OTHER HELPFUL PUBLICATIONS AND VIDEOS YOU CAN ACCESS ON OUR WEBSITE OR BY CONTACTING RSDSA

- **Dental Guidelines for the CRPS Patient: Handle with Care!**
  Planning a dental procedure? Please read and share with your dental professional.
- **Emergency Guidelines for the CRPS Patient: Handle with Care!**
  This sheet contains patient tips and hospital procedures for an emergency room protocol for the CRPS patient. Included are hospital procedures, how to take blood pressure and pulse rate, transport, and identify CRPS patient. Don't leave home without it!
- **Hospital Guidelines for the CRPS Patient: Handle with Care!**
  The document lists over two dozen specific suggestions for a care plan in areas including: setting up the patient room, performing medical procedures, taking blood pressure and pulse rate, transporting, feeding, and identifying CRPS patients.
- **Guidelines for Health Care Aides, Personal Care Assistants, and Certified Nurse Assistants**
- **I Have CRPS Cards**
  This card describes CRPS from the point of view of a person with the syndrome and some suggestions on how others might help. Cards are free. We only ask for a small good-will donation to defray costs and to support our mission.
- **An excellent Guide on Functional Rehabilitation for CRPS**
- **A video on desensitization with CRPS**
- **The experience of having CRPS and the need for early diagnosis and treatment: a video for friends & family.**
- **A video on brain retraining and mirror therapy.**
- **A video on Aqua Therapy: a key ingredient in treating CRPS.**

rsdsa
SUPPORTING THE
CRPS COMMUNITY

RSDSA is committed to assisting those who suffer from CRPS as well as the people who support them.

RSDSA offers hope and emotional, financial, educational, and medical support to people suffering with CRPS. Please contact our organization.

Join us and receive our informative monthly digital newsletter free.

WE ARE HERE TO SUPPORT YOU

- YOU ARE NOT ALONE -

Reflex Sympathetic Dystrophy
Syndrome Association
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Milford, CT 06460
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Toll Free: 877.662.7737
Fax: 203.882.8362
Email: info@rsds.org
Website: http://rsds.org

Raising awareness of CRPS since 1984

COMPLEX REGIONAL PAIN SYNDROME

THE FACTS

WHAT IS CRPS?

CRPS, formally known as reflex sympathetic dystrophy (RSD) is a complex, rare pain syndrome characterized by intense, persistent pain associated with changes in the peripheral and central nervous system. There are two types: Type 1- no major nerve injury and Type 2-dectectable peripheral nerve injury.

WHAT CAUSES IT?

It generally occurs after trauma such as fracture, surgery, a crush injury, sprain, and in a small number of cases, there is no known trauma. Although we do not know why one individual may develop CRPS while another who sustains the same injury and does not; however research into CRPS, and consequently our understanding of the condition have both grown extensively in the past 20 years.The trauma causes the sympathetic nervous system and the immune system to malfunction—the nerves throughout the body misfire, overwhelming the brain with pain signals.

WHAT ARE THE EFFECTS?

Although CRPS is classified by the McGill Pain Index as the most painful condition, most individuals with CRPS can improve with appropriate interdisciplinary treatment. In one large (n=102) retrospective longitudinal study of patients who had already experienced CRPS for at least a year, 30% of patients reported resolution of chronic CRPS, 54% reported stable symptoms, and 16% reported progressive deterioration over the subsequent six years.

WHO CAN DEVELOP CRPS/RSD?

Anyone. Children and adults. Two retrospective population-based studies have assessed the incidence of CRPS in the general population. Both found that it is three to four times more common in women than in men, more commonly affects the upper limbs, and peaks in incidence at 50-70 years of age.

WORKING FOR A CURE

Since the Federal Drug Administration classified CRPS as a rare disease, RSDSA has been even more committed to supporting those in the CRPS community.

In 2014, RSDSA established the International Research Consortium, uniting forty participating research sites and specialists worldwide. By pooling their coniderable resources, the IRC will facilitate RSDSA's mission to develop better treatments for the disease and ultimately a cure.

COMMON SYMPTOMS

- Pain described as deep, aching, burning, or stinging
- A prior trauma (fracture, sprain, surgery, etc.)
- Abnormal swelling
- Excessive sweating in the affected area
- Changes in skin color
- Noticeably altered skin temperature (increased or decreased) in the affected limb
- Weakness of affected limb
- Limited range of motion
- Paralysis or dystonia (muscle contractions resulting in abnormal positions)
- Allodynia (pain from stimuli that are not normally painful, e.g., the touch of fabric or the wind blowing)
- Hyperalgesia (excessive sensitivity to pain)

THE RIGHT TREATMENT

CRPS is a multifaceted medical condition best managed by an interdisciplinary team coordinated by a physician or pain specialist with a special interest and experience in treating CRPS. You must become the "captain" or CEO of your team. Although no one treatment works for everyone, remain hopeful. Your first step is to educate yourself. RSDSA's website has a very informative section, Diagnosed: Now What? Learn about current research especially about neuroplasticity by visiting https://noigroup.com, The Retrain Pain Foundation - MOVE Pain Care, and www.curablehealth.com

An interdisciplinary team typically includes physical and/or occupational therapists (ideally, trained in Graded Motor Imagery), pain psychologists especially trained in cognitive behavioral therapy and current neuroscience of pain, anesthesiologists, or interventional pain specialist (when warranted), and your support people. Your treatment goal is to reduce your pain while focusing on improving function.

Treatments may include medications especially corticosteroids during the acute phase (first six months), topical medications, oral medications, warm-water therapy, physical and occupational therapies, pain-focused psychological interventions, virtual reality, acupuncture, biofeedback, an anti-inflammatory diet, participation in a virtual or face-to-face support group, and more invasive treatments such as, nerve blocks, intrathecal drug infusion, neurostimulation, IV ketamine or IVIG infusions.
If you are unsure of the evidence for a particular therapy, visit https://pubmed.ncbi.nlm.nih.gov/ or, https://rsds.org/wp-content/uploads/2022/06/CRPS-practical-diagnostic-treatment-guidelines-5-edition.pdf. Investigate whether there is a CRPS clinical trial by visiting https://clinicaltrials.gov.

THE DIAGNOSIS

There is no definitive diagnostic test for CRPS. Only a careful exam and review of medical history can produce the proper diagnosis.