MS Society
Scotland

Care and Support Mini Manifesto Scottish Parliamentary Elections 2021

February 2021

Let's stop MS **together**

Contents

Foreword

Everyone living with MS, their family and friends has a unique MS story. We listened to their stories. We asked what was most important to people. And last year we launched our new strategy ‘Every MS Story’ which focuses on three long term goals:

- Helping people with MS to live well with MS
- Connecting people and making sure their voices are heard
- Working to find effective treatments and prevent MS

It only seems like yesterday that we were gathered outside the Scottish Parliament launching our 2016 election manifesto. We asked you to ‘Get Loud for MS’ and as a result received significant cross-party support of MSPs elected to the current parliament.

In December 2020, we launched our MS manifesto for the 2021 Scottish Parliamentary election focussing on three themes of care, support and treatment, social security, and wellbeing and connecting communities. This mini-manifesto focuses on wellbeing and connecting communities and explores the key issues in more detail.

We want the next government to raise the standard of MS services across Scotland, so that people with MS are able to access the right treatment, care and support, at the right time. No matter who they are, where they live or what their circumstances are.

In 2019, Healthcare Improvement Scotland published ‘General Standards for Neurological Care and Support’. This is a welcome step in tackling this variation. The standards commit to:

> “…set out the same high level of care and support for all adults in Scotland regardless of their neurological condition, care setting, geographical location or personal circumstance.”

In December 2019 the Scottish Government published the ‘Neurological Care and Support: Framework for action 2020-2025’. The Government then announced a funding programme to support collaborative work in achieving the priorities of the framework. While the pandemic has delayed elements of this work, we were delighted to receive funding to support the MS community during these difficult times.

These publications are welcome but we want the next Government to go further to make sure they result in meaningful improvements to MS services across Scotland. So this election time we’re asking you to get ‘Louder for MS’ to make sure the voices of everyone living with MS in Scotland are heard in parliament.

Morna Simpkins
Scotland Director

About MS and the MS Society

Over 15,700 people in Scotland have MS. It's unpredictable, and different for everyone. It's often painful, exhausting and can cause problems with how we walk, move, see, think and feel.

But it doesn't have to be this way. We're driving research into more – and better – treatments. For everyone.

Together, we are strong enough to stop MS.

Executive summary

Over the lifetime of the next Scottish Parliament we want to see bold action taken and tangible differences made in the following areas:

Care, support and treatment for people living with MS is person centred, consistent and based within the community

1. Creation of a 'Right to Rehab', giving everyone in Scotland equal access to the right support in the right place at the right time
2. Access to appropriate Disease Modifying Therapies(DMTs) no matter where you live in Scotland
3. Access to MS Nurses when you need them no matter where you live in Scotland

Creation of a world-leading, rights based social security system co-produced with people affected by MS

4. Scrap the 'PIP 20m rule' and use appropriate assessment criteria
5. Sufficient additional help to cover the associated extra costs such as heating, transport and disability equipment for people living with MS
6. Sufficient additional financial support to unpaid carers

Supporting physical and mental wellbeing and building resilient communities

7. Greater provision of mental health services including emotional support when needed
8. Tackling digital exclusion and connecting people and communities
9. Addressing isolation and loneliness as a result of living with MS which increased during the Coronavirus pandemic

Care, support and treatment for people living with MS is person-centred, consistent and based within the community.

MS is a progressive, fluctuating condition and as a result people live with uncertainty about what the future will bring. It is vital that person-centred care and support, as well as treatments, are consistently available locally. People with MS need this so that they can effectively manage their condition.

The past two years have seen developments in public policy, informing what and how services for people living with MS in Scotland are delivered.

In 2019 the Scottish Government published 'Neurological Care and Support in Scotland: A Framework for Action 2020-2025'[a].And Healthcare Improvement Scotland revised the 'Standards for Neurological Care in Scotland'[b]. These, alongside other policy initiatives – such as Realistic Medicine and Modern Outpatient – outlined a new approach to treating and managing neurological conditions in Scotland.

This revised approach to MS and broader neurological services provides an opportunity to improve the long term outcomes for people living with MS regardless of where they live in Scotland.

Disease modifying therapies (DMTs)

In recent years the treatment landscape for people living with MS has evolved with new DMTs becoming available on the NHS in Scotland. For the first time a treatment is available for some people with early primary progressive MS. And just recently the first new treatment for active secondary progressive MS in over a decade was approved.

DMTs can decrease the number and severity of relapses and slow the progression of disability. And experts now agree that early treatment with a DMT can improve long-term outcomes[a].

But if we compare the results from our My MS My Needs surveys from 2016 and 2019, they show that the number of people taking a DMT who could potentially benefit from one hasn't changed much. In 2016 57% of people were taking one and 61% in 2019.

So it's more important than ever that people with MS can access the best treatment for them, regardless of where they live. Our research, which includes patient feedback and freedom of information data provided by health boards, shows a prescription postcode lottery - however unpopular this term is with policy makers[b].

Another significant development is that in October 2019 The Scottish Health Technologies Group approved Autologous Haematopoietic Stem Cell Therapy (HSCT) as a treatment for highly active relapsing remitting MS. This approval brought the Scottish treatment landscape in to line with England, making HSCT a more viable treatment option. This development has been widely welcomed by the MS community but in Scotland it's not yet offered as a treatment. While we recognise that this is

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[a] MS Society (2015) Time to Act - a consensus on early treatment, London, MS Society
[b] World MS Day Report – Barriers to prescription

partly related to COVID-19 and the impact that HSCT has on the immune system, a Scottish HSCT treatment pathway needs to be developed and rolled out as soon as possible.

What matters most to people living with MS?

Between November 2019 and January 2020, we held four face-to-face forums for people living with MS to better understand what aspects of their treatment, care and support matter most to them.

Through our previous work with the MS community, we thought we had a good idea of what range of services should be available to people living with MS. We wanted to test these assumptions and drill down further into what a good experience or outcome would be for people.

These forums took place in Glasgow, Kirkwall, Melrose and Stirling. We chose these areas to get a good geographic spread. And we knew local people with MS were keen to share their experiences. We wanted these forums to help shape our national programme of work supporting innovation and best practice. We also hoped they would generate specific information on local unmet needs that health boards and clinicians could use to improve services.

We asked people what a good DMT service should look like. They told us it should look like this:

- People with a confirmed diagnosis who are eligible and choose to take a DMT will start treatment within 12 weeks.
- The majority of DMTs are available locally.
- Travel is not so far that it limits your choice of a DMT.
- You are given good quality, accessible information about treatment options and can discuss options with a specialist to reach a shared decision.
- You are informed when you start a DMT if and when you might have to stop taking it and why (i.e. under certain clinical conditions) and this is a subject of ongoing discussion at annual review appointments.

But currently, while participants agreed that treatment should be available locally, many felt that this wasn’t the case. They felt they had experienced a postcode lottery and not been offered DMTs because of where they lived or accessed services.

We therefore ask for there to be fair and equitable access to appropriate DMTs no matter where you live in Scotland.

MS nurses

The MS Trust report that a sustainable caseload for a specialist MS nurse is one nurse to 315 people with MS. There are three prerequisites for this model to be sustainable:

- Availability of sufficient administrative support to enable MS nurses to focus on clinical tasks (this was calculated at 0.57WTE per full time MS nurse).
- Availability of clinical supervision, most often achieved where MS nurses aren’t working in isolation but rather are part of a wider team. This also allows for cross cover for leave.

- Availability of the full multi-disciplinary team for people with MS, so people with MS can access specialist input outside the scope of the MS nurse role.

Across Scotland there are health boards where these three requirements aren't met. Many MS nurse services don't have access to any administrative support. While in other areas, the MS nurse works in isolation and so it could be argued that they work without appropriate clinical support and supervision. Access to a full multi-disciplinary team also varies across the country.

The lack of these three prerequisites place the MS nurse services under increased pressure. And, the average MS nurse caseload in Scotland is 1 nurse to 384 people living with MS[c], higher than the MS Trust sustainable caseload ratio.

The role of the MS nurse

While the MS nurse role and service design varies across the country their involvement in DMT provision is one aspect that remains consistent. This is an aspect of an MS nurse's workload that's become increasingly complex, as there are now more DMTs available in Scotland. These increased treatment options mean that some people with primary and secondary progressive MS are now eligible for DMTs, increasing MS nurses' active caseload numbers. This pressure is only likely to increase as the treatment landscape expands and more of the MS population become eligible for DMTs.

MS nurses play a key role in all aspects of care and support for people living with MS. Our 2019 My MS My Needs survey showed that people that have seen either their neurologist or MS nurse in the previous 12 months, are more likely to be taking a DMT than people that haven't seen their neurologist or MS nurse. MS nurses also play a key role as a gateway to other support and services. Our survey highlighted that people who've seen their MS nurse in the past twelve months are more likely to have had their needs met for physiotherapy, emotional wellbeing and continence support.

In 2017 we campaigned with local MS groups for increased MS nurse provision, due to the dangerously high workload. It's difficult to ask for a specific number of new MS nurses. Different service models combined with the inconsistency in current staffing levels mean that each individual health board's requirements will be very different. We continue to believe that every health board should ensure adequate dedicated MS nurse provision to meet the needs of the local community now while they begin to plan for the future need of the services.

Rehabilitation Support

Thousands of people with MS rely on services like physiotherapy, occupational therapy and continence support to do the everyday things many people take for granted. Things like making a cup of tea or moving around their home safely.

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[c] MS Specialist Nursing in the UK 2018: Results from the 2018 MS Trust Mapping Survey, Hannan G, Sopala J, Roberts M, MS Trust, 2018

But too often people with MS can't get the support they need to stay active and independent. And this has only worsened during the pandemic. Our 'Too much to lose[d]' report demonstrated that missing out on vital rehabilitation support is having a devastating impact on the lives of people with MS. Too many are losing their mobility, confidence and independence. That's why, beyond the pandemic, we're calling for an expanded right to rehabilitation on the NHS - to keep people with MS moving forward.

There is currently no cure for MS. More treatments exist than ever before to slow the progression of the disease, but not everyone with MS is eligible. Most DMTs are licensed for relapsing forms of MS, with limited options for primary and secondary progressive MS.

Certain therapies, such as symptom management treatments, physio and occupational therapy, can keep symptoms under control and support people to maintain function. This can enable many people with MS to live independent lives less restricted by fatigue, incontinence, pain, immobility, cognitive fog and other debilitating symptoms.

Rehabilitation is an umbrella term for such treatments and therapies. The aim of rehabilitation is to reduce the impact of health conditions on a person's life, independence and goals. Rehabilitation is key to managing long-term conditions and maintaining a person's physical and emotional wellbeing. It's delivered by a wide range of health and care professionals and many people with MS will need to see a professional with expertise in MS or similar neurological conditions. The stories in our 'Too much to lose' report show just how varied rehabilitation is.

The common perception of rehabilitation is often about treatment in hospital after an MS relapse or fall. That could be intensive physiotherapy to get someone walking again or an occupational therapist arranging equipment to help make life easier after discharge home. But rehabilitation also happens outside of hospital. Not just to help continue recovery from a fall or relapse, but to manage the symptoms and emotional and cognitive effects of MS and maintain activity, function and quality of life.

Rehabilitation often relies on self-management – regularly doing exercises recommended by a physiotherapist or following a particular diet, for instance. Some support requires a professional to work 'hands-on' with their client – for example a physiotherapist may hold and move limbs for passive stretching to maintain range of motion.

Sometimes the terms reablement (short-term support following discharge from hospital) or prehabilitation (support before stress on the body from things like surgery or possible infection) are used to describe this kind of support. These are all points on the broad spectrum of rehabilitation, from recovery to maintenance. Whatever we call it, it's essential for people with conditions like MS.

The effect of the COVID-19 pandemic on rehabilitation

Rehabilitation has become more of a priority in the NHS in the wake of the pandemic, with many people needing support to recover from the effects of the virus. However, the degree to which improving rehabilitation for people with neurological conditions

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[d] Too much to lose, MS Society, October 2020

has been prioritised by governments before and during the pandemic varies across the UK.

The Scottish Government have demonstrated leadership by publishing a strategic framework for 'Recovery and Rehabilitation during and after the COVID-19 Pandemic', in August 2020.[1] This comes after the Government published an action plan to improve neurology services in 2019. Both documents commit the Government and NHS in Scotland to improve the support available to people with conditions like MS. Importantly, the framework states that:

> 'The coronavirus (COVID-19) pandemic has resulted in impairments for some people as a result of delayed healthcare treatments and social restrictions (which can lead to decreased physical activity, changes in nutritional intake and decreased psychological wellbeing). As a result, a public health approach to prehabilitation where early intervention for prevention is warranted to maximise resilience and promote general health and wellbeing.'

In August 2020 the UK MS Register life in lockdown survey vividly demonstrated the impact that the COVID-19 pandemic has had on people living with MS in Scotland. 44% of respondents reported that their MS symptoms had deteriorated during the lockdown period.

- 85% reported that their walking ability or balance had got worse
- 49% were experiencing more fatigue
- 42% reported that the muscles in their arms and legs felt weaker

While these statistics relate specifically to the impact of the pandemic, they shouldn't be viewed in isolation. Our My MS My Needs 2019 report and survey highlight that people with MS in Scotland weren't having their rehabilitation needs met prior to the pandemic:

- 29% of people with MS had an unmet need for physiotherapy
- 34% of people with MS had an unmet need to remain physically active
- 29% of people with MS had an unmet need for continence support
- 40% of people with MS had an unmet need for low mood or emotional support
- 33% of people with MS had an unmet need for care and support in relation to activities of daily living.

In the autumn of 2020 we campaigned to highlight the importance of rehabilitation to the MS community. This has become even more of an issue as a result of the pandemic and the impact it's had on people and the services they relied on for support. 'The Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 pandemic' must be resourced appropriately, both locally and nationally, so that people can access the rehabilitation support they need in their local community.

While the post-pandemic commitment to rehabilitation is welcomed, further commitment beyond this period is required. As a member of the Right to Rehab coalition we agree there should be a commitment from all political parties to deliver a Right to Rehab and we endorse the coalition's calls for:

1. A Right to Rehab which ensures that everyone has access to rehab when needed, and **no one is excluded by a 'no rehab potential'**.
2. People's needs to be met locally by having the right **workforce and professional leadership.**
3. The **Right to Rehab** to be incorporated in a new national Health and Social Care Strategy, **placing it at the heart of integrated health and social care.**

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[1] Scottish Government, August 2020, Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic, https://www.gov.scot/publications/framework-supporting-people-through-recovery-rehabilitation-during-covid-19-pandemic/pages/1/