MS Society

Scotland

Wellbeing Mini-Manifesto

Scottish Parliamentary Elections 2021

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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. 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 gathered outside the Scottish Parliament to launch our 2016 election manifesto. Then we asked you to ‘Get Loud for MS’. We subsequently received significant cross-party support of MSPs elected to the current parliament.

In December we launched our Scottish Parliamentary Election 2021 Manifesto. It covers three themes: care, support and treatment, social security, and wellbeing and connecting communities. This mini-manifesto relates to wellbeing and connecting communities. It explores the key issues in more detail.

We’ve long understand the importance of wellbeing and connecting communities through the work of our local MS groups, volunteers and fundraisers. Together we’ve adapted our services during the coronavirus pandemic to meet the needs of the MS community.

So this election time we are asking you to ‘Get Louder for MS’ to make sure the voices of everyone living and affected by 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 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. Those who are living with MS get sufficient additional help to cover the associated extra costs such as heating, transport and disability equipment
6. Increase in the earnings threshold for unpaid carers seeking to access Carers Allowance

Supporting physical and mental wellbeing and building resilient communities

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

Greater provision of mental health services including emotional support when needed

In 2018 we published a report that highlighted a significant number of people living with MS experience loneliness and social isolation.

In our survey of people living with MS 42% of respondents reported they had experienced both loneliness and social isolation.

Around 50% of people living with MS will experience depression at some point in their life. The UK MS register states that between a third and two thirds of people with MS will report symptoms of anxiety.

We are more aware of the issues that impact people's mood and emotional wellbeing. But the number of people reporting they haven't received the support they need has remained consistent. In our 2016 My MS My Needs survey, 41% of people with MS hadn't received the support they needed for mood or emotional issues. When we repeated the survey in 2019 it was 40%.

The COVID-19 pandemic has only increased these feelings. With lockdown, people haven't been able to use their usual support mechanisms. Many services were paused. Our Life in Lockdown report, published in June 2020, found that 36% of respondents felt anxious, 13% felt scared and 28% felt frustrated.

These findings are mirrored in Public Health Scotland's survey of people who have been shielding. Seventy two percent of respondents reported that lockdown has had a negative impact on their mental health.

Our 'What Good Looks Like' report on MS services highlighted that people view emotional support as something that's needed throughout their life with MS. From the time of diagnosis, people valued this support. It could help them come to terms with the impact of a diagnosis, consider how to tell family and friends, and understand the implications of their diagnosis and their options.

The pandemic has had an impact on the support people can get. Since COVID-19 more people have been getting their MS diagnosis by telephone or video. And people have found it harder to get appointments for worsening symptoms. It's also been harder for people to access self-management services.

We've seen an increase in calls to our MS Helpline from people with MS who've lost their carer because their carer was self-isolating. They then found it difficult to find new carers. As a result people increasingly relied on unpaid carers to provide support throughout lockdown - . Highlighting the essential role of friends and family who care. It's just as important that unpaid carers receive the support they need to stay physically and mentally well. Not only does this add additional pressure to the Carers involved but it can also be the source of increased anxiety and concern for people with MS.

Throughout the pandemic we've been here for people living with MS, helping our community stay informed and connected. Our Wellbeing Hub provides a one-stop shop for people affected by MS to access a range of virtual services. These include counselling and physiotherapy support. Our award winning freephone helpline also offers emotional support to people affected by MS.

Connecting people and communities by tackling digital exclusion

MS is different for everyone and many symptoms are invisible. People living with MS often face barriers and challenges in everyday life.

We believe that no one should face this alone, feel overwhelmed or misunderstood.

In our 2020-2024 strategy we make the commitment to increase the ways people affected by MS can share their experiences, tackle common issues, foster friendships, build confidence and reduce isolation.

Like most organisations we've had to adapt quickly to the COVID-19 pandemic and lockdown. The restrictions mean that we've paused our local group services. These services included things like exercise classes and social activities, delivered in community settings and supported by our volunteers, many of whom have MS.

In response we developed online services and information provision, like our Wellbeing Hug...

Over 400 people have received support from the Wellbeing Hub. Roughly half of these people have benefitted from one-to-one virtual support with the other half joining online group activities. Some have taken part in both.

We've also been running a series of online information webinars. These have covered a range of topics including COVID-19 and MS, dealing with health anxiety, relationships and MS, exercise and MS and, more recently, one dedicated to MS and the COVID-19 vaccines.

While this change to online service delivery has been well received by the MS community it doesn't suit everyone. One of the main barriers is poor digital infrastructure. Slow broadband speeds are a major factor. This either interrupts streaming or is not fast enough to support online delivery at all. Other major barriers to digital engagement include lack of devices, fear of technology and a lack of confidence and digital know-how.

We responded to this by developing our 'Keep in Touch' service. This phone-based service offered people a chance to talk to somebody during lockdown, helping to maintain social contact. Our MS Helpline has also offered support and advice to people living with MS during these challenging times.

The demand for our phone based services, despite our increased digital offer, highlights there's still a long way to go to achieve digital inclusion. A number of factors contribute to this but without investment we will never address digital exclusion. The importance of this has never been greater as a large proportion of healthcare appointments are currently being delivered virtually due to the pandemic.

We run the risk of inadvertently creating a two tier health system which excludes people.

We ask the Scottish Government to invest in the digital infrastructure needed to support people to use the digital revolution to improve their quality of life. This investment must address physical issues such as low speed broadband. But there must also be investment in programmes that will support people to access the appropriate technology and access courses to increase digital confidence and learn new skills. This will enable them to fully connect with their friends, families and their wider support teams.

Tackling isolation and loneliness as a result of MS, which increased during the Coronavirus pandemic

A key outcome of our strategy is to reduce loneliness and social isolation for all those affected by MS. By helping to forge communities that promote health and wellbeing we want to provide friendship and support for all of our community.

Loneliness is commonly defined as a painful emotion when a person feels they don't have the quality of emotional relationships they need to be happy. It's a mismatch between the relationships a person has and the relationships they want[1]. Loneliness is a subjective measure. A person can still feel lonely within a family or a social setting[a].

Social isolation differs from loneliness. It means a person has limited access to a range and frequency of social contact.

Chronic loneliness and lack of social network have been identified as having a direct and detrimental effect of physical health, particularly in relation to raised stress hormones, poorer immune function and reduced cardiovascular health.[b]

In 2018 we did some research on the role our local groups play 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 had 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 research 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

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[a] Campaign To End Loneliness: About Loneliness

[b] Cacioppo J., T., Patrick W (2009) "Loneliness: Human Nature and the Need for Social Connection, (pp336) London WW Norton & Company

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 people's usual support mechanisms haven't been available.

Over the past year the MS Society and the MS community have, through necessity, changed the way we support each other. While there have been positive developments, such as the roll out of our wellbeing hub and the keep in touch telephone service it is clear that there is still much more to do to build a fully inclusive connected community. There are many barriers to achieving this including our digital infrastructure and the social restrictions placed on us as a result of the pandemic.

The MS Society has demonstrated the impact that Government funding can have in supporting people to address loneliness, social isolation and people's mental health and physical wellbeing by providing funding for our wellbeing hub.

One person with MS who has used the wellbeing hub told us

> The Wellbeing Hub provides counselling as well which is not something I would have thought of as an option unless I'd seen it through the MS Society. But I've just had my first session and I took a lot from it.
>
> "I'm really glad it was suggested to me as I don't think I ever really dealt with my diagnosis and I needed it. Because I wasn't in the middle of a relapse when I was diagnosed I didn't think MS was affecting me too much so didn't really come to terms with it.
>
> "That just means it's all the better to do it, so that when issues do arises I'm more able to deal with them.
>
> "Even just speaking out loud helps and I can see how it will help more in the future. "Getting the chance to speak to someone impartial and neutral is welcome because the sort of people you will speak to about it you know really well.
>
> "Particularly during lockdown things have been harder for everyone so having that outlet has been great.

This is just one example of the benefit of the support that has been available. It is therefore vitally important that the next Scottish Government invests in wellbeing services, services to support social inclusion and in the digital infrastructure that is required.