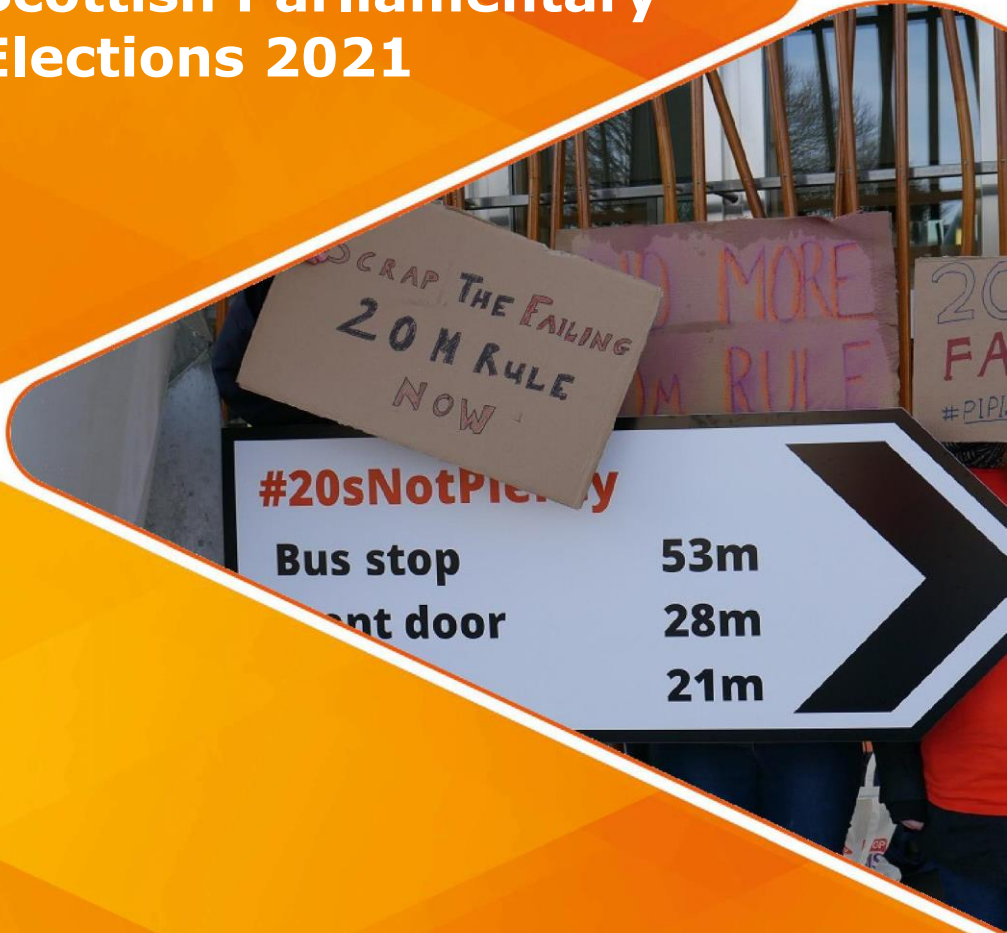




### Social Security Mini-Manifesto Scottish Parliamentary Elections 2021



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## 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. Then we asked you to 'Get Loud for MS' and subsequently received significant cross-party support of MSPs elected to the current parliament.

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

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. However, there is still much work to be done. We want 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 truly want to see dignity, fairness and respect being at the heart of devolved disability assistance. All too often we hear stories of how people's experiences couldn't be further removed from these principles. We're keen to work with the next Scottish Government and Social Security Scotland to make sure people get the right support with minimum stress during the application process. We want to work together to install confidence in the new system, but will always reserve the right to challenge when we believe the principles of dignity, fairness and respect are not being adhered to.

This mini-manifesto sets out some of the ways we believe the system can be changed to improve the experiences of people living with MS. So this election time we are asking you to get 'Louder for MS' to make sure the voices of everyone 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 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

## Scrap the PIP 20 metre rule and use appropriate assessment criteria.

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.

The devolution of social security to the Scottish Parliament has been a key feature of our influencing work since the last election. We're pleased that many of our suggested improvements in the application and assessment processes for disability assistance have been adopted. But there's still much work to do to reach the longer term vision of social security outlined in the Scottish Campaign on Rights to Social Security (SCORSS) report Beyond a Safe and Secure Transition. As a member of SCORSS we share this vision.

### **We welcome improvements to the application and assessment process**

We've focussed on improving the application and assessment processes so that people are treated with dignity, fairness and respect.

To understand what people with MS need from Scotland's new social security system, over the past three years we've:

- conducted focus groups around the country
- held online sessions and engaged with people via social media
- surveyed people living with MS

A recurring theme was that people felt the system is stacked against applicants. People told us they felt discouraged from appealing assessments as they didn't want to risk the level of award they currently had. This can't be right for any system which seeks to place dignity, fairness and respect at the heart of its work. So we support the Scottish Government in its intention to introduce Short Term Assistance payments<sup>a</sup> for people who are challenging decisions.

### **Proposed changes should make a big difference**

We also welcome many of the proposals in the five policy papers and consultation document published by the Scottish Government in October and December 2020<sup>b</sup>, such as changing the nature of the assessments to become person-centred'. If enacted properly, this could make a big difference to people's experience of a system they've described in the following ways:

"Feel like being watched – Big Brother – by the time you enter the building"

"It should be simpler and clearer with less jargon"

"Why do they assess every three years? For the likes of [name], he's not going to get up and run anywhere. Do you think he's going to improve overnight?..."

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<sup>a</sup> <https://www.gov.scot/news/new-benefit-system-to-offer-short-term-assistance/>

<sup>b</sup> <https://www.gov.scot/publications/disability-benefits-overview/>

We were pleased to read in the second of the five policy papers that the Scottish Government is planning on adopting a multi-channel approach to the application process. That is something which was requested by many of the people we spoke to and formed part of our response to the consultation on Improving Disability Assistance in Scotland<sup>c</sup> in May 2019.

### **So far, the government have failed to remove a discredited rule**

In December last year the Scottish Government published their Draft Regulations for Disability Assistance for consultation. We have been particularly interested in the assessment criteria for the proposed Adult Disability Payment, the successor to Personal Independence Payment (PIP). We are incredibly disappointed that currently the Scottish Government is looking to retain such a discredited assessment criteria.

We've been campaigning for changes to PIP since the summer of 2018. Since it began to replace Disability Living Allowance (DLA) in 2013, one in three people with MS moving over to this benefit have had their support downgraded, including one in ten who have lost support altogether. This is happening even though MS is a progressive condition where people's needs are only likely to increase.

For people living with MS, the biggest change to Personal Independence Payments (PIP) has been the introduction of the 20 metre rule to measure mobility. Under this rule, 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.

### **Why this rule doesn't work for people with MS**

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. Our own research also highlights the unfairness of the 20 metre rule for people living with MS.

In June 2018 we published our report 'PIP: A step too far' which looked at the impact of the changes on people living with MS. We carried out further research, published in April 2019 'The cost of the PIP 20 metre rule.' We found that over the (then) spending review period of 2020-2023 "the total knock-on costs to the UK Government outweigh what it will save by reducing PIP support for people with MS via the 20 metre rule"<sup>d</sup>. In November 2019 we published additional research focussing on the application, assessment and decision making processes - 'PIP fails: how the PIP process betrays people with MS'.

Many aspects of our findings are reflected in the Scottish Government's 'Welfare Reform Report<sup>e</sup>' which looked at the impact of welfare reforms on disabled people. The report cited evidence from the government's Lived Experience Panels and compared the differing approaches between the UK and Scottish Government.

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<sup>c</sup> <https://consult.gov.scot/social-security/improving-disability-assistance/>

<sup>d</sup> <https://www.mssociety.org.uk/sites/default/files/2020-08/20190408-Full-report-The-cost-of-the-PIP-20-metre-rule-FINAL.pdf>

<sup>e</sup> [Welfare Reform Report, Scottish Government, January 2020](#)

## Scrap the 20 metre rule in Scotland

We recognise that PIP is currently a reserved benefit and that the potential for radical changes are influenced by the attitude of the DWP, so we continue to lobby MPs for such change.

But when the new disability assistance is introduced in Scotland, we want the Scottish Government to scrap the 20 metre rule for the highest rate of mobility support - a position which is supported by CAS<sup>f</sup>.

If the Scottish Government feels it has to continue with the 20 metre rule, it should be thinking creatively about how to support people who would otherwise have been in receipt of the higher level mobility payment. For example, how feasible would it be to introduce a mobility allowance in a manner similar to the Carers Allowance Supplement? A review and design exercise should be carried out with disabled people, charities and healthcare professionals to design an agreed appropriate alternative. In the meantime the 50 metre threshold should be reinstated.

## Sufficient additional help to cover the associated extra costs such as heating, transport and disability equipment for those living with MS.

Life is more expensive if you have MS. Things like an adapted car, treatments and therapies, and higher gas and electricity bills are just some of the extra costs many people with MS face. On average people with a neurological condition like MS spend an extra £200 per week to cover expenses related to their condition.<sup>g</sup>

One study<sup>h</sup> estimated the average cost in the UK of MS per person, per year as:

- £11,400 for people with mild levels of disability
- £22,700 for people with medium levels of disability
- £36,500 for people with advanced disability.

Other studies put these costs as even higher, particularly for people with advanced disability. Living with advanced disability can cost more because of higher community services and informal care costs, and absence or exit from employment.

A social security system that supports people with the extra costs associated with their disability can help people to stay in work for longer. However too many people with MS leave employment because they don't get the support they need.

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<sup>f</sup> [A New Future for Social Security, Citizens Advice Scotland, October 2016](#)

<sup>g</sup> Extra Costs Commission – Driving down the extra costs disabled people face: final report, June 2015, pp.13

<sup>h</sup> Reference: Thompson A, Kobelt G, Berg J et al. New insights into the burden and costs of multiple sclerosis in Europe: Results for the United Kingdom. Multiple Sclerosis Journal. 2017, Vol. 23(2S) 204–216.

## Coronavirus has increased people's financial pressure

In our 2019 'My MS My Needs Survey' we found that people receiving benefits are twice as likely to be struggling on their current household income than people with MS who aren't receiving any benefits<sup>i</sup>.

In June last year we published a report<sup>j</sup> about the impact of the Coronavirus pandemic on people living with MS. Unsurprisingly we found that that lockdown had exacerbated the financial strains. Those who responded told us:

- 10% had seen a reduction in their pay or hours. 16% also reported that this was the case for another member of their household.
- 13% said that the coronavirus pandemic will have an impact and the damage will be long lasting on their household finances.

Living with a long-term condition such as MS already has a significant impact on your finances. Living with MS is expensive. With the additional financial implications of being at home more, along with concerns around job security, there is a risk that people with MS will become more financially insecure as a result of the pandemic.

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.

## Sufficient additional financial support to unpaid carers

**40% of people with MS in Scotland are receiving unpaid care from their family or friends.** This has a massive impact on everyone involved, changing the dynamic of relationships, as well as making it difficult for the care giver to balance work, education and enable them to take care of their own health and wellbeing. A study published in 2017 calculated that this unpaid care and support equates to, on average 5 hours support per day for 19 days a month.

We want to see a focus on increased financial support within the future system, particularly for the thousands of family members and friends who act as unpaid carers. The Scottish Government have addressed this, to some extent, with the introduction of the Carers Allowance Supplement. However continued research identifies that more needs to be done to support unpaid carers at a time when people with MS become more reliant on their friends and families for support.

Our 'My MS My Needs 2019 Report'<sup>k</sup> highlighted the unmet needs of people living with MS in respect of their care:

- 27% of people with MS didn't receive enough support to enable them to move around their home safely in the past twelve months

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<sup>i</sup> [My MS My Needs Report 2019, MS Society, May 2020](#)

<sup>j</sup> [Life in Lockdown with MS, MS Society, June 2020](#)

<sup>k</sup> [My MS My Needs Report 2019, MS Society, May 2020](#)



- 16% of people don't have enough support to enable them to wash and bathe while 18% have an unmet need for support with eating

One of our recommendations in the report was that "Family and Friends that provide unpaid care are offered an Adult Carer Support Plan to ensure that they receive the care and support they need as detailed in the Carers (Scotland) Act 2016."

In 2019 we also conducted our Family and Friends survey<sup>l</sup> which highlighted the significant financial impact of being an unpaid carer. We found that only 16% of respondents received Carers Allowance with 1 in 3 of those still experiencing financial hardship despite receiving the benefit. A fifth of respondents were 'struggling or really struggling' on their current income.

Financial struggles have led to 80% of respondents feeling stressed or anxious, 74% have been unable to take part in hobbies or leisure activities, 59% have seen less of family and friends, and 57% have been unable to afford a break from their role supporting someone with MS.

### **The impact of lockdown on carers**

In June 2020 we reported<sup>m</sup> that there had been an increase in enquiries to our MS Helpline related to people with MS who had lost their carer due to the carer self-isolating, and had difficulties finding new carers.

There was also an increased reliance on unpaid carers to provide support throughout lockdown. While this is not surprising it further highlights the essential role of friends and family who care – and that they must also receive the support they need to stay physically and mentally well.

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<sup>l</sup> MS Family and Friends Survey results 2019, MS Society, June 2020

<sup>m</sup> Life in Lockdown with MS, MS Society, June 2020