Understanding progressive MS

Causes, treatments and support

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

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

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

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

Understanding progressive MS

Contents

A word from Ronny, who has progressive MS

For about 10 months before I was diagnosed with MS, I was going back and forth to my GP. I felt tired all the time, with achy legs, night cramps, and when I walked, it felt as though I was wading through water.

Then my leg gave way under me in the street, and I couldn't get my balance when I tried to get up again.

After more tests and a second scan, I was told that I had primary progressive MS. I was completely unprepared. I knew nothing about MS. I'd heard of it but that was about it. I didn't even know what the initials stood for, never mind the fact that there are different types. All I was told was that there was no treatment.

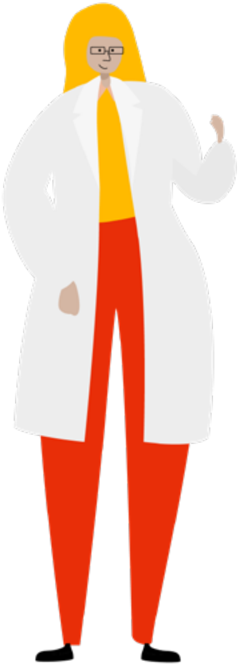
I went home and got straight on to the computer and immediately found so many horror stories. I had visions of being bedridden and not even being able to feed myself. I just wondered how long it would take. On that day, I felt broken, devastated. Everything seemed to stop for a while.

Thankfully I found the MS Society's Facebook page, and from then on just focused on its research and information from the International Progressive MS Alliance. Reading booklets like this one and about research has really helped, as has coming into contact with others who have MS through the MS Society's forum.

I now take each day as it comes and tend not to think too much about the future. It's massively changed my approach to life. I appreciate sunshine much more now and every second I spend with my daughter. Moments are more treasured. I'm making the most of things I can do now.

Ronny

Five things to know



1. Multiple sclerosis (MS) is different for everyone. There's no way of knowing exactly how it will develop or affect you
2. After a diagnosis of progressive MS, you might feel you've lost the life you expected to have. But by making some changes, you can live a full life with MS
3. If you've been told you have progressive MS, there's lots of support for you. There's no need to deal with this on your own
4. For people with a certain type of progressive MS ('active' MS), there are new drugs that can slow it down
5. Finding more treatments for everyone with progressive MS is an international priority. Drug trials are underway to find them

About this booklet

Perhaps you've recently been told you've got progressive MS. Or maybe someone you know has it and you want to know more.

We hope this booklet goes some way to answering your questions. There's a lot to take in, but hopefully it'll make you less uncertain or worried.

A diagnosis of progressive MS can bring up lots of feelings. Knowing more about it could help you feel more in control.

On page 46 you'll find details of how you can get support or your questions answered from our MS Helpline. We also have an online forum at **forum.mssociety.org.uk**

Life with MS these days is less about what you can't do, and more about what you can do. At the MS Society we're here to help you find ways to live out your plans and hopes.

"My family helped me to come to terms with MS. Over time, I've gradually come to accept – if not exactly embrace – the condition. I don't have to feel in control. I just accept things as they are."

John, diagnosed with relapsing MS aged 46, which became secondary progressive 10 years later

"MS is a life-long condition with no cure and your life will be changed. But it's not a terminal disease."

Mike, secondary progressive MS

What is MS?

Multiple sclerosis (MS) is a neurological condition. That means it affects your nerves. Specialist doctors who look after people with MS are called neurologists.

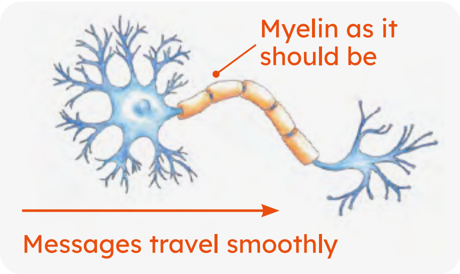
You can't catch MS. You get it when your immune system isn't working properly. It normally protects you by fighting off viruses and bacteria. But, for reasons we don't fully understand, in MS your immune system attacks nerves in your brain or spinal cord by mistake.

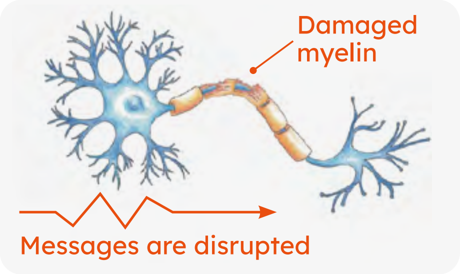
Your immune system strips away myelin from the nerves. This is the fatty covering around nerves that protects them. It also helps messages from your brain and spinal cord pass easily along these nerves to other parts of your body. These messages control how you move, and how you feel things (like pain and touch).

When myelin is missing or damaged, messages become slower, distorted or blocked. It also leaves the nerve underneath open to more damage.

Which part of your brain or spinal cord is damaged by MS plays a big part in what symptoms you get and where.

Progressive MS is a particular type of MS. 'Progressive' here means 'gradually getting worse'. With progressive MS you see a steady worsening of symptoms over a long time. This is unlike another, more common kind of MS called relapsing MS, where things can be stable for long periods of time, with occasional relapses. A relapse is when symptoms suddenly get worse, then mostly or completely get better again. Some people with progressive MS also get the occasional relapse, too.





When first diagnosed with MS, most people are told they have 'relapsing remitting MS' (shortened to 'relapsing MS'). After many years a lot of them see their relapsing MS turn into progressive MS. But for a small minority of people their MS is progressive from the start.

We don't understand progressive MS as well as we understand relapsing MS. That's why there are far fewer treatments for progressive MS. But this is slowly changing. Read more about this in the chapter 'New treatments, new hopes'.

Symptoms of MS

Everyone with MS has their own set of symptoms unique to them. Some of these can be invisible. The most common are:

- fatigue (extreme tiredness)
- muscle weakness
- difficulty walking
- your bladder or bowel not working like they should
- strange feelings, like numbness or tingling in your arms, legs, hands or feet
- muscle stiffness and movements you can't control (spasms)
- pain
- shaking in your arms or legs ('tremor')
- balance problems or feeling dizzy
- eye problems. Your sight might become blurred, or you see double. For a while you might not see through one or both eyes
- problems with your memory or thinking
- difficulties with swallowing or talking
- emotional issues like depression
- sexual problems

Many of these you may never experience. And treatments can help you manage most of them. Read more about this in the chapter 'Managing your symptoms' on page 30.

Different types of progressive MS

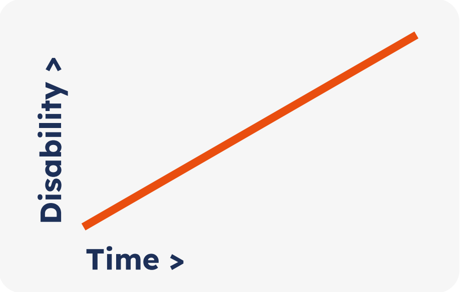
When a neurologist diagnoses someone with progressive MS, it will be one of two kinds: primary progressive or secondary progressive MS.

About 150,0000 people in the UK have MS. We don't have exact numbers, but probably at least half of them have been diagnosed with either primary or secondary progressive MS.

The line between the different types of MS isn't always clear, even to specialists. Someone's type of MS might become clearer over time. Then the neurologist might need to change their original diagnosis.

Primary progressive MS (PPMS)

Primary progressive MS is called this because, from the very first signs of MS, someone's symptoms get steadily worse. This build-up of symptoms is usually quite slow.



From the very beginning with this type of MS you get no – or very few – relapses. You don't get much – or any – inflammation caused by immune system attacks on your myelin. On MRI scans doctors can see this inflammation as 'lesions' (areas of nerve damage). Most people with progressive MS don't get new lesions, although some might.

Instead of your immune system attacking your nerves, something else happens called 'neurodegeneration'. For reasons we don't fully understand, nerves break down and can eventually stop working.

When people are first diagnosed with MS, about 10-15% are told they have primary progressive MS. Young people can have this type of MS, but it tends to be diagnosed in people in their 40s or older. Men are just as likely as women to get it, unlike relapsing MS which affects women more.

At the moment one drug can slow down primary progressive MS if it's in early 'active' stage. Read more about this on page 12.

Secondary progressive MS (SPMS)

In secondary progressive MS the progressive stage comes second after an earlier stage of relapsing MS.

During this earlier stage, the body can still repair myelin after each attack by the immune system. If the attack causes a relapse, this is why people can often recover well from it. But with each attack the body finds it harder to repair myelin and recover.

Eventually the pattern of immune attacks and relapses followed by recovery usually comes to an end. Relapses stop, or happen much less often. There's no longer much or any of the inflammation caused when the immune system attacks the nerves. No, or few, new lesions can be seen on MRI scans.

At this stage relapsing MS has changed into secondary progressive MS.

Just like with primary progressive MS, something we don't fully understand is now causing nerves to break down and stop working. This in why symptoms can carry on slowly getting worse.

In the past it usually took up to 20 years on average for relapsing MS to become secondary progressive MS. But things are changing for the better now that people with relapsing MS are treated with disease modifying therapies (DMTs):

- fewer people go on to secondary progressive MS
- for those that do, this takes longer to happen

It's not always easy for doctors to know when relapsing MS has changed into secondary progressive MS. But this is likely if your symptoms get slowly worse over at least six months without a relapse.

If this happens, and you're on a DMT, your neurologist might talk to you about stopping the drug. That's because there's not yet enough evidence that a DMT is likely to help anymore. See page 39 for an exception to this.

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

Progressive MS with an active side to it

For some people with primary progressive MS, their MS gets steadily worse as you'd expect, but they might still have the occasional relapse. Or their MRI scans show inflammation in the shape of new or growing lesions.

In the past this was called 'progressive relapsing MS'. Now it's called 'active primary progressive MS'. It happens to about 1 in 20 of all people with MS.

Some people with secondary progressive MS can also still have a relapse now and again. Or scans show signs of inflammation like new lesions. This is 'active' secondary progressive MS.

In both cases these people have progressive MS (with neurodegeneration) that also has an active side to it (with inflammation in the shape of new lesions or relapses).

Can progressive MS be treated?

People with progressive MS often think there are no treatments for them. But that's not the case.

There are lots of treatments for individual symptoms. To find what treatments are available, put the name of the symptom that interests you in the search box of our website. You can also speak to an MS nurse on our helpline about managing your symptoms.

Can disease modifying therapies (DMTs) help with progressive MS?

If you get relapses, DMTs lead to fewer and less serious ones. They also slow down how fast your disability or symptoms get worse. Around 20 DMTs can help with relapsing MS.

DMTs don't seem to be much help to most people with progressive MS. The ones we have right now work by stopping attacks by the immune system, and by dampening down inflammation these cause. But most people with progressive MS don't have immune system attacks, so don't have inflammation (with relapses and new lesions).

But a minority of people with progressive MS are an exception to this. Their progressive MS is 'active', with immune system attacks causing inflammation (new lesions and maybe an occasional relapse).

At the moment two DMTs can help these people:

- ocrelizumab (Ocrevus) for early active primary progressive MS
- siponimod (Mayzent) for active secondary progressive MS

In 2024 came the news that, for the first time ever in a drug trial, a new DMT slowed down MS in people whose progressive MS wasn't active. Read more about this and other drugs going through trials on page 40.

Another way of seeing MS

Separating MS into relapsing MS and primary or secondary progressive MS has been the traditional way to describe MS. But many neurologists now divide MS into just two broad types: active or progressive. For some people their MS is a mix of both.

People whose MS is 'active' qualify to have a disease modifying therapy (DMT). So once you know if your MS is 'active' or 'progressive', that helps you understand if the DMTs we have at the moment might work for you.

Active MS

- the immune system attacks myelin around nerves
- this causes inflammation that shows up on MRI scans as lesions (areas of nerve damage)
- these attacks can trigger relapses
- you can benefit from DMTs currently available

Progressive MS ('MS with progression')

- something we don't fully understand causes nerves to break down
- there are no immune system attacks on myelin
- no signs on MRI scans of inflammation (new lesions) caused by immune system attacks
- no relapses
- you can't benefit from the DMTs currently available

This next bit can be confusing: someone with a diagnosis of progressive MS can fall into the 'active MS' category above, not the 'progressive' one. That's because they still get inflammation (causing new lesions) or the occasional relapse.

For most people, in the early years at least, their MS is active.

If your MS doesn't involve attacks by your immune system (causing inflammation or relapses), doctors say it's 'not active'. And if your symptoms keep getting worse, doctors will instead call it 'progressive' or 'MS with progression'.

Progressive MS doesn't have the many treatment options we have for active MS. In the chapter 'New treatments, new hopes' we look at the few options we do have for progressive MS with an active side to it.

How fast will my MS get worse?

It's impossible to answer this as everyone's MS is different. Researchers are hoping to find ways to better predict this for each individual.

But we do know that MS tends to get worse faster if you:

- never took a DMT
- took a DMT but still had relapses
- have lesions on your spinal cord
- have more or bigger lesions (or other unusual signs) on MRI scans of your brain
- had more symptoms early on
- are older
- are male
- or if the rate that your brain shrinks (atrophy) is faster

When it comes to how fast MS gets worse, there's no real difference on average between primary and secondary MS.

> **"I try to walk every day. I feel lucky because when I was first diagnosed with progressive MS, 20 years ago, I assumed I'd be in a wheelchair all the time by now, needing 24/7 care."**
>
> Eiona, secondary progressive MS

Why do people get MS?

Nobody knows for sure why people develop MS. But what we know is growing all the time. It's probably not just one thing that triggers MS, but a combination of your genes, something in your environment and your lifestyle.

Genes

There's not one gene that causes MS. Over 200 genes could 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. Genes play some part, but they don't explain everything.

Most people with MS have no history of it in the family. A close relative with MS does mean the chance you'll get it are a bit higher, but it's still low. Of people who have a parent with MS, around 1 in every 67 of them will get it too. In other words, there's a 1.5% chance that the child of someone with MS will also get it.

Search our website for 'genes' for more on genes and the risk of MS in families.

Environment

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

- certain infections
- lack of sunshine (and being low in the vitamin D that you get from being in the sun)

Infections

Infections caused by some viruses (and perhaps bacteria) might act with other things to trigger MS. Most studies have looked at Epstein-Barr virus as a likely trigger. This virus causes glandular fever.

Vitamin D

Studies point to a link between MS and having low levels of vitamin D, especially when you're young. Our body makes most of the vitamin D we need when sunlight is on our skin.

There's no proof that extra vitamin D protects against getting MS. But researchers are looking into that.

In people with MS, studies have found a link between low levels of vitamin D and how bad their MS is. Many people with MS take extra vitamin D. There's no hard evidence that doing this slows down MS or helps with symptoms, but studies are looking at this.

Your GP or neurologist can check your levels with a blood test. They'll advise you if you need to take more of this vitamin and at what dose (too much can be harmful).

Put 'diet' or 'vitamin D' in the search box on our website for more about MS, food and vitamin D.

Lifestyle

Two lifestyle factors have so far been linked to MS:

- smoking
- being very overweight (obese)

Smoking

There's strong evidence that people who smoke are more likely to get MS. In fact, they're up to 50% more likely than non-smokers to get MS.

What does '50% more likely' look like? Imagine if two non-smokers get MS but three people who smoke get it. Or the likelihood of something happening goes from a 1 in 2 chance to a 3 in 4 chance.

If you already have MS, quitting smoking can make a big difference to your symptoms (see page 32).

Obesity

Studies show being very overweight (obese), especially when a child or young adult, is linked to getting MS. This could be because being very overweight can make you low in vitamin D. It could make your immune system overactive and cause inflammation inside your body. There may be other reasons we don't yet understand.

The risk is low of a family member of someone with MS also getting it. Keeping a healthy weight is one way to keep that risk as low as possible.

MS is no one's fault

Hearing all this, you might ask: 'Could I have done something to avoid MS?' The answer is likely to be 'no'.

Things that make MS more likely – smoking, your weight or vitamin D levels – may be linked to things you have no control over, like your genes, your sex, or what infections you've had.

A number of things play a role in getting MS. So you can never point to one thing and be sure that was to blame.

How MS is diagnosed

If you've been diagnosed with progressive MS, what follows will be familiar.

There's no simple test for MS. A blood test won't show it. But blood tests might help to rule out other causes for your symptoms. Only a neurologist can diagnose MS, not a GP.

Whatever the type of MS, it can take time, sometimes months, to finally get a diagnosis. Neurologists use guidance called the McDonald criteria to diagnose MS. An update to these is expected in 2025. But that won't change anything for people who already have their diagnosis. Search our website for 'McDonald criteria' to learn more about them.

Tests that help diagnose MS

Neurological examination

A neurologist tests your balance, movement, coordination, reflexes or eyesight. They might also check your speech, swallowing, and your sense of touch.

Other tests can check your attention span, how you use words, and how your memory and thinking is working.

The doctor might ask how your bowels and bladder are working. They'll want to see how far you can walk. They'll ask about your health problems and symptoms, now and in the past. Even if a neurologist suspects MS, other tests are needed to be sure.

MRI scans

A machine called an MRI scanner uses magnetic fields and radio waves to build up a picture of inside your brain or spinal cord.

These pictures (scans) show if your immune system is attacking myelin around your nerves and causing inflammation and damage there. Areas of damage and scarring ('lesions') show up on MRI scans.

Lumbar puncture

A needle is placed into your lower back, into the space around your spinal cord. This collects fluid from there, which doctors check for antibodies. Antibodies are signs made by your immune system when it comes across viruses or bacteria.

Antibodies in your spinal fluid show your immune system has been active in your spinal cord and brain. This won't happen if you don't have MS. So antibodies here mean there's a strong chance you have MS.

More tests will then rule MS in or out.

A lumbar puncture can leave you with a headache for a few days. This test isn't always needed to diagnose MS.

'Evoked potentials' tests

These tests measure how fast messages go from your brain to your eyes, ears and skin. Your reactions are slower if MS has damaged the myelin around your nerves.

To measure your eyes, you will be shown patterns on a screen. Small pads on your head then measure how your brain reacts to what you see.

To test your hearing, you listen to clicks through headphones.

Another test measures how fast your muscles react. You will have tiny shocks on your skin that feel like 'pins and needles'.

Doctors use evoked potentials tests less now than they did in the past.

Diagnosing primary progressive MS

To get this diagnosis, your disability or symptoms must have got worse over a year at least, without a relapse during that time.

On top of that, two of the following three things must be true:

- MRI scans show one or more lesions (areas of nerve damage) in your brain
- scans show two or more lesions in your spinal cord
- a lumbar puncture shows signs of MS (antibodies) in the fluid around your spinal cord

Diagnosing secondary progressive MS

For a diagnosis of secondary progressive MS you must have had relapses in the past. You must see a steady increase in disability or symptoms for at least six months, but this can't be linked to any relapse. It's not easy to decide if this has happened.

Your neurologist may use the Expanded Disability Status Scale (EDSS) to measure your disability or symptoms and track if it's getting worse. To find where you are on the scale, a neurologist will ask you to do certain actions, with a focus on walking. This scale focuses on walking and doesn't take into account a lot of other symptoms. Search our website for 'EDSS' for more on this scale.

Sometimes your neurologist will also look at your MRI scan for changes in your brain or spinal cord that are typical of secondary progressive MS.

Coming to terms with your diagnosis

Being diagnosed with a lifelong condition can have a huge emotional impact, even if you were expecting it.

It's common to feel shock, fear, vulnerable, angry and worried about the future. You may feel your old life is over. Some people go into denial about having MS.

There's no right way to react. Each person's response is as individual as their symptoms. But it's common to go through a grieving process for the loss of the life you expected to have. It can take months, maybe years, to really accept your diagnosis.

> **"In those terrible first few days after diagnosis, I felt like my life was over. But it's not the case. You realise that, once you calm down and find out more about it. You learn to look for the positives and concentrate on what you can do now. You have to adapt your expectations."**
>
> Ronny, primary progressive MS

> **"There's a way of living a full life within your own parameters. It's still a life worth living – it just may not be the life you'd planned. There's always a solution to obstacles and a way to maximise your potential."**
>
> Eiona, diagnosed with relapsing MS, progressive since 1996

Worries about your health

Progressive MS doesn't have the many DMTs to treat it that relapsing MS has. That might make you feel frustrated or angry.

It can be especially hard if you were on a DMT for relapsing MS. But now your MS is progressive, your doctor might be talking about stopping your DMT.

You might fear that your symptoms will now quickly get worse. But the speed at which this happens varies a lot. There's no way of predicting how you'll be affected. And that unpredictability can be difficult to deal with.

Your GP, or MS nurse if you have one, can point you towards places that offer support and counselling.

Other worries

You might worry you'll have to stop working, and the effect that would have on your money situation.

If you're in a relationship, you may worry about how MS will affect it. Or what the impact on your family might be, especially if you have children. Over the next few pages we look at where to get support with these concerns.

Some possible positives

If you've been told you have primary progressive MS, you may feel relieved to have a diagnosis that explains your symptoms. You now know that you weren't imagining it. Finally you can get the services and support you need.

If your diagnosis was secondary progressive MS, you might feel relief that the threat of the next relapse no longer hangs over you. That uncertainty is gone.

> **“Three years later, I was told it had become progressive. This time I was prepared. I’d been on website forums and found out all about it and I thought, ‘This is do-able’. There’s even an advantage in that there’s no longer the constant fear of relapses.”**

Eiona, 60, diagnosed with relapsing MS, progressive since 1996

Information

Some people want to find out everything about MS as soon as possible. Others don’t feel ready for lots of information. Either way it’s important to know how to get information if and when you want it.

If you do your own research, make sure the information is from somewhere reliable, like ourselves or the MS Trust. If in doubt, check with your MS nurse, neurologist or GP.

Official guidelines now say that when doctors diagnose people with MS, they should make sure they get information about it. This includes their treatment options and ways to manage symptoms.

These guidelines also say doctors should give you ongoing information and support if your MS changes to progressive MS.

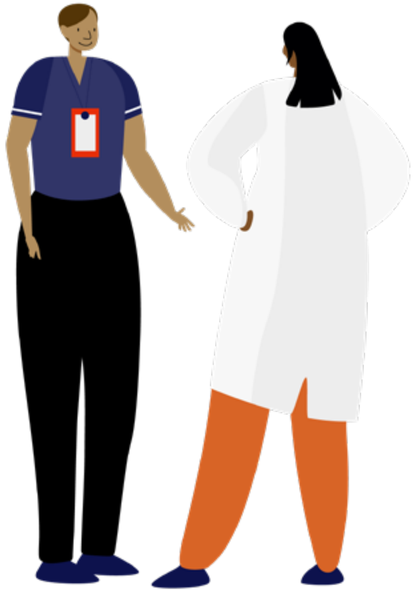
Your MS team should be able to give you information about local support groups and services, help from social services, national MS organisations, and your legal rights.

And remember, if you drive, you must tell the DVLA that you have MS (or the DVA in Northern Ireland).

If you never got this information, ask your GP, MS nurse, or contact our MS Helpline. We have online or printed information covering everything, from help with a recent diagnosis, to work and benefits issues, and lots more.

> **“My MS nurse offered a course for people newly diagnosed with MS, which was extremely useful. Two hours per week for six weeks covering a whole range of things like diet, exercise, nutrition, continence, fatigue, depression... Every week specialists discussed different topics with time for questions. It helped a lot.”**

Catherine, 45, primary progressive MS



Support from the MS Society

Support often comes from talking to family and friends about what you’re going through. Our information can help you and them understand more about MS.

The MS Helpline offers emotional support and practical information for you and those close to you. See page 46 for what they offer and ways to contact them. Our online forum and local groups are places to get support too. Search our website for ‘local support’ to find a group near you.

We offer online help as part of our Living Well support. This covers information sessions (‘webinars’), online support groups, and sometimes courses for newly diagnosed people.

See what’s coming up by putting ‘virtual support events’ in the search box of our website. Or search for ‘newly diagnosed’ to find details of what we offer.

Support groups not part of the MS Society exist for people with specific backgrounds. These include for those under 35 (MS Together), Asian MS or JEMS for Jewish people. Mutual Support is a group for those who were in the armed forces. The MS Helpline has details.

“I don’t know where I’d have been without the forums. They’ve become like friendship groups. People there understand the illness 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.”

Catherine, 45, primary progressive MS

Talking to a professional

Professionals can help people come to terms with an MS diagnosis and dealing with its challenges. They can teach better ways to cope.

Counselling lets you talk about your feelings in a safe environment with someone trained to help. Cognitive behavioural therapy (CBT) teaches practical problem-solving techniques to help change how you think and behave.

Your GP or MS nurse should know how you can get services like these. But what you can get on the NHS can be limited. Counselling is available from some regional MS Therapy Centres. Or you might get it at a discounted rate through your local MS Society group.

If you can pay, find a qualified counsellor or therapist through the British Association for Counselling and Psychotherapy (BACP).

Managing your symptoms

There are treatments to help you manage your symptoms. Making changes to your lifestyle can make a difference to your MS.

You can contact someone in your MS team, usually an MS nurse, about your symptoms. Through them you can coordinate your care and help get the right health and social care services.

A range of people can help with your symptoms. These include physiotherapists, occupational therapists, speech and language therapists, psychologists, dietitians, social care workers and continence specialists for bladder or bowel problems. Your MS nurse or GP can refer you to them.

> **“As my symptoms progressed so too I needed to adjust time and again. Coming to terms with a progressive condition isn’t a once and for all event.”**
>
> Sally, Secondary progressive MS

Treating symptoms

Ask your MS nurse, GP or neurologist for help with your symptoms. Drugs, therapies and equipment can make life easier. Enter a symptom in the search box of our website to find details about what the treatments for it are.

Some newer drug treatments have made a big difference for many:

- fampridine (Fampyra). This tablet might help you walk faster (up to 25% quicker for one in three people). It’s available on the NHS in Wales, Scotland and Northern Ireland. A decision for England is coming in 2025. Search our website for ‘fampridine’ for the latest news
- injections of botulinum toxin (‘botox’) can help with an overactive bladder
- Sativex (brand name nabiximols). This cannabis-based mouth spray can help with muscle stiffness and spasms. It doesn’t work for lots of people, but for some their symptoms get significantly better. It’s available on the NHS

Self-management courses

On these courses you learn techniques to help you deal with the challenges that come with MS. For example, you can learn to manage symptoms like fatigue or pain. You can learn action-planning, problem-solving, how to exercise, eat healthily and techniques for relaxing. See our website, or ask your local MS Society group or MS nurse what’s on offer near you. We have an online course to help you manage MS fatigue at: **mssociety.org.uk/fatigue-course**

Rehabilitation

Rehabilitation helps keep different parts of your body working well so you stay as active and independent as possible. It can help you:

- deal better with fatigue
- move more easily
- deal with bowel and bladder problems
- sleep better
- manage side effects from medication

Rehabilitation is available from different health professionals within the NHS.

Local services

Your GP, the team that treats your MS, or an MS nurse if you have one, can all tell you what local services exist. These could include free or discounted exercise classes, care services, carers groups, shop mobility schemes, transport and disability schemes. A local MS Society group can fill you in what's available.

> **"I'd say to someone who's recently been diagnosed, find out what's available in your area. Call the MS helpline, get onto websites, and ask your local MS Society group or MS nurse about services. Find out what equipment could help, and what benefits you can get. There is help out there. People can advise you on the best way to get it, through charities and support groups."**
>
> Eiona, secondary progressive MS

Brain health

Health problems that involve the heart or blood vessels, like high blood pressure or heart disease, can speed up how fast MS symptoms get worse.

The good news is that studies show lifestyle changes may protect the health of your brain. They might slow down how fast your symptoms get worse. For example, evidence suggests that, when you have MS, smoking and lack of exercise are threats to your brain health.

Giving up smoking

Evidence gets clearer all the time: smoking has extra risks for people with MS. That's on top of the well-known risks of cancer, heart disease, stroke, and so on.

Studies that included people with progressive MS found that, compared to people with MS who don't smoke, if you keep smoking, you're more likely to:

- have more relapses
- get more lesions in your brain
- become more disabled at a faster rate

The more cigarettes you smoke, and the longer you smoke, the worse it makes MS.

Smoking causes brains to shrink (atrophy). Our brains get a bit smaller as we get older, whether we have MS or not. But this happens faster in MS. And people with MS who smoke have even more shrinkage.

Brain atrophy is linked to having more symptoms, poorer memory and thinking. It's also linked to being less able to recover from the damage MS does to your brain.

For people with MS, including progressive MS, there are real benefits to quitting smoking (or never starting).

Stop smoking and the rate at which you get more lesions can go down to the rate of a non-smoker. How fast your brain shrinks also returns to the same rate of someone with MS who's never smoked. There's also a drop in how much disability people develop when they quit smoking.

Your GP can suggest things to help quit. At **nhs.uk/smokefree** you'll find ideas and support, from nicotine gum and patches to vaping.

Staying active

Short bursts of moderate aerobic exercise, like walking or steady cycling, can help with fatigue and your quality of life. People can also benefit from resistance training and activities include stretching, yoga, Pilates and weights. They can be adjusted to the level that suits you.

A physiotherapist can advise you on the best exercises. Our website has videos showing you exercises and activities you can do no matter what your symptoms or level of disability are. There are special ones for certain symptoms. Find them by putting 'staying active' in our site's search box.

“I used to love being fit before. I can still go to the gym, but I adapt what I do. I only work on my upper body now and always sitting down. I’ve also taken up Pilates and yoga, which I do at home with a DVD. I’ll never be able to do all the exercises, but it helps with core strength. I find yoga especially peaceful and relaxing.”

Ronny, 29, primary progressive MS

More help with your symptoms

Your diet

With a long-term condition like MS, a healthy, balanced diet helps your body cope better with its effects. For example, what you eat is very important in managing bowel problems.

You might hear about special ‘MS diets’ that claim to slow down MS or reduce relapses. At the moment, the evidence doesn’t back these claims. But there is evidence that some diets might help with fatigue. Find out more about these diets by searching our website for ‘special diets’.

Steroids

If you have the occasional relapse, a short course of steroids can dampen down the inflammation in the brain or spinal cord that’s caused it.

Steroids can help you get over a relapse around two weeks faster. You can be offered them if the relapse is serious, for example, if it’s affecting your eyesight or walking.

People who take steroids don’t make a better long-term recovery than people who don’t.

Search our website for ‘steroids’ or read more about them in our booklet ‘Managing your relapses’.

Cognitive behavioural therapy (CBT)

This focuses on teaching you practical problem-solving techniques. It can help you manage fatigue, anxiety and depression.

Cognitive rehabilitation therapy

This can help with problems with your memory, attention span or concentration. It’s provided by occupational therapists and psychologists, either in a group or one-to-one.

“One of the hardest things is that it’s affected my cognitive skills. I didn’t realise how much until I went for tests with a neuro-psychologist. I have trouble with figures and dealing with money so I always get someone to check anything to do with figures. I use memory aids and strategies to help me deal with other things. I’ll do demanding things in the morning when I have more energy, and stop after half an hour.”

Eiona, secondary progressive MS

Relaxation

Some research suggests meditation, mindfulness and other relaxation techniques can help reduce fatigue, anxiety and stress. They might improve memory, attention, and help you plan better.

The Mental Health Foundation charity has details of courses, including an online course about reducing stress, anxiety and depression. Find out more on their website: **mentalhealth.org.uk**

> **“The effect on my mental health has been the most challenging thing. I can’t handle any form of stress or anxiety now. It causes rapid mood swings. I manage it by using a relaxation technique I learned on a course, which has been wonderful. I’ve also found cranial head massage helpful.”**
>
> John, diagnosed with relapsing MS aged 46, which became secondary progressive 10 years later

Complementary therapies

Many people find that complementary therapies help them de-stress and relax. They include reflexology and massage. They’re often available at spas, health clubs and MS Therapy Centres. Find your nearest MS Therapy Centre at **neurotherapynetwork.org.uk**

The MS Helpline can also tell you what’s near you. You can find details of qualified practitioners through the professional body for each therapy.

If you’re thinking of trying an alternative or complementary therapy, talk first to your GP, neurologist or another health professional. Some, like herbal remedies, can interfere with medications you’re taking.

Search our website for ‘complementary and alternative therapies’ to find out more.

New treatments, new hopes

When it comes to drugs for progressive MS, research is focussing on treatments that protect nerves and repair damaged myelin. But in the last five years we’ve also seen new DMTs that can slow progressive MS down for some people.

Most DMTs we have right now don’t seem to help most people with progressive MS (but research is still looking at this). DMTs reduce attacks by the immune system on myelin, but that’s not happening in most people with progressive MS.

A small number of DMTs can treat progressive MS if it’s active. ‘Active’ means your immune system still attacks your myelin, causing inflammation. With inflammation, new or growing lesions can be seen on your MRI scans, or you get occasional relapses.

What existing DMTs can’t do is stop the other side of progressive MS, the slow breakdown of nerves (neurodegeneration).

Treatment options for progressive MS

Active progressive MS = a small number of DMTs can help

Progressive MS that’s not active = no evidence that current DMTs can help. This includes HSCT, a kind of stem cell therapy.

Your medical team or our helpline can answer your questions about treatment and drugs going through trials.

DMTs for active progressive MS

The DMT siponimod (brand name Mayzent) can help if you have active secondary progressive MS.

If you're in the early stage of primary progressive MS and it's active, ocrelizumab (Ocrevus) is available. A neurologist decides what 'early' is based on how long you've had symptoms, and how much they affect you. People of any age can have ocrelizumab if they meet the conditions.

During a trial that lasted six months, ocrelizumab reduced the risk of someone's disability getting worse by 25%. It helped people walk better, slowed down how fast their brains were shrinking, and made lesions in their brains smaller.

HSCT and progressive MS

HSCT, a kind of stem cell therapy, can be available on the NHS (in some hospitals that offer it) to a small number of people with early progressive MS. But this is only true if you have signs of active inflammation caused by immune system attacks (relapses or new lesions on an MRI scan). Trials have shown that HSCT isn't likely to help with progressive MS that's not active.

For more on when people with progressive types of MS might get HSCT, put 'HSCT what to expect' in the search box of our website.

If you use a wheelchair

No matter what kind of MS you have, if you've been using a wheelchair for over six months, you won't be offered a DMT. This is because in DMT trials the main focus was whether the drugs improved people's walking. So people who use wheelchairs didn't take part.

But some studies are now including people who use wheelchairs. They're measuring symptoms and disability in new ways. For example, they're looking at whether DMTs can help people keep use of their arms and hands.

What if your progressive MS isn't active?

DMTs we have right now dampen down attacks on myelin that come from the immune system. If your progressive MS doesn't have these attacks, you need drugs that protect nerves from damage or repair myelin. Research is making progress to find these.

On page 42 you can read about a DMT called tolebrutinib, a promising drug for people with progressive MS that's not active.

Finding drugs for everyone with progressive MS is an international priority for researchers. We're already seeing results.

Research and drug trials

The past

Early drug trials of DMTs gave disappointing results for people with progressive MS. They didn't help them walk better, the main measure of success. Trials usually only lasted two years. This might not be long enough to show the full benefit to people with progressive MS.

Trials are now looking again to see if DMTs might be more useful than it first seemed. They're looking at whether DMTs can help people who use a wheelchair keep their arm and hand function. This benefit was seen in some earlier DMT trials.

In 2012 the International Progressive MS Alliance was formed to speed up the development of treatments for progressive MS. The MS Society is one of its members. The Alliance has so far given over €30 million to research and drug trials, with a total investment of €60 million by the end of 2030. See the progress they're making at **progressivemsalliance.org**

Now

A big international effort is going into research on progressive MS. Finding treatments for progressive MS is at the heart of our Research Strategy. We're working to make sure it's a global priority. Each year we give millions of pounds to this research.

Researchers are looking at why nerves break down and stop working. The search is on for drugs to protect nerves and repair damaged myelin.

Trials are investigating whether existing DMTs might slow down progressive MS after all.

Drugs used for other conditions are being tested to see if they protect nerves. We already know these drugs are safe, so they'll pass through trials much faster.

The future

There's now a very real prospect of treatments to slow down or stop progressive MS from getting worse. In the future it's likely that progressive MS will be treated with 'combination therapy', a mix of drugs. One might tackle inflammation that damages nerves. Another might repair damaged myelin. A third might help in other ways, like making sure nerves have enough energy.

Research is also looking at ways to predict how fast someone's MS will get worse. Doctors can then better fit treatments to each individual.

Improvements in MRI scans and other ways of looking into the brain will mean doctors can better see if the body or promising new drugs are repairing myelin.

Drugs in trials now

Here are some of the drugs being tested at time of writing, in 2025.

Drugs to prevent attacks by the immune system (immunomodulatory drugs)

Cladribine

In the US the DMT cladribine (Mavenclad) is already given to people with active secondary progressive MS. In some UK treatment centres doctors are giving it to patients with active primary progressive MS 'off label'. This means they're using it in a way it's not officially approved for.

A trial called ChariotMS is testing whether cladribine can slow down the worsening of hand and arm function in people with advanced MS. It's the first trial of a DMT that focuses on people with advanced MS. We won't know the results for a few more years.

Ocrelizumab

This drug is already used for relapsing and early primary progressive MS. A trial called ORATORIO-HAND began in 2019. It's looking at whether this drug can help people who've had primary progressive MS for a longer time. This includes people who use a wheelchair. The trial will see if this drug helps people keep the use of their arms and hands. An earlier trial showed promising results. We'll know the first results in 2025/2026.

Tolebrutinib

Tolebrutinib is a new type of drug called a BTK inhibitor. These drugs stop cells from your immune system attacking myelin, but they do this in a different way to existing DMTs.

In 2024 results from the Hercules trial showed promising results. Tolebrutinib slowed down by 31% how fast disability got worse in people with secondary progressive MS who didn't have relapses.

This is the first drug to slow down MS in people whose MS is progressive but not active.

Liver damage was a side effect of this drug. If this can be solved, it will take several years for tolebrutinib to get the green light for use in the UK. If this happens, this drug would be the first DMT for people with secondary progressive MS who don't have relapses.

In 2025 we'll know results from a trial to see if tolebrutinib works against primary progressive MS.

To read more about this drug and these trial results search our website for 'tolebrutinib hercules'.

Another BTK inhibitor in trials is fenebrutinib. This drug is being tested to see if it helps with primary progressive MS, with results due around 2027.

Drugs to protect nerves (neuroprotective drugs)

When nerves no longer have enough myelin around them, we need ways to keep these nerves as healthy as possible. Researchers are looking for ways to keep them alive by:

- clearing up debris left when the immune system attacks myelin
- making sure nerves have the energy they need
- helping important molecules in the nerves move around

Researchers are now working on these drugs:

Phenytoin

In an earlier trial this epilepsy drug gave some protection to nerves in the eyes of people with optic neuritis, a common symptom of MS. A larger trial is now needed.

Metformin

In 2019 researchers at the MS Society Cambridge Centre for Myelin Repair showed that this diabetes drug could encourage the repair of myelin in rats. It did this by copying the effect of fasting every other day. Metformin might also protect nerves.

Metformin is one of the drugs now being tested in the Octopus trial (see page 44).

Metformin is also being tested in a different, smaller trial in combination with the hay fever drug clemastine. This is the CCMR2 trial. Read more about it under the entry for clemastine.

Lipoic acid

An earlier trial found lipoic acid (also called alpha lipoic acid) slowed down how fast people's brain shrank. The hope is that taking this tablet might stop the immune system from attacking and damaging myelin. It might also protect nerves from damage. We should have results in the next few years that tell us if the drug helps people with progressive MS to walk better.

Lipoic acid is one of the drugs now being tested in the Octopus trial.

Octopus trial

The Octopus trial is an example of how researchers are doing trials in new ways so that results come quicker. It's testing several drugs for progressive MS at the same time. If one drug doesn't work, they can quickly drop it and add another one. Results from Octopus will come in the next few years.

Drugs to repair myelin (remyelination drugs)

Bexarotene

This skin cancer drug targets the RXR-gamma molecule which encourages your body to make myelin. A small trial showed it repaired myelin, but the side effects were too serious. So a trial is planned where people take a lower dose of bexarotene together with another drug.

Clemastine

This drug is an anti-histamine used for hay fever. It boosted the repair of myelin in tests on mice who had a condition like MS. A small trial in the US found that, taken with a DMT, it was better than a DMT on its own at speeding up messages going from the eye to the brain in people with relapsing MS. A bigger trial called the CCMR2 trial is now underway testing the safety and effectiveness of clemastine with the diabetes drug metformin, in people with relapsing remitting MS. We expect results in 2025

Other drugs

Ibudilast

This drug is thought to reduce inflammation and repair myelin. It might also protect nerves from damage. In an earlier trial, ibudilast had a benefit for people with secondary progressive MS who didn't get relapses. The risk of their disability getting worse almost halved. This was compared to people who took a placebo (a dummy drug with nothing in it).

In 2024, results from a trial showed that people with progressive MS taking ibudilast saw a significant slowing down in how fast their brain lesions grew.

Keep in the know about research

Keep up to date with MS research by calling the MS Helpline, or check out the research pages of our website. Search our website for 'latest research' for news on the trials.

Inside our magazine MS Matters is a supplement called Research Matters with all the latest research news. To subscribe search our website for 'MS Matters magazine'.

Get involved in trials

Find out more about signing up to clinical trials and research studies by clicking on 'Take part in MS research' in the Research section of our website at: **mssociety.org.uk/research**

On that page find out more about our Research Network where people with MS help shape our research programme.

You can also visit

clinicaltrials.gov
(clinical trials worldwide)

bepartofresearch.nihr.ac.uk
(UK trials)

Raise money or campaign

See how you can raise money for research, or campaign for better access to treatments at: **mssociety.org.uk/get-involved**

Read about our ambitious Stop MS campaign to fund research into drugs for everyone that will stop or slow their MS at: **mssociety.org.uk/get-involved/fundraise/stop-ms**

Join the UK MS Register

We're gathering information about how MS affects people's day-to-day lives so that we can understand MS better and shape research. Details on how to join are at **ukmsregister.org**

MS Society Tissue Bank

People can donate their brain and spinal cord to be used in research. This is open to everyone, whether they have MS or not. The MS Society Tissue Bank is partly funded by us. Find out more about its work and how you can help at: **mssociety.org.uk/tissue-bank**

Further information

MS Helpline

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

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

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

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

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

helpline@mssociety.org.uk

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

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.

Two more booklets for family members and carers

'Supporting someone with MS - a guide for family and carers' has more about the help available if you provide care and support to someone with MS.

'Advanced MS – a carer's handbook' is for people who look after someone who is severely affected by their MS and needs much more support.

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

About this resource

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

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

References

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

Photography

Credit for photography belongs to page Amit Lennon (p6, p19 and p35), Alex Grace (p20) and Simon Rawles (p16, p29 and p38).

This resource is also available in large print.

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

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This title will be reviewed within three years of publication (April 2028).