Complex regional pain syndrome and osteoporosis

What is osteoporosis?
Osteoporosis occurs when the struts which make up the mesh-like structure within bones become thin causing them to become fragile and break easily, often following a minor bump or fall. These broken bones are often referred to as ‘fragility fractures’. The terms ‘fracture’ and ‘broken bone’ mean the same thing. Although fractures can occur in different parts of the body, the wrists, hips and spine are most commonly affected. It is these broken bones or fractures which can lead to the pain associated with osteoporosis. Spinal fractures can also cause loss of height and curvature of the spine.

What is complex regional pain syndrome (CRPS)?
CRPS is a rare but debilitating and painful condition of a limb that cannot be fully explained. It is often associated with sensory (pain to light touch), colour, temperature and tissue changes which can cause distress and difficulty in using the affected limb.

It is often defined as type 1 or type 2 depending on the possible cause:

**CRPS type 1:** is often triggered by an injury to a limb such as a sprain, fracture or operation however there is no significant nerve damage present.

**CRPS type 2:** also develops after an injury to a limb but in these cases there is significant nerve damage present.

In the past, terms such as algodystrophy, regional osteoporosis, shoulder hand syndrome and reflex sympathetic dystrophy have been used to describe the condition but now the term CRPS is used to cover them all.

How common is CRPS?
CRPS can occur in both adults and children of any age and ethnic background although data suggests it is more common in women and between the ages of 50 and 70 years. Some people experience longer term pain after a limb fracture but a large proportion (approximately 80-85%) of those affected recover spontaneously with or without treatment and many are never diagnosed with CRPS by a doctor. For a very small number of people CRPS can result in a severe disability and this can have a negative impact on their quality of life.

What are the symptoms of CRPS?
The overriding symptom with CRPS is pain, which can be a severe burning pain that appears to be out of proportion to the injury that triggered it. This pain is not well understood. Current research has suggested that after an injury or operation, the nervous system provokes inflammation in the tissues, which in turn sets off a number of other malfunctions in the way the nervous system controls limb function.

Some people experience pain, swelling, difficulty moving the limb and also have a disrupted perception of their limb. Other symptoms can include redness and changes in skin colour and temperature, as well as abnormal hair and nail growth.

CRPS is a well-recognised condition and is not considered a psychological problem; however it can be very distressing because chronic pain can affect our mood and ability to lead a full life.

Is CRPS a risk factor for osteoporosis?
No, in CRPS a localised loss of bone density occurs in the affected limb only. This does not mean that the individual has generalised osteoporosis or is at an increased risk of developing osteoporosis at a later date. But there is a debate as to whether the affected limb may have a higher risk of fracture.
How is CRPS diagnosed?
Diagnosing CRPS is difficult as there is no single blood test, x-ray or scan that can confirm it. Medical professional knowledge and experience is the key and the doctor will need to take a detailed history of any injury, as well as examining the signs and symptoms the patient is experiencing. A diagnosis of CRPS is made clinically based on combinations of these signs and symptoms. New UK guidelines on CRPS highlight these under a number of categories:

- Sensory (pain to light touch)
- Vasomotor (temperature/skin colour changes)
- Sudomotor/oedema (swelling and/or sweating changes)
- Motor dysfunction (weakness) and trophic changes to the hair, nails and skin

It is important that doctors rule out other reasons for the symptoms being experienced, such as arthritis or infection, before a diagnosis of CRPS is made.

What treatments are available for CRPS?
In most cases recovery is spontaneous, but treatment centres on pain relief and rehabilitation of the limb affected. If the condition persists referral to a local specialist should be considered. Ideally this should include access to a multidisciplinary team (which includes physiotherapists, occupational therapists, medical specialists such as rheumatologists and psychologists) who will work together to manage the condition and offer support as required. Throughout the UK there are a small number of recognised centres of excellence for the treatment of CRPS. If necessary a referral can be made by your doctor to one of these centres to gain specialist treatment.

The treatment of CRPS involves a number of different approaches and when used together will help to control its symptoms. Important aspects include:

- Information and education; appropriate leaflets should be given about the condition and reassurance given to the person with CRPS and their family about causes and possible outcomes.
- Pain relief; a doctor or a pain specialist will be able to offer advice about appropriate analgesia and monitor its effectiveness.
- Other medication and procedures; recent evidence suggests some people may benefit from an injection of a bisphosphonate drug (such as pamidronate) through a needle inserted into a vein or a short course of steroids. Other procedures include nerve blocks and spinal cord stimulation although there is some debate about how effective they are.
- Rehabilitation; this aims to restore normal function and activity of the limb through the use of therapies such as mirror imagery, encouraging the use of the limb, desensitisation to pain by gentle stroking, as well as encouraging pacing and relaxation strategies to manage pain. Exercise may also help to prevent any bone loss in the affected limb and reduce the risk of fracture but they need to be undertaken with the guidance of a therapist.
- Psychological management; this includes the evaluation of mood and coping skills and can follow the principal of cognitive behavioural therapy by promoting more positive thoughts and feelings about how to manage the pain experienced. Relaxation and body visualisation techniques can be useful.

What happens in the long term?
Many people recover spontaneously, or within a few months, but for some people this will unfortunately become a longer term condition. In these cases it is important to get a diagnosis and a referral to a specialist clinic. The quicker a rehabilitation programme is put in place the better the long term outcome.

How can I help myself?
It is important to understand and take part in the rehabilitation programme that has been devised for you. The best approach is to keep moving and touching your limb, even if it is uncomfortable. You will not cause any damage but at times this will be difficult.

There are self-help groups available which may help you to maintain your independence and support you through social and exercise activities. If you are able to gain an insight into the condition and its treatment, through education and support by the healthcare professionals involved, this will help you to manage day to day.
Useful contacts

**CRPS Network** (Clinical & Research Network in Complex Regional Pain Syndrome)
Lisa Buckle, CRPS Network Administrator
Royal National Hospital for Rheumatic Diseases
Upper Borough Walls
Bath
BA1 1RL
Tel: 01225 473462
www.crpsnetworkuk.org
The network aims to improve clinical care and promote research into CRPS. It also helps to raise understanding and awareness of this condition amongst health professionals, patients and general public.

**Arthritis Research UK**
Copeman House
St Mary’s Gate
Chesterfield
Derbyshire
S41 7TD
www.arthritisresearchuk.org
Tel: 0300 790 0400
Charity that has an information leaflet about CRPS

**The British Pain Society**
Third Floor, Churchill House
35 Red Lion Square
London
WC1R 4SG
www.britishpainsociety.org
Tel: 020 7269 7840

The **National Osteoporosis Society** is the only UK-wide charity dedicated to improving the prevention, diagnosis and treatment of osteoporosis and fragility fractures. The Charity receives no Government funding and relies on the generosity of individuals to carry out its vital work.

For osteoporosis information and support contact our Helpline:

- 0808 800 0035
- nurses@nos.org.uk

To become a member or make a donation:

- 01761 473 287
- join online at www.nos.org.uk

To order an information pack or other publications:

- 01761 471 771
- info@nos.org.uk

or download from our website at www.nos.org.uk

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This fact sheet is one of a range of publications produced by The National Osteoporosis Society. If you would like more general information about osteoporosis see our booklet *All about Osteoporosis*.

This information reflects current evidence and best practice but is not intended to replace the medical advice provided by your own doctor or other health professional.