

Complex Regional Pain Syndrome (CRPS)

What is CRPS?

Complex Regional Pain Syndrome (CRPS) is a debilitating condition which causes persistent pain in the affected limb. CRPS usually occurs following injury however, in some cases the condition may arise with no traumatic injury at all. The body's response can cause pain much more severe and long lasting than the original injury. It commonly only affects one limb. Only rarely will CRPS spread to other areas of the body. CRPS can affect individuals of all ages including children.

CRPS may be divided into two types;

- CRPS type 1 is defined by the absence of nerve damage. It may occur following an injury such as; a fracture or sprain without damage to a major nerve.
- CRPS type 2 may be diagnosed where there is presence of nerve damage.

The distinction between the two types does not affect the management of the condition.

Symptoms of CRPS

The most predominant symptom of CRPS is continuous pain that may be severe and debilitating. The pain may be experienced as a burning, stinging or stabbing pain. The skin of the affected area can become highly sensitive to even light touch. Changes in temperature, pressure, bumps or the weight of clothing can increase pain. There are two medical terms commonly used to describe these sensory changes as explained below;

- Hyperalgesia – is the term used to describe an increased pain response/ sensitivity to a normal painful sensation such as; a pinprick.
- Allodynia – refers to pain felt from stimuli that would not normally cause pain such as; light touch.

CRPS causes changes to the temperature and colour of the skin and people may experience swelling of the affected limb, which can lead to stiffness. People may notice that their affected limb feels cold or warmer than other areas of the body and the skin may change colour appearing; purple, red, blue or mottled.

Other common signs of CRPS are described below and may vary between individuals;

- Excessive sweating in the affected and surrounding areas
- Texture of skin appearing shiny or thin
- Changes to the growth patterns of nails and hair in the affected area
- Reduced movement in the affected area and difficulty coordinating muscle movements
- In some cases, people may experience abnormal movements of the affected limb which may present as fixed postures or jerking movements known as Dystonia.

Living with persistent pain can have a substantial impact upon an individual's emotional wellbeing which may affect a person's mood, their sleep or their ability to live the life they wish to. Increased pain can lead to reduced activity which can further impact our mood and create a vicious cycle. If you feel you are experiencing

any of these changes and feel you would benefit from support or advice, seek support from your GP.

Causes of CRPS

CRPS is a poorly understood condition and the exact cause remains unknown. However, there is lots of research going on which is helping to improve our understanding and options for treatment.

CRPS is associated with an abnormal response to pain which magnifies the experience of an injury. Research suggests that the nerves of the affected limb are highly sensitive and there are changes with how messages are transmitted between the affected limb and the brain. This results in severe pain which becomes persistent, continuing long after an injury has healed.

In most cases, CRPS is triggered following a trauma or injury which could include; sprains/strains, fractures/ immobilised limb due to being in a cast, soft tissue injuries or surgical procedures. Although it may be difficult for healthcare practitioners to initially understand or diagnose CRPS, the pain and other sensory changes are very much real and people living with CRPS can benefit from working with a multidisciplinary pain team, who can support with the physical and emotional aspects of managing a chronic pain condition like CRPS.

What to do if you think you have CRPS

If you are experiencing persistent pain that is impacting your daily activities, you should see your GP. The correct diagnosis is important and research has shown that treatment is most effective during the early stages of CRPS. There is no single definitive test for CRPS. The diagnosis is based upon clinical examination and various tests to exclude other possible causes of pain.

How is CRPS managed?

As with other persistent pain conditions, there is no known cure for CRPS. However, a combination of physical, medical and therapeutic interventions can effectively manage the symptoms and reduce the impact upon your quality of life. The purpose of treatment methods is to support an individual to improve functioning in daily activities and reduce the experience of pain. Treatment in the early stages, within six months of receiving diagnosis is considered best practice to prevent secondary physical or psychological difficulties associated with living with persistent pain. A referral to a multidisciplinary pain service can give you access to specialists who can support you to develop a management plan that meets your individual needs. There may also be options to attend groups where you can meet other people developing new skills to live well with CRPS.

The overall aim is to support you to self-manage your condition and improve quality of life. Your treatment plan will be developed considering the following areas;

- Physical and Vocational Rehabilitation
- Education to Support Self-management
- Pain Relief – (Medication and Procedures)
- Psychological Support

Physical and Vocational Rehabilitation

The aim of physical and vocational rehabilitation is to support you to gradually improve your function to engage in activities that are meaningful to you. Physical rehabilitation is provided in a gradual approach to prevent a negative impact on the pain. A specialist can provide gentle exercises including simple stretches or weight-bearing exercises with a graded approach. Other aspects of physical rehabilitation include techniques such as; desensitisation which is used to reduce the sensitivity of areas of the body affected by CRPS and graded motor imagery which aims to improve functional movements.

Self-management Education

Education on self-management strategies support you to independently control your condition. We have compiled resources that you may find beneficial to explore new methods of managing your pain. Self-management advice from a multidisciplinary team may include;

- Listening to your experience and providing information to improve your understanding of the condition, to be able to manage it. This is important because there is evidence to suggest that those who understand pain mechanisms have better outcomes and are able to manage pain better.
- Advice on remaining active and how to reduce the severity of a flare up of symptoms
- Using relaxation techniques to manage the impact of pain on your quality of life
- Activity management and pacing advice to support you to engage in meaningful activities despite pain
- Advice on how to engage in rehabilitation techniques at home
- Support to access groups
- Psychological and emotional support (including psychological therapy) to address any barriers to the self-management of pain – identifying what may “turn up” or “turn down the volume” of pain in your life.

Pain Relief

Type 1 and type 2 CRPS are managed the same in terms of pharmacological interventions. Unfortunately, there is no current licensed treatment for CRPS in the UK. The evidence that we do have is not entirely conclusive and not robust enough to make general recommendations. Therefore decisions are made on a case by case basis taking into account your best hopes and tolerability of the medication trial. For mild symptoms sometimes pain relievers such as paracetamol, anti-inflammatories or codeine based products may help in the short term. These drugs do not necessarily affect the specific pain of CRPS but may reduce ongoing injury-related pains and assist in the process of mobilisation. Long term use of opioids (such as codeine, morphine or tramadol) are not usually appropriate especially due to the long term risks associated with their use.

We do know that some medication used for nerve type pain (neuropathic pain) can sometimes help. These include medications such as gabapentin and pregabalin and sometimes traditional antidepressants such as amitriptyline, nortriptyline or duloxetine which we often use at different doses for pain. Often they can be associated with side effects and if there is no significant benefit they should be reviewed, reduced down

and stopped. Often your GP may start some medication but will often refer to a specialist for further advice on medication.

The important thing to note about medication is that it is 'one tool in the box' to help manage pain. Therefore it is important to use medications to provide some relief to help facilitate the other management strategies mentioned above.

Psychological Support

As previously mentioned, living with persistent pain can be very upsetting and may have an impact on your mental health and wellbeing. CRPS can have an impact on your usual roles and responsibilities and engagement in daily activities. The loss or change of roles can be distressing and can be associated with low mood, stress or anxiety. We know dealing with stress has a direct impact on our experience of pain itself due to the impact on the nervous system. One common example is that when we are stressed we can lose sleep. We may then feel more irritable and this may create a 'vicious cycle' of pain and stress.

Dealing with persistent pain may also impact our ability to feel like we can think clearly – some people describe a “brain fog” where it can feel difficult to concentrate and remember things. Looking after your psychological wellbeing is important and can have a positive impact on the experience of pain. Looking at ways of managing stress in your life can help to improve pain. When managing a persistent pain condition like CRPS, it is important to look after the ‘whole person’ – mind and body. Psychological therapies can support you to understand and accept your diagnosis and understand what this means for you in your life, whilst supporting you to develop strategies to manage your symptoms. A clinical psychologist can support you to understand the interrelationship between emotions, thoughts, behaviours and pain and explore with you how you might improve your quality of life, despite pain.

Resources to support your self-management

- **Burning Nights:** <https://www.burningnightscrps.org/>
- **Complex Regional Pain Syndrome Fact Sheet:** <http://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Complex-Regional-Pain-Syndrome-Fact-Sheet>
- **CRPS UK:** <https://crps-uk.org/resources/>
- **Flippin'Pain:** www.flippinpain.co.uk
- **Live Well with Pain:** <http://my.livewellwithpain.co.uk>
- **Mind;** <https://www.mind.org.uk/> - Support for mental health and wellbeing.
- **The Pain Toolkit:** <https://www.pain toolkit.org/>
- **Versus Arthritis – CRPS:** <https://www.versusarthritis.org/about-arthritis/conditions/complex-regional-pain-syndrome-crps/>