



Complex Regional Pain Syndrome (CRPS)

Information for patients from the Orthopaedic Hand Service

Complex Regional Pain Syndrome (CRPS) is a distressing condition. It is little understood by most health professionals let alone by yourself, family, and friends who probably cannot understand why you are taking so long to recover from your injury. It is quite natural to feel frustrated and confused by the condition. You may feel low in mood and experience a full range of emotions during your recovery: anger, grief, depression, tearfulness, anxiety, fearfulness, and stress.

As it is not well understood, it is often difficult to diagnose. It is usually, but not always, triggered by a trauma, such as a wrist fracture. The pain usually only affects one limb (one arm or leg), but it can sometimes spread to other parts of your body.

Mild forms of CRPS are quite common, and get better without any special treatment. However, severe forms of CRPS can be very disabling and difficult to treat. Several different names have been used to describe CRPS; these include reflex sympathetic dystrophy (RSD) and Sudeck's atrophy.

It is likely that all your immediate family will be impacted by your condition and there will be difficult adjustments to be made, sometimes in every part of life. For example:

- not being able to work or take part in pastimes
- having less patience and concentration, and
- not wanting to socialise.

It is important to acknowledge these changes and support each other as best you can. Share information; get support where you can, get in touch with someone who is a good listener. The worst thing you can do is bottle it all up.

If you feel overwhelmed by your condition or emotions, please get in touch with your therapist and / or your GP.

What causes CRPS?

Nobody knows what causes CRPS; however there are certain things that can 'trigger' the condition. For example, after someone has suffered a fracture or some other injury, although most people injured in this way recover without any complications.

- It is thought to affect approximately 26 in 100,000 of the general population.
- More women are affected than men.
- There is also a known increase in CRPS among smokers.
- There are suggestions that there may be a genetic link (it can be passed from parent to child).

How long will I have CRPS for?

The symptoms of CRPS will continue long after your original injury has healed, which can be very confusing. In a healthy person, bone and soft tissue injuries take about 12 weeks to heal completely. This is the same for patients with CRPS.

It is like this:

1. A burglar breaks into your house setting off the alarm and giving you a shock. This is the injury and all the normal pain and inflammation you would expect to get.
2. The police come and arrest the burglar and remove them from your house. This means your injury has now healed and the body tissues are strong again.
3. You cannot find a way to turn off the burglar alarm even though the threat has gone. This represents your body's complex systems continuing to act as though the injury is still there. This is CRPS.

What are the signs and symptoms?

- **Pain**

The skin of your affected body part can become sensitive. A slight touch, bump, or even a change in temperature can cause intense pain. The pain you feel and how long it lasts is disproportionate to what you should expect from your injury. It usually only affects one limb, but can sometimes spread to other parts of your body. You will often have burning feelings, which can be very painful and do not settle when you take normal painkillers (such as paracetamol). Pain is often worse when you move about. Your hand can be very tender and sensitive to normal touch.

- **Swelling**

The painful area may become swollen and firm over time.

- **Stiffness**

Your joints may become stiff, as you are not using them (a natural reaction to pain) and they have become swollen.

- **Colour and temperature changes**

This varies between patients, but to start with your hand may be red and warm (with a lot of sweating). Later it may become blue or white, and very cool and dry.

- **Skin changes**

Your skin may look glossy, shiny, and feel tight. You may notice more hair growing on your hand. Your finger nails may become brittle (break easily).

Is there a cure?

No, unfortunately there is no known cure for CRPS.

The aim of treatment is to reverse and manage your symptoms. This is done with a combination of:

- medication
- physical therapy / rehabilitation
- self management strategies for pain and stress,
- plus other treatments, as needed.

Our ultimate goal is to get your hand working properly again.

What can make it worse?

- Keeping your joints still and not using them for long periods of time can make your condition worse. Or doing too much exercise and activity will increase your symptoms.
- Ignoring your arm / hand or not using it properly, is telling your body that there is still an injury.
- Stress, anger, and anxiety are known to exaggerate and cause pain. This is because, with CRPS the nervous system becomes highly sensitive to the substances your body makes when you are stressed.
- Other symptom triggers might be:
 - bright light
 - loud noises
 - strong food
 - alcohol
 - caffeine
 - smoking
 - frustration, and
 - the threat of others coming near your limb.

Tips for coping with CRPS

As you are encouraged to use your affected hand as normally as possible, please consider the following tips.

- Actively participate in your therapy program and use your medications routinely, even if your progress seems painfully slow.
- Learn about your condition and try not to be afraid of the symptoms. If you choose to use the internet, please remember that the effect of CRPS ranges from mild to very severe. Web sites tend to show the worst case scenario, and suggest treatment and drugs that are not appropriate for you.
- Continue to touch, look at, use and love your arm / hand, regardless of how it feels. When we are in pain it is natural to avoid using your arm / hand; this is the body's way of preventing further injury. However, in the case of CRPS, the pain is not due to body tissue damage, so you are unlikely to hurt your arm / hand if you use it. In fact, it has been proven that not using your arm / hand actually makes the pain worse, and over time your arm / hand becomes weaker and increasingly disabled.
- Do not try to take on something that you know is too difficult, as you will only feel bad when you can't do it. Try to break the task into manageable chunks.
- Balance rest, exercise and activity as much as possible.
- Think about the things that you can do and focus on these.
- Find activities that are enjoyable and / or distracting. Do these as much as is practical.
- Make a note of the things that improve your pain. Refer to this list when your pain has increased. Your therapist can help with this.
- Compared to non-smokers, smokers are more likely to have complications in tissue healing and infections after injuries or surgery. For free friendly support and medication to help you stop smoking, contact:
 - **One YOU Kent**
Telephone: 0300 123 1220
Email (kentcft.oneyoukent@nhs.net)
Web (<https://www.kentcft.nhs.uk/service/one-you-kent/>)
- Try to identify things that trigger your symptoms. Is it worse when you feel stressed or frustrated? Or, when you eat strong food? It may be possible to find ways to prevent or lessen the possibility of a 'flare up'.
- Remember that some symptom triggers are actually good for you in other ways, such as practical and social activities. Before avoiding an activity, try to weigh up the short-term gains (less effort, less pain) with the long-term consequences (low self esteem, reduced quality of life, becoming weaker).
- Find ways to help yourself relax. This may be a breathing technique or a place to retreat to. Your therapist may be able to help you with this.
- Practice positive statements, such as:
 - "I can have pain and even suffer but still be going forward, doing well and coping."
 - "I am learning the skills to live my life, even if the CRPS doesn't go away."
 - "I will do everything I can to make my condition improve."

- “I can go out because the risk of getting my hand knocked is smaller than the risk of feeling isolated and frustrated.”
- “I am in charge of my arm / hand, it is not in charge of me!”
- Change your own statements from “I can’t”, to “I’ll try” to “I will”.

Other suggestions

- Get some fresh air and take regular walks.
- Go swimming (or even just relax in the pool).
- Remember that every activity you do using your affected hand, is an important part of your rehabilitation.
- If you are feeling stressed / anxious, stop for a minute and look in a shop window or check your phone. Do something different to take your mind off the current situation.

What if I have any questions or concerns?

Please ask questions, and discuss your concerns and symptoms with your therapist, no matter how strange they may seem.

If you have any questions or concerns about your treatment, please contact the Orthopaedic Hand Service on 01227 783065.

Remember

- It is your arm, so caring for it is up to you.
- Pace yourself and know your limitations. Do not do too much.
- Think positive.

This leaflet has been produced with and for patients.

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 783145 (tel://+441227783145), or email ekh-tr.pals@nhs.net (ekh-tr.pals@nhs.net)

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals website (<https://www.ekhuft.nhs.uk/information-for-patients/patient-information/>).

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