

# Life Changing

The hopes and fears of the MS community in 2022



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# Executive summary

**Multiple sclerosis (MS) can impact on every part of a person's life - from relationships, to work and finance, to the ability to live independently.**

MS is a condition which affects the central nervous system leading to a range of different symptoms including mobility problems, visual difficulties, bladder and bowel issues, thinking and memory problems, and fatigue. MS can affect people in different ways.

In February and March 2022, the MS Trust ran an online survey to understand in more detail how MS impacts upon people's lives. 718 people living with MS responded to the survey.

MS had impacted the lives of **95%** of people who responded to the survey. **A third** of people with MS said that their condition had severely or moderately impacted their ability to live independently and **43%** said their MS had severely or moderately impacted their ability to complete daily activities such as eating and dressing.

The most common symptom reported was fatigue, which can be both physical and cognitive. Other frequently experienced physical symptoms included problems with mobility and balance and altered skin sensations. Inability to concentrate, difficulties with word finding, brain fog and memory issues were frequently experienced cognitive issues.

People's mental health and emotional wellbeing were also impacted. **94%** of people who responded to the survey said that their mental health or emotional wellbeing had been impacted by their MS. Common mental

health impacts included anxiety, depression and mood swings. **Two in five** people had experienced suicidal thoughts.

When asked about the wider impacts of MS on their lives, work and career was most often chosen as severely impacted by people with MS. **88%** of people said their work and career had been impacted; for **40%** this impact was severe. Many people had given up work or taken early retirement, reduced their hours or responsibilities, or changed career. This meant **39%** had faced a decrease in their income. This impact is particularly potent when **a quarter** of people faced significant costs as a result of their MS for things such as adaptations or alternative therapies.

Around **three quarters** of people said that their MS had impacted their relationship with loved ones, their relationship with friends and their sexual relationships. **14%** of people had ended a relationship with a partner because of the impact of their MS. People were worried about the impact of their MS on loved ones in the future, especially partners and children. Some people had chosen not to start a family as a result of their MS.

**Nine in ten** people said their hobbies and pastimes had been impacted by their MS and **56%** of people were unable to partake in the activities they once enjoyed because of their MS. About a half of people said their plans for the future had changed because of MS. Many of these people told us they could no longer go on holiday, take trips or undertake activities such as walking and cycling.

However, the impact of MS was not always negative. Just under **three quarters** of people who responded to the survey said that they had a greater appreciation of the positive aspects of their life as a result of their MS. Some had taken up new hobbies and some had made new friends as a result of their MS.

Despite the impact on people's lives, many people with MS were not receiving the support they needed. **88%** of people felt unable to cope with their MS some or all of the time. **7%** of people did not have a carer but needed one.

More needs to be done to increase understanding and awareness of MS and the often invisible nature of the symptoms people are living with. More support is needed for people with MS to manage all aspects of their lives including specialist clinical support, help to stay in work or to access financial support, emotional and psychological support and help to access hobbies and pastimes.

The MS Trust believes that no one should have to manage MS alone. Our vision is to enable people with MS to live their lives to the full, and we aim to fulfil our mission by providing trusted information on MS, securing the future of specialist MS healthcare and raising awareness of the diverse and holistic needs of people affected by MS.

**88%** of people felt unable to cope with their MS some or all of the time.



**7%** of people did not have a carer but needed one.

**75%** of people said that they had a greater appreciation of the positive aspects of their life as a result of their MS.

# Introduction

## What is MS?

**MS is a condition which causes damage to the nerves in your brain and spinal cord (the central nervous system). In MS the immune system mistakenly attacks the central nervous system.**

The damage caused to the nervous system in these attacks can leave a person with different symptoms.

Everyone's MS is different so no two people will have the same range and severity of symptoms. Symptoms can include physical effects such as problems with mobility, bowel and bladder functions and eyesight. Cognitive impacts can include fatigue, difficulty concentrating and memory problems.

The condition is nearly three times more common in women than in men. Most people are diagnosed in their 20s and 30s but it can be diagnosed in younger and older people too. It's estimated that at least 130,000 people in the UK have MS. MS is a lifelong condition.

There are three main types of MS: relapsing remitting MS (RRMS), secondary progressive MS (SPMS), and primary progressive MS (PPMS). At the moment, there is no cure for MS but there is a wide range of possible treatments which can help with symptoms or reduce the number and/or severity of relapses.

The MS Trust fights to make sure everyone affected by MS can access good quality, specialist care and live the best life they possibly can.

## About the MS Trust

**The MS Trust is here for everyone affected by MS, from the moment of diagnosis and throughout their journey.**

We fight to make sure everyone affected by MS can access good quality, specialist care and live the best life they possibly can.

We support and train 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 with anyone who needs to know more about MS.

The MS Trust aims to represent and reach all people affected by MS, including those in Black, Asian, minority ethnic and LGBTQ+ communities, and people living with disabilities. This report documents some of our work to ensure that all voices and viewpoints within the MS community are heard, and to amplify the voices of people who have been marginalised.

## How we ran this survey

In February 2022, the MS Trust held three online focus groups with thirteen people with MS. These people had different types of MS, different backgrounds and different life experiences. They discussed the impact MS had had on their lives.

This helped inform the creation of an online survey of 30 questions asking people with MS specific questions about the impact of the condition on their lives. After quality testing with a further panel of people with lived experience of MS, we circulated the survey to people with MS from across the UK via the MS Trust mailing list and social media channels.

The survey ran from 11th February until 7th March 2022. 718 people with MS answered the survey. The survey results were analysed and the key findings are included in this report.

In addition, the MS Trust conducted four in depth interviews with people with MS. Their stories are included in this report.

## Who responded to our survey

**718 people responded to the survey.**

**83%** of respondents were female and **16%** were male (the remaining either chose the option other or chose not to say).

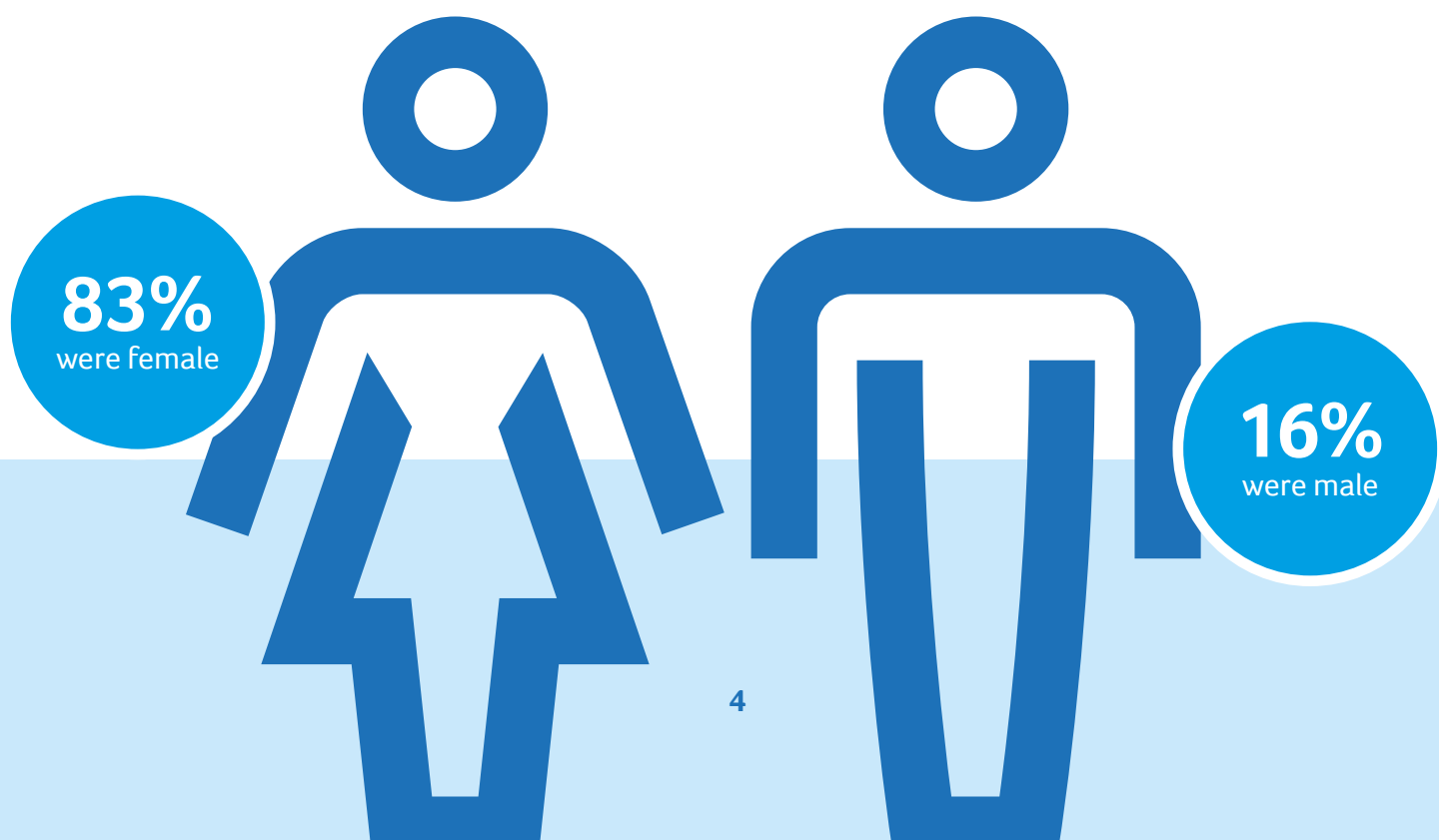
The majority of people who responded were from England and were aged between 30 and 60.

**A third** of people had caring responsibilities and around **40%** had an additional health condition.

People with all three of the main types of MS responded to the survey, although the majority had relapsing remitting MS.

Around **a quarter** of respondents had been diagnosed since 2020, **another quarter** between 2015 and 2019 and the **remaining half** before 2015.

**Two thirds** of respondents had experienced symptoms for more than a year before they were diagnosed.



# The impact of multiple sclerosis on people's lives

**A diagnosis of MS can be life changing, bringing uncertainty and the possibility of living with both physical and cognitive disability.**

MS had changed the lives of **95%** of people who responded to our survey. For **45%** their lives had changed completely.

Nearly all aspects of a person's life is touched by MS, from the ability to carry out day to day activities, to relationships with friends and family, to the way people feel about themselves.

**18%** of people with MS said that their condition had a severe impact on their ability to live independently and another **22%** said it had a moderate impact.

**15%** said their MS had a severe impact on their ability to complete daily activities such as eating and dressing and another **28%** said the impact on this was moderate.

For **nine in ten** people with MS, their condition had impacted their self esteem. People with MS told us that MS had restricted their ability to get out and meet people or do the activities and hobbies they had once enjoyed. For many, MS had meant the need to take early retirement, reduce their working hours or give up work entirely.

However, MS can also bring positive aspects to a person's life. People told us that MS had allowed them to find new friends or new pastimes, and that it had given them a greater appreciation of the positive aspects of their lives.

MS had changed the lives of **95%** of people who responded to our survey.

For **45%** their lives had changed completely.



*"MS is so unpredictable you just don't know what's next. It's very debilitating and consuming. It is like I am grieving for my life. Nothing will ever be the same again."*

## Physical impact

People with MS may experience the following physical health issues:

- mobility problems
- problems with balance
- skin sensations such as tingling, burning or numbness
- pain
- eyesight problems
- bowel and bladder difficulties.

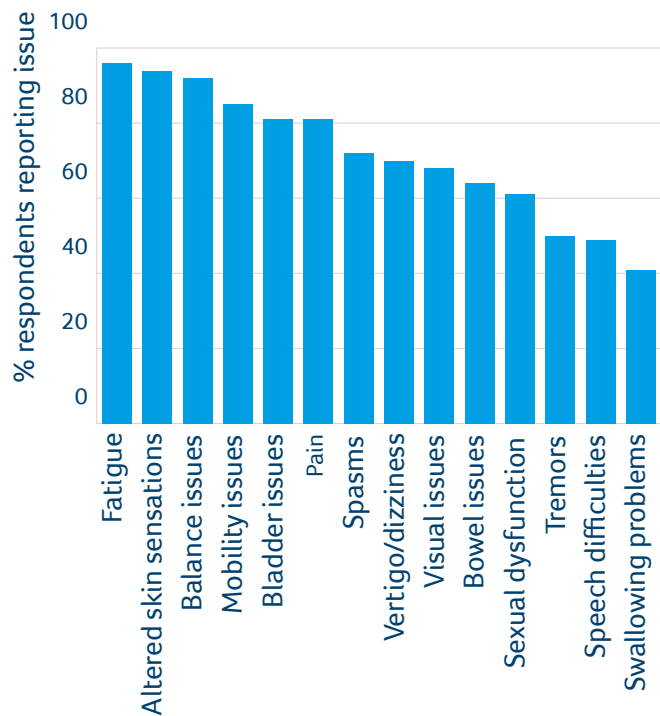
Fatigue was the most common symptom that people told us they experienced, with **96%** experiencing fatigue. For **two in five** people the impact of fatigue was severe.

Altered skin sensations (such as tingling, burning, numbness) and balance issues were also common problems people encountered with **94%** and **93%** of people experiencing these issues respectively. Again for many these impacts were severe (around **a quarter** of people for both).

Less common issues were swallowing and speech difficulties, although this might reflect the level of disability encountered by those responding to our survey. For the majority of people experiencing these kinds of physical difficulties, the impact was minor for the majority (**two thirds** of those with swallowing difficulties and **70%** of those with speech issues).

Those with primary and secondary progressive MS experienced more severe or moderate impacts on the following physical symptoms than those with relapsing remitting MS: mobility, balance, bladder function, bowel function, sexual dysfunction. Those who had been diagnosed a long time ago were more likely to experience severe impacts on different physical functions.

The impact of MS on physical health



**96%** of people experienced fatigue.

For **40%** of people the impact of fatigue was severe.



# Case Study - Johanna

## Retired Teacher, Scottish Borders

**It was back in 2012 that I first noticed something was wrong.**

Climbing down the steps from my bungalow into the garden on a sunny day, I felt a weakness in my legs. I made a mental note that I needed to strengthen them and made an effort to go up and down the steps three times a day. However, this made no improvement and on a walking holiday with my husband my legs just stopped working. We were in the middle of nowhere and I had to send him off to fetch the car while I hobbled to the nearest village.

By early 2013 I decided it was time to see my GP. I'd already done my research via the internet and had a fair idea what was wrong. My GP's father had had MS as well and she quickly came to the same conclusion as me, that I had the condition.

I was sent off for an MRI scan in Edinburgh and they confirmed I had primary progressive MS.

I've been living with the condition and getting on with things ever since. I see my neurologist once a year and at the moment my MS is not progressing fast enough for me to qualify for any medication – which, as far as I am concerned, is a good thing! I'm also part of an MS support group which stopped meeting during the pandemic but that we hope to start up again soon.

I was a teacher and was determined to retire at 60. I achieved this, although the final year was a challenge as I struggled with mental and physical fatigue and brain fog. I was lucky to have very supportive colleagues who helped me. The children were also very kind. I didn't want sympathy. I wanted understanding.

Life has changed but not as horribly awfully as it could have. I've had to amend what I do. We don't go abroad on holiday anymore and I'm not volunteering in the village as I was planning to do in my retirement. I now walk on a treadmill rather than going out walking. However, I swim regularly and I sew for three different businesses making all sorts from hats to oven gloves. It's about calibrating your expectations and not pushing yourself.

My advice for people newly diagnosed? I think it's important to try and keep a positive mindset and to go with what's happening. Don't battle it, work with it, but also don't give in to it. Be careful what you read on the internet – don't believe all the horror stories – and try to avoid falling into the trap of looking for symptoms. Finally, find like minded people who will listen to you.

*“Be careful what you read on the internet – don't believe all the horror stories – and try to avoid falling into the trap of looking for symptoms.”*



Keep a positive mindset  
and go with what's  
happening. Don't  
battle it, work with it,  
but don't give in to it.

## Cognitive impact

MS can also affect the functions of the brain leading to thinking and memory difficulties. Cognition problems can include:

- mental fatigue
- difficulty concentrating
- difficulty finding words
- problems with forward planning.

Mental fatigue was the most common cognitive impact experienced. **92%** of people experienced this and for just over a **quarter** this impact was severe. People in our focus groups talked about the impact mental fatigue had on their day to day lives with many explaining that it was this that had been the reason for giving up work or reducing their working hours. They were also concerned about making mistakes at work. **86%** of people had experienced problems with concentration and with their memory.

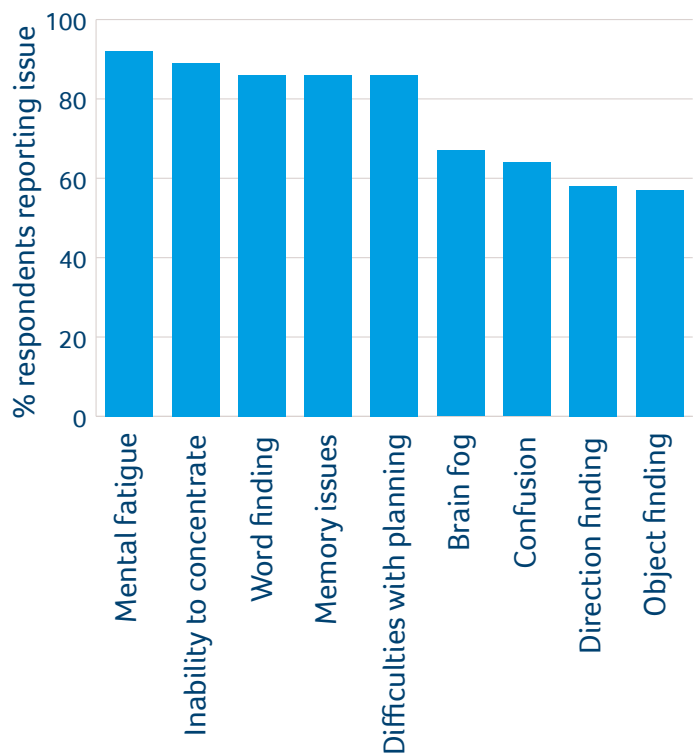
Difficulties finding the right word was also another common impact that people experienced. **Nine in ten** people had experienced this impact. For **15%** this impact was severe.

People with primary progressive MS were less likely to experience severe cognitive symptoms than people with other kinds of MS.

**86%** of people had experienced problems with concentration and with their memory.



The impact of MS on cognitive function

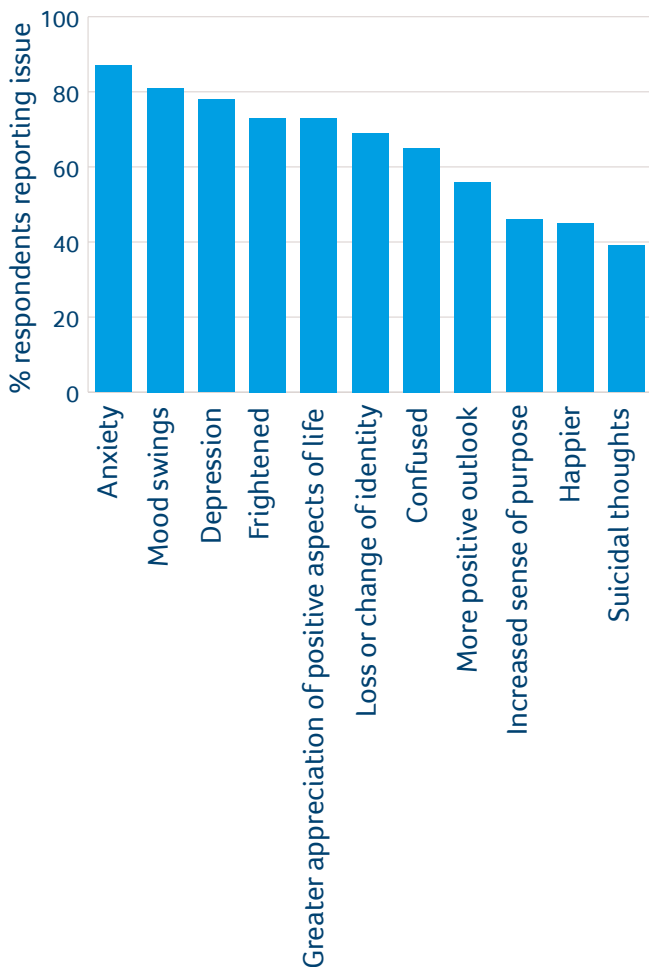


## Mental health

A diagnosis of MS and the ongoing difficulties that can occur with living with the condition can impact people's mental health and emotional wellbeing. **94%** of people who responded to the survey said that their mental health or emotional wellbeing had been impacted by their MS. For **a quarter** of people this impact was severe and for a further **two fifths** the impact was moderate.

The most common mental health impact experienced was anxiety. **87%** of people had experienced this and for one fifth this was severe. Depression (**78%**) and mood swings (**81%**) were also commonly experienced mental health impacts. **Two in five** people had experienced suicidal thoughts and **two thirds** said that their MS had impacted their identity.

The impact of MS on mental health



*"I have completely lost the will to live and find it hard to accept I have this disease."*

The impacts on mental health did not vary much between people with different types of MS, although those with secondary progressive MS were more likely to say that they had experienced a severe impact of depression and/or suicidal thoughts. Those who had been diagnosed very recently were more likely to say the impact on their mental health had been severe.

However, the mental health impacts of MS are not always negative. Some people with MS told us that it had given them a greater purpose to their life or that they had developed a more positive outlook on life. Just under **three quarters** of people who responded to the survey said that they had a greater appreciation of the positive aspects of their life as a result of their MS.

People with MS in the focus groups talked about the benefits of good emotional or psychological support. However, some people had struggled to find this support particularly from professionals with an understanding of MS.

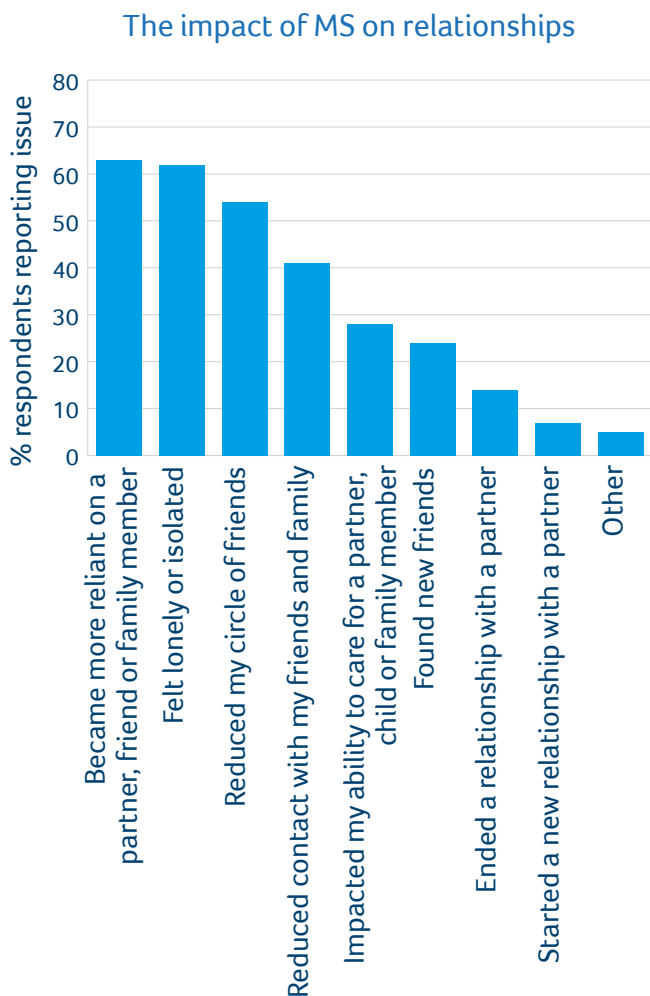
*"I'm single and scared of how MS will affect my chances of finding a relationship."*

## Relationships

Living with MS can impact upon a person's relationships with friends, family and loved ones.

A partner may need to take on more caring responsibilities that can alter the dynamics of a relationship. It may become more difficult to take part in the activities once enjoyed with friends, or problems with bowel and bladder control can knock people's confidence to socialise.

Around **three quarters** of people said that their MS had impacted their relationship with loved ones, their relationship with friends and their sexual relationships. **14%** of people had ended a relationship with a partner because of the impact of their MS.



*"I worry most about my family and the restrictions my MS has for us. I need more help with day to day things like cooking. That means instead of looking after my grandchildren it makes me dependent. I cry inside and am fearful that as I can't share activities everyone will just leave me out and not help me to join in."*

Nearly a **half** of people who responded to the survey said they had reduced their circle of friends as a result of their MS and **two fifths** had reduced contact with their friends or family. People in the focus groups told us that this was because they did not have the energy to manage many friendships or that they had chosen to concentrate on the friendships that were positive or helpful.

**63%** of people had become more reliant on a partner, friend or family member since developing MS. A **similar number** said they felt more lonely or isolated. People also expressed worries about the future. People were concerned about the impact on their loved ones, particularly their partner or children, if their MS was to progress and they faced increased disability. They were also worried that the limitations imposed on them by their MS would increase their loneliness.

**A third** of people who responded to the survey had a caring responsibility (such as caring for children or an elderly relative). **A quarter** of people said their MS had impacted their ability to care for a partner, child or family member.

However, the impact was not entirely negative. **A quarter** of people had made new friends as a result of their MS and **7%** had started a new relationship with a partner.

# Case Study – Rich

## Marine Ornithologist, Scotland

### **I was diagnosed with relapsing remitting MS in 2017, a week before my wedding.**

It was a huge shock, especially as the diagnosis was picked up from an unrelated scan of my optic nerve due to migraines. In some ways the diagnosis was more difficult for those around me – particularly my wife, a lead nurse, and my father, a benefits adviser, who both have experience of helping people with MS, often in more advanced stages. Once the news had set in, the diagnosis started to make sense. It helped explain some of the odd (but very typical) symptoms I had experienced over the years (numbness, tingling, dizziness, double vision). It also allowed me to do something about it, and I started a disease modifying drug (DMD) as soon as possible.

Although I've experienced only subtle changes to my symptoms since my diagnosis, my recent scans show that I have new lesions in my brain. I've now started a highly effective treatment, which leaves me immunosuppressed. As I now have no B cells, any infection could be very dangerous for me. This has impacted every part of my life – I have to be careful what I eat, ask others not to meet up with me when they're ill, and consider how I would handle raising my own children. Unfortunately, MS has also impacted my work as a seabird scientist – I can no longer carry out field work due to the heightened risk of me catching wild diseases, such as bird flu.

Fortunately, my employer has been extremely supportive. Together we've assessed my needs and they've put in place lots of things to support me. For example, they've allowed me to work flexibly around my symptoms, and supported me to do mindfulness and yoga.

I'm also now permanently working from home and they are providing the equipment I need to be able to do this. I also have an Employee Passport, which sets out the challenges that I face and the adjustments that my employer have agreed. This is helpful because it means I won't have to tell my story again and again if I move role within the organisation or change managers.

The greatest challenge I face with MS is living with the uncertainty of not knowing what the future will bring. Will I need a wheelchair? Will I be able to work? Will I be able to support my family? Despite this, I've tried to future-proof my life. I've bought a downstairs flat by the sea to prepare for any mobility challenges. I also go to the beach almost every morning to keep active and practise mindfulness. Having MS often means you're burdened with complex thoughts, which can be difficult to process, especially given the damage to your brain. Giving myself the time and space to let my mind reset is important.

To look at me, I don't think you'd know I have MS. My symptoms are invisible but I've found the best approach is to be open and honest. For me, it's helpful for others to be aware of the challenges I face – such as difficulty finding words – and to understand.

My advice to others newly diagnosed with MS? MS isn't a death sentence and there are things you can do to help. Most importantly, you can still live a full life, things just might need a little more thought and planning!



You can still live a full life, things just might need a little more thought and planning!

## Work and careers

The cognitive and physical impact of MS can mean many find doing the job they once did much more challenging.

With the right support, many people can continue to work or can find alternative careers. However, for many people with MS the support is not there and they struggle to work. Some are forced to change their career or study plans.

**88%** of people said their work and career had been impacted by their MS. For **40%** this impact was severe. In fact, of all the different parts of a person's life, work and careers was most commonly cited as impacted severely in our survey.

People's work had been impacted in different ways.

- **36%** of people had given up work or medically retired.
- **29%** had reduced their responsibilities or hours at work.
- **16%** had changed their career.

Those people who had been diagnosed a longer time were more likely to say that their work had been severely impacted by their MS. Those with primary and secondary progressive MS experienced a more severe impact on their work and career than those with relapsing remitting MS. This is likely to reflect the more severe physical symptoms that these people told us they experience, such as poor mobility and bladder and bowel function.

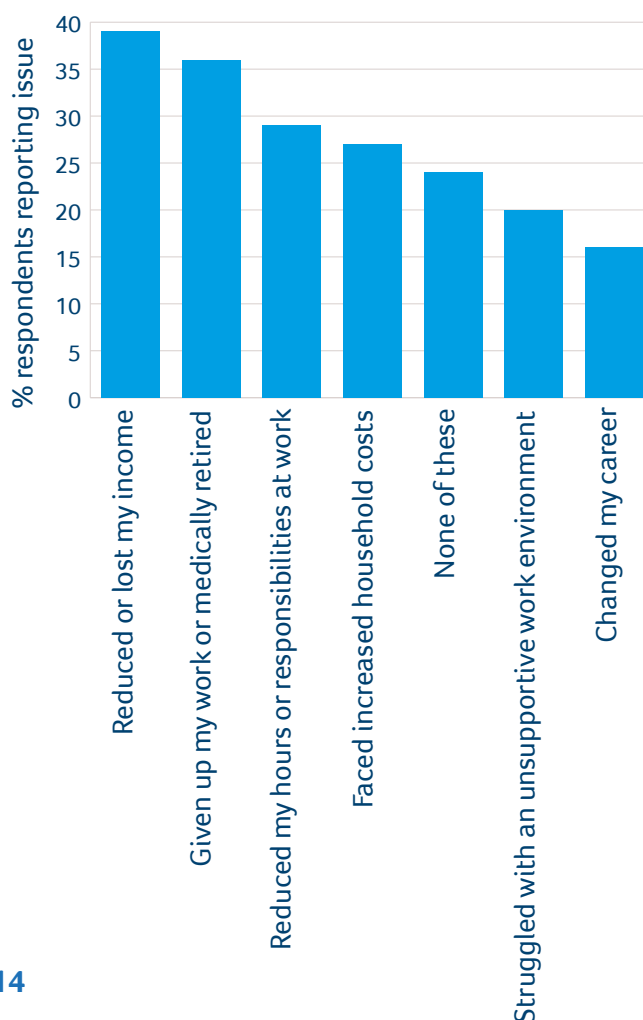
When questioned about the future, many of our respondents expressed concerns about being able to continue to work. Several people were the main financial contributors to their family and were worried about how their families' finances would be affected if they could no longer work.

Disappointingly, **one fifth** of people had struggled with an unsupportive workplace.

People in our focus groups told us that people without experience of MS struggled to understand the disease and its impact, and that workplaces were not always as flexible as they could be.

*"Not knowing when, or even if, my symptoms will get worse and become progressive, this particularly worries me in terms of my work (how long I will be able to work and the long-term effect on my financial security)..."*

The impact of MS on work and careers





## Money and finances

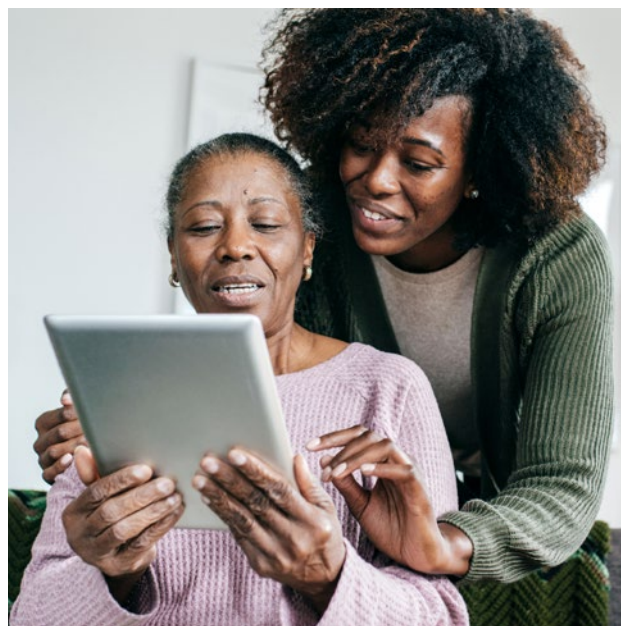
Many people with MS are struggling with the double whammy of a reduced income at the same time they are facing increased costs because of their MS.

**70%** of people said their finances and money had been impacted by their MS. For **18%** this impact was severe. People were worried about increasing costs in the future and making their finances last. A few were planning for this eventuality.



*"No longer earning a good wage so living very much day to day with no ability to save or plan for the future."*

**70%** of people said their finances and money had been impacted by their MS. For **18%** this impact was severe.



**39%** of people with MS had faced a reduced income or lost their income altogether as a result of their MS. This meant many were struggling financially, particularly as their MS had resulted in increased household costs - **27%** of people experienced increased household costs. Increased costs can include special diets, supplementary medicines, adaptations to the house or car, and vitamin supplements.

The longer people live with an MS diagnosis, the greater the impact on their money and finances. This is further compounded with a progressive MS diagnosis, so that people who have been living with secondary progressive MS or primary progressive MS are most at risk of financial stress.

# Case Study - Sandra

## Business Consultant, London

**After two bouts of optic neuritis, I was diagnosed with MS at the age of 51 in 2017. Even though I'd had optic neuritis, I didn't suspect MS.**

I was referred to St George's Hospital because my local hospital in Croydon doesn't have an MS service. I was in hospital for five weeks and then off work for five months.

I was a business consultant in the printing industry, driving regularly around the south of the UK to visit clients. I loved my job and was really good at it, but after my MS diagnosis I couldn't drive anymore as my vision is slightly impaired. Instead I took trains and taxis but the company I worked for weren't keen on me using taxis because I still had a company car. I felt I maybe wasn't as effective in my role which I suppose made me less of an asset.

In March 2019, the company announced a restructure and I was the only one of my team to be made redundant. I was offered support after my role ended to find a new job but it wasn't the right kind of support for me and didn't really take account of my MS diagnosis.

Instead, I set up my own business, project managing home improvements for clients. I could fit this around my symptoms of MS, for example, by taking a nap if I needed to do so in the afternoon. It was going well until Covid came along and decimated my business.

*"If there seems to be no light at the end of the tunnel, you WILL find an inner strength to deal with whatever MS wants to throw at you."*

I had to rely on benefits for a while, which felt strange after working in full time employment for almost 30 years and receiving an income that way. Now I'm still pursuing my business but focusing on it a bit less and putting me first instead – I want to live life to the fullest and enjoy my time with my son and friends.

One impact of MS is that it makes starting new relationships difficult. I'm single and would like to meet someone, but when I mention MS, usually quite early on as I want to be upfront with people, they seem to lose interest or want to just be friends.

MS is a part of me but doesn't define me. I've got a range of symptoms including that my eyesight is blurred and my mobility is impaired so I have a blue badge now. But that doesn't stop me from travelling. I went to Italy with my family and was really impressed with the help I had to board the plane and I sailed through customs.

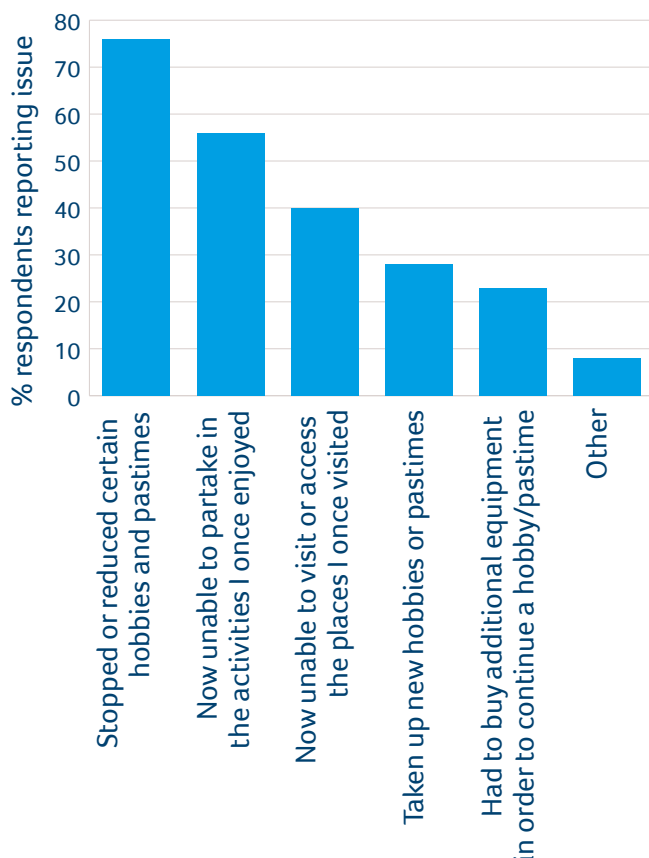
My advice to anyone diagnosed with MS? Take time to reflect on the impact on your life and stay positive. How will you deal with life now? If there seems to be no light at the end of the tunnel, you WILL find an inner strength to deal with whatever MS wants to throw at you.

## Hobbies and holidays

As well as impacting on relationships and work and finances, MS can also impact on hobbies, pastimes and holidays.

People with MS may find they can no longer do the hobbies they enjoyed or have to find new hobbies that fit around their cognitive and physical disabilities. Problems with fatigue, mobility and balance may make exercise more difficult. Whereas eyesight, memory and concentration issues may make hobbies such as bridge, reading or sewing challenging. Despite the challenges associated with keeping up hobbies and exercise, people in the focus groups told us that they were important to help manage their mental health

The impact of MS on hobbies and holidays



*“Mainly it is about not being able to be impulsive about going out! Everything needs to be thought through to see if it is possible.*

*We cannot go on the sort of days out, or holidays (walking), we used to do...”*

**56%** of people were unable to partake in the activities they once enjoyed because of the impact of their MS. However, **nine in ten** people said their hobbies and pastimes had been impacted by their MS. For nearly **a third** of people this impact was severe. More than **three quarters** of people with MS had stopped or reduced certain hobbies and pastimes.

The survey found that just over **a quarter** of people had taken up new hobbies or pastimes.

People responding to the survey talked about the increased forward planning associated with visiting places when living with MS and the restrictions this had placed on their lives. For example, they needed to know places would have appropriate facilities such as ramps or accessible toilets. **40%** of people said they were unable to visit or access the places they once visited because of their MS. Nearly **a quarter** of people had also had to buy additional equipment in order to continue a hobby/pastime.

*“We travel less, we worry more.”*

# Case Study - Jayne

## Occupational Therapist, Northern Ireland

### **It was in 2017 that I first started having problems balancing.**

At first I thought I had sore feet from my shoes. I was a very fit and active individual – I was a keen and accomplished horse rider owning six horses and regularly competing in competitions, as well as being an international judge and team selector. I also ran a lot, hiked, cycled and was a boxer.

At the beginning of April I couldn't walk and then a few days later I felt numb from the waist down. Everyone said it was stress. I ended up going for a private consultation, and that was when I was diagnosed with clinically isolated syndrome. I had six months off work. Then later in 2018, after more symptoms, I was diagnosed with MS. The doctors who told me about my diagnosis were positive and upbeat and this helped me deal with my diagnosis.

I've been lucky to get the medicine I need and my management team at work have been very supportive, as are my fabulous family. My best friend was also diagnosed in 2018, so we support each other.

Now I'm in a good place. I'm back at work. I look after myself and manage my MS with meditation, Pilates and using skills I have learned in my role as an occupational therapist in the NHS. I have a positive outlook on life and take one day at a time. MS could be curable in the next ten years. I've tackled some of my fears since having MS, like going in lifts and flying on a plane. Nothing phases me now.

I can't do exactly the same hobbies that I used to do before my diagnosis but I have adapted. I still have horses, but only three now. I do miss the social aspect of competitive horse riding – I was away every weekend either riding or judging. I also miss the ability to do the other sporting activities I love but it's important to find alternatives. Now I do arts and crafts with my daughter and we go to the beach instead of cycling or running, though it would be nice to be able to teach her to ride or take her for a hike or run. I used to be incredibly independent and strong and now sometimes I need to rely on others.

The pandemic has knocked appointments back – I am still waiting for an MRI that was supposed to happen last September. And the vaccine led to a pseudo-relapse. I try to take a positive approach. Sometimes at work if I am slow on the stairs someone might joke "Are you drunk or something?" and I try to be open and say "Well, I have MS".

My advice to people diagnosed with MS? MS doesn't define your life and who you are.

*"Now I'm in a good place. I'm back at work. I look after myself and manage my MS with meditation, Pilates and using skills I have learned in my role as an occupational therapist."*



MS doesn't define  
your life and  
who you are.

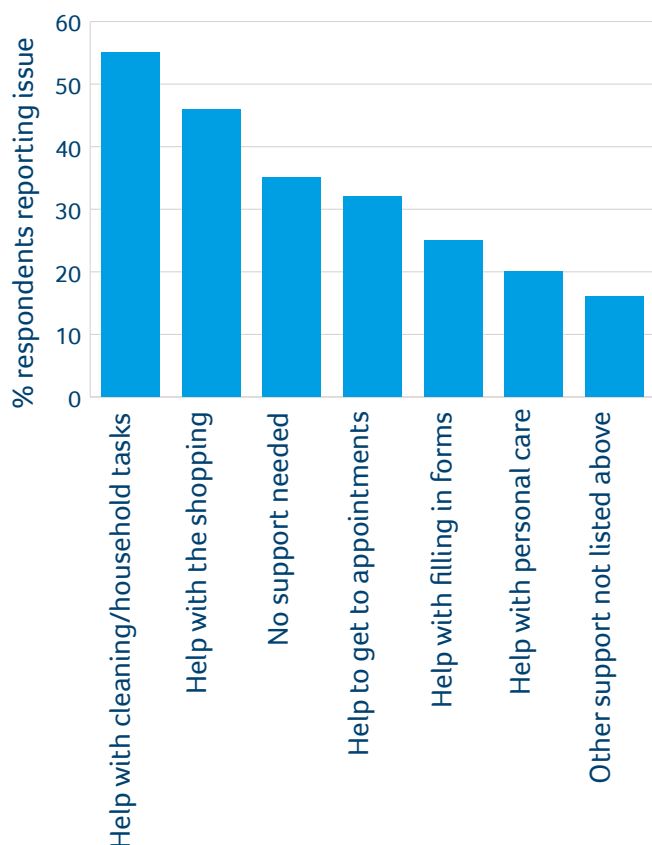
## Support

The impact of MS on people can make day to day life more challenging.

For some people these challenges are particularly difficult. **5%** of people with MS said they were unable to cope. A further **65%** said, although they usually felt able to cope, there were times they found it difficult.

**8%** of people were reliant on a carer to help them and a further **7%** did not have a carer but needed one. Those people with relapsing remitting MS (RRMS) were less likely to rely on, or need, a carer than those people with progressive MS. These people were also more likely to say they could cope with their MS.

Areas where respondents needed support



*"I won't be able to pay for the care that I will need, so my husband will have to provide it and our relationship will change."*

Although many people did not have a carer or did not need one, the majority of people with MS require support with some part of their life. The most common things people needed help with were cleaning and household tasks, and shopping. These are tasks deeply embedded in being able to negotiate the world, access benefits and support, or just survive in the modern world.

Also, even with RRMS, people report needing help sometimes. Ad hoc care can be trickier to engage, (including informal or family care) compared with a stable condition where personal care needs are well understood. **A fifth** also needed help with personal care and dressing, which suggests more people may need help from a carer than indicated when asked.

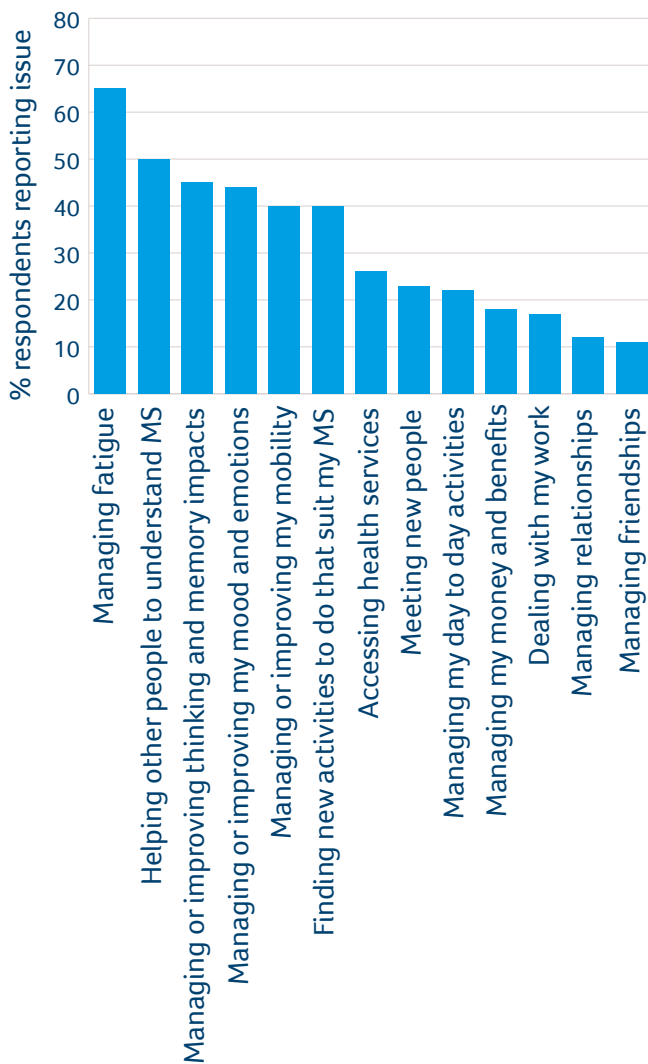
When asked if there was anything they would like more support to manage, there were many people who needed more support with a whole range of different parts of their life. This suggests that many people with MS are not receiving the help that they need, and therefore being excluded from activities ranging from sport and hobbies to working life.

Nearly **two thirds** of respondents said they needed more support managing their fatigue. **45%** wanted support with managing their mood or emotions, and another **45%** with the memory and thinking impacts of their MS.

A **half** of respondents also wanted support to help other people understand MS. People with MS in our focus groups spoke to us about the misconceptions and misunderstanding surrounding the condition. They felt frustrated that people failed to grasp the variability of MS and that people were quick to make assumptions, or to offer unsolicited advice. So many of the symptoms of MS can be invisible, which can make the impact hard to communicate to others, even family members or work colleagues.



Where respondents would like more support



People with MS have taken steps to manage the impact of their MS and to support themselves. Many had made efforts to reduce their stress levels or manage their time more carefully. For some people, this could mean reducing their hours at work, or turning down career or social opportunities. Nearly a **half** use aids and adaptations to help with mobility and household tasks, the costs of which can represent a significant impact on household finances.

**50%** of respondents also wanted support to help other people understand MS.

## Making plans

The unpredictability surrounding future relapses and the progression of the disease can leave people with MS living with uncertainty. When asked if their MS had meant they'd needed to change their plans for the future, **55%** of respondents responded yes.

We asked those who responded yes to explain what had changed. Most commonly people wrote about changing their career, study or work plan, with several mentioning the need to give up work or retire early.

People also wrote about limiting or curtailing their travel and holiday plans for the future. People did not feel confident to travel, both in the UK and abroad. Many also mentioned that their plans to enjoy certain pastimes in their retirement, such as walking or visiting family, had now been abandoned.

Many people were giving consideration to where they would live in the future; some choosing to no longer move abroad, some moving closer to family, or some finding a suitable house that would accommodate their disabilities.

Several people also said that they had reconsidered their plans for a family, deciding not to have children in the future, or limiting their family to the children they already had. These people were worried about the impact of pregnancy and childbirth on their MS, and of the impact of their condition on their children and the ability to care for them. Several grandparents said they would no longer be able to help care for their grandchildren as they had planned.

A few people mentioned that they were no longer making plans, or felt that they did not have a future. While others were taking one day at a time and not thinking too far ahead, some people said they were future proofing their lives by moving to single-level or shared accommodation. A couple of these people mentioned making plans to end their lives if they were no longer able to cope.

*"Everything feels uncertain and insecure from finances to living arrangements."*

## Concerns for the future

Finally, we asked respondents to think about their MS and its impact on their life, and tell us what concerned them most about the future. This was a free text response so people could write what they wanted.

Most commonly people were concerned about their mobility deteriorating and their ability to walk. Similarly they were concerned about future relapses and their condition progressing further.

Many were also concerned about their ability to live independently in the future and becoming a burden or having to rely on others. Several were fearful that they would not have the support they needed in the future, including medical and social care support, particularly if something were to happen to their current carer.

Lots of people talked about the uncertainty of the future, whether they would be able to cope and whether they would be left living in loneliness.

Many people were worried about the impact of their condition worsening on their family. In particular they were concerned about their children and their partner. Many people were worried about their finances and whether they would be able to keep doing the activities they enjoyed.

**19** people said they were worried about everything.

*"I am scared of dying alone. I am single with no children and feel that this will be my life now, because who wants to put up with my struggles."*



# What needs to change?

Our survey of people with MS has revealed the wide-ranging impacts MS can have on people's lives.

These impacts can often be invisible, and while they are preventing people from working, joining in with friends and family, and enjoying pastimes; people with MS are often not receiving the support they need.

Many people feel insecure about their future and are worried about whether the support and help they need will be there for them in the future. Our report demonstrates the resilience and pragmatism that people with MS need in order to face uncertainty. Not everyone has the social and material reserves to support themselves through choices they never expected to have to make.

The MS Trust believes that there is more that can, and should be, done for people with MS. We will listen to what people with MS have told us and encourage other agencies to look at where they can make changes to their services to benefit people living with MS.

As a starting point, we call for better recognition of the individual needs of people with MS. Both the symptoms and the impact of those symptoms on a person with MS are highly personal. Two different people with MS will need different kinds of support, and it should be easier for people to identify and access the support they need for themselves. Complex, variable and invisible disabilities are often preventing people with MS from living life to the full, when the right support at the right time would have a dramatic impact on quality of life.

## Everyone can play their part

The MS Trust recognises that a holistic and personal approach to MS care, delivered by MS specialist health professionals, makes an enormous contribution to the long-term outcomes for people living with MS. A well supported multidisciplinary healthcare team, considering the individual priorities for each person with MS, can achieve excellent care. However, the MS Trust is also aware that unsustainable caseloads and overstretched MS services are common across the UK, particularly after two years of a pandemic.

We are working to enhance MS services in the areas of greatest unmet need, by training and supporting MS specialist nurses into the NHS. We will continue to make the case for targeted resources for people living with complex and advanced MS, and for MS services to have administrative support so that clinicians can give more people with MS the care they deserve.

However, people living with MS have clearly told us that healthcare is only part of the picture. Everyday life with MS can be difficult to negotiate, and people face obstacles, misunderstandings and additional costs that people without MS do not. Those costs can be financial, impacting both the ability of people with MS to stay in work, and the everyday costs of aids and adaptations. Employers should have advice on how to best support employees with MS, and consider the impact of their working practices to ensure that the workplace is truly accessible.

The hidden costs of MS can also be less tangible, in terms of the costs to relationships of all kinds, in opportunity costs and in the costs to personal goals. People with MS may face partnerships breaking down, they may struggle to parent in the way they hoped, have to step away from responsibilities they valued, or have to give up activities that they loved.

Unsurprisingly, these hidden costs come with a stark impact on mental health among people with MS. People with MS have told us about the effort required to access health care, benefits and support, and the sheer exhaustion derived from that constant battling. People with MS are reporting high levels of stress and anxiety, and the percentage of people with MS who have reported suicidal feelings is of particular concern.

People with MS need access to a whole range of different types of support. This should include emotional support from professionals with an understanding of MS, to protect the mental health of people living with MS. The MS Trust also recognise that people living with MS need reliable information about their condition and their options to treat and manage it.

The MS Trust is proud to be here to provide information and support to people living with MS. We aim to meet the information needs of the whole MS community, and we encourage people with MS to engage with our Information Service to find personalised support to help them navigate life with MS and get the best out of their relationships with their health professionals.



Our helpline, website, publications and social media channels reach thousands of people every year. In response to what we have heard from people with MS through this research, we can now plan to strengthen our resources around areas that are priorities for people with MS. We will be expanding our information delivery around areas such as work, finances and securing the right support to live well with MS, as well as continuing to highlight the impact of living with MS to the wider world, particularly invisible symptoms such as fatigue, pain and cognitive problems.

The MS Trust is committed to empowering people who live with MS to speak up and be heard. If you have a story to tell or would like to find out more about how you can get involved with our work visit [mstrust.org.uk/get-involved](https://mstrust.org.uk/get-involved)

# Appendix A

## List of survey questions

1. What is your age?
2. What is your gender?
3. What is your sexual orientation?
4. In what year were you diagnosed?
5. What is your ethnicity?
6. Is English your main language?
7. What is the highest level of education you have completed?
8. Do you have caring responsibilities? (For example, do you regularly provide care for children or an elderly relative?)
9. What is your religion or belief?
10. Do you have any other health conditions?
11. What is your relationship status?
12. In what country do you live?
13. What type of MS do you have?
14. For how long did you have MS symptoms before you were diagnosed?
15. Has your MS altered your life?
16. How has MS affected the following aspects of your life?
17. Have you experienced any of the following physical MS symptoms?
18. Have you experienced any of the following mental health or emotional effects as a result of your MS?
19. Have you experienced any of the following cognitive effects as a result of your MS?
20. Have you experienced any of the following impacts on your work or finances and money as a result of your MS? (Tick all that apply)
21. Have you experienced any of the following impacts on your relationships as a result of your MS? (Tick all that apply)
22. Have you experienced any of the following impacts on your hobbies, pastimes or social life as a result of your MS? (Tick all that apply)
23. Overall, do you feel able to cope with your MS?
24. Do you currently rely on a carer (paid or unpaid) to manage the impact of MS on your life?
25. Do you currently require support with any of the following activities? (Tick all that apply)
26. Is there anything you would like more support with? (Tick all that apply)
27. Have you made lifestyle changes with your MS in mind? (Tick all that apply)
28. Have you changed any of your plans for the future as a result of your MS?
29. Thinking about your MS and its impact on your life, what concerns you most about the future?
30. Are you willing to share your story? If so, we may contact you.

# Appendix B

## Analysis of open questions

Q28. Have you changed any of your plans for the future as a result of your MS?

| Theme                                                         | Count |
|---------------------------------------------------------------|-------|
| Given up job/<br>changed career plans                         | 125   |
| Limited travel plans/<br>no longer take holidays              | 88    |
| Reconsidering accommodation/<br>where I live                  | 79    |
| Reconsidering family plans<br>(eg children and grandchildren) | 56    |
| No longer visit places/do certain<br>activities               | 39    |
| Planning less/no plans/<br>take one day at a time             | 33    |
| Moved plans forward                                           | 15    |
| Future proofing<br>(including end of life)                    | 15    |
| No longer visit people/<br>impacted relationships             | 14    |
| Study plans changed                                           | 13    |
| Need more support from others                                 | 12    |
| Can't visualise the future                                    | 1     |

Q29. Thinking about your MS and its impact on your life, what concerns you most about the future?

| Theme                                      | Count |
|--------------------------------------------|-------|
| Walking/mobility                           | 155   |
| Losing independence/<br>being a burden     | 154   |
| Relapses/progression                       | 126   |
| Relationships/children                     | 125   |
| Uncertainty                                | 86    |
| Being able to keep doing what<br>I'm doing | 69    |
| Finances                                   | 66    |
| Will I get support/treatment               | 59    |
| Coping                                     | 32    |
| Loneliness                                 | 27    |
| Brain function                             | 25    |
| Everything/have a future                   | 19    |
| Blindness/sight                            | 17    |
| Mental health                              | 12    |
| Pain management                            | 7     |
| No holidays                                | 3     |
| Quality of life                            | 3     |
| Not working                                | 2     |

## Acknowledgements

We would like to thank all those who have given their time and shared their experiences for this report. Without their input, it would not have been possible.

In particular, we would like to thank all those people living with MS who took the time to complete our online survey and to those who also joined us for our online focus group discussions. Your honesty and openness was much appreciated.

We are also very grateful to Rich, Johanna, Jayne and Sandra for allowing us to share their stories in this report, and helping us to shine a light on the lives of people with MS.

Finally, we would like to thank Jennifer and Laura from Brighter Together Consulting for helping us to conduct this research and draft this report, Brian from Making Sense for the design of this report, and to all our colleagues at the MS Trust who contributed to this work.

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