Northern Ireland

MS: Enough

Make welfare make sense

Foreword from Patricia Gordon, Director of MS Society Northern Ireland

We know that having MS can be costly, with many people relying on the safety net and support provided by disability benefits just to get by every week. But people with MS have aspirations no different to anyone else. They want to live fulfilling lives and participate in society.

Our survey found that people with MS in Northern Ireland are finding the application process stressful. In some cases, people reported that the assessment process had a negative impact on their emotional and mental wellbeing.

We also know that people with MS are finding it hard to navigate the disability benefits system and to access the financial 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 the findings of this survey so that people with MS don't face unnecessary barriers to support. We encourage decision makers in Northern Ireland to seriously consider our recommendations and make common sense changes to the system to ensure people with MS can access the support they need.

Multiple Sclerosis Society

About MS

Multiple sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. Symptoms are many and varied, but unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, fatigue, brain atrophy and muscle spasms among many other things. MS affects more than 4000 people in Northern Ireland, many of whom experience their first symptoms during the peak of their working lives, between the ages of 20 and 30. MS is a fluctuating and progressive condition. The causes of MS are unknown and there is currently no cure.

About MS Enough: Northern Ireland findings

The MS Society has conducted a new survey of 1,780 people with MS about their experiences of claiming disability benefits – this includes 83 people from Northern Ireland. This survey found that financial support plays a vital role in allowing people with MS to cover the costs of their condition, as well as remain independent, participate in society and live fulfilling lives. However, for many people with MS, the disability benefits system is not making sense and people are struggling to access what they need.

The following outlines the key findings from responses to our survey from those living in Northern Ireland. Due to the small sample size these should be seen only as indicative of the wider population, and comparisons should not be made with findings from the UK as a whole or with the other nations.

Having MS can be costly – the condition can bring with it substantial associated costs as well as impacting ability to work. Over three quarters of people with MS will give up work within 15 years of being diagnosed.[1] This means that financial security can be a major issue for people with MS and many people with MS rely on the safety net and support provided through disability benefits.

Currently the major disability benefits for people with MS in Northern Ireland are Disability Living Allowance (DLA), a non-means tested extra costs benefit, and Employment and Support Allowance (ESA). ESA replaced Incapacity benefit as the main out of work benefit for disabled people and provides financial assistance for those who can no longer work as

Three quarters of respondents in Northern Ireland (77%) agreed that disability benefits have helped them manage the extra costs of their MS whilst nearly four out of five respondents (78%) said that without the support of disability benefits they would be unable to maintain their current level of independence as well as employment support for those who could return to work in the future.

A crucial difference for the lives of people with MS

Given that as many as 80% of people with MS are forced to give up work within 15 years of diagnosis , many rely on the safety net and support provided by disability benefits just to get by week to week. At their best, these benefits can also enable people to work for longer, live independent family lives and participate fully in society.

The MS Society believes the welfare system should work to make life easier not harder. Many people with MS rely on disability benefits to assist with the additional costs of living with a disability.

Over two thirds 67% of NI respondents said they would have to reduce spending on essential items such as food or heating without disability benefits. 76% reported that without disability benefits they would be unable to main their current level of independence.

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[1] The Work Foundation, Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, pp. 4

> “Because of DLA I can get to work and remain independent”
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> “Without it [Disability Living Allowance] I would be housebound”
>
> “Without DLA I would not live with MS”

People with MS are struggling to access the support they need

Despite the positive impact adequate financial assistance from disability benefits can have for people MS, currently many people cannot access what they need. It is vital that people with MS are fairly and accurately assessed and given adequate support. The findings of our survey suggest that a significant number of people with MS are falling through the cracks of the welfare system and are struggling as a result.

The assessment process is often stressful and prolonged. Inaccurate assessments are leading to inadequate support, which does not always reflect the reality of living with MS. The on-going uncertainty around welfare reform in Northern Ireland is adding to this stressful situation with many people affected by MS worried about the impact on their independence and unsure where to turn for help.

Over half of NI respondents (58%) to our survey agreed that benefits assessments were stressful with just 18% stating that the assessment considered the hidden symptoms of MS such as pain and fatigue.[2] More than 60% agreed that the assessment process had a negative impact on their emotional and mental wellbeing with around 40% reporting that the difficulty of the process had caused their condition to deteriorate or relapse.

> “I was bullied by one of the assessors when I appealed my award. He had me in tears. I had to leave the room to gather myself. I withdrew my appeal. I just couldn't handle the stress. I felt as if I was on trial”
>
> “Generic claim form not designed for highly variable illnesses such as MS – more suited to permanent physical impairment. Assessors need better understanding of MS symptoms. It seemed that the person who assessed me had his mind made up before he interviewed me”

The system is not making sense

People with MS are finding it hard to navigate the disability benefits system and to access the financial assistance and support they need. Elements of the assessment process are not making sense for people with MS. In particular assessments are not adequately capturing the fluctuating nature of MS or its hidden symptoms. 61% of the people surveyed from Northern Ireland said they need more information to help them understand the process of claiming benefits.

> “They cancelled by assessment twice. On the third occasion I was in the middle of a relapse and had to cancel. I received no compassion and was told my benefits would stop. I was flat on my back in bed. There was no way I was going anywhere. As a last resort I forwarded by last Consultant's report which did the trick but as a single parent with a 3 year old, in the middle of a relapse, I really did not need the added stress”

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[2] This figure is in relation to a question on Disability Living Allowance.

Stigma and Harassment

Perceived societal attitudes towards people who receive disability benefits is acting as an additional barrier to people with MS getting the help they need. An overwhelming majority (84%) agreed that they felt the public judge people who receive disability benefits whilst almost a third (28%) reported experiencing harassment specifically because they receive disability benefits.

> ‘I have been told I was useless and would never get anywhere in life’
>
> ‘It's comments like "I'm lucky to have a motability car!" I'd give it up in a heartbeat if they'd take my MS and I could go back to the job I loved’
>
> ‘A better understanding of MS is needed to make correct and confident decisions. It's important that those have a genuine medical condition and require help are given the support and help they need’

Conclusions and recommendations

Having a chronic, neurological condition like MS is difficult enough. The MS Society believes the disability benefits system should work to make life easier not harder. Common sense changes can and should be made to make the system make sense for people with MS. This will ensure that they can access the support they need to live their lives, participate in society and be as independent as they are able.

To achieve this, this report makes the following recommendations for Northern Ireland.

- Benefits criteria and assessments must accurately take into account the varied and hidden symptoms of MS and their impact. It is essential that assessors have appropriate training to recognise and understand the fluctuating nature of MS and its many symptoms.
- Assessments for disability benefits should be timely and should not have a negative effect on a person's health or cause stress and anxiety.
- People with MS must be able to rely on support when they need it, without the unnecessary burden or constant fear of having it taken away. The MS Society supports the call by Advice NI for the introduction of a statutory right to independent advice, to ensure that people with MS receive the benefits they are entitled to.
- MPs, MLAs, the media and other public figures should recognise their role in promoting a positive attitude towards people with a disability by leading the way in challenging stereotypes and removing the stigma attached to receiving benefits so that people with MS can play an active role in society.

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[i] The Work Foundation, Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, pp. 4