

MS MATTERS

Senedd Cymru 2021



Multiple sclerosis (MS) is a neurological condition which affects more than 5,600 people in Wales.ⁱ

Since 2016, some progress has been made. Most notably, the Welsh Government's New Treatment Fund has afforded quicker access to some new treatments for MS - however a renewed effort is required for everyone living with MS in Wales to have the standard of services they need.

We've worked closely with our MS community to understand current gaps in treatment, care and support, and the issues that require action. Here are our priorities for the next Welsh Government;

Stop Wales lagging behind on MS treatments and support!

We've seen huge advances in the treatment options for people living with relapsing remitting MS (RRMS) over the last 20 years. Crucially, they've helped people to manage their condition, identify early signs of complications and put in place prevention and treatment strategies to avoid unscheduled hospital admissions.

There are now 13 Disease Modifying Therapies (DMTs) available for RRMS – but each new DMT leads to additional assessment and monitoring requirements which places further demand on a service which is already working at full capacity.

2019 saw the first treatment being licensed for some people living with early primary progressive MS (PPMS) – and with others in development, clinicians in Wales have voiced

concerns over the lack of infrastructure to administer and monitor them.

Far too many people living with MS in Wales still face barriers accessing vital treatments, care and support – and they are less likely to access specialist help when they need to.

Since 2013, the number of people taking a DMT* in Wales who could potentially benefit has risen - but compared to the rest of the UK, access remains the lowest.

36% of people living with primary progressive MS in 2019 who needed to see a neurologist couldn't - compared to 21% in the UK as a whole.ⁱⁱ

* All figures related to DMTs are calculated among those who could benefit from these treatments (i.e. those with relapsing remitting MS or secondary progressive with relapses.

The next Welsh Government must -

- Ensure that the prescribing options are in place so that people with living MS in Wales get the best access to all available DMTs and SMTs
- Improve the NHS infrastructure to cope with existing treatments and new treatments
- Audit the implementation of the NICE Quality Standard and guidelines on MS consistently across Wales
- Invest in a workforce that can meet the needs of everyone living with MS
- Review and refresh service models and delivery in partnerships with LHBs, RPBs, MS professionals and everyone living with MS to ensure they meet NICE guidelines

Improve Social Care & Support Services!

1 in 3 people living with MS struggle without the support they need to do the basics like getting washed, dressed and eating.ⁱⁱⁱ

Not only is this unfair, it is unsustainable and is having a detrimental effect on the health and well-being of people living with MS.

A study conducted by the Swansea University Medical School^{iv} found that people living with MS and their families are funding up to 75% of non-medical costs from their own pockets.

Items like wheelchairs, home and car adaptations are a necessity and make a significant impact for people living independently, stay at home or get out of hospital more quickly, safely and efficiently.

The Social Services & Well Being Act (2014) has meant very little to people living with MS and

their family members or friends who provide unpaid care. 'What Matters' conversations are not taking place - they are missing out on vital information, support and services as a result.

"I have primary progressive MS. It's been a very poor experience, Continuing Health Care (CHC) was started by a year of campaigning by my family. Since being on CHC we've had no contact about changing needs and don't know who to call."

The Welsh Government must -

- Provide Local Authorities with the funding and resources to deliver social care services to people living with MS
- Instruct Local Authorities to undertake a robust population needs assessment of people living with MS and their carers to better understand those in need
- Undertake a workforce review to determine gaps in provision
- Ensure opportunities are available at local, regional and national for people living with MS to participate in service planning

Tackle poverty for people living with MS!

As MS progresses from diagnosis, many people reduce or change their working pattern before withdrawing from employment altogether.

Income levels vary by time since MS diagnosis - higher among those recently diagnosed and lower among those with more advanced MS.^v

In 2019, only 49% of people living with MS in Wales who had retired early said that they felt supported by their employer.^{vi} Effective condition management and supportive employers are key to employment outcomes, and preventing early exit from the workforce.

MS affects 3 times as many women than men, and typically starts affecting people at pivotal times in their professional and personal lives.

MS can increase living costs by around £200 a week. Disability benefits such as Personal Independence Payment (PIP) are meant to

help manage these extra costs, but too many people living with MS are having their benefit reduced or cut altogether.^{vii}

“When I think about the decrease in my PIP I feel stressed and depressed. They didn’t consider what I said (about my condition), they even put the opposite. The evidence that they have is only what they wrote, they had no idea what it was. I am trying to stay positive, but I hate that I am losing my mind and my body. I live in the darkness because I can’t even go outside.”

Welfare reforms are contributing to deteriorating health as well as compounding poverty and isolation for the MS community in Wales. Having MS is hard enough – it is being made even more difficult by a benefits system that doesn't make sense.

Benefits for disabled people which are administered in Wales such as Concessionary Transport Schemes; Housing Benefit; Discretionary Housing Payments and Disabled People's Facilities Grants are vital but do not fully mitigate the day-to-day financial costs of living with MS or the impact of welfare reforms.

People living with MS in Wales face an inequality in access to emotional, social care and rehabilitation support; physiotherapists and continence advisors that corresponds directly to income, education and employment status.^{viii}

At least 1 in 4 people living with MS applying for PIP are losing out on PIP.^{ix}

Failures in the PIP process mean that people living with MS are going through exhausting, demoralising and unnecessary appeals - 83% of people who move from DLA to PIP and challenge their decision win their appeal.

The next Welsh Government must -

- Adopt work as an appropriate clinical outcome within the health service
- Create a strategy of targeted improvement of the devolved benefits for disabled people
- End the inequality in access to vital support services
- As more powers are devolved to Wales, commit to addressing the poverty and hardship that people living with MS face
- Pledge to hold the UK Government to account for the humiliating and degrading system of welfare which is failing disabled people

i MS Society UK. January 2020. MS Prevalence Report.

ii MS Society UK. March 2019. My MS My Needs survey results.

iii Ibid.

iv Nicholas R.S. et al. Personal and societal costs of multiple sclerosis in the UK: A population-based MS Registry study. Multiple Sclerosis Journal— Experimental, Translational and Clinical. January–March 2020, 1–11

v Ibid

vi As ii

vii MS Society UK. November 2019. PIP fails: how the PIP process betrays people with MS.

viii As iv

ix As vii