

Choices

Is it MS?



Multiple sclerosis information

Welcome to this Choices booklet about multiple sclerosis...

MS-UK listens 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.

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Is it MS?

People affected by MS may experience a variety of symptoms over time. These include pain, both neuropathic and musculoskeletal, fatigue, bladder and bowel issues, problems with vision, balance and gait, and spasticity. These symptoms are not exclusively associated with MS and determining their root cause can take a while.

It could be that you, or someone you know, have been experiencing similar symptoms and are anxious as to what could be the cause, with concerns that it could be MS. Perhaps someone in your family has MS – you may be experiencing symptoms and are worried about your risk of developing it.

If you suspect MS is the cause of your health problems, it may be of interest to know that we often receive calls on the MS-UK Helpline from people with similar concerns. 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 what might first be thought of as symptoms of MS may well be due to the impact of another condition entirely (2).

This booklet provides a brief insight into some of the conditions which present similar symptoms to MS.

We are not clinicians or health professionals, but we do have experience of supporting the MS community. This booklet will do its

best to answer questions you may have and make useful suggestions. However, this should not be a replacement for advice from medical professionals.

More information

Our 'What is MS?' Choices information booklet offers more information about MS including the most commonly associated symptoms.

www.ms-uk.org/what-is-multiple-sclerosis-choices-booklet

What can I do?

If you feel that you are affected by MS, but unsure about how to pursue this further, below are a few tips and information which may help you.

Keep a symptom diary

If you believe your symptoms are of a neurological origin, it is worth keeping a symptom diary. It can be a helpful tool in documenting the things you experience and help health professionals to see them as a whole, joining the dots rather than looking at each one in isolation. Our sample diary includes important pointers such as

- How each symptom affects you
- Whether it is a new symptom or one previously experienced. If so, is it worse than before?
- Is the symptom constant or 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

These are all key to help you to build a picture of what you are experiencing, while giving medical professionals vital information to help them understand what may be going on. It is wise that you keep your symptom diary up to date as this will provide a detailed view of your personal health history over longer periods.

Speak to your GP

If you suspect that you may have MS your GP may ask you to undergo a blood test. While 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 those found in MS, such as fatigue. Discounting other potential conditions in this way is an important first step to diagnosis.

Be aware of how MS is diagnosed

A neurologist is the only person who can give a formal diagnosis of MS and if your blood test does not provide any clarity in terms of what may be causing your symptoms, your GP may decide to refer you to one.

Neurologists have to follow strict diagnostic criteria to support an MS diagnosis. This is called the McDonald Criteria and the last revision was published in 2024. The latest update to this criterion has been designed with the intention of giving more tools to neurologists that will help speed up the MS diagnosis process.

If a neurologist suspects that you have MS, they may request that you have a magnetic resonance imaging (MRI) scan on your brain and/or spine. However, that alone may not offer enough evidence for them to provide a formal diagnosis. 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 in order to rule out or confirm MS.

Prepare for medical appointments

While getting answers about the root cause of health problems may feel like a case of going backwards and forwards to your GP, preparing well for medical appointments can have a positive impact. It is worth going to these appointments with a list of questions you wish to ask and a copy of your symptom diary, if possible. Be aware that medical appointments are usually time limited, so make sure that you prioritise asking questions that you feel are the most important.

Here is a list of prompting questions for you to think about before attending medical appointments. They may help you to formulate questions that you wish to ask health professionals.

- What do I want to get from this visit?
- What do I need to say to the doctor?
- What do I need to know from the doctor?
- What is my priority for this visit?
- What am I already doing to help myself?
- How am I feeling today?
- How have I felt since my last visit, and what difficulties have I had?
- What have I achieved since my last visit, and what is my next goal?
- What else is happening in my life to affect my health?
- 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 encourage open communication with 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 ask to see a different GP within your surgery, or alternatively you could register at a different GP surgery.

If you have seen a neurological consultant and are not happy with the outcome, you can 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).

For dedicated guidance regarding any concerns you have about your healthcare, speak to your local Healthwatch team in England, the Patient Advice & Support Service Scotland, Llais in Wales or the Patient and Client Council for those who reside in Northern Ireland. They can offer you expert guidance about getting the most out of your local NHS service. You can find more details of these organisations in the Further Information section situated at the rear of this booklet.

More information

Our 'Diagnosis' Choices information booklet provides a full summary of the MS diagnosis process, including the most recent version of the McDonald Criteria. www.ms-uk.org/diagnosis-of-multiple-sclerosis-choices-booklet

We have created a useful Symptom Diary template which you can find at the rear of this booklet or on our website. Our website version

also includes guidance to help you get the most out of keeping this form of diary. www.ms-uk.org/ms-symptoms-diary

Conditions with symptoms similar to MS

People with MS can experience many symptoms which are found in a variety of other conditions. If MS has been ruled out by health professionals, you may wish to explore the possibility that one of these conditions could be the root cause of your symptoms. The following is a summary of some of these conditions and where you can find more dedicated information and support.

Fibromyalgia

Fibromyalgia, also known as fibromyalgia syndrome (FMS), is a long-term condition that causes widespread muscular pain and fatigue (3). It affects more women than men and it most commonly develops between the ages of 25 and 55. That said, people outside of this age group can still be affected.

The exact cause of Fibromyalgia is not yet known, but it is thought that changes in the way the central nervous system (CNS) processes pain messages which are carried around the body could be the most influential factor (3). Genetics may also be at play in the onset of Fibromyalgia, or it could develop as a reaction to triggers such as viral infections or trauma.

How people are affected by it varies a great deal from one person to another and from day to day. One important fact to note is that Fibromyalgia cannot be evidenced via MRI, and tests used for diagnosis include blood and urine tests and X-rays.

Treatments focus on symptom management and include medication, exercise and talking therapies (3).

Symptoms of fibromyalgia which are similar to MS include

- Fatigue
- Joint and muscle pain
- Disturbed sleep
- Bowel problems
- Headache
- Numbness and tingling in the feet and hands

More information

The UK-based charity Fibromyalgia Action UK offers a host of information and support for people affected by Fibromyalgia, including detailed information booklets and an online forum. www.fmauk.org

Functional neurological disorder (FND)

FND is a medical condition in which there is a problem with the functioning of the nervous system (4). It is also referred to as 'brain network disorder'. In FND the brain and body fail to send and receive nerve signals in the correct way which results in a variety of symptoms occurring.

Unlike MS, there are no structural indicators on conventional MRI scans that indicate FND, as the condition is caused by functional problems which disrupt how the brain works. Historically some people affected by FND have been told by health professionals that nothing was wrong with them given this absence of radiological evidence.

The approach to treating FND varies from person to person but can include physiotherapy, psychological therapies and medication.

Symptoms of FND which are similar to MS include

- Muscle spasms and spasticity
- Muscle and limb weakness
- Tremor
- Fatigue
- Sensory disturbances

More information

FND Action is a UK charity that provides a host of information and support about this condition. This includes details of the tests that are used to underpin diagnosis. www.fndaction.org.uk

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) it is a common autoimmune disease that makes the blood thicker or sticky and therefore more prone to clotting in the veins or arteries. It is diagnosed by a simple blood test and symptom analysis.

Hughes Syndrome is thought to be caused by the body producing abnormal antiphospholipid antibodies that make blood more susceptible to clotting.

This condition is treatable using blood thinning medication such as warfarin and aspirin. Drugs such as corticosteroids and

hydroxychloroquine, which are anti-malarial, can also be used to manage associated symptoms.

Symptoms of Hughes Syndrome which are similar to MS include

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

More information

APS Support UK is a charity that provides further information and support for those living with Hughes Syndrome.

www.aps-support.org.uk

Long COVID

Long COVID, sometimes referred to as post-COVID syndrome, occurs when symptoms of the COVID-19 virus last for more than 12 weeks (6). A recent review involving the Universities of Oxford and Leeds has found that in the UK almost two per cent of the population are affected by Long COVID. Just under three quarters of those affected had experienced symptoms for over 12 months (7).

While there is currently no cure for this condition, treatment focuses on symptom management and can include guidance on fatigue management, physiotherapy and psychological therapies.

Symptoms of Long COVID which are similar to MS include

- Fatigue

- Pins and needles
- Pain and aching in the joints and muscles
- Problems with memory and concentration

More information

Long Covid Support is a UK-based charity that provides news, information and support for people affected by this condition. They also offer signposting to other UK support groups situated around the UK. www.longcovid.org

Lupus

Lupus is a condition that affects the immune system. As with 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 of the body (8). It affects more women than men. Some people do not present with its typical rash and arthritis straight away, making symptoms seem even more like MS.

The exact cause of lupus is not yet known, but it is thought to be a response to viral infections, some medications, puberty, menopause and childbirth.

A rheumatologist will diagnose lupus via a series of tests such as analysis of the blood and urine. MRI and Computed Tomography (CT) scans may also be required to confirm their diagnosis.

Lupus can be treated using a range of drugs which control the condition. These include corticosteroids, immunomodulators and hydroxychloroquine.

Symptoms of lupus which are similar to MS include

- Extreme fatigue
- Joint and muscle aches, pains and weakness
- Problems with memory and concentration

More information

Lupus UK is a nationally registered charity in the UK that supports people with this condition. They offer a wide range of information and support and host an online forum. www.lupusuk.org.uk

Lyme disease

Lyme disease is an infection of the central nervous system caused by a bacteria called borrelia, which is transmitted from the bite of an infected tick (9). Ticks which carry this infectious bacterium can be found in many places such as woodlands, the open countryside and even the domestic garden. Domestic pets that go outdoors, such as dogs and cats, can transfer ticks into the home, which can then bite and infect others (9).

This condition is diagnosed via a blood test and may also be identified by the presence of an oval or circular shaped rash around the tick bite area.

Antibiotics, usually doxycycline, are used to treat Lyme disease.

Symptoms of Lyme disease which are similar to MS include

- Fatigue
- Pins and needles
- Poor balance

- Difficulty walking
- Headaches
- Muscle and joint aches and pains
- Visual problems

More information

The charity Lyme Disease UK provides detailed information about this condition, including treatment and prevention approaches. Their aim is to promote awareness of the condition and support those who are affected. www.lymediseaseuk.com

Myalgic Encephalomyelitis (ME)

ME, also known as chronic fatigue syndrome (CFS), is a complex condition which is known in the main for its common symptom of extreme fatigue. However, it impacts those affected in many different ways. These include cognitive problems, chronic pain, sensory hypersensitivity, and issues with sleep. Post-exertional malaise (PEM) is the main characteristic of ME/CFS. This is where even the most minimal exertions, mental or physical, can exacerbate symptoms.

It is still unknown what causes ME/CFS although it sometimes follows a viral infection, hence researchers believe that ME/CFS could be due to a reaction to common viruses. Other potential causes include a dysfunctional immune system and genetic susceptibility (10).

At present there is no diagnostic test for ME/CFS and therefore diagnosis relies on clinical presentations (the symptoms reported to and signs observed by a doctor). Managing this condition is focused on developing personalised care and support plans. These are aimed at symptom management, such as pacing approaches to help manage fatigue.

Symptoms of ME which are similar to MS include

- Fatigue
- Chronic pain
- Cognitive problems
- Sleep problems

More information

The ME Association is a charity based in the UK that provides a wealth of information and support for people affected by the condition. They also signpost to local support groups. www.meassociation.org.uk

Neuromyelitis optica (NMO)

NMO is a rare autoimmune condition that is also known as Neuromyelitis Optica Spectrum Disorder (NMSOD) or Devic's disease. It occurs when a person's immune system attacks the nerves in the spinal cord and eyes (11). Sometimes the attack is focused on just one of these areas of the body. NMO is very similar to MS in that it is a relapsing demyelinating condition, however, MS can affect the CNS as a whole.

What causes NMO is currently unknown, however it is thought to be a post-viral condition, and it is more common in those who are affected by other autoimmune conditions, or those who have close family members that are. Women and people of black African and Asian origin are demographics most affected by NMO (11).

NMO is diagnosed by a neurologist using a combination of clinical tests including MRI, lumbar puncture, blood and visual tests.

Treatment for NMO focuses on managing the inflammation it causes, preventing relapses and treating them when they occur. This is done

using medication including corticosteroids, immunosuppressants and monoclonal antibody drugs such as rituximab.

Symptoms of NMO which are similar to MS include

- Visual problems
- Neuropathic pain
- Muscle and limb weakness
- Muscle spasms and spasticity
- Loss of sensation
- Bladder and bowel problems

Transverse myelitis (TM)

TM is a rare condition of the CNS. Like MS it involves inflammation and is demyelinating, however TM specifically affects the spinal cord. People affected by TM will usually only experience a single episode. However, on rare occasions people can experience multiple episodes, not due to a new demyelinating event, but in the form of a pseudo relapse. This is when symptoms occur or worsen temporarily due to factors including infections or temperature changes (12).

The cause of TM is unclear, however it is thought to be due to a range of autoimmune conditions, bacterial and viral infections. To date there has been no evidence to suggest a genetic or hereditary link to developing this condition.

Treating TM focuses on symptom relief and speeding up the recovery process. Corticosteroids can be used to reduce the levels of inflammation within the spine, aiding recovery. The use of

physiotherapy is also recommended to aid rehabilitation, preferably led by a therapist with a neurological speciality.

Symptoms of TM which are similar to MS include

- Muscle and limb weakness
- Neuropathic pain
- Loss of sensations
- Bladder and bowel problems
- Muscle spasms and spasticity

More information

The Transverse Myelitis Society is a charity based in the UK who offer information and support to people affected by TM. They also extend their services to people affected by related conditions such as NMO. www.myelitis.org.uk

Vitamin B12 deficiency

Vitamin B12 helps the body to perform a number of vital functions. It plays an important role in the production and repair of DNA, assists the production of red blood cells that distribute oxygen around the body, and also aids the metabolism of fatty acids needed to maintain the myelin sheath which protects nerve fibres in the brain and spinal cord. It is also heavily involved in helping the body to release the energy provided by food that is consumed (13).

Deficiency in this most vital of nutrients can be caused by a number of factors. A diet that is low in vitamin B12 is the most obvious cause, however, conditions that affect the functions of the stomach

and intestines can reduce the body's ability to absorb it. Some medications, including proton pump inhibitors (PPIs) can also reduce vitamin B12 levels in the body (14).

A blood test is the simplest way to check if someone has low levels of vitamin B12 in their system. If deficiency is found, then further blood tests can be arranged to help medical professionals identify the root cause (14).

Treatment approaches will vary depending upon the cause of the deficiency.

If it is assumed to be related to diet, supplements can be prescribed to help bring levels back to a satisfactory level. Dietary advice will be provided to ensure that the person affected is aware of foods that are good sources of vitamin B12, these include oily fish, dairy and eggs. For non-diet related deficiency, regular injections of the drug hydroxocobalamin, a manufactured version of vitamin B12, can be prescribed. These may be required on a long-term basis.

Symptoms of vitamin B12 deficiency which are similar to MS include

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

Further information

The Brain Charity

This charity is based in the UK and provides a wealth of information and vital support for people affected by neurological conditions, both in person and online. www.thebraincharity.org.uk

Brain and Spine Foundation

For over 30 years this foundation has provided people affected by any neurological condition with support, including access to a helpline and peer support. www.brainandspine.org.uk

Healthwatch

An independent body offering important information, guidance and signposting for people looking to navigate the NHS and social care services in England. They have local offices situated around England which can be found via their national website. www.healthwatch.co.uk

Patient Advice and Support Service (PASS)

A body delivered independently by the Citizens Advice Network offering important information, guidance and signposting for people looking to navigate the healthcare services provided by NHS Scotland. www.pass-scotland.org.uk

Llais

An independent body set up by the Welsh government offering important information, guidance and signposting for people looking to navigate the health and social care services provided by NHS Wales. They have local offices situated around Wales which can be found via their national website. www.llaiswales.org

Patient and Client Council (P&CC)

Serving the people of Northern Ireland since 2009, the P&CC promote better understanding of the NHS services throughout the nation, offering information, guidance and signposting. They have local offices situated around Northern Ireland which can be found via their national website. **www.pcc-ni.net**

Symptom diary

Date	Describe your symptom. How are you affected?	Is this a new symptom? Or one you have experienced before? Is it worse than previously experienced?
eg. 01 Jul	eg. tight, stiff legs – difficult to walk	eg. I have experienced this before but not this tight/stiff

When did it start/stop?	Is the symptom constant or does it fluctuate? What makes it better or worse? (eg. heat, stress, time of day)	Score how the symptom affects you? One – not at all Five – extreme
eg. a week ago and is continuous	eg. continuous but worse in the morning	eg. two/three

About MS-UK

MS-UK is a national charity 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 MS, 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

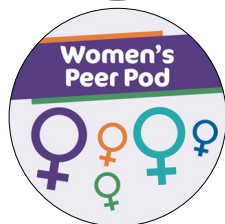
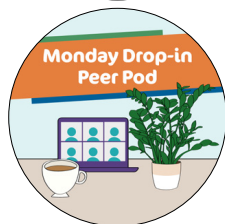
Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.
Visit [ms-uk.org/new-pathways-magazine](https://www.ms-uk.org/new-pathways-magazine)

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 [ms-uk.org/peer-support-service](https://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 for those affected by MS to stay active, connected with others and to manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. To get involved, please go to www.ms-uk.org or email register@ms-uk.org.

MS-UK 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 an accredited eLearning course that can help you do this. Visit www.ms-uk.org/ms-awareness-e-learning to find out more.

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Stay in touch

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