



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 chronic pain condition of a limb that may occur following a broken bone (fracture). However limb surgery, sprains or crush injuries may also trigger this condition and the cause is still unclear and very complex.

The pain can be so severe that it causes distress and problems with using the affected limb which in turn impacts on a person's ability to function independently and on their quality of life.

CRPS 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.

So is CRPS a risk factor for developing osteoporosis?

No. In some cases CRPS may cause some localised loss of bone density in the affected limb but this does not mean that the individual has generalised osteoporosis or is at an increased risk of developing osteoporosis at a later date.

Am I more at risk of developing CRPS if I have osteoporosis?

Not really. The only link would be if you were unfortunate enough to fall and break a bone in any of your limbs and then go on to develop CRPS in the affected limb.

Knowing that you have a low bone density or being diagnosed with osteoporosis does not increase your risk of developing CRPS should you break a bone.

Tell me more about CRPS

How common is it?

CRPS occurs in about 7% of people who break a limb, have limb surgery or have other injuries to a limb and in the majority of cases it will get better within the first year. It 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 broken bone 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?

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. Some people will also experience swelling, difficulty moving the limb and also have an altered awareness of their limb. Other symptoms can include redness or a dusky skin colour, sweating, either warm or cold skin temperature, as well as abnormal hair and nail growth.

CRPS is a well-recognized 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.

What causes the pain?

This pain is not well understood and it is still unclear whether it can be considered purely as neuropathic pain (nerve pain). After an injury the nervous system responds to the trauma by increasing our response to pain and causing inflammation (swelling) to the injured area. This helps to protect the area and stops us from using the limb which may cause further injury. It may be this response that becomes over sensitized or changes to the signaling along the pain pathway that then leads to CRPS developing. However the cause is still unknown.

How is it diagnosed?

Diagnosing CRPS is difficult as there is no single blood test, x-ray or scan that can confirm it so it is made solely on the clinical signs and symptoms that are present. In 2018 UK guidelines on CRPS were updated to help doctors diagnose CRPS and make timely referrals to the correct specialists. The doctor will see if there are a range of symptoms that fall into some or all of these categories:

- Vasomotor (temperature/skin colour changes)
- Sudomotor/oedema (swelling and/or sweating changes)
- Motor dysfunction (weakness) and 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.

Are there any treatments available for CRPS?

In most cases recovery is spontaneous, but treatment centres on pain relief and rehabilitation of the affected limb. 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 recognized 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 and zoledronate) 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, desensitization 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 visualization 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 the pain will make this 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.

Getting more information and support

We hope this fact sheet will help you feel more informed and more confident when discussing your bone health with your medical team.

For more information about osteoporosis and bone health, including fact sheets on all available drug treatments, please visit our website at theros.org.uk/info

If you need more information or support, talk to your healthcare professional.

You can also call our specialist Helpline nurses with any questions or concerns about bone health, for free, on **0808 800 035**, or email them at nurses@theros.org.uk

You may also find the following organisations helpful:

British Pain Society

britishpainsociety.org

Tel: 020 7269 7840

CRPS Network

The Clinical & Research Network in Complex Regional Pain Syndrome aims to improve clinical care and promote research into CRPS. It also helps to raise understanding and awareness of this condition among health professionals, patients and the general public.

Lisa Buckle, CRPS Network Administrator

crpsnetworkuk.org

Tel: 01225 821767

Versus Arthritis

versusarthritis.org

Helpline: 0800 5200 520

Charity with an information leaflet about CRPS.

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This information is based on the latest evidence and clinical practice. It should not replace advice from your own healthcare professionals.

To give us feedback on this fact sheet, email us at health.info@theros.org.uk

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