



Complex Regional Pain Syndrome





When you have been diagnosed with complex regional pain syndrome (CRPS), it is important that you learn how to live and cope well with it.

After you have been diagnosed and received some form of treatment, you will benefit from learning to 'self-manage'. The term self-management refers to all the things you can do to cope with your CRPS. To self-manage well, you need to:

- understand CRPS;
- know about different coping strategies;
- feel confident about using different coping strategies; and
- have support

What is CRPS?

Complex regional pain syndrome is a persistent and chronic pain condition. It usually develops after an injury or surgery, but in a small number of cases it is thought to happen spontaneously (that is, for no obvious reason). Severe pain is the most common symptom, but people also report a range of other symptoms. These can include swelling, changes in temperature, oversensitivity and increased sweat and hair or nail growth on the affected limb. People usually have symptoms affecting a single limb, but CRPS can occur in other limbs or parts of the body.

Research shows that the majority of people (up to 85%) improve within the first year of experiencing symptoms. This means that up to 15 to 20% of people with CRPS will experience symptoms for more than one year, or longer.

What causes CRPS?

CRPS usually develops within a month of an injury, though for some people it is thought to happen spontaneously. Most people will recover from these injuries without any significant long-term effects. Some people develop pain that's much more severe and long-lasting than usual. We don't know why this happens.



CRPS is described as a stronger-than-normal reaction of the body to injury. This reaction happens in both the affected area of the body and the brain. Research suggests that the nerves in the affected limb are much more sensitive than other nerves in the body and that this is what causes some of the tenderness to touch and pressure. It is thought that the way the brain communicates with the affected limb also changes. These changes can cause some of the problems with sensations and movement.

When some people hear that the brain is thought to be involved, they can worry that their CRPS is caused by psychological factors. This is not the case – there is no evidence to suggest that CRPS is caused by psychological factors.

How is CRPS diagnosed?

It can take a long time for CRPS to be diagnosed because the symptoms could also be a sign that other serious conditions are developing. These other serious conditions need to be ruled out first. This can be frustrating – not just for the person who is in pain, but for their loved ones and for the health professional who is trying to work out what is going on. You can find more

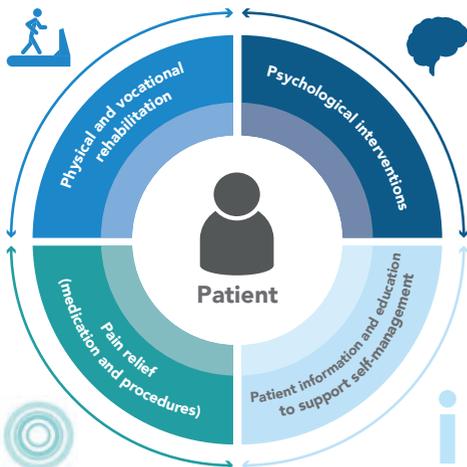
information about diagnosing CRPS in the CRPS clinical guidelines, originally written by a team led by doctors Andreas Goebel and Chris Barker in 2012 and updated in 2018.



Putting life first and CRPS second: How can I learn to live with CRPS?

The Royal College of Physicians has published guidance on treating CRPS. This guidance emphasises the importance of what are called 'the four pillars of treatment.' These involve different health professionals working with you and with one another. Together, these four pillars aim to provide you with a 'toolbox' of strategies that will help you cope.

Four pillars of treatment for CRPS – an integrated interdisciplinary approach



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Patient information and education is one of the most important pillars of treatment. If you don't understand what CRPS is, or what the treatments are, you are unlikely to be able to understand how best to cope with it.

It is wise to tread carefully when searching the internet for information – a lot of websites do not base their information on scientific evidence. It is also important to remember that people's experience of CRPS is unique to them. Reading other people's stories online can be useful because they can help you realise you are not alone, but it is important to recognise that just because one person has had a certain experience, this does not mean that the same things are in store for you.

A good plan would be to talk with a health professional that you trust and ask them which websites and sources of information they would recommend.

Psychological interventions – psychological factors are not thought to cause CRPS. However, feelings such as fear, anxiety, stress, sadness or worry can make your experience of pain worse. They can also make it more difficult to take part in rehabilitation and social activities with friends and family.

Psychologists will look at how you are coping and explore ways to help you learn to cope better. Common issues include the following.

- **Loss:** for example, coming to terms with loss of identity, self-esteem, hobbies, independence, a job, social life or intimacy.
- **Communication:** explaining CRPS to others, asking for help when you are the person who always used to give help, dealing with other people's questions.
- **Managing stress:** dealing with negative thoughts, anxiety about treatment, difficulties relaxing, fear of going out, fear of someone bumping into you and hurting the affected area.
- **Setting goals:** working out how to set short- and long-term goals, learning how to make sure your goals are realistic and how to pace yourself when working towards those goals.
- **Sleep problems:** learning how to improve your sleep by managing sleep disruption.
- **Acceptance:** coming to terms with living with a persistent, chronic condition (some

psychologists may use ACT (acceptance and commitment therapy) to help with this).

- **Support:** learning skills that will help you find support that works for you.

Pain relief – You may be prescribed medication for your pain. However, there is not yet a drug that can completely take the pain away. Many people find that, at best, their medication 'takes the edge off the pain' and for some there are problems with side effects. Specialist pain doctors often describe getting an appropriate combination of pain medication as a process of trial and error. This can be very frustrating, and some people decide they will try to learn to live without medication and use other methods of coping instead. You can talk to your doctor about your medication options, including whether you might be better off reducing your medication.

Patients who decide not to use medication say that they use a range of other strategies, including the following.

Acupuncture. Fine needles are inserted at certain sites in the body to stimulate sensory nerves under the skin



and in the muscles. This results in the body producing natural substances, such as pain-relieving endorphins. If you choose to have acupuncture, make sure your acupuncture practitioner is either a regulated healthcare professional, such as a doctor, nurse or physiotherapist, or a member of a recognised national acupuncture organisation.

TENS machine. Transcutaneous electrical nerve stimulation (TENS) is a method of pain relief that uses a mild electrical current. A TENS machine is a small, battery-operated device that has

leads connected to sticky pads called electrodes. The pads attach directly to your skin. When the machine is switched on, small electrical impulses are delivered to the affected area of your body, which you feel as a tingling sensation. The electrical impulses can reduce the pain signals going to the spinal cord and brain, which may help relieve pain and relax muscles. They may also stimulate the production of endorphins, which are the body's natural painkillers.

Hydrotherapy. Hydrotherapy is the use of water in treatment.



Hydrotherapy differs from swimming because it involves special exercises done in a pool that is much warmer than a typical swimming pool. The NHS cannot offer indefinite hydrotherapy sessions, so many patients join local spas which have hot tubs where they can continue their exercises. This can be expensive, but Arthritis Research UK note that some swimming pools have special sessions when the water temperature may be increased and some sports centres offer water-based exercise classes. You should ask your doctor or physiotherapist for advice before you join a class, to make sure it's suitable.

Amputation as a form of pain relief.

Some patients strongly believe that the only way for them to cope with their pain is to have the affected limb amputated. If you are considering this, it is very important that you talk to your doctor and your pain-management team. There is not enough reliable research on this issue, and the guidelines on CRPS recommend caution. Current evidence suggests that amputation is unlikely to stop the pain and CRPS may move to the remaining stump, which means that you may not be able to use a prosthesis (artificial limb).

Get advice from your doctor and pain-management team to help you understand the risks of amputation.

Physical and vocational rehabilitation. Research shows that, in the early stages, physiotherapy and occupational therapy can help reduce pain and help you to function better. It is strongly recommended as a treatment, even if you have had CRPS for some time. It is essential that you play an active role in rehabilitation; it is not about having things done to you but about working with the therapists. Therapists will usually encourage you to continue to use your affected limb (or limbs). They will also introduce the idea of learning to pace yourself, so that you get the right balance between being active and resting.

Physical rehabilitation can also help to reduce the extra sensitivity some people with CRPS develop. Also, some people living with CRPS will begin to hate the part of their body that is affected. This is known as body perception disturbance (Lewis and colleagues, 2007). This is obviously upsetting, but the therapists can work with different techniques to help you 'retune' how you feel about your CRPS. 'Move it, touch it, love it' is an easy way to remember these techniques.

What happens if I have a flare-up?

A flare-up is an increase in pain and other symptoms above the level that is usual for you. Flare-ups can last for a few minutes to a few days. Some people have flare-ups related to specific causes, like changes in temperature, overdoing things or bumping the affected area. But flare-ups can also start for no obvious reason. Whatever the cause, if you experience a flare-up it is important to remember all the coping strategies that you have learned. Have the confidence to know that a flare-up is just that – a flare-up – and that it will pass. The following five suggestions may help you to cope when you have a flare-up. It is important to accept that you are experiencing a flare-up. Flare-ups are part of living with chronic pain. For example, Macleod (2016) suggests that if you can see the flare-up as a nuisance but not something to worry about, you are less likely to get annoyed and stressed and will be more able to manage the situation. This is because how you think can affect how you feel, and the more stressed you feel the more likely your pain is to increase.

- Do what you can to soothe the pain. Even on a bad day, there

will usually be some things that you can do. Remember all the different coping strategies you have learned. Think about which ones you could use right now – maybe relaxation, distraction, noticing your negative thoughts, or doing some light exercise.

- See if you can identify a trigger for the flare-up. Sometimes, something you have done the day before, or even two days before, may trigger a flare-up. For example, was there anything you did that was unusual for you? Did you forget to pace yourself and do too much? If you can work out what the trigger was, you can plan to avoid the same thing happening again. But if you can't, don't let it worry you.
- While preventing flare-ups is important, sometimes it is just as important to do something, even though you know it is likely to cause a flare-up. One of the most isolating parts of living with chronic pain happens when you do fewer activities because you fear they may cause more pain. If an activity will give you pleasure – maybe a family day out, catching up with friends, or going to a



wedding – it is OK to go ahead and enjoy it. The important thing is to become aware of the causes of flare-ups but not let the fear of one stop you from doing things that make you happy and give meaning to your life.

- Finally, think about developing a plan for managing flare-ups. Some people make 'crisis cards' that they can carry with them. That way, when they have a flare-up and it can be hard to think straight, they have already written down the things that help them

to cope and just need to look at their card to remember what to do. Other people create a 'flare-up box' which contains objects that help, like a CD of calming music, favourite chocolates, phone numbers of reliable friends and so on. You could also think about developing your plan with your friends and family so that they also know what will work for you. If you have already worked out a plan beforehand, you will feel more confident about managing future flare-ups.

Are there things that my friends and family can do to help?

Yes!

In the same way that you are learning to cope with the condition, so are your friends, family and loved ones. Loved ones can see just how difficult coping with CRPS is. They can feel just as frustrated, angry and sad about CRPS as you do.

One of the most important things that you and your loved ones can do is to find a way to talk to each other openly and honestly about how CRPS is affecting your lives. Having support is an important part of being able to self-manage. It might be that you are afraid that you are becoming a burden. If this is how you are thinking, the chances are you will be working very hard to keep these feelings to yourself. Friends and family may also avoid talking about CRPS because they don't know how to help. If this happens it can lead to upset and misunderstanding for everyone concerned. Without open and honest communication, it won't be possible to identify problems, which in turn means it also won't be possible to work out how to solve them.

If you are part of a couple, talking to one another can be hard. Clear communication is one of the hardest

things to get right when you are both dealing with a difficult, stressful and life-changing situation. Many couples find that those first few conversations can be easier if they use a counsellor.

Where can I find more information and help?

Websites

Burning Nights: a UK charity that raises awareness of CRPS.

www.burningnightscrps.org/

CRPS UK: a patient led charity, raising awareness and supporting people with CRPS through experience, understanding and education.

www.crps-uk.org/

CRPS Network UK: a research network made up of a number of UK NHS trusts and academic institutions with an interest in CRPS. One of its main aims is to raise awareness and understanding of CRPS among health professionals, patients and the general public. www.crpsnetworkuk.org/

Relate: an organisation which aims to help couples to find a way through any difficulties they may be facing in their relationship.

www.relate.org.uk/relationship-help/help-relationships/relationship-counselling

Books and leaflets

Arthritis Research UK: an organisation which aims to improve the quality of life of people with arthritis. They have produced a leaflet about CRPS.

www.arthritisresearchuk.org/arthritis-information/conditions/complex-regional-pain-syndrome.aspx

Hydrotherapy leaflet:

www.arthritisresearchuk.org/arthritis-information/therapies/hydrotherapy.aspx

Macleod, L. (2016). Manage your pain, Pain Concern

Peacock, S. (2016). Sleeping with Pain: Strategies for a restful night from a pain-management expert. Sheffield: Ann Jaloba Publishing.

Rodham, K. (2015). Learning to cope with CRPS/RSD: Putting life first and pain second. London: Singing Dragon.

Royal College of Physicians CRPS guidelines

www.rcplondon.ac.uk/guidelines-policy/complex-regional-pain-syndrome-adults

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Pain Concern is a charity providing information and support to people with pain and those who care for them, whether family, friends or healthcare professionals.

Find out more at **painconcern.org.uk**

**Listen to Airing Pain
radio show • online**

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