

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 re-port 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 longterm effects. Some people develop pain that's much more severe and long-lasting than usual. We don't know why this happens.

Versus Arthritis describes CRPS 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

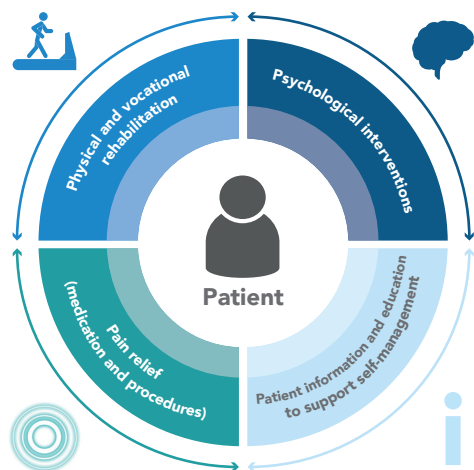
information about diagnosing CRPS in the Versus Arthritis CRPS page and in the CRPS clinical guidelines, originally written by a team led by doctors Andreas Goebel and Chris Barker in 2012 and updated in 2018.



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



© 2018 Royal College of Physicians. Reproduced from: Goebel A, Barker CH, Turner-Stokes L et al. *Complex regional pain syndrome in adults: UK guidelines for diagnosis, referral and management in primary and secondary care*. London: RCP, 2018.

Patient information and education

is one of the most important pillars of treatment. After all, 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 work with you on the things you are finding tough and help you learn new ways of coping. For example:

- **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, some people living with CRPS say that, at best, the medication 'takes the edge off their pain' but does not take their pain away and on top of this, some people have problems with side effects from the medication. 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.

Whether you use pain relief or not, you might try other strategies to help with your pain. For example:

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 Versus Arthritis 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.

As well as reducing pain, physical rehabilitation can help in other ways. For example, some people find that although other people say that their affected limb looks 'normal', they see their limb very differently. This is known as body perception disturbance (Lewis and colleagues, 2007) and can be upsetting to experience. Other people might develop extra sensitivity in their affected limb(s). The therapists can work with different techniques to help you 'retune' how you feel about your CRPS.

In short, 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. "Move it, touch it, love it" is an easy way to remember these techniques.

Learning these physical and vocational exercises as well as the art of pacing can be challenging and so it is important that you work with your physical and vocational therapists to make sure that they understand how your world works so that their recommendations are designed for your life.

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 sometimes there is not an obvious reason. Whether you know the cause or not, if you experience a flare-up it is important to remember all the coping strategies that you have learned. Remember that a flare up will pass. Macleod (2016) suggested that if you can see the flareup 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.

WHAT CAN I DO IF I HAVE A FLARE-UP?

Coping Strategies: Remember all the different coping strategies you have learned. Think about which ones you could try right now – maybe relaxation, distraction, noticing your negative thoughts, or doing some light exercise. If one does not work, try another.

Flare-up Management Plan: It can be difficult in the middle of a flare-up to think straight, so it can be a good idea to take some time to *develop a plan* for managing your 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. 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 you have already



worked out a plan beforehand, you will feel more confident about managing future flare-ups. 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.

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 or put in place strategies to help you reduce the likelihood of a flare-up.

Ignoring a trigger: Sometimes it is important to do something, even

though you know it is likely to cause a flare-up (maybe a family day out, catching up with friends, or going to a wedding). If an activity is really important to you and will give you pleasure but you know that it may trigger a flare-up, you might decide that the benefits of doing the activity outweigh the costs. The important thing here is making a conscious decision about your activity and having plans in place to help you cope.

ARE THERE THINGS THAT MY FRIENDS AND FAMILY CAN DO TO HELP?

Yes!

This is why the term 'self-management' can be a bit misleading. It is true that there are many things that you can do to live well in spite of your CRPS,

but what we can do in terms of 'self-managing' will also be influenced by lots of other things. For example, where we live, who we live with, how much money we have, what support we have, whether we have a job and how supportive our employer is and so on. So YES, there are things that your loved ones can do to help.

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.
<https://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/relationshipcounselling

Books and leaflets

Versus Arthritis [www.versusarthritis.org]: an organisation which aims to improve the quality of life of people with arthritis. They have information about CRPS. www.versusarthritis.org/about-arthritis/conditions/complex-regional-pain-syndrome-crps/
Information about Physiotherapy, Hydrotherapy and Occupational Therapy: www.versusarthritis.org/about-arthritis/treatments/therapies/

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.

Rodham, K. (2020). *Rodham, K. (2020). Self-Management for Persistent Pain: The Blame, Shame and Inflammation Game?* Palgrave Macmillan

Royal College of Physicians CRPS guidelines www.rcplondon.ac.uk/guidelinespolicy/complex-regional-painsyndrome-adults

The author: Karen Rodham is a Health Psychologist at the University of Chichester. She has worked in the NHS with people living with CRPS and she has written extensively about CRPS and persistent pain. For more information about her, you can access her website: <https://sites.google.com/site/profkarenrodham/>

An award from the RS MacDonald Charitable Trust allowed us to produce this leaflet and two Airing Pain radio programmes (number 94 and number 95) on CRPS.

Living with Complex Regional Pain Syndrome. © Karen Rodham. All rights reserved. Revised April 2022. To be reviewed April 2025. First published June 2018.



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**

info@painconcern.org.uk

**Pain Concern, 62-66 Newcraighall Road,
Edinburgh EH15 3HS.**

**Charity number SC023559, a company limited by
guarantee number SC546994**

**CRPS UK, 58 Station Road
Aldridge, Walsall WS9 0BN.
admin@crps.org.uk**

Charity number 1165597

