

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC51: Ymateb gan: | Response from: Multiple Sclerosis Society Cymru

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**Senedd Cymru Health and Social Care Committee  
Inquiry: Supporting people with chronic conditions  
MS Society Cymru Response (May 2023)**

**About MS**

Multiple sclerosis (MS) is the most common disabling neurological condition affecting young adults. More than 130,000 people in the UK have MS, the equivalent of one in every 500 people across the UK, with approximately 5,600 of these living in Wales.

MS is a progressive condition and symptoms often present in a person's 20s and 30s. Symptoms often fluctuate, many are invisible, and they vary greatly between individuals, including: loss of balance, fatigue, pain, bladder and bowel problems, visual and memory impairment, and issues with speech.

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.

The Multiple Sclerosis Society is the largest charity for people living with MS in Wales, with 16 volunteer-led groups, and is the largest charitable funder of research into MS in the UK.

MS Society Cymru welcomes this opportunity to respond to the Health and Social Care Committee inquiry into supporting people living with chronic conditions, and we thank the members of the committee for giving this matter your consideration.

## **1. NHS and social care services - The readiness of local NHS and social care services to treat people with chronic conditions within the community.**

1. 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.
2. 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.
3. Public policy and guidance about how to treat and manage MS have been substantially revised and, crucially, we now know that treatment with a DMT as close to diagnosis as possible improves long-term outcomes for people living with MS – they can decrease the number and severity of relapses and delay the progression of disability and slow down the speed at which it happens.
4. There are currently over 13 DMTs licensed for relapsing forms of MS, all with different efficacies, side effects and methods of administration.
5. The Association of British Neurologists (ABN) guidelines for prescribing disease modifying treatments in Multiple Sclerosis recommends that given the significant impact of Disease Modifying treatments on MS that treatment should start as early as possible in eligible patients.
6. With the increasing number of treatments options, it is more important than ever that people living with MS are supported to make choices about their treatment, and can access the best treatment for them, regardless of where in Wales they live.
7. The MS Society MY MS My Needs survey is the largest collection of patient-reported data from the UK MS community to date. The initial survey was run in 2013, this was followed by surveys in 2016, 2019, and 2022. It provides an opportunity to understand in detail how people living with MS feel about their treatment, care, and support.
8. Results of the 2022 MS Society My MS, My Needs survey in Wales has showed that the focus on service improvement in neurology over recent years has brought about some positive developments. However, in the past year, people living with MS in Wales still report substantial barriers to accessing the treatment, services and support that they need from health and social care services;
  - a. **Access to disease modifying therapies (DMTs).** 57% of those who could benefit from taking these treatments were doing so; 78% of respondents started a DMT within 12 weeks of the decision being made to start;

- b. **Access to a neurologist and specialist nurse:** 17% said that their need to see a neurologist had not been met within the past year; 13% of respondents reported that they needed to see their MS specialist nurse but couldn't;
  - c. **Physiotherapy:** 23% of people in Wales had unmet need for physiotherapy compared to 19% in England;
  - d. **Emotional support:** 17% of people living with MS had not received any emotional/ psychological support despite needing it, compared to 13% across the UK;
  - e. **Continence support:** 20% of people living with MS needed to see a specialist about continence advice in relation to their MS but couldn't.
9. Overall, people living with MS in Wales rated the quality of healthcare received for their condition during the past 12 months as follows;
- a. Very Good (18%)
  - b. Good (28%)
  - c. Neither Good/ Poor (35%)
  - d. Poor (12%)
  - e. Very Poor (5%)

## **2. Impact of COVID-19 on people living with MS and MS services**

1. COVID-19 has had a disastrous impact on people living with MS and for those who provide services for them.
2. Research conducted by the UK MS Register [funded by the MS Society and operated by the Swansea University College of Medicine] found that 39% of people living with MS in Wales had medical appointments cancelled or delayed.
3. Health professionals within the MS specialist teams did their utmost to deliver services and support under extremely difficult circumstances. They prioritised urgent cases, and worked hard to provide as many of their appointments as possible via telephone or video call to avoid people from going to hospital.
4. However, some of the workforce had been redeployed or affected by COVID-19 themselves. Consequently, certain high efficacy treatments were stopped because they increased the risk of infection. Infusions were happening less regularly than they should. Monitoring regimes had been relaxed and MRI scans had stopped in many localities.
5. The MS landscape has changed a great deal since the publication of the first My MS My Needs survey results in 2013 and although improvements have been made, significant challenges remain.

6. Timely and equal access to services and treatments across the country was a significant issue before the pandemic and it has only served to exacerbate them.
7. Prior to the pandemic, MS Specialists in Wales told us that timely follow up was becoming more and more difficult resulting in less time to assess people effectively, discuss treatment options and manage risks. They felt as though they are 'always behind the curve in providing appropriate treatments'.
8. With this added pressure on MS Neurologist and Specialist Nurse case-loads, people living with progressive forms of MS are being pushed further down the waiting lists with little or no support.
9. Local Health Boards are expected to put newly approved drugs onto their formulary and to have their implementation plans in place within 3 months, however there are a number of challenges;
  - a. Implementation planning documents/ protocols/ business plans are not completed so no service plan exists for the drugs e.g. change to services, resource allocation, monitoring requirement.
  - b. There is a competitive process within LHBs as to the local approval of new medication; it is therefore largely dependent on MS drugs taking priority.
  - c. The implementation planning documents may be inaccurate in relation to expected patient number and cost impact and need to be clarified.
10. As one consultant said; 'The process of adding the formulary should be straightforward but our experience has identified that the process of implementation can be far more challenging and as a result, medicines can be delayed'.
11. In relapsing remitting MS (RRMS), people have attacks [relapses] of new and old symptoms. Taking a disease modifying therapy (DMT) can mean fewer relapses and slow down a person's MS. Delaying or cancelling treatments over a sustained period of time will increase the likelihood of relapses among people with MS. Given the significant potential impact a relapse can have on someone's condition and quality of life, measures that minimise the likelihood of relapse should be considered priority.
12. Due to the lack of capacity to be seen by the MS Teams, people living with progressive forms of the condition have previously told us that they have felt like they were on the 'scrap heap'. The pandemic has served only to further exacerbate this feeling.
13. The All Wales Medicines Strategy Group recommendation in December 2019<sup>i</sup> that the drug fampridine should be made available in Wales was greatly welcomed.

14. 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). It is a symptomatic drug that requires prescription from 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.
15. 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 such as Aneurin Bevan University Health Board not at all.
16. For many people living with MS, the consequences of such delays are immense. We know of many who have been informed that fampridine may be beneficial for them, but are being denied it on the NHS in Wales as there are no clinics where they live.
17. 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 were unable to obtain it on the NHS until years after it was approved by the AWMSG.
18. MS 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.
19. Alarming, as one consultant informed us that for some of this group, it may be too late;
  - a. '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'.
20. 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.
21. 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.
22. 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.

### **3. The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.**

1. MS is a lifelong condition and issues associated with growing older will present additional challenges to people also living with the condition. As most people are diagnosed in their 20's and 30's, MS is sometimes described as a young person's condition. However, with more than half of people living with MS aged 50 or older, this is not the case.
2. Along with coping with the continuing, possibly increasing, effects of MS, people living with the condition are more likely to develop other health issues or comorbidities as they grow older.
3. Greater understanding among health and social care professionals about MS is a priority in Wales. For example, people living with the condition who are admitted to general wards in hospital have repeatedly told us that staff are not aware of MS symptoms and there is no communication with their MS team.
4. Many people living with and affected by MS say that health and social care professionals often display a lack of knowledge and understanding of the cognitive impact of MS, nor that it can affect the person's ability to communicate in a social environment, often leading the person to appear rude and aggressive. This can lead to a failure to give optimum high standard care as social relations are compromised.
5. In particular, there is a need to significantly improve understanding of the cognitive impact of neurological long term conditions such as MS. Many of those living with cognitive impairment (not learning disability) are unable to identify their own needs, nor articulate those needs or use means of communication to make them known to anyone.
6. 45 – 65 percent of people living with MS will experience some type of cognitive impairment which impacts on the person's thinking ability and involves:
  - a. Executive function, such as planning actions, sequencing tasks in the correct order, controlling one's impulses, transferring learning from one situation to another, and working with abstract concepts.
  - b. Focusing, maintaining and shifting one's attention
  - c. Learning, remembering and recalling information
  - d. Understanding and using language appropriately and effectively
  - e. Performing maths calculations

7. 31% of respondents to the 2022 My MS My Needs Survey from Wales said that they needed support with cognitive issues in the past 12 months but didn't get it.
8. Whilst people living with MS value health and social care professionals, many have concerns about the recruitment and retentions of staff:
  - a. 'Social care workers should be valued and paid a decent salary and also paid for their travelling time. This would help retain staff and provide a continuity of service for service users and carers'.
9. Trust between the cared for and care givers is essential especially when tasks of an intimate nature are performed. However, people living with MS report that given the high turnover of social care staff, they often see many different care workers in any given week. Continuity of carers is therefore paramount for people living with MS as it can build trust and decreases feelings of loneliness and isolation.
10. As previously identified, the journey from diagnosis, treatment, support and care for many people living with MS in Wales is not an easy one and this is especially the case for many who are at the end of their lives.
11. The following evidence of end of life care for people severely affected by MS in Wales was not provided by individuals themselves as their condition precluded them from doing so, it was however shared by their loved ones who cared for them on a daily basis;
  - a. Diane was diagnosed with Primary Progressive MS in 1986, I say "diagnosed" but we actually found out by accident when we overheard a nurse say "the lady with MS". As Diane's condition worsened we received support with carers coming into our home three times daily and then four times through Bridgend Social Services. The carers were good as were the District Nurse and GP from our local surgery.

Unfortunately, Diane developed an abscess on her bottom and was prescribed medication to help with this, however, the side effects caused raised her blood pressure and the GP admitted her to the Princess of Wales hospital.

At the hospital Diane's case was passed from consultant to consultant no-one really taking responsibility to improve her condition. So many anti-biotics were pumped into her that it affected her liver and kidneys and her condition worsened.

Diane needed help to be able to eat and drink and this was not forthcoming on the ward. The staff failed to keep her hydrated and they didn't feed her. I took in a special cup with



a long straw for her to try and drink herself but this was often on the floor when I visited. There were no records either on fluid intake.

I complained about her treatment and asked on numerous occasions for her to be seen by a physiotherapist as she was left in bed all the time. Eventually a physiotherapist came and it was agreed that Diane be moved to a chair for just an hour a day. The following day this did happen, however, the next day Diane was left in the chair all day! They did not get her out of bed after this.

Diane developed another abscess on her heel and a very low point for me was the day I visited and on lifting the bedding to check her heel I found it resting in a pool of blood. I asked the nurse who was dispensing medication on the ward to come and help and she said 'I will be there once I have finished dispensing the medication'. I then went to find the lead nurse on the ward and he then made the nurse stop what she was doing to attend to Diane.

As Diane neared the end of her life there was no privacy, we asked for her to be moved to the side rooms near the nurses' station so that the staff could keep a close eye on her. They did move her to a more private room but this was even further away from the nurses' station. To us it felt as if they knew that nothing more could be done for her and they just left her.

There was no understanding of Multiple Sclerosis on the ward and no input from the Multiple Sclerosis team. They did not keep up to date records and there was little or no communication. We occasionally would see the doctor and he would speak to us but they just didn't give her the care that she needed'.

- b. Rosemary was diagnosed with Secondary Progressive MS in 1976 and was able to remain in work until 1992.

Since that time, Rosemary's condition had become progressively worse. Urinary Tract Infections were the biggest problems that Rosemary faced. For instance, one year she along with her husband who was her main carer had to make

6 separate visits by ambulance to A&E to get intravenous anti-biotics.

Rosemary relied on a peg-feed for her nutrition and liquids and was under the care of a specialist nurse to change the device. She had to go to hospital as her condition deteriorated. Whilst there, Rosemary's peg feed device came out which had gone unnoticed by hospital staff. Fortunately her daughter was visiting and alerted them but as they had not been trained to replace it, they were reluctant to do so. Due to staffing issues, there was a problem in locating the specialist peg feed nurse who covered the West Wales area and Rosemary's husband was asked to replace the device. This is a task that he had not been trained to do and had to do so on another occasion.

On another stay in hospital, Rosemary was put in a bed with a metal frame upon which her feet rubbed against for 24 hours.

Due to the risk of her choking, Rosemary was unable to be left on her own. For 11 years, the family bought in care at their own expense and were never officially told about continuing health care provision. During this time, they had bought all the equipment and apparatus themselves from hoists, beds to wheelchairs and adaptations to their home.

#### **4. The interaction between mental health conditions and long-term physical health conditions.**

1. A diagnosis of MS can have a significant impact on someone's mental health and emotional wellbeing. It 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.
2. 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. <sup>ii</sup>
3. Unmet health care needs can contribute to ongoing MS symptoms, resulting in physical, psychosocial, and occupational consequences for people living with the condition.
4. 24% of respondents to the 2022 My MS My Needs survey in Wales said that they didn't get support for emotional issues but needed to (compared to 19% in England).

5. A study in Wales highlighted the lack of psychological support, particularly around the transition from Relapsing Remitting MS (RRMS) to Secondary Progressive MS (SPMS). Transitioning to SPMS is demanding for both people affected and healthcare professionals. <sup>iii</sup>
6. Since the beginning of the pandemic, the UK MS Register has been collecting information about COVID-19 from people with MS. The Register found that people living with MS have had;
  - a. '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' <sup>iv</sup>
7. From MSS research and regular contact with the MS community in Wales, it is clear that mental health and well-being is a long-standing issue in the care of people living with the condition.
8. 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.
9. 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).
10. 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.
11. 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.
12. 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 MS.
13. 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.

## **5. The impact of the pandemic on quality of care across chronic conditions.**

1. People living with MS in Wales experience acute social and health inequalities due to a lack of specialist support and the complexity of existing social care pathways.
2. Evidence gathered from the MS Society's My MS My Needs surveys has consistently shown that 30-40% of people living with MS in Wales report that they had received only some or no support at all and had needed to.
3. For those who required support with Instrumental Activities of Daily Living (IADLs) such as housework, cooking meals, getting out of the house and shopping, 56% of respondents had received all the support they needed however, over 40% reported that they had received only some or no support at all and had needed to.
4. Such support for practical tasks is vital for people living with MS to enable them to manage living independently and with dignity.
5. When asked about the provision of care, the overwhelming majority of respondents (86%) said that friends and family provided some degree of unpaid support for practical tasks.
6. This demonstrates the vital importance of those providing unpaid care and support to people living with MS.
7. People living with more progressed forms of the MS, in particular, often require significant levels of care and supervision. Unpaid carers often face additional costs associated with keeping those they care for safe, providing extra care, nutrition, and support;
8. Over half (51%) of unpaid carers in Wales are currently unable to manage their monthly expenses. <sup>v</sup>
9. The Social Services and Well-being (Wales) Act (2014) underpins the way social services are delivered and contains important legal rights for people who use the services and their carers.
10. Social care is vitally important to enable many people with MS to live healthy, full and independent lives and have equal opportunities.
11. MS Cymru is concerned that people living with MS have not been able to access the social care support they needed both during and after the pandemic.
12. Prior to the outbreak, there was significant unmet need. One in three people with MS in the UK struggled without the support they need to do the basics like getting washed, dressed and eating. This prevented them and their family members and friends providing unpaid care from living dignified, independent lives. This is not fair and it is unsustainable.

13. Social care funding in the Wales has not kept pace with increasing demand and we now face a significant shortfall, with too many people with MS shut out of the system.
14. People with MS are disproportionately likely to require social care services at some point in their lives. Seven years on from the implementation of the Social Care and Wellbeing Act, the Welsh Government and Local Authorities need to act swiftly to assess the level of unmet need among the MS population in Wales, and to determine the service improvement that is required.
15. The Coronavirus Act gave local authorities powers to temporarily suspend duties in the SSWB (Wales) Act if pressures on social care got too high, during which time some people did not get the care and support they would normally have been entitled to.
16. We understand that some local authorities reduced care in response to funding and demand pressures. Also, the lack of Personal Protective Equipment (PPE) for care workers caused some people to decide to cancel their care in order to protect themselves from infection. Together, this situation meant that some people's health and wellbeing deteriorated without support, or that of their unpaid carers had to take on increased responsibilities.
17. MS Cymru know of many people in the MS community who live with significant disability and faced several days when carers refused to attend because they didn't have access to PPE equipment.
18. We are aware of others who were forced to live in care homes because their care package could not be fulfilled by the local authorities.
19. There have been many who although were medically fit to be discharged from hospital were unable to do so for considerable periods of time due to a lack of available support in the community.
20. The current direction of care and support in the community depends on an increased contribution from the community and voluntary sector. There is no analysis of the current strength, assets, or community capacity or willingness to take up this challenge. In rural areas due to lack of funding voluntary services are being withdrawn.
21. Without adequate investment and long-promised reform after the pandemic, social care will continue to let people with MS and other neurological conditions down, limiting their ability to live full and independent lives.

## **6. The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.**

1. A third of people living with MS say that they are either struggling on their current income. This rises to over half (51%) for people living with MS who are claiming means-tested benefits.
2. The reality for those who responded to the 2022 My MS My Needs survey in Wales is revealing and disturbing;
  - a. Going without essentials like food or heating (30%)
  - b. Borrowing money (30%)
  - c. Falling behind with utility bills (13%)
  - d. Falling behind with rent or mortgage payments (13%)
  - e. Going without care and support (13%)
  - f. Feeling stressed and anxious (71%)
  - g. Using a food bank (5%)
  - h. Making their MS worse (16%)
3. The current benefits system frequently leaves people living with MS confused, anxious and angry, and assessors reach incorrect decisions far too frequently.
4. Tens of thousands of people living with MS in the UK have been on the receiving end of UK Government cuts for years.
5. In addition, estimates from the National Institute of Economic and Social Research show that the poorest households in Wales are being hit hardest and the Welsh Government has said disabled people are being disproportionately impacted by cost of living pressures.<sup>vi</sup>
6. People living with higher socioeconomic status may have better access to high-quality care, better social support, eat healthier foods or have healthier lifestyles than those with lower socioeconomic status.
7. People living with MS face an inequality in access to emotional, social care and rehabilitation support; physiotherapists and continence advice that corresponds directly to income, education and employment status.
8. Social determinants of health, including sex, race/ethnicity, socioeconomic status, and education among others, have been found to be associated with worse outcomes in MS.<sup>vii</sup>
9. In particular, socioeconomic factors may have a particularly negative impact on people living with MS because the condition affects the entire family and requires adjustments in the workplace, regular visits to doctors, check-ups, expensive investigations, and lifelong treatment.
10. Those in desperate financial need are struggling with basic necessities and can ill afford the luxury of an internet connection or a smart phone. A recent Audit Wales report found that 12 percent of those with a limiting long-term illness are digitally excluded.<sup>viii</sup>

11. People without digital skills are the group already most likely to experience health inequalities. For many people living with a neurological condition like MS, COVID-19 has intensified the digital divide.<sup>ix</sup>
12. Anxiety and depression go hand in hand with advanced MS and the wider social determinants of health. Poverty is both a cause and effect of poor mental health.

## **7. Progress**

1. Neurology has historically been an underfunded, low priority service in Wales. People living with neurological conditions experienced poor access to treatments, services and support prior to COVID-19.<sup>x</sup>
2. In 2022, the Wales Neurological Alliance (WNA) collaborated with the Neurological Alliances of Scotland, England and Northern Ireland for the first time to gather evidence from people living with neurological conditions across the UK.
3. The My Neuro Survey<sup>xi</sup> provided an important insight from over 8,500 people living with and affected by neurological conditions into whether they are getting the treatment and support they need.
4. The My Neuro Survey results in Wales found that there were;
  - a. Significant delays to treatments and care
  - b. A crisis in psychological and mental health support
  - c. Lack of information and support especially at the time of diagnosis
5. The Welsh Government's Neurological Conditions Implementation Group has incorporated the findings of the My Neuro Survey into their priorities and pledged to set up several working groups to oversee this work.
6. Working groups have already been established on improving diagnosis and creating a resource for GPs; neuro- rehabilitation; and neuro-psychology.
7. The Quality Statement on Neurological Conditions<sup>xii</sup> was published last year and sets out how specialist neurological services should be provided across Wales.
8. All Health Boards are expected to have a local Neurological Conditions Delivery Group, which will need to plan services effectively for their population. These will be integrated into their overall Health Board Integrated Medium Term Plan (IMTP).
9. Access to treatments, services and support helps people living with neurological conditions manage their condition; to identify early signs of complications; and put in place prevention and treatment strategies to avoid unscheduled hospital admissions.

10. It is vital that local neurological services are planned, organised and delivered in a way that is responsive to patients needs and makes the best use of existing resources.

**8. Recommendations:** Whilst it is positive to see progress being made, we ask the Health and Social Care Committee to;

1. Challenge health boards on improving access to treatments, services and support for people living with MS and other neurological conditions;
2. Ask the Welsh Government and health boards to commit to a workforce development and commissioning strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with neurological conditions in a timely manner and in an appropriate place;
3. Hold the Welsh Government to account as to why the New Treatment Fund has not delivered for people living with MS;
4. Ask Local Health Boards to demonstrate the active participation of people living with neurological conditions and carers in decisions about improvements by establishing a Neurological Conditions Service User Forum, or other mechanisms to support service user participation.

**Additional information:**

- ✓ I am submitting on behalf of Multiple Sclerosis Society Cymru.
- ✓ I confirm that I am over 18 years old.
- ✓ I give permission for my name and that of the Multiple Sclerosis Society Cymru to be published alongside our evidence.
- ✓ I do not wish for any of our written evidence to be treated as confidential.

**Contact:**

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<sup>i</sup> <https://awttc.nhs.wales/accessing-medicines/medicine-recommendations/fampridine-fampyra/>

<sup>ii</sup> <https://www.sciencedirect.com/science/article/abs/pii/S0163834312001065>

<sup>iii</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6429969/>

<sup>iv</sup> <https://journals.sagepub.com/doi/10.1177/13524585211020435>

<sup>v</sup> <https://www.carersuk.org/news/financial-pressure-on-unpaid-carers-unsustainable-for-carers-in-wales/>



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- vi <https://research.senedd.wales/research-articles/how-is-the-cost-of-living-crunch-affecting-heating-eating-and-housing-in-wales/>
- vii <https://www.msbrainhealth.org/evidence/social-determinants-of-health-impact-on-multiple-sclerosis-outcomes/>
- viii <https://www.audit.wales/publication/digital-inclusion-wales>
- ix <https://www.goodthingsfoundation.org/insights/digital-exclusion-and-health-inequalities/>
- x <https://www.walesneurologicalalliance.org.uk/news/building-the-foundations-for-change/>
- xi <https://www.walesneurologicalalliance.org.uk/news/my-neuro-survey-wales-report/>
- xii <https://www.gov.wales/quality-statement-neurological-conditions-html>