

INFORMATION FOR NEW PATIENTS

Complex Regional Pain Syndrome is broken into 3 different types.

Type I: RSD (Reflex Sympathetic Dystrophy) – where there is no major nerve damage.

Type II: Causalgia – where there is major identifiable nerve damage

Type III: NOS – Not Otherwise Specified – partially meets diagnostic criteria, no other diagnosis better fits the symptoms.



Complex Regional Pain Syndrome is a debilitating condition that is characterised by continuous pain, that begins in one region of the body and usually has a distal predominance of sensory, motor, autonomic, skin and bone abnormalities in the affected region. The pain is disproportionate, in time or degree, to the inciting event. There is variable progression in the signs and symptoms over time.

CRPS is usually precipitated by a trauma, such as an accident, a fracture or a surgery, or following a medical emergency such as a heart attack or a stroke, but CRPS can also occur after a very trivial incident and, on occasion, can develop spontaneously. CRPS Type I develops after any type of trauma, especially fractures and soft tissue lesions, such as crush injuries, and has no identifiable nerve damage. CRPS Type II occurs after major nerve damage. The mechanism of CRPS is unknown, however, it is believed that CRPS occurs as a result of damage to, or a malfunction of the nervous system and the immune system at the site of the injury.

CRPS is a multi-system disorder that affects the musculoskeletal system, the peripheral nervous system and the central nervous system.

The diagnosis may be delayed as it might take some time for this somewhat uncommon condition to be recognised by your Healthcare Professionals. There is no definitive test for CRPS and your doctor has to exclude all other conditions that may appear to be similar to CRPS.

Most people have not heard of CRPS before being diagnosed with it and many people in the healthcare profession including GP's, nurses, disability, community services and other allied healthcare professionals may never have come across this 'rare disorder' in their career or may have an incorrect understanding of the disease.

Common symptoms include:

- Severe pain, lasting longer than expected and being disproportionate to the original condition/injury
- Hypersensitivity to touch and/or pain from non-painful stimuli (such as from breezes, sheets, the shower etc)
- Swelling
- Colour and/or Temperature changes (eg. mottled, red/blue skin; hot/cold)
- Pain Sensitivity to changes in the weather
- Increased or Decreased sweating
- Skin, Nail or Hair Growth changes
- Limb Weakness, Numbness, Spasms or Tremors
- Contractions of the hand or foot, abnormal muscle postures or clumsiness

The earlier your diagnosis, the better your prognosis. A multi-therapy approach works best for CRPS. This means a team approach is required and includes:

- **You** – there is a lot you can do to self-manage your condition
- **Your GP** – to co-ordinate your care
- **Your Pain Specialist** – with expertise in CRPS
- **A Physiotherapist** – with knowledge of CRPS pain therapies, de-sensitisation and pacing
- **An Occupational Therapist** - to assist with activities of daily living
- **A Psychologist** – someone that can help you to de-stress, with CBT, mindfulness etc

To help manage your CRPS:

- **Take 500 - 1000mg of Vitamin C per day for 3 months.** This can help to reduce the inflammation in the CRPS affected area.
- **Take 500 – 1000mg of magnesium per day in divided doses.** (glycinate or malate form is preferred).
- **Consider taking 1500 – 3000mg of omega 3 (EFA) fish oil per day.** (high strength formulation).
- **Reduce your stress levels.** Stress can increase your pain levels. Schedule time for meditation, deep breathing or reflecting on the positive things in your life. Keep a gratitude journal. Enjoy time in nature or with family and friends. Don't over-commit yourself. Enjoy a soak in a warm Epsom Salts bath occasionally.
- **Get as much rest and sleep as possible.** Try to get at least 8 hours of sleep each night as this encourages healing.
- **Eat an anti-inflammatory diet.** Eat fresh, unprocessed, whole foods. Avoid packaged, boxed, canned, and prepared food items which contain inflammatory preservatives and additives. Eat fresh fruits and vegetable with lots of colours. Drink at least 2l of water per day, perhaps with lemon to help de-toxify.
- **Stop smoking.** Nicotine reduces blood flow, which can make CRPS worse.
- **Your GP** may initially recommend a combination of medications to lower your pain levels. These will often consist of an anti-nerve pain drugs such as gabapentin, pregabalin, cymbalta or amitriptyline and sometimes a low dose opioid. These medications will allow your therapist to work with you to better to improve your condition.

- **Your pain specialist** will review your medications and may recommend nerve blocks, a topical ketamine cream or a ketamine infusion to further lower your pain levels so that your therapy can progress even more.
- **Your psychologist** works with you to address any psychosocial issues to help you understand, identify and change any thoughts and feelings that you may have that are causing you stress and increasing your pain. It is important that you find a psychologist that you feel comfortable with as they are quite often the only person that you can really talk openly and honestly with. A good psychologist is a vital part in any pain management team!
- **Your physiotherapist** will work with you to give you appropriate exercises to keep your CRPS area mobilised to retain or improve function and de-sensitise the area. They may ask you to keep a pain diary to ensure that you aren't over-stimulating the area of pain and are pacing yourself appropriately to keep pain within manageable levels.
 - **Exercise Daily.** The aim is to retain function of your affected limb.
 - **Do your exercises in small batches often**, so that you do not become overly sore. (e.g. for 5 minutes every hour). There is a fine line between 'Use it or Lose it' and 'No Pain, No Gain'. If your pain flares up for too long after doing your exercises and this is a warning sign that you have done too much, and you need to do less the next time.
 - **Try to use your affected arm or leg in your normal activities.** Your therapist can advise you of the best way of doing this. Great exercises if you have an affected hand or wrist is to do handicrafts such as knitting or crocheting which is a great way to keep the fingers and joints active. Using playdoh to roll into different shapes and then pulling it apart using different fingers and blowing up a balloon to the size of an orange to gently squeeze while you are watching tv.
 - **Try to de-sensitise the limb** by exposing your skin to different textures such as fabrics, tissues, feathers, a ball or being touched or massaged.
 - **Use passive and active stretching** of the limb and joints to increase your range of movement (ROM), especially if you are experiencing any stiffness or contractures like clawing of the hand.
 - **Use brain training therapies** such as left/right recognition cards or the app 'Recognise', mirror box therapy from noigroup or any of the Graded Motor Imagery programs at www.gradedmotorimagery.com.
- **An Occupational Therapist** evaluates your Activities of Daily Living (ADL's) and addresses any issues you may have with achieving your physical needs, both vocationally and at home. They can help supply any aids you may need such as ramps and grab rails etc.
- **It is important to keep a positive attitude. Remission is possible and attainable.**
- **It may take up to 12 months to stabilise your CRPS and for many people, who are diagnosed within 3-6 months of the inciting event, their symptoms are completely resolved within this time frame.**
- **Have realistic expectations and goals. You have to put in the work to get the results.**
- **There is no quick fix and no magic treatment. CRPS treatments work differently for each patient. What works for one person may not work for another.**