

# A different path: Rethinking MS hospital care



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**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<sup>1</sup>.
- **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<sup>A</sup> 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. 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.

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

## 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.

