

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

MS Society

A young woman with long, wavy red hair and black-rimmed glasses is sitting on a grey wicker chair outdoors. She is wearing a dark green, ribbed, short-sleeved top and blue jeans. She is holding a wooden cane with a curved handle in her right hand. The background shows a stone wall and a window.

**Understanding
progressive MS**

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

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

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

- Calling us on: **0300 500 8084**.
Lines are open Monday to Friday
- Visiting us at: **mssociety.org.uk/donate**
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

Contents

A word from Ronny, who has MS	4
Five things to know	5
About this booklet	7
What is progressive MS?	8
The different types of MS	10
How progressive MS is diagnosed	15
Why do people get MS?	18
Coming to terms with your diagnosis	22
Managing your symptoms	27
New treatments, new hopes	33
New words explained	43
Further information	46

A word from Ronny, who has MS

For about 10 months before I was diagnosed, I was going back and forth to my GP. I felt tired all the time, with achy legs and night cramps. When I walked it felt like 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 and about research has really helped, as has coming into contact with others who have MS through the 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.

A handwritten signature in black ink that reads "Ronny". The letters are cursive and slightly slanted to the right. The signature is positioned on a white background that is part of a larger graphic element consisting of a vertical line on the left and a white rectangular area on the right.

Five things to know

- 1 Everyone's MS is different. Unfortunately there's no way of knowing exactly how it will develop or affect you
- 2 In recent years we've seen new drugs that can slow down progressive MS for some people
- 3 Finding more treatments for everyone with progressive MS is an international priority. Drug trials are underway to find them
- 4 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
- 5 After a diagnosis of progressive MS, it's common to feel you've lost the life you expected to have. But by making some changes, you should still be able to achieve the things in life you always hoped to



About this booklet

Perhaps you've recently been told you've got progressive multiple sclerosis (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.

A diagnosis of progressive MS can bring up lots of feelings. Knowing about it could help you feel more in control of what's happening. Hopefully it'll make you less uncertain or worried.

In this booklet you'll hear about what's happening in progressive MS, why MS might happen, ways you can manage your symptoms, and what treatments might be available. It also covers how research is looking for drugs to slow your MS down, and protect your nerves.

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

At the MS Society we're here to help you find ways to live out your plans and hopes.

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

You can send us a private message through our Facebook page [facebook.com/MSSociety](https://www.facebook.com/MSSociety). Use the 'send message' tab there.

On our online forum you can ask other people with MS questions and get support. They'll know what you're going through. Find it at [mssociety.org.uk/forum](https://www.mssociety.org.uk/forum)

“MS is a lifelong condition with no cure and your life will be changed. But it's not a terminal disease.”
Mike, secondary progressive MS

What is progressive MS?

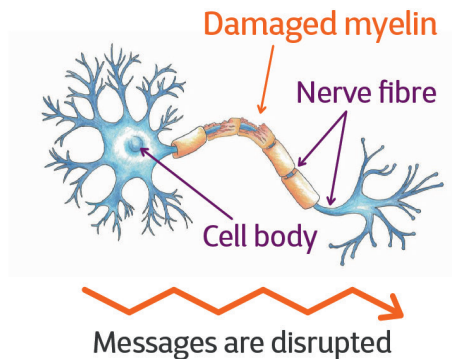
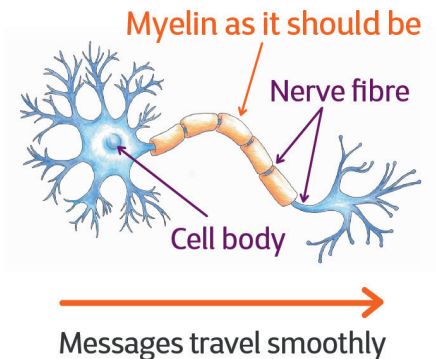
MS, short for multiple sclerosis, is a neurological condition. That means it affects your nerves. The specialist doctors who look after people with MS are called neurologists.

MS comes in different types. Read more about these, including 'progressive MS', on page 10.

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

In MS, instead of just attacking viruses and bacteria, your immune system attacks nerves in your brain or spinal cord by mistake. This causes **inflammation** and strips away the fatty covering around nerves called myelin. Myelin protects the nerve and helps messages pass along it.

These messages go from your brain and spinal cord to other parts of your body. They control how it moves and how you feel things like pain and touch. When you have MS, these messages may become slower, distorted or even blocked. That happens because MS has damaged myelin.



The nerve fibre underneath can become damaged too.

This damage causes the symptoms of MS. The symptoms you get, and where you get them, depend on the part of your brain or spinal cord that MS affects.

We've mentioned the immune system attacking myelin and causing inflammation. But in progressive MS there's a second way in which nerves become damaged. Something that we don't yet understand makes the nerves break down.

The longer someone has MS, the less we tend to see inflammation caused by attacks from the immune system. Instead we usually see more of this second kind of slow damage to the nerves.

Symptoms of MS

Everyone with MS has their own set of symptoms unique to them. These might be easy to see, or could be invisible. The most common are:

- fatigue (extreme tiredness)
- muscle weakness

- difficulty walking
- your bladder or bowel not working as they should
- strange feelings like numbness or tingling in your arms, legs, hands or feet
- muscle stiffness and spasms (movements you can't control)
- 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 thinking or your memory
- swallowing or talking difficulties
- emotional issues like depression
- sexual problems

You may never get most of these. And there are treatments to help you manage many of them. The chapter 'Managing your symptoms' on page 27 has more on this.

The different types of MS

These days neurologists divide MS into one of two broad types: active or progressive. For some people their MS is a mix of the two.

Active MS

In active MS the immune system attacks myelin, the fatty protective covering around nerves. When this happens doctors often see inflammation on **MRI scans** of the brain or spinal cord. They see new lesions, areas of damage to nerves that the inflammation has caused.

Another sign that your immune system is attacking myelin is when you have a relapse. This is when MS symptoms suddenly get worse, or new ones appear. A relapse is usually followed by some sort of recovery as your body does its best to repair the myelin.

For most people, in the early years at least, their MS causes relapses and inflammation, and

so they're diagnosed with relapsing MS (also called 'relapsing remitting MS').

Active MS has the best treatment options. Over a dozen **disease modifying therapies (DMTs)** can help with this type.

If your MS doesn't cause relapses or inflammation, doctors say it's 'not active'. If your symptoms and disability keep getting worse, doctors will call it 'progressive' instead.

People with all types of MS might describe it as 'active' during a flare up of their symptoms, or if their MS is generally getting worse.

But that shouldn't be confused with when doctors use 'active' to mean someone's MS is causing inflammation or relapses.

Progressive MS

For some people, from the very start their symptoms and disability get slowly worse. They usually don't get relapses. Doctors also can't see obvious signs of inflammation on their MRI scans – or they see very little. We don't see the pattern of relapses followed by recovery, like with relapsing MS.

For these reasons this kind of MS isn't classed as active. If your symptoms and disability gradually keep getting worse over the years, it's instead called 'progressive', or 'MS with progression'. Here 'progression' means 'things are getting worse'.

In progressive MS inflammation has stopped, or there wasn't much to begin with. Instead something else is now damaging the nerves directly. We don't yet know what's causing the nerves to break down and stop working.

Another, and much bigger, group of people start off with relapsing (that is, active) MS. But after many years their body

can't repair or replace damaged myelin any longer. Relapses and inflammation stop: their MS has now become progressive.

Compared to active MS, progressive MS doesn't have as many disease modifying therapies (DMTs) to treat it. We look at what there is in the chapter 'New treatments and new hopes'.

Progressive MS: the two main kinds of diagnosis

Doctors diagnose progressive MS as either:

- primary progressive MS
- or
- secondary progressive MS

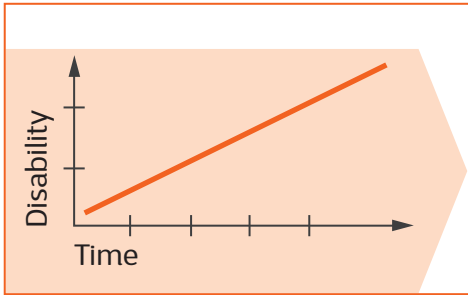
The lines between these two types (and between them and relapsing MS) sometimes aren't clear, even to specialists. The type someone has may become clearer over time. Their neurologist might then change the original diagnosis.

Primary progressive MS (PPMS)

This type of progressive MS is called 'primary' because, from

your first symptoms your disability slowly gets worse. From the start you get no – or very few – relapses. Doctors see no – or very little – inflammation on your scans. Instead something else is damaging the nerves. We don't yet know what.

With primary progressive MS the build-up of disability or symptoms is usually quite slow.



When people are diagnosed with MS, about 10–15% are told they have primary progressive MS. People tend to be diagnosed with it in their 40s or older. Men are just as likely as women to get it, unlike relapsing MS which affects women more.

The DMTs we have right now reduce inflammation. So they don't work for most people with primary progressive MS. But there

are exceptions (see the chapter 'New treatments and new hopes')

Secondary progressive MS

This type of progressive MS is called 'secondary' because the progressive stage comes second, after an earlier stage that had inflammation and relapses.

So, you only get this MS when you had relapsing MS earlier and it's now become progressive MS.

A lot of people who start off with relapsing MS see it turn into secondary progressive MS many years later.

Your body can repair myelin on its own, but after each attack on it, it finds it harder to repair.

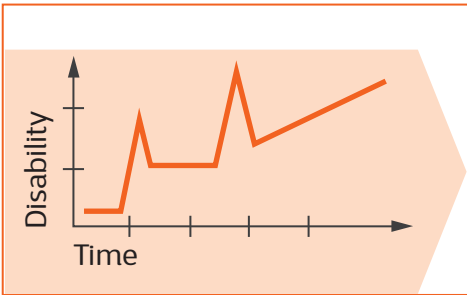
As myelin gets stripped away – called **demyelination** – the nerve underneath becomes exposed. Over time, it suffers damage, stops working and doesn't grow back. When nerves break down like this, it leads to a build-up of symptoms and disability.

Eventually the pattern of relapses followed by recovery comes to an

end. Inflammation and relapses usually stop, or they happen much less often.

Once the relapses and inflammation of the active phase of MS stop, something else is left damaging nerves in a way doctors don't yet fully understand.

Disability or symptoms used to be stable between your relapses, but now things gradually get worse.



In the past it usually took up to 20 years on average for relapsing MS to change into secondary progressive MS. Now that people with relapsing MS take DMTs, this is changing for the better:

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

It's not always easy for doctors to know when relapsing MS has changed into secondary progressive MS.

But it's likely your MS has now become secondary progressive if your disability or symptoms get slowly worse over at least six months without a relapse happening.

If this has happened, and you were taking a DMT, your neurologist may talk to you about stopping it. That's because there's not yet strong evidence that a DMT is likely to help anymore.

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

Progressive MS with an active side to it

Some people with secondary progressive MS can still sometimes have a relapse or get inflammation on their MRI scans.

This happens to some people with primary progressive MS too. Their MS gets steadily worse, but, on top of that, they have occasional relapses or scans show inflammation is still happening. 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.

How can this happen? It’s because that person has, at the same time, two things going on that are damaging their nerves:

1. their immune system is still attacking the myelin around their nerves and causing inflammation and maybe the occasional relapse
2. a second thing, which we don’t yet understand, is directly making nerves break down and stop working.

A few DMTs can help with the inflammation and relapses that come with progressive MS if it has an active part to it (see the chapter ‘New treatments and new hopes’).

How fast will my MS get worse?

It’s impossible to answer that as everyone’s MS is different. Research is hoping to find ways to better predict this for each individual.

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

- have never been on a DMT
- still had relapses while you were on a DMT
- have **lesions** on your spinal cord
- have more or bigger lesions (or other unusual signs) on your brain scans
- had more disability early on
- are older
- are male
- or if the rate that your brain shrinks (**atrophy**) is faster

On average there’s no difference between people with primary and secondary MS when it comes to how fast their MS gets worse.

How progressive MS is diagnosed

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

Whatever the type of MS, it can take time, sometimes months, to finally get a diagnosis. There's an official set of standards that your neurologist will use to diagnose MS. These are called the McDonald criteria.

Tests that help diagnose MS

Neurological examination

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

Other tests might also look at 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, or ask to see how far you can walk. You'll be asked 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 MS is causing inflammation and damage to myelin around nerves. Any lesions (areas of damage and scarring) show up on the scan.

Lumbar puncture

During a lumbar puncture, a needle is placed into your lower back, into the space around your spinal cord. It collects fluid from there, and if **antibodies** are in it,

that's a sign your immune system has been active in your spinal cord and brain. This doesn't happen if you don't have MS. So antibodies there mean there's a strong chance you have MS.

A lumbar puncture can leave you with a headache for a few days.

'Evoked potentials' test

These 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 nerves that control these parts of your body.

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

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

Another test measures how fast your muscles react by giving you tiny shocks on your skin that feel like 'pins and needles'.

Diagnosing primary progressive MS

To be get this diagnosis, you must

have had no relapses, and your disability must have got worse over at least a year.

An MRI scan must show two or more lesions in different parts of your brain or spinal cord. These must have happened at different times.

A lumbar puncture must also show signs of MS (antibodies) in the fluid around your spinal cord.

Diagnosing secondary progressive MS

You must have had relapses in the past, with a steady increase in disability for at least six months that's not linked to any relapse. It's not easy to decide if this has happened.

Your neurologist may use the **Expanded Disability Status Scale** to measure your disability 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.

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



Why do people get MS?

Nobody knows for sure why people develop MS, whether it's progressive MS or other types. But what we know grows all the time.

It's probably not just one thing that triggers MS but a combination of:

- your genes
- something in your environment
- 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 doesn't automatically get MS. Genes play some part but they don't decide who gets MS.

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.

Find more information on genes, including the risk within families, on our website mssociety.org.uk Just put 'genes' in the search box.

Environment

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

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

Infections

Some viruses, and maybe bacteria, might help cause MS. Infections might act with other things to trigger MS. Most studies have looked at Epstein

Barr virus as a likely trigger (it 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 skin makes this vitamin when we're in the sun, and most of what we need comes from sunshine.

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 too.

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.

Read more about MS and what you eat, including vitamin D, in our diet information. Put 'vitamin D' in the search box on our website.

Lifestyle

Two lifestyle factors have so far been linked to MS:

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

Smoking

The evidence is getting clearer all the time: if you have MS, smoking has extra risks for you. That's on top of the well-known risks of cancer, heart disease, stroke and so on.

For people with MS – including progressive types of it – there are real benefits if you quit smoking (or never start).

Studies that have included people with progressive MS have 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. This happens faster in MS, and people with MS who smoke show even more shrinkage.

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

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 that of someone with MS who's never smoked. If you quit, you can also expect a drop in how much disability you develop.

Your GP can suggest things to help quit. This website has ideas and support, from nicotine gum and patches to e-cigarettes:

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

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.

MS is no one's fault

Hearing all this, you might ask: 'Could I have done something to avoid MS?'

The answer's 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.

Quite a number of things may have played a role in you getting MS. You can never know for sure what they were.



Coming to terms with your diagnosis

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

Shock, fear, feeling vulnerable, angry and worried about the future are common. You may feel your old life is over. Some people go into denial.

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, even years, to really accept the diagnosis.

Worries about your health

You may feel frustrated or angry at the lack of treatments to stop or slow down progressive MS. It can be especially hard if you've been on a DMT for relapsing MS

and your doctor is talking about you coming off it now that your MS has become progressive.

You might fear that progressive MS means you'll quickly become very disabled. But the speed at which disability gets worse varies a lot, with no way of predicting how you'll be affected. That unpredictability can be difficult to deal with.

“In those terrible first days after diagnosis, I felt my life was over. But it's not true. 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

Other worries

You might worry that you'll have to stop working, and how this will affect your finances.

You may worry about how MS will impact on your relationship if you're in one, or on your family, especially if you have children. Over the next few pages you'll read about where to get information and support that deals with these concerns.

Some possible positives

You may feel relieved to have a diagnosis that explains your symptoms. You know now you weren't imagining it, and can finally get services and support.

If you've been told you have secondary progressive MS, you might feel relief that the threat of

the next relapse no longer hangs over you. That uncertainty has gone.

“I was relieved I had a diagnosis that explained why I'd felt so unwell. 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 what I can't do today, I do tomorrow. I look at things in a totally different way now.”
Catherine, primary progressive MS

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

Eiona, 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. However you feel, it's important to know how to get information if you want it.

If you do your own research, make sure that where you get information from is 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.

It should include information about local support groups and services, help from social services, national MS organisations, and legal rights.

It should also cover things the law says you must do, like, if you drive, tell the DVLA you have MS.

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. It was extremely useful. Two hours per week for six weeks. It covered a whole range of things, including diet, exercise, nutrition, continence, fatigue and depression.”
Catherine, primary progressive MS

Support

We offer lots of support, much of it comes from people who have MS.

Our local groups meet regularly and are a great place to get information and swap experiences. There are also national support groups for people with specific

backgrounds, including for ex armed forces, or Asian and Jewish people affected by MS.

“Online forums and local support groups have been a great help. I help out at a local group for newly diagnosed people, and have found that I’m still learning things from other people. We encourage them to bring a partner, friend or parent along. It’s really helpful for them to learn about MS.”

Eiona, secondary progressive MS

Find out if we have a group near you here:

mssociety.org.uk/care-and-support/local-support

We have an online forum where you can ask questions, and share experiences or support with others affected by MS.

Our MS Helpline offers emotional support plus practical information. If you’ve been recently diagnosed,

they’ll know of any support available locally or online. You can contact them by email or through Facebook too, not just by phone. See how on page 7.

“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, primary progressive MS

Talking to a professional

Professional help can be useful in coming to terms with your diagnosis and dealing with challenges.

Counselling lets you talk about your feelings in a safe environment with someone who’s trained to help.

They can teach ways to cope better, using things like cognitive behavioural therapy (CBT). This teaches practical problem-solving techniques to help change how you think and behave.

Your GP or MS nurse should know how you can get these kind of services. 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, you can find a qualified counsellor or therapist through the British Association for Counselling & Psychotherapy (BACP).



Managing your symptoms

There are treatments to help you manage your different symptoms.

You should have a person in your MS team who you can contact, usually an MS nurse. Through them you can coordinate your care and help get the right health and social care services.

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

Treating symptoms

There are many treatments that can help with your symptoms or disability, including drugs, therapies and equipment.

Some newer drug treatments that have come along in recent years include:

- Fampyra (fampridine), a tablet

that can help you walk better and faster (up to 25% better for one in three people). It's available on the NHS in Wales and Scotland

- injections of botulinum toxin ('botox') for an overactive bladder
- Sativex (nabiximols), a mouth spray based on cannabis that's used for muscle stiffness and spasms. It doesn't work for lots of people, but for those it does work for, symptoms get significantly better. It's available on the NHS in England, Wales and Northern Ireland. We hope it will be available in Scotland in 2021.

Ask your MS nurse, GP or neurologist about things to help with your symptoms. If there are no drug treatments, they'll know about other therapies and ways of managing their effect on you.

Self-management courses

On these you learn techniques to help you deal with the challenges that come with MS. For example, to manage symptoms like fatigue or pain, action-planning, problem-solving, exercise, healthy eating and relaxation techniques.

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. You'll find it at mssociety.org.uk/fatigue-course

Rehabilitation

This helps keep different parts of your body working well so that 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

“You don’t have to put up with symptoms. I’ve had continence issues, but they’re now under control thanks to my continence adviser. I also take pills for muscle spasms. I refuse to suffer. There’s always some way you can make it better.”
Eiona, secondary progressive MS

You get rehabilitation from different health professionals within the NHS.

Local services

Your local MS Society group or your MS nurse, if you have one, can tell you about local services. These could include free or discounted exercise classes, care services, carers groups, shop mobility schemes, transport and disability schemes.

Changes to how you live

Studies show that lifestyle changes can protect the health of your brain. That could slow

down how fast your disability gets worse, and protect you from other problems like diabetes.

Exercise

Studies show that keeping active can slow down how fast your disability gets worse. Short bursts of moderate aerobic exercise, like walking or steady cycling, can help with your fatigue and quality of life.

Resistance exercise 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 shows you exercises and activities that you can do no matter what your level of disability is.

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, primary progressive MS

What you eat

A healthy, balanced diet helps you stay as well as possible. 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.

Find out more about these diets and healthy eating by putting ‘eating and drinking’ in the search box of our website.

Steroids

Some people with progressive types of MS might have the occasional relapse. Then 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. But they don’t work for everyone every time.

You’ll be offered steroids if the relapse is serious and stopping you doing the day-to-day things you need to do, 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 take them. Whether you have steroids or not, the chances of a relapse leaving you with lasting effects are the same.

Steroids are usually taken at home as tablets, or you might have them in hospital as an infusion (a drip that goes into your hand).

Read more about steroids and their side effects in our booklet 'Managing your relapses', or search our site for 'steroids'.

Cognitive behavioural therapy (CBT)

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

Cognitive rehabilitation therapy

This is designed to 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.

Relaxation

Meditation and **mindfulness** are relaxation techniques. Some research suggests that these 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 on reducing stress, anxiety and depression at:

mentalhealth.org.uk

Complementary therapies

Many people find complementary therapies help them de-stress and relax. Examples include reflexology and massage.

These are often available at MS Therapy Centres, spas and health clubs. Or find details of qualified practitioners through the professional body for each therapy.

Always talk to your GP, neurologist or another health professional if you're thinking of trying an alternative or complementary therapy. Some, such as herbal remedies, can interfere with medications you're taking.

Find out more about these treatments by searching our website for 'complementary and alternative therapies'.



New treatments, new hopes

We know that what people with progressive MS need are treatments that tackle the condition itself, not just their symptoms.

They need drugs that will slow their MS down, protect their nerves, and repair the damaged myelin around them.

There are over a dozen disease modifying therapies (DMTs) to treat active MS, with its relapses and inflammation. But DMTs don't seem to help most people with progressive MS.

There are a few DMTs for people with active progressive MS (see next page). Active progressive MS means you get the occasional relapse or doctors still see inflammation on your MRI scans. These DMTs can stop your immune system attacking the myelin. That means fewer relapses and less inflammation.

What a DMT can't do is stop the other side of progressive MS, that slow breakdown of the nerves which takes place when there's no inflammation. That's why you won't qualify for a DMT if your MS has no active side to it.

Treatment options at a glance for progressive MS

- progressive MS that's also active (still some relapses or inflammation) = a few DMTs might help
- progressive MS that's not active (no relapses or inflammation) = no evidence that DMTs we have at the moment can help, (including HSCT, a kind of stem cell therapy)

DMTs for active progressive MS

If you have active secondary progressive MS, and relapses are the main reason why your disability is getting worse, the DMT Extavia (a beta interferon) might help. And since 2020, there's also siponimod (brand name Mayzent).

If you're in the early stage of primary progressive MS, and it's active, since 2019 ocrelizumab (Ocrevus) has been available.

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 brain smaller. This drug can also delay the need for a wheelchair by seven years.

A small number of people with progressive MS might also be able to get HSCT on the NHS. That's a kind of stem cell therapy.

HSCT

HSCT (haematopoietic stem cell transplantation) can slow active MS down or stop it getting worse. HSCT isn't a cure for MS, and it can't undo damage that MS has already done.

Researchers are learning how well HSCT works compared to its risks. Around one in 330 people who go through it die from having it. Trials are also now comparing how well it works compared to DMT drugs.

HSCT uses chemotherapy to wipe out cells that are a part of your immune system. These cells are faulty and are attacking your nerves.

Before the chemotherapy, new healthy immune system cells (stem cells) are taken from your bone marrow or blood, then later put back into your body. From these a new immune system grows back, hopefully free of MS.

Who can have HSCT?

It's sometimes offered to people on the NHS, but usually only if they have active relapsing MS and other treatments haven't worked.

HSCT can be available on the NHS (in some hospitals that offer it) to people with progressive MS.

But this is only true if they have signs of active inflammation (either relapses or new lesions on an MRI scan).

Trials have shown that HSCT isn't likely to help with progressive MS when it's not active.

There's more about HSCT on our website. Find it by putting 'HSCT' 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 any DMTs.

This is because earlier drug trials seemed to show DMTs make no real difference to your MS if it's affected your legs this much. But new studies are looking at this again.

What if your progressive MS isn't active?

In this case a DMT won't help as there's no inflammation for it to

dampen down, or relapses to stop. Instead you need drugs to protect nerves from damage, or repair their myelin. These aren't available yet, but research is making progress.

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

We're helping to pay for a trial called MS-STAT2 to see if the statin drug Simvastatin can help against secondary progressive MS. Read more on this on page 39.

Research and drug trials

The past

In the past most research went into relapsing MS. It had a lot of success in finding drugs that dampened down the inflammation that comes with this type of MS.

We now have many drugs that do this. They should mean fewer people go from relapsing to secondary progressive MS. Or this will take years longer to happen.



Early trials with DMTs gave disappointing results for people with progressive MS. These trials also didn't include people who use wheelchairs. They'd had MS so long that researchers didn't think the drugs would make much of a difference.

The drugs were also judged to be successful or not on how much people's walking got better. That was another reason people using wheelchairs were kept out of the trials.

On top of this, trials usually only last around two years. So researchers were looking for fast results. This wasn't likely with people who use wheelchairs.

But new trials are now looking again to see if DMTs might be more useful than it first seemed. They'll look at, for example, how much DMTs can help keep your arm and hand function if you use a wheelchair. This benefit was seen in some earlier DMT trials.

In 2012 the International Progressive MS Alliance formed to speed up the development of treatments for progressive MS. We're one of its members.

Since 2014 they've spent €24m on research. They've pledged that will reach €60m by the end of 2025. See the progress they're making at progressivemsalliance.org

Now

A big international effort is going into research into 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. We give millions of pounds to this research push each year.

Research is still looking for answers as to why nerves break down and stop working in progressive MS. It's also searching for drugs to protect nerves from attacks and repair damaged myelin.

Researchers are looking again at whether DMTs might slow down progressive types of MS after all.

Some drugs used for other conditions are being looked at to see if they can protect or repair nerves. We already know these drugs are safe, so they'll pass through trials much faster.

Researchers are also doing trials in new ways so that results come quicker. The Octopus trial is an example. It'll test several drugs for progressive MS at the same time. If one drug doesn't work, they can quickly drop it and add another one.

The future

There's now a very real prospect of treatments to stop or slow down how fast progressive MS gets worse.

In the future it's likely that progressive MS will be treated with 'combination therapy', a mix of drugs. One might tackle the inflammation that damages nerves. Another might repair myelin already damaged by the immune system. A third might help in other ways, such as making sure nerves have enough energy.

Research is also looking at ways to predict how fast someone's MS will get worse. Once we know this, doctors can 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 now in trials

Here are some of the drugs being tested when this booklet was written in 2021.

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. And 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 that's not officially approved.

A new trial called ChariotMS is testing whether cladribine can slow

down the worsening of hand and arm function in people with advanced progressive MS.

It's the first trial of a DMT that focuses on people with advanced primary or secondary MS. It will include people who use a wheelchair.

The trial team began inviting people to take part in 2021. If you think you might qualify for the trial, get in touch with your neurologist or MS nurse, or email the trial team directly at chariot@qmul.ac.uk

We'll know if the results of the trial are good news by the summer of 2024.

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 ocrelizumab 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 and we'll know the first results of this trial in 2025.

Masitinib

A trial with 300 people with primary and secondary progressive MS that wasn't active showed that this drug slowed down how fast their MS got worse. Their **EDSS** scores, which measured their disability, got better. A bigger study is now planned.

Drugs to protect nerves (neuroprotective drugs)

When there's not enough myelin to protect nerves, we need ways to keep 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:

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.

Simvastatin

This drug is a statin used to lower people's cholesterol (a kind of fat in your blood). Statins reduce inflammation and seem to protect nerves.

We're helping fund a trial where people with secondary progressive MS get high doses of simvastatin. We expect results in 2023.

In an earlier trial this drug slowed down by 43% how fast MS made people's brains shrink over two years. Brain shrinkage (**atrophy**) is linked to becoming disabled.

Lipoic acid

This drug is also called alpha lipoic acid. An earlier trial found it 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 summer of 2023 that tell us if the drug helps people with progressive MS to walk better.

Drugs to repair myelin (remyelination drugs)

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. Metformin might also protect nerves, too.

A trial with people with MS is now happening, using metformin along with clemastine (a hay fever drug). We expect results around 2023.

Bexarotene

This skin cancer drug targets the RXR- γ molecule which encourages your body to make myelin. A small trial showed it repaired myelin, but the side effects were too serious. The challenge now is for research to find a similar drug, but without such side effects.

Clemastine

This drug is an anti-histamine used for hay fever. In tests on mice with a condition like MS, it boosted the repair of myelin.

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 is now underway using clemastine with the diabetes drug Metformin. We expect results in 2023.

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 still 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).

By 2021 the drug's makers were planning a trial of the drug with people with secondary progressive MS. It will only include people with this type of MS who don't still get relapses. This is the type most people have when they've got secondary progressive MS.

Ibutilast's makers are testing it with this group because their MS is one that we don't yet have any DMTs for. They're also hopeful ibutilast will get the best results with this group of people.

Keep in the know about research

You can keep up to date with what's going on in the world of MS research by calling the MS Helpline, or checking out the research pages of our website. There's news on the latest trials at: mssociety.org.uk/trials-taking-us-closer

Our magazine MS Matters has sections in each issue about research news. Find the latest issue (and back issues) by putting

'MS Matters' in the search box of our website.

If you search for 'Research Matters', you'll find old issues of a separate magazine about research that we published until 2021 (when it became part of MS Matters).

Get involved in trials

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

On that page you can find out more about our Research Network, too. In it people with MS help shape our research programme.

You can also visit:

clinicaltrials.gov (clinical trials worldwide)

<https://bepartofresearch.nih.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 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

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 Tissue Bank is partly funded by us. Find out more about its work and how you can help at:

mssociety.org.uk/tissue-bank



New words explained

Active – used to describe MS when your immune system attacks the myelin around nerves, causing relapses, or there's inflammation on your MRI scans

Antibodies – when things that make you ill (like viruses and bacteria) get into your body, your **immune system** makes these proteins to help kill them. If antibodies are found in the fluid around your spinal cord, it's a strong sign that you have MS. Together with other tests, this can help diagnose MS

Atrophy – this means shrinkage. As we age, everyone's brain shrinks a little each year, whether they have MS or not. But brain atrophy in MS is faster and linked to worsening disability and poorer thinking and memory

Continence specialist – also known as a continence nurse or adviser. They work in an NHS continence service, part of a hospital or health centre. They

test for and treat bladder or bowel problems

Demyelination – when your immune system attacks the myelin that covers nerves in your brain and spinal cord. It strips it away, leaving damaged, thinner myelin

Disease modifying therapy (DMT) – a treatment that changes for the better how your MS develops. DMTs change how your **immune system** behaves so that it's less likely to attack nerves. They also mean there's less **inflammation** which damages nerves.

There's not much evidence that DMTs help with progressive MS. The exception is if the person also has signs of active inflammation on their **MRI scans**

EDSS Scale – Expanded Disability Status Scale. A way doctors measure disability in MS and record changes over time. It focuses on walking. It goes from 0 to 9.5. The higher the score, the worse your disability

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

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 inflammation of nerves in the brain and spinal cord is left untreated, it starts to damage the nerves, leading to MS symptoms

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

Mindfulness – a type of meditation. You train yourself to focus on the present, your breathing and how you’re feeling. You become more aware of your body, thoughts and feelings. It can

help you manage your emotions. Studies show it helps with stress, anxiety, depression and pain

Molecule - the smallest amount of a chemical substance that can exist

MRI scans – pictures of inside your brain or spinal cord made by using radio waves and strong magnetic fields (‘magnetic resonance imaging’). They show where MS is causing damage to nerves through inflammation and damage to the **myelin** around these nerves

Myelin – a fatty covering that protects your nerves. When you have MS, your **immune system** attacks the myelin around nerves in your brain and spinal cord. The damage to it stops messages travelling like they should along these nerves. This causes the symptoms of MS

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

Occupational therapist (OT) – 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

Plaque – see ‘lesion’

Progressive – used to describe MS when there is no (or little) **inflammation** seen on **MRI** scans and you get no (or few) **relapses**. Instead something we don’t yet understand is directly causing nerves to break down and stop working

Relapse – a flare up or attack of your MS that happens when your **immune system** attacks myelin around your nerves. Damage to **myelin** causes new MS symptoms, or old ones get worse. Your body does its best to repair the myelin, so symptoms often get better, or go away completely (but they can become permanent)

Remyelination – when your body makes new **myelin** to replace the myelin that your **immune system** has damaged

Further information

Resources

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

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

MS Helpline

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

We can provide information

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

mssociety.org.uk/helpline

0808 800 8000

(closed weekends and bank holidays)

helpline@mssociety.org.uk

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet, in particular Dr Waqar Rashid.

We'd love to hear what you think about this information

mssociety.org.uk/yourviews

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. Availability and prescribing criteria for drugs in various parts of the UK may change. Seek advice from the sources listed.

References

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

Photography

Credit for photography belongs to Alex Grace (cover), Simon Rawles (p6, 17, 21, 26, 42), Amit Lennon (p29, 32) and Joe McGorty (p36).

This resource is also available in large print.

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

Contact us



MS Helpline

Freephone 0808 800 8000
(closed weekends and bank holidays)
helpline@mssociety.org.uk

MS National Centre

0300 500 8084
supportercare@mssociety.org.uk

Online

www.mssociety.org.uk
www.facebook.com/MSSociety
twitter.com/mssocietyuk

MS Society Scotland

0131 335 4050
enquiries-scotland@mssociety.org.uk

MS Society Northern Ireland

028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru

0300 500 8084
mscymru@mssociety.org.uk

BK07

© MS Society. August 2021

This title will be reviewed within three years of publication.

