

Submission to the Health and Social Care Committee on behalf of the MS Society

About the MS Society

The MS Society is the largest charitable funder of MS research in the UK. Our goal is to see a world free from the effects of MS. We provide emotional wellbeing and financial support and information for people affected by MS, and campaign for positive changes to welfare, social care, access to medicines and health services, more generally.

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 Wales¹.

MS can be relentless, painful and exhausting. It's a condition which damages nerves in your body, making it harder to do everyday things like walk, talk, eat and think. Symptoms can fluctuate, making life unpredictable.

Introduction

- 1.1. Many people with MS will have some increased risk of infection to Coronavirus or complications as a result of infection, because of the progression of their MS, or the effects of their DMT. Some are "extremely vulnerable" and have been advised to shield. This includes those with breathing and swallowing difficulties or those on particular immune-suppressive treatments according to Association of British Neurologists (ABN) guidance.
- 1.2. As a result of this, and to release capacity in the NHS, routine appointments and therapies (such as physiotherapy) and many treatments have been cancelled or delayed where they cannot be delivered safely or virtually. This is creating a backlog and people with MS are concerned about the long term impact on their health, and when the treatment and care they need to stay well will resume. Our helplines and our Lottery Funded My MS, My Rights, My Choices project have experienced a huge volume of calls from people looking for information and advice about treatment and care during the COVID-19 pandemic.
- 1.3. Timely and equal access to services and treatments across the country was an issue before the pandemic, with Wales lagging behind the rest of the UK.

¹ MS Society UK. MS Prevalence, January 2020

The 2019 My MS, My Needs survey² showed that a recent focus on service improvement in neurology has brought about some improvements. However, Wales still lags behind the rest of the UK in terms of:

- Access to disease modifying therapies. 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.
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Neurology has historically been an underfunded, low priority service, contributors to a recent report by the Cross Party Group³ stated that neurology services in Wales are 'chronically underfunded'. They described large gaps in service provision which resulted in:

- Delays to diagnosis of months and sometimes years
- Lack of follow up and community support
- Long, gruelling journeys to access specialist support
- Low levels of access to specialist end of life care

One individual living with MS who provided evidence to this report said: *"From my point of view accessing services has been very difficult. I am in mid-Wales, North Powys. There is absolutely no specialist that covers our area. I was referred to Wolverhampton to see a neurologist there. So that for me is two and a half hour drive... I've got two young children so I have to coordinate school pick-ups and stuff because it is essentially a whole day to go to the neurologist."*

In addition, clinicians and LHB managers that responded to this report stated that until recently, the lack of an all-Wales service improvement network and clinical lead has hampered the progress of system improvement. They also described complex, cross border commissioning arrangements that are in operation to attempt to address the gaps in Wales based provision.

² MS Society – My MS My Needs 3, 2019 (unpublished)

³ Building the foundations for change: The impact of the Welsh Government's Neurological Delivery Plan. A Cross Party Group on Neurological Conditions Inquiry Report (unpublished)

- 1.4. There will be an inevitable lengthy backlog when services resume and lengthy waits will mean some people's MS or disability gets worse, which could have lifelong effects.
- 1.5. This is a very concerning time for those with a long-term condition like MS. Over a third of respondents (34%) to a recent survey said their mental health has suffered as a result of the pandemic⁴.

2. Impact on MS services during the pandemic

- 2.1. The MS Society carried out an online survey of more than 1,100 people living with multiple sclerosis (MS) in the UK, through Survey Gizmo, from 8th to 14th April 2020. It found 32% of respondents have had medical appointments cancelled or delayed during the outbreak, recent interim data from Wales identify that 39% of people with MS in Wales had had medical appointments cancelled or delayed⁵. Although, the survey was not detailed enough to capture whether these were a result of clinically appropriate decisions as opposed to a result of staff shortages or other directly COVID-19-related measures. However, the following quotes make clear the impact this is having on people.

Michele, who is living with MS, told us:

"I have secondary progressive MS, degenerative discs and also am awaiting surgery on both my knees. I require total knee replacements. I was supposed to have the knee operation in January but it was postponed. Then I was to have it middle of March and that was cancelled due to COVID-19. I have no idea when I will be able to have the operations. I am constantly in pain and suffer with chronic fatigue"

Frank, who is living with MS, told us:

"I get bladder and bowel problems. I'm concerned at the moment because I was due to get Botox which has really helped with me being able to hold my bladder during the day. So I'm concerned about that...I'm waiting to see my neurologist because the pain in my legs is getting so bad, and the appointment has been put back. I've got an appointment in September."

- 2.2. MS services are doing their best to deliver care in difficult circumstances. Health professionals have been prioritising urgent cases, and working to provide as many of their appointments as possible via telephone or video call to avoid people needing to come into hospital. However, some of the workforce has been redeployed, certain high efficacy treatments have been stopped because they increase the risk of infection, infusions are happening less regularly than

⁴ MS Society online survey of more than 1,100 people living MS in the UK, carried out between 8-14 April 2020, Survey Gizmo

⁵ Interim data from the UK MS Register, 2020, Funded by the MS Society and Operated and Maintained by Swansea University College of Medicine

they should, monitoring regimes have been relaxed and MRI scans have stopped in many localities.

- 2.3. In relapsing remitting MS (RRMS) people have attacks of new and old symptoms. This is called a relapse. Around 85% of people with MS are diagnosed with RRMS. 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.

Elaine told us

"Well in my case I am at home my employer sent me home in March. My Ocrevus treatment has been postponed and I really don't know when it's going to start up again. I had wait a long time to get the treatment and even then it was a battle to get it approved by the hospital and now it's stopped... although I understand why, it's still hard."

Gabriella, living with relapsing remitting MS, told us:

"I have had several flare ups and relapses, resulting in numbness and at its worst I can't walk. I was taking Tecfidera but reacted terribly to it. I was due to start a new treatment but due to COVID 19 I have been unable to start it, I was told it would be too risky. I have had a flare up since being home and I have been using crutches, I am scared. Two of my boys also had autism and their demands are complex, I worry constantly about my ability to be a good mother, and feel like I'm a ticking time bomb."

Andrew, living with relapsing remitting MS, told us:

"For the last seven years I've had Tysabri every 4 weeks and on an IV drip. Now that 4 weeks has been pushed to six weeks. That's OK, I understand the pressures on the NHS, but will we be pushed further back?"

Since starting Tysabri, everything has been stable, it's helped so much. I haven't had a relapse since I started on it.

I've seen myself go downhill and go from being pretty active to being in a wheelchair. And I understand the toll that coronavirus can have on the NHS, but I don't want to see myself go downhill."

If I didn't have Tysabri now then God knows what would happen. I'm in a wheelchair now, and I can see things without the Tysabri getting a lot worse."

- 2.4. We're hearing from professionals that fewer patients are presenting to services and people with MS are telling us they are scared to attend hospital appointments, because of the perceived or real risks of contracting COVID-19, or because they do not want to add to pressure on the NHS. MS

Clinicians have asked us to use our networks to encourage people with MS to contact them if they are concerned they are having a relapse. The concern is that patients will present sicker at a later date, which could have been avoided with timely treatment.

- 2.5. Realistic expectations of services should be communicated to patients, in order that no one is wrongly deterred from accessing the treatment and care they need. Information about alternative resources and sources of help and information from charities such as ourselves must also be communicated.
- 2.6. The impact on rehabilitation, including physiotherapy and physical activity, services has been huge. Professionals have been able to continue supporting some patients using telemedicine, of benefit to many. However, 'hands on' work with patients has stopped, leaving many without their essential therapy. Physiotherapy, for instance, is used to help people with MS recover from a relapse, and to treat and manage pain and muscle spasms, stiffness and common difficulties with mobility, balance, posture, fatigue and bladder problems.
- 2.7. Many people will quickly become deconditioned due to this lack of support and reduced exercise opportunities during the lockdown. Recent data revealed that 29% of people with MS in Wales said they were struggling to stay physically active⁶. Function lost in this way can be very difficult for people with MS to recover even over the longer-term.
- 2.8. We want to see all MS services adhere to at least the minimum service standards set out in the MS Trust's recently published minimum service specification, during the pandemic crisis phase⁷. However, restarting all DMTs as soon as safe and feasible to do so should be a priority, as should rehabilitation services; both slowing disease progression and maintaining function are vital to healthy, good quality of life for people with MS.

Recommendations:

- 1) All services should deliver at least a minimum service to people living with MS during the pandemic crisis, as detailed by the MS Trust's minimum service specification.
- 2) The NHS needs to include neurological services as part of its broader plan to start releasing and redeploying capacity to non-COVID-19 related care over the next six weeks and beyond, working with the Association of British Neurologists and other professional bodies to prioritise which services can be safely delivered.

⁶ Interim data from the UK MS Register, 2020, Funded by the MS Society and Operated and Maintained by Swansea University College of Medicine

⁷ MS Trust, Minimum MS service specification: for guidance during COVID-19 crisis, <https://www.mstrust.org.uk/sites/default/files/ms-trust-minimum-ms-service-specification-v4.0-apr-2020-FINAL.pdf>

- 3) Restarting all DMTs and rehabilitation services as soon as safe and feasible to do so should be an absolute priority; both slowing disease progression and maintaining function are vital to healthy, good quality of life for people with MS.
- 4) Realistic expectations of services should be communicated to patients now and on an ongoing basis, in order that no one is wrongly deterred from accessing the treatment and care they need.
- 5) Post-pandemic, NHS Wales should evaluate the impact of delays and cancellations of treatments and care on people with neurological conditions including MS. This Committee should also continue to monitor the pace of service resumption across the NHS.

3. Coping with uncertainty, to shield or not and impact in mental health.

- 3.1 Being diagnosed with MS, coping and then adapting to the uncertainty can lead to stress and anxiety. Before the Covid epidemic, three in five pwMS reported feeling lonely and nearly half have experienced depression⁸. Distressingly, pwMS are seven times more likely to attempt suicide than the general population⁹. The anxiety and uncertainty of living through a time of unprecedented change, increased difficulty in navigating/ accessing our usual support services (health, social care), increased loneliness and isolation gives real concern as to how those already experiencing mental health issues as a result of living with a long term condition will cope both now, during the national crisis, and in the future..
- 3.2 In our recent online survey, 51% of people living with MS said that they felt anxious at the moment, 26% felt scared and 16% felt confused. Mental health problems are common in people with neurological conditions and can have a huge impact on people's day to day lives.
- 3.3 We have seen increased traffic on our social media and helplines with people feeling very confused as to whether they are extremely clinically vulnerable and therefore shielding or whether they are at medium risk being clinically vulnerable or at the same risk as the general population. This hasn't been helped by an apparent lack of consistency in terms of those receiving the 'shielding letter' from the Chief Medical Officer.

Some people living with MS had not received the CMO letter but had received a letter from primary/ secondary care staff telling them that they should shield for 12 weeks. Secondary care services have in some cases generated their own list and sent out letters using their own criteria, which can differ from

⁸ MSS Loneliness Report, 2018

⁹ Depression in MS, RJ Siegert, D A Abernethy, 2017

location to location within the same speciality, causing significant confusion and uncertainty. Some specialist services have assessed people on the basis of their relevant health professional bodies' criteria for identifying high risk people. The criteria devised by WG did not match the criteria developed by a number of health professional bodies. For example the Association for British Neurologists identify that people with MS who have swallowing/breathing difficulties are 'extremely vulnerable', however these people were not included in the Welsh Government criteria.

- 3.4 Data from the MS Register's recent survey identified that by far the greatest need for people with MS was to have accurate information on how coronavirus relates to their MS (48%)¹⁰

Recommendations

Welsh Government must

- 1) Provide clearer information about access to support and services across Wales.
- 2) Provide clarity as to who should and should not be shielding, working alongside clinicians across Wales to ensure a consistent approach.
- 3) Provide greater support and funding to charities (who are facing large falls in their income at a time when demand has never been higher) during and in the recovery period of the pandemic to ensure that they are able to support the physical, emotional and psychological needs of their client group who are some of our most vulnerable members of society.

4. Virtual services

- 4.1. As described above, most MS services have moved to virtual delivery of services where possible, during the pandemic. The ABN recently observed, that as we move out of the peak of the pandemic, "the 'new norm' is likely to include more telemedicine, greater reliance on digital tools, and more flexibility about how we conduct clinics."
- 4.2. In many ways, the necessity of working differently during the pandemic has sped up uptake of telemedicine and technology which we, and the wider health care sector, have long been calling for¹¹, though this uptake hasn't been equitable across the UK, recent findings show that only 19%

¹⁰ Interim data from the UK MS Register, 2020, Funded by the MS Society and Operated and Maintained by Swansea University College of Medicine

¹¹ Nuffield Trust, Improving care for people with MS: the potential of data and technology, July 2018, <https://www.nuffieldtrust.org.uk/research/improving-care-for-people-with-ms-the-potential-of-data-and-technology>

of people with MS who completed the survey had appointments by phone or by video, compared to 31% in England, 32% in Scotland and 23% in Northern Ireland¹².

- 4.3. In 2019, the MS Society conducted a series of patient engagement forums across the UK and asked people with MS for their views on remote appointments. Benefits around reducing the fatigue or anxiety associated with travelling to appointments came up a lot, as did the expense of travel. The option of virtual appointments for more routine appointments was welcome. However, they felt strongly that face appointments were more appropriate if experiencing new symptoms and deteriorating function and should always be offered as an option.
- 4.4. Given people living with MS may continue to be anxious about attending hospitals for some time and in order effectively triage the elective backlog, virtual services will play a very important role in care going forward. However, a 'digital first' approach must account for the fact such services will not be accessible for everyone for whom alternatives must be offered, and should not replace face to face appointments where appropriate.
- 4.5. It is also the case that the capability of NHS IT systems varies massively and as such investment is needed in such IT infrastructure.

Recommendations:

- 1) Learning from the increase in virtual services and telemedicine during the pandemic, including the experiences of patients, should be evaluated with a view to creating more efficient and accessible services in the future. Increased resources should be invested in upscaling appropriate such services and IT to enable this and ensure parity of access across the UK.

5. Adult Social Care

- 5.1. Social care is vitally important to enable many people with disabilities to live healthy, full and independent lives and have equal opportunities. We are concerned that people will not get the social care they need both during and after the pandemic. There was huge unmet need prior to the outbreak. One in three people with MS in the UK struggle without the support they need to do the basics like getting washed, dressed and eating. This prevents them – and their family members and friends providing unpaid care – from living dignified, independent lives.¹³ This is not fair and it is unsustainable. Social care funding in the UK has not kept

¹² Interim data from the UK MS Register, 2020, Funded by the MS Society and Operated and Maintained by Swansea University College of Medicine

¹³ Morrish PK, Inadequate neurology services undermine patient care in the UK, BMJ 2015;350:h3284 doi: 10.1136/bmj.h3284

pace with increasing demand and we now face a huge 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. Six years on from the implementation of the Social Care and Wellbeing Act, 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 gives local authorities powers to temporarily suspend duties in the SSWB (Wales) Act if pressures on social care get too high, during which time some people may not get the care and support they would normally be entitled to. We are concerned that some local authorities will not report as operating under these modifications, but will nonetheless be reducing care in response to funding and demand pressures. Also, the lack of Personal Protective Equipment (PPE) for care workers is already causing some people to decide to cancel their care in order to protect themselves from infection. Together, this situation will mean some people's health and wellbeing deteriorating without support, or that of their unpaid carers having to take on increased responsibilities.

For example Glyn who has secondary progressive MS 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.

- 5.2. Interim data from a survey of people with MS in the UK found, of a total of 364 respondents, 9% said that their care and support had been reduced or

cancelled and a further 9% had reduced or cancelled their own care and support due to concerns about infection¹⁴.

- 5.3. 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.

Recommendations:

- 1) Transparency from Welsh Government as to which local authorities are operating SSWB Act modifications and to what extent way, so that people that rely on services know what it means for them and voluntary sector organisations can target support where it may be most needed.
- 2) A coordinated monitoring operation across Government, local authorities, providers, regulators and patient organisations, on the impact of the pandemic on people that rely on social care both in areas officially operating modifications and those that are not. An evaluation of that impact to inform the six-month review of the legislation.
- 3) Sufficient funding to stabilise the system as we move forward during the coronavirus pandemic. In the immediate future, the Government must continue to give the system 'whatever it needs', as it has promised to ensure providers can meet the increased costs they're facing and ensure local authorities can continue to meet need.

¹⁴ Interim data from the UK MS Register, 2020, Funded by the MS Society and Operated and Maintained by Swansea University College of Medicine