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 pain in one of your 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.

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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
   – Other treatments
11 Self-help and daily living
   – Exercise
   – Diet
   – Work
   – Dealing with stress
11 Research and new developments
12 Glossary
13 Where can I find out more?
16 We’re here to help
What is CRPS?
CRPS is a condition which causes burning pain in the arms or legs. It’s not well understood and can be difficult to diagnose.

What are the main symptoms of CRPS?
The main symptom of CRPS is pain in the affected limb, which may also change colour or temperature and may swell or sweat.

Should I see a doctor?
We would always recommend you see a doctor if you have pain that won’t go away. 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 causes it?
The exact cause of CRPS 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, and if it does it’s usually within a month of the injury.

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

Treatments for rehabilitation:
• physiotherapy including transcutaneous electrical nerve stimulation (TENS) and t’ai chi
• occupational therapy including desensitisation (touching the affected area with different fabrics), relaxation and stress management techniques, and body perception awareness (which encourages more positive feelings about the affected limb)
• psychological therapies including cognitive behavioural therapy (CBT)
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Complex regional pain syndrome (CRPS)

Treatments for relieving pain:
- painkillers (for example paracetamol and codeine), or stronger painkillers (for example morphine) for more severe pain
- drugs that reduce nerve signals to the brain (for example gabapentin, pregabalin)
- low-dose antidepressants which also reduce pain signals (for example amitriptyline)
- bisphosphonates
- spinal cord stimulation
- sympathetic blocks (which stop pain signals from the sympathetic nervous system reaching the brain by injecting drugs and possibly a local anaesthetic).

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.
What is complex regional pain syndrome (CRPS)?

Complex regional pain syndrome (CRPS) is a condition that isn’t well understood and is often difficult to diagnose. Its main feature is a burning pain in one of the limbs which won’t go away. 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 weight of clothing can cause severe pain. The painful area is often swollen and, after a time, may become weak, making movement difficult.

You may notice that the colour or temperature of affected areas changes.
These changes often vary a great deal, sometimes during the course of a day. For example, your hand or foot could initially be warmer than expected, but later it may become 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.

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 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 these 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.

In the early stages of CRPS it’s thought that inflammation plays a key role.

What is the outlook?
It’s difficult to predict how CRPS will progress in any one person but early diagnosis and treatment are helpful. In some cases it can last for months or even years, and some people may be left with some degree of pain permanently. Most cases will settle over the course of a few weeks or months with good rehabilitation therapy, but where symptoms have lasted for more than six months it’s much more likely that some pain will still be felt, even after treatment.
People who have had CRPS in one limb may develop it in another, but this is relatively unusual – only 7% of people report this. People with CRPS often alter their posture to adapt to their painful limb, and this can cause musculoskeletal pain (especially frozen shoulders) which can be misinterpreted as CRPS.

**How is CRPS diagnosed?**
CRPS is often difficult to diagnose, and there’s no specific test that will confirm that you have the condition. Doctors mainly base diagnosis on your symptoms and the results of a physical examination, although the following tests may be used:

- **An x-ray or bone scan** of the affected limb may show thinning of the bone (osteopenia) or other bone abnormalities.

- **Blood tests** and **magnetic resonance imaging (MRI) scans** 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 may be involved in causing the condition.

**What treatments are there for CRPS?**
The longer CRPS goes on, the more difficult it is to treat, so it’s important to begin treatment as soon as possible. This includes 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, and therapists use a number of techniques to do this. Most therapies will begin very gently to avoid a flare-up of your symptoms, and you’ll need to build up the length of time 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 also 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.
Hydrotherapy (exercises performed in warm water) and t’ai chi may also be useful.

A new treatment known as mirror visual feedback therapy is becoming more widely used as it’s very easy to do and can produce effective results. Exercises are performed with the aid of a mirror positioned so that the user 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’s only occasionally used.

See Arthritis Research UK booklet Hydrotherapy and arthritis; 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 if you develop negative feelings about the affected limb. It encourages you 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.

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, cognitive behavioural therapy (CBT), acceptance and learning how to ask for support.

Drugs

No single drug treatment works for everyone with CRPS, but medications can be useful.

- Painkillers such as paracetamol and codeine (often combined) or non-steroidal anti-inflammatory drugs (NSAIDs) can be helpful, but they won’t always give enough pain relief.

- Tramadol, 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.

• Lidocaine patches are filled with local anaesthetic and can be particularly helpful for people with very sensitive and painful skin.

• Temporary blocking of the sympathetic nervous system can be carried out using injections of local anaesthetic or guanethidine (a drug sometimes used to treat high blood pressure). If temporary blocks help, you may be given them again from time to time, or your doctor may recommend a permanent block.

Other treatments

Spinal cord stimulation
Electrodes (an electrical conductor) are surgically implanted next to the spinal cord and provide low level electric stimulation that reduces pain levels. Spinal cord stimulation can be very effective, but because of the risk of complications it’s only used in a very small number of carefully selected patients.

See Arthritis Research UK drug leaflets Amitriptyline; Non-steroidal anti-inflammatory drugs; Painkillers.
Walking and swimming are good low-impact exercises that will help keep you fit and healthy, maintaining strength and function in the affected limb without putting too much strain on it.

Although there’s no direct link between your diet and CRPS, keeping to a sensible 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 to do a little each day. Walking and swimming are good low-impact exercises that will help keep you fit and healthy, maintaining strength and function in the affected limb without putting too much strain on it.

See Arthritis Research UK booklet Keep moving.

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

See Arthritis Research UK booklet Diet and arthritis.

Work
Most people with CRPS are able to continue in their jobs, although you may need to make some alterations to your working environments, especially if you have a physically demanding job. Speak to your employer’s occupational health service if they have one, or your local Jobcentre Plus can put you in touch with Disability Employment Advisors who can arrange work assessments. They can advise you on changing the way you work and on equipment that may help you to do your job more easily. If necessary, they can also help with retraining for more suitable work.

See Arthritis Research UK booklet Work and arthritis.

Dealing with stress
Living with a long-term condition like CRPS can lower your morale and may affect your sleep. It’s important to tackle problems like these as they could lead to depression and will certainly make the CRPS more difficult to cope with. It often helps to talk about negative feelings, so it could be useful to speak to your healthcare team, or your family and friends. Support groups are also available – your doctor may be able to tell you about organisations in your area.

See Arthritis Research UK booklets and guide Fatigue and arthritis; Pain and arthritis; Living with long-term pain: a guide to self-management.

Research and new developments
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

**Anaesthetic** – a substance that stops you feeling pain. A local anaesthetic only affects the area it’s applied to.

**Bisphosphonates** – drugs used to prevent the loss of bone mass and treat bone disorders. They work by reducing high levels of calcium in the blood and by slowing down bone metabolism.

**Cognitive behavioural therapy (CBT)** – a psychological treatment based on the assumption that most of a person’s thought patterns and emotional or behavioural reactions are learned and can therefore be changed. The therapy aims to help people resolve difficulties by learning more positive thought processes and reactions.

**Hydrotherapy** – exercises that take place in water (usually a warm, shallow swimming pool or a special hydrotherapy bath) which can improve mobility, help relieve discomfort and promote recovery from injury.

**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.

**Magnetic resonance imaging (MRI) scan** – scan that uses high-frequency radio waves in a strong magnetic field to build up pictures of the soft-tissue structures and bones. It works by detecting water molecules in the body’s tissue that give out a characteristic signal in the magnetic field.

**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 therapy** – a therapy which uses a range of strategies and specialist equipment to help people to reach their goals and maintain their independence. It’s given by a trained specialist who gives practical advice on equipment, adaptations or changing the way you do things.

**Osteopenia** – a condition where bone density is lower than normal, but not low enough to be classified as osteoporosis.
Physiotherapy – a therapy given by a trained specialist that 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.

T’ai chi – a Chinese martial art that involves a slow sequence of movements and aims to improve balance and strength.

Transcutaneous electrical nerve stimulation (TENS) – a small machine which can help to relieve pain. 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**
- *Hydrotherapy and arthritis*
- *Occupational therapy and arthritis*
- *Physiotherapy and arthritis*

**Self-help and daily living**
- *Diet and arthritis*
- *Fatigue and arthritis*
- *Keep moving*
- *Living with long-term pain: a guide to self-management*
- *Pain and arthritis*
- *Work and arthritis*

**Drug leaflets**
- *Amitriptyline*
- *Non-steroidal anti-inflammatory drugs*
- *Painkillers*

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

**Arthritis Research UK**
Copeman House
St Mary’s Court
St Mary’s Gate, Chesterfield
Derbyshire S41 7TD
Phone: 0300 790 0400
www.arthritisresearchuk.org
Related organisations

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

**Arthritis Care**
Floor 4, Linen Court
10 East Road
London N1 6AD
Phone: 0207 380 6500
Helpline: 0808 800 4050
Email: info@arthritiscare.org.uk

**Action on Pain**
PO Box 134,
Shipdham
Norfolk IP25 7XA
Phone: 01362 820 750
Helpline: 0845 603 1593
Email: aopisat@btinternet.com
www.action-on-pain.co.uk

**British Pain Society**
Third Floor, Churchill House
35 Red Lion Square
London WC1R 4SG
Phone: 0207 269 7840
Email: info@britishpainsociety.org
www.britishpainsociety.org

**Disabled Living Foundation**
380–384 Harrow Road
London W9 2HU
Phone: 0207 289 6111
Helpline: 0845 130 9177
Email: info@dlf.org.uk
www.dlf.org.uk

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Notes
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

Please send your views to: feedback@arthritisresearchuk.org or write to us at: Arthritis Research UK, Copeman House, St Mary’s Court, St Mary’s Gate, Chesterfield, Derbyshire S41 7TD

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 rheumatology clinical trials nurse specialist Sally Giles, clinical manager Daniel Lawrence, GP Dr Lisa le Roux and consultant physiotherapist Nicky Wilson. 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, Prof. Anisur Rahman, 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 products from our online and high-street shops.

To get more actively involved, please call us on 0300 790 0400, email us at enquiries@arthritisresearchuk.org or go to www.arthritisresearchuk.org