Stroke Helpline: 0303 3033 100
Website: stroke.org.uk

Pain after stroke

After a stroke you might experience various physical effects, such as weakness, paralysis or changes in sensation. Unfortunately you may also experience pain. This factsheet will help you to understand some of the causes of pain after stroke and the treatments that may be available. It also gives details of useful organisations that can provide you with further information and support.

There are many different types of pain you may experience after having a stroke. Weakness on one side of your body is one of the most common effects of stroke. This can lead to painful conditions such as muscle stiffness (spasticity) and shoulder problems. Some people also experience central post-stroke pain, headaches and sore swollen hands after stroke.

As with many effects of stroke, pain may persist for some time, but **treatments such as medication and physiotherapy are often successful in relieving pain**. Many people also benefit from attending pain management clinics and learn coping techniques to help them to manage any long-term pain (see page 7 for details).

Spasticity and contractures

After a stroke you may find that you have **muscle tightness or stiffness** – this is called spasticity. It is a common problem and affects over a third of stroke survivors. **Usually it occurs on the weaker side of your body**.

Spasticity happens when there is damage to the area of your brain that controls your muscles. If you have spasticity you will have **increased muscle tone**. Muscle tone is the amount of resistance or tension in your muscles, and it is what enables us to hold our bodies in a particular position. This increased muscle tone can make it difficult to move your limbs. Spasticity may also cause your muscles to tense and contract abnormally, causing **spasms**, which can be very painful. Spasticity can also damage your tissues and joints and can sometimes cause painful night cramps.

It is important to treat spasticity as soon as possible because your joints and muscles may become so stiff that it is impossible to move them (this is called a **contracture**).

How is spasticity treated?

If you have weakness after your stroke you should be assessed for spasticity. A team of specialists will decide on the best treatment for you. This may include a combination of physiotherapy, medication and Botox.

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. This is called **passive stretching** and should be taught to your family and carers so that they can help you to practise your exercises. See our factsheet *F16, Physiotherapy after stroke* for more information.

Botox

If spasticity affects only one or two specific parts of your body, you may be given botulinum toxin A (**Botox**) as an injection directly into your muscle. Botox works by blocking the action of the nerves on the muscle, reducing your muscle's ability to contract. It reduces muscle tone, which can **help you to straighten out your limbs**. Botox is only useful for small muscles, such as those in the hands. The muscle-relaxing effects of Botox usually last for about three months and you should not notice any changes in sensation in your muscles.

Botox treatment should be given with further rehabilitation such as physiotherapy, or other treatments like splinting or casting. You should also have an assessment three to four months after the treatment, and be offered further Botox treatments if helpful.

Medication

If you find that you are still experiencing muscle stiffness, you may be prescribed medication to help **reduce this stiffness** and the pain that often accompanies muscle spasms. 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 your spasticity is not fully controlled and 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.

Surgery

If you have severe contractures, you may need surgery to **lengthen your tendons**. Tendons are the bands that connect your muscle to the bone, and lengthening your tendons allows the joint to be stretched

out. This procedure is performed under anaesthetic. Surgery is always a last resort.

Shoulder pain

Shoulder pain is common after a stroke, and usually affects the side of your body that is affected by the stroke. There are different types of shoulder pain that you might experience and experts do not yet fully understand the exact causes.

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. Muscles and ligaments around our shoulder joints hold the bone in our upper arms 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 cause of shoulder pain is shoulder subluxation. This means **partial dislocation** – where the bone of the upper arm and the shoulder blade have moved apart. 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**. **Overhead arm slings should not be used** because there is not enough evidence that they work and they may increase your risk of developing shoulder pain or contractures. Your physiotherapist may use **cuffs or straps** to keep your arm and shoulder in the correct position, but for some people this may lead to spasticity.

Your physiotherapist may also use **electrical stimulation** on the muscles around your shoulder to help prevent or treat subluxation. (See page 6 for further information about electrical stimulation.)

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 **diclofenac** or **ibuprofen**. These types of drug help to relieve pain and can also help to reduce swelling in your shoulder capsule.

If you have an inflamed shoulder a **steroid**, such as triamcinolone, may be injected into your joint to help reduce the pain. **Botox** can sometimes be injected into specific muscles around your shoulder to help **reduce pain** and **increase flexibility**, particularly where the pain is associated with spasticity.

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 12 per cent of people who have a stroke will develop a particular type of pain called central post-stroke pain (CPSP). This is also known as Dejerine Roussy Syndrome, or central pain syndrome.

There are different types of pain you might experience if you have CPSP. Many people describe it as an **icy burning 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.

The exact cause of CPSP is unknown, but it is thought to be due to damage to certain parts of the brain and body. CPSP is a form of **neuropathic pain**, which means that the **painful sensation does not occur because your body is injured** or because something is making it hurt.

The pain may be caused by damage to the brain, brainstem or spinal cord (together, these are called the central nervous system) or be due to damage to the sensory pathways. These are pathways between the brain and the body which carry messages about pain. In some cases, CPSP is due to damage to the thalamus, which is the brain's pain centre. When this part of the brain is damaged it can sometimes cause feelings of pain when you are feeling a sensation that is not normally painful.

How is CPSP treated?

Unfortunately there is no cure for CPSP, but **around 70 per cent of stroke survivors with CPSP find that medication helps to relieve their pain**. Ordinary painkillers are not usually helpful in relieving CPSP, but some drugs which were originally created for treating other conditions are helpful for some people. They include **amitriptyline**, which is a drug used to treat depression, and **gabapentin** and **pregabalin**, which are used to treat epilepsy.

You will usually be started on a low dose, which is then gradually increased. If the first medication you try does not work, you should be offered another drug to try either with, or instead of, the first one.

In rare cases, if your pain is severe and other treatments have been unsuccessful, your medical team may offer you **deep brain stimulation**. 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 it is not suitable for everyone. Research shows that deep brain stimulation is effective in reducing pain for some people, though only a small number of people have taken part in the studies.

Other painful conditions

Swollen hand

You might find that after your stroke your hand swells up and becomes painful. This usually happens if you are **not moving your hand very much**, for example, if it is paralysed. The swelling happens because the fluid in the tissue in your hand cannot circulate properly because the muscles are not moving. When your muscles are not moving regularly, this fluid can collect, causing swelling and discomfort. This can get worse if your hand is often hanging downwards. This painful swelling can make it even 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. Wearing a tight-fitting glove can sometimes help to push the fluid out of your hand – this is called an **oedema glove**. This will need to be fitted correctly to avoid causing too much pressure. Your physiotherapist should be able to make a referral for you to have this done. You might find that **painkillers** such as paracetamol help to relieve the pain caused by this swelling in your hand.

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 stress, depression or lack of sleep.

If you are having headaches after your stroke, they could be a **side effect of medication** that you have started taking. Common examples include nifedipine (Adalat), which is given for high blood pressure, dipyridamole (Persantin), a blood-thinning medication, and glyceryl trinitrate, which is given for angina and to lower blood pressure. **Talk to your doctor**, because if you are experiencing headaches or any other side effects from medication, there may be an alternative drug you can try instead.

Occasionally, headaches may be a direct after-effect of your stroke if there is **swelling of the brain**. This swelling, which can be caused by a stroke, can irritate the membrane that covers the brain, resulting in a headache. This is more common if you have had a stroke caused by a bleed in the brain.

Headaches can also occur because of a **change to the levels of cerebrospinal fluid** (CSF). This is the fluid that fills the space between our brain and our skull. If there is an increased or reduced amount of CSF, this can cause headaches.

The pain from the headaches you are experiencing **should lessen over time** and can usually be controlled by **painkillers** such as paracetamol. **You should not take aspirin if your stroke was caused by a bleed**.

Drinking plenty of water (two to three litres per day) and **avoiding caffeine and alcohol** (which cause dehydration) may help to reduce these headaches. Increasing the amount of fluid in your body will improve the blood circulation to your brain.

Sometimes taking painkillers for headaches too often (for more than about 10 days a month) can cause headaches. Treatment usually involves stopping all pain relief medication for one month, but talk to your GP first if you think this is the cause of your headaches. Do not stop taking any medication without getting medical advice.

If you ever experience a sudden, severe headache or a persistent headache, you should seek medical attention urgently to find out what is causing it. One of the symptoms of a stroke caused by bleeding on the surface of the brain (subarachnoid haemorrhage) is a very sudden and severe headache, as if you have been hit on the back of the head. For more information about strokes caused by bleeding, please see our factsheet *F25, Bleeding in the brain – haemorrhagic stroke*.

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**, or speaking to a **counsellor** may also help you to cope. A pain clinic can give you more advice about your options (see page 7).

Transcutaneous electrical nerve stimulation (TeNS)

If you have severe and persistent pain, your medical team may consider treating this with transcutaneous electrical nerve stimulation (TeNS).

TeNS treatment uses **electrical impulses to reduce pain**. Sticky pads are attached to your skin close to the area that hurts. These pads are linked to leads called electrodes, which are attached to a battery-operated machine. Electrical impulses are then sent from the machine, through the electrodes and 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. Clinical trials have shown that it works well for some people but not for others, and that the amount of pain relief and the length of time that this lasts for varies from person to person. The majority of people who have found TeNS to be effective noticed benefits whilst the machine was switched on, but found the pain relief did not last.

This form of pain management is widely used by hospitals and pain clinics throughout most of the UK (see the section on *Pain clinics and pain management programmes*). TeNS could be a helpful way to manage your pain but it is important to check with your doctor first before trying this treatment. This is because there are lots of different causes of pain and types of pain, and TeNS has not yet been

recommended for all of them.

There are **no side effects** to TeNS and you can use it alongside other medication. TeNS is **unsuitable for some people**, for example people fitted with a cardiac pacemaker, so if you are interested in trying TeNS to manage your pain, it is important to **check with your doctor first**. TeNS treatment may be available from your physiotherapist, or alternatively you can buy the machines from some pharmacies.

Pain clinics and pain management programmes

You should be referred to a specialist pain service if you are still in pain despite initial treatment, and it is causing you distress or significantly limiting what you are able to do. If this has not happened, ask your doctor to refer you to one. Pain clinics and pain management programmes can **help you to find ways to manage your pain** in the longer-term to improve your quality of life.

At a pain clinic, you can have an assessment to determine the cause of your pain and they can provide treatment and advice to help you to manage this 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 **physical, psychological** and **practical methods** to deal with managing your pain and the effects 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 will be there to carry out the programme. For example, a physiotherapist might help you to work on the physical difficulties that the pain causes by strengthening your muscles; a psychologist might help you to manage the emotional effects that pain can have, such as depression and frustration.

Useful resources

Pain relief audio tapes/CDs

A series of simple and effective audio resources for home use, describing techniques used on the pain management programme at the Walton Centre for Neurology and Neurosurgery. They are available from the Pain Relief Foundation (see *Useful organisations*). Titles: *Coping with Pain*, *Coping with Back Pain*, *Coping with Headache and Migraine*, *Anxiety* (all priced at £8.50 inc. P&P), *The Relaxation Kit*, and *Feeling Good* (£13.99 inc P&P).

Books

The Pain Relief Handbook: Self-help methods for managing pain. By Dr Chris Wells & Graham Nown Vermilion, London 1996. Available from book shops.

Taking Control of your Pain. By Toni Battison. Age Concern Books (2005). Available from book shops.

Pain Relief without Drugs. By Jan Sadler. (2007) Healing Arts Press (price £12.99). Available from The Pain Relief Foundation.

Useful organisations

All organisations are UK wide unless otherwise stated.

Stroke Association
Stroke Helpline: 0303 3033 100
Email: info@stroke.org.uk
Website: stroke.org.uk
Contact us for information about stroke, emotional support and details of local services and support groups.

Action on pain
Tel: 0845 603 1593
Website: www.action-on-pain.co.uk
Provides information and advice about pain. Campaigns and raises awareness of those living with chronic pain.

The British Pain Society
Tel: 020 7269 7840
Website: www.britishpainsociety.org
Has various publications for patients and information about pain management.

Central Pain Syndrome Alliance
Website: www.centralpain.org
International internet resource with online information and a discussion forum for support.

Chronic Pain Policy Coalition
Tel: 020 7202 8580
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 their website.

Pain Association Scotland
Tel: 0800 783 6059
Website: www.painassociation.com
Provides information about pain and runs self-management programmes across Scotland for people living with chronic pain.

Pain Concern
Helpline: 0300 123 0789
Website: www.painconcern.org.uk
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
Tel: 0151 529 5820
Website: www.painrelieffoundation.org.uk
Provides information about pain and pain management and supports research into treatments.

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
Helpline: 0808 800 3333
Website: www.scope.org.uk
Provides information sheets about spasticity, splinting and Botox treatment.

Talking Life
Tel: 0151 632 0662
Website: www.talkinglife.co.uk
Runs training courses and produces materials for professionals.

TeNS Medical Services Ltd
Tel: 0845 0900 800
Website: www.tens.co.uk
Produces and sells TeNS machines.

Disclaimer: The Stroke Association provides the details of other organisations for information only. Inclusion in this factsheet does not constitute a recommendation or endorsement.

Glossary of terms

Capsulitis = see 'Frozen shoulder'.

Central nervous system = the name for the system in the body containing the brain, brainstem and spinal cord.

Contracture = abnormal shortening of a muscle that results in deformity.

CPSP = central post-stroke pain.

Cerebrospinal fluid (**CSF**) = fluid that fills the space between the brain and skull.

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

Lumbar puncture = a procedure to take a sample of cerebrospinal fluid, which can be used to diagnose conditions such as a subarachnoid haemorrhage.

Oedema = an increase of fluid in the tissues which can cause swelling.

Spasticity = a form of muscle tightening.

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

Subarachnoid space = the space between the membranes that surround the brain and protect it from the 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).

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