Just diagnosed

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

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

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

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

Contents

A word from Cath, who has MS

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

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

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

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

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

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

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

Cath

Five things to know

1. Most people are diagnosed with relapsing remitting MS. The other 10 to 15% are diagnosed with primary progressive MS

2. A combination of our genes, things in our environment and our lifestyle could all play a part in why people get MS

3. The last twenty years have seen huge advances in how relapsing MS is treated and managed. Recently we've seen more exciting breakthroughs, especially for people whose MS is relapsing

4. If you've been diagnosed with relapsing MS, doctors recommend that you start taking a disease modifying therapy (DMT) as soon as possible after you're diagnosed

5. Life with MS these days is more about what you can do, not what you can't. We're here to support you, with information, the MS Helpline, local and our online connections

About this booklet

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

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

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

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

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

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

If there's something on your mind, you can contact our MS Helpline on **0808 800 8000** (closed weekends and bank holidays).
Email: **helpline@mssociety.org.uk**
Facebook: **facebook.com/MSSociety**

Our MS Helpline will also have details of local and online support for recently newly diagnosed people, friends and family.

One last thing. Where you see a word in **bold** in this booklet, it means you can turn to page 32 and find it explained.

What is MS?

Multiple sclerosis (MS) affects the nerves in your brain and spinal cord. Together these two things are known as your central nervous system (CNS).

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

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 parts of your body, and it can affect lots of things your body does. This is why everyone's MS is different.

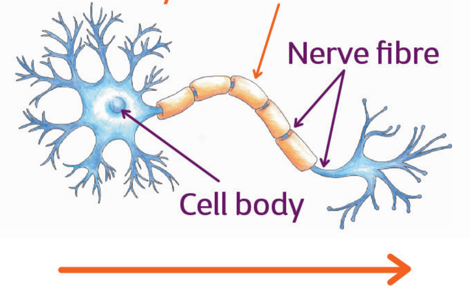
What's happening in MS?

Your immune system protects you from infections. It does this by attacking and killing viruses and bacteria that get into your body.

But in MS your immune system attacks nerves in your brain and spinal cord by mistake. This damages the covering around your nerves.

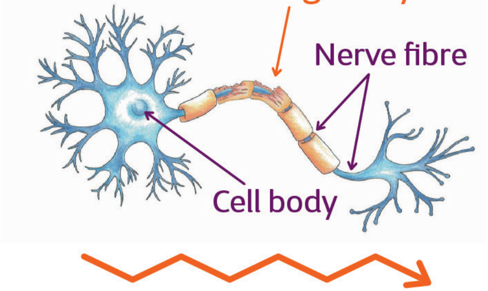
This covering is made of a fatty coating called **myelin**. It protects

Myelin as it should be



Messages travel smoothly

Damaged myelin



Messages are disrupted

each nerve from harm and helps messages travel along it.

When myelin becomes damaged, messages find it harder to pass along the nerve – or can't get through at all. That's when symptoms of MS begin. Myelin can't always be repaired, and MS can also damage the nerve fibre inside.

Damage to nerves in the brain and spinal cord can cause MS symptoms that are easy to see, such as difficulties walking, or problems with your balance. But many symptoms can't be seen by other people, such as **fatigue,** pain or unusual feelings in your skin, or bladder and bowel problems.

Types of MS

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

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

We explain these over the next two pages. Knowing what type of MS you have won't tell you how your MS will develop over the years to come. MS is unpredictable. No two people are affected in the same way. For some there'll be growing difficulties and disability. For others life goes on without major problems.

Relapsing remitting MS

This is the type most people with MS – around 85% – are first diagnosed with. It's sometimes just called 'relapsing MS'.

When you have this type, you have relapses (attacks of symptoms). These can last days, weeks or possibly months, then mostly or completely get better.

In the early stages of relapsing MS, your symptoms often get better between relapses. This is known as 'remission'. But symptoms might not completely go away. That depends on how much damage has been done to the myelin or to the nerve fibre.

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

Primary progressive MS

If you have primary progressive MS, you get a steady build-up (or 'progression') of symptoms over time. You usually don't have relapses.

Something else that we don't yet understand damages the nerves and causes the progression.

About 10 to 15% of people who are diagnosed with MS are told they have primary progressive.

Early on in primary progressive MS, some people also have relapses. That's sometimes called 'active' primary progressive MS. 'Active' means there's inflammation happening in the central nervous system, as well as progression.

You might see this type of MS shortened to 'PPMS'. You can read more in our booklet 'Understanding progressive MS'.

Secondary progressive MS

Many people with relapsing remitting MS will, years later, see it turn into secondary progressive MS.

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

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

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

You might see this type of MS shortened to 'SPMS'. You can read more in our booklet 'Understanding progressive MS'.

First questions

Why do people get MS?

We don't know what the exact cause of MS is. We do know there are probably a number of things involved: your genes, your environment and your lifestyle.

There's not just one single reason someone gets MS. And some of the reasons you have no control over. But if MS is in the family, people could lower their risk by not smoking, trying to keep a healthy weight and getting enough vitamin D.

Your genes

MS isn't directly inherited like some conditions. It's likely that a combination of things cause MS – and genes are one of these.

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

MS isn't directly passed on from a parent to their child. There's

For every 1000 people...

...who grow up in the UK	**about 3** will get MS (997 won't)
...with a parent with MS	**about 15** will get MS (985 won't)
...with a brother or sister with MS	**about 27** will get MS (973 won't)

no one gene that causes MS. In fact, over 200 genes might affect your chances of getting it - each making a small increase or decrease in your risk.

Genes alone don't decide who gets MS. Identical twins have almost identical genes. But when one gets MS, the other usually doesn't. That twin does have a higher risk of getting MS but most don't get it. This shows genes play a part but it's far from the whole story.

Your environment

We know that you're more likely to get MS if you live further away from tropical countries near the equator. There are fewer people with MS in these sunny countries.

More and more studies point to a link between MS and having low levels of vitamin D. The risk seems highest if you're low in this vitamin before you become an adult.

Vitamin D is known as the sunshine vitamin. Our bodies produce it when sunlight shines on our skin. Lots of us in less sunny countries, like the UK, become low in vitamin D, especially when it's not summer.

Research has also looked into whether an infection, such as the Epstein Barr virus, can trigger MS. This virus can cause glandular fever in teenagers and adults.

Most adults have had this infection, so getting it doesn't mean you'll get MS too. But we know it plays a part because people don't get MS unless they've had the infection first.

Other infections might also have an effect. The link isn't totally understood, but infections could act together with other things to trigger MS.

Your lifestyle

Smoking

Studies show you're more likely to get MS if you smoke. Passive smoking – breathing in other people's smoke – might also be linked to getting MS but more studies are needed to be sure.

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

Studies show smoking can speed up how fast you become disabled. This includes your walking getting worse and a worsening in how other parts of your body move. Smokers are more likely to get more lesions (areas of damage caused by MS in your brain or spinal cord), disability and relapses.

Smoking makes some MS drugs work less well. People on these drugs who smoke have more relapses than non-smokers.

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

If you have relapsing MS, studies show that stopping smoking could slow down the rate at which your disability is getting worse and how fast MS can change to secondary progressive MS.

So if you smoke, it's a good idea to stop. Then these risks quite quickly go down to those of a non-smoker.

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

Diet and nutrition

Research shows if you're **obese** (very overweight) before your 20s, you're more likely to develop MS.

Low levels of vitamin D can also increase the chances of getting MS.

We know that it's important to eat a balanced diet like the one recommended on the NHS website (**www.nhs.uk/live-well**). It's also important to get more vitamin D if your body doesn't have enough of it.

If you have MS, or you're related to someone with it, an MS specialist can advise you about taking vitamin D supplements. If you decide to take them, a neurologist might suggest a higher amount than official guidelines say for the general population.

Your GP can give advice on vitamin D and healthy eating. They can also refer you to specialist support.

Find out more about healthy eating and vitamin D in our booklet 'Diet and nutrition'. And our website has the latest on research into vitamin D, smoking and obesity.

MS is no one's fault

Hearing about things that may cause MS might make you ask: "Could I have done something to avoid it?"

But you couldn't, because we don't know for sure which things come together to cause MS in each person. Besides, in the past we all knew much less about what might cause MS. You weren't likely to be in a position to do anything to lower your risk.

What's going to happen now?

The short answer is that nobody knows. MS is unpredictable and no two people are affected by MS in the same way.

There's no standard pattern that your MS will follow. Even knowing what type of MS you have won't tell you how it will develop.

It's impossible to know how quickly MS will get worse, or what will be affected. Symptoms can occur randomly, at any time, in any order. And if you get relapses, you won't know when your next one will be.

MS has many symptoms, but not everyone will experience all of them. Common symptoms include eye problems, weakness, numbness or tingling feelings, fatigue and pain.

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

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

This unpredictability, and not knowing what the future holds, can be one of the hardest parts of living with MS. It can take some

time to come to terms with it, but there's support available.

You can talk things through with an MS nurse, or neurology nurse. Or talk to someone on our MS Helpline on **0808 800 8000** (closed at weekends and on bank holidays). The Helpline includes MS nurses.

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

You can read more about the emotional effects of MS on our website.

Am I going to die from MS?

People don't die directly from MS. But someone who's severely affected by MS, with many complicated symptoms is more likely to pick up infections. These can be very serious, even life-threatening.

At the moment people with MS live on average about seven years less than people who don't have it.

But this gap could be closing as treatments get better.

Can MS be cured?

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

Research is trying to find ways to stop MS. Until then, there are ways to manage your condition.

This includes disease modifying therapies (DMTs).

If you have relapsing MS, a DMT can curb how many relapses you have or how bad they are. And it can reduce the damage to nerves in your brain and spinal cord. That can slow down how fast you're likely to become disabled.

Read more about treatments on pages 22 and 23.

Will I need to use a wheelchair?

This is a question a lot of people with MS ask when they're first diagnosed. Because we don't know how your MS will affect you, it's impossible to answer.

Most people with MS will never need to use a wheelchair. But some will need to use a wheelchair at some point, either all or some of the time.

Some symptoms can make walking safely difficult or impossible. That could be because of **fatigue,** weakness, balance problems or when your muscles contract and feel stiff and tight (spasticity), for example.

People who do need a wheelchair find it lets them do things they wouldn't be able to do otherwise. They can carry on with everyday activities.

Can I still have children?

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

If you get pregnant, it won't make your MS worse in the long run. Most people are less likely to have a relapse while they're pregnant. But this risk can go up if you stop taking certain disease modifying therapies (DMTs).

The chances of having a relapse go up for three months after giving birth. But balanced across the year as a whole, being pregnant doesn't change the risk.

Some DMTs might harm unborn babies. Your neurologist can talk with you about any precautions you might need to take. Like using reliable contraception while on these drugs – for example, the pill, condoms, implants or injections. This is true while you're on the drug and sometimes for several months after you stop taking it.

If you want to have a child, or you're pregnant already, discuss your options with your neurologist. Some DMTs are safer to use when pregnant than others. So the choices you make could also depend on how active your MS is and the DMT you take.

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

Will my children get MS too?

Many people with MS worry that their children will get it as well. There's a small chance that this will happen, but there's a much bigger chance it won't.

If you have a close relative with MS, the chances you'll get it are a bit higher, but the risk is still low. The figures in detail are on page 11.

Will I have to give up work?

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

Because MS is unpredictable and people do all kinds of different jobs, it can make the workplace situation difficult. Lots of people are able to carry on working. But some people do find that work – or the kind of work they've been doing – is no longer possible.

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

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

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

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

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

MS and how you're feeling

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

You might:

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

All of these reactions are perfectly normal.

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

If you're finding it difficult, there's support available. You can talk to your medical team, including your MS nurse if you have one. Or talk to someone on our MS Helpline on **0808 800 8000** (closed on bank holidays and weekends).

You can also connect with other people with MS through the forum on our website, virtual support events and our wellbeing hubs, or through your local MS Society group (see page 31 for more about all these).

We've got more information about MS and emotions on our website at **mssociety.org.uk/emotions**

Telling people

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

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

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

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

They may think everyone with MS needs a wheelchair, for example. So you'll have to be prepared to answer their questions.

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

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

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

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

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

Do I have to tell my employer?

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

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

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

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

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

Is there anyone I must tell?

Yes, there are a few people you must tell.

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

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

Find out more about insurance and driving on our website.

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

Treatments for MS

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

What are DMTs?

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

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

You might have a choice of DMT you can take. In 2022 we're launching an online tool to help you decide which might be a good option for you. You can find out about all the available DMTs on our website **mssociety.org.uk/dmts**

Taking a DMT means you're less likely to get relapses, or your relapses will be less serious. A DMT can also reduce inflammation and prevent MS from damaging nerves in the brain and spinal cord.

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

When should I start treatment?

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

If your MS causes relapses or signs of inflammation, doctors recommend that you start taking a DMT as soon as possible. In England, Wales or Northern Ireland, guidelines say you should be offered a follow-up appointment within six weeks of being diagnosed. Guidelines in Scotland say you should be contacted by an MS nurse within two weeks of being diagnosed. You can ask about treatment options at these appointments.

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

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

Guidelines say that, whether you're on treatment or not, you should have a yearly review. MRI scans can check how active your MS is and whether treatment is working. Ideally a scan at least every year is best, particularly in the early years after the diagnosis, but it's up to your neurologist.

Are there DMTs for progressive MS?

DMTs are usually only available if your progressive MS also has relapses or shows signs of active inflammation on MRI scans. Your neurologist might describe your MS as 'active' if that's the case.

If you have secondary progressive MS and have relapses or inflammation, there are two DMT drugs that might help – Extavia (a beta interferon) or siponimod (Mayzent). HSCT might also be an option.

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

If you have primary progressive MS and have relapses or inflammation, one DMT might be available – ocrelizumab (Ocrevus). And HSCT might also be an option.

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

Researchers are looking at other DMTs to see if they can help people with progressive MS that has inflammation. Find the latest research on our website.

How can I manage my symptoms?

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

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

Managing symptoms

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

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

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

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

Depending on your symptoms, you might see:

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

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

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

Managing relapses

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

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

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

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

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

Who'll be looking after me?

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

You

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

You're best placed to monitor changes in your condition and to avoid triggers that make symptoms worse.

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

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

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

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

Your GP

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

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

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

Your MS nurse

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

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

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

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

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

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

Your neurologist

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

Your neurologist will be interested in how your MS is developing long term, rather than the day-to-day management of it. Most people with MS only see their neurologist once or twice a year. You can ask to see them more often if you need to.

A neurologist can:

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

Your multi-disciplinary team

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

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

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

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

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

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

What can I do to look after myself?

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

Finding the right information

Having the right information about MS can mean you'll be more able to make better decisions for yourself.

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

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

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

You can get reliable information on managing MS from your health care team, from us, NHS websites and the MS charities listed on page 31.

Don't smoke

On page 13 you'll have read about how smoking makes MS worse.

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

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

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

Find more about the evidence on how smoking makes MS worse at **mssociety.org.uk/smoking**

Eat well

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

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

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

Staying active

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

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

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

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

Complementary therapies

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

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

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

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

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

Where can I get support?

MS Helpline

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

Call **0808 800 8000** (closed weekends and bank holidays), email **helpline@mssociety.org.uk** or private message on Facebook at **facebook.com/MSSociety**

MS Society local and online support

We've got around 300 MS Society groups offering support. Meet others with MS in your area, find out about local services and get support to help deal with your MS.

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

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

MS Society forum

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

Other MS organisations

Shift MS

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

MS National Therapy Centres

A network of UK centres offering a range of therapies including physiotherapy and counselling: **msntc.org.uk**

MS Trust

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

UK-MS

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

New words explained

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

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

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

inflammation – when your immune system reacts to attack or damage, it sends more blood and immune cells to the damaged area, making it swollen. When MS causes inflammation in your brain and spinal cord it starts to damage it, triggering MS symptoms

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

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

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

NICE (National Institute for Health and Care Excellence) – NICE is the organisation that produces guidelines about which treatments should be available on the NHS, and how they should be used. Those guidelines apply in England and Wales. They are often applied in Northern Ireland as well. In Scotland, the SMC (Scottish Medicines Consortium) decides on treatments

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

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

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

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

Further information

MS Helpline

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

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

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

Find out more at
mssociety.org.uk/helpline

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

helpline@mssociety.org.uk
Or direct private message us on **Facebook** (Mon-Fri 9am to 5pm)

Resources

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

You can read them online or download at **mssociety.org.uk/publications**

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

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet, including Dr Bruno Gran, Consultant Neurologist at Nottingham University Hospitals NHS Trust.

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

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

References

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

Photography

Photography: Simon Rawles (cover and p25), David Dunne (p6), Rebecca Cresta (p15).

This resource is also available in large print.

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

Contact us

MS Helpline

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(closed on weekends and bank holidays)
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This title will be reviewed within three years of publication.