

Useful resources

Royal National Hospital for Rheumatic Diseases:

www.rnhrd.nhs.uk/page/79

IASP: www.iasp-pain.org

Royal College of Physicians:

<https://www.rcplondon.ac.uk/guidelines-policy/pain-complex-regional-pain-syndrome>

CRPS Network UK:

www.crpsnetworkuk.org

Carers UK: a charity set up to help those who look after family members or friends

www.carersuk.org

CRPS-UK: patient-led support for people with CRPS

<https://crps-uk.org/>



The CRPS mantra is:

Move it, touch it, love it.

People with CRPS are encouraged to:

Move the affected limb to maintain function

Touch the limb to reduce its sensitivity

Love the limb—many people with CRPS feel that their limb does not belong to them; they should be encouraged while touching their limb to look at it.



Leaflet produced by
Rodham, Gavin, Coulson and Watts
(2013) in consultation with people
living with CRPS

Funded by NIHR (Ref10/2000/40)

© Rodham et al 2017 v2

Complex Regional Pain Syndrome (CRPS)



*What people with
CRPS want
Friends and
Family
to know*

CRPS: What you need to know. . .

What is CRPS?

CRPS is a pain condition that usually occurs after an injury but can start spontaneously. Burning pain is the most characteristic symptom, but people also report swelling, coldness, colour changes, hypersensitivity as well as increased sweat, hair and nail growth. There is currently no cure.

Although the symptoms are usually experienced in one limb, it is possible for CRPS to occur in more than one limb, and indeed in other body regions. For an estimated 7% of people with CRPS, the condition can spread to other limbs.

How is CRPS diagnosed?

The Royal College of Physicians have published some helpful guidelines about CRPS. The guidelines explain diagnosis and management of people living with CRPS and provide recommendations for diagnosis, treatment and referral in a variety of clinical settings. It can be helpful to read this document because you will understand more about your loved one's condition.

It is important to remember that:

"Guidelines help, but creativity, compassion and flexibility are essential" (Harden, 2001)

What CRPS is NOT:

There are a lot of misconceptions about CRPS. Many of them come from the lack of knowledge about the condition. CRPS is very difficult to diagnose because other explanations have to be ruled out first. This can mean that it takes a long time for health professionals to make a diagnosis. This wait can be very frustrating and sometimes doubts can creep in. It is important to recognise that:

- CRPS is not a psychological condition.
- CRPS is not depression.
- CRPS is not a personality disorder
- CRPS is not all in your head
- CRPS is not cured overnight.
- CRPS is not a 'low pain threshold'
- Anxiety and stress do not cause CRPS but they can make it worse.



How can you help?

People with CRPS are very aware that CRPS affects friends and family too:

"CRPS has certainly turned mine and my family's world upside down."

It can be really hard for friends and family to know how best to help someone with CRPS. CRPS is itself difficult to understand and it can be unpredictable: one day the person with CRPS will be able to do something, whereas the next, that same thing is impossible.

People with CRPS often feel guilty about the impact they think their condition is having on other people. They can become afraid that they might be a burden and this fear can make them isolate themselves. There are ways that friends/family can support those with CRPS. They can:

- Believe that the person with CRPS is in real pain
- Learn about CRPS & rehabilitation
- Avoid temptation to do things *for* the person with CRPS. Instead find ways to help them to do the things they want to.
- Ask them how you can best help
- Above all, work together on finding ways to cope