A better MS future: We shouldn't have to fight

A manifesto for living well with MS

Living with MS is already a fight.

MS is unpredictable and different for everyone. It can be painful, exhausting and disabling. Many symptoms are invisible, but their impact is real. For too many people, life is made harder not just by MS, but by systems that are too slow, too complex and too difficult to access.

It can mean fighting fatigue, pain, mobility problems, cognitive changes and symptoms other people can't see. It can mean fighting to get a diagnosis, fighting for treatment, fighting for social care, fighting for a suitable home, fighting to stay in work and fighting for financial support that should be there when it's needed most.

People living with MS in Northern Ireland are being forced to navigate a system that is fragmented, inconsistent, and too often only responds in crisis. That should not be their reality.

Over 5,300 people live with MS in Northern Ireland, with many more waiting for diagnosis. They deserve timely healthcare, flexible employment support, accessible homes and transport, a social care system that works, and financial support that recognises the extra costs of MS.

This manifesto is grounded in co-production and shaped directly by people living with MS. Their message is clear; people with MS should not have to fight for support that should already be there.

We're calling on all political parties to commit to practical action in the next Assembly mandate and help build a better MS future rooted in fairness, dignity and independence.

System wide failure

Adequate health care is vital to living well with MS. Everyone with MS should have access to the health services they need to best manage their condition. Neurology and wider support services are stretched, underfunded and have been overlooked for years. This can't continue.

Many people with MS work. But many are forced to leave work before they need or want to because employment support is inadequate. We need an employment system that better supports people with MS find, move into, and stay in work.

Living with MS is hard. It shouldn't be made harder by a welfare system that doesn't make sense. We need a welfare system that understands MS and ensures people with MS have sufficient financial support to cover the extra costs of the condition and live with dignity. This isn't happening.

Adult social care in Northern Ireland is in crisis. It's failing to deliver the quality care that people of all ages affected by MS rely on to live independently. This means too often people with MS can't get the support they need to stay active and independent. We need a social care system that works for people with MS.

Everyone with MS needs a safe, suitable home. Too many are stuck in inaccessible housing or waiting too long for adaptations. We need accessible, affordable homes that support independence.

Accessible transport and infrastructure are essential to independence. Too many people with MS face barriers getting to appointments, work and everyday life. We need accessible, affordable transport and public spaces designed around disabled people.

Improving access to neurology services

Neurology services in Northern Ireland are in crisis. Staff are overstretched, services are under-resourced and people are waiting far too long for basic care.

Severe workforce shortages across all disciplines within neurology is limiting access to care with many unable to access support at all, while others report negative or dismissive experiences due to overstretched services.

For people waiting for a diagnosis, delays are unacceptably long. Many feel they have no choice but to pay privately or face years of uncertainty while their symptoms worsen and their condition progresses. Many more present to A&E in crisis and are left without the specialist care they need.

After diagnosis, too many people with MS are left to navigate their condition alone. Without a clear clinical pathway, many feel overwhelmed and isolated. Mental health support should not depend on geography, crisis, or charity provision; it should be built into MS care from diagnosis and available again at key points when people are adjusting to life-changing symptoms, treatment decisions, changes in mobility, relationship pressures or leaving work.

For those living with MS for years, the struggle didn't end at diagnosis. People told us they are waiting too long for treatment, going years without a review appointment with their neurologist, not being offered MRI scans and have no access to rehabilitation services such as physiotherapy to help them live well with MS. Delays in treatment including missed or postponed infusions also leaves many with deteriorating symptoms causing avoidable stress and anxiety risking longer term poorer health outcomes.

Too often, people are forced to chase appointments, fight to be heard and manage a progressive condition without the consistent care they need. This is not good enough and leads to avoidable progression. People with MS are carrying the burden of widespread system failure.

On health we're calling for:

- Commit to urgent investment in neurology services, including full implementation of the Regional Review of Neurology Services with clear timelines and accountability.
- Deliver a clear MS care pathway across Northern Ireland, with timely access to diagnosis, MRI scans, treatment, physiotherapy, occupational therapy and mental health support.
- End the postcode lottery in MS care by expanding the specialist workforce and improving MS awareness among GPs and other frontline healthcare professionals.
- Guarantee timely access to counselling, neuropsychology and mental health support at diagnosis and at key transition points, including changes in symptoms, mobility, relationships, employment, caring needs or treatment.

Case study: Fighting for diagnosis

Olivia was diagnosed with MS in February 2026, after months of worrying symptoms and uncertainty. When numbness became impossible to ignore, she went to A&E looking for answers. Instead, she left feeling dismissed, upset and as though she had wasted everyone's time. Like too many people with suspected MS, Olivia was left in limbo at one of the most frightening moments of her life.

Olivia was able to access private care but still faced months of waiting before getting answers and starting to plan her treatment.

Her experience shows the emotional toll of delays, poor communication and a lack of support after diagnosis.

No one should be left to face fear, uncertainty and life-changing decisions without clear information, timely care and the mental health support they need.

Improving access to employment

Most people are diagnosed with MS in their 30s and 40s, when careers, families and finances are under pressure. People with MS want to work but many need additional support to stay in work.

Our survey to inform the Disability and Work Strategy showed 72% of respondents are in paid employment, including 46% full-time, 26% part-time and 4% self-employed. But too many are being pushed out:

- 50% of respondents said MS significantly affects their ability to work.
- 44% have left a job because of MS.
- 38% are working below their skill level.

Fear of disclosing a diagnosis also remains a major barrier, driven by concerns about stigma, reduced opportunities, or job loss.

This is not only a matter of good employment practice; it is a matter of rights. Employers already have legal duties to support disabled employees and make reasonable adjustments. When people with MS are denied adjustments, pushed out of work, or treated as a problem because their condition fluctuates, that can amount to discrimination.

Government must make sure those rights are understood, enforced and reflected in employment policy.

Good support keeps people in work. Supportive managers, flexible hours, home working, time off for appointments, phased returns, accessible parking and regular adjustment reviews can make the difference between staying in work and being forced out. But too often levels of support are inadequate and can change between managers.

People told us they had been managed out of work, pushed towards ill-health retirement, left to navigate complex processes alone or made to feel like a problem. Others reported having to use holiday leave to attend appointments and recover from treatment.

While many feared disclosing MS to employers especially when applying for promotion or new jobs because they worried they would be judged and not appointed.

Flexible working must be standard practice. Flexible working is one of the most effective ways to help people with MS remain in work, but too many people still can't access the flexibility they need. Working from home, flexible hours, part-time work and phased returns should be normal, not exceptional.

Employment support must be joined up with health and financial security. Delays in diagnosis, treatment, neurology follow-up, rehabilitation, mental health support and fatigue management all make it harder to stay in work. People with MS should not be left unsupported until employment becomes unsustainable.

Existing support is not reaching enough people. Our survey found 72% were not aware of Access to Work (NI), Workable (NI) or the Condition Management Programme, only 6% had applied for Access to Work, and over half had not accessed any financial or employment support to help them stay in work.

Leaving work because of MS can mean losing income, identity, independence and confidence.

Employment support must help people stay in work where possible, progress in work where they can, and be properly supported when work is no longer possible.

On employment support we're calling for:

- Use the Good Jobs agenda and the Disability and Work Strategy to strengthen protection from discrimination and ensure employers meet their legal duties to disabled employees.
- Make job retention a central principle of the Disability and Work Strategy.
- Keep people with MS in work through flexible working, phased returns, time off for appointments and timely reasonable adjustments.
- Strengthen employer accountability on reasonable adjustments, MS awareness and manager training.
- Raise awareness of existing employment support programmes so support is visible, fast and easy to use.
- Join up employment, health and financial support so people are not forced out of work by system failure.
- Provide counselling, advice and transition support when people have to reduce hours, change roles or leave work because of MS.

Case study: Fighting to stay in work

Margaret* was diagnosed with MS while on maternity leave after having her third child. She had been working in a community-based role supporting people into employment, travelling across a wide area.

Instead of exploring how her role could be adjusted, her employer focused on why adjustments would not work. She was left feeling pushed out, expected to explain MS herself, and forced to navigate a major life change without the support she needed.

Leaving work meant losing income, confidence and a major part of her identity. And she was left to deal with these feelings alone with no support.

Margaret's experience shows why employers must act early, understand fluctuating conditions and explore practical adjustments such as reduced travel, flexible hours, home working, phased returns or redeployment.

People with MS should not be forced out of work because support is considered too difficult.

*Not her real name

Improving access to financial support

The PIP process is causing harm. It's complex, exhausting, and fundamentally misaligned with the realities of living with MS.

Living with MS brings unavoidable extra costs, including transport, support at home, treatment, therapies and mobility aids. PIP helps people meet these costs, stay independent and, for many, remain in work. But too often the current system is stressful, mistrustful and poorly designed for fluctuating, invisible and progressive conditions. People with MS need a welfare system that understands MS.

People described a 40-page form, delays, cancelled assessments, confusing communication and the distress of having to describe their condition at its worst, with little recognition of the psychological toll this creates. Assessments were described as interrogations, not conversations. They leave many feeling humiliated, disbelieved and forced to fight for support they should have been able to access fairly.

Assessments must reflect the reality of MS. Medical evidence, specialist evidence and the person's own account must be given proper weight. Informal observations, such as how someone appears when they arrive for their assessment, can't capture fatigue, pain, cognitive symptoms, bladder and bowel issues, recovery time or day-to-day fluctuation.

People with MS are regularly reassessed. This is unnecessary and must end. Reassessment anxiety can sit in the background for months, damaging mental health.

On financial support we're calling for:

- Redesign PIP around fairness, dignity and respect so it reflects fluctuating, invisible and progressive conditions like MS.
- Give proper weight to clinical evidence and the person's own account.
- End informal observations.
- End unnecessary reassessments for people with long-term, incurable and progressive conditions replacing with light-touch check-ins focused only on whether support needs have increased.
- Adequately fund independent welfare advice and advocacy so people with MS are not left to navigate PIP, Universal Credit or wider benefits alone.

Case study: Fighting to access financial support

Treasa was diagnosed with MS 10 years ago and recently applied for PIP. She describes her telephone PIP assessment as exhausting, confusing and inaccessible.

Fast questioning and sudden changes of topic made it difficult to follow, especially while managing cognitive fatigue and processing difficulties.

Rather than feeling listened to, she felt cross-examined, with questions that seemed to test or undermine her answers instead of exploring how MS affected daily life. In a process that should have been designed around her needs she felt forced to explain MS, challenge assumptions and make sure medical evidence was properly understood. The assessment left her distressed and under pressure.

Treasa's experience shows why PIP is not fit for purpose and must be reformed. Assessors should understand fluctuating conditions and treat people fairly with dignity and respect.

Improving access to adult social care

People living with MS deserve to live independent and fulfilling lives. But for too many people this isn't the case due to a social care system that is at breaking point. Severe workforce shortages have led to demand outstripping supply, with rural areas particularly at risk of the withdrawal of care.

Formal carers are essential to helping many people with MS stay safe, independent, in work and connected to their communities. They support people to manage a condition that is both fluctuating and progressive.

Reliable care can prevent avoidable hospital admissions, support timely discharge and reduce pressure on wider services. But too often care packages are difficult to access and often fail to reflect real-life needs. Rigid structures that prioritise system convenience over individual needs force many people to lose their independence and access to adequate support.

In the absence of formal provision family and friends are forced to step in. Although unpaid carers provide invaluable support, they should not be expected to make up for failures in formal care.

Many people have reported not knowing how to access social care when they need it. This can result in crisis situations and avoidable hospital admissions highlighting a critical gap in awareness and signposting within existing MS clinical pathways.

On social care we're calling for:

- Invest in the adult social care workforce so people with MS can access reliable care.
- Make social care flexible, person-centred and easy to access, with clear pathways, direct payments and carers' assessments.
- Improve access to Carer's Allowance and benefits advice for unpaid carers.
- Strengthen rights for working carers, including carer's leave, flexible working and employer support.
- Guarantee timely respite and short breaks, including in rural areas, so carers can protect their own health.

Case study: Fighting for care

Caroline's care package was scheduled at times that made it impossible to live a normal life. Her morning call arrived so late she could not get out in time for work, while evening calls came far too early. The package did not reflect the reality of her day.

After months of fighting, she finally secured times that worked for her.

Caroline's experience shows why care packages must be flexible and built around people's lives, not provider convenience.

Improving access to housing

Suitable affordable housing is essential to living well with MS. But too many people can't access a home that meets their needs.

People told us there is too little accessible social housing, too little support to navigate the system and too many delays in getting the right home or the right adaptations.

Unsuitable housing undermines independence, increases risk and can leave people isolated.

On housing we're calling for:

- Speed up access to home adaptations and grants, and shift housing policy towards prevention, independence and early support.
- Fix the housing system so accessibility needs are identified early, properly prioritised and backed by clear information and advice.
- Build more accessible and adaptable social housing across Northern Ireland, including more ground-floor homes and bungalows.

Case study: Fighting for housing

Samuel* was repeatedly offered housing that did not meet his access needs, including a property on a steep hill with poor transport links. He had little information about how the system worked and no one to explain his options or support him with his application for suitable housing. Only after a long and exhausting fight was he able to secure suitable accommodation.

His experience shows why accessible housing must be prioritised from the start, with better advice and support to help people navigate the system.

*Not his real name

Improving access to infrastructure and transport

Accessible infrastructure and transport are essential to everyday life. Yet too many people with MS face unnecessary barriers getting to appointments, work, public buildings and social activities.

People told us about inaccessible public spaces, limited wheelchair taxi provision, poor rural transport, inconsistent parking and public transport that does not meet disabled people's needs.

They also described how uneven paths, missing or poorly placed dropped kerbs, narrow pavements, steep gradients, poor surfaces can make everyday journeys unsafe, exhausting or impossible.

These barriers limit independence, increase isolation and show why transport and public spaces must be designed around disabled people from the start.

On infrastructure and transport we're calling for:

- Embed co-production with disabled people as a requirement in the planning, design, delivery and review of public spaces, streets, transport, parking and buildings, so decisions are shaped by people with lived experience and meet real access needs.
- Deliver a fully accessible public transport system, with better support for wheelchair users.
- Invest in wheelchair-accessible taxis and review concessionary travel and wider transport support for disabled people particularly in rural areas.
- Make inclusive design the standard in parking, pavements, dropped kerbs, crossings, public spaces and buildings, with accessibility built in from the start and maintained over time.
- Require regular accessibility audits of pavements, crossings, dropped kerbs, parking and public spaces, with disabled people involved in identifying barriers and prioritising fixes.

No one should have to fight the system to live well with MS.

For people living with MS a consistent theme emerges across health, housing, welfare, employment, transport and infrastructure; people are forced to fight for basic access to support.

This manifesto calls for urgent, systemic change to ensure that people living with MS in Northern Ireland can access timely care, live independently, participate fully in society, and do so with dignity.

The next Northern Ireland Assembly has the opportunity to build a fairer, healthier future one where every person with MS can live well, work, and thrive in their community.

We're calling on all political parties to fight for people living with MS so they don't have to.