

Have I got MS?

And why is it taking so long to find out?

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It can be worrying not knowing for sure whether MS is the cause of your symptoms. MS can take time to diagnose because there are often other things that have to be ruled out first.

Here we explain how MS is diagnosed, and why it can be a lengthy process. We hope it will help you talk to doctors with confidence and understand what's happening.

The resource also looks at your rights to support and how to cope with symptoms, even if you don't have a definite diagnosis.

Remember, you can always call the free MS Society helpline on **0808 800 8000** if you have any questions or just want to talk to someone in confidence. You can also connect with other people going through the same experience on the MS Society forums at mssociety.org.uk/forum

Why does diagnosis take so long?

MS is a neurological condition that affects the body's brain and spinal cord (the central nervous system). MS is a very individual condition and no two people are affected in the same way.

The symptoms you have will depend on which part of your brain and spinal cord are affected. Not only does everyone have different symptoms, but over time the symptoms someone has can also change.

This makes it difficult for your doctor to spot, as they first have to identify that your symptoms might be caused by MS.

They then have to refer you to a specialist who will give you a number of tests to make sure the symptoms are not caused by something else.

Being referred to a specialist and having tests done to confirm this suspicion can take time.

Some people call this period of waiting for a diagnosis 'Limboland'. It's normal to find this period frustrating and upsetting.

But getting the right diagnosis, even if that takes time, means you'll receive the best possible treatment.

"I know that diagnosing MS has become more complex as they have to rule out more things – but that's not a bad thing. I would rather get a correct diagnosis, because then you can move forward." **Anna**

What are the early symptoms of MS?

MS can cause a wide range of symptoms, and there's no definitive list of early signs. What could be a first symptom for one person may never be experienced by another.

Some of the more common symptoms include problems with your sight, vertigo (dizziness or feeling like the room is spinning), loss of balance and coordination, numbness, tingling, stiff muscles, and bladder or bowel problems. These are often accompanied by fatigue (extreme tiredness).

We produce a number of booklets on the individual symptoms of MS.

mssociety.org.uk/symptoms

MS usually appears as attacks known as 'relapses'. Relapses are symptoms that occur for a period of time – days, weeks or months – and then improve, either partially or completely.

In order to be classed as a relapse, these symptoms would need to last for at least 24 hours, and not be caused by a fever or infection. They would also need to happen at least 30 days after any previous relapse.

Read more in our booklet **Understanding relapsing MS**.

In other people with MS, symptoms get slowly worse over a long period, sometimes years. For instance, they may find it increasingly difficult to walk.

Read more in our booklet **Understanding Progressive MS**.

Your symptoms are clues that help show the full picture. Try to keep an open mind. Some or all of them may point to MS but may be caused by something else. They can occur in a number of other neurological conditions, including relatively minor ones like migraine or a trapped nerve.

“On that day, I felt broken, devastated. Everything seemed to stop for a while”, Ronny, 29, talks about when he was diagnosed with primary progressive MS in 2014.

‘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.

‘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.’

Who should you see to get a diagnosis?

The usual first point of call is your GP, who may be able to rule out some other possible causes of your symptoms. GPs cannot diagnose MS – only a neurologist, who specialises in conditions involving the central nervous system, can do that.

Seeing your GP

Your GP will ask about your symptoms and carry out an examination of your nervous system. They may arrange some blood tests. If you're having problems with your vision, they may recommend you see an optician.

If your GP suspects you have a neurological condition like MS, they will refer you to a neurologist.

Suspected cases of MS should be seen by a specialist as soon as possible. But there's a shortage of neurologists in the UK and not all hospitals have neurology departments. So it can sometimes take several weeks to get an appointment. You may be referred more urgently if your symptoms are very disabling.

“I felt ridiculous going to the GP and trying to explain feelings like ‘ants crawling in my stomach.’” **Claire**

Seeing a neurologist

When you see a neurologist they will ask you a lot of questions about your symptoms and how they've changed over time.

The neurologist will also want to know if you've had similar symptoms in the past. This may suggest that you've had previous attacks. You'll be asked other things about your medical history and any medical conditions that run in your family.

The neurologist will then carry out an examination of your walking, movements, coordination, balance, reflexes, speech and eyes.

Your neurologist will want to rule out other conditions first, before confirming a diagnosis of MS.

How is MS diagnosed?

There's a clear 'pathway' agreed by the National Institute for Health and Care Excellence (NICE) for the diagnosis and treatment of MS.

The NICE pathway for MS shows the diagnosis process you should expect: [pathways.nice.org.uk/pathways/multiple-sclerosis](https://www.nice.org.uk/pathways/multiple-sclerosis)

Neurologists follow guidelines called the McDonald criteria to diagnose MS. A diagnosis of MS using the McDonald criteria is based on finding evidence of damage to different parts of your central nervous system – the brain, spinal cord and optic nerves – which has occurred at different times. This damage takes the form of scars, or 'lesions'. The name multiple sclerosis means 'many scars'.

A neurologist will use the symptoms you describe, and the results of their examination, to build up a picture of whether there may be multiple sites of damage in your nervous system. They will then order tests to check for this damage.

The main test is magnetic resonance imaging (MRI), but this may be backed up with other tests, including blood tests, to rule out other conditions.

Types of tests

MRI scan

Your neurologist will want an MRI scan of your brain, but may wish to do one of your optic nerves or spine as well, depending on your symptoms.

It can take a while to get this test since not all hospitals have MRI facilities, and in those hospitals

that do have them they are always in demand.

The MRI produces detailed pictures of your brain, spinal cord and optic nerves. It's very sensitive at picking up damage due to MS and also other causes of damage that might mimic MS, such as a slipped disc pressing on the spinal cord.

To have an MRI scan you'll be asked to lie still in a small tunnel for up to an hour. Sometimes a contrast dye is injected into your arm first, to help make the images clearer. It can be noisy and a bit claustrophobic, but it's a painless and safe procedure and the best way to diagnose MS and rule out other conditions.

You may have to wait a number of weeks for your results. The images have to be interpreted by trained radiologists, which can be time-consuming.

A report is sent to the doctor who arranged the scan, usually your neurologist, who may wish to discuss the results with the radiologist before talking to you about them.

"The neurologist told me it was 95% certain it was MS and the lumbar puncture would make it definite – which it did." **Chris**

Sometimes MRI results cannot provide an answer because damage showing on an MRI scan are not always specific to MS. Your neurologist may wish to monitor any damage by carrying out another MRI scan at a later date, or to arrange further tests, including the following:

Evoked potentials

In these tests, small pads are taped to your scalp and linked to a machine that measures how quickly electrical signals are sent around your nervous system. This is done because electrical signals are usually slower if you have MS.

It may involve looking at a changing pattern on a screen in front of you, listening to clicks while wearing headphones or small and painless electric shocks of the skin.

Lumbar puncture ('spinal tap')

In this test, a sample of fluid is taken from your spine. The procedure involves cleaning the skin, deadening it with local anaesthetic and then passing a small needle between the bones of your lower back.

"I've read comments on the forum that people refuse to have a lumbar puncture after they hear what it involves – but I'd like to reassure people that they are not as painful as you would believe!" **Cath**

This can be uncomfortable. It may cause a headache afterwards. But checking the pattern of any antibodies found in your spinal fluid can provide strong evidence to support a diagnosis of MS.

What types of MS are there?

While everyone's MS is different, most people's experiences will fall into one of a number of broader 'types'.

However, the lines between the different types aren't always clear. It's not always obvious what types of MS someone has, and not two people, even with the same type of MS, will follow exactly the same pattern.

Clinically isolated syndrome (CIS)

Clinically isolated syndrome (CIS) describes a one-off episode of symptoms which, like MS, might be due to damaged myelin around nerve fibres.

Some people with CIS go on to have further attacks and, if test results support it, are diagnosed with MS. Some people never develop MS and the CIS remains an isolated incident.

The tests listed are used to help diagnose a CIS but can also help in deciding how likely it is that someone with a CIS will go on to develop MS.

Sometimes MS can be diagnosed after the first attack if an MRI scan shows evidence of past MS activity in the brain as well as new damage.

“It's not going away, you could have MS”, Danielle is 24 and was diagnosed with Clinically Isolated Syndrome in 2013. She is still waiting to see if it is MS.

‘In December 2012 I started having visual problems and temporary blindness in my left eye. I thought I just needed new glasses. The optician did a thorough eye exam but had no idea what the problem was. An eye specialist suspected inflammation but couldn't see any nerve damage.

‘In April 2013 I noticed I needed to go the loo more and kept feeling like I was going to wet myself. There was numbness in my feet – I couldn't feel the ground beneath me.

‘I was a student at the time and put a lot down to pre-exam stress. One night, I was studying and moved from sitting to kneeling and there was an explosion of pain in my back. The numbness spread from my waist down and it felt like there was fire running down my legs.

‘I went to see the doctor, a new one just out of medical school, and explained all my problems. She tested my reflexes and checked for urine infection.

‘She asked if anyone in the family had MS – I thought ‘what a stupid question’ – but she said she thought I might have it and arranged an immediate neurology appointment.

‘The neurologist was very impatient because I couldn't really say whether I could feel the pinprick test or not, and told me I should have an MRI scan in four weeks. You don't really take it seriously if that's how long you're going to wait.

‘Over the weekend my arm went numb and my hand started tingling, and my back was extremely painful. On the Monday my GP rang to see how I'd got on, and immediately arranged another hospital appointment; she even drove me there.

‘I told the neurologist things had got worse. This time I couldn't feel the pinprick test at all. I was admitted to hospital for an MRI scan of my spine. The consultant said there was some inflammation but it could be anything and he didn't think it was MS.

‘The next morning an MRI scan on my brain found some inflammation. I was told I had MS ... but not really. The MS specialist described Clinically Isolated Syndrome (CIS) as a once in a lifetime, horrible experience, and said I would be better by Christmas.

‘I thought I'd look on it as a gap year and everything would be fine. But it wasn't. My symptoms got worse when I moved home after college. I had regular MRI scans and my neurologist told me “it's not going away, you could have MS”. I'm still classified as CIS, which some people don't recognise as a diagnosis, although technically you have MS.’

“My GP thought it was carpal tunnel syndrome”, Marika, 29, was diagnosed with relapsing remitting MS in 2014.

‘I first noticed in August 2013 that my right arm felt numb, heavy and itchy. The feeling moved into my hand, so it was difficult to use. I was convinced it was a trapped nerve and was going to go away on its own. But when it hadn’t improved after a month my fiancé insisted I went to the doctor.

‘My GP thought it was carpal tunnel syndrome. He asked what was tingling, and because it was the three fingers typical of this condition he didn’t do any tests. My fiancé made me go back again and I was referred to a hand surgeon who ruled out carpal tunnel syndrome, but we still thought it was a slipped disc or that I’d pulled something.

‘I was sent for an MRI on my spine. The next day I was told they wanted to do another one of my brain and that was when alarm bells started ringing. I didn’t look on the internet because I was scared of what I’d find if I Googled brain scan.

‘I had the scan the following day – my company has health cover so I could get it done privately. The neurologist showed me images of my brain without saying too much, but I knew about MS because an ex-boyfriend had it for 10 years, and I recognised what the white patches were. But I was still hopeful it was something else.

‘My consultant said he was pretty sure it was MS – and I was hanging on to that ‘pretty’. It wasn’t a typical pattern – only two lesions in the brain, where he would have expected more. He wanted to do another scan in January to confirm the diagnosis, which it did.’

Radiologically isolated syndrome

Sometimes typical MS changes are seen on a brain MRI scan carried out for another reason, such as headache, in someone who has never had any MS-like symptoms before. They may be diagnosed with a ‘radiologically isolated syndrome’ (RIS) and closely monitored because they risk developing MS.

Relapsing remitting MS

In relapsing remitting MS people have relapses or attacks of symptoms that occur for a period of time – days, weeks or months – and then improve, either partially or completely.

“You need to use some judgement about what you read online. Some people want to make out MS is the worst thing in the world, which isn’t helpful.” **Ruth**

Secondary progressive MS

Many people with relapsing remitting MS go on to have secondary progressive MS years later. If your MS symptoms become progressively worse over a period of at least six months, independent of any relapses, you can be said to have moved on to secondary progressive MS.

Primary progressive MS

In some cases of MS, symptoms gradually get worse over time, rather than appearing as relapses.

Find out more about the different types of MS on our website:

mssociety.org.uk/what-is-ms/types-of-ms

What can I do?

There are things that can help you feel more in control of your condition – even if you don't know exactly what it is yet.

Be well informed

You may want to know more about MS, although it's possible that your symptoms are related to something else.

It's tempting to look up symptoms on the internet and make your own diagnosis. But a lot of online information is unreliable and can be scary. Don't forget that everyone's experience is different.

Stick to reputable websites like the MS Society, MS Trust or NHS Choices. Focus on facts based on clear evidence.

This will help you talk to health professionals. Don't be afraid to ask them to repeat anything that's unclear. They have a duty to make sure you understand.

Make notes you can refer to later. There can be a lot to take in. A partner, family member or friend can be a second set of ears and offer moral support.

Record your symptoms

Keep a diary of your symptoms to take to appointments. Write things down when they happen – a brief episode you quickly forget, or think is due to something else, could be significant to a doctor. There are symptom tracker apps you can download on your phone or tablet to help record your symptoms.

Providing lots of details – including how long individual symptoms last – can help your doctor make a more accurate diagnosis or a decision to refer you.

Describe symptoms as clearly as possible, using whatever words make sense to you, so your doctor understands exactly what you mean. This makes it easier to get to the root of your problem.

“At the time I didn't really know what results they were expecting to get from the neuro exam or the various scans and no one really explained.” **Jane**

Ask the right questions

Before an appointment, you may want to write a list of things to ask in order of importance.

Don't be afraid to ask your doctor outright what they think could be causing your symptoms. This will help start a conversation about the possibility of it being MS or something else, and what action your doctor would recommend.

Questions you may want to ask

- What do you think is wrong?
- What's the next step?
- Are tests required? Why?
- When and where will they be done?
- What do they involve?
- When will I get the results?
- What might they show?
- What happens if the results are normal?
- Where can I get more information or support?
- Is there anything I can do to help myself?
- Who should I call if I start to feel worse?

Manage your symptoms

There are ways to manage symptoms, whatever they are caused by. You don't have to wait for a diagnosis.

If you're fatigued, you may find it helps to pace yourself more, and allow yourself time to rest. A healthy, balanced diet and regular exercise can help you feel better generally.

Get expert help

Your GP is your gateway to specialist advice and treatment for individual symptoms. Don't be afraid to ask for help even if you've had tests done and are waiting for results.

“I could read the results on the computer – ‘urgent brain scan required’. It sent me into a tizz”, Ruth, 41, was diagnosed with relapsing remitting MS in 2014

‘The first sign something was wrong was that one morning in June my hands went numb. Then it became difficult to walk, I was extremely tired and I felt numb across my stomach.

‘My symptoms got worse and I went to the doctor, who did blood and other tests.

‘I was sent for an MRI scan on my spine but had to wait until September for my appointment. It took 10 days to get the results because of IT problems.

‘My GP asked me to come in immediately. I could read the results on the computer – there was inflammation on my spine – and the words ‘urgent brain scan required’. It sent me into a tizz. I subsequently had a further MRI. I went to the GP for my results and was told bluntly they'd found lesions and it was MS.

‘The doctor had contacted an MS nurse, who rang the next day and told me my GP shouldn't have made the diagnosis, only a neurologist could do that. So then I started worrying that it might be a mistake.

‘When I saw the neurologist in October he said he couldn't diagnose MS because I'd only had one relapse and I needed more scans, but if it did turn out to be MS, it was likely to be primary progressive MS.

‘I was now in a lot of pain, with muscle cramps. The MS nurse was so convinced that it was MS she sent me on a six-week MS course that put me in touch with physiotherapists, occupational therapists and neurology specialists. She is fantastic, always at the end of the phone or email.

‘My neurologist suggested a lumbar puncture, which came through negative. The MS nurse, suggested I see a different neurologist, this one was an MS specialist, and I was finally diagnosed with relapsing remitting MS.

‘For me, diagnosis was very much a relief at first, and then reality kicked in. But you can put a label on it – albeit not a great label – and know that your symptoms are not just in your head.

‘The MS nurse helped explain things to me, and to my dad, who was in denial. Dad doesn't do the internet, so it was good to have someone help him understand MS and what I go through.’

Steroids

While you're waiting for a definite diagnosis, your GP or neurologist may suggest a course of steroids for your symptoms.

Steroids are often used to treat relapses of MS, particularly when they're disabling, to speed up recovery. These are either given as tablets (usually over five days) or injected into a vein (usually over three days). Injected steroids are often used if symptoms are particularly severe and require admission to hospital.

Search 'steroids' on [nhs.uk](https://www.nhs.uk) for more information

Treatments and therapies

GPs can prescribe stronger painkillers than you could buy yourself, and drug treatments for different symptoms. For instance, anticholinergic drugs can help an overactive bladder.

Your GP can also refer you to experts in specific symptoms, including:

- a physiotherapist to help with mobility and stiffness
- an occupational therapist to offer practical solutions if you struggle with everyday activities
- a continence adviser to advise on managing bladder and bowel problems
- a speech and language therapist to help with communication and swallowing.

Visit our symptoms pages for ways to manage symptoms: [mssociety.org.uk/symptoms](https://www.mssociety.org.uk/symptoms)

"I ended up switching GPs – the one I had previously basically told me my symptoms were all in my head, although they were getting worse." **Penny**

Try not to worry

It's hard not to be anxious when you don't know what's wrong. Writing down your feelings can help. Think about what normally calms you down or makes you feel better when you're worried.

Your GP can refer you to a counsellor to help you cope with what can be an emotional rollercoaster.

Remember, you're not alone. Other people are in a similar position, even if they've had different symptoms or tests, and your experience – and eventual diagnosis – may not be the same as theirs. They may have useful tips on what you can do while waiting for a definite diagnosis.

You can call our helpline for reassurance and support. MS treatment centres run by local charities may be able to offer physiotherapy, counselling and the chance to talk to a specialist MS nurse even if you've not been diagnosed.

Our forum (and others) can connect you with other people going through the same thing.

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

[Shift.ms/forum](https://www.shift.ms/forum) for people in 'Limboland'

Catherine, 45, was diagnosed with primary progressive MS in May 2013.

'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 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.

'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.'

Know your rights

You still have certain rights even without a definite diagnosis.

Choosing who you see

All NHS patients have the right to choose which hospital they're referred to by their GP – unless it's an emergency – including some private hospitals. You can also ask to be seen by a particular consultant at your first hospital appointment.

You could check whether any hospitals in your area have an MS specialist in their neurology department. It might be worth travelling further afield to see them.

You're also entitled to ask for a second opinion or to switch GPs if you really aren't happy with the support you're getting. This isn't always easy to do, so don't rush into a decision.

Access to information

You have the right to see most health records held about you, including test results. You're also entitled to find out about local health services, including how long you may have to wait for an appointment or to get results.

Refusing tests

Under the NHS Constitution no one can give you a physical examination or any treatment without your consent. If you refuse a procedure that could help your diagnosis, your doctor should explain the consequences and if any alternatives are available.

Making a complaint

You should expect certain standards of care from every health professional you see while you wait for a diagnosis. You can complain to the NHS if you're not happy about the way you've been treated.

For instance, you may feel you've had to wait longer for an appointment or results because of administrative errors – like emails, letters or records

getting lost, or not getting a reply to phone calls or messages.

Every NHS organisation has a complaints procedure. To find out about it, ask a member of staff, look on the hospital or trust's website.

Workplace rights

You may want to tell your employer if your symptoms – whatever the cause – are making it harder for you to do your job. You still have certain legal rights to extra support at work.

Even without a definite diagnosis, if your symptoms are affecting your ability to do your job it is good practice for your employer to make adjustments for you. This could be something like giving you a stool to sit on if you have to stand a lot, or allowing you to work from home on some days.

Ask your doctor for a letter to show your employer. It should clearly say your symptoms are medical problems that are being investigated.

mssociety.org.uk/work

“It’s important I point out how I’m feeling – it’s not up to my boss to automatically know and make allowances.” **Sonia**

Financial support

Eligibility for some benefits is based on how symptoms affect you at work or in everyday life, not on whether you’ve had a definite MS diagnosis.

You may be able to claim Employment Support Allowance if your symptoms mean you’ve had to reduce your hours or stop working altogether, or are struggling to find suitable work. Personal Independent Payment may be available if you have extra costs – for example, paying for taxis if you’re finding driving or using public transport too difficult.

You will usually need a letter from your doctor to support your claim. The Citizens Advice Bureau can help you apply for benefits.

Find out more about available benefits in our books **Claiming Personal Independent Payment and Claiming Employment Support Allowance.**

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

Together, we are strong enough to stop MS.

The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call **0800 100 133** or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

Contact us

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