MS: Enough
Make welfare
make sense

The Scottish Picture

Multiple
Sclerosis
Society

> ‘With conditions like MS that have no cure, and don’t just go away, there must be a fairer way for people to be treated throughout the benefit process.
>
> To be assessed less than a year since my original assessment makes me feel like a benefit scrounger, a cheat, as if they are trying to catch me out.
>
> Living with MS on a day to day basis is hard enough without being scrutinised by the DWP/Atos.’

Front cover image © Graeme Allison

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Foreword from Morna Simpkins, Director of MS Society Scotland

Right now people in Scotland with MS need the welfare system to change so that it makes sense.

It is simply not good enough that people in Scotland who have MS are being forced to make difficult choices between heating their homes or attending hospital appointments.

It's also deeply saddening that almost 90% of the people we spoke to during this work feel that the public negatively judge those who claim disability benefits.

People with MS need and deserve more from their welfare system.

Our MS: Enough campaign is our promise to fight for those in Scotland who face poverty, inequalities, deprivation and discrimination due to the failures of the current system.

Our aspiration is for people with MS to get the support they need to live fulfilling and independent lives – something many people take for granted.

We know that having MS can be costly with many people relying on the safety net and support provided by disability benefits just to cope every week. Our survey found that people with MS in Scotland are finding the application process stressful and are not accessing the financial assistance and support they need.

Too many people with MS also face stigma and harassment because they receive disability benefits. This must change.

It is important that we act upon these findings so that people with MS don't face unnecessary barriers to support. We encourage decision makers in Scotland to seriously consider our recommendations to make a fairer welfare system.

We are in a time of unique opportunity, with so much public hope for the creation of a fairer and more equal Scotland through the devolution of new social security and employment powers.

We welcome the Scottish Government's commitment to a Social Security Bill in its latest Programme for Government. We hope this Bill will reflect our vision for a fair, equal and socially just Scotland.

We remind the Government of their duty to carefully consider the impact of devolved welfare negotiations on the vulnerable within our society, who are watching and waiting for clarity on decisions that could change their lives.

About MS

Multiple sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. Scotland has one of the highest incidence rates of MS in the world, and around 11,000 people in Scotland live with the lifelong condition. Many experience their first symptoms during the peak of their working lives, in their 20s and 30s.

We are Scotland's leading charity dedicated to supporting people affected by MS. It is our mission to beat MS. We raise awareness of MS, make it a priority for Scottish politics and provide support and information to people affected by MS from the Borders to the Highlands and Islands.

Make welfare make sense

We have a strong message for the Scottish Parliament as it plans for the further transfer of powers under the Scotland Bill:

- People with MS must be at the heart of shaping a new welfare system.
- Decision makers must look at how Scotland's approach to welfare can mitigate against some of the challenges of funding constraints and ensure people with MS are not disadvantaged.
- The welfare system in Scotland must not threaten the financial security of people affected by MS through unmanageable assessment processes and short-term awards, but instead show a greater understanding of the complexity of the condition.

MS: Enough builds on our extensive work, including our Voices for Change programme, to gather the views and experiences of the benefits system and welfare reforms from people in Scotland affected by MS.

65%

agreed that without disability benefits they would be unable to afford essential items such as food and heating

As part of the campaign, we conducted a survey of 1,780 people with MS across the UK about their experiences of claiming disability benefits (see full UK report).

The figures used in this report are based on the 242 responses from within Scotland. This sample is those respondents who have ever made a claim for at least one of the following disability benefits: Disability Living Allowance (DLA), Personal Independence Payment (PIP), Incapacity Benefit (IB), Employment and Support Allowance (ESA) or Access to Work.

Key findings from our Scottish survey are discussed in this report:

- 65% agreed that, without disability benefits, they would be unable to afford essential items such as food and heating.
- 85% agreed that, without disability benefits, their independence would be negatively impacted.
- 91% found the process of claiming disability benefits stressful.
- Almost 90% feel that the public judge people who claim disability benefits.

People with MS need access to benefits to take care of themselves. Without this many will need more from public services, putting a further a strain on health and social care budgets.

By making welfare make sense we can prevent people with MS needing additional support in the future.

We need the Scottish Government to work with the MS community. To listen to the issues they face. To push for reform and to protect people with MS under a new devolved Scottish benefits system.

Welfare in Scotland

The Scotland Bill proposes to devolve new welfare powers worth £2.5bn – giving Scotland greater autonomy over a range of benefits for carers, disabled people and the elderly as well as more control of employment support.

As a result the welfare landscape in Scotland may develop quite differently from the rest of the UK.

Scottish Ministers propose scrapping the roll-out of PIP. However to date, there has been no clear blueprint provided for what might replace it. The Scottish Government also wants to implement Universal Credit flexibilities as soon as possible, remains committed to removing the bedroom tax and is opposed to any cuts to disability benefits.

Through its Programme for Government the Scottish Government has made a commitment to outline their policy statement on new social security powers before the end of 2015 and introduce a Social Security Bill in the first year of the next Scottish Parliament.

UK Ministers plan to pass the Scotland Bill before the Scottish Parliament dissolves at the end of March 2016.

Together with many in the third sector, we want to see the Scotland Bill include clauses which enables Scotland to take a holistic, integrated approach to supporting people with disabilities. This will build on ambitions identified within the Fairer and Healthier Scotland national conversations and facilitate maximum policy autonomy in shaping new benefits alongside devolved welfare services.[1]

A crucial difference to the lives of people with MS

Disability benefits enable those who rely on them to carry out everyday activities that many people take for granted, like attending medical appointments, caring for family and socialising with friends. For some individuals disability benefits also play a vital role in enabling them to stay in or access employment.

*Extra costs commission interim report

Currently the major disability benefits that people with MS can claim are:

- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- Employment and Support Allowance (ESA)

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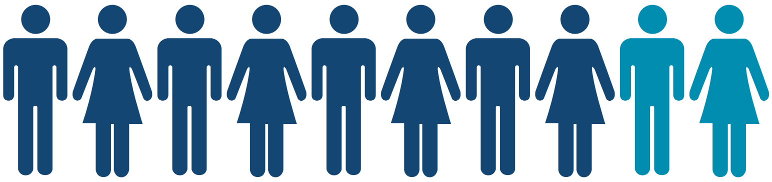
[1] SCVO Response to Devolution Committee call for written evidence on the Scotland Bill www.scvo.org.uk

80% of people with MS are forced to give up work within 15 years of diagnosis



DLA and PIP are non-means tested benefits intended to help cover the additional costs of an impairment or health condition. ESA replaced IB as the main out of work benefit for disabled people and provides financial assistance for those who can no longer work, as well as employment support for those who may be able to work in the future. People with MS placed in the Work Related Activity Group (WRAG) are expected to undertake work related activity – WRAG is a group within ESA. See the full UK MS: Enough report for more information on WRAG and details on the benefits available to people with MS.

Repeated periods of incapacity can unfortunately restrict or determine someone's career capability. Up to 80% of people with MS stop working within 15 years of the onset of the condition.[2] Others find themselves in unstable and low-paid jobs – 70% of our Scottish survey respondents agreed that MS limits the range of jobs they can do and the support they have received in the WRAG reflects this.

Further to impacting on ability to work, MS can have substantial associated costs, for example the need for accessible transport, specialist equipment and domestic help.

Benefits are a lifeline for people facing the additional costs associated with MS. They help them to remain independent and in many cases, financially stable.

74% of survey respondents agreed that disability benefits help them manage the extra costs of their MS, 65% agreed that without disability benefits they would be unable to afford essential items such as food and heating and 85% agreed that, without disability benefits, their independence would be negatively impacted.

People with MS are struggling to access the support they need

When people with MS cannot access the benefits they need, they must make difficult decisions. Some people cannot access essential items and support. Life with MS should not mean doing without the necessities, such as keeping your home warm or being able to get to work and medical appointments.

> “I can't keep my home warm. I need but can't afford domestic help.”
>
> “When I got my Motability car I went from working 12 -16 hours a week to working full-time because of my car. I'm really worried I will lose it.”

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[2] The Work Foundation, Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis

CASE STUDY

Jamie, Glasgow

Jamie, 26, is studying environmental science with the Open University. He was diagnosed with MS in December 2014, but his symptoms started two years ago.

"I've worked since I was 15-years-old and never had any experience of the welfare system. Until recently, I had a professional salary and a typical 20-something lifestyle. This is my first experience of claiming benefits, and it's been a minefield. I've been late with my rent, threatened with eviction and have got into debt.

I'm still waiting for a decision on my ESA claim, despite telling the Department of Work and Pensions (DWP) about my MS diagnosis seven months ago. I'm currently in the WRAG, which means I have to attend regular work-focussed interviews, and receive less money. I've been rejected for the Support Group several times and each time have gone back with more evidence. I'm appealing their decision and am waiting for another assessment.

Living on what I currently receive is very difficult and even a small amount of extra money would make a big difference. My housing allowance doesn't pay all my rent, so I make up the shortfall from my disability benefits, which doesn't leave me with a lot to live on. **I've had to give up many things that people take for granted, like hobbies and socialising. The financial impact of MS, along with mobility problems, can make it a very isolating condition**.

I often have extra costs to budget for. I have a disabled person's bus pass but on the days when my fatigue restricts my mobility I have to take taxis for things like medical appointments. I would like to learn to drive as it would give me so much more independence, but I can't afford lessons, let alone a car and insurance. I receive the lower rate of PIP, which enables me to get my bus pass, but not to get help with the costs of a car.

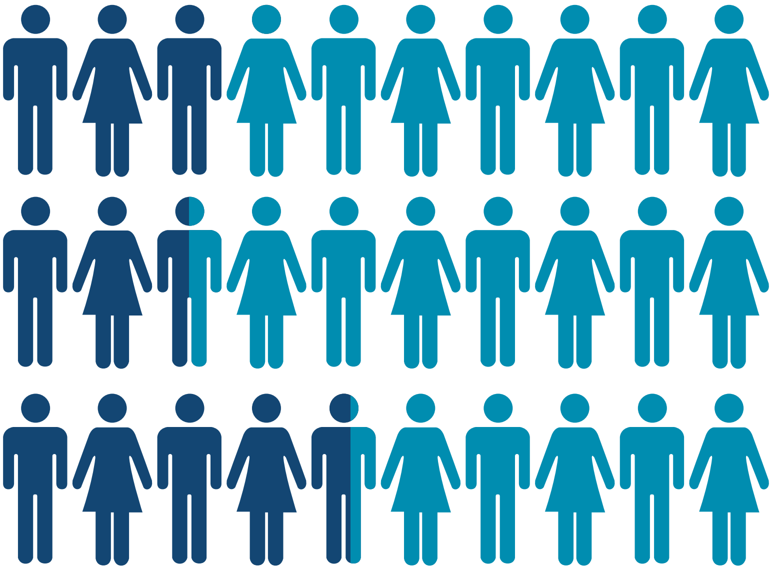
MS tends to strike younger people and the disability isn't always obvious. You can't see my fatigue, visual difficulties, pain and anxiety, but they exist, and I'm going to keep fighting for what I'm entitled to."

People with MS have had to reduce spending on basic essentials and socialising as a result of disability benefit changes

30%
Food

25%
Gas and electricity

47%
Socialising with family or friends



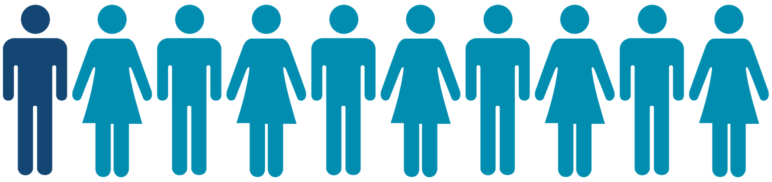
Our helpline is now taking an increased number of calls about benefits, the impact of changes already introduced to disability benefits and concerns about the wider welfare reforms.[3]

Respondents to the survey suggested that changes to disability benefits have caused stress, anxiety and financial difficulties which affect their ability to remain socially active and indeed their health and wellbeing.

In Scotland, 50% of our survey respondents agreed that changes to disability benefits have had a negative impact on them.

However we know that when people receive the financial support they need, the positive difference to people's lives can be hugely meaningful.

1 in 10
Have had to reduce spending on attending hospital appointments as a result of disability benefit changes



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[3] 'Voices for Change: What impact are welfare reforms having on people living with MS in Scotland and how can this impact be mitigated?' MS Society 2014

CASE STUDY

Ange, Scottish Borders

Ange, 44, lives in the Scottish Borders with her husband. She was diagnosed with MS in 2000.

"I was in my 20s when I was diagnosed, and my life was ahead of me. I had dreams of getting my degree and having a career. Sadly, MS had other plans, and I had to drop out of my studies. I tried to work part-time but after a while I couldn't manage it, so now I'm reliant on DLA and ESA.

It's very obvious that I have an illness which has an impact on my life, but recently when there was a problem finding my paperwork, I was treated with suspicion. I had sent the DWP my DLA renewal form and supporting evidence, and my evidence was returned to me, as is usual. I phoned to check on my claim and was told there was no record of it. The onus was put on me to rectify their mistake, and by the time I sent in new paperwork it was a day or two late. There was no understanding or sympathy, my DLA was stopped, and I was without it for around two months.

I need DLA. It enables me to pay for all the extra costs that come with MS, like my Motability car which I use to travel to medical appointments. I need to have the heating on all the time because I really feel the cold, especially if I'm tired, so my energy bills are higher. **When my benefit was stopped I had to consider if I could afford to turn the heating up. I cut back on my shopping and I was late paying my bills. The stress and anxiety triggered a downward spiral into depression.**

However, I was determined to challenge the DWP so I got in touch with my MP. As soon as he was involved, everything changed. The DWP couldn't apologise enough: they awarded me my claim – this time indefinitely – and backdated my payments.

There seems to be an underlying assumption that benefit claimants are scamming the system, but I have a degenerative illness and there is no cure. I hope that when disability benefits are devolved to Scotland the new system will be more forward-thinking.

It doesn't cost anything to treat people like human beings."

The system is not making sense

Life for a person with MS is unpredictable. Some experience periods of relapse and remission, for others it follows a progressive pattern from onset. Even those with relapsing forms of MS typically experience increasing disability.

The process of assessing eligibility for ESA and PIP currently relies heavily on face-to-face assessments.

MS is both a fluctuating and progressive condition the nature of which presents particular challenges for such assessments.

Not only are assessments often problematic in evaluating fluctuating conditions but they frequently fail to recognise the barriers created by hidden symptoms. These symptoms are often distressing and debilitating and can include intense pain, problems with mobility and co-ordination, depression, fatigue, incontinence and loss of vision.

> “The process pushed me to the limit of my resilience. My feelings were as close as I have ever been to suicidal. Feelings of low self-esteem completely took over my life and it took a great deal of effort to get back to coping with my MS.”

The current welfare system can be seen to be fraught with bureaucratic obstacles and delays – causing people with MS confusion and stress as a result.

91%

found the process of claiming disability benefits stressful

A number of studies have now demonstrated a relationship between stressful life events and disease activity in people with MS[4] and this is repeatedly reflected in feedback from our MS community.

> “I suffered a relapse during the process of claiming, which I put down to the stress. I was initially awarded 0 points at assessment and the decision-maker overturned it, but put me into the WRAG.”

Unnecessary reassessments can be a problem for people with MS. They are put under pressure to repeatedly prove they need support even when they have medical evidence that their condition will only get worse.

As MS is a progressive condition reassessments are often unnecessary and disproportionately burdensome for claimants, as well as costly to the system.

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[4] Mohr et al., ‘Association between stressful life events and exacerbation in multiple sclerosis: a meta-analysis’, BMJ. 2004 Mar 27; 328(7442): 731.

Stigma and harassment

Respondents to our survey reported a perceived culture of stereotype and prejudice towards people claiming the benefits they need to live day-to-day.

Participants in our Voices for Change programme also stated how the welfare reform changes and negative media portrayal of people on benefits has exacerbated their experience of stigma.

Nearly

1/3

said they do not claim all the benefits they need because of the stigma

> ‘Being on benefits is stigmatising. I feel I'm on the scrapheap of life.’

> ‘I am too embarrassed to tell my own family that I am receiving DLA because of the stigma being on benefits brings.’

> ‘We want to work. We're not the same as people abusing the system but you're lumped together. No employer wants to take you on because of your unpredictability.’

The hidden symptoms of MS are not understood and people are often criticised for claiming benefits while not appearing to be obviously disabled or unwell. Fatigue is often perceived as laziness.[5]

Almost 90% of our survey respondents feel that the public judge people who claim disability benefits. Of further concern, is the number who do not claim all the benefits they need because of the associated stigma.

> ‘My daughter looks alright but some days she can't walk or brush her hair. How do you expect people like that to get up and go to work? The assessors don't see what a person with MS goes through, what it's like living with MS on a daily basis.’

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[5] MS Essentials, Third Edition August 2014, MS Society

CASE STUDY

Gary, north east Scotland

Gary, 58, was diagnosed with MS aged 29, after which he completed two degrees and re-trained as a social worker.

"I took ill-health retirement from my job two years ago. Social work is stressful and my MS was getting worse. I currently receive DLA and ESA, but I'd like to find a part-time job that I can cope with. I've looked into becoming a counsellor, but I haven't been able to get funding for the course.

My DLA helps me with the extra costs of MS, such as getting my Motability car. Without it, I'd be stuck as my mobility problems mean I can't access public transport. MS gives me problems to face every day, and my benefits help me deal with them. Yet I've been subjected to abuse as a 'benefits scrounger'.

Recently I went shopping in my local supermarket and parked in the disabled bay. **I was getting out of my car when a passer by spat at me and called me a 'skiver' and a 'scrounger'. She spat on my head.** Why would she do that to me? I got into my wheelchair and followed her into the shop to challenge her, and she said: "even the government say you're all scroungers."

It was a disgusting way to treat someone, but it hit me like a sledgehammer. I began to have self doubts and worry about how people saw me. I've moved on now, but at the time I retreated into myself and stayed in a lot more.

I think the changes to the benefits system and the way claimants are portrayed by the media has altered society's view of us. People used to be more compassionate and could see why people needed help, but now we've been vilified. I'd like people to realise that I didn't ask for this, and my MS diagnosis could happen to anyone."

Of particular concern is the number of people who have experienced discrimination in the work-place and the reported impact that this had on people's motivation to continue in employment.

1/3

of employers say they deliberately exclude people with a history of long term sickness or incapacity when recruiting staff[6]

Supporting people with MS to continue working is not only beneficial to the people themselves, but for employers who can retain experienced and loyal staff throughout much, if not all, of their working life.[7]

> Shortly after diagnosis (18 months), my employer sacked me, citing the MS as the reason. I was told "You will get a lot worse, and your illness will cost me money, hiring in temporary staff to cover." My employer was a GP.

Our part in a fairer Scotland

We want to see Scotland create a more level playing field for people affected by MS where the welfare system is fairer and people can live free from discrimination and stigma. We want the system to be based on the principles for public services identified by the Christie Commission:

- Built around people, communities and their needs, aspirations and skills.
- Services working together to effectively achieve outcomes – integrated services to help secure improvements in quality of life and wellbeing.
- Services which focus on prevention, reducing inequalities and promoting equality.
- Constant improvement with services that are open, transparent and accountable.

We have been dismayed by the lack of consensus and collaboration between the UK and Scottish Governments during the committee stages of the Scotland Bill. We are concerned that political and administrative differences between the two governments could shift the focus of the Bill away from the true spirit of Lord Smith's recommendations.

In designing a welfare system following further devolution of powers, the Scottish Government must recognise:

- The important role of the third sector in designing the delivery and determining the outcomes of devolved welfare and employment services for our MS community.
- The reality of living with MS and engage the MS community in the creation of a Scottish welfare system that makes sense for people with the condition to end the struggle for welfare support people face.

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[6] http://www.susescotland.co.uk/employers/

[7] http://www.susescotland.co.uk/employers/

Our asks

The findings from the MS: Enough survey builds on our existing evidence to drive for welfare reform and we fully support the recommendations in the UK report. We strongly urge the Scottish Government to take this report into consideration when designing any new benefits system.

Devolution of welfare powers will give Scotland greater autonomy to set the rules over a range of benefits which affect carers, people with disabilities and the elderly. These proposals, along with many others, may see the welfare landscape in Scotland developing quite differently from the rest of the UK.

The changes we want to see to the benefits system in Scotland for people with MS include:

1. **We want to see a welfare system in Scotland which does not threaten the financial security of people affected by MS.** This means an end to unmanageable assessment processes and unnecessarily short-term awards, but instead shows a greater understanding of the complexity of the condition. This must include adequate recognition of fluctuating and hidden symptoms such as pain and fatigue.

2. **We welcome the Smith Commission recommendations related to welfare and employability.** The link between financial security and health outcomes is well established, and Scotland's current journey towards more integrated health and social care services can only be enhanced by the inclusion of these two vital elements.

3. **The Scotland Bill must legislate for the transfer of powers from the UK to Scottish Parliament.** The Bill should not be used to devolve power directly to local government, bypassing the Scottish Parliament.[8]

4. **We want people with MS to be at the heart of shaping the new powers.** We urge the Scottish Government to recognise the reality of living with MS and to make the system make sense for people with the condition to end the struggle for welfare support people with MS face.

5. **We want to see a Scotland which creates a more level playing field for people affected by MS; where the welfare system is appropriate and people can live free from discrimination and stigma.** Many people with MS want to remain in work as long as possible, so we strongly support the development of an employability programme that is tailored to this outcome, but does not penalise those for whom the barriers to work are too great.

6. **We ask that the UK Government provides greater clarity on the freedom and powers of Scotland to set discrete social policy without their sign-off.**

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[8] SCVO Response to Devolution Committee call for written evidence on the Scotland Bill www.scvo.org.uk

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