

Pain covers a wide range of unpleasant physical sensations, but everyone - people living without or with multiple sclerosis (MS) - experiences it differently. Pain can be long lasting and impact daily life, or come in short irritating bouts. For many people with MS, pain may occur at any point, is often chronic and can be caused by other symptoms (like spasticity). For others, pain can be minimal or non-existent. It's important to assess whether any pain is caused by your MS or other reasons. With the right information and support, pain can be minimised or managed effectively to maintain a healthy and active lifestyle.

MS and pain

What is pain?

No two people experience MS pain in the same way – it can be slightly annoying, uncomfortable or excruciating. MS pain can cause great discomfort yet seem invisible to people around you, and is often described by how long it lasts:

- **Acute pain** in MS begins suddenly, then improves or disappears or may reappear from time to time. Often an intense, sharp, burning or shooting feeling, related to injury or short-term illness (for example, a broken bone or gout).
- **Chronic pain** is longer lasting and the most common type of pain for people living with MS. May sometimes feel better, but never goes away. Generally lasts longer than three months. Also known as persistent pain. Needs a more complex management plan.
- **Paroxysmal symptoms** start suddenly, only lasting for a few seconds or minutes at most. May reappear a few or many times a day in similar short bursts.

MS pain can feel very odd and seem difficult to explain. The more common descriptions include:

Aching ~ An electric shock ~ Burning ~ Crawling ~ Gnawing ~ Itching ~ Numbness ~ Pinching ~ Pins and needles ~ Prickling ~ Shooting ~ Squeezing ~ Stabbing ~ Steady ~ Tickling ~ Throbbing ~ Tightness ~ Tingling ~ Trickling of water

You may have another description for your pain. Nerve pain (see below) is particularly difficult to describe and people with MS sometimes worry that they won't be believed or they're 'going mad'. Pain and unusual sensations are common in MS and like other symptoms, treatment should be discussed with your healthcare team.

What causes pain?

There are two main causes of pain in MS:

1. Nerve pain (neuropathic pain) results from damage caused by MS to the nerve covers in the brain and spinal cord. This damage interferes with the normal transmission of messages to the brain – which can interpret these disrupted messages as pain or unusual feelings like numbness, pins and needles, crawling or burning. These feelings can occur anywhere in your body.

Although the pain feels like it's in a particular part of your body, like your fingertips, there's no damage to the tissues in your hand. The only damage is in the nerves which report to your brain about your hand and this is what makes it seem like there's something wrong with your fingertips.

Nerve pain examples include:

- **Trigeminal neuralgia** – an intense sensation in the side of the face
- **Lhermitte's sign** - electric shock feelings in the neck and spine
- **Optic neuritis** – a sharp, knife like feeling behind the eyes which may cause vision issues.
- **Painful altered sensation** - sometimes called dysaesthesia or paraesthesia, described variously as pins and needles, burning, numbness, prickling, itching and crawling.
- **The MS hug** (banding or girdling). A feeling of pain in the chest or rib, tightness or being squeezed around the chest, which can also occur around your hands, feet, legs or head.

2. Musculoskeletal pain (nociceptive pain) is caused by damage to muscles, tendons, ligaments or soft tissue. Musculoskeletal pain in MS feels like the pain from common injuries unrelated to MS, such as a sprain or pulled muscle.

Musculoskeletal pain examples include:

- **Hip and back pain** caused by alterations in how you walk due to MS, possibly because of muscle stiffness (spasticity), weakness or problems with balance.
- **Back pain** due to sitting for long periods, a result of fatigue, walking difficulties or inability to stand for long.
- **Muscle or joint pain** due to posture changes, spasms or muscle stiffness (spasticity).

Other causes of pain

You may experience pain for other reasons including:

- Medication side effect e.g. headaches or injection site reactions to disease modifying therapies.
- From an infection, such as a bladder infection.
- From an accident or other health condition not related to MS.

People with MS often experience more than one type of pain.

Other life events can make pain feel better or worse, so it's important to manage stress, get support and try to remain positive about managing your pain. Like many MS symptoms, heat (or sometimes cold) sensitivity can make pain worse, as can fatigue, lack of sleep, feeling isolated or depressed.

What's different about MS pain?

Whilst pain is common to most, for many people living with MS it can be chronic, debilitating and affect your daily life, and worsen or be caused by other MS symptoms.

Pain is one of the challenging invisible symptoms of MS. It can be hard for someone to tell if you're in pain, so it's important to tell them. Due to its invisibility, others may need help to understand your pain, learn what makes it better or worse and what they can do to help.

Tell your family, friends, carer and/or co-workers about your pain so they can understand what you're going through.

In MS there's no 'one size fits all' solution to pain management, so a team approach – you, your healthcare team, family, carer and others – can be helpful.

With the right advice, you can manage or reduce pain. Like MS itself, MS pain varies from person to person, so an individual approach is best.

What should I do if I experience pain?

If you have pain concerns talk to your MS nurse or GP, and at your next visit, tell your neurologist. It's important to investigate your pain and why it occurs, and to develop strategies for any daily, sudden, severe or new pain, changes in your pain or unusual sensations.

You may be referred to a pain clinic, physiotherapist and/or psychologist, for further assessment and advice. A thorough evaluation can help to identify the contributing factors and develop a tailored approach, for your circumstances.

Describe and discuss your pain

To help your healthcare team understand your pain and its effect, it's often useful to describe:

- **Where you feel it.** For example in your head, neck, arms or left leg.
- **When you feel it.** Such as day/night, whilst walking or first thing in the morning.
- **How it feels.** Perhaps sharp, dull, aching, burning, crawling, tight, like a pressure or something else.
- **What changes your pain.** For example it may worsen in hot weather or improve with ice, applying heat, by relaxing or sitting in an upright chair, or feel different after exercise.
- **How it affects you.** Perhaps you find it harder to fall asleep or sit for long, it impacts your walking or stops you doing a favourite activity. It's good to say exactly what's happening, for example, it takes two hours to get to sleep or you can only sit still for 20 minutes at a time.

And discuss:

- **What you've done to attempt to relieve it.** For example taking painkillers or other pain relief medication, stretching, physiotherapy or rest.
- If your pain is **worse**, has **changed** or **stopped**.
- **How you're managing all your MS symptoms**, including pain.
- Any **major life changes** such as a new job, exercise program, personal events, diet changes or medical diagnosis.

Useful questions to ask your healthcare team may include:

- **How can I tell** if a particular medication or pain management strategy is working?
- **What can I do** to better manage my pain?

Think about whether the pain:

- Comes in short or long lasting bursts or is there all the time
- Started suddenly or increased bit by bit
- Started at the same time as other new symptoms or when previous symptoms came back quite suddenly. This may suggest that your pain is part of a relapse.
- Has happened before. When? Does it feel the same?

What can I do to manage this symptom?

It can be useful to learn to recognise the early signs of pain and how it affects you, and tell people close to you, to help them understand any limitations.

Create a pain management plan

It's important to have a personal pain management plan that details who can help with pain, what's being done to manage it, when these strategies should be reviewed and what to do in an emergency.

How is pain treated?

How your pain is treated depends on the cause and severity. A thorough assessment to decide whether it's nerve or muscle pain or due to something other than MS is recommended.

Treating pain often means trying several treatments one after the other, or perhaps at the same time, to see what works best for you. Some people find physiotherapy and other non-drug treatments effective.

Besides following the advice of your healthcare team about treatments (they should review your treatment regularly and suggest alternatives if something isn't working well), it's also wise to make changes to your daily life to minimise your pain and its effects. It may not be possible to stop your pain completely, so it may be a case of managing it as well as possible to reduce its impact.

Treatments

Medication may help if used in conjunction with pain management strategies, or you may need to review your current treatment program. The type of medication used to treat MS-related pain usually depends on its source.

Not all nerve pain will be treated, for example, numbness and loss of sensation may not be treated unless they are causing particular distress.

Although nerve pain can usually be improved with drug treatments, it's often best to take other steps to managing the pain yourself (see below).

Generally speaking, if your pain is from neurological sources (MS-related damage to the brain, spinal cord and nerves), your doctor will most likely suggest taking an anti-convulsant medication. These medications affect the way messages are sent along nerves. Pain from neurological sources can also be eased by low doses of anti-depressant medications.

If your pain is from musculoskeletal sources (damage or changes in joints, muscles and soft tissues), your doctor may recommend a simple or strong analgesic, as these specifically ease pain that is related to the body's soft tissues.

Alternatively, your doctor may suggest an anti-spasmodic medication if your pain is likely to be caused by muscle spasticity or spasm.

Other treatments for musculoskeletal pain

TENS (transcutaneous electrical nerve stimulation) is the application of small harmless electric signals to reduce pain. TENS may work for burning, tingling or shooting pain, for back pain and painful leg spasms, especially if medications for spasms and spasticity aren't tolerated.

Rehabilitation or **rehab** can reduce the impact of symptoms on daily life and help to minimise the impact of your pain on work, studies and/or family life.

Speak with your healthcare team about potential reactions with other medications you may be taking, and tailored options to improve your individual situation.

How can I manage pain myself?

Managing pain includes learning useful psychological strategies and making changes to daily life to reduce its impact. Effective pain management can help you to get enough sleep and avoid irritability, anger or depression, all of which can exacerbate the symptom.

You may need to try different options to find what works best for you. Several at once may have the best effect. Some people prefer the approaches below to drug treatments, as there's less worry about side effects.

- **Exercise.** Lack of activity or exercise due to pain or other symptoms, can cause a gradual loss of strength and fitness. 'Deconditioning' can worsen your pain but improves with regular exercise, which also helps ease your pain. Less vigorous forms of exercise include gentle stretching exercises, t'ai chi, yoga, walking, aquatic exercise, classes or gym work. It's important to find something enjoyable which helps, rather than aggravates your pain.
- **Movement.** If pain is a concern, if you can, it's better to move around often, rather than lie down or sit for long periods. (Try small regular position changes when seated or move around or limit time spent lying down). If you find it difficult to move, someone may be able to help you with general stretching exercises. These small gentle movements may ease the pain and help prevent pressure sores.
- **Posture.** Small changes to your posture can make a big difference to pain, especially in the back and neck. Try placing a rolled-up towel in the small of your back to ensure that the spine is held in a good position. Regular upright standing against a vertical surface (such as a wall) or in a standing frame can also help to improve posture and reduce muscle or ligament pain.
- **Pacing.** If possible, break large tasks into smaller chunks, short bursts or over several days and take regular, short breaks before you overdo it. This can seem frustrating at first, but can help keep your pain to a minimum.
- **Change your habits.** Making changes can help, for example a better mattress, read while sitting or order goods online, to avoid heavy bags. Challenge yourself to come up with new, creative ways of doing things that are kinder on your body and ease your pain. Ask people to work with you, so that they understand how these changes will help you.
- **Heat.** Although heat sensitivity can worsen MS symptoms, heat applied to the affected area can help. You could try a hot water bottle or heat pad but be sure to check the temperature on an unaffected area first, as the affected area may have reduced sensation. A warm bath can reduce pain, as long as it doesn't worsen your other symptoms.

- **Cold.** Some people find that applying ice or a cold pack helps. Ice should be wrapped in a tea towel not applied straight to the skin, or you could try a pack of frozen peas.
- **Complementary and alternative treatment.** There's some evidence that acupuncture can help MS pain. Aromatherapy and massage can reduce muscle stiffness and promote relaxation and wellbeing.
- **Slow breathing and relaxation techniques.** Symptoms of stress or tension can worsen pain but slow breathing or other relaxation exercises can help. Other ideas include listening to music, managing your sleep patterns, meditation, mindfulness and yoga.
- **Keeping a diary.** A daily or weekly symptom diary helps many people to manage their MS better and review their MS with their health professionals. It can be useful to note when you experience pain, how it feels and what else is happening with your MS and elsewhere in your life. This can help to identify factors that trigger or aggravate your pain so you can then make changes to manage your symptoms better. A way to grade pain is to describe it as a number between 0 and 10, where 0 = no pain and 10 = the worst pain imaginable. A daily pain level diary may help you discover whether treatments are working to reduce the pain.
- **Stay positive.** Dealing with pain can be hard so it's good to stay as positive as possible. In some cases, your MS nurse or GP may be able to refer you to a clinical psychologist to help with this. Seeing a psychologist or using psychological techniques to manage your pain doesn't mean it's 'all in your head'. It can be one of the ways that helps you deal with and manage your pain and manage it well. Many pain-support organisations (see below) have helplines, resources and some may offer useful self-management toolkits.
- **Share your thoughts.** With invisible symptoms of MS such as pain, it can be good to share how you're feeling and to ask for help when required – from your healthcare team, family, friends or carer, or to hear from other people living with MS who have experienced pain.

Exercise and pain management in MS

Exercise is an essential part of managing your MS as it can help with balance, mobility and fatigue, and can even improve your mood. People who exercise regularly tend to be able to cope better with the demands of daily activity. Exercise provides pain relief to some, and is an essential part of any pain management plan.

You could try an exercise class, exercise at home, walking, gym, or aquatic exercises like swimming or hydrotherapy. It's important to find a way to exercise that suits you.

Information and assistance:

General

There is support available to help you manage your MS:

- **Your MS Nurse or GP** should be the first contact for any new and/or persistent concerns related to pain.
- **Your neurologist, MS Nurse or other healthcare provider** can help you to manage symptoms on an ongoing basis and discuss the best approach for your individual circumstances.
- **Contact your state MS organisations** (details below) to access services including peer and/or online support and other resources.
- For information about MS and MS treatments visit www.msaustralia.org.au
- **Contact details for your state/territory MS organisations:**

MS Limited (Victoria NSW ACT Tasmania)	1800 042 138	msconnect@ms.org.au	www.ms.org.au
MSWA (Western Australia)	1300 097 989	communications@mswa.org.au	www.mswa.org.au
MS Society SA & NT (South Australia NT)	1800 812 311	msassist@ms.asn.au	www.ms.asn.au
MS Queensland	1800 177 591	info@msqld.org.au	www.msqld.org.au

Other organisations

The following support services may be able to provide other advice:

- **Pain Australia 02/ 6232 5588** <http://www.painaustralia.org.au> is the national peak body and works to prevent and manage pain. Pain Australia provides resources, service information, support, help lines and links to other useful organisations via this link: <http://www.painaustralia.org.au/getting-help/support-groups-help-lines>
Pain Directory: <https://www.painaustralia.org.au/getting-help/pain-directory>
- **The Australian Pain Society 02/ 9016 4343** www.apsoc.org.au provides resources and information on pain clinics, services and more.
- **Chronic Pain Australia** <http://chronicpinaustralia.org.au> works towards de-stigmatising chronic pain, provides support, information and runs National Pain Week.
- **Independent Living Centres 1300 885 886** www.ilcaustralia.org.au has a range of products to assist with day-to-day living including to prevent and manage pain.
- **Carers Australia 1800 242 636** www.carersaustralia.com.au provides information and advice to carers, their friends and families about carer support and services.

Other resources

The articles and posts on the MS Australia Wellbeing Wednesday platform, Facebook page and MS Uninterrupted blog, often include health and wellbeing topics, sometimes related to pain management:

<https://www.msaustralia.org.au/living-ms>

<https://www.facebook.com/MSAustralia/>

<https://www.uninterrupted.org.au/>

Sources: This fact sheet comprises material from previously published Australian state/territory MS Organisation leaflets plus Multiple Sclerosis (MS) UK Trust online resources (and associated references), and has been endorsed by a medical expert, an MS Nurse and a person living with MS.

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