



Welcome to RSDSA,

RSDSA is celebrating its 40<sup>th</sup> 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](https://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](https://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](https://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

## Important Articles & Videos for those are Newly Diagnosed

- <https://www.youtube.com/watch?v=b49DtFigbbw> (good video for family and friends who may not understand)
- <https://www.youtube.com/watch?v=PhE9Z9JUzz0&t=27s> (peripheral nerve stimulator for people with CRPS Type II)
- <https://rsds.org/educational-presentations> (our recent Facebook Live presentations)
- <https://rsds.org/existing-papers/#Surgery> (peer-reviewed articles on surgery with preexisting CRPS)
- <https://rsds.org/wp-content/uploads/2020/05/Early-Treatment-of-Acute-CRPS.pdf> (steroids are the go-to treatment for early onset CRPS)
- <https://rsds.org/how-crps-is-diagnosed/>
- <https://rsds.org/empower-yourself-with-the-latest-crpsrd-information/> (latest newsletters)
- <http://rsds.org/joinmembership/> Individuals can receive the newsletter via postal mail or email
- <https://rsds.org/medication-summary-intractable-pain-rsd/> Read Nancy Sajben blog Medication Summary for Intractable Pain, CRPS/RSD details good non-opiate medications.
- <https://www.youtube.com/watch?v=9fTqE-GFy3M> (good non-threatening video on desensitization)
- Watch Dr. Chopra's video: <https://www.youtube.com/watch?v=wloFDUqHA1g&t=653s> (just skip the diagnosis part and go to treatment. His main weapons are LDN & ketamine)
- Dr. Getson discusses the many different faces of CRPS: <https://www.youtube.com/watch?v=o9q6ApLysQ8>
- <https://rsds.org/youve-been-diagnosed-with-crpsrd-now-what/> the above page is the treasure trove-you can download or print out our introductory information packet, view some excellent videos, an excellent overview article by Steven Bruehl.
- Link to our peer-reviewed journal articles: <https://rsds.org/existing-papers/>
- Link to our YouTube videos of our conferences: <https://www.youtube.com/user/RSDSAofAmerica/>
- Free accredited on-line course for docs & nurses:  
<https://rsds.org/accredited-course-on-crps-for-mds-and-rns/>
- Our stories of hope: <https://rsds.org/stories-of-hope/>
- other related websites and organizations: <https://rsds.org/related-web-sites/>
- Our weekly blog: <https://rsds.org/blog/>
- Our patient assistance application-one-time \$500 emergency patient financial grant:  
<https://rsds.org/jenkins-patient-assistance-fund/>
- If individuals are not on opioids, LDN is a good anti-inflammatory compounded medicine
- <https://www.youtube.com/watch?v=wUnwbNsIk1c&t=75s> (warm-water therapy)
- <https://www.youtube.com/watch?v=iiagiUE6kxg&t=5s> (Brain Retraining)
- Good video on non-medical interventions with Dr. Melanie Levine, a practicing psychologist who also has CRPS:  
<https://www.youtube.com/watch?v=Jj4bYhgBO14&t=104s>
- Hospital, Dental, and Emergency Department Guidelines: Dental - <https://rsds.org/wp-content/uploads/2020/12/Dental-Guidelines-11-24-2020.pdf>, Emergency - <https://rsds.org/wp-content/uploads/2020/12/Emergency-Department-Guidelines-11-24-2020.pdf>, Hospital - <https://rsds.org/wp-content/uploads/2020/12/Hospital-Guidelines-11-24-2020.pdf>

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## Complex Regional Pain Syndrome- What to Do About It Published on January 30, 2018 By Dr. David Brady

Chronic pain affects more individuals than diabetes, cancer, and heart disease combined and yet its origins can be so elusive that an accurate diagnosis of a chronic pain syndrome can be difficult. Determining precisely *what* you are experiencing and identifying the cause of those specific symptoms is undoubtedly important to unweave the complexity of chronic pain syndromes and find the treatment approach that best addresses your specific condition.

### Complex Regional Pain Syndrome

One less common, but severe, chronic pain syndrome that requires early attention is known as complex regional pain syndrome (CRPS). It was formerly called reflex sympathetic dystrophy (RSD), but as research progressed, RSD seemed to only represent a subset of a larger syndrome. This discovery led to the introduction of two new chronic pain syndromes: complex regional pain syndrome type 1 (CRPS 1), formerly known as RSD, and complex regional pain syndrome type 2 (CRPS 2), formerly known as causalgia.<sup>1</sup>

#### CRPS Defined

Like most chronic pain syndromes, CRPS is often confused with similar conditions including fibromyalgia and regional pain syndromes. Its central feature is severe, often debilitating pain in one or more limbs. Usually arising from an injury, surgery, and sometimes illness, the pain seems to be out of proportion to the severity of the cause. Occasionally, CRPS develops spontaneously.

The pain receptors of the affected limb are hypersensitive causing immense pain when triggered by a stimulus that doesn't normally provoke pain such as contact with clothing, bedding, wind, and water. The pain may be described as burning, throbbing, or sharp. The skin temperature of the affected limb may alternate between hot and cold, and temperature hypersensitivity is common. Changes in skin color and texture, and abnormal hair or nail growth are often visible. Sometimes, CRPS is accompanied by bone and muscle abnormalities.

CRPS 1 arises from a generalized illness or injury and represents most CRPS sufferers, while CRPS 2 is linked specifically to nerve injury. It has been suggested that many of the symptoms of CRPS are rooted in inflammation, poor oxygenation of the affected tissue, and abnormalities in the brain, and central and peripheral nervous systems.<sup>2</sup>

If left untreated, decreased mobility, muscle wasting, and muscle contracture can ensue, making it critical to get a quick and accurate diagnosis, as well as appropriate treatment. CRPS often leads to sleep disturbances and emotional stress, both of which exacerbate the symptoms of CRPS, causing a vicious cycle that leads to poor quality of life. Occasionally, CRPS will resolve spontaneously, but relapses can occur, and the symptoms can affect other limbs.

#### Management of CRPS

Traditional treatment of CRPS focuses on symptom management and is limited to the use of physical therapy, epidural infusions, steroids, non-steroidal anti-inflammatory drugs (NSAIDs), and mild

analgesic drugs to relieve pain. Sadly, these options do not seek to address the root causes of heightened pain perception.

As the research of CRPS continues, various ideas regarding the cause of CRPS lead to experimental treatments. For example, in response to the proposal that CRPS may be an autoimmune condition, therapies targeting the immune system have been attempted including intravenous immunoglobulin (antibody) treatment<sup>3</sup> and a plasma exchange.<sup>4</sup> Spinal cord stimulation is also used to reduce pain, but doesn't provide long-term relief.<sup>5</sup> As with the traditional treatment approaches, these options ignore the complex interaction between all body systems and do not focus on comprehensively supporting the whole body. Therefore, they fall short.

The lack of successful therapies for managing CRPS point to the need for a more comprehensive approach that may be found by taking a step back and considering the underlying biochemical, physiological, environmental, and psychological factors that influence pain perception, inflammation, immunity, and tissue healing. Functional medicine presents a perfect paradigm whereby we can help correct root causes of pain associated with CRPS, rather than focusing on temporarily patching the pain.

Heightened pain perception can be rooted in a malfunctioning neurological system or a structural problem, but it can also arise from chronic inflammation, of which pain is a primary symptom. In fact, multiple studies have shown persistent inflammation associated with CRPS, evidenced by significantly elevated levels of inflammatory factors in the blood, blister fluid of affected limbs, and in the cerebrospinal fluid of CRPS sufferers.<sup>6</sup> Chronic pain is often associated with inflammation and points to a confused immune system, which regulates inflammation in the body. Functional medicine focuses on restoring balance to the immune system to reduce inflammation using natural methods such as an anti-inflammatory diet, **proteolytic enzymes, omega-3 fatty acids, bioflavonoids, and botanicals** that target the inflammatory pathways of the **immune system** to reduce inflammatory factors.

Pain perception is a function of the brain and nervous system; therefore, a comprehensive and functional approach to managing chronic pain would explore the possibility of anomalies in these organ systems and seek to support them accordingly. Magnetic resonance imaging (MRI) scans of the brains of individuals with CRPS show decreased amounts of gray matter in the areas of the brain and limbic system responsible for pain perception and emotions, similar to findings from other chronic pain syndromes such as fibromyalgia.<sup>7</sup> A functional approach to managing these structural anomalies provides dietary and nutraceutical support to help build **brain matter** while reducing destructive agents (**toxins**, allergens, etc.) that may hinder healing and function of these organ systems. Chronic pain syndromes such as CRPS are emotionally challenging and often exacerbated by stress, anxiety, mood disorders, and disturbed sleep. Both emotional and physical trauma influence the development of neurological pathways that are linked to pain perception. Therefore, it is important to address emotional and lifestyle habits that may be reinforcing negative pathways in the brain and enhancing pain perception. A comprehensive and functional approach to reducing pain addresses stress-management, sleep habits, relaxation, and hormone or neurotransmitter imbalances that may affect mood and emotions.

CRPS is one of many chronic pain syndromes that share a host of symptoms stemming from complex functional, biochemical, and/or psychological roots. There is a great need for a comprehensive approach to symptom management – not a drug to cover the pain, but an inside-out approach. This approach will first determine precisely *what* you are experiencing, identify the cause of those specific symptoms, and then comprehensively support the body's structural, biochemical, and psychological needs to foster healing. By addressing the root causes of CRPS such as inflammation and structural

anomalies with dietary and nutraceutical support, detoxification, stress-management, sleep support and relaxation techniques, the whole body is given the opportunity to heal and quality of life is significantly improved.

### **So, what steps can you start taking to reduce pain, increase function, and foster healing?**

- 1. Begin Consuming an Anti-Inflammatory Diet.** This first step will lay down a foundation of health by which all other actions can work more successfully. An anti-inflammatory diet focuses on fresh, unprocessed, whole foods. Avoid packaged, boxed, canned, and prepared food items which contain inflammatory preservatives and additives. Make the bulk of your diet fresh vegetables of various colors. Consume fresh, cold-water fish such as salmon a few times each week. Avoid commercial and processed meats, choosing pastured, grass-fed meats, instead. Use plenty of healthy fats such as olive oil, coconut oil, avocado, or hemp oil. Use beans and legumes in place of inflammatory grains and be sure to drink 6 to 8 glasses of pure water each day, perhaps with added lemon to encourage detoxification.
- 2. Reduce Your Stress Level.** Chronic stress initiates inflammation and pain, and yet it so easily intrudes upon our lives. Schedule daily meditation, prayer, deep breathing, and time to “empty your mind” and reflect on positive things in life. Keeping a gratitude journal is a proven way to encourage positive thinking, which is vital for healing. Don’t overcommit and make sure you are setting aside adequate time for supportive relationships. Enjoy nature and take walks outdoors. Both the sounds of nature and smells of essential oils from trees and herbs can help reduce stress. Soaking in a hot, magnesium bath will also encourage rest and relaxation. Adaptogenic or calming botanicals, and nutrients to help reduce stress may include:
  - a. Magnesium**, 500-1,000mg per day in divided doses (malate or glycinate form preferred)
  - b. Valerian, passionflower, skullcap, and/or lemon balm**, 100-200mg per day each
- 3. Get Adequate Sleep.** Sleeping at least 8 hours each night encourages healing and restoration of all organ systems and is required for chronic pain conditions. Restoration best occurs when you sleep between the hours of 10pm and 6am. Unfortunately, most people have trouble falling asleep or staying asleep. Minimizing exposure to blue light from electronics will encourage melatonin production so you can fall asleep. Sleep in a dark room and begin relaxing at least an hour before you retire. If you battle insomnia, try resetting your circadian rhythm with the following:

#### **References:**

1. Todorova, J., Dantchev, N., & Petrova, G. (2013). Complex Regional Pain Syndrome Acceptance and the Alternative Denominations in the Medical Literature. *Medical Principles and Practice*, 22(3), 295–300. <http://doi.org/10.1159/000343905>
2. Palmer, G. (2015). Complex regional pain syndrome. *Australian Prescriber*, 38(3), 82–86. <http://doi.org/10.18773/austprescr.2015.029>
3. Immunoglobulin Treatment for Complex Regional Pain Syndrome. (2017). *Annals of Internal Medicine*, 167(7). doi:10.7326/p17-9046
4. Aradillas et al. (2015). Plasma Exchange Therapy in Patients with Complex Regional Pain Syndrome. *Pain Physician*, 18(4), 383-94.
5. Kriek, N., Groeneweg, J., Stronks, D., & Huygen, F. (2015). Comparison of tonic spinal cord stimulation, high-frequency and burst stimulation in patients with complex regional pain syndrome: a double-blind, randomised placebo controlled trial. *BMC Musculoskeletal Disorders*, 16, 222. <http://doi.org/10.1186/s12891-015-0650-y>
6. Parkitny, L., McAuley, J. H., Di Pietro, F., Stanton, T. R., O’Connell, N. E., Marinus, J., ... Moseley, G. L. (2013). Inflammation in complex regional pain syndrome: A systematic review and meta-analysis. *Neurology*, 80(1), 106–117. <http://doi.org/10.1212/WNL.0b013e31827b1aa1>
7. Barad, M. J., Ueno, T., Younger, J., Chatterjee, N., & Mackey, S. (2014). Complex Regional Pain Syndrome is associated with structural abnormalities in pain-related regions of the human brain. *The Journal of Pain : Official Journal of the American Pain Society*, 15(2), 197–203. <http://doi.org/10.1016/j.jpain.2013.10.011>

## **Pain and Activity**

**By: Michele Gargan, Ph.D.**

The human body is meant to move. Yet a person who experiences intense, persistent pain will probably move less and less over time. He or she is also likely to develop a number of “pain behaviors” such as lying down for long periods, using unusual postures to brace against the pain, or favoring one side of the body over another when moving. After a while, these pain behaviors take on a life of their own and actually add to the pain.

Long periods of immobility disrupt the body’s pain sensing mechanisms because pain perception relies on feedback from normal muscle activity, particularly the larger muscle groups of the body. Avoidance of activity under stimulates the large sensory nerves and results in more pain when movement is resumed. The habitual use of unusual postures results in secondary pain in other areas of the body as certain muscle groups go into chronic spasm while other muscle groups atrophy from lack of use. So rather than decreasing pain by avoiding certain patterns of movement, a person is actually increasing his or her pain as well as creating new pain.

A common pattern that I see in my pain patients is a burst of activity on a good day followed by several days of increased pain and immobility. As much as I preach consistently moderate activity, my patients habitually try to get everything done when they feel good. But when they do this, they get nothing at all done in the following two or three days. A prudent and effective pattern to follow is to do the approximately the same amount of physical activity each day. On “bad” pain days, you will have to push yourself, while on “good” days you will have to hold yourself back. If you do this, you will see that you get the same amount done as when you do a burst on Monday and nothing on Tuesday and Wednesday. If you do a little each day, you will get the same amount done without misery on Tuesday and Wednesday.

The following are some suggested techniques you can use to maximize you functioning:

- Keep an activity log for a two day period. Write down everything you do including quantity (how many dishes you washed) and how long you spent at it. You will probably be surprised at how much you do accomplish even though it feels to you as if you are doing little or nothing. Keeping this type of log will make you more aware of your patterns as well as help you set reasonable expectations. Challenge the artificial deadlines you set for yourself. What does it matter if the whole task is completed in one hour or one day, or in three hours or three days? How perfect does the work have to be? Learn to say, “That’s good enough.”
- Breathe while you move. Be aware of using your breath to support physical exertion instead of holding your breath again pain. Also be aware of the amount of energy you are using to accomplish a task as well as the quality of your movement. Replace short, quick intense movements with longer, slower, lighter movements. Elongate the muscles when dusting, scouring, or reaching, and low down to allow a full range of motion.
- Take frequent breaks. Every twenty minutes or so, change positions, change activity, or just rest. It may take you longer to do what you used to do in the blink of an eye. So What? It is important to learn to pace yourself.
- Schedule a rest period in the middle of the morning and the middle of the afternoon. A half-hour is usually effective, but some people take an hour or longer. If you have to nap, go ahead. But many people find that just relaxing, listening to music, taking a bath, daydreaming, or meditating is effective in extending their ability to function throughout the day. Go back to your activity log and find the natural breaks where you can insert rest periods. If you think there is not time to rest, you are trying to accomplish too much.

- Make conscious transitions between tasks. For example, if you are cooking dinner, take a few seconds to breathe and stretch between peeling the potatoes and molding the meat loaf. This allows you to release muscle tension and adjust your posture as well as tune into your physical effort in order to maintain a steady, easy pace.
- Put some type of regular physical exercise into your life. Don't deprive your whole body of exercise and fitness because part of you is in pain. Yoga is excellent for person with pain because it increases flexibility and strength while focusing on breathing to support movement. Most yoga instructors will modify the poses to fit your needs. Walking and swimming are also good activities to keep the whole body healthy.
- Explore new recreational activities. If you used to play soccer or go skydiving for fun, you have to find new pursuits. Music, painting, gardening, creative writing, and handicrafts do not offer the same physical thrills, but they are relaxing and rewarding. Make time for fun even if you have not completed all the chores that need to be done.

If you have a chronic pain condition, you have to accept that much of your life has changed permanently. This does not mean your life is over. It just means that you can't do things the way you used to before the pain set in. If you set realistic goals, learn to pace yourself, maintain a moderate level of daily activity, and engage in pleasurable pursuit, you will be able to have a full life.



## How to Obtain the Best Medical Care for CRPS

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If you are reading this, it unfortunately means you or a friend or loved one have been diagnosed with complex regional pain syndrome (CRPS). This article is not about diagnosing and treating CRPS but rather about how to obtain the best medical care for this diagnosis.

There are lots of good reasons to obtain the best medical care possible for this diagnosis. First and foremost is that early quality treatment has the best chance of resulting in the best outcome. Second, the wrong treatment can actually lead to a worsening of this condition. Third from a practical standpoint your insurance coverage may be limited and thus getting the right treatment first which is covered is very important.

There is both good and bad news. We will start with the bad news. Many of you will not have adequate insurance coverage to provide the absolute best care for CRPS. Problematic as well is that even with good insurance coverage, treatment available in your local community may not be ideal or even available. With that said, the good news is that if you will take time to educate yourself about your CRPS condition, you have a much greater chance of getting what you need to get better and to manage this condition.

While some treating physicians may focus on medications and interventional procedures (i.e., injections, device implantation, etc.), and these can certainly be an important part of treatment, the best treatment is approached from a biopsychosocial perspective by an interdisciplinary team of treaters. This means treating you as a whole person and paying attention to both the physical and psychological aspects of chronic pain. This approach involves coordinated medical care with a treatment team, other than yourself and significant others, including a physician pain specialist, a physical and/or occupational therapist and a psychologist.

In this type of biopsychosocial approach, it is critical that the person with CRPS, become educated about the condition and be the "Captain of the Ship" when it comes to managing medical care. Being passive and leaving it all up to the doctors and therapists just won't work. The person with CRPS needs to understand about his or her condition and how to treat it. That means becoming informed and educated. Whatever therapy is provided, it will not be enough if the CRPS patient doesn't "practice" what they are taught 24/7 both at home and away from the doctor and the therapy center.

The ideal setting for treatment is where the physician is a rehabilitation oriented pain specialist and not just a doctor focused on prescribing pills and doing procedures (i.e., nerve blocks, implanted devices, etc.). This means ideally, that the physician works closely with a physical and/or occupational therapist and a psychologist with expertise in treating CRPS. It is always best if they work out of the same facility as a team (this is called interdisciplinary) but even if they are in separate offices, it is important that they communicate and work together as a team (this is called multidisciplinary).

Getting back to the issue of education, while some physicians and therapists feel threatened by an educated patient who is knowledgeable and asks questions- and you need to be careful not to make the treater feel uncomfortable- it is perfectly okay to be educated about your problem and ask questions. High quality treaters enjoy questions and are not threatened by knowledgeable patients. Have you read up about CRPS? Have you made yourself familiar with the usual medications and treatments prescribed for this condition?

Here are some other things to consider when you are evaluating obtaining the best treatment for CRPS.

1. Identify other individuals with this condition in your community to find how they have done with their treatment and who they have treated with. Does their physician, physical therapist and psychologist listen to them and provide effective treatment? Are they being provided education about the condition and a good home program to expand and work on what they are learning when they're in therapy?
2. Tell your primary care family physician that you are familiar with the diagnosis and want to make sure you are being referred to a pain physician who is rehabilitation oriented and not someone who focuses on prescribing medications and injections and other invasive treatments.
3. Interview the doctor and therapist to see if they are truly familiar with and experienced in treating CRPS. Is the medical care provided truly coordinated between the various disciplines?
4. Ask the physical therapist how commonly they treat people with CRPS and if they are familiar with some of the more recent graded motor imagery approaches such as mirror box therapy.
5. If there is no physical therapist in your community that consistently treats people with CRPS, ask to treat with the therapist that sees the most people with chronic pain. Many of the same pain management skills can be applied to managing CRPS.
6. As you speak with the physical therapist, see how willing they are to provide full answers to your questions. Quality CRPS treatment requires a lot of education and your therapist should be eager to provide you with the answers to your questions.
7. Many psychologists deal with symptoms like depression and anxiety, but ideally, the psychologist needs to be trained in pain management. It is very important that they use cognitive behavioral therapy (CBT) as part of their therapy as CBT has been found to be highly effective for managing pain. Cognitive behavioral therapy is a form of psychological treatment that focuses on examining and changing the relationships between maladaptive or faulty thoughts, feelings and behaviors.

The RSDSA website <http://rsds.org> is a great source of information. Another source of good information is The American Chronic Pain Association ([www.theacpa.org](http://www.theacpa.org)) in general and the ACPA Resource Guide to Chronic pain Medications and Treatment (<http://www.theacpa.org/Consumer-Guide>) in particular.

# Tips for Managing Complex Regional Pain Syndrome

September 11, 2015 by [Jim Ducharme, MD, CM, FRCPC](#)



Hands of a patient with early CRPS, before atrophic changes set in.

Complex regional pain syndrome (CRPS), previously known as reflex sympathetic dystrophy (RSD), is a chronic neuropathic pain condition that can arise from trauma of any kind. It can be the result of something as minor as a blood draw that initiates a reaction. The condition arises more frequently than many emergency physicians may realize: roughly 3 percent of patients suffering a Colles fracture develop CRPS. Often the traumatic event cannot be remembered, and CRPS has been associated with trauma happening anywhere from a day to a year after the event. Its most consistent feature, however,

is how often physicians fail to make the diagnosis on initial presentation. Furthermore, our lack of understanding about how to manage the severe pain that occurs during acute flare-ups of this chronic condition worsens the suffering that many patients with CRPS endure over decades.

## Early Diagnosis Is Key

As can be seen with diabetic neuropathy, CRPS has both a sensory and an autonomic dysfunction. Unlike patients with diabetic neuropathy, both will be present from the start. Not only do patients suffer from intense pain that does not correspond to a specific nerve distribution, they also suffer visible changes as the result of their autonomic dysfunction.

Initially, the involved painful area (usually part of an extremity) becomes red, warm, and edematous; it is often initially misdiagnosed as cellulitis. The presence of severe allodynia (pain induced with a nonpainful stimulus such as light touch) should make the physician consider the true diagnosis. It is very important that CRPS be diagnosed early on because active treatment can reverse and eliminate the condition. Treatment includes neuropathic analgesics (eg, tricyclics, gabapentinoids) combined with active physiotherapy and mindfulness. Many patients who develop this condition will come to the emergency department with their painful condition when it begins, so the emergency physician needs to be able to diagnose and refer appropriately. I personally diagnose two to three new cases per year in my emergency medicine practice.



**Feet of a patient with more advanced CRPS, which show clear skin atrophic changes.**

Failure to treat within the first weeks of symptom onset will allow the physical changes to start. The involved area will develop dystrophic skin changes: a shiny, thin, erythematous appearance. Underlying muscles atrophy so that the involved area becomes wasted in appearance over time. Typical burning neuropathic pain persists. If left untreated (or if poorly treated), CRPS can spread, involving larger parts of the body.

## Treating Flare-ups

Patients will also present to the emergency department because of an acute flare-up of their chronic pain. CRPS can become acutely more painful because of N-methyl-D-aspartate (NMDA) activity and hyperresponsiveness to NMDA. NMDA is a neurotransmitter present in the dorsal horns and spinothalamic tracts, and it is the number-one initiator of wind-up in acutely painful conditions. With CRPS flare-ups, it is almost as if wind-up starts over again. The burning pain becomes acutely worse; pain is severe and unresponsive to almost all analgesics. Opioids will not control the pain of a flare-up unless given in a quantity that would make the patient somnolent. Opioids should not be considered a first-line treatment in this situation. It is recognized that many patients with CRPS ask for opioids for their severe pain. As with any patient asking for opioids when suffering from a chronic pain condition, this can create distrust and a stressful environment. Increasingly, national patient groups are educating patients that opioids will not be effective.

Given the cause of the pain flare-up, the treatment needs to be directed at stopping the NMDA activity. This is best accomplished with ketamine, an NMDA antagonist. A patient can only receive intravenous ketamine in a hospital environment, so emergency physicians need to be able to recognize and treat these severe pain flare-ups.

## Treatment Is Straightforward:

1. Initial bolus of 0.2–0.3 mg/kg of ketamine infused over 10 minutes. Giving this dose as an IV push will produce a high rate of dissociative side effects (up to 75 percent of patients) and should be avoided. Almost diagnostic is the patient's response: severe pain should be resolved by the end of the 10-minute bolus.
2. An infusion of ketamine (0.2 mg/kg/hr) for four to six hours. Although the medical literature for this is almost nonexistent, clinical experience has shown that an infusion of this duration resets the NMDA activity to baseline. Patients can return home on their usual medications, with the expectation that the flare-up, which can normally last weeks, will be over. Return rates for the same flare-up after ketamine treatment approach zero. For readers who feel four to six hours is too long, I encourage them to try shorter periods (two or three hours) and publish their results. No discharge prescription from the emergency department will be required.

Patients do not require admission, and they should not receive opioids. They do require the acute ketamine intervention, or they will suffer severe pain for weeks as a result of the flare-up. To date, there is no other effective treatment for a CRPS pain flare-up. Some researchers have studied an infusion of 5 mg/kg of lidocaine over a 60-minute period as an alternative treatment plan, but results are variable. Referral of newly diagnosed patients to physiotherapy and a comprehensive pain program is critical.

With better understanding of CRPS, emergency physicians will know when and how to intervene. Concern over drug seeking should be allayed, allowing appropriate care to be provided.

# Medication Summary for Intractable Pain, CRPS/RSD

Published on November 15, 2016 under [Guest Blogger for RSDSA](#)



**By Nancy Sajben, MD**

The following blog post was written on 11/6/16 by Nancy Sajben, MD for her website. You can visit her website by <https://painsandiego.com/2016/11/06/medication-summary-for-intractable-pain-crpsrds/>.

I spoke only briefly this morning at the RSDSA conference but there is so much to add. Most importantly, thanks to RSDSA for helping so many people with CRPS. They fund pain research, they are starting a free children's camp, and now offer physicians [one hour free CME](http://rds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/) (<http://rds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/>) teaching about CRPS.

Holistic view, 36 points – that's how I view caring for brain and nerves, very similar to the details used by UCLA Alzheimer's Research Unit. In June 2015, I posted on their work on [memory loss, dementia](https://painsandiego.com/2015/06/27/dementia-memory-loss-brain-atrophy-not-always-alzheimers-disease-we-are-all-at-risk/) (<https://painsandiego.com/2015/06/27/dementia-memory-loss-brain-atrophy-not-always-alzheimers-disease-we-are-all-at-risk/>). We know chronic pain means inflammation in the brain, excess of proinflammatory cytokines. CT scans show memory loss and brain atrophy in those with chronic low back pain. Can this inflammation lead to Alzheimers? Even if it doesn't, why not maximize what we know we can do to help brain. As I view it, simply be meticulously detailed in giving the central nervous system (CNS) the best chance to relieve or prevent pain or disease.

Below is a *brief* list.

To find detail and sometimes depth, check the alphabetical lists on either side column [on [Nancy Sajben's website](#)] until you see the category or tag when I first posted on that. Or simply plow through 7.5 years of detail with references. You do the work to check the side columns as I have no time to embed links below, taken from throughout this site.

For now just a list of medication players that may be strikingly important in trying to bring intractable pain into remission even after 20 years. Yes, even chronic for decades. The list applies to intractable pain of all causes. I omitted listing standard interdisciplinary approaches commonly used by every pain specialist around the world. My patients have failed all those.

Some patients with CRPS combine my medications with ketamine infusions.

For those who remain on opioids, ultra-low dose naltrexone (10 to 60 mcg three times daily) can significantly reduce pain, reduce opioid induced hyperalgesia, reduce windup, and thus reduce the dose of opioid needed to give improved relief. Opioids cause pain and trigger pro-inflammatory cytokines that create more pain. I strongly recommend slowly, gently tapering off opioid, and remaining off for 3 weeks before the following is trialed:

1. Vitamin D is anti-inflammatory. Important. Helps pain, depression. If bone loss is an issue, you will not absorb calcium from food if D is low. Mayo Clinic's publication in 2012 showed more morphine is needed for pain if D is low. Huge literature of its benefit for depression. First topic I posted on – it is that important.<sup>74</sup>
2. Vitamin B6 can cause burning pain from scalp to toe, a toxic neuropathy. It can be toxic to brain. It is loaded in tons of soft drinks, "energy" drinks, and supplements.
3. MTHFR mutation may be present. Body cannot process the B12 and folic acid you are eating or taking in supplement. A simple blood test, costly. Treatment is as simple as buying methyl folate and methyl B12 – no prescription needed. Folic acid in particular is profoundly important for one of the major energy cycles in the body. Can cause multiple conditions, some fatal, all from one single cause.
4. Minocycline 100 mg/day is the dose I use but higher doses could be given. It is used daily for decades for acne. I may prevent spread of CRPS if given before surgery, dental work, even minor procedures. I start 24 hours before, and continue for days *after* full recovery from surgery.
5. Testosterone in either male or female is depleted by opioids, it may be depleted by stress. Low T is a risk for depression, weakness and osteoporosis.

6. Naltrexone low dose (LDN) – profoundly important. A glial modulator. Lifelong use.
7. Dextromethorphan – reduces hyperexcitable glutamate
8. Oxytocin
9. Memantine – double the Alzheimers dose for CRPS. Like ketamine, it blocks the NMDA receptor.
10. Lamotrigine
11. Palmitoylethanolamide (PEA, PeaPure) a glial modulator, also acts on mast cells. A food supplement. No Rx. Your body makes it. Plants make it. Capsules & cream
12. Ketamine via nasal spray, under tongue combined with IV or not, works on glutamate-NMDA receptor. Not an essential drug. Where ketamine has stopped working, patients have become pain free after years of CRPS.
13. Creams combinations, so many. Most of my CRPS pts very much like Mg<sup>++</sup>/guai 10% each. You may or may not trial various combinations lido/keto/keta, etc. Numerous. DMSO 50%.
14. Medical Marijuana (CBD, THC, terpenes) [Marijuana saves lives](https://painsandiego.com/2016/11/06/medical-marijuana-proven-to-save-lives-science-november-4-2016/) (https://painsandiego.com/2016/11/06/medical-marijuana-proven-to-save-lives-science-november-4-2016/). Entire issue of Science, November 4, 2016, devoted to pain. NAC and alpha lipoic acid are noted by research from the Netherlands.

#### Appendicitis

If it has not burst, treat it like the infection that it is. Surgery may never be needed. I posted details of publications early 2016 with a case report. That young man was being rolled into the OR, instead was discharged 100% better without surgery 2 days later.

Medications target 3 main systems, as discussed at the conference

The opioid receptor – opioids create pain. They trigger glia to produce pro-inflammatory cytokines. Opioid induced hyperalgesia may occur. Cannot be used with low dose naltrexone.

The glutamate NMDA receptor – ketamine, memantine.

Glia, the innate immune system – glial modulators.

Before they see me, my patients have failed all prior therapies even ketamine coma. I view it like football. You have one guy running down the field with one ball. Do you want to win the game? You've dealt with this for years. Let's not prolong it. Hit it with my main choice of meds all at once. Jump on it. What if you get 10% relief – will you even notice 10% after many years of severe pain? But if you get 10% from each of 5 meds, then you are talking 50% relief as a start. Address those 3 main pain systems – even without ketamine – and I have posted a case report after 20 years and 3 suicide attempts before seeing me, she has been pain free for about 4 years as I recall. A surgeon nicked her sciatic nerve when she was 27. Two years ago, pain free, running on her treadmill, she twisted her ankle. She has permanent foot drop from the sciatic nerve injury, but even spraining her ankle did not flare her CRPS. Twenty years of CRPS, pain free for about 4 years. And ultimately, years ago, she was tapered off all the drugs with one exception: LDN lifelong.

Most importantly, I did not have time to relay a very special message from my patient in Brooklyn: "Surround yourself with friends and family who love you. Never give up hope." She had her first 2 or 3 pain free days this week, as she slowly increases doses of medication. She's not yet at maximal effect and even then there can be increases. Sending love and courage.

#### MOVEMENT

Watch this on the RSDSA video [to be posted soon], afternoon speakers, the parents of young ones who had RSD discussed today all the toys and games they had to devise to slowly force yourself to move through the pain, every single day, several times a day, all day, begin to move the body as much as you can. Set goals and slowly, at a pace you set, do the work. Make progress. Go forward. Keep moving. Do whatever you can to keep moving.

RSD support groups are essential and I am glad to see the [RSDSA list](http://rsds.org/find-a-support-group-near-you/) (http://rsds.org/find-a-support-group-near-you/) of so many throughout the country. There is so much more. Indeed, at least 36 points discussed on June 2015.

#### Disclaimer

The material on this site is for informational purposes only.

It is not legal for me to provide medical advice without an examination.

It is not a substitute for medical advice, diagnosis or treatment provided by a qualified health care provider.

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### **Are steroids useful in the treatment of complex regional pain syndrome?**

Steroids are one of the oldest treatments for complex regional pain syndrome. They appear to be most effective in the very early stages of the condition, or during acute flares.

### **How much steroid should be taken, and for how long?**

For new onset of symptoms of complex regional pain syndrome, I typically treat patients with either a 12 day or an 18 day course. Methylprednisolone is available in blister packs (commonly referred to as Medrol dosepacks). Each dosepack is a six day treatment course. We will use two dosepacks in an alternating fashion so that the patient will get 24 mg of methylprednisolone on day one and on day two, then 20 mg on day three and four, and continuing to reduce the dose by 4 mg every two days. For more severe symptoms, we may use prednisone, starting at 60 milligrams per day for three days, decreasing the dose every three days until the course of treatment is completed after 18 days. For acute flares of CRPS, I will. Typically the limit usage to a 6 day course of methylprednisolone (a single dose pack).

### **Are there risks of using steroids?**

The use of steroids is associated with multiple side effects and potential complications that is why we are so careful to limit their use to short time periods. Complications include increase blood sugar, increase blood pressure, osteoporosis, thinning of head hair, increased facial or bodily hair, increased weight especially in the face and abdomen, muscle atrophy, easy bruising, thinning of the skin, and effects on mood and cognition. Even this extensive list is not a comprehensive list of all the potential problems with the use of steroids.

### **Given these risks, should a patient with complex regional pain syndrome still consider the use of steroids as a possible treatment?**

In the vast majority of situations steroids are not appropriate for chronic treatment of CRPS. Nevertheless, they are potentially very useful for brief treatment of the acute symptoms that might be seen with new onset or flares. For brief treatment courses, the side effects are usually minimal to mild. For patients who have repetitive flares, I will limit the use of a six-day course of steroids to two to three times per year.

### **Why do steroids work?**

This is far from clear, but steroids have several properties that seem to be helpful. Steroids reduce the abnormal firing of damaged or irritated nerves. In addition, steroids are powerful anti-inflammatory agents and also suppressors of immune function. At least one component of CRPS appears to be an autoimmune disorder: The anti-inflammatory and immunosuppressive properties of steroids appears to be very helpful for acute neuropathic pain conditions, including CRPS.

The Smart Patient's Guide to  
Chronic Pain Management

### **Communicating What You Need in the Emergency Department**

*Tips for “speaking doctor” when you live with chronic pain*

By Amy Baxter, MD, FAAP, FACEP (</author/29618/baxter>)

Emergency department visits can be demoralizing. It’s bad enough to be scared and sick, but as a friend of mine once said, “Having to go to the hospital is admitting defeat. You can’t deny you have a disease that worsens your life.”

Even with a team of doctors, individuals living with chronic pain may find themselves requiring a trip to the emergency room from time to time.

As an emergency doctor, I know that not all of my colleagues understand chronic pain. To make matters worse, the healthcare environment in the US often pressures doctors to see a new patient every 15 minutes, leading their empathy to wear thin. In the spirit of making things better for both the patient *and* the doctor, below are a few ways to have a more successful experience in the emergency department (ED). While it’s still possible you’ll end up with a doctor that seems burned out, these tips should help you communicate what you need in a way that an ED doctor will respond to and respect.

You may be interested in these related articles:

[Pain Patients and COVID: How to Prepare for Potential Hospitalization](/patient/covid-pain-management-hospital-ER-pack) (</patient/covid-pain-management-hospital-ER-pack>)

[Physical Therapy at Home: Exercises and Devices to Relieve Pain](/patient/treatments/physical-therapy-rehabilitation/physical-therapy-home-exercises-devices-relieve-p) (</patient/treatments/physical-therapy-rehabilitation/physical-therapy-home-exercises-devices-relieve-p>)





([https://www.practicalpainmanagement.com/sites/default/files/imagecache/lightbox-large/images/2019/02/28/47900935\\_ML.jpg](https://www.practicalpainmanagement.com/sites/default/files/imagecache/lightbox-large/images/2019/02/28/47900935_ML.jpg))

Tips for “speaking doctor” when you find yourself visiting the emergency room. (Source: 123RF)

### **Fill The Doctors in on Your Condition**

Although it may sound burdensome, it can be very helpful to provide your ED care team with a one-page summary of your condition. For example, you could write the summary and then ask your doctor’s office to put it on their letterhead with an additional list of diagnoses, allergies, recent lab tests, medications, and any treatments to avoid. Keep a few copies of the summary in a safe, easily accessible spot at home and maybe one in your car. You likely know more about your disease and how it impacts your body than anyone else, so this summary can speed things along in the case of emergency. At the same time, it’s important to remain humble about what you *don’t* know, and be respectful of your ED doctor’s training. For instance:

**You could say:** “I’ve had a complicated course, so my doctor helped me to put this summary together to explain my current condition and treatment plan.”

This preemptive approach lets the ED doctor learn about you from another doctor, thereby enabling him or her to “save face” for not knowing much about endometriosis, for example. If you go for regular lab work, adding those results as a request from your doctor could also save you a trip or phone call. “If bloodwork is necessary, please add a calcium, magnesium, and phosphorus panel if it has been more than 2 months since my patient’s last blood draw.” Patients living with chronic pain have very different tolerances of, and responses to, stimuli than others. Therefore, it’s important to let the ED know why you came in *now*, since many patients may feel like they should be living in the emergency department.

**You could say:** “Normally I can do this/feel like this/handle this, but for the past [time period], I’ve noticed this...”

This information is particularly important if the issue is pain. In addition, anchor your baseline pain with a concrete description. For instance,

**You could say:** “I’ve handled my chronic migraine without needing extra medication for over a year, but now...” Or, “I have no cartilage in my knees, but I’m usually able to get around by using NSAIDs. For the past three days, however...”

If you’re asked to rank your pain on a scale, let your doctor know what the most painful experience is for you *before* deciding on a number. For instance,

**You could say:** “Before I started treatment, I was at an 8. With my meds, my pain ranking came down to a 6, and when I added acupuncture treatment, I believe it came down to a 4. Today, I’m back up to an 8 or 9 – this is pretty extreme for me.”

### **Be Proactive about Sensitive Areas and Treatments**

After you’ve presented your chief complaint about why you came to the emergency room, let the team know if there are any areas of your body, or any types of treatments, that you are very sensitive about. For example, if a simple touch to your right shoulder may make you jump or scream, give them a fair warning. Or, if you had an unpleasant experience with a previous treatment or emergency visit, let them know in advance.

**You could say:** “I’m sorry to be a bother, but could you let your team know that I’m paranoid about what goes in my IVs? A nurse once gave me X by accident, and I had [side effect], so now I double check when people give me meds. I don’t want anyone to be offended.”

### Avoid Certain Phrases

Below is a brief list of phrases that make many emergency team members cringe, why they do, and what you could say instead to get a better reaction.

**“I know my body.”** People often use this phrase as a way of disagreeing with their care plan, or as code for “I think you’re wrong.” Instead, try to be concrete about why you’re worried, and how abnormal your symptoms are at this particular time. Use your medical history, current context, and goals to frame what’s happening and what you need.

**You could say:** “I’ve had fibromyalgia for 6 years [history] and this feeling is new [context]. I’m most worried about this new flare-up, and because this pain is severe, I just want to make sure there’s not something else going on in this area that could cause it to hurt so abruptly [goal 1], and ultimately feel better [goal 2].”

**“I have a high pain threshold.”** This phrase is often used by patients seeking medications, wanting faster service, or who may feel embarrassed about seeking emergency care to try to justify their visit. While you likely DO have a high pain threshold, emergency staff see a wide range of patients over their careers – they’ve undoubtedly seen someone with a bone sticking out of their skin saying, “No, I’d prefer not to have pain medicine, I’m ok.” Instead, use the script above for more specific history, context, and goal phrasing.

**You could say:** “I have sickle cell disease [history], so going through labor without medication was nothing for me [context], but today my pain feels different.”

The phrase “feels different” always gets a doctor’s attention.

**“I’m allergic to [x].”** In many doctor’s minds, the word “allergy” exclusively refers to something that may cause hives or lead to a severe reaction, such as anaphylaxis. Medications that make you nauseous, anxious, or dizzy, on the other hand, are *not* allergies. So, it’s important to be more specific.

**You could say:** “Morphine gives me a huge rash, fentanyl makes my nose itch, and Toradol has done nothing for me.”

**“I’m not leaving until you figure this out.”** Emergency doctors are not the best trained to solve complex pain conditions; they do, however, want to figure out if what they prescribe, if anything, will be potentially helpful. Know what you really need or are worried about and relay that information to your doctor.

**You could say:** “I’ve been feeling like this for [x] days; I called my doctor and she can see me Tuesday. I just want to be sure this isn’t appendicitis, and it would be great if I could get something today to have a good night’s sleep.”

**“I need a test.”** A rule of thumb in the emergency room when it comes to laboratory tests, such as blood tests, is that a doctor will not order any test that is irrelevant to the problem at hand. However, if you are already getting blood drawn, your doctor may do you a favor and add a scheduled lab at your request. However, at the end of the day, it’s not their job to do so.

**“The only thing that works for me is [a specific drug].”** Doctors realize that patients know which medications have worked best for them in the past, but they also are keenly aware of drug-seeking behavior. Having your list of prescribed medications on your doctor-signed medical history summary (as noted above) can go a long way in the emergency department. For example, if you were traveling and a prescription was lost, or if there’s an extenuating circumstance that caused you to run out of a prescription unexpectedly, the doctor may be more responsive when you have your list in hand.

Overall, individuals living with chronic pain, and those trying to treat them, each face unique challenges. But the goal of relieving suffering always comes first. By being specific and knowing how to communicate your needs quickly, your emergency visits can be less frustrating.

*\*After practicing as a double-boarded pediatric emergency physician for 20 years, Amy Baxter, MD, is now the founder and CEO of Pain Care Labs (<https://paincarelabs.com/>), an all-woman company with the mission to eliminate unnecessary pain. The company’s Buzzy needle pain reliever has blocked pain from over 31 million procedures, and their VibraCool vibrating cryotherapy has been used to reduce opioid use. DuoTherm, a new hot and cold low back pain device with acupressure points and multiple vibration cycles, will be available in late 2019.*

Updated on: 06/03/20

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Conditions

CancerCarpal Tunnel SyndromeCRPS/RSDDiabetic NeuropathyEhlers–Danlos Syndrome (EDS)FibromyalgiaGouthATTR AmyloidosisLow Back PainLupusLyme DiseaseMigraine and HeadachesNeck PainOpioid Use Disorder/AddictionOsteoarthritisOsteoporosisPlantar FasciitisPostherpetic NeuralgiaInsomniaPelvic PainPsoriatic ArthritisRheumatoid ArthritisSickle Cell DiseaseThigh PainTraumatic Brain InjuriesTMJ Disorders

Treatments

Alternative TreatmentsBracing/SplintingHormone TherapyInterventional Pain ManagementManipulation and MassageMarijuana/CannabisMedication-Assisted Treatment (MAT)MedicationsMental and Emotional TherapyNutraceuticalsPalliative CarePhysical Therapy/RehabilitationTapering

Resources

Smart Patient’s Guide to Managing Chronic PainMed Guides, Quizzes, Lifestyle Tips, Organizational Resources & MoreManaging Pain in the WorkplaceFrom posture & flexible schedules to difficult conversations, keep your career on trackPain Self-ManagementDevices, Wearables, Gear & Practices for Managing Your Pain at Home or on the Go

Community Advice

👤 VISIT OUR CLINICIAN SITE

Take Our Chronic Pain Quiz

Introduction to Chronic Pain

Your 1st Visit to a Pain Clinic

The Weight-Pain Connection

Children in Pain

Pregnancy & Pain Management

**Non-Pharmacological Pain Management**

The BioPsychoSocial Model

Alternative Ways to Treat Pain

Non-Opioid Medication Guide

Gut Health and Inflammatory Pain

Can Diet Relieve Pain?

The Power of the Mind: Using Your Head to Control Pain

Psychotherapy to Control Pain

**Opioids**

Starting Opioid Therapy? What to Expect

Opioids & Chronic Pain: It's Complicated

5 Qs to Ask Your Doc

How to Taper off Opioids

Addiction or Dependence: Know the Difference

#NotAnAddict: The CDC Guideline and You

What to do with Leftover Meds

**Resources**

Anti-Inflammatory Diets for pain

Pain Devices to Use at Home

A Clinical Glossary for Chronic Pain Warriors

Support Groups for Pain

Pain Rehab: What It's Like

Get Involved in Pain Research

When Pain Drives You to the ER

Insurance Woes & Pain Patients

For the Caregiver

50-Plus Resources Every Pain Patient Needs

# Hospital Guidelines for CRPS/RSD 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 rated 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 the RSDSA Hospital and Emergency Guidelines, along with the “I HAVE CRPS” card, to validate and educate practitioners.
- Have your health insurance information.
- Have a list of **ALL** your allergies, medical conditions, and physicians treating you.
- Have a copy of **ALL** your medications, dosages and frequency prescribed, including vitamins, over the counter and compounded specialty medications as some may not be on hospital formulary.
- Have a list of **ANY** medical device and or implants including: spinal cord stimulators, intrathecal pain pump, implantable cardioverter defibrillators, pacemaker, cardiac stents, etc.
- Be patient when educating others about CRPS
- Consider having a letter from your doctor and or pain specialist as to conditions you are being treating for and your medical regime.
- Ask hospital staff to always **ask** before touching
- When possible, ask for a quiet, temperature/light controlled area to minimize triggers (allodynia). Dark sunglasses may help.
- When possible ask for **hypo-allergenic** items to minimize skin sensitivity (allodynia), such as; sheets, blankets, gown, cardiac monitoring EKG leads, tape, soap, cream, etc.

TJC provides accreditation to *healthcare institutions* to evaluate standard compliance. TJC requires each organization to create Pain Policies to Assess, Manage and, Respect the “Patients Right” to pain management.

## Tips Medical Professional:

- When possible, avoid frequent *needle* sticks or injections as CRPS can cause increased sensitivity to pain (Hyperalgesia).
- If PICC site is available, see if blood can be obtained from PICC instead of using vena puncture technique.
- When possible, use **smallest gauge** needle and topical numbing cream as many have thin and fragile veins. (EMLA, Synera, Lidocaine).
- When possible, obtain blood work during IV insertion to minimize additional trauma.
- Some are sensitive to **rate and temperature** of IV fluids, responding better to slower infusion.
- **Hypoallergenic** materials may be needed for Allodynia (things that shouldn’t be painful are)
- Frequent linen changes may be needed for Hyperhidrosis (increased sweating).
- **Avoid ice** to CRPS limb to prevent nerve damage
- Patients may not be able to tolerate hospital socks
- Identify affected limb/s to avoid blood drawing, vital signs and or sheets/blankets from touching.
- Before moving/transporting patient, assess for possible limb *atrophy* (skin, muscles, and bone weakness) and for adaptive equipment and mobility aids.
- When moving/transporting patient avoid sudden movements and or bumps which can increase *Dysesthesia* (Creepy, crawly sensation to touch) and *Dystonic* movement (abnormal movements, involuntary muscle spasms) & *Allodynia* (things that shouldn’t be painful are painful).
- A minor/major injury or surgery can require additional pain management plan, IV ketamine should be considered.
- CRPS is a REAL medical condition requiring support, education, and a plan of action.



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## Emergency Department and Urgent Care Guidelines for CRPS/RSD 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 rated 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 the RSDSA Hospital and Emergency Guidelines, along with the “I HAVE CRPS” card, to validate and educate practitioners.
- Have your health insurance information.
- Have a list of **ALL** your allergies, medical history, and physicians treating you.
- Have a copy of **ALL** your medications, including: dosage and frequency prescribed, vitamins over the counter medications (OTC), and or compounded specialty medications as some may not be on hospital formulary. \*Bring your own medication.
- Have a list of **ANY** active implantable medical device (**AIMD**): spinal cord stimulators, pain pump, cardiac pacemaker, defibrillators, stents and monitoring devices, etc.
- Have a list of **ANY** implants: breast, cochlear (ear). Intra-ocular lens (eye), heart valves, contraceptive, hip, heart, valves, etc.
- Have a list of **ANY** organ transplants and or prosthesis devices.
- Consider having a letter from your doctor and or pain doctor with conditions you are being treating for and your medical routine.
- When possible, bring someone with you, keep a journal.
- Ask hospital staff to 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 minimized triggers (allodynia) especially if staying overnight in the Emergency Department. Dark sun glasses 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, band aids, etc.)



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TJC provides accreditation to *healthcare institutions* to evaluate standard compliance. TJC requires each organization to create Pain Policies to Assess, Manage and, Respect the “Patients Right” to pain management.

### Tips Medical Professional:

- 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 **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** minimizes 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.
    - Avoid ice to CRPS limb, prevent further nerve damage
    - Use **NON-** CRPS limb for vital signs when possible
    - Identify CRPS limb(s) to avoid blood drawing, v/s, and or sheets/blankets from touching.
    - 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:**  
**A minor**/major injury or surgery may require additional pain management plan, including IV Ketamine.
- Many have secondary conditions (POTS, MCAS, EDS)
  - **CRPS is a REAL medical condition requiring support, education, and a plan of action.**

# Dental Guidelines for CRPS/RSD 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 rated 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 the RSDSA Hospital, Emergency, Dental Guidelines, along with the “I HAVE CRPS” card, to validate and educate practitioners.
- Hand the following to your dentist:
  - A computer printout of your detailed medical history since your 1st episode of CRPS, including the precipitating event.
  - Your treatments for CRPS and treating physicians. List of any allergies-List of current medications prescribed, OTC, 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 (ear), intra-ocular lens (eye), 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. <http://rds.org/crps-and-dentistry/>
- Be patient while educating your dental team: dentist, dentist anesthesiologist, periodontist, orthodontist, dental assistants/hygienist, lab technicians, etc.
- 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)

## **Tips for Medical Professional:**

- RSDSA’s Financial Assistance Resource Directory [https://rds.org/wp-content/uploads/2014/12/2012-13Directory\\_final\\_web.pdf](https://rds.org/wp-content/uploads/2014/12/2012-13Directory_final_web.pdf)
- 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, numbing gel, prior to injections, cleanings, X-Rays.
- Consider anesthesia options including moderate sedation & general anesthesia with long dental appointments or procedures such as a root canal treatment which can exacerbate CRPS symptoms.
- Extreme gentleness using dental equipment (spit suction, drill, eater 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 to be adjusted per patients’ needs.
- Avoid being in the path of vented air from HVAC systems or fans
- Avoid ice to CRPS area, prevents further nerve damage
- Avoid anything bumping into patient.
- Patient position is key to positive outcomes consider utilizing bolsters, pillow, gel support, blankets to support 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 fan for some patients (do NOT place patient in the direct path of a fan).
- Hair/nail changes and swelling

### **Movement Disorders**

- Assess the need to alter dental treatment due to motor disorders, involuntary muscle spasms & 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 & 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)

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## Mirror Therapy and Other Brain Retraining Treatments

By Sarah M. Whitman, MD

The abnormalities in CRPS are not confined to the parts of a patient's body which hurt, but are also found in the central nervous system, particularly the brain. Ongoing pain signals may cause disturbances in the brain's "body map," which is the internal representation of the body in the brain. Patients with CRPS often use the painful parts of their bodies less. This causes fewer signals of normal movement to feed back to the brain, lessening any opportunity to correct the abnormal body map.

However, this knowledge presents an opportunity for new treatment approaches, and exercises which retrain the brain can decrease pain.

Mirror therapy uses a patient's visual system to register normal movement in the brain. The patient's painful, difficult-to-move body part is hidden behind the mirror, while the contralateral body part is moved. The patient watches the reflection, and this simulates comfortable, easy movement. When successful, mirror therapy reverses abnormalities in the body map and decreases pain.

Graded motor imagery is a step-wise program which breaks down movement into components. This allows a more gradual resumption of movement without producing pain. The components include right/left discrimination, imagined movement, and lastly actual guided movement.

Research has demonstrated mirror therapy to be effective in early CRPS, and graded motor imagery in chronic CRPS. These are exciting, effective treatments. Once a practitioner understands the underlying theory and how to implement the treatments, they can be used creatively in most patients with CRPS. An excellent website for more information is [www.noigroup.com](http://www.noigroup.com).

## What People with CRPS Should Expect from Therapy

By Anita L. Davis, PT, DPT, MSM, D-AAPM

Before developing CRPS, chances are you have never had a major injury or illness, but now you may find yourself going from doctor to doctor and have a shelf full of medications. Some have worked, some have not, and others had such side effects that you had to stop taking them. The doctors have talked about injections and maybe neurostimulators--and, by the way, now you need to start physical therapy.

The intent of therapy is to help you regain your strength and mobility, and even reduce your pain. There will be days you would rather not follow the home program or go to therapy, and moments that your pain increases and you question the reason for making yourself hurt even worse. In those moments, let your hope of recovery and the support of close ones cheer you to continue.

Therapeutic activities that involve walking, stepping, carrying, or lifting present their own challenges. The aim of these types of tasks is to simulate a normal, functional motion while allowing your nerves to adapt to the sensation by readjusting their sensitivity. The pain will increase with these tasks, since your nerves have become so sensitive that they overreact to what used to be normal. It takes time and repetition to retrain this response. Medical literature and clinical experience tell us that this ultimately leads to less pain within 10 to 14 days.

In the midst of performing these painful activities, you should have strategies to reduce the flare-up. Your therapist may share relaxation techniques, imagery, breathing, or other movements that can ease the pain. Learn these and use them--for in this you can gain confidence in your ability to control what has otherwise seemed uncontrollable.

### Home Exercise Programs

A home exercise program is a select group of exercises or activities that a therapist designs. Frequency/participation in therapy sessions may vary from one week to the next, but what is done outside of therapy can have a significant impact on the patient's overall progress. Following an individualized home exercise program

can be an important component of treatment as it helps the patient continue to make progress in strength, endurance, movement and function in between therapy sessions.

Home exercise programs vary depending on your individual needs. Often home exercise programs will initially focus on scrubbing/weight loading and desensitization techniques to begin actively engaging the muscles in the affected area and help you manage your pain better. After the initial phase of scrubbing and desensitization, the home exercise program may be upgraded to focus on increasing range of active movement and improving strength.

Many home exercise programs will include functional activities in addition to stretches and exercises. Such activities may include drinking from a cup with the affected hand or wearing a shoe on the affected foot. Often these activities are based on tasks that the patient currently has difficulty performing. They may be things that you do for short periods of time frequently throughout the day to help you incorporate the affected area back into routine activities. Consistent participation in exercises/activities outside of therapy sessions, as directed by a therapist, may help the patient achieve his or her goals more quickly.

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*Raising awareness of complex regional pain syndrome since 1984*

# Treating Complex Regional Pain Syndrome

## A Guide for Therapy



## What is Complex Regional Pain Syndrome

Complex Regional Pain Syndrome (CRPS) is a chronic pain syndrome. CRPS generally involves a dysfunctional response of the nervous system and may develop after a traumatic injury or a period of immobilization.

CRPS is divided into two categories: Type I (formerly known as Reflex Sympathetic Dystrophy) and Type II (formerly known as Causalgia).

## What Does CRPS Look Like?

CRPS pain is often described as deep, aching, cold, and/or burning and is frequently associated with increased skin sensitivity. Pain is generally rated moderate to severe and is disproportionate to any inciting event.

Symptoms of CRPS can include abnormal swelling, abnormal hair or nail growth, abnormal skin color or temperature changes, abnormal sweating, limited range of motion, and movement disorders.

## Evaluation of CRPS for Functional Rehabilitation

Principal areas to evaluate are range of motion, strength, edema, dexterity, skin/vasomotor changes, pain/sensation, the presence of abnormal guarding or protection postures/movements and active use of the extremity during functional activity. Barriers to movement that are important to assess include fear and avoidance, reliance on passive coping tools, lack of education on CRPS and motivation/readiness for change. If psychological distress such as depression and/or anxiety is noted, a psychological evaluation may be required.

## Treatment Protocols

Treatment objectives for CRPS are to minimize edema, normalize sensation, promote normal positioning, decrease muscle guarding, promote use of active pain management skills and increase independence in all areas--mobility, work, leisure and activities of daily living (ADL). Education on CRPS, chronic pain and appropriate goals should be an emphasis early on and throughout treatment. Active movement and weight bearing exercises are emphasized. Treatment of CRPS can be painful and both mental and physical active coping tools are useful.

**Edema** is managed using specialized garments (Jobst® garments, Isotoner® gloves, Coban™) and manual mobilization techniques.<sup>1</sup> Stress loading and AROM (active range of motion) activities are also fundamental in managing edema. Elevation of the extremity can be effective; however it can sometimes become part of a cycle of guarding and disuse.

**Desensitization** techniques are implemented to assist with normalizing sensation to the affected area. This consists of progressive stimulation with very soft material to more textured fabrics or materials. Stimulation can be graded from light touch to deep pressure and from consistent to intermittent with each material. Wearing jewelry, clothes and shoes on the affected areas are also ways to normalize sensation.

Contrast baths that gradually broaden the temperature difference between the two can work toward tolerance of heat or cold.<sup>1</sup>

**Posture** is an important component to consider in treating CRPS. Proper posture and alignment can minimize protective guarding of the extremity, promote balanced use of muscles and facilitate improved functional use of the affected extremity. Relaxation breathing and awareness can help to decrease guarded posturing.

**Stress Loading** consists of two principles: scrubbing and carrying. A stress loading program promotes active movement and compression of the affected joints for a minimum of 3-5 consecutive minutes, three or more times each day. Though stress loading may initially produce an increase in pain or swelling of the extremity, after several days a decrease in symptoms will begin to be evident. Use of the affected extremity in daily tasks is encouraged throughout rehabilitation to inhibit muscle guarding and disuse atrophy.<sup>2,4,5</sup>

**Scrubbing** consists of moving the affected extremity in a back/forth motion while weight bearing through the extremity.<sup>4,5</sup> The patient scrubs against a hard surface, keeping the bristles of the brush in constant contact with the surface, while maintaining constant pressure on the brush. The amount of weight placed through the affected extremity and the duration of the activity are gradually increased.

Scrubbing is performed with the patient in quadruped for upper extremity involvement and in elevated sitting or standing for lower extremity involvement.<sup>2</sup> For upper extremity involvement, the patient holds a scrub brush with the affected hand. For lower extremity involvement, a long Velcro® strap can assist in fastening the brush to the bottom of the affected foot.

**Modifications** can be made to enhance performance or compliance. For example, upper extremity scrubbing may be done standing at a table or counter. Persons with limited wrist extension may benefit from using a handled brush.<sup>2</sup> The Dystrophile® can be used to gauge reliable performance. It is a device designed to facilitate consistent weight bearing and compliance

during scrubbing by activating a light when the patient has reached the preset load.

**Carrying** or loading, is the second component in the stress-loading protocol. Small objects are carried in the hand on the affected side, progressing to a handled bag loaded with increasingly heavier weight. Carrying should be performed throughout the day, whenever the patient is standing or walking.<sup>4,5</sup>

The lower extremity can be loaded in a variety of ways. Walking is an important loading technique if care is taken to ensure weight bearing through the affected leg during gait, especially when an assistive device is used. Increased weight bearing can be accomplished with verbal/physical cueing or by having the patient carry a weighted object or bag on the affected side. Loading can also be facilitated by engaging the patient in activities that promote weight shifting and balance (i.e., ball toss) or by placing the unaffected foot onto a small footstool during static standing tasks.

**Mind-Body Interventions** facilitate stress reduction, desensitization of the nervous system and provide coping tools for dealing with pain. They include relaxation, meditation, guided imagery, biofeedback, hypnosis, and art and music. Mindfulness based stress reduction (MBSR) is a form of meditation practices that is commonly used to help treat chronic pain. The practice of these interventions should begin immediately.

**Brain Retraining** is a set of rehabilitation processes used to treat pain and movement problems related to an altered nervous system, including the brain. The three different treatment techniques include limb laterality training, graded motor imagery exercises, and mirror therapy. These techniques are delivered sequentially or individually. This type of treatment is done over a long period of time and fast results should not always be expected.

**Splinting/Bracing** is used in severe cases of CRPS. Splinting or bracing may be utilized to promote increased circulation and nutrition to the area, facilitate normal tissue length, and improve functional positioning.

**Functional Training** begins once the patient is actively engaged in an edema management and stress-loading program. As the pain and edema decrease, the patient will be better able to tolerate and participate in AROM, coordination, dexterity, and strengthening tasks. Proprioceptive neuromuscular facilitation (PNF) patterns are often well tolerated during treatment.<sup>2</sup>

The therapist can help the patient to gradually improve AROM and flexibility through gentle progression of active and active-resistive exercises or gait training. The patient should be encouraged to gradually return to daily life activities. These treatments and activities can be very painful and the therapist must understand and be able to explain the differences between pain and damage to alleviate the fear of the patient. While these treatments should be done within the patient's tolerance, the patient must understand that they will have to push through pain to achieve their goals. Care must be taken to ensure safety of the anatomical structures in insensate situations (as after a nerve block). Pacing and pain management techniques, such as appropriate rest breaks, alternating tasks, thermal or EMG biofeedback, diaphragmatic breathing, and relaxation techniques, can assist the patient in minimizing pain flares while participating in intensive rehabilitation.

## Treatment Summary

The overall role of the therapist during rehabilitation of CRPS is to guide the patient through a program designed to minimize pain and edema while maximizing functional use of the extremity. As CRPS varies greatly in severity and duration, it is very important for the therapist to demonstrate enthusiasm, support and encouragement of the patient during the treatment process.

The patient, in turn, must be actively involved in integration of treatment techniques into all daily activities to achieve optimal function of the affected extremity.

## References

1. Harden RN, Swan M, King A, Costa B, Barthel J. Treatment of Complex Regional Pain Syndrome. Clin J Pain. 2006;22(5):420-424. Review.
2. Phillips ME. OT treatment for complex regional pain syndrome. OT Pract. August 20, 2001. Updated July 6, 2007. <http://www.aota.org/Pubs/OTP/1997-2007/Features/2001/f-082001.aspx>. Accessed May 5, 2010.
3. Phillips ME, Katz J, Harden RN. Occupational and block therapies for complex regional pain syndrome. Paper presented at Midwest Pain Society, Seattle, Washington: AOTA National Conference; 2000.
4. Carlson LK, Watson HK. Treatment of reflex sympathetic dystrophy using the stress-loading program. J Hand Ther. 1988;1:149-154.
5. Watson HK, Carlson L. Treatment of reflex sympathetic dystrophy of the hand with an active "stress loading" program. J Hand Surg. 1987;12(5 Pt 1):779-785.



**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.**



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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.

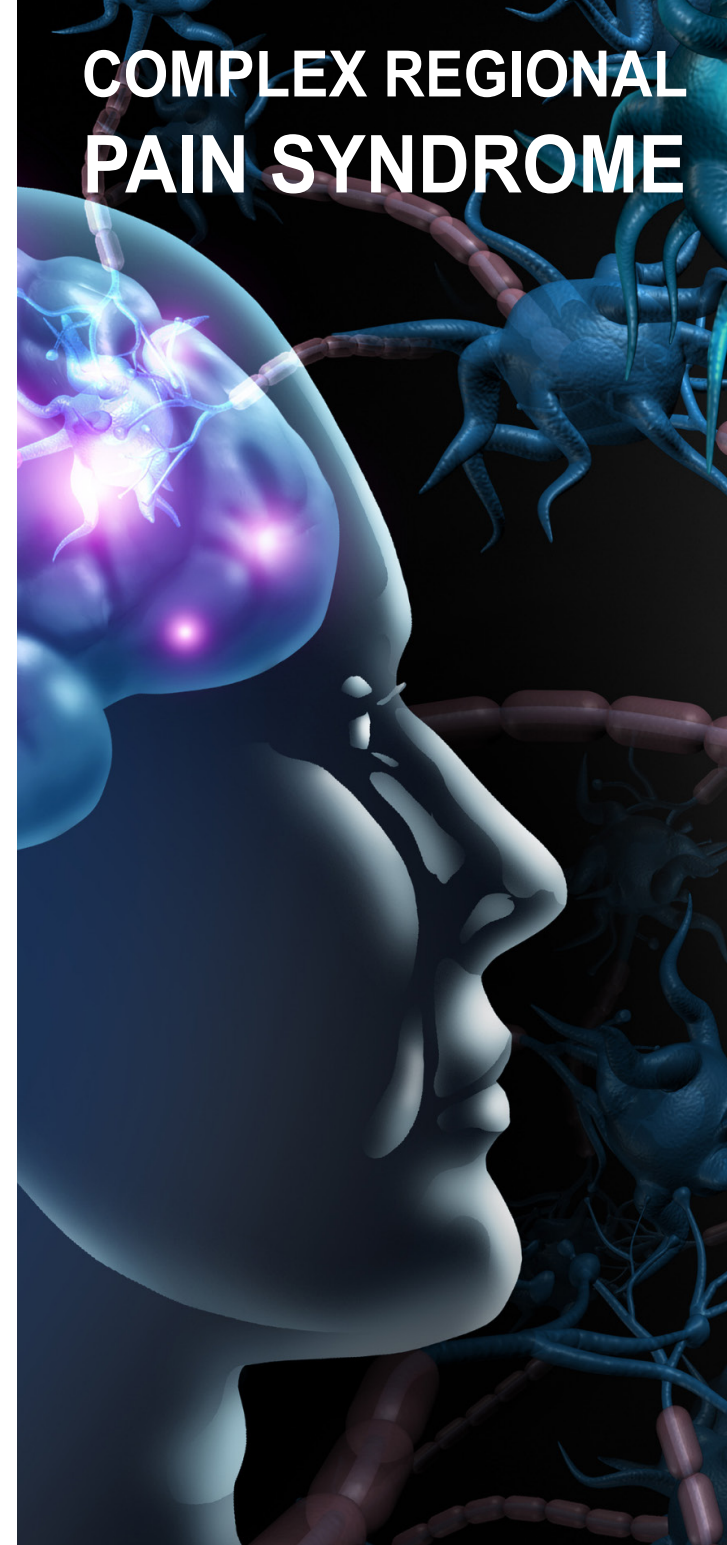
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*Raising awareness of CRPS since 1984*

# 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](http://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.

# I have CRPS

## What is CRPS?

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- Physicians do not know why CRPS develops or what causes it, but CRPS is a nerve disorder that usually occurs after a traumatic injury, surgery, sprain, fracture, or a period of immobilization. **The principal symptom is chronic pain that is dramatically disproportionate to the original injury.**
- More than 150 years ago, Dr. Silas Weir Mitchell, a Union Army surgeon, first described the excruciating pain that we know as CRPS.
- CRPS can lead to depression for those who can no longer work or participate in life the way they did before the onset of CRPS.
- CRPS can lead to disability. CRPS can spread to other body parts that were not originally affected.
- I may look “healthy,” but I often suffer unbearable, unrelenting, and burning nerve pain. The McGill pain scale rates the pain of people with CRPS higher than that of people with cancer, amputation, kidney stones, and childbirth.
- My skin may swell, sweat, change colors, change temperature, or hurt to the slightest touch.
- For some, lights, noise, or vibrations can cause disproportionate pain.

## Here's How You Can Help Us

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- My pain is real even though it is sometimes invisible and may not be readily apparent in my demeanor or activities.
- I am learning various coping mechanisms to get through the day, but the chronic pain is always there. I have good and bad days; my pain may even change hourly, and I cannot predict how I will feel each day.
- Sometimes it hurts to be touched anywhere so please ask before you touch me.

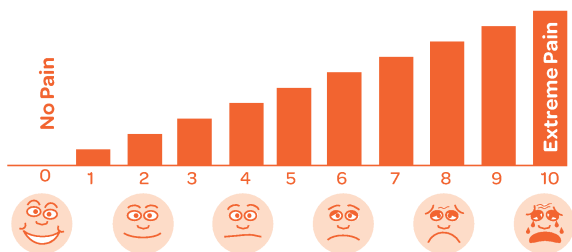
It is OK to ask me about CRPS.

Better yet, visit [www.rds.org](http://www.rds.org) and learn all you can.

CRPS is a diagnosis of exclusion for anyone who suffers with moderate to severe pain that exceeds the scope of their original injury and who presents with some of the following characteristics:

- Pain is described as deep, aching, cold, burning, and/or increased skin sensitivity.
- The presence of an initiating noxious event (sprain, fracture, surgery, etc.).
- Continuing pain (moderate to severe) associated with allodynia (hypersensitivity), or hyperalgesia.
- Abnormal swelling in the affected part.
- Abnormal hair or nail growth.
- Abnormal skin color changes.
- Abnormal skin temperature (greater than 1°C asymmetry).
- Abnormal sweating.
- Limited range of movement, weakness, stiff joints, or other motor disorders (paralysis, dystonia, etc.).
- No single test can diagnose CRPS. Physical exam and medical history are the main criteria. Diagnosis is challenging and is made by ruling out other conditions.

## Pain Scale



The RSDSA provides support, education and hope to everyone affected by the pain and disability of CRPS/RSD while driving research to develop better treatment and a cure.



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Thank you for considering a donation to RSDSA. Contributions like yours are the pillars supporting our financial foundation. By making an unrestricted gift, you enable RSDSA to host conferences for adults, sponsor Young Adult Weekends, and support research. Our conferences empower patients with current information to help them make better decisions for their health and optimize their wellness as they deal with CRPS. Thus, inspiring them with positivity and strength to take control of their illness and their life. RSDSA strives to make a difference in the lives of people affected by CRPS. We also provide emergency financial assistance for those that need help with medical expenses, as many people with CRPS/RSD are unable to work.

RSDSA is a 501(c)3 not for profit organization. All donations are tax-deductible.

Thanks to the generosity of donors like you, RSDSA has been fighting CRPS/RSD and supporting the CRPS/ RSD community for more than 35 years. We are grateful for your support!