Choices

MS symptoms

Multiple sclerosis information

www.ms-uk.org
Welcome to this Choices leaflet about MS symptoms...

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

This Choices leaflet 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 see a box with an icon like this, it is a quote directly from someone affected by multiple sclerosis.
MS symptoms

Multiple Sclerosis (MS) causes different symptoms in different people at different times. This leaflet explains some of the more common symptoms and is not intended as an exhaustive list. Most people will only experience a small number of these. The combination, severity and frequency will be different for everyone.

Symptoms can come and go; some are much more responsive to treatment and others can be more difficult to manage.

Outside influences can exacerbate symptoms – hot weather may make fatigue worse and an infection can cause a temporary worsening of existing symptoms, or give rise to a symptom previously not experienced.

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.

New symptoms may not always be down to your MS. It is important to remember that not every ache and pain is connected to MS and, if a new symptom persists, you should seek medical advice.

It is also important to acknowledge that some people have found that it is possible to help reduce the likelihood of these symptoms from occurring by making adjustments to lifestyle. For instance, listening to your body, manage stress levels, sleep patterns, adjustments to diet, exercise (1).
Below are some of the more common symptoms experienced, with a brief explanation. 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 even your GP. You could also ask to be referred to the appropriate specialist if necessary. Most symptoms can be treated.

**Balance**

In some people with MS, problems with balance can cause unsteadiness, clumsiness, and affect limb movement and posture.

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.

Muscle spasms, fatigue, tremor, numbness and neuropathic pain in the legs can also cause balance problems, as walking becomes more tentative. See the relevant sections below for more information on these. Once these are managed any balance issue may be eased.

For some people, problems with balance are short-term, for others they may last longer.

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.

If muscle weakness is affecting you, your MS nurse can refer you to a neuro-physiotherapist who can develop an exercise programme to assist you in addressing this.
Bladder and bowel function

Bladder problems are one of the most common symptoms in MS. In fact, problems with the bladder are common, whether a person has MS, or not. There is no need to feel embarrassed, and talking to your GP and MS nurse, is the first step to addressing this symptom.

Bladder problems tend to fall into four areas

• Urgency – the need to ‘go’ with little or no warning
• Frequency – having to ‘go’ more than eight times per day or hesitancy
• Finding emptying the bladder difficult
• Retention – you can empty the bladder, but have a feeling of incompleteness

Many people experience a combination of these symptoms.

There are medications and treatments available to help with bladder issues (2). Your GP and MS nurse can also refer you to a continence advisor (3) to help you find ways to deal with bladder problems.

Many people with MS will experience bowel problems to some degree – constipation and difficulties emptying the bowel are the most common. The other problem area is incontinence and lack of control over the bowel opening.

Again, a referral to a continence advisor will help to find ways in which to deal with problems in all these areas.
Cognition

Almost half of people with MS will have cognitive problems (4). These will range 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.

The most common problems affect memory, information processing, problem solving, word-finding and concentration. There are a number of things you can do to manage these such as

- Creating aide memoirs
- Using technology
- Avoiding jobs which need concentration when fatigued or stressed

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.

The National Institute of Care Excellence (NICE) stated in their guidelines for the management of MS (5), that people with persistent memory or cognitive problems are considered for referral to both an occupational therapist and neuropsychologist to assess and manage these symptoms.

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

Fatigue is more than tiredness, it is a feeling of complete exhaustion and a common symptom of MS. It is an invisible symptom that is difficult to describe and whilst 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.

There are a number of ways in which people manage their fatigue (5). Initially, other things should be considered to make sure fatigue isn’t being caused by anxiety, depression, anaemia, thyroid disease, or even difficulties with sleeping.

Sometimes a drug called amantadine may help ease symptoms of fatigue. Other things that may help are gentle exercise like yoga, cognitive behavioural therapy (CBT) and mindfulness. All of which are suggested in the NICE guidelines section on easing the symptoms of MS (5).

Some MS therapy centres offer fatigue management courses. It is worth asking your GP or MS nurse if this is something offered within your hospital trust.

Energy is a limited resource. Manage your use of it carefully. One big effort in a day is enough – two is too many and three is setting yourself up to fail.
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. People who experience foot drop are more vulnerable to tripping and falling.

Different treatments 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
- Using functional electrical stimulation (FES). 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 (6). The FES device is activated by a pressure sensor worn in the shoe. A physiotherapist referral would be required
Heat sensitivity

Some people with MS experience a temporary worsening of symptoms in heat (7) – for example during warm weather, or while taking a bath. You might feel fatigued, or experience an increase in pain, or feel your cognitive symptoms are worse. A change in body temperature can also give rise to Uhthoff’s Sign – causing blurred vision. See the ‘Sensory’ section for more details.

Although uncomfortable, such symptoms are temporary and will resolve when the body is cooled down.

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, and putting ice in a tray of water in front of a fan to create an air-conditioning effect.

Mobility issues

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), 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.

"Take the advice from the experts, I was too stubborn to use my sticks so I had loads of falls."
Depending on what may be attributing to the mobility issue, there may be various treatments available, from spasticity medications and fatigue management, to seeing a physiotherapist and learning about exercises and stretches that may help.

Fampridine was licensed to help improve walking speed, but is not recommended in the 2014 NICE guidelines for the treatment of MS (5) as it was found to not be a cost effective treatment.

It can be paid for privately with a private prescription that needs to be obtained from a neurologist.

**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.

Mindfulness helps maintain equanimity in the face of fluctuating symptoms and the uncertainties of MS.
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 term for these uncomfortable, abnormal sensations is dysesthesia or paresthesia. These feelings are classed as neuropathic pain symptoms.

Another sensory symptom 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.

Lhermitte’s Sign 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. 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 associated with heat fatigue is Uhthoff’s Phenomenon or Uhthoff’s Sign. This 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 vision or a ‘greying-out’ of vision.

The symptom takes its name from Wilhelm Uhthoff, a German ophthalmologist, who first described this symptom in 1890.

Uhthoff’s Sign can be worrying, but if it happens stop exercising or move away from the heat source, and cool the body down with a cold drink or fan. Once you are at normal body temperature, Uhthoff’s sign will slowly abate.
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.

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

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.

Speech and swallowing

Speech and swallowing disorders can arise as a symptom of MS for some people. Speech disorders include dysarthria – slurring of speech due to weakness or lack of coordination in the muscles used in speech and dysphagia – swallowing difficulties.

Difficulties with speech can develop at any stage. However, they are more common in the later stages of the condition.

Studies have found that around a third of people with MS experience swallowing difficulties to some degree (8). 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.

If swallowing problems are more advanced and eating is putting you at risk, nutrition can be provided through a procedure called percutaneous endoscopic gastrostomy (PEG). A PEG is a feeding method whereby a small tube is inserted directly into the stomach through the abdominal wall.
This helps to ensure sufficient nutritional intake and reduces the risk of aspiration, where food can get into the lungs, causing chest infections.

If you are experiencing these symptoms, contact your MS nurse who can refer you to a speech and language therapist.

**Spasticity and spasms**

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.

There are many ways in which spasticity can be alleviated (5). Drug treatment may be offered by your medical team. The most commonly prescribed are baclofen, dantrolene and tizanidine. They all help to relax the muscles. In some cases people may find the drugs are not effective, or cause unwanted side effects. The NICE Guidelines (5) 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.

In some cases where the drug treatments may not be effective, Botox may be considered. Botox is injected directly into the affected muscle to help reduce the tightness caused by spasticity.
Sativex is a cannabis based spray that may help reduce spasticity. It is not generally available on the NHS. For more detailed information, see our Choices leaflet, Cannabis and MS.

Spasms are different to spasticity in that, although they involve similar muscle contractions they can come on very suddenly, and relax just as suddenly. 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 spasm.

An MS nurse with a holistic perspective has written about other suggested ways in which spasms can be managed. They are exercise, magnesium (either by tablet/spray/powder, or by rubbing directly into the skin), CBD oil and TENS machine (9).

Many people with MS use other complementary therapies to help manage spasm too. A combination approach to treating spasms is often a more preferred option.

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

**Tremor**

Many people with MS may experience tremor in some way. There are different types of tremor; for some it may be very mild and only noticeable by the individual. For others it may be difficult to manage and incredibly disabling.
Intention tremor is the most commonly experienced type. This is involuntary and a movement that is uncontrolled. Intention tremor in the upper limbs often worsens when reaching for an object. This can be exacerbated by stress and also fatigue.

For mild tremor, adjustments in posture such as holding an arm closer to your body when moving a cup to your mouth, can help with the stability of the movement.

Your MS nurse or GP can refer you to an occupational therapist who can offer practical advice in managing tremor – perhaps suggesting aids or appliances which can help, such as cups with easy-grip handles. A physiotherapist can also set up an exercise programme to increase strength in muscles which are weaker and may be contributing to the tremor’s severity. There are some drug therapies but these often only provide minor benefit. Sometimes the beta blocker, propranolol can have some effect, whilst in other cases, Botox has been shown to reduce head tremors.

**Visual symptoms**

There are several problems 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 eye ball 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
What is a relapse?

Sometimes a temporary onset, or worsening of symptoms is actually a relapse. It can often be difficult to determine if you are having a relapse. 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 therefore if treatment is required.

According to the NICE guidelines (5) a relapse can be diagnosed by a GP or neurologist 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.’

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

Further information

MS-UK Choices leaflets – Bladder and bowel, Fatigue, Pain, Complementary and other therapies, Visual symptoms

www.ms-uk.org/choicesleaflets
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.

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.
Sources


Last reviewed: May 2017
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