

Supporting your MS journey



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Over

Mental health and MS: Joint policy position

May 2023

1.Who we are

This joint policy position was produced by six charities that support the multiple sclerosis community: MS Society, MS Trust, Overcoming MS, MS-UK, Shift.MS and MS National Therapy Centres. We came together to better understand the mental health experiences of the MS community, and what can be done to ensure everyone can access support when they need it.

2.Introduction

2.1. About MS

Multiple sclerosis (MS) is a neurological condition that affects over 130,000 people in the UK. It damages nerves in the body, causing symptoms such as fatigue, pain, mobility issues, visual impairment and cognitive problems, which can differ from person to person. Because it is both a fluctuating and progressive condition, MS makes life unpredictable.

MS can affect people's quality of life and threaten their ability to work, to be independent and to look after themselves. MS also affects people's families and loved ones, who have to cope with their condition and often take on caring responsibilities.

2.2. MS and mental health

The uncertainty and unpredictability of MS can cause significant distress, anxiety and frustration. Symptoms can come and go, and the ones that persist can be difficult to live with.

People with MS are more likely to experience poor mental health than the general population [1]. Although prevalence rates vary between studies, a meta-analysis of over 87,000 people with MS found that 30.5% of people with MS have depression, and 22.1% have anxiety [2]. Research also suggests that around half of all people will MS will experience depression at some point in their life [3].

The impact of MS on mental health goes beyond the individual with MS. It also affects their families, friends and loved ones. They might struggle to adapt to the new roles and dynamics of their relationship, experience a sense of loss, and struggle to cope with the uncertainty MS introduces to their lives [4].

2.3. Lack of support

Despite the high prevalence of mental health issues in people with MS, many are not able to access the care and support that they need.

In a 2022 survey by the Neurological Alliance, 37% of adult respondents with MS felt that their mental wellbeing needs were not being met at all, while 1 in 4 (25%) said they were only being met to a small extent. More than half (56%) said they had not been asked about their mental wellbeing by a health or social care professional within the last 3 years [5].

Research also shows that people with MS are not receiving the support they need around the time of diagnosis. The diagnosis process can be lengthy and stressful, and usually takes months or years. And once an individual receives the diagnosis, they often experience strong emotions such as shock, denial, anger or fear that limit their ability to make sense of and adjust to their diagnosis [6].

A recent systematic review of people's experience receiving an MS diagnosis shows that people with MS often have negative experiences with healthcare professionals, including not being provided with enough information, leading to further distress and frustration [6].

However, with the right care and support, people with MS can learn to cope better with the impacts of MS and live fulfilling lives. For example, accessing peer support and talking to others who truly understand what life with MS is like can be invaluable, and can improve people's mental wellbeing [7, 8].

2.4. This research

This joint qualitative project aims to explore the mental health experiences of the MS community and develop policy recommendations based on them.

The six charities carried out interviews with people living with MS, and their loved ones. In total, 21 interviews took place between December 2022 and February 2023. Interview questions were developed with a co-production group drawn from the MS community. Interview participants were recruited from across the charities' networks.

The core focus of the interviews were: common mental health symptoms that people with MS experience, what support they have accessed and how they have accessed this support. The interviews did not focus on one specific mental health condition (e.g. depression). Instead, they explored people's experiences of common mental health issues.

Below we have summarised key findings from those interviews, broken down by core themes, followed by our policy recommendations for change.

3.Key findings

3.1. Denial around diagnosis

MS can be life-changing and unpredictable, making it harder to estimate how it will affect a person over the course of their life. This is why, for many people, an MS diagnosis takes time to come to terms with.

Many people we spoke to went through stages of denial after they were diagnosed. This could be affected by how much information they were given about their MS. In some cases, it was presumed that people already knew what MS was:

'Then I had a phone call (it was meant to be in person) with a [doctor]. And he said:

"Oh, it's probably MS but I'm gonna have to refer you to someone else."

And I was like, I have no idea what this is, I didn't know what MS was. I was really expecting him to come back and give me the all clear. I burst into tears on the phone.'

Few people we spoke to had been told about the impact that MS could have on their mental health. This left many people struggling with mental health symptoms and not knowing where to find help. The first six months is an important transitional time for people with MS as they come to terms with their condition. Without the right mental health support early on, people described how they felt overwhelmed and found it hard to reach out for help:

'There is lots [of information] available, I know... It's just I don't go looking for it. If that makes sense, because, to be honest, I feel ashamed. I think of how it makes me feel on a daily basis.'

Others found it hard to talk about their MS. Just saying "I have MS" could be difficult.

'When I'm down though, and really struggling I can't actually talk about it. I'm too much in the eye of the storm to be able to go there.'

Coming to terms with MS can be a personal and difficult journey. While every person deals with their diagnosis differently, the attitudes of medical professionals can have a significant impact.

3.2. Grief and change in identity

As people came to terms with having MS, many began to go through a grieving process for their lives before their diagnosis. This grief can be personal and hard to articulate. Some people described their MS as a loss which felt sudden and unjust. This left people feeling distressed and that they had lost part of their identity:

'I cried because I was tired. I cried because I was fed up. I cried because I most probably wanted to leave the house by myself. That all the things that I've been doing for at that time the last 28, nearly 29 years just got taken away from me in an instant.'

Some people we spoke to had previous knowledge of MS and found it hard to separate their experience from others'. One person had previously worked as a nurse and described how that shaped her impression of MS:

'I did go into huge bit of denial, and because I think because of my background, and I'd only ever seen the worst, because [of] people who end up in hospital.'

The majority of people we spoke to worried about the future; many described struggling to make plans. People told us that these anxieties do not go away and threaten their identities and wellbeing:

'I think I'm still grieving for my old life. And what I used to be able to do on a day-to-day basis, because I never know how I'm gonna feel when I wake up in the morning. So it's been hard. Been really hard.' People also found it hard to look back and remember things they had been able to do but no longer could. This made them feel low and frustrated:

'My mobility [has] reduced the activities I saw as important. You know I was very active before, and that's kind of gone... those are the kind of decisions that [have] kind of [been] forced upon me which have sort of left a big, big gap.'

Having MS can leave people mourning the lives they had before diagnosis. People told us how poor mental health days left them feeling fatigued, unmotivated and stuck in a spiral of comparing themselves to who they were before MS. When we asked what support they needed, many people said that they wanted better support and information to help them cope with these realities of living with MS.

3.3. Masking symptoms

Many people we interviewed said that they 'masked' or hid their MS symptoms. Though reasons for this varied, many wanted to protect family and loved ones from seeing the true extent of their condition and the toll it was taking. Some parents wanted to protect their children:

'I didn't want to sort of look upset for [their children], because I didn't want them to worry, so you've got all of that as well. So really there was just a lot of internal rage, there was a lot of tears I have to say, especially when nobody was around.'

Similarly, some people avoided worrying their parents:

`If I'm at my parents' house, I try to hide it... I know that's not great at all, but it's the truth. It's to protect them.'

People with family members with MS wanted to avoid re-exposing them to trauma or worries:

'I knew what had happened to my dad and my brother [both had previously been diagnosed with MS]. I was worried about my Mum and wanted to try and protect her. She had lost a husband and her son had it and now me. I think when we have MS, [we] try to protect other people.'

Similarly, people also told us they had to hide the impact of their MS so that they could go about their daily lives:

'I have my bad days, but I still have to get out of bed to be a wife and a mother, and go to work, and I put a mask on to get through the day, and then it slips when I get home. It does play havoc with your mind and how you think about things.' Several people told us how they masked or downplayed the emotional impacts of their symptoms in medical appointments and social situations. Reasons for this included feeling that people didn't actually care how they were, that nothing that could be done to help them, or that being honest was too difficult:

"How are you feeling?"... It's more a pleasantry rather than people actually wanting to know or caring about the answer. They want you to say "yes I'm fine" and then move on. And half the time I'm lying if someone asks that question, I'm not fine.'

Whilst some people were able to get support when speaking out about their mental health, people also said that they had to be proactive to get this. This could be challenging:

'I've not been asked questions about my mental health even when I moved MS teams after my big relapse in 2017... if you're not overly like crying and loud about your issues, if you're not saying "I need help, I need help, I need help", you're not asked or offered anything.'

Having MS can impact every aspect of a person's life, including the lives of those around them. For many reasons, people with MS that we spoke to felt that they had to mask or downplay their symptoms to protect themselves and others. We need to ensure that people with MS have access to spaces to talk about their mental and physical health when they need to.

3.4. Impact on relationships

Many people we interviewed described the impact of their MS on their relationships with loved ones. Shifts in family dynamics, roles and responsibilities could be a strain, particularly for people with progressive MS or more severe symptoms. Several said that their diagnosis was shocking or traumatic for loved ones, making it difficult to ask for support from them:

'So my husband has always been fantastic... But obviously he was going through his own trauma because his wife has suddenly just been diagnosed with this bloody condition so he... also needed to go through the process of dealing with this on his own.'

Some said that they sometimes didn't realise how the stress and frustrations of their MS affected their loved ones, especially if they were struggling:

'On my bad days... I'm just not a nice person to be around, but I don't see that when it's happening. Afterwards my husband sits me down and says to me look, you can be snappy, short, not a nice person basically. And I don't see it until I like reflect on it afterwards.'

Meanwhile, some people said they felt frustrated by how their MS was everchanging, resulting in them needing ongoing family support: 'I was complaining to my mum... because I was feeling so isolated and alone... And she was really shocked because she couldn't see it that way. She thought by asking "how are you" she was filling that gap but she isn't. There is not the realisation that just because I've been diagnosed a long time ago doesn't mean I cope with it any better.'

People with children told us how they felt worried or guilty about the impact of their MS on their children's present and future lives:

'You start to notice that you know that your children and your wife, or whatever, they're starting to miss out on all life experiences because of my restriction... So you just kind of think what's the future gonna be, you know. And that just kind of weighs on your mind.'

Even when faced with significant challenges, however, people's loved ones gave them comfort and strength. People told us about the benefits of being honest about their struggles and learning to communicate more openly about living together with MS:

'Having a supportive partner is like, personally without her, I don't know what I would've... But genuinely, I don't have no idea. Without her it would've been a whole different kind of MS.'

MS can have a long-term impact on loved ones, yet support for them is lacking. It is vital that the emotional needs of carers and loved ones are recognised and met alongside people with MS.

3.5. Bidirectional nature of MS and mental health

In our conversations with people with MS, we found that people experienced mental health and MS impacting each other bidirectionally. This means that MS symptoms impacted people's mental health and that mental health difficulties also impacted MS. Some people experienced MS flare-ups during a period of stress or anxiety:

'If I'm feeling low or very anxious, it affects my mobility, it has an effect on my balance, has an effect on my fatigue. Sometimes I spend the whole day in bed.'

Others described how their MS symptoms or flare-ups affected their mental health:

'Up until a few months ago I was doing ok from a mental health perspective, but my [MS] symptoms have worsened over the last 6 months and this has really affected my mental health, my feelings and any sense of self-worth.' Some people discussed how the two-way relationship between mental health and MS meant it was hard to identify the cause of some symptoms:

'And that's a vicious circle, isn't it? Because does [my partner with MS] sleep badly because he's depressed? Or is he depressed because he didn't sleep well? I think it's pretty difficult to pinpoint it.'

Many felt that the relationship between mental health and MS wasn't considered enough in medical appointments, with the focus being on physical symptoms instead:

'One of the first things I was asked by a Neurologist... was 'how far can I walk' not how I was feeling, or how I was doing. This actually made me miss my next appointment because I didn't want to talk to them.'

Many people told us that focusing more on mental health in routine appointments would help to normalise those conversations. This would also help people understand the relationship between mental health and MS:

'They talk about all of these DMTs but if they also said "and this is the mental health support person that you can go and see as well, because this is really important", that would have been brilliant. Because in the same way as you don't have to take a DMT, you don't have to go and see a mental health advisor. But the fact that you can it gives you that kind of positive message, and something you can do about this.'

Our research indicates that there can be a lack of regard to the bidirectional relationship between mental health and MS by some health professionals. We need to ensure that mental health support for people with MS is integrated into MS care, fully recognising and responding to the ways in which mental health impacts MS and vice versa.

3.6. Peer support

Several people we spoke to found peer support to be one of the best and most accessible ways to manage their mental health. From online communities to giving talks, people found numerous ways to meet others and share their experiences.

Local peer support opportunities run by charities and community services were popular, as people were able to meet others within their local community:

'Spring 2019 [was] the first time I met [my peer support group]... That for me was life changing, just to be able to. I just sat down with this group of women who I could connect with on so many levels.' Online spaces such as Facebook groups also gave people access to a global MS community in flexible and accessible ways:

'I'm on a lot of Facebook groups for people with MS... Great way of supporting each other... You can dip in and out at any time of day. And know that you will get a response and support.'

Some interviewees led peer support services as they had noticed gaps in what support was available. For these people, helping others enabled them to reflect on their own wellbeing while supporting others:

'That was like my counselling, that was my therapy... I say all the time, I speak for people who maybe have no voice or are just tired of talking.'

Community rehabilitation services such as physiotherapy were also avenues to accessing local peer support:

"There's someone who will give you a massage or a bit of reflexology or something like that. But the best bit, the best bit is the cup of tea and the chat... I feel better mentally having been there. I even feel better thinking about it."

However, not everyone found the right service for them. Some found that local groups didn't represent them or that they perpetuated negative attitudes about MS. This took a toll on their wellbeing:

'I tried to go on another Facebook group... they were a lot older... And they knew each other already. And it was kind of like a complaining call which at that point was not what I needed. They had a very negative outlook on the progression of the disease as well.'

Peer support opportunities empower people with MS by giving them a voice, bringing people together and maintaining the MS community. However, not everyone will be supported appropriately by these services and they should not be treated as a replacement for formal support.

3.7. Counselling and other support

Several people we spoke to had accessed counselling or talking therapies. These are psychological treatments for common mental health problems provided either by the NHS, the third sector (charities) or private-sector providers.

Some people had accessed forms of counselling through their MS nurses and GPs. Some people were referred directly, whilst others were given information about what was available and told to self-refer. But, several people said that mental health had never been raised in interactions with healthcare professionals. People we spoke to who had counselling had mixed experiences. Some found it hard to access counsellors with knowledge of neurological conditions or MS, even though they wanted to:

'There is not enough counsellors, I feel, that are specific to neurological diseases... Because yes, you can have a personal development counsellor, you can have a grief counsellor, you can have a marriage counsellor. But the counsellor that we need is not generic.'

Some chose not to access common mental health services as they did not consider them suitable. But for others, counselling had a positive impact on their mental health:

'I think it helped me so much, put me into a completely different headspace. It's given me the tools to carry on now positively with my way of being.'

Among those who accessed talking therapies, some found that the support they received didn't go far enough. Barriers included only being offered a small number of sessions, as well as services having a poor understanding of MS. Some people had to pay for talking therapies which created an additional barrier to accessing enough support.

'Towards the end of 2020, I started talking therapy. This was one to one, like private service, and that helped. But it wasn't quite enough.'

Although several people said that a combination of medication and counselling worked best for them, some people were only offered medication. One person said that he had been taking anti-depressants for years without a proper conversation with his doctor about what they were or why he was prescribed them:

'The only medication [the doctor] gave me was an antidepressant. Now, I didn't know that's why he was giving me the antidepressant and when I asked him about it some years later, he said, "well, I thought you were a bit down at the time." And at that point I was thinking, why am I taking these?'

Our conversations with people with MS have shown us how mental health services can have a lasting positive impact. Nevertheless, gaps in the support offers from the NHS, third and private sectors mean that many people are still going without the support they need.

3.8. Isolation

We heard from our interviewees how peer support and counselling have helped them to cope with their MS. But we also heard how being unable to access support took a toll on their mental health, making them feel isolated, lonely and struggling with symptoms. Many people described that not receiving enough treatment could be exhausting and frustrating:

'I don't know whether it's different now, but the whole, "yes you've got MS but we don't really know how it's going to progress."... I don't know why they didn't put me on any treatment. I don't know whether I just got a really raw deal.'

One person told us how his MS symptoms weren't taken seriously by doctors, leading him to pay for a private neurologist to have his concerns listened to:

`[The doctors] just kept fobbing me off, and every new flare up I was having, they would just prescribe me vitamin D pills... I went to private healthcare... because I knew something big was going on.'

People described how a lack of signposting to mental health support was disorienting and left them feeling unsupported. Though they were given leaflets or links to websites by health professionals, people found that signposting lacked a holistic approach:

`[My neurologist] did tell me about the websites, but... most people do things just to say they've done it.'

Lack of good quality MS treatment, signposting and mental health support services create unmet emotional needs for many people with MS. This unmet need can put further pressure on peer support, mental health services and people with MS's loved ones and carers.

3.9. The role of MS nurses

We heard from people that MS nurses can play a significant role in their mental health support. Some people said their MS nurse worked with them to identify their needs so they could signpost and refer them on to further treatment:

`My MS team and one of the MS Nurses... she's amazing, and they do say contact us. ``Anytime, just contact us.'''

While this worked well for most, not everyone had such a positive experience. Some people told us their MS nurse was overstretched and hard to contact, resulting in only infrequent phone appointments. This impacted what services they accessed and the amount of support they were given:

`MS nurses don't have the time. On the phone it's almost even worse. They can't see your body language or tell how you're feeling from the way you look, so it makes it harder.'

MS nurses play a crucial role in support for people with MS. In many cases, the quality and range of support which MS nurses can signpost to is based on their knowledge and available resources. But, when these resources are limited or workloads become overwhelming, people with MS risk losing out on opportunities for mental health support.

3.10. Conclusion

People with MS and their loved ones kindly took the time to tell us about their experiences with common mental health issues. Our research has shown that mental health and MS are often intrinsically linked, but that support often doesn't go far enough to meet people's needs.

The bidirectional relationship that exists between mental health and MS can change over time and is different for everyone. Recognition of this relationship is largely missing from mental health or MS treatments, making it even harder for people with MS to have all their needs met. Lack of understanding of MS, inappropriate treatment and intense workloads can all impact the quality of the support people receive from health professionals. The fact that only some people with MS will receive the right support for their mental health is simply not good enough.

Our recommendations below set out seven ways to improve the quality, range and accessibility of mental health support for all people with MS and their loved ones. These steps will ensure all people with MS, loved ones and carers receive high-quality, holistic support when and where they need it.

4. Policy Recommendations

4.1. Develop and implement a neurological conditions Talking Therapies pathway

NHS England Talking Therapies provide mental health services such as Cognitive Behavioural Therapy and counselling. The Long Term Conditions Talking Therapies pathway currently provides mental health support for people with physical health conditions, including MS. However, this service can be difficult to access and does not always support people with MS in the right ways.

We need a neurological conditions Talking Therapies pathway to give people with MS access to bespoke mental health support. This pathway should be coproduced and evaluated in partnership with mental health practitioners, people with neurological conditions and their carers. Support offered through the programme should take a person-centred, holistic approach to mental health which is integrated into people's wider MS care.

4.2. Develop and implement a training package for the neurological workforce on mental health awareness

Gaps in health practitioners' knowledge and skills prevents them from providing high-quality, holistic support for people with MS. A new mental health training package should be developed specifically for the neurology workforce as part of their Continuing Professional Development (CPD). This should train neurologists to compassionately diagnose people with MS, identify people's mental health needs and signpost people to relevant support. The training should also cover support for family and friends on coping with, and supporting people with, MS and should be developed working closely with the MS community.

NHS England must co-produce this training package with mental health practitioners, people with neurological conditions and their carers. NHS England should also work with MS charities to develop an annex of support services available in each local area, so that the training equips local workforces with information about what is available in their community.

4.3. Better equip the neurology workforce to provide mental health support

Improving access to neurologists, MS nurses and mental health practitioners is key to improving treatments and quality of life for people with MS. We need a realistic NHS workforce plan which sets clear targets for neurology and related roles like mental health support workers. At the same time, Integrated Care Systems must establish MS patient forums and work in partnership with local services, including MS and mental health charities.

Plans to increase the number of neurologists and MS nurses should be included in the workforce plan, setting clear targets for the number of roles and plans to uplift education opportunities, pay, working conditions and incentives to remain in the role. MS coordinators' roles should also be expanded to assist in identifying and referring people to mental health support. This would free up MS nurses' and neurologists' capacity and workloads.

4.4. Ensure MS annual reviews consider mental health holistically and alongside cognitive difficulties

Current NICE guidance outlines that people with MS and their carers should have an annual comprehensive review that covers all of their needs. These reviews should consider mental health in the round, including cognition difficulties, and not be focused solely on the presence or absence of formal diagnoses such as anxiety or depression.

Health practitioners must ensure that annual treatment reviews consider MS and mental health bidirectionally, having regard to the effects of mental health on MS and vice versa. Whilst current NICE guidance states that annual reviews should assess cognitive problems, this guidance should be updated to ensure that the impacts of cognitive difficulties are considered alongside mental health. Reviews should take a holistic approach to mental wellbeing, with health practitioners also evaluating the extent to which the mental health support people accessed has impacted people's emotional needs.

4.5. Health professionals must signpost people with MS and their carers to support for carers

MS can have a life-changing impact on friends, families and carers as well as people with MS. We know that information about caring for someone with MS is out there. However, people with MS and their carers told us that they weren't signposted to carers' support.

Health professionals must ensure that they identify people with caring responsibilities for people with MS and signpost them to relevant support. This should include self-management support services, as well as support from charities, local community organisations and government support. Health professionals should take a holistic approach to carers' needs to ensure that they signpost people to the right information when they need it.

5. Additional recommendations

5.1. NHSE and DHSC should:

• Work with the sector to produce and promote self-management resources for family and friends to help them cope with their loved one's MS.

5.2. Charities should:

- Publish more information about MS which is representative of different types of MS and symptoms.
- Provide more direct support for carers, friends and family of people with MS.

6. References

 Marrie RA, Fisk JD, Tremlett H, Wolfson C, Warren S, Tennakoon A, Leung S, Patten SB; CIHR Team in the Epidemiology and Impact of Comorbidity on Multiple Sclerosis. Differences in the burden of psychiatric comorbidity in MS vs the general population. Neurology. 2015 Dec 1;85(22):1972-9. https://doi.org/10.1212/WNL.00000000002174

- Boeschoten RE, Braamse AMJ, Beekman ATF, Cuijpers P, van Oppen P, Dekker J, et al. Prevalence of depression and anxiety in multiple sclerosis: a systematic review and meta-analysis. J Neurol Sci. 2017;372:331–41. https://doi.org/10.1016/j.jns.2016.11.067
- Siegert RJ, Abernethy DA. Depression in multiple sclerosis: a review. Journal of Neurology, Neurosurgery & Psychiatry 76:469-475, 2005. https://doi.org/10.1136/jnnp.2004.054635
- 4. Parkinson A, Brunoro C, Leayr J, Fanning V, Chisholm K, Drew J, Desborough J, Phillips C. Intertwined like a double helix: A meta-synthesis of the qualitative literature examining the experiences of living with someone with multiple sclerosis. Health Expect. 2022 Jun;25(3):803-822. https://doi.org/10.1111/hex.13432
- Neurological Alliance. 2022. Together for the 1 in 6: UK Findings from My Neuro Survey. [MS specific data tables provided by the Neurological Alliance]. https://www.neural.org.uk/publication/together-for-the-1-in-6-uk-findings-from-myneuro-survey/
- Topcu G, Mhizha-Murira JR, Griffiths H, Bale C, Drummond A, Fitzsimmons D, Potter KJ, Evangelou N, das Nair R. Experiences of receiving a diagnosis of multiple sclerosis: a meta-synthesis of qualitative studies. Disabil Rehabil. 2023 Mar;45(5):772-783. https://doi.org/10.1080/09638288.2022.2046187
- Ng L, Amatya B, Khan F. 2013. Outcomes of a Peer Support Program in Multiple Sclerosis in an Australian Community Cohort: A Prospective Study. J Neurodegener Dis. 2013:429171. https://doi.org/10.1155/2013/429171
- Gerritzen, EV, Lee, AR, McDermott, O, Coulson, N, Orrell, M. Online Peer Support for People With Multiple Sclerosis: A Narrative Synthesis Systematic Review. Int J MS Care 1 November 2022; 24 (6): 252–259. doi: https://doi.org/10.7224/1537-2073.2022-040

7. Annex: Further information and support

7.1. MS-UK

D3 Knowledge Gateway, Nesfield Road, Colchester, CO4 3ZL 0800 783 0518.

www.ms-uk.org

MS-UK is a national charity supporting people affected by multiple sclerosis (MS) to live happier, healthier lives. We work with the MS community, supporting them to make their own choices and empower them to manage their symptoms and live life to the full. We provide holistic services for people throughout their journey. These include:

• Online neurological exercise classes tailored for different physical abilities

- Chair yoga classes
- Courses such as mindfulness and writing for wellbeing
- Peer support online friendship groups for people with shared interests
- Expert-led online information sessions such pregnancy and MS
- Helpline providing MS-related information and emotional support over the phone, webchat and email
- Online and printed information through our website, booklets and magazine

7.2. MS Society

Carriage House, 8 City North Place, London N4 3FU

www.mssociety.org.uk

The MS Society is here for everyone living with MS – to provide practical help today, and the hope of a cure tomorrow. We fund world-leading research, share the latest information and campaign for everyone's rights. Together we are a community and together we can stop MS. We let people with MS know they're not alone, and offer advice and support to help them manage their symptoms.

Our free MS Helpline gives emotional support and information to anyone living with MS. It's free to call from landlines and mobiles within the UK. What you tell us is confidential and when you call us, it won't show on your phone bill. Freephone: 0808 800 8000

7.3. Overcoming MS

c/o Critchleys LLP, Beaver House, 23-38 Hythe Bridge Street, Oxford, OX12EP. <u>www.overcomingms.org</u>

Overcoming MS is the world's leading multiple sclerosis (MS) healthy lifestyle charity. We are here for everyone with MS who wants to live a full and healthy life, as part of our supportive community. We help people with MS to live well by making informed lifestyle choices. They have clear, practical actions to take, by following an evidence-based self-management program.

Our resources include:

Information on the Overcoming MS Program for Health Care Professionals <u>https://overcomingms.org/for-healthcare-professionals</u>

Evidence-based Overcoming MS Program - Multiple Sclerosis (MS) Recovery Program - UK, USA & Australia | Overcoming MS Overcoming MS Circles – Over 100 Volunteer Ambassadors providing peer support to people living with MS across our global Circles network. OMS Circles Online | Overcoming MS

Information resources – including a Podcast and Webinar series, publications and evidence-based research. Multiple Sclerosis Books & Resources | Overcoming MS

Overcoming MS for Healthcare professions - <u>https://overcomingms.org/for-professionals</u>

7.4. Multiple Sclerosis Trust

Spirella Building, Bridge Road, Letchworth Garden City, Hertfordshire, SG6 4ET

The MS Trust are here to help you make sense of MS on every step of your journey. We're here for you today, tomorrow and every day after that.

We fight to make sure everyone affected by MS can access quality, specialist care and live the best life they possibly can. We support and train your MS health professionals and fund MS specialist nurses and Advanced MS Champions across the UK.

We produce practical, evidence-based information, online and in print, and our dedicated Helpline team are a friendly and knowledgeable voice to speak to for anyone who needs to know more about MS.

For information on living and working with MS visit <u>www.mstrust.org.uk</u>, call the MS Trust Helpline on 0800 032 38 39 or email <u>ask@mstrust.org.uk</u>.

7.5. Shift.ms

www.Shift.ms

Shift.ms is the digital community for people with multiple sclerosis (MSers). Founded by MSers, for MSers, the charity offers social and emotional support, inspiring MSers to take charge of their health as soon as possible after diagnosis. It's independent and it's free.

Shift.ms aims to minimise the negative impact of diagnosis on quality of life. Shift.ms helps MSers adapt to the uncertainties of an MS diagnosis and build resilience to combat these, connect with others with MS and learn to manage their health.

Key resources:

• <u>Buddy Network</u> - 1:1 peer support from an experienced MSer

- <u>Learn about MS</u> explore key topics about MS, a useful resource particularly if you're newly diagnosed
- <u>Blogs</u> read about the real lived experience of others living with MS
- Follow us on YouTube, Instagram, Facebook and Twitter

7.6. MS National Therapy Centres

www.msntc.org.uk

MS National Therapy Centres represents a thriving network of 50 therapy centres throughout the UK. We provide centres with support, training, and operational guidance, as well as promoting their work nationally so that more people living with MS, and other life-limiting conditions, can access their services.

Collectively, our member centres support more than 15,000 people every week. They provide a wide range of physical and holistic therapies to complement clinical treatment, as well as counselling, emotional support and an active social community.