



MS symptoms



Multiple sclerosis information

www.ms-uk.org

Welcome to this Choices booklet about MS symptoms

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 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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MS symptoms

Multiple sclerosis (MS) can cause a variety of symptoms which can affect people differently. This booklet provides a summary of some of the symptoms more commonly associated with MS, although it is not an exhaustive list. Generally, people affected by MS will only experience a small number of these and it is rare for individuals to experience all the symptoms listed (1).

The combination of symptoms, their severity and frequency will be different for everyone. Equally, symptoms can come and go, with some being responsive to treatment, whereas others can be more difficult to manage. Outside influences can exacerbate symptoms. For example, hot weather may make fatigue worse, and an infection can cause a temporary worsening of existing symptoms.

Be in charge of your own complex health needs and sourcing the best way of dealing with them. Nobody cares about your health more than you do

It is important to remember that not every ache or pain is connected to MS and, if a new symptom persists, you should seek medical advice so that appropriate treatment can be administered, when required.

A healthy brain that functions well is very important for people

with a diagnosis of MS. The MS Brain Health initiative recommends positive lifestyle choices to keep your brain as healthy as possible, which may help to reduce your symptoms or the likelihood of new ones developing. They suggest six ways which may help you to keep your brain as healthy as possible (2).

- Keep as active as you can being active can help to preserve brain health in people with MS
- Keep your weight under control obesity is associated with higher numbers of MS lesions
- Keep your mind active protect against cognitive problems with reading, education, hobbies, artistic or creative pastimes
- Avoid smoking cigarette smoking can decrease brain volume in people with MS, as well as increase relapse rates, disability progression and cognitive problems
- Watch how much you drink excessive alcohol consumption can worsen symptoms of MS
- Continue taking other medicines that your doctor has prescribed

 other conditions such as high blood pressure, high cholesterol, heart disease and diabetes can negatively impact the MS disease course. It is important to be responsible for managing and monitoring them

Quitting drinking and smoking helped me to reduce the relapses

5

It is also important to note the growing body of evidence that underpins the role which a healthy diet and gut plays in the management of MS. This is especially significant as having a gut which is healthy, one that has a balanced bacterial composition, has been found to minimise the leakage of bacteria from the gut into the bloodstream. The effect of bacterial leakage is an increase in inflammatory influences on the central nervous system, which can lead to disease progression (3).

More information

Our 'Diet and Supplements' Choices booklet provides further reading on the link between our diet and MS, including more information about gut health and the specific diets that have been developed and used by people with MS, with positive results. www.ms-uk.org/choices-diet-and-supplements-content

Below you will find a summary of the more common symptoms experienced, with a brief explanation of how they may affect you. If you are experiencing any of these symptoms and they are causing you problems, in the first instance you should consider contacting your MS nurse or GP. You could also ask to be referred to the appropriate specialist if necessary.

Balance

The National Institute for Health and Care Excellence (NICE) guidelines on diagnosing MS states that problems with balance are one of the most common clinical presentations of MS (4).

Areas of the brain involved in balance and movement can be affected by the inflammation associated with MS. Messages from the brain to the body can be disrupted, resulting in a loss of coordination. There are no specific medications for balance. However, it is important to make sure that any balance issues are not being caused by something else. For example, relating to another symptom or an inner ear infection. Other MS symptoms that can cause balance issues include muscle tightness (spasticity and spasms), muscle weakness, fatigue, tremor, numbness and other altered sensations, pain and visual problems.

It is important to note that not all balance problems are MS-related. However, MS can also cause dizziness and vertigo.

For some people, problems with balance are short-term, while for others they may last longer. If the balance problem is the result of another symptom, once that is managed more effectively, it could be that your balance improves. A referral to a neurophysiotherapist can help to investigate the root cause of balance issues and identify suitable remedies.

For dizziness and vertigo, a referral for vestibular rehabilitation may be offered. This is an exercise-based programme which is used by physiotherapists to help people affected by balance issues (5).

More information

Our 'Exercise' Choices booklet provides more information about exercise and how it can help with balance and coordination problems.

www.ms-uk.org/choices-exercise-content

Bladder and bowel

Bladder and bowel problems are common and can impact us at any stage of our lives. However, they are a particularly regular and uncomfortable problem for people with MS. It is a highly sensitive and personal issue for most people who are affected but there is no need to feel embarrassed if you are experiencing problems. Talking to your GP and MS nurse is the first step to addressing symptoms and finding suitable solutions.

> This is a bit of a taboo subject, however, there are solutions out there. Talk to your MS nurse or GP who can refer you to someone who is a specialist in this area

The most common bladder symptoms include

- · Urgency the need to 'go' with little or no warning
- Frequency having to 'go' to the toilet often
- Hesitancy difficulty in passing urine
- Retention feeling of not emptying properly

Many people experience a combination of these symptoms. Occasionally, control of the bladder can be lost which can lead to leakage. This is otherwise known as incontinence.

Similarly, many people with MS may experience bowel problems such as constipation and difficulty emptying the bowel. The other problem area is incontinence and lack of control over the bowel opening. There are various medications and treatments available to help with bladder and bowel issues (6) (7).

Your GP and MS nurse can also refer you to a continence service to help you find ways to manage bladder and bowel problems. In some areas self-referrals may also be possible.

More information

Our 'Bladder and Bowel' Choices booklet offers more information about symptoms, causes, treatments and therapies. www.ms-uk.org/bladder-and-bowel-choices-leaflet

Cognition

Around 50 per cent of people diagnosed with MS will experience cognitive dysfunction to some degree (8), ranging from fairly mild on a day-to-day basis to an increased worsening during a relapse. Initially, people may not realise that their cognitive problems are associated with their MS.

Writing everything down and having white boards spotted around in easy to see areas to help prompt and remind me of things helps a huge amount, also the reminder setting on my iPhone is a life saver! The most common problems affect memory, information processing, problem solving, word-finding and concentration.

Symptoms can become more pronounced if you are tired, upset or anxious and sometimes it is difficult to distinguish between cognition, depression and fatigue. It is important you talk to your GP and MS nurse about what you are experiencing.

NICE have stated in their guidelines for the management of MS that people with persistent memory or cognitive problems should be considered for referral to both an occupational therapist and neuropsychologist to assess and manage these symptoms (4).

Speak to your MS nurse about whether you would benefit from such a referral.

More information

Our Cognition Choices booklet provides more information about how people with MS may be affected by cognitive issues, with a summary of relevant treatment, therapies, tips and tricks.

www.ms-uk.org/cognition-choices-content

Fatigue

Fatigue is more than tiredness. It is a feeling of complete exhaustion and is another common symptom of MS. It is an invisible symptom that is difficult to describe and while not obvious to other people, it can be quite difficult to manage. There are a number of ways in which people learn to live with their fatigue and find ways to manage it effectively (4).

The NICE guidelines for the management of MS state that causes for fatigue, other than MS, should be considered to ensure that appropriate treatment is provided. For example, any issues with sleep, side effects

A fatigue management course helped me unlock and understand what fatigue is, how I can split my energy better during the day, how I can incorporate activity back into my life and improve satisfaction

of medicines and illnesses such as infections, anemia and thyroid dysfunction can aggravate fatigue (4).

Sometimes a drug called amantadine may help ease symptoms of fatigue. Other things that may help are gentle exercise like yoga, cognitive behavioural techniques, and mindfulness, all of which are suggested in the NICE guidelines (4).

Some therapy centres offer fatigue management courses. It is also worth asking your GP or MS nurse if this is something available locally to you via the NHS.

> I try to ensure I balance myself better with not overdoing things, constantly re-evaluating what I need to do to, what has to be done, or what can wait

More information

Our 'Fatigue' Choices booklet is a good resource to learn more about how this symptom can affect MS, with details of the various treatments and therapies that can be used to lessen the impact.

www.ms-uk.org/choices-fatigue-content

Foot drop

Foot drop is a symptom experienced by some people with MS and is caused by a weakness in the ankle that causes the foot to drag along the ground or hang down when walking. This can be due to the nerve pathways that connect the lower legs to the brain being compromised. People who experience foot drop are more vulnerable to tripping and falling.

Treatments for foot drop may include

- Strengthening exercises as recommended by a physiotherapist
- The use of an ankle splint to hold the foot in a rigid position. A referral to an orthotist would be required
- Functional electrical stimulation (FES) uses small electrodes either stuck to the surface of the skin or implanted under the skin, to deliver small electrical impulses to activate the muscles and support the foot's movement into a more natural position for walking. Studies show positive change to walking speed and functional walking ability (9). The FES device is activated by a pressure sensor worn in the shoe. NICE have confirmed that FES can be used as a routine treatment option for patients who experience foot drop (10). Access to FES is therefore available via the NHS with referrals from your GP, MS nurse or neurologist being required

More information

Our online activities portal provides access to a foot drop specific exercise worksheet which you may find helpful.

www.ms-uk.org/online-activities

Temperature sensitivity

A distinctive aspect of MS is that those affected by it are especially sensitive to changes in temperature, whereby some symptoms worsen temporarily due to a change in the body's temperature. Temperature sensitivity episodes are known as pseudoexacerbations or pseudo-relapses and can be triggered by very small changes in the core body temperature, from both heat and cold exposure. However, reported rates of cold sensitivity in people with MS are generally lower than that of heat sensitivity (11).

It follows that some people with MS may experience a temporary worsening of symptoms due to the effects of heat stress (12) – for example during warm weather, or while taking a bath or a sauna. You might feel fatigued, or experience an increase in pain, or feel your cognitive symptoms are worsening. An increase in body temperature can also lead to Uhthoff's Sign, a temporary phenomenon that commonly impacts visual symptoms, but is also thought to aggravate other existing symptoms (13). See the 'Sensory' section for more details.

If you are sensitive to heat, there are a number of strategies to help keep cool in hot weather including taking regular cold drinks, wrapping a damp towel around your neck or by wearing a cooling scarf. Putting ice in a tray of water in front of a fan to create an airconditioning effect can also help. While less regularly reported, cold temperatures can exacerbate MS symptoms, leading to a temporary worsening of pain, stiffness and spasticity (14). A review of case studies that looked into the effect of decreases in core temperature in people with MS found that the common pseudo-exacerbations were impaired cognitive and sensory functions (11).

Although uncomfortable, the impact of temperature-sensitive episodes is temporary and will resolve when the body returns to its normal core temperature.

Mobility

Loss of mobility is defined as any limitation of movement caused by different factors, such as lack of motor coordination, muscle weakness, spasticity (muscular rigidity and spasms), or balance problems and fatigue, all of which are associated with MS.

Mobility difficulties can cause general problems with day-to-day living and make tasks such as getting in and out of a car and going up and down stairs difficult and frustrating.

Get an MS occupational therapist to work with you. These highly skilled professionals will be able to help you regain more independence Depending on what is causing the mobility issue, various treatments may be available, from spasticity medications and fatigue management, to seeing a physiotherapist and learning about exercises and stretches that may help. Exercise is encouraged to keep the muscles and limbs moving.

NICE guidelines suggest that all those who experience mobility problems should have access to an assessment by a rehabilitation specialist and a physiotherapist with expertise in MS (4).

Fampridine is no longer recommended in the NICE guidelines to help improve walking speed, as it was found to not be a costeffective treatment. However, it has been approved for use for this purpose by the NHS in Scotland and Wales for people who have an Expanded Disability Status Scale (EDSS) score between 4 and 7. For those who reside in England and Northern Ireland it can be paid for privately, but you will need a private prescription from a neurologist.

More information

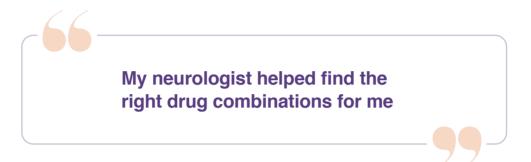
Our 'Exercise' Choices booklet provides more information about exercise and how it can help with managing mobility. www.ms-uk.org/choices-exercise-content

Pain

Pain is often described as a stabbing, burning, tingling or pins and needles feeling. It's subjective and no two people will experience it in the same way.

There are two main types of pain that can occur – neuropathic and musculoskeletal. If the cause of the pain is found to be neuropathic,

medication may be prescribed. If it's musculoskeletal you may be referred to a physiotherapist.



Pain can be challenging to manage, but there are many medications, therapies and management strategies available.

More information

Our Pain Choices booklet explores the issue of pain and MS in more detail, including information about pain management and where to find additional support.

www.ms-uk.org/choices-pain-content

Sensory

The impairment of sensory perception includes the loss of feeling in limbs and other areas. The sensations can include tingling, a crawling feeling over the skin, numbness or tightness, and sometimes pain. The medical terms for these uncomfortable abnormal sensations are dysesthesia and paresthesia. These feelings are classed as neuropathic pain symptoms.

A sensory symptom experienced by many people with MS is the

feeling of an 'electrical rush' radiating from the neck and down the spine, when the head is flexed towards the chest. This is known as Lhermitte's Sign and was named after the French neurologist who first described it in 1924. It is thought to be a signal that the nerves are inflamed and flexing the head causes this transient feeling.

Lhermitte's Sign is associated with MS, sometimes even before diagnosis, but is not sufficient in itself to confirm a diagnosis of MS as it is associated with other conditions, too. It is important to talk to your GP if you are experiencing this sensory symptom to rule out any other causes, such as injury to the neck.

Another sensory symptom is Uhthoff's Sign, also known as Uhthoff's Phenomenon, which studies have shown impacts between 60 and 80 per cent of people with MS (11). The symptom takes its name from Wilhelm Uhthoff, a German ophthalmologist, who first described it in 1890.

Uhthoff's Sign is a temporary worsening of symptoms – often visual disturbances, but sometimes motor or sensory symptoms – caused by a rise in body temperature, for example while exercising or taking a hot bath. The visual symptoms may present as double vision, a blurring of vision, and loss of colour or a 'greying-out' of vision.

If you are affected by Uhthoff's Sign it is essential that you stop exercising or move away from the heat source and cool the body down. This could be by consuming a cold drink or using a fan. Once your body temperature returns to normal, Uhthoff's Sign will slowly dissipate.

'Banding' is a sensory symptom where it feels as if there is a tight elastic band around the ribs, or one side of the torso. Sometimes it is called the 'MS hug', although it can also affect feet and hands, as if you are wearing gloves or socks. Banding associated with MS can be treated with pain medication and, although uncomfortable, most people find it will pass without needing treatment. Some people find that wearing tight clothing, such as a sports vest or elasticated gloves or socks, actually helps alleviate the discomfort. Be careful to ensure you are not restricting your blood circulation.

If you experience tightness across the chest, contact your GP.

Speech and swallowing

Problems with speech and swallowing can be a symptom of MS for some people. The most common speech disorders include dysarthria, dysphonia and dysphasia, all of which impact speech in different ways. Fatigue can also affect the voice, making it weak, such as towards the end of the day.

The medical term for swallowing difficulties is dysphagia. Studies have found that around a third of people with MS experience

I relapsed a long time ago and my swallowing became a problem. I was seen by a speech therapist who gave me mouth exercises. This solved the problem. I still get the odd problem. I just ensure I eat my food slowly and don't rush it swallowing difficulties to some degree (15). This can be caused by damage affecting the coordination of the various muscles involved in swallowing. The result can be difficulty chewing or episodes of coughing or choking when eating and drinking.

Difficulties with speech and swallowing can develop at any stage of your MS journey. A referral to a speech and language therapist is recommended to help with symptom management and various strategies can be provided to help reduce problems. Ask your GP or MS nurse to refer you.

More information

Our Speech and Swallowing Choices booklet delves deeper into the ways in which people with MS are affected by speech and swallowing problems, and provides information about treatments and self-management tips.

www.ms-uk.org/choices-speech-and-swallowing-content

Spasms and spasticity

Spasticity is a symptom where the signals from the brain are interrupted, and the muscle remains in its shortened, contracted state. This causes the affected muscle to feel stiff or tight and to be resistant to movement. The degree of spasticity will vary from person to person and can greatly impact on many activities. Nevertheless, spasticity can be successfully managed. Sometimes spasticity is triggered by infections or bladder and bowel problems. Left untreated, spasticity can lead to complications such as frozen or immobilised joints and pressure sores.

Spasms are different to spasticity in that they are a sudden, uncontrolled movement caused by muscles moving in an involuntary way. Most spasms occur in the legs and arms, and less commonly the throat. Spasms can be painful and lead to interrupted sleep. The same drug treatments for spasticity are offered to help reduce spasms.

There are many ways in which spasms and spasticity can be alleviated. Drug treatment may be offered by your medical team, with the first line drug being baclofen, and gabapentin being offered as a secondary option. These can also be prescribed as a combined solution (4). Tizanidine and dantrolene are among other possible drug treatments that can be used to manage spasms and spasticity.

The NICE guidelines also suggest being referred to a specialist spasticity service for further treatment. This could include seeing a physiotherapist and/or occupational therapist for specific exercises and stretches which may help (4).

Do regular exercise (even when you don't feel like it). It can be really helpful for many symptoms like stiffness and fatigue

There are other treatments and therapies that can be used to manage spasms and spasticity, such as Botox, cannabis-related products (Sativex, CBD) and complementary therapies including massage, reflexology and acupuncture.

An MS nurse with a holistic perspective has published information

about natural treatments for MS spasms. These include exercise, magnesium (either by tablet/spray/powder, or by rubbing directly into the skin), CBD oil and electrotherapies (16).

More information

Our 'Spasms and spasticity' Choices booklet provides further reading on this subject, including information about the different treatments and therapies that are used to manage the impact on people with MS. www.ms-uk.org/spasms-and-spasticity

Our 'Exercise' Choices booklet provides more information about exercise and how it can help with managing spasms and spasticity. www.ms-uk.org/choices-exercise-content

Tremor

Many people with MS may experience tremors, with studies estimating between 25 and 58 per cent being impacted. Tremors involve parts of the body being affected by uncontrolled movements, shaking or trembling. Tremors in people with MS most commonly affect the arms but they can also impact the head, neck, vocal chords and trunk (17).

There are many different types of tremor and these can impact in a variety of ways. For people with MS the intention and postural tremor are the ones most commonly experienced and can be exacerbated by stress, fatigue and extremes of temperature.

An intention tremor is an involuntary movement in the upper limbs which often worsens when reaching for an object or if the limb is guided to move towards a particular body part. The postural tremor occurs when your muscles are working to maintain a static position, against the forces of gravity, such as when out-stretching an arm (18).

For people with MS, tremors can be associated with the term 'ataxia' as this is the medical name given to some disorders that affect coordination and balance. More specifically the type of ataxia associated with MS is known as 'acquired ataxia' given it has developed due to trauma of the brain or nervous system (19).

Currently, NICE have not made any recommendations for pharmacological management of ataxia and tremors in people affected by MS, citing lack of sufficient evidence available. However, they have developed a recommendation to support future research in this area (4).

There are some drug therapies that have been used to treat tremors in MS 'off label', but with limited impact. These include beta blockers, propranolol and gabapentin, while in other cases, studies have shown that Botox has been effective in tremor management for people with MS (17).

For many, tremors can be managed practically with a few simple lifestyle changes. Your MS nurse or GP can refer you to an occupational therapist who can offer practical advice in managing tremor. A physiotherapist can also set up an exercise programme to increase strength in muscles which are weaker and may be contributing to tremor severity. Limb cooling and weighted bracelets may also offer some relief.

Surgical treatments such as deep brain stimulation (DBS) may be offered to people with MS who experience severe issues with tremors that are not responding sufficiently to any drug or practical treatments and therapies. A recent systematic review and meta-analysis of over 1,000 articles which looked at the benefits of DBS in treating MS related tremors concluded that improvement was shown in MS patients after treatment (20). DBS involves inserting fine needles into the brain via small holes in the skull. Electrodes are then placed within the targeted area of the brain. Wires from the electrode are threaded under the skin of the chest and are connected to a pulse generator placed inside the body. An electrical current sent from the pulse generator helps to control the tremor (21).

Visual symptoms

There are several symptoms that can affect the vision of people with MS. The most common symptom is optic neuritis – inflammation of the optic nerve, which is also one of the more common first symptoms that can lead to a diagnosis of MS. Optic neuritis is sometimes treated with steroids to help reduce the inflammation.

Other problems can include

- Diplopia (double vision) often an early symptom of MS but can also occur as part of a relapse of MS where steroids may help
- Nystagmus rhythmical oscillations of the eyeball which sometimes goes unnoticed by the person, but is obvious to others. A difficult symptom to treat but occasionally the drugs gabapentin and memantine may be offered (22)

Get your eyes checked by an optician and speak to your MS team

More information

Our 'Visual symptoms' Choices booklet offers further information on this topic, including ways to support eye health. www.ms-uk.org/choices-visual-symptoms-content

Pseudobulbar affect

The pseudobulbar affect (PBA) is a symptom of MS and other neurological conditions. It can present itself in episodes of uncontrollable, exaggerated laughing and/or crying or even episodes of anger. Those affected often report that PBA usually happens suddenly and often at inappropriate times.

PBA can happen without any kind of emotional trigger and is often associated with cognitive impairment and mood problems. It is also known as emotional lability, or emotional disinhibition and is thought to be caused by damage that affects the specific parts of the brain that control emotions.

The scientific theory behind PBA is that damage to the brain, such as in the form of lesions, disrupt the nerve pathways from different areas of the brain, generally the frontal and temporal cortices, to the cerebellum, which is the part of the brain that ensures emotional responses are appropriate. The cerebellum acts as a 'gate control' for these responses and when these pathways are compromised, the result can be socially inappropriate or situationally disproportionate emotional expression (23).

PBA is often a difficult symptom to understand and manage

and can be quite distressing. It can present with a person having an outburst of uncontrollable laughter, which can mask actual tears. The person may not realise that they are crying inside, yet it comes out as laughter on the surface. A person's outward responses may not match how they feel inside. This can be misinterpreted by others around them and real emotions misunderstood.

A small study suggests that PBA is likely to be more common in women living with secondary progressive MS (SPMS). This study also concluded that many people do not discuss this symptom with their MS team, suggesting that more awareness is needed (24).

Sometimes PBA is mistaken as depression, but both are separate symptoms of MS. They can be experienced in isolation or simultaneously. PBA is distinguishable from depression due to its sudden onset. It also doesn't last long.

In many cases, the symptoms of PBA often go undetected and are therefore not treated appropriately. It may be that the person experiencing an episode of PBA doesn't realise this is a symptom of MS, or it could be their MS team is not asking about these symptoms.

In order to treat PBA, tricyclic antidepressants and selective serotonin reuptake inhibitors (SSRIs) such as citalopram or sertraline can be prescribed. NICE guidelines state that the tricyclic antidepressant amitriptyline should be considered to treat people affected by MS who report issues with emotional liability behaviours such as involuntary laughing or crying (4).

Hints and tips...

We asked the MS community what advice they would give to others on how to manage MS symptoms and here is what they said.

- I now make it a routine and part of my daily life to keep lists and reminders, and they are a tool that I can use to keep some sense of control over what I can do
- I'd like to say best thing is to listen to your body and I think that is part of it but I also think this goes with pushing yourself and being positive
- Look for the can rather than can't. Understand your limitations and push to them rather than give up
- Exercise helps with strength. Massage helps with relaxation. Oxygen therapy helps with strength
- Yoga, meditation and breathing are rejuvenating, energising, maintain flexibility in joints, improve wellbeing and positivity, and are calming
- Make sure you look after yourself and don't feel guilty for having rest days or taking naps. Also do not to be scared to ask for help
- Research, read, and find out as much as you can from other MSers
- Find small helpful ways of making your life easier and try to build them as new habits

What is a relapse?

Sometimes a temporary onset, or worsening of symptoms, is actually a relapse, however it can often be difficult to determine if you are having one. Therefore, it is important to let your GP and MS nurse know if you think you are experiencing a change in symptoms so they can determine if it is a clinical relapse and if treatment is required. Relapses can often be treated, most commonly, with a course of steroids (4).

According to NICE guidelines a relapse can be diagnosed if 'The person with MS has developed new symptoms or has a worsening of existing symptoms, and these symptoms have lasted for more than 24 hours in the absence of infection or any other cause after a stable period of a least one month.' (4).

Do one thing at a time and take each day as it comes rather than stressing about the past or the future

We have created a document you can use called 'Am I having a relapse?' which provides a list of questions to ask yourself. These questions may help you to determine whether what you are experiencing is a clinical relapse or not. It is important to rule out other possibilities first, such as an underlying infection which can exacerbate certain symptoms greatly.

This document can be downloaded from our website and a template can also be found towards the end of this booklet.

More information

MS-UK, Am I having a relapse? www.ms-uk.org/wp-content/uploads/2022/09/Am-I-having-arelapse%EF%80%A5.pdf

Use me for your notes

Symptom diary

If you are experiencing new symptoms, or a change in your current symptoms, it is important to inform your MS nurse and/ or GP to discuss them. By writing down and describing your symptoms and how they affect you, whether it is a new symptom or one previously experienced, you will have everything to hand, which will help medical professionals build a bigger picture of your health issues. A diary should include vital information such as when did the symptom start/stop, does it fluctuate and do certain things make it better or worse.

We have a downloadable symptom diary accompanied by a useful guide, available on our website. You may find this resource useful to help you keep track of any new symptoms and how they are affecting you. This may help you to explain them in detail to your medical professionals, reflecting any patterns that may be emerging.

More information

Downloadable symptom diary template and guide www.ms-uk.org/symptoms-diary

The following is a sample symptom diary template.

Symptom diary

Date	Describe your symptom. How are you affected?	Is this a new symptom? Or one you have expereinced before? Is it worse than previously expereienced?
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 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

- NHS. Multiple Sclerosis Symptoms. Last reviewed March 2022, Accessed March 2023.
 www.nhs.uk/conditions/multiple-sclerosis/symptoms
- (2) MS Brain Health. Six ways to lead a brain-healthy lifestyle. Accessed March 2023. www.msbrainhealth.org/people-with-ms/ six-ways-to-lead-a-brain-healthy-lifestyle
- Medical Sciences, The Gut Microbiome in Multiple Sclerosis: A Potential Therapeutic Avenue, Kirby et al, 2018 September; 6(3): 69. Accessed March 2023.
 www.ncbi.nlm.nih.gov/pmc/articles/PMC6163724
- (4) National Institute for Health and Care Excellence (NICE). Multiple sclerosis in adults: management [NG220]. Published June 2022. Accessed March 2023. www.nice.org.uk/guidance/ng220
- (5) Chartered Society of Physiotherapy. Vestibular rehabilitation. Last reviewed July 2017. Accessed March 2023. www.csp.org.uk/ publications/physiotherapy-works-vestibular-rehabilitation
- (6) National Institute for Health and Care Excellence (NICE). Urinary incontinence in neurological disease: assessment and management [CG148] Pub-lished August 2012. Accessed March 2023. www.nice. org.uk/guidance/cg148/ifp/chapter/About-this-information
- (7) National Institute for Health and Care Excellence (NICE). Faecal incontinence in adults; management [CG49] Published June 2017. Accessed March 2023. www.nice.org.uk/guidance/cg49/ifp/ chapter/About-this-information

- (8) Very well health. An overview of cognitive impairment in multiple sclerosis. Updated March 2021. Accessed March 2023. www.verywellhealth.com/cognitiveimpairment-in-ms-2440794
- (9) Science Direct. Effectiveness of functional electrical stimulation on walking speed, functional walking category, and clinically meaningful changes for people with multiple sclerosis. Street T, Taylor P, Swain I. Published Dec 2014. Accessed March 2023. www.sciencedirect.com/science/article/abs/pii/ S0003999314012817
- (10) National Institute for Health and Care Excellence (NICE). Functional electrical stimulation for drop foot of central neurological origin [IPG287]. Pub-lished January 2009. Accessed March 2023. www.nice.org.uk/guidance/ipg278/informationforpublic
- (11) National Library of Medicine. Temperature sensitivity in multiple sclerosis: An overview of its impact on sensory and cognitive symptoms. Christogianni A, Bibb R, Davis SL, Jay O, Barnett M, Evangelou N, Filingeri D. Pub-lished September 2018. Accessed March 2023. www.ncbi.nlm.nih.gov/pmc/articles/PMC6205043
- (12) National Center for Biotechnology Information (NCBI). The effects of heat stress on physical functioning in persons with multiple sclerosis. A Romberg et al. Published May 2012. Accessed March 2023. www.ncbi.nlm.nih.gov/pubmed/22647586?dopt=Abstract
- (13) Healthline. Uhthoff's Phenomenon: Understanding Overheating. Last re-viewed January 221. Accessed March 2023. www.healthline.com/health/multiple-sclerosis/ uhthoffs-phenomenon

- (14) MS Nurse Pro. Winter and its impact on people with MS. Published March 2023. Accessed March 2023. www.msnursepro.org/blog/winter-impact-ms
- (15) National Center for Biotechnology Information Prevalence of dysphagia in multiple sclerosis: a systematic review and metaanalysis. XL Guan et al. Published: May 2015. Accessed March 2023. www.ncbi.nlm.nih.gov/pubmed/25647290
- Mirandasmsblog. Natural treatments for MS spasms.
 Published: April 20 2016. Accessed March 2023.
 www.mirandasmsblog.com/2016/04/20/natural-treatmentsfor-ms-spasms
- (17) National Center for Biotechnology Information (NCBI). Understanding Tremor in Multiple Sclerosis: Prevalence, Pathological Anatomy, and Phar-macological and Surgical Approaches to Treatment. A. Labiano-Fontcuberta. Published 14 Sept 2012. Accessed Sept 2020. www.ncbi.nlm.nih.gov/pmc/articles/PMC3500135
- (18) National Tremor Foundation. What is Tremor? Accessed March 2023. www.tremor.org.uk/what-is-tremor
- (19) NHS. Health A to Z. Ataxia. Last reviewed April 2021. Accessed March 2023. www.nhs.uk/conditions/ataxia
- (20) ScienceDirect. Deep brain stimulation for multiple sclerosis tremor: A systematic review and meta-analysis. A Zali et al. Published November 2021. Accessed March 2023. www.sciencedirect.com/ science/article/abs/pii/S221103482100523X

- (21) National Institute for Health and Care Excellence. Deep brain stimulation for tremor and dystonia (excluding Parkinson's disease) [IPG188]. Published August 2006. Accessed March 2023. www.nice.org.uk/guidance/ipg188/chapter/2-The-procedure
- (22) Journal of Neuro-Ophthalmology. Vol 40 Issue 2. Gabapentin and Me-mantine for Treatment of Acquired Pendular Nystagmus: Effects on Visual Outcomes. E. Nerrant et al. Published June 2020. Accessed March 2023. www.journals.lww.com/jneuroophthalmolo-gy/Abstract/2020/06000/Gabapentin_and_ Memantine_for_Treatment_of_Acquired.11.aspx
- (23) National Library of Medicine. Pseudobulbar affect: prevalence and man-agement. Ahmed A, Simmons Z. Published November 2013. Accessed March 2023. www.ncbi.nlm.nih.gov/pmc/articles/PMC3849173/
- (24) National Library of Medicine. Pseudobulbar affect in multiple sclerosis patients. Vidović V, Rovazdi MČ, Kraml O, Kes VB. Published June 2015. Ac-cessed March 2023. www.pubmed.ncbi.nlm.nih.gov/26415311

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