Welcome to this Choices booklet about MS symptoms

MS-UK believe 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 find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis.
MS symptoms

Multiple Sclerosis (MS) can cause a variety of symptoms which can affect people at different times. This booklet explains some of the more common symptoms although it is not an exhaustive list. Most people will only experience a small number of these. It is unlikely a person will experience all the symptoms listed, all at once. The combination of symptoms, severity and frequency of them will be different for everyone.

Symptoms can come and go. Some are much more responsive to treatment, whereas others can be more difficult to manage and may persist.

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.

New symptoms may not always be down to your MS. 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.

MS Brain Health recommends positive lifestyle choices in order to keep your brain as healthy as possible. A healthy brain that
functions well is very important for people with a diagnosis of MS. A healthy brain may help to reduce your symptoms or reduce the likelihood of new ones developing. MS Brain Health suggest six positive steps to keep your brain as healthy as possible (1).

- 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 increase cognitive problems
- Watch how much you drink – unsafe levels of alcohol are associated with reduced survival in people with 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

Below are some of the more common symptoms experienced, with

"Quitting drinking and smoking helped me to reduce the relapses"

Visit www.ms-uk.org to find out more
a brief explanation of how the symptom can 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 even your GP. You could also ask to be referred to the appropriate specialist if necessary.

**Balance**

The NICE guidelines on diagnosing MS states that problems with balance can be one of the first clinical presentations of MS (2).

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, for others they may last longer. If the balance problem is the result of another symptom, once that is managed more effectively, hopefully the balance problems will be reduced.
A referral to neurophysiotherapy can help to investigate the root cause of the balance issue.

For dizziness and vertigo, a referral for vestibular rehabilitation may be offered. This type of therapy can help to improve symptoms.

Bladder and bowel

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’ to the toilet often
• Hesitancy – difficulty in passing urine
• Retention – feeling of not emptying properly

Occasionally, control of the bladder can be lost and leakage happens, this is otherwise known as incontinence.

Many people experience a combination of these symptoms.

There are medications and treatments available to help with bladder issues (3). Your GP and MS nurse can also refer you to a continence advisor (4) 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.

For further information please see our Choices booklet ‘Bladder and Bowel’.

Cognition

Around 50 per cent of people diagnosed with MS will experience cognitive dysfunction to some degree (5), 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.

The most common problems affect memory, information processing, problem solving, word-finding and concentration.

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 iphone is a life saver!

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 (2) 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.

For further information please see our Choices booklet ‘Cognition’.

**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 (2).

"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"

Initially, other things should be considered to make sure fatigue isn’t being caused by anxiety, depression, anaemia, thyroid disease, or
even general 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 these are suggested in the NICE guidelines section on easing the symptoms of MS (2).

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

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

**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. Studies show positive change to walking speed and functional walking ability (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 lead 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 or by wearing a kool-tie. Putting ice in a tray of water in front of a fan to create an air-conditioning effect can also help.

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), 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 attributing to 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 suggests that all those who experience mobility problems should have access to an assessment by a rehabilitation specialist and a physiotherapist with expertise in MS (2).

Fampridine is no longer recommended in the NICE guidelines to help improve walking speed, as it was found to not be a cost effective treatment. It can be paid for privately but you will need a private prescription 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 available.

For further information please see our Choices booklet ‘Pain’.

**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.

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 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.

If this symptom happens, it is best to 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 settle down.

‘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

Problems with speech and swallowing can be 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. A referral to a speech and language therapist is recommended. Ask your GP or MS nurse to refer you. Various strategies can be discussed to help reduce problems occurring from the symptom.

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.

For further information please see our Choices booklet ‘Speech and swallowing’.

**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.

There are many ways in which spasticity can be alleviated (2). 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 (2) 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 booklet, Cannabis and MS.

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 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 spasms 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

For further information please see our Choices booklet ‘Spasms and spasticity’.

**Tremor**

Many people with MS may experience tremor. 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.

Tremor most commonly affects the arms but it can also affect the head, neck, vocal chords and trunk (10).

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. 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. Limb cooling and weighted bracelets may also offer some relief.

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 upper limb tremors (10).

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 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 (11)

For further information please see our Choices booklet ‘Visual symptoms’.
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

Visit www.ms-uk.org to find out more
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 (2) 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.

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. MS-UK has a symptom diary that can be used to help monitor your symptoms. It is available to download via our website.

Visit www.ms-uk.org/sites/default/files/SymptomDiary.pdf
When showing signs of initial symptoms before a diagnosis is given, a symptom diary can help you to gather information and show how your symptoms can present when looked at together rather than in isolation. It can save time when visiting a GP for the first time. Rather than trying to explain what has been happening, it can help to share a diary.

Appointments with GPs or neurologists can sometimes be overwhelming, certainly when trying to discuss and explain how you have been feeling. It can be a difficult time talking about symptoms, and sensations, and trying to explain just how you feel. By writing down and describing your symptoms and how they affect you, whether it is a new symptom or one experienced before, you’ll have everything to hand, for example, when did it start/stop, does it fluctuate and do certain things make it better or worse, for example, heat, stress, or time of day? Score how the symptoms affect you, one meaning it doesn’t affect you much at all, five meaning it has an extreme impact. All of this information helps to build a bigger picture when seeing your GP and/or neurologist.

Further information

MS-UK Choices booklets
The following are all mentioned within this booklet. They can all be downloaded from our website. www.ms-uk.org/choicesleaflets

• Bladder and bowel
• Cognition
• Fatigue
• Pain
• Spasms and spasticity
• Speech and swallowing
• Visual symptoms

As well as these, we have a full range of Choices booklets that include other subjects such as

• What is MS?
• Newly Diagnosed with MS?
• Diagnosis
• Disease modifying therapies
• Complementary and other therapies
• Diet and supplements
• Exercise
• MS and mental health
Use me for your notes


# Symptom diary

<table>
<thead>
<tr>
<th>Date</th>
<th>Describe your symptom. How are you affected?</th>
<th>Is this a new symptom? Or one you have experienced before? Is it worse than previously experienced?</th>
</tr>
</thead>
<tbody>
<tr>
<td>eg. 01 Jul</td>
<td>eg. tight, stiff legs – difficult to walk</td>
<td>eg. I have experienced this before but not this tight/stiff</td>
</tr>
<tr>
<td>When did it start/stop?</td>
<td>Is the symptom constant or does it fluctuate? What makes it better or worse? (eg. heat, stress, time of day)</td>
<td>Score how the symptom affects you? One – not at all Five – extreme</td>
</tr>
<tr>
<td>------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>eg. a week ago and is continuous</td>
<td>eg. continuous but worse in the morning</td>
<td>eg. two/three</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

Visit www.ms-uk.org to find out more
About MS-UK

Peer Support Service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.
MS-UK Online offers a range of activities for people living with multiple sclerosis (MS). Our aim is to help people manage their wellbeing independently through exercise, information and connecting with others.

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

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

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


Reviewed October 2020

Visit www.ms-uk.org to find out more
Stay in touch

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

www.ms-uk.org

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

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

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