Just diagnosed

An introduction to 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, 9am – 5pm
- Visiting us at: **donate.mssociety.org.uk**
- Posting your donation to:
  MS Society,
  8 City North Place,
  London N4 3FU.
- Please make cheques payable to the 'MS Society.'

Contents

A word from Cath, who has MS

It took about four years for me to be diagnosed. Right up to the final test, I was being reassured by the doctors that my symptoms were due to a spinal cord injury in my neck.

So when the diagnosis was confirmed, I was in a state of shock. I didn't want to tell my family, especially my daughter.

I don't know where I'd have been without the online forums. They've become like friendship groups.

People there understand the condition better than medics because they have first-hand experience of it. They can give tips that doctors aren't taught, especially with some of the unusual symptoms.

But it's not all doom and gloom. You also talk about hobbies and other things. You don't feel alone anymore and it's all very supportive.

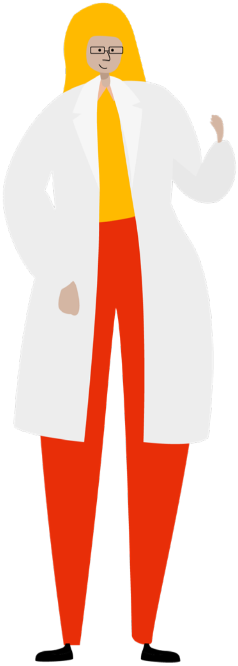
I now know that there are lots of different treatments for symptoms. And if one doesn't work or has side effects, there are usually other options. There are lots of health professionals who can help, including your MS nurse, continence nurses, physiotherapists, dietitians and your GP.

Oddly, I feel less stressed now. I'd always had high expectations of myself in my career and was a stickler for a clean, tidy home. Now if I've made someone smile today, I feel that I've achieved something. What I can't do today I do tomorrow. I look at things in a totally different way now.

Cath

Five things to know

1. Most people with MS are diagnosed with 'relapsing remitting' MS. Some people are diagnosed with 'progressive' MS
2. If you've been diagnosed with relapsing MS, doctors recommend that you start taking a disease modifying therapy (DMT) as soon as possible
3. Some people with progressive MS can also take a DMT
4. Life with MS is more about what you can do, not what you can't
5. We're here to support you, with information from our MS Help Hub, on the phone, online and with local connections



About this booklet

This booklet is for you if you're going through a diagnosis of MS, or have already been diagnosed with it. It'll also answer many of your questions if you're the partner, relative or friend of someone with MS.

Whatever your situation, you might be going through a huge range of emotions. Among them could be anger, shock or fear. You might even feel relief if it's taken some time to be diagnosed.

This booklet gives you an introduction to MS and points you towards other information and support if you need it. Your neurologist and, if you have one, your MS nurse are also there to answer your questions.

Find out more about MS and the support that's available on our website at **mssociety.org.uk**

You can sign up for emails with information and support that might be helpful (just search 'newly diagnosed').

You can ask questions and get support on our online forum. There you'll find other people who know what you're going through. It's at **forum.mssociety.org.uk**

If there's something on your mind, you can contact our MS Help Hub on **0808 800 8000** (9am to 5pm, closed weekends and bank holidays).

The email before April 2026 is **helpline@mssociety.org.uk** From April 2026 the new email is **helphub@mssociety.org.uk**

And from May 2026 you can speak with the MS Help Hub on our website using webchat.

Our MS Help Hub has details of local and online support for recently diagnosed people, friends and family.

One last thing. Where you see a word in **bold** in this booklet, you can turn to page 38 and find it explained. And on page 40 there's space for your own notes.

What is MS?

MS (multiple sclerosis) is a condition that affects nerves in your central nervous system. That's your brain and spinal cord. In MS, the coating (called myelin) that protects your nerves is damaged. Because it affects your nerves, it's called a 'neurological' condition.

Once diagnosed, MS stays with you for life, but treatments and specialists can help you to manage the condition and its symptoms.

Why is it called multiple sclerosis?

'Sclerosis' means scarring and refers to the scars that MS causes in your brain or spinal cord. These scars are also called **lesions** or plaques. They show up in magnetic resonance imaging (**MRI**) scans.

It's 'multiple' sclerosis because the lesions happen in more than one place and at more than one time.

What's happening in MS?

You can't catch MS from someone. You get it when your **immune system** isn't working properly. In MS your immune system attacks the nerves in your brain and spinal cord by mistake.

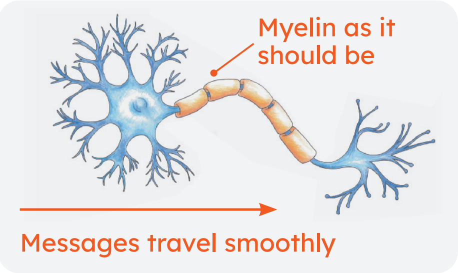
To understand what happens in MS, it's useful to understand a little bit about the immune system and what happens in the **central nervous system**.

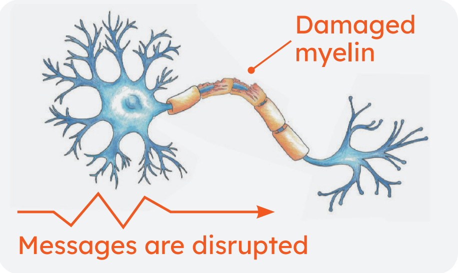
In the central nervous system, a substance called **myelin** protects the nerve fibres. Myelin helps messages travel quickly and smoothly along the nerves in your brain and spinal cord.

Your immune system fights off infections. But in MS it mistakes myelin for something that shouldn't be there, and attacks it. It damages the myelin, stripping it off the nerve fibres.

This damage disrupts messages travelling along nerve fibres. They can slow down, become distorted, or not get through at all. As well as losing the myelin, there can sometimes be damage to the actual nerve fibres too. Nerve damage can cause more lasting symptoms over time.

The central nervous system controls everything your body does. So multiple sclerosis can cause many different types of symptoms. Different symptoms can happen depending on which part of your central nervous system has been affected.





How many people have multiple sclerosis?

We estimate there are over 150,000 people with MS in the UK, and each year over 7,000 people are newly diagnosed.

This means around 1 in every 400 people in the UK lives with MS, and each week around 135 people are diagnosed with MS.

In the UK people are most likely to find out they have MS in their thirties and forties. But the first signs of MS often start years earlier.

Types of MS

Everyone's MS is different, but most people will be diagnosed with one of these main types:

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

We explain these over the next two pages.

You might have been told about MS if you've been diagnosed with clinically isolated syndrome (CIS) or radiologically isolated syndrome (RIS). You can talk to someone about this with our MS Help Hub on **0808 800 8000**. And you can find out more at **mssociety.org.uk/types-of-ms**

Knowing what type of MS you have won't tell you how your MS will develop over the years to come. MS is unpredictable and it affects everyone differently. Even if you have the same type of MS as someone else, you probably won't experience exactly the same symptoms in the same way.

Relapsing remitting MS

This is the most common type of MS. Around 85% of people with multiple sclerosis are diagnosed with relapsing remitting MS. It's sometimes just called relapsing MS.

In relapsing remitting MS, people have distinct attacks of symptoms (**relapses**), which then fade away either partly or completely.

In the early stages of relapsing MS, your symptoms often get better between relapses. This is known as 'remission'. But symptoms might not completely go away.

As time goes on, your body finds it harder to repair the damage each relapse brings. So your symptoms can get worse, especially if you don't start treatment. Recent studies also show that change is possible even when you aren't having relapses at all, though this is usually very gradual.

In online forums and elsewhere you often see this type of MS shortened to 'RRMS'. Read more about this type of MS in our booklet 'Managing MS relapses' or on our website.

Primary progressive MS

When people are diagnosed with MS, about 10 to 15% get a diagnosis of primary progressive MS.

It has this name because from the first (primary) symptoms it's progressive. Symptoms gradually get worse over time, rather than appearing as sudden attacks (**relapses**). You might see this type of MS shortened to 'PPMS'.

Early on in primary progressive MS, some people also have signs of new MS activity (**lesions**) on their **MRI scans**, or the occasional relapse. That's called 'active' primary progressive MS. 'Active' means there's **inflammation** happening in the **central nervous system**, as well as progression.

You can read more in our booklet 'Understanding progressive MS'.

Secondary progressive MS

Secondary progressive MS describes a stage of MS which comes after relapsing remitting MS for many people. You might see this type of MS shortened to 'SPMS'.

It can be hard to tell when you move to this type of MS. But it could be diagnosed if your disability has got worse over at least six months and you've stopped having relapses (or they happen much less often).

In the past it took, on average, around 20 years for relapsing remitting MS to become secondary progressive. But now, disease modifying therapies (DMTs) mean fewer people are likely to go on to secondary progressive MS and it takes longer for those who do.

No one's MS starts out as secondary progressive. But it is possible to be told you have this type when you're first diagnosed. That could happen if you've had symptoms for a long time but they weren't diagnosed as relapsing remitting MS at the time.

You can read more in our booklet 'Understanding progressive MS'.

First questions

What causes MS?

We don’t know what the exact cause of MS is. And we definitely can’t say why you got MS. We do know there are probably a number of things involved: genes, something in your environment, and lifestyle. There’s not one single reason someone gets MS. And some of the reasons people have no control over.

It’s likely to have been a combination of things. You weren’t in a position to know what these things were – or what to do about them. The chances are there was nothing you could do to avoid MS.

Is MS a genetic condition?

MS isn’t directly inherited like some conditions. But genes are involved.

The child of someone with MS has a higher (but still low) chance of getting it themselves, compared to the child of someone who doesn’t have MS.

For every 1000 people...

...who grow up in the UK

about 3 will get MS

(997 won’t)

...with a parent with MS

about 15 will get MS

(985 won’t)

...with a brother or sister with MS

about 27 will get MS

(973 won’t)

MS is not directly passed on from parent to child. There’s no single gene that causes it. Over 200 genes might affect your chances of getting MS. But genes are only one part of the story.

Are you born with MS?

You're not born with symptoms of MS. If you develop MS, it's usually diagnosed in your 30s or 40s. But it can also develop earlier or later than that. There's currently no way to tell for certain whether someone will develop MS later in life.

The environment

Where you live

MS is less common in tropical countries near the equator that get lots of sunshine. More people have MS in places further away from the equator like the UK, and that's true no matter what your ethnic background is. Other countries where MS is more common include Canada, the US, Scandinavia, southern Australia and New Zealand.

Infections

There's evidence that some viruses, and maybe bacteria, play a part in triggering MS.

A common virus called Epstein Barr virus (it causes glandular fever) has been linked to MS. But most people have had this virus and never get MS. This shows that, like genes, infections might play a role but they aren't the whole story.

Vitamin D

There's more and more evidence that low levels of vitamin D, especially before you become an adult, could be a factor in why people get MS.

Our skin makes most of our vitamin D when we're out in the summer sun. We also get some from food like oily fish, eggs, spreads and breakfast cereals with added vitamin D in them. You can also get extra vitamin D from supplements (but too much can be harmful).

A blood test can show if your levels of vitamin D are low.

You can find more on vitamin D and MS on our website.

Lifestyle factors

Smoking

Studies show people who smoke are more likely to get MS. It's less certain if passive smoking also affects the risk (breathing in other people's smoke).

Some studies have found passive smoking might increase the risk if you have MS in your family.

People with MS who smoke can also see their MS develop from relapsing remitting MS to secondary progressive MS earlier than people who don't smoke.

Studies show smoking can speed up how fast your symptoms or disability get worse. This includes your walking getting worse and a worsening in how other parts of your body move.

Smokers are more likely to get more areas of MS damage in the brain or spinal cord, disability and relapses.

Smoking makes some disease modifying therapies (DMTs) work less well. People on these drugs who smoke have more relapses than non-smokers.

We don't know yet for certain why smoking has these effects.

If you have relapsing MS, studies show that stopping smoking could slow down the rate your symptoms or disability gets worse and how fast relapsing remitting MS changes to secondary progressive. In fact, it slows it down to the rate we see in people who never smoked. So if you smoke, it's a good idea to stop.

Your GP can help you stop smoking, and you can find out more from NHS websites.

Obesity

Studies show there could be a link between getting MS and being very overweight (**obese**), especially if someone was obese as a child or teenager.

This might be because obese people are often low in vitamin D, which might increase the risk of developing MS. Obesity can also make your immune system overactive and cause inflammation in your body. There might be other reasons we don't understand yet.

Of course, not all people who are very overweight get MS. And having MS doesn't mean you are, or were, obese. But if your risk of getting MS is on your mind, perhaps because a close relative has it, then weight could be a risk factor you can change.

How will MS affect me?

The truth is, no one can be certain how your MS will affect you. Many predictions made for MS are based on averages across many people. As with any average, people can be on either side of this 'average experience'. It doesn't always accurately reflect what each person experiences.

MS has lots of symptoms, but not everyone will experience all of them. Common symptoms include eye problems, weakness, numbness or tingling feelings, **fatigue** and pain. You might notice difficulty walking, or problems with your balance.

Not all symptoms are visible to other people, like fatigue, pain, or bladder and bowel problems.

Being tired, stressed, ill or feeling too hot can make your symptoms worse. And getting an infection can trigger a relapse.

Your symptoms can change from day to day, or hour to hour, and for no obvious reason. You might have days, weeks, months and sometimes years when you feel fine, with no obvious or difficult symptoms.

Learning how to deal with this unpredictability and being prepared to manage changes will help you take back the control you might feel MS has taken away.

You can talk things through with an MS nurse, or neurology nurse. Or talk to our MS nurses in our MS Help Hub on **0808 800 8000**.

Through our local groups you can get in touch with other people who have MS, and experienced volunteers. And our online forum is there to share what you're going through and answer questions. It's at **forum.mssociety.org.uk**

Living with a long-term condition isn't always easy. It's not unusual for people with MS to experience depression, stress or anxiety. Everyone needs support from time to time and there are treatments and techniques to help you cope. You can read more about the emotional effects of MS on our website.

Do people die from MS?

Most people with MS live into old age. Life expectancy for people with MS is, on average, reduced by a few years.

MS is not considered a terminal illness and it's very rare for someone to die directly because of MS. But MS is a lifelong condition and if someone is severely affected, the risk of dying from a complication related to MS (like an infection) is greater.

A person with MS can live as long – or longer – than anyone else. When we talk about life expectancy, it's based on averages across large numbers of people. MS is different for everyone, and it's not possible to predict how you'll be affected over time.

Several studies have shown that MS reduced life expectancy – on average – by about 7 years.

But more recent research has suggested it might be as low as 2 years. The difference between life expectancy for people with MS and other people has got smaller over the years. And could get even smaller in the years to come. That improvement is probably because of better healthcare being available to more people.

Is there a cure for MS?

At the moment, there's no cure for MS. Once you've been diagnosed with MS, you have it for life.

Research is trying to find ways to stop MS. Until then, there are ways to manage your condition. These include disease modifying therapies (DMTs).

If you have relapsing MS, a DMT can reduce how many relapses you have or how bad they are. This can slow down how fast you're likely to have symptoms or disability.

Read more about treatments on pages 24 to 29.

Will I need to use a wheelchair?

Many people worry about needing to use a wheelchair at some point. No one can be certain how your MS will affect you, but most people with MS don't use a wheelchair.

Some disease modifying therapies (DMTs) can delay the need for a wheelchair for years.

Some symptoms can make it difficult to walk safely. For example, that could be because of weakness, balance problems or when your muscles contract and feel stiff and tight (spasticity).

If your MS does start to affect your mobility, the decision to start using a walking stick, mobility scooter or wheelchair can be a difficult one. But once you start using one you might find how useful they are, and how they can help you stay independent.

Can I have children?

Yes. Having MS doesn't mean you can't get pregnant or father a child.

There is no reason having MS should stop you having children and being successful parents. MS doesn't affect fertility.

A parent with MS may be faced with more day-to-day problems in looking after children than the average parent – but lots of people with MS have children after being diagnosed.

If you want to have a child, or you're pregnant already, discuss your options with your neurologist.

Some disease modifying therapies (DMTs) are safer to use when pregnant than others. So the choices you make could also depend on how active your MS is and the DMT you take.

We've got lots more information about pregnancy and all the DMTs available on our website.

Will my children get MS?

Many people worry their children will also get MS. Genes are involved, but it's not the whole story and MS is not directly inherited.

If you have a close relative with MS, the chances you'll get it are a bit higher, but the risk is still low. The figures in detail are on page 12.

Do I have to stop work?

Being told you have MS can make the future seem uncertain. It's natural to worry about the effects on your job, home and financial situation. Over time you're likely to reassess things and adjust, but it's important not to rush into any major decisions.

Some of the symptoms of MS may only be temporary, while some might be long term.

MS is unpredictable, and there's a huge variety of jobs that people do. So MS can raise quite complex issues for people in the workplace.

For example, **fatigue** is a common symptom of MS and stress can make symptoms feel worse. Some activities – like travelling or standing all day – might sometimes be very tiring.

Some people do find that work – or the kind of work they've been doing – is no longer possible. But lots of people with MS continue to work after a diagnosis.

To do this, you might find you or your employer need to make changes. These could be to your workplace, the work you do, or how you do it.

Small changes to support you to stay in work are known as 'reasonable adjustments'. The Equality Act and, in Northern Ireland, the Disability Discrimination Act give you the right to ask for them.

These laws also protect you from being treated unfairly by your employer because of your MS.

Read more about working when you have MS and the help that's available on our website and in our booklet 'Work and MS: An employee's guide'.

Whether you work or not, our website and our 'Benefits and MS' booklet tell you about help you might qualify for. This includes welfare benefits and help with transport and fuel costs.

MS and how you're feeling

There's no right or wrong way to react when you're diagnosed with MS.

You might:

- burst into tears or feel stunned into silence
- feel sorry for yourself and ask 'why me?'
- feel angry and want to lash out at people
- feel grief because you don't see yourself as a healthy, carefree person anymore
- go into denial about your diagnosis
- feel relief to hear you have MS – especially if you had unexplained symptoms for a long time.

All of these reactions are perfectly normal. You might find that your reaction varies from day to day, perhaps changing from fear to anger to sadness, to relief. Lots of people compare their emotional reaction to the ups and downs of a rollercoaster ride.

If you're finding it difficult, there's support available. You can talk to your medical team, including your MS nurse if you have one. Or talk to someone in our MS Help Hub on **0808 800 8000**.

You can also connect with other people with MS through the forum on our website, virtual support events and our wellbeing hubs, or through your local MS Society group (see page 36 for more about all of these).

We've got more about mental health on our website at **mssociety.org.uk/mental-health**

Telling people

At some point it's likely you'll want to tell people you have MS.

This can feel like a scary thing to do. But it can help you feel less alone with your MS. And it can help you get the support you need from those around you.

You might want to tell everyone about your diagnosis. Especially if you've been unwell for some time. Or you might want to tell only the people closest to you or people who need to know.

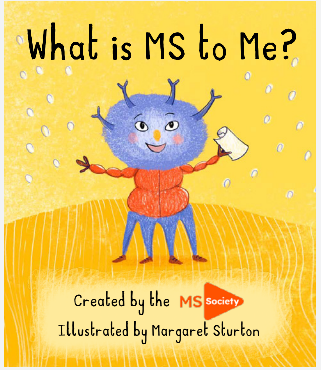
Sometimes it helps to plan what you're going to say. Lots of people don't know about MS, or have their own ideas about it.

They might think everyone with MS needs a wheelchair, for example. So try to be prepared to answer their questions. But you don't need to know everything. No one can. With someone close, you might both go away and find things out if questions come up.

You might want to give them copies of our booklets 'What is MS?' and 'For family and friends – when someone close to you has MS'. They can read these in their own time. You could also point them to our website.

Talking with children about MS

Our free illustrated book 'What is MS to Me?' can help you talk about MS with young children (primary school age). The team that created it included people living with MS and their children.



Before you tell people, be aware that they might not react like you'd expect, no matter how well you know them. They could be more upset than you expected, or be surprisingly calm about it. You're the one with MS, but the diagnosis might affect their lives, too.

You can find more about telling people you have MS at **mssociety.org.uk/telling-people-you-have-ms**

Our MS Help Hub is here for anyone affected by MS, including family and friends.

You might want to link up with others affected by MS. That could be online or in person. Find out about local and online support for everyone affected by MS on our website at **mssociety.org.uk/local**

Do I have to tell my employer?

Most people don't have to tell their employer that they have MS. But you must if you're in the armed forces, or if your MS might affect health and safety at work.

You must also say something if you drive for your job. This includes if you drive vehicles that need a special licence, like a taxi or HGV (heavy goods vehicle).

You also have to mention your MS if it has led to restrictions on your driving licence. Or if you're covered by your employer's insurance when you drive.

Even if you don't need to tell your employer, you might still want to tell them, so they can give you any support you need at work.

There's more about work in our booklet 'Work and MS: an employee's guide' and our toolkits for employers and employees on our website. This includes basic information about MS and outlines what they can do to support you, as well as what the law says they have to do: **mssociety.org.uk/work**

Is there anyone I must tell?

Yes, there are a few people you must tell.

If you drive, you have to tell the DVLA (DVA in Northern Ireland). Most people with MS can carry on driving.

You'll also have to declare your MS when you buy some types of insurance, for example travel insurance. And check all of your existing policies, to make sure you're still covered.

Find out more about insurance and driving on our website.

> **"Once I had a diagnosis I told everyone at work, and I never found it difficult to talk to colleagues about my MS. They were very sympathetic. I worked from home for two months, and am slowly building up my hours."**
>
> Jane

Treatments for MS

There are around 20 disease modifying therapies (DMTs) to treat relapsing MS.

What are DMTs?

If your type of MS causes relapses, then DMTs could make a real difference. DMTs aren't a cure, but they can change for the better ('modify') how MS behaves.

Most DMTs are tablets, injections or given as an infusion (through a 'drip'). Some are taken several times a week, some twice a year, and others only used once or twice in total. One DMT – called HSCT – is an intense chemotherapy treatment which uses your own stem cells to rebuild your immune system.

You might have a choice of DMT you can take. Our online DMT decision tool can help you explore your DMT options and prepare for conversations with health professionals.

You can use the tool and find out about all available DMTs at **mssociety.org.uk/dmts**

Taking a DMT means you're less likely to get relapses, or your relapses will be less serious. A DMT can also reduce inflammation. That will mean fewer areas of nerve damage (lesions) in your brain or spinal cord.

That's why DMTs are available on the NHS if your MS causes relapses or has signs of inflammation on **MRI scans**. And that includes some people with progressive MS.

When should I start treatment?

DMTs work better the earlier you start taking them. Damage caused by MS builds up over time. So the earlier you begin treatment, the more damage you can prevent.

If your MS causes relapses or signs of inflammation, doctors recommend that you start a DMT as soon as possible.

In England, Wales or Northern Ireland, **guidelines** say you should be offered a follow-up appointment within six weeks of being diagnosed. Guidelines in Scotland say you should be contacted by an MS nurse within two weeks of being diagnosed. You can ask about treatment options at these appointments.

You and your neurologist will make decisions about your treatment based on your MRI scans and what they find when they examine you.

Only a neurologist can start you on a DMT. They'll follow guidelines about which DMTs you can take.

Official guidelines say you should get a review once a year with an MS specialist. This might not be a neurologist. It could be an MS nurse. This review is to check in with you about all aspects of your medical care. You might have MRI scans at some reviews, to check how active your MS is and how well treatment is working.

Are there DMTs for progressive MS?

DMTs are usually only available for progressive MS if your neurologist confirms you also have relapses, or signs of active inflammation on MRI scans.

If this is the case, your neurologist will describe your MS as 'active' (active progressive MS).

If you have active secondary progressive MS (with relapses or inflammation), siponimod (Mayzent) may be an option for you. HSCT might also be an option for some people.

In England, siponimod might be prescribed even if relapses or inflammation don't show up – if they're being controlled by another DMT you're already taking.

If you have active primary progressive MS ocrelizumab (Ocrevus) might be an option. And HSCT might also be an option for some people.

With progressive MS that's not active, there's no evidence that current DMTs can help. But researchers are looking into this.

To help you understand your choices, we've got more about all the available DMTs on our website **mssociety.org.uk/dmts**

Researchers are looking at other DMTs to see if they can help people with progressive MS. There have been some encouraging trial results in the last couple of years. Find the latest research news on our website.

How can I manage my symptoms?

If you get relapses, taking a DMT might reduce your symptoms or stop new ones happening. There are also treatments for individual MS symptoms whether or not you have relapses.

Treatments for MS symptoms don't always make the symptom go away, but they can make it easier to deal with.

Managing symptoms

What you eat or drink, medication, complementary therapies, and exercise can help with a lot of symptoms.

But don't struggle alone with a new symptom or an old one that's getting worse. Tell your MS nurse or neurologist so they can see if anything can be done.

Sometimes the first treatment you try might not work, or you might find the side effects too much to deal with. If you do, tell whoever prescribed it that it's not right for you. There'll often be another treatment you can try. You might need to try a few before you find the right one.

As well as drug treatments, there are other ways to manage your symptoms. These include things like physiotherapy for muscle stiffness, or Botox for bladder problems.

Depending on your symptoms, you might see:

- **occupational therapists**
- physiotherapists
- continence advisers (for bladder and bowel problems)
- psychologists
- speech and language therapists

To see more of the professionals who might look after you, check out our who's who page at **mssociety.org.uk/whos-who**

Our website and printed booklets have information on how to manage different symptoms. See what's available at **mssociety.org.uk/symptoms**

Managing relapses

You might be prescribed **steroids** if a **relapse** is especially painful or has a big impact on your daily life. Steroids speed up recovery from a relapse by dampening down **inflammation** in your brain or spinal cord. They're taken as tablets or as an infusion (a 'drip').

You don't have to take steroids for every relapse. Because of possible side effects, your doctor might want to limit how many times you have steroids each year. If it's a mild relapse, or you decide the steroid side effects are too much, you can choose not to take them.

Whether you take them or not won't make any difference to how you are once the relapse is over. They don't protect you from any lasting effects of a relapse, just speed up how soon you get over it.

Once the relapse is over, you might want support ('rehabilitation') to recover from it. This can combine different things like physiotherapy, **occupational therapy**, or support at home or work.

Read more on our website or in our booklet 'Managing MS relapses'.

Who'll be looking after me?

You might have a number of different people looking after you. It's worth knowing who can do what, and where to get the help you need.

You

You know more about your MS than anybody else. You understand how symptoms affect you, mentally and physically.

You're best placed to monitor changes in your condition and to avoid triggers that make symptoms worse. It can take some time to notice and learn about what triggers symptoms for you.

Family or friends might also help you notice any changes. And if you find it helpful you could ask for someone to be with you at appointments with professionals.

You might find it useful to keep notes about any symptoms, treatments and how you feel. Some people use a diary or symptom apps on their phone.

This record of how you've been helps to explain things to health professionals.

Having the right information about your MS puts you in a position to make better decisions for yourself. The more you know, the more you can help the professionals help you.

Your GP

GPs aren't MS specialists. Many only see a few people with MS in their careers, so don't expect them to fully understand MS.

Your GP can help you deal with many of your symptoms, referring you on to more specialist help when you need it.

They can also contact your neurologist or, if you have one, your MS nurse when necessary (for example, if you have a **relapse**).

Your MS nurse

MS nurses are nurses with specialist training in MS. They're a great source of information and advice. They can be a link between hospital, community services and social services.

You should be referred to an MS nurse as soon as you're diagnosed. They're often the first point of contact if you've got any concerns about your MS.

If you haven't already been offered an appointment with an MS nurse, you can ask your GP or neurologist for a referral.

Sometimes MS nurses take self-referrals, which means you can ring them directly and ask for an appointment.

Not everywhere has MS nurses. If there isn't one in your area, ask if you can be referred to a specialist neurology nurse. Or to someone else with an understanding of MS who you can contact if you need to.

To find MS nurse services in your area, the MS Trust has a service finder on their website at **mstrust.org.uk/about-ms/ms-services-near-me**

Your neurologist

Neurologists are doctors who specialise in treating conditions that affect the brain, spinal cord and nerves. You saw a neurologist when you were diagnosed with MS. Only neurologists can make the diagnosis.

Your neurologist will be interested in how your MS is developing long term, rather than the day-to-day management of it. Most people with MS only see their neurologist once or twice a year.

A neurologist can:

- prescribe DMTs
- arrange for scans and any other tests to check how active your MS is
- talk over new symptoms with you and ways to manage them

Your multi-disciplinary team

The multi-disciplinary team (or MDT for short) is the group of health care specialists who work together to help you manage your MS.

As well as your neurologist and MS nurse, your multi-disciplinary team could have these people in it:

- a physiotherapist – for advice and treatment of difficulties with moving around or other physical problems
- an **occupational therapist** – to help you deal with **fatigue** and offer practical solutions for problems that affect your life at home and work
- a social worker – for information and help with things like applying for benefits and housing
- a counsellor – to help you and people close to you deal with the impact of MS on your life and relationships

Your GP or MS nurse can refer you to any of these or to other experts, like specialist pharmacists, continence advisers, dietitians and pain specialists.

You might not want or need to see these people now, but they're there in case you do in the future.

There's more on our website about the professionals who could be included in your team at **mssociety.org.uk/whos-who**

What can I do to look after myself?

The treatments you get from your health care team are only part of managing MS. There's a lot you can do to help look after yourself.

Finding the right information

Having the right information about MS can help you make better decisions for yourself.

There's so much information around, especially on the internet. It can be hard to know where to start.

It's important that the information you read is accurate, unbiased and up to date, so you can use it to make the right choices.

Be wary of anything that claims to be a miracle cure. Lots of companies try to cash in on conditions like MS by trying to sell unproven supplements, therapies and equipment.

You can get reliable information on managing MS from your health care team, from us, NHS websites and the MS charities listed on page 37.

Don't smoke

On page 14 you'll have read about how smoking makes MS worse.

Research also shows that quitting smoking can have very real benefits. Studies have shown that giving up smoking slows down how fast disability gets worse. In fact, it slows down to the rate we see in people who have never smoked.

Although we don't know for sure, there's evidence that passive smoking could be bad for MS too. That's an extra reason to go smoke-free at home.

Get inspired to quit at **nhs.uk/better-health/quit-smoking**

Read about the evidence for the benefits of quitting smoking at **mssociety.org.uk/smoking**

Eat well

If you eat a healthy, balanced diet your overall health and quality of life could improve. This is even more important when your body has to cope with living with a long-term condition like MS.

A lot of claims are made about how special diets can control MS. But there's no strong evidence that any diet is right for everyone with MS.

Our booklet 'Diet and MS' looks at everything to do with food, drink and MS. It covers vitamins, diets, and foods that could help with specific MS symptoms. Find it and more at **mssociety.org.uk/diet**

Staying active

Regular exercise can help with MS symptoms such as **fatigue**, balance difficulties, muscle stiffness, and bladder or bowel problems. It can make you feel better mentally too.

Being active doesn't have to mean playing a sport. It's all about finding the right activities to suit you and what you can do. It includes things like gardening, yoga and swimming.

There's information about exercise in our booklet 'Moving more with MS', and we've got a range of videos including yoga, Pilates, football drills, aerobics and exercises for specific symptoms.

Our MS Help Hub can talk to you about ways to move more with MS. And you'll find all our videos and information at **mssociety.org.uk/staying-active**

Complementary therapies

Lots of people with MS use complementary therapies to help with particular symptoms, or to feel better.

These therapies include acupuncture, yoga, meditation, massage, hyperbaric oxygen therapy, homeopathy and osteopathy – although that's not all of them.

There's not a lot of evidence for many complementary therapies in MS and sometimes there can be risks or costs involved. So check with a health care professional before trying a complementary therapy.

You can find out lots more about complementary and alternative therapies on our website.

> **"It's a matter of trial and error. I've just started a treatment that works for some people, so I'm giving it a try."** Chris

Where can I get support?

MS Help Hub

The MS Help Hub offers confidential emotional support and information to anyone affected by MS.

Call **0808 800 8000** (closed weekends and bank holidays)

Our email until April 2026 is **helpline@mssociety.org.uk**

From April 2026, email **helphub@mssociety.org.uk**

From May 2026 you can get in touch using webchat on our website.

MS Society local and online support

Our UK-wide network of local groups offer ways to meet other people with MS in your area, find out about local services and get support to help deal with your MS.

Online support includes webinars, befriending services, counselling, exercise groups, and virtual meet ups.

Find out what's available in person and online where you are: **mssociety.org.uk/local**

MS Society forum

The message boards on our website let you connect with other people affected by MS. There's one just for people who are newly diagnosed or going through the process of being diagnosed: **forum.mssociety.org.uk**

Other MS organisations

MS Together

A charity offering social and mental health support to people affected by MS, with a particular focus on young adults aged 18–35. **mstogether.org**

MS Trust

A charity offering information for anyone affected by MS. **mstrust.org.uk**

MS-UK

A charity offering a telephone counselling service for people with MS. **ms-uk.org/counselling**

Neurotherapy Network

A network of UK centres offering a range of therapies including physiotherapy and counselling for people with neurological conditions, including MS. **neurotherapynetwork.org.uk**

Shift MS

An online community popular with younger people with MS. Users share, support and interact with each other through the website **shift.ms**

New words explained

Central nervous system or CNS – this is your brain and spinal cord. The CNS has a network of nerves carrying messages. These messages control how different parts of your body work, and your memory and thinking.

Fatigue – an overwhelming physical or mental tiredness common in people with MS. It can affect things like your arms, legs, concentration, memory, balance and eyesight. It takes longer to get over than normal tiredness

Guidelines – in England and Wales, NICE is the organisation that produces guidelines about which treatments should be available on the NHS, and how they should be used. NICE stands for National Institute for Health and Care Excellence. Their guidelines are often applied in Northern Ireland as well. In Scotland, the SMC (Scottish Medicines Consortium) decides on treatments. In each nation the NHS sometimes has other guidance too. For example, about which treatments are available

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 attacks your central nervous system

Inflammation – when your immune system reacts to attack or damage, it sends more blood and immune cells to the damaged area, making it swollen. When MS causes inflammation in your brain and spinal cord it starts to damage it, triggering 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 over 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 (MRI). They can show where MS is causing damage through inflammation and show damage to the myelin that’s wrapped around the nerves

Myelin – a protective, fatty covering around a nerve. 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

Obese – being very overweight. Defined by the NHS as a body mass index (BMI) of 30 and over. Find out your BMI at **nhs.uk/live-well/healthy-weight**

Occupational therapist – someone who supports you to do daily tasks and keep your independence. They suggest practical changes to how you do things and alterations to where you work or live

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

Steroids – corticosteroids (not to be confused with anabolic steroids that some body builders take). They dampen down inflammation in your brain or spinal cord during a relapse. They’re man-made versions of the hormones your body makes to deal with inflammation

My notes

Further information

MS Help Hub

Through our MS Help Hub anyone affected by MS can get emotional support and information, and access services including:

- MS nurses
- MS benefits adviser
- MS legal adviser
- Moving More with MS service
- Short breaks service

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

Find out more about all our services on our website. And from May 2026 you can get in touch using webchat.

Call **0808 800 8000**
(Mon-Fri 9am to 5pm except bank holidays)

Email before April 2026:
helpline@mssociety.org.uk

Email from April 2026:
helphub@mssociety.org.uk

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**, select option 4

Photography

Credit for photography belongs to: David Dunne (p6), Simon Rawles (p27), Alex Grace (p13, 35).

About this resource

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

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 9 of this booklet 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.

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

This resource is also available in large print.

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

Contact us:

MS Help Hub
Freephone 0808 800 8000
(weekdays 9am-5pm)
helpline@mssociety.org.uk
New email from April 2026:
helphub@mssociety.org.uk

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This title will be reviewed within three years of publication (February 2029).

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