

Choices

Diagnosis



Multiple sclerosis information

Welcome to this Choices booklet about diagnosis

MS-UK listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis

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Diagnosis

The initial signs of MS can present with a variety of symptoms in different people at different times and the process of diagnosis can occasionally be a lengthy one.

Don't jump to conclusions until you're told you have MS by an experienced neurologist

There is no set pattern to the range and severity of the symptoms each individual will experience. Some people will be affected by symptoms that others will not and these can also vary from time to time, occurring in isolation or in combination.

Additionally, some people may experience milder symptoms, noticing slow, gradual changes in their physical condition with no obvious episodes. Others may have problems that are moderate or severe, taking the form of episodes or 'relapses' (a temporary worsening of symptoms).

Believe in yourself. You know your body better than anyone

It is also important to stress that some symptoms such as mobility changes are more obvious to the naked eye, while others are not, for example, fatigue or sensory disturbances.

**Explain every single symptom
or pain however trivial**

Unfortunately, there is no single test or procedure that can be used to diagnose MS. Diagnosis is based on a number of factors such as a review of your medical history, neurological examinations and a series of tests.

Other conditions, which share a commonality of symptoms with MS, also need to be ruled out before an MS diagnosis can be confirmed. The diagnosis pathway can, therefore, be a process of elimination.

It is often a case of monitoring over a period of time to see if new symptoms appear or previous symptoms recur. This can prove frustrating for many as it can be hard to accept that a conclusive MS diagnosis can take months or even years.

McDonald diagnostic criteria

The McDonald criteria are a set of guidelines that neurologists use to accurately diagnose MS, as it helps them to distinguish it from other neurological conditions. The first set of criteria was published in 2001 and it is updated regularly, with the latest version being published in 2017 (1).

The MRI, together with the lumbar puncture in some cases, provides the bulk of evidence to be reviewed during the diagnostic process, alongside the McDonald criteria.

More information

We provide more detailed information about the McDonald diagnostic criteria on our website, www.ms-uk.org/diagnosis

Our 'Is it MS?' Choices booklet provides a summary of other conditions which have similar symptoms to MS.

www.ms-uk.org/choices-is-it-ms-content

First steps to diagnosis

The National Institute of Health and Care Excellence (NICE) guidelines for the management of MS include the steps medical advisors, such as GPs and neurologists, should take to reach, or exclude, a diagnosis of MS (2).

NICE states that the most common symptoms or 'clinical presentations' a person would visit their GP with are

- Loss or reduction in vision in one eye, with painful eye movements
- Double vision
- Ascending sensory disturbance or weakness (a change in sensation or strength that moves up the body)
- Altered sensation travelled down the back when bending the neck forward called Lhermitte's Syndrome – this can feel like a finger being run down the spine, or a tingling feeling
- Progressive difficulties with balance and gait

NICE guidance also suggests that clinicians should be aware that these symptoms usually affect people with MS for more than 24 hours and they may have persisted over several days or weeks.

Initial symptoms may also include numbness in different parts of the body and other sensory disturbances such as twitching and tingling.

More information

Our 'MS Symptoms' Choices booklet offers more information on the common symptoms associated with MS.

www.ms-uk.org/choices-ms-symptoms

Recording and explaining symptoms

If you are experiencing symptoms it is important to make an appointment with your GP to discuss them. It might be helpful for you to use a symptom diary as it can help you to gather information and show how symptoms can present when looked at together rather than in isolation. It can save time when visiting a GP for the first time. Rather than trying to explain what has been happening, it can help to share a diary.

Appointments with GPs or neurologists can sometimes be overwhelming, certainly when trying to discuss and explain how you have been feeling. It can be a difficult time talking about symptoms, and sensations, and trying to explain just how you feel. By writing down and describing your symptoms and how they affect you, whether it is a new symptom or one you've experienced before, you'll have everything to hand. For example, when did the symptom start and stop, does it fluctuate, and do certain things make it better or worse, for example, heat, stress, or time of day?

Score how the symptoms affect you using a scale from one to five. A score of one means it doesn't affect you much at all and five

means it has an extreme impact. All of this information helps to build a bigger picture during GP and/or neurologist appointments.

More information

We have a downloadable symptom diary accompanied by a useful guide, available on our website, www.ms-uk.org/symptoms-diary



Keep talking, and describe everything you experience – everyone is different

Initial medical tests

A GP may perform a number of blood tests to exclude alternative diagnoses, before referring you to a neurologist, if MS is suspected.

The following is a list of tests which may be conducted, although not all of these may be required.

- A full blood count
- Inflammatory marker test
- Liver function tests
- Renal function tests
- Thyroid function tests

- Calcium
- Glucose
- Vitamin deficiencies
- HIV serology test

Once your GP feels that specialist neurological investigations are required, they will refer you to a neurologist.

Being referred to a neurologist

Only a neurologist, a specialist on central nervous system conditions, is qualified to diagnose MS. A neurologist will perform specific tests to ensure that symptoms are consistent with an inflammatory process in the body and that all other alternative diagnoses have been excluded.

Take someone with you if you can, if not, take notes. If you are unsure about something, ask for clarification. Ask who you should contact if or when you have questions after your appointment

The process starts with a neurological examination during which your full medical history will also be taken into account. Collecting your history is important as prior symptoms such as visual disturbances or

numbness may have been treated or classed as something other than MS at the time. The neurologist will then perform simple tests to check movement, coordination, balance, reflexes and sensory compliance. The aim of these tests is to establish whether there are signs of the inflammatory process in the body.

Stay open-minded and go armed with any questions written down. If possible, go with a friend who can listen with you - it'll probably be a lot to take in

If your medical history and neurological examination suggests MS, more tests will be conducted to look for further evidence. The neurologist will be looking for lesions on the brain and/or spinal cord. These lesions occur when the inflammation process has left scarring on the fatty myelin sheath that surrounds the nerve. A neurologist will need to establish that lesions have developed at different times, and in different areas of the body for a diagnosis of MS. This is known as the McDonald criteria, which we mentioned earlier in this booklet.

Know what tests you are having. Read about them prior and make a list of questions to ask. Follow up on any results and ask questions

NICE guidelines state that a diagnosis of MS should take into account a combination of history, examination, MRI and laboratory findings, and following the McDonald criteria (2).

Neurological tests

Further tests that may be suggested by a neurologist are listed below.

MRI scanning

A Magnetic Resonance Imaging scan (MRI) is used to identify any areas of the brain and spinal cord that may have scarring. An MRI scanner consists of a large doughnut-shaped magnet with a tunnel in the centre which, with the help of radio waves, is used to take pictures of the brain and/or spine. You will be placed on a table that slides into the tunnel. It is a painless procedure, although it can be quite noisy.

I am claustrophobic and was terrified at the thought of going into an MRI machine. But when I realised that it was open at the ends and that there was a panic button, I felt much better about it

Timewise, the MRI scan can take approximately one hour, with more or less time required depending on the number of scans required. It can feel a little claustrophobic, but earplugs can be provided and you can contact the MRI operator at any time. The units are open-ended and some hospitals may provide MRI-safe mirror goggles that allow you to view the end behind your head, enabling you to see outside the unit,

which can help relieve any feelings of claustrophobia. Sometimes a video screen is placed at the end of the unit, or a member of the medical team may be positioned there, both of which can be seen by using the goggles.

I have just completed the four-week mindfulness programme with MS-UK and it really helped me when I was in the MRI machine for an hour. I was able to relax much easier and just go with what was happening. I definitely recommend that course if it comes around again

Additionally, it may be possible to be sedated during the scan which can help relieve the impact of claustrophobia. To request this speak to your consultant well in advance of the date of the scan. Be aware that you will not be able to drive for 24 hours after sedation.

Occasionally a dye called gadolinium is used to enhance the image. The dye is injected into a vein before the MRI starts and can assist the neurologist to distinguish between new or 'active' lesions and older areas of scarring.

Just relax. Breathe calmly and close your eyes. Just remember that this test helps give a clear picture of everything going on inside you

Lumbar puncture

A lumbar puncture is a procedure where a small sample of cerebrospinal fluid (CSF), which surrounds and protects the brain and spinal cord, is taken and analysed for any abnormalities that can indicate MS, such as oligoclonal bands (OCBs). These are proteins known as immunoglobulins and they indicate the presence of inflammation in the central nervous system.

Lumbar punctures can be uncomfortable, but relaxing helps. Lay down after for 24 hours and drink coffee or full-fat coke

This procedure is done by first injecting a local anaesthetic into the lower back and then inserting a needle between the lower discs of the spine to draw off the CSF. It may be performed as either an inpatient or a day patient in a hospital. You need to be in a hospital environment so they can monitor your health and rest will be needed for several hours after the procedure to allow your body to recover.

Evoked potentials

These are very simple, painless electrical tests that measure the time it takes for your nerves to respond to stimulation and are sometimes used in the diagnosis of MS. Visual evoked potentials (VEP) are most commonly used in the diagnostic process.




**This is a painless, simple experience –
nothing to worry about**




For VEP tests, a conducting gel and electrodes are applied to the scalp, specifically to the rear of your head, which is close to the occipital region of your brain. This is the area of the brain that is responsible for registering visual stimuli. The stimuli for VEP are delivered by a strobe light or a screen with a checkerboard pattern. The electrodes measure the time it takes for the eye to see the image and the nerve impulse to reach the occipital region. The test takes around 30-45 minutes to complete.

It is important to keep in mind that these tests do not always give a conclusive result. Most people with MS will show some lesions or areas of inflammation on an MRI but there is still a small proportion whose MRI shows nothing at all. Similarly, with a lumbar puncture, there is a minor percentage of people with MS who will have a negative result.



**Make a list of and ask questions regarding tests,
symptoms, diagnosis time, treatments and any
other questions that you want to ask**



Support during diagnosis

If you need to speak with someone, MS-UK has a trained helpline team that can offer emotional support and give more information and signposting on anything related to MS.

Contact our team by telephone free on 0800 783 0518, via live web chat at www.ms-uk.org or by email at info@ms-uk.org.

Post diagnosis

If you have been given a confirmed diagnosis of MS, it is important to access support and information that is not only reliable but also right for you. Our Choices booklet 'Newly diagnosed with MS' is a good place to start, providing information, tips and signposting that will help you in the early post-diagnosis days.

www.ms-uk.org/newly-diagnosed-multiple-sclerosis

More information

You can view our full range of Choices booklets and order hard copies to be delivered to your door, free of charge, on our website.

www.ms-uk.org/choicesleaflets

Don't let MS define you. You are still you but may have to change a few ways of doing things

We asked the MS community for their tips, hints and words of wisdom on the subject of diagnosis



Keep a diary of how you feel and any incidents that are different to your “normal”, the frequency, triggers, how long they last. You’ll build a picture of your MS and learn how to keep yourself as well as possible



It will take time to sink in, keep talking to your family, tell them how you feel, read a little but not too much, speak to someone else with MS



Knowledge is power. Whatever your diagnosis it’s your opportunity to move on and deal positively with your new situation in life. Accept offers of help and investigate all new experiences that could potentially help you



It gave me a wake up to make me really appreciate my life and what I can do. I try to take the positive from it and got myself fitter than I've ever been which I know wouldn't have happened if I hadn't been diagnosed. Obviously, I'd rather not have it, but I always try to see the positive!

Understanding your condition actually helps you to be able to deal with it as positively as you can. You may be afraid but looking back it was the not knowing and the fear of what it might be that was the worst thing for me

Take it in your stride. There is nothing you can do to prevent the diagnosis, but it doesn't mean that it's all downhill. The treatment offered can do a lot to alleviate any future concerns you had

Go to social media! MS does not mean an end to all your dreams and plans. While you'll never find someone whose disease is the exact same as yours, it's important to talk with others with similar experiences

There is no right or wrong way to react to the news that you have MS. However, if you are looking for information make sure that you find a reliable source. The MS charities are always a reliable source

As scary as it is, treatment has come a long way. The MS teams are amazing, and knowledgeable so make the most of them! Also, get to know the community online, we're lovely!

About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.

About MS-UK

Peer support service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





MS-UK's online activities

MS-UK offers a variety of online activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. Visit our website to explore and find out more.

MS-UK elearning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created accredited Learning courses that can help you do this. Visit <https://ms-uk.org/excellence-ms/> to find out more.

Sources

- (1) Sage journals. Multiple Sclerosis Journal. 2017 McDonald MS diagnostic criteria: Evidence-based revisions. Published February 2018. Accessed May 2023.
<https://journals.sagepub.com/doi/full/10.1177/1352458517751861>
- (2) National Institute for Health and Care Excellence (NICE). Multiple sclerosis in adults: management [NG220]. Published June 2022. Accessed May 2023.
www.nice.org.uk/guidance/ng220

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Check out MS-UK's online activities

Live a happier and healthier life with MS



- ✓ Accessible online exercise classes
- ✓ Chair yoga classes
- ✓ Mindfulness courses

- ✓ Interactive workshops
- ✓ Information sessions
- ✓ Peer Support Service

Don't miss out – sign up for our new online activities today!

Visit www.ms-uk.org or contact us at register@ms-uk.org

 **MS-UK**
Supporting your MS journey

Registered charity number 1033731

Stay in touch

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▶ www.youtube.com/c/ms-ukorg

in www.linkedin.com/company/ms-uk

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MS-UK Helpline
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