

A large, stylized orange and yellow graphic element resembling a speech bubble or a callout box, containing the title text.

**Life in Lockdown with MS**

Lived experience of those living  
with MS during lockdown

17 June 2020

Let's stop MS **together**

## Life in Lockdown, Living with MS

For the over 15,000 people living in Scotland with Multiple Sclerosis (MS) the impacts of the Covid-19 pandemic have been far reaching and life changing. Many have felt anxious, isolated and concerned about the future. As we move into the next phase of easing lockdown, this anxiety is set to continue as we now navigate living with MS in a Covid world.

Some had seen a deterioration in their condition, manifesting in both their physical and mental wellbeing. The longer term consequences of being unable to access the services and support normally used to manage MS may be seen for years to come.

This report seeks to highlight some of the key issues and experiences of those living with MS. Data is taken from several sources including;

- MS Society UK helpline<sup>1</sup>
- MS Society webinar, time to chat and wellbeing sessions feedback
- The MS Society and UK MS Register Impacts of Covid 19 survey<sup>2</sup>

Our findings can be categorised into 6 main themes;

- Emotional wellbeing
- Ability to stay physically active
- Access to health and care services and support that help manage MS
- How coronavirus has impacted daily life
- Financial health
- Role of friends and family in caring roles

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<sup>1</sup> Findings are UK wide

<sup>2</sup> The MS Society and the UK MS Register surveyed 181 people with MS between 24/04/20 and 11/05/20. The survey was only able to be completed online on the UK MS Register. The study was promoted via MS Society social media and direct mail, UK MS register direct mail and via professional contacts. As none of the questions were compulsory for respondents and some questions were filtered based on answers the total respondent sample can vary for certain results. For more information or to see the raw data please contact [Rebecca.duff@mssociety.org.uk](mailto:Rebecca.duff@mssociety.org.uk)

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## Emotional wellbeing

- 36% of respondents told us they felt anxious
- 13% said they felt scared
- 28% said they felt frustrated

Many MS Helpline callers told us they felt overwhelmed with the added pressures of home schooling/distance learning and working from home themselves. This had a significant impact on their stress levels, fatigue, and ability to exercise during the school week.

There was also confusion around the definition of vulnerable and extremely vulnerable and the implications of self-isolation or shielding. We had enquiries from people who thought they should be shielding based on the criteria, but had not received a shielding letter. The volume and inconsistency of information circulating caused a great deal of anxiety for people. While only 9% of survey respondents had received a shielding letter, 55% had been shielding or self-isolating during the lockdown period. This highlights not only the confusion around the different criteria, but also the extreme health anxiety and fear that people have been feeling in relation to catching Covid-19.

*Wading through all the information out there and trying to guess what it means for my MS was getting boring and stressful! Webinar participant*

*Concerns from participants came from anxiety around getting next DMT infusion, what will happen when this all ends, will they be able to get out the house as normal, anxious when going shopping and anxious about booking online delivery slots. Some concerned that MS Nurses now being redeployed in the NHS and cannot make contact with them - webinar leader*

## Ability to stay physically active

- 31% struggling to stay physically active
- 25% wanted support in the form of exercise tips, classes or videos I can do from home
- 24% wanted information on how to stay physically active at home

We know from our research that staying active makes a huge difference for people in managing their MS. The benefits include; managing symptoms (including fatigue, and problems with balance and walking) and improved mood and mental health. For those with mild MS, exercise can improve overall health and for those with more severe symptoms exercise can help to stay more mobile.

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With leisure and community services closing, and restrictions around exercise many people with MS have seen a deterioration in their mobility, strength and may have seen an increase in pain. For those who are shielding, and therefore already likely to be the most vulnerable, the consequences are felt even more sharply.

*"I am struggling physically. My body is getting more spasms and my legs hurt as soon as I try to walk. I have been diagnosed with Lhermitte's which is very painful and has gotten worse since lock down. Also, I was caring for my elderly dad and he's passed away in February (I now believe was Covid 19) so I became less active, I am grieving I'm finding it hard to answer the questions properly as I feel grief has an impact more than covid."*

### **Access to health and care services and support that help manage MS**

- 32% had appointments by phone or video call
- 24% had appointments cancelled or delayed with a further 6% cancelling appointments due to concerns about infection.
- 6% had to wait a long time or not been able to speak to an MS specialist when they needed to
- 15% had care and support reduced or cancelled. Of those 60% of this was provided by a private company or local authority and 40% was unpaid support from friend or family member.
- a further 8% had cancelled their care due to fear of infection

The ability to access support to manage the symptoms and progression of MS- including access to treatment- is paramount for people to live as well as possible with the condition. The redeployment of specialist nurses and other staff has meant that MS services have changed and reduced for many people living in Scotland.

However, some people also reported that they liked having their appointment virtually, as it reduced the need for travel or waiting around in hospitals.

*"I haven't had results from my MRI from 11th march 2020. To check the state of my Relapsing Remitting MS and the meningioma that I have. Neurologist was going to put me on disease modifying therapy possibly from the results of this MRI. I haven't had any contact from anyone about these and I am very worried the longer I'm waiting now. I am practising social distancing as much as I can and just leaving house for shopping essentials exercise etc."*

*"I don't normally have contact with MS specialists. But equipment I have to assist has broken and won't be fixed at this time."*

*"Was hoping to get offered a new drug for Primary Progressive MS but not being supplied as suppresses immune system"*

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## How coronavirus has impacted daily life

- 8% going without essentials because they can't access shops or deliveries
- 5% can go days without speaking to anyone they know
- 32% felt better able to use technology to stay in touch with people
- 21% felt more connected to neighbours or community

Many people reported to us that they were now relying on friends and families to help with accessing essentials. For many people, going shopping themselves had become unmanageable due to the necessary restrictions and systems that had been put into place.

*"Queueing at shops is difficult as I can't stand for long. I have to pick a day and make sure I am there early. Planning is difficult for me as I do not know from one day to the next how I will be feeling and if I will have the energy to go the next day."*

*"Unable to do food shop is affecting my diet and interest in eating."*

On a more positive note, some people have told us that they are feeling more connected within their communities, and that they have upskilled in their use of technology to stay connected. In response to this, we launched our MS Wellbeing Hub-providing support to manage physical and mental wellbeing and finances.

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Many of our local groups have started virtual social meetings to stay connected, with some moving many or all of their usual activities online.

*We started with an online social and quickly started to explore whether we could run our classes and sessions online as well.*

*The result has been we now have everything we had before available to people from the comfort of their own homes and on the same timetable as well to keep the continuity.*

*It's been a great idea and it's been cost-effective. The main downside has been a lack of face-to-face contact for people but even then participants are joining classes early to have a catch-up before things kick off.*

*The engagement we're seeing is brilliant, too. There hasn't been a drop in numbers from what we see in person and we expect it to increase so we may end up reaching a few extra people as we keep things moving.*

*To such an extent that we've even gone international. One of our members joined with her daughter who lives in the UAE which is a new area to reach for us to say the least.*

*It's been quite eye-opening and I really hope we're able to keep some online presence when things start to return to the way they were. We cover a relatively small area so travel isn't a huge issue but I expect that groups who are more remote might find a different way of working that really suits them.*

## **Financial Health**

- 10% had seen a reduction in their pay or hours. 16% also reported that this was the case for another member of their household.
- 13% said that the coronavirus will have an impact and the damage will be long lasting on their household finances.

This was very much reflected in the calls we received to our MS Helpline. Our callers asked us about;

- Their benefit entitlement
  - Some are currently furloughed / on sick leave but don't expect to go back to work
  - Others are working and have just been diagnosed with MS
  - Others wondering what will happen if hours are reduce hours or stop working
  - Others are unemployed and have recently been diagnosed with MS
  - Others calling on behalf of a family member or friend
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- Someone wanted to know how getting the Self Employed Income Support Scheme grant would affect their ESA

We were contacted by people looking for advice on how to challenge PIP decisions – many had had phone assessments. We were also hearing from people who were not getting the result of a PIP application or review until months after the face to face assessment. These are not new issues, but have been exasperated by lockdown.

We were also hearing that the PIP helpline has been incredible busy and so claimants are unable to get through to do PIP mandatory reconsideration by phone or request an extension to the time limit.

Living with a long-term condition such as MS already has a significant impact on your finances. Living with MS is expensive. It costs, on average, an extra £200 a week to live with a neurological condition like MS. With the additional financial implications of being at home more, along with concerns around job security, there is a risk that people with MS will become more financially insecure as a result of the pandemic.

### **Role of friends and family in caring roles**

We also saw an increase in enquiries around people with MS losing their carers due to the carer self-isolating and having difficulty finding new carers. There was an increased reliance on unpaid carers to provide support throughout lockdown. While most of our callers and survey respondents said this was working well, it further highlights the essential role of friends and family who care. They must also receive the support that they need to stay physically and mentally well.

*“Husband and friends give me support all the time and are continuing to do so. I am very grateful for that.”*

*“My partner is my carer and she spends a lot of her time helping me with personal care and shopping cleaning etc. When we were advised to stay at home (I'm 75) my partner and I chose to self-isolate together. This is working well.”*

### **We're here for everyone living with MS**

Throughout the Covid-19 pandemic we've been here for people living with MS, helping the community to stay informed and connected.

[Information webinars](#)

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Our webinars provide a place for the MS community to get the information they need, and ask the questions that matter to them. They're presented by an expert speaker alongside someone who has lived experience of MS. These themed webinars have covered topics like Covid-19, exercise and mental health. Since the beginning of lockdown we've delivered 15 webinars.

Explained in terms that we need to know.

Too much information to scroll through online and can become confusing and the news is information overload. This webinar helped make it clearer for people with MS.

The PPE for the Mind webinar has made a lasting positive change in my life and I am very grateful I had the opportunity.

There are exercises and information on the website that I've have used and found helpful.

I am very grateful to the MS Society for everything that has been available over this extremely challenging time.

### Time to Chat sessions

We have delivered 63 time to chat sessions since lockdown began. These informal meetings are an opportunity for all those living with MS to connect.

### Taster wellbeing sessions

Since the beginning of lockdown we have delivered 11 taster wellbeing sessions on a range of topics, responding to the needs of people with MS. These have included sessions on exercise and movement, mindfulness and creative writing.

I think that has got to be the best video with explanations and advise that I have received. I look forward to receiving their information and drop foot exercise videos.

I have learnt a lot today and am now on a mission to fix myself. Looking forward to receiving the links they talked about. I feel more positive now I can improve my walking.

I really enjoyed the session. The exercises were so useful for me. I particularly need help with balance so look forward to being able practice what they told us. Some of their tips on things we can buy ourselves ie the finger stretchers, was very useful and mine have now been purchased.



Thanks to funding from the Scottish Government's Wellbeing Fund we've created the MS Wellbeing Hub. It's a one-stop shop for the information and support the MS community during through the COVID-19 crisis in Scotland.

These **free** services are available to anyone with MS and their families in Scotland:

- [One-to-one support](#)
  - [Physiotherapy](#)
  - [Counselling](#)
  - [Financial wellbeing](#)
  - [Wellbeing sessions](#)
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## **We're the MS Society.**

Our community is here for you  
through the highs, lows and  
everything in between.

We understand what life's like with MS.

Together, we are strong enough to stop MS.

[mssociety.org.uk](http://mssociety.org.uk)



## **Contact us**

MS National Centre 020 8438 0700  
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### **Online**

[mssociety.org.uk](http://mssociety.org.uk) [www.facebook.com/MSSociety](http://www.facebook.com/MSSociety)  
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Multiple Sclerosis Society.  
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 **Let's stop MS together**