

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/>



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Complex Regional Pain Syndrome (CRPS)



*What people with
CRPS want
Health
Professionals
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 is important to remember that:

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

Do Take your patient seriously:

Many people feel that they have not been believed or taken seriously. This impacts on the therapeutic relationship negatively:

"When I saw some doctors they really did make me feel like I was making it up and it was all in my head and I did start to wonder myself some days."

Do encourage them to 'Move it, touch it, love it': This is the CRPS mantra. Encourage patients to:

Move the affected limb to maintain function.

Touch the limb to reduce its sensitivity.

Love the limb: many patients feel that their limb is alien and does not belong to them; they should be encouraged whilst touching their limb to look at it.

Don't touch the affected area:

People with CRPS find it very difficult to have their limb touched by someone else, often they can barely tolerate touching it themselves. If you touch their limb, you will increase their pain and reduce their trust in you. Please ask before you touch.

Access to other people with CRPS: CRPS UK is a patient-led group. Email address overleaf.



Where can I refer people with CRPS?

The Royal National Hospital for Rheumatic Diseases in Bath is a national centre for the management of CRPS. Details can be found on their website (overleaf). Other centres with CRPS expertise are listed in the UK CRPS guidelines on the RCP website.

What else is helpful?

Psychological Support: some patients find it difficult to cope with the challenges CRPS brings. Having access to a psychologist with whom they can share their worries can be helpful. Psychologists can teach a range of coping strategies which can make patients feel more confident about their ability to cope with CRPS

Ongoing physiotherapy: People with CRPS may need ongoing physiotherapy.

Ongoing hydrotherapy: many patients find hydrotherapy extremely beneficial. Ongoing access to a hydrotherapy pool can enable them to maintain functional progress.

Access to Occupational Therapists (OTs): OTs can recommend home improvements to enhance the person's ability to cope. OT can help patients learn to desensitise their affected limb. OTs also know a lot about gadgets that can make a huge difference to patients' ability to do things.