Making Sense of MS

Multiple Sclerosis Trust MS

Telling people at work that you have MS

- Starting the conversation
- Promoting understanding about MS
- Getting the right adjustments at work
- Staying healthy in employment

This document is designed to make it easier for you to disclose an MS diagnosis to colleagues and managers at work. It explains how MS can affect people in different ways and describes some common symptoms. There are spaces for you to indicate how your MS symptoms affect you, and suggestions for ways that people with MS have successfully managed these symptoms at work.

You are not obliged to disclose that you have MS, but it if you want to ask for reasonable adjustments to your work situation, your manager or HR team will need to understand your diagnosis and how it relates to your work.

Before you start

It's usually best to arrange a meeting specifically for this conversation. Consider who you want to be in the meeting and who might need to be involved. This might be just your line manager, or you might want to have an HR representative, a union representative or a trusted colleague to support you.

You don't have to tell everyone at once. By law, when you share medical information with your employer, they must not tell other people without your consent.

You can use this document to prepare for the meeting and give it to your manager for reference. You can just tick the boxes by the statements that apply to you or fill in more details in the spaces given. It's up to you to decide how much you want to share.

If possible, take notes during the conversation to remember the key points that were discussed. Ensure you have records of the support requested and any actions that you and your manager agreed should take place.

Give yourself time to prepare before and recover afterwards. Having this conversation could trigger strong feelings.

To my line manager,

I have been diagnosed with multiple sclerosis (MS).

MS is a progressive neurological condition. It can cause a variety of different symptoms, which can be treated. However, there is currently no cure.

I value my career and remaining at work is good for my health and wellbeing. I would like to discuss how we can work together to make modifications to my work schedule or duties to allow me to continue to make a valuable contribution in the workplace. These are formally known as reasonable adjustments and can help me overcome the difficulties that my MS may cause.

We are likely to need to return to this conversation regularly to ensure that our mutual needs continue to be met.

MS can change over time and can also impact me differently from day to day. Each person with MS has a different range of symptoms and experiences.

MS and the Equality Act
(the law around disability)

The Equality Act (2010) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

The Act states that a person who has multiple sclerosis is a disabled person and is protected by the Act from the point of diagnosis (Schedule 1, Paragraphs 6 and 8).

The Equality Act requires employers to make reasonable adjustments to support a person with a disability to remain in employment.

The aim is to remove the disadvantage caused by MS compared to other colleagues without a disability.

Here are some of the ways that my MS affects me

Fatigue

MS fatigue is not like ordinary tiredness or exhaustion. It is not related to the amount of sleep I have had, or the amount of exertion I have had. It is not beneficial to 'push through' MS fatigue, as that may lead to me being unwell for longer.

- ☐ I may benefit from changing how I travel to work. We could explore using Access to Work funding to cover the cost of taxis.
- ☐ It may be helpful to change my start or finish time to avoid peak traffic for my journey.
- ☐ I may benefit from working from home for some days each week, so I can avoid the commute and conserve my energy to get my work done.
- ☐ I may benefit from being able to rest when I need to, using seats or stools, or having a safe place to take short breaks.
- ☐ I may benefit from being allowed to take small breaks during the day.
- ☐ I may benefit from being allowed to redistribute my workload to do more complex tasks in the morning when I am less fatigued and other tasks later in the day.

I find that my fatigue can be triggered by…

I find that my fatigue is best managed by…

Cognition

I may sometimes have trouble with my thinking or memory. All my existing skills and expertise are still there, but in stressful or busy situations or when I am fatigued, I may find it harder to concentrate or remember some information.

- ☐ A calmer or quieter working environment can help me to stay focused and productive. This could be achieved using equipment like noise-cancelling headphones or by positioning my personal workspace somewhere I am less likely to be disturbed.
- ☐ I may benefit from having instructions or guidance written down rather than just shared verbally, so I can refer to them again.
- ☐ I may benefit from changes to our working practices, such as using shared calendars and alerts to help me prioritise my tasks.
- ☐ Reducing stress can help with MS cognition. I may benefit from having clear timelines, expectations and priorities in my work.
- ☐ I may benefit from having meetings recorded so that I can revisit key parts of the meeting with my actions.

Cognition issues that affect me at work…

Mobility

MS can cause muscle weakness, muscle spasms or tremors, as well as vertigo or balance problems. Some people with MS find these can lead to difficulties walking and an increased risk of falls.

- ☐ I may need to use a walking aid when getting around at work.
- ☐ I may benefit from adjustments to keep me safe and comfortable as I move around the workplace. These might include fitting handrails and ensuring that routes are clear and safe.
- ☐ I may need to allow longer to travel to work or move around the workplace, and I may prefer to reduce the travelling I do as part of my role.
- ☐ If access points and doors around our workplace are faulty or awkward, this may impact me more than other members of staff.
- ☐ Step free access to my workplace may be helpful.
- ☐ I may need a fire safety evacuation plan.

Mobility issues that may affect me at work…

Toileting

MS can affect both the bladder and bowel in various ways.

- ☐ I may need to make more frequent visits to the toilet than other staff members.
- ☐ I need clear access to safe, clean toilet facilities quickly and easily.
- ☐ I may need a short break during meetings or shifts to go to the toilet.
- ☐ I may need a clean shelf or cabinet in the toilet for my medical equipment.
- ☐ If toilet facilities are out of order, this may impact me more severely than other members of staff. For example, if I then need to travel to facilities further from my workplace.

How toilet issues may affect me at work…

Pain or altered skin sensations

MS damage to my nerves means that my brain can misinterpret signals from my skin as pain, prickling, burning or numbness. Regular painkillers are not effective on this kind of sensation.

- ☐ I may have mobility or dexterity problems because of these altered skin sensations. Assistive equipment to help with writing, lifting, typing or other activities may help me stay comfortable in the workplace.

How altered skin sensations might affect me at work…

Relapse

For many people with MS, their symptoms can fluctuate, worsening for a time, and then improving. A period of time when I develop new symptoms, or my symptoms worsen, is called a relapse.

Relapses are unpredictable in terms of when they occur, how long they last and how they might affect me. Medications that reduce the risk of relapse are available for some people with MS, but they will not rule out the risk completely.

- ☐ I may have periods of time when my symptoms are harder to manage than other times.
- ☐ I have not had a relapse in a long time, but if I were to have one, I would inform you as soon as possible.
- ☐ I recently had a relapse, and I am still recovering with some symptoms affecting me more than usual. I am following the advice of my MS team to help me recover.

How relapses might affect me at work…

Vision

Some people with MS find that they have trouble with reduced, blurred or double vision. This usually resolves after a few weeks but can lead to lasting vision problems.

- ☐ If this affects me, I may be temporarily unable to travel, use a computer screen or perform other work tasks.
- ☐ If I have lasting vision problems, I may benefit from assistive technology to help me use a computer, telephone or other equipment.

How vision problems might affect me at work…

Emotions

Coming to terms with an MS diagnosis can be challenging. People with MS may be at higher risk of developing depression or anxiety.

- ☐ I may benefit from mental health support at work.
- ☐ I may benefit from reduced stress at work, as stress can worsen other MS symptoms. Setting clear expectations and reasonable deadlines for my work will help.

As my line manager, you could also support me by…

Infections

If my body is fighting an infection, that can make my MS symptoms worse. Once I recover from the infection, my MS symptoms should also improve.

- ☐ As a result of my MS, I am considered **clinically vulnerable to infection,** including covid infection. This is because having an infection may make me feel more unwell than other people due to the impact on my MS symptoms.
- ☐ As a result of the immune suppressing medicine I take for MS, I am considered **extremely clinically vulnerable to infection,** including covid infection. This is because I may not fight off infection as well as other people and could become more unwell or be unwell for longer.
- ☐ I may benefit from working from home when there is a season of colds or flu to ensure I protect myself. Protecting myself against infection could help to reduce the amount of sick leave I take.

How infection precautions might affect me at work…

Healthcare appointments

Being proactive about my treatment will keep me as well as possible for as long as possible. Under the Equality Act, time off for appointments relating to my MS should not be counted as sick time.

- ☐ I may need to take additional disability leave to visit a clinic or hospital for infusion treatment, blood monitoring, scans or other healthcare appointments.

How healthcare appointments might affect me at work…

Got a question about MS?

Ask our Helpline Team on 0800 032 3839
or email ask@mstrust.org.uk

Scan to support the MS Trust

Access to Work Scheme
(employer and employee support)

Access to Work is a government programme designed to allow disabled people to take up or remain in work. Access to Work has a discretionary grant scheme for employers that provides personalised support to disabled people in the workplace. It can cover specialist equipment or alterations to existing equipment to suit the needs of the disabled person in work. It can also cover help for the disabled person, such as a contribution towards taxi fares where public transport is not suitable.

Access to Work also involves access to a free and confidential Mental Health Support Service which can help develop a personalised support plan for a disabled person in the workplace.

Further information

For more information and support for working life with MS:

Working life with MS – Web based information on MS and work from the MS Trust. *mstrust.org.uk/work*

ACAS – Independent information about dealing with disability at work. *acas.org.uk/disability-at-work*

Disability Law Service – Independent charity providing legal advice to disabled people. *dls.org.uk*

Access to Work – The government scheme to support employers and employees. *gov.uk/access-to-work*

To find out more about MS and how it might affect me:

Someone I know has MS – Download or order this free leaflet from the MS Trust. *shop.mstrust.org.uk/publications/someone-i-know-has-ms/*

What is MS? – An online introduction to MS including common misunderstandings. *mstrust.org.uk/information-support/about-ms/what-is-ms*

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

T. **01462 476700**
T. **0800 032 3839**
E. **ask@mstrust.org.uk**
W. **mstrust.org.uk**

Registered charity no. 1088353

Telling people at work you have MS

This information is part of a set of resources for people who are newly diagnosed with MS. You might like to look at our introductory resource, Making Sense of MS: newly diagnosed with MS, which answers the questions most commonly asked around the time of diagnosis.

MS Trust Information Team
Telling people at work you have MS (Order code: IF459)

DG459-Telling people at work that you have MS.10.024.2K

Produced by verdicottsdesign.com