

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol ar anghydraddoldebau iechyd meddwl](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [mental health inequalities](#)

MHI 49

Ymateb gan: | Response from: Multiple Sclerosis Society Cymru

Senedd Health Committee inquiry: Triple barrier of mental health inequality:

Response from Multiple Sclerosis Society Cymru

23rd February 2022

Introduction

MS Society Cymru welcomes the opportunity to respond to the Health and Social Care Committee inquiry into mental health inequalities.

Multiple Sclerosis (MS) is an incurable neurological condition, which affects approximately 5,600 people in Wales, and more than 130,000 people in the UK.

Around 85% of people with MS are diagnosed with Relapsing-Remitting MS. People with this kind of MS have distinct attacks of symptoms which then fade away either partially or completely.

Many go on to have secondary progressive MS. It means they have a sustained build-up of disability, completely independent of any relapses.

Primary progressive MS affects about 10 to 15% of people diagnosed with MS. Symptoms gradually get worse over time, rather than appearing suddenly.

Psychological well-being and MS

A diagnosis of MS can have a huge impact on someone's mental health and emotional wellbeing. A diagnosis can present in many different ways and can raise all sorts of thoughts and feelings around a person's future and how MS will play a part in it.

Dealing with the unpredictability of the condition can be hard and can often take its toll on a person's emotions. It can take time to adjust to a life with MS.

A study in Wales highlighted the lack of psychological support, particularly around the transition from RRMS to SPMS. Transitioning to secondary progressive MS is demanding for both people affected and healthcare professionals. The particular challenges and the ways patients cope are poorly understood.ⁱ

MS is linked with a wide range of psychological difficulties; and people living with the condition often report lower quality of life and increased psychological distress, even when compared to other neurological conditions.ⁱⁱ

There is a significant body of evidence which shows that people being diagnosed with MS need prompt intervention after diagnosis and ongoing screening for mental health problems; they need providers with knowledge about MS and experience working with people with MS; they appreciate being able to access mental health services that were on-site at their MS centre and note the benefit of inclusion of family members in treatment.ⁱⁱⁱ

Since the beginning of the pandemic, the UK MS Register [funded by the MS Society and operated by the Swansea University College of Medicine] has been collecting information about COVID-19 from people with MS.^{iv}

The UK MS Register found that people living with MS have had;

‘higher rates of anxiety and depression than the general population before the COVID-19 pandemic, placing them at higher risk of experiencing poor psychological wellbeing during the pandemic’

From our research and regular contact with the MS community in Wales, it is clear that psychological well-being is a long-standing issue in the care of people living with the condition.

Whilst we appreciate that the NHS across Wales remains in extremely challenging times, we must also acknowledge that for people living with MS, the pandemic has served only to further exacerbate both the physical and psychological problems they experience.

We are aware of a significant group of people living with MS in Wales who have poor psychological adjustment and poor well-being. They live with complex issues and not only do they not meet the mental health criteria, they are without the support of a psychologist with expertise in MS/neurology.

In their research into the mental health and emotional impact of COVID-19 on people living with MS, the UK MS Register concluded that;

‘It is important that multidisciplinary teams improve their support for the wellbeing of people living with MS who are vulnerable to the negative effects of the pandemic on their lifestyle and social support’.

People living with a condition like MS need to see a psychologist with expertise in MS/neuro (i.e. a psychologist embedded in the MS Multi-Disciplinary Team (MDT) who will work closely with the team and develop specialist knowledge of the condition).

General mental health practitioners are lacking in specialist knowledge about MS symptoms especially the complex cognitive problems that many people living with the condition experience, nor do they provide any specialist family or systemic work.

This lack of knowledge means that these practitioners are unable to adjust their intervention to meet the individual needs of people living with MS and their families.

Some of the barriers to accessing health services for people living with MS include; information available to them, health care provider knowledge of and familiarity with Senedd Health Committee inquiry: Triple barrier of mental health inequality: Multiple Sclerosis Society Cymru response February 2022

MS.^v Finding a mental health care provider who is a “good fit” and is knowledgeable about MS is a barrier that people living with MS face.^{vi}

NICE guidelines recommend that people living with MS have a comprehensive review at least once a year of all symptoms and difficulties, and that this should include a review of issues with anxiety, depression, sleep, fatigue and pain, with the aim to refer the them to an appropriate professional.^{vii}

More specifically, NICE guidelines for MS recommend that care for affected individuals should be via a multidisciplinary approach with one person coordinating the care.

The Wales Neurological Conditions Delivery Plan highlighted the need for ‘holistic approaches including psychological and emotional wellbeing and the need for integrated and coordinated care’.

However, the Cross Party Group on Neurological Conditions Inquiry Report; Building the foundations for change: The impact of the Welsh Government’s Neurological Delivery Plan found significant problems related to poor access to mental health services and emotional support^{viii}

MS Society UK undertakes regular in depth research with people living with MS and their families; this has consistently shown that Wales has lagged behind the rest of the UK in terms of:

- Access to disease modifying therapies (DMTs)
- Access to a neurologist
- Access to physiotherapy
- Access to emotional/ psychological support

Our 2019 survey suggested that nearly 28 percent of people in Wales wanted more support for mood and emotional issues (compared with 20 per cent in England).

Research conducted by the MS Trust as the pandemic was emerging in April 2020 revealed that over half (53%) of people with MS did not feel that their mental health needs were being met.^{ix}

72% of those living with MS felt anxious or depressed for more than several days a month

78% of respondents were not offered any mental health support when they were diagnosed.

The unpredictable nature of MS was cited as one of the main factors as to why people are experiencing a decline in their mental health, followed by a lack of specialist support.

The results of the survey also showed the stark reality of the impact MS can have on the emotional wellbeing of family members and friends providing regular care and support to a loved-one;

81% of respondents reported a decline in their mental health since MS became a factor in their lives

83% said they were not offered any additional mental health support to cope with these changes.

It is clear that the guidelines are not currently being implemented for people living with MS equally across Wales and their needs are not being met.

Unmet health care needs can contribute to ongoing MS symptoms, resulting in physical, psychosocial, and occupational consequences for people living with the condition.^x

The difference it can make

The biopsychosocial model of health recognises important interactions among biological, psychological and social factors in illness, including those relating to illness management, which contribute to the experience of those diagnosed with MS.^{xi}

Louise from Swansea was medically retired due to her MS, here she shares her experience of the holistic model of support she received from a Neuropsychologist and the difference it made to both her and her family;

As part of my treatment / rehabilitation, I was lucky enough to see the Lead Consultant, Clinical Neuropsychologist and the only Neuropsychologist in Swansea/Hywel Dda that sees patients that have MS. This means that the wait to see her was 9 months and that was a few years ago before COVID. I don't even think you could get on a waiting list now.

Seeing her helped me greatly. She arranged a family session with her to help my family understand what my cognitive issues are, what I can't do and how it affects my mood, processing skills, memory and lots more. I was able to talk to her about how I felt, my worries, frustrations and concerns for the future.

She monitored the decline or stability of my memory and cognition with specific tests and supported any help I needed. She also wrote a detailed and explanatory letter for my Personal Independence Payment (PIP), Pensions, ill health retirement and ESA applications.

Cognitive issues are invisible but can be devastating and are rarely understood by employers, DWP and families. This service is absolutely imperative but many people with MS are unable to access this service due to availability. It will also support the Mental Health of patients which is also not supported directly for MS patients.

With my personal experience of MS, the friends I have in the MS Community, I see on a near daily basis the lack of resources that are available and the incredibly long wait, while suffering, to get to see someone. So many are struggling with the stress of having no one to talk to, particularly someone who understands MS, cognition and mental health.

Many give up, I was close to it, their mental and physical health will decline and they may not get the support they need at home, work or with benefits. It is not just the person with MS that suffers but also their family.

Cognitive and emotional issues are not easy to understand and can cause many arguments and tension at home and work. My cognition was the largest factor in why I was ill health retired and having the information and support I had from the Neuropsychologist was vital in securing the best exit possible from the workplace.

My family meeting with the Neuropsychologist helped my family understand that I am not rude, ignorant, lazy, selfish or uncaring, but I have physical damage in my brain that makes processing, understanding, memory, etc. so much more difficult and slower. Without this there undoubtedly been many more arguments, without the memory diagnostics and checks it would have been more difficult to provide medical proof of my cognitive difficulties and how they affect me, I would have become more depressed for longer and definitely lonelier, as I would not have been able to talk to someone who understands and believes me.

Louise was fortunate to have received such a specialist service which is denied to many others living with MS across Wales.

There is limited psychology provision for people living with MS in only some of the Local Health Board areas in Wales but provision is patchy and there are lengthy waits. In addition, specialist support is often restricted to younger people 'with vocational needs'.

Third Sector Resilience

People living with disabling MS can lead rewarding and fulfilling lives. To this end, they will do best if they adjust early to the diagnosis and its implications, if disabling symptoms are kept to a minimum and if they get all possible support from both professional and voluntary sectors.^{xii}

Activities offered by voluntary sector organisations such as MS Society Cymru have been a lifeline during the pandemic. Although by no means have they filled the gaps in specialist psychological provision, they have gone a long way to complement existing MS services and provide a holistic package of activities to support and improve the wellbeing of people living with MS in Wales and reduce isolation and loneliness amongst the MS community.

The MS Society Cymru pan-Wales Wellbeing Hub provided virtual activities and services to people living with MS between February 2021 and January 2022. It was funded by the Wales Council for Voluntary Action (WCVA) Third Sector Resilience Fund.

The Hub was focused on supporting people's physical and emotional wellbeing, and offered a new programme of activities that was open to everyone living with MS in Wales, and sometimes their carers/family members as well.

The Wellbeing Hub had a high level of impact for those who engaged with activities and the planned outcomes; improved physical health, mental wellbeing and community were achieved.

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With physical access to local support groups being stopped due to the pandemic and limited contact with health professionals, the Wellbeing Hub was vital to those who engaged with it;

'I think because of COVID, and everything shut down, it was a very good time, because it helped reduce that sense of isolation, you know? I was still able to see people that I knew, friends [from MS groups]. And then I've made further friends through using the Hub.'

Like many in the voluntary sector however, as a result of the pandemic, MS Society Cymru has adapted in many different ways but at the same time, has had to make significant changes in the face of financial challenges. As restricted income project funding comes to an end, it diminishes the ability for organisations like ours to provide all the services the MS community continues to need.

The Charity Commission has acknowledged that the pandemic presents significant long-term challenges for charities.^{xiii}

The impact of COVID-19 will be with us for many years to come and without sustainable financial support, charities like MS Society Cymru will not be able to play its part as the country recovers from the impact of the pandemic.

In its Review of the Together for Mental Health, the Welsh Government is committed to 'make sure vulnerable groups of people and people with additional needs get a better service'.^{xiv}

Whilst this is an aim that we share, unless charities like MS Society Cymru have the resilience to continue to support people living with MS in the way that we do, given the existing gaps in psychological support across Wales, the emotional wellbeing of the MS community will be further impacted.

The contribution made by the voluntary sector should be better recognised, and projects which enable people to live well should be funded for a longer period in order to give them the support they need long term.

Recommendations;

NHS services should be drawn from the significant evidence base and adopt a biopsychosocial model which is about enabling people to live well and thrive in the community despite living with a chronic condition.

Neuropsychologists should be embedded within all Multi-Disciplinary Teams in Wales. For this to happen, Local Health Boards must commit to incorporating neuropsychology provision within business planning.

People living with MS should have equitable access to specialist psychology support as part of their MS care. They should;

Have access to mental, cognitive and emotional health support and treatment, as needed, which addresses both their needs arising from their condition as well as taking into account their individual needs and preferences.

Have their mental, emotional and cognitive wellbeing effectively and systematically screened to pick up on their changing needs and functioning, from predictive testing, first symptoms and diagnosis, through to the end of their life.

Experience mental, cognitive and emotional healthcare and treatment that is systematically tailored to their individual communication needs, including needs arising as a result of MS.

Have access to specialised neuropsychological and neuropsychiatric assessment, care and treatment, as well as local mental health services, as needed.

Be provided with psychoeducation around their condition, including what they can expect, and when to seek additional help.

The Welsh Government's COVID-19 mental health and wellbeing recovery action plan should include further financial support to the voluntary sector to enable it to mitigate and respond to the continuing and long lasting mental health impacts of the pandemic.

Access to MS treatments, services and support;

We have seen significant 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 over 13 Disease Modifying Therapies (DMTs) available for RRMS – but each new DMT and Symptom Management Treatment (SMT) leads to additional assessment and monitoring requirements which places further demand on a service which is already working at full capacity.

2019 saw Ocrevus, the first treatment being licensed for some people living with early primary progressive MS (PPMS) – and in 2020, Siponimod was approved as the first ever oral treatment for people living with active secondary progressive MS (SPMS) in Wales.

Fampridine is effective as a treatment option for the improvement of walking in adult patients with MS with walking disability (Expanded Disability Status Scale [EDSS] 4 to 7) and was approved by AWMSG in December 2019. It is a symptomatic drug that requires prescription, often by a consultant following a face to face consultation. Face to face consultations are necessary to allow assessment of a patient's eligibility by way of a 25m walk assessment.

Fampridine poses significant challenges to MS services in terms of the number of patients potentially eligible for treatment, the requirement for clinic assessment at two intervals one month apart.

Whilst the pandemic has played a significant part in preventing face to face assessments from taking place, the lack of infrastructure and capacity to see patients

has been a decisive factor also. In some LHBs, fampridine clinics have started slowly, in others not at all.

For example, the team who cover MS patients in Swansea Bay and Hywel Dda Health Boards have screened their MS population and identified approximately 1,200 people who might benefit from fampridine. By August 2021 however, only 56 patients had completed their assessments. In North Wales, some prescriptions have only recently been provided (January 2022). In the Aneurin Bevan Health Board area, the MS team expect half the MS population to meet the inclusion criteria but do not have the capacity to assess them.

For many people living with MS, the consequences of such delays are immense, not only physically but emotionally too. We know of many who have been informed that fampridine may be beneficial for them, but have and continue to be denied it on the NHS in Wales as there are no clinics where they live.

We are aware of some people living with MS who have tried fampridine as part of a clinical trial or via a private prescription and their walking has improved significantly, but they are unable to obtain it on the NHS.

MS Society Cymru is also well aware that there are many people living with MS who have become deconditioned from shielding and are now exhibiting symptoms of a far more advanced nature than they should be. Function lost in this way can be very difficult for people with MS to recover from even over the longer-term.

Alarmingly, as one consultant informed us recently, for some of this group, it may be too late; 'It would be difficult to argue against the fact that some patients may have become ineligible [for fampridine] over the last year as their disease has progressed'.

According to the Welsh Government, the New Treatment Fund has cut the average time it takes for newly recommended medicines to become available to patients in Wales by 85%, from 90 to just 13 days.

This is most certainly not the case for access to fampridine for those people living with MS who could benefit from it. The AWMSG recommended fampridine in December 2019 and the pandemic did not take full effect on the NHS in Wales until March 2020, yet it is only recently that some clinics have been set up, albeit slowly.

Fampridine is not the only MS drug which has experienced significant delays; tysabri, ocrelizumab and siponomid are among some of the other treatments which have and are continuing to be impacted by the lack of capacity and infrastructure to prescribe them.

Access to treatments and services helps people living with MS manage their condition, and to identify early signs of complications, and put in place prevention and treatment strategies to avoid unscheduled hospital admissions.

By preventing relapses and disability progression, people living with the condition should be able to take greater control of their condition and their lives, directly and indirectly improving physical, economic, emotional and social outcomes.

Recommendation;

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The Health and Social Care Committee must undertake an urgent inquiry into why the Welsh Government's New Treatment Fund has not delivered for people living with MS in Wales.

As per the guidance, Local Health Boards must adhere to putting newly approved drugs onto their formulary and to have their implementation plans in place within 3 months.

The Welsh Government must commit to improving access to treatments, services and support for people living with MS in Wales.

Poverty and 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.

In 2019, only 49% of people living with MS in Wales who had retired early said that they felt supported by their employer. 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 – and disability more generally – often places substantial extra costs on individuals and families as they go about their daily lives. In order to have a similar standard of living as someone without a disability, someone living with MS will often need to spend more.

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.

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.

Welfare reforms are contributing to deteriorating physical and emotional 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.

In addition, we know from the UK MS Register that;

'people with MS and their families are having to fund up to 75% of non-medical costs from their own pockets' and this financial strain, within the societal impact of COVID-19 will be having an impact on those living with MS.

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.^{xv}

Recommendations

Measures of poverty and standards of living should not be viewed in isolation of the costs of living households face.

The Welsh Government and Local Health Boards must adopt work as an appropriate clinical outcome within the health service and to facilitate that, Neuropsychologists should be embedded within all Multi-Disciplinary Teams in Wales.

The Welsh Government must create an action plan of targeted improvement of the devolved benefits for disabled people and address the wider determinants of mental health.

The Welsh Government must end the inequality in access to vital support services.

As more powers are devolved to Wales, the Welsh Government commit to addressing the poverty and hardship that people living with MS face

Hold the UK Government to account for the humiliating and degrading system of welfare which is failing disabled people.

Multiple Sclerosis Society Cymru

Contact name; **Fiona McDonald**

3. Would you like to be added to the Health and Social Care Committee's contacts list in order to receive updates about our work?

Yes

4. Please tell us in what capacity you are responding to this consultation.

I am responding on behalf of Multiple Sclerosis Society Cymru

5. Are you under 13 years old?

I am 13 or over

6. Please choose one of the following options to confirm whether you would prefer that your name is not published alongside your evidence.

I am aged 18 or over and I am content for you to publish my name alongside my evidence

7. Please choose one of the following options to confirm whether you have agreement from any third parties referred to in your evidence that you can share information that may be used to identify them and that they understand that it may be published.

I confirm that any third party I have referred to in my evidence has agreed that I can share information that may be used to identify them, and that they understand that it may be published.

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- ⁱ [Multiple challenges for people after transitioning to secondary progressive multiple sclerosis: a qualitative study](#)
 - ⁱⁱ [Psychological interventions for people with Huntington’s disease, Parkinson’s disease, motor neurone disease, and multiple sclerosis. Evidence-based guidance](#)
 - ⁱⁱⁱ [Patients' perspectives on quality of mental health care for people with MS](#)
 - ^{iv} [Mental health of people with multiple sclerosis during the COVID-19 outbreak: A prospective cohort and cross-sectional case–control study of the UK MS Register](#)
 - ^v [Identifying Barriers to and Facilitators of Health Service Access Encountered by Individuals with Multiple Sclerosis](#)
 - ^{vi} [As iii](#)
 - ^{vii} [Multiple sclerosis in adults: management Clinical guideline \[CG186\]](#)
 - ^{viii} [Building the foundations for change: The impact of the Welsh Government’s Neurological Delivery Plan](#)
 - ^{ix} [People with MS aren’t getting enough mental health support](#)
 - ^x [As v](#)
 - ^{xi} [Biopsychosocial implications of living with multiple sclerosis: a qualitative study using interpretative phenomenological analysis](#)
 - ^{xii} [Supporting individuals with disabling multiple sclerosis](#)
 - ^{xiii} [Listening to charities’ experiences of the coronavirus pandemic](#)
 - ^{xiv} [Review of the Together for Mental Health](#)
 - ^{xv} [Personal and societal costs of multiple sclerosis in the UK: A population-based MS Registry study. Multiple Sclerosis Journal](#)