Choices

Pain

Multiple sclerosis information

www.ms-uk.org
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, we 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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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 activities, such as work and leisure, their mood and pleasures of life.

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

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.

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

"Don’t put up with [pain], get help"
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 it being too painful to touch the skin. It can disturb sleep even though you may be 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 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 anywhere in the body. It can be symmetrical – for example, occurring in both feet and 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, a 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.

The type of pain 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.

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 worse. This can be anything from heat to extreme fatigue or even anxiety.
Neuropathic pain

The National Institute for Health and Care Excellence (NICE) have guidelines (2) for the management of multiple sclerosis which include recommendations for the treatment of neuropathic pain.

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.

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

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 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 will be appropriate such as physical therapies or psychological therapies.

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 the pain is 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 (3)

- amitriptyline
- duloxetine
- gabapentin
- pregabalin

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 (3). 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 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 methylprednisolone, which helps to resolve the inflammation, resulting in the pain subsiding.

**Spasms and spasticity**

Another form of acute pain comes from spasms – sudden, uncontrolled movement caused by muscles moving in an involuntary way. These are usually 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.

NICE’s guidelines for the management of multiple sclerosis (2) include recommendations for the treatment of spasm and 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. There are second-line options that can be considered if first-line drugs are not effective, these are tizanidine or dantrolene.

Benzodiazepines can be considered as a third-line option, such as diazepam.

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.

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.

“My neurologist helped find the right drug combinations for me”

A GP can prescribe all of the drugs mentioned but they may well refer you to a pain management clinic or to your neurologist for more specialist support. The goal of a pain management clinic is to help reduce the pain to a level that is bearable and manageable. They will aim to support you in developing self-help skills to control and relieve your pain.
Don’t be afraid to try out different medications

Both gabapentin and pregabalin are classified as class C controlled drugs which means the amount prescribed is limited so more frequent prescriptions will be required (4).

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. Most hospitals have a neurophysiotherapy department for more specialist support. Also, if there is an MS Therapy Centre nearby you can contact them directly to see what treatments they have available.

Physiotherapy helped with ‘over-sensitive’ hands
For more information please see our Choices booklet Spasms and spasticity.

**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 pain relief.

“Physiotherapy exercises really help a lot

NICE’s clinical guidelines (2) seek to promote a multidisciplinary 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 and lower back. 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 realign the body and to help keep it moving.

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

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

1. Try physio for sensitivity type sensations/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/arm sleeves as the pressure helps relieve the pain

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

As well as the conventional medicine approach to pain management, many people affected by MS have looked into other ways of managing their pain levels. Great results have been experienced with drug-free approaches. When a person is in pain, it is worth trying almost anything to gain some relief. Sometimes benefit can be found in the simplest of ways.

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 safe and effective drug free pain management system suitable for both neuropathic and nociceptive (from damage/injury to the body) pain. It 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 (6).

APS Therapy is used by numerous MS therapy 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. For more details please see further information.

Cannabis

Cannabis is classified as a class B drug and possessing, producing and supplying it are against the law. However, MS-UK recognise 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 such as pain.

In November 2018, the government legalised cannabis (in England and Wales) for medicinal usage. However, there is strict criteria in place which still make it very difficult for people to access it. The NICE guidance suggests its usage in helping to reduce chronic pain and spasticity (7). Only adults who had started cannabis-based medicinal products to manage chronic pain in the NHS before the guidance was published should be able to continue treatment, until their clinician feels it appropriate to stop. 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 considered 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 (7).

Studies suggest that cannabis-based medicines may increase the number of people achieving greater pain relief compared with placebo (8). More evidence and studies are required.

For more information please see our Choices booklet Cannabis and MS.

**Complementary therapies**

Some people prefer to use complementary therapies rather than, or as well as, conventional medicine. Some drugs may cause adverse effects that cannot be tolerated meaning people choose different management techniques. Many people choose a complementary route for pain management or use different therapies alongside 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 to show 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. Many MS Therapy Centres offer a variety of different complementary therapies so it is worthwhile contacting your nearest centre to find out more.

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 booklet, Complementary and other therapies for more information.

**Mindfulness**

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 improvements in quality of life for people with MS and have found that mindfulness has helped people cope better with their MS related pain (11).

Mindfulness Based Pain Management (MBPM) is an approach which provides specific applications for people living with pain. It has been shown to have a significant impact on catastrophising thinking. Studies show that if you catastrophise pain it has the greatest impact on quality of life, especially social functioning, vitality, mental health and overall general health.

Studies report significant improvements in the mental wellbeing of patients and their sense of being able to control their pain.
symptoms, pain acceptance and improved mood (12).

There are courses available online via Breathworks. One particularly relevant one is called ‘Methods for living well with pain and illness’. To find out more, see further information.

Other Support

There are a number of self-help groups from a variety of organisations who support people living with long term pain. These include the following

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.

Monday 2pm – 4pm, Friday 10am – 12pm and 2pm – 4pm
Call 0131 669 5951
Helpline 0300 123 0789
Email info@painconcern.org.uk
Visit www.painconcern.org.uk

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

Monday to Friday 9.30am to 5.30pm
Call 020 7269 7840
Email info@britishpainsociety.org
Visit www.britishpainsociety.org
Pain Support
The charity’s aim is 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

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 hire a machine, which allows you to trial an APS Therapy machine at home for four weeks, for the cost of £25 to cover batteries, electrodes and shipping. 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
Visit www.painfreepotential.co.uk

MS-UK Choices booklets
A range of publications including Complementary and other therapies, Exercise, Visual symptoms, Spasms and spasticity

Visit www.ms-uk.org/choicesleaflets

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

Call 01296 711699
Email info@msntc.org.uk
Visit www.msntc.org.uk

**Breathworks**
Helping people living with pain, illness and stress to re-claim their lives through mindfulness and compassion. Courses available online.

Call 0161 834 1110
Email info@breathworks.co.uk
Visit www.breathworks-mindfulness.org.uk
Use me for your notes

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

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

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

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

The MS-UK Helpline

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

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

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

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

MS-UK Counselling

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

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

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


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