



MS: Enough

Make welfare make sense

Foreword from Lynne Hughes, Country Director of Wales

People with MS have aspirations no different to anyone else. They want to live fulfilling lives and participate in society. At their best, disability benefits can enable people with MS to lead full, more independent lives and participate in society. 92% of Welsh survey respondents said that without the support of disability benefits they would be unable to maintain their current level of independence.

We also 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 are finding it hard to navigate the disability benefits system and to access the financial support they need. Our survey found that people with MS in Wales are finding the application process stressful. In some cases, people with MS across the UK reported that the assessment process had a negative impact on their emotional and mental wellbeing.

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

Common sense changes are needed to make the disability benefits system make sense for people with MS. It is important that we act upon the findings of this survey so that people with MS don't face unnecessary barriers to support.



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 Wales, 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.

For our new MS Enough campaign to make welfare make sense, the MS Society has conducted a new survey of 1,780 people with MS about their experiences of claiming disability benefits. This survey found that disability benefits play a crucial role in the lives of people with MS – helping them to cover the extra costs of their condition and lead more independent and full family lives.

However, currently the disability benefits system is not making sense for people with MS and they are struggling as a result. Many people with MS find the process of claiming stressful and assessments are failing to adequately capture the effect of hidden symptoms and fluctuation. In addition people with MS report facing hostility and harassment as a result of claiming.

MS Enough: Wales findings

There were 106 respondents to the survey from Wales. The results from this sample are mostly consistent with the UK results; however the small sample size limits some of the analysis that is possible on the Welsh figures specifically. However, they do provide a number of important insights into the experience of people with MS in Wales.

Welfare policy is still centrally determined in Westminster and is therefore currently uniform across England, Scotland and Wales

A crucial difference to the lives of people with MS

Many people with MS use disability benefits to cover the extra costs of their condition and lead as independent lives as they can. From the MS Enough survey 84% of the total respondents in Wales (n =106), had claimed Disability Living Allowance (DLA) at some point and 25% had made a claim for Personal Independence Payment (PIP), 53% had made a claim for Employment and Support Allowance (ESA) and 20% had made a claim for Incapacity Benefit (IB).

DLA and PIP are extra cost benefits designed to help with the additional costs associated with having a disability. ESA and IB are out of work benefits designed to provide financial assistance to those who are unable to work due to disability or ill-health as well as support to help those who could return to work back into employment.

Extra cost benefits also allow claimants to access passported schemes and connected sources of support. These include Carer's Allowance, the Disabled Parking Blue Badge Scheme, Disabled Rail Cards and the Motability Scheme. Households where an individual is receiving DLA or PIP are also exempted from the household benefit cap. 23% of survey respondents from Wales who were receiving DLA or PIP indicated that a member of their household was receiving Carer's Allowance and 40% were currently enrolled in the Motability scheme.

Independence, family and social life

Across the UK, our survey found that appropriate disability benefits can allow people with MS to maintain their independence and continue to participate in social and family activities. These findings were replicated in the responses from Wales: 92% said that without the support of disability benefits they would be unable to maintain their current level of independence (compared to 83% for the whole of the

UK), and 67% agreed that without disability benefits they would be unable to participate in their hobbies.

Users of the Motability scheme highlighted strong positive impacts on social and family activity. The Motability scheme allows those receiving higher rate Mobility component of DLA or PIP to lease a suitable adapted vehicle, powered wheelchair or mobility scooter, in return for their weekly award. Of the 42 people responding to our survey in Wales who were Motability users, 37 agreed that the scheme had enabled them to maintain their independence and similar numbers (40) reported that it had enabled them to get out and about.

“ I think the Motability scheme is such an excellent scheme and is such a lifeline to me in being able to go out. MS has significantly altered my lifestyle already and it is such a reassurance to me to know I can still regain that bit of independence that having a car affords me. ”

“ The vehicle enables me to get out of the house and do voluntary work so I’m not sat in my armchair all day, be independent to attend doctor or medical appointments locally and occasionally visit the cinema, garden centre, chiropodist. ”

Extra costs and financial security

The financial assistance provided by disability benefits is also used to afford basic essentials and maintain financial security. 77% of Welsh respondents (n=106) agreed that disability benefits have helped them manage the extra costs of their MS, while 65% agreed that without the support of disability benefits they would be unable to afford essential items such as food and heating.

“ Living well with MS requires money. It is as simple as that. Money for heating, transport (using buses is not as easy so cabs are needed), money to get the garden sorted for example. ”

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 with MS, currently many people with the condition cannot access what they need. The findings of our survey suggest that a significant number of people with MS throughout Wales, and the rest of the UK, are falling through the cracks and struggling as a result.

Almost half of respondents from Wales (43%) disagreed that they had enough financial support whilst only 18% of respondents agreed that disability benefits currently provide appropriate and adequate support to people with MS.

Impact of disability benefit changes

On-going changes to disability benefits appear to have exacerbated the difficulties some people with MS are facing. Nearly half the survey respondents from Wales (49%) agreed that changes to disability benefits have had a negative impact on them.

In some cases, inadequate disability benefit provision is leading to isolation and financial difficulty. A large number of survey respondents reported having to reduce expenditure in several areas as a result of disability benefit changes. 38% had reduced spending on social interaction with family or friends and 36% had reducing spending on transport. 21% reported that they had reduced spending on gas and electricity as a result of changes and shockingly, nearly a third (30%) reported reduced expenditure on food.

MS brings with it additional costs while also impacting on individual's ability to work. Up to 80% of people with MS are forced to give up work within 15 years of diagnosis.¹ Previous research by the MS Society² found that more people with MS in Wales were out of work than the UK average. In Wales 81% of those of working age who replied to our survey are unemployed, compared to 75% across the UK. This research suggests there may be a greater need for out of work support among people with MS throughout Wales.

The MS Society is concerned that inappropriate and inadequate employment support is available for those who may be able to return to work in the future. More needs to be done to support people with MS to find or retain employment. Only a third (33%) of people with MS in Wales who identify a need for support to find, or hold on to, a job say they get the help they need, compared to a UK average of 41%.

‘ I am well enough to do some work but not well enough to work full time. I need financial help because of not being able to work enough hours due to the MS but it's not coming from anywhere! ’

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.

Over half of Welsh respondents (57%) disagreed that disability benefits assessments accurately determine the impact of their MS.

Furthermore, across the UK responses to individual questions about the PIP face-to-face assessment and the Work Capability Assessment (WCA) for ESA yielded similar results, although the sample sizes from Wales were too small to be conclusive.

The fluctuating nature of MS and its hidden symptoms, such as cognitive difficulties and chronic fatigue, have been a particular source of inaccuracy at assessment despite regulations detailing how these should be accounted for.

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

² MS Society. A lottery of treatment and care – MS Services across Wales and the UK 2013

“They didn’t understand the good and bad days with MS or the invisible symptoms. They didn’t get MS at all.”

“With MS you have the odd good day, on those days I feel like I’m going to be told that I’m not entitled anymore. I feel like everyone watches you, to try and catch you out. The system makes me feel constantly uneasy and anxious.”

“They are carried out by people who don’t seem to have any experience of MS patients let alone understand the impact on a person’s life the symptoms have. They take things on “face value” how a patient appears, not how the affects complicate their lives & those that care for them.”

“The assessment cannot accurately determine the impact of my MS because no assessor has to live and manage with this unpredictable condition. I can/have gone to bed feeling okay at night, yet wake up completely different and my walking can be absolutely dreadful.”

“First time I applied for pip, I was refused pip as I was having a good day. I had to reapply and am now eventually receiving pip as was having a bad day when being assessed. Yet I now feel that if someone saw me on a good day that they would think I didn’t need the pip benefit and I would have to repay any monies received, which does play on my mind”

Complicated and confusing processes

These issues are exacerbated by procedural concerns. Accessing disability benefits is often made more difficult by a complicated, confusing and often extremely stressful process. Of respondents in Wales 87% agreed that the process of claiming is stressful and 81% agreed that the process of claiming is difficult to understand. Yet 49% of those who responded to the survey in Wales reported that they hadn’t received sufficient information to help them understand the process.

“I live in dread of the assessment for PIP. If I lose any of my DLA I don’t know how we will manage. My son claims for looking after me while my husband is at work. Without the[support] my son wouldn’t be able to care for me and my husband would have to give up work to look after me and I cannot see how we would cope, I don’t know what we would live on! I lie awake at night worrying about what lies ahead.”

“I wish to repeat I did not choose to have MS. Before HAVING to give up work, I was a successful solicitor with a promising future. Now all the years of hard work I put into my career before my disability took hold of me have been robbed from me and it feels like whenever I try to apply for any benefit to make my life easier I always feel judged like I am “trying it on” which I certainly am not. The person who assessed me had his mind made up before he interviewed me.”

Across the UK high number of respondents who had been through the assessment processes for ESA and PIP, reported a negative impact on their emotional and mental health and in some cases a deterioration in their condition as a direct result of disability benefit processes.

Of the 22 people who had had a face to face assessment for PIP, 16 agreed that their emotional and mental wellbeing had been negatively affected by the experience, and 9 agreed that it had caused their MS to relapse or deteriorate.

If the process is drawn out or lengthy, this can add to the stress and anxiety as well as exacerbating financial difficulties. Our survey found evidence that the waiting periods had negatively impacted people with MS with some reporting not being able to afford some essential items such as food, heating and clothing as a result of experiencing a long wait or delays and others reporting that they had been isolated in their home and struggled to attend medical appointments.

Stigma and harassment

Across the UK, our survey found that hostility and harassment due to their condition may be acting as an additional barrier to support for some people with MS. 88% of respondents to our survey in Wales agreed that they felt that the public judge people who claim disability benefits, and 33% didn't claim all the benefits that they need because of the stigma associated with it.

Of significant concern, was that a section of respondents reported that they had experienced harassment because of claiming benefits. Almost a third of Welsh respondents (33%) reported that they had experienced harassment as a result of their condition and a fifth (21%) had experienced harassment because they claim disability benefits.

Across the UK as a whole, a number of the encounters detailed in response to our survey suggested that the impact of MS is not always believed by members of the public. This suggested that wider public awareness about MS continues to be needed.

“ I have remitting relapsing MS but my mobility is poor now too. I feel that people have, on occasion, questioned my having MS. ”

Conclusion and recommendations

When disability benefits provide appropriate and adequate support, which addresses the everyday impact of MS, they can have a substantial positive impact.

For many people with the condition, extra cost and out of work benefits provide a vital lifeline, allowing them to afford basic essentials and maintain their independence, as well as participate in family and social activities.

However, too often people with MS are struggling to access the support they need and have had to reduce spending on essential items as a result. The disability benefits system is not making sense for people with MS. In particular, benefit processes are difficult for people with serious, chronic health conditions to navigate and understand, and assessments are failing to reflect the reality of daily life for people living with MS. A number of common sense steps need to be undertaken to make the disability benefits system make sense for people with MS:

- Disability benefits assessments must accurately take into account the fluctuating and hidden symptoms of MS and their impact.
- The disability benefits system must take adequate account of evidence provided by experienced professionals who know the person and understand their condition.
- Existing criteria which do not reflect the barriers faced by people with MS should be changed.
- People with MS must be able to rely on support when they need it, without unnecessary burden or constant fear of having it taken away.
- Negative stereotypes must be challenged and greater awareness raised about the crucial impact disability benefits can have on the lives of people with MS.
- The Government should undertake a full impact assessment of any further changes they undertake to disability benefits – including exploring the knock on effects on other areas of public spending such as health and social care.
- The Government should work with the Disabled community and disability organisations to ensure that back to work support is adequate and addresses the barriers individuals face.

For the full list of recommendations please see the UK report.

Appendix 1: Respondent demographics

- Health Board Area

The geographical breakdown of respondents by healthboard was as follows: 20% of respondents lived in Abertawe Bro Morgannwg Health Board area, 16% in Aneurin Bevan, 12% in Betsi Cadwaladr, 14% in Cardiff and the Vale, 14% in Cwm Taf, 14% in Hywel Dda and 11% in Powys. This does not reflect the geographical breakdown of the wider Wales MS population.³

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³Public Health Wales,