Multiple
Sclerosis
Society

Understanding progressive MS

The Multiple Sclerosis Society

More than 100,000 people live with multiple sclerosis in the UK. Every one of them shares the uncertainty of life with MS.

We're funding research and fighting for better treatment and care to help people with MS take control of their lives.

With your support, we will **beat MS**.

As a charity, we rely on the generosity of people like you to fund our vital work. Thousands of people affected by MS turn to us for help and advice each year, and we want to make sure we are there for them whenever they need us. 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**
- 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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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 or slow it down. But trials of several drugs are underway, with promising results already being seen.

However, the speed at which MS symptoms build up (progress) varies greatly between individuals 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. Recently, there has also been a huge investment in research to find drugs and treatments that could stop or slow progressive MS.

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

Progressive MS explained

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

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

For more about symptoms, visit our website

www.mssociety.org.uk/what-is-ms/signs-and-symptoms

or read our booklets *Just diagnosed* and *What is MS?*

Types of MS

There are three main types of MS: relapsing remitting, secondary progressive and primary progressive. Around 85% of people are initially diagnosed with relapsing remitting MS, which means that they experience symptoms for a period of time (relapses), followed by periods of remission, when there are no 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 greatly 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

Progression is defined as an increase in permanent disability without recovery in between.

1 Primary progressive MS

People with this type of MS never have distinct periods of relapses and remissions but begin with mild symptoms that slowly get worse (progress) over time. Primary progressive MS affects around 10 to 15% of people with MS.

2 Secondary progressive MS

This type follows relapsing remitting MS. There are no longer distinct periods of relapses and remissions and disability gets steadily worse. Evidence shows that before Disease Modifying Therapies (DMTs) became widely prescribed, around 65% of people diagnosed with relapsing remitting MS developed secondary progressive MS within 15 years.

In a small number of cases, some people are not diagnosed with MS until their condition has reached the secondary progressive stage.

3 Progressive relapsing MS

A small number of people with either type of progressive MS also experience relapses as well as progression.

4 How many people have progressive MS?

It's estimated that 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 an estimated 107,000 people living with MS and around 60,000 people with a progressive form.

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 remitting type is usually diagnosed earlier, between the ages of 20 and 40.

Unlike relapsing remitting MS, which affects three times as many women as men, progressive MS affects equal numbers of men and women. We don't yet know why.

How is progressive MS diagnosed?

Diagnosis of either type of progressive MS can take time, sometimes months, as there's no one definitive test that can confirm it. Also, if you don't already have an MS diagnosis, other conditions may need to be investigated and ruled out first.

There is an official set of criteria, known as the McDonald criteria, that your MS specialist 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. A relatively routine procedure where a small needle is inserted into the lower back; it's not as painful as people believe.

Secondary progressive MS

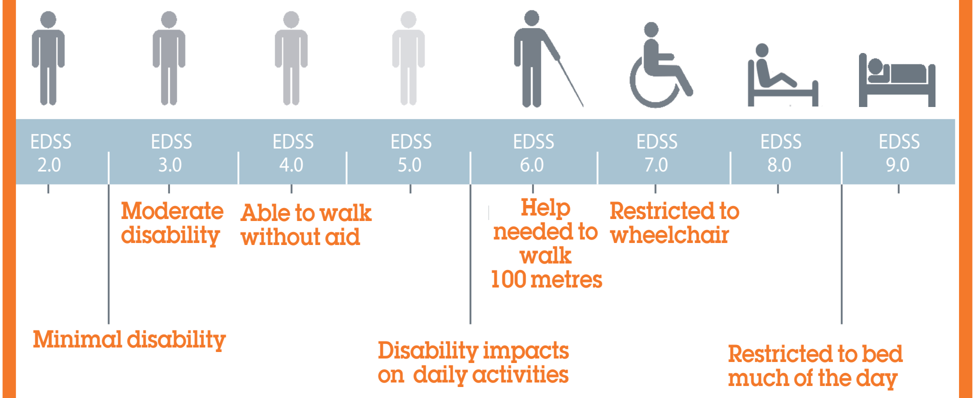
You must have had relapses and remissions in the past, and shown a steady increase in disability for at least six months, outside of relapses. However, determining this isn't straightforward. It can take months to recover from a relapse, which can leave permanent damage. This doesn't necessarily mean that your condition has progressed. The neurologist may use a scoring system 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 may be used to check for certain changes in your central nervous system.

The tests

Neurological examination

Your neurologist may carry out simple tests for balance, movement, coordination, reflexes or vision.

Sections two to nine of the Expanded Disability Status Scale (EDSS)



MRI scan

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

Lumbar puncture

Under local anaesthetic, a needle is inserted into the space around your spinal cord to take a small sample of fluid, which is then tested for abnormalities associated with MS. You can find more information on ways that people are diagnosed on our website.

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 the 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, how bad they are and the speed of progression will vary throughout the course of your illness.

Research suggests 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**

Eiona's story

"I was diagnosed with relapsing remitting MS in 1991 but no one told me until 1993 when a new consultant mentioned it casually. For some time, I'd been suffering from vertigo, tiredness and eye problems, and although I'd started to suspect MS, it was devastating.

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

I'm pragmatic in my outlook. I have a good health care team and dealing with symptoms is just a matter of trial and error.

I've had drug treatment and physiotherapy for spasms and vertigo and my continence adviser has shown me how to self-catheterise when I retain water. My take on it is that if I were diabetic, I'd have to inject myself every day.

My social life is affected by my fatigue and I had to stop driving because of the vertigo. It can be isolating at home but I try not to let my activities be curtailed. I take a cab to the bus stop then catch a bus to the coast and go for a wander and take photographs.

One of the hardest things I've had to deal with is that it's affected my cognitive skills. I didn't realise how much until I went for tests with a neuro-psychologist. It turns out I have dyscalculia, which means I have trouble with figures and dealing with money so I always get someone to check anything to do with figures now. I also use memory aids and strategies to help me deal with other things. For instance, if I have to do something demanding, I'll do it in the morning when I have more energy and stop after half an hour.

I appreciate life far more now and try to keep it full of good experiences, even if it's just simple things like walking on the beach. We still go on holiday and we did a hot air balloon ride a few years ago, which I'd always wanted to do.

Not everything has to revolve around MS. I like to meet friends who don't have MS and have a girlie day or a photography day. There's a way of living a full life within your own parameters. It's still a life worth living – it just may not be the life you'd planned. There's always a solution to obstacles and a way to maximise your potential.”

In 1991, Eiona, now 60, was diagnosed with relapsing remitting MS, which became progressive in 1996.
A former teacher, she lives with her husband and has one grown-up son.

What's going on in your body?

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

In the case of MS, it affects the 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 to conscious actions such as movement, bladder, bowel and sexual function.

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, telling 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, the 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).

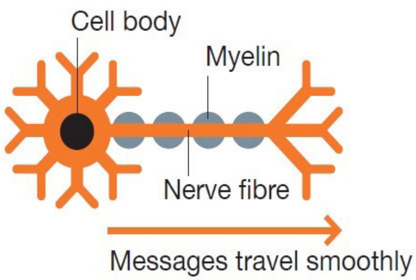
As the myelin becomes damaged, the nerves' ability to send messages efficiently and quickly is affected. This is what leads to symptoms. And because the central nervous system governs all bodily functions, symptoms can be incredibly wide-ranging, depending on the area that's affected.

Move to progression

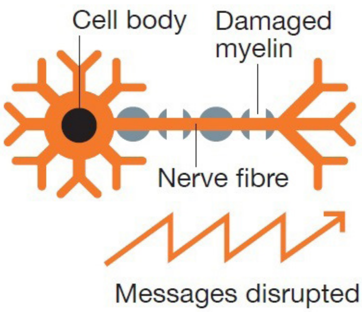
The brain has some natural ability to repair myelin, but with repeated attacks, myelin can no longer re-grow. As it gets more damaged – a process known as demyelination – the nerve fibres (axons) are exposed and also become damaged. Over time, they begin to die off.

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



A nerve with intact myelin coating



A nerve with damaged myelin

A useful comparison

It can be easier to understand the process of MS if 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 arrive 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 are not repaired, the water pipe system becomes less efficient.

> “My 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 ‘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 the causes aren't yet fully understood. However, we do know that some or all of following factors may be involved:

Genes

You don't directly inherit MS – if one of your parents has it, you still only have a 2% (or one in 50) chance of getting it compared with one in 600 for the general population. But there is a genetic element and more than 100 types of genes have now been linked to MS.

Vitamin D deficiency

MS is more common in geographic areas that are far away from the equator and don't get much sun, like northern Europe. Research shows that low levels of vitamin D – made by the action of sunlight on the skin – particularly during childhood or before birth increases the risk of developing MS later in life.

Smoking

Studies suggest that smoking could increase the risk of getting MS possibly by affecting the immune system. Smoking is also linked to going from relapsing MS to progressive MS at a faster rate.

Infections

Recent research suggests that clostridium perfringens type B, a bacterium that can cause food poisoning and is normally found in cows and sheep, could be a potential trigger for MS. Other research has suggested that the Epstein-Barr virus, which can cause glandular fever, may act as a trigger. This doesn't mean that these infections are direct causes but they could contribute to risk.

> “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**

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 (DMTs) for relapsing 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 – before DMTs became widely prescribed, around 65% of people diagnosed with relapsing remitting MS developed secondary progressive MS within 15 years.

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 unpredictability 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*, on the next page, for getting help on practical matters.

Positives

You may feel relieved to have a diagnosis that explains the many and seemingly unrelated symptoms you have been having. You may have feared that you were being labelled a ‘hypochondriac’. Now you have a diagnosis, you can get access to treatment for symptoms, 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.

> “I’d say to someone who’s recently been diagnosed: find out what’s available in your area. Call the MS Society helpline, get on to websites, and ask your local MS Society branch or MS nurse about services. Find out what equipment could help and what benefits you can get. There is help out there are people who can advise you on the best way to do it.”
> **Eiona**

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 our free helpline (see below).

📖 You may also find some of our following free booklets useful:

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

If doing your own research, check that your information source is reputable. This is especially important with regard to health products and treatments.

> “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. Every week there were specialists discussing different topics with time for questions and discussions. It helped a lot.”
> **Catherine**

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 the charity Sense about Science, which you can download from our website.

Support

- Groups – many of our local branches have regular support group meetings, plus each branch has an MS support officer who can offer guidance on local services. There are also national support groups, including for minority groups

- MS helpline – we offer emotional support plus practical information by our free helpline

☎ 0808 800 8000

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

🖱 **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 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 branch.

Otherwise, you can find a qualified counsellor or psychotherapist through the British Association for Counselling & Psychotherapy (BACP).

🖱 **www.itsgoodtotalk.org.uk**

☎ 01455 883300

- For more about emotional support, visit: the Support section of our website:

🖱 **www.mssociety.org.uk/ms-support/emotional-support**

☎ 0808 800 8000.

Catherine's story

“It took about four years for me to be diagnosed. Right up to the final test, I was being reassured by the doctors that my symptoms were due to a spinal cord injury in my neck. So when the diagnosis was confirmed, I was in a state of shock. I didn't want to tell my family, especially my daughter.

For weeks, I was reeling. I'd been off sick for two years and one of the worst things was being told that I'd never work as a nurse again. This was a huge blow along with worry about money, whether I'd be able to carry on driving and dealing with complicated benefits claims.

I came very close to losing my house. It's like your whole life has come to a stop and everything you expected for your future has been buried. My family was devastated and I felt I had to keep a brave face on all the time for them. I spent hours at home crying alone.

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 and can give tips that doctors aren't taught, especially with some of the unusual symptoms.

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

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

There's still quality of life. I get out and about. I can walk, even if it is with the help of a stick, and I volunteer in a charity shop every week.

I've found new creative hobbies I'd never have had time to try before like sewing and I go on education courses offered by the local council, which are very varied. If you're not working, it's important to find a focus, something you enjoy.

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

Catherine, 45, was diagnosed with primary progressive MS in May 2013. A former nurse, she's no longer able to work but regularly volunteers in a charity shop. Catherine is single with a 17-year-old daughter.

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 appropriate health and social care services.

A range of health professionals including physiotherapists, occupational therapists, speech and language therapists, psychologists, dietitians, 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 neurology nurse, MS 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.

- Access to **Sativex** and **Fampyra** is patchy across the UK because they haven't been deemed cost-effective by NICE. If you're having problems accessing licensed treatments, find out more about our *Treat me right* campaign at

www.mssociety.org.uk/treatmeright

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 branch 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 branch 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**

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. 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.

☎ **020 8438 0799**

Healthy eating

Certain diets are promoted as effective therapies for MS but there's no clinical research that supports this. However, a healthy, balanced diet will help you stay as well as possible.

> “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.”
>
> **Ronny**

Therapies

Cognitive behavioural therapy

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.

Mindful meditation

Some research suggests that this technique 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.

www.mentalhealth.org.uk/

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 have failed to support this.

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)*.

> “I used to love being fit before and did lots of cardiovascular exercise. I can still go to the gym but I have had to 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**

John's story

“I was diagnosed with relapsing remitting MS in 1987 after I lost the feeling in my left leg, hand and arm, but I'd had been having what I now know were relapses since 1970. I also had falls and sight problems and although plenty of tests were carried out, there was no diagnosis.

The news wasn't a shock as it was obvious I had a neurological problem, but I was concerned for my daughters in case there was a genetic component. There was little or no information available 30 years ago and no such thing as an MS nurse. Things have changed massively since. I missed out on the disease modifying drugs but it's much better for anyone diagnosed today.

My job, as a business development manager in two leading UK defence companies, involved long hours and lots of travel, which was difficult with the fatigue and other symptoms. I changed to a less demanding job but even so I retired on medical grounds at 55.

Ten years after the official diagnosis, I was told my condition had developed into secondary progressive, but I was more concerned about dealing with the symptoms than the fact that it had a new label. I tackle problems as they arise rather than worrying about tomorrow.

I've probably deteriorated about 20 to 30% more than I would have without MS. Luckily I started from a strong position -

I used to run five to 10 miles each day, I played squash and rugby and was very fit. Now I go to the outdoor gym in our local park, when I'm able, and I do what I can to help my coordination and strength. I have a wheelchair for going out but I can still walk a little so consider myself fortunate.

Some symptoms are more difficult to deal with than others. Double incontinence doesn't do a lot for your self-esteem, but you have to work around problems. A continence nurse taught me how to self-catheterise without infection, which has made a huge difference.

The effect on my mental health has been the most challenging thing. Once I loved stress, but I can't handle any form of stress or anxiety now. It causes rapid mood swings. I manage it by using a relaxation technique I learned on a course, which has been wonderful. I've also found cranial head massage to be helpful.

My family helped me to come to terms with MS. My wife is incredible – she doesn't get fazed – and I've had good support from my daughters and people in my village. Over time, I've gradually come to accept – if not exactly embrace – the condition. I don't have to feel in control. I just accept things as they are. I shall live what's left of my life to the fullest that I can.”

John, 74, was diagnosed with relapsing remitting MS aged 46, which became secondary progressive 10 years later. He's a retired professional nuclear engineer and is married with two grown-up daughters and six grandchildren.

Why can't we slow or stop progressive MS?

Eleven disease modifying treatments (DMTs) are now available in the UK to treat relapsing MS but unfortunately there are still no treatments that can stop or delay the course of progressive MS. You may find this frustrating.

DMTs are designed specifically 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.

However, guidelines from the Association of British Neurologists (ABN guidelines) say that DMTs may be prescribed for someone with secondary progressive MS who also has relapses if it's clear that the relapses are the main 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 trials for DMTs on progressive MS?

Some of the DMTs have been 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 but the results so far have been negative. More trials are underway, including on drugs not yet on the market. There's more information about these and on the trials for DMTs **natalizumab** (Tysabri) and **fingolimod** (Gilenya) on page 31.

What about steroids?

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

Is there a lack of research into progressive MS?

In the past, research revolved around relapsing remitting MS. As 85% of people with MS start off with this type, it made sense for research to focus on it. Also, there was the 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 - the underlying cause for relapsing MS - is easier to understand and treat than dying nerve cells (the process that triggers progressive MS). It is only recently that scientific tools, such as the latest sophisticated MRI scans, have been 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. Although ocrelizumab has shown promising results (see page 29), so far most 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 and there have recently been some positive findings that could lead to new treatments. Read about some of the latest research on page 29 and the Research section of our website.

www.mssociety.org.uk/ms-news-research/ms-research

> “I was very upset that I had a form of MS for which there's no treatment. When MS had first been suggested, the research I'd done made constant references to steroids and disease modifying drugs. It seemed so unfair that nothing was available to me.”
> **Catherine**

Ronny’s story

“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, night cramps and when I walked it felt as though I was wading through water. Eventually I was referred to a neurologist who suspected a trapped nerve but an MRI scan on the lumbar area showed up fine.

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 and research has really helped as has coming into contact with others who have MS through the forum.

Since then, I’ve heard lots of stories of people whose progression has been a steady but slow flow and others of people who are in a wheelchair after a couple of years. The truth is no one can tell how it will affect them.

So now I 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 and have booked a holiday to Egypt next year.

For me, talking has really helped. I felt like closing myself off from the world at first but talking lets out the worry and stress. Cry, shout but let it out, get it off your chest.”

Ronny, 29, was diagnosed with primary progressive MS in October 2014. He’s single with one daughter, seven, and works full-time for a supermarket chain.

Research into progressive MS

Finding treatments for progression is top of the MS Society's Research Strategy but more importantly, 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 made up of MS societies in six countries 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.

Drug repurposing

- **Simvastatin** – A mid-stage 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 needed to further monitor the effects on disability. Statins are anti-inflammatory and seem to have a protective effect on nerves, too.

- **Ocrelizumab**, developed to treat rheumatoid arthritis and lupus erythematosus, is an intravenous infusion treatment. In a 2015 trial, treatment with ocrelizumab showed a reduction in disability progression in people with primary progresive MS by 24%. This reduction was sustained for at least 12 weeks and was measured by the Expanded Disability Status Scale (EDSS). If licensing is successful, it could potentially become available as early as 2017.

- **Rituximab**, which is currently used for rheumatoid arthritis, is about to undergo trials to see whether it can prevent further damage in people with progressive MS. It works by destroying a certain type of immune cell believed to be responsible for attacking healthy nerve cells in progressive MS.

- MS-SMART trial – This two-year, mid-stage trial will test three drugs (**ibudilast**, **riluzole**, **amiloride**) currently used for other conditions against a dummy drug in people with secondary progressive MS. These drugs have shown promise in previous research.

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 Society-funded Cambridge Centre for Myelin Repair and the Edinburgh Centre for Translational 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.

- **MD1003** is a highly concentrated form of biotin, a vitamin that activates some enzymes involved in cell growth and myelin production.

This is an oral medication (also known as biotin or Cerenday) that is in development for progressive MS, and is currently in phase 3 clinical trials for progressive MS and optic neuritis.

A larger phase 3 trial may be required to confirm its effectiveness in progressive MS. Research is still at an early stage, and it will be a few years before we know if this is an effective treatment for people with MS.

Disease modifying therapies (DMTs)

- **Natalizumab** (Tysabri), a 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 had not been successful. Natalizumab did show some positive effects on upper limb function but did not slow disability progression.

- **Fingolimod** (Gilenya), a DMT licensed for relapsing MS, revealed that it could not 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.

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.

Stem cells (AHSCT)

You may have heard in the media of a stem cell treatment for MS called AHSCT (which stands for autologous haematopoietic stem cell transplantation).

A clinical study at Sheffield Hospital is one centre in an international clinical trial that is looking to see whether stem cells found in bone marrow could prevent inflammation and help repair damage in the nervous system caused by MS.

Does it work for progressive MS?

So far results of the trial have shown little evidence of the effectiveness of AHSCT 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 AHSCT. This treatment can't repair damage already done to the nervous system which is why it is more likely to be effective in relapsing forms of MS.

What does it do?

AHSCT stops an immune attack. 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.

If you have progressive MS this procedure might be considered too dangerous for you.

There's more information on our website:

www.mssociety.org.uk/ms-research/research-blog/2016/01/7-things-you-need-know-about-ahsct

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** (clinical trials worldwide)

🖱 **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 influence future research. Visit

🖱 **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**
☎ 020 7594 9734.

Help us fund research

The breakthroughs achieved by our investment projects are only possible with your support. To donate, visit

🖱 **www.mssociety.org.uk/brighterfuture**
☎ 0800 100 133.

Further reading

The following books are all available to borrow from the MS Society library. Email **librarian@mssociety.org.uk**, call 020 8438 0900 or visit **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.

Further information from the MS Society

Library

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

☎ 020 8438 0900

✉ librarian@mssociety.org.uk

🖱 www.mssociety.org.uk/library

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)

✉ helpline@mssociety.org.uk

Resources

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

☎ 020 8438 0999

✉ shop@mssociety.org.uk

🖱 www.mssociety.org.uk/publications

About this resource

With thanks to Shona Flucker, Jane Bradshaw and all the people affected by MS who contributed to this booklet.

First edition written by
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EDSS chart illustration by
Richard Cooke

If you have any comments on this information, please send them to **resources@mssociety.org.uk** or you can complete our short online survey at **www.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. The law and government regulations may change. Be sure to seek local 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 **www.mssociety.org.uk/library**

This resource is also available in large print and audio.
Call 020 8438 0999 or email shop@mssociety.org.uk

Multiple
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This title will be reviewed within three years of publication.

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