

# MS

Multiple Sclerosis Society



# Fighting back

**Ordinary  
people  
batting the  
everyday  
effects of MS**





“When I was diagnosed with MS I thought my life was over. The person I had been was gone, and I no longer felt I had a role in society. I sought help, but it took two or three years before I began to rebuild my life and confidence. I started volunteering at my local branch of the MS Society, where I made new friends – they’re like an extended family now. I feel like I’m a different person to who I was pre-MS... but I’ve found that’s not necessarily a bad thing.”

**Su Rollinson, age 64, from Montgomeryshire was diagnosed with MS in 2000.**

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## Foreword



Multiple sclerosis is destructive and attacks at random, usually first affecting people in their 20s or 30s. It affects the nervous system, leading to a multitude of symptoms which differ for every person, including problems

with balance, vision, fatigue, bladder, bowel, speech, memory and muscle spasms.

Around 100,000 people in the UK are living with MS and approximately twice as many women as men have the condition.

Yet despite this prevalence, MS is poorly understood – even by those who know people with MS, who often struggle to comprehend the range and nature of its symptoms, and the way the condition fluctuates for the majority who have the ‘relapsing remitting’ form.

Because it is poorly understood, living with MS can turn a simple shopping trip or social event into an ordeal where strange looks and hurtful remarks can all be part of everyday life.

Yet people with MS have the same aspirations as anyone else. Most want loving relationships, an active social life and a successful career. Of course MS presents many challenges, but society can place further unnecessary barriers

in the way of people with MS, making it harder than it needs to be to live a full life.

We surveyed over 1,400 people with MS, and over 2,000 without MS, to inform this report. It does not attempt to provide a comprehensive audit, but does bring the everyday issues people with MS face, and perceptions around them, into the spotlight.

It is clear that many people with MS feel that stigma has a significant impact on their lives: work, friendships, personal relationships, going out and even just conversations with strangers. Sadly, there is also evidence that people with MS may be right to sense such prejudices, with many people believing people with disabilities should accept they cannot have the same opportunities in life.

The MS Society wants to challenge these perceptions and support thousands to fight back against MS and live full, active lives. With greater understanding and awareness, we can all make the fight that little bit easier.

**Together we can beat MS. Join the Fightback at [www.msfightback.org.uk](http://www.msfightback.org.uk).**

**Simon Gillespie**  
Chief Executive of the  
MS Society



“Many people are diagnosed with MS in their twenties and thirties - a time when people are settling down in terms of relationships and employment; most people are making commitments and plans for the future, mortgages and children and it is a huge shock to receive a diagnosis that shakes these plans for the individual, but also for their family.”

Jo Johnson, Consultant Neuropsychologist

# Emotional impact

When MS is diagnosed, individuals and families are often hit by a rollercoaster of emotions. For some it can come as a relief – a diagnosis that explains and gives a label to an array of mysterious symptoms, and opens the door to treatments to manage them. For others, it can be the start of a confusing, upsetting and anxious journey, filled with uncertainty and fear.

## Our survey showed:

■ **It's hard to talk about MS.** Almost one in three (30%) people with MS often avoid telling people that they have MS and the same proportion worry about the reactions of others when they tell people they have MS. Some (36%) don't like to talk about it as they don't want to be treated differently.

■ **MS can impact on mental wellbeing.** As many as three-quarters (75%) of those surveyed have felt more anxious and uncertain about the future since their diagnosis, while 44% say they have felt depressed. The majority (59%) say MS has negatively affected their self-confidence and the same number report a detrimental impact on their general happiness and wellbeing.

■ **MS can bring families together, but is equally capable of tearing relationships apart.** For many (41%), having MS has strengthened the bond with their immediate family, but the harsh reality is that the same proportion report a negative impact on their relationship with their partner or potential partners. Half of those in relationships (50%) find it hard to be intimate with their partner, while even more (53%) say romance is harder to achieve. As many as 40% say their partner has become their carer rather than their lover, while 37% say MS has put a significant strain on their relationship. One in 10 of all respondents even admitted they had separated from a partner as a result of having MS, while more than half (54%) of those not in relationships find it difficult to meet new potential partners since being diagnosed.

‘Having MS and being a father is challenging at times, but I won't let it be the reason I can't be there for the kids’

## How people with MS can fight back

Download ‘MS Essentials’ on ‘Mood, depression and emotions’ and ‘Sex, intimacy and relationships’ from our website.

Contact our Helpline on 0808 800 8000 or [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk) for information and emotional support.

‘Our Dad makes the best boats’ and ‘Our Mum makes the best cakes’ are two publications by Jo Johnson, available on our website, that can help parents explain MS to their young children.

Speak to a support volunteer at a local MS Society branch, who can offer a listening ear and information about MS and relevant local services.



**Ruth Curtis, age 48, is currently single and lives in Oxford**

“I'm very particular about how to tell potential partners I have MS; I prefer face-to-face and let them ask as many questions as they like. For me, having this conversation earlier rather than later is always best in case they can't handle it. I actually met my last boyfriend at a MS Society fundraising event, so he knew about my MS even before we met. It was probably a blessing in disguise as I didn't have to think about what to say, and when to say it, I could just be myself. I definitely have more concerns about dating since my diagnosis but the right man for me is out there somewhere - we just have to find each other.”



**Reggie Greaves, age 37, lives in Middlesex. He and his wife have six children**

“Having MS and being a father is challenging at times, but I won't allow it to be the reason I can't be there for the kids. I may have to do things differently, but I'm still their Dad. We spend time together - going to the park, the fair, swimming, training together and they come to MS events with me too. The way they see it is: Dad has MS, and that's that.”



"My patients report not being able to plan social events or accept invitations as they are unsure whether they will be 'well enough' to attend. They worry about being seen as drunk, due to balance problems, or what others will think if they need to leave a party early due to fatigue."

Dr Anita Rose,  
Consultant  
Neuropsychologist.

# Social impact

We all want an enjoyable social life – whether that's going out and enjoying a drink or dinner with friends, going shopping or taking part in sport, hobbies or interests. For people with MS, these aspirations are no different, but the condition presents unique challenges. For people with 'invisible' symptoms, which may fluctuate wildly, it can be hard to explain their MS. For those with mobility problems, there are practical considerations to getting out and about, requiring almost military planning. For all groups, there is often anxiety and uncertainty about interactions with both friends and strangers.

## Our survey showed:

■ **Alarming stigmas and attitudes still exist about people with disabilities.** One in five (21%) British adults surveyed think disabled people need to accept they can't have the same opportunities in life, with men (28%) more likely than women (15%) to hold this view. More than one in four (26%) Britons think bars and nightclubs are not places for people with wheelchairs, a belief more commonly found in men (31%) and 18-24 year olds (32%), compared to women (21%) and 45-54 year olds (22%).

■ **Such attitudes may be fuelled by poor knowledge and understanding.** One in four (24%) Britons believe disabled people often exaggerate the extent of their physical limitations, with men (28%) again more likely to hold this view than women (20%). More than three quarters of people with MS (76%) can think of at least one occasion when someone has questioned the fact they have MS because they 'looked well', with over half (53%) able to recall at least one occasion when their symptoms have been mistaken for drunkenness.

■ **Understanding of MS is particularly poor.** A large majority (71%) of British adults admit that they don't feel they know enough about MS. Most people don't realise MS attacks in early adulthood, with almost 4 in 5 people (79%) either estimating that MS is most commonly diagnosed among people aged over 35 or answering 'don't know'. Just 15% answered correctly that MS is most commonly diagnosed aged 25-34, with younger people aged 18-24 particularly unaware of this fact (9%). Almost one in three (31%) people couldn't name any of the common symptoms of MS, rising to almost half (47%) of people aged 18-24 and a similar proportion (45%) of those aged 25-34, the most common age to be diagnosed.

■ **Even among people who know someone with MS, understanding is still poor.** Significant numbers of people who know someone with MS are under-equipped to understand the condition, with just one in five (20%) feeling they know enough about it. More than one in ten (11%) of those who know someone with MS were even unable to name a symptom, with as many as 40% of this group believing the condition to be terminal.

■ **MS, and misconceptions about it, can make it harder to have an active social life – but not impossible.** Over half (56%) of people with MS find it harder to socialise since their diagnosis, with around two-thirds (67%) saying their MS has hampered their ability to enjoy everyday social activities like drinking, eating out or shopping. As many as 42% feel that, as a result of their MS, people often don't consider them an equal, while just under one in three (30%) say they have been visibly ignored because of their MS. As many as 41% say they have lost touch with friends due to their MS, but almost half (49%) say the condition has led them to take up new hobbies or interests – demonstrating their determination not to let MS rule their lives.

## How people with MS can fight back

Contact a local MS Society branch. There are around 300 across the UK - many provide social groups to support younger people living with the condition. Check out the 'near me' page on our website for more.

Our 'Exercising with MS' fitness DVD, fronted by Sally Gunnell, offers a range of exercises for people with MS. View it on our YouTube channel or order a copy from our info team.

Download our 'What is MS?' booklet, available from the information team or website, which explains MS in an easily digestible format and is available in several alternative languages.

Organise a team fundraising event, like a Cake Break or a sponsored walk, to raise awareness of MS and money for the MS Society. Contact our fundraising team for tips and advice.



**Naomi O'Loughlin, age 33, lives in Limavady, Northern Ireland**

"I have always liked the idea of yoga but never thought I'd be able to manage it. After my diagnosis I was introduced to a specialist MS yoga class, and I love it. We do what we feel comfortable with, and it's helped to meet others with MS. My social life has changed since being diagnosed with MS, but not for the worse. I now just do things differently, like meeting friends for coffee in the morning, which is when I'm at my best, rather than a bar at night. Having support around you is so important when you live with a condition like MS."



**Cat Johnson, 25, a student from Edinburgh**

"Like most people my age, I want a social life. I want to get dressed up and go out for drinks with my friends and my MS hasn't stopped me from doing that, but I know what my limits are. I can't wear heels or dance all night, and getting drunk with MS isn't helpful, but my friends don't mind and have been really supportive. MS might restrict me, but I won't let it define me; life is too short."



“Many people with MS want to work, yet during periods of economic downturn and job losses people with long term or chronic health problems, such as MS, may feel especially vulnerable. Research from The Work Foundation shows that many employers lack knowledge about the condition and may not always understand that the needs of employees with MS can and should be accommodated at the workplace.”

**Stephen Bevan,**  
Director of the  
Centre for Workforce  
Effectiveness at The  
Work Foundation

## Work & career impact

For many adults diagnosed with MS, one of the biggest worries is the thought of having to prematurely give up work at some point. MS tends to attack at the point in your life when you may just be starting to build a career. For some, stopping work is unavoidable, but for many, MS should not stop them being successful and making a strong contribution in the workplace – as long as they get the right support from their employer and colleagues.

### Our survey showed:

■ **Most younger people with MS are in work, but there is a significant drop-off in employment rates after 50.** Of the people with MS we surveyed, 62% of those aged under 31, 54% of those aged 31-40 and 47% of those aged 41-50 were employed. There is then a significant drop-off in employment rates among people with MS, with 27% of the 51-60 age group and just 8% of the over 60s in work.

■ **MS does not have to impact someone’s ability to work.** Over a third (37%) of employed people with MS feel their MS does not impact on their work, but over half (51%) feel it makes it harder for them to find work. The attitudes of the public are revealing here, with just 59% disagreeing that people with MS cannot make valuable employees. That may help explain why 42% of people with MS admit to being concerned about telling their employer about their condition in the current economic climate.

■ **But MS does have a big impact on people’s careers.** Over two thirds (70%) of employed people with MS who specified an answer reported that their diagnosis has had a negative impact on their career. Thankfully, most (76%) say their employer supports them and accommodates their needs, but almost as many (74%) say their MS has forced them to re-assess their career ambitions, and 62% say their career progression has been hampered by having MS.

■ **The private sector may have a lot to learn from the public sector.** Only one in three (34%) of people who work in the private sector think their workplace welcomes people with disabilities, compared to over half (55%) of those in the public sector.

“I’ve never wanted to be treated differently because of my condition, but decided to tell my employer straight away - I’m pleased I did”

## How people with MS can fight back

Our website has information on working with MS, including employment rights, how to look for work and how to tell your employer.

Download ‘Work and MS’ from our website or the ‘Working yet worried’ toolkit – designed for people with MS to use with their health care professional.

For people with MS unable to work, download our ‘MS Essential’ on ‘Employment and Support Allowance’, available on our website, for advice on claiming the disability benefit.



**Gareth Binsale, 25,** teaching assistant from Marshfield, south Wales

“I’ve had MS for eight years. I’ve never wanted to be treated differently because of my condition, but decided to tell my employer straight away – I’m pleased I did, fortunately for me they’ve been incredibly supportive. It’s a worry when I’m off work with a relapse, but they understand and have support in place.”



**Mark Lewis, 47,** a lawyer living in London

“I was diagnosed with MS 22 years ago; I didn’t tell anyone for many years for fear of being labelled ‘disabled’. I can see why some people avoid telling their employer - I’ve been unsuccessful in job interviews after I’ve divulged my MS, and had clients express concern over my ability after my hand went numb... I just told them, ‘my hand doesn’t work but my mind does’. Everyone’s MS is different; I’ve had my share of set-backs, and I appreciate not everyone is as ‘lucky’ as me, but I’m determined to lead a successful career.”

# Conclusion

There can be no doubt that MS is a devastating condition, but for most it is a fork in the road rather than a dead end.

Our findings show that MS can place a heavy strain on some relationships, particularly with partners, while bringing others closer together. It can see some friendships and social activities fall by the wayside, while new ones emerge. And it can severely blunt career ambitions for many, while having a smaller impact for others.

In short, MS is unpredictable and, perhaps largely because of this, widely misunderstood. It is different for everyone, and everyone responds to it differently.

But what most with MS have in common is a desire to live as full and active a life as possible before the condition strips more and more choices away from them. And that's where we can all help.

With greater awareness of what people with MS – and other long-term debilitating conditions – have to cope with, there would be greater understanding and empathy. Stigmas and prejudices may be in the minority, but they still exist in large enough numbers to cause considerable distress and anxiety for people with MS. And even among the well-intentioned, simple misconceptions and poor awareness can place unnecessary additional obstacles in the way of someone with MS who is just trying to get the most out of life.

Part of the problem is that many people without disabilities may struggle to conceive of a life with a disability. To some it may seem inferior. But we should challenge such perceptions: people with MS have every right to the same opportunities in life as anyone else. There is no such thing as a 'normal' life – just different lives.

Indeed, our report includes stories of many individuals who are just getting on with life as they know it, without allowing MS to define them. Cat is a 20-something who wants to have fun with her friends. Reggie is a dad and husband in his late 30s, who happens to have MS. Mark is a successful lawyer in his late 40s whose career has hit incredible highs in the last couple of years.

These are just a few ordinary people fighting back against the everyday effects of MS with determination and resolve.

**You can support them, by joining the Fightback and making a donation to the MS Society. Visit [www.msfightback.org.uk](http://www.msfightback.org.uk). All donations help beat MS.**

## How your donations will help people with MS fight back

Our research into a cure could see major breakthroughs within the next 20 years. Fightback is our campaign that will raise money to make this possible. Even now, the support we receive is enabling our scientists to turn their breakthroughs on myelin repair into a possible treatment.

Donations to the MS Society mean we can also continue to give help and information day-to-day to all those affected by MS – people with MS and their carers, families and close friends.

The end is nearly in sight – we just need to keep up the fight.

## Methodology

ComRes interviewed 2,056 GB adults online, between 23 and 25 March 2012.

The questionnaires were weighted to be demographically representative of all GB adults. ComRes interviewed 1,419 UK adults who have MS online, between 28 March and 5 April 2012.



Thank you to everyone who agreed to share their stories for this research. All quotes, stories and photographs are real.



Multiple Sclerosis Society

**MS Society National Centre**

372 Edgware Road  
London  
NW2 6ND  
020 8438 0700

**MS Society Scotland**

Ratho Park  
88 Glasgow Road  
Ratho Station  
Newbridge  
EH28 8PP  
0131 335 4050

**MS Society Northern Ireland**

34 Annadale Avenue  
Belfast  
BT7 3JJ  
028 9080 2802

**MS Society Cymru**

Temple Court  
Cathedral Road  
Cardiff  
CF11 9HA  
029 2078 6676

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

**Helpline 0808 800 8000**

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