Too much to lose

The importance of improving access to community rehabilitation for people with MS

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#TooMuchToLose

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Foreword

Like most of us, many people living with MS have struggled to stay physically active during the pandemic. Disruption to health and care services has made it more difficult to access support to maintain mobility and manage MS symptoms.

Rehabilitation services and support are key to helping people with MS to do just that. From physiotherapy, to speech and language therapy, seeing a continence specialist, or taking part in physical activity, rehabilitation is about maintaining physical and emotional health and wellbeing.

But despite thousands of people with MS relying on this support to lead active and independent lives, far too often they're unable to access it. Now, in the midst of a pandemic, our new research highlights how this has only got worse during lockdown.

Over a third (34%) of people told us they felt their MS symptoms had got worse, with many saying their ability to walk had deteriorated, they were experiencing increased fatigue and pain, and were struggling with low mood.

When it came to speaking to a rehabilitation professional during this time, 7 in 10 (69%) of those who needed it said they were unable to. Of those whose symptoms had worsened, over half (51%) felt a reduction in, or changes to, specialist support had contributed to their symptoms getting worse.

In this report, six people living with MS across the UK describe what this means to them. Their accounts make clear that this support is too much to lose.

We also hear from five professionals and MS services about how quality rehabilitation can change people's lives, and how they have moved to virtual delivery to meet evolving needs over the past few months.

Getting through the pandemic continues to present immense uncertainty and challenges to all of us. But understanding what works across health and care services is vital and, if these learnings are acted upon now, it will allow everyone with long-term neurological conditions to get the support they need.

With investment currently directed into coronavirus rehabilitation, there is an opportunity to realise the benefits of community support services that keep people with MS living well for longer. That's why, beyond the pandemic, we're calling for an expanded right to rehabilitation on the NHS - to keep people with MS moving forward.

I would like to thank everyone who has been involved and shared their stories.

Nick Moberly
Chief Executive, MS Society

About MS

Multiple Sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. In MS, the body's immune system attacks myelin, the protective cover around nerve fibres. Damage, which can occur anywhere in the central nervous system, interferes with messages travelling from the brain and spinal cord to other parts of the body.

Symptoms are many and varied, unique to each person. They can include problems with balance, vision, bladder and bowel function, speech, memory, fatigue and painful muscle spasms, among many other things.

MS affects over 130,000 people in the UK, many of whom experience their first symptoms in their 20s and 30s, during the peak of their working lives.

MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary progressive MS (PPMS) affects around 10 to 15% of people with MS. This type of MS is progressive from the very first symptoms. The remaining 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Many people with MS will go on to develop secondary progressive MS (SPMS) within 15 years of being diagnosed.

About this report

This report presents new data from an online survey of 1,674 people with MS by the MS Society and UK MS Register.[1] Data was collected between 12 – 26 August 2020. This data is the third in a series of surveys hosted on the UK MS Register between May and August 2020.[2] The survey was promoted by MS Society and UK MS Register by direct mail, by MS society social media and via professional contacts. Some figures in this report refer to unmet need for services or support. This refers to the proportion of respondents that had a need for said service or support, and were unable to access it.

Further research which informed this report included telephone interviews with MS professionals, stakeholder and partner organisations and people living with MS – some of whose stories are included here.

Introduction

What is rehabilitation?

There is currently no cure for MS. More disease modifying treatments (DMTs) exist than ever before to slow the progression of the disease, but not everyone with MS is eligible. Most DMTs are licensed for relapsing forms of MS, with very limited options for PPMS or SPMS.

Certain therapies can keep symptoms under control and maintain function. They can allow many people with MS to live independent lives less restricted by fatigue, incontinence, pain, immobility, cognitive fog and other debilitating symptoms.

Rehabilitation is an umbrella term for such treatments and therapies. The aim of rehabilitation is to reduce the impact of health conditions on a person's life, independence and goals. Rehabilitation is key to managing long-term conditions and maintaining a person's physical and emotional wellbeing. It is delivered by a wide range of health and care professionals and many people with MS will need to see a professional with expertise in MS or similar neurological conditions. The stories in this report show just how varied rehabilitation is.

The common perception of rehabilitation is often about treatment in hospital after an MS relapse or fall. That could be intensive physiotherapy to get someone walking again or an occupational therapist arranging equipment to help make life easier after discharge home. But rehabilitation also happens outside of hospital. Not just to help continue recovery from a fall or relapse, but to manage the symptoms and emotional and cognitive effects of MS and maintain activity, function and quality of life.

Rehabilitation often relies on self-management – regularly doing exercises recommended by a physiotherapist or following a particular diet, for instance. Some support requires a professional to work 'hands-on' with their client – for example a physiotherapist may hold and move limbs for passive stretching and range of motion.

Sometimes the terms reablement (short-term support following discharge from hospital) or prehabilitation (support before stress on the body from things like surgery or possible infection) are used to describe this kind of support. These are all points on the broad spectrum of rehabilitation, from recovery to maintenance. Whatever we call it, it is essential for people with conditions like MS.

Rehabilitation provision in the UK

Ongoing support to maintain function isn't widely available on the NHS, and rehabilitation in the community is limited, for example to six physiotherapy sessions within a 12 month period. This is despite acknowledgement within the NHS that there is strong evidence showing continued, co-ordinated multidisciplinary rehabilitation in the community improves long-term outcomes and can help to reduce hospital re-admissions.[3]

Emergency admissions to hospital for people with MS in England increased by over 15% between 2016/17 and 2018/19. In 2017/18, there were over 30,000 emergency admissions costing the NHS a staggering £86 million.[4] Many of these admissions were for problems which could have been avoided with better access to services or self-management. These include things like bladder and bowel issues, urinary tract infections, and respiratory problems. These findings reflect a strong economic case for investment in rehabilitation across the NHS, as described in NHS England's own commissioning guidance for rehabilitation.[5]

Responsibility for funding rehabilitation is split between national and local NHS bodies, depending on the level of complexity, need, and specialist support required. However, there aren't specific requirements for local NHS bodies to fund community rehabilitation services. This means provision varies between regions and nations creating unfairness for people with MS. There isn't enough data collected to know how many community rehabilitation services there are and how they are performing, but the MS Society has consistently identified significant unmet need in surveys of people with MS (see page 8).

It's widely acknowledged there aren't enough health and care professionals to deliver this kind of support. The Chartered Society of Physiotherapy estimate the number of newly qualified physiotherapists needs to increase by at least 500 each year for multiple years to meet rising demand[6 7]. There is an over 6% vacancy rate among occupational therapists[8] and the 9,000 registered dietitians across the UK are becoming more reliant on support staff to maintain safe staffing levels[9]. Anecdotally, there is understood to be an even greater shortage of professionals with expertise in neurology - neuro-physiotherapists and neuro-psychologists, for example.

The MS Society and the Nuffield Trust jointly published a report identifying strong potential for digital tools to help people with MS to self-manage symptoms like fatigue, cognitive difficulties and pain. However, it noted that in many cases these tools worked best when combined with interaction with health and care professionals, rather than in isolation.[10]

The report also identified the potential for local commissioners to take a more data-driven approach to planning services, detailing a range of data sources available on MS (and neurology more widely). This points the way for local commissioners to stratify patients not just by their potential to benefit from rehabilitation services, but also by their risks and the potential preventative benefit of the prehabilitation approach described below. In the short-term this is most relevant for a public health emergency like the pandemic, but in the longer term could be adapted to a more proactive, preventative approach in general.

Policy context

Rehabilitation has become more of a priority in the NHS in the wake of the pandemic, with many coronavirus-survivors needing support to recover from the effects of the virus. However, the degree to which improving rehabilitation for people with neurological conditions has been prioritised by Governments before and during the pandemic varies across the UK.

The Scottish Government have demonstrated leadership by publishing a strategic framework for 'Recovery and Rehabilitation during and after the COVID-19 Pandemic', in August this year.[11] This comes after the publication of an action plan to improve neurology services in 2019. Both documents commit the Government and NHS in Scotland to improve the support available to people with conditions like MS. Importantly, the framework states that:

> "The coronavirus (COVID-19) pandemic has resulted in impairments for some people as a result of delayed healthcare treatments and social restrictions (which can lead to decreased physical activity, changes in nutritional intake and decreased psychological wellbeing). As a result, a public health approach to prehabilitation where early intervention for prevention is warranted to maximise resilience and promote general health and wellbeing."

In England, prevention and rehabilitation were key themes throughout the NHS Long Term Plan, published in 2019. This included a welcome commitment to increased funding for community services as a proportion of the overall health budget. Further to that, NHS

RightCare - a programme aimed at reducing variation in care across England – published two toolkits aimed at supporting Clinical Commissioning Groups (CCGs) to improve services in the same year. One toolkit focused on community rehabilitation and the other on progressive neurological conditions. Additional resources have since gone into rehabilitation support for people recovering from coronavirus. What is missing are national incentives for local NHS bodies to deliver community rehabilitation and a coordinated national plan to improve rehabilitation that addresses access and workforce issues.

In August this year, the Welsh Government published 'Rehabilitation: a framework for continuity and recovery 2020 to 2021'.[12] The framework aims to help plan for an expected increase in demand for rehabilitation for those directly or indirectly impacted by coronavirus. Most importantly, the framework recognises the potential deterioration in the physical and mental health of those who have been shielding and/or self-isolating, as well as those who have been waiting for paused routine or urgent support. To meet demand for rehabilitation, the Welsh Government are proposing rehabilitation must become 'everyone's business' and promote self-management and the coproduction of care. As part of the implementation of the Neurological Conditions Delivery Plan, a task and finish group has been established to focus on the work of community rehabilitation services, and to better understand current pathways, patient flows and the value-added care.

Acknowledging the need for an increased workforce to manage rising demand for rehabilitation, the Northern Ireland Department of Health recently published a physiotherapy workforce review uplifting undergraduate physiotherapy training places to 86 per year by 2022/23.[13] However, rehabilitation services respond to the presenting need/s and activity data isn't recorded by condition, so cannot tell us whether services are meeting the needs of people with MS.

> **There are common challenges across the UK. From a lack of data to understand the provision of rehabilitation, outcomes for people with MS and how to improve them, to a recognition of the need to meet rising demand for rehabilitation in the wake of the pandemic.**

However, some Governments are further ahead than others in terms of strategic plans to improve both rehabilitation and neurology services, for which the challenge is now implementation.

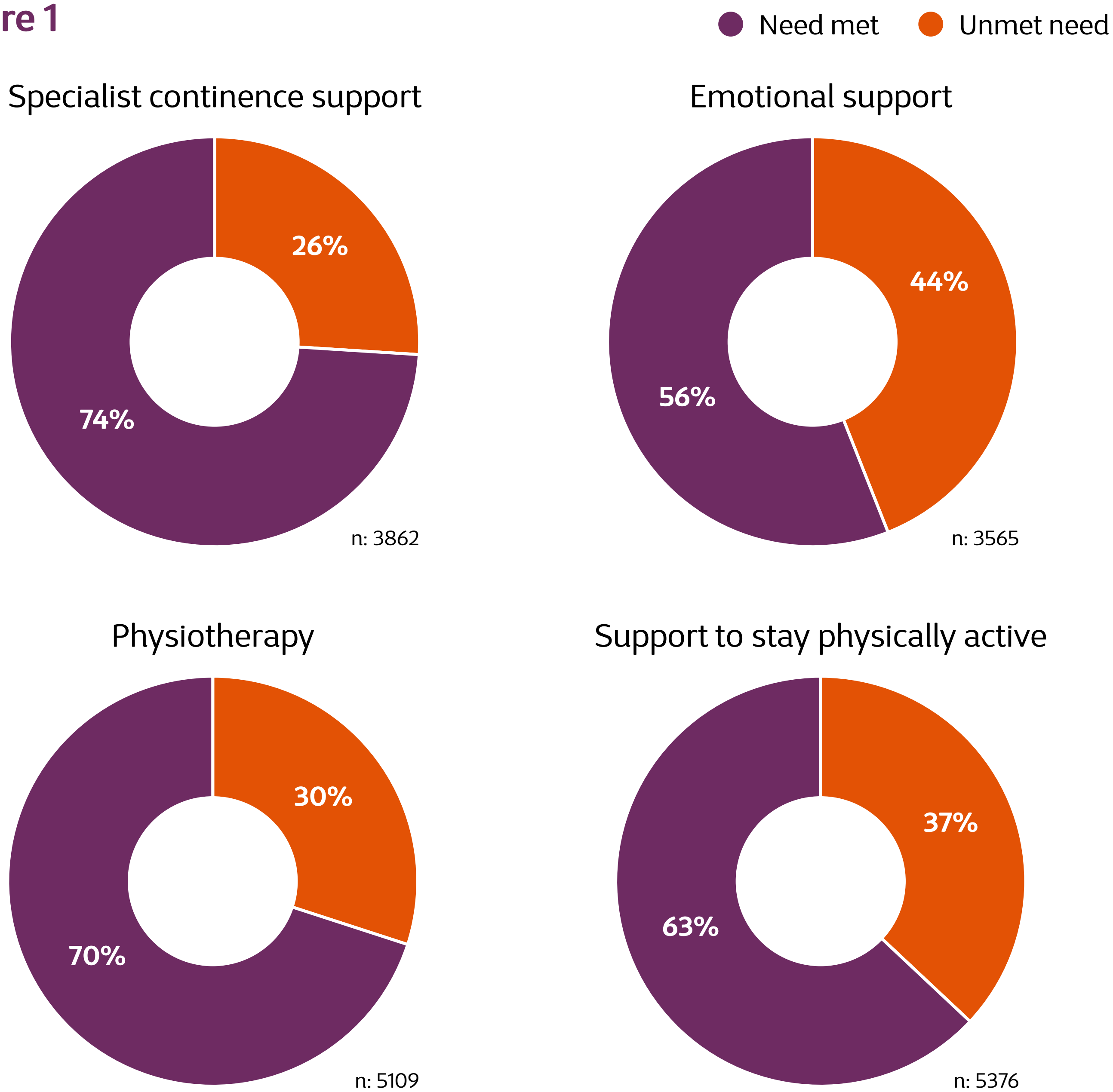
Access to rehabilitation and the impact of the pandemic

In 2019, our My MS My Needs survey found high unmet need for access to specialist services, from physiotherapy to continence support, help to remain physically active and emotional support (see figure 1).[14]

This unmet need is echoed across neurological conditions. The Neurological Alliance Patient Experience Survey 2019 found low proportions of people with neurological conditions had been offered such support, including physiotherapy and occupational therapy.[15]

The coronavirus pandemic has since disrupted health and care services for people with MS. The effects of this continued well beyond the peak of the first wave over summer 2020 – and without further action there's a real risk they'll be compounded in a potential second wave over the winter.

Figure 1



Specialist continence support

Emotional support

Physiotherapy

Support to stay physically active

In June 2020, a MS Society and MS Trust survey of MS healthcare professionals found a quarter (24%) said more than half of the workforce in their MS service were redeployed away from MS care. While we expect this to have improved in the intervening months, the majority of respondents (67%) didn't know when services would return to pre-pandemic capacity.

Three quarters (73%) of professionals also told us that rehabilitation was the most common type of care that had been delayed, cancelled or limited. They further stated that dealing with the backlog of patients was a key challenge in getting back to pre-pandemic service capacity.[16]

Professionals are clearly very concerned about the impact not receiving rehabilitation will have on those who need it. Nearly 8 in 10 (76%) respondents wanted to see rehabilitation resume as soon as possible, more than any other type of service.

New data published in this report, collected in August 2020 via the UK MS Register, also suggests access to rehabilitation has worsened since the start of the pandemic. 7 in 10 (69%) people with MS who needed to see a professional said they hadn't had an appointment with a rehabilitation professional since March. Of those who had seen appointments cancelled or delayed reported the most common were physiotherapy (31%), continence specialist services (18%), and occupational therapy (8%).

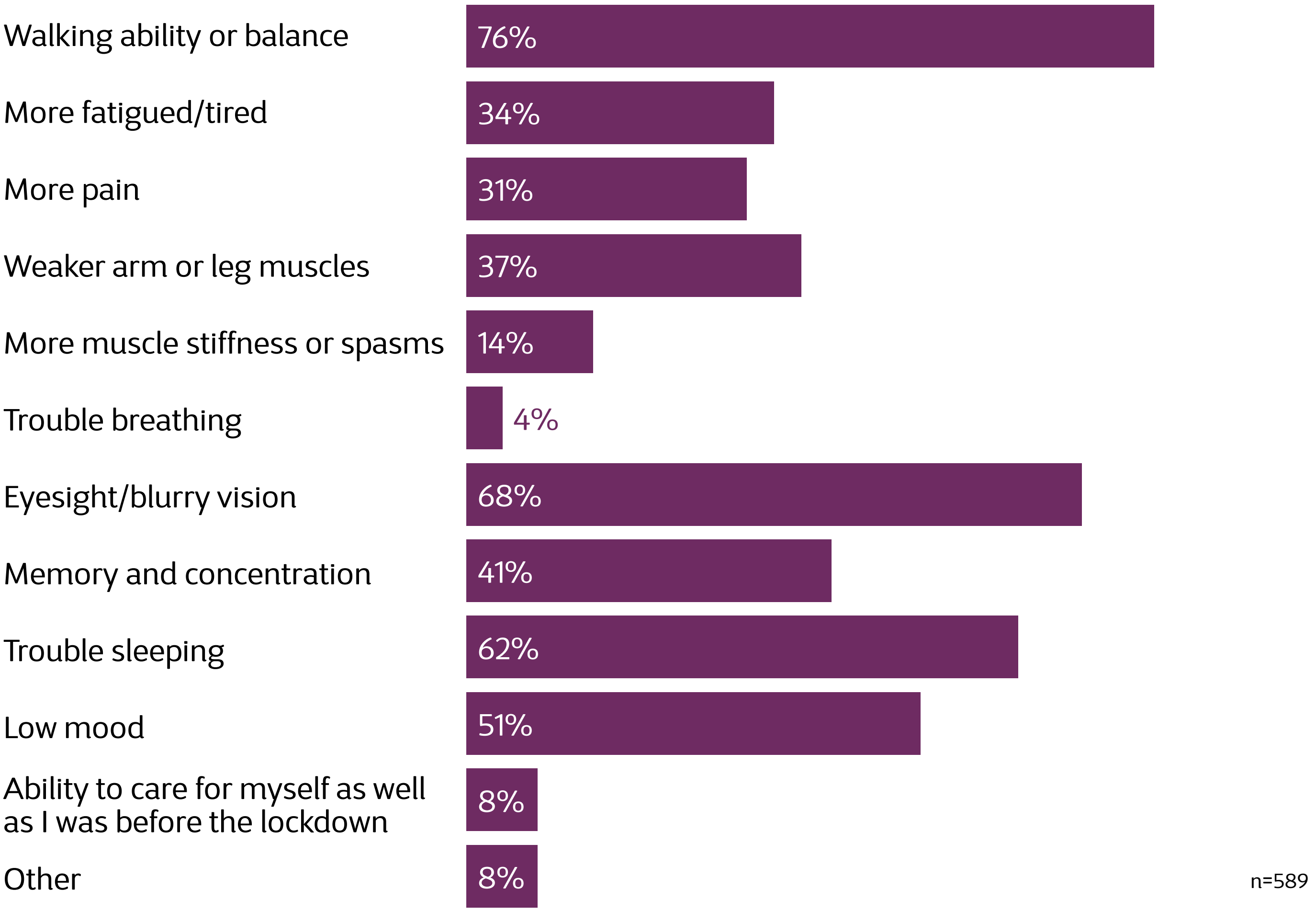
> One third (34%) of people living with MS felt their MS symptoms had changed or worsened since the beginning of the lockdown.

Those with an unmet need for rehabilitation were much less likely to say they felt supported or that they're coping during the pandemic than those who had seen a professional. In addition, half (50%) of respondents have been doing less physical activity, and a third (34%) feel their MS symptoms have changed or worsened since the beginning of the lockdown. Over half of those (51%) felt a reduction in, or changes to, specialist support had contributed to their symptoms getting worse – varying from worsening balance, increased fatigue and muscle weakness, to pain and stiffness (see Graph 1 on page 10).

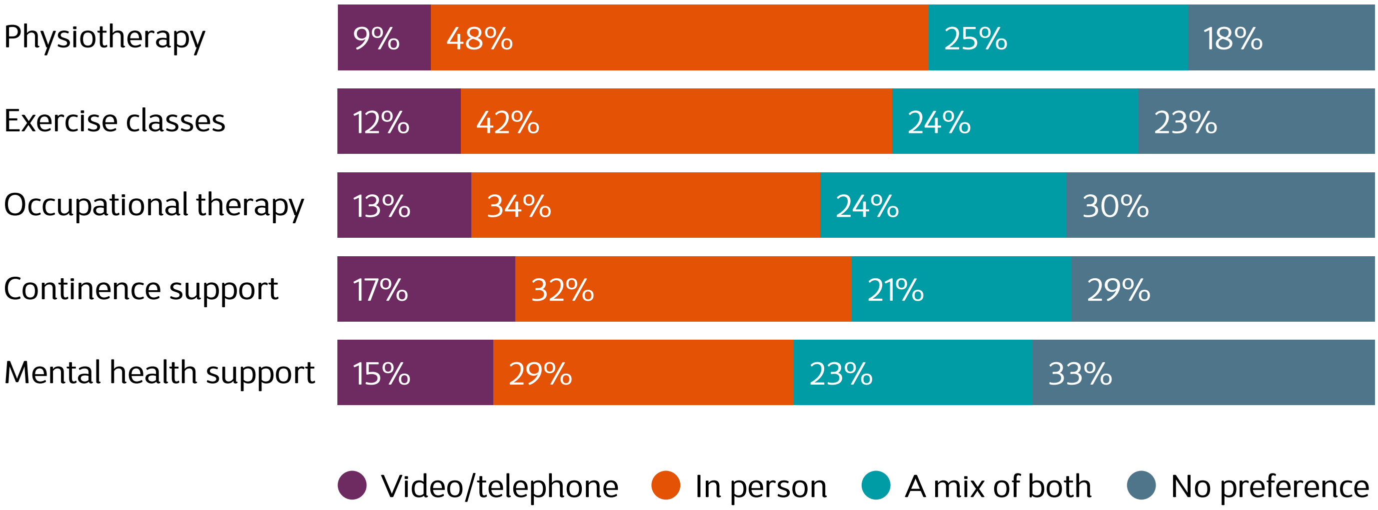
Appointments by phone or video were more common than in-person appointments – 60% of respondents had virtual appointments in August, this was 45% when we asked people in June and 30% in May. Of those who had appointments by phone or video, 6 in 10 (63%) said they had received all the support and information they needed – but 3 in 10 (35%) said they hadn't had enough support through virtual or telemedicine. Overall, the majority of respondents said they would prefer in person appointments in future (see Graph 2 on page 10). These findings broadly reflect wider research into patient experience of virtual appointments during the pandemic. A joint report by Traverse, National Voices, and HealthWatch[17] found:

> "Most people felt they received adequate care and more people than not said they would be happy with consultations being held remotely in future. However, there is no one size that fits all solution. Key to a successful shift to remote consultations will be understanding which approach is the right one based on individual need and circumstance."

Graph 1: Self-reported deterioration of symptoms since the beginning of lockdown



Graph 2: Preferences for future appointments



Respondent numbers vary as this was not a required question. Physiotherapy, n=1200. Exercise classes, n=1122. Occupational therapy, n=976. Continence support, n=979. Mental health support n=875.

Recommendations

We recognise some nations and regions of the UK will already be implementing some of these recommendations, and others, to improve rehabilitation services and support. We think there is strong potential for different nations of the UK to learn from each other and each implement a comprehensive package of support that both helps people to maximise their chances of staying well during the pandemic, and lays the groundwork for longer-term reform.

Recommendations for CCGs in England and Health Boards in Scotland, Northern Ireland and Wales

1. Commission appropriate community rehabilitation services and support for people with neurological conditions to recover and maintain their physical and mental health and prevent deterioration.
2. Involve patients in decisions about how local NHS services are delivered in the wake of the pandemic, particularly in the wider use of digital tools in delivering care.
3. Do not make any short-term rehabilitation contracts with lower service specifications that were introduced to cope with the coronavirus pandemic permanent.
4. Work with the third sector as partners to ensure people with neurological conditions are aware of the variety of local support available to help them live well and can access it where appropriate.
5. Invite professionals in commissioned services to join the MS Society's professional network for information about our resources to support people with MS, as well as the latest in MS education, policy and research.

Recommendations for all UK Governments

1. Create an expanded right to rehabilitation on the NHS which allows people to access support to maintain their health and wellbeing and prevent deterioration.
2. Ensure additional provision is made for both in-patient and community rehabilitation for people with neurological conditions to receive the neuro-rehabilitation they need, alongside recovering coronavirus patients.
3. Establish clear national leadership of rehabilitation and neurology within the NHS in each nation.
4. Ensure a funded, national strategy to improve rehabilitation is developed by each nation (where there isn't one already) in collaboration with clinicians and patient groups, and progress against it reviewed.
5. Ensure health and care workforce strategies provide appropriate numbers of Allied Health Professionals and other staff, with appropriate specialism, to deliver rehabilitation.
6. Evaluate the effectiveness of digital delivery of rehabilitation during the pandemic, including examining patient experience and digital inequalities. Work with local NHS bodies to embed this learning in practice, providing investment in new models of care where appropriate.

People with MS's experiences during the pandemic

Sara

Sara, 49, was diagnosed with secondary progressive MS in 2008 and lives in Norfolk. Sara has been waiting for physiotherapy to help with strength and balance for nearly a year.

"My legs are affected mostly. They don't feel strong, there's pins and needles, and they feel heavy. I've learnt to live with it. I know my ability and what I can and can't do. I know if a particular activity will upset it – if I do too much walking it tends to really affect my legs. I tend to be a bit less mobile because I'm scared of the repercussions.

I wasn't having any rehabilitation before the pandemic. I was referred by the MS nurse for physiotherapy, but I'm at the bottom of the list. I was referred nine months ago. It will be a year this November. It's physiotherapy for strengthening my body. I haven't called and asked because everything is up in the air at the moment. I think they'll contact me when they're able to.

I'm really hoping the physiotherapist can help to strengthen the parts of me which are a bit weak. My balance is awful too but that might be because my legs aren't strong.

It makes me feel angry that they've left me so long. This pandemic has knocked a lot of things for six. It's upset a lot of projects and everyday living. I feel like I've been left under the pile and forgotten. I feel like I've been ignored.

I know they deal with people who have other neurological conditions. They have a very wide area of people they have to see. I don't know if I'm being selfish and expecting too much. I'm not the only person who's waiting to be seen. There aren't enough of them, there should be a lot more. The government needs to make more services and more physiotherapists available. It would be good if they're specialists in neurological conditions, but if that's not possible we just need more of them!"

> "I try to look at the positives, not the negatives. I just want to be told I'm not forgotten."

Mary

Mary, 68, from the Scottish Borders, was diagnosed with relapsing remitting MS in 1983. Mary experiences daily fatigue, sight issues and bladder weakness. She has been waiting nearly 12 months for a bladder Botox assessment to help manage her continence. This, along with a referral for physiotherapy and her regular Pilates class, was postponed as a result of the pandemic.

"Most of my MS symptoms are unrecognised ones – I have a lot of issues with my bladder, fatigue and sight. Now my mobility isn't as good, it's [the decline] very gradual. It seems that the older I am when I have a relapse the longer it takes to recover, and I don't regain all the abilities I had before.

I was doing Pilates before the pandemic, which helped me keep mobile – I used to roam the hills all day but now I can only manage a few miles. That's one of the effects of MS, it takes away things you like doing.

I'd recently been referred to the physiotherapist at the local hospital, but everything was shut down because of coronavirus and it is only in past few weeks that I was able to see one. I am still waiting to see the urologist about my bladder, to assess whether Botox injections could help me stop having to rush to the loo. I was referred in September 2019 having had the issues for quite a while.

That's the trouble with living in an area like this, we have one small hospital covering a big area, many of the wards were turned into coronavirus wards and many services were stopped.

I've been doing Pilates for about six years. We were in a local gym, but that's shut down at the moment. I think it's reduced my mobility. I can't walk for as long and my joints don't feel as good, or my bladder.

I think it's important to emphasise rurality and lack of access to services. If you're out in the country it's hopeless, you can't access anything. I feel it's been hellish here. We don't have super-fast broadband. They put super-fast broadband in a mile away, but didn't bring it to our village.

> **"The internet access is so bad it's not worth trying to find YouTube videos or online classes."**

My nearest big city is Edinburgh, about 40 miles away. I wouldn't want to go that far to access services. The waiting lists are longer there too. More local services are needed otherwise it just costs the government more in the long run, the government are so short-sighted, I think."

Susan

Susan, 42 from Morayshire, was diagnosed with secondary progressive MS in 2009. Susan has had to pay for private physiotherapy as the NHS physiotherapist didn't have the specialist knowledge to help with her MS symptoms.

"Walking isn't impossible but I can't walk far. I've got very little feeling in my fingers and I had a relapse in January last year (2019) and lost the feeling in my right arm. My hand never recovered fully from that. It's all stiff and numb. I've no feeling in my feet and have pins and needles in my calf muscles. Over the years my walking has just gone.

The physiotherapists I've been using – I've been paying privately because I thought the NHS ones were never doing much good – are so helpful. I was out of the wheelchair and walking at one point, we were really making headway.

The NHS physiotherapist would give me exercises to do for six weeks, and see me for six weeks, and then that was that – I was left to do it myself. I had to refer myself every so often to get another six week bout. The physiotherapists at the NHS centre weren't neuro specialists. My dad has a different condition, and they were giving us both the same kind of exercises to do, even though we have different areas affected. I felt I was just left to my own devices and so I tried private physiotherapy. The people there are trained in neuro-physiotherapy.

The physiotherapists were doing Zoom sessions at the start of the pandemic, but I don't have the space at home. They've started doing house calls now, so they've been here two or three times over the past few weeks and they bring some of the kit. It's every second week they come now, but that doesn't seem to be enough. For definite the exercises have made the joints a bit more supple and my legs move a little bit easier.

> **"The physiotherapy really does help with movement, with walking, but also just being able to transfer from my wheelchair to the sofa."**

Since I've not been going, it's just got worse. The pain in my legs is worse, and I'm noticing pains I've not had for months. It's like I've taken a big step backwards. I need more help to move my legs when I'm trying to transfer from the wheelchair to the toilet. Even getting in and out of the car, I can't get my left leg moving. I need a lot more help with it than I did before.

I really hope this doesn't affect my symptoms in the long run, I hope I can go back to my weekly sessions. It's just going to be a case of trying to do what I can from home."

Donna

Donna, 35 from the West Midlands, was diagnosed with relapsing remitting MS 18 years ago. Donna has experienced worsening symptoms and mobility since her rehabilitation stopped as a result of the pandemic.

“Before the pandemic I was getting physiotherapy. That was as and when I needed it. I’d self-refer when I thought I needed some sessions. I wasn’t able to do that during the pandemic. I had visited a private physiotherapy provider in the past, but I’m on a limited income so that was so expensive. If I could afford it I would have it more often. If there was something like that on Zoom that was available on the NHS that would be brilliant.

Before the pandemic the physiotherapy was really helping. It’s the guidance, the motivation and the increased mobility that is really important for me. It just made me feel more stable. I’m not saying I was running or anything, but it was making the little things easier, like transferring to and from the wheelchair. That makes such a difference. Because with the fatigue, being slightly more mobile and being a bit stronger makes a huge difference. It helps so much being physically active.

I wasn’t told that the physiotherapy had stopped, because I was just self-referring and I didn’t have anything booked when the pandemic kicked off. But I knew that if I did, no one would be able to come to see me.

I was really suffering with anxiety prior to the lockdown and I’d lost a lot of weight because of it so I was seeing a dietician. Because of the lockdown I wasn’t able to see them, but we did do a telephone consultation.

Moving before was difficult, but now it really takes it out of me because I have to use more energy. It also means I’m having to ask my family to do more things for me and that’s really frustrating. My family are amazing, but before coronavirus there was always the worry at the back of my mind that I would be a burden, and now those feelings are heightened.

It’s really important for someone with MS to hold on to their independence for as long as they can, but this pandemic has taken it away from me somewhat. Now, more than ever, I’m thankful for the community support I’m involved with.

> “It’s so important for everyone with MS to know they’re not in this alone and we’re stronger together.”

Robert

Robert supports his daughter Alison, 37, who was diagnosed with relapsing remitting MS aged 18. They live in Northern Ireland. Since the lockdown started Alison hasn't been able to have sessions with her physiotherapist and her mobility has worsened as a result. She's hoping to move to a new flat, but this isn't possible at the moment. Robert feels Alison's independence has been taken away.

"Alison was quite independent – her walking wasn't good, but she was living very independently with MS. She was very active, swam a lot and went to the gym in a wheelchair.

Unfortunately, in January 2017 she was hit by a car when she was crossing the road and there was a 50/50 chance she would survive. The accident left her with several fractures up the left side of her body and her right side was affected by the MS. There was also a brain injury that took a long time to heal.

The health service wrote Alison off with regards to physiotherapy. They put her through an assessment but said 'there's just no potential for her to develop'.

I think with MS you're given a label and expected to just get on with it yourself, so we took her to a very good private physiotherapist and paid £50 a week. My wife and I were determined to give Alison as much help as we could get her.

I then thought of the MS Society. It wasn't easy for us to get to Belfast (an hour in the car during the rush hour), but we would go monthly to see Rachel Flinn, a neuro-physiotherapist at the MS Society Resource Centre in Belfast, and have weekly physiotherapy.

Alison is residing in a care home as her apartment isn't right for showering. She's hoping to live in a purpose built apartment and is hopeful she'll get there. She's a cheerful person and we have to be optimistic.

Just before lockdown Rachel had Alison up walking with the parallel bars and the very last time we saw her she walked with a rollator.

During the pandemic the care home wouldn't let anyone in or out so the sessions stopped. And Rachel can't do online sessions with Alison as she needs to be with her to work hands-on. Both Rachel and I stand either side of Alison for reassurance – you can't do that online."

> "The physiotherapist has made the world of difference and has been the one person that's given us more hope than anyone else."

The difference the right support makes

Dr Diane Playford is Professor of Neurological Rehabilitation at the University of Warwick Medical School and a practicing Consultant in Rehabilitation Medicine at South Warwickshire NHS Foundation Trust. She explains the preventative impact of rehabilitation for people living with MS.

“Neurological rehabilitation is critical to maintaining function and quality of life in MS, with a clear evidence base to support its use.

Disability can be caused by the direct effect of MS, but disability can also occur indirectly because people are at risk of health problems that can be prevented. These problems include increasing stiffness of joints compounding mobility problems, poor levels of fitness aggravating fatigue, low mood driven by preventable job loss, and pressure sores caused by immobility. All these aspects of disability can be prevented by a good community neuro-rehabilitation team.

Unfortunately, provision of such services is patchy and during coronavirus many of these services have been withdrawn. Tele-rehabilitation classes can go some way to mitigate this but only if the service is adequately staffed to deal with both the workload related to coronavirus, the pre-existing workload and the backlog.

Every area should be asked to audit their community rehabilitation service using the self-assessment questionnaire provided by NHS England/Improvement RightCare, and identify the steps needed to provide a comprehensive rehabilitation pathway across the disease trajectory.”[18]

The MS Society has been running the Moving More service since 2018 to support people living with MS to stay physically active. Emily Luis, Physical Activity Specialist, tells us how the service works and the difference it can make.

“In the Moving More service, I provide support and information to people who would like to become more active, and I respond to inquiries regarding equipment, falls, and weight management. In many ways, my role includes my favourite aspects of physical therapy. I get to know my clients and I coach them to follow through with their physiotherapist’s advice. I have clients that need physiotherapy, occupational therapy, and speech/swallowing assessments, but have been discharged from their health and care team(s) or who have been unable to access these services due to coronavirus. This role has opened my eyes to a larger problem – the NHS isn’t able to fully meet the needs of the entire MS community when it comes to rehabilitation.

The Moving More service is based on the individual – I fill out an assessment form and have a chat about what the client’s goals are. For most people, I’m able to email links to our videos, but others use our DVD or they exercise in their community. Others may use activities around the home as exercise; for example, chopping vegetables or cleaning. For someone who’s working on their dynamic sitting balance, chopping vegetables is a great activity!

I enjoy empowering people to see exercise as a form of self-care. I like to coach people to focus on activities they enjoy.

> “I love to see my clients find ways to make their favourite activities work for them!”

Because I don’t provide advice or direct physical therapy, I’m cautious about giving people specific exercises. If someone asks about hip strengthening, for example, I might send them a YouTube link from an established physiotherapist and/or our videos, but I don’t offer prescriptive exercises.

I speak with a lot of clients who have come into the service and don’t know where to start, because they haven’t had rehabilitation before. I have a few clients who have issues with speech and swallowing who haven’t been assessed by speech and language therapy. I have clients who report frequent falls yet they haven’t been evaluated for a walking aide. Unfortunately, there are acute and chronic needs that have been missed.

Occasionally, I get clients who have been sedentary for quite some time because they’re waiting for a rehabilitation referral. While some people may wish or need to check in with their GP prior to starting an exercise programme, there are things that can be done at home to improve health and mobility. Home-based general exercise can complement rehabilitation services rather than replace it. Our videos are a great place to start! I don’t want people to assume that a reduced baseline is a new normal with MS just because they’ve been isolating at home during the pandemic. I hope to educate the MS community to know that general exercise can be accessible and inclusive.

My vision for the MS community is that everyone has access to a neuro-physiotherapist for assessment and exercise prescription and everyone has access to the kind of ongoing support our Moving More service offers.”

Ben, 70 from Cornwall, was diagnosed with primary progressive MS in 2004. He is a client of the Moving More service and tells us his thoughts about the programme and the benefits it's brought.

"We're forced into this situation by the lockdown. I missed the daily exercise. I used to go to the gym and use the exercise bike and some of the strength machines. I could feel, after several years of doing this, it was helping me. I was fairly mobile.

I phoned the MS Society helpline initially, and told them that the past two weeks I'd struggled and was really missing some of the exercises (like riding the bike). So I was passed onto Emily straight away. Emily has been excellent. She rings once a week to see how I'm progressing. She told me progress isn't a straight-line, it will go up and down.

I worked out an exercise programme with help from Emily. I started getting into a routine. I do some exercises when I wake up – yoga inspired. I now do running on the spot for 5 minutes, yoga exercises and some Pilates – a simple little routine every morning which takes me about 15 minutes, then I go for a walk. Then I meditate for about 20 minutes. That's helped me to keep positive during the lockdown.

It's all about self-motivation. I didn't want to do it, but I did and I'm really glad I did. It's about having a target and moving forward."

> "They've been so good with working on a programme with me, no expensive equipment is needed."

Delivering rehabilitation differently

In the future, the way people living with MS access rehabilitation is likely to change. Telemedicine has long been recognised as having an effective part to play in the delivery of care in the NHS. Previously, people with MS have told us having to travel a long way to see a professional for a routine appointment is inconvenient. The pandemic has fast-forwarded the delivery of virtual services. From speaking to patients and professionals it's clear virtual services have provided a lifeline during the pandemic.

But virtual medicine is clearly not appropriate or accessible to everyone. Before making any services digital permanently, it's important patients' experiences of these services and their outcomes, and digital inequalities, are considered. People should always have a right to a face-to-face appointment if they prefer.

What's suitable for one person with MS may not be for another – how care is delivered should be personalised.

We spoke to professionals in two services supporting people with MS for their perspective on delivering care differently during the pandemic.

Kiran, Therapies and Service Manager, and Jane, Centre Director, are based at the Neuro Therapy Centre (a charity) in Chester.

“On 16 March we had to shut the centre. We didn’t know when we were opening again. We had to rethink how to provide a service for our members.

We started with the Virtual Centre – a telephone service to understand how our members are getting on with their condition, offer support and signposting, Zoom sessions with seated classes, gym classes, balance and Pilates, and group and 1:1 counselling. We started with a couple of classes a week, now we do 10 a week.

To keep members engaged we’ve done lockdown activities such as virtual social events with coffee mornings, quizzes and #lockdownrecipes, and #workoutathome so people can revisit the classes if they can’t attend the live Zoom session. Our therapists have recorded exercise videos for the website so people can do classes in their own time. We’ve run Pilates and coffee sessions for carers. The feedback has been phenomenal! They’re so thankful for what we’ve done and how we’ve adapted to give support.

When members come to the centre they come for our services, but also friendship. After the Zoom classes we leave five minutes so people can talk – its peer to peer support and a real sense of community. We’ve built that relationship over many years, not just with the members, but with their families, carers and friends. Having that connection and trust is so important.

Now we’re in a phase of reopening the centre, with cleaning and social distancing protocols in place.

> “We’ve done a survey of members – half can’t wait to come back to the Centre, the other half feel safer at home and are happy with the virtual services.”

We have to reduce face-to-face contact, so the Virtual Centre will have to continue to maintain that level of support. Coming back to the centre is by invitation only. The people we’re inviting back initially are those we know can’t access virtual clinics and those who have deteriorated over this time. We want to start addressing some of those issues first.”

Rachel Flinn, neuro-physiotherapist at the MS Society Resource Centre in Belfast, tells us about her experience during lockdown and what virtual rehabilitation can and can't do.

"In mid-March my job changed completely. The centre closed and we were asked to work from home with our laptops.

I started with setting up two Pilates classes via Zoom. These have since developed into three classes. The two original classes were easier to monitor as all the participants had been at my classes pre-lockdown and knew the exercises, and I knew them. The new class participants were new to me, so I did an individual Zoom session just to get to know their particular issues and complete an assessment. The classes have been particularly successful and I've continued to run them all through lockdown.

The virtual sessions are very beneficial for exercise therapy – stretching or strengthening, advice about posture, gait re-education – now I know where to ask people to put their screen. Sometimes it can be on the floor or at the end of their kitchen worktop. At the beginning I saw a lot of people's ceilings!

I was aware that all outpatient physiotherapy was cancelled due to redeployment of all NHS staff to help with the coronavirus pandemic. At the beginning I continued with my previous caseload, and also those who were on my waiting list. I contacted the MS nurses and MS consultants in the Belfast Trust to let them know I was offering virtual physiotherapy and classes. I started to receive an increased number of referrals.

My experience of working online has also shown me the gaps which can't be filled by virtual classes and sessions:

- Hands on physiotherapy – this includes massage of soft tissue, manual assistance with stretching and mobilising stiff joints to increase range of movement of specific joints.
- Those who require assistance to move – sit to stand transfers, assistance with standing, using a standing frame, assistance with walking and walking in parallel bars.
- The social aspect of coming in to the centre and meeting others with MS and the staff.
- Those who struggle with technology – because they don't have any devices with screens or have a device but don't know how to use it, or have difficulty processing virtual information.
- Treating lower back pain – assessment and treatment of lower back pain or specific joints is limited without hands-on contact, though general advice and exercise can be provided.

Overall, I've had a good experience of working in this virtual world. But, there are some people in our community who need, and want, that face–to-face care and support."

Conclusion

The stories detailed in this report reflect the experiences of many people in the MS community. They highlight the barriers to accessing rehabilitation, both before and during the pandemic, and the impact of receiving and not receiving the support they need. They make clear the pressing need to prevent further deterioration in the function and quality of life of people with MS.

Many spoke about the difference being supported to stay physically active made to their quality of life. They also highlighted the lack of rehabilitation to maintain their condition on an ongoing basis, beyond a limited initial period of support. Sara and Ben both talked about the knock-on effect on their confidence and mental health of being less mobile and active.

An expanded right to rehabilitation on the NHS would mean people with MS receive support to prevent their condition deteriorating, not just support when their needs are acute. All UK Governments must show clear leadership and produce a funded strategy to improve rehabilitation, where there isn't already one. As well as ensure appropriate numbers of staff with the expertise needed to deliver it. To make a difference to the lives of people with MS, such a strategy must include reforms to incentive structures for local health bodies to deliver preventative rehabilitation, and progress against it reviewed regularly.

All UK Governments need to address the lack of data regarding provision of community rehabilitation. This must include working with clinicians, health and care professionals and patient groups to understand how to improve access to, and outcomes of, rehabilitation for people with conditions like MS. This will enable consistent comparison between services and help reduce inequalities in access.

Mary's experience demonstrates some of the barriers to accessing virtual health services facing many patients, while Donna expresses the desire others have for virtual support options. Their differences make clear why patient choice must be prioritised around questions over digital or face-to-face contact. Patients should be involved in decisions about how local NHS services are delivered in the wake of the pandemic, particularly around the wider use of telemedicine.

Services providing effective virtual rehabilitation during the pandemic, such as the Neuro Therapy Centre in Chester, have clearly been a lifeline to some of the people featured in this report. Across the UK, there is a need to evaluate the effectiveness of digital delivery of treatment and care during the pandemic, and understand how to address inequalities in digital access. Such research must be rooted in the experiences of patients and their outcomes.

Alison's story and the reflections of neuro-physiotherapist Rachel make clear certain treatment must be hands-on and face–to-face. Such services can be made safely available now, where virtual alternatives aren't appropriate, using coronavirus-free "green sites" and ensuring appropriate personal protective equipment for staff across care settings.

Anecdotally, we hear local health bodies don't always take advantage of the fantastic support the third sector has to offer. The support provided by charities, such as ourselves and others described in this report, presents an opportunity to make more effective use of resources in the NHS. By working with the third sector as partners, we can ensure that people with neurological conditions are aware of support available locally.

For people living with MS, there is too much to lose if we don't take action. Together we can help them to keep moving forward.

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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.

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▶ Let's stop MS together

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