

Choices

Is it MS?



Multiple sclerosis information

Welcome to this Choices leaflet about multiple sclerosis

MS-UK believes in listening 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 and we hope it will answer some of your questions about MS.

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Is it MS?

It may be that you, or someone you know, has been experiencing some symptoms and are anxious as to what these could be. Perhaps someone in your family has MS and you are worried about some symptoms you have and the risk of developing it. Or you may be experiencing symptoms that make you think that it could be MS.

If you suspect MS is the root cause of your symptoms and issues, it may be of interest to you to know that we often receive calls on the MS-UK Helpline from people with concerns that they have signs and symptoms of MS. You are not alone, and our helpline team is there if you need someone to talk to.

Whilst on a journey towards a diagnosis of MS, some people's symptoms may be misdiagnosed as a different condition (1). You may have already been diagnosed with something else but have had a change in symptoms that now have led you to suspect it could be MS.

It is also important to note that there are many conditions where symptoms are very similar to those experienced in MS. What might first be thought of as symptoms of MS, may well be symptoms of another condition entirely (2). This booklet provides a brief insight into some of what those may be.

We are not clinicians or health professionals, however we do have experience of supporting the MS community. This booklet will do its best to answer questions you may have and hopefully make useful suggestions. However, this should not be a replacement for medical advice.

What can I do?

If you believe your symptoms are of a neurological origin, it is worth keeping a symptom diary. There is a template of a symptom diary at the end of this booklet that you can use. It can be a helpful tool in documenting the symptoms experienced and help health professionals to see you as a whole, rather than looking at symptoms in isolation.

The diary includes things like

- How each symptom affects you, whether it's a new symptom or one previously experienced, is it worse than before?
- Write down when the symptom started and stopped, does it fluctuate?
- Do other things seem to have an impact, for example, stress, heat, diet, the time of day...?
- Score how the symptom affects you. One meaning not much impact, five meaning extreme impact on quality of life

This will all help to build a picture of what you are experiencing and will also help medical professionals understand what may be going on.

Initially, whilst seeing your GP, they may take a full blood test however it may be useful to know that there is nothing in a blood test that would indicate MS. A GP will use the results to explore other possible issues that may be affecting your health. For example, vitamin B12 deficiency can lead to some symptoms that mimic aspects of MS.

A neurologist is the only person who can give a formal diagnosis of MS. Your goal may be to get a referral to a neurologist who will have to follow fairly strict diagnostic criteria.

If they suspect MS, a magnetic resonance imaging (MRI) scan alone is normally not enough to be able to give the neurologist all they need to be able to diagnose or rule out MS. The MRI and other tests (such as a lumbar puncture), along with your personal history (and any neurological symptoms you may be experiencing) should be enough to give the neurologist all they need to know/see, in order to rule out or confirm MS.

To help gather your personal history in the most efficient way possible to communicate with health professionals, it is suggested you keep your symptom diary up to date.

We have good quality information about the diagnostic criteria on our website and a helpful checklist of questions you may wish to ask a neurologist when you see them. It will be useful for you to read about the MS diagnosis process as it may help manage your expectations. It could be helpful in case you continue to experience symptoms and you feel you need to push for further tests and referrals to other specialists. There is a link to further information on the diagnosis process at the end of this booklet.



Although it may feel like a journey where you keep going backwards and forwards to your GP it is always worth speaking to them about how you feel, with a list of questions you wish to ask and a copy of your symptom diary if possible.

Here is a list of prompting questions for you to think about before appointments

1. What do I want to get from this visit?
2. What do I need to say to the doctor?
3. What do I need to know from the doctor?
4. What is my priority for this visit?
5. What am I already doing to help myself?
6. How am I feeling today?
7. How have I felt since my last visit, and what difficulties have I had?
8. What have I achieved since my last visit, what is my next goal?
9. What else is happening in my life to affect my health?
10. Is there something I may find difficult to talk about today?

Using this list of questions will help you to be reflective of your health and to encourage open communication with your health professionals.

It can be a frustrating time when you are experiencing symptoms and have no answers as to why.

If you feel you are not being listened to, it would be reasonable to ask for a second or further opinion. You could perhaps ask to see a different GP within your surgery, or alternatively you could re-register at a different GP surgery.

If you have seen a consultant and are not happy with the outcome you would usually need to go back to your GP and ask to be referred to another consultant. You can also discuss any concerns with the hospital's patient advice and liaison service (PALS) or your local Healthwatch.

MS is a condition that exhibits many similar symptoms to a variety of other conditions as we will explore in this booklet. If MS has been ruled out, it could be that you may wish to explore the possibility that one of these conditions could be the root cause of your symptoms.

Fibromyalgia

Fibromyalgia, also known as fibromyalgia syndrome (FMS), is a long-term condition that causes widespread muscular pain and fatigue (3). More women than men are affected, and it is most commonly developed between the ages of 25 and 55. It varies a great deal from one person to another and from day to day. One important fact to note is that it does not show up on an MRI.

Symptoms of fibromyalgia which are similar to MS are

- Fatigue
- Joint and muscle pain
- Disturbed sleep

- Bowel problems
- Headache
- Numbness and tingling in the extremities

Functional neurological disorder (FND)

FND is a medical condition in which there is a problem with the functioning of the nervous system (4). The brain and body fail to send and receive nerve signals in the correct way which results in a variety of symptoms occurring. There is usually no physical markers on MRI scans. However, FND can encompass a variety of neurological symptoms. FND is a common cause of disability. It can also cause a lot of distress as historically people were told nothing is wrong as there was nothing to show on scans.

Symptoms of FND which are similar to MS are

- Spasms and spasticity
- Tremor
- Weakness in limbs and muscles
- Fatigue
- Sensory disturbances

Hughes Syndrome

Hughes Syndrome is a blood disorder which in some ways mimics MS (5). Also known as 'sticky blood syndrome' or antiphospholipid syndrome (APS), Hughes is a common autoimmune disease that

makes the blood thicker or 'sticky' and therefore more prone to clotting in the veins or arteries.

Some of the symptoms of Hughes Syndrome which are similar to MS are

- Double vision
- Fatigue
- Balance and mobility issues
- Speech and memory problems
- Pins and needles in arms or legs

Hughes Syndrome is easy to diagnose by a simple blood test and easy to treat with blood thinning medication such as warfarin or aspirin.

Lupus

Lupus is a disease of the immune system. Like MS, the immune system gets confused and begins to attack itself. With Lupus, however, this causes the blood stream to have too many antibodies, which leads to inflammation and damage in the joints, muscles and other areas (6). It affects more women than men. Some people do not have its typical rash and arthritis straight away, making symptoms seem even more like MS.

Some of the symptoms of Lupus which are similar to MS are

- Extreme fatigue
- Weakness
- Joint and muscle aches and pains

Lyme disease

Lyme disease is an infection of the central nervous system caused by bacteria from a tick bite (7). If you live in an area known for Lyme disease or have travelled to a known area recently, let your doctor know so that they can rule it out.

Some of the symptoms of Lyme disease which are similar to MS are

- Numbness
- Pins and needles
- Poor balance
- Difficulty walking
- Tremor
- Problems with vision
- Headache
- Muscle and joint ache

ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome)

Someone with ME/CFS is so fatigued that it impacts on their daily life. It is still unknown what causes ME/CFS although it sometimes follows an illness and some researchers believe that ME/CFS could be due to a reaction to common viruses (8).

Some of the symptoms of ME which are similar to MS are

- Fatigue
- Chronic pain
- Cognitive problems

Neuromyelitis optica (NMO or Devic's disease)

NMO is a very rare condition. It is estimated that (in Europe) there is one case of NMO for every 100,000 people. This means that it potentially affects less than 1,000 people in the UK.

NMO can affect any age group and is predominantly a female disease with only one man being affected to every four women. Neuromyelitis is very similar to MS in that it is a disease of the nervous system where there are episodes of myelin damage. In NMO however this inflammation is almost always in the optic nerves and spinal cord (9).

Some of the symptoms of NMO which are similar to MS are

- Vision problems (including temporary or permanent blindness in one or both eyes)
- Weakness of limbs
- Loss of sensation
- Bladder and bowel problems

Transverse myelitis (TM)

Transverse myelitis is a rare condition of the central nervous system. Like MS it involves inflammation, however in TM the inflammation is specifically in the spinal cord (10).

Some of the symptoms which are similar to those of MS are

- Weakness
- Loss of sensations
- Bladder and bowel problems

Vitamin B12 deficiency (also known as folate deficiency anaemia)

Vitamin B12 aids the metabolism of fatty acids needed to maintain the myelin sheath which protects the axons (nerve fibres) in the brain and spinal cord. It can be identified by a simple blood test (11).

Some of the symptoms of B12 deficiency which are similar to MS are

- Fatigue
- Memory loss
- Pins and needles
- Muscle weakness
- Disturbed vision

For more information on all of the above conditions please see the following links. If you would like to discuss anything mentioned in this booklet then please call our [helpline](tel:08007830518) on 0800 783 0518.

Further information

MS-UK symptom diary

www.ms-uk.org/symptoms-diary

MS diagnosis process

www.ms-uk.org/diagnosis

Healthwatch

www.healthwatch.co.uk

Fibromyalgia Action UK

www.fmauk.org

Functional neurological disorder (FND)

www.fndaction.org.uk

Hughes Syndrome Foundation

www.hughes-syndrome.org

Lupus UK

www.lupusuk.org.uk

Lyme Disease Action

www.lymediseaseaction.org.uk

The ME Association

www.meassociation.org.uk

Neuromyelitis Optica UK Specialist Services

www.nmouk.nhs.uk

Transverse Myelitis Association

www.myelitis.org

NHS Vitamin B12 information

[www.nhs.uk/conditions/Anaemia-vitamin-B12-and-folate-deficiency/
Pages/Introduction.aspx](http://www.nhs.uk/conditions/Anaemia-vitamin-B12-and-folate-deficiency/Pages/Introduction.aspx)

Symptom diary

[illegible]

[illegible]

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.





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.

E-learning

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

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