

**MS** Society



**Understanding  
progressive MS**

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to 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: **[mssociety.org.uk/donate](https://mssociety.org.uk/donate)**
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

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# A word from 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 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 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.

# Five things to know

1 MS isn't infectious – you can't catch it – and, we don't yet fully understand why you get it. But, we do know that factors such as your genes, your lifestyle and your environment may be involved

2 When we talk about progression we're saying that your symptoms, like fatigue or tremor, are getting worse. You're experiencing them more often and that there's less recovery time in between

3 We don't know how or how quickly your MS will progress. With progressive MS, there are no periods of remission and the condition gradually gets worse over time. But, the speed at which this happens is different from one person to the next and it's not yet possible to say exactly how it will affect one person

4 There are treatments that we hope will be available in 2017 or 2018 that can help stop or slow down the course of progressive MS

5 Research into treatments for progressive MS is an international priority and there have recently been some positive findings that could lead to new treatments





# About this booklet

It's not unusual to feel shocked, frightened and worried about your future after receiving a diagnosis of progressive MS.

Compared to other types of MS you might feel a diagnosis of progressive MS is especially hard to come to terms with. It's true there are no treatments available at the moment that can stop it or slow it down. But trials of several drugs are underway. Recently, there has also been a huge investment in research to find drugs and treatments that could stop or slow progressive MS.

However, the speed at which MS **symptoms** build up (progress) is different for everyone and there are lots of treatments and therapies that can help you manage your symptoms so you are better able to maintain a good quality of life.

In this booklet, we explain about the two different types of progressive MS, provide ideas on how to manage your condition and how to access the information, treatments and support you need to do this. We also share quotes from people who are living with progressive MS and take a look at the latest research, plus how you can get involved.

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

# Progressive MS explained

Multiple sclerosis (MS) affects the **nerves** in your brain and spinal cord (also together known as your **central nervous system** or **CNS**).

You can't catch MS from someone. You get it when your **immune system** isn't working properly. Your immune system is how your body fights off infections. But in MS it attacks your nerves by mistake.

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

Think of your central nervous system as a pathway by which messages travel between your brain, spinal cord and other parts of your body. For instance, when you walk, messages must

travel from your brain to your leg muscles. If that pathway becomes damaged, their journey may become slower, distorted or even blocked. That's what causes MS symptoms. You might experience several or a few different symptoms, depending on the part of the central nervous system that's affected.

Not only are there differences in MS symptoms between individuals, but also how and when you experience them can be very different. The most common symptoms are fatigue, muscle weakness, difficulty walking, bladder problems, pins and needles, dizziness, muscle spasms, pain, visual disturbances and difficulties with memory.

For more about **symptoms**, visit our website: [www.mssociety.org.uk/what-is-ms](http://www.mssociety.org.uk/what-is-ms) or read our booklets Just diagnosed and What is MS?



However, you may never experience all of these symptoms, and it's very unlikely that you'd get them all at once.

## Types of MS

The main diagnoses of MS are: relapsing remitting, secondary progressive and primary progressive. Around 85% of people are initially diagnosed with relapsing remitting MS.

This means they experience symptoms for a period of time (**relapses**). This is followed by periods of 'remission' - their symptoms go away completely or get better (but they may be left with some symptoms). A relapse may last for anything from 24 hours to three months or more and remission can last anything from one month to many years.

With progressive MS, there are no periods of remission and the condition gradually gets worse over time. However, the speed at which this happens varies a lot and it's not yet possible to predict exactly how it will affect one person.

**“Online forums and local support groups have been great. 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 or friend or parent along and it’s really helpful for them to learn about the condition.”**

**Eiona**

## Progressive types

When we talk about progression we're saying that your symptoms, like fatigue, tremor, bladder and bowel problems, are getting worse. You're experiencing them more frequently and that there's less recovery time in between.

## Primary progressive MS

If you have this type of MS, you never have clear periods when

your disability stops or gets better (remissions). Instead, your condition begins with mild **symptoms** that slowly get worse (progress) over time. Primary progressive MS affects around 10 to 15% of people with MS.



## Secondary progressive MS

This type follows relapsing remitting MS. You no longer have clear periods when your disability stops or gets better (remissions) and your disability gets steadily worse. In the past, before DMTs came along, it usually took around 20 years for relapsing MS to change into secondary progressive MS. But thanks to today's MS drugs this is changing:

- fewer people are likely to go on to secondary progressive MS
- for those that do this could take longer to happen

In a small number of cases, some people are not diagnosed with MS

until their condition has reached the secondary progressive stage.

## Progressive relapsing MS

For a small number of people (about one in twenty) their MS gets steadily worse but they have relapses on top of that. Treatments can help with the **inflammation** that comes with the relapsing part of this type but not with the progressive part.



## How many people have progressive MS?

There are roughly one million people worldwide who have progressive MS out of 2.3 million with any type of MS. In the UK, there are about 130,000 people living with all types of MS.

## Who does it affect?

People are usually diagnosed with progressive MS in their 40s or 50s but it can happen at any age. The relapsing type is usually diagnosed earlier, between the ages of 20 and 40.

There are just as many men as there are women affected by progressive MS. That's unlike relapsing remitting MS, which affects three times as many women as men. We don't yet know why.



## How is progressive MS diagnosed?

Diagnosis of either type of progressive MS can take time, sometimes months, as you'll need several different kinds of tests to confirm it. Also, if you don't already have an MS diagnosis, other conditions need to be investigated and ruled out first.

There's an official set of criteria, known as the **McDonald criteria**, that your neurologist, a doctor who specialises in the nervous system, should use to help diagnose your condition.

### Primary progressive MS

To be diagnosed with primary progressive MS you must have no history of relapses and remissions and your condition must have progressed over at least a year. A **magnetic resonance imaging (MRI)** scan must show two or more areas of scarring, known as **lesions** or **plaques**, in different parts of the brain or spinal cord that have occurred at different times. There must also be evidence of MS in the spinal fluid. This can be detected through a lumbar puncture. This is a relatively routine procedure where a small needle is inserted into the lower back.

### Secondary progressive MS

You must have had relapses and remissions in the past, and shown a steady increase in disability for at least six months, outside of relapses. But determining this isn't straightforward. It can take months to recover from a relapse, which can leave permanent damage.

This doesn't necessarily

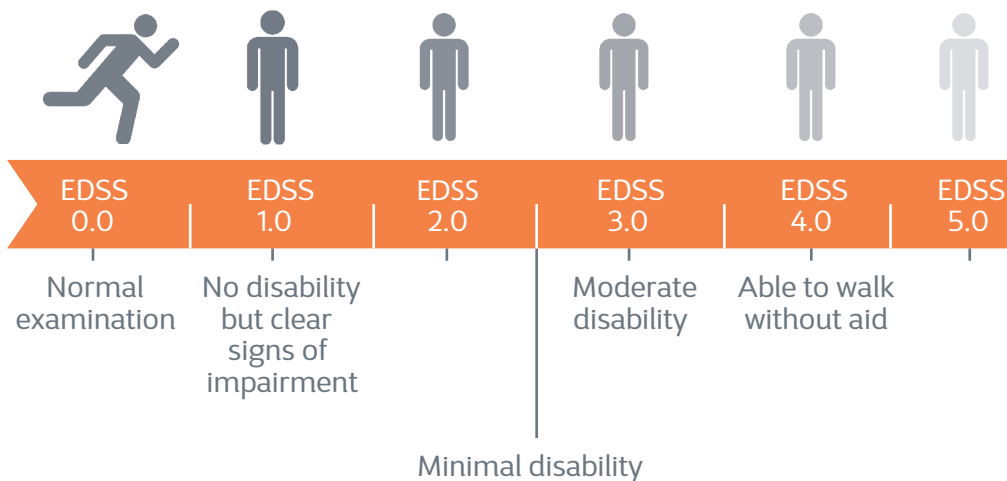
mean that the condition has progressed. Your neurologist may use a clinical tool called the Expanded Disability Status Scale. This measures levels of disability on a scale of 0 to 10, as well as asking you how your ability to complete certain tasks has changed. Sometimes an MRI scan is used to check for certain changes in your central nervous system.

## Neurological examination

Your neurologist may carry out simple tests for balance, movement, coordination, reflexes or vision. Your coordination, sensation, speech and swallowing, and mental function may also be tested. They may also ask you other questions about any symptoms you may be experiencing such as problems with your bladder and bowels.

## The tests

# The Expanded Disability



You may be asked to see how far you can walk (if appropriate).

### MRI scan

An MRI scan creates images of cross-sections of the brain and spinal cord, showing any permanent damage to nerve cells (scars or lesions) that may be caused by MS.

### Lumbar puncture

During a lumbar puncture (or 'spinal tap') a needle is put into

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

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

## Status Scale (EDSS)



Death

EDSS  
6.0

EDSS  
7.0

EDSS  
8.0

EDSS  
9.0

EDSS  
10.0

Help needed  
to walk  
100 metres

Essentially  
restricted to  
wheelchair

Disability impacts  
daily activities

Essentially  
restricted to  
bed much  
of the day

Bedridden and  
unable to  
communicate  
effectively or  
eat/swallow

have MRI scans, lumbar punctures aren't used so often.

## How fast will your condition progress?

There is no way to predict this yet. Just as symptoms vary between individuals and at any one given time, so does the speed at which your condition progresses. Even though progressive MS means that you won't have symptom-free periods, that doesn't necessarily mean that you will quickly become disabled.

Changes can happen very slowly, over years, and symptoms, their severity and the speed of

progression will vary throughout the course of your illness. Research tells us that there's no difference between people with primary and secondary MS when it comes to how fast their MS gets worse.

**“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**





# What's going on in your body?

MS is a complex condition that isn't yet fully understood. However, we do know it's an autoimmune condition. This is when your **immune system**, which is meant to protect you from infections, gets confused and mistakes a part of your body for an 'invader' such as a virus, and attacks it.

In the case of MS, it affects your **central nervous system**, which consists of the brain and the spinal cord. The central nervous system is the control centre of the body, governing every function, from unconscious actions like breathing or arousal to conscious actions such as movement, bladder and bowel function and sex.

The spinal cord receives information from around your body and passes it on to your brain, which analyses and stores it. Your brain then sends out

messages to parts of your body, instructing it to perform various tasks. For instance, if you want to walk over to the other side of the room, your brain will send instructions to your leg muscles.

## Message interruption

These messages are sent by electrical impulses transmitted by **nerves**, which are covered by a fatty substance called **myelin**. The myelin has two functions: it protects the nerves and it ensures that the messages travel smoothly and quickly to the correct destination.

But in MS, your immune system mistakes myelin for an 'invader'. As a result, it allows its white disease-fighting cells out of the bloodstream, through the blood-brain barrier and into the central nervous system, where it attacks myelin and the cells that make myelin (oligodendrocytes).

As the myelin becomes damaged, something happens to the

nerves' ability to send messages efficiently and quickly. This is what leads to **symptoms**. And because the central nervous system governs all your bodily functions, symptoms can be incredibly wide-ranging, depending on the area that's affected.

### Move to progression

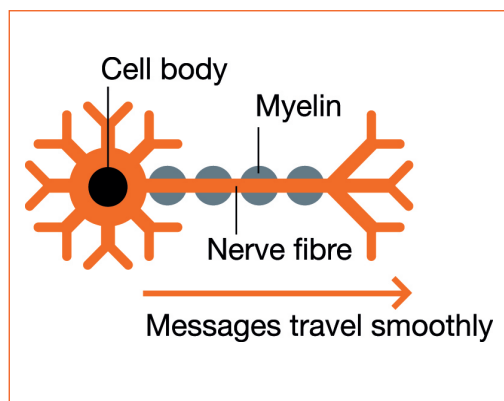
The brain has some ability to repair myelin on its own, but with repeated attacks, myelin can no longer re-grow. As it gets more damaged – a process known as demyelination – the nerve fibres are exposed and also become damaged. Over time, they begin to die off. This happens naturally as part of the ageing process but

faster in people with MS. Once the nerve fibres have died, they can't grow back and this leads to a build-up of disability.

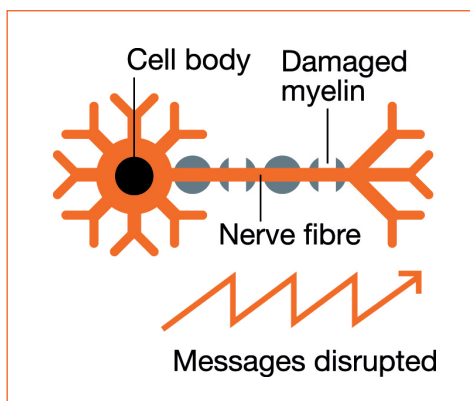
We know from **MRI scans** that the affected areas at first become inflamed – this is part of your immune system's natural defence process. As time goes on, scars, known as **plaques** or **lesions**, form in your brain and spinal cord. Scans reveal that, as your condition becomes progressive, the **inflammation** dies down but there's a higher level of nerve damage.

### A useful comparison

It can be easier to understand the mechanism underlying MS if



Myelin as it should be. Messages travel smoothly



Myelin damaged. Messages are disrupted

you compare what is happening in the central nervous system with something that's familiar in everyday life, such as your water pipe system at home.

Imagine that your nerves are like water pipes, sending water (messages) around your home (body). The protective myelin around your nerves is the lagging. Just as lagging helps to insulate your pipes, ensuring that hot water is delivered efficiently, the myelin insulates the nerves, allowing the messages to travel swiftly to the right destination. And, as lagging also protects the pipe from damage, myelin helps protect the nerve.

In MS, sections of the lagging (myelin) on the pipes (nerves) get damaged and fall off, leaving the pipes exposed. If the lagging continues to be damaged, the pipes become vulnerable and, when a cold winter comes along, they may crack and burst. If the pipes aren't repaired, the water pipe system becomes less efficient.

**“Life doesn't have to be insular and isolated and 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 hand, foot and leg spasms. I refuse to suffer. I don't say 'I suffer from MS'. There's always some way you can make it better.”**

**Eiona**

### **Why does this happen?**

We know that MS isn't infectious – you can't catch it – but we don't yet fully understand why you get MS either. However, we do know that some or all of the following factors may be involved:

#### **Genes**

You don't directly inherit MS – if one of your parents has it, you still only have a one in 67 (or 1.5%)



chance of getting it, compared with one in 500 for the general population. But there is a genetic element and more than 200 types of genes have now been linked to MS.

### Vitamin D deficiency

There are more people with MS in areas of the world that are far away from the equator, like northern Europe. Research shows that low levels of vitamin D – made by the action of sunlight on the skin – particularly in your childhood years, increases your chances of developing MS later in life.

### Smoking

Studies suggest that smoking could increase risk, possibly by affecting the immune system. Smoking is also linked to going from relapsing MS to progressive MS at a faster rate. So, just as for everyone else, it's a good idea not to smoke and to stop if you do.

### Infections

Recent research tells us that certain bacterial or viral infections may act as a potential trigger for MS, including the Epstein-Barr virus

(also known as the kissing disease or mononucleosis), which causes glandular fever. This doesn't mean these infections cause MS, but they could add to your chances of developing it. And just because you've had the Epstein Barr virus doesn't mean you'll get MS as most people carry it.

### Obesity

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

- make you low in vitamin D
- make your immune system overactive and cause inflammation inside your body
- other reasons we don't understand yet

Of course, not everyone who's obese gets MS and not everyone who got MS is or was very overweight. But if your risk of getting MS is on your mind, your weight is a risk factor you can change.



# Coming to terms with your diagnosis

Being diagnosed with any lifelong condition can have a huge emotional and psychological impact, even if you were expecting the diagnosis.

It's not unusual to feel shocked, frightened, vulnerable and worried about the future. You may feel totally devastated or you may be in denial. You may feel angry, tearful, confused, overwhelmed, anxious, depressed, withdrawn or all those things in the weeks and months afterwards.

There's no right or wrong way to react. Each person's response is as individual as their **symptoms** but it's generally recognised that many people go through a grieving process for the loss of the life they had expected. This is a normal, emotionally healthy response.

Don't beat yourself up if you are still struggling to come to terms with the diagnosis for some time afterwards. It can take many months and even years to do this.

For more information on how to cope with your diagnosis read our booklet *MS and your emotions: understanding and dealing with your feelings*.

**“In those terrible first few days after diagnosis, I felt like my life was over. But it's not the case and 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.”**

**Ronny**



## Health concerns

You may feel frustrated or upset that there are no treatments to stop or slow the progression of your MS. This can be difficult if you have been taking disease modifying therapies for relapsing remitting MS and are told that you can no longer have them.

You may worry that you have done something wrong. This is not the case – in the past, before DMTs came along, it usually took around 20 years for relapsing MS to change into secondary progressive MS.

A major fear is that having progressive MS means you will become severely disabled within a short period of time. However, the rate at which the condition progresses varies widely and there is no way of predicting how someone will be affected. This uncertainty can be difficult to deal with, too.

## Wider concerns

You may be worried about your ability to carry on working

and how this will impact on your finances. You may also be concerned about the effects of your condition on your family, especially if you have young children. See ‘What can help’, below for getting help on practical matters.

## Relief

You may feel relieved to have a diagnosis that explains the many and seemingly unrelated symptoms you have been having. Now you have a diagnosis, you can get access to MS services, support and other forms of help.

Some people with secondary progressive MS say they feel relieved at not having to worry about when the next **relapse** will happen. Others say that they have found new much-loved hobbies or changed their approach to life for the better.

## What can help?

Some people want to find out as much about MS as soon as possible. Others don't feel ready to take in lots of new information.

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

## Information

Guidelines from the National Institute for Health and Care Excellence (NICE) recommend that written information about MS and how to manage symptoms should be made available when you're diagnosed.

You should also be advised about local support groups and services, relevant social services, national charities, and any legal requirements or rights. If you haven't received this, ask your GP, MS nurse or contact the free MS Helpline (see below).

You may also find some of our free booklets useful:

- Living with the effects of MS
- Just diagnosed
- MS and your emotions

**“My MS nurse offered a course for people newly diagnosed with MS, which was extremely useful. It was two hours per week for six weeks and covered a whole range of things including diet, exercise, nutrition, continence, fatigue, depression and a range of other topics.”**

**Catherine**

## Support

- Groups – Many of our local groups have regular support group meetings. Each local group also has an MS support officer who can offer guidance on local services. There are also national support groups
- MS Helpline – We offer emotional support plus practical information through our free MS Helpline (0808 800 8000).



- Online forums – Our forums offer a way to share experiences and support with others affected by MS

**[community.mssociety.org.uk/forum](https://community.mssociety.org.uk/forum)**

## Talking therapies

Counselling, psychotherapy and cognitive behavioural therapy (CBT) all offer ways to help you come to terms with your diagnosis and deal more positively with challenges. They allow you to talk about your feelings in a safe environment

If you're doing your own research, check that your information source is reputable. This is especially important when it comes to health products and treatments. If in doubt, check with your MS nurse, neurologist or GP. Or read 'I've got nothing to lose by trying it', a free guide by charity Sense about Science, which you can download from their website **[www.senseaboutscience.org/](http://www.senseaboutscience.org/)**

with someone who is trained to help you in a positive way. However, a recent study showed better results for CBT in helping people adjust to the early stages of MS. CBT uses practical problem-solving techniques to help you change how you think and behave.

You may be able to get talking therapies through your GP or MS nurse. However, access on the NHS can be limited. Counselling is available from some regional MS Therapy Centres or you may be able to access it at a discounted rate through your local MS Society group.

Otherwise, you can find a qualified counsellor or psychotherapist through the British Association for Counselling & Psychotherapy (BACP) or the British Association for Behavioural and Cognitive Psychotherapies (BABCP) for a qualified CBT therapist.



For more information, visit:

[www.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.uk)

01455883300

For more about emotional support, visit the Support section of our website or call our free helpline.

[mssociety.org.uk/ms-support/emotional-support](http://mssociety.org.uk/ms-support/emotional-support)

0808 800 8000

**“Having the right information is so important. At first, I thought that every symptom I had would stay with me forever and get worse. People need to be told right away that this isn’t the case. You can get one symptom for ages, then it may stop for a while and may or may not come back later.”**

**Catherine**



# Managing your condition

You should receive information about symptom management when you're diagnosed, but symptoms and needs change over time so you should also be offered a management care plan.

This should include a single point of contact, usually an MS specialist nurse, to coordinate care and help you and your family access the right health and social care services for you.

A range of health professionals including physiotherapists, occupational therapists, speech and language therapists, psychologists, dieticians, social care and continence specialists can help with symptom management. Your MS nurse or GP can refer you.

## Treating symptoms

There are many treatments, including drugs, devices and therapies that can help with

**symptoms**, from muscle pain, stiffness, spasms and poor balance to continence issues, difficulties with speech, swallowing, sight, memory and thinking, and sexual function.

Drug treatments licensed over recent years include Fampyra (fampridine), a tablet that's been found to improve walking speed and ability by up to 25% in four out of 10 people.



and injections of botulinum toxin (commonly known as 'botox') for overactive bladder. There's also Sativex (nabiximols), an oral spray derived from cannabis, which can reduce muscle spasms.

Ask your MS nurse, neurology nurse, GP or neurologist about symptoms. Even if there are no drug treatments, a health professional can advise you on



appropriate therapies or coping strategies.

- Free access to Sativex and Fampyra, which is not deemed cost-effective by NICE, is limited across the UK. If you're having problems accessing licensed treatments, find out more about our Treat me right campaign at [www.treatmerightms.org.uk](http://www.treatmerightms.org.uk)

## Self-management programmes

Tried and tested techniques are used to help you deal with MS challenges. Topics may include managing symptoms such as 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.

## Rehabilitation

Its aim is to help you maintain function, staying as active and independent as possible. It may involve helping you deal better

with fatigue, improving mobility, addressing continence issues, or tackling sleep problems or side effects from medication. It encompasses a multi-disciplinary approach, where you benefit from the input of several health professionals, depending on your needs.

**“I try to walk as much as possible, resting when I need to. I know it's 48 steps to the bus stop and 103 to the shop. I always plan the quickest route because if I overdo it I'll fall and my legs become like rubber.”**

**Ronny**

## Local services

Your local MS Society group can tell you about the services in your area. These may include free or discounted exercise classes, care services, carers' groups, shop

mobility schemes, transport and disability schemes.

### Quit smoking services

There's now good **evidence** that smoking can speed up the progression of MS. Ask your GP about your local NHS Stop Smoking Service or visit [www.nhs.uk/smokefree](http://www.nhs.uk/smokefree)

### Lifestyle changes

#### Suitable exercise

Short bursts of moderate aerobic exercise, like walking or steady cycling, have been shown to help improve fatigue and quality of life in people with MS. Many people find resistance exercise (stretching, yoga and weights) less challenging. A physiotherapist can advise on the best exercises for you. There's a free downloadable Exercise and physiotherapy booklet and a free DVD, *Exercising with MS*, which you can order or watch online, plus a library of exercise DVDs. Details of how to order these can be found on page 42.

### Healthy eating

Certain diets are promoted as effective therapies for MS but there's no clinical research that supports this. But a healthy, balanced diet will help you stay as well as possible. Find out more in our booklet *Diet and nutrition*.

**“You have to adapt your expectations. I'd planned to get a boat when I retired but that wasn't possible. Instead I've found other hobbies: photography, creative writing and sugar craft. I make and decorate wedding cakes, creating peonies, roses and orchids from icing. It's something I'd never have tried before.”**  
**John**

## Therapies

### Cognitive behavioural therapy (CBT)

This therapy, which focuses on specific, practical problem-solving techniques, can help you to manage fatigue, as well as dealing with anxiety and depression.

### Cognitive rehabilitation therapy

This is designed to help combat the problems with memory, attention span or concentration that occur in between 50 to 60% of people with MS. It's provided by occupational therapists and psychologists in a group or on a one-to-one basis.

### Relaxation

Some research suggests that relaxation techniques, including meditation and mindfulness, can help reduce fatigue, anxiety and stress and improve working memory, attention and planning abilities. The Mental Health Foundation charity has details of courses, including an online course that has been found to be effective in reducing stress, anxiety and depression.

Visit [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk) for more information.

### Complementary therapies

Some people report that hyperbaric oxygen therapy, in which you breathe in pure oxygen under increased air pressure, helps relieve symptoms. However, scientific studies don't support this, and there are some associated risks.

Many people find that other complementary therapies such as reflexology and massage can help with relaxation, and these are often available at MS therapy centres, spas and health clubs, or you can find details of qualified practitioners through the relevant professional bodies.

Always discuss treatment options, whether orthodox or complementary, with your GP, neurologist or other professional. Some, such as herbal remedies, may interfere with drug treatments. Find out more in our booklet *Complementary and Alternative Medicine (CAMs)*.

# A breakthrough for progressive MS

Not long ago there were no treatments for progressive MS. There are now two that can slow down some types of progressive MS.

The first is ocrelizumab (brand name Ocrevus). It's a disease modifying therapy (DMT) for both relapsing MS and primary progressive MS. It's been available around the world since 2018.

The second treatment is only suitable for a few people with progressive MS. It's a kind of stem cell therapy called Haematopoietic Stem Cell Transplantation (HSCT).

HSCT isn't likely to work if you have primary or secondary progressive MS that has no inflammation in your brain or spinal cord.

But it might be suitable for a small number of people who have progressive MS, and where

doctors can see active inflammation (new lesions) on their MRI scans.

## Existing DMTs

Ocrelizumab is an intravenous infusion treatment. In a 2015 trial, ocrelizumab showed a 25% reduction in disability progression in people with primary progressive MS. This reduction was sustained for at least 24 weeks and was measured by the Expanded Disability Status Scale (EDSS) – see pages 12 and 13.

Ocrelizumab is not yet available on the NHS for primary progressive MS because of its cost. We're campaigning to change this. The NHS and the drug's makers are in discussions about how to make ocrelizumab available. For updates on this visit [mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies/ocrelizumab](https://mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies/ocrelizumab)

## Future DMTs

The DMTs we have now are designed to reduce the frequency and severity of **relapses**.

They work in slightly different ways to modify the behaviour of cells in the **immune system**. The aim is to prevent or reduce the **inflammation** that leads to relapses and ultimately damage to the nerve fibres.

Most people with progressive MS don't get relapses, which is why DMTs aren't usually prescribed. Current DMTs are helpful for relapses because they focus on the immune system. More options will be available to people with progressive MS once DMTs that focus on **myelin** repair and neuroprotection are developed and made available.

However, guidelines from the Association of British Neurologists (ABN) say that one DMT (beta interferon) may be prescribed for someone with secondary progressive MS who also has relapses if it's clear that the relapses are the predominant cause of increasing disability.

So if you think you may be having relapses, tell your neurologist who can assess whether you may benefit from DMTs.

## Have there been other trials of DMTs for progressive MS?

Some of the DMTs have shown to slow down the time it takes for someone to go from relapsing remitting MS to secondary progressive MS.

Several trials have been carried out to see whether DMTs may have a benefit for progressive MS. Unfortunately, overall the results have been disappointing.

## Stem cells (HSCT)

You may have heard in the media of HSCT, a stem cell treatment. It's still at the stage where researchers are trying to discover how well this treatment works and what the risks of it are .

HSCT works by allowing aggressive chemotherapy to destroy the immune system, and with the collected stem cells hopefully regrow an immune system without MS. It's not the





transplanted cells that prevent inflammation, the chemotherapy does this by killing the malfunctioning immune cells.

### Does HSCT work for progressive MS?

So far results of trials have shown little evidence of the effectiveness of HSCT in progressive MS. Some people with progressive MS have seen their condition stabilised, while others have not. This suggests that, as each person's MS is different, so is their reaction to HSCT.

HSCT can't repair damage already done to the nervous system. This is one reason why it's more likely to be effective for people with relapsing MS.

### What does it do?

HSCT aims to stop all immune attacks. So, if you have progressive MS and are still getting some relapses which are causing damage (and worsening your disability) then the treatment may be able to stop this and as

a result stopping things from getting worse.

What the treatment can't do is reverse damage already done, so things may become more 'stable' but they won't improve your disability.

### How does it work?

Stem cells are removed from your bone marrow and grown in a lab. Then your immune system is wiped out by using intensive chemotherapy and the stem cells are reinjected back into your bloodstream to 'reset' the immune system. This is a single procedure and requires long-term follow-up.

If you have progressive MS, or if you have relapsing remitting MS that's being controlled well by less risky DMTs, then HSCT might be considered too dangerous for you.

There's more information on our website: [mssociety.org.uk/hsct](https://mssociety.org.uk/hsct)

## What about steroids?

Again, **steroids** work specifically for relapses, speeding up recovery, and are not used for progressive MS unless someone also experiences relapses.

Even though they speed up recovery, steroids aren't offered to non-relapsing forms of progressive MS as they don't reduce the damage you already have.

## Other research

There are also projects investigating the causes of progressive MS. This could lead to ways to predict the rate of progression in individuals and personalised treatment plans.

A lot of research is looking to develop treatments for progressive MS, not just understand it. This includes drug repurposing and finding new targets to help remyelination and neuroprotection.

## Is there a lack of research into progressive MS?

In the past, research revolved around relapsing remitting MS for several reasons. As 85% of people with MS start off with this type, it made sense for research to focus on it.

There was the logical assumption that if relapsing remitting MS could be successfully treated, then secondary progressive MS may be prevented.

Another reason is that unusual activity in the immune system – was, and still is, better understood and easier to treat, than dying nerve cells (the process that triggers progressive MS).

It's only recently that there have been the scientific tools, such as the latest sophisticated **MRI scans**, available to allow scientists to study the underlying causes and processes of progressive MS in more detail.



Several drugs have been trialled for progressive MS, but so far these trials haven't led to treatments that can stop or slow the condition.

However, research into treatments for progressive MS is now an international priority. There have recently been some positive findings that could lead to new treatments. Read about some of the latest research on page 36 and the Research section of our website.

**“I was very upset that I had a form of MS for which there’s no treatment. It seemed so unfair that nothing was available to me.”**  
**Catherine**

# Ongoing research into progressive MS

Finding treatments for progression is top of our Research Strategy and we are working to make sure it's a global priority. In 2012 the International Progressive MS Alliance was formed with the aim to fund progressive MS research on a global scale.

In 2014 the International Progressive MS Alliance, of which the MS Society is a founding member, and the MS International Federation (formerly the International Progressive MS Collaborative) launched 22 innovative research projects.

It plans to invest €22.4 million between 2014 and 2019. Here are some of the latest research developments, some of which were funded by Alliance:

## Drug repurposing

- **Simvastatin** – A mid-stage, MS Society-funded, trial giving high doses of this cholesterol-lowering drug to people with secondary progressive MS showed that brain shrinkage, which is linked with disability, was slowed by 43% over two years compared with a dummy drug. A larger trial is now happening to see its effects on disability. Statins are anti-inflammatory and seem to have a protective effect on **nerves**, too
- **MS-SMART trial** – This trial, funded by the MS Society, tested three drugs (ibudilast, riluzole, amiloride) currently used for other conditions against a dummy drug in people with secondary progressive MS. Unfortunately none of the drugs had any effect on MS.

## Myelin repair

Nerve cell damage happens when the protective layer of **myelin** covering the nerve fibres has been destroyed and can no longer repair itself. Scientists at the MS-funded Cambridge Centre for Myelin Repair and the Edinburgh Centre for MS Research are working together to understand more about how damage to myelin happens and discover ways to encourage it to regenerate, a process called remyelination. Three breakthroughs include:

- **RXR-gamma** – This is a molecule that researchers have found encourages the production of myelin. A drug that targets RXR-gamma has already been identified, and a clinical trial is now being developed to assess its potential as a treatment
- **Activin-A** – Researchers have discovered that this protein found in immune cells can stop **inflammation** and encourage the production of myelin. They are now looking

for a treatment that stimulates activin-A to encourage myelin repair. This is at a very early stage of development so no trial is currently planned

## Disease modifying therapies (DMTs)

- **Natalizumab** (Tysabri) – This DMT, licensed for relapsing MS, is an antibody, just like those found in the **immune system** (where **antibodies** help fight infection). By attaching itself to receptors on the outside of certain immune cells, natalizumab prevents these cells from leaving the blood stream and entering the brain and spinal cord where, in MS, they can cause inflammation and damage. In October 2015, a final-stage trial to assess whether it can delay progression of disability in people with secondary progressive MS, showed it hadn't been successful. Natalizumab did show some positive effects on upper limb function but didn't slow disability progression.



- **Fingolimod** (Gilenya) – This is a DMT licensed for relapsing MS. It was revealed that it couldn't delay the progression of disability in people with primary progressive MS. This was disappointing as the trials were in phase III, the final phase before licensing and approval
- **Rituximab** – This is currently used for rheumatoid arthritis. It works by destroying a certain type of immune cell believed to be responsible for attacking healthy nerve cells in progressive MS. In 2019 one study found this drug slowed down secondary progressive MS. On average people taking it had less disability progression after 3-4 years, or experienced it later.

## Other research

There are also projects investigating the causes of progressive MS. This could lead to ways to predict the rate of

progression in individuals and personalised treatment plans.

## How to get involved

### Take part in clinical trials

To find out more about getting involved in clinical trials and research studies, click on 'Get involved' in the Research section of our website. Also, visit:

- [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (clinical trials worldwide)
- [www.ukctg.nihr.ac.uk](http://www.ukctg.nihr.ac.uk) (UK trials)

### Join the MS Register

We are compiling information about how MS affects people's day-to-day lives in order to understand the condition better and influence future research. Visit [www.ukmsregister.org](http://www.ukmsregister.org).

### Register with the MS Society Tissue Bank

People with and without MS can donate their brain and spinal cord tissue for research after their death. For a registration pack

email: [ukmstissuebank@imperial.ac.uk](mailto:ukmstissuebank@imperial.ac.uk) or call 020 7594 9734.

## Help us fund research

The breakthroughs achieved by our investment projects are only possible with your support. To donate, visit [mssociety.org.uk/donate](http://mssociety.org.uk/donate) or call 0800 100 133.

### Further reading

The following books are all available to borrow from the MS Society library. Email [librarian@mssociety.org.uk](mailto:librarian@mssociety.org.uk), call 020 8438 0900 or visit [www.mssociety.org.uk/library](http://www.mssociety.org.uk/library)

**Living with progressive multiple sclerosis. Overcoming the challenges** by Patricia K. Coyle and June Halper. Published by Demos Medical Publishing (Second edition 2008), ISBN: 1932603476. This American book includes chapters on managing the social, economic and medical aspects of progressive MS.

**Multiple Sclerosis: A self-care guide to wellness** edited by Nancy J. Holland and June Halper. Published by Demos Medical Publishing (Second edition 2005), ISBN: 1932603077. This American book focuses on managing MS and living well. It contains many practical tips for keeping as healthy, fit and active as possible.

**300 tips for making life easier with multiple sclerosis** by Shelley Peterman Schwarz. Published by Demos Medical Publishing (2006), ISBN: 1932603212. This book has tips on many aspects of living with MS – for people with MS, their families, friends and carers.

# New words explained

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

**Central nervous system (CNS)** – your brain and spinal cord. Nerves carry messages between the two that control how parts of your body work.

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

**Inflammation** – when your immune system reacts to attack or damage it sends more blood and immune cells to the damaged area, making it swollen. When inflammation of the brain and spinal cord is left untreated it starts to damage it, leading to MS symptoms

**Lesions (also called 'plaques')** – areas of damage caused by MS in your brain or spinal cord. They

slow down or stop messages travelling down nerves, affecting your control of parts of your body. Lesions can be seen on MRI scans

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

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

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

**Neurological symptoms** – we talk about neurological symptoms when we want to describe

symptoms you might have as a result of the effect your MS has on your nervous system. Some of these symptoms include blurred vision, difficulty walking, weak muscles and fatigue.

**Obese** – being very overweight. Defined by the NHS as a body mass index (BMI) over 30 and over. Find out your BMI at [www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx](http://www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx)

**Plaques** – see lesions

**Relapse** – a flare up or attack of your MS when you get new symptoms or old ones get worse. Symptoms then go away, get less noticeable or they can become permanent

**Scientific or clinical evidence**  
– we use the term evidence to describe when tests have been done to prove a (medical) claim does or doesn't work. Usually, the larger the test, the more reliable the proof is. When we say there is 'little evidence' we mean that there have been few tests and/or tests with a small number of persons.

**Steroids** – are used to reduce inflammation and make your immune system less active. They're man-made versions of the hormones you normally produce in your adrenal glands (two small glands that sit on top of your kidneys).

# Further information

## Library

For more information, research articles and DVDs about MS contact our librarian.

**020 8438 0900**

**[librarian@mssociety.org.uk](mailto:librarian@mssociety.org.uk)**

**[mssociety.org.uk/library](http://mssociety.org.uk/library)**

## Resources

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

**020 8438 0999**

**[shop@mssociety.org.uk](mailto:shop@mssociety.org.uk)**

**[mssociety.org.uk/](http://mssociety.org.uk/publications)**

**[publications](http://mssociety.org.uk/publications)**

## MS Helpline

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

Information is available in over 150 languages through an interpreter service.

**0808 800 8000**

**(weekdays 9am–9pm,**

**closed bank holidays)**

**[helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)**



# About this resource

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

If you have any comments on this information, please send them to: [resources@mssociety.org.uk](mailto:resources@mssociety.org.uk) or you can complete our short online survey at [surveymonkey.com/s/MSresources](https://surveymonkey.com/s/MSresources)

**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

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge).

Contact the librarian on **020 8438 0900**, or visit [mssociety.org.uk/library](https://mssociety.org.uk/library)

## Photography

Credit for photography belongs to Simon Rawles (cover, p14, 18, 23, 25 and 32), Alex Grace (p6), Amit Lennon (p18) and Joe McGorty (p35).

This resource is also available in large print.

Call **020 8438 0999**  
or email [shop@mssociety.org.uk](mailto:shop@mssociety.org.uk)

# Contact us



## MS Helpline

Freephone 0808 800 8000  
(weekdays 9am-9pm, closed bank holidays)  
helpline@mssociety.org.uk

## MS National Centre

0300 500 8084  
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## Online

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This title will be reviewed within three years of publication.

