

EARLY INTERVENTIONS

While you are waiting to see specialist health professionals, there are many things you can start doing that will help you to improve. Early intervention has been shown to help people improve, so you need to start now.

Your brain has made new pathways telling you that you have constant pain. You will now be setting up new paths in your brain so that you control CRPS, not the other way around. This takes time.

Steps to manage your pain include:

- Contact a psychologist, mental health nurse etc., for psychological support,
- Try to desensitise the body part,
- Move the body part if you can,
- Know that you are not alone.

SUPPORT NETWORKS

The following support networks are credible pain information and support services in Australia.

CRPS Awareness

The Purple Bucket Foundation
Australian Registered Charity.
<https://www.tpbf.org.au/>

Chronic Pain Australia

A non-profit, non-government registered organisation.
<https://chronicpainaustralia.org.au/>
Pain Link Helpline 1300 340 357

This research was funded by a CQUniversity Internal Research Grant. This brochure was put together by a research team comprised of people living with CRPS, health professionals from CQUniversity, the University of the Sunshine Coast, CRPS Awareness - The Purple Bucket Foundation and Chronic Pain Australia.

This is a draft brochure (Version DEC23) while we continue our research.

To provide feedback, please contact:

Dr Colleen Johnston-Devin:
cjohnst2@usc.edu.au and/or
Kim Allgood: admin@tpbf.org.au



For the latest updates and further information about CRPS, please see our online version of this brochure by scanning the QR

1. NeuRA. MEMOIR Trial 2023 [Available from: <https://neura.edu.au/project/memoir-a-clinical-trial-forcomplex-regional-pain-syndrome>].
2. Bruehl S. Complex regional pain syndrome state of the art review. *BMJ*. 2015; 350: h2730. doi: 10.1136/bmj.h2730
3. Goebel A, Barker CH, Birklein F, Brunner F, Casale R, Eccleston C, et al. Standards for the diagnosis and management of complex regional pain syndrome: Results of a European Pain Federation task force. *European Journal of Pain*. 2019; 23(4): 641-51. doi: 10.1002/ejp.1362
4. Johnston-Devin C, Oprescu F, Gray M, Wallis M. Patients describe their lived experiences of battling to live with complex regional pain syndrome. *The Journal of Pain*. 2021; 22(9): 1111-28. doi: 10.1016/j.jpain.2021.03.151
5. Russo M, Georgius P, Santarelli DM. A new hypothesis for the pathophysiology of complex regional pain syndrome. *Medical Hypotheses*. 2018; 119: 41-53. doi: 10.1016/j.mehy.2018.07.026

COMPLEX REGIONAL PAIN SYNDROME

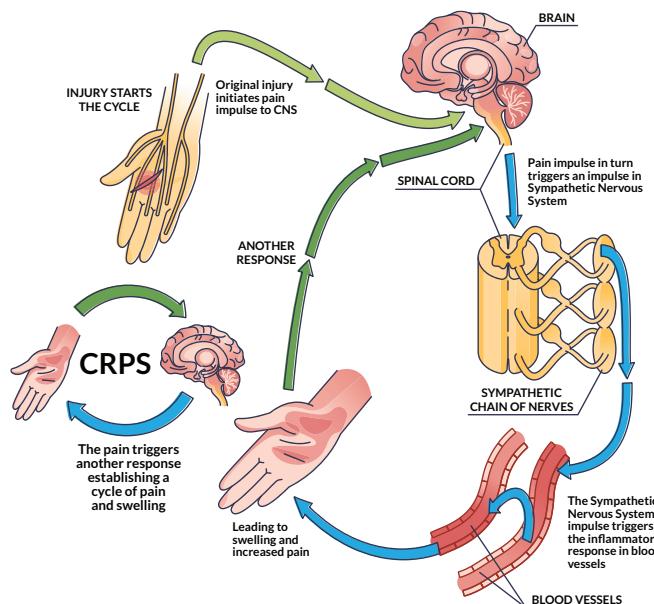


Your health professional thinks you might have *Complex Regional Pain Syndrome (CRPS)*. You have probably never heard of this condition because it is relatively rare with approximately 5,000 people being diagnosed with it annually in Australia ⁽¹⁾.

WHAT IS COMPLEX REGIONAL PAIN SYNDROME (CRPS)?

CRPS usually develops after an injury, but it can also occur spontaneously^(2,3). Injury can include fractures, sprains, a bruise, stroke or even a heart attack⁽⁴⁾.

The cause of CRPS is yet to be fully understood. Recent research points to it being due to a combination of tissue trauma, abnormal pain processing, nervous system imbalances, altered immune responses, abnormal inflammatory responses and brain changes⁽⁵⁾.



Symptoms can include swelling, temperature and colour changes, sweating, abnormal hair growth, and pain from things that don't usually cause pain; but the common symptom of CRPS is pain out of proportion to the original event⁽⁴⁾.

DIAGNOSIS

CRPS will not appear in a blood test or imaging such as an x-ray. You may be sent for tests to rule out other conditions, though. The Budapest Criteria⁽³⁾ is used for the diagnosis of CRPS. Your health professional will discuss this with you.

FEELINGS

You might feel your affected body part is sensitive to touch, feels like it is on fire, or constantly throbbing. This is normal for someone with a new diagnosis of CRPS.

It is easy to feel overwhelmed, and given how difficult this is, we recommend that you seek psychological support as it can be highly beneficial in managing your symptoms.

WHY ME?

Why not you? The cause of CRPS is yet to be determined. It is not known why one person gets it while another does not. This is not your fault.

IS THERE A CURE?

Not at the moment. There is also no cure for diabetes, the common cold, or many other health conditions. CRPS is a condition that you will learn to manage, and most people will improve. You can live a meaningful life and still have CRPS.

It is important to start treatment as soon as possible. Although it sounds difficult, it is important to try to move the affected body part and start using it. You also need to get the body part comfortable with being touched so it becomes less sensitive.

DOES CRPS GO AWAY?

Most cases of CRPS improve⁽²⁻⁴⁾. CRPS can go into remission, meaning your pain and other symptoms can significantly reduce or disappear. In some people, the pain symptoms may reappear if they happen to become sick, tired or rundown.

With the help of health professionals and peers who understand CRPS, you can learn to manage your symptoms.

HOW AM I GOING TO LIVE WITH THIS?

This condition will take time to get on top of and you will need the help of health professionals, peer support networks and people who are close to you.

CRPS should be diagnosed and treated early to minimise progression. With appropriate management long term symptoms can improve.

WILL CRPS CHANGE MY LIFE?

It may. However, you will recognise your cues, triggers and strategies that work best for you. You may feel overwhelmed. This is normal for people who have just been diagnosed with CRPS.

HOW DO I STOP THE PAIN?

Medication alone may not ease all your pain and other symptoms, but it may help to make it more manageable. Your GP can get you started, but CRPS is a pain specialty area, so you are likely to need an appointment with a pain specialist and knowledgeable allied health professionals.