



# Multiple Sclerosis

An Advice Guide  
for Usdaw Reps



# What is Multiple Sclerosis?

**Multiple Sclerosis (MS) is a neurological condition, affecting the brain and spinal cord (central nervous system). In MS, the coating around the nerve fibres (called myelin) is damaged, causing a range of symptoms.**

Myelin protects the nerve fibres in the central nervous system, which helps messages travel quickly and smoothly between the brain and the rest of the body.

In MS, the immune system, which normally helps to fight off infections, mistakes myelin for a foreign body and attacks it. This damages the myelin and strips it off the nerve fibres, either partially or completely, leaving scars known as lesions or plaques.

This damage disrupts messages travelling along nerve fibres - they can slow down, become distorted, or not get through at all.

As well as myelin loss, there can also sometimes be damage to the actual nerve fibres. It is this nerve damage that causes the increase in disability that can occur over time.

MS (like many conditions) 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.

The MS Society estimates that there are approximately 107,000 people with MS in the UK, and that each year 5,000 people are newly diagnosed with the condition. This means around one in every 600 people in the UK has MS. Each day, approximately 14 people are diagnosed with MS.

Most people are diagnosed between the ages of 20-40, but it can affect younger and older people too.

Roughly three times as many women have MS as men.



## Supporting Disabled Members in the Workplace

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Someone with MS is automatically entitled to the protection of the Equality Act or the Disability Discrimination Act (DDA) in Northern Ireland - they don't have to 'make a case' as to why they should be covered. This is important because it can help them get the right support at work and protects them from suffering less favourable treatment (or discrimination) at work for reasons relating to their MS.

Members with MS may need the support of their Union as it might impact on their attendance or performance at work. This in turn might lead to them being threatened with or receiving

disciplinary action under capability procedures or absence management policies. They may also find that certain aspects of their job make their condition worse.

Unfortunately managers don't always realise that members with MS have rights under the Equality Act (or DDA in Northern Ireland) or that the Act places them under certain legal obligations.

This guide explains what MS is and how reps can use the Equality Act (or DDA in Northern Ireland) to support members with this condition.



## Different types of MS

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There are different types of MS. For some, their MS is characterised by periods of relapse followed by remission. For others it follows a progressive pattern.

### *Relapsing MS*

In relapsing MS people have relapses or attacks of symptoms that occur for a period of time – days, weeks or months – and then improve either partially or completely. Around 85% of people with MS are diagnosed with this type.

### *Primary Progressive MS*

People with primary progressive MS don't have any distinct attacks or remissions, but begin with subtle problems that slowly get worse over time. Around 10 – 15 % of people with MS have the primary progressive form. They tend to be diagnosed slightly later in life than people with the other forms – usually in their 40s or later. Some people with this type of MS also have relapses.

### *Secondary Progressive MS*

Many people with relapsing MS go on to develop secondary progressive MS. This is when someone's MS symptoms become progressively worse over a period of at least six months. Roughly two-thirds of people with relapsing remitting MS will have developed secondary progressive MS 15 years after being diagnosed.

### *Benign MS*

Some people may be told that they have benign MS perhaps because their symptoms have been quite mild. This diagnosis can only be applied when looking back at the course of someone's MS over a period of 10 – 15 years. Where someone's MS hasn't worsened over this period of time or they have little or no disability they might be said to have benign MS. However this doesn't mean that someone's MS has been completely problem-free, or that it will continue in that way.



# What Are the Symptoms of MS?

MS is complex and has many symptoms. Most people won't experience them all, certainly not at the same time. There are also other conditions with similar symptoms to MS.

Common symptoms include:

- Fatigue – an overwhelming sense of tiredness making physical or mental activity difficult or even impossible.
- Sensory problems – such as numbness or tingling of the hands or feet.
- Visual problems – such as blurred or double vision or a temporary loss of sight in one or both eyes.
- Dizziness – sometimes called vertigo.
- Pain.
- Loss of muscle strength and dexterity.
- Problems with walking, balance and co-ordination.
- Muscle stiffness and spasms – tightening or rigidity in particular muscle groups.
- Difficulties with speech and swallowing.
- Bladder and bowel problems.

- Problems with memory and thinking, also known as cognitive problems.
- Emotional difficulties – nerve damage can affect the way a person feels, thinks, reacts and behaves.
- Mental health problems – it is not unusual for someone with MS to experience stress, depression and/or anxiety. The MS Society estimate that 50% of people with MS will experience a problem with their mental health.

## Invisible or Hidden Symptoms

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Some MS symptoms are obvious to other people, while others aren't. It might be easy to look at a person and notice they have difficulties walking, but it isn't so easy to tell whether they are in pain or are fatigued.

The hidden nature of many of the symptoms of MS can cause problems at work. A person can 'look well' which can lead to managers or colleagues making false assumptions about them. The hidden or invisible symptoms are just as real as the visible ones.

## Supporting members with MS

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### *Receiving a diagnosis*

Being diagnosed with MS can be a life-changing moment. Some people can feel overwhelmed, frightened, confused, angry and distressed. Other people might experience a sense of relief, especially if they've had symptoms for a long time.

If a member is struggling to come to terms with a diagnosis of MS you might want to suggest they contact the MS Helpline run by the MS Society (the lead UK charity supporting people and their families living with MS). Their contact details are at the very end of this guide.

### *The Equality Act (or Disability Discrimination Act in Northern Ireland)*

Although not everyone with MS will think of themselves as disabled, MS is defined as a disability under the law - The Equality Act (or the Disability Discrimination Act (DDA) in Northern Ireland). This gives them certain rights at work. It also places certain legal responsibilities on their employer.

In order to be covered by the Equality Act (or DDA in Northern Ireland) almost everyone has to meet a particular legal definition of disability. This is not the case for those people who have been diagnosed with MS. They are automatically covered.

They are deemed to fit the legal definition from the point at which they are diagnosed with the condition, regardless of whether or not they are experiencing symptoms or how they are affected by their MS. This is only the case for people with MS, cancer or HIV. The only other people who are treated as being disabled without having to fit the definition are people who are registered blind or partially sighted, or people who have 'severe disfigurements'.

### *Confidentiality*

You need to be careful not to tell anyone else about a member's diagnosis of MS unless they give you permission. You might want to encourage a member to tell their manager about their condition, particularly if it is starting to affect them at work, as unless they do so (and their manager could not reasonably be expected to realise) they are not entitled to reasonable adjustments (see the section in this factsheet under the heading 'Reasonable Adjustments'). Members with MS, however, do not have to tell their employer. Managers are also bound by confidentiality.

## The Duty to Make Reasonable Adjustments

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Once a member is diagnosed with MS then their employer falls under a legal duty to make adjustments to the workplace, their job duties, their working hours and policies and procedures to remove the disadvantage they may face in doing their job, compared to non-disabled colleagues.

It is impossible to generalise about what may be a reasonable adjustment because every situation will be different, particularly for members with MS. There is no 'one size fits all' approach when it comes to MS so what adjustments members with MS might need will very much depend on how their MS affects them, what job they do and their own abilities and coping strategies. Clearly the best way to find out what would help is to talk this through with the member, but examples of reasonable adjustments could include:

- A chair or stool to sit on.
- A change to working hours or a temporary reduction in working hours.
- Changes to start and finish times.
- Extended breaks to help with tiredness and fatigue.
- Moving where they work away from heat, or closer to a toilet.
- Time off for medical appointments.
- Car parking near the entrance to work.
- Somewhere to rest for short periods during the working day.
- Where the member's vision is affected, providing written information in 14 to 16 point font and ensuring written materials are provided in advance of any discussions/meetings or training.
- Allowing extra time to complete tasks (adjusting performance policies and targets).
- Allowing the member to be accompanied to meetings.
- Where the member has been off sick, allowing a 'phased' return to work.

### Remember:

- The law allows employers to treat disabled people more favourably than non-disabled people (see Page 7) and sometimes this may be part of the solution.
- Removing the disadvantage a disabled person might experience at work may take a combination of adjustments.
- There isn't a time limit on reasonable adjustments. As long as they are effective at removing the disadvantage a disabled member experiences, they must continue to be made.

## Adjusting sickness absence procedures so that absences related to MS are counted separately and not used to trigger disciplinary action

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Guidance for employers to the Equality Act 2010 published by the Equality and Human Rights Commission states:

*'... to avoid direct or indirect discrimination because of disability, or discrimination arising from disability and to make sure you have complied with the duty to make reasonable adjustments you should record the worker's disability-related time off separately from general sick leave. This will mean that you are not calculating bonuses or making other pay or employment decisions in a way that unlawfully discriminates against them.'*

The Employment Code of Practice to the Equality Act gives the following advice:

*'Employers are not automatically obliged to disregard all disability-related sickness absences, but they must disregard some or all of the absences by way of an adjustment if this is reasonable. If an employer takes action against a disabled worker for disability-related sickness absence, this may amount to discrimination arising from disability.'*

## Treating Disabled People More Favourably Than Non-disabled People

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The Equality Act (the DDA in Northern Ireland) openly acknowledges that treating people exactly the same isn't the same as treating people equally. The law allows employers (sometimes employers must) to treat disabled workers more favourably or better than non-disabled workers because of the many barriers disabled people face that simply don't exist for non-disabled people. The Equality Act (and the DDA in Northern Ireland) makes it clear that sometimes the only way to achieve an equal outcome is to treat disabled people more favourably.

Sometimes this can be difficult for other members to understand and it can cause resentment, but usually when members understand the circumstances they understand the need for reasonable adjustments. But remember, before discussing with other members make sure you get the permission of the disabled member to do this.

## Access to Work

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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. However, it can pay for extra equipment or support 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% of the costs of any equipment or support if it is for a new employee who has been in employment for six weeks or less, regardless of the size of the company. It can also cover all of the costs for existing employees if the company has 49 or fewer employees. If the company is larger than this, they will need to pay a proportion of the costs for an existing employee.

The disabled person will need to make the initial contact with Access to Work. After they do, an Access to Work advisor should talk to the employer about the kind of support they need.



# Support and information

## National MS Helpline

Tel: Freephone **0808 800 8000**  
(weekdays 9am-9pm)  
web: [www.mssociety.org.uk](http://www.mssociety.org.uk)

## MS National Therapy Centres

Support for people affected by MS and other neurological conditions in the UK  
email: [info@msntc.org.uk](mailto:info@msntc.org.uk)

## MS Society Scotland

Tel: **0131 335 4050**  
email: [enquiries-scotland@mssociety.org.uk](mailto:enquiries-scotland@mssociety.org.uk)

## MS Society Northern Ireland

Tel: **028 9080 2802**  
email: [nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)

## MS Society Cymru

Tel: **0208 438 0700**  
email: [mscopyru@mssociety.org.uk](mailto:mscopyru@mssociety.org.uk)

## MS Society England

Tel: **0208 438 0700**  
email: [supportercare@mssociety.org.uk](mailto:supportercare@mssociety.org.uk)



# The Social vs the Medical Model of Disability

For some time now disabled people have emphasised that it is not so much their disability that prevents them from fully participating in society, but instead it is the way in which society fails to make adjustments for their disability that excludes them.

This emphasis on changing the barriers put up by society, rather than seeing the disabled person as the 'problem', is known as the 'social model of disability'. In other words, disabled people are people with impairments/health conditions who are disabled by discrimination, exclusion, prejudice and negative attitudes towards disability. Their impairment is not the problem.

The 'medical model' attributes the problems resulting from a disability to medical conditions alone. It concentrates on a person's impairment. Rather than focusing on the barriers society throws up that prevent disabled people from participating equally, the 'medical model' focuses on what disabled people should do to adapt to fit into the world as it is. If they are unable to adapt, the medical model accepts their exclusion.

For example, while a mobility difficulty can have an adverse effect on a person's ability to walk, the fact that the transport system is inaccessible to them has a far greater effect on their ability to get around.

The law is unfortunately rooted in the medical model. It has been rightly criticised for focusing on an individual's impairments and their ability to carry out normal day-to-day activities, rather than on getting rid of the barriers society puts in the way of disabled people.

This leaflet is designed to help understand how the law can support disabled members in the workplace and therefore tends to focus on the medical model.



# More Information

## Usdaw Nationwide

Wherever you work, an Usdaw rep or official (Area Organiser) is not far away. For further information or assistance, contact your Usdaw rep or local Usdaw office. Alternatively you can phone our Freephone Helpline **0800 030 80 30** to connect you to your regional office or visit our website: [www.usdaw.org.uk](http://www.usdaw.org.uk)

You can also write to the Union's Head Office. Just write **FREEPOST USDAW** on the envelope and put it in the post.

## Join Usdaw

You can join online at:  
[www.usdaw.org.uk/join](http://www.usdaw.org.uk/join)



Scan to  
join today

## What Happens Next

Once we process your application, you will receive a membership card with our Helpline telephone number and a New Member's Pack giving details of all the benefits and professional services available to you.

