Multiple Sclerosis Society

MS in the workplace: an employer's guide

The Multiple Sclerosis Society

More than 100,000 people live with multiple sclerosis (MS) in the UK. Every one of them shares the uncertainty of life with MS.

We're funding research and fighting for better treatment and care to help people with MS take control of their lives.

With your support, we will **beat MS**.

The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call 0800 100 133 or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

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Introduction

If you're reading this, chances are you have an employee who has told you they have multiple sclerosis (MS). Or perhaps they have had unexplained symptoms and MS has been raised as a possible cause for them.

As their employer, you may have lots of questions, such as: What is MS? How will it affect my employee? What can I do to support them? What impact will their MS have on the company and the rest of the team?

Not everyone with MS will need extra support in the workplace, and many of those who do will only require small changes – known as reasonable adjustments – to continue working. It's important to remember that there's no 'one size fits all' approach to managing MS in the workplace: the support your employee will need – if any – will be individual to them.

Who is an employer?
All workplaces are different, so the person within the company who is responsible for providing this support will vary. In a small company it might be the company director, and in a larger company it might be the person's line manager or the HR team.

To avoid confusion, throughout this booklet we use the term 'the employer' to refer to the person within the company who has this responsibility, and the person with MS is referred to as 'your employee'.

As well as this guide, there are further resources available on the MS Society website.

There are sample forms and examples of best practice that you and your employee can use to keep track of how you manage their MS at work. These are indicated in the text by a . You can find the toolkit at **www.mssociety.org.uk/work-toolkit**

Remember

MS affects everyone differently
There are different types of MS, and no two people are affected in the same way. This makes it impossible to predict the symptoms someone will have, or the order in which they may have them. While some symptoms, such as fatigue, balance and sensory problems, are more common than others, most people will only have a few – and it's unlikely that anyone will have all of them.

Don't be afraid to ask
Because MS is such an individual condition, it's difficult to know exactly how it will affect your employee. Some symptoms are invisible, so you may not be able to see how it is affecting them.

It's important to try to establish an open dialogue with your employee, so you can find out what support they need, and ask them any questions you may have. As the effects of MS often change over time, it's good to have regular chats about how things are going and whether extra or different support is required.

There's more on talking to your employee on page 9.

The importance of employee support
People with MS often cite lack of support from their employer as a reason for giving up work. But those who have supportive employers, and for whom reasonable adjustments are made, tend to stay in work for many years after being diagnosed. Often, it's just a matter of working out how to use their skills and experience in a slightly different way.

There's more on supporting your employee on page 9.

Supporting your employee with MS isn't expensive

While your employee may need some changes to their workspace or to their daily routine, many such changes cost little or nothing. They can be as simple as moving their workstation away from a source of heat, or allowing them to start and finish half an hour later to avoid commuting during the rush hour.

These changes are known as 'reasonable adjustments' and your employee is legally entitled to ask for them. There's more on reasonable adjustments on page 12.

If your employee needs specialist equipment or adaptations to existing equipment, you may be able to get help to cover the costs from Access to Work (see page 14).

What is MS?

Key points

- MS is different for everyone
- Some MS symptoms are obvious to others, and some are invisible
- There's no cure, but there are ways to manage it

Multiple sclerosis (MS) is a condition that affects the brain and spinal cord, also known as the central nervous system.

Inside the brain and spinal cord, messages controlling your body's actions travel along nerve fibres. These fibres are coated with a fatty substance called myelin, a protective layer that helps messages travel quickly and smoothly.

In MS, the body's immune system turns against itself and starts attacking this myelin coating.

When the myelin is damaged by an attack from the immune system, this disrupts the messages in the brain and spinal cord. Messages can slow down, become distorted, jump from one nerve fibre to another or not get through at all. It's this damage that causes the symptoms of MS.

MS is a very individual condition: no two people are affected in the same way. The symptoms someone has will depend on which parts of their brain and spinal cord are affected. There are many different symptoms of MS,

"...The hardest part is you spend a lot of time disguising it, and people aren't aware as many symptoms are invisible. I dislike the comment, 'But you look so fantastic.' All I can I think is, 'You don't know my legs feel like 10 ton weights, and the effort I have to make my legs move, left, right, left, right is exhausting." **Jon**

and it's unlikely that anyone will have all of them.

Most people are diagnosed with the relapsing remitting form of MS. This means they will have an attack of symptoms – known as a relapse – which can last for days, weeks or possibly even months. This will be followed by a period of remission, when symptoms improve or go away completely. These periods of remission can last for many months or years.

After a number of years, many people with relapsing remitting MS go on to develop secondary progressive MS. This means that their symptoms get steadily worse over time, without any periods of remission.

A smaller number of people are diagnosed with primary progressive MS. This means they have a steady build-up of symptoms from the start, without any distinct periods of relapse and remission.

Regardless of the type of MS someone has, it is impossible to predict how they will be affected.

While there is currently no cure for MS, there are ways to manage it. These include drugs to reduce the number of relapses someone has (if they have relapsing remitting MS), and symptom management treatments.

You can read more about MS by visiting our website, or by reading one of our information resources, such as our short introductory booklet called *What is MS?*

MS and the law

Key points

- As the employer of someone with MS, it's your responsibility to ensure they're treated fairly in the workplace
- Any information your employee gives you about their MS is confidential

Although many people with MS don't see themselves as disabled, MS is defined as a disability under equality law (the Equality Act, or the Disability Discrimination Act [DDA] in Northern Ireland).

This means it is unlawful to discriminate against someone because they have MS. This applies from the moment they are diagnosed, no matter how their MS affects them.

As the employer of someone with MS, you have certain duties:

- To put in place any reasonable adjustments your employee needs in order to do their job. There's more on reasonable adjustments on page 12.
- Not to treat them unfairly. This means you can't harass them or discriminate against them, or allow them to be harassed or discriminated against by someone else at work. For example, if you or someone else made jokes about their symptoms, this would be harassment. And if you decided not to promote them because of their MS, even though they were capable of doing the job, this would be discrimination.
- A legal duty of care to protect your employees under the Health and Safety at Work Act.

This is just a brief overview of your duties as the employer of someone with MS. For more information, you can contact:

- The Equality and Human Rights Commission, if you are in England, Scotland or Wales
- The Equality Commission for Northern Ireland, if you are in Northern Ireland

Confidentiality

You should take care to ensure that any information your employee shares with you about their MS remains confidential. For example:

- Do not discuss their MS with anyone else, unless they have said you can.
- Do not discuss their MS with them in situations where other people may be able to find out – for example, in an email that could be passed on to someone else, or in an open-plan office.
- If your employee has an occupational health assessment, clarify with them exactly who can see the report.
- If you have any meeting notes discussing your employee's MS, or any other documents that give any details of their condition, make sure they are kept secure.

If you do have to share information about the workforce as a whole, for example, for health and safety purposes or when tendering for a contract, you should do this in a way that maintains the privacy of your employee.

Most people with MS don't have to tell their employer about their diagnosis. As a result, the decision to reveal their MS is often a difficult one to make. Many people are afraid they will be seen as less capable, or that it might affect their career progression – or even that they could lose their job as a result.

The chances are that it's taken your employee a lot of courage to tell you about their MS. It's important to recognise this, and to provide them with the reassurance and the support they need.

Supporting your employee

Key points

- The best way to find out what support your employee needs is by talking to them
- Many reasonable adjustments cost little or nothing to put in place
- Access to Work funding can pay for any adjustments that cost more than is reasonable for your company to pay
- Supporting your employee during a relapse is an important part of their ongoing management

For many people with MS, having a supportive employer is what enables them to manage their condition at work, and to remain in employment.

This section looks at what you, as an employer, can do, as well as what the law says you have to do.

Talk to your employee

There's no 'one size fits all' approach when it comes to MS, so the support your employee will need depends on how their MS affects them, the job they do, and their own abilities and coping strategies.

Establishing an ongoing dialogue is the best way for both you and your employee to express your concerns, determine what they need from you and how you can help.

"I've had people in HR telling me about MS, but they don't ask me about **my** MS. And I've had some managers who've been really good, they've said, 'Tell me about how it affects you,' and other people who don't ask anything." **Jennifer**

How you choose to approach this conversation will depend on you, your employee and the relationship you have with them. When you do so, it's worth bearing the following in mind:

- Don't make assumptions about what your employee can and can't do. They might be able to continue doing their job as usual, without any additional support.
- If you know someone else who has MS, try to avoid making any comparisons between your employee and the other person. Everyone's MS is different.
- While your instinct might be to show sympathy, an emotional response isn't helpful. It's better to focus instead on the support you can offer to your employee.
- Don't pressure your employee into making decisions, or

"There's more to her than her MS",

Michelle talks about managing an employee with MS.

I've only ever knowingly been the boss of one person with MS, who I've now been managing for five years.

I try to treat her the same as everyone else and, for me, that means treating her as an individual. When I ask her to do a task I'll discuss with her if there's anything she can't do or anything she needs help with.

Other members of my team have other issues and I take them into account too. People work far better for you when you treat them as individuals.

"Over time, as her MS has progressed, her needs have changed. She now has special equipment, like a 'joystick' mouse – I'm not sure what the technical term is – and a specially designed chair.

She walks with a stick so we've made sure her desk is near to the toilets. In addition, she works short shifts and has split breaks,

changes to any aspect of their job, particularly if they are newly diagnosed or recovering from a relapse. Give them time to process their situation and think through their options.

- While you may have feelings of resentment – for example, if you feel your employee should have told you about their MS sooner – it's important not to share these with your employee. You might find it helpful to discuss your feelings with a line manager, although you should ensure you respect your employee's confidence.
- Talking to your employee needs to be more than a one-off conversation. Try to foster a relationship in which they feel they can trust you, and you can both talk about any of your concerns. For example, you could arrange a quarterly meeting – separate from their performance review – to talk about how their MS is affecting them and whether any reasonable adjustments you've agreed on are working for them.

Your company may already have policies in place that say how you should record any discussions you have with your employee about their MS. If not, you may want to use the forms included in the employment toolkit.

and she also has a rest day every Wednesday. This all helps her to manage her fatigue.

"There's a lot more to her than her MS. She doesn't let it get in the way or hold her back and I don't believe anyone thinks of her or treats her differently because of it.

The team just accommodates it – picking up faxes for her, for example, because the machine is at the other end of the office.

Interestingly, she almost never takes a day off sick. She enjoys working here and it shows.

Reasonable adjustments

A reasonable adjustment is a change, perhaps to the job or the working environment, that enables your employee to continue to do their job. Your employee's right to ask for reasonable adjustments is a key part of the Equality Act, or DDA in Northern Ireland.

What is considered 'reasonable' will depend on the company and the job your employee does. Many reasonable adjustments cost little or nothing to put in place. Examples of reasonable adjustments that people with MS have asked for include:

- a chair or stool to sit on
- flexible or reduced working hours
- working from home
- moving their work station away from a source of heat, or closer to a toilet
- time off for medical appointments
- a car parking space near the entrance to work
- voice recognition software, or an adapted keyboard or mouse
- changes to the workplace layout to make it more accessible
- more breaks
- somewhere to rest for short periods during the working day

An occupational health assessment (see 'Support for you', page 18) can identify any reasonable adjustments that would help your employee.

The cost of an adjustment can be a factor in deciding whether it is reasonable or not. If your employee has asked for a piece of specialist equipment, or adaptations to existing equipment, that goes beyond what would be

"My workplace has been very supportive since my diagnosis, making accommodations where needed (car parking space near entrance, fan to cool me, work from home agreed if required)." **Emma**

considered reasonable for your company, you may be able to get funding for it through Access to Work.

Whatever reasonable adjustments you agree with your employee, you should review them on a regular basis – perhaps quarterly – to make sure they are working for both you and your employee. Because MS is a progressive condition, your employee may need further reasonable adjustments over time.

Your company may have policies in place to record any reasonable adjustments that you agree with your employee. If not, you may want to use the forms included in the employment toolkit.

Access to Work

Access to Work is a government-funded service that offers financial support to help someone who is disabled or has a long-term health condition to stay in work.

It can't be used to pay for any equipment they would normally need to use to do their job, or for any reasonable adjustments.

Time off work

Your company may already have policies in place regarding time off related to a disability or long-term health condition. If not, a reasonable adjustment you could put in place might be to allow your employee time off to attend appointments related to their MS.

You may also want to consider recording any time off related to their MS separately from ordinary sick leave, and discounting it from any absence management procedures. This is particularly important if your company places sanctions on people who take too much time off sick.

However, it can pay for extra equipment or support for your employee with MS, such as:

- adaptations to the equipment they use
- special equipment
- taxi fares to work if they can't use public transport or drive
- a support worker or job coach to help them in the workplace
- disability awareness training for their colleagues
- a communicator at a job interview

Access to Work can pay 100 per cent of the costs of any equipment or support if it is for a new employee who has been working for you for six weeks or less, regardless of the size of your company. It can also cover all of the costs for existing employees if your business has 49 or fewer employees. If your company is larger than this, you will need to pay a proportion of the costs for an existing employee.

Your employee will need to make the initial contact with Access to Work. After they do, an Access to Work adviser will talk to you and your employee about the kind of support they need. This can be particularly useful if your employee isn't sure about the kind of help they need, as it can help to identify the specific areas of work or tasks that could be adjusted.

The Department for Work and Pensions has a factsheet called 'Employers' guide to Access to Work', which you can download from the gov.uk website.

Managing relapses

Many people with MS will have distinct relapses, when they develop new symptoms or old symptoms come back. These can come on quite quickly, typically over a few days or possibly even a few hours. They can last for anything from a few days to many weeks.

If your employee is having a relapse, they may not be able to work. Supporting them through this time is a vital part of their ongoing management. In addition to any policies your

company may have for managing long-term sickness absence, you may want to consider the following:

- Keep in touch with your employee, without pressuring them into returning to work. Although you may want to know when they'll be back, the unpredictable nature of MS makes it impossible to know how long it will take them to recover.
- Encourage your employee not to make any major decisions about work – such as changing jobs, reducing their hours or stopping work completely – during a relapse. They may be feeling particularly vulnerable, and any decision they make at this time may not be the best one for them.
- When your employee is ready to return to work, meet with them beforehand to discuss any extra support they may need. This gives you time to put into place any reasonable adjustments they may ask for.
- Consider a phased return – building up their hours over a number of weeks until they're back to their normal hours. This also gives you and your employee time to learn whether any reasonable adjustments you've put in place are working for them.

Keeping in contact

Your company may already have policies in place for keeping in contact with an employee who is off sick. If not, this may be something you want to discuss with your employee, so that you both know what to do if they are off for a number of weeks. We've included some template forms you may want to use in the employment toolkit.

Supporting other members of staff

Key points

- Your employee's MS may have an impact on other members of the team
- If your employee doesn't want the rest of the team to know about their MS, you must respect that decision

Your employee's MS can also have an impact on other members of staff.

They may be worried about what's happening to the person with MS, particularly if the person hasn't told anyone else at work about their MS. They may also have to take on extra work if the person with MS is off sick for a number of weeks.

As the employer, it's your responsibility to ensure these issues are addressed sensitively, while also respecting your employee's confidentiality.

You may want to discuss with your employee whether they want to tell their colleagues about their MS. If the other members of staff know why they are being asked to do extra work, for example, they may be happier to do so.

Any decision about telling other members of staff has to come from the person with MS. If they decide to tell their

"The team needs some help as well, because resentment can build, particularly in the little things. In our team we have our niggles sometimes, for example it can be a bit frustrating that you have to go to a particular part of the building because it's accessible but we are a team and with time have got used to it." **Marianne**

colleagues, you can help them do so – perhaps by giving them time in a team meeting, or by telling the other members of staff on their behalf, if they ask you to.

However, if they decide not to tell their colleagues, you must respect that decision.

"I felt like a freak", Hilary talks about her manager's well meant, but over the top, reaction.

One morning, just a week into a new job, I woke up with no sensation from the waist down. I rang my new boss to explain what had happened and why I wouldn't be in that day. She was very shocked, sympathetic and understanding.

The next day I was no better but I knew I had no choice but to get myself into work or I'd probably lose my job. After all, I was still on probation. It was a two-site job, and this was to be my first day in the central London office. Somehow, I managed to stumble to my desk and sit down.

About 20 minutes later, my boss came into the office. She stood at the front of the room and asked everyone to be quiet. 'I'd like you all to meet Hilary,' she said. 'She's starting today. Please be nice to her. She's had some very bad news and she can't walk properly, so help her with anything she needs.' Then, to my mortification, she presented me with a huge bouquet of flowers.

Unsurprisingly, everyone stared at me. I felt like a freak, like I would never fit in. Nobody knew me or anything about me except that I was disabled and to be pitied; it certainly wasn't the way I wanted to present myself, or the way I would have wanted people to find out. I know my boss meant well, and I am grateful for her kindness, but her reaction was way over the top.

Support for you

There are a number of different sources of further support and information to help you in managing your employee with MS.

Occupational health

Occupational health services can help assess what reasonable adjustments your employee may need. If you don't have an occupational health department, you can contact Fit for Work in England, Scotland and Wales. In Northern Ireland, there isn't a specialist occupational health service, but you can contact the Disability Employment Service for advice.

Disability employment service (NI)

Part of NI Direct, the Disability Employment Service provides support to employers to recruit and retain disabled staff. It can also help people with disabilities find employment.

- 028 9025 2237
- des@delni.gov.uk
- www.delni.gov.uk

AbilityNet

AbilityNet's Workplace Assessment Service can help you to find the right IT equipment to meet the needs of your employee.

- 0800 269 545
- enquiries@abilitynet.org.uk
- www.abilitynet.org.uk

Business Disability Forum

A national membership organisation for businesses, helping them to recruit and retain disabled people.

- 020 7403 3020
- enquiries@businessdisabilityforum.org.uk
- www.businessdisabilityforum.org.uk

Equality and Human Rights Commission (EHRC)

The EHRC has detailed information about the Equality Act and how it applies to employment. If you have any questions, you can contact the Equality Advisory Support Service.

www.equalityhumanrights.com

Equality Commission for Northern Ireland

The Equality Commission can help you to meet your responsibilities as an employer under the DDA if you're in Northern Ireland.

028 9050 0600

information@equalityni.org

www.equalityni.org

ACAS (Advisory, Conciliation and Advisory Service)

ACAS can provide information and advice to help prevent or resolve workplace disputes in England, Wales and Scotland.

0300 123 1100

www.acas.org.uk

Labour Relations Agency

Public body with responsibility for improving employment relations in Northern Ireland.

028 9032 1442

info@lra.org.uk

www.lra.org.uk

"I strongly believe that the only way your employer can help you is if you are completely open and honest with them. At the end of the day, companies don't necessarily want to lose an employee and have to go through the whole recruitment process, find somebody new then train them up. It's not just you that's going to be benefitting, the company's going to be benefitting as well." **Trishna**

MS Help Hub

The MS Help Hub offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

Call 0808 800 8000
(weekdays 9am - 5pm)

Email
helphub@mssociety.org.uk

Resources

Our award winning information resources cover every aspect of living with MS.

020 8438 0999

shop@mssociety.org.uk

www.mssociety.org.uk/publications

Employment toolkit

A collection of forms, case studies and best practice examples.

www.mssociety.org.uk/work-toolkit

About this resource

This book is the result of MS Society-funded research 'Working yet worried 2: Working with employers to ensure employees needs are met', conducted by Research Occupational Therapist, Dr Joanna Sweetland and Honorary Consultant Neurologist, Diane Playford. You can read or download a copy of the report from our website.

With thanks to Angela Brosnan, Angela Matthews, Gideon Schulman, Jan Spencer, Tina Law, and all the people affected by MS who helped shape this book.

If you have any comments about this book, please send them to resources@mssociety.org.uk or you can complete our short online survey at www.surveymonkey.com/s/MSresources

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, or visit www.mssociety.org.uk/library

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

This resource is also available in large print.
Call 020 8438 0799 or email shop@mssociety.org.uk

Multiple Sclerosis Society

Contact us

MS National Centre

020 8438 0700

info@mssociety.org.uk

MS Help Hub

Freephone 0808 800 8000
(weekdays 9am - 5pm)

helphub@mssociety.org.uk

Online

www.mssociety.org.uk
www.facebook.com/MSSociety
twitter.com/mssocietyuk

MS Society Scotland

0131 335 4050

msscotland@mssociety.org.uk

MS Society Northern Ireland

028 9080 2802

nireception@mssociety.org.uk

MS Society Cymru

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