

Complex regional pain syndrome (CRPS)

This booklet provides information
and answers to your questions
about this condition.



What is complex regional pain syndrome?



Complex regional pain syndrome (CRPS) is a condition that causes persistent pain in an arm or leg. It's sometimes referred to as reflex sympathetic dystrophy (RSD), Sudek's atrophy or algodystrophy. In this booklet we'll look at the symptoms and possible causes of CRPS, and explain what treatments are available.

At the back of this booklet you'll find a brief glossary of medical words – we've underlined these when they're first used.

What's inside?

2 Complex regional pain syndrome (CRPS) at a glance

4 What is complex regional pain syndrome (CRPS)?

4 What are the symptoms of CRPS?

5 What causes CRPS?

5 What is the outlook?

7 How is CRPS diagnosed?

7 What treatments are there for CRPS?

- Rehabilitation therapies
 - Physiotherapy
 - Occupational therapy
 - Psychology, education and coping techniques
- Drug treatments
- Other treatments

12 Self-help and daily living

- Exercise
- Diet
- Work
- Dealing with stress

13 Research and new developments

13 Glossary

14 Where can I find out more?

16 We're here to help



At a glance

Complex regional pain syndrome (CRPS)

What is CRPS?

CRPS is a condition which causes pain in an arm or leg. It usually develops after an injury, but the pain is more severe and lasts much longer than would be expected from the injury itself.

What are the main symptoms of CRPS?

The main symptom of CRPS is a burning, stabbing, stinging or throbbing pain in the affected limb. It may also become more sensitive to touch, change colour or temperature, or sweat. The limb may swell, leading to stiffness, and many people say that the limb 'feels strange'.

Should I see a doctor?

We would always recommend you see your GP if you have pain that won't go away. CRPS is rare but it's important to get the right diagnosis so that appropriate treatments can begin. Research shows that treatment for CRPS is usually most effective when it's started early on.

What causes it?

The exact cause of CRPS isn't yet known, but it's thought that abnormal pain signals in the brain play an important

part. It's often triggered by an injury, but sometimes occurs after an operation or a stroke. In about 1 case in every 10 there's no obvious trigger event.

What treatments are there?

CRPS is best treated with a combination of pain medications and rehabilitation therapies. Rehabilitation therapies are vital to normalise sensation in the limb and to improve function and mobility. There's no single drug treatment that's effective for everyone with CRPS, but medications may be helpful to allow you to start the rehabilitation therapies.

Treatments are likely to include the following:

- pain relief medications such as paracetamol, codeine or morphine-based drugs
- drugs which alter pain signals between the nerves and the brain – e.g. gabapentin, pregabalin
- low doses of antidepressants (e.g. amitriptyline, duloxetine), which can reduce pain signals and/or help you sleep
- drugs such as pamidronate which are mainly used to prevent thinning of bones but also have pain-relieving properties

- pain relief therapies such as TENS (transcutaneous electrical nerve stimulation)
 - a personalised programme of exercises to improve the function and mobility of the affected limb
 - desensitisation techniques to help restore normal sensation in the limb.
- Depending on your individual needs, you may also be offered:
- psychological therapies which can help with developing coping strategies, stress management techniques and encouraging more positive feelings about the affected limb
 - specialised techniques such as mirror therapy which aim to retrain or trick the brain into 'seeing' a normal, pain-free limb
 - electrical stimulation of the spinal cord (only available in specialist centres).

What is the outlook?

The outlook for people with CRPS varies a lot and is hard to predict. Most people with CRPS will improve within weeks or months but for some, the symptoms can last longer. Unfortunately, some people will always have some pain even though other symptoms may improve. We do know that rehabilitation therapies are an important part of the treatment and are especially helpful when started early on.



What is complex regional pain syndrome (CRPS)?

Complex regional pain syndrome (CRPS) is a condition that causes severe pain which won't go away. It usually affects just one arm or leg and often follows an earlier injury to the limb. However, the body's reaction to the injury is much stronger than usual and may affect more of the limb than the original injury did.



Doctors sometimes make a distinction between two types of CRPS, though the symptoms and the treatments are usually very similar:

- **CRPS type 1** follows an injury such as a fracture or sprain but with no nerve damage – sometimes referred to as reflex sympathetic dystrophy (RSD) or Sudeck's syndrome.
- **CRPS type 2** follows damage to a nerve in the limb – sometimes referred to as causalgia.

Anyone can be affected by CRPS, including children. The parts of the body most commonly affected are the hand and wrist, foot and ankle, or the knee, although the whole limb can be affected.

What are the symptoms of CRPS?

Pain is the main symptom of CRPS. People often describe the pain as burning, stinging, stabbing or throbbing pain. The affected limb is often extremely sensitive to touch. Even light stroking or the weight of clothing can cause severe pain. The painful area is often swollen (which can lead to stiffness) and, after a time, the muscles in the affected limb may weaken. Movements may be difficult to control, shaky or jerky.

You may notice that the temperature of the affected area changes. Similarly, the skin of the affected area could look more red or blue than normal, and may appear mottled or unusually shiny.

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Complex regional pain syndrome (CRPS)

These changes often vary a great deal, sometimes during the course of a day. Some people notice stiffness, changes to the hair or nails, or more or less sweating in the affected limb. Many people say that the limb 'feels strange' or that it feels larger or smaller than the normal one.

People with CRPS may become anxious or depressed. This is normal for anyone with long-term (chronic) pain and needs to be recognised and addressed. Some people may have negative feelings about the affected limb.

i See Arthritis Research UK booklet *Pain and arthritis*.

What causes CRPS?

We don't yet know exactly what causes CRPS but a fracture or other injury sometimes seems to act as a trigger. Symptoms of CRPS start within a month of the injury. It's thought that the nerves of the affected limb are much more sensitive than normal and that pain pathways between the affected limb and the brain may change so that pain continues long after the original injury has healed. The pain and other symptoms of CRPS also affect a wider area than the original injury.

More rarely, CRPS can occur after other problems such as a stroke or multiple operations to a limb. In other cases (about 1 in 10) CRPS develops without any obvious trigger factor.

A holistic approach including pain medication, rehabilitation and psychological therapies is likely to be most effective in treating CRPS, especially when started early.

What is the outlook?

It's difficult to predict how CRPS will progress in any one person but early diagnosis and treatment are helpful. Many people find their CRPS settles over a few weeks or months with good rehabilitation therapy. However, if you've had symptoms for more than six months then it's more likely that you'll still have some pain even after treatment. Some people will find that other symptoms may improve even if the pain continues.

CRPS often affects a wider area than any previous injury and it may affect the whole of the limb. Occasionally, people who've had CRPS in one limb may go on to develop it in another, but this is relatively unusual. It's also possible for symptoms to return in people who've had a previous improvement in symptoms.

Even if you have the condition for a long time CRPS will not damage the body's tissues. However, you should try not to alter your posture to adapt to the painful limb as this can sometimes lead to secondary problems in other parts of the body.



How is CRPS diagnosed?

There's no specific test that will confirm you have CRPS. Doctors mainly base diagnosis on your symptoms and a physical examination, although tests may be helpful – sometimes to rule out other conditions:

- **An x-ray** or bone scan of the affected limb may show thinning of the bone (osteoporosis) or other abnormalities.
- **Blood tests** may help to rule out infection or autoimmune conditions such as rheumatoid arthritis.
- **Magnetic resonance imaging (MRI)** scans may help to rule out problems with the bones or other tissues.
- **Regional anaesthesia** or blocking of the sympathetic nervous system with a local anaesthetic is occasionally used as a diagnostic test. If this block eases the pain, then it's likely that you have CRPS.
- **Nerve conduction studies** are sometimes used to check for nerve damage.

The International Association for the Study of Pain have set criteria, called the Budapest criteria, to help with diagnosis. These take into account signs and symptoms in each of the following categories:

- unusual sensitivity to touch
- differences in temperature or skin colour between the affected and unaffected limb
- swelling and/or unusual sweating in the affected limb

- reduced range of motion or loss of function in the affected limb and/or changes in the skin, hair or nails of the affected limb.

If your GP is in any doubt about the diagnosis you may be referred for a specialist opinion. Once you've been diagnosed with CRPS it's likely that you'll be referred to a specialist pain clinic for treatment – usually at a local hospital.

What treatments are there for CRPS?

There's no single treatment available that will help everybody with CRPS but movement (as far as possible) is probably the most important aim. This will usually be achieved with a combination of physical rehabilitation therapies and pain-relieving medication. You will also be offered advice on managing the condition and may be offered psychological therapies which can help you develop coping strategies.

Rehabilitation therapies

The most important goal of rehabilitation therapies is to restore or maintain function in the affected limb and to help improve quality of life. They probably won't stop the pain completely but will help you use the limb more normally. They should also help to avoid secondary problems like weakening of the muscles through lack of use.

Most therapies will begin very gently to avoid a flare-up of your symptoms, and you'll probably need pain medication to help lessen the pain so that you can start the therapies. You'll need to build

up the length of time and intensity of your therapies gradually, even if progress seems slow at times. Rehabilitation will involve elements of physiotherapy and occupational therapy but in some areas you may see the same person for both these strands of your treatment.

! Rehabilitation therapies play a very important part in the treatment of CRPS and are most effective when started early.

Physiotherapy

Physiotherapy is probably the single most important treatment for CRPS. The aim is to reduce pain and keep the affected limb mobile. This will help prevent stiffness and loss of muscle tone as well as promoting circulation. Exercise can be difficult if you have severe pain so you'll need to work with your physiotherapist to find out which exercises work best for you, when you should stop, and the various techniques you can use to cope if your pain does increase for a time.

Your therapist will also be able to advise on pain-relief therapies such as transcutaneous electrical nerve stimulation (TENS), and they may be able to loan you a TENS machine to try or advise on where you might be able to hire one. Hydrotherapy (exercises performed in warm water) and combinations of mind/body exercises such as t'ai chi may also be useful.

Your therapist may also suggest more specialised therapies such as mirror visual feedback therapy and/or graded motor imagery (GMI). These therapies are becoming more widely used and can be very effective. They aim to 'retrain' the way the brain interacts with the limbs.

Graded image therapy consists of three elements:

- **Left-right discrimination:** It's thought that in CRPS, the ability of the brain to quickly recognise left and right may be reduced. You will be shown images of different parts of the body and asked to identify whether each is the left or right side. You may also be shown moving images and asked whether the movement is to the left or right. Repeating this exercise regularly improves how quickly and accurately the brain recognises left and right.
- **Explicit motor imagery:** You will be shown images of a movement or action and asked to imagine how it would feel without actually performing the movement or action.
- **Mirror visual feedback therapy:** A mirror is placed so that the painful limb is hidden behind it and you see only the normal limb and its reflection. The brain processes visual feedback more readily than other senses, so when you move both limbs in the same way, the brain 'sees' both limbs moving easily and painlessly.

i See Arthritis Research UK booklet *Hydrotherapy and arthritis; Physiotherapy and arthritis.*

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Occupational therapy

Your therapist can suggest a range of techniques, but practising these on your own whenever you can will increase the benefit:

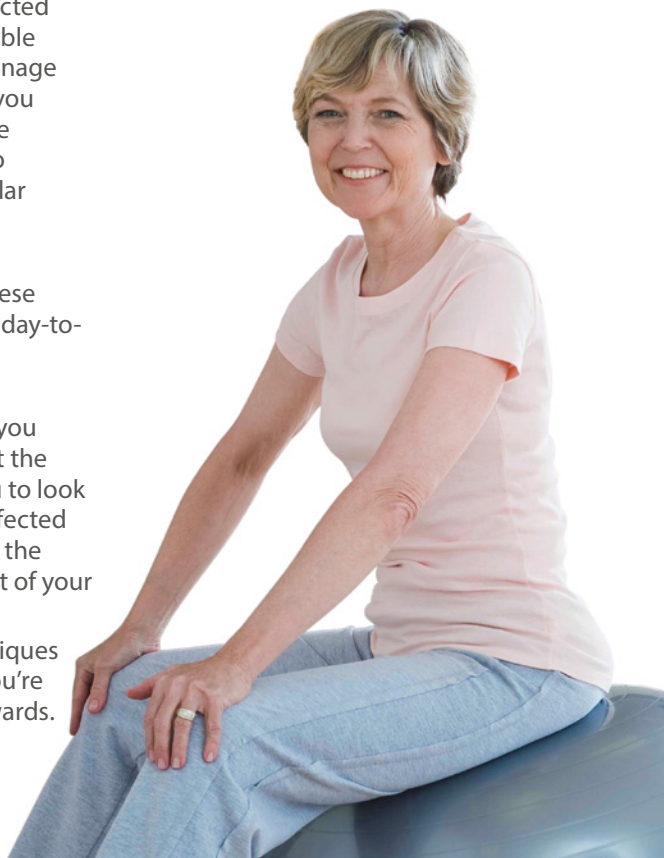
- **Desensitisation** – This is a technique that aims to normalise touch sensations in the affected limb. It involves touching the skin frequently with different-textured fabrics and other substances (for example, wool, silk, cotton wool), gradually working towards the painful areas. It's important to focus fully on the sensation of touching the normal limb and to remember that feeling when you touch the affected limb. Getting as relaxed as possible before starting can help you manage these touches. As you practise, you can start to progress from gentle movements like light stroking to firmer stroking, tapping or circular movements.
- **Relaxation and/or stress management techniques** – These can help in managing pain on a day-to-day basis.
- **Body perception awareness** – This can be especially helpful if you develop negative feelings about the affected limb. It encourages you to look at, touch and think about the affected limb as often as possible so that the limb begins to feel a normal part of your body again.

You may find some of these techniques uncomfortable or painful while you're doing them and for a while afterwards. If any of these activities cause

intolerable pain then try a different one to begin with.


Try to build some of the activities into your everyday life – for example, by concentrating on the feel of the bed sheets or your clothes against your skin or the feel of water on your skin as you shower. If you can, try different water temperatures (cool, warm, hot) and different textures (soft flannel, sponge, 'scrunchy') as you wash.

i See Arthritis Research UK booklet *Occupational therapy and arthritis*.





Your therapists can teach you a range of techniques to improve mobility, function and sensation in the affected limb.



To get the best from these therapies you should try to practise them as often as possible, building them into your everyday life.

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Complex regional pain syndrome (CRPS)

Psychology, education and coping techniques

We know that CRPS isn't 'all in the mind' but long-term severe pain is very likely to affect your mood and can sometimes lead to depression. A psychologist can help you develop coping strategies to help you manage this. This may include stress management and relaxation exercises, cognitive behavioural therapies (CBT), acceptance and learning to ask for support.

Drug treatments

No drugs are specifically licensed in the UK to treat CRPS and no single drug treatment works for everyone with CRPS. However, pain medications can be useful in reducing pain to a level that enables you to begin rehabilitation therapies.

- Anticonvulsants such as gabapentin and pregabalin can help with the symptoms of CRPS by reducing pain signals from the nerves to the brain.
- Pain medications (analgesics) such as paracetamol, tramadol and codeine may play a part in controlling moderate pain – your doctor will advise on the best options for you.
- Pamidronate, a drug used to prevent thinning of the bones, may also provide relief from pain, although the reasons for this aren't fully understood. It's usually given as a one-off infusion into a vein if you've had CRPS for less than six months.
- Tricyclic antidepressants such as amitriptyline, given in low doses, can

also reduce pain signals to the brain and may be helpful if you have trouble sleeping because of pain.

- Other antidepressants, such as duloxetine, also have pain-relieving properties.
- Some pain physicians may suggest steroids (prednisolone).
- Patches filled with lidocaine (a local anaesthetic) may also be used.
- Blocking of the sympathetic nervous system can be carried out using injections of a local anaesthetic – this will be given by an anaesthetist with expertise in pain management.

i See Arthritis Research UK drug leaflets *Amitriptyline; Painkillers.*

Other treatments

Pain management programmes

These are offered in specialist pain centres or clinics, usually on an outpatient basis, though some centres may offer residential programmes. The programmes are group-based and may last for a few days or a few weeks. There will often be people on the programme with other painful conditions besides CRPS. These programmes draw on the skills of a wide range of professionals, including physiotherapists, occupational therapists, pain specialists, social workers and employment advisors, and aim to improve your quality of life.

A pain management programme can help to lessen the impact of long-term

pain, but it isn't designed to take the pain away. Group sessions are often led by psychologists who can offer therapies such as cognitive behavioural therapies (CBT) to help you develop new skills to cope with the pain and the anxiety that it can cause. These skills can often help people through difficult times in their rehabilitation programme.

Spinal cord stimulation

In spinal cord stimulation (SCS), a fine wire is implanted in the epidural space close to the nerves in your back. This is connected to an external hand-held control unit that allows you to control the stimulation. This is usually done for a trial period and if it helps then a battery unit can be implanted in your buttock or tummy. The wire and battery can be removed later on if you no longer need SCS. This treatment is only available in specialist centres for people who haven't benefited from other treatments.

Self-help and daily living

Exercise

Regular exercise is important for your general health. Your instinct may be to avoid exercise if you're in pain, but you should still try to do a little each day in addition to the specific exercises you've been shown for your painful limb. Walking and swimming are good low-impact exercises that will help keep you fit and healthy, maintaining strength and function in the affected limb without putting too much strain on it. Your

physiotherapist will be able to advise you on the best exercise approach.

i See Arthritis Research UK booklet
Keep moving.

Diet

Although there's no direct link between your diet and CRPS, keeping to a sensible weight and eating a healthy, balanced diet is important for your overall well-being. There's some evidence that high doses of vitamin C may reduce the risk of developing CRPS following an operation, and it's been suggested that vitamin C may be helpful in the early stages of CRPS.

i See Arthritis Research UK booklet
Diet and arthritis.

Work

Most people with CRPS are able to continue in their jobs, although you may need to make some alterations to your working environments, especially if you have a physically demanding job. Speak to your employer's occupational health service if they have one, or your local Jobcentre Plus can put you in touch with disability employment advisors who can arrange work assessments. They can advise you on changing the way you work and on equipment that may help you to do your job more easily. If necessary, they can also help with retraining for more suitable work.

i See Arthritis Research UK booklet *Work and arthritis*.

Dealing with stress

Living with a long-term condition like CRPS can lower your morale and may affect your sleep. It's important to tackle problems like these as they could lead to depression and will certainly make the CRPS more difficult to cope with. It often helps to talk about negative feelings, so it could be useful to speak to your healthcare team, or your family and friends. Support groups are also available – your doctor may be able to tell you about organisations in your area.

i See Arthritis Research UK booklets and guide *Fatigue and arthritis; Pain and arthritis*.

Research and new developments

Trials of new medication have included studies looking at strong anaesthetic agents such as ketamine, and medications to block inflammation such as anti-TNF and intravenous immunoglobulins. These have so far only been used on very small numbers of patients and with variable results, so at present they're not recommended for general use.

Glossary

Anaesthetic – a substance that stops you feeling pain. A local anaesthetic only affects the area it's applied to.

Anaesthetist – a medically trained doctor, some of whom specialise in aspects of pain management including nerve blocks and placing spinal cord stimulators.

Cognitive behavioural therapies (CBT)

– a number of psychological therapies based on the assumption that most of a person's thought patterns and emotional or behavioural reactions are learned and can therefore be changed. The therapies aim to help people resolve difficulties by learning more positive thought processes and reactions.

Hydrotherapy – exercises that take place in water (usually a warm, shallow swimming pool or a special hydrotherapy bath) which can improve mobility, help relieve discomfort and promote recovery from injury.

Inflammation – a normal reaction to injury or infection of living tissues. The flow of blood increases, resulting in heat and redness in the affected tissues, and fluid and cells leak into the tissue, causing swelling.

Magnetic resonance imaging (MRI) scan – a scan that uses high-frequency radio waves in a strong magnetic field to build up pictures of the soft-tissue structures and bones. It works by detecting water molecules in the body's tissue that give out a characteristic signal in the magnetic field.

Occupational therapy – a therapy which uses a range of strategies and specialist equipment to help people get on with their daily activities through practical advice on aids, appliances or changing the way you do things.

Osteoporosis – a condition where bones become less dense and more fragile, which means they may break or fracture more easily.

Physiotherapy – a therapy given by a trained specialist that helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

Sympathetic nervous system – part of the nervous system that controls many of the involuntary actions of the body's glands and organs.

T'ai chi – a Chinese martial art that involves a slow sequence of movements and aims to improve balance and strength.

Transcutaneous electrical nerve stimulation (TENS) – a small battery-driven machine which can help to relieve pain. Small pads are applied over the painful area and low-voltage electrical stimulation produces a pleasant tingling sensation, which relieves pain by interfering with pain signals to the brain.

Where can I find out more?

If you've found this information useful you might be interested in these other titles from our range:

Therapies

- *Hydrotherapy and arthritis*
- *Occupational therapy and arthritis*
- *Physiotherapy and arthritis*

Self-help and daily living

- *Diet and arthritis*
- *Fatigue and arthritis*
- *Keep moving*
- *Pain and arthritis*
- *Work and arthritis*

Drug leaflets

- *Amitriptyline*
- *Painkillers*

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You can download all of our booklets and leaflets from our website or order them by contacting:

Arthritis Research UK

Copeman House
St Mary's Court
St Mary's Gate, Chesterfield
Derbyshire S41 7TD
Phone: 0300 790 0400
www.arthritisresearchuk.org

Related organisations

The following organisations may be able to provide additional advice and information:

Arthritis Care

Floor 4, Linen Court
10 East Road
London N1 6AD
Phone: 0207 380 6500
Helpline: 0808 800 4050
Email: info@arthritiscare.org.uk

Action on Pain

PO Box 134,
Shipdham
Norfolk IP25 7XA
Phone: 01362 820 750
Helpline: 0845 603 1593
Email: aopisat@btinternet.com
www.action-on-pain.co.uk

British Pain Society

Third Floor, Churchill House
35 Red Lion Square
London WC1R 4SG
Phone: 0207 269 7840
Email: info@britishpainsociety.org
www.britishpainsociety.org

Complex Regional Pain Syndrome UK Network

www.crpsnetworkuk.org

Disabled Living Foundation

380–384 Harrow Road
London W9 2HU
Phone: 0207 289 6111
Helpline: 0845 130 9177
Email: info@dlf.org.uk
www.dlf.org.uk

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We're here to help

Arthritis Research UK is the charity leading the fight against arthritis.

We fund scientific and medical research into all types of arthritis and musculoskeletal conditions.

We're working to take the pain away for sufferers with all forms of arthritis and helping people to remain active. We'll do this by funding high-quality research, providing information and campaigning.

Everything we do is underpinned by research.

We publish over 60 information booklets which help people affected by arthritis to understand more about the condition, its treatment, therapies and how to help themselves.

We also produce a range of separate leaflets on many of the drugs used for arthritis and related conditions. We recommend that you read the relevant leaflet for more detailed information about your medication.

Please let us know if you'd like to receive an email alert for our quarterly online magazine, *Arthritis Today*, which keeps you up to date with current research and education news, highlighting key projects that we're funding and giving

insight into the latest treatment and self-help available.

We often feature case studies and have regular columns for questions and answers, as well as readers' hints and tips for managing arthritis.

Tell us what you think

Please send your views to:

**bookletfeedback@
arthritisresearchuk.org**

or write to us at:

Arthritis Research UK, Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD

A team of people contributed to this booklet. The original text was written by Dr Rachel Gorodkin, who has expertise in the subject. It was assessed at draft stage by consultant in pain management Dr Dominic Hegarty, consultant rheumatologists Dr Nicholas Shenker and Dr Dipak Roy, lecturer in physiotherapy Joe McVeigh and hand therapy practitioners Jo Ellis and Ellen Bramall. An **Arthritis Research UK** editor revised the text to make it easy to read, and a non-medical panel, including interested societies, checked it for understanding. An **Arthritis Research UK** medical advisor, Dr Mark Lillicap, is responsible for the content overall.

Get involved

You can help to take the pain away from millions of people in the UK by:

- volunteering
- supporting our campaigns
- taking part in a fundraising event
- making a donation
- asking your company to support us
- buying products from our online and high-street shops.

To get more **actively involved**, please call us on **0300 790 0400**, email us at **enquiries@arthritisresearchuk.org** or go to **www.arthritisresearchuk.org**



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