Choices

Supporting your MS journey

Diagnosis

Multiple sclerosis information

www.ms-uk.org
Welcome to this Choices booklet about diagnosis

MS-UK believes we must 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.
Contents

Diagnosis ____________________________ 4
First steps to diagnosis ____________________________ 5
Being referred to a neurologist ____________________________ 8
Further information ____________________________ 13
After diagnosis ____________________________ 13
About MS-UK ____________________________ 16
Sources ____________________________ 20
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 be a lengthy one for some.

Don’t jump to conclusions until you’re told you have MS by an experienced Neurologist

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 slow, gradual changes in their physical condition with no obvious episodes.

Believe in yourself. You know your body better than anyone
Unfortunately, there is no one single test or procedure that can be used to diagnose MS. It is often a case of monitoring 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 even 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

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 (1).

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

Visit www.ms-uk.org to find out more
• 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 days or weeks.

Other first symptoms may include numbness in different parts of the body, changes to gait - the manner in which you walk, other sensory disturbances such as twitching and tingling.

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.

A symptom diary 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.

"Keep talking, and describe everything you experience, everyone is different"
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 experienced before, you’ll have everything to hand, for example, when did it start/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, one meaning it doesn’t affect you much at all, five meaning it has an extreme impact. All of this information helps to build a bigger picture when seeing your GP and/or neurologist.

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 booklet Is it MS?**

### Being referred to a neurologist

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.

**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**

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.

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 2017 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.

Know what tests you are having. Read about them prior and make a list of questions to ask. Follow up any results and ask questions.
Further tests that may be suggested by the neurologist are listed below.

**MRI scanning**

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 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 it can be 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 from 20 to 40 minutes. It can feel a little claustrophobic but headphones can be provided and you can contact the MRI’s operator at any time.

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 is 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.

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 so as to monitor your health and rest will be needed for several hours after the procedure to allow your body to recover.

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

Evoked Potentials

These are very simple electrical tests that measure the time it takes for your nerves to respond to stimulation and are sometimes used

For an MRI, take earplugs and an eye mask if you’re claustrophobic. Learning mindfulness helps
in the diagnosis of MS. 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 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. The test takes around 30-45 minutes to complete.

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

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 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

Symptom diary
A useful template can be downloaded from our website. It can be helpful to keep a note of the symptoms you are experiencing and when they occur.

Please see the following links to our website
www.ms-uk.org/sites/default/files/SymptomDiary.pdf
www.ms-uk.org/sites/default/files/Symptom%20Diary.docx

After diagnosis
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.

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.

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.

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

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.
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.
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.

**MS-UK Counselling**

MS-UK Counselling is open to anyone living with MS and is the only service of its kind available in the UK. Whether you want support coming to terms with a diagnosis or to improve your mental wellbeing, our counselling service is focused on helping you.

All of our MS-UK counsellors are BACP registered or accredited with an in depth knowledge of MS.
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 Online offers a range of activities for people living with multiple sclerosis (MS). Our aim is to help people manage their wellbeing independently through exercise, information and connecting with others.

The activities offered online have been chosen by the MS community and future activities are guided by the feedback we receive.

Our current online activities include exercise classes, chair yoga, information sessions, interactive workshops and courses such as mindfulness and poetry.

To get involved, please visit the website www.ms-uk.org/ms-uk-online-exercise or email register@ms-uk.org.

Visit www.ms-uk.org to find out more
Sources


Last reviewed June 2020
Use me for your notes
MS-UK Online!

- 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 services today!

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

MS-UK
Supporting your MS journey
Charity number 1033731
Stay in touch

MS-UK
D3 Knowledge Gateway,
Nesfield Road,
Colchester,
Essex, CO4 3ZL

www.ms-uk.org

@MSUK6
www.facebook.com/MultipleSclerosisUK
www.youtube.com/c/ms-ukorg
www.linkedin.com/company/ms-uk
www.instagram.com/multiplesclerosis_uk

MS-UK Helpline
0800 783 0518
info@ms-uk.org

Registered Company Name:
Multiple Sclerosis-UK Limited, trading as MS-UK
Company Number: 2842023
Registered Charity Number: 1033731
VAT Number: 632 2812 64
Registered Office: D3 Knowledge Gateway,
Nesfield Road, Colchester, Essex, CO4 3ZL