

## What is MS?



Multiple sclerosis information

# Welcome to this Choices booklet about MS...

MS-UK listens to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

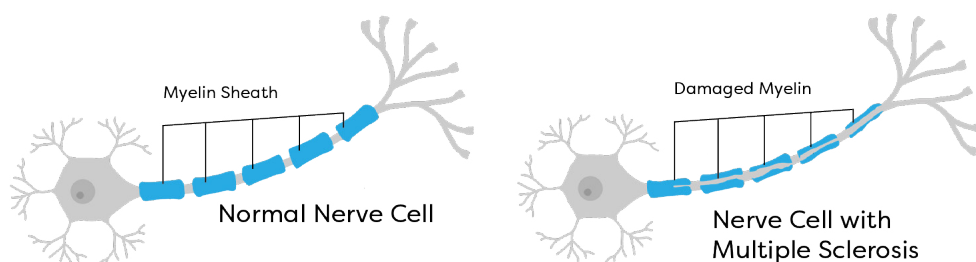
This Choices booklet has been designed with you in mind, and we hope it will answer some of your questions about MS.

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# What is MS?

MS is a condition that affects the central nervous system (CNS). The CNS consists of your brain and spinal cord, and as the name suggests it plays a central role in the regulation and management of key bodily functions (1).



Nerve cells in the CNS are covered by a protective layer of fatty protein called the myelin sheath, which is a bit like the insulation which surrounds an electrical cable. MS is an autoimmune condition where the immune system gets confused and attacks the nerve cells. Instead of attacking an infection or virus, it damages this protective sheath. This process is called demyelination. The effect of demyelination is to disrupt the messages that are transmitted from and to the brain, causing them to slow down, become distorted or not get through at all.

The term 'sclerosis' is a Greek word that means scarring. Demyelination causes many scars or lesions in different places within the central nervous system. The symptoms that occur depend on the site and severity of the lesions and this is why people with MS experience different symptoms at different times.

It is estimated that there are 150,000\* people in the UK diagnosed with MS, with around 135 people diagnosed each week (2). MS is commonly diagnosed in people between the ages of 20 and 40. There are roughly three times as many women with MS as men. MS is also the most common non-traumatic cause of significant neurological disability in people aged under 40 (3).

In the early stages of MS, the central nervous system can sometimes repair the damaged myelin or use different pathways for the signals. This is why episodes of symptoms, known as relapses, can be followed by periods of time when symptoms improve or disappear altogether, known as remission.

People with a diagnosis of MS will usually experience it very differently. There are so many symptoms which may affect individuals in a variety of ways. No two people are the same.

## Common symptoms experienced at diagnosis

- Fatigue
- Optic neuritis
- Weakness of limbs
- Reduced co-ordination
- Balance problems
- Numbness
- Pins and needles
- Unexplained pain

## More information

Our MS Symptoms Choices information booklet offers more information on the common symptoms associated with MS.

[www.ms-uk.org/multiple-sclerosis-symptoms-choices-booklet](http://www.ms-uk.org/multiple-sclerosis-symptoms-choices-booklet)

## What causes MS?

Although it is not yet certain exactly why people develop MS, research suggests that combinations of genetic, environmental and viral factors are involved. We look at some of those most commonly associated with MS below.

### Genetic

MS is not directly inherited, however, there does appear to be a genetic component, possibly a combination of certain genes which makes people more susceptible. Family members of someone diagnosed with MS have a slightly higher chance of developing MS themselves.

Research to date has found that variants of the gene HLA-DRB1, particularly the variant known as HLA-DRB1\*15:01, may be associated with an elevated risk of developing MS (4). Additionally, a study of more than 22,000 people with MS found that variants of two genes called DYSF and ZNF638, were associated with faster MS progression (5).

Looking at genetics from a historical perspective, research has unfolded a connection between genes linked to MS development with those of nomadic tribespeople who travelled around northern Europe and Scandinavia around 5,000 years ago. This again involves a variant of the gene HLA-DRB1, known as HLA-DRB1\*04:01, which was found to be present

in the DNA of these nomadic tribes and their modern-day ancestors.

It is suggested that this gene protected the tribespeople from infections associated with exposure to herding animals such as sheep and cattle but is no longer needed by people in the modern day given our changing lifestyles. As such its prominent role is now not one of protecting people from viruses, but one which is linked to the development of conditions such as MS. The researchers suggested that their finding could explain why MS is prevalent in northern Europe and Scandinavia (6).

### **Epstein-Barr virus (EBV)**

There is a growing body of scientific evidence which suggests that the development of MS may be triggered by infection of the Epstein-Barr virus (EBV). This virus causes glandular fever, usually in teenagers and young adults. Up to 95 per cent of all adults have been exposed to the virus but not all will know they were unless they had glandular fever and experienced symptoms.

One of the most significant studies which underpins this link was published in early 2022. It took place over a 20-year period and focused on 10 million United States military personnel who had blood samples taken from them regularly and then stored, allowing testing for EBV. Just five per cent of the participants were noted as being infected with the virus upon analysis of their first blood sample. However, 955 participants went on to develop MS, on average about 10 years after the initial sample, with only one of these testing negative for EBV antibodies. It was found that the risk of developing MS increased 32-fold after EBV infection (7).

It has also been found that people with specific EBV antibodies and genetic traits associated with MS are at a significantly higher risk of developing the condition. Upon analysing antibody profiles of 650 people with MS and comparing them with the profiles of 661 people without an MS diagnosis, scientists found that those in the MS group were significantly more likely to have EBV antibodies that attack proteins in the brain. Additionally, they identified that people who also had the genetic variant HLA-DRB1\*15:01 were nine times as likely to develop MS, compared to those who did not (8).

Not everyone with EBV will develop MS. However, given the growing evidence of the link between the virus and MS onset, it is suggested that the development of an EBV vaccine could be beneficial (7).

## Environmental

Geography is just one environmental factor associated with the onset and progression of MS. Studies have shown that the further north from the equator you live, the more chance you have of being diagnosed with MS. For example, figures reflect a higher rate of MS in the UK, North America and Scandinavia when compared to countries which are very close to the equator. There is a need to gather more information from less developed countries in order to obtain a fuller picture of global MS prevalence (9).

The influence of vitamin D in the health of human immune systems has been proven over time, with scientific studies showing that avoiding deficiency helps to underpin good immune health and reduces susceptibility to autoimmune conditions (10).

Further, research has found that people living in countries situated closer to the equator are less likely to be diagnosed with MS than those living in more northerly nations - ones which do not enjoy as much sunlight in terms of both hours and intensity when compared to their equatorial counterparts. Our body creates vitamin D naturally when our skin receives direct sunlight whilst outdoors, hence it is sometimes referred to as the 'sunshine vitamin'. Therefore, exposure to sunlight is important to ensure deficiency in this nutrient is avoided.

Studies have shown a link between genetically reduced levels of vitamin D and MS. This means people who had naturally lower levels of vitamin D were more strongly associated with increased susceptibility to MS (11). Interestingly, it has been found that vitamin D could inhibit the influence that the genetic variant HLA-DRB1\*15 has on the immune system (12). We mention how this variant is thought to play an active role in MS onset earlier in this booklet.

### **More information**

Our Vitamin D Choices booklet provides more information about this nutrient and its connection with MS.

[www.ms-uk.org/vitamin-d-and-multiple-sclerosis-choices-booklet](http://www.ms-uk.org/vitamin-d-and-multiple-sclerosis-choices-booklet)

## **How is MS diagnosed?**

Only a neurologist, a specialist on central nervous system conditions, is qualified to diagnose MS. A neurologist will perform specific tests to ensure that symptoms are consistent with MS and that all other alternative diagnoses have been excluded.

## Blood tests

These are taken to rule out other conditions or nutrient deficiencies being the root cause of undiagnosed health issues. Some of these may have symptoms that are very similar to MS.

## Magnetic Resonance Imaging (MRI) scan

This scan is used to identify any areas of the brain and/or spinal cord that may have damage indicative of MS. An MRI scanner consists of a large doughnut-shaped magnet with a tunnel in the centre, which along with radio waves is used to take pictures of the brain or spine.

## Lumbar puncture

A lumbar puncture is a procedure where a small sample of cerebrospinal fluid (CSF) is taken from the base of the spine. CSF is the fluid that surrounds and protects the brain and spinal cord. This is then analysed for any abnormalities, such as the presence of certain proteins which can indicate inflammatory activities such as myelin damage.

## Evoked potentials

These are very simple and painless electrical tests which measure the time it takes for the nerves to respond to stimulation. Visual evoked potentials (VEP) are most commonly used in the MS diagnostic process. It involves a conducting gel and electrodes being applied to the head and face. Audio and visual stimuli are then used, and the outcomes are assessed to identify any areas of concern.

## More information

Our Diagnosis Choices booklet provides more detailed information about how MS is diagnosed. [www.ms-uk.org/diagnosis-of-multiple-sclerosis-choices-booklet](http://www.ms-uk.org/diagnosis-of-multiple-sclerosis-choices-booklet)

## Types of MS

As medical science progresses, so does knowledge of MS, with particular weight being given to the notion that rather than there being different types, it is a single continuous condition which impacts the whole CNS. This is known as 'smouldering MS' and it is thought to be the main driver of MS progression with and without inflammatory activity (13). Lesions associated with smouldering MS have a dark rim, grow slowly over time and appear to play a significant role in MS progression.

The growing evidence that supports the notion of smouldering MS may eventually lead to changes in how the condition is viewed and addressed from a clinical perspective (14). For now, it is important to be aware of the types of MS which are predominantly used by neurologists and are significant in terms of determining treatment approaches for MS patients.

## Relapsing remitting MS

Official figures show that around 85 per cent of people with MS are diagnosed with relapsing remitting MS (RRMS) at onset (3). People affected by RRMS experience relapses periodically, often months or years apart. When a relapse resolves, the person moves into remission, hence the term 'relapsing remitting'.

The severity and type of relapse experienced can vary between people and individuals. New symptoms can appear or existing symptoms may worsen.

It can often be difficult to determine if you are having a relapse, so it is important to let your MS nurse know if you are experiencing a change in symptoms. They can then determine if you are experiencing a clinical relapse and offer treatment if they feel it is required.

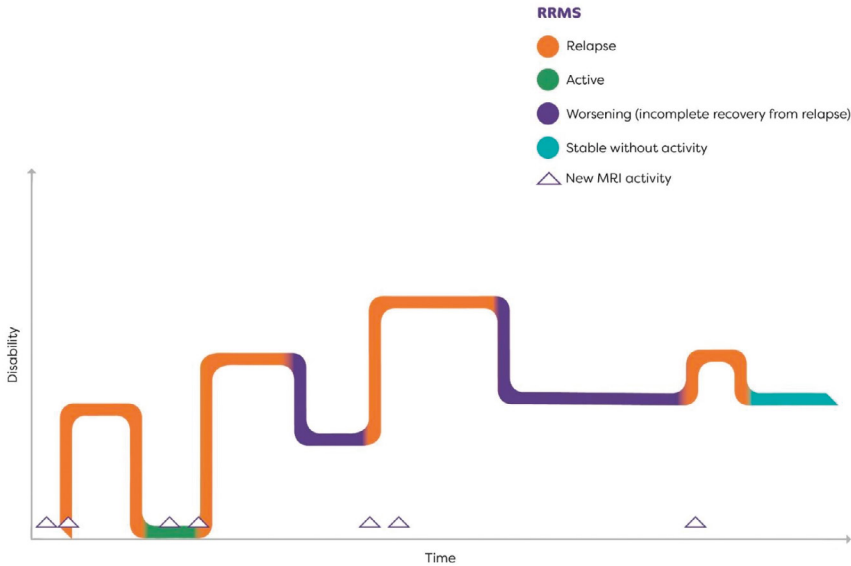
You may be offered steroid treatment to reduce inflammation in the body and to help aid recovery from a relapse.

The National Institution for Health and Care Excellence (NICE) have published guidelines for the management of MS. They state that a relapse can be diagnosed if the person with MS has

- developed new symptoms
- or
- has a worsening of existing symptoms
- and
- these symptoms have lasted for more than 24 hours in the absence of infection or any other cause, after a stable period of at least one month (15)

Some people with RRMS are eligible for disease modifying therapies (DMTs) which can help to reduce the number of relapses. There are a number of different types of DMT that are approved for use in the UK. Talk to your neurologist or MS nurse about what DMT you may be eligible for.

The following is a graphical illustration of the general course of RRMS.



There are sub-categories of RRMS used by neurologists, these can include the following.

## Benign MS

A person will initially be diagnosed with RRMS and it is only after several years of living with a mild form of RRMS that a neurologist may suggest that their MS is benign.

Studies show that people with benign MS (BMS) will have little or no disability, equal to two or three on the Expanded Disability Status Scale (EDSS), at ten years after onset (16).

A person with BMS can still experience relapses and symptoms, and their MS may change as they grow older. A study of just

under 150 people with a BMS diagnosis showed that symptoms such as fatigue, depression and impaired cognitive function are those which are more commonly experienced (17).

## **Rapidly evolving severe relapsing remitting MS**

Also called highly active or severe RRMS, rapidly evolving severe RRMS (RES-RRMS) is categorised as having two or more disabling relapses in one year in addition to evidence of new MS activity showing up as lesions on an MRI (18).

People with rapidly evolving severe RRMS may be eligible for treatment with a DMT. Talk to your neurologist or MS nurse about the DMTs you may be eligible for.

## **Secondary progressive MS**

People who are initially diagnosed with relapsing remitting MS (RRMS) may later transition to secondary progressive MS (SPMS).

Secondary progressive MS is characterised by fewer or no relapses and a gradual worsening of symptoms.

Some people with SPMS may still experience relapses, but remission following a relapse is less complete, or there is less time between relapses.

Only a neurologist can diagnose SPMS after careful observation of MS symptoms over time. A small number of people are diagnosed with SPMS from the outset. This is

because looking back, it becomes apparent that the person has experienced MS relapses for a number of years prior to diagnosis.

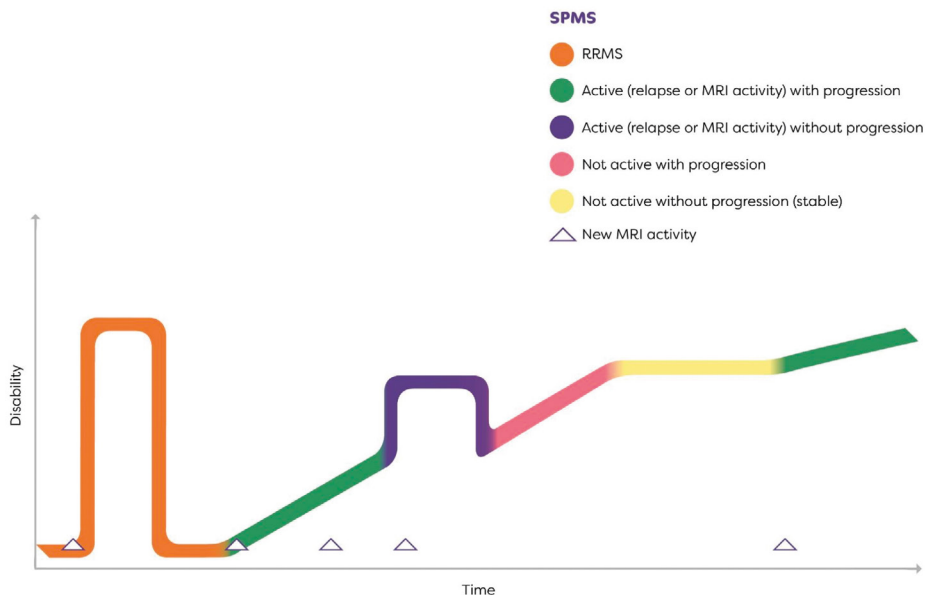
Generally, over half of those diagnosed with RRMS will develop SPMS between 10 and 20 years after its onset (3). However, a Swedish study has shown that the first generation of DMTs have been effective in not only slowing down this transition but reduced the risk of people developing SPMS by 42 per cent. This is when compared with RRMS patients in the pre-DMT world (19). Given time, it is expected that studies will show the more recently introduced DMTs are playing an even more significant role in reducing this risk and at the very least slowing down the transition from RRMS to SPMS.

How SPMS is experienced varies between individuals with some people noticing a gradual worsening of symptoms and disability progressing but at varying speeds.

Currently, there are no DMTs recommended to treat non-relapsing, or non-active SPMS. However, some people who experience relapsing SPMS, or 'active' SPMS, whereby relapses are present or there is activity shown on MRI scans, may be eligible for one.

Mayzent is approved to treat 'active' SPMS, evidenced by at least one relapse in the previous two years and/or inflammatory activity is shown via MRI, and/or progression is identified independent of relapses.

The following is a graphical illustration of the general course of SPMS.



## Primary progressive MS

Between 10 and 15 per cent of people are diagnosed with primary progressive MS (PPMS) at onset (3). PPMS begins with a slow progression of neurological symptoms which usually steadily worsen. However as with all MS types, the speed at which progression takes place can vary, this includes disability.

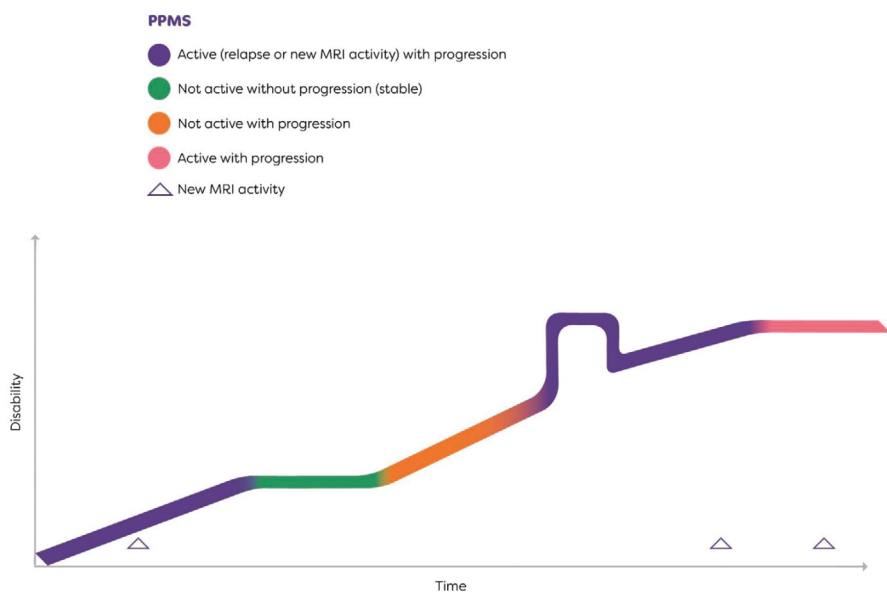
PPMS is mostly diagnosed in people over 40 years. It can take many months or years for a neurologist to arrive at a definitive diagnosis of PPMS as changes can be subtle over an extended time. It is commonly a diagnosis of exclusion, which means discounting any other potential causes, before reaching the point of confirming PPMS officially (20).

Many people with PPMS will not have relapses, but some do.

If relapses are part of your PPMS, your neurologist may use the sub-category 'progressive relapsing MS'.

Ocrevus is available to treat early-stage, inflammatory PPMS. It is the first drug to show evidence in clinical trials of slowing down and reducing disability progression in PPMS.

The following is a graphical illustration of the general course of PPMS.



## Progressive relapsing MS

Around five per cent of people affected by MS have the progressive relapsing form (PRMS) (21).

A person with PRMS will have progressive symptoms, including disability, that continues to worsen over time, again at varying

rates depending on the individual. A relapse in PRMS is an exacerbation of symptoms that have already been occurring.

## Other

### Clinically Isolated Syndrome

Although not technically a classification of MS, it is important for it to be included within this booklet. Clinically isolated syndrome (CIS) is used to describe the first neurological episode that lasts at least 24 hours and is caused by inflammation or demyelination in one or more sites in the CNS.

CIS is diagnosed before a formal diagnosis of MS can be made. Around 60-80 per cent of people with CIS, who present with brain lesions, will go on to develop MS within ten years (22).

Those with CIS who show abnormalities on further MRI scans within one year may be offered treatment with a DMT.

### Advanced MS

The term advanced MS is not about the type of MS a person has, but rather about the level of impact and difficulties MS is causing.

This terminology is used when MS has progressed and is having a greater impact, with significant physical symptoms or cognitive impairment that does not improve. This is most typical in the later stages of SPMS or PPMS. A person identified as having advanced MS is more highly affected by their symptoms and requires additional support from carers and/or family members (15).

The level of impact of these symptoms means they can be complex and difficult to treat. A person living with advanced MS is still entitled to an annual neurology review and may need referrals

to a wider variety of health professionals in order to find the best ways to manage symptoms and maintain a good quality of life (15).

### **More information**

Our Disease modifying therapies Choices booklet provides further reading about the different DMTs that are used to treat MS.

[www.ms-uk.org/disease-modifying-therapies-choices-booklet](http://www.ms-uk.org/disease-modifying-therapies-choices-booklet)

Our website resource Planning for a future with advanced MS offers a range of information which is designed to support people with advanced MS, their families and carers.

[www.ms-uk.org/planning-for-a-future-with-advanced-ms](http://www.ms-uk.org/planning-for-a-future-with-advanced-ms)

## **Common misconceptions about MS**

We asked people affected by MS what were the most common misconceptions they have heard from others about MS.

Below are our findings and explanations.

### **‘I am going to lose my independence’**

MS impacts everyone in different ways. Many people with MS continue to enjoy an active life for many years after they are diagnosed, although others may require increasing levels of support over time.

### **‘My children will get MS’**

It is thought there is a genetic susceptibility towards developing MS in the future, but it is not directly inherited as many other factors come into play. The origin of MS is not fully understood.

For a child of a person with MS, the chance of them developing MS in the future is approximately two per cent over their lifetime (23).

### **‘MS is a terminal illness and I am going to die early’**

Most people with MS live just as long as anyone else. Although MS cannot yet be cured, it is not a life-threatening or terminal illness, but what is known as a chronic long-term health condition. This means that once you have it, you have it for life.

### **‘Everyone ends up in a wheelchair’**

This is not true. One of the most common aspects of MS is that everyone is affected differently. Each individual with MS will experience progression at different rates, this includes disability, and so it is impossible to say with any certainty if or when they will need to use mobility aids.

### **‘MS just affects your legs and mobility, doesn’t it?’**

Again, this is not true. The nature of MS is that it can impact a wide range of bodily functions, including those associated with mental health, cognition, the bladder and bowel, speech and swallowing – to name but a few.

### **‘You look ok, you must be better!’**

We know that MS is a lifelong condition and cannot be cured. There will be good days as well as bad and others will notice this. MS can fluctuate. Many symptoms are invisible and not obvious to others.

### **‘Being fatigued is the same as being tired’**

MS-related fatigue is not a symptom that can be solved by having

a good night's sleep and it is much more impactful than 'feeling tired'. It can feel like 'bone weariness' with limbs 'feeling lead-like' and can be detrimental to quality of life. There are various strategies which help people affected by fatigue such as specific management courses, pacing tasks, dietary approaches and regular exercise.

### **'You look or sound like you are drunk'**

MS can impact speech and balance. People with MS have sometimes been told they appear drunk by the sound of their voice, perhaps they may experience slurring of words. This can be heightened when fatigued. Balance issues can impact how a person walks and again others may think this is due to alcohol rather than MS. This is generally due to a lack of understanding of the condition.

### **'Exercise will make your MS worse'**

Because chronic fatigue is so common in people with MS, clinicians and the medical community used to advise that people avoided activity and exercise. There is now strong evidence which shows that regular, planned, moderate exercise can significantly reduce the impact of fatigue for people with MS.

### **'People with MS cannot work'**

People with MS are valuable members of the workforce. Some people with MS will face barriers, challenges and obstacles in the workplace that can be managed with the right support. Others may eventually need to retire on the grounds of ill health, but this is not inevitable for everyone.

## **‘There are no treatments or medications for MS’**

Although there is currently no cure for MS there are ways to manage it, including drug therapies, complementary therapies, dietary and lifestyle approaches and various aids to give you relief from your symptoms.

MS does not need to be as devastating a diagnosis as it may first seem. If you have access to good information, the right treatments and support from both your family and healthcare professionals, you can still live a happy and fulfilling life.

### **More information**

Knowledge of MS is key to ensuring that the myths and misconceptions of the condition which exist in the wider society are addressed. MS-UK plays a significant role in raising awareness of the condition, including our Choices range of information booklets, our MS and Work website resource, plus free MS awareness training and CPD accredited e-learning.

#### **MS-UK - Choices information booklets**

[www.ms-uk.org/multiple-sclerosis-choices-booklets](http://www.ms-uk.org/multiple-sclerosis-choices-booklets)

#### **MS-UK - awareness training options**

[www.ms-uk.org/ms-uk-multiple-sclerosis-online-awareness-training-sessions](http://www.ms-uk.org/ms-uk-multiple-sclerosis-online-awareness-training-sessions)

#### **MS-UK - MS and work information**

[www.ms-uk.org/ms-and-work](http://www.ms-uk.org/ms-and-work)



# About MS-UK

MS-UK is a national charity supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

## The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



## New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

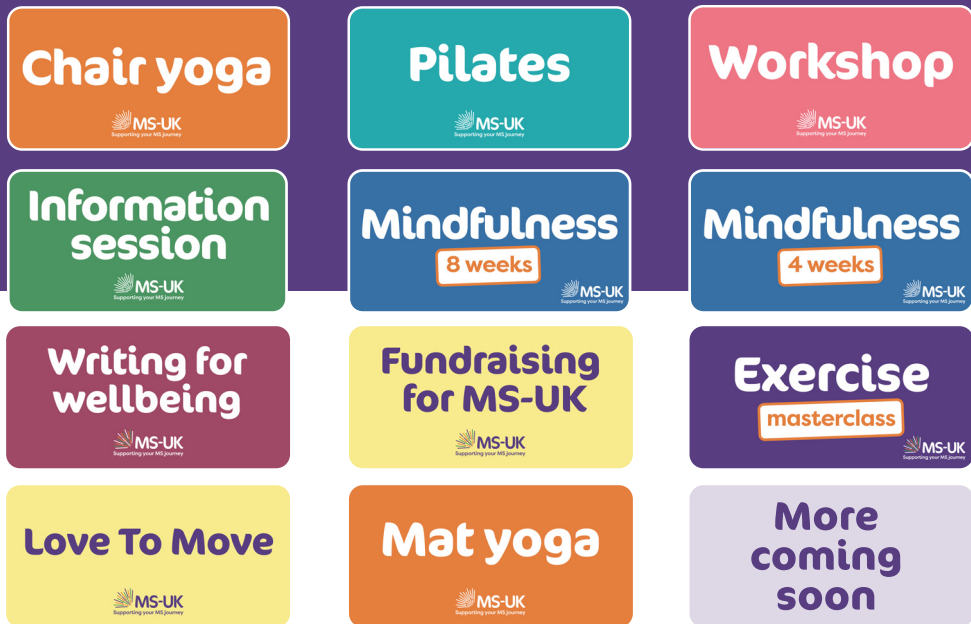
Available in print, audio version, large print and digitally.

# About MS-UK

## Peer support service

Our peer support service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more [ms-uk.org/peer-support-service](https://www.ms-uk.org/peer-support-service) or email [peersupport@ms-uk.org](mailto:peersupport@ms-uk.org).





## MS-UK's online activities

MS-UK offers a variety of online activities for those affected by MS to stay active, connected with others and to manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. To get involved, please go to [www.ms-uk.org](http://www.ms-uk.org) or email [register@ms-uk.org](mailto:register@ms-uk.org).

## MS-UK E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created an accredited eLearning course that can help you do this. Visit [www.ms-uk.org/ms-awareness-e-learning](http://www.ms-uk.org/ms-awareness-e-learning) to find out more.

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**Last reviewed** April 2025

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## Stay in touch

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**Registered Company Name**

Multiple Sclerosis-UK Limited, trading as MS-UK

**Company Number** 2842023

**Registered Charity Number** 1033731

**VAT Number** 632 2812 64

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