

What is in the second of the s

Knowing more about multiple sclerosis (MS) can help you feel in control of what's happening. You might have just been diagnosed or perhaps you know someone who has been recently diagnosed. Hopefully reading this will make you less uncertain or worried.

Living with MS can bring real challenges, but breakthroughs in treatments mean it's less about what you can't do and more about what you can.

At the MS Society we're here to help everyone live well with MS.



"MS is a significant part of me, but it's far from the most interesting part."
Helen

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What is MS?

MS is a neurological condition.
That means it affects your nerves. You can't catch MS from someone. You get it when your immune system isn't working properly. Your immune system normally protects you by fighting off infections, but in MS, it attacks your nerves by mistake.

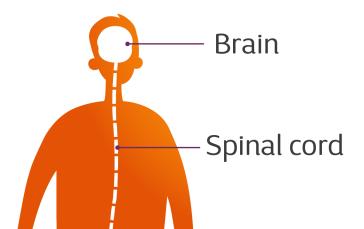
Your nerves control lots of different parts of your body and how they work. That's why if you have MS you can get all kinds of symptoms. And why everyone's MS is different.



"I was just sent away with my diagnosis. No one gave me any information or help then, which made things worse and made me worry more. Thankfully I contacted the MS Helpline for some much needed help and information." Carole

What's happening in MS?

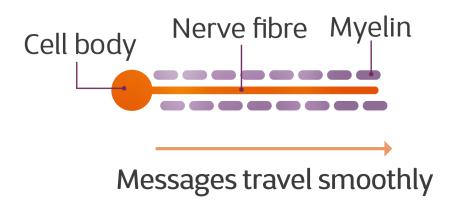
Your brain and spinal cord make up your central nervous system. Your spinal cord connects nearly all parts of your body to your brain. Messages go between your brain and spinal cord, travelling along your nerves. And our nerves control everything we do. Billions of them join together to send messages from our brain to every part of our body.

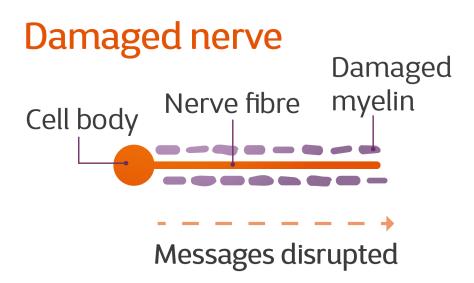


Your immune system protects you from infections. It does this by attacking and killing viruses and bacteria that get into your body. In MS your immune system attacks nerves in your brain and spinal cord by mistake. This damages the fatty covering around your nerves, called myelin.

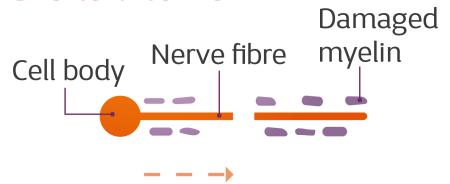
When myelin is damaged, messages travelling along our nerves become distorted or don't get through at all. This can affect how you see, move, think or feel.

Healthy nerve





Broken nerve



Messages can't get through

The different types of MS

Everyone's MS is different. But MS is usually split into two broad types.

Relapsing (remitting) MS: Most people with MS have relapses – flare ups that cause inflammation in the brain or spinal cord. Disease modifying therapies (DMTs) can reduce the number of relapses you get and slow down any onset of disability. They work better the earlier you start taking them.

Find out more about relapsing MS

Progressive MS: A smaller number of people have MS that gets steadily worse over time without relapses or inflammation. This is progressive MS. It's been much harder to find treatments that help with this type, but research teams are working on it.

Progressive MS is split down further into <u>primary progressive MS</u> and <u>secondary progressive MS</u>.

Find out more about types of MS

How is MS diagnosed?

Diagnosing MS isn't easy. Symptoms can be confused with more common problems. Doctors must rule these out first before they look for signs of MS. It can take a long time from when you first notice something's wrong to when you're officially told you have MS.

There's no simple test, like a blood test, for MS. If your GP thinks MS is causing your symptoms they'll send you to a neurologist, a specialist doctor who looks after people with

MS. Even when you see a neurologist, it can take a few tests and several months before you have a final diagnosis. This can be a frustrating time.

The tests your neurologist could use include an MRI (magnetic resonance imaging) scan, blood tests and assessments of your reaction times. Although it can be frightening, the health professionals involved should reassure you and make it as easy for you as possible.

Find out more about tests to diagnose MS

We're here to support you!

Finding out you have MS can bring up strong feelings. It's natural to feel afraid, confused, upset or overwhelmed. You may feel relieved you know what's wrong, and can take steps to look after yourself and think about treatment.





"I felt relieved when I was told. It took a weight off my shoulders, nothing had changed about me. So I went off on holiday and decided to throw myself wholeheartedly into learning about it when I got home."

We have lots of services to support you

- MS Helpline 0808 800 8000
 (Open Monday to Friday, 9am to 7pm except bank holidays)
- Find your nearest MS group
- Join our <u>online community</u>
- MS Society grants to help you live well with MS



Treating MS

There's no cure for MS yet but it can be treated in different ways. These include disease modifying therapies, physiotherapy and exercise and complementary therapies.



People with relapsing MS can make the biggest long-term difference to their MS by taking a disease modifying therapy (DMT). They're called 'disease modifying' because they change the course of MS, not just tackle symptoms. Health professionals should offer DMTs as close as possible to diagnosis.

Here's some questions you can take to your appointment to talk to them about it.

Early treatment improves long-term health and wellbeing by slowing down the build up of damage and reducing the number of relapses. Starting treatment early is best, but if you can start at any time to see some benefits.

The DMTs available right now only work on relapsing MS.

But the infusion, ocrelizumab has been approved for people who have early primary progressive MS in England and Wales. We expect it will be available across the UK in 2019.

Find more information about ocrelizumab

Pregnancy and MS

MS often affects people at an age when they might be thinking about starting a family. Some worry they might pass MS on to their children. The reality is there's only a 1 in 67 chance the child of someone with MS will get it too.

MS doesn't make it harder to get pregnant or give birth and having MS shouldn't stop you having a baby. But careful planning with your family, friends and your doctor becomes even more important.

Find out more about pregnancy and MS

Why do some people get MS?

Nobody knows for sure why people get MS. Certain things seem to play a part in triggering MS, but it's no one's fault.

It's likely to be due to a mix of:

- your genes
- infections
- your lifestyle
- where you live

Find out more about causes of MS

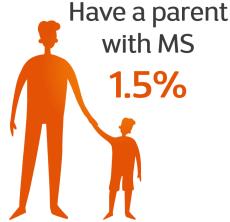
Genes

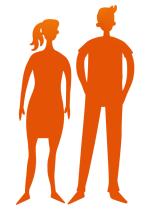
MS isn't directly passed on from a parent to their child. There's no one gene that causes MS. In fact, over 100 genes might affect your chances of getting it. If you have a close relative with MS, the chances you'll get it are a bit higher, but the risk is still low.

Find out more about genetics and MS

Risk of you having MS if you:



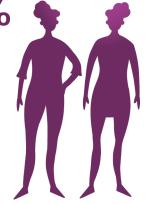




Have a brother or sister with MS 2.7%

twin with MS
18%

Have an identical



Viruses

There's evidence that some viruses, and maybe bacteria, can trigger MS, especially the Epstein Barr virus. This is the virus that causes glandular fever. This doesn't mean you'll get MS if you've had glandular fever (most people have had this virus). The link isn't totally understood but infections could act together with other things to trigger MS.

Where you live

You're more likely to get MS if you live further away from the equator. The UK, Scandinavia, Canada, Southern Australia and New Zealand report higher numbers of people with MS.

Vitamin D

Researchers are looking at a lack of vitamin D, the 'sunshine vitamin', as a possible cause of MS. Our skin makes this vitamin when we're in the sun. We also get some vitamin D from food (oily fish, eggs, spreads and breakfast cereals with added vitamin D). Lots of us in less sunny countries like the UK become low in vitamin D over the winter.

If you want to know if you're low in vitamin D, your MS specialist nurse or GP can check your levels with a blood test. If your levels are low, get medical advice about boosting them.

Find out more about vitamin D

Lifestyle

Two lifestyle factors have been linked to MS:

- smoking
- being very overweight (obese)

Smoking and MS: You're more likely to get MS if you smoke. Chemicals in cigarette smoke might affect your immune system, helping to trigger MS. Passive smoking – breathing other people's smoke – is also linked to a higher risk of getting MS. Studies show that stopping smoking could slow down how fast you go from having relapsing MS to secondary progressive MS.

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

- make you low in vitamin D
- make your immune system overactive and cause inflammation inside your body

If you want to try to lose weight or stop smoking speak to your GP or call our MS Helpline to talk through your options.

MS symptoms

MS damages nerves in different parts of your brain and spinal cord. Where this damage is affects which part of your body gets symptoms.

Symptoms are unpredictable, changing from day to day, even hour to hour. They can last days, weeks or months. Depending on your MS, symptoms could stay, ease off or go.

Some people find getting hot, tired or stressed, or exerting themselves can make symptoms worse or trigger a relapse (a flare up of your MS symptoms). Everyone has their own symptoms.

Most people don't get every MS symptom. Here are the more common ones:

- Fatigue, an overwhelming feeling of tiredness
- Problems with eyesight, many people with MS have problems with their vision
- Balance and feeling dizzy
- Pain and other sensations
- Problems with speech or swallowing
- Muscle stiffness and spasms
- Your bladder or bowels not working properly

- Shaking in your arms or legs (called 'tremor')
- Difficulties with your memory and thinking
- Sex and relationship problems
- Mental health and emotional problems

Feeling depressed or crying a lot can be a normal reaction to being told you have MS but it can also be one of the ways MS affects your brain.

We're always here for you. Our MS
Helpline gives emotional support and
information to anyone living with MS

Invisible symptoms

If people can see symptoms of MS they can understand and offer help. But many symptoms can't be seen, so sometimes people overlook them. It might not be easy to explain invisible symptoms like fatigue to people.

Find out more about talking to people about your MS symptoms, including at work



"I manage my time carefully due to fatigue but I sometimes have a day where I sail through without much difficulty at all. Those days are precious and I really appreciate them. People without MS would just take that for granted!" Ellie

Managing symptoms

There are lots of drugs and therapies for dealing with MS symptoms.
They might not be able to get rid of a symptom totally but can make it easier to live with.

Some people with MS use exercise and complementary therapies to manage symptoms and improve their wellbeing. Call our MS Helpline to learn about our Moving More with MS programme.

Exercise

Staying active has real health benefits if you have MS. This doesn't have to mean sport if that isn't right for you. You may like gardening, walking or exercises you do at home.

Exercise for MS symptoms can help with fatigue, bladder and bowel problems and muscle stiffness or spasms. It can help keep you mobile, making your muscles stronger or improving your posture. It can help boost your mood and keep your memory and thinking sharp.

Find out more about exercises for MS symptoms

Stress

Many people with MS say stress and anxiety affects how they feel, making their MS worse. Lowering your stress levels can definitely improve your overall health and how you feel.

Find out more about stress and anxiety

Healthy eating

A healthy, balanced diet is good for all of us. It's all the more important if you have a long-term condition like MS.

A lot of people with MS take care about what they eat. Some follow special 'MS diets' but there's little evidence these are any more effective than just eating a balanced diet. Find out more about eating healthily with MS.

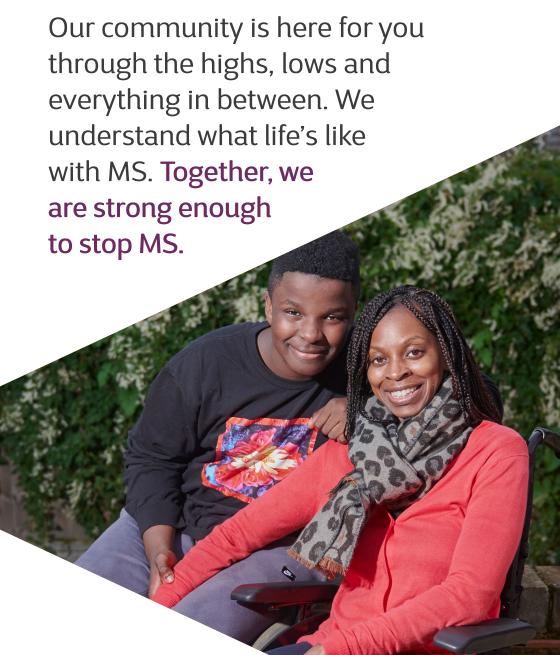
Find out more about healthy eating

Who can help you manage your symptoms?

Lots of different health and social care specialists can help. These include speech and language therapists, continence advisers (for problems with your bladder or bowels), physiotherapists, psychologists and occupational therapists.

Meet some of the specialists who could be on your team

We're the MS Society



Find out more:

- Living well with MS
- First questions about MS
- Browse our other MS publications

How you can help:

- Our publications are free but if you want to contribute towards the cost, we'd love you to <u>make a donation</u>.
- If you'd like to donate some time, there's lots of ways you can volunteer and help stop MS.

Get in touch

<u>Contact us</u> for local support from our offices in England, Scotland, Northern Ireland and Wales.

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