

# Life changing: mental health and MS



## In brief

Mental health concerns are widespread among people with MS and can be distressing and debilitating.

MS symptoms, in particular walking difficulties, fatigue and bladder and bowel issues, are major contributing factors to poor mental health among people with MS.

Too many people with MS are struggling with poor mental health alone or with inadequate support.

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## About the survey

In January 2023, we surveyed people living with MS on a range of issues relating to everyday life. Our 2022 survey had indicated that mental health was a key concern for people with MS, and so we asked questions to elicit further insight into mental health and MS, including prevalence, causes, impacts and access to treatment.

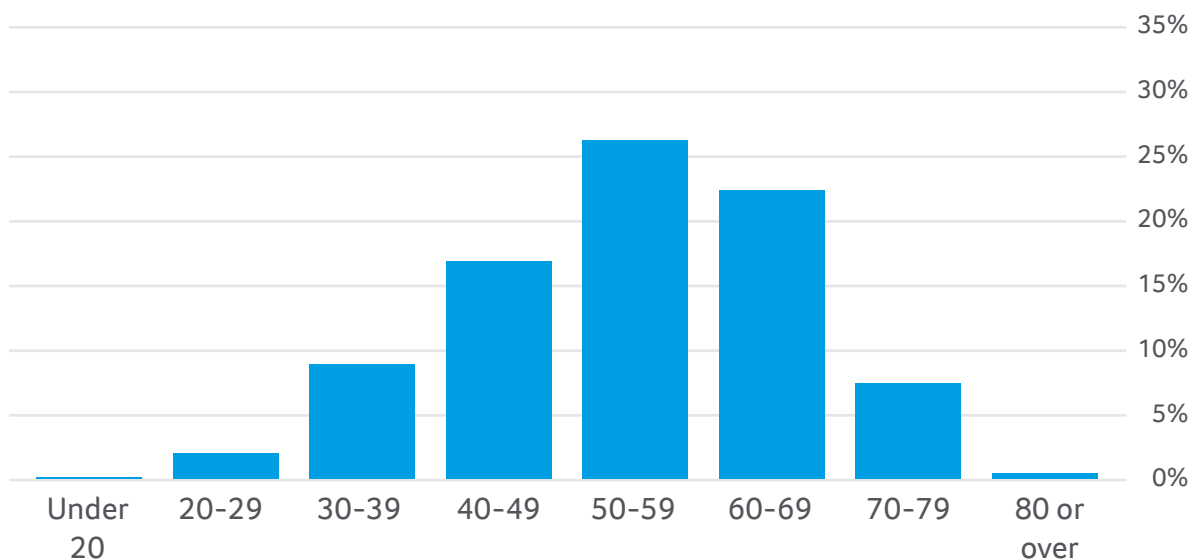
Our dataset consists of responses from **2,068** people

with MS who listed one of the UK nations as their home. We removed responses from outside the UK prior to analysis.

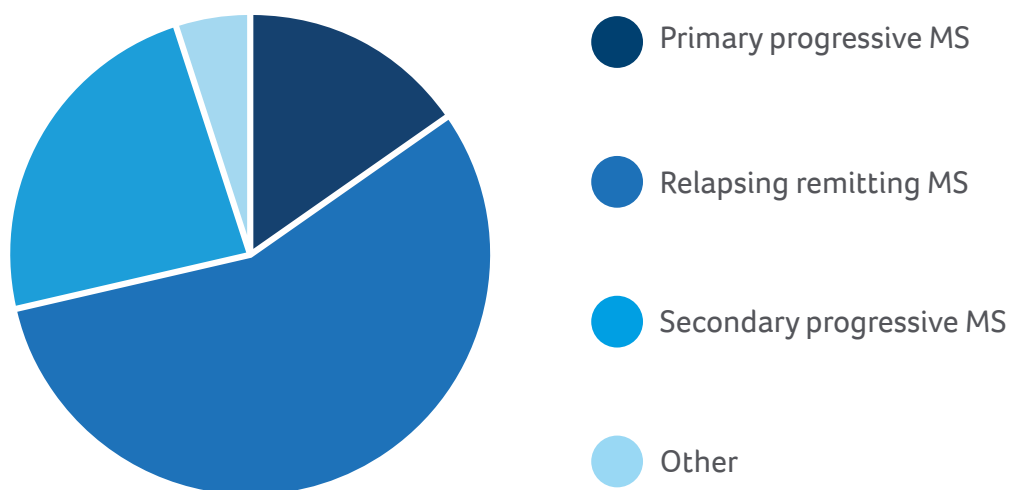
Over **77%** of respondents identified as female, **90%** of respondents identified as heterosexual and **88%** described their ethnicity as White British. English is the main language for **98%** of respondents. **82%** of respondents live in England, **11%** live in Scotland, **5%** live in Wales, and **2%** live in Northern Ireland.

These demographic features, as well as the age range and the types of MS represented in the sample, broadly match what we know about the MS community in the UK, such that we can reasonably extrapolate from this data set.

## What is your age?



## What kind of MS do you have?



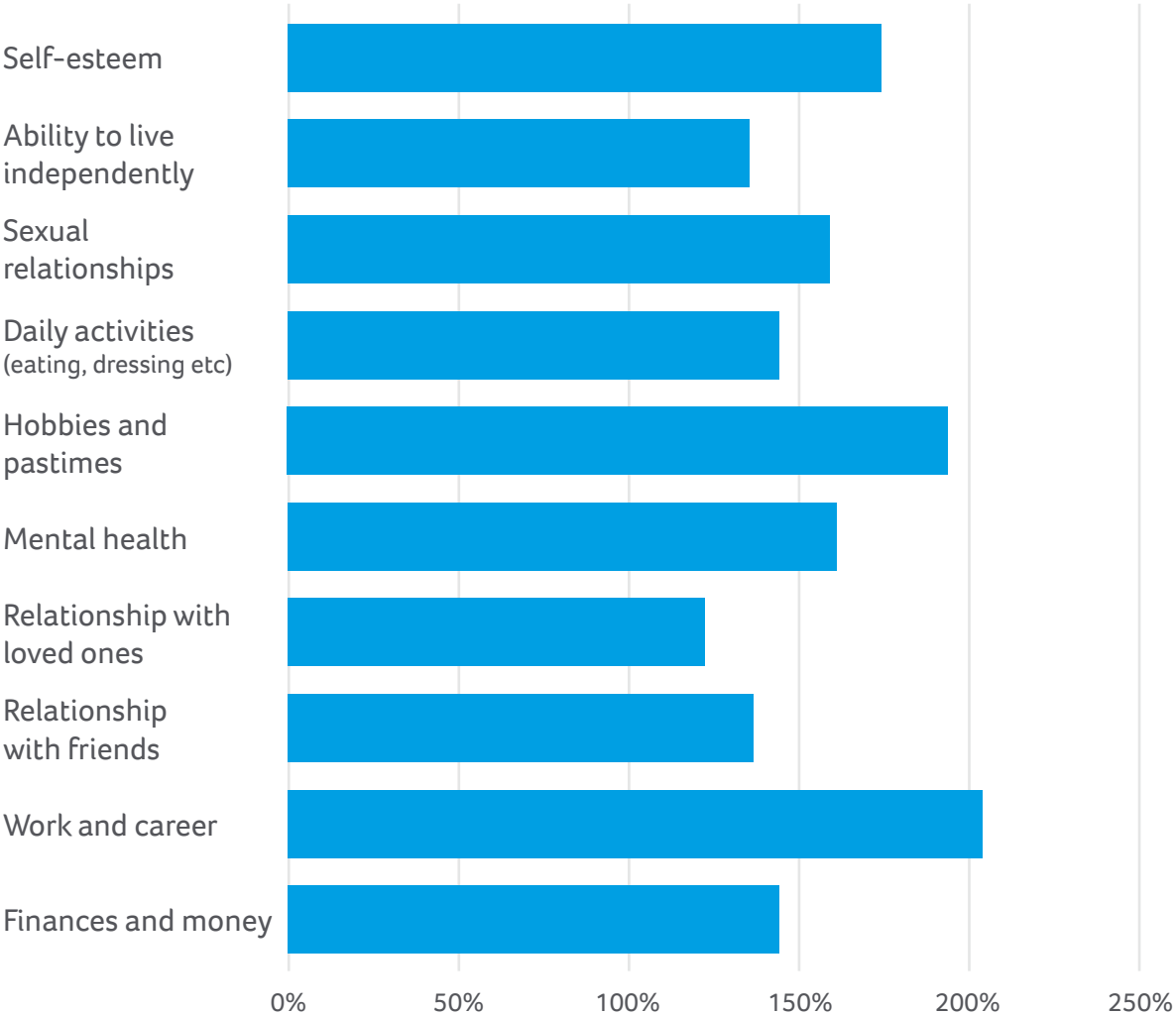
# What you said about MS and mental health

**94%** of people surveyed said that MS had altered their life.

**50%** said it had completely changed their life.

When we explored the aspects of life that had been most affected by MS using weighted averages of the responses, this revealed that self-esteem, sexual relationships, hobbies, mental health and work were most severely affected.

## What aspects of your life have been affected by MS?



Having MS does not mean one is exempt from other stresses in life.

**44%** of our respondents live with another health condition as well as MS.

These include cardiovascular disease, diabetes, severe allergies and other autoimmune conditions. Although we may think of people with MS as recipients of care or support,

**29%** of respondents have caring responsibilities themselves, either for children or elderly relatives.

Our respondents spoke eloquently about how having MS makes them feel.

*"MS means I experience a real lack of confidence in myself, in mixing with friends and going out. I feel MS has changed me from the bubbly confident lady I was to an anxious shadow of my former self."*

*"Just really makes me so frustrated as I can't do the things I used to. I really try to think positively about things but then again I think, 'What is my purpose in life now?' It's just a horrible illness."*

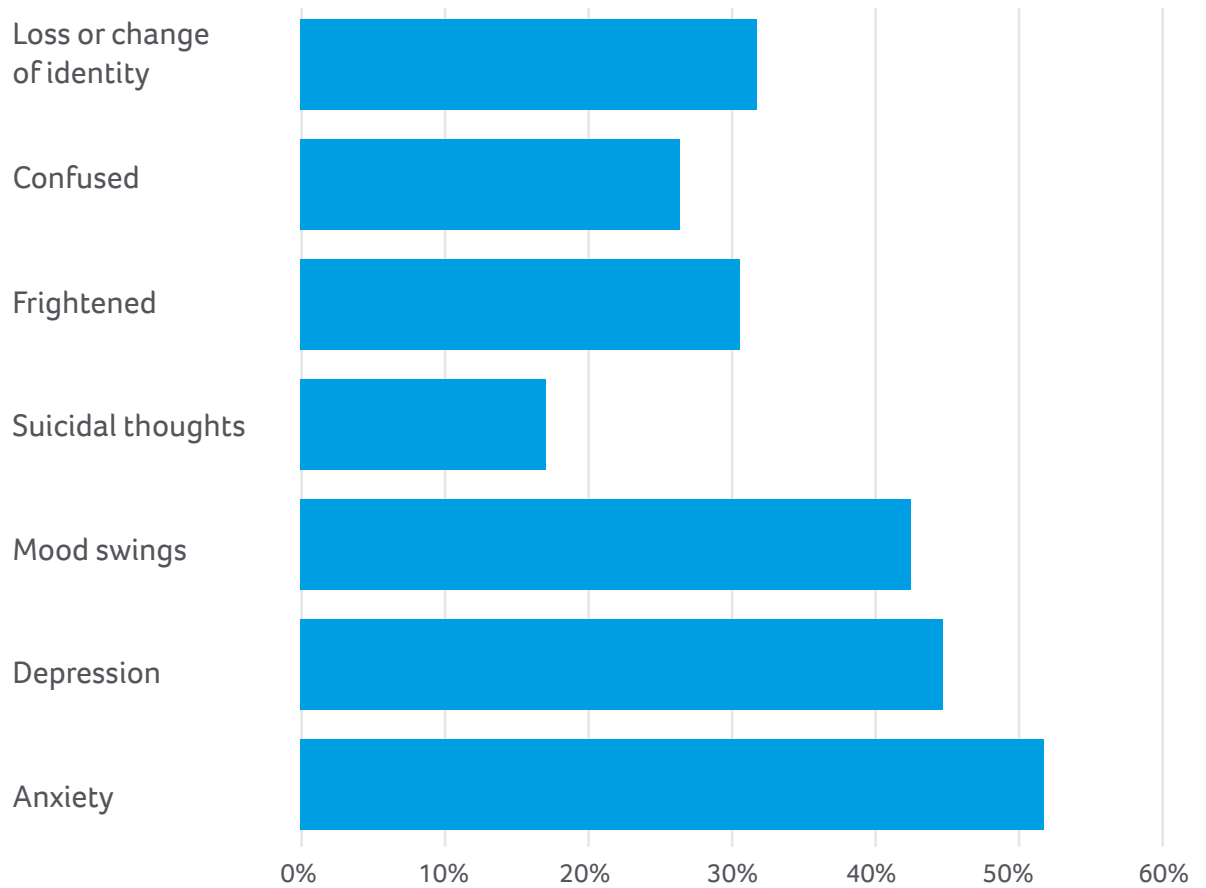
When asked directly,

**56%** of survey respondents reported that MS had impacted their mental health moderately or severely.

However, many more respondents reported experiencing mental or emotional health symptoms. Anxiety, depression and mood swings are common experiences for people with MS, each issue having a moderate to severe impact on over **40%** of respondents.

Of particular concern is the finding that **17%** of respondents were troubled by thoughts of suicide, but there are also significant numbers suffering a loss or change to their sense of identity, confusion or fear.

## How does MS affect your mental health?



### MS symptoms and mental health

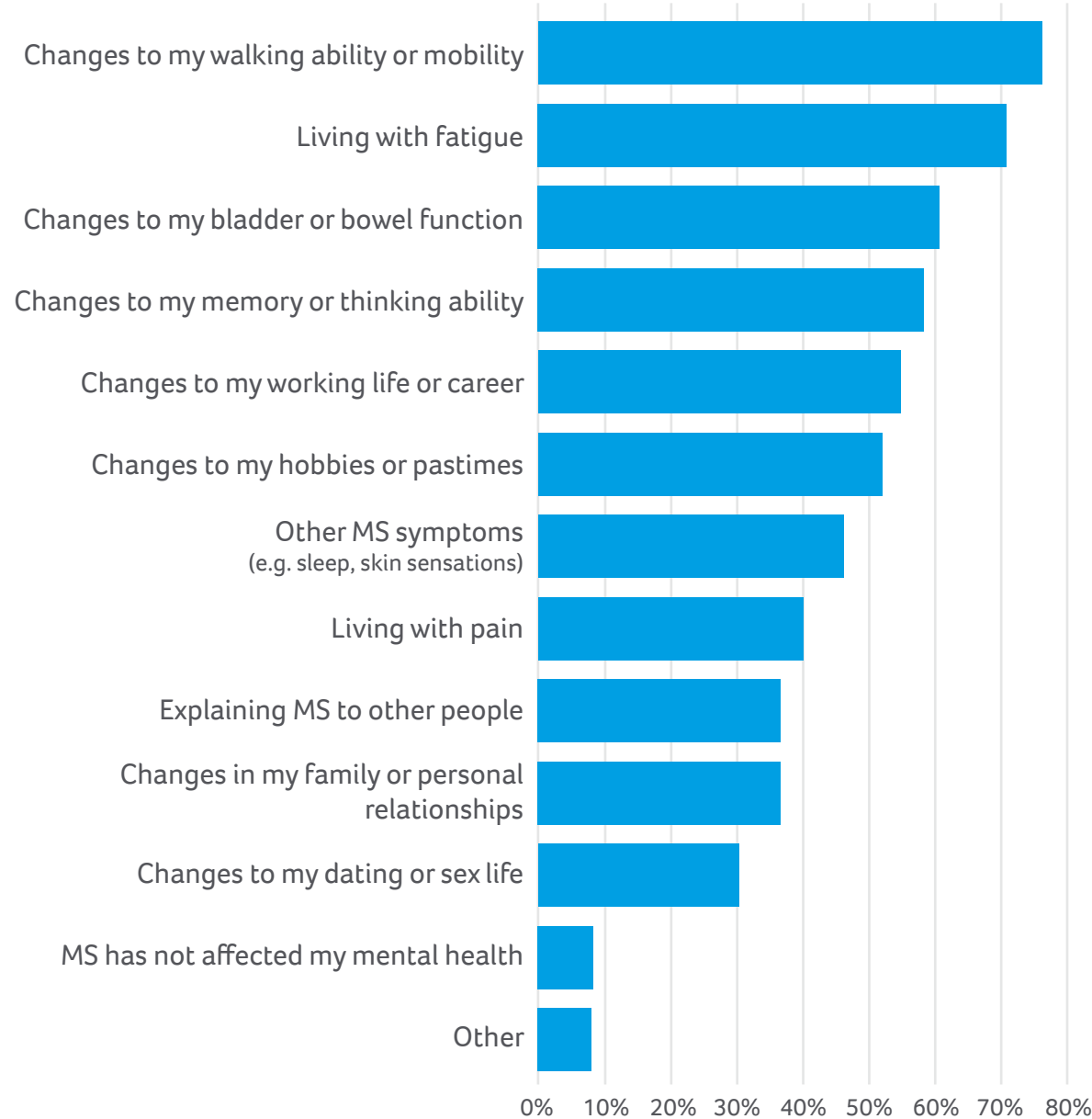
MS symptoms are highly variable between individuals, but we wanted to find out whether there were any common factors that people living with MS found most significant in affecting their mental health. Respondents could tick as many factors as they felt applied to them.

Using weighted averages, this revealed that

**76%** of respondents felt that changes to their mobility or walking ability had affected their mental health.

Independence is a significant part of self-identity and self-efficacy. Restrictions to personal mobility can be profoundly disempowering, resulting in isolation and loneliness, poor physical health and poor engagement with work or activities outside the home.

# What aspects of life with MS affect your mental health most?



**71%** of respondents said that fatigue was an important factor in determining mental health.

Fatigue is highly prevalent in MS, and yet fatigue can sometimes be seen as simply a functional problem, in that it prevents people from doing or achieving as much as they want. This research shows that it's important to see fatigue as a mental health problem too.

This explicit connection between physical symptoms of MS, psychosocial impacts and mental health highlights how important it is that MS symptoms are effectively managed. Poor or patchy access to physiotherapy, fatigue or pain management, or continence advice can have debilitating effects on people with MS and their mental and emotional wellbeing.

*"The impact isn't directly on my mental health because I'm pretty well balanced, I think. But the pain, fatigue, not being able to do stuff upsets me and I can feel an increased reluctance to even try to do stuff that causes me pain/fatigue, or because I'm afraid of falling etc. Even going to the shop, will I be able to get round holding a trolley before I reach my limit, will I be able to get back to the car, drive home, get back in the house? I can't carry shopping in, I have to wait for my son. My world has contracted, and I'm scared to try because failure means I'm stuck until help arrives."*

*"I think the hardest thing to overcome mentally is that you are no longer the same person you were. I was 23, an active jogger, I liked to go out with friends, I had a social life. My life was starting, no kids yet, not married, no mortgage, at the beginning of my career. Diagnosed at 24 then all of a sudden, I'm walking with a stick, I'm tired all the time so don't want to socialise, everything needs to be planned – does the restaurant have a lift? If not, then we can't go there. I've had to reduce my hours in work, I can't drive – what do I do about money? I'm coming to accept that with this illness I won't ever get better. Yes, you have good days, but they aren't the same as pre-MS good days really."*

## Talking about mental health and MS with others

We asked the subset of respondents who agreed that MS had affected their mental health whether they had disclosed that impact to other people.

**30%** of this group had not told anyone about their mental health concerns and had no plans to do so.

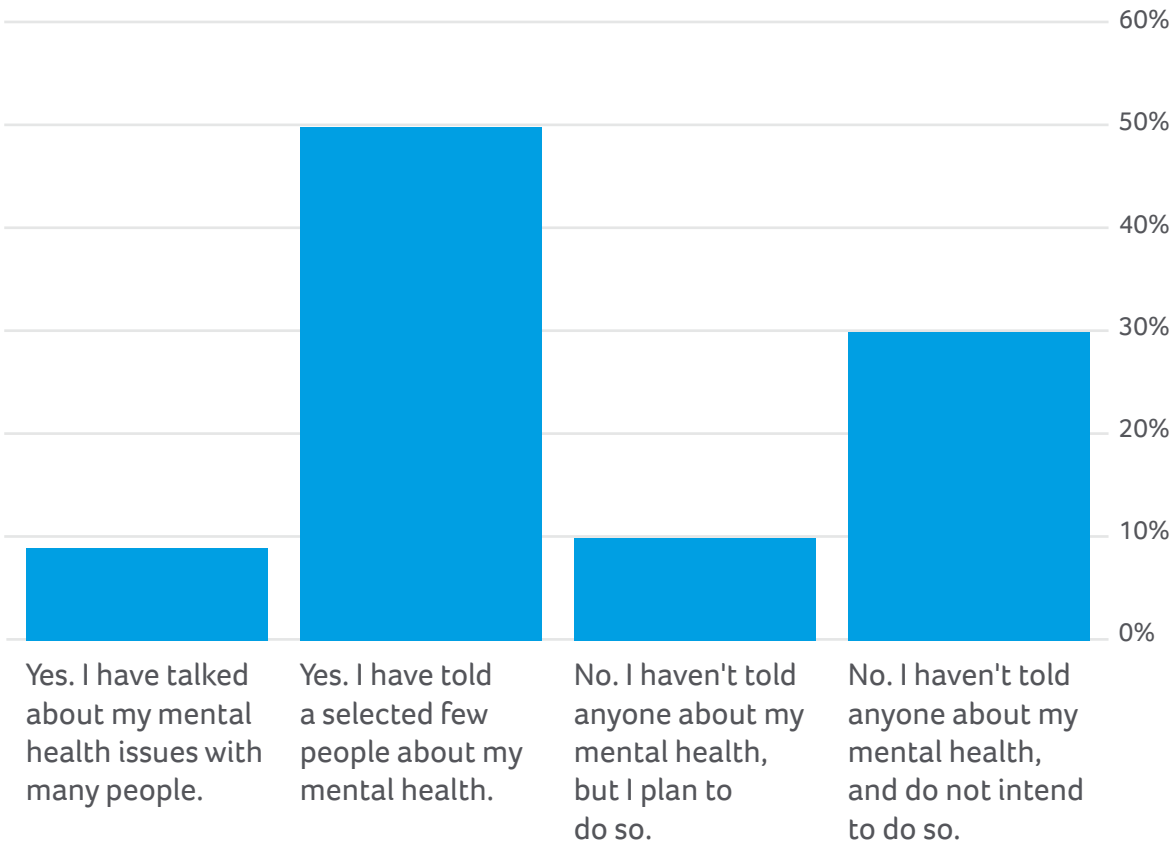
Only **10%** of this group felt that they were open about their mental health with many people.

Most commonly, **50%** of our survey respondents had told a selected few people about their mental health, and a further **10%** of respondents planned to tell others about their mental health but had not yet done so.

This indicates a prime opportunity for us and other MS organisations to offer support or resources to help people begin that conversation. The focus on mental health in MS Awareness Week in **2023** offered that opportunity, supported by a joint campaign delivered by seven MS charities. We empowered people with MS to speak up about their mental health concerns and signposted to the resources and information we offer across all media channels.

*"Have not been able to tell my family. I feel under supported by healthcare and even critiqued. Feel like I'm living a lie and I'm exhausted after 13 years of fighting for help."*

# Have you told anyone about the impact that MS has on your mental health?



To explore this further, we asked our respondents who they were likely to talk to about their mental health. Understandably, partners and family members are the most likely to hear from a person with MS about their mental health concerns, but friends and work colleagues or online support groups are also used by people with MS to explore their emotional health concerns.

Less than **9%** spoke about mental health to a member of their MS team.

The burden of support for people with MS with poor mental health therefore falls on their closest family and friends, who are unlikely to have training in mental health. This may be due to a lack of mental health services or a lack of awareness that such services may be useful to people with MS.



## Getting professional help with your mental health

**38%** of respondents to this survey said that they would like more support to manage or improve their mood or emotions.

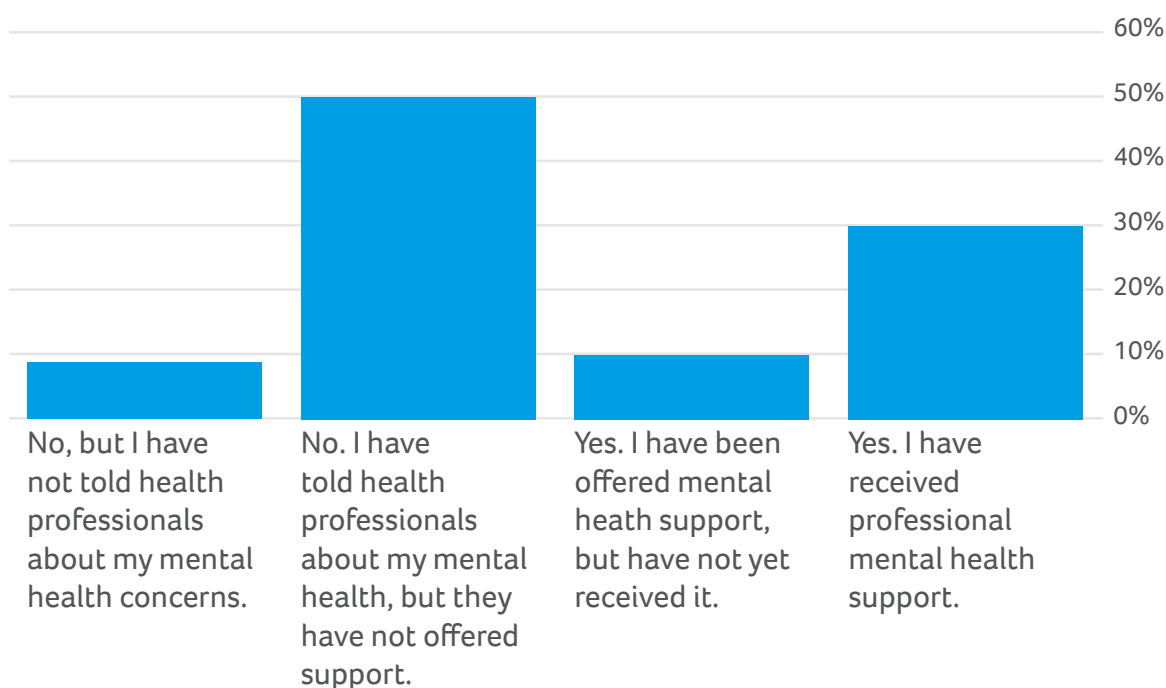
Health professionals should therefore be aware that they may need to start the conversation about emotional health. MS services may struggle to set up appropriate pathways for mental health support for their patients, given capacity issues throughout the NHS. The MS Trust has been proactive in addressing this through our health professional education programmes, but there remains a great deal of unmet need.

We asked those people who agreed that they had mental health concerns what support they had been offered by health professionals. Of the 1,675 respondents who answered this question, less than **22%** had received professional mental health support. A further **12%** had been offered but had not yet received professional mental health support. Worryingly, over **9%** of respondents had disclosed mental health problems to health professionals but had not been offered support. Extrapolating this to the wider MS community, it indicates a significant unmet need.

In the absence of appropriate support to live a comfortable, dignified life with MS, survey respondents referred to seeking voluntary euthanasia as an option.

*"I've joined and been green lighted by Dignitas. Not sure when to go but will do when I feel the need."*

### Have you been offered professional support for your mental health concerns?



## How do people with MS manage their mental health?

People living with MS frequently practice self-management strategies for their MS symptoms. These include behaviours and choices to manage stress (**52%**) as well as taking care with their diet (**28%**), exercise (**44%**) and time management (**45%**). Proactive behavioural changes like this can be positive, and can reflect a realistic approach to living well with MS.

*"I have aimed to reduce my long-term stress levels and have started planning (mentally at least) for a contingency plan if I become unable to do certain things or need more support. For example, I am pregnant with a second child and envisage needing some 'mothers help' type support in order to juggle two young children, a job and my fatigue and wellbeing without relying on my own mum more than is reasonable, and with a partner who works VERY long hours."*

*"I changed my career pathway from an 'active' nursing role to a teaching specialism and a flexible role that does not require shift work."*

Where change is imposed from outside, by circumstances, symptoms and systems within society, this can feel less positive.

**47%** Of respondents agreed that they had changed their plans for the future.

The details of those changes make stark reading, indicating the uncertainty, loss and disappointment caused by life with MS.

*"My entire life changed. I'm a full-time wheelchair user and chronically depressed and isolated."*

*"I no longer have family holidays because of the cost and finding suitable places for me to visit. I have also had to cash in most of my pension to pay the mortgage and help with day to day finances as I no longer work and I was the main earner in the household."*

*"I do not make long term plans. This means I have given up on a career, buying a house or having a romantic relationship."*

*"I always thought once my children were older, I would start my hairdressing career again, but I know I won't be able to now."*

*"I no longer plan for the future, it seems pointless. I had to quit my dream job, now I don't have the income to travel and do all the things I wanted to do."*

## **Summary**

Mental health problems among people with MS are widespread and can be debilitating. Although mental health problems can derive from external strains, people with MS report that their MS symptoms are a key factor causing mental health concerns. Of particular concern are walking difficulties, fatigue, bladder and bowel continence and cognition. These contribute to feelings of anxiety and distress related to loss of identity and loss of independence. The resulting reduction in quality of life, disengagement with work and hobbies, and isolation represents a severe and complex mental health problem.

Too many people with MS are struggling with their mental health alone. They may not have discussed their concerns with their families or health professionals and as such may not have been able to access treatments or support. The MS Trust offers trusted information and support to people affected by multiple sclerosis, including a helpline where we can signpost people to mental health support. We also deliver education and training for MS specialist health professionals where the mental health impact of MS is prominently discussed. Nonetheless, we recognise that there is more to do in terms of mental health service provision for people with MS.

The MS Trust is working with other MS charities to open up the conversation about mental health in MS. We want to make sure that people with MS recognise that MS can impact their mental and emotional health and are empowered to speak up and seek appropriate support. This support needs to address both primary mental health itself, but also the underlying causes of mental health concerns, where under-treated MS symptoms have had a profound impact on identity and independence.

**If you have been affected  
by the issues in this report,  
there is help available.**



Our information sheet, 'MS and your feelings' is available free to order or download here:

**[shop.mstrust.org.uk/publications/ms-and-your-feelings](https://shop.mstrust.org.uk/publications/ms-and-your-feelings)**



Browse our wellbeing webpages here:

**[mstrust.org.uk/wellbeing](https://mstrust.org.uk/wellbeing)**



Find other sources of information and support here:

**[mstrust.org.uk/emotions-help](https://mstrust.org.uk/emotions-help)**



And for any questions about MS, including questions about mental and emotional wellbeing, contact our helpline on

**0800 032 38 39 or [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk)**