

Choices



Diagnosis



Read me...

Diagnosis

Multiple sclerosis (MS) can present different symptoms in different people at different times and the process of diagnosis can be a lengthy one for some.

'It's not the end of the world. The neurologist who was leading my tests said to me: I have seen the range of people with this condition. There are mild cases as well as the famous ones.'

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

Some symptoms such as mobility changes are more obvious, but some are not, for example, fatigue or sensory disturbances. There is no set pattern and some people will experience symptoms that others will not and these can also vary from time to time, occurring singly or in combination.

Some people have mild symptoms, while others have problems that are moderate or severe, taking the form of episodes or 'relapses' (a temporary worsening of symptoms). Other people experience a slow, sometimes almost imperceptible change in their physical condition with no obvious episodes.

'Believe in yourself. You know your body better than anyone.'

'Explain every single symptom or pain however trivial.'

Unfortunately there is no one single test or procedure that can be used to diagnose MS. It is often a case of watching and waiting to see if new symptoms appear or previous symptoms recur. This process can be frustrating; it is hard to accept that a conclusive diagnosis can take months, or years.

Diagnosis is based on a number of things such as looking into medical history, neurological examinations and a series of tests. Other conditions need to be ruled out before a diagnosis can be confirmed.

First steps to diagnosis

In October 2014, the National Institute of Health and Care Excellence (NICE) issued new guidelines (1) for the management of multiple sclerosis, including guidelines for the steps medical advisors, such as GPs and neurologists, should take to reach (or exclude) a diagnosis of MS.

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‘Ask what they are actually thinking what’s wrong with you. I went in suffering severe migraines to be told after the tests I had MS, it was a total shock for me as I had never had it told to me I was being tested for this or that’s what they thought it might be.’

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)
- Balance problems or clumsiness
- 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

NICE also suggests that, to be recognised as a symptom of MS, these should last over 24 hours and may have persisted over several weeks or months.

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 the ‘Symptom Diary’ that is available to download via our website.

‘You need to feel comfortable when identifying ‘odd’ symptoms as you are special and an individual with individual needs.’

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

NICE recommends a GP carry out the following blood tests before such a referral is made, although not all may be performed:

- A full blood count
- Inflammatory marker test
- Liver function tests
- Renal function tests
- Thyroid function tests
- Calcium
- Glucose
- Vitamin B12
- HIV serology test

It is worth noting that many other conditions may and do produce symptoms almost indistinguishable from MS symptoms. For more information see our Choices leaflet – ‘Is it MS?’

Being referred to a neurologist

‘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/when you have questions after your appointment.’

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Only a neurologist can make the diagnosis of MS. A neurologist will perform other tests to ensure that symptoms are consistent with an inflammatory process in the body and that all other alternative diagnoses have been excluded.

'Be honest - totally honest and take lists with you - the neurologist is busy and doesn't have time to chat and prize information from you. Go prepared.'

The process starts with a neurological examination during which your full medical history will be taken into account. Collecting your history is important as prior symptoms such as visual disturbances or numbness may have been treated or passed by without the consideration of MS at the time. The neurologist will then perform simple tests to check movement, coordination, balance, reflexes and other sensory tests. The neurologist performs these tests to establish whether there are signs of the inflammatory process in the body.

'Make a list of your concerns before your appointment and have the courage to ask lots of questions.'

If your medical history and neurological examination suggest MS, more tests will be conducted to look for further evidence in your body. The neurologist will be looking for 'lesions' on the brain 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.

The neurologist will make a diagnosis of MS based on established criteria, such as the revised 2010 McDonald criteria (2). The McDonald criteria is detailed later in this leaflet under 'Further Information'. In summary, a diagnosis of MS is undertaken through a combination of your medical history, clinical and neurological assessment and judgment by a neurologist.

'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.'

Further tests that may be suggested by the neurologist are as follows:

MRI scanning

'If you're worried, tell the radiographers. They're experienced and helpful, will talk to you whilst you're in the machine (or not, if you prefer to just lie there whilst they scan). It's quite noisy, although lying with your eyes closed makes it less claustrophobic.'

A Magnetic Resonance Imaging scan (MRI) is used to identify any areas of the brain or spinal cord that may have scarring. An MRI scanner consists of a large doughnut-shaped magnet with a

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tunnel in the centre which along with radio waves is used to take pictures of the brain or spine. You will be placed on a table that slides into the tunnel. It is a painless procedure, although quite noisy.

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

The MRI test can last between 20 to 40 minutes. It can feel a little claustrophobic but headphones are provided and you can contact the MRI's operator at any time.

'Don't worry, it's loud, but if like me your legs are restless when lying on your back ask for a cushion to raise your calves. The difference is amazing.'

Sometimes a dye called gadolinium is used to enhance the image. The dye is injected into a vein before the MRI starts. The dye can assist the neurologist to determine what is a new or 'active' lesion, and what are older areas of scarring.

NICE states that MS cannot be diagnosed on the basis of the MRI findings alone and other tests are needed, including the initial neurological examination.

Lumbar Puncture

A lumbar puncture is a procedure where a small sample of cerebrospinal fluid (CSF) is taken and analysed for any

abnormalities that can indicate MS. CSF is the fluid that surrounds and protects the brain and spinal cord.

'It's not as scary as it seems. They numb you and talk to you throughout. You might feel even more off balance after though, so make sure you have someone to look after you for a couple of days.'

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. This procedure may be performed as either an inpatient or a day patient in a hospital. You need to be in a hospital environment due to the need to monitor your health and rest will be needed for several hours after the procedure to allow your body to recover.

'It's not as bad as you think it may be, be prepared and research before you go for it. Rest after and plenty of water to try and prevent a headache.'

Evoked Potentials

'This is a painless, simple experience - nothing to worry about.'

These are very simple electrical tests that measure the time it takes for your nerves to respond to stimulation. Visual Evoked Potentials (VEP) are most commonly used in the diagnostic process. A conducting gel and electrodes are applied to the scalp. For VEPs, the electrodes are

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applied to the rear (occipital region) of the scalp over the brain areas that register 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 of the brain.

‘Prepare to laugh at yourself with a head full of probes that make you look like you've stepped out of sci-fi movie but don't worry they don't hurt.’

It is important to keep in mind that these tests do not always give a conclusive result. Mostly people with MS will show some lesions or areas of inflammation on a MRI but there are still a small proportion of people whose MRI shows nothing at all. As 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.’

Further information

McDonald Diagnostic Criteria

The McDonald criteria (2) are used to seek to establish evidence of damage to the central nervous system (CNS) comprising of the brain and spinal cord.

The MRI, together with the lumbar puncture in some cases, provides the

evidence to be reviewed alongside the McDonald criteria to diagnose MS.

If you are interested to read more about this diagnostic criteria, please see our website where you can download it in full. www.ms-uk.org/diagnosis

After diagnosis

‘Go only to those websites directly linked to MS. Remember often Dr Google is not our friend.’

If you have been given a confirmed diagnosis of MS, you can download or send off for our ‘Newly diagnosed with multiple sclerosis?’ booklet. This booklet will give you more information and hints and tips on life after diagnosis.

‘Do not panic. You can have a life as well as MS.’

‘Listen carefully to what they have to say and only query short term events. I bombarded my consultant with queries about what could happen in years to come instead of concentrating on how to manage now and in the next few months.’

‘MS doesn't mean the end of all your plans and dreams. Life will still be good, just a bit different from what you might have imagined. It will be ok - we people with MS are known for being very resourceful and feisty!’

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How we create our Choices leaflets

MS-UK believes we must listen to the voices of people affected by multiple sclerosis to shape the information and support we provide. It is these people that bring us perspectives that no one else can give, and all of the quotes in this leaflet are from real people.

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

Thank you to everyone affected by MS who made this leaflet possible.

Sources

- (1) National Institute for Health and Care Excellence. NICE Guidance – Multiple sclerosis in adults: management. Published October 2014. Accessed November 2016-
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- (2) National Center for Biotechnology Information. Diagnostic criteria for multiple sclerosis: 2010 Revisions to the McDonald criteria. Published February 2011. Access November 2016 -
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