

Complex Regional Pain Syndrome (CRPS) Patient information

Complex Regional Pain Syndrome (CRPS) (otherwise named 'Reflex Sympathetic Dystrophy' [RSD], or 'Causalgia') is sometimes called,

"The strange pain in the strange-looking limb".

CRPS may develop weeks or months after an arm or leg injury, such as a sprain or fracture (eg. broken wrist, sprained ankle) and sometimes following surgery. The diagnosis may be delayed, as health care 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).
- Swelling.
- Colour and temperature changes (red, blue, pale, hot, cold).
- Temperature-sensitive pain.
- Increased or decreased sweating.
- Sometimes skin, nail or hair growth changes.
- Limb weakness, numbness, spasms, 'clumsiness', or abnormal muscle 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 can affect anyone of any age, but is most common in females (4:1), especially around the time of puberty, or aged 30-60.

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*. In many ways, the pain of CRPS is like 'phantom limb pain' after an amputation, with changes in the brain causing the pain.

Management of CRPS

1. Treatment of 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 (all acting as 'coaches').
2. *Take vitamin C 1000 mg and Vitamin E 500 IU per day for 3 months*-this helps to reduce the inflammation in the limb.
3. Take N-acetylcysteine 600 mg 3 x daily for 2M (obtain from pharmacy, reduces inflammation).
4. Stop smoking; nicotine reduces blood flow in the limb, making CRPS worse.
5. Pain medications: Your doctor may recommend a combination of pain medications (eg. paracetamol, tramadol, 'anti-inflammatories', 'anti nerve pain drugs' such as pregabalin, amitriptyline, lignocaine patches) to reduce your pain, so the physio or hand therapist can work with you to improve your condition. Sometimes nerve blocks or ketamine drips are used as an outpatient procedure.
6. "*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.
7. Try and use you affected arm or leg 'as normally as possible'-be guided by your therapist. For example, if you do handicrafts (eg crochet, knitting), this is excellent therapy for CRPS of the hand and arm (if it's not too uncomfortable).

8. Do your prescribed exercises *often* (eg. five minutes, every waking hour).
9. 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).
 - Promoting 'normal everyday movements'; this 'reprograms the brain back to normal' and reduces the risk of the limb becoming stiff and contracted.
 - 'Brain retraining' therapies. There's good evidence these programmes are very helpful: Using cards with pictures of arms or legs, imagined movements and mirror boxes: via the *Recognise* Graded Motor Imagery Programme www.noigroup.com. (go to home page). Able to purchase *Recognise* computer programme by Dr Lorimer Moseley. <http://recognise.noigroup.com/recognise/>. Specialised *clinical psychologists* can also help with these programmes (imagined movements, mapped relaxation-based responses).
10. Get help for anxiety, depression and social problems-don't ignore them: see a clinical psychologist *early*. *Stress* makes your CRPS *worse* (by directly affecting the nervous, hormone & immune systems) and needs to be managed.
11. 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 you recovery.

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

Managing CRPS is like 'running the 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 months to stabilize your condition, even longer in some cases.

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.

A team approach and specialised pain management programmes like STEPS is very helpful.

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

Disclaimer: generic information only-not intended as specific clinical direction