



Welcome to RSDSA,

RSDSA is celebrating its 40th year of service to the CRPS community. It is our honor to provide support, education, and hope to everyone affected by CRPS while we drive research to develop better treatment and a cure.

We invite you to join our community dedicated to working for you and your future.

I recommend you sign up for our free electronic e-Alerts if you haven't done so already at rsds.org join in order to receive our In Rare Form electronic newsletter, information on upcoming RSDSA fundraisers, and our frequent online educational presentations.

Please connect with RSDSA on social media. You can find us on Instagram via the handle [@rsdsa_official](https://www.instagram.com/rsdsa_official), on Facebook at [@RSDSA](https://www.facebook.com/RSDSA) and X (formerly Twitter) at [@RSDSA](https://twitter.com/RSDSA). We also have over 250 educational videos on our [YouTube channel](https://www.youtube.com/channel/UC...).

RSDSA has state-specific listings of healthcare professionals interested in treating CRPS. Please call us to obtain a list for your state. If you need a support group, visit rsds.org/community/support-groups.

You are not alone in your fight against this horrific disorder. Please donate to RSDSA today online at rsds.org/donate, by using the enclosed envelope, or by calling us at 203.877.3790. **If you choose not to join our community, please consider making a good-will donation to cover the cost of this mailing. We will not sell or rent your name.**

Sincerely,

Sharon Weiner
Executive Director

**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

99 Cherry Street
PO Box 502
Milford, CT 06460
Tel: 203.877.3790
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-detectable 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 considerable 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://rds.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.

Resources for the Newly Diagnosed

How CRPS is Diagnosed

<https://rds.org/living-with-crps/how-crps-is-diagnosed>

Post-Diagnosis Steps

<https://rds.org/living-with-crps/post-diagnosis-steps>

RSDSA Publications and Brochures

<https://rds.org/media>

RSDSA News and Blog Updates

<https://rds.org/news>

Case Report: Early Treatment of Acute Complex Regional Pain Syndrome after Fracture or Injury with Prednisone: Why Is There a Failure to Treat? A Case Series

<https://rds.org/wp-content/uploads/2020/05/Early-Treatment-of-Acute-CRPS.pdf>

Complex Regional Pain Syndrome – What To Do About It

<https://rds.org/complex-regional-pain-syndrome-brady>

How to Obtain the Best Medical Care for CRPS

<https://rds.org/how-to-obtain-the-best-medical-care-for-crps>

Tips for Managing Complex Regional Pain Syndrome

<https://rds.org/wp-content/uploads/2014/12/Tips-for-Managing-Complex-Regional-Pain-Syndrome.pdf>

Videos from the RSDSA YouTube Channel

The Experience and Impact of Having CRPS and the Need for Early Diagnosis & Treatment

<https://www.youtube.com/watch?v=b49DtFigbbw>

A great video for family and friends who may not understand CRPS

Videos from our 2025 RSDSA Conference

<https://www.youtube.com/playlist?list=PLY7ORLsaAjGARutYEZ8jRXYCaql0VBHGj>

Our 2025 Q&A with Dr. Philip Getson

<https://www.youtube.com/live/1xKGOizli4E?si=spf4MvFUV0m495ax>

You can find numerous videos from Dr. Getson on the RSDSA YouTube Channel



Hospital, Emergency Room, and Urgent Care Guidelines for CRPS Patients - *Handle With Care!*

Complex Regional Pain Syndrome (**CRPS**), previously known as Reflex Sympathetic Dystrophy (**RSD**), is a neuro-inflammatory condition causing the nervous and immune systems to malfunction, sending constant pain signals to the brain. **CRPS** is characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rates CRPS higher than childbirth, amputation, and cancer pain. Those with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, and needle sticks.

Tips for Patients

Carry a copy of RSDSA's Hospital/Emergency Room and Dental Guidelines, along with the "I Have CRPS" card, to educate practitioners.

- Have your health insurance information handy
- Have a list of **ALL** allergies, medical history, and physicians treating you
- Have a copy of **ALL** medications, including dosage and frequency prescribed, vitamins, over the counter medications, and/or compounded specialty medications as some may not be on hospital formulary. Bring your medications with you as well
- Have a list of **ANY** active implantable medical device (AIMD): spinal cord stimulators, pain pump, cardiac pacemaker, defibrillators, stents, monitoring devices, etc.
- Have a list of **ANY** implants: breast, cochlear, intra-ocular lens, heart valves, contraceptive, hip, heart, valves, etc.
- Have a list of **ANY** organ transplants and or prosthesis devices
- Consider having a letter from your primary care provider and/or pain physician with conditions you are being treated for and your medical routine
- When possible, bring someone with you and keep a journal of the appointment
- Request that staff always ask before touching. Share where you can be touched and/or positioned
- When possible, ask for a quiet, temperature and light controlled area to minimize triggers (allodynia), especially if staying overnight in the emergency department. Dark sunglasses may help with bright lights.
- To minimize allodynia (things that shouldn't be painful but are painful) bring items that are helpful with you
- Ask the staff to use **hypoallergenic** items when possible (sheets, blankets, gown, cardiac monitoring EKG leads, paper tape, soap, cream, bandaids, etc.)



PO Box 502
Milford, CT 06460
(877) 662-7737
info@rdsd.org
rdsd.org

CRPS is a REAL medical condition requiring support, education, and a plan of action

Tips for Medical Professionals

CRPS has both a sensory and autonomic dysfunction resulting in central sensitization of pain, causing:

Hyperalgesia (increased sensitivity to pain)

- Avoid frequent needle sticks and injections
- Assess if patient has PICC line access for bloodwork, medications, and infusions
- Use the **smallest gauge** needle (butterfly) when possible
- Numbing cream prior to needle sticks can be helpful as many have thin and fragile veins (EMLA, Synera, and Lidocaine)
- Obtain blood work **during IV insertion** to minimize trauma
- Adjust **rate and temperature** of IV fluids if possible, as some respond better to slower and warmer infusions
- Illness, injury, trauma can exacerbate CRPS symptoms

Allodynia (pain induced from non-painful stimulus such as touch, clothing, sheets, temperature, exam, diagnostics)

- Hypoallergenic materials may be helpful
- Patients may not be able to tolerate hospital socks
- Bright lights and temperature variations can be painful
- **Identify CRPS limb(s) to avoid blood drawing, vital signs, and or sheets/blankets from touching**
- Avoid ice to CRPS limb to prevent further nerve damage
- Use NON-CRPS limb for vital signs when possible
- Moving and transporting patient: avoid bumps, sudden movements, vibrations and touch of affected area
- Noise from monitors, pumps, diagnostics, voices, phones, TV, intercom, can elevate pain

Atrophy (skin, muscles and bone weakness)

- Assess for limited ROM, weakness and need for adaptive equipment and or mobility aids

Hyperhidrosis (abnormal sweating pattern)

- Frequent linen changes may be needed

Abnormal Skin Changes

- Color changes (mottle, cyanotic, red, purple)
- Skin temperature difference
- Hair/nail changes and swelling

Movement Disorders

- Assess for motor disorders, involuntary muscle spasms and movements (bradykinesia, dystonia, myoclonus, excessive startle, and tremor)

Dysesthesia (creepy, crawly, sensation to touch)

- Avoid using CRPS limb for treatment

Overview:

An injury or surgery may require an additional pain management plan, including IV Ketamine

- Many have secondary conditions (POTS, MCAS, EDS)

Revised 10/02/25

Dental Guidelines for CRPS Patients - *Handle With Care!*

Complex Regional Pain Syndrome (**CRPS**), previously known as Reflex Sympathetic Dystrophy (**RSD**), is a neuro-inflammatory condition causing the nervous and immune systems to malfunction, sending constant pain signals to the brain. **CRPS** is characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rates CRPS higher than childbirth, amputation, and cancer pain. Those with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, and needle sticks.

Tips for Patients

Carry a copy of RSDSA's Hospital, Emergency, and Dental Guidelines, along with the "I Have CRPS" card, to educate practitioners.

Hand the following to your dentist:

- A computer printout of your detailed medical history since your first episode of CRPS, including the precipitating event
- Your treatments for CRPS and treating physicians
- List of allergies
- List of current medications prescribed, over the counter, specialty compounded medications (dosage & frequency)
- List of any AIMD (active implantable medical devices), SCS (spinal cord stimulators), pain pumps, cardiac pacemakers, defibrillator, stents, and monitoring devices
- List of any implants: breast, cochlear, intra-ocular lens, heart valves, contraceptive, prosthesis, etc.
- List of any organ transplants
- Research practices specializing in treating patients with chronic pain conditions ([American Dental Association](#)) and willing to learn about CRPS
- Be patient while educating your dental team
- To prevent losing YOUR teeth and maintain YOUR overall health, begin with a comprehensive dental evaluation to develop a treatment plan to suit YOUR needs as a CRPS patient
- Share any dental and oral health issues including:
 - Allergic reactions or sensitivities to dental products or ingredients
 - Burning mouth, dry mouth, erosion, dental decay, chronic mouth inflammation/irritation, orthodontics, muscle issues of the head, neck and jaw, the tongue, or salivary glands changes
- Develop YOUR daily oral hygiene plan with practitioner including:
 - Type of toothbrush i.e. soft bristle
 - Use of mouthwash and or moisturizing spray
 - Use of floss
 - Adopt a Health dental diet and take vitamins (approved by your doctor)



PO Box 502
Milford, CT 06460
(877) 662-7737
info@rsds.org
rsds.org

Tips for Dental Professionals

- CRPS is a REAL medical condition requiring support, education, and a plan of action to minimize further pain
- CRPS has both a sensory and autonomic dysfunction resulting in Central Sensitization of pain, causing:

Hyperalgesia (increased sensitivity to pain)

- Consider anesthesia options including: topical anesthesia and numbing gel prior to injections, cleanings, and X-rays
- Consider anesthesia options including moderate sedation and general anesthesia with long dental appointments or procedures such as a root canal which can exacerbate CRPS symptoms
- Extreme gentleness using dental equipment (spit suction, drill, water spray, dental tooth pick, etc.) to minimize pain

Allodynia (pain induced from non-painful)

- Hypoallergenic materials may be helpful with sensitivities
- Bright lights can be a patient trigger, sunglasses may help
- Room temperature may need adjustment per patients' needs
- Avoid being in the path of vented air or fans
- Avoid ice to the CRPS area in order to prevent further nerve damage
- Avoid anything bumping into the patient
- Patient position is key to positive outcomes. Consider utilizing bolsters, pillow, gel support or blankets to support the patient
- Noise from monitors, dental equipment, diagnostics, voices, phones, TV, intercom, etc. can elevate pain
- Shorter treatment sessions may help minimize CRPS flares

Atrophy (skin, muscles and bone weakness)

- Assess for limited ROM, weakness for assistance in and out of the dental chair
- Assess patient need for adaptive oral hygiene devices

Hyperhidrosis (abnormal sweating pattern)

- Abnormal skin sweating, skin temperature and skin color changes (mottle, cyanotic, red, purple) may require adjustment of environmental room controls including use of a fan for some patients (do NOT place the patient in the direct path of a fan)

Movement Disorders

- Assess the need to alter dental treatment due to motor disorders, involuntary muscle spasms and movements (bradykinesia, dystonia, myoclonus, excessive startle & tremor); use of bite blocks, positioning the patient, use of sedation or general anesthesia can be helpful

Dysesthesia (creepy, crawly, sensation to touch)

- Avoid coming into contact with affected CRPS sites
- If more comfortable for the patient and if possible, provide dental treatment standing/sitting

Overview

- A minor/major dental procedure may require: pre-medication, additional pain management plan including Ketamine (IV, troche), nitrous oxide, oral, topical anesthesia (numbing gel) to minimize exacerbations
- Maintain access to emergency equipment and certifications
- Many have secondary conditions (POTS, MCAS, EDS)

Revised 10/02/25

Tips for Healthcare Assistants (HCAs), Patient Care Assistant (PCAs) and Certified Nursing Assistant (CNAs)

Complex Regional Pain Syndrome (CRPS), previously known as Reflex Sympathetic Dystrophy (RSD), is a neuro-inflammatory condition causing the **nervous and immune systems** to malfunction, sending constant pain signals to the brain. CRPS is characterized by severe burning pain, changes in bone, skin, hair and teeth, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rated CRPS higher than childbirth, amputation, and cancer pain.

Tips for HCAs, PCAs, or CNAs

- CRPS, is a REAL medical condition, experienced 24/7, 365 days a year as intractable, unrelenting pain, that “waxes and wanes”
- Pain is an invisible disability. Individuals may look fine but are struggling
- Good days are often followed by days spent in bed, with extreme exhaustion. Many tire easily
- Please always ask before touching a CRPS individual
- Individuals with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, smells, pressure, material, and basic medical care such as vital signs, pin pricks, etc.
- Please, do not put blankets, sheets, clothing, socks, or shoes on the person without first asking. Some individuals are super-sensitive and cannot tolerate the slightest touch
- Individuals with CRPS may need help cooking, shopping, housework, bathing, grooming, toileting, ambulation, mobility, positioning, and transportation to the doctor's office
- Pain levels may depend on the time of day. For *some*, mornings are best and evenings become brutal
- Individuals with CRPS may be sensitive to aromas (perfume, fragrances, cigarette smoke) lighting, sunshine, wind, lights, loud noise, and vibrations
- Individuals with CRPS can feel approaching weather fronts. Changes in weather (hot to cold, vice versa), and humidity can cause CRPS pain flares, even on sunny days
- CRPS can cause hair and nails to become thicker, fragile, and/or brittle
- CRPS can impact teeth and mouth changes (dry, thin, brittle, sores). Gentle oral hygiene can be helpful. (i.e., soft toothbrush, warm water rinses, etc.)
- CRPS can change the color and temperature of skin. Many have itchy, dry, thin skin, which requires attention to skin care to avoid breakdown. May see skin lesions, and/or rashes, etc.
- Ask if there are special food preparation needs (i.e., soft, pulverized, room temperature, etc.)
- During CRPS pain flares, individuals may need to rest in a calm, quiet, dark room to decrease environmental triggers
- CRPS can impact any internal organs such as the gastrointestinal system (i.e.: bloating, diarrhea, constipation, pain), urinary, respiratory, etc.
- Individuals with CRPS may need additional pillows, bolsters, soft blankets and frequent linen changes to help with comfort
- CRPS can cause “brain fog”, which may cause short-term memory issues and instructions may need to be repeated. Be patient

Tips For Individuals with CRPS

- Develop a clear list of your expectations that correspond to the healthcare aide's scope of practice
- Use a chart, marking each day what needs to be done and require that the aide mark off the chore when he/she completes it
- If transportation is needed, develop beforehand your expectations regarding volume of music, windows open or closed, air conditioning temperature, etc.
- Acquaint your aide with your medication schedule to help avoid pain flareups
- Inform what may cause your pain to increase. What smells? What sounds? What touch and the pressure? Where on your body? What foods hurt/help?
- Discuss your mobility challenges (cane, walker, wheelchair)
- Discuss positioning and/or positioning aides utilized (bolsters, pillows, soft blankets, linens, etc.)
- Discuss any skin care challenges
- Discuss any food preparation issues (allergies, temperature considerations, types of food)
- Remember CRPS is hard to understand ourselves, be patient while educating others



PO Box 502
Milford, CT 06460
(877) 662-7737
info@rsds.org
rsds.org