Reflex Sympathetic Dystrophy (Complex Regional Pain Syndrome)

An Information Booklet

About this booklet

This booklet has been produced for anyone interested in finding out more about reflex sympathetic dystrophy (RSD). Many people now prefer the term 'complex regional pain syndrome (CRPS)' to 'RSD'. There are also a number of other names which have been used to describe the condition in different situations, including 'Sudek's atrophy' and 'algodystrophy'. However, the term RSD is still in widespread use, probably because it is much easier to remember and say. So RSD is the term used in this booklet.

We want to explain as much as possible about the condition; how it is diagnosed and how it can be treated. However we cannot hope to answer all your questions. Everyone is different and this booklet is not intended to replace an individual consultation with a doctor.

What is reflex sympathetic dystrophy (RSD)?

RSD is a condition which is not well understood, and is often difficult to diagnose. Its main feature is pain that is persistent and often has a burning quality. Mild forms of RSD are probably quite common: these get better without any special treatment. However, severe forms of RSD can be very disabling and difficult to treat.

What causes RSD?

We do not know. There are probably several factors that are involved, but for the present we do not understand them fully. We do know that certain factors can 'trigger' the development of RSD. For example, it may start after someone has had a fracture or some other injury, although most people injured in this way recover without any complications. At the moment we do not know why some people develop RSD after injuries and others do not.

As well as being a complication of a fracture, RSD can also occur after other problems, such as heart attacks or head injuries. However, some people develop RSD without any apparent underlying cause.

It is thought that a group of special nerve fibres called the 'sympathetic nervous system' is in some way involved in the development of RSD. This system has several functions including the regulation of blood flow and skin temperature. Doctors have found that blocking the action of the sympathetic nervous system can be helpful in people with RSD (this is described later under 'How is RSD diagnosed?' and 'Can RSD be treated?').

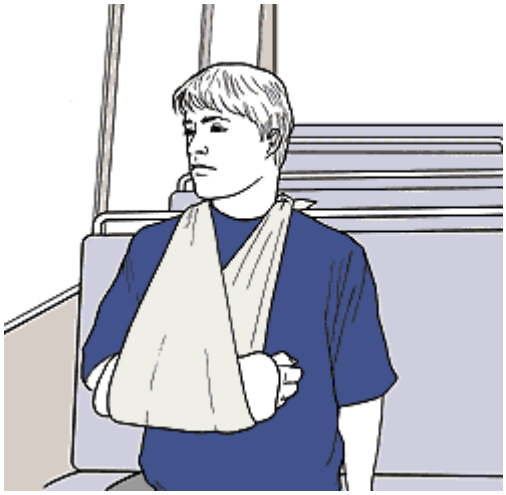

Figure 1. RSD can sometimes start after a fracture.

Who does it affect?

Anyone can be affected by RSD, including children.

Which parts of the body are involved?

The parts of the body most commonly affected by RSD are the hand and wrist, foot and ankle, or the knee. Sometimes a whole limb can be affected. For example, the arm might be painful from the shoulder down to the wrist. Sometimes people who have had RSD in one limb may also develop RSD in another – but this is relatively unusual.

Figure 2. The part of the body affected may be painfully sensitive to touch.

What are the symptoms and signs?

The most usual complaint of people with RSD is pain. Some people with RSD may become frustrated and depressed, particularly if they do not know what is causing the pain. In severe cases RSD can have a profound effect on a person's life – interfering with many of his or her everyday activities. If a diagnosis has not been made, the uncertainty makes it more difficult to deal with.

The area of the body affected by RSD is often very sensitive to touch. Just stroking the affected place can cause severe pain. Also the colour or temperature may be different from the unaffected parts. These changes often vary a great deal. For example, a hand or a foot could initially be warmer than expected, but later in the course of the RSD it becomes colder. Similarly, the affected area could be more red or blue than normal – or may become mottled in appearance. The painful area is often swollen. When RSD has been there for some time the affected part may become weak, making movement more difficult.

How is RSD diagnosed?

RSD is often difficult to diagnose. This is partly because there is no specific 'test' which will define whether or not someone has RSD. Doctors diagnose RSD mainly on the basis of the person's symptoms and the results of a physical examination. However, some tests can be useful:

- An x-ray of the affected part may show thinning of the bone (osteoporosis).
- A bone scan may show abnormality.
- On the whole, blood tests are not useful, but the doctor will probably ask for certain blood tests, mainly to exclude other causes of pain and swelling.
- Sometimes 'blocking' the sympathetic nervous system with a local anaesthetic is used as a diagnostic test (see below). If this 'sympathetic block' eases the pain, then it is likely that the sympathetic nervous system is contributing to the pain.

The blocks mentioned above may not only help to diagnose the condition but also can be helpful in treatment (see below). When a diagnostic sympathetic block is performed and is successful, then the pain relief lasts only a short time. However, at least the doctor will know that it may be worthwhile considering further blocks as part of the plan of treatment.

How long does RSD last?

There is no easy answer to this. If someone has mild RSD, symptoms can settle quickly without any specific treatment. In severe cases, however, RSD can last for months or years. Regrettably, some patients are left permanently with a certain degree of pain and disability.

Can RSD be treated?

Yes, and it is important to begin treatment as soon as the diagnosis is made. The longer RSD lasts, the more difficult it is to treat. Unfortunately, treatment may be delayed because of the difficulties in making a correct diagnosis.

Here are some of the treatments that are most commonly used for people with RSD:

Physiotherapy

Physiotherapy is recommended for most people with this condition and it is often useful in combination with some of the other treatments outlined below. The objective is to keep the affected limb mobile and prevent it stiffening up. However, this can be difficult where there is severe pain.

Sympathetic blocks

As mentioned above, it is thought that the sympathetic nervous system may play a role in RSD. If a patient has benefited from a diagnostic sympathetic block, then further blocks may be recommended. Blocks of the sympathetic nervous system can be either 'temporary' or 'permanent'.

Temporary sympathetic blocks Temporary blocking of the sympathetic nervous system can be carried out using either local anaesthetic or guanethidine (a drug sometimes used for hypertension), both of which are given by injection.

- ***Local anaesthetic blocks*** Local anaesthetic is injected around the sympathetic nerves. If RSD affects the upper limb (hand or wrist), then the injection is made into the side of the neck. If RSD affects the lower limb (foot, ankle or knee), then the injection is made into the flank (the side). The procedure is carried out by a doctor experienced in this technique, usually an anaesthetist. If the block is successful, then its effect will be apparent within a few minutes.
- ***Guanethidine block*s** A tourniquet is applied to the limb and guanethidine is injected into a vein. This acts to suppress the activity of the sympathetic nervous system. Guanethidine blocks are much less commonly used than local anaesthetic blocks.

Both these techniques are called 'temporary blocks' because they do not last long. Providing improvement occurs, further blocks may be given at intervals as a course of treatment. Alternatively the doctor may recommend a 'permanent block'.

Permanent sympathetic blocks A permanent block of the sympathetic nervous system may be performed either surgically or by injection. However, before recommending one of these procedures the doctor will consider the potential risks as well as the potential benefits.

Other treatments

A variety of other treatments (mainly tablets) have been suggested for RSD. Unfortunately none is uniformly successful. Some people with RSD find that using a transcutaneous electrical nerve stimulator (TENS or TNS) machine helps. A

physiotherapist will usually loan you a TENS machine and only recommend buying one if it is definitely helpful.

Conclusion

The cause of RSD is not fully understood. There are treatments which can be helpful, but research being carried out now should enable doctors to offer better ways of dealing with the condition in future.