

**Complex
regional pain
syndrome (CRPS)**

This booklet provides information
and answers to your questions
about this condition.



What is complex regional pain syndrome?



Complex regional pain syndrome (CRPS) is a condition that causes persistent, burning pain in one of the limbs. It's sometimes referred to as reflex sympathetic dystrophy (RSD), Sudek's atrophy or algodystrophy. In this booklet we'll look at the symptoms and possible causes of CRPS, and explain what treatments are available.

At the back of this booklet you'll find a brief glossary of medical words – we've underlined these when they're first used in the booklet.

What's inside?

- 2 Complex regional pain syndrome (CRPS) at a glance**
- 4 What is complex regional pain syndrome (CRPS)?**
- 4 What are the symptoms of CRPS?**
- 5 What causes CRPS?**
- 5 What is the outlook?**
- 7 How is CRPS diagnosed?**
- 7 What treatments are there for CRPS?**
 - Rehabilitation therapies
 - Physiotherapy
 - Occupational therapy
 - Psychology
 - Drugs
 - Sympathetic blocks
- 11 Self-help and daily living**
 - Exercise
 - Diet
- 11 Research and new developments**
- 12 Glossary**
- 12 Where can I find out more?**
- 16 We're here to help**



At a glance

Complex regional pain syndrome (CRPS)

What are the symptoms?

CRPS is a condition which causes burning pain in the arms or legs. There may also be colour or temperature changes in the affected limb.

What causes it?

The exact cause isn't known, but it's thought that a number of different processes are involved, including inflammation, damage to nerve fibres and abnormal pain signals in the brain. It can sometimes occur after an injury or operation.

What treatments are there?

CRPS can be difficult to treat. Treatment is aimed at controlling your pain (drug treatments) and helping you to use your affected limb as fully as possible (rehabilitation).

Drug treatments include:

- painkillers – e.g. paracetamol, codeine, tramadol
- stronger painkillers – e.g. morphine
- drugs that reduce nerve signals to the brain – e.g. gabapentin, pregabalin

Causes of CRPS could include inflammation, damage to nerve fibres and abnormal pain signals in the brain.

- low-dose antidepressants which also reduce pain signals – e.g. amitriptyline
- bisphosphonates
- capsaicin cream – where smaller areas are affected.

Rehabilitation therapies include:

- physiotherapy
- transcutaneous electrical nerve stimulation (TENS)
- occupational therapy
- desensitisation (touching affected area with different fabrics)
- relaxation and stress management techniques
- psychology
- body perception awareness, which encourages more positive feelings about the affected limb.

Sympathetic blocks (block the transmission of pain signals from the nerves) include:

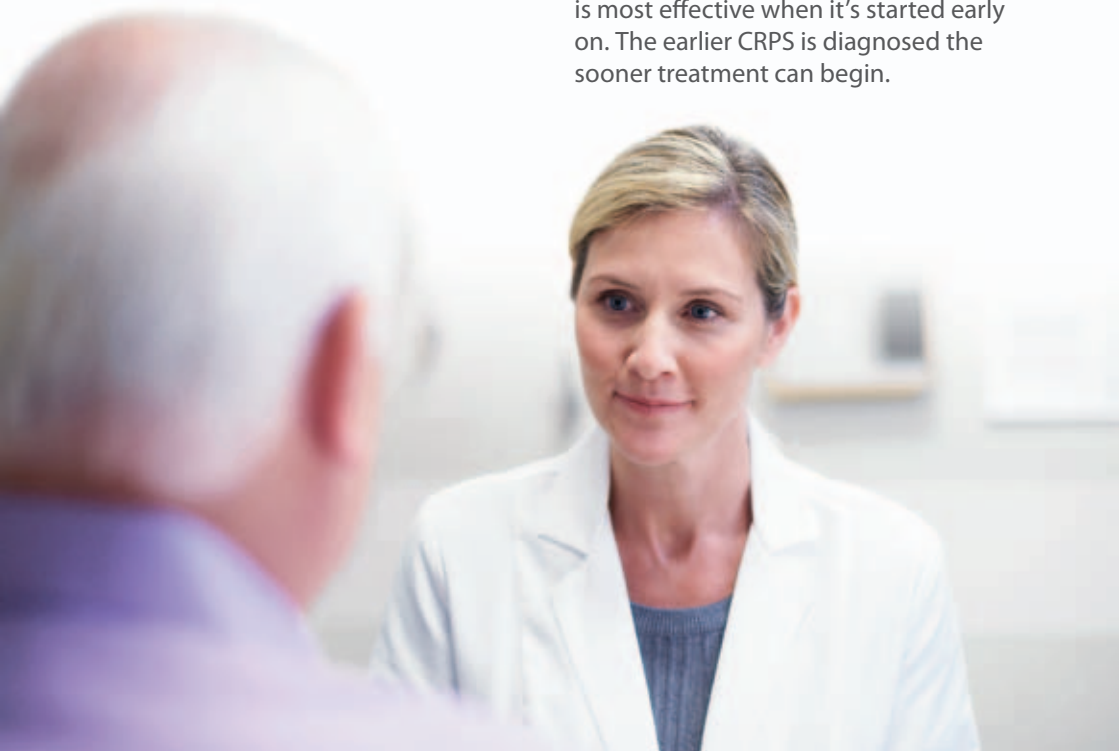
- temporary blocks using injections of a local anaesthetic or occasionally a drug called guanethidine
- permanent blocks, either by injection or by surgery.

What is the outlook?

The outlook for people with CRPS is variable and difficult to predict. It can settle within weeks or months, but may last longer. The treatments described above can help with your recovery.

Should I see a doctor?

We would always recommend you see a doctor if you have persistent pain. Research shows that treatment for CRPS is most effective when it's started early on. The earlier CRPS is diagnosed the sooner treatment can begin.



What is complex regional pain syndrome (CRPS)?

Complex regional pain syndrome, referred to as CRPS, is a condition that isn't well understood and is often difficult to diagnose. Its main feature is a persistent, burning pain in one of the limbs. It's sometimes referred to as reflex sympathetic dystrophy (RSD), Sudek's atrophy or algodystrophy.

Anyone can be affected by CRPS, including children. The parts of the body most commonly affected are the hand and wrist, foot and ankle, or the knee, although sometimes a whole limb can be affected.

What are the symptoms of CRPS?

Pain is the main symptom of CRPS. The affected limb is often very sensitive to touch. Even light stroking or the touch of clothing can cause severe pain. The painful area is often swollen and, after a time, may become weak, making movement difficult.

The colour or temperature of affected areas may be different from the unaffected parts.



Arthritis Research UK

Complex regional pain syndrome (CRPS)

These changes often vary a great deal, sometimes during the course of a day. For example, a hand or a foot could initially be warmer than expected, but later it becomes colder. Similarly, the affected area could be more red or blue than normal or may become mottled in appearance.

Some people with CRPS become depressed, and others have negative feelings about the affected limb.

i See Arthritis Research UK booklet *Pain and arthritis*.

What causes CRPS?

We don't yet know exactly what causes CRPS but there are probably several factors involved.

A fracture or other injury sometimes seems to act as a trigger, although the vast majority of people recover from such injuries without any complications. It's not known why some people go on to develop CRPS following an injury, although it's thought that communication pathways between the affected limb and the brain may be disrupted so that pain continues long after the injury has healed.

More rarely, CRPS can occur after other problems such as a stroke or multiple operations to a limb. But in other cases it develops without any obvious trigger factor.

A limb affected by CRPS may be so sensitive that even the touch of clothing can be painful.

In the early stages of CRPS it's thought that inflammation plays a key role. Slightly later on, problems with nerve fibres become more important, including special nerve fibres called the sympathetic nervous system. This system has several functions including the regulation of blood flow and skin temperature, and doctors have found that blocking the action of the sympathetic nervous system can sometimes be helpful in the early stages of CRPS. Changes can also occur in the spinal cord and brain, and in the amount of oxygen in the affected limb.

What is the outlook?

It's difficult to predict how CRPS will progress in any individual. In some cases it can last for months or even years, and a few people may be left with some degree of pain permanently. However, in the majority of cases and with good rehabilitation therapy, it can settle over the course of a few weeks or months.

Occasionally, people who have had it in one limb may develop it in another – but this is relatively unusual.



How is CRPS diagnosed?

CRPS is often difficult to diagnose, and there is no specific test that will confirm the diagnosis. Doctors mainly base diagnosis on your symptoms and the results of a physical examination. However, tests may be used, often to rule out other possible causes of the pain and swelling.

- **An x-ray** or bone scan of the affected limb may show thinning of the bone (osteoporosis) or other bone abnormalities.
- **Blood tests** may help to rule out other causes of pain and swelling.
- **Blocking the sympathetic nervous system** with a local anaesthetic is occasionally used as a diagnostic test. If this block eases the pain, then it's likely that the sympathetic nervous system is contributing to the pain.

What treatments are there for CRPS?

It's important to begin treatment as soon as possible. The longer CRPS goes on, the more difficult it is to treat. Experts believe the important thing is to restore as much function as possible to the affected limb through a combination of physical rehabilitation therapies and pain-relieving medication.

Rehabilitation therapies

The most important goal of rehabilitation therapies is to restore as much function and quality of life as possible.

There are a variety of techniques used by therapists to achieve this. Most of these therapies will begin very gently to avoid a flare-up of your symptoms, and you'll need to build up the duration and intensity gradually, even if progress seems slow at times.

- ! **Rehabilitation therapies play an important part in the treatment of CRPS and are most effective when started early.**

Physiotherapy

Physiotherapy is probably the single most important treatment for CRPS. The aim is to relieve pain and keep the affected limb mobile. This will help prevent stiffness and loss of muscle tone as well as promoting circulation. Exercise can be difficult if you have severe pain so you'll need to work with your physiotherapist to find out which exercises work best for you, when you should stop and the techniques you can use to cope if your pain does increase for a time.

Your physiotherapist will advise on pain relief therapies such as transcutaneous electrical nerve stimulation (TENS), and they may be able to loan you a TENS machine to try.

-
- i **See Arthritis Research UK booklet *Physiotherapy and arthritis*.**
-

Occupational therapy

Your occupational therapist can help with a number of therapies and techniques:

- **Desensitisation** – This is a technique that aims to normalise touch sensations in the affected limb. It involves touching the skin frequently with different-textured fabrics and other substances (for example, wool, silk, cotton wool), gradually working towards the painful areas.
- **Relaxation and/or stress management techniques** – These can help in managing pain on a day-to-day basis.
- **Body perception awareness** – This can be especially helpful for people who develop negative feelings about the affected limb. It encourages people to look at, touch and think about the affected limb as often as possible so that the limb begins to feel a normal part of your body again.

i See Arthritis Research UK booklet *Occupational therapy and arthritis*.

Psychology

A psychologist will focus on helping with coping techniques which may include stress management and relaxation exercises, acceptance and learning how to ask for the support available.

Drugs

There is no single drug treatment that works for everyone with CRPS, but medications can be useful.

- Painkillers such as paracetamol, codeine and tramadol (often combined) or non-steroidal anti-inflammatory drugs (NSAIDs) can be helpful, but won't always provide adequate pain relief.
- Morphine and similar medications (for example, oxycodone or buprenorphine) may be prescribed for very severe pain.
- Neuromodulatory drugs such as gabapentin and pregabalin can help by reducing pain signals from the nerves to the brain.
- Antidepressants such as amitriptyline and duloxetine, given in low doses, can also reduce pain signals to the brain.
- Bisphosphonates, which can be given as tablets or injections, seem to help in some cases, although the reasons for this aren't fully understood.
- Capsaicin, a cream made from chilli peppers, relieves pain, although it causes a burning sensation for the first few days so it might not be suitable if a large area or a whole limb is affected.
- Lidocaine patches are impregnated with local anaesthetic and can be particularly helpful for people with very sensitive and painful skin.
- Steroids may be of some benefit, especially in the early stages and where there might be some swelling, heat and redness.

i See Arthritis Research UK **drug leaflets** *Non-steroidal anti-inflammatory drugs; Steroid tablets*.

Arthritis Research UK

Complex regional pain syndrome (CRPS)

Sympathetic blocks

Blocks of the sympathetic nervous system can be either temporary or permanent.

Temporary blocking of the sympathetic nervous system can be carried out using either local anaesthetic or guanethidine (a drug sometimes used to treat high blood pressure), both of which are given by injection.

- **Local anaesthetic blocks** – Local anaesthetic is injected around the sympathetic nerves. If CRPS affects the upper limb (hand or wrist), then the injection is given into the side of your neck. If CRPS affects the lower limb (foot, ankle or knee), then the injection is given into your flank (side). If the block is successful then its effect will be apparent within a few minutes.
- **Guanethidine blocks** – A tourniquet is applied to the limb and guanethidine is injected into a vein. This suppresses the sympathetic nervous system. Guanethidine blocks are only rarely used.

If one of these temporary blocks helps, further blocks may be given from time to time. Alternatively, the doctor may recommend a permanent block, which are performed either surgically or by injection.



Walking and swimming are good low-impact exercises that will help keep you fit and healthy without putting too much strain on painful limbs, while also maintaining strength and function in the affected limb.

Although there is no direct link between your diet and CRPS, keeping to a healthy weight and eating a healthy, balanced diet is important for your overall well-being.

Self-help and daily living

Exercise

Regular exercise is important for your general health. You may feel like avoiding exercise if you're in pain, but you should still try and do a little each day. Walking and swimming are good low-impact exercises that will help keep you fit and healthy without putting too much strain on painful limbs, while also maintaining strength and function in the affected limb.

i See **Arthritis Research UK booklet**
Keep moving.

Diet

Although there's no direct link between your diet and CRPS, keeping to a healthy weight and eating a healthy, balanced diet is important for your overall well-being.

i See **Arthritis Research UK booklet**
Diet and arthritis.

Research and new developments

A few hospitals offer a new treatment known as mirror visual feedback therapy. Exercises are performed with the aid of a mirror positioned so that the patient sees a reflection of the unaffected limb while the affected limb is hidden from view. Graded motor imagery is another type of rehabilitation which uses mirror therapy, but it also includes other techniques to try to retrain the brain and improve symptoms. Although these techniques haven't yet been widely used, early research suggests that these therapies may be helpful for some people with CRPS.

Trials of new medication have included studies looking at strong anaesthetic agents such as ketamine, and medications to block inflammation such as anti-TNF and intravenous immunoglobulins. These approaches remain very experimental and have so far only been used on very small numbers of patients with variable results.



Glossary

Bisphosphonates – drugs used to prevent the loss of bone mass and treat bone disorders such as osteoporosis and Paget’s disease. They work by reducing high levels of calcium in the blood and by slowing down bone metabolism.

Inflammation – a normal reaction to injury or infection of living tissues. The flow of blood increases, resulting in heat and redness in the affected tissues, and fluid and cells leak into the tissue, causing swelling.

Non-steroidal anti-inflammatory drugs (NSAIDs) – a large family of drugs prescribed for different kinds of arthritis that reduce inflammation and control pain, swelling and stiffness. Common examples include ibuprofen, naproxen and diclofenac.

Occupational therapist – a therapist who helps you to get on with your daily activities (e.g. dressing, eating, bathing) by giving practical advice on aids, appliances and altering your technique.

Osteoporosis – a condition where bones become less dense and more fragile, which means they break or fracture more easily.

Physiotherapist – a trained specialist who helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

Sympathetic nervous system – part of the nervous system that controls many of the involuntary actions of the body’s glands and organs.

Tourniquet – a band that is drawn tightly around a limb to temporarily decrease blood flow to a specific area.

Transcutaneous electrical nerve stimulation (TENS) – a small battery-driven machine which can help to relieve pain. Small pads are applied over the painful area and low-voltage electrical stimulation produces a pleasant tingling sensation, which relieves pain by interfering with pain signals to the brain.

Where can I find out more?

If you’ve found this information useful you might be interested in these other titles from our range:

Therapies

- *Occupational therapy and arthritis*
- *Physiotherapy and arthritis*

Self-help and daily living

- *Diet and arthritis*
- *Keep moving*
- *Pain and arthritis*

Drug leaflets

- *Non-Steroidal anti-inflammatory drugs*
- *Steroid tablets*

Arthritis Research UK

Complex regional pain syndrome (CRPS)

You can download all of our booklets and leaflets from our website or order them by contacting:

Arthritis Research UK

PO Box 177
Chesterfield
Derbyshire S41 7TQ
Phone: 0300 790 0400
www.arthritisresearchuk.org

Related organisations

The following organisations may be able to provide additional advice and information:

Arthritis Care

18 Stephenson Way
London NW1 2HD
Phone: 020 7380 6500
Helpline: 0808 800 4050
www.arthritiscare.org.uk

Action on Pain

PO Box 134,
Shipdham
Norfolk IP25 7XA
Phone: 01362 820750
www.action-on-pain.co.uk

British Pain Society

Third Floor, Churchill House
35 Red Lion Square
London WC1R 4SG
Phone: 020 7269 7840
www.britishpainsociety.org

Disabled Living Foundation

380-384 Harrow Road
London W9 2HU
Phone: 020 7289 6111
Helpline: 0845 130 9177
www.dlf.org.uk



We're here to help

Arthritis Research UK is the charity leading the fight against arthritis.

We're the UK's fourth largest medical research charity and fund scientific and medical research into all types of arthritis and musculoskeletal conditions.

We're working to take the pain away for sufferers with all forms of arthritis and helping people to remain active. We'll do this by funding high-quality research, providing information and campaigning.

Everything we do is underpinned by research.

We publish over 60 information booklets which help people affected by arthritis to understand more about the condition, its treatment, therapies and how to help themselves.

We also produce a range of separate leaflets on many of the drugs used for arthritis and related conditions. We recommend that you read the relevant leaflet for more detailed information about your medication.

Please also let us know if you'd like to receive our quarterly magazine, Arthritis Today, which keeps you up to date with current research and

education news, highlighting key projects that we're funding and giving insight into the latest treatment and self-help available.

We often feature case studies and have regular columns for questions and answers, as well as readers' hints and tips for managing arthritis.

Tell us what you think of our booklet

Please send your views to:
feedback@arthritisresearchuk.org
or write to us at:
Arthritis Research UK, PO Box 177,
Chesterfield, Derbyshire S41 7TQ.

A team of people contributed to this booklet. The original text was written by Dr Rachel Gorodkin, who has expertise in the subject. It was assessed at draft stage by consultant rheumatologist Dr Nick Shenker. An **Arthritis Research UK** editor revised the text to make it easy to read, and a non-medical panel, including interested societies, checked it for understanding. An **Arthritis Research UK** medical advisor, Dr Ben Thompson, is responsible for the content overall.

Get involved

You can help to take the pain away from millions of people in the UK by:

- Volunteering
- Supporting our campaigns
- Taking part in a fundraising event
- Making a donation
- Asking your company to support us
- Buying gifts from our catalogue

To get more **actively involved**, please call us **0300 790 0400** or e-mail us at enquiries@arthritisresearchuk.org

Or go to:
www.arthritisresearchuk.org



Providing answers today and tomorrow

Arthritis Research UK

Copeman House,
St Mary's Court,
St Mary's Gate, Chesterfield,
Derbyshire S41 7TD

Tel 0300 790 0400

calls charged at standard rate

www.arthritisresearchuk.org

Registered Charity No 207711
© Arthritis Research UK 2011
Published April 2011 2035/CRPS/11-1

