

Pain after stroke

Stroke Helpline: 0303 3033 100
or email: helpline@stroke.org.uk

This guide will help you to understand some of the causes of pain after stroke, and the treatments that are available.

After a stroke, up to half of all survivors experience pain. It can happen soon after a stroke, or may develop later on. People can have muscle and joint pain, headaches, and painful sensations like pins and needles. Pain after stroke may last a long time, and it can have an impact on your quality of life and emotional wellbeing. Everyone feels pain differently, and responds in their own way.

There are effective treatments and ways of controlling pain, so it's important to seek help. Tell your doctor or therapist about the pain and how it affects you. They can help to find out the cause of the problem and get the right treatments.

Some of the main ways that stroke survivors experience pain are:

- Shoulder pain.
- Spasticity and contractures.
- Central post-stroke pain.
- Other conditions, including swollen hands and headaches.

Depending on the cause of the pain, treatments like medication and physiotherapy are often helpful. Some causes of pain can be treated, but for some people, post-stroke pain can last a long time. This guide also examines techniques for managing long-term pain with help from pain clinics.

Shoulder pain

Shoulder pain affects up to a quarter of stroke survivors, and usually happens on the side of your body that is affected by the stroke. There are many different conditions that cause shoulder pain and while some improve with targeted treatment, it sometimes becomes a long-term condition.

Frozen shoulder

After a stroke you may find that your shoulder is very stiff and that it hurts when you move it. This is called frozen shoulder, or capsulitis. The shoulder is a 'ball and socket' joint, with a rounded shape at the end of the upper arm fitting into a hollow space in the shoulder blade. Muscles and ligaments hold the arm bone in place. There is a layer of tissue that surrounds this joint which is called a capsule.

If your arm muscles are very weak, stiff or paralysed, the effect of gravity puts a strain on your ligaments and your capsule. This can cause these parts of your shoulder joint to become inflamed, stretched and damaged. Having weakness in your arm muscles may contribute to this pain in your shoulder.

Subluxation

Another common cause of shoulder pain is shoulder subluxation. This means partial dislocation, when the rounded end of the upper arm bone moves slightly out of its socket. This happens because the muscles that normally hold this joint in place are weakened due to the stroke, and the weight of the arm can pull and stretch the soft tissues. This can be helped by positioning the arm correctly. A physiotherapist may suggest supporting the weak arm on pillows early after stroke.

How is shoulder pain treated?

Prevention

If you have weakness in your arm following your stroke, your therapist will try to prevent shoulder pain developing. They will make sure that anyone who handles your arm knows how to do so with care and without causing strain on your shoulder joint. They should also ensure that your arm and shoulder are positioned correctly.

Correct positioning is vital because it can help to reduce the strain on your ligaments and capsule, helping to prevent frozen shoulder from developing. It may also help to prevent your shoulder blade and upper arm bone from moving apart (subluxation). You may need to use foam supports to make sure that your shoulder is supported in the correct position. Your arm can also be supported using a pillow.

Shoulder taping or orthotic supports may be useful. However they should be prescribed by your therapist, with clear guidance on usage. Supports should be regularly monitored and should not stop you moving your arm.

Your physiotherapist may also use electrical stimulation on the muscles around your shoulder to help prevent or reduce subluxation. If this is prescribed, the device often needs to be used throughout the day, following the advice of your therapist.

See the 'Alternative methods of treating pain' section later in this guide.

Reducing pain

You may be given painkillers such as paracetamol or a non-steroidal anti-inflammatory drug (NSAID) such as ibuprofen. NSAIDs can also help to reduce swelling. You should only take painkillers on the advice of a doctor as they can increase the risk of bleeding if you are on a blood thinning medication such as aspirin.

If you also have inflammatory arthritis, a steroid may be injected into your joint to help reduce the pain.

Moving your shoulder

It is important to keep the muscles in your shoulder and arm active so that any stiffness does not get worse. Your physiotherapist may use stretching exercises to move your shoulder joint in all directions. They can also provide you with advice about how to protect your shoulder during everyday movements such as reaching for something or getting dressed.

Spasticity and contractures

A stroke can damage the way the nerves control your muscles. This can lead to muscles contracting for long periods or going into spasm, which can be painful. This muscle tightness is known as spasticity, or hypertonia. A stroke can cause muscle weakness down one side, also known as hemiparesis. Spasticity affects the weakened muscles, often in the arms and hands, but also in the legs. It may affect up to a third of stroke survivors. If it's not treated, spasticity can lead to the muscles being permanently shortened. The joints and muscles can become so stiff that it is impossible to move them, causing a contracture.

How is spasticity treated?

If you have muscle weakness after your stroke you should be assessed for spasticity, and receive therapy to reduce the risk of contractures. Treatments may include a combination of physiotherapy, injections of botulinum toxin type A, and other medications.

Physiotherapy

If you have spasticity you should be given physiotherapy exercises to do... This will help to keep muscles and joints flexible and reduce the possibility of contractures. Your physiotherapist will give advice and pictures for positioning your arm when in bed or sitting up. They will also give you stretches and exercises to build strength. See our guide 'Physiotherapy after stroke' for more information.

Botulinum toxin type A

Botulinum toxin type A is given as an injection directly into your muscle. Botulinum treatment is only effective as part of a programme including rehabilitation such as physiotherapy, or other treatments like splinting or casting to ensure that any range gained in the muscle is maintained. You should also have an assessment three to four months after the treatment, and be offered further injections if they are considered helpful.

The main brand names used for this treatment are Botox, Dysport and Xeomin. Botulinum toxin type A works by blocking the action of the nerves on the muscle, reducing your muscle's ability to contract. This reduces muscle tone (makes the muscle less tight), which can help you to straighten out your limbs. This treatment is mainly used for post-stroke spasticity in the hands, wrists and ankles. The muscle-relaxing effects of botulinum toxin type A usually last for about three months, and you should not notice any changes in sensation in your muscles.

Medication

If you have generalised spasticity, or if botulinum toxin type A treatment doesn't reduce spasticity in the injected muscle, other types of medication can help reduce the stiffness and pain that often comes with spasticity. Muscle relaxants can help you move and stretch more easily and may reduce muscle spasms.

There is a range of medication available for spasticity, and you may need to try more than one or take a combination that works for you. Each type of drug has different benefits and side effects. Your doctor and pharmacist can support you with practical advice on the best way of taking them.

- Baclofen and tizanidine are muscle relaxants that work on the central nervous system to reduce nerve activity in the spinal cord.
- Diazepam and clonazepam work on the chemicals that transmit messages between brain cells. They often make you drowsy, so might be used at night.
- Gabapentin and pregabalin also affect brain chemicals and are often used as epilepsy treatments, but have many other treatment uses.
- Dantrolene works on muscle cells. It has a bigger risk of side effects such as nausea.

Cannabinoid medications are a new treatment sometimes offered to people with multiple sclerosis to help with spasticity. These medications are not given for use after stroke, as the current evidence doesn't show how effective they are.

How are contractures treated?

Splinting and casting

If you develop contractures, your therapist may use a splint or a cast that moulds to or lies along your affected limb and holds it in place. This treatment helps to stretch out the muscles in your tight limbs and is usually combined with physiotherapy.

Sometimes this treatment is used to try to prevent contractures from forming by making sure that your body is not in an abnormal position. Unfortunately splints and casts can sometimes be uncomfortable. Talk to your physiotherapist about what would be best for you.

Central post-stroke pain (CPSP)

Up to 30% of people who have a stroke may develop central post-stroke pain (CPSP). It is also known as neuropathic pain, or central pain syndrome. It usually starts within three to six months after a stroke, but it can begin earlier. CPSP happens when areas of the brain that interpret pain are affected by the stroke. This is also known as neuropathic pain, or central pain syndrome.

There are different types of pain you might experience if you have CPSP. Many people describe it as a burning or burning cold sensation, or a throbbing or shooting pain. Some people also experience pins and needles or numbness in the areas affected by the pain. For most stroke survivors with CPSP, the pain occurs in the side of their body that has been affected by the stroke. The pain may begin immediately after your stroke but more often it begins several months later. Some people find this pain becomes worse because of other factors such as movement or a change in temperature.

How is CPSP treated?

Ordinary painkillers such as paracetamol or ibuprofen don't help with CPSP. Some types of drug that change the chemicals in the brain can be helpful. The main drugs that are used are amitriptyline, and the anti-epilepsy drugs gabapentin and pregabalin. Your doctor and pharmacist will support you to find the right dose or combination of drugs that work for you.

Other approaches to reducing pain include pain clinics and TENS (transcutaneous electrical nerve stimulation).

If treatments have been unsuccessful, you might be able to access a pain clinic. Contact your GP for help.

Other painful conditions

Swollen hand

Developing a swollen hand can happen if you are not moving your hand very much, or are unable to move it. Older people and those who have experienced more severe strokes are most likely to experience this condition. The swelling may happen because fluid builds up in the tissue if the muscles are not moving around. It's more likely to happen if the hand is hanging downwards. The painful swelling can make it more difficult to move your hand and arm, which can make spasticity worse.

To overcome this problem it is best to raise your hand and place it on a pillow or a cushion, and to get your hand moving again gently with the help of your physiotherapist.

Headache

There are many reasons why you might experience headaches following your stroke. Some reasons might be the same as before your stroke, such as migraines, stress, or lack of sleep.

If you are having headaches after your stroke, they could be a side effect of medication. If you think that a medication may be causing your headaches, visit your GP. They can find out what could be behind your headaches, and can give you alternative medications if necessary. Don't stop any treatments before talking to your doctor, as some types of drug depend on being taken regularly.

If you had a stroke due to a bleed in the brain (haemorrhagic stroke or brain haemorrhage), it can take a while for the headache to reduce while you are recovering.

Headaches can usually be controlled by painkillers such as paracetamol. You should check with your doctor or pharmacist before taking aspirin or a non-steroidal anti-inflammatory such as ibuprofen, as these can cause bleeding.

Drinking plenty of water (around two litres a day) and avoiding caffeine and alcohol helps you to stay hydrated and may reduce headaches. Migraines may be triggered by fatigue, which is common after stroke.

Sometimes, taking painkillers for headaches too often (for more than about 10 days a month) can cause medication over-use headaches. Treatment usually involves stopping all pain relief medication for about 12 weeks. However, you should contact your GP before doing so, as some painkillers contain codeine which can cause withdrawal symptoms if you stop taking it suddenly.

If you have a persistent headache, you should seek medical attention urgently. If you have any of the signs of a stroke, including a sudden, severe headache, call 999.

Alternative ways of managing pain

If you find that medication and or physiotherapy has not helped to relieve your pain, there are some other approaches you can try.

Pain clinics and pain management programmes

Pain clinics and pain management programmes can help you find ways to manage your pain in the longer-term to improve your quality of life. If you are in pain despite initial treatment, and it is causing you distress or significantly limiting what you are able to do, ask your GP to refer you to a pain clinic.

Pain clinics provide different treatments and advice to help you manage your pain. The kinds of treatment that are available from pain clinics vary across the UK

Some pain clinics run pain management programmes. They use psychological and practical methods to deal with managing your pain, and the effect that it has on your life. The programmes usually run for a set amount of time over a number of weeks. Doctors, nurses, psychologists, physiotherapists and occupational therapists may be involved with the programme. For example, a physiotherapist might help you to work on the physical difficulties that the pain causes by strengthening your muscles, and a psychologist might help you to manage the emotional effects that pain can have, such as depression and frustration.

Transcutaneous electrical nerve stimulation (TENS)

TENS treatment uses electrical impulses to reduce pain. Sticky pads are attached to your skin and linked to electrodes, which are attached to a battery-operated machine.

Electrical impulses are then sent through the electrodes onto your skin. These impulses can help to block the pain signals from travelling along the nerve pathways to your brain. At a low frequency, TENS can help your body to release natural painkillers called endorphins.

There is not enough evidence to say definitively whether TENS is an effective and reliable way of reducing pain. It provides temporary pain relief with no side effects, other than possible skin redness. You should ask your doctor before using it if you have a heart pacemaker or other type of electrical or metal implant in your body. It may not be suitable early in pregnancy, or for people with epilepsy or heart problems.

Complementary therapies

Although there is limited evidence on using complementary therapies after stroke, it's possible that massage or acupuncture and relaxation techniques like meditation or yoga may be helpful.

Where to get help and information

From the Stroke Association

Helpline

Our Helpline offers information and support for anyone affected by stroke, including family, friends and carers.

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100**
Email helpline@stroke.org.uk.

Read our information

Get more information about stroke online at stroke.org.uk, or call the Helpline to ask for printed copies of our guides.

My Stroke Guide

The Stroke Association's online tool My Stroke Guide gives you free access to trusted advice, information and support 24/7. My Stroke Guide connects you to our online community, to find out how others manage their recovery.

Log on to mystrokeguide.com today.

Other sources of help and information

Action on pain

Website: action-on-pain.co.uk

PainLine: **0345 603 1593**

A charity run by volunteers who are all affected by chronic pain in some way. Provides information and advice about pain, and raises awareness of those living with chronic pain.

The British Pain Society

Website: britishpainsociety.org

Tel: **020 7269 7840**

Professional body promoting best practice in supporting patients with pain. Provides patient information about pain and managing pain.

Pain Association Scotland

Website: painassociation.com

Tel: **0800 783 6059**

Provides information about pain and runs self-management programmes across Scotland for people living with chronic pain.

Pain Concern

Website: painconcern.org.uk

Helpline: **0300 123 0789**

UK-wide information and support for people living with pain. They have a digital radio programme on Able Radio, a helpline and online forum.

Pain Support

Website: painsupport.co.uk

Provides information about pain relief and advice about treatments.

SCOPE

Website: scope.org.uk

Helpline: **0808 800 3333**

Provides information sheets about spasticity, splinting and botulinum toxin type A treatment.

TMS Healthcare

Tel: **0121 355 6555**

Website: tens.co.uk

An online shop that sells TENS machines and other pain management aids.

Books

There are many books available on pain and managing pain. Visit reading-well.org.uk for suggestions on books about long term conditions like pain. Titles include: 'Overcoming chronic pain' by Frances Cole and Helen Macdonald, which uses techniques based on cognitive behavioural therapy (CBT).

'Pain is really strange' by Steve Haines and Sophie Standing is an illustrated guide about understanding pain and tools for managing pain.

'Manage your pain' by Nicolas Michael is recommended by the British Pain Society, and gives clear information and tips for reducing the impact of pain.

Glossary

Contracture: permanent shortening of a muscle that can leave a limb in an abnormal position.

Frozen shoulder: a very stiff shoulder which can be painful.

Spasticity: a form of muscle tightening.

Subluxation: partial dislocation of the shoulder, where the bone of the upper arm and the shoulder blade have moved apart.

TENS: Transcutaneous electrical nerve stimulation (a treatment that uses electrical impulses to block pain signals).

About our information

We want to provide the best information for people affected by stroke. That's why we ask stroke survivors and their families, as well as medical experts, to help us put our publications together.

How did we do?

To tell us what you think of this guide, or to request a list of the sources we used to create it, email us at feedback@stroke.org.uk.

Accessible formats

Visit our website if you need this information in audio, large print or braille.

Always get individual advice

This guide contains general information about stroke. But if you have a problem, you should get individual advice from a professional such as a GP or pharmacist. Our Helpline can also help you find support. We work very hard to give you the latest facts, but some things change. We don't control the information provided by other organisations or websites.

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