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:

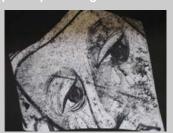
www.crpsnetworkuk.org

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)

 \odot Rodham et al 2017 v2

Complex Regional Pain Syndrome (CRPS)



What people with CRPS want **Employers** 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 Physician's 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 so that you understand more about your employee's condition.

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. Many people with CRPS have come across the following assumptions and we want to take the opportunity to be clear:

- 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.

Life with CRPS

Living with severe pain can be exhausting and CRPS is itself unpredictable which might mean that an employee may be able to complete a task one day, but not the next.



How can employers help?

There needs to be a collaboration between you and your employee. Putting supportive working arrangements in place reduces the likelihood that the person with CRPS will need to take time off. Employees should not be penalised in performance reviews on the grounds of their disability and the associated changes to working arrangements.

It IS POSSIBLE for a person to work when they have CRPS but employers need to make reasonable adaptations within the workplace. This might include conducting an ergonomic assessment of the employee's workstation, or perhaps allowing the person with CRPS to take their breaks 5 minutes early, enabling them to miss the rush and so reducing their stress and keeping their pain levels low. In short, employers need to work to the Equality Act 2010 and the United Nations (UN) Convention on disability rights.

Adaptations such as wheelchair access and ergonomic desk set up can make all the difference: if people with CRPS are not battling unnecessarily with access or with poorly set up workspaces, they will have more energy to direct towards their jobs.

"I am having problems at work because they don't have doors wide enough to get in some of the buildings and they are being really slow to sort it out despite six month's notice"