Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Flaenoriaethau'r Chweched Senedd

This response was submitted to the Health and Social Care Committee consultation on Sixth Senedd Priorities

HSC PSS 18
Ymateb gan: | Response from: Cymdeithas Sglerosis Ymledol Cymru | Multiple Sclerosis Society Cymru

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Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor

Initial priorities identified by the Committee

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrysgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?

Q1. Which of the issues listed above do you think should be a priority, and why?

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 MS 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 consultation. In particular, we welcome that the Committee has highlighted access to services for long-term chronic conditions and the health and social care workforce as potential priority areas for the Sixth Senedd.

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.

Timely and equal access to services and treatments across the country was a significant issue before the pandemic.

The 2019 MS Society My MS, My Needs survey showed that the focus on service improvement in neurology over recent years has brought about some positive developments. However, Wales still lagged behind the rest of the UK in terms of:

Access to disease modifying therapies (DMTs). Only 52 % of those who could benefit from taking these treatments were doing so;

Access to a neurologist. One fifth of respondents said their need for a neurologist had not been met within the past year;

42% of people in Wales people had unmet need for physiotherapy compared to 30% in England;

17% of people living with MS had not received any emotional/ psychological support despite needing it, compared to 13% across the UK.

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.

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’.

With this added pressure on MS Neurologist and Specialist Nurse case-loads, people living with progressive forms of MS were being pushed further down the waiting lists with little or no support.

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;

- 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.

- 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.

- The implementation planning documents may be inaccurate in relation to expected patient number and cost impact and need to be clarified.

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'.

COVID-19 has had a disastrous impact on people living with MS and for those who provide services for them.

In the months following the start of the pandemic, the MS Society carried out an online survey of more than 1,100 people living with MS in the UK. This found;

- 32% of respondents had medical appointments cancelled or delayed during the outbreak

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.

Health professionals within the MS teams have done their best to deliver services and support under extremely difficult circumstances. They have 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.

However, some of the workforce had been redeployed or affected by COVID-19 themselves. Consequently, certain high efficacy treatments had been 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.

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.

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.

The All Wales Medicines Strategy Group recommendation in December 2019 that the drug fampridine should be made available in Wales was greatly welcomed.

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, 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.

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 patient who might benefit from fampridine. To date, only 56 patients have completed their assessments. It is anticipated that establishing clinics will continue to run slowly until another MS consultant is in post.

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.

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 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.[1]

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.

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[1] https://gov.wales/new-treatment-fund-cuts-average-access-time-new-medicines-90-13-days

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.

The Welsh Government must be held account as to why the New Treatment Fund has not delivered for people living with MS.

Access to effective treatments and support is the top priority for people living with MS in Wales. We therefore respectfully ask the Committee to prioritise;

access to services for long-term chronic conditions, and;

the health and social care workforce.

As part of this scrutiny, we ask the Committee to;

conduct an urgent inquiry into the disparity in access to MS treatments and services across Wales;

evaluate the impact of delays and cancellations of treatments and care on people living with MS and other neurological conditions, and;

monitor the pace of service resumption across the NHS.

Blaenoriaethau allweddol ar gyfer y Chweched Senedd
Key priorities for the Sixth Senedd

C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:

a) gwasanaethau iechyd;
b) gofal cymdeithasol a gofalwyr;
c) adfer yn dilyn COVID?

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

a) health services;
b) social care and carers;
c) COVID recovery?

Gofal Cymdeithasol a gofalwyr
Social care and carers

Social care is vitally important to enable many people with MS to live healthy, full and independent lives and have equal opportunities.

MS Cymru has been concerned that people living with MS have not been able to access the social care support they need both during and after the pandemic.

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.

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.

In Wales, action was taken to improve access to social care through the Social Care and Wellbeing Act 2014. However, a survey conducted by the Wales Neurological Alliance 2018 found that the system is still failing people with neurological conditions.

Of those who responded to this survey:

- 73% of respondents had not been offered or requested a formal assessment
- 80% of respondents did not receive any services from a local council as a result of a care plan
- 64% of respondents did not see any information that would help them with a social care or support need

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.

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.

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.

MS Cymru knows of people living with MS for example Glyn who has secondary progressive MS. He faced several days during the pandemic when his carers refused to attend because both he and his husband had Covid-19 symptoms and they didn't have access to PPE equipment. More recently, Glyn [in his 40's] has been told that carers had to put him to bed at 6pm because due to the crisis in social care, the local authority was not able to provide a carer later in the evening.

We are aware of others who although are medically fit to be discharged from hospital are unable to do so due to a lack of available support in the community.

Without adequate investment during the pandemic, and investment and long-promised reform afterwards, social care will continue to let people with MS and other disabilities down, limiting their ability to live independent lives.

We respectfully ask the Committee to;

- conduct an urgent inquiry into the social care needs of people living with MS and other neurological conditions and their carers.