

PRESS RELEASE

RSD Awareness Week

1st week November 2002

Most people feel the pain before they know the words. It starts with a minor accident or surgery but can result in permanent pain and paralysis. It was first recognised during the American Civil War, but few doctors and even fewer nurses recognise the symptoms. It is called Reflex Sympathetic Dystrophy and it hurts.

RSD Awareness Week is a joint effort by Support Groups, Websites and individuals across the world. In the UK these groups are working together under the banner of RSD UK Alliance. Efforts in the USA are being led by RSD Association of America and by RSD Hope. Other groups are working in Australia and New Zealand in collaboration with their counterparts in the Northern Hemisphere. The aim of RSD Awareness Week is to focus the attention of the medical profession, the media and the public on this poorly understood chronic pain condition. Greater awareness will result in people seeking treatment earlier, (which increases the chance of recovery) and will help those who already suffer RSD pain and disability.

What can YOU do to help?

Include a feature or interview about RSD. Relate stories from people who have the condition and from their carers. Draw attention to the risk for active people and others who may suffer minor injuries. We are not looking for money, but increased awareness for the sake of current and future sufferers. Twenty years ago, people with dyslexia or ME faced problems due to lack of awareness and understanding... RSD is still at that point today, and we want this situation to change.

What is RSD?

Reflex Sympathetic Dystrophy is a painful reaction to minor trauma that makes the pain increase though the original injury seems to have healed. In some cases it is possible to identify specific nerve damage, but many people who experience this pain have no clear medical explanation of why they are suffering. It is believed to be a fault in the Sympathetic Nervous System, which is the body's inner messaging system for pain and healing.

Who is at risk from RSD?

Anyone who is at risk of injury. It affects women more than men and commonly strikes fit, active, healthy people - people who have always considered themselves fit, but suddenly find their life changed forever. About 5% of people who break an arm, leg, wrist or ankle may present with RSD symptoms. People who receive surgery to an ankle or wrist (e.g. treatment for carpal tunnel syndrome) are also at high risk of developing RSD.

How does anyone know if they have RSD?

The principal indicator for an RSD diagnosis is intense pain in the area surrounding the original injury (usually an arm, hand, leg or foot). Patients normally describe the pain as "burning". The area is likely to be swollen and the skin surface may be shiny and bluish-red in colour. Sometimes the area shows unusual hair growth (typically coarse black hairs) and the growth of toe and fingernails may be unusual. Surface temperature may be erratic (sometimes warmer and

sometimes colder than the unaffected limb). The affected extremity may also seize up (become paralysed) and the pain can spread to other parts of the body

What does RSD pain feel like?

Patients' experience varies, but the most common word they use to describe the pain is "intense burning". It has been described as "one of the most exquisite pains known to man" and is intense and persistent.

Does RSD have other names?

Yes. The new medical name for RSD is Complex Regional Pain Syndrome (CRPS) with two sub-classifications, depending whether specific nerve damage can be identified (CRPS Type 2) or not (CRPS Type 1). Other terms related to this condition are Causalgia, Sympathetically Maintained Pain (SMP) and Sudecks Atrophy.

What treatments can help RSD sufferers?

The first stage of treatment offered is usually physiotherapy, which has its best chances of success in the first three months after onset. If diagnosis is delayed this inexpensive solution becomes less effective, whereupon treatment focuses on pain management. A wide range of pain-killing and anti-inflammatory drugs may be prescribed and, increasingly since their recent discovery, drugs normally used for epilepsy may be tried because of their effect on the nervous system. Several forms of surgically implanted pain-control devices may also be offered. In extreme circumstances surgery may be offered to destroy the nerves in the painful region. Recent publicity has been given to Hyperbaric Oxygen Therapy for RSD sufferers (in oxygen chambers as used for aqualung divers who have "the bends").

Is RSD curable?

It is not possible to give a definite answer. Children seem to respond to treatment more readily and many seem to have been cured. Adults have their best chance of success in the first three months following onset of the pain; but "remission" is the term normally applied to adults who recover from this condition. RSD seems still to lurk in the background for those patients and further injury may cause the aggressive return of the pain. Patients whose diagnosis is delayed, or those whose early treatment is unsuccessful for whatever reason, are likely to be in pain for the rest of their lives and may be more drastically disabled.

Internet power

The campaign for RSD Awareness sprung into new life with the growth of the Internet. Already identified for over 150 years, RSD received little attention from most medical professionals and almost none from the drugs industry. The worldwide web gave power to the patients, who found a new way to contact each other and develop the campaign from bedrooms and front rooms around the world. Dedicated individuals developed websites and formed support groups, meeting on-line or, where possible, in real meeting rooms and conference centres. They discovered they were not such a minority and began to raise their voices.

RSD Awareness Week 2001

This is the second RSD Awareness Week. Last year's campaign produced more publicity for RSD than had ever been seen before. Patients and carers appeared on numerous radio stations, in newspaper and magazine articles - and leaflets were mass-mailed to doctors' surgeries. The week was a success - but only a start. Please support our campaign to raise awareness even more in 2002 and bring forward the time when every new sufferer will be correctly diagnosed from the start - and be rescued from unnecessary pain.