

Complex Regional Pain Syndrome (CRPS)

**Hand Therapy Services
Community & Therapy Services**

This leaflet has been designed to give you important information and to answer some common queries that you may have.



Information for patients and visitors

What is complex regional pain syndrome (CRPS)?

CRPS pain usually develops in an arm or leg after an injury. Only rarely are other areas affected. It can affect people of all ages, including children. There are two types of CRPS:

- CRPS type 1 follows an injury to a limb, such as a broken bone or even a minor sprain
- CRPS type 2 follows partial damage to a nerve in the limb. The symptoms are very similar. This form is very rare

What causes CRPS?

CRPS is a stronger-than-normal reaction of the body to injury. We don't know what causes CRPS. What we do know is that the abnormal reaction to injury happens both in the affected limb and in the brain. The nerves in the affected limb are much more sensitive than other nerves and this causes some of the tenderness to touch and pressure. The brain is also involved. The way the brain communicates with the affected limb often changes and this can cause some of the problems with movement.

CRPS is not in your mind. We also know that your mindset cannot cause CRPS, but that some psychological factors such as fear or worry can make the pain worse than it already is.

What is it like to have CRPS?

CRPS pain continues after the original injury has healed. It is often severe.

The main symptom is pain in the arm or leg. The pain is often burning, sharp, stabbing or stinging, with tingling and numbness. There are a range of other symptoms which can change over time. The skin may become

oversensitive to light touch. Clothes brushing the skin or even air blowing on the skin may be felt as severe pain. This unusual sensitivity is called 'allodynia' and is common in CRPS.

Other symptoms include skin colour change, swelling, stiffness, feelings of hot or cold, less or more sweating and changes to the hair, skin or nails. The pain and other symptoms often spread beyond the site of the original injury. For example, if you hurt a finger, the whole of the hand or forearm can be affected.

Often there is difficulty in moving the limb, together with weakness and sometimes shaking or jerking.

Sometimes the muscles in the area can waste and the hand or foot can become twisted.

Many patients say that their limb 'feels strange'. It can feel as if it does not belong to the rest of the body and as if it is not your own limb. Sometimes the limb feels bigger or smaller than the opposite, normal limb.

Sometimes the pain and sensations are so extreme that the person can become depressed with the symptoms and we would advise you to speak to your GP or specialist contact if you feel like this.

Does CRPS run in families?

It may be that genes have something to do with who develops CRPS pain after injury, but they are certainly not the only factor in deciding who gets it. It is also very unlikely that anyone else in your family will ever develop CRPS pain.

Could it have been prevented?

It is very unlikely that CRPS pain after your injury could have been prevented. The right

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diagnosis and treatment can reduce suffering from CRPS pain.

Will it get better?

CRPS usually gets better by itself or with treatment. In some people, it can take several months to improve.

We have no way of predicting how soon it will improve, everyone varies so much. Unlike cancer or rheumatoid arthritis, CRPS does not destroy body tissues. Even if you have CRPS for several years, the rest of your body will continue to work as normal.

Does treatment help?

Treatment aims to improve your quality of life, functioning and reduce pain. It is likely that you can get some pain relief with treatment. The success of some treatments depends on the amount of effort you put into them. There is a range of treatments and your consultant or therapist will discuss these with you.

Exercise Treatment

Most patients see physiotherapists (PTs) or occupational therapists (OTs). These therapists will work with you in a way which is specially geared towards your CRPS. For example, they may not even touch your limb. It is very important to exercise the limb gently following advice by a PT or OT.

Medication Treatment

Drugs can sometimes reduce CRPS pain and may also help you to sleep. Your consultant will discuss the correct drug treatment with you. If appropriate, your consultant may also decide to offer you an injection treatment and for this situation you will receive special information about it.

Psychological Intervention

Sometimes psychological intervention can be helpful to reduce distress (this does not mean that the pain is in your mind; it is not). Your consultant or therapist will be happy to discuss this with you.

What are specialised treatments for CRPS?

Specialised treatments either require a special team of healthcare professionals to deliver them, or these are new treatments, which need to be followed closely to make sure they work.

Should I be treated with a specialised treatment for CRPS?

The right treatment for CRPS varies from patient to patient. There are two specialised CRPS treatments which need to be given by teams of clinicians. These are: pain management programme (PMP) and spinal cord stimulation (SCS). Research shows that in some patients these treatments can work very well. Your consultant will discuss these treatments with you, if he or she thinks you may need either of them. You may also receive a PMP and/or SCS information leaflet.

The PMP is a programme designed to help you to improve your quality of life and manage your pain better.

It is group-based, and lasts between a few days and a few weeks. This is 'multidisciplinary treatment', which means therapists from different professions work together (e.g. physiotherapists, doctors, occupational therapists and psychologists etc). The PMP is suitable for patients with CRPS, and also for people with other chronic pains. It is designed to improve your quality

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of life. It is important to understand it is not designed to take your pain away.

The second treatment, SCS, is a fine wire which is placed close to the nerves in your back and connected to a 'stimulator'. The doctor puts the wire in the right place by using a similar technique to putting in an epidural for pain relief during pregnancy. The wire is usually kept in place like this for a short time, and if it works well, an operation is done to make it permanent. The SCS can be taken out in the future when it is not needed anymore.

Are there any other treatments?

There may be other treatments, but these are not as well researched as the treatments mentioned in your patient information leaflets. Your consultant will discuss with you whether or not other treatments would be suitable in your case.

Sources of information for patients on the web:

Arthritis Research UK

www.arthritisresearchuk.org/arthritis_information/arthritis_types_and_symptoms/complex_regional_pain_syndrome.aspx

Reflex Sympathetic Dystrophy Association (RSDSA)

<http://rsds.org/index2.html>

CRPSUK

www.crpsuk.org

Burning Nights – a forum set up by sufferers of CRPS

www.burningnightscrps.org

Other Information

The following information has been compiled and produced by the CRPS Patients Forum at the Royal National Hospital for Rheumatic

Diseases (RNHRD) after adaptation from a version produced by the Reflex Sympathetic Dystrophy Syndrome Association in America.

This following information may be useful if you need to explain your condition to your doctor:

I have CRPS (complex regional pain syndrome)

CRPS is a nerve disorder that usually occurs after an injury or period of immobilisation. The principle symptom is pain which can lead to disability. I may look healthy but I often suffer from severe, unrelenting, nerve pain. My skin may swell, change colour or temperature, sweat or hurt to the lightest touch.

Often it is difficult for me to sleep, which affects my attention and concentration, or I may be on drugs which do the same.

Chronic pain often leads to depression. Stress increases pain. I have good or bad days, or even hours.

There is no cure at present.

Please help me by...

- believing that the pain is real even though it is invisible and may not be readily apparent by my demeanor or activities
- remembering that it can even hurt to be touched
- remaining positive.

Please email crpsuk@hotmail.com if you require more information about the CRPS Patients Forum. Please also email any suggestions you may have to the same address.

Information reprinted from the Royal College of Physicians 2012.



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Concerns and Queries

If you have any concerns / queries about any of the services offered by the Trust, in the first instance, please speak to the person providing your care.

For Diana, Princess of Wales Hospital

Alternatively you can contact the Patient Advice and Liaison Service (PALS) on (01472) 875403 or at the PALS office which is situated near the main entrance.

For Scunthorpe General Hospital

Alternatively you can contact the Patient Advice and Liaison Service (PALS) on (01724) 290132 or at the PALS office which is situated on C Floor.

Alternatively you can email:
nlq-tr.PALS@nhs.net

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