

Choices

Pain



Multiple sclerosis information

Welcome to this Choices booklet about pain...

At MS-UK we 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 use 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

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Pain

Two-thirds of people with multiple sclerosis (MS) will experience pain at some stage (1). Pain associated with MS can be difficult to manage and may persist for a long time. For some people it can be continuous at a low intensity and for others it can be more severe. It can come and go over the course of a few weeks, or it can vary throughout the day.

Not everyone with MS experiences pain, but for those who do, it can have an enormous impact on their daily lives, with relationships, at work and leisure, their mood and enjoying the simple pleasures of life.

No two people will experience pain in the same way, and so an understanding of how it is affecting the individual is reliant on the person's ability to describe the pain they are feeling.



Don't put up with pain, get help




It is not necessary for a person with MS to put up with pain. There are a number of treatments, including medications and management strategies, which can be effective in alleviating pain, although it is often difficult to initially find the right one.

Working with your GP and neurologist is the first step towards establishing a pain management strategy.



As long as I maintain my regime of diet, exercise and meditation, I stay mostly symptom and pain free



It is also important to remember that not all pain experienced is due to MS. It could be due to things such as infections or an injury. Therefore, other possible causes of the pain should be thoroughly looked into and investigated.

In this booklet we will take a deeper look at pain and its relationship with MS, including a summary of the different medications and therapies that can be used to manage its impact.

What is pain?

The International Association on the Study of Pain (IASP) is a longstanding global organisation whose mission is to stimulate and support the study of pain and ultimately foster a wider understanding on a global scale, particularly regarding pain relief. Their work is undertaken collaboratively with pain specialists around the world, including scientists, clinicians, health care providers and policymakers.

The IASP's definition of pain is as follows

“An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (2)

This definition was updated recently as previously it referred to an individual's ability to describe the pain they were experiencing, and that can be problematic. For instance, pain can be very difficult to describe, and its interpretation can differ from person to person. Some people with MS have reported pain as a feeling of burning or gnawing, like immersion in ice cold water, or it being too painful to touch the skin. It can also be a stabbing, throbbing or crushing feeling.

Later in this booklet we will explore ways which may help you to describe the pain you are experiencing to others, for instance when speaking to medical professionals.

Types of pain

There are different ways in which pain can be classified. Some are in accordance with the length of time that pain lasts, such as acute and chronic, and others are grouped by the cause of the pain, for instance tissue and nerve damage (3). To aid understanding we will firstly look at what constitutes acute and chronic pain, then delve deeper into the relationship between pain and MS, including causes and treatments.

Acute pain

This is a sudden pain that does not persist for long periods and can be intermittent. It starts out sharp or intense and serves as a warning sign of disease or threat to the body. Acute pain usually disappears whenever the underlying cause is treated or healed (2).

Chronic pain

This is defined as a pain that can last for more than a month. It is usually continuous, but it can fluctuate in severity and sometimes it never fully disappears.

The type of treatment you receive will depend on the type of pain you are experiencing and what is causing it. It may be that a drug treatment is the solution or that physiotherapy will help provide relief without the need for any drugs at all. Later in this booklet we will look deeper into conventional treatments and alternative therapies.

Pain and MS

Global studies have shown that approximately two thirds of people with MS are impacted by pain (4), with over half being affected by chronic pain at some point during their MS journey (5).

There are many ways in which pain affects people with MS, with causes being as a direct result of the condition or as a secondary consequence. For example, neuropathic pain is the result of the damage that MS causes to the central nervous system, while musculoskeletal pain can be caused by damage to ligaments, muscles and other soft tissues, which occur as a result of our bodies compensating for damage caused by MS, such as gait correction when walking.

Additionally side effects of pain can include disturbed sleep, which may cause problems with fatigue and the onset of other MS symptoms such as impaired cognitive performance, emotional and mental wellbeing.

Pain and MS have an incredibly complex relationship, therefore it is important to understand more about how people with MS are affected and how it can be managed.

In the production of this booklet we asked the MS community to let us know about the methods they use to manage the impact of pain. The overriding majority said that they took a multi-disciplinary approach, using a combination of medication, complimentary therapies, physiotherapy and pain management apps. We take a look at all of these throughout this booklet.

Neuropathic pain

This is the most common and impactful form of pain experienced by people with MS (1). It is caused by damage to the nerves that occurs due to demyelination, described by some as ‘short-circuiting’ that leads to false signals being sent to the brain, which in turn interprets these signals as accrued damage. It can be acute or chronic in nature, for example during a relapse you may encounter acute neuropathic pain which disappears after treatment. Eventually this pain may reappear and become more persistent.

The sensations people may feel because of neuropathic pain can differ, with some reporting feelings of burning, stabbing, and squeezing. Others have described prickling sensations, an electrical shock and sensitivity to temperature and touch (3).

There are different ways in which neuropathic pain can affect people with MS. Below we will look at some of the most common examples along with recommended treatments.

Trigeminal neuralgia

This is a very intense, severe stabbing pain, which may also feel like a burning sensation or electric shock that travels down the face. It

normally affects one side of the face at a time with the pain travelling down the pathway of the trigeminal nerve. It can be excruciating and set off by simply eating, drinking or talking. The onset is sudden and will reduce or disappear over time. Unfortunately, this pain can become chronic.



Using heat packs like wheat bags can help the pain of trigeminal neuralgia



For trigeminal neuralgia, the National Institute for Health and Care Excellence (NICE) recommends offering the drug carbamazepine as the initial treatment (7). If this is not effective, or well tolerated, or is contraindicated then NICE suggests seeking a referral to a specialist pain management service.

Optic neuritis

This is a common symptom in MS and presents as the first symptom of MS in approximately 30 per cent of people. It is often described as a sharp stabbing-like feeling behind the eyes and is caused by inflammation or demyelination of the optic nerve at the back of the eye, which transmits the signals of the visual image from the eye to the brain.

Optic neuritis causes a disturbance in vision – sometimes blurring, and often a reduction in colour vision, particularly for the colour red. It can also cause a headache, or a pain behind the eye when the eye moves.

Depending on how severely you are affected, you may or may not need treatment for optic neuritis. In some cases, a course of steroid treatment is prescribed if this symptom does not improve over time, which helps to resolve the inflammation, resulting in the pain subsiding. Your GP or ophthalmologist can also provide advice about pain relief, should this be required.

Lhermitte's sign

Also known as Lhermitte's syndrome or phenomenon, this is an electric shock feeling in the neck and spine that happens as a result of bending or flexing. Occasionally the feeling can spread into your limbs. It is estimated that just under 40 per cent of people with MS will experience at least a single episode of Lhermitte's sign (8).

Lhermitte's sign can be triggered by factors such as fatigue and heat exposure, so managing these can help reduce the possibility of its onset and help to manage the impact, once affected. If you are affected by Lhermitte's sign persistently despite managing these forms of trigger, it may be worth seeking further support from your GP, MS nurse or neurologist. Drug treatments that are designed to help with neuropathic pain management may be offered, such as gabapentin and pregabalin, or you could ask about the possibility of being referred to a neuro-physiotherapist service.

Dysesthesia

These are physical sensations, usually presenting as feelings of discomfort on the skin, which are caused by damage to the nervous system. People affected by this symptom report a range of different sensations including burning, prickling, stabbing and pins and needles. Dysesthesia can affect people with MS intermittently. It is more commonly found in people with secondary and primary progressive MS, and as such is more likely to be a chronic type of pain (9).

Pruritis is a form of dysesthesia and is a feeling of itchiness on the skin. The ‘MS Hug’ which is a feeling of banding, girdling or other irregular sensations around the chest area, can also be classified as a form of dysesthesia. However, this depends on what is causing the altered sensations in the chest area. For example, if the underlying cause is found to be muscle spasms, it would be a musculoskeletal rather than neuropathic issue, which we will look at later in this booklet.

As with Lhermitte’s sign, if the cause of dysesthesia is found to be neuropathic, then associated pain management medication may be offered.



**My MS nurse has been my saviour.
Without her I wouldn’t be able to
access my consultant so quickly**




Neuropathic pain treatment


NICE guidelines for the management of MS include recommendations for the treatment of neuropathic pain (6,7).

As part of the process of agreeing a pain treatment and management plan with you, a GP, neurologist or MS nurse will consider the severity of the pain, its impact on your daily life and all underlying causes.

They will discuss with you proposed drug treatments, the benefits of a particular medication and the possible adverse effects, while considering any other medications you may be taking. Additionally,




The MS nurse is always my first port of call, second is the pain management team, between them a mix of medication was found that helped ease the pain (didn't get rid of it altogether but made it manageable)




they will also take into consideration appropriate dosage and the steps required to increase it if this is needed.

It may be that non-drug treatments will be appropriate such as physical and psychological therapies. These will also be considered and explained to you in terms of what they consist of and how they may be effective in managing the pain that you are experiencing.

If your pain is severe, you may be referred to a specialist pain management service, usually through the local hospital.



Don't think you have to put up with the pain. There are many treatments for symptoms. It may not be the first thing you try that helps relieve the pain, but persevere, you will find something eventually



The GP, neurologist or MS nurse should conduct regular reviews to check the effectiveness of the treatment plan, if the pain is still affecting your lifestyle, if any medications are causing any adverse effects and whether there is a continued need for treatment.

For initial treatment of neuropathic pain, with the exception of trigeminal neuralgia, NICE recommends offering one of the following drugs (7)

- amitriptyline
- duloxetine
- gabapentin
- pregabalin

The drug tramadol should only be considered for short-term use in acute situations.

If the initial treatment proves not to be effective or well tolerated, NICE recommends offering one of the remaining three drugs, and switching again if the second drug is not effective.

For people with localised neuropathic pain, capsaicin cream can be offered if the person wants to avoid or cannot tolerate oral drug treatments.

Importantly, if upon your regular review your medical consultant suggests that there is a need to withdraw from or switch your medication, NICE guidelines suggest that this should be achieved by tapering the dosage to manage any discontinuation issues.

Musculoskeletal pain

This type of pain, also referred to as nociceptive pain, is very different to that of neuropathic pain as its primary cause is not nerve damage.

Fundamentally, musculoskeletal pain arises due to injury to soft tissue, tendons, bones, muscles, joints and nerves, which can be caused by impact or as a secondary result of your body compensating for a particular weakness. It can be both acute or chronic, depending upon the underlying cause and efficacy of treatment.

Musculoskeletal pain in people with MS can occur in so many ways. For example, if someone is affected by foot drop, they may naturally amend their gait to compensate for the impact this has upon their ability to walk safely. By changing their walking gait, it could lead to more strain being put onto other parts of the body, such as the hips and back, leading to injuries in those areas. In this instance a solution would be to identify ways that alleviate the impact of foot drop, helping the person to walk with a more natural gait before the damage caused to the other areas of the body becomes more ingrained.

Similarly, musculoskeletal problems can arise in people who spend long periods of time sitting or lying. Solutions may include reviewing the suitability of equipment, such as wheelchairs and beds, and could also incorporate interventions from occupational therapists (OT) and physiotherapists. Certain exercises may be recommended to help strengthen particular muscle groups, which in turn may help to provide pain relief.



Physiotherapy exercises really help a lot



Musculoskeletal pain treatment

NICE's clinical guidelines underpin the commonality of musculoskeletal pain in people with MS and seek to promote a multidisciplinary approach which aims to identify and then treat the cause of the pain (6).

As we touched on in the previous section, where appropriate, solutions may include assessments by specialist therapists, such as an OT or physiotherapist. They can see if any new equipment is required to help improve muscle function and relieve pain. Something simple like a different type of walking stick can help to improve balance problems which may be affecting the body and causing postural problems.

If immobility is a problem this can result in very painful hips, pelvis and lower back. If the limbs are stiff due to lack of mobility, pain in muscles, tendons and ligaments can also occur. Pain can also be caused by cramping which may be due to muscle strain or muscle fatigue. Regular stretching exercises can help, and a physiotherapist can assist in creating a bespoke exercise or stretching regime.

Over-the-counter medications such as paracetamol or anti-inflammatory drugs such as ibuprofen can help with the management of musculoskeletal pain. Talk to your GP if you are using paracetamol or anti-inflammatory drugs regularly, as there may be other, more effective medications available.

My osteopath really helped with painful muscle spasms in my neck and shoulder

Spasms and spasticity

While the pain that you feel from the impact of spasms and spasticity is musculoskeletal in nature, the cause is nerve damage that affects the movements of muscles. This damage disrupts the messages from the brain to the nerves causing irregular muscle activity. Pain from spasms and spasticity is generally acute, therefore sudden but short-lived, however at times can be incredibly uncomfortable.

NICE's guidelines for the management of MS include recommendations for the treatment of spasm and spasticity (6).

The guidance suggests that baclofen can be offered initially to treat spasticity in a person with MS, depending on contraindications, with gabapentin being a second-line option if required. If each individual drug is not effective, these can be offered in combination.



My neurologist helped find the right drug combinations for me



From April 2019 gabapentin was reclassified as a class C controlled drug within the UK, which means, along with other controls, repeat prescriptions will not be available. A new prescription will need to be signed off by your doctor when you need more medication (10).

Some anti-spasticity drugs can cause the muscles in the legs to weaken, reducing mobility, so it is important to get the correct

dosage and find the balance between getting the right amount of pain relief while maintaining muscle function.

Spasticity can also be made worse by other factors such as a urinary tract infection or other infections, or even constipation. It is important if you are experiencing spasticity to talk to your GP about whether these are factors contributing to your pain.



**Physiotherapists helped, they explained
how relaxation and movement can help**

Physiotherapy may be used in conjunction with medication to help achieve pain relief and improve muscular function (11).

More information

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

Alternative ways to manage pain

In addition to the conventional approach to pain management, there are other methods which studies suggest can be used to provide

relief. Great results have been experienced by people with MS when using alternative approaches and we will now look at a few of the more commonly known methods.

If you are experiencing pain and it is getting worse, if you are able to, find a safe place to sit down and take a few long deep breaths in and out

Action Potential Simulation therapy (APS)

APS therapy is a safe and effective drug free pain management system suitable for the treatment of both neuropathic and musculoskeletal pain. It is a type of micro-current therapy whereby an electrical current is transmitted through the human body via electrodes that make contact with the skin. The currents used are designed to mimic the electrical pulses that the body produces naturally, these are known as action potentials.

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 neuropathic pain, or improper nerve firing, such as with restless leg syndrome, applying waves of correct action potential frequencies seems to reduce the improper nerve impulses, reducing or completely alleviating pain or symptoms.

APS therapy is a way of reducing pain without using medication. During a small trial at the Bedford MS Therapy Centre, 57 per cent of participants reduced or discontinued analgesic medications as

a result of the effects of APS therapy. In addition, 78 per cent of participants had a significant reduction in pain (12).

APS therapy is used by numerous neurotherapy centres across the UK. There are also many independent therapists using APS and it is possible to hire or purchase APS therapy machines for use in the community.

More information

A good place to find out more about APS therapy is the Painfree Potential website, which provides information about relevant scientific studies and research, testimonials from people who have used APS therapy for pain relief, where to find an APS clinic, buying and hiring equipment and much more. For more information, visit www.painfreepotential.co.uk



Meditation – learning to embrace the pain



Cannabis

Cannabis is classified as a class B drug and possessing, producing and supplying it are against the law. However, MS-UK recognise the need for personal choice within the MS community and wish for people to be as informed as is possible on the use of cannabis for managing MS symptoms, including its use for pain relief.

The use of prescribed cannabis for medicinal purposes is now legal throughout the UK. However, there are strict criteria in place which still make it very difficult for people to access it via the NHS.

For example, in England and Wales, NHS guidance suggests that, while there is some evidence that medical cannabis can help with the management of certain types of pain, this evidence is not robust enough yet for it to be recommended for pain relief. The caveat is that medicinal cannabis could be prescribed for pain if it is as part of a clinical trial (13).

A four-week trial of THC:CBD spray can be offered to treat moderate to severe spasticity in adults with MS only if other treatments are not effective. It can only be prescribed following the trial if the person shows at least a 20 per cent reduction in spasticity as recorded on a numeric rating scale. Only those who are health professionals with a specialist expertise in treating MS related spasticity can initiate treatment (14).

To date research has shown that the use of cannabis to relieve the impact of MS-related pain can be effective, with modest pain relief being reported by people with MS who took part in various trials. However more widespread evidence is required to enable further understanding in the part that cannabis can play in MS related pain management (15).

More information

Our 'Cannabis' Choices booklet offers more information about the use of cannabis in managing the symptoms of MS, including information about accessing medicinal cannabis in the UK. Visit, www.ms-uk.org/choices-cannabis-and-ms-content

Low dose naltrexone (LDN)


Naltrexone is a drug that was initially developed to treat addiction to opiate-based drugs such as heroin and morphine and it is currently licensed in the UK to manage opiate dependency. LDN is fundamentally naltrexone taken in much smaller doses and is used as an 'off label' treatment for many different conditions including

gastrointestinal conditions, neurological conditions including MS and Parkinson's disease and chronic pain.


While more robust evidence is needed to determine the efficacy and safety of using LDN, a review of almost 50 studies has found that LDN offers promising results for people looking for help with managing chronic pain (16).

More information

Our 'Low Dose Naltrexone' Choices booklet provides further reading on LDN and the part it may play in managing MS symptoms. Visit, www.ms-uk.org/low-dose-naltrexone-multiple-sclerosis-choices-booklet



My GP was prepared to prescribe off-label remedies, low dose naltrexone (LDN), as well as restricted drugs like tramadol/maxitram to help me find a treatment that worked for me



Complementary therapies

Some people prefer to use complementary therapies rather than, or in conjunction with, conventional medicine to help them manage the impact of pain and other MS symptoms. These are generally therapies that fall outside of mainstream healthcare provisions and include practices such as acupuncture, reiki and meditation.

Research into the efficacy and safety of using complementary therapies for people with MS is still relatively sparse, however from the studies and trials that have taken place to date, the results

are encouraging, particularly regarding the role they play in pain management. For example, a meta-review of studies that took place since the turn of the century, all of which were focused on the effectiveness of acupuncture in helping people manage the impact of neuropathic pain, concluded that it was an effective alternative or adjunctive therapy (17).

Mindfulness is a meditative-based psychological intervention that involves learning to focus attention on the body, emotions and personal thoughts in an accepting and non-judgmental way. Mindfulness can be used to manage some of the symptoms of MS and other long-term conditions. Studies have shown significant evidence that mindfulness can exact improvements in quality of life for people with MS and have found that it has helped people cope better with their MS-related pain (18).

Mindfulness Based Pain Management (MBPM) is an approach developed by the charity Breathworks which combines mindfulness and compassion practices in order to help people manage the impact of chronic pain. There have been a number of studies which have evaluated this technique with the results showing significant improvements in the mental wellbeing of patients and their sense of being able to control their pain symptoms, pain acceptance and improved mood (19).

More information

Our 'Complementary Therapies' Choices booklet provides more detail about the use of these therapies for managing MS symptoms and outlines those most commonly used. Visit, www.ms-uk.org/choices-complementary-and-other-therapies-content

Our online activities portal provides access to some complementary therapies that can help with pain management, such as meditation and mindfulness courses. Visit our website to find out what is currently available. www.ms-uk.org/multiple-sclerosis-online-activities

The Breathworks website provides more information about practicing MBPM as a means of pain management. Visit, www.breathworks-mindfulness.org.uk/mbpm



Using apps for meditation helps you relax and concentrate on the voice of the coach instead of the pain

Pain management apps and programs

There is an ever-growing catalogue of pain management tools that can be accessed as applications or as online programs on smartphones, tablets and desktop. Some are available free of charge while others will demand a fee, be that in the form of a one-off charge, subscription or a series of in-app purchases.

Each tool will differ in terms of content, look and feel and the methods they use. Many are focused on helping people manage the impact of pain using techniques such as Cognitive Behavioural Therapy (CBT), mindfulness and breathing exercises.

Some applications allow the user to track their pain, so can be used as an electronic pain diary, recording things such as pain intensity, location and duration. They can also be used to record responses to the methods you use to manage pain, all of which can be helpful when explaining how pain is affecting you, for example during medical consultations.

More Information

You may find our blog 'A brief guide to pain management apps' a good place to start if you wish to find out more. This is available to view on our website. www.ms-uk.org/blog/pain-management-apps/

We asked the MS community to share their 10 top tips for managing pain, they are...

1

Try physio for sensitivity type sensations or pain

2

Plenty of rest and avoiding stress helps reduce symptoms

3

Create a positive soothing image to use when in pain

4

Use distraction/focus on something else. Try and do something you enjoy

5

Heat or cold applied to the area may help

6 **Steady breathing. Breathing in for the count of three and out for the count of five works for me**

7 **Stretching exercises like yoga and physiotherapy exercises can help a lot**

8 **Aromatherapy massage, or just inhaling appropriate oils, can help calm sensations and helps the ‘feel good factor’**

9 **Moisturising helps to calm down tingling and itching before bedtime**

10 **I use a tubigrip bandage or elastic leg or arm sleeves as the pressure helps relieve the pain**

Describing pain

Describing pain accurately can be a difficult task. As individuals, our perspectives of how pain feels are completely subjective, relying on our own interpretations of the sensations that pain causes. As such, two people affected by the same type of pain, caused by the same issue, may describe the pain that is affecting them quite differently. It is not just how pain feels to you that is important when describing

pain to others. For example, health professionals will require more detailed information when tasked with providing you with the right type of support for pain management. This may include how intense the pain is according to your pain threshold, the regularity of the pain, any trigger factors and an overall view of how the pain impacts your daily living.

For people with MS describing pain can be particularly complex given that the cause can be both neuropathic and musculoskeletal in nature, acute and chronic, can affect different parts of your body simultaneously and can fluctuate.

All pain can be described as a type of sensation, so focusing on this can help you to more accurately explain the nature of the pain that you are experiencing (20).

It may be helpful to be aware of some of the more common words that people use to describe their experiences of pain. These include

- Stabbing
- Burning
- Cramping
- Hot
- Electric shock
- Shooting
- Sharp
- Tingling
- Squeezing
- Aching
- Pins and Needles
- Tightness

Keeping a pain diary can help you succinctly record how it is affecting you over periods of time, outlining trends such as pain regularity, severity, causes and methods that you use to help manage its impact. It should reflect how pain impacts your life, and in terms of management, what does and does not work.

There are various pain diary templates with accompanying guidance available on the internet, with some pain management apps also offering this facility.

More information

Our pain diary sample template and guidance on how to document your experiences of pain is available to view on our website.

Pain Diary

This diary is designed to help you record and explain how pain is affecting you. It can be used in preparation for, and during, medical appointments.

Keeping a pain diary can help you succinctly record how it is affecting you over periods of time, outlining trends such as pain regularity, severity, causes and methods that you use to help manage its impact. It should reflect how pain affects you, and in terms of management, what does and does not work.

We have produced a [sample](#) of what a pain diary can look like, however you may wish to create your own diary so that it records information in ways that work for you. When doing so, as a guide, try to keep the information you record focused on the information that both you and health professionals will find helpful when attempting to review what you have recorded. Some areas of focus include:

- Record the date, time and length of time during the day which the instance of pain has affected you.
- Was the pain constant over this period or intermittent?
- Were there any particular triggers for the episode of pain?
- Was the pain made worse by anything? For example, by lifting your arm, doing any specific activity.
- What helped to ease the pain? Medication, mindfulness, limiting movement etc.

- Rate the pain in terms of severity. While pain severity is always subjective, rating different instances of pain can help to identify trends such as if pain is getting worse over a period of time and how different types of pain are affecting you. A rule of thumb is to use a scale between 1 to 10, with 1 being the least impactful and 10 being pain that is the worst possible, pain that you can barely endure.
- Always allow space for adding comments for each entry into your diary. Keep them short, where possible, but descriptive. Use this space to connect instances of pain that are reoccurring over the past weeks/months, documenting if the pain is gradually worsening over time.

During the production of this booklet, we asked the MS community to choose words that they use to describe the MS related pain and altered neuropathic sensations they experience.

They said...

- | | |
|--|---------------------------------|
| • Pins and needles | • Stabbing pains |
| • Burning sensations | • Sensitive skin |
| • Tingling | • Running or pouring sensations |
| • Numbness | • Intense aching |
| • Tightness, such as the 'MS Hug' – a particular tightness around the chest and ribs | • Electric shock-type feelings |
| | • Itching, stinging, prickling |
| | • A hot, fizzing pain |

Pain diary

Date and time	Describe the pain, where was it focused, how did it feel?	How long did the pain last? Was it constant or intermittent?
22/09/2023 12.00PM	Sharp stabbing pain in back of left leg, from hamstring to calf.	Intermittent since late morning, lasted around 2 hours before subsiding.

Did anything relieve the pain or make it worse?	With 1 being least and 10 being most, rate the severity of the pain	Additional information (e.g. any trends, how it affects you)
Tensing muscles in left leg brought attacks on. Paracetamol seemed to help with pain.	Rated it as '4' at its peak. Less severe after taking paracetamol.	Pain has occurred every few days or so since July 2023.

Further support and information

Aside from the resources that we have already signposted to within this booklet, you may find the following helpful.

Pain Concern

They are a registered UK charity that offers support and information for people who experience pain. Their services include a helpline and online resources designed to support you in the management of pain.

Visit www.painconcern.org.uk

Call 0300 123 0789

Email help@painconcern.org.uk

The British Pain Society

The oldest multidisciplinary professional organisation in the field of pain within the UK. This registered charity is a professional alliance comprising of healthcare professionals whose aim is to promote awareness and excellence to benefit people affected by pain.

Visit www.britishpainsociety.org

Email info@britishpainsociety.org

Pain Support

This UK based charity's website aim to help people in pain move forward in their lives with better pain management, with or without drugs, and to live a fulfilling and meaningful life.

Visit www.painsupport.co.uk

Action on pain!

A UK based charity that provides support and advice for people affected by chronic pain.

Visit www.action-on-pain.co.uk
Call 0345 603 1596
Email painline@action-on-pain.co.uk

Pain Association Scotland

A charity that promotes self-led chronic pain management in the community, including support groups for people affected by pain.

Visit www.painassociation.co.uk
Call 0800 783 6059
Email info@painassociation.com

Pain toolkit

A website that is full of resources, including workshops and webinars, to help people with the self-management of pain.

Visit www.paintoolkit.org

Neuro Therapy Network

A charity representing individual therapy centres across the UK. The centres provide access to a variety of treatments, complementary therapies, help and support to people affected by MS. Find your nearest centre by visiting the network website.

Visit www.neurotherapynetwork.org.uk

MS-UK Helpline

Our helpline can provide, at the very least, emotional support to people with MS who are experiencing problems with pain. They can also offer signposting to further support and information regarding pain management.

Visit www.ms-uk.org/ms-uk-helpline

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.

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

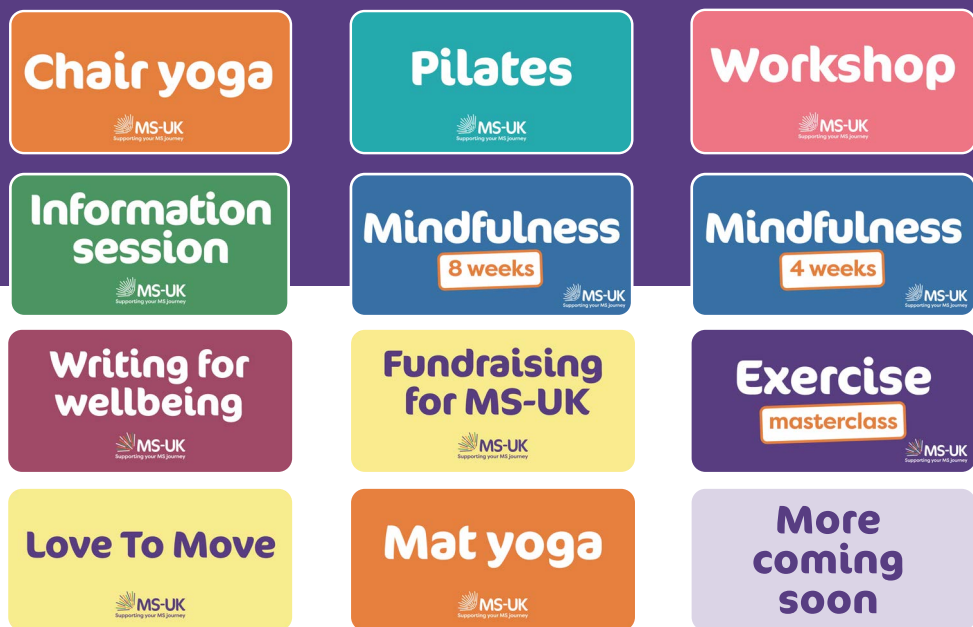
Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country. Available in print, audio version, 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 [ms-uk.org/peer-support-service](https://www.ms-uk.org/peer-support-service) or email peersupport@ms-uk.org.





MS-UK online activities

MS-UK offers a variety of online activities for those affected by MS to stay active, connected with others and to manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. To get involved, please go to www.ms-uk.org or email register@ms-uk.org.

MS-UK eLearning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created an accredited eLearning course that can help you do this. Visit www.ms-uk.org/ms-awareness-e-learning to find out more.

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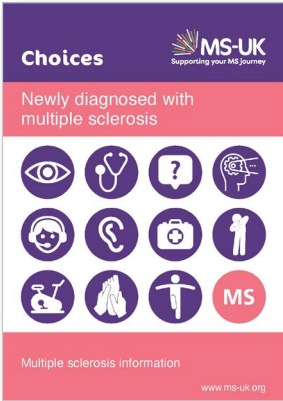
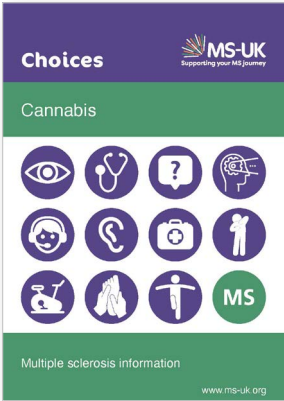
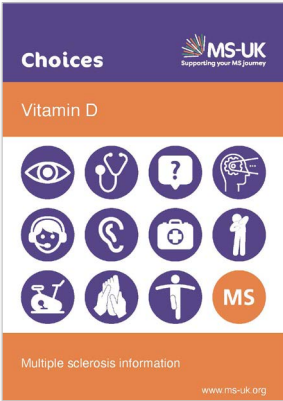
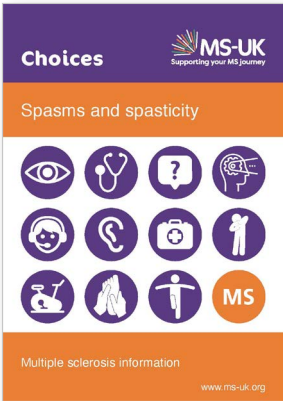
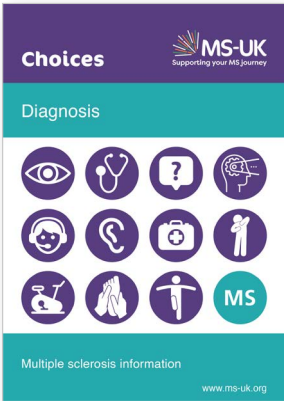
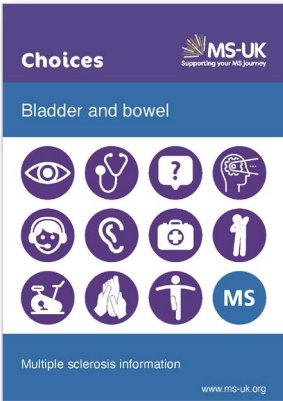
MS-UK

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Read more Choices booklets

For more information about living well with multiple sclerosis, visit www.ms-uk.org/choicesleaflets where you can read more and download your free copy of any of our Choices booklets.



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

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