MS Society

What is MS?

Causes, treatments and support.

We're the MS Society and we're here for you. Funding world-leading research, sharing information, making voices heard and campaigning for everyone's rights.

Together we are a community. And together we will stop MS.

We rely on the generosity of people like you to fund our vital work. If you would like to make a donation, you can do so by:

- Calling us on: **0300 500 8084**.
  Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **donate.mssociety.org.uk**
- Posting your donation to: MS Society,
  Carriage House, 8 City North Place,
  London N4 3FU.
- Please make cheques payable to the 'MS Society.'

What is MS?

Contents

A word from Eiona, who has MS

After my own diagnosis, I sought out all the information I needed from trusted and reliable sources. After all, knowledge is power.

The information in MS Society booklets and publications has been invaluable throughout my life with MS, as have their website discussion forums. People on the Helpline were equally helpful in answering my questions and directing me to the relevant information.

I discovered early on that my MS could be a source of concern, bewilderment and fear of the unknown for close family and other relatives and friends. I attended local awareness events. I came away from them with enough information to set everyone's mind at rest, and to help us all adapt to living with MS.

These days I also follow the MS Society on Facebook and Twitter, for the latest on potential new treatments and research into MS.

A life with MS may take a lot of time in adjusting to, but ultimately it's possible to live a full life and a very happy life. We face the future with what we have got, not on what we haven't got.

Eiona

Five things to know

1. No-one has to face MS alone. There's lots of support out there

2. Everyone's MS is different

3. Research is making progress all the time

4. Treatment can make a real difference to many people's MS. It works best if you start it soon after you're diagnosed

5. You don't have to give up hope of living the life you want. But you might need to make some changes

About this booklet

Perhaps you've recently been told you have multiple sclerosis (MS). Or maybe someone you know has it and you'd like to know more. We hope this booklet goes some way to answering your questions.

Life with MS these days is less about what you can't do, but more about what you can do.

Knowing more about MS can help you feel more in control of what's happening. Hopefully it'll make you less uncertain or worried.

Living with MS can bring real challenges. But a lot has changed since the first effective treatments became available in the nineties. What we know about MS is growing all the time. Research into even better treatments is making progress, and new ones keep being launched. Recent years have seen major breakthroughs.

Life with MS these days is less about what you can't do, but more about what you can do. Whether you have MS or know someone who does, we're here to help you find ways to live out your plans and hopes.

Where you see a word in **bold** in this booklet, it means you can turn to the back and find it explained.

Contact our MS Helpline to talk about anything to do with MS. Page 48 has more details on what it offers. Call **0808 800 8000** or email **helpline@mssociety.org.uk**

Or send us a private message through our Facebook page **facebook.com/MSSociety**. Use the 'send message' tab on the page.

You can ask other people with MS questions and get support on our online forum. They'll know what you're going though. Find it at **mssociety.org.uk/forum**

What is MS?

Multiple sclerosis, MS for short, is a neurological condition. 'Neurological' means 'to do with your nerves'. The specialist doctors who look after people with MS are called neurologists.

MS affects nerves in your brain and spinal cord, which together make up your **central nervous system**. Your spinal cord connects nearly all parts of your body to your brain. Messages go between your brain and spinal cord, travelling along the nerves. These signals control how parts of your body move or work. They let you feel things like pain and touch.

You can't catch MS from someone. You get it when your own immune system isn't working properly. Your immune system protects you by fighting off viruses and bacteria that get into your body. But in MS it attacks nerves in your brain or spinal cord by mistake.

These nerves control lots of different parts of your body and how they work. That's why you can get MS symptoms in many parts of your body. And it's why everyone's MS is different.

> **"MS is a significant part of me, but it's far from the most interesting part"**
> Helen

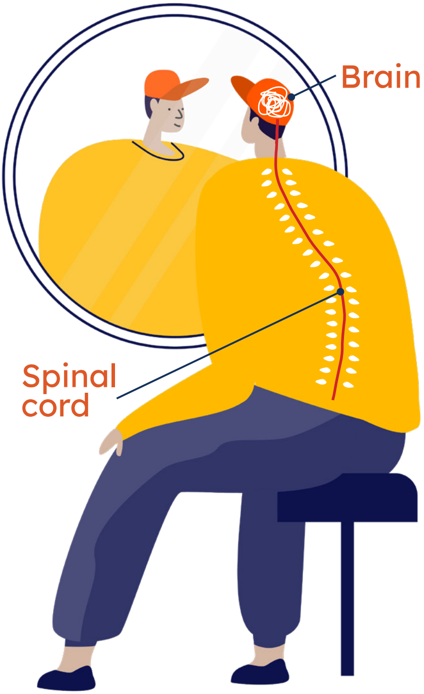
What exactly is happening in MS?

We're learning more all the time about what happens in MS. Two things seem to take place.

The first is what we see in **auto-immune diseases**. Instead of attacking viruses and bacteria, your immune system attacks a part of your body by mistake. In MS it attacks the fatty covering called myelin around nerves in your brain and spinal cord.

There's also a second side to MS. For reasons doctors don't fully understand, the nerves themselves break down and stop working. This usually becomes more common after people have had MS for many years.

Messages travel along nerves between your brain and spinal cord, controlling how parts of your body work.



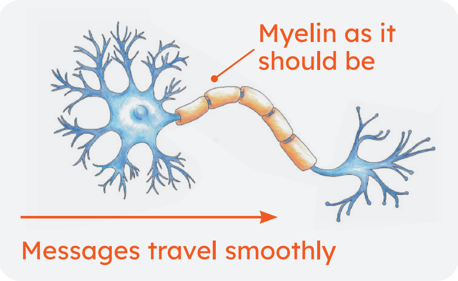
How your immune system damages nerves

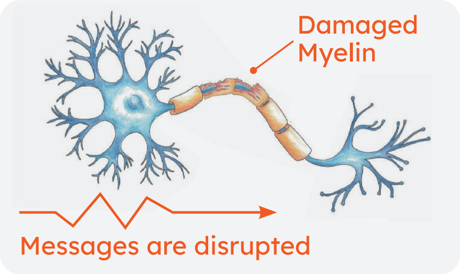
The fatty covering around nerves called myelin protects them. It helps messages travel along nerves faster. In MS your immune system wrongly sees myelin as something that shouldn't be there. So it attacks, stripping away the myelin. When myelin is damaged the nerve stops working like it should.

Early on in MS your body repairs the damaged myelin. But over time it finds this harder to do. Eventually the nerve can stop working.

Another part of this attack is **inflammation**. Left untreated, inflammation will also harm the nerve. When nerves get damaged, it's harder for messages to get through – or they can't get through at all.

Think of this being like an electric cable. The wire inside is like your nerve. Electricity travels down the wire to make the equipment at the other end work. This is like when your brain sends a signal down your nerve to make a part of your body work. A cable has a plastic covering around the wire to protect it. If this gets damaged, electricity won't get through like it should and the equipment won't work properly. Myelin protects your nerves in the same way.





Why do some people get MS?

In the UK around 1 in 400 of us has MS. That's over 150,000 people. Each week around 135 people are told they have it. Seven in ten people with MS are women. That's nearly two and a half times as many women as men. We don't know why.

In the UK people are most likely to find out they have MS in their thirties and forties. But the first signs often start years earlier. MS can happen in children but that's quite rare.

Nobody knows for sure why MS happens to some people. But what we know grows all the time. Slowly we're putting together more pieces of the puzzle.

Certain things seem to play a part in triggering MS. It's probably not just one thing but a combination of:

- your genes
- something in your environment
- your lifestyle

Genes

There's no one gene that causes MS. In fact, over 200 genes might affect your chances of getting it. A parent with MS can pass on the genes that make the risk of getting MS higher. But their child won't automatically get MS. That's because genes alone don't decide who gets MS.

Identical twins have more or less the same genes. But when one gets MS, the other usually won't get it too. That twin does have a higher risk of getting MS, but most don't get it. This shows genes play a part, but it's far from the whole story.

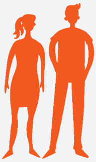
Most people with MS have no history of MS in their family. But if you do have a close relative with MS, the chances you'll get it are a little higher.

The risk is still low, though. Researchers have worked out figures for the risk of getting MS.

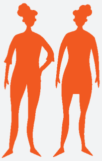
Your risk of MS in your lifetime

If you have:

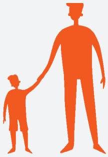
a parent with MS
1.5% chance
(1 in 67 get it)



a brother or sister with MS
2.7% chance
(1 in 37 get it)



an identical twin with MS
18% chance
(1 in 5 get it)



a child with MS
2.1% chance
(1 in 48 get it)

The risk is around 1% if an aunt, uncle, cousin, nephew or niece has MS.

If you have MS and have a child, there's only a 1 in 67 chance they'll get it too.

In 2014 a very big study found that MS may be even less likely to be passed on than these figures suggest.

For more about genes, just put 'genes' in the search box of our website.

Environment

Things in the world around you might affect your risk of getting MS. These can be:

- **some infections**
- **a lack of sunshine. This causes low levels of vitamin D, which your body makes when you're in the sun**

Infections

There's growing evidence that some viruses (and maybe bacteria) could help cause MS. Most studies have looked at Epstein Barr virus as a likely trigger. This is the virus that causes glandular fever. That doesn't mean you'll get MS if you've had glandular fever. Nearly all of us have had this virus, but very few people get MS.

The link isn't totally understood. Infections could act together with other things to trigger MS.

Vitamin D

It was noticed years ago that you find more people with MS the further away you go from tropical countries near the equator, where there's lots of sun. Researchers started to look at a lack of vitamin D, the 'sunshine vitamin', as a possible cause of MS.

More and more studies point to a link between MS and having low levels of vitamin D. The risk seems highest if you're low in this vitamin before you become an adult.

Lots of us in less sunny countries, like the UK, become low in vitamin D, especially when it's not summer.

We get some vitamin D from food. It's in things like oily fish, eggs, fatty spreads like margarine, and breakfast cereals with added vitamin D. It's almost impossible to get all the vitamin D you need just through food. Most of it comes from sunshine. Our skin makes this vitamin when we're in the sun.

Within the UK, there are higher rates of MS in Scotland and Northern Ireland. This could be because this far north people are even more likely to be low in vitamin D.

Other reasons you might not have enough of this vitamin are:

- **you have genes that make it harder for your body to make it**
- **you're a pregnant woman**
- **you have dark skin. It's harder for darker skin to make vitamin D**

Guidelines say people in Britain should think about taking extra vitamin D, especially from October until April. This advice is for everyone and it's not to do with MS. It's to keep bones healthy.

People with dark skin are advised to take it all year round as they might not get enough of this vitamin through their skin. Studies have looked at whether taking extra vitamin D would protect against getting MS. But it's not been shown to make any difference.

If people already have MS, studies have found a link between their levels of vitamin D and how bad their MS is. Many people with MS take extra vitamin D.

Studies have looked at whether taking extra vitamin D slows down MS or helps with its symptoms. There's no hard evidence it slows down MS or reduces relapses. Research is still looking at if it helps with symptoms. Some studies show it might help with MS fatigue. We'll need more studies before we have a definite answer.

Guidelines from the Association of British Neurologists say all women with MS should take vitamin D supplements if they're old enough to have children. This is in case the woman becomes pregnant. Supplements might lower the risk that the baby will get MS later in life.

If you want to know if you're low in vitamin D, your GP (family doctor) or MS doctor can check your levels with a blood test. If your levels are low, get medical advice before you try to increase them. Taking too much can be harmful. Some MS doctors suggest people with MS take vitamin D all year round and at higher doses than people who don't have MS.

In our diet information you'll find more about MS and what you eat, including vitamin D. Put 'diet and nutrition' or 'vitamin D' in our website's search box.

Lifestyle

Two lifestyle factors have so far been linked to MS:

- **smoking**
- **being very overweight (obese)**

Smoking

Studies show you're more likely to get MS if you smoke. Chemicals in cigarette smoke might affect your immune system, helping to trigger MS. Passive smoking – breathing other people's smoke – has been linked to a higher risk of getting MS in some studies.

Smoking makes MS get worse faster, causing more relapses and disability. But studies show that stopping smoking can slow down how fast your disability gets worse. It can also mean relapsing MS turns into secondary progressive MS less quickly. These MS risks drop quite soon to the risk for people who don't smoke. Read more about the different types of MS on page 28.

If you want to quit, your GP can suggest things to help. Find ideas and support, from nicotine gum and patches to vaping, at **nhs.uk/smokefree**

Obesity

Studies have found a link to getting MS if you're very overweight (obese), especially when you're a child or young adult. This could be because being very overweight can:

- **make you low in vitamin D**
- **make your immune system overactive. This can cause inflammation inside your body**

There may be other reasons we don't yet understand. Of course, not everyone who is obese gets MS. And not everyone with MS is – or was – very overweight.

MS is no one's fault

Hearing about things that can make MS more likely, you might ask: 'Could I have done something to avoid it?'

The answer's very likely to be 'no'. That's because things that can make MS more likely – smoking, your weight or vitamin D levels – don't decide on their own who gets MS. They're linked to other things that you have no control over. These include what sex you are, your genes, or what infections you get.

A number of things may have played a role in you getting MS. But you can never know for sure which ones.

What are the symptoms of MS?

MS damages nerves in different parts of your brain and spinal cord. Where this damage takes place affects where symptoms show up in your body. For example, damage in the spinal cord can affect your legs or bowel or bladder. Damage in your brain might affect your eyesight or your memory.

Everyone has their own symptoms, and they can be unpredictable. Symptoms can change from day to day, even hour to hour. They could last days, weeks or months. These could stay for good, slowly get worse, or ease off. They might go away completely.

Some people find their symptoms get worse for a while if they get hot, tired or stressed, or if they exert themselves.

Types of MS symptoms

No one is likely to get all these symptoms of MS. But here are the more common ones:

- **'fatigue'. This feeling of being exhausted isn't like normal tiredness. It can make doing things (even thinking) very hard or impossible**
- **strange feelings like numbness or tingling in your arms, legs, hands or feet**

- eye problems. Your vision might become blurred, or you may see double. You might not see through one or both eyes for a while.
- feeling dizzy and having problems with your balance
- pain
- problems with walking
- problems with talking or swallowing
- muscle stiffness and spasms (sudden movements you can't control)
- your bladder or bowels not working properly
- shaking in your arms or legs called 'tremor'
- forgetting things and difficulties with your thinking
- sexual problems
- emotional issues. Feeling depressed or crying a lot can be a normal reaction to being told you have MS. But it can also be one way MS affects your brain.

Our website has information on managing MS symptoms. Just put in the search box the name of the symptom you're interested in. Or see pages 48 and 49 for how to order booklets or speak to our MS Helpline.

We also have an online course to help with fatigue. Put 'fatigue course' in the search box on our website.

Symptoms that you can't see

Not all symptoms of MS are obvious, so people might sometimes be less understanding. Symptoms that are invisible to others include pain, bladder or bowel problems and fatigue. Difficulties with your eyesight, balance, memory or thinking aren't obvious straight away, too.

When you have MS it can be frustrating if someone says ‘you look so well’. It can feel like they’re not taking seriously or even noticing your very real but invisible symptoms.

If you don’t have MS, bear these invisible symptoms in mind. For example, someone might not want to do something because their MS is making them feel exhausted. It’s not because they’re can’t be bothered.

> **“I manage my time carefully due to fatigue but I sometimes have a day where I sail through without much difficulty at all. Those days are precious and I really appreciate them. People without MS would just take that for granted!”**
> Ellie

What can help with symptoms?

If your MS has **relapses** (flare-ups of symptoms), treating it early with a **disease modifying therapy (DMT)** should make a real difference. You should get fewer relapses. And if you do get one, it should be less serious. You could also see a slowing down in how fast your symptoms or disability get worse. This can mean fewer symptoms to deal with. But when symptoms do happen, there are ways of managing them. Turn to pages 37 and 38 to learn more.

How is MS diagnosed?

Diagnosing MS isn't easy. Its symptoms can be confused with more common problems. Doctors must rule these out first before they look for signs of MS. It can take a long time from when you first notice something's wrong to when you're officially told you have MS.

There's no simple test for MS. A blood test won't show it. But blood tests might be used to rule out other causes for your symptoms.

Your GP can't diagnose MS – only a neurologist (a nerve specialist) can. If your GP thinks MS could be causing your symptoms, they'll send you to a neurologist for tests.

You can learn more by putting 'diagnosis' in the search box of our website. Or search 'have I got MS' to find our factsheet called 'Have I got MS? And why is it taking so long to find out?'.

Seeing the neurologist

When you see a neurologist, it can take a few tests and several months before you have a final diagnosis. This can be a frustrating time. Four types of tests can be used to diagnose MS:

- **a neurological examination**
- **MRI scans**
- **a lumbar puncture**
- **'evoked potentials' tests**

What are the tests looking for?

A neurologist looks for signs of how much damage has happened to your brain or spinal cord. To diagnose MS, they need to know that damage happened at different times and in at least two different parts of your brain or spinal cord.

Neurological examination

A neurologist will ask about your 'history' (your health problems and symptoms, now and in the past). A physical examination will check your movements, reflexes and senses, like your eyesight. Even if a neurologist suspects MS, you'll have other tests to be sure.

MRI (magnetic resonance imaging)

A machine called an **MRI** scanner takes pictures of your brain or spinal cord. You lie on a bed that slides into the scanner. You stay in it for a few minutes or up to an hour.

It uses strong magnetic fields and radio waves to build up a picture of the inside of your brain or spinal cord. On the scan an MS specialist can see any **inflammation** and damage MS has caused. These areas of damage are called **lesions**. Having a scan is painless, but it can be a bit noisy and feel a little claustrophobic.

MRI scans are the most accurate way of diagnosing MS. Over 90% of people have their MS confirmed this way.

Lumbar puncture

When you have a lumbar puncture (or 'spinal tap'), they put a needle into your lower back. It goes into the space around your spinal cord. You're given something to numb where the needle goes in. It can still be uncomfortable, and might give you a headache.

Some of the fluid around your spinal cord is taken out and checked. A doctor looks for signs that your immune system has been active in your brain and spinal cord (which shouldn't normally happen). If a doctor sees these signs, it means you're very likely to have MS.

'Evoked potentials' tests

These tests measure how fast messages travel between your brain, eyes, ears and skin. Your reactions will be slower if MS has damaged the **myelin** around nerves that control these parts of your body.

To test eyes, you're shown patterns on a screen. Electrode pads measure how fast your brain reacts to what you see.

To test your hearing, you'll listen to clicks through headphones. In another test you're given tiny shocks on your skin (it feels like 'pins and needles'), and the reactions of your muscles are measured.

People might still have evoked potential tests, but doctors use them less now. For example, instead of the eye test, you might have a scan of the main nerve in your eye.

When you're told you have MS

Finding out you have MS can bring up strong feelings. It's natural to feel afraid, confused, upset or overwhelmed. But you may feel relieved. You might have feared you had something fatal, like a brain tumour. Finally you know what's wrong, and that you're not imagining it. You can take steps to look after yourself. You can talk to your medical team about what treatments you might have.

Whatever your reaction, we're here to help you.

You can ask questions or talk to someone in confidence on our MS Helpline. Just call **0808 800 8000**. Page 48 tells you what services the helpline offers. We have MS nurses working on the helpline. In the 'How we can help you' section on page 42 you'll see what other services we offer.

> **"I felt relieved when I was told. A big weight off my shoulders. Nothing had changed within those split seconds. So I went off on holiday and decided to throw myself wholeheartedly into learning about it when I got home."**
> Eleanor

The different types of MS

When you’re diagnosed, you’ll usually be told you have one of three main types of MS.

Types of MS people are diagnosed with

When doctors tell someone they have MS, they usually give it one of these names:

- **relapsing remitting MS**
- **primary progressive MS**
- **secondary progressive MS**

The lines between these aren’t clear, even to specialists. A big difference between them is whether symptoms come and go (in the shape of relapses), or slowly keep getting worse. If you get relapses, there are now around 20 MS treatments called **disease modifying therapies (DMTs)** that can reduce your relapses. They can also slow down your MS.

Sometimes the type of MS that a person has becomes clearer over time. Then their neurologist might need to change the original diagnosis.

Relapsing remitting MS (RRMS)

This type of MS is often just called relapsing MS. You have a pattern of relapses (symptoms getting worse) followed by recovery (‘remission’). A relapse is a sign that your **immune system** is attacking part of your brain or spinal cord. It’s causing **inflammation** there.

Doctors used to believe that during ‘remission’ MS wasn’t causing any harm. We now know that even when you’re not having a relapse, MS can be damaging the myelin around your nerves.

With relapsing MS doctors can see inflammation on MRI scans in the form of new lesions. These are areas of nerve damage in your brain or spinal cord that the inflammation causes.

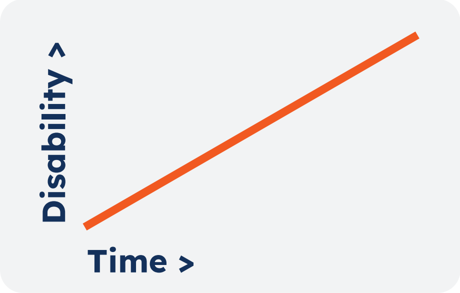
Your disability or symptoms don't get worse between relapses. But after each one things can end up worse than before. As time goes on your body finds it harder to repair the damage each relapse brings. So your disability or symptoms are likely to get worse, especially if you don't start treatment.

About 85% of people diagnosed with MS have this type to begin with. Women get relapsing MS more than men. We don't yet understand why. People are most likely to be diagnosed with MS in their 30s and 40s. But with relapsing MS the diagnosis often happens at a younger age. Relapsing MS has the best treatment options.

Put 'relapsing remitting MS' in the search box of our website to find more information about this type of MS. Or get our booklet 'Managing your relapses'.

Primary progressive MS (PPMS)

From the start, with primary progressive MS you usually don't have relapses. Instead there's a build-up of disability or symptoms that's usually quite slow. There's no (or much less) **inflammation** with this type of MS. The main damage to the nerves isn't caused by the immune system attacking the myelin around the nerves. Instead something else damages the nerves. We don't yet know what causes this. But eventually it causes them to stop working.



About 10-15% of people with MS have this type when they're first diagnosed. Men are just as likely as women to get it. People tend to be diagnosed in their 40s or older. Because the DMTs we have at the moment reduce inflammation, they don't work for most people with progressive MS.

For some people (about 1 in 20) their MS gets steadily worse, but they have inflammation on top of that, and maybe the occasional relapse. In the past this was called 'progressive relapsing MS'. Now it's more likely to be called 'active primary progressive MS'.

At the moment the drug ocrelizumab (also called Ocrevus) can help with the inflammation that comes with the early stages of primary progressive MS. The treatment called HSCT (stem cell therapy) might also be a possibility.

Put 'primary progressive MS' in the search box of our website to find more information about PPMS. Or get our booklet 'Understanding progressive MS'.

Secondary progressive MS (SPMS)

You only get this MS if you've already had relapsing remitting MS. Many people with relapsing MS see it turn into secondary progressive MS years later. With this type of MS your body can no longer repair the myelin. The pattern of relapses followed by recovery comes to an end. Inflammation and relapses usually stop, or they happen much less often.

Instead MS is now damaging your nerves in another way, a way we don't yet understand. Disability or symptoms used to be stable between the relapses. Now things gradually get worse. In the past it took around 20 years on average for relapsing MS to become secondary progressive.

Thanks to DMTs this is changing. Treatment is likely to mean:

- **fewer people go on to secondary progressive MS**
- **for those who do, it should take longer to happen**

It's not always easy for doctors to know when relapsing MS has become secondary progressive. If your disability or symptoms get steadily worse over at least six months, then it's likely your relapsing MS is now secondary progressive.

No one’s MS starts out as secondary progressive MS. But a few people, when first diagnosed with MS, are told this is the type they have. That happens if earlier they had symptoms of relapsing MS, but these were overlooked or misdiagnosed.

Put ‘secondary progressive MS’ in the search box of our website to find more information about this type of MS. Or get our booklet ‘Understanding progressive MS’.

Two broad types of MS

More and more doctors are simplifying things by dividing the different sorts of MS into two broad types: ‘active’ or ‘progressive’. Doing this helps people understand who will benefit from a DMT.

‘Active’ covers relapsing remitting MS. But it also includes a minority of people with primary and secondary progressive MS who still get relapses or their scans show new lesions. DMTs work against active MS.

‘Progressive’ covers most people with primary and secondary progressive MS. These people don’t have relapses or new lesions on their scans. DMTs don’t work for them.

Active MS

Your **immune system** is active, causing relapses or **inflammation** in your brain or spinal cord. Doctors can see signs of this activity on your MRI scans in the shape of lesions, areas of nerve damage.

For most people, in the early years at least, their MS is the active kind. A relapse is a clear sign that your immune system is attacking the myelin covering around your nerves.

Your body does its best to repair the damaged myelin. That's why your symptoms usually get better or go away completely after a relapse. Your brain can also send signals along different nerves to get around the damaged ones.

Active MS has the best treatment options. Around 20 DMTs can help with this type. They dampen down inflammation or stop attacks by your immune system. When you're on a DMT you get less inflammation and fewer (and less serious) relapses. A DMT can also slow down how fast your disability or symptoms get worse.

If your MS doesn't cause relapses or inflammation, then doctors say it's 'not active'. Your MS is called 'progressive' instead.

Progressive MS

From the very start of their MS a smaller number of people have MS that gets steadily worse over the years. They don't get relapses or inflammation (or get very little), so it's not described as 'active'. This kind of MS is called 'progressive', or 'MS with progression'.

In progressive MS it's not inflammation that's damaging the nerves, but something we don't yet understand. Eventually the nerves can stop working completely.

Another much bigger group of people start off with active MS. But many years later they see their relapses and inflammation stop. This means their MS has now become progressive.

Progressive MS doesn't have the many treatment options that we have for active MS. your eye.

Do DMTs help with progressive MS?

DMTs don't work for most people with progressive MS. That's because there's no inflammation for a DMT to dampen down or attacks by the immune system to stop.

But there's an exception. The minority of people with progressive MS who still get some relapses and inflammation can benefit from a DMT.

Since 2020 there are two new drugs to treat progressive MS when it also has an 'active' side to it (with inflammation or relapses). One is ocrelizumab (Ocrevus) for early active primary progressive MS. The other is siponimod (Mayzent) for active secondary progressive MS. HSCT might also be a possibility for some people with active primary or secondary progressive MS.

What about people with progressive MS who have no relapses or inflammation? They need drugs to protect the nerves and repair the myelin that covers them. These don't exist yet, but trials are now underway to test several promising drugs.

You'll find more on treating MS on page 36.

Treatment options and types of MS at a glance

Active MS

(with relapses or inflammation seen on scans)
= around 20 DMTs can help

Progressive MS that's also active

(still inflammation or the occasional relapse)
= a small number of DMTs might help

Progressive MS that's not active

(with no relapses or inflammation)
= no strong evidence that DMTs we have at the moment can help

Read more about the different types of MS on our website by searching for 'types of MS'.

Treating MS

There's no cure for MS. But there treatments for the symptoms of MS. And some can slow down the MS itself.

Slowing down MS and cutting relapses

The biggest long-term difference people can make to their MS is to take a disease modifying therapy (DMT). They're called 'disease modifying' because they change the underlying course of MS, rather than just help make symptoms better.

They can:

- **slow down how fast your disability or symptoms get worse**
- **reduce how many relapses you get, and make the ones you have less serious**

For some people these drugs work so well that there are no signs that their MS is still active at the moment. DMTs include tablets, injections or **infusions**.

Most DMTs we have right now only work against MS that causes relapses or inflammation in your brain or spinal cord. So all DMTs work against relapsing MS. Two or three also work against progressive MS if it still has relapses or doctors can see inflammation on MRI scans.

For more on these treatments search our website for 'disease modifying therapies'.

Treating a relapse

Some milder relapses won’t need any special treatment. Just keep on taking your DMT if you’re on one. A short course of steroids can speed up how fast you get over a more serious relapse. Steroids are taken as a pill or through a ‘drip’ that goes into a vein in your arm.

Steroids make a relapse shorter. But they don’t make any difference to how much permanent disability the relapse might leave you with.

Rehabilitation after a relapse can help you revover. This includes physiotherapy, occupational therapy, advice on what you eat, and support at work and in your home.

Put ‘managing relapses’ in the search box of our website to find more information.

> **“My life had another big change a few months after my diagnosis. I met my future husband and although in some respects the brakes were put on in my life, in others I did the things I had always hoped for.”**
> Rachel

Managing symptoms

Treatments for MS symptoms include medicines, physiotherapy, and alternative or complementary therapies. They might not get rid of a symptom totally, but they can make it easier to live with.

Over time people learn what makes their symptoms worse or better. They learn how to best use the treatments on offer, and how to get help from their medical team. All this helps them control the things that can be controlled, and deal better with what can't be.

Physiotherapy can help with muscle stiffness. Occupational therapy can help you make adjustments and find practical solutions or techniques for a particular symptom (like tremor, which is shaking that you can't control). This can be at home or in the workplace.

Some people with MS use complementary and alternative therapies. Massage, reflexology, yoga, acupuncture and t'ai chi are some examples. For a lot of these kinds of treatments there's not much evidence showing they have an effect. But some people say they can help with symptoms or make them feel better in general.

To find out more put 'alternative therapies' in the search box on our website. Search 'stay active' for yoga and Pilates videos, and support with keeping active.

Stress and sleep

Many people say stress affects how they feel and makes their MS worse. Lowering your stress levels can definitely improve your overall health and how you feel. Some studies show a link between MS and stress, but others don't. Some show stress over a long time or poor sleep can trigger a relapse.

Our website has a page on stress, anxiety and how to better manage it. Find it by putting 'stress' in the search box.

What you eat

If you have a long-term health problem like MS, a healthy, balanced diet is especially important. Lots of people say they feel better for it. It also helps you avoid infections and recover from illness faster. Healthy eating keeps up your strength and energy levels.

There are people who follow special MS diets. They say it helps with certain symptoms, makes them feel better or gives them a feeling of control. But that's not the case for everyone.

Some people believe a special diet will make a difference to their MS, its symptoms and how many relapses they have. There's little evidence these diets can slow down MS or reduce relapses. But some studies have shown certain special diets could help with MS fatigue.

We have more information on food, including special diets, on our website. Find it by putting 'diet' in the search box on our site. Or see pages 48 and 49 for how to order booklets or speak to our MS Helpline.

Staying active

Staying physically active has real health benefits if you have MS. It could be any activity that suits you. Gardening, walking or exercises you do at home all count.

Regular exercise has been shown to help with some MS symptoms such as bladder and bowel problems, fatigue, and muscle stiffness or spasms. It can help keep you mobile by making your muscles stronger or improving your posture. It can boost your mood and keep your memory and thinking sharp. This is important as MS can affect all these.

Find our exercise information and videos by searching our website for ‘MS and exercise’. Our MS Helpline can tell you about our service that helps people boost their physical activity.

Who can help with symptoms?

Lots of different health and social care specialist can help, including your neurologist and GP. There are also MS nurses, speech and language therapists, continence advisers (for bladder or bowel problems), physiotherapists, psychologists and occupational therapists.

For information just put the name of the symptom you’re interested into the search box on our website.

Pregnancy and MS

MS often affects women at an age when they're thinking about having children. You can still do this. MS doesn't make it harder to get pregnant. You're less likely to have relapses while pregnant. But you might be more likely to have one after you've given birth if you don't take a DMT. In the long run getting pregnant doesn't make MS worse.

If you get pregnant, it doesn't always mean you must stop taking your MS drugs. Some DMTs you must not take during pregnancy but others you can. Tell your MS specialist if you're thinking of starting a family. They'll advise you.

Read more about pregnancy and DMTs on our website. Put the name of the DMT in the search box on our website. You'll find information on pregnancy included for each drug.

How can we help you?

We support thousands of people with MS and their families, carers and friends.

As part of our Living Well support we have a range of online help. This covers courses for newly diagnosed people, information sessions (‘webinars’) and online support groups. See what’s on offer by putting ‘virtual support events’ in the search box of our website. Or search for ‘newly diagnosed’ to find details of what we offer.

You can get confidential support and information from our freephone MS Helpline on **0808 800 8000**. Or email them on **helpline@mssociety.org.uk**

We have local groups across the country offering support and information. Find ones close to you by searching our website for ‘local support’.

If you’ve recently found out you have MS, our booklet ‘Just diagnosed’ should be useful. On page 49 you’ll see how to order it and other booklets and factsheets covering every part of living with MS. See what’s available for searching our website for ‘resources and publications’.

Join our online community

You’ll find lots of people with or affected by MS on our online forum: **forum.mssociety.org.uk** There’s a section for people who’ve recently found out they have MS.

Research

Research is seeing great progress. It's making a real difference to the lives of those of us with MS. The MS Society is funding new research into why MS happens and treatments to stop or slow it down. We're helping to find better treatments for symptoms, too. We're also developing services to make people's lives better.

Find out what we're funding, the latest scientific breakthroughs and ways you can help by searching our web site for 'explore our research'.

Help us raise vital funds

For how to help us search our web site for 'my MS fundraising'.

Volunteer

To find ways to put your spare time to good use, search our web site for 'volunteer with us' or call **0300 500 8084.**

Campaign with us, locally and nationally

To help change things for people with MS search our website for 'campaign with us', call **0300 500 8084** or email **campaigns@ mssociety.org.uk**'

Join the MS register

The UK MS Register is a unique project aiming to revolutionise our understanding of MS and the impact it has on the lives of people with MS. There are many things we know about MS, but so much more that only people with MS can tell us. How many people are there with each type of MS? How does it affect them? What services are most needed?

That's where the UK MS Register comes in. This ground-breaking work combines clinical and NHS data with the first-hand experiences of people with MS, to build a picture of what it's like to live with MS.

Knowing this could transform the development and delivery of research, care and services for people with MS.

Anyone over the age of 18 with a confirmed diagnosis of MS and an email address can join the UK MS Register at **ukmsregister.org**

New words explained

Auto-immune disease – a type of disease where a person's own immune system attacks a part of their body by mistake. In MS the attack targets the myelin around nerves

Central nervous system – your brain and spinal cord. Nerves carry messages between the two. These signals control how parts of your body work

Disease modifying therapy (DMT) – a treatment that can be used if your MS has relapses, or doctors see inflammation on your MRI scans. DMTs reduce how many relapses you get or make them less serious. They can also slow down how fast your symptoms or disability get worse. Most DMTs available at the moment don't work for most people with progressive MS

Immune system – how your body defends you against things that give you infections or diseases (like viruses and bacteria). In MS this system goes wrong and it attacks nerves in your central nervous system

Inflammation – this is your body's reaction when a part of it is damaged or attacked. In MS your immune system attacks the myelin covering around nerves in your brain and spinal cord. The attack causes inflammation along the nerve that strips away the myelin. Left untreated, inflammation can damage the nerve for good, causing MS symptoms

Infusion – a way of taking a drug. Also called a 'drip'. The drug goes into your body through a needle into a vein in your arm while you sit in a chair or lie on a bed. An infusion takes two to four hours depending on the drug.

Lesions (also called 'plaques') – areas of damage caused by MS in your brain or spinal cord. They slow down or stop messages travelling down nerves, affecting your control of parts of your body. Lesions can be seen on MRI scans

MRI scans – pictures of inside your brain or spinal cord made by 'magnetic resonance imaging'. They show where MS is causing inflammation and damage to the myelin around the nerves

Myelin – a fatty covering around a nerve that protects it and helps it work better. In MS, myelin is attacked by mistake by your immune system. This damages the myelin causing the symptoms of MS. Signals along your nerves that control parts of your body get interrupted

Obese – being very overweight. Defined by the NHS as a body mass index (BMI) over 30 and over. Find out your BMI at **nhs.uk** Search for 'BMI calculator'.

Plaques – see lesions

Relapse – a flare-up or attack of your MS. New symptoms appear or old ones get worse. Symptoms then go away, get less noticeable, or become permanent. To qualify as a relapse any new or worsening symptoms must last more than 24 hours. And 30 days must also have passed since your last relapse or flare-up of symptoms. There must be no other possible reason for your symptoms, like an infection or you being hot.

Further information

MS Helpline

Our MS Helpline gives emotional support and information to anyone living with MS. And through the helpline you can also access our:

- **MS nurses**
- **MS benefits adviser**
- **MS legal adviser**
- **Physical activity service**
- **Short breaks service**

We can provide information in different languages through an interpreter service. And by text relay and British Sign Language interpreters.

Find out more at **mssociety.org.uk/helpline**

0808 800 8000
(Mon-Fri 9am to 7pm except Bank Holidays)

helpline@mssociety.org.uk

Or direct private message us on **Facebook** (Mon-Fri 9am to 7pm)

> **“I was just sent away with my diagnosis. No one gave me any information or help, which made things worse and made me worry more. Thankfully I contacted the MS Society for information and the MS Helpline for some much-needed help.”**
> Carole

Resources

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

You can read them online or download at **mssociety.org.uk/publications**

You can order printed resources from **onlineshop.mssociety.org.uk** or call **0300 500 8084** and select option 4.

Two more of our booklets you might be interested in:

‘For family and friends’ is for when someone in your life finds out they have MS.

‘Supporting someone with MS’ has practical information if you look after someone with MS.

Search our website using those titles to download them. Or order them free as explained above.

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet.

We’d love to hear what you think about this information at **mssociety.org.uk/yourviews**

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. Seek advice from the sources listed.

References

Email us if you'd like to know the references for this information at **supportercare@mssociety.org.uk**

The number of people with MS figure on page 12 comes from The Health Improvement Network (THIN) Database (A Cegedim Proprietary Database). That uses data provided by patients and collected by the NHS as part of their care and support.

Photography

Credit for photography belongs to Rebecca Cresta (p9), Paul Moane (p22), Simon Rawles (p26) and Davie Dunne (p45)

This resource is also available in large print.

Call **0300 500 8084** or email **shop@mssociety.org.uk**

MS Society

Contact us:

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This title will be reviewed within three years of publication (July 2027).