

A close-up photograph of a man with white hair and glasses, looking down with a thoughtful expression. He is wearing a dark jacket. The background is blurred green foliage.

Pain

and unpleasant
sensations in MS



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A word from Eiona, who has MS

I live with moderate pain caused by my MS. Over time I've found different ways of coping.

Personally, I don't tolerate medications too well. To distract myself from pain, I like to become engrossed in the moment, doing things I love.

For example, one of my hobbies is photography. When I'm in the moment, and I'm trying to get the composition right - or I see something which captures my eye - it takes my mind away from the pain.

Every morning while I'm in the shower, I do a brief series of positive affirmations. I try to turn negative emotions into positive ones by simply repeating a positive statement five times.

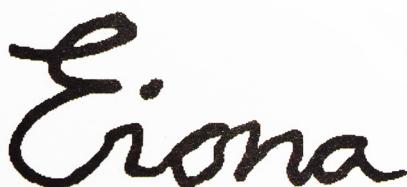
Sometimes I say to myself "I feel no pain", with each affirmation getting louder and more forceful.

To those who've been newly diagnosed with MS, I'd say: remember that MS is different for each one of us.

You may not necessarily experience any pain at all. If you do, the pain is relative to you alone, so don't compare yourself with others.

I'd recommend seeking information from publications such as this, plus from the links in it.

No one needs to suffer. Even the worst pain imaginable can be managed and minimised to help you live a full and happy life.

A handwritten signature in black ink that reads "Eiona". The signature is fluid and cursive, with the letters "E" and "i" being particularly prominent.

Five things to know

- 1** How you feel pain is individual to you. One part of pain is the uncomfortable physical feeling in your body. But the other part is how you react to this emotionally
- 2** Pain in multiple sclerosis (MS) can take many different and unusual forms. It can be caused by nerve damage in the brain or spinal cord. Or it can come from your symptoms and the strains they place on your body
- 3** People with MS often get pain. You can reduce its impact on your life by using different medications, therapies and relaxation techniques
- 4** Pain can be easier to cope with if you stay active, learn ways of relaxing, reach out for support, and if you're kind to yourself
- 5** There's support available to help you cope with pain. This booklet has lots of suggestions



About this booklet

You can dip in and out of this booklet to find the information you need. Feel free to skip parts. The detail's there if you ever need it.

The booklet covers the physical side of living with pain and unpleasant sensations, and also the emotional challenges.

We explain different types of pain, and how you can describe them to doctors and other medical staff. That way, it'll be easier to work out the cause and how to treat it.

There are different ways to manage and treat pain. That could include medication, changes to how you do everyday things, using relaxation techniques, and emotional support.

Perhaps your pain can't be completely got rid of. If it can't, hopefully after reading this booklet you'll be better able to cope with it.

One last thing. If you see any words in **bold**, you can turn to page 53 and find them explained.

What do we mean by ‘pain’?

Pain is a very individual symptom. It takes many different forms, sometimes unusual ones. It changes over time. And, unlike many MS symptoms, other people can’t see it. All this can make it hard to describe.

What is pain?

Pain is any feeling that’s both physically uncomfortable and somehow affects your mood.

Everyone feels pain differently. Only you’ll know if a feeling in your body is causing you discomfort (and how much).

The unpleasant physical feeling will cause an emotional reaction in you. This could be fear, anger, frustration or distress. These reactions can affect how you cope with the painful sensations.

MS can involve a range of unusual sensations, which can be painful. For example, a ‘pins and needles’

feeling, a burning sensation or a feeling of things crawling or itching under your skin.

These sensations can be the first signs of MS. And they might strike you as being very odd. If you get them before you’re diagnosed with MS, they might even make you feel you’re ‘going mad’, not having an explanation.

Sometimes you might describe these strange feelings as ‘pain’. Sometimes you might not. Doctors might describe them as nerve pain, ‘paresthesia’ or ‘dysesthesia’.

They might also define pain by how long it lasts, like in the table opposite.

Finding the words

When you talk to your medical team, describe your pain or unpleasant sensation in detail. That helps find the best ways of treating and managing it.

Some of the unusual sensations could be tricky to put into words.

Type of pain	Explanation
Acute pain	Short-term pain that starts suddenly, but then gets better or goes away. It typically lasts less than 12 weeks but might sometimes come back
Chronic pain	Ongoing, long-term pain that might be mild, moderate or severe. It never completely goes away. It usually lasts more than 12 weeks. But you don't have to wait 12 weeks to ask for help in managing it
Paroxysmal pain	Occasional, unpredictable pain that comes on in a sudden attack that lasts only a few seconds or minutes. It usually comes back later. This can happen several or many times a day in short but intense bursts

Use whatever words come naturally to you. Use words that sum up how it is for you, even if it sounds odd.

There are some examples of the words people use on the next page.

Recording your pain or unpleasant sensations

Keeping a pain diary can be very helpful. You try to write down

exactly how a sensation feels in your body on a particular day. You can also score and record day by day your levels of pain, fatigue and anxiety.

The details that should be included in a pain diary can be remembered using the abbreviation OLD CARTS. This is explained in the table on page 11.



Put in your diary how much the pain interferes with things like:

- sleeping
- washing and getting dressed
- work
- family life
- moving around
- enjoying your hobbies

Try to give specific examples, like:

"It took me one hour to fall asleep on Tuesday night because I had a bad headache and painful **spasms** in my legs."

Another could be:

"I could only sit at my office

desk for half an hour at a time on Wednesday because of my continuous back pain."

Keeping a pain diary helps you remember details of your symptoms to share with your doctor.

This helps your doctor understand what you're feeling. It'll help them give you an accurate diagnosis and suggest the right treatments.

You might also find a pain diary helps you manage your MS better. It can highlight how your symptoms change from day to day and what makes a difference.

Judging your pain using the OLD CARTS abbreviation

Things to make a note of	What you should write down
Onset	When did your pain start?
Location	Where in your body do you feel the pain?
Duration	How long does your pain last?
Characteristics	How would you describe your pain? For example, is it a sharp, dull, aching or a tingling sensation?
Aggravating factors	Does anything make your pain worse? Examples could be hot or cold weather, stress, or doing too much or too little
Relieving factors	Does anything make the pain better? Examples could be resting, or changing how you stand or sit
Treatments	What are you doing or taking to relieve your pain?
Severity	How would you rate your level of pain from 0 to 10, when 0 = no pain and 10 = the worst pain you can imagine? It might help to score your pain at the same time twice each day. Using the same scale, you could score your fatigue level (how tired you feel) and your mood. You'll then understand how these two things affect your pain levels

Why do I have pain or unpleasant sensations?

MS causes pain in two ways. It causes it through damage to your nerves in the brain and spinal cord. Or it's caused indirectly, as a result of your MS symptoms, or from living with disability.

Pain can also be a side effect of medication. And it could be due to other health conditions, just like for people who don't have MS.

Nerve pain and unpleasant sensations

Nerve pain affects up to 1 in 4 people with MS. It's caused by damage to the nerves in your central nervous system (your brain and spinal cord). You might hear this pain called 'neuropathic' pain.

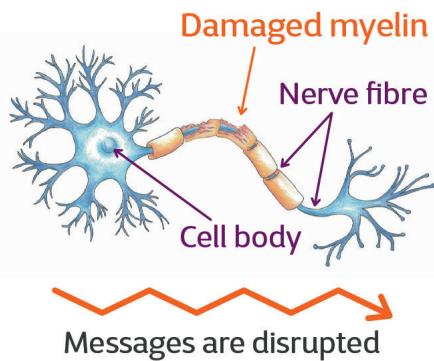
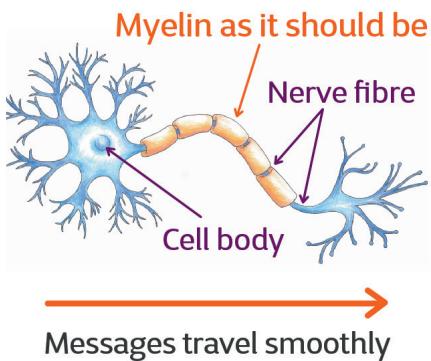
Signals to and from the brain travel through the spinal cord and then out to the nerves for the rest of the body.

MS damages the protective coating round nerves in the brain or spinal cord. That coating is called **myelin**. When that happens, these nerves don't work so well at transmitting signals to and from the rest of the body.

The messages become disrupted and the brain might interpret these signals as pain or unpleasant sensations.

MS can also cause nerves in your spinal cord to become extra sensitive, misfire and send pain signals to the brain.

Although you might feel sensations like pins and needles under your skin or in a particular part of your body, these feelings are caused by nerve damage in the brain or spinal cord. Its not damage to skin or muscle, so this is classed by doctors as a type of nerve pain.



Musculoskeletal pain

Musculoskeletal pain is pain you get in your muscles and joints. It can happen from living with the stresses and strains that MS places on your body.

For example, if you have symptoms to do with fatigue, muscle weakness or balance, this could give you problems with how you stand or sit.

This then puts a strain on your joints, **ligaments** or other muscles. This is more likely if you use one side of your body more to make up for weakness on the other side.

If you're less mobile than you once were, this could cause stiffness in your muscles and joints, leading to pain. A poorly adjusted stick or wheelchair can also cause problems.

Muscle spasms and stiffness are common MS symptoms. This is called '**spasticity**'. It can sometimes make doing everyday things uncomfortable or painful.

You can find out more about managing muscle spasms and stiffness on our website, or by calling our MS Helpline.

Symptoms inside you

Pain can be caused by symptoms inside your body. These include bladder infections or problems with your bowel.

Instead of trying to mask the pain with painkillers, get it looked at by a doctor. That way it can be diagnosed and treated.

Pain from medication

Some medications used to treat MS can have painful side effects.

For example, drugs that you inject like beta interferons don't usually have serious side effects. But they can cause flu-like symptoms, like headaches and aching muscles.

These usually last for no more than a couple of days (48 hours). Injecting the drug just before you go to bed, and taking paracetamol or ibuprofen, can help reduce side effects.

Talk to your doctor or MS nurse about unpleasant side effects from any medications. There might be alternative treatments or ways to manage side effects.

If you inject a disease modifying therapy like beta interferon, an MS nurse can teach you good injection technique and suggest ways to lessen skin reactions.

Other health conditions

If you get a new pain, speak to a doctor or nurse about it. Don't think the pain must be due to your MS. There could be a separate medical problem that needs treating.

How you react emotionally

The body and mind work together closely. That's not to say you're imagining your symptoms, just that your reaction to pain can affect how you feel overall.

The way you think about your pain and how you cope with the stress that it causes might influence how much your symptoms interfere with your daily life.

These things are just as important as the underlying physical problems, such as nerve damage or muscle strain.



Types of pain MS can cause

If you do get pain with your MS, it might vary, and have different medical names to describe it. We've set them out below as either acute (short-term) or chronic (long-term).

Having MS doesn't mean you'll experience all the symptoms we list below.

Surveys show that the most common pains people with MS get are headaches, a sense of burning in the hands or feet, back pain and muscle **spasms**.

Acute pains

MS pain can be acute (short-term, but it may come back) or paroxysmal (unpredictable in a sudden attack). These are examples of acute pains:

Nerve pains

Painful tonic spasms: If MS causes nerve damage that affects muscle movements, you might

get painful tonic spasms. These spasms make your arms or legs bend or shoot out unexpectedly (often at night). They cause a pain that's described as being like a cramp, or a pulling type of pain.

Spasms affect about 1 in 10 people with MS and usually last for seconds rather than minutes.

Optic neuritis: This is **inflammation** of your optic nerve. This nerve carries messages from your eye to your brain. It's a common first symptom of MS. It usually just affects one eye.

Problems with your sight (like temporary blurred or double vision) might sometimes come with a sudden sharp pain behind your eye. This might get worse when you move your eye.

Lhermitte's sign: This is a sudden brief pain or electrical buzzing sensation. It runs down your neck into your spine and may then spread into your arms or legs.

It can be triggered when you bend your neck forward, or after a cough or sneeze.

About 40% of people with MS at some point get this sharp but short-lived pain (usually lasting a few seconds). It's caused by damaged nerves responding to the movement of your neck.

Trigeminal neuralgia: This is a sudden, severe pain in your face that tends to come and go in short, unpredictable episodes. It's relatively rare, with 2% to 6% of people with MS getting it.

It's caused by damage to the trigeminal nerve. That's a large nerve inside your head with three main branches.

This nerve sends sensations of pain and touch from your face, teeth and mouth to your brain.

Where in your face you get pain depends on which of the three branches of the nerve is damaged.

This pain is most common in the lower part of one side of the face. It can be confused with toothache.

This pain usually lasts from a few seconds to about two minutes. It sometimes keeps coming back in quick succession.

Usually the pain disappears between episodes, but for some people it doesn't always completely fade away.

It may be triggered by things that lightly touch the face. Examples are brushing your teeth, eating, or being outside in a breeze. There may be no obvious trigger.

Musculoskeletal pains

Muscle cramps or spasms: Muscle cramps or **spasms** occur in at least 1 in 5 people with MS at some time. They can disturb you most at night. This pain can be made worse by not keeping active, or problems with how you stand and sit.

Chronic pains

These are examples of **chronic** (long-lasting) **pains**:

Nerve pains

Unpleasant sensations: A common type of discomfort or pain in MS is unpleasant, unusual sensations that appear to be in your skin.

They're caused by damage to nerves in your brain or spinal cord. They may happen anywhere in your body, but are most likely in the face, arms and legs (sometimes with numbness).

Even if you wouldn't describe them as painful, they can be distressing or distracting.

Some people feel pain caused by a light touch. This is where you appear to have extra sensitive skin. The lightest touch, like from brushing your hair or pulling bed covers over you, feels unpleasant or painful.

You might describe a feeling like pins and needles or a crawling sensation. This is an unusual feeling of prickling, tingling, numbness, itching or 'crawling insects' underneath the skin.

Some people feel a sensation they describe as like burning, or an electric shock, stabbing, aching or a tightening feeling.

It might be triggered, or happen on its own.

Musculoskeletal pains

Pain in your shoulders, neck, arms, hips or back: This pain can be made worse by how you stand, sit or walk. Or if your arms and legs are usually in a fixed position, causing tension to build up.

Your muscles might be stiffer or weaker because of MS. If this changes how you walk, it can add a strain to joints and muscles.

The 'MS hug'

The 'MS hug' is a symptom where you feel an uncomfortable, sometimes painful, tightness or pressure, usually around your stomach or chest. It can stretch all around the chest or stomach, or it can be just on one side.

It's not dangerous, but it can be frightening, especially if you haven't come across it before.

The feeling can be caused by changes in sensation (called dysaesthesia) or by **spasms** in the small muscles between the ribs. It can be triggered by stress, fatigue or heat.

What can help with the MS hug?

People with MS use lots of different things to help with the MS hug, including:

- looking for possible triggers to avoid
- wearing loose or tight clothes
- moving or stretching
- applying pressure or hot or cold
- physiotherapy
- relaxation techniques
- drug treatments

Although it's not dangerous, you should get it checked out. That's in case there's something else causing that feeling which needs treating. And contact a doctor or nurse straight away if you're ever worried about any chest pain.

How can I manage my pain?

Pain and unpleasant sensations can have a major impact on your life. So it's important they're treated and managed effectively.

Once a doctor has looked into your pain and what's causing it, they can recommend treatments and other approaches to manage it. That could include:

- medical (including drugs)
- physical (such as massage, physiotherapy or acupuncture)
- self-help (such as relaxation)
- surgery

Pain is a complicated symptom and controlling it often needs a mix of approaches.

Your doctor or MS nurse might refer you to other specialists to find the best ways of managing your pain.

You can also help yourself by staying as active as you can. Try to make time for relaxation. Get the help you need to deal with the difficult emotions of living with pain.

Treating pain is sometimes a process of trial and error. This is especially true if it keeps coming back or it's long-lasting.

It's not always obvious which treatments will work for each person. You might need to try a number of them to find a way of reducing your pain.

Looking into the causes and how it affects you

To manage your pain, your doctor or MS nurse will first check whether something other than MS is causing it (like a bladder infection).

Sometimes stress, anxiety, lack of sleep or feeling down can increase the impact of pain.

If it is MS causing your pain, you need a medical assessment to find out whether it's nerve or musculoskeletal pain.

Your neurologist or MS nurse might assess your pain. Or you might be referred to a physiotherapist, occupational therapist or a specialist pain clinic.

If you've kept a pain diary, show it to the person looking into your pain. It'll help them understand what kind of pain you have, how serious it is, and how it affects you.

By comparing your diary entries before and after treatments, medical staff can see if the treatments are helping.

Identifying triggers

Some people find certain things set off painful sensations or make them worse.

If you can recognise these triggers it can help you find solutions.

For example, muscle pain might get worse with heat, cold, or infections. It could also get worse through doing too little or too much activity.

Bending your neck forwards sometimes brings on the sharp, shooting pain of **Lhermitte's sign**.

Make a note of triggers in your pain diary and mention these at medical appointments.

Drug treatments

Drug treatments are often an effective part of managing pain. But drugs on their own aren't usually the solution.

This is because the usefulness of drugs always needs to be balanced against possible side effects. Drugs also rarely give complete pain relief.

There are different medications for managing pain in MS. Your doctor will agree a treatment plan with you.

The **National Institute for Health and Care Excellence (NICE)** has guidelines on managing nerve pain with drugs. According to these, your treatment plan should take into account what your concerns are, and what you expect from treatment.



Your doctor should talk over with you things like:

- how serious your pain is
- its impact on your life
- the reason behind the pain
- why you're being offered a particular drug
- its benefits and possible side effects
- ways of coping and other non-drug treatment options for managing your pain

When deciding whether to take a drug, weigh up the benefits against potential risks. Your doctor can give you guidance.

Once your body gets used to the drug, its side effects can get better. Or there may be ways to make them less of a problem.

For example, you could take a medication that makes you feel drowsy just before you go to bed. That can help you sleep better if pain has been making this difficult.

If your side effects last a long time, bring this up with your doctor. It

might be possible to change to another drug that suits you better.

It can take time for enough of the drug to build up in your body for it to work - or to find the right dose for you. Your doctor or MS nurse will help with this.

Pain-relieving drugs usually come as a tablet. There are alternatives if you find it hard to swallow.

For example, you can use pain patches that deliver a dose of pain relief. There are other drugs that you can put on your skin where you feel the pain.

NICE guidelines recommend that you have a regular review to check how the drug is working. Your doctor or nurse should check:

- whether your pain is being controlled well enough
- how you feel physically and emotionally
- if side effects are troubling you
- whether you need to keep taking the drug

Drugs for nerve pain and unpleasant sensations

Standard painkillers like paracetamol and ibuprofen don't normally work with nerve pain and unpleasant sensations. So other types of medication are often prescribed.

Antidepressant and anticonvulsant drugs

NICE guidelines say that for your first treatment for most nerve pain, you should be offered a choice of drugs. These are amitriptyline, duloxetine, gabapentin or pregabalin. You might also be offered nortriptyline.

If you have trigeminal neuralgia, NICE guidelines recommend you get a drug called carbamazepine as your first treatment.

At first you'll probably be prescribed a low dose of one of these drugs. This will slowly get higher until you notice an effect.

If the first treatment you try doesn't work, or your body won't

tolerate it, your doctor should offer you one of the other drugs. You might need to switch again until you find the right treatment.

Many of the drugs used to treat pain in MS are also used with other conditions. For example, amitriptyline treats mood problems such as depression. And gabapentin is used to control epileptic fits or other convulsions (seizures).

If your doctor prescribes these drugs, it doesn't mean they think you have depression or epilepsy.

Antidepressants can be useful for treating long-lasting nerve pain. For example, if your skin is painfully sensitive to touch.

Anticonvulsants can help to control acute nerve pains. They might also give some relief from 'burning', 'throbbing' or 'pins and needles' sensations.

Possible side effects vary between the different drugs. They can include a skin rash, dizziness, blurred vision and drowsiness.



These drugs may also make you sleepy. So they could help stop pain from disturbing your sleep.

With some treatments, including pregabalin, your neurologist might discuss contraception with you, because of possible risks to a baby in the womb.

Opioid drugs

With acute pain your doctor might consider offering an opioid drug. The NICE guideline for

managing pain recommends a drug called tramadol if an opioid might be appropriate. It can help with nerve and muscle pain.

This is a powerful painkiller related to morphine. Like all opioids, long-term use can lead to addiction.

It shouldn't be prescribed for long periods without your GP or specialist services regularly reviewing you.

But some people with severe pain that's not responded to other treatments might benefit from tramadol in the short term. Each case should be looked at on an individual basis.

Side effects can include dizziness, constipation, feeling sick or vomiting. Tramadol can interact dangerously with some antidepressant drugs.

Capsaicin cream

If you want to avoid, or can't tolerate, the drugs mentioned above, capsaicin cream might be an option. It's not licensed for MS, and a specialist pain clinic might be more likely to prescribe this than a GP or neurologist.

It's sometimes prescribed if your nerve pain is limited to specific small areas of your body (such as parts very sensitive to even light touch).

Capsaicin is what makes chilli peppers hot. When you put it onto your skin, it helps block pain messages to the nerves.

Steroids

Steroids are often used to speed up recovery from a **relapse**. They dampen down **inflammation** in your brain and spinal cord.

A relapse might involve painful symptoms, for example optic neuritis (inflammation of a nerve in your eye). Treating the relapse can make this pain go away.

Find out more about steroids in our booklet 'Managing your relapses'. Or go to our website, where you'll also find more about optic neuritis.

Drugs for musculoskeletal pain

The following types of medication are often prescribed if you have musculoskeletal pain:

Painkillers

Many drugs help with pain in the muscles, joints and **ligaments**.

Here are some:

Mild pain: Simple painkillers like paracetamol can relieve mild musculoskeletal pain.

Moderate to severe pain: Drugs called codeine, dihydrocodeine and co-codamol can treat musculoskeletal pain that doesn't respond to simple painkillers.

Severe pain: Tramadol might be prescribed for severe musculoskeletal pain. It can help with nerve pain, too. This will usually be only for short-term use.

There are lots of other painkillers. If you find one isn't working, tell your doctor. Through trying a few, you'll find one that suits you.

Always check with a pharmacist or doctor before you make any changes to the treatments you take.

Anti-inflammatory drugs

Anti-inflammatory drugs such as ibuprofen and naproxen are used to reduce pain, swelling and stiffness in muscles and joints.

When these drugs are in a tablet, you must take them with food. Avoid them if you have stomach problems, are prone to strokes, or

have a bleeding disorder. Talk this over with your doctor. They might suggest ways to manage any side effects.

Muscle relaxant drugs

If your pain is caused by muscle spasms or stiffness, you might be given muscle relaxants. Examples are baclofen or tizanidine.

You'll find more about managing muscle spasms and stiffness on our website.

Cannabis-based drugs

There's evidence that cannabis can help to treat chronic pain.

But in November 2019 **NICE** made a ruling for England that said no cannabis-based products could be given to treat pain.

We want the government to set up a system that lets people with MS get cannabis in a safe and responsible way.

Sativex

As of June 2022, Sativex is the only cannabis-based drug licensed in the UK to treat muscle

spasms and stiffness caused by MS (known as **spasticity**). It comes as a mouth spray.

This drug has been given the go-ahead to treat people on the NHS in England, Wales and Northern Ireland who have ‘moderate’ to ‘severe’ spasticity and other treatments haven’t worked.

We hope it’ll soon be made available in Scotland.

Sativex isn’t routinely given to people to treat other MS symptoms, such as pain.

You can find out more on our website.

CBD oil

CBD (cannabidiol) is a chemical in cannabis. You can legally buy CBD oil (sold as a food supplement). But only if it has no more than 0.2% of another chemical in it called THC (tetrahydrocannabinol). THC is what gets you ‘high’.

As of June 2022, no CBD medicines are licensed to treat MS symptoms. There’s no evidence to prove whether or not these medicines help pain in MS.

Before you buy CBD products, speak to a pharmacist or medical person. That’s because CBD oil can interact with other common drugs you might be taking.

Physical treatments

Physical ways of easing pain can get overlooked. But some people prefer these to drugs. You don't have to worry so much about side effects.

Physical treatments include physiotherapy and occupational therapy. You can also use electrical stimulation of your nerves to disrupt pain signals.

There are also lots of complementary and alternative therapies that help with pain relief and relaxation.

Transcutaneous Electrical Nerve Stimulation (TENS)

Transcutaneous Electrical Nerve Stimulation (TENS) is a way of easing pain. It uses a small, battery-operated machine.

Sticky pads (electrodes) are placed on your skin. A low electrical current stimulates your nerves in the painful area.

You feel a mild tingling sensation passing through your skin. The type and strength of the electrical impulses can be changed so that they stimulate different nerves for different pains.

TENS works like acupuncture. The idea is that stimulation of the nerves can disrupt pain signals going to your brain and spinal cord. It can relax your muscles, too.

TENS might help with nerve pain. That includes burning, shooting and tingling sensations.

It might help with musculoskeletal pain, too. This includes chronic back pain and painful leg **spasms**.

The benefits of the treatment often wear off quickly after using the TENS machine.

We need more research into whether TENS is reliable. It doesn't suit everyone. Some people find it irritates their skin. Special pads are available if you have skin allergies.

TENS is generally safe, with no side effects. But don't use it if you have:

- a pacemaker
- epilepsy
- a heart condition
- you're in the early stages of pregnancy

If TENS gives you effective short-term pain relief, you might want to buy your own machine. Get medical advice first. Make sure its settings are correctly adjusted for you.

Physiotherapy

Your doctor or MS nurse might refer you to a physiotherapist to help manage musculoskeletal pain.

Physiotherapy covers a range of treatments:

- exercise plans tailored to you
- gentle stretching
- massage
- manipulation
- water-based exercises (hydrotherapy)

If pain makes movement or exercise difficult, physiotherapy could be really useful.

Physiotherapy can help prevent problems that may build up over time if left untreated. This could be things like stiff joints, painful pressure sores, or when your muscles waste away because you don't use them.

Staying as active as you can is good for your physical and mental health. It can be something you enjoy doing, and that can fit into your daily routine.

Your physiotherapist can give you advice on specific exercises that suit what you're able to do. Exercises can target pain or muscle stiffness, and keep your body flexible.

Find more information in our booklet 'Moving more with MS'.

Check out our exercises for MS symptoms and other videos to help you keep active at mssociety.org.uk/staying-active



Physiotherapists can advise you on better posture (how you stand and sit). They'll also know about mobility aids, which could reduce muscle strain.

You might be able to access physiotherapy through our local groups. Find out more at mssociety.org.uk/local

And our Moving more with MS service can help you find ways to stay active that work for you. Call our Helpline to find out more: **0808 800 8000**.

Occupational therapy

An occupational therapist (OT) can help you manage nerve and musculoskeletal pain. They can suggest practical methods of coping with other symptoms such as numbness.

OTs assess where you live and work. They make sure these places are as easy as possible for you to use and live in. They can also check that any existing pain isn't being made worse by how you stand and sit and the way you

do things. They can guide you on how to avoid triggers that make your pain worse.

Doing some things can make pain worse. You may have to do them slightly differently or do them for less time.

For example, an occupational therapist might recommend breaking down a demanding household chore into a few short stages with rest intervals. This stops you getting tired, aching muscles.

At home, changes to the layout of your kitchen or bathroom might save you from bending or twisting. This will take the strain off your muscles and joints.

Different furniture, such as a reclining chair or a firmer, more supportive bed mattress, might ease painful symptoms.

You can find more about home adaptations on our website.

If you work, some changes could help you manage your pain. This

could be more flexible hours or changes to your workspace.

By law most employers must make ‘reasonable adjustments’ to allow you to keep working. For more on this see our booklet ‘Work and MS’. Our website has information for you and your employer.

Complementary and alternative therapies

Complementary and alternative therapies can help some people relax, feel better and control their pain levels.

These therapies aren’t seen as part of mainstream medicine. More research is needed to show if they work.

You can find out more about complementary and alternative therapies on our website.

Before beginning any complementary and alternative therapy, talk it over with your doctor. If you can, use people who are registered with a nationally recognised body.

Some complementary and alternative therapies may be available on the NHS. But you might be asked to pay towards the costs of some services. Other therapies are only available privately.

Let’s look at a few popular complementary and alternative therapies used for pain relief.

Acupuncture

You can get acupuncture through some GP surgeries, pain clinics and physiotherapists.

It comes from ancient Chinese medicine, and involves sticking fine needles into specific points on your body. This makes your body release its own natural pain killers.

You can use acupuncture to treat chronic tension-type headaches, migraines and musculoskeletal problems like neck and back pain.

There have only been a few small studies of acupuncture in MS. It seems to relieve pain in other conditions, and doesn’t have significant side effects.

Chiropractic

Chiropractic is when a registered practitioner called a chiropractor uses their hands to help relieve problems with your bones, muscles and joints, such as neck or lower back pain.

This is a low-risk procedure, regulated by law, but more research is needed into the use of it with MS.

Massage

Massage is a healing method that goes back thousands of years. It might be useful for relaxing muscles and reducing painful stiffness.

Osteopathy

In osteopathy a registered practitioner (osteopath) uses their hands to move, stretch and massage your muscles and joints.

This allows them to find and treat problems like muscle tension and lower back pain. More research is needed into how it can help people with MS.

Osteopathy is regulated by law.

Reflexology

Reflexology is a type of massage, where pressure is put on specific areas or ‘zones’ of your feet and hands.

It’s believed these are linked to different areas of your body. The pressure is meant to release the body’s natural healing powers.

There’s no convincing evidence this works for any medical problem. But some people find it helps with pain, muscle stiffness and symptoms affecting your senses.

T'ai chi

T'ai chi is a Chinese martial art. It features deep breathing and slow, graceful movements that are gentle on the joints and muscles. These can be altered to suit people with disabilities.

T'ai chi might relax you, help ease pain, make muscles less stiff and improve tension-type headaches. More studies of how it can help MS symptoms are needed.



Yoga

Yoga is an ancient Indian form of exercise. It focuses on strength, flexibility and breathing. Its movements ('yoga postures') can be altered to suit people's abilities.

Yoga is a low-risk therapy that might help reduce aches, pains (including lower back pain) and fatigue. There are relatively few studies of its effects on MS.

You can find out more about keeping active through yoga, Pilates and exercise on our website at mssociety.org.uk/staying-active

Surgery

You might be offered surgery to manage your pain. This will be if medical, physical and self-help treatments haven't worked, or drug side effects are too severe.

Before you agree to surgery, make sure you have all the information you need. Talk over its benefits and risks with a specialist.

Surgery for trigeminal neuralgia

One painful MS symptom in particular, trigeminal neuralgia, can be treated with surgery. The trigeminal nerve in your head will be deliberately damaged to stop pain signals travelling along it.

Examples of surgical methods to treat this condition are:

- injections of a medication called glycerol into the nerve
- radiofrequency treatment, where a needle is used to apply heat to the trigeminal nerve

- balloon compression, where a tiny balloon is inflated around the trigeminal nerve in order to squeeze it
- gamma knife surgery where a beam of radiation damages the root of the nerve
- decompression surgery, where, under a general anaesthetic, the head is opened up and blood vessels pressing on the nerve are moved away from it

These treatments can relieve the pain for a few months to a few years. There might be complications such as numbness (perhaps permanent) or painful tingling on the side of your face that was treated.

For some people with MS decompression surgery can give long-lasting pain relief. For others it won't be suitable because their pain isn't caused by pressure on this nerve.

How will I cope with living with pain?

Pain is more than a physical feeling - it's your emotional reaction to it, too. Relaxation techniques, talking therapies and self-help can all make it easier to manage.

Living with pain can be draining. You might feel anger, fear, stress, frustration, hopelessness or isolation.

A recent survey found that 29% of people with MS suffered from pain and depression at the same time. It found pain can be linked with disability, and cause depression and anxiety.

The difficult emotions of living with pain should be looked at as part of your treatment.

Your pain is very real, but the way that you deal with the stress it causes can affect your physical and emotional health. This

doesn't mean you're imagining or exaggerating your pain.

You can find more about treating depression and anxiety on our website or by calling our Helpline on **0808 800 8000**.

Research has helped identify different ways of coping with pain. We look at these in the next few pages.

Sharing your thoughts and feelings

Pain is a hidden symptom of MS. Others, even close family and friends, might not realise how much it's affecting you. You might sometimes feel isolated.

But don't 'bottle up' or suppress distressing emotions. One of the first steps in feeling better is to reach out to others and share how you're thinking and feeling.

How you cope with pain is individual to you. But it's important to speak to your doctor if you feel low or unhappy.

We're here to help you too. You could:

- join your local MS Society group, for friendship, support and information
- contact our free, confidential MS Helpline on **0808 800 8000** for emotional support and information
- join our online forum. It's a welcoming space for you to share experiences and get support from people who understand life with MS. It's at forum.mssociety.org.uk
- You might find counselling or other support through local or online support. Find out more at mssociety.org.uk/local

All these let you talk about how you're feeling, ask questions or meet other people who know what it's like to live with MS pain.

Relaxation and controlled breathing

Pain and stress can make your muscles tense up for a long time. This is likely to cause you more discomfort.

For example, you might get headaches, other aches and pains, or feelings of tightness in your chest or throat. An ongoing cycle of pain can develop.

By practising relaxation (even just for a short time each day), you can calm your mind and body. This can control how pain affects you.

Pain clinics sometimes use this approach. Several of the complementary and alternative therapies we talked about earlier include relaxation.

There are lots of relaxation methods you could try by yourself or with help. Many involve deep or controlled breathing.

This is because if you're feeling stressed and anxious, you breathe in more oxygen than your body needs. Then you'll get dizzy,

light-headed, a dry mouth, a fast heartbeat, sweaty hands, tingling sensations and muscle stiffness

Learn a simple ‘calming technique’ to slow down your breathing. You’ll then feel more relaxed, helping to control your pain.

Practise the calming technique as part of your daily routine

and more relaxed breathing will become a habit.

Then you can reduce your stress and anxiety levels quickly when your pain is getting to you more than usual.

Even if you have ongoing pain, try to make time to unwind every day.

The Calming Technique

- Sit down in a comfortable chair or lie on a bed.
- Put one hand on your stomach and the other hand on your chest.
- Breathe in deeply through your nose. Count to four. Make the hand on your stomach rise as you count.
- Briefly hold your breath and count to two.
- Breathe out through your mouth with your lips slightly parted and count to six.
- Pause briefly before taking another breath.

Notes

- When you start practising the calming technique, you may find it easier to use a 3-in, 1-hold and 4-out breathing pattern at first.
- Imagine you’re breathing in a calming colour, like **blue**, and breathing out a colour you link with stress and tension, like **red**.
- Aim to practise the calming technique at least three times a day and take at least 10 full breaths every time.

Do things you particularly enjoy and that give you a break, like:

- exercise, such as gentle walking, swimming or stretching
- reading
- listening to soothing music
- stroking a pet
- having a bath
- creative activity, like arts and crafts
- getting fresh air outdoors
- meeting up with a family member or friend
- online relaxation exercises

Distraction

Pain can make it hard to think about anything else. You can become overwhelmed by the discomfort. You could benefit by training your mind to shift the focus of its attention.

Some people find relief for a while when they're completely involved in something they enjoy doing.

Distraction doesn't take pain away. But it can help reduce the impact. Set aside some time for practice.

This could be things like colouring a picture, listening to a favourite piece of music or doing a crossword or puzzle.

Here are other ways of taking your mind off the pain:

- place your hand on your stomach. Focus on the gentle movement of your breath in and out of your body. Think of your stomach as a balloon, slowly inflating and deflating as you breathe in and out
- take time to notice and appreciate the sights sounds, smells and any physical sensations in your surroundings
- think of a pleasant and peaceful place, like a beach, the countryside or a garden
- You can try visualisation and guided imagery exercises for free at moodcafe.co.uk

Self-hypnosis and hypnotherapy

Self-hypnosis is a way of using the power of your imagination to make you feel better.

“I try to find something to distract me. It can be something different every time, but it could be listening to an audio book or watching a film.”

It could be giving a friend a ring and having a chat about everything but my pain.

I don't have the correct answer for everyone, just the answer that works for me. But remember it's not your fault.”

Shirlee

You can learn self-hypnosis from a few training sessions with a professional, or from audio recordings.

You remain in control of yourself during self-hypnosis. You get into a deeply relaxed state of mind.

Then you're more open to suggestions about how to think about and manage your pain, stress and anxiety.

There are many approaches, and creative imagery you could use to change your experience of pain into something more bearable.

Here are some examples:

- imagine yourself as an injured marathon runner, who's determined to keep going in spite of the pain and reach the finish line

- try to think about or describe your pain using different words (for instance, ‘sharp’ rather than ‘painful’ and ‘vibrating’ rather than ‘hurting’)
- if you think of your pain as ‘stabbing’, imagine it being cushioned. If you think of your pain as ‘burning’, imagine it being cooled
- repeat calm, reassuring words to yourself. For example: ‘I’ve often had this much pain before. I know I’ll feel better in time’
- pretend you’re a detached observer. Compare the painful sensations in one part of your body with the comfortable sensations in another part of your body
- imagine a small amount of your pain escaping from your body and drifting away every time you breathe out
- imagine diving into cool, soothing waters with your pain gradually floating away
- think of pain as a colour (such as bright red). Imagine this colour fading into softer, gentler shades (pale pink at first and eventually a calming blue)

Self-hypnosis doesn’t suit everyone. But the limited research there is suggests it can benefit people with MS who have chronic (long-lasting) pain.

Hypnotherapy involves the same principles, but a professional hypnotherapist guides the whole process.

They lead you into the deeply relaxed or ‘hypnotised’ state (sometimes called a trance). Then they suggest how you can improve how you feel when you come out of it.

You stay in full control of yourself during hypnotherapy. You can bring yourself out of the trance whenever you want.

You can’t normally get hypnotherapy on the NHS. Find

qualified, insured hypnotherapists who are registered with a professional body at:
hypnotherapy-directory.org.uk

Cognitive Behavioural Therapy (CBT)

Cognitive Behavioural Therapy (CBT) is a popular talking therapy available on the NHS (although access will vary across the UK).

You can get it on a one-to-one basis with a professional therapist or in a group. You can also get it online or even over the phone.

CBT is used more and more to manage chronic pain and fatigue.

Pain affects four areas of your life:

- **thoughts**
- **feelings**
- **behaviours**
- **physical reactions**

CBT is based on the idea that these are all closely connected and influence each another.

Here's an example.

Anne's had backache all day and goes to bed. Her thoughts, feelings, behaviours and physical reactions affect each other and prevent her from getting a good night's sleep.

Anne's unhelpful pain-related thoughts directly influence her behaviours, leading to distressing feelings and even more uncomfortable physical reactions.

Anne finds herself trapped in an ongoing cycle.

This makes her experience of pain worse because she has a sleepless night and feels exhausted the next morning.

CBT can help you make practical changes to how you think ('cognitive') and behave ('behavioural'). This will make you feel better, both emotionally and physically.

Anne could break out of the cycle by learning how to challenge her unhelpful thoughts and

replace them with more balanced alternatives.

She'd feel calmer if she thought to herself:

"My backache has bothered me today, but no point in worrying about whether I'll sleep. I'll just close my eyes and try to get as much rest as possible, so that I don't feel too bad tomorrow."

Another way Anne would feel better is by changing her unhelpful behaviours.

Instead of watching the clock anxiously, she could shift her attention to the rhythmic movement of her breath in and out of her body.

She could practise the calming technique on page 39 for a few minutes and visualise a pleasant place in her mind.

CBT would also encourage Anne to plan some things that would do her good.

This could be gentle exercise. She might have avoided this due to her backache. As a result she's had even more muscle stiffness.

She could have had a bubble bath before bedtime. This would relax her tense muscles and make it easier to fall asleep.

Goal setting

This is a major part of Cognitive Behavioural Therapy (CBT). By setting goals for managing your pain, you might feel less overwhelmed about coping with your symptoms.

You could feel more motivated to make changes that make you feel better.

Talk about targets for pain relief with a health care professional. For example, you might want to get a good night's sleep, have four pain-free hours each day, or reduce your pain enough to take part in a social event.

The health care professional can then suggest treatments to help you achieve these goals. Together, you can identify which treatments work well for you.

The table on the next page can help you set goals that are

achievable and useful for you (sometimes called 'SMART' goals).

In the example in the table, Kevin wants to cope with his chronic pain and stress levels by relaxing more.



Setting personal goals using the 'SMART' abbreviation

Characteristic of goal	Explanation	Example situation: Kevin wants to cope with his chronic pain and high stress levels by relaxing more
Specific	Choose a goal that is clear and focused	Kevin's goal of wishing to relax more is too vague. Instead, he can set himself the specific goal of practising the calming breathing technique on page 39
Measurable	Make sure you can measure your progress	Kevin can aim to practise the calming technique three times a day and put a tick in his diary when he does this
Achievable	Don't have a goal that's too high. Make sure you can achieve it	Kevin can plan to practise the calming technique for short periods of three to five minutes at a time. That way it won't get in the way of other things he needs to do
Realistic and relevant	Choose a goal you can meet using things you have to help you	Kevin can practise the calming technique anywhere for just a few minutes. This won't cost him money. It will help him learn to breathe in a more relaxed way
Time limited	Set a reasonable time limit, deadline or target date for achieving your goal	Kevin can aim to practise the calming technique over the next month. He can then look at whether his pain control and stress levels have got better

Mindfulness

Mindfulness is when you bring your full attention to whatever's happening in the present moment. It's a valuable skill that you can learn through meditation.

There's an eight-week programme called 'mindfulness-based stress reduction' for people with chronic pain. It's taught by instructors in hospitals.

Mindfulness meditation offers a different way of approaching and thinking about your pain.

You're encouraged to give your complete focus to whatever's happening in your body, mind and the outside world during the present moment. You need to have a non-judgemental attitude of openness and curiosity.

You'll be asked to explore your sensation of pain in a kind and gentle manner. Rather than struggling or trying to 'fix the problem', the idea is simply to allow your experience to unfold in the here and now.

It may seem it makes no sense to focus on your pain when you want to avoid discomfort. But this approach can have unexpected benefits:

- By gently observing the sensations in your body from moment to moment, you might notice your pain isn't severe all the time. There may be subtle changes or times when you don't feel so bad
- If there's an unpleasant sensation in your body, just allow it to be there. Don't let your distress take over your whole experience
- You might notice some pleasant sensations as well. This could be the warmth of your hands or a beam of sunlight through the window
- By keeping your mind on an unpleasant sensation for a while and continuing to engage with the outside world, you might realise you can cope with your present experience much better than you imagined

Mindfulness teaches you to keep your mind on the present moment by following the natural movement of breath in and out of your body.

You'll be encouraged to breathe into any feelings of discomfort, tension or resistance. You'll be asked to develop an attitude of 'loving kindness' towards yourself.

A 2018 study suggested mindfulness helped with MS pain.

Another study found people with MS got benefits from the eight week mindfulness-based stress reduction course. At first they became more aware of their disability. But this was generally followed by greater acceptance, and they were more able to treat themselves with more kindness. They also had better relationships, walking and sleep, with less stress and pain.

You can find out more about mindfulness at mssociety.org.uk/mindfulness including a link to our mindfulness podcast.



What else might help if the pain won't go away?

If the treatments we've looked at in this booklet don't help, what then? You might need to approach things from a different angle. It might be time to ask for more specialist advice and support.

Pain clinics

If your pain is ongoing or keeps coming back, and this has lasted longer than 12 weeks, you might need a pain clinic. Your doctor or MS nurse can refer you.

Pain clinics specialise in helping you find ways of coping, managing and adapting to living with pain. They'll help you lessen its impact on your quality of life.

Clinics offer a range of treatments that help you learn how to control your pain day-to-day.

These can include:

- drug treatments
- exercise classes
- TENS machines
- physical or talking therapies
- complementary and alternative therapies

Pain management programmes

Pain clinics sometimes run 'pain management programmes'. A group of people who have persistent pain and discomfort meet over several weeks.

The programme's main goal is not to reduce pain, but improve your quality of life in spite of your pain.

Sessions could include group discussion, gentle exercise, relaxation and mindfulness.

You learn how to pace what you do to prevent flare-ups of painful symptoms. You'll manage the distressing emotions that come with chronic pain.

Self-management courses

A self-management course can help you find new ways of managing your pain. These free courses are run by, and for, people with a long-term health condition.

You can ask your doctor or MS nurse about local courses.

A self-management course should give you the knowledge, skills and confidence you need to feel better and cope with the daily challenges of your MS.

You might learn practical techniques to:

- manage chronic pain
- handle unhelpful emotions
- stay active
- relax both your body and your mind
- set personal health goals

Going on a self-management course means you can get support from other people living with persistent pain.

You'll feel better able to manage your MS symptoms and hopefully find a way forward.

Useful organisations

Action on Pain

This charity provides support and advice for people affected by chronic pain.

Pain Line **0345 603 1593**

(10am to 4pm on Monday to Friday)

Email: painline@action-on-pain.co.uk

action-on-pain.co.uk

The British Pain Society

This charity has information about pain, details of pain clinics and self-help groups. They also have publications about managing pain.

020 7269 7840

Email: info@britishpainsociety.org

britishpainsociety.org

healthtalk.org

A website featuring people talking about their own experiences of health issues, including chronic pain.

healthtalk.org

Pain Association Scotland

This charity runs self-management courses in Scotland for people affected by chronic pain and for family or friends who help look after them (carers).

Freephone **0800 783 6059**

(8.30am to 4.30pm Monday to Friday)

Email: info@painassociation.com

painassociation.com

Pain Concern

Support and information for people with pain and those who care for them.

They publish news and information about pain-related topics on their website and in their magazine and leaflets.

They have an online forum and podcast called ‘Airing Pain’ (featuring interviews with experts and those managing their pain),

Helpline: 0300 123 0789
(Monday 2pm to 4pm, Wednesday 6pm to 8pm)

Email: help@painconcern.org.uk
painconcern.org.uk

The Pain Toolkit

This website has video tips on managing pain. They also have an information booklet for sale as a download, audio or print version.

paintoolkit.org

Samaritans

Confidential 24-hour helpline that gives you the time and space to talk through what’s troubling you (for example, if you are struggling to cope with your pain).

They can help you explore different options and find a way through your problems.

You don’t need to feel suicidal to call the Samaritans.

They also offer support by email or face-to-face at your local Samaritans branch.

Free helpline: **116 123** (open 24 hours a day, 365 days a year)

Email jo@samaritans.org
samaritans.org

TNA UK (Trigeminal Neuralgia Association)

Information and support for people with the painful condition of trigeminal neuralgia.

They aim is to raise awareness of trigeminal neuralgia.

Helpline: 0800 999 1899

Email Helpline: help@tna.org.uk
tna.org.uk

New words explained

inflammation – when your immune system (which defends your body against infection and disease) reacts to an attack or damage, it sends more blood and immune cells to the damaged area, making it swollen and often painful

Lhermitte's sign – an electric shock feeling often triggered by leaning your head forward. It goes down your neck and spine, and sometimes into your arms or legs

ligaments – strong pieces of tissue in the body that hold your bones together and support your muscles

myelin – a fatty covering around the nerves in your brain and spinal cord. In MS it becomes damaged by your immune system. This damage interrupts messages that travel along these nerves, causing the symptoms of MS

relapse – a flare up of your MS. You get new symptoms or old ones get worse. The relapse symptoms usually fade away completely or get less noticeable. But they can leave some lingering problems, however slight

spasms – sudden movements or tightening of your muscles that you can't control. Arms or legs kick out. Spasms can be painful, with muscles clenching tightly

spasticity – an increase in resistance or tension in muscles. They feel rigid when you move them, maybe with pain, cramping and unexpected jerking of your arms or legs

Further information

MS Helpline

Our MS Helpline gives emotional support and information to anyone living with MS. And through the helpline you can also access our:

- MS nurses
- MS benefits adviser
- MS legal adviser
- Moving More with MS service
- short breaks service

We can provide information in different languages through an interpreter service. And by text relay and British Sign Language interpreters.

Find out more at

mssociety.org.uk/helpline

0808 800 8000 (Mon-Fri 9am to 7pm except Bank Holidays)

helpline@mssociety.org.uk

Or direct private message us on
Facebook (Mon-Fri 9am to 5pm)

Resources

Our award winning information resources cover every aspect of living with MS.

You can read them online or download at

mssociety.org.uk/publications

And you can order printed resources from

onlineshop.mssociety.org.uk

or call **0300 500 8084** and select option 4

About this resource

With thanks to all the people affected by MS and professionals who reviewed this booklet, including Dr Kate Petheram, Consultant Neurologist at South Tyneside and Sunderland NHS Foundation Trust.

We'd love to hear what you think about this information

mssociety.org.uk/yourviews

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions.

Availability and prescribing criteria for drugs in various parts of the UK may change. Seek advice from the sources listed.

References

Email us if you'd like to know the references for this information

supportercare@mssociety.org.uk

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This resource is also available in large print.

Call **0300 500 8084**

or email **shop@
mssociety.org.uk**

Contact us



MS Helpline

Freephone 0808 800 8000
(closed on weekends and bank holidays)
helpline@mssociety.org.uk

MS National Centre

0300 500 8084
supportercare@mssociety.org.uk

Online

mssociety.org.uk
facebook.com/MSSociety
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MS Society Scotland

0131 335 4050
enquiries-scotland@mssociety.org.uk

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