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Introduction

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Although reflex sympathetic dystrophy syndrome (also referred to as RSDS and RSD) is relatively unknown, it is not a new condition, and many will agree that it is no longer considered a rare disorder. Between 1 million and 6 million men, women and children in the United States have been diagnosed with RSD. Historical accounts indicate that the first cases of RSD date back to the Civil War. In 1864, a condition of hot, burning pain, known as “causalgia,” was first described by soldiers who had suffered gunshot wounds.

In addition to causalgia, RSD is also known as Sudeck’s atrophy, post-traumatic neuralgia, and shoulder-hand syndrome. All of these names are used interchangeably, adding to the confusion in diagnosing and treating RSD. In 1995, specialists held a workshop to discuss RSD. They agreed that it was possible that what was called RSD might actually be two or more separate conditions with similar symptoms. The committee recommended that the name be changed to complex regional pain syndrome (CRPS), Types I and II, in an attempt to further clarify diagnosis of the disease. CRPS I is frequently triggered by tissue injury and presents the following symptoms, but with no underlying nerve injury. Patients with CRPS II experience the same symptoms, but their cases are clearly associated with a nerve injury.

What is RSD?

RSD is a chronic pain disorder. Common symptoms include intense burning pain, extreme sensitivity to touch, swelling, sweating, and changes in the color and temperature of the skin over the affected limb or body part. Some experts believe that RSD is an exaggerated response of the sympathetic nervous system, and there are no studies that show RSD affects a person’s life span. In advanced stages of the illness, patients may experience significant psychological problems, develop dependency on narcotics, and be completely physically incapacitated by the disease.

Causes of RSD

The etiology, or cause, of RSD is most commonly a trauma or injury to an extremity, although it can affect any part of the body. The trauma does not have to be severe. Unfortunately, something as

common as a sprained ankle or even a sliver in a finger can lead to this potentially disabling and lifelong problem. Other possible causes include a heart attack, infection, surgery, and repetitive motion disorders. In some patients, an exact cause cannot be identified.

Signs and Symptoms

The first symptom associated with RSD is pain, usually described as a constant burning or deep aching pain. It progresses into severe chronic pain, and swelling usually occurs in the injured extremity. At this point, the edema is localized and the skin is very tender to the touch. Diminished motor function and a decrease in muscle strength are associated with the joint in the extremity. Tremors and muscle spasms may also be present. Over time, the skin may appear to have atrophied, and changes in the nails will begin to occur. Most patients experience a significant difference in the temperature of one limb compared to the other. Osteoporosis may be noted on bone scans and, as swelling in the injured area becomes pitted, chances for skin infections increase. In some cases, these symptoms spread to other extremities where no injury has occurred and the disorder becomes much more difficult to manage. The spread to areas that have not been injured adds to the difficulty of diagnosing and treating RSD for a physician who is unfamiliar with this common characteristic.

Diagnosis

The diagnosis of RSD is reached by ruling out other diseases through a process of elimination, and it requires a complete medical history and a physical and psychological evaluation. There is no single laboratory test for RSD, but some tests help to confirm a diagnosis. A thermogram is a noninvasive means of measuring heat emission from the body surface using a special infrared video camera. It is one of the most widely used tests in suspected cases of RSD, but these test results alone are still not conclusive for a diagnosis. Injected sympathetic nerve blocks help determine what portion of the patient's pain is being caused by a malfunction of his or her sympathetic nervous system. A good sympathetic block should increase the temperature of the extremity without producing increased numbness or weakness. This ensures the doctor that only the sympathetic nerves were blocked so a careful evaluation can be made of how much the pain has decreased or not changed at all.

Although the results of X-rays, electromyograms (EMG), nerve conduction studies, CAT scans and MRI studies may be normal in RSD, they help to identify other possible causes of pain. Any other medical problems must be identified and treated because RSD may be a factor in another disease or condition such as a heart attack, carpal tunnel syndrome or a broken bone. Many times, a dual diagnosis is missed because the doctor has identified the primary problem or disease and does not continue to look for any other affliction, such as RSD

Treatment

Because this condition is so complex, the patient may require care from any combination of healthcare providers, including a pain specialist, an internist, a neurologist, an orthopedist, a psychiatrist, and a physical therapist, depending on the severity of the case and other conditions that are present.

Medications such as analgesics, muscle relaxers and narcotics are used. Sympathetic nerve blocks help to relieve pain and increase blood circulation. Morphine infusion pumps have also been used to alleviate pain, and spinal cord stimulators implanted under the skin of the spine send out electrical signals to block pain. Physical therapy and rehabilitation to increase joint function and range of motion should be used throughout all stages of this condition. One of the most important things for a patient to do is to stay active and keep the extremities as mobile as possible. Daily exercise should always be part of the pain management program. Psychological counseling is also important.

RSD is very frustrating for the patient and the medical team because it changes and spreads, causing new symptoms to appear. For some RSD patients, the pain expressed is radically out of proportion to the type of injury they have, and it is not uncommon for them to be told that the problem could be psychological.

The opportunity for early aggressive and productive treatment is often lost as healthcare providers focus on the mental state of the patient, who may be understandably demonstrating signs of depression and anxiety due to severe pain and uncertainty about what is happening to him or her. Although psychological support is beneficial, a barrier can develop between patients and others if patients feel that others do not understand their pain or do not believe that it is as intense as they say.

Even when recognized and treated, RSD can progress and lead to a life of long-term disability with unremitting pain, muscle weakness, and loss of mobility due to permanent deformities. There have been cases of limb amputation from severe pain or life-threatening infections; however, the RSD can still spread to other areas even after the affected limb has been removed.

Coping with RSD

Imagine having a disease that many doctors still have not even heard of and have no experience treating. Try to explain how a normal bruised foot from a falling drawer can lead to both legs being extremely swollen, very cold and bluish in color, and feeling so weak that you can't even stand on them. The pain is so intense that even oral morphine does not take it away, so you can't sleep very well, you can't work, and you are having financial difficulties. And as the doctor is trying to figure out what is going on and how to treat it, your hand begins to start burning and becomes swollen and cold. Family members and friends are having a hard time trying to understand what is happening, and some may even turn away from you because you are overwhelmed and depressed.



The woman in the photographs knows a great deal about some of these things. She bumped her lower back on a table at work in 1994. RSD was not identified for a year so there was no treatment and no validation of what caused such horrible pain down her left leg that it felt as if it were immersed in scalding water.

It was hard for doctors to believe that such a small injury to her back was the catalyst for all of the problems in her leg and foot. As the years went on, the woman developed deformity in her leg, chronic inflammation and total immobility. Once there was a diagnosis, she was not responding to the treatment because the disease had progressed to involve the muscle, skin and circulation. The skin on her leg was characteristically red and shiny, and the pain was extreme and unrelenting.

After a very painful procedure known as an electromyogram, her foot developed massive swelling, eventually leading to a very severe infection and destruction of the skin tissue on her left foot. In December 2002, the woman's leg was amputated above the knee.

Because of the hypersensitivity caused by RSD, she cannot wear a prosthesis. Unfortunately, she now has problems in her other foot and leg as well as in her right hand because the RSD has spread. This woman's experience with some doctors not knowing much about RSD and others not believing that her pain was as bad as she claimed in the beginning is not uncommon for RSD patients. Many times, patients are told that it's just "all in your head."

Support Organizations

Many RSD support groups can be found online and are located in many cities across the United States. These groups offer RSD patients a chance to find information and emotional support. Nonprofit RSD organizations present national conferences, disseminate information, maintain web sites, and present periodic medical conferences.

Research

The National Institutes of Health is currently conducting clinical trials for the treatment of early CRPS I and II. University medical centers and private laboratories are also involved in sponsored and

independent research studies. Today, there is greater hope for advances in treatment and, ultimately, a cure for RSD.

□ Resources

The International Research Foundation for RSD/CRPS

<http://www.rsdfoundation.org>

National Institutes of Health, Diseases and Strokes

<http://www.nih.gov>

Reflex Sympathetic Dystrophy Syndrome Association of America

<http://www.rsds.org>

□ About the Author

Alfie Burns is the founder and president of the Reflex Sympathetic Dystrophy Syndrome Association of California. She became afflicted with RSD after stepping on a stone in 1984. A simple bone spur led to over 25 operations on her left foot and lumbar sympathetic nerves. Muscle atrophy in the leg muscle and extreme edema made walking very difficult. A skin infection on the foot almost resulted in an amputation. In 1990, implantation of a morphine infusion pump in her abdomen provided about 40 percent reduction in pain and some improvement in the circulation in her legs. This treatment continued, and, in 2002, Burns began an aggressive exercise program to help strengthen her legs. Today, the RSD is more in control with two to three hours of daily exercise. Endorphins and the infusion pump therapy help her manage the pain and keep her legs mobile. Without the aggressive exercise, the leg muscles quickly begin to weaken.

Ed Note: While we recognize that the name “reflex sympathetic dystrophy” has been changed to “complex regional pain syndrome”(CRPS), Types I and II, the term “RSD” is still commonly used by most people.