

## Patient Information Leaflet

# Learning to live with Complex Regional Pain Syndrome (CRPS)

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## **Impact of Complex Regional Pain Syndrome (CRPS)**

Developing CRPS is likely to have a huge impact on you, as well as your family and friends.

The process of getting a diagnosis may have run over a long time. This is because CRPS is often diagnosed by a process of elimination. Many health professionals may have been involved in attempts to investigate the cause of your pain. This process can feel daunting and bewildering as each health professional concludes that the cause of your pain does not lie within their area (e.g. Neurology, Rheumatology).

At times, people can therefore feel like it is “all in their minds” it is not.

CRPS is a condition which is still unfortunately poorly understood. Health professionals themselves are still learning about the condition. However, equally there are teams who have specialist knowledge of CRPS. It is important that you ask questions if you do not understand CRPS.

It is much easier to comply with treatment if you understand why it is being recommended. Thereby it is the job of your team to ensure you have an adequate knowledge of CRPS and that any uncertainties or concerns you have are addressed.

The following is a list of the ways that CRPS can affect someone. Not everyone with CRPS will be affected by the same issues.

## **Physical**

Severe, persistent pain is the hall mark of CRPS. Pain will limit you in your daily life, and may mean that daily activities, or your job, are difficult or impossible to carry out. Lack of movement in the limb can mean that people often feel that it no longer belongs to them.

Many people do not like the look of, or to look at, their limb.

The pain typically affects people's sleep pattern.

## **Emotional**

It can feel like the pain, and the CRPS, has overtaken your life, which can feel exhausting.

It can be difficult to explain to other people what CRPS is. It is hard to summarise CRPS in a single sentence that is easily understood by other. People can then feel somewhat isolated, and it can perpetuate the confusion they already feel.

Pain can impact on your sense of well being and self esteem. People can describe feelings of depression, anxiety and fear of the future. People can lose their sense of identity if they are unable to fulfil daily roles. This can be extremely frustrating and saddening.

## **Socially**

The isolation you may feel around family or friends has previously been mentioned. This isolation may be exacerbated by the unpredictable nature of CRPS. People may become fearful of planning ahead.

Venturing out sometimes means that people are feeling they need to monitor the environment, looking out for potential sources that may exacerbate their condition. This can mean that people are unable to relax during social engagements, and that such engagements appear easier to avoid, hence exacerbating isolation.

## **What can I do to help myself?**

It is imperative that you comply with the advice given to you by your therapist. Re-engaging is using the limb again is the key. Due to pain it can feel easier to “nurse” your limb and protect it from use. This will simply perpetuate the cycle of pain and lack of movement.

## **Pacing**

Try to achieve the correct balance between activity and rest. The key is to maintain your energy levels (energy conservation), without over or under activity. Continue a certain level of exercise irrespective of “good” or “bad” days.

Try not to aim too high, and be realistic. It is important to recognise that a simple activity such as washing and dressing is still physical exertion, and should not be underestimated.

Establish a routine so that activity and rest patterns are more consistent.

Pacing can allow you to gradually increase your stamina for different activities. Pacing will allow you to conserve your energy and thereby reduce fatigue.

## **Pacing:**

- Can I break the activity down into manageable “chunks”?
- Can I rest in-between?

## **Planning**

Write down your goals, this makes goals easier to fix in our mind, and therefore achieve. You can gain a lot of satisfaction at being able to tick off an achieved task, no matter how simple.

Ensure that your goals are **SMART**.

- **S**pecific
- **M**easurable
- **A**chievable
- **R**ealistic
- **T**imely

Start within your realistic energy levels, not what you wish you could do.

Take small steps, one step at a time.

## **Planning:**

- What do I need for this activity?
- What is involved?

## **Prioritising**

Prioritise what matters most to you. This can help to increase your control over your life.

## **Prioritising:**

- Does it need to be done today?
- Does it need to be done at all?
- Can I delegate / get someone to help me?

## **Acceptance**

It can be a long process to reach a level of acceptance. Allow yourself time to grieve. People generally tend to underestimate this process. You may go through some, if not all of, these stages. There is no precise order as you grieve for a loss of role, or loss of independence or perceived health. Try to be gentle on yourself. Work with your therapist to gain a knowledge of your condition.

Talk to friends and family. If family or friends are not available, seek further professional help, perhaps your GP or helpline like The Samaritans, your GP can refer you for counselling. The important thing is to have good support around you. Also trying to deal with things alone sometimes means that our ability to keep things in perspective lessens. The way we feel can then spiral lower and lower.

Employing positive coping strategies will help you to manage your condition, and feel more in control. This can aid you on the road of acceptance. With acceptance you are able to move forward.

### **1. Denial**

This is a defence mechanism that buffers the initial shock. We can tend to hide from the facts. This is a normal reaction.

### **2. Anger**

Reality starts to hit and we can become angry. This can be directed at anyone, and anything. You may hear yourself asking “why me?”

### **3. Guilt**

We can start to feel guilty for feeling angry, and we may start to recognise the impact on people around us.

### **4. Depression**

Living with a painful condition can be distressing, anxiety and Depression can develop.

### **5. Acceptance**

Allowing this process, and your grief to take place, will help you to reach a level of acceptance.

**Your notes:**



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