

Patient Information

Complex Regional Pain Syndrome (CRPS)

Complex Regional Pain Syndrome (CRPS) is sometimes called:

“The strange pain in the strange-looking limb.”

CRPS may develop weeks or months after an (often minor) arm or leg injury, such as a sprain or fracture (broken wrist, sprained ankle) and sometimes following surgery. The diagnosis may be delayed, as healthcare professionals can take some time to recognise this relatively uncommon condition. Don't be surprised if many people haven't heard of it!

Your doctor has to exclude other conditions that 'look-like' CRPS, such as infection or bruising.

Patients may complain of:

- Severe pain (often under a plaster cast), lasting longer than expected.
- Touch sensitivity (of the skin).
- Temperature-sensitive pain.
- Swelling.
- Colour and temperature changes (red, blue, pale, hot, cold).
- Increased or decreased sweating.
- Sometimes skin, nail or hair growth changes.
- Limb weakness, numbness, spasms, 'clumsiness', abnormal postures (claw-like hand).
- Patients sometimes feel as if their arm or leg, "doesn't belong to them anymore" ('neglect') or "isn't working properly".

CRPS is most common in females (4:1) and can develop at any age—most often puberty or middle age.

CRPS is more common in people with asthma, migraine, inflammatory bowel disease and eczema. To some extent, CRPS is a kind of 'inflammatory disorder', just like these conditions.

Patients with an *anxiety* problem such as panic, post-traumatic stress (PTSD) or obsessive compulsive disorder have a greater risk of developing CRPS. 'Life stresses' can make the condition worse.

It's thought that tissue (muscle & bone) and nerve damage in the injured limb starts off an immune 'chain reaction', producing lots of pain, heat and swelling early on. This may reduce after a few months—the limb may then become painful, cold, dry and stiff in some cases.

Because of the ongoing pain in the arm or leg, after a few weeks, the *brain* tries to 'switch off' attention to the area (as a way of dealing with the 'irritation') and increases muscle tone (to stop the limb from moving, 'splinting' it—this can make the pain and function of the limb even worse.

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Management of CRPS

- Managing CRPS is a *team effort*—most importantly *yourself* (as the main player), the doctor, physiotherapist or hand therapist ('OT') and other health care professionals such as psychologists.
- There is no special test or x-ray that diagnoses CRPS.
- Information about CRPS: The *PainHealth* website:
- <https://painhealth.csse.uwa.edu.au/pain-module/complex-regional-pain-syndrome/>
- Stop smoking— nicotine reduces blood flow in the limb and makes CRPS worse.
- **Vitamin C 1000 mg daily and Vitamin E 500 IU daily for 2 months**—this helps reduce inflammation in the limb.
- Your doctor may also prescribe *N-acetylcysteine 600 mg 2 x daily for 2 months* (a safe amino acid 'vitamin' obtain from a compounding pharmacy, reduces inflammation).
- Pain medications: Your doctor may prescribe a combination of pain medications (e.g. paracetamol, tramadol, tapentadol, anti-inflammatories and nerve pain medications (pregabalin, amitriptyline, duloxetine, baclofen, clonidine) to reduce your pain, so the physiotherapist or hand therapist can work with you to improve your condition.
- **Use it or lose it: Physiotherapy (hand therapy) is the most important part of your treatment**—the aim is to get your arm or leg working as *normally* as possible.
- Use your affected arm or leg *as normally as possible*—be guided by your therapist. For example, if you do handicrafts (e.g. crochet, knitting) this is excellent therapy for CRPS of the hand and arm (if it's not too uncomfortable).
- Do your prescribed exercises *often* (e.g. five minutes, every waking hour).
- Physiotherapy for CRPS includes:
 - Making the limb *less sensitive to touch and movement* (desensitizing); this includes exposing your skin to different textures such as fabrics, rice etc. to get it used to being touched. Patients with CRPS are often afraid to move the limb or it being touched by others (this is called 'kinesiophobia').
 - Passive and active stretches and movements; loosening-up the limb, especially if you have stiffness or contractures (like clawing of the hand or foot).
 - Doing *normal everyday movements*; this reprograms the brain back to normal and reduces the risk of the limb becoming stiff and contracted.
 - **Brain retraining therapies:** good evidence these programmes are very helpful.

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- **Recognise Graded Motor Imagery Programme:** Mirror box, cards or computer programme with pictures of arms or legs, imagined movements.
Link: <http://www.gradedmotorimagery.com/>
- **See a clinical psychologist *early*:** Stress makes CRPS worse (by directly affecting the nervous, hormone & immune systems).
- Get help for anxiety, depression and sleep problems—don't ignore it.
- **Stay at work or at school:** If you are working or at school, the pain team will help you get back in action as soon as possible; this is very important for your recovery.

Specialised therapies

- Steroids (short course of *prednisolone* may reduce pain and inflammation).
- Bisphosphonate IV infusion (bone strengthening medication) (zoledronic acid).
- Lidocaine (local anaesthetic) patches (to reduce extreme touch sensitivity).
- Calcitonin injections (bone strengthening medication).
- Ketamine or lidocaine IV infusions.
- Nerve blocks or sympathectomies (block painful nerves signals in the limb).
- DSMO, ketamine/clonidine, or capsaicin (capsicum) creams or patches.
- Low dose naltrexone capsules (safe, experimental treatment for inflammation).
- P.E.A (safe, soy-based nutraceutical, possibly helpful?).
- Spinal cord or nerve stimulation (implantable nerve stimulator).

Realistic expectations: It's hard work and there will be 'ups and downs'

Managing CRPS is like 'running a marathon.' It requires constant effort and plenty of endurance, especially keeping up with physical therapies.

Unfortunately, there's no 'quick fix'; it may take up to 12-18 months to stabilize your condition. However, **most patients do get better**. Many patients improve quickly, although some are left with a degree of long-term pain and physical impairment.

The key to managing CRPS is getting your arm or leg working *as normally* as possible, *as soon as possible*, with the help of pain relief and physiotherapy.

Please take this handout with you to your doctor, physiotherapist or hand therapist, or clinical psychologist.



**The Churack Chair of Chronic Pain
Education and Research**

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