn't recorded.

Inpatient care doesn't always meet people's needs. People often tell us that their MS is poorly understood by hospital staff. And they don't understand how it affects them as an individual. This can result in missing medication or not being referred or seen by appropriate healthcare professionals as an inpatient. Including physiotherapists, speech and language therapists and occupational therapists. In turn this can cause symptoms to worsen, increase the risk of infections, and avoidable deconditioning.

'I felt the staff and carers knew little about how MS affected my illness. I was treated like a normal patient, which I didn't feel I was. They couldn't understand why I needed to take medication so regularly to control my MS and spasticity. It was the worst experience of my life.' Woman with relapsing remitting MS, aged between 55 and 64, with an unplanned admission due to cellulitis.

In some places, MS teams are automatically alerted when someone on their caseload presents to an emergency department or is admitted. But this isn't standard practice. Proactive ward staff may get in touch but often it rests on the person with MS or their carer. When MS nurses are informed, they can provide advice, potentially visit or support someone to attend a clinic.

But specialist nurse teams are mostly stretched to capacity. This means supporting patients admitted unexpectedly may be a 'nice to have' that can't be prioritised.

Box F outlines a pilot to improve care of people with progressive and advanced MS during unplanned hospital stays. This is by providing general wards with tools and support from the MS team.

'The issue for advanced MS sufferers is that they can treat the issue, usually infection, but they are unable to give any meaningful care and so the overall situation deteriorates. They don't have equipment or skills to manage a person with severe disability.' Man with primary progressive MS

Testing a pathway for advanced and progressive MS after an unplanned admission

People with progressive MS are more likely to experience unplanned hospital admissions. They're more likely to stay in hospital for longer and risk deteriorating significantly while an inpatient. That's why we're supporting a pilot in Northamptonshire. It aims to support better care for people with advanced and progressive MS after an unexpected admission.

Specialist MS nurses, Emma Matthews and Miranda Olding, wanted to do something about the impacts of unplanned hospital stays.

People they support experienced pressure sores, reduced mobility, worsened spasticity, hospital acquired infections and weight loss.

So, in collaboration with people with MS and ward staff, they created a pathway to support unplanned care for people with advanced or progressive MS. The pathway features simple prompts for key actions, such as infection screening on admission and when to refer to specialists.

The aim is to help ward staff identify risks, prevent deterioration, and support a safe and timely discharge from hospital. The pathway also assigns a 'link nurse', who receives regular training from the MS nurse team and can speak to them directly for guidance.

If the pilot is successful, a full implementation package will be produced to support other health care professionals to introduce the pathway.

Roshana's experience

Roshana is a woman in her 40s. She has relapsing remitting MS and has had two relapses since being diagnosed. Both times she ended up in hospital.

On the second occasion, her day started normally. When she felt the 'MS hug', she followed the usual steps to manage it, but this time, the pain didn't improve. 111 called an ambulance that arrived swiftly. 'By the time they got to the house, I had lost the feeling in my lower leg and part of my arm'.

Roshana was taken to the A and E of her nearest hospital, where she was sitting for 12 hours before being moved to a bed. Tests showed an infection that couldn't be identified. By this time, she had no feeling in her leg.

'What annoyed me most was I had to say to them, 'can you call my MS Nurse?' I'd already given them the information.' It took the staff some time to contact the MS team. The MS nurse asked why Roshana hadn't been sent for an MRI as it could be a relapse. MRI and CT scans confirmed it was, likely triggered by the infection.

After being on an acute ward a couple of days, Roshana was moved to a general women's ward. She has mixed feelings about the experience. The staff were kind and positive and, generally, the care was good. But they didn't have a good understanding of MS, and they were overstretched.

'I started to realise that this ward or this hospital didn't know how to support neuro patients, especially when you're younger. I needed help to go to the toilet. I would ring the bell and by the time they came, I'd wet myself three or four times because the nurses were short staffed. I do not blame the nursing staff at all, but the agency staff had no idea what to do.'

Roshana wanted 'acknowledgement that MS patients understand their bodies better.' At first, she was told that she couldn't take her prescribed medications because they didn't stock them in the hospital. Fearing the impact of pausing medications for her fatigue, neuropathy and bladder function, Roshana asked her family to get them from home. 'I openly said I'm going to break your rules because you're going to make me more ill.' She felt things could have been smoother if the medications were available, or the ward staff had rung her GP practice to confirm what she takes.

This wasn't the only time Roshana had to advocate for herself. 'When I asked to see my MRI, they said, 'why do you need to see your MRI?". She called her MS nurse, who reassured her that she'd be visited by a consultant from the neurocentre, where her MS care is based. 'The doctor that came, she was amazing. She went through my MRIs exactly as if I was seeing my consultant on an annual basis. It's exactly the same language, same process. It was what I'd expect, but I had to ask for that.'

Roshana's experience (continued)

Once the infection was under control, Roshana no longer needed to be on the ward. But because she still couldn't walk, she needed inpatient neurorehabilitation before going home. Unfortunately, her transfer was delayed: 'I had a seven or eight day period where I could have been in rehab if there had been beds available.' The waiting was tough, but following several weeks in the neurorehabilitation facility, Roshana was discharged.

She isn't surprised by her experience, because she feels that disjointed care and self-advocacy can be the norm for people with MS. 'The left hand doesn't talk to the right hand, and I think that's a massive thing.'

Solutions

1. **Improved access to liaison and acute neurology**. Everyone who would benefit from neurology expertise in hospital should be able to do so as close to home as possible. Specialised centres and DGHs must work together to make this happen. They should use the NHSE guidance on Delivering Acute Neurology Services and the Acute Inpatient and Liaison Neurology dashboard data. The Specialised Adult Neurology Services Service Specification for neurology sets out an expectation for networked approaches.
2. **Improved knowledge of MS on general wards and better link up with MS teams**. MS teams may be able to provide training for general staff, and advice and support while someone's an inpatient. But this depends on the capacity of MS nurses. And highlights the necessity to address pressures on this workforce in the short and long term.

7. Recommendations

People with MS can face delays and barriers at every stage of their care. People find diagnosis can take longer than it should and many have to travel further than necessary. More people with MS are experiencing emergency hospital admissions since the pandemic. This could be avoided if better support is provided earlier.

Many people with MS experience long hospital stays where their MS is poorly understood. And some are repeatedly admitted, showing gaps in inpatient and follow-up care. Variation between regions also points to a lack of national standards.

These issues are connected. They reveal a system that needs clearer national guidance and greater investment. This would better join up services, reduce variation and improve outcomes.

We need stronger leadership, more effective use of data, and increased support for the neurology workforce. Otherwise people with MS will continue to face unnecessary delays and poorer care. The following recommendations outline the national steps needed to address these challenges. And help ensure care works better for everyone living with MS.

Adoption of the Optimum Clinical Pathway

A clear, evidence-based MS Optimum Clinical Pathway already exists. It has a major role to play in reducing avoidable hospital admissions for people with MS. Our analysis of hospital activity shows delays in diagnosis, varied access to DMTs, and gaps in community-based support. These are having an impact on care for people with MS. The pathway provides a framework to tackle these issues, ensuring people get the right care at the right time.

NHS England has acknowledged the pathway within its broader neurology guidance. But to achieve consistent adoption across the country, it must take a more active role. This includes making it clear to integrated care boards that implementing the pathway is expected. As well as providing the funding and resources needed to do so. Without this level of leadership and support, the pathway risks being underused. This limits its ability to reduce pressure on planned and unplanned care.

NHS England and in future The Department of Health and Social Care should formally endorse the MS Optimum Clinical Pathway. And dedicate funding for ICBs to implement it as a priority for reducing hospital admissions.

Accountability

Local accountability

MS care is complex and the system has to navigate competing priorities. So we need specialist, experienced leaders in ICBs to allocate neurology services efficiently. They should be accountable for planning and delivering care pathways around the needs of people with MS. This will help ensure that people have consistent access and high-quality care.

Dedicated neurology leads within ICBs can help to make care proactive, better coordinated, and less reliant on crisis intervention. We need this kind of local leadership. Otherwise efforts to improve care risk being deprioritised within wider system pressures.

NHS England and in future The Department of Health and Social Care should mandate that each ICB appoints a neurology champion or lead. They will be responsible for overseeing neurology services and improving care across the pathway.

National accountability

At a national level, we need strong leadership to maintain focus on neurology. Especially as NHS England merges into the Department of Health and Social Care. There's a risk that, without clear structures and leadership, specialist knowledge could be lost. This would affect how services for people with MS are developed.

The NHS England neurology transformation programme plays a key role in supporting ICBs to improve neurology care.

Its goals include reducing waiting times for diagnosis and treatment and improving coordination between primary and specialist care. And ensuring fair access to services. This programme must remain to champion these issues.

National leadership has a key role in setting expectations for how MS care should be delivered. And ensuring these are reflected in local planning. Without this level of national accountability, improvements risk stalling or reaching people unevenly. This would leave some areas with less support to reduce avoidable admissions and improve care.

The Department of Health and Social Care should preserve senior neurology leadership roles. This includes the National Clinical Director for Neurology and the NHS England neurology transformation programme in any new structures.

Data

We need better use of data to understand the drivers of hospital use among people with MS. And identify where services can be improved. Our analysis shows variation across England in admissions, length of stay and readmissions. But this picture is incomplete without consistent local monitoring and insight. The Adult Neurology ICS Dashboard offers a valuable opportunity to support this work.

The dashboard brings together data across neurology, including non-elective admissions, inpatient and outpatient waits, prescribing activity, and workforce information. It includes MS-specific metrics and allows for comparisons between ICS areas. This helps to identify variation in access, outcomes and service use.

The dashboard has a lot of potential. But it remains underused by many local systems. Developing this dataset alongside improving visibility and accessibility would support commissioners, providers and clinicians to get more from it.

We believe there's a strong case for a dedicated clinical audit of MS hospital care. This could provide a more in-depth view of care quality, pathways and outcomes across inpatient and outpatient settings. It could examine areas such as timeliness of access, use of disease-modifying treatments, delayed discharges. And whether people are receiving support to manage their condition outside of hospital.

An audit would help identify where care could be improved. But it could also highlight good practice and inform more coordinated planning across neurology. There are also opportunities for the third sector to contribute to or support this work. And ensure that the priorities and experiences of people with MS are reflected throughout.

ICBs should actively use neurology dashboard data to identify and address causes of high hospital admissions for people with MS.

NHS England, and in future The Department of Health and Social Care, should make the neurology dashboard publicly available. This would enhance transparency and support informed patient choice.

NHS England, and in future the Department of Health and Social Care, should commission a national clinical audit of MS hospital care. This should be coordinated with the third sector.

Workforce

We need a well-supported and sustainable workforce. It's essential to improving care for people with MS and reducing avoidable hospital admissions.

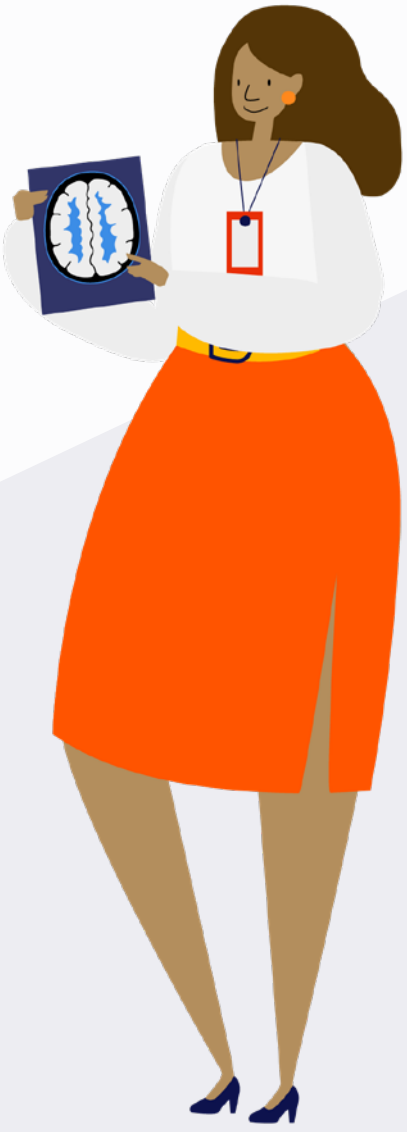
Specialist MS nurses, neurologists, and allied health professionals play a key role in managing symptoms and ensuring appropriate treatment. And supporting people to manage their condition in their own communities. Evidence shows that proactive input from MS nurses can reduce unplanned hospital stays. And urgent neurology appointments can prevent some admissions altogether.

But shortages and staff changes disrupt the continuity of care and result in more people relying on hospital services. Rural hospitals can also struggle to attract and retain staff as neurologists are often drawn to working in cities and specialist centres.

This means that people in those areas have less access to specialist care.

Workforce planning must support MDTs working within neighbourhood health frameworks. As well as ensure that we keep specialist expertise. Recruitment and training shouldn't be limited to specialist or teaching hospitals. It should also involve partnerships to encourage staff to work in rural and underserved areas. We need steady investment and good planning. Otherwise pressure on hospital beds will grow, and people with MS will face worse outcomes and experiences.

NHS England should include comprehensive neurology workforce planning in the NHS long-term workforce strategy.



A neurology Modern Service Framework

The 10 Year Health Plan's introduction of 'Modern Service Frameworks' gives us an opportunity. It can help to decrease hospital admissions and tackle the variations experienced by people with MS. The first wave of implementation will begin in 2026 by focusing on cardiovascular disease, mental health, and frailty and dementia. Neurology including MS isn't currently included as a priority.

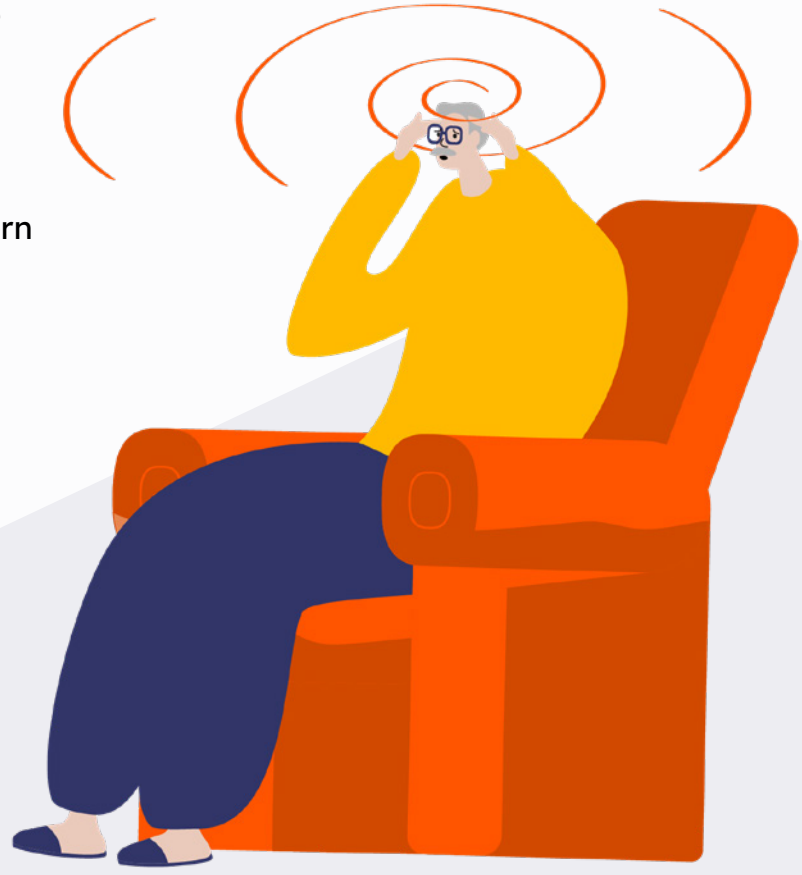
One in six people in the UK live with a neurological condition. So excluding neurological conditions from the first wave is a major omission. The Modern Service Frameworks establish long-term goals. They select the most effective evidence-based interventions and create uniform care standards. Neurology needs this type of national focus to improve coordination and decrease preventable hospital admissions.

The 10 Year Health Plan aims to move healthcare services from hospitals to community settings. A Neurology Modern Service Framework would help achieve this goal.

It would make sure that local services have the necessary capabilities to deliver prompt diagnosis, DMTs and neurorehabilitation. And sustained specialist care. The framework would set out guidelines about how specialist services and neighbourhood teams should work together.

We need to be included in this programme. Without it, neurology risks being overlooked in national efforts to improve access, quality, and consistency across the NHS.

The Department of Health and Social Care should include neurology within the Modern Service Frameworks programme. This would help ensure it receives comparable focus, investment, and clinical leadership.



8. Conclusion

This report lays bare the reality of MS care within today's NHS. People are waiting too long for first appointments. Many are struggling to access the care they need. And too often, people end up in hospital when this could have been avoided. The figures reflect the experiences of thousands of people with MS. Too many are living with unmet needs and reduced quality of life.

Access to care varies widely across the country. Some areas offer excellent support. But others struggle to meet people's needs. This inconsistency is a sign of deeper pressures within the system. Workforce shortages, limited resources, and competing demands across clinical specialties all contribute to the challenge.

But the analysis points to clear opportunities for change. Many of the most common causes of emergency admissions can be prevented with the right support in place. Including urinary tract infections and respiratory problems. The MS Optimum Clinical Pathway sets out a practical approach to joined up, effective services.

Solutions will depend on collaboration across the health system. This is not just about spending more. It's about making better use of what's already available. Preventing health problems early on avoids higher costs later. Quicker diagnosis and timely treatment help people stay well for longer. When care is coordinated, people with MS find it easier to navigate.

The evidence in this report sets out what needs to happen. If the recommendations are taken forward, MS services could be more consistent and more effective. And better able to meet the needs of those who rely on them.

The NHS has the skills and knowledge to provide excellent care. But this will require a rethink of how services are organised and delivered. With shared commitment, the changes set out here are within reach. People with MS deserve a different path. One that ensures timely treatment, reliable support, and care that truly meets their needs.

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