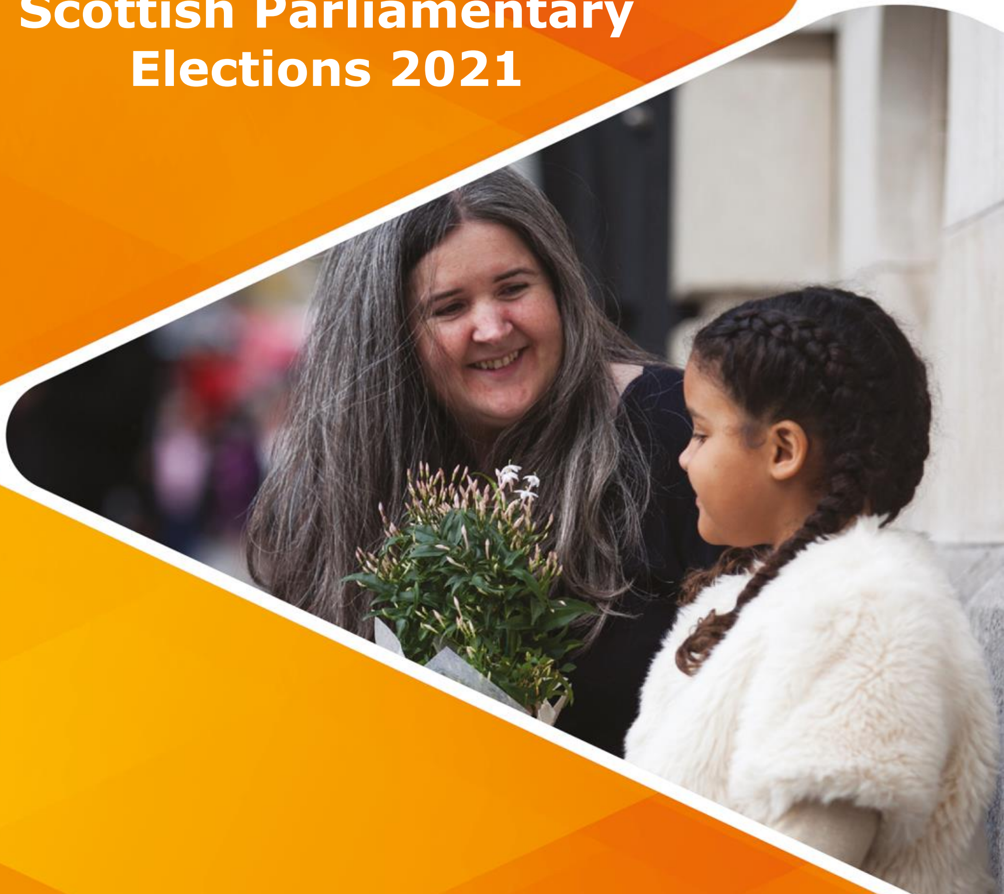
MS Society

Scotland

Manifesto Scottish Parliamentary Elections 2021



December 2020

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 earlier this year we launched our new strategy 'Every MS Story' which focuses on three long term goals:

- Helping people 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 only yesterday that we were gathered outside the Scottish Parliament launching our 2016 election manifesto. Then we asked you to "Get Loud for MS" and subsequently received significant cross-party support from MSPs elected to the current Parliament.

The past four years have seen advances in new disease modifying treatments (DMTs) being approved by the Scottish Medicines Consortium (SMC) including the first ever treatment for primary progressive MS in Scotland.

However, despite these advances our 2019 My MS, My Needs survey[a] told us that people still face many challenges in accessing the **care, support and treatments** that they need to effectively manage their condition. We know this needs to change and continue to campaign with and for people affected by MS.

The devolution of **social security** to the Scottish Parliament has been a key feature of our work since the last election. We're heartened by the progress made in influencing the Scottish Government's approach. There is still much work to be done to reach a longer term vision of social security which removes the financial barriers to independent living for people with fluctuating neurological conditions such as MS.

We have long understood the importance of **wellbeing and building resilient communities** through the work of our local MS Groups, volunteers and fundraisers. Together we have adapted our services during the global Coronavirus pandemic to meet the needs of the MS community.

Each of the three themes in this manifesto has a corresponding mini-manifesto setting out in more detail the stories the MS community has told us and the changes they'd like to see. We will be launching the first of these in January 2021.

So this election time we are asking you to get "Louder for MS" to ensure the voices of everyone affected by MS in Scotland are heard in Parliament.

Morna Simpkins
Scotland Director

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[a] My MS My Needs Report 2019, MS Society, June 2020

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 Treatments 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 therefore that person-centred care, support and treatments are readily available in their local community on a consistent basis so they can effectively manage their condition.

Disease Modifying Treatments

In recent years the treatment landscape for people living with MS has evolved with new DMTs becoming available on the NHS in Scotland. Comparisons from our My MS MY Needs surveys in 2016 and 2019[b] show that the number of people taking a DMT who could potentially benefit from one, has however remained consistent.

Regardless of where they live people with MS should be able to access the best treatment for them. Our research, which includes both patient feedback and freedom of information data provided by health boards, has shown a prescription post-code lottery; however unpopular this term is with policy makers[c]. We will be looking to the Neurological Care and Support: Framework for Action 2020-2025 to address this.

MS Nurses

The MS Trust report that a sustainable caseload for a specialist MS nurse is one nurse to 315 people with MS. In Scotland the average MS nurse caseload is 1 nurse to 384 people living with MS[d]. In 2017 we campaigned with local MS groups for increased MS nurse provision due to the dangerously high workload. We continue to believe that every health board should ensure adequate dedicated MS nurse provision to meet the needs of the local community. MS Nurses are often a gateway to accessing services and support.

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.

But too often, people with MS can't get the support they need to stay active and independent. And this has only got worse during the Coronavirus pandemic Our Too much to lose[e] 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.

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[b] My MS My Needs Report 2019, MS Society, June 2020

[c] World MS Day Report – Barriers to prescription

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

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

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

The devolution of social security to the Scottish Parliament has been a key feature of our influencing work since the last election. Whilst we're pleased that many of the suggested improvements in the application and assessment processes for disability assistance have been adopted there is still much work to be done to reach a longer term vision of social security; one which we share with many other organisations involved in the Scottish Campaign on Rights to Social Security (SCORSS).

We have focussed on improving the application and assessment processes so that people are treated with 'dignity, fairness and respect'. Over the past three years we have conducted focus groups around the country, held online sessions, engaged via social media and surveyed people living with MS to understand what they need from the new social security system in Scotland.

We want to see a system which understands and accommodates the fluctuating and degenerative nature of MS. We want to see a system that helps people get the support they need when they need it.

In our 2019 My MS My Needs survey people receiving benefits are twice as likely to be struggling on their current household income as people with MS who are not in receipt of any benefits[f].

On average people with a neurological condition like MS spend an extra £200 per week to cover expenses related to their condition.[g] We want to see a focus on adequacy within the future system.

Thousands of family members and friends who act as unpaid carers also bear additional financial costs. Our MS Family and Friends survey[h] found that only 16% of respondents received Carer's Allowance and 1 in 3 of those still experienced financial hardship despite receiving the benefit.

For people living with MS, the biggest change in Personal Independence Payments (PIP) has been the introduction of the 20 metre rule. This measure of mobility means that people who are able to walk even the smallest distance over 20 metres can no longer get the highest level of financial support under PIP.

The UK Government has never been able to produce any evidence that people who can walk over 20 metres have lower levels of need for mobility support. It is disappointing that as things stand the Scottish Government is looking to retain such a discredited assessment criteria in the new system. We believe the Scottish Government should scrap the 20 metre rule for the highest rate of mobility support within the new Disability Assistance. In the meantime the 50 metre threshold should be reinstated.

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[f] My MS My Needs Report 2019, MS Society, June 2020

[g] Extra Costs Commission – Driving down the extra costs disabled people face: final report, June 2015, pp.13

[h] MS Family and Friends Survey Results 2019, MS Society, June 2020

Supporting physical and mental wellbeing and building resilient communities

In 2018 we undertook research Local Groups – reducing loneliness[i] to understand the impact MS Society local groups have in reducing feelings of loneliness and isolation. We surveyed people with MS to find out if they have ever felt lonely or isolated, and whether being part of a local group helped.

As a result of being affected by MS the majority of survey respondents reported having felt isolated or lonely. There is a strong correlation between having felt isolated and also having felt lonely, 42% of respondents had felt both.

58% of respondents identifying as having felt isolated, with 60% identifying as having felt lonely. Almost 80% of respondents, who had felt isolated or lonely, said being part of a local group reduced their feelings of isolation and loneliness.

The research supported our anecdotal evidence that participating in local MS groups (and other such activities) helps to reduce feelings of loneliness and isolation. We have continued to undertake research on these themes in both our My MS My Needs 2019 and our MS Family and Friends 2019 surveys.

Our MS Family and Friends survey found that over half of those supporting someone with MS don't have the practical, emotional or financial support they need. This is despite the fact that 41% of people spent 35 hours or more a week providing support – the equivalent of a full-time job.

The Covid-19 pandemic has only increased those feelings as the usual support mechanisms were no longer available. Our Life in Lockdown report published in June 2020 found that: 36% of respondents told us they felt anxious; 13% said they felt scared and 28% said they felt frustrated[j].

We also saw an increase in calls from people with MS losing their carers because their carer was self-isolating and having difficulty finding new carers. There was an increased reliance on unpaid carers to provide support throughout lockdown. It further highlights the essential role of friends and family who care. They must also receive the support that they need to stay physically and mentally well.

Throughout the Coronavirus pandemic we've been here for people living with MS, helping our community to stay informed and connected. Our Wellbeing Hub is designed to provide a one-stop shop for people affected by MS to access a range of virtual services including counselling and physio support. Our award winning Freephone Helpline also offers emotional support to people affected by MS.

Despite the approval ratings from users of our Wellbeing Hub this is not an option which will suit everyone. We want to see the next Scottish Government commit to continuing to tackle digital exclusion, particularly with the increasing shift to digital by default in NHS services utilising the Attend Anywhere platform.

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[i] Local-groups---Reducing-Loneliness-and-Isolation, MS Society, August 2018
[j] Life in Lockdown with MS, MS Society Scotland, June 2020