

The logo for MS Society, featuring the letters 'MS' in a bold, orange font, followed by the word 'Society' in a smaller, white font, all contained within an orange triangle pointing to the right.

MS Society

A photograph of two women sitting at a table, smiling. The woman on the left has blonde hair and is wearing glasses and a dark patterned sweater. The woman on the right has dark hair and is wearing a grey sweater. The background is a simple, light-colored wall with a wooden chair back visible.

What is MS?

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.
- Visiting us at: **mssociety.org.uk/donate**
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

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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 MS 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 with what we haven't got.

A handwritten signature in black ink that reads "Eiona". The signature is written in a cursive, flowing style with a large initial 'E'.

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, especially if treatment starts early
- 5 If you have MS, it may mean making some changes. But you can still achieve what you always wanted to



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.

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, new ones keep being launched. Recently we've seen some major breakthroughs.

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

At the MS Society we're here to help you – or the person with MS that you know – 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.

You can contact our MS Helpline to talk about anything to do with MS. Call us on **0808 800 8000** (closed weekends and bank holidays). Or email **helpline@mssociety.org.uk**

You can send us a private message by visiting our Facebook page **facebook.com/MSSociety**. Use the 'send message' tab on the page.

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

What is MS?

Multiple sclerosis, or MS, is a neurological condition. That means it affects your **nerves**. The specialist doctors who look after people with MS are called **neurologists**.

You can't catch MS from someone. You get it when your **immune system** isn't working properly. Your immune system normally protects you by fighting off infections. In MS it attacks your nerves by mistake.

“MS is a significant part of me, but it's far from the most interesting part.”

Helen

“Yes, MS is serious and, yes, it does change your life. But you can still enjoy your life.”

Louisa

These nerves control lots of different parts of your body and how they work. That's why, if you have MS, you can get its symptoms in many parts of your body and it can affect lots of things your body does. This is why everyone's MS is different.

“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

What's happening in MS?

Your brain and spinal cord 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.

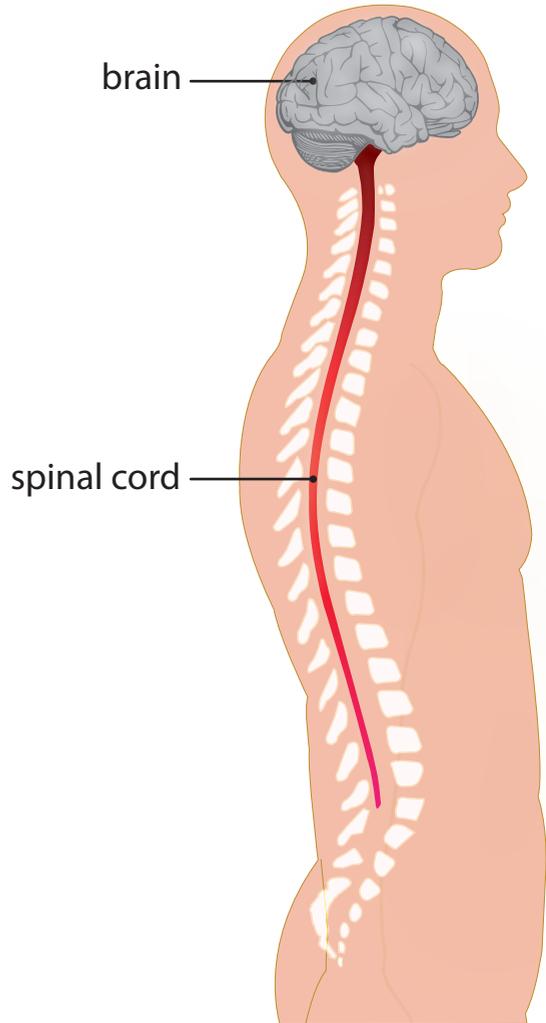
These signals control how parts of your body move or work. They let you feel things like pain, touch and so on.

Your immune system protects you from infections. It does this by attacking and killing viruses and bacteria that get into your body.

But in MS your immune system attacks the covering around nerves in your brain and spinal cord by mistake. This can damage the nerve.

How your immune system damages nerves

Around nerves there's a fatty covering called **myelin**.



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

It protects each nerve from harm and helps messages travel along it.

When you have MS, your immune system attacks this myelin covering. It strips the myelin away, leaving the nerve open to damage.

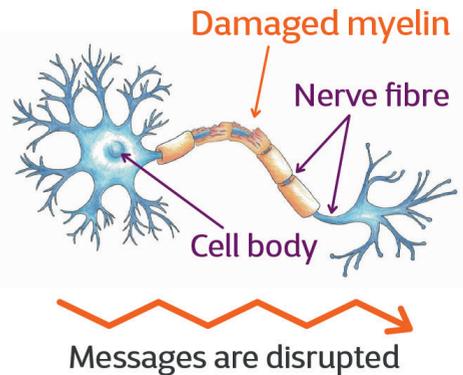
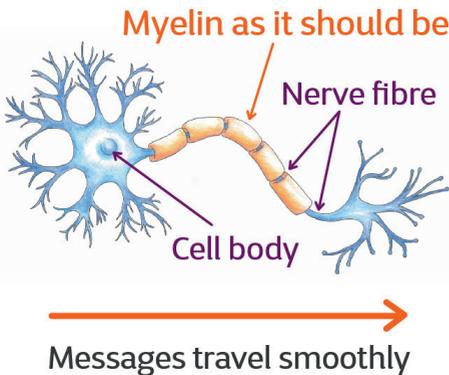
Inflammation also happens as part of this attack. Left untreated, inflammation will damage the nerve underneath too.

All this damage means messages find it harder to get through – or can't get through at all. That's when symptoms of MS begin. Eventually so much damage takes place that the myelin can't repair itself and the nerve dies.

Think of this being like an electric cable. The wire inside it is like your nerve. Electricity travels down the wire so the machine at the other end will work.

This is like when your brain sends a signal down your nerve to tell a part of your body what to do.

A cable has a plastic covering around the wire to protect it from damage. If the cable's covering gets broken it can mean electricity won't get through like it should and the machine won't work properly. Myelin protects your nerves in the same way.



Why do some people get MS?

In the UK around 1 in 500 of us has MS. That's over 130,000 people. Each week over 100 people are told they have it. Nearly three times as many women have MS as men. We don't know why yet.



In the UK, people are most likely to find out they have MS in their thirties, forties and fifties. But the first signs of MS often start years earlier. It's rare that children get MS.

Nobody knows for sure why MS happens to some people. What we know is growing 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 too. That's because genes alone don't decide who gets MS.

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

Most people with MS have no history of MS in the family. But if you do have a close relative with MS, the chances that you'll get it are a bit higher, although the risk is still low.

Researchers have worked out figures for the risk of getting MS. The next page looks at these risks.

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) |
| a child with MS | 2.1% chance (1 in 48 get it) |
| an identical twin with MS | 18% chance (1 in 5 get it) |

If your aunt, uncle, cousin, nephew or niece has MS, your risk is around 1% (1 in 100 get it).

Risk over your lifetime of getting MS if you:



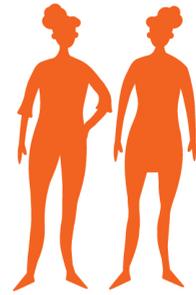
Have a parent
with MS

1.5%



Have a brother or
sister with MS

2.7%



Have an identical
twin with MS

18%

If you have MS and want a child, there's only a 1 in 67 chance he or she will get it too. In 2014 a large study found that MS may be even less likely to be passed on than these figures suggest.

Find more information on genes on our website mssociety.org.uk. Just put 'genes' in the search box.

Environment

There are things in the world around you that might affect your risk of getting MS, such as:

- some infections
- sunshine (and the vitamin D you get from being in the sun)

Infections

There's growing evidence that some viruses, and maybe bacteria, can help cause MS, especially the Epstein Barr virus. This is the virus that causes glandular fever.

This doesn't mean you get MS if you've had glandular fever. Most of us have had this virus but very few of us get MS.

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



Vitamin D

Years ago it was noticed that you find more people with MS the further away you go from tropical countries near the equator, where there's a lot 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 (oily fish, eggs, spreads and breakfast cereals with added vitamin D, for example). It's almost impossible to get all the vitamin D you need through food alone. 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 (then it's harder for your 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 isn't 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. There's no proof that extra vitamin D protects against getting MS. Researchers are looking into that.

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

take extra vitamin D. There's no hard evidence yet that doing this slows down MS or helps with symptoms, but studies are looking into this, too.

That said, 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 of her baby getting 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 as taking too much can be harmful. Some MS doctors suggest people with MS take higher doses than other people, all year round.

You can read more about MS and what you eat, including vitamin D, in our diet information. Put 'diet and nutrition' or 'vitamin D' in the search box on our homepage.

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 - is also linked to a higher risk of getting MS.

Studies show that stopping smoking could slow down how fast you go from having relapsing MS to secondary progressive MS. You can read more about these different types of MS on page 24.

If you want to stop smoking, your GP can suggest things to help. This website has ideas and support, from nicotine gum and patches to e-cigarettes:

[nhs.uk/smokefree](https://www.nhs.uk/smokefree)

Obesity

Studies have found that being very overweight (obese), especially when a child or young adult, is linked to MS. This could be because being very overweight can:

- make you low in vitamin D
- or make your immune system overactive and cause inflammation inside your body

There may be other reasons we don't yet understand.

Of course, not everyone who's obese gets MS - and not everyone with MS is - or was - very overweight. But if the risk of getting MS is on your mind, for

example, because a close relative has it, your weight is a risk factor you can change.

MS is no one's fault

Hearing about things that 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 can be linked to other things that you have no control over. These include your genes, what sex you are, or what infections you've had.



What are the symptoms?

MS damages nerves in different parts of your brain and spinal cord. Where this damage is will affect which part of your body gets symptoms.

Symptoms can be unpredictable. They can change from day to day, even hour to hour. They could last days, weeks or months. Depending on the type of MS, these symptoms could stay, ease off or go away completely.

Some people find getting hot, tired or stressed, or exerting themselves can make symptoms worse or trigger a **relapse** (a flare up of your MS symptoms).

Everyone has their own symptoms and they won't be the same as other people's. And how MS develops over time is unique to each person.

Types of MS symptoms

No-one is likely to get all the 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. You may get numbness or tingling in your arms, legs, hands or feet
- Eye problems. Your sight might become blurred or you may see double. For a while you might not see through one or both eyes
- Feeling dizzy and having problems with your balance
- Pain
- Problems 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

We have information on managing the symptoms of MS. Search our website or see page 38 for how to order booklets or speak to our MS Helpline.

We also have an online course to help you with fatigue – search our website for 'fatigue course'.

Symptoms you can't see

If people see someone has a symptom of MS, they can understand and offer help. But some symptoms you can't see.

Things that aren't obvious include pain, bladder or bowel problems, fatigue and difficulties with your balance, memory or thinking. It might not be easy to explain these to people.

When you have MS it can be frustrating if someone says 'you look so well'. It can feel like your very real but invisible symptoms are being overlooked. This can be even more of an issue at work.

“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

If you don't have MS, bear these invisible symptoms in mind. Someone might not want to do something because their MS is making them feel exhausted, for

example. It's not because they're being lazy or can't be bothered.

What can be done about symptoms?

If your MS has **relapses**, treating it early with a **disease modifying therapy (DMT)** can make a real difference. It can mean you get fewer relapses and you 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 page 30 to learn more.



How is MS diagnosed?

Diagnosing MS isn't easy. 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 that you have MS.

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

Only a neurologist can diagnose MS, not your GP. If your GP thinks MS could be causing your symptoms, they'll send you to a neurologist for tests.

You can learn more in our information about 'Have I got MS? And why is it taking so long to find out?' Find it by putting 'have I got MS' in the search box on our website's home page.

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 are used to diagnose MS:

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

What do the tests look for?

A neurologist looks for signs of how much damage has happened to your **central nervous system**.

To diagnose MS, they need to know that damage has happened at different times and in at least two different parts of your brain or spinal cord. In most cases MRI scans are used to help show this.

Neurological examination

A neurologist will ask about your 'history'. This means your

health problems and symptoms, now and in the past. A physical examination will check your movements, reflexes and senses, such as your eyesight. Even if a neurologist suspects MS, other tests are needed 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 there for a few minutes or up to an hour.

Using strong magnetic fields and radio waves it builds 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** (or sometimes **plaques**).

Having a scan is painless but 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

During a lumbar puncture (or ‘spinal tap’) a needle is put into your lower back, into the space around your spinal cord. A little bit of fluid is taken out and checked for signs that your immune system has been active in your brain and spinal cord (which doesn’t happen if you don’t have MS). These signs, which can include ‘**antibodies**’, show that you’re very likely to have MS.

You’re given something to numb where the needle goes in. It can still be uncomfortable and might give you a headache.

‘Evoked potentials’ test

This test measures how fast messages travel between your brain and your eyes, ears and skin. If MS has damaged the myelin around nerves that control these parts of your body, then your reactions will be slower.

To measure your eyes, you’re shown patterns on a screen. Pads on your head measure how 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'). The reactions of your muscles are measured.

When you're told that you have MS

Finding out that you have MS can bring up strong feelings. It's natural to feel afraid, confused, upset or overwhelmed.

You may feel relieved. You might have feared you had something that could be fatal, like a brain tumour. Finally you know what's wrong, and that you're not imagining it. And 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 support you. There's our MS Helpline, our online and printed information, our local groups and the forum on our website.

- MS Helpline **0808 800 8000** (closed weekends and bank holidays). Our helpline will know if we run sessions for

newly diagnosed people in your area

- Find your nearest support group at mssociety.org.uk/near-me
- Chat to people with MS on our forum at mssociety.org.uk/forum

If you've recently found out that you have MS, two of our booklets could be useful: 'Just diagnosed' and 'Living with the Effects of MS'.

If someone close to you has been diagnosed with MS, check out our booklets 'For family and friends' and 'Supporting someone with MS'.

"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

We can put MS into two broad types. More and more doctors describe it as either ‘active’ or ‘progressive’. The type you have will decide whether you can benefit from the MS drugs called DMTs.

Active MS

Active MS means you get relapses, or MRI scans show signs that your MS is causing **inflammation** in your brain or spine.

For most people with MS, in the early years at least, they get relapses. These are periods when your immune system attacks the myelin covering around your nerves. During a relapse new MS symptoms appear or old ones get worse.

Your body does its best to repair the damaged myelin. That’s why your symptoms usually get better or even go away completely after a relapse.

When the relapse is over, this is called ‘remission’. 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 active MS doctors can see inflammation on MRI scans in the form of new lesions. This is an area of damage to nerves in your brain or spinal cord caused by the inflammation. Active MS, with its relapses and inflammation, has the best treatment options.

Over a dozen treatments can help with this type of MS. They’re called **disease modifying therapies (DMTs)**.

They work by dampening down the immune system’s attacks so that you get less inflammation. They can also cut the number of relapses you have, or make relapses that you do get less serious. Taking a DMT can also

slow down how fast your disability or symptoms get worse.

If your MS doesn't cause relapses or inflammation, then it can be described as 'not active'. Then your MS can be called 'progressive' instead (see next section).

People with all types of MS often describe it as 'active' during a flare up of their symptoms, or if their MS is generally getting worse. But that shouldn't be confused with when doctors use 'active' to mean someone's MS is causing inflammation or relapses.

Progressive MS

A smaller number of people have MS that, from the start, gets steadily worse over the years. They don't get relapses or inflammation (or get very little), so it's not described as 'active' in that sense.

This kind of MS is called 'progressive' (or 'MS with progression'). In progressive MS something is damaging the nerves but it's not only inflammation. We don't yet know what.

Another, and much bigger, group of people start off with active MS.

But many years later they see their relapses and inflammation stop and their MS becomes progressive. Progressive MS doesn't have the many treatment options that we have for active MS (with relapses and inflammation).

Can DMTs help with progressive MS?

DMTs don't work for most people with progressive MS. There's one exception: the minority of people with progressive MS who still get some relapses or inflammation. They might benefit from a DMT because it can dampen down this inflammation and reduce relapses.

Since 2020 there are two new DMTs to treat progressive MS when it also has an 'active' side to it (with inflammation or relapses).

What about people with progressive MS who have no relapses or inflammation? They need drugs to protect nerves and repair the **myelin** that covers them. Research is making progress on finding these drugs. Page 29 has more on treating MS.

Treatment options and types of MS at a glance

- active MS (with relapses or inflammation on scans) = over a dozen DMTs can help
- progressive MS that's also 'active' (still some relapses or inflammation) = a few DMTs might help
- progressive MS that's not active (no relapses or inflammation) = no evidence that DMTs we have at the moment can help

Other names for types of MS

You can further divide MS into three main types. When doctors tell someone they have MS, they usually give it one of these names:

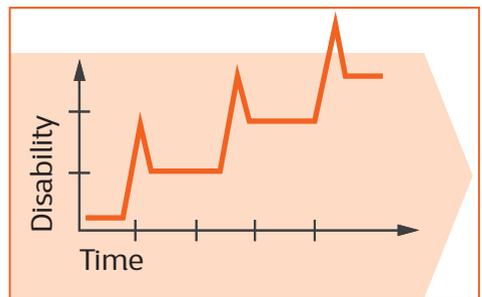
- relapsing remitting MS
- primary progressive MS
- secondary progressive MS

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 (usually without relapses). There are only treatments if you get relapses or doctors see inflammation on your scans.

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

Relapsing remitting MS

With this type of MS you have a pattern of relapses (symptoms getting worse) followed by recovery ('remission'). Your disability or symptoms don't get worse between relapses. But after each relapse it 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 of MS to begin with. Women get relapsing MS more than men. We don't yet understand why.

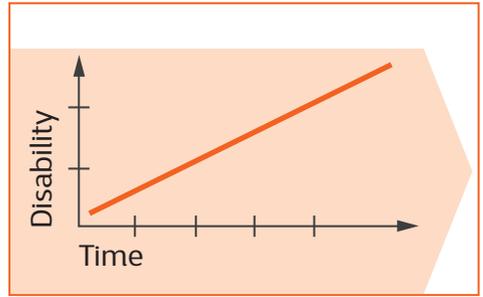
Most people are diagnosed with MS in their 30s to 50s. But with relapsing MS the diagnosis is more likely to happen at a younger age. Over a dozen **disease modifying therapies (DMTs)** can help with relapsing MS.

Put 'relapsing remitting MS' in the search box of our website to find out more. Or get our booklet 'Understanding relapsing remitting MS'.

Primary progressive MS

From the start, with primary progressive MS you usually don't have relapses. That's because there's no (or much less) **inflammation** with this type of MS.

The immune system isn't attacking myelin around the nerves. And inflammation isn't hurting the nerves either. Instead something else is damaging them. We don't know what. With this MS there's a build up of disability or symptoms that's usually quite slow.



10–15% of people with MS have this type. 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 right now 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 relapses and inflammation on top of that. This was called 'progressive relapsing MS'. Now it's more likely to be called 'active primary progressive MS'.

A few DMTs can help with the inflammation that comes with the relapsing part of this type of MS.

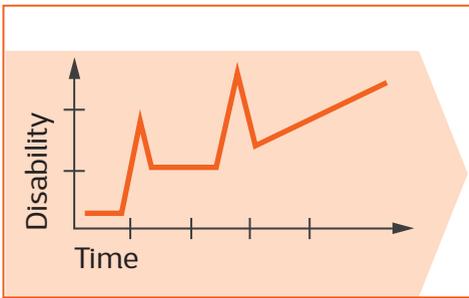
For more information put 'primary progressive MS' in our website's search box. Or get our booklet 'Understanding progressive MS'.

Secondary progressive MS

You only get this MS if you've already had relapsing remitting MS. Many people start off with relapsing MS then see it turn into secondary progressive years later.

With this type of MS your body can't repair the myelin anymore, so the pattern of relapses followed by recovery comes to an end. Inflammation and relapses usually stop, or happen much less often.

Instead MS is now damaging your nerves in another way, a way we don't yet understand. Your disability or symptoms used to be stable between your relapses. But now it gradually gets worse.



In the past it usually took around 20 years on average for relapsing MS to change into secondary

progressive MS. But thanks to DMTs this is changing. Treatment is likely to mean:

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

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

No one's MS starts out as secondary progressive MS. But a few people, when they're first diagnosed with MS, are told this is the type they have. That can happen if earlier on you 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'.

Treating MS

There's no cure for MS but it can be treated in different ways. Some treatments tackle the underlying MS. They slow down how quickly it gets worse. Other treatments help with particular MS symptoms, but don't make any difference to the MS underneath.

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 make its 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 can work so well that there are no signs that their MS is still active at the moment.

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.

A small number also work against some types of progressive MS. But only if the person with progressive MS still gets relapses, or inflammation can be seen on their MRI scans.

For more on these treatments check out our information at mssociety.org.uk/dmts

Treating relapses

Some milder relapses won't need any special treatment (just keep on taking your DMT if you're on one). You can speed up how fast you get over more serious relapses with a short course of steroids. These are taken as a pill

or through a 'drip' that goes into a vein.

Steroids make a relapse shorter but they don't make any difference to how much permanent disability the relapse can leave you with.

Rehabilitation after a relapse can help you get over it. This includes physiotherapy, occupational therapy, advice on what you eat and support at work and with help 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 any 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 might help with something like tremor (shaking that you can't control). Occupational therapy means making adjustments and finding practical solutions or techniques for a particular symptom. 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 examples. For a lot of these kind

of treatments there's not much evidence showing they have an effect. But some people say they can help with symptoms, or just make them feel better in general.

To find out more about these treatments put 'alternative therapies' in our website's search box. Search 'stay active' for yoga 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.

We have information on stress, anxiety and how to better manage it. To find it put 'stress' in the search box on our website.

What you eat

A healthy, balanced diet is good for all of us. Eating healthily is all the more important if you have to

cope with a long-term condition like MS. Lots of people say they feel better for it. It also helps you avoid infections, recover from illness faster, and keeps up your strength and energy levels.

Some people follow special 'MS diets'. They hope it will make a difference to their MS, its symptoms and, if they get relapses, how many they have. But there's little evidence these can slow down MS or reduce relapses.

We have more information on food, including special diets. Find it by putting 'diet' in the search box on our website.

Exercise

Staying physically active has real health benefits if you have MS. This doesn't have to mean sport if you don't feel that's right for you. It could be any activity that suits you such as gardening, walking or exercises you do at home.

Regular exercise has been shown to help with some MS symptoms such as fatigue, bladder and



bowel problems and muscle stiffness or spasms.

If you have some disability, exercise 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 these.

Find information and videos by searching our website for 'MS and exercise'. Our MS Helpline can tell you about services that can boost your physical activity.

Who can help with symptoms?

Lots of different health and social care specialist can help. These include speech and language therapists, continence advisers (for problems with your bladder or bowels), 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 of 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. You mustn't take some DMTs during pregnancy, but others you can. Tell your MS specialist if you're thinking of starting a family. They'll advise you.

More detailed information on getting pregnant and taking a DMT is in our factsheet about each individual drug. Find each factsheet by putting the name of the DMT you're interested in the search box on our website.

How can we help you?

We support thousands of people with MS and their families, carers and friends. We have local groups across the country offering support and information.

Find ones close to you at:

mssociety.org.uk/near-me

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

You can check out our booklets and factsheets covering every part of living with MS at: mssociety.org.uk/ms-resources/key-publications

Our MS Helpline can discuss the information available and order it for you.

Join our community

You'll find lots of people with or affected by MS on our online forum, a part of our website. There's a section for people

who've recently found out they have MS.

mssociety.org.uk/forum

Research

Research is seeing great progress against MS and making a real difference to the lives of those of us with MS.

We are 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 at mssociety.org.uk/research

Help us raise vital funds

mssociety.org.uk/fundraising

Volunteer

mssociety.org.uk/volunteering
0300 500 8084

Campaign with us, locally and nationally

campaigns@mssociety.org.uk
0300 500 8084

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 msregister.org

New words explained

Antibodies – these are made by your immune system to kill things like viruses and bacteria that get into your body. If antibodies can be found in the fluid around your spinal cord, it's a strong sign that you might have MS

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 drug that can be used if your MS has relapses. They 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 against 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 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

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 that protects parts of your nerves. When you have MS, myelin is attacked by mistake by your immune system. This interrupts messages that travel along your nerves and that control parts of your body, causing the symptoms of MS

Nerves – bundles of fibres along which signals travel from your brain or spinal cord. These nerve signals control how parts of your body work and make sure your thinking and memory work correctly

Obese – being very overweight. Defined by the NHS as a body mass index (BMI) over 30 and over. Find out your BMI at [nhs.org.uk](https://www.nhs.org). Search for 'BMI calculator'

Plaques – see **lesions**

Relapse – a flare up or attack of your MS when you get new symptoms or old ones get worse. Symptoms then go away, get less noticeable, or they can 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, such as an infection or you being hot.

Further information

Resources

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

You can read them online or download. And you can order printed resources from onlineshop.mssociety.org.uk or call **0300 500 8084** and select option 4.

MS Helpline

Our free MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

We can provide information

- in different languages through an interpreter service
- by text relay and British Sign Language interpreters

mssociety.org.uk/helpline

0808 800 8000

(closed weekends and bank holidays)

helpline@mssociety.org.uk

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet, in particular Alan Izat, Maureen Ennis, Audrey Owen and Carmel Wilkinson.

We'd love to hear what you think about this information
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
supportercare@mssociety.org.uk

Photography

Credit for photography belongs to Simon Rawles (p13, 16 and 23), Rebecca Cresta (cover and p6), Davie Dunne (p32) and Amit Lennon (p19).

This resource is also available in large print.

Call 0300 500 8084 or email supportercare@mssociety.org.uk

Contact us



MS Helpline

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MS National Centre

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