What is CRPS/RSD?

Complex Regional Pain Syndrome (CRPS) or Reflex Sympathetic Dystrophy (RSD) are diagnostic terms for extreme pain resulting from the nervous system going amiss.

This chronic systemic disorder results from a malfunction of the peripheral nervous system. The filter that normally tells the nerves that healing has taken place fails. The nerves continue sending pain messages long after the initial injury has healed. They begin increasing the number of pain messages and the pain worsens as time passes. It is similar to a computer that has gone haywire and will not shut down.

CRPS can stay localized in the area of the original injury; it can become bi-lateral or shift to the same area on the opposite side of the body; and it can spread to other areas not associate with the original injury. **The severity of the disorder varies from person to person.**

CRPS is divided into two types that are differentiated by the absence or presence of direct nerve damage. Most CRPS cases are Type I, but the symptoms and treatments for both types of CRPS are the same.

Type I — Pain that develops after an event in which no direct nerve damage is identifiable i.e., a twisted ankle, broken bone or a simple paper cut.

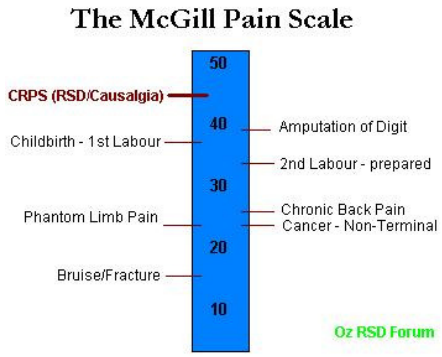
Type II— Pain that develops after an event that results in direct nerve damage, i.e., war wound, a car accident, or surgery.

Symptoms of CRPS. . .

- Intense "burning" sensation under the skin
- Increased skin sensitivity
- Heightened senses to sound, light, smell, touch, i.e., a slight breeze
- Changes in skin temperatures—warmth radiating or cold to touch (actual body temperature is normal)
- Changes in skin color—shiny, blotchy, matte white, pale, flush, red or purple
- Changes in nail and hair growth patterns – nail ridges, and/or thinning, darker, courser hair
- Swelling and stiffness in affected joints
- Motor disability, with decreased ability to move affected body part(s)
- Tremors and abnormal movement in effected limbs
- Abnormal sweating

The Burning Pain of CRPS

There is no pain as severe, intense and deep as that of CRPS. A filter on the spine has failed to monitor the messages appropriately. As the nerves continue to send pain messages, the number of neurotransmitters and receptors begins to increase along the nerve highway, causing an escalation in the number of pain messages and an intensification the sensations. As the disorder progresses the pain, perceived as a burning sensation, heightens beyond all other disorders. The McGill Pain Index is used to assess/compare pain levels of various disorders.



CRPS registers at 42+, the highest on the McGill Pain Scale and continues 24 hours a day, 7 days a week. Compare this to an amputation of a finger or toe which rates at 40. In 2-6 weeks, you will have a stub, but no pain. Childbirth falls between 35-39 on the scale. In 3-48 hours, you are handed a bundle of joy and a new set of issues, but the pain will be gone. Fibromyalgia is found in the 30s. It is often a disease concurrent with CRPS, heaping pain on pain.

In short, **CRPS ranks the highest on the pain scale of all disorders and is continuous**. Those affected by it often can find no relief from this intense pain. The pain is not created in the head, rather it is an interaction between the nerves and the brain as the central manager of the system. However, it definitely affects the mind and the emotional state of the person. The inescapability of the pain often leads to depression, sleep disturbances, anxiety and, sometimes, even suicidal ideation.

Who gets CRPS

CRPS can be triggered by something so simple as a paper cut or horrific as a war wound. The most common causes are sprains and surgeries. There is some indication that a genetic predisposition may exist. **CRPS is a rare disorder** with approximately 1.5—3 million (.5—1%) people in the United States having it. Women are three times more likely than men to get CRPS. The average age is 40 with children and the elderly the least likely age groups.

Diagnosis of CRPS

There is no specific list of symptoms or tests to use in the diagnosis of CRPS nor are there any pathognomonic clinical features that identify the disorder. The difficulty in identifying CRPS is further complicated by the lack of education available in the medical field with doctors getting an average of 5 hours related to pain. Both issues hamper a successful cure, since there is only a 3-6 month window open after onset in which treatment can attain full remission.

Diagnosis is secured through a thorough study of the medical history and clinical examinations supported by laboratory findings. Not one of these is definitive and often a lot of "ruling out" is done in the process. Two of the most important aspects of the process are: 1) the doctor's willingness to listen to the patient, not automatically assigning the pain to a mental creation; and 2) his/her knowledge concerning pain and its ramifications since doctors get an average of 5 hours education in pain management.

Treatment of CRPS

CRPS treatment is a multifaceted process, involving pain management, physical therapy, occupational therapy, and psychotherapy. **The severity of the case, which varies from person to person, and the uniqueness of each person dictates the treatment plan.** What works for one person does not necessarily work for another person.

The first and foremost objective in dealing with CRPS is to reduce the pain and get it under control. Medications such as non-steroidal and anti-inflammatory drugs (NSAIDs), oral corticosteroids, blood pressure medications, anti-convulsants are early first line medications. Anti-anxiety and anti-depressants as appropriate are important to reduce the stress which can exacerbate the pain cycle.

Opioids, i.e., ketamine, are administered further along in the treatment process. Ketamine infusions slow or stop the nerve process giving the nervous system time to reset itself. These can come in low dose or high dose infusions for 5-10 days and for some advanced cases high dose 20 day infusions. In special cases, a ketamine coma may be induced for 7 days during which the nervous system will reset itself, returning the system to normal. These comas are not done here in the United States. One must travel to Mexico or Germany to obtain this treatment. (Note: Studies have shown that dependence on an opioid drug to reduce pain is different than addiction to the drug. In one study, 99% of those using opioids weaned themselves from the drugs with no evidence of addiction, belying a major fear of their usage in medicine.) continued on next page. . .

History of CRPS

Silas Weir Mitchell first described CRPS in a treatise concerning sympathetically maintained pain during the Civil War. Later, he elaborated on what he called *causalgia* in his book *Injuries of Nerves and Their Consequences* (1872).

Rene Leriche treated WWI soldiers who had nerve damage, documenting the classic signs of CRPS and noting its sympathetic nerve aspect.

The German doctors, Paul Herman Martin Sudeck and Robert Keinbock, explored the atrophying and inflammation that occurs as the disease advances.

Expanding the connections to include higher cortical centers of the brain and emotional factors, William Livingston worked with WWII patients, emphasizing the multifaceted aspects of CRPS.

With each new advance came a new name, i.e., Mitchell's causalgia, Sudeck's dystrophy, limb dystrophy, reflex and sympathetic were combined into reflex sympathetic dystrophy (RSD). In 1999, the International Consensus Conference ended the confusion by combining all the names given to the disorder under one umbrella name — *Complex Regional Pain Syndrome* (CRPS).

Treatment continued. . .

Several mechanical devices can be implanted within the nervous system to aid with pain reduction and control. Sympathetic nerve blocks are sometimes used to disrupt the nervous system. Spinal cord stimulators can be implanted along the spinal cord, delivering mild electric impulses to the affected nerves. Pain pump implantations can also be inserted to deliver medication.

Any medicinal procedure needs to be augmented by physical/occupational therapy directed at functional restoration of the affected areas. In combination with the appropriate medications, they may work by "resetting altered central processing and/or normalizing the distal environment." They are based on a progression from very gentle contact and movement to more normal active contact and movement, gradually desensitizing the impacted limbs.

Psychotherapy provides an avenue to address any Post Traumatic Stress from the original injury. Beyond that psychotherapy provides a means to deal with the feelings resulting from the continuous, extreme pain. Suicide ideation can become an issue, appearing as an answer of escape. Psychotherapy also helps the patient to deal with the ups and downs of the treatment process. Through psychotherapy the patient can learn to let go of their identity as being the sickness and move out into the world once again. Finally, psychotherapy can help the family to let go of the sickness. CRPS tends to define the whole family becoming all consuming.

Organizations

American RSD Hope
P.O. Box 875
Harrison, ME 04040
207-583-4589
rsdhope@roadrunner.com
http://www.rsdhope.org

International Research Foundation
1910 East Busch Boulevard
Tampa, FL 33612
813-907-2312
info@rsdfoundation.org
http://www.rsdfoundation.org

NIH Neurolopgical Institute
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424 or (301) 496-5751
http://www.ninds.nih.gov/disorders_reflex_sympathetic_dystrophy/reflex_sympathetic_dystrophy.htm

PARC (Promoting Awareness of RSD/CRSP in Canada)
P.O. Box21026
St. Catharines, Ontario L2M 7X2, Canada
905-934-0261
carlayoung74@hotmail.com
http://www.rsdcanada.org/parc/english/

RSDSA (Reflex Sympathetic Dystrophy Syndrome Association)
P.O. Box 502
99 Cherry Street
Milford, CT 06460
203-877-3790 or 877-662-7737

Articles/Videos

R.N. Harden, et. al. (2013) "Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines 4th Edition". http://www.rsds.org/pdfsall/CRPS-guidlines-4th-ed-2013-PM.pdf

J. Lohnberg, et. al. (2013) "A Review of the Psychosocial Factors in Complex Regional Pain Syndrome". *Journal of Clinical Psychology in Medical Settings.* 20:2. 247-254.

Mayo Clinic. (2011) "Complex Regional Pain Syndrome". http://www.mayoclinic.com/health/complex-regional-Pain-syndrome/0500265

Joshua Prager. "Recent Advances in Complex Regional Pain Syndrome" . http://qqq.youtube.com/watch?v=jLUQpa2Kf8

Josua Prager. "Imagine new information on neuropathic pain". http://qqq.youtube.com/watch?v-OvsztVTdA

R. J. Schwartzmann. (2012) "Neuroscience and Medicine." *Journal of Neuromedicine.* 3:3. 225-242.

R. J Schwartzmann. (2009) "Natural History of Complex Regional Pain Sydrome". *Journal of Pain*. 25:4. 273-280.

See above organizations for additional references.

"no pain as severe or deep"

CRPS/RSD

Complex Regional Pain Syndrome

aka

Reflex Sympathetic Dystrophy

"Perhaps few persons who are not physicians can realize the influence which long-continued and unendurable pain may have on both body and mind. . . Under such torments the temper changes, the most amiable grow irritable, the bravest soldier becomes a coward. . .Nothing can better illustrate the extent to which these statements may be true than the cases of burning pain, or, as I prefer to term it, Causalgia, the most terrible of all tortures which a nerve wound may inflict." (Silas Weir Mitchell, M.D. *Injuries of Nerves and Their Consequences.* Philadelphia: J.B. Lippincott, 1872.)

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