

Information for Patients

**Chronic Regional Pain
Syndrome**

Physiotherapy Service

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.

Other names: complex regional pain syndrome type 1 (CRPS 1) was known as 'reflex sympathetic dystrophy (RSD)' or 'Sudeck's syndrome', and complex regional pain syndrome type 2 (CRPS 2) was known as 'causalgia'.

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. Some patients have frequent thoughts about wishing to cut off the limb. Unfortunately even surgical amputation does not help the pain (actually, it may make it worse). In extreme pain, some people may consider suicide. If you do feel like this, please see your doctor.

What causes CRPS?

CRPS is a stronger-than-normal reaction of the body to injury. We do not 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.

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 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, CRPS does not get better. We have no way of predicting whether your CRPS will get better and when. 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 or occupational therapists. 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 physiotherapist or Occupational Therapist.

Medication treatment

Drugs can sometimes reduce CRPS pain and may also help you to sleep. Your GP, Physiotherapist or Consultant will discuss the correct drug treatment with you.

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 would be happy to discuss this with you.

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