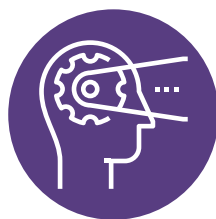


Choices



Spasms and spasticity



Multiple sclerosis information

www.ms-uk.org

Welcome to this Choices booklet about Spasms and spasticity

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

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis

Contents

Spasms and spasticity _____	4
What are spasms and spasticity? _____	4
What causes spasms and spasticity? _____	6
Effects of spasms and spasticity _____	7
Self-management techniques _____	9
Physiotherapy _____	13
What treatment options are available? _____	14
Further possible treatments _____	17
Complementary therapies _____	21
Electrotherapies _____	24
Supplements _____	26
Symptom diary _____	29
About MS-UK _____	32
Sources _____	36

Spasms and spasticity

If muscle stiffness, spasms (sudden involuntary movements) or pain associated with tight muscles is something you experience, we hope this booklet will be supportive for you.



People don't understand what spasticity or spasms are, which can be frustrating. One person thought spasticity meant I was having regular fits! It's disappointing that there is still a real lack of awareness of these types of symptoms and how they affect us with MS



This booklet looks into what exactly spasticity (including spasms) is, what are the causes and effects, possible treatments, the support you can get, and self-management ideas and techniques.

What are spasms and spasticity?

Spasms are a sudden, uncontrolled movement caused by muscles moving in an involuntary way. They may cause a limb to twitch or jerk and can be painful. There can be different types of spasms including clonus (rapid or repeated jerking or twitching), extensor spasms (making a limb jerk away from your body), and flexor spasms (making a limb, usually your leg, contract towards your body).

I think ‘spasticity’ is a harsh word that makes me feel worse than I actually am

I get a spasm in both legs if I just yawn or if someone just touches me unexpectedly

The MS hug (or banding/girdling) is a symptom involving muscles in the torso going into spasm and contracting, which causes a tightness or girdling sensation around the upper body. This symptom can affect people in different ways and can be quite distressing. For some people it can be very painful and make breathing difficult, for others it can be quite moderate and can be managed with lifestyle changes.

Muscle tightness or stiffness is referred to as spasticity. This stiffness is due to increased muscle tone and exaggerated response to muscle

I would describe spasticity as ‘limbs behaving badly’ - not bending when required or locking up

stretch. Spasticity is a very common symptom experienced by people living with MS and yet it is often overlooked. In a large study with results taken from a survey and existing data from the 'North American Research Committee on Multiple Sclerosis' (NARCOMS) 84 per cent of participants said that they had some experience of spasticity (1). Between 30-50 per cent of people with MS rated their spasticity as moderate to severe. It should also be said that individuals may well need a degree of spasticity, or at least enough to be able to stand and mobilise.

What causes spasms and spasticity?

Spasticity is a symptom that is caused when 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 often be managed.

Sometimes spasticity is triggered by infections or bladder and

It affects my walking when it affects my legs. I'm an administrator for my job which I love, however the spasticity can really challenge my day sometimes. I'm determined to not let it get the better of me though, I'm keen to continue in my job role and find ways to work around it

bowel problems. Left untreated, spasticity can lead to complications such as frozen or immobilised joints and pressure sores.

Effects of spasms and spasticity

Spasticity can affect the way people living with the symptom function and can have an impact on movement, mobility and posture. Spasticity can also cause pain and can increase levels of fatigue. Muscle stiffness caused by MS related spasticity can range from quite a mild feeling of tightness to a much more severe feeling affecting mobility, gait and the ability to walk. Spasticity is often reported to interfere with other aspects of daily living including climbing stairs and quality of sleep. If spasticity is not managed well, it can lead to permanently shortened muscles, called contractures, and can have a lasting impact on a person's general day to day ability (2).

Spasms in the upper body make simple tasks take longer, for example, washing up

When affected muscles spasm and jerk, this can be distressing, unexpected and have an impact on daily living ability. When it comes to spasms, affected muscles are mostly in the arms and legs and they can be caused to move and twitch in different ways. As with other symptoms of MS, spasms can vary in severity and are likely to be different from person to person.

Spasms generally happen when I change positions (lying to sitting, sitting to standing), everything sort of tightens, goes rigid, there is like a type of electric shock feeling and then it returns to normal

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.

In my case my legs go straight, heavy and will not bend. They are painful

Your MS team or GP should be following the National Institute for Health and Care Excellence (NICE) guidelines for the management

My legs especially jump when relaxing


of MS. They will likely assess and offer treatment for issues which may worsen or exacerbate spasticity such as constipation, infections (including urinary tract infections), inappropriately fitted mobility aids, pressure ulcers, poor posture and pain.

These 'trigger factors' need to be dealt with first and this may mean referrals for further support from a multidisciplinary team which may include physiotherapists, occupational therapists or community based nurses to help reduce any of these issues prior to offering any medicinal treatment (3).


Self-management techniques


Whilst exercise is generally great for our overall physical wellbeing, it is especially good for maintaining flexibility. Stretches in particular have been shown in some studies to help decrease stiffness and are regularly promoted by physiotherapists and rehabilitation teams (4). In a recent small study that looked at group-delivered self-management programmes with an aim to reduce spasticity, it was found that taking part in a planned, regular exercise and stretching regime had clinically important positive impacts on spasticity in people with MS (5).

There are many resources to aid with exercise and stretches to




I do stretching exercise before work and in the evening






I find warmth relieves my spasms quite well. Warm baths at the end of a busy day at work are great! I always wear gloves when I go out, I use a hand warmer at home which helps. I also find swimming helps stretching out my hands, arms and legs and I find it relieves the spasticity quite well




support spasticity. A local MS therapy centre or local MS Society group will likely have suitable and accessible exercise classes to participate in. It is worth speaking with your GP to see if there is a local GP exercise referral scheme as this may mean that your local leisure centre will offer additional support for people with long-term conditions.

There are many resources to aid with exercise and stretches to



I do regular exercise, stretching and walking. I have very long deliberate stays in bed and I spend time monitoring my current state and exercise for ten minutes several times a day



support spasticity. A local MS therapy centre or local MS Society group will likely have suitable and accessible exercise classes to participate in. It is worth speaking with your GP to see if there is a local GP exercise referral scheme as this may mean that your local leisure centre will offer additional support for people with long-term conditions.



Most of the drugs I tried made my fatigue and walking worse. The best thing I have found is physiotherapy. For me, exercise helps a lot. Also I use a heat treatment like a wheat bag



There are many MS specific videos on YouTube modelling stretches that you can use at home. You can also download or order a copy of MS-UK's Choices booklet on exercise where there are demonstrations of stretches and exercises suitable for all abilities.

Taking part in exercise activities like yoga, Pilates, tai-chi and Qigong are a good way of introducing stretching exercise. All of



I have tried stretching and exercising and sitting down tai chi but with little success in my case



these can involve gentle stretches, can be adapted to any ability and all are also associated with promoting overall physical and mental wellbeing.

When it comes to self-management a big part of looking after yourself and your symptoms will come down to using reflection techniques. It is important to observe and monitor any identifiable triggers and other environmental factors that may be negatively influencing how you feel. MS-UK has a symptom diary that can be used to help monitor your spasticity. By completing a symptom specific diary you and your health team may be able to unpick any patterns or influencing factors that may be impacting on your spasticity and spasms. Triggers to be aware of could be

- Emotional and psychological issues
- Bladder issues including urinary tract infections (UTI's)
- Bowel issues including constipation
- Heat
- Pain issues
- Fatigue levels
- Skin issues including pressure sores and any skin irritation or breakdown

If I'm upset, stressed or emotional it's worse

You will find a symptom diary at the back of this booklet, or you can download a copy from our website, just visit www.ms-uk.org/sites/default/files/SymptomDiary.pdf

Physiotherapy

A physiotherapist or specialist neurological rehabilitation physiotherapist will be able help in a number of ways. A physiotherapy assessment will involve measuring posture, movement and functional ability. They can address any issues with posture which can affect an individual's independence and may possibly increase the risk of falls. Physiotherapists can advise over specific stretches and can manipulate specific muscle groups to maximise benefit. Physiotherapists will have a detailed knowledge of human physiology and will work to ensure, as much as is possible, that muscles do not become permanently shortened.

My physio has helped me to think through the spasms to prepare for them but it doesn't always work. Especially at night when you can't prepare for them

Physiotherapists will be able to give guidance over a sustainable and achievable exercise and stretching programme that will be shaped to the needs of the individual and can be followed at home and in the community.

Depending on the location, size of the team and resources available to them, physiotherapists have a range of specialist interventions to bring into play that can help with spasticity. This could be hydrotherapy, therapeutic exercise, postural training, electrical stimulation, stretching and range of motion activities (6).

Physiotherapists can use measurement tools such as the Modified Ashworth Scale, the Multiple Sclerosis Spasticity Scale 88 or the Penn Spasm Frequency Scale within their clinical practice to be able to support assessment and measure for changes over time (7).



I use Hyperbaric Oxygen Therapy, physio, and massage and stretching exercises, they all help



Neurological specialist physiotherapists will often be part of a wider neuro-rehabilitation team and will likely have a multidisciplinary team approach to supporting people. This may well mean that your physiotherapist will be able to tap into or refer people to specialist colleagues such as occupational therapists (3).

What treatment options are available?

There are many ways in which spasticity can be eased with the support of your healthcare professionals.

MS Clinical Nurse Practitioner Miranda Olding wrote about spasticity




My spasticity is controlled with baclofen and Sativex spray




medications in MS-UK's New Pathways magazine and said 'because MS involves both stiffness and weakness in the muscles, you can find that a degree of stiffness is needed to maintain the strength needed for standing, so it can be a fine balance' (8).

If your symptom is affecting your quality of life, 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.



I take baclofen. Occasionally if I forget to take my tablet, I'm soon reminded by how my legs are behaving



The first medication usually tried is baclofen, and the most common side effects are drowsiness, or feeling too weak.

Gabapentin is the next treatment to try if baclofen is not right for you. This is often used for nerve pain in MS, but also has a muscle relaxant effect. However, some people find the sedating side effects,

or the fact that they are putting on weight (which is another potential side effect), too difficult.

Another muscle relaxant that can be tried, which is less sedating, is tizanidine. But you will need a blood test before and for the first three months of treatment, to check that your liver is coping and is not being harmed.

Occasionally, an older muscle relaxant, dantrolene, is tried. Diazepam (Valium) is also effective as a short term muscle relaxant, but it is easy to become dependent on this. Clonazepam can also be tried.



**I take clonazepam 0.5 micrograms at night,
which does settle my legs down**



If other treatments are not as effective as hoped, a baclofen pump can be considered. This involves a tiny dose of baclofen being delivered straight to the spinal column via a small plastic tube, fitted to a pump, about the size of a shoe polish tin, which is inserted just under the skin in the abdomen. As the dose is so small, people have a lot less side effects than with tablets (8).

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.

When just a couple of defined muscles are causing the problems, botulinum toxin (Botox) can be very effective when injected to paralyse these muscles. Botox is injected directly into the affected muscle to help reduce the tightness caused by spasticity. This needs to be repeated around every three months (8).

The same drug treatments for spasticity are offered to help reduce spasm.

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

Further possible treatments

Cannabis related products

There has been evidence for some time that components of the cannabis plant (cannabinoids) can help some people with MS with some symptoms, particularly spasticity and pain (8).

Cannabidiol CBD

Cannabidiol, which is commonly known as CBD, is a cannabinoid which can be extracted from the cannabis plant. There is a common myth that CBD is not psychoactive, but as CBD has an effect on the brain, it is therefore psychoactive, but is better described as 'non-intoxicating'. CBD is one of many cannabinoids that exist within cannabis and is legal in the UK as long as it is not sold with medicinal



If I have a good CBD oil I am able to exercise more, which helps



claims and is derived from hemp. To be legal, CBD products should contain extremely low amounts of delta-9-tetrahydrocannabinol (THC), the cannabinoid that has intoxicating properties.

In New Pathways magazine Miranda Olding says 'In studies where there was evidence of effectiveness, [CBD] doses ranged from 0.8 to 1.8mg, taken between two and four times per day. The easiest way to control the dose is to take it in liquid form, and start with one drop under the tongue, then increase as necessary' (8).

In a study published in 2018 titled 'Cannabidiol to Improve Mobility in People with Multiple Sclerosis' the study leads gave an opinion that CBD supplementation may be advisable for people with MS to reduce fatigue, pain, and spasticity, and improve mobility. The study recognises that the benefits related to cannabis use in people with MS are still under investigation. However, data and existing studies indicate that cannabis, with 1:1 or greater CBD:THC ratio, reduces muscle spasticity (9). It is worth bearing in mind that the CBD



I use cannabis to relax tension of muscles



available in the UK contains extremely minimal THC.

If you are considering supplementation with a CBD product it would be worth speaking to your health professionals to ensure that there would be no contraindications with any existing medications.

Sativex

Sativex is a cannabis-based medicine that is licensed in the UK for the treatment of moderate to severe spasticity in those who have not responded sufficiently to other anti-spasticity medication and who can show clinically significant improvement in spasticity-related symptoms during an initial trial of medication (10).

Sativex contains both THC and CBD and is used orally, as a spray. An individual begins by taking one spray in the evening and over time gradually increasing the amount of doses per day until optimum symptom relief is achieved. Sativex can be taken up to a maximum of 12 times per day, with the average dose being eight times a day. Sativex is generally well tolerated with common side effects being dizziness in the first few weeks of taking the medication and mild anxiety has been reported in some cases. It is felt that people taking Sativex are unlikely to develop a dependency on the medication. Sativex is not recommended for people with a sensitivity to cannabinoids, children, pregnant women or people with a history of psychotic or psychiatric illness (10).



**I have found baclofen is very good and
Sativex spray is a good add-on treatment**



The NICE guideline on cannabis-based medicinal products state that a person who is eligible should be offered a four-week trial of Sativex via the NHS. To be eligible for Sativex a person should have moderate to severe spasticity, have tried other spasticity medications and found them ineffective. To be considered for ongoing prescriptions of the medication you will need to have had at least a 20 per cent reduction in spasticity related symptoms after four weeks of trying the medication (11). This should also be the case with Northern Ireland and Wales, whilst campaigners hope the same will follow in Scotland soon (12).

Even if a person can get a sample four-week trial of Sativex, it may not be possible in all cases for the NHS to be able to fund the medicine on an ongoing basis. The funding decision will be a local one and local NHS funding may work in different ways.

Low Dose Naltrexone (LDN)

Naltrexone is a drug developed initially to treat addiction to opiate based drugs, such as heroin or morphine. It belongs to a class of medications called opiate antagonists.

Naltrexone delivered in lower doses – Low Dose Naltrexone (LDN) – has been used in the USA to treat the symptoms of autoimmune conditions, such as MS, since 1985, and more recently has been used in Europe and the UK (13).

LDN is used ‘off label’ as a treatment for the symptoms of many conditions including Crohn’s disease, fibromyalgia, chronic fatigue syndrome and Ulcerative Colitis – conditions with an autoimmune origin, or potential autoimmune origin. Whilst LDN is not licensed specifically for these conditions, physicians are permitted to prescribe LDN for treatments they think are appropriate (14).

As an opiate antagonist, naltrexone is thought to inhibit endorphins

– the body’s natural painkiller. It is believed that by inhibiting endorphins, the body reacts by producing more. This increase in endorphins reduces pain and increases a sense of wellbeing (15).

An Italian six-month phase II pilot trial of 40 people with primary progressive MS was conducted in 2008, with the main purpose of looking at safety and tolerability. This study found Low Dose Naltrexone to be well-tolerated by the patients who also reported an improvement of their symptoms, including pain, fatigue and depression. A significant reduction of spasticity was also measured at the end of the trial. There were also reported improvements to overall quality of life outcomes (16).

I take 3mls of LDN, adjusting dosage when needed. It has stopped my heat intolerance and twitching legs but has not stopped progression

MS-UK has a Choices booklet on LDN which has some more detailed information on the existing but limited research and accessing LDN in the UK.


I take magnesium. I stretch my muscles after short walks. I vigorously massage the soles of my feet before going to bed. I also have infections in mind such as UTIs and thrush

Complementary therapies


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

Acupuncture

Acupuncture is a complementary therapy that is used in some MS therapy centres and is often used by people with MS. There is much anecdotal and soft evidence that acupuncture can help with stiffness and spasticity, however there is minimal hard evidence from studies. The studies that have been conducted have often been small but have had some positive findings. Overall it is felt that as most treatments for spasticity are medicines which may have undesirable side effects, acupuncture may be a viable alternative to management with medicines for some people (17).



I use acupuncture, yoga, and meditation. They help me relax and take my mind off the symptom



Biofeedback

Biofeedback involves using a monitoring device that gives feedback over a person's bodily functions. For treating spasticity it would monitor muscle tension. When monitoring spasticity, biofeedback creates a signal, perhaps a sound, as a muscle experiencing spasticity relaxes. The person undergoing the therapy may be able

to 'train' themselves to consciously reduce muscle tone and find a relaxed state. Biofeedback has been studied in MS for a variety of symptoms including bladder and bowel issues. However there have been no significant studies relating to MS and spasticity but studies with people with cerebral palsy indicate that benefits are possible. Although there is no body of evidence to support the therapy, this whole mind-body approach may play a role in reducing spasticity for people with MS (18). Biofeedback is used in a few NHS specialist centres but is more often found in private therapeutic practices.

Massage

Massage therapy is used by many people with MS to help manage and live well with a variety of symptoms. Many therapists offer specialist services for people with MS and many of the various independent MS therapy centres up around the UK offer massage as part of their menu of services. For people with MS, massage therapy is thought to improve a sense of overall wellbeing including increased self-esteem and lower anxiety levels (19). It has also been found in a small practical trial that the sense of competently coping with challenging situations is improved, potentially resulting in a better overall adjustment to living well with MS (20). When it comes to treating spasticity, pain and fatigue with massage therapy, a small pilot study was carried out in 2016 with a small group of people with MS. Of the 28 participants only three actually reported spasticity at the start of the study, however a significant finding from the study was that massage therapy did not increase spasticity. The study concluded that if massage therapy can decrease fatigue and pain in some people with MS, this would mean that at least some people with MS had improved wellbeing and quality of life outcomes (21).

Reflexology

Reflexology is a therapy where reflex points on the feet are

manually stimulated with the idea that stimulating pressure points will increase circulation and energy to organ systems. Reflexology is used widely by people with MS and many MS therapy centres across the UK offer this complementary therapy. In a 2003 study, reflexology was found to have a positive impact on spasticity as well as other symptoms including altered sensations and urinary issues (22). A further study from 2009 specifically looking at reflexology for the treatment of pain in people with MS had positive impacts on a range of symptoms including spasm. The randomised controlled trial used precision reflexology and a mock reflexology technique. The study found that there were significant improvements to symptoms that were maintained for up to 12 weeks, however precision reflexology did not have significantly better outcomes to the mock technique. It was felt that this was either to do with a possible placebo effect or that stimulating reflex points using a non-specific massage technique also gave symptomatic benefit (23).

Electrotherapies

Action Potential Simulation (APS) therapy

APS therapy is a drug-free pain management system and is a type of micro-current therapy. Micro-current therapies transmit an electrical current through the human body, using electrodes to make contact with the skin, at biological frequencies. Action potentials are the change in electrical potential associated with the passage of an impulse along the membrane of a muscle cell or nerve cell. In cases of improper nerve firing, applying waves of correct action potential frequencies seems to reduce the improper nerve impulses, reducing or completely alleviating pain or symptoms.

In a small trial using APS therapy to treat pain in people with MS one of the additional benefits found was that a number of participants

reported that the therapy also helped alleviate stiffness/spasm (24).

APS therapy is now being used by at least 12 MS therapy centres or wellbeing centres across the UK. There are also many independent therapists using APS and it is possible to trial, hire or purchase APS therapy machines for use in the community.

Functional Electrical Stimulation (FES)

Functional Electrical Stimulation (FES) can help people with MS move more easily. FES has been used often in rehabilitation settings for therapy, restoration of function and maintenance of vital function in muscle weakness. FES uses small electrical impulses to activate muscles by 'exciting' the nerves leading to the muscles. Electrodes are placed on the skin close to the nerve supplying the muscle and an electrical signal is sent by the stimulator, producing an impulse within the muscle. FES technology is most often used to treat foot drop but the technology is also incorporated within exercise cycling machines. When used to treat foot drop in a study from 2010 people with MS had fewer falls and had positive outcomes and satisfaction scores (25). When using FES cycling a case study report from 2007 found that there was a significant reduction in spasticity (26). In further studies using FES cycling there were positive outcomes relating to cognitive processing speed, decrease in pain and fatigue but no increase or decrease in spasticity measures (27). FES cycles are used at specialist NHS rehabilitation centres and may be used at MS therapy centres, wellness centres, specialist accessible gym environments and private neuro-rehabilitation services.

Transcutaneous Electrical Nerve Stimulation (TENS)

Transcutaneous electrical nerve stimulation (TENS) is one of the most common forms of electrical stimulation used for management

of pain. It can be used for people with MS to treat a variety of painful symptoms including painful altered sensations, spasticity and spasms. The machines themselves are commonly available and can often be hired or borrowed from pain specialist services. In a small pilot study conducted in 2003 using TENS machines for 20 minutes a day, for a period of four weeks there were clinically significant reductions in spasticity (28). However a further trial in 2007 using TENS to support spasticity it was found that using TENS led to a significant reduction in spasm and pain but did not have a significant effect on spasticity (29).

Supplements

There are some supplements that are thought to be useful for supporting people with spasticity and spasm. Many people with MS will choose to take supplements to support symptom management, however hard evidence is limited when it comes to supplements that can help with spasms and spasticity.

With spasms I either drink at least half a pint of water or take a magnesium tablet

In a case study report magnesium supplementation was found to give significant improvements in spasticity and spasm in a patient with MS. No side effects were reported (30). MS Clinical Nurse



I take daily supplements of calcium and magnesium and use CBD oil to help



Practitioner Miranda Olding writes on her blog that magnesium can be effective as a relaxant in the nervous system, and so can assist with reducing spasm and nerve pain. Miranda goes on to say that there can be a risk of magnesium toxicity and magnesium may also have some possible drug interactions. So if you are considering supplementation, it would be worth speaking to your health professionals. On Miranda's blog she also shares some case studies of people who have positive experiences of supplementation (31).

L-threonine, which is a naturally occurring amino acid, has been tested in some studies to treat muscle stiffness, or spasticity in people with MS. Research suggests that threonine improves stiffness as measured in a clinical setting. During the 1992 study, a daily dose of 7.5g was given to participants and there were reduced signs of spasticity, although no symptomatic improvements were detected by clinicians or by the study participants. In the study no side effects or toxic effects were identified (32). In a blog post titled 'The top 15 supplements for natural MS treatment', Dr Ronald Hoffman, who is a complementary medicine practitioner from New York recommends supplementation of magnesium threonate which he says combines the benefits of threonine and magnesium to alleviate muscle spasm (33).

Symptom Diary

This diary is to help you record information about how you are feeling to share with your doctor. It may be that you have been referred to a neurologist, or you have seen a neurologist and are undergoing diagnostic tests.

Symptoms of MS may include: fatigue; pain; muscle stiffness or spasms; balance problems; weakness; numbness and tingling, or both; bladder and bowel problems; changes to vision; changes to thinking and memory; coordination issues. These symptoms are not unique to MS.

Recording symptoms can be helpful towards a diagnosis and to assist you in understanding what you are experiencing.

Questions for your doctor

e.g. my legs are feeling very tight and stiff

Other information

e.g. the stiffness makes it difficult for me to walk

Symptom diary

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

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

About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



New Pathways

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

Available in print, audio version, large print and digitally.

About MS-UK

Peer Support Service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





Online activities

MS-UK offers a variety of online activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. Visit our website to explore and find out more.

E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created accredited Learning courses that can help you do this. Visit <https://ms-uk.org/excellence-ms/> to find out more.

Sources

- (1) 1. European Neurology, Overview of MS Spasticity, Pozzilli, Epub 2014 Jan 22
www.karger.com/Article/FullText/357739
2. The Patient - Patient-Centered Outcomes Research, A Cross-Sectional Study of the Impact of Spasticity on Daily Activities in Multiple Sclerosis, Bethoux et al, Volume 9, Issue 6, December 2016, p 537–546
<https://link.springer.com/article/10.1007/s40271-016-0173-0>
3. National Institute for Health and Care Excellence. NICE Guidance – Multiple sclerosis in adults: management. Published October 2014. Accessed 14 November 2019
www.nice.org.uk/guidance/CG186
4. Archives of physical medicine and Rehabilitation, The Effects of Stretching in Spasticity: A Systematic Review. Bovend'Eerd TJ et al, vol 89 July 2008
[www.archives-pmr.org/article/S0003-9993\(08\)00210-4/pdf](http://www.archives-pmr.org/article/S0003-9993(08)00210-4/pdf)
5. Multiple Sclerosis Journal – Experimental, Translational and Clinical, A group-delivered self-management program reduces spasticity in people with multiple sclerosis: A randomized, controlled pilot trial Hugos et al, 2017 Mar 23
www.ncbi.nlm.nih.gov/pmc/articles/PMC5433226
6. MS Multiple Sclerosis, Physiopedia accessed 14 February 2020 www.physio-pedia.com/MS_Multiple_Sclerosis
7. Archives of Neuropsychiatry, Spasticity Measurement, Belgin Petek Balci, 2018 Sep 14
www.ncbi.nlm.nih.gov/pmc/articles/PMC6278623

8. Olding, Miranda. Managing spasticity. New Pathways issue 94, Sep/Oct 2018, p 32-33
9. Frontiers in Neurology, Cannabidiol to Improve Mobility in People with Multiple Sclerosis, Thorsten Rudroff et al, 2018; 9: 183 www.ncbi.nlm.nih.gov/pmc/articles/PMC5874292
10. The Electronic Medicines Compendium, 'Sativex: Oromucosal Spray, Summary of Product Characteristics' last updated 03 Sep 2019 www.medicines.org.uk/emc/product/602
11. National Institute for Health and Care Excellence. NICE Guideline 144 – Cannabis-based medicinal products Published November 2019. Accessed 22 January 2020 www.nice.org.uk/guidance/ng144
12. McArdle, Helen. Scots 'missing out' on cannabis-type MS and epilepsy drugs. The Herald, Herald & Times Group. 12 November 2019. Accessed 23.01.20. www.heraldscotland.com/news/18029185.i-able-stand-walk-again-ms-patient-hails-benefit-cannabis-based-drug-available-nhs-england---not-scotland
13. What is LDN?, The LDN Research Trust. Accessed 23 January 2020. www.ldnresearchtrust.org/what-is-low-dose-naltrexone-ldn
14. What is LDN Used for?, LDNscience.org is a public information project of the MedInsight Research Institute. Accessed 23 January 2020. www.ldnscience.org/ldn/what-is-ldn-used-for
15. How Does LDN Work?, LDNscience.org is a public information project of the MedInsight Research Institute. Accessed 23 January 2020. www.ldnscience.org/ldn/how-does-ldn-work

16. Multiple Sclerosis Journal, A pilot trial of low-dose naltrexone in primary progressive multiple sclerosis. Gironi et al. Published September 2008. Accessed 23 January 2020.
www.ncbi.nlm.nih.gov/pubmed/18728058
17. Evidence-Based Complementary and Alternative Medicine, Acupuncture and Multiple Sclerosis: A Review of the Evidence, H. I. Karpatkin et al, vol. 2014, Article ID 972935, 2014.
<https://doi.org/10.1155/2014/972935>
18. Allen C. Bowling, MD, PhD, Biofeedback, Neurology Care PC, 27.04.11, date of access 22.11.19
www.neurologycare.net/biofeedback.html
19. Journal of Bodywork and Movement Therapies, Multiple sclerosis patients benefit from massage therapy, Hernandez-Reif et al, Volume 2, Issue 3, July 1998, p 168-174
www.sciencedirect.com/science/article/abs/pii/S1360859298800090
20. Journal of bodywork and movement therapies. A pragmatic investigation into the effects of massage therapy on the self efficacy of multiple sclerosis clients. Finch et al, January 2014 Volume 18, Issue 1, p 11–16
www.ncbi.nlm.nih.gov/pubmed/24411144
21. International Journal of Therapeutic Massage & Bodywork, Impact of Massage Therapy on Fatigue, Pain, and Spasticity in People with Multiple Sclerosis: a Pilot Study, Backus et al, Published online December 9 2016
www.ncbi.nlm.nih.gov/pmc/articles/PMC5142712
22. Multiple Sclerosis, Reflexology treatment relieves symptoms of multiple sclerosis: a randomized controlled study, Siev-Ner et al 2003 Aug;9(4):356-61
www.ncbi.nlm.nih.gov/pubmed/12926840

23. Multiple Sclerosis, Reflexology for the treatment of pain in people with multiple sclerosis: a double-blind randomised sham-controlled clinical trial, Hughes CM et al, November 15 2009 www.ncbi.nlm.nih.gov/pubmed/19825891
24. ECTRIMS Online Library, Action potential simulation (APS) therapy for pain in people with MS: results of a three year pilot study, Matthews et al, accessed 04 March 2020
www.painfreepotential.co.uk/wp-content/uploads/2014/01/Action-Potential-Simulation-Therapy-APS-Therapy-for-pain-in-people-with-MS-Report-on-a-Two-Year-Pilot-Study.-double-spaced.pdf
25. Multiple sclerosis journal, Impact on activities of daily living using a functional electrical stimulation device to improve dropped foot in people with multiple sclerosis, measured by the Canadian Occupational Performance Measure. Esnouf et al, September 2010 www.ncbi.nlm.nih.gov/pubmed/20601398
26. Neurorehabilitation, FES cycling reduces spastic muscle tone in a patient with multiple sclerosis, Krause, 19 October 2007
<https://content.iospress.com/articles/neurorehabilitation/nre00362>
27. Archives of physical Medicine and Rehabilitation, Training Effects and Safety of Functional Electrical Stimulation (FES) Cycling in People With Multiple Sclerosis, Backus et al, volume 95, issue 10, October 01, 2014
[www.archives-pmr.org/article/S0003-9993\(14\)00587-5/fulltext](http://www.archives-pmr.org/article/S0003-9993(14)00587-5/fulltext)
28. Neurorehabilitation and neural repair, The Effect of Transcutaneous Electrical Nerve Stimulation on Spasticity in Multiple Sclerosis Patients: A Pilot Study, Armutlu et al, June 1,

2003, Volume: 17 issue: 2, page(s): 79-82

<https://journals.sagepub.com/doi/10.1177/0888439003017002001>

29. Multiple Sclerosis, The effects of transcutaneous electrical nerve stimulation (TENS) on spasticity in multiple sclerosis. Miller et al, 2007 May;13(4):527-33
www.ncbi.nlm.nih.gov/pubmed/17463075
30. European Journal of Neurology, The effect of magnesium oral therapy on spasticity in a patient with multiple sclerosis, Rossier et al, November 2000.
www.ncbi.nlm.nih.gov/pubmed/11136367
31. Miranda Olding. Mirandas MS blog. Natural treatments for MS spasms. Published: April 20 2016. Accessed February 2020.
www.mirandasmsblog.com/2016/04/20/natural-treatments-for-ms-spasms
32. Archives of neurology, an antispasticity effect of threonine in multiple sclerosis. September 1992
www.ncbi.nlm.nih.gov/pubmed/1520082
33. Ronald L. Hoffman MD, The top 15 supplements for natural MS treatment, 28 April 2017. Accessed February 2020.
www.drhoffman.com/article/the-top-15-supplements-for-natural-ms-treatment

Check out MS-UK's online activities

Live a happier and healthier life with MS



- ✓ Accessible online exercise classes
- ✓ Chair yoga classes
- ✓ Mindfulness courses

- ✓ Interactive workshops
- ✓ Information sessions
- ✓ Peer Support Service

Don't miss out – sign up for our new online activities today!

Visit www.ms-uk.org or contact us at register@ms-uk.org

 **MS-UK**
Supporting your MS journey

Registered charity number 1033731

Stay in touch

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

www.ms-uk.org

✕ @MSUK6

f www.facebook.com/MultipleSclerosisUK

▶ www.youtube.com/c/ms-ukorg

in 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



Registered with
**FUNDRAISING
REGULATOR**