

Pain after stroke

This guide will help you to understand some of the causes of pain after stroke, and the treatments that are available. It also gives details of useful organisations that can provide information and support.

After a stroke, around 30% of survivors experience pain. This is most likely to happen soon after a stroke, but can also develop some time later. Types of post-stroke pain include muscle and joint pain, headaches, and painful sensations like tingling. Some of the main types of pain are:

- spasticity and contractures
- shoulder pain
- 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 like pain clinics and TENS devices for managing any long-term pain.

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 have physiotherapy every day to move your joints. This will help to stretch your muscles, keeping them flexible and reducing the possibility of contractures. Your physiotherapist will gently place your affected limb into as many different positions as possible using techniques called positioning, passive movement and active

Pain after stroke

movement. See our guide F16, *Physiotherapy after stroke* for more information.

Botulinum toxin type A

You may be given botulinum toxin type A as an injection directly into your muscle. 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.

The treatment should be given with further 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.

Medication

If you have generalised spasticity, or if botulinum toxin treatment doesn't reduce spasticity in the injected muscle, other types of medication can help reduce stiffness and pain that often comes with spasticity. There are different types of drugs that you could be given. They all work in slightly different ways, but they all help to relax your muscles. When your muscles are relaxed they can move more easily and you can stretch them further. You may also find that it becomes easier to straighten or bend your affected limbs, and you may notice fewer muscle spasms.

You will usually be prescribed baclofen or tizanidine first. If these drugs do not work, there are other drugs that may help, but they should only be prescribed by someone who specialises in managing spasticity.

How are contractures treated?

Splinting and casting

If you develop contractures, your physiotherapist 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 sometimes splints and casts can be uncomfortable. Talk to your physiotherapist about what would be best for you.

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.

Pain after stroke

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 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 might be because the muscles that normally hold this joint in place are too weak to do this properly.

How is shoulder pain treated?

Prevention

If you have weakness in your arm following your stroke, your medical team 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).

Your medical team may 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 codeine to help relieve the pain in your shoulder. For more severe pain you may be given a non-steroidal anti-inflammatory drug (NSAID) such as ibuprofen. These types of drug help to relieve pain and can also help to reduce swelling in your shoulder capsule (the tissue around the shoulder joint).

If you also have inflammatory arthritis, a steroid, such as triamcinolone, 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.

Central post-stroke pain (CPSP)

Up to 20% of people who have a stroke may develop central post-stroke pain (CPSP). This problem may occur if structures in the brain that interpret pain are affected by the stroke. It is often diagnosed by excluding other more common causes first. 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 are not helpful in relieving CPSP. Some other types of drug can be helpful, including antidepressants and anti-epilepsy drugs. If the first medication you try does not work, you should be offered another drug to try with, or instead of, the first one.

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

In rare cases, if your pain is severe and other treatments have been unsuccessful, you may be offered deep brain stimulation (DBS). This

is a procedure where small electrical leads are placed deep within your brain and are connected to a battery-powered machine, which sits under your skin. This procedure can only be carried out in specialist centres, and is not routinely available on the NHS. It is not suitable for everyone, and success rates after one year of treating pain with DBS are still very variable.

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 patients 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,

Pain after stroke

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.

A headache can be caused by a stroke, such as a subarachnoid haemorrhage (SAH). SAH is a stroke caused by bleeding on the surface of the brain. One of the symptoms of SAH is a severe headache, and after a stroke the headache may take a while to go completely.

Headaches soon after SAH can be due to hydrocephalus. This is a build-up of the cerebrospinal fluid (CSF) which surrounds the brain and spinal cord. If the CSF can't drain due to bleeding in the brain, the increased levels of fluid can cause headache, nausea and balance problems. This can be treated with an operation to drain the fluid by inserting a thin tube, called a shunt, to drain the fluid away from the brain.

Headaches can usually be controlled by painkillers such as paracetamol. You should not take aspirin if your stroke was caused by a bleed (haemorrhagic stroke).

Drinking plenty of water (around two litres a day) and avoiding caffeine and alcohol can help you to stay hydrated and 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 one month. However, you should visit 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 methods of treating pain

If you find that medication and or physiotherapy has not helped to relieve your pain, you may wish to try some alternative techniques. You may gain temporary relief from TENS, massage or acupuncture. Learning a relaxation technique, such as meditation or yoga, having psychological therapy such as counselling, or attending a pain clinic may be helpful.

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.

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. More information about what pain services are available for you can be obtained from your local health service, for example your GP.

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. Carried out in groups, 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.

Where to get help and information

From the Stroke Association

Talk to us

Our Stroke Helpline is for anyone affected by a stroke, including family, friends and carers. The Helpline can give you information and support on any aspect of stroke.

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100** or email **info@stroke.org.uk**.

Read our publications

We publish detailed information about a wide range of stroke topics including reducing your risk of a stroke and rehabilitation. Read online at **stroke.org.uk** or call the Helpline to ask for printed copies.

Other sources of help and information

Websites

Action on pain

Website: www.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: www.britishpainsociety.org

Tel: 020 7269 7840

Produces booklets about different types of pain and how they can be treated. Includes a glossary of pain-related words and phrases.

Chronic Pain Policy Coalition

Website: www.policyconnect.org.uk/cppc

A forum uniting professionals, members of parliament and patients to campaign for improved strategies on chronic pain issues. Information about pain is available on the website.

Pain Association Scotland

Website: www.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: www.painconcern.org.uk

Helpline: 0300 123 0789

Information and advice about pain is available through a range of publications and their helpline. Runs a radio programme called Airing Pain. They also have an online forum.

The Pain Relief Foundation

Website: www.painrelieffoundation.org.uk

Tel: 0151 529 5820

Provides information about pain and pain management and supports research into treatments. Publishes CDs and books that aim to help people cope with different types of pain, including headache, back and joint pain.

PainSupport

Website: www.painsupport.co.uk

Provides information about pain relief and advice about treatments. Offers an online forum and a contact club so that people suffering from pain can contact each other.

SCOPE

Website: www.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: www.tens.co.uk

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

Books

The Pain Relief Handbook: Self-help methods for managing pain

Dr Chris Wells & Graham Nown Vermilion
1996, Firefly Books

Taking Control of your Pain

Toni Battison
2005, Age Concern Books

Pain Relief without Drugs

Jan Sadler
2007, Healing Arts Press

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.

Subarachnoid haemorrhage = a type of stroke caused by bleeding in the space between the brain and skull.

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).

We would like to thank Allergan, Ipsen and Merz for funding the cost of producing this guide. The Stroke Association keeps full independent control over all content.

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

Please be aware that this information is not intended as a substitute for specialist professional advice tailored to your situation. We strive to ensure that the content we provide is accurate and up-to-date, but information can change over time. So far as is permitted by law, the Stroke Association does not accept any liability in relation to the use of the information in this publication, or any third-party information or websites included or referred to.

© Stroke Association 2017
Version 2. Published November 2017
To be reviewed: September 2020
Item code: **A01F30**



We rely on your support to fund life-saving research and vital services for people affected by stroke. Join the fight against stroke now at stroke.org.uk/fundraising
Together we can conquer stroke.

The Stroke Association is registered as a charity in England and Wales (No 211015) and in Scotland (SC037789). Also registered in Northern Ireland (XT33805), Isle of Man (No 945) and Jersey (NPO 369).