Choices

Pain

Multiple sclerosis information

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

MS-UK believes we must listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

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

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

Every time you see a box with an icon like this, it is a quote directly from someone affected by multiple sclerosis.
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Pain

Over half 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 lifestyle.

No two people will experience pain in the same way, so it is best described by the person experiencing it.

Pain levels vary greatly individually, but I have taught myself to cope.

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

Don’t put up with it [pain], get help.

Working with your GP and neurologist is the first step towards establishing a pain management strategy.
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 accident. Therefore other possible causes of the pain should be thoroughly looked into and investigated.

**What is pain?**

Pain can be very difficult to describe. Some people with MS describe it as burning or gnawing, like immersion in ice cold water, or being too painful to touch the skin. It can disturb sleep even though you are exhausted. It can also be a stabbing, throbbing or crushing feeling, but often people find it hard to characterise.

There are a number of MS symptoms that may be classed as pain. MS-UK recently used a survey to ask the MS community to choose words to describe MS related pain and the altered neuropathic sensations they experience.
They said:

- Pins and needles
- Burning sensations
- Tingling
- Numbness
- Tightness, such as the ‘MS Hug’ – a particular tightness around the chest and ribs
- Stabbing pains
- Sensitive skin
- Running or pouring sensations
- Aching
- Electric shock type feelings

Pain can occur in the legs and arms, hands and feet, torso or face – in fact, anywhere on the body. It can be symmetrical – for example, occurring in both feet or both arms. Or it can be asymmetrical – and present itself on just one side of the body, or in one leg.

Pain is divided into two categories – acute and chronic.

**Acute pain**

This is described as very intense, sharp or a shooting pain. It can be intermittent and come on very quickly. It can also disappear very quickly.

**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.
Pain management

The type of pain treatment you receive will depend on the type of pain you’re experiencing and what’s 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 (5).

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

Management of pain is not always achieved easily or completely. Some pain may persist. There are a number of factors that can make it feel a lot worse. This can be anything from heat to extreme fatigue or even anxiety.

Neuropathic pain

In October 2014 the National Institute for Health and Care Excellence (NICE) published new guidelines (2) for the management of multiple sclerosis including recommendations for the treatment of neuropathic pain.

MS nurse has been my saviour. Without her I wouldn’t be able to access my consultant so quickly.
In agreeing a treatment plan with a person with MS experiencing pain, a GP, neurologist or MS nurse will consider the severity of the pain, its impact on daily life and determine the underlying cause.

They will discuss drug treatments, the benefits of a particular medication and the possible adverse effects (considering any other medications you may be taking). They will also discuss the dosage and the steps to increase the dosage if needed.

It may be that non-drug treatments may be appropriate such as physical therapies or psychological therapies. Surgery may be offered in some circumstances.

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).

Physiotherapists helped - they explained how relaxation and movement can help.

If your pain is severe, you may be referred to a specialist pain management service, usually through the local hospital.
The GP, neurologist or MS nurse will carry out regular reviews to check the effectiveness of the treatment to see if the drug is controlling the pain, if it’s still affecting your lifestyle, if the drug is causing any adverse effects and whether there is a continued need for treatment.

**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 will also assess if there is a need to withdraw from or switch treatments, and then suggest how this can be achieved by tapering the dose before starting a new drug, if needed.

For initial treatment of neuropathic pain (except trigeminal neuralgia) NICE recommends offering one of the following drugs: amitriptyline, duloxetine, gabapentin or pregabalin (3).

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.

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

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

This symptom can be experienced by people with MS. It’s 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. The pain travels 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 (trigeminal neuralgia).

For trigeminal neuralgia, NICE recommends offering carbamazepine as the initial treatment (4). 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 another form of acute neuropathic pain. It is often described as a sharp stabbing like feeling behind the eyes. It is very often a common first symptom of MS. This is caused by the optic nerve becoming inflamed. In some cases a course of steroid treatment is prescribed if this symptom does not improve over time – usually methyl-prednisolone, which helps to resolve the inflammation, resulting in the pain subsiding.

Pain from spasticity

Another form of acute pain comes from spasms – when a muscle seizes into an extended, outreached position resulting in pain. These are mostly felt in the legs.
The main cause of a spasm is the disruption of messages from the brain to the nerves at the bottom of the spinal cord, which are used to control the legs. Spasms are sudden and at times can be incredibly painful.

There is also another type of spasm called a tonic spasm, which is a spasm of the arm or leg in an unusual position. They usually last for less than 90 seconds, and can occur several times throughout the day.

NICE’s guidelines for the management of multiple sclerosis (2) included recommendations for the treatment of spasticity.

NICE suggest that either baclofen or gabapentin can be offered initially to treat spasticity in a person with MS, depending on contraindications (interactions with other medications the person may be taking). If each individual drug is not effective, these can be offered in combination.

The GP, neurologist or MS nurse will work with you to understand how to manage your own spasticity by explaining how to manage dosages of the drugs within agreed limits.

My neurologist helped find the right drug combinations for me.

The GP, neurologist or MS nurse will ensure that you have tried the optimal dose of these drugs, or the maximum dose that can be tolerated. They will ensure that the drug is stopped if there is no benefit at the maximum tolerated dose and that any drug treatment is reviewed at least annually until the optimal dose is reached.
Other drugs can be considered as a second-line treatment for spasticity. These are tizanidine and dantrolene.

Don’t be afraid to try out different medications.

Benzodiazepines can be considered as a third-line option.

NICE’s guidelines (2) also state that Sativex – a drug derived from the cannabis plant – should not be offered to treat spasticity. See our Choices leaflet, Cannabis and MS, for more information.

A GP can prescribe all of these drugs but they may well refer you to a Pain Clinic or your neurologist. 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 whilst maintaining muscle function.

Physiotherapy may be used in conjunction with a drug treatment to help achieve pain relief and improve muscular function (5).

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

You can easily be referred to a physiotherapist by a GP or neurologist. Also, if there is an MS Therapy Centre nearby you can contact them directly to see what treatment they have available.
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.

Musculoskeletal pain

This type of pain is very different to that of neuropathic pain and is quite often successfully treated by either physiotherapy or exercise (5). Changes to posture and certain exercises may be recommended that may help to strengthen certain muscle groups, which in turn may help to provide relief.

NICE’s October 2014 guidelines (2) seek to promote a multi-disciplinary approach where people with MS experiencing musculoskeletal pain are assessed by a specialist therapist such as a physiotherapist or occupational therapist. They can see if any new equipment is required to help improve the 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, lower back etc. If the limbs are stiff due to lack of mobility, pain in muscles, tendons and ligaments can also occur. Painkillers may be required and regular exercise can help. Physiotherapy is also very beneficial as it helps to keep the body moving and helps to realign the body.

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

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 an exercise or stretching programme.

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

Potassium and sodium deficiency are thought to be a cause of muscle cramps and spasms. Bananas are a good source of potassium (eating one a day can reduce the risk of a potassium deficiency). It is also thought that keeping hydrated can also assist in preventing cramps although strong evidence is lacking.
We asked the MS community to share their 10 top tips for managing pain, they are...

- Try physio for sensitivity type sensations/pain.
- Plenty of rest and avoiding stress helps reduce symptoms.
- Create a positive soothing image to use when in pain.
- Use distraction/focus on something else. Try and do something you enjoy.
- Heat or cold applied to the area may help.
- Steady breathing. Breathing in for the count of three and out for the count of five works for me.
Pain Management Clinics

If all other treatments tried have not reduced the pain, a referral to a specialist Pain Management Clinic is available by your GP or neurologist. If it’s not completely eradicated by various treatments tried, then the goal will be to help reduce it to a level that is bearable and manageable for the person. To find out where your nearest Pain Clinic is, you can contact The British Pain Society. See further information for more details.

Stretching exercises like yoga and physiotherapy exercises can help a lot.

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

Moisturising helps to calm down tingling and itching before bedtime.

I use a tubigrip bandage or elastic leg/arm sleeves as the pressure helps relieve the pain.
Expert Patients Programme

Self-Management UK is national charity that runs expert patient programmes for those who live with any long-term health condition(s). The purpose of the programme is to help manage their condition better on a daily basis and improve quality of life.

Courses are usually run over six weekly sessions of 2.5 hours and will cover various topics, including how to deal with pain and extreme tiredness and relaxation techniques. The aim of these courses is to help encourage people to take more responsibility and to self-manage their condition. To find a course near to you, see further information.

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 (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 neuropathic pain, or improper nerve firing (such as 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.

APS Therapy is now being used by at least eight MS therapy centres or wellbeing centres across the UK including MS-UK’s Josephs Court. There are also many independent therapists using APS and it is possible to hire or purchase APS Therapy machines for use in the community. For more details please see further information.

**Cannabis**

Although laws are changing in some parts of the world, cannabis remains illegal in the UK. MS-UK does not encourage the use of an illegal drug but we recognise personal choice within the MS community and wish for people to be as informed as is possible. There is an increasing body of evidence that suggests that cannabinoids (the active parts of cannabis) have beneficial effects on the symptoms of MS, including spasticity and pain. For more information please see our Choices leaflet Cannabis and MS.

**Mindfulness and pain management**

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-judgemental way. Mindfulness can be used to manage some of the symptoms of multiple sclerosis and other long term conditions.

**Meditation – learning to embrace the pain.**
Studies have shown significant improvements in quality for people with multiple sclerosis and have found that mindfulness has helped people cope better with their MS related pain (8).

**Complementary therapies**

Some people prefer to use complementary therapies rather than conventional medicine. Also, some drugs may cause adverse effects that cannot be tolerated meaning people chose different management techniques. Many people choose a complementary route for pain management or work it in partnership with traditional medicines. It is mainly anecdotal evidence that is used to report the benefits found from using complementary therapies to manage pain and aid relaxation. There is not much hard evidence suggesting that complementary therapies are effective in pain management for neuropathic pain.

However the research that exists suggests that more studies should take place particularly in respect of cannabis extract, magnets and electrostimulation (9). There is some evidence that shows that some complementary therapies can be effective for relief of other types of pain particularly musculoskeletal pain, especially acupuncture, Mind Body Therapy (MBT), nutritional supplements and spinal manipulation (10).

It is possible that some complementary therapies may be available through your GP, but for most you will have to pay privately.

It is important that a reputable qualified practitioner is used. Most practitioners would not advocate completely abandoning traditional medicine for a complementary approach; instead they see its role as being there to complement modern medicine. Practitioners will usually advise you to consult with your doctor before receiving any significant treatments. See our Choices leaflet, Complementary and other therapies for more information.
Further information

APS Therapy (Action Potential Simulation)

You can buy APS Therapy machines with a full money back guarantee within eight weeks if you don’t have success. You can also rent a machine, which allows you to try out the therapy. The website lists all the centres that deliver the therapy as well as all the independent therapists around the country.

Call 01908 799870
Email miranda@painfreepotential.co.uk
www.painfreepotential.co.uk

The British Pain Society

The largest multidisciplinary professional organisation in the field of pain within the UK.

Third Floor, Churchill House, 35 Red Lion Square, London WC1R 4SG
Monday to Friday 9.30am to 5.30pm
Call 020 7269 7840
Email info@britishpainsociety.org
www.britishpainsociety.org

Expert Patients Programme

Free self-management courses for people living with any long-term health condition.

03333 445 840
hello@selfmanagementuk.org
www.selfmanagementuk.org
MS-UK Choices leaflets – Complementary and other therapies, Exercise, Visual symptoms, MS Therapy centres

www.ms-uk.org/choicesleaflets

NHS Choices

www.nhs.uk/conditions/stress-anxiety-depression/pages/mindfulness.aspx

Pain Concern

An organisation that offers support and information for people who experience pain. A listening ear helpline giving the chance to talk to others in the same situation.

Unit 1-3, 62-66 Newcraighall Road, Fort Kinnaird, Edinburgh EH15 3HS

Call (office) 0131 669 5951
Helpline 0300 123 0789
Monday to Friday 10.00am – 4.00pm
Email info@painconcern.org.uk
www.painconcern.org.uk
About MS-UK

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

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

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

The MS-UK Helpline

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

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

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

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

MS-UK Counselling

MS-UK Counselling is open to anyone living with MS and is the only service of its kind available in the UK. Whether you want support coming to terms with a diagnosis or to improve your mental wellbeing, our counselling service is focused on helping you.

All of our MS-UK counsellors are BACP registered or accredited with an in depth knowledge of MS.
Sources


(2) The National Institute for Health and Care Excellence (NICE), Multiple sclerosis in adults: management . www.nice.org.uk/Guidance/CG186


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Use me for your notes
Stay in touch

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