



Welcome to RSDSA:

The RSDSA is a 39-year-old not-for-profit organization. Our mission is to provide support, education, and hope to everyone affected by CRPS/RSD 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 <http://rds.org/joinmembership/> to receive not only the *In Rare Form* electronic newsletter but information on upcoming RSDSA fundraisers and other important information.

Please join RSDSA on social media on Instagram @rds_official, RSDSA Facebook and Twitter #@RSDSA.

RSDSA has state-by-state listing of healthcare professional interested in treating CRPS. Please call us to obtain a list for your state. If you are in need of a support group, visit <https://rds.org/find-a-support-group-near-you/> on the RSDSA website.

We also have over 170 educational videos on our YouTube channel: RSDSA of America.

You are not alone in your fight against this horrific disorder. Please donate to RSDSA today online at <https://rds.org/donate/>, use the enclosed envelope or call 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,

James W. Broatch, MSW
Executive Vice President and 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.¹

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.²

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) treatment³ and a plasma exchange.⁴ Spinal cord stimulation is also used to reduce pain, but doesn't provide long-term relief.⁵ 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.⁶ 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.⁷ 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:

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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) 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, FRCP**



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.⁷⁴
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++/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>)

Physical Therapy at Home: Exercises and Devices to Relieve Pain (</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)

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

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Gut Health and Inflammatory Pain

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

Psychotherapy to Control Pain

Opioids

Starting Opioid Therapy? What to Expect

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5 Qs to Ask Your Doc

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For the Caregiver

50-Plus Resources Every Pain Patient Needs

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.

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.

Reflex Sympathetic Dystrophy Syndrome Association

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Raising awareness of complex regional pain syndrome since 1984

Treating Complex Regional Pain Syndrome

A Guide for Therapy



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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.¹ 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.¹

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.^{2,4,5}

Scrubbing consists of moving the affected extremity in a back/forth motion while weight bearing through the extremity.^{4,5} 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.² 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.² 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.^{4,5}

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.²

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.

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

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COMPLEX REGIONAL PAIN SYNDROME



THE FACTS

WHAT IS CRPS?

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

WHAT CAUSES IT?

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

WHAT ARE THE EFFECTS?

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

WHO CAN DEVELOP CRPS/RSD?

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

WORKING FOR A CURE

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

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

COMMON SYMPTOMS

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

THE RIGHT TREATMENT

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

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

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

THE DIAGNOSIS

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

I have CRPS

What is CRPS?

- 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

- 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.

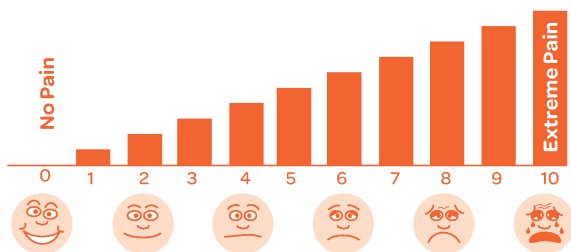
It is OK to ask me about CRPS.

Better yet, visit www.rsds.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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rdsda community update

VOLUME NO.7

ISSUE NO.1

WWW.RSDS.ORG/NEWSLETTER

Fall 2022



We are very pleased to publish our first print newsletter in two years thanks to the very generous donations by **Lynn and Michael Coatney and Dr. and Mrs. Lawrence and Judy Zager in memory of Hunter Lia Zager.**

RSDSA's income was adversely impacted by the pandemic and the print newsletter became a casualty of our reduced budget. To compensate, RSDSA began our monthly electronic newsletter, *In Rare Form*, because a single printed issue of this newsletter costs almost \$14,000. All issues of previously published print and digital newsletters are archived on our website at bit.ly/rdsanewsarchive.

This issue contains the most informative articles and important announcements previously published in *In Rare Form* as we realize that a significant number of RSDSA community members do not have access to the internet. It is our intention to publish additional printed issues as funds become available. To kickstart a print newsletter fund, we have included a special donation envelope with this newsletter. Thank you for your understanding.

Kelly Considine Joins RSDSA's Board of Directors

It is with great pleasure we announce that Kelly Considine will be joining the RSDSA Board of Directors in 2023!

Kelly developed CRPS in 2005 after an ankle sprain while playing volleyball. Since then, she has become a fierce advocate for CRPS Warriors across the globe through numerous efforts, including a Color the World Orange™ proclamation in Torrington, Connecticut.

She has taken on many roles within RSDSA over the years, such as Chairing the 2nd and 3rd Annual Virtual CRPS Awareness Walks and through membership of RSDSA's Development Committee, Patient Protective Task Force, and the Patient Representative on the Practical Pain Management Advisory Board.

Kelly has met with members of Congress regarding ADA accessibility and regularly participates in events as a part of Rare Disease Legislative Advocates' Advisory Committee. In addition to CRPS, Kelly also suffers from Ehlers-Danlos Syndrome (EDS) hypermobility, dysautonomia, Postural Orthostatic Tachycardia Syndrome (POTS), and gastroparesis.

Kelly resides in Connecticut with her service dog, Gunner. You can follow their adventures on Instagram at [instagram.com/gunner_the_golden_boy](https://www.instagram.com/gunner_the_golden_boy).

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ISSUE

RSDSA's sponsored scientific meeting on CRPS subtypes charts new direction for future CRPS research See. Page 4

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CALL FOR AUTHORS & IDEAS

*Do you have a personal story, art, or knowledge to share with the CRPS community? Did one of these articles resonate with you? **Is there a special topic you would like to see included in the RSDSA Community Update?** We would love to hear from you. Please email your thoughts to info@rds.org.*

SPECIAL THANKS

Our title sponsors make RSDSA events and awareness activities possible. Please join us in thanking and supporting them! Abbott | The Baker Family Charitable Fund | Diana and Peter Smith in memory of Stephanie Theresa Smith | Dr. & Mrs. Lawrence and Judy Zager, in loving memory of Hunter Lia Zager | Lynn & Michael Coatney | The Cochran Firm, National CRPS/ RSD Lawyers

Updates

2022 Treating the Whole Person: Optimizing Wellness Virtual Conference Videos

Thank you to everyone who joined last month's virtual conference! All sessions were recorded and have been uploaded to the RSDSA YouTube Channel. Be sure to subscribe to our channel while you're there! <https://www.youtube.com/@RSDSA/videos>

Looking for a therapist trained in Graded Motor Imagery?

Last year, the NOI group launched a NOI clinician directory of clinicians who have attended a recent Explain Pain course. You can search by location in the filters, then in the search tab type graded and it will filter down to clinicians who have also attended a Graded Motor Imagery course: <https://www.noigroup.com/clinician-directory/>

Interested in writing for the RSDSA blog?

We're always looking for Warriors who want to tell the story of their CRPS journey story on the RSDSA blog! If you're interested in sharing your story with us and fellow Warriors as a form of therapy and/or to help those who may be in the same part of their journey as you, send us an email at alexisdavis@rsds.org.

Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines

RSDSA has funded the publication of the fifth edition of *Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines* in the May issue of Pain Medicine. The Guidelines are intended for a medical audience. We hope to publish a lay version for the CRPS community in the future. <https://rsds.org/wp-content/uploads/2022/06/CRPS-practical-diagnostic-treatment-guidelines-5-edition.pdf>

Moms and Future Moms with CRPS

If you are a mother or mom-to-be who has CRPS, then consider joining the Moms and Future Moms CRPS/RSD Facebook Group to find support and resources that you need during pregnancy and motherhood. <https://www.facebook.com/groups/crpsrdsdmoms/>

WANTED

Individuals to:

- ✓ Set up a collection canister in your local grocery/convenience store.
- ✓ Plan an event with the help of RSDSA by emailing us at info@rsds.org.
- ✓ Fill up a Penny Pig with your spare change to help RSDSA sponsor children in pain at summer camp.
- ✓ Help educate health care professionals by promoting the availability of our accredited courses on adult and pediatric CRPS.
- ✓ Blog for our weekly Tuesday's Burn. Do you have a story or experience to share?
- ✓ Write an article for the RSDSA Community Update.
- ✓ Promote awareness of CRPS by sharing your story with TV or newspapers (we can help you).
- ✓ Share your story of hope. Inspire others who are struggling as you have.
- ✓ Join our peer-to-peer program (see our back cover).

Are There Distinct Subtypes of CRPS?

BY **STEPHEN BRUEHL** • PH.D.

PROFESSOR OF ANESTHESIOLOGY AT VANDERBILT UNIVERSITY SCHOOL OF MEDICINE, RSDSA BOARD MEMBER

In 2013, the U.S. Food and Drug Administration for the first time granted CRPS the designation of an Orphan Condition, providing important financial incentives for development of CRPS-specific drugs. Despite much promise, large-scale clinical trials funded by pharmaceutical companies over the past 10 years have failed to show efficacy for several potential CRPS drugs evaluated. As a result, development of promising CRPS interventions has been halted, to the detriment of those suffering from CRPS.

All of these FDA-regulated clinical trials have studied samples of patients meeting the current international diagnostic criteria for CRPS (i.e., the Budapest criteria). CRPS is a broad diagnostic category with multiple contributing mechanisms, and in many cases, any two given patients meeting diagnostic criteria may look very different due to various mechanisms being involved to differing degrees. For example, one patient may have an exquisitely sensitive cold limb in which touch is painful, whereas another may have a hot, sweaty limb that is extremely swollen. Large clinical trials carried out to date have all tested efficacy of the drugs in samples that lump together these patients showing very different CRPS characteristics, so in essence have tested drug efficacy in a hypothetical average CRPS patient. Intriguingly, results of some trials have hinted that the

drugs being tested may have worked well in certain types of CRPS patients and not in others, resulting in overall negative findings for the average patient. This situation highlights the importance of testing potential CRPS interventions working via specific mechanisms in CRPS patients likely to be experiencing those particular mechanisms. This approach, termed precision medicine, is now quite common in cancer treatment but has yet to be applied widely in pain management.

For a precision medicine approach to be applied successfully to improve treatment of CRPS, it is crucial to identify mechanistically-distinct subtypes of CRPS patients. On September 18, 2022, the RSDSA sponsored a meeting of international CRPS experts in Toronto, Canada with the goal of coming to a consensus as to the key CRPS subtypes relevant for targeting in future clinical trials and to identify the mechanistically-relevant interventions for each. Attendees included Stephen Bruehl, Norman Harden, Gary Bennett, and Peter Moskovitz (U.S.); Candy McCabe (U.K.); Frank Birklein, Ralf Baron, Heike Rittner, and Christian Maihofner (Germany); Peter Drummond (Australia); and Lone Knudsen (Denmark). All participants reviewed the research literature relevant to CRPS subtypes prior to the meeting and made

recommendations based upon this literature review and their own clinical experience. One broad recommendation was to focus on subtypes of CRPS-I in precision medicine trials given potentially unique involvement of neuropathic pain mechanisms in CRPS-II. Although optimal subtype terminology remains to be determined and there may be some overlap among subtypes, the group identified several potentially distinct CRPS subtypes supported by existing research. These include:

- 1) Warm vs. Cold CRPS (overlaps to some extent with #2)
- 2) Early Acute vs. Persistent CRPS (Immune/Inflammatory vs. Non-Inflammatory)
- 3) Sympathetic-Mediated vs. Non-Sympathetic CRPS
- 4) Regional vs. Centralized + Regional CRPS
- 5) Sensory CRPS Subtypes (Thermal Hyperalgesia vs. Sensory Loss vs. Allodynia)
- 6) Painful Bone CRPS vs. CRPS Without Bone Involvement
- 7) CRPS With and Without Significant Psychosocial Involvement

As a proof-of-concept to demonstrate the value of targeting specific interventions towards distinct CRPS subtypes to optimize intervention responses (i.e., precision pain medicine), the group recommended initially conducting a clinical trial focused on Warm vs. Cold CRPS subtypes. The trial would use objective

temperature asymmetry (≥ 1.5 - 2.0 deg C) between the affected and unaffected limb to identify patients with Warm CRPS (i.e., affected side warmer) vs. cold CRPS (affected side colder). Patients with atypical symptom patterns (Early Acute Cold CRPS and Chronic Warm CRPS) would be excluded. Based on prior research and hypothesized mechanisms, the intervention provided to both groups would be high dose oral steroids, with the expectation that steroids would be significantly more effective for pain and CRPS symptom reduction in the Warm CRPS group than in the Cold CRPS group.

RSDSA is committed to funding this type of proof-of-concept trial in order to demonstrate to the field of CRPS research the value of adopting a precision medicine approach for optimizing CRPS intervention efficacy.

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TO DONATE



Support RSDSA's End of Year Appeal

For the second year in a row, the pandemic has impacted all our lives. Some of us have lost loved ones, some have lost their livelihoods, still others have lost their good health. Many businesses, including non-profits, have had to close their doors. We were fortunate here at RSDSA. We were able to continue serving those who suffer from unimaginable pain, for whom the isolation imposed by COVID-19 is particularly devastating. Your generosity made that possible.

Your donation enabled us to expand our online presence during the pandemic. By helping us raise awareness of new pain management techniques, you provided hope and critical information to the community plagued by constant pain, a community which too often considers suicide their only option. Last year, we lost 244 individuals that way. At each of our presentations, over 1,000 CRPS Warriors have taken the opportunity to become informed and to engage with others. With your help, we will continue providing information and support to our community. Together, we can work to reduce that staggering statistic.

Your support gives hope. You help provide a place where one can search for information on the latest research and treatments. Your contribution enables the community to share experiences and connect with others.

Finally, you helped us publish the 5th edition of CRPS: *Treatment Guidelines* (last updated in 2013) an invaluable resource for both the medical community and those with CRPS.

None of this is possible without you! Please consider making a gift to our end of the year appeal here. TOGETHER WE CAN MAKE A DIFFERENCE!

The Importance of Developing a Special Care Plan for ED/Hospital Care

CRPS Warrior Jeff Doyle has several health conditions which necessitated frequent trips to Emergency Department (ED). In the beginning, the ED and hospital were not helpful as they were not familiar with CRPS or his comorbidities. He was treated as a "drug-seeker."

After several visits to the hospital and advocating strongly for himself, Jeff successfully had what's called a special care plan put in his electronic health record. This notifies the staff when he goes to the ED what are his health conditions, his medications, and his special needs. It took two years to establish this plan.

But now, when Jeff recently went to the ER with his care plan in place, it was flawless. He arrived, was admitted, and they started administering pain medicine. His recommendation is that others with CRPS schedule a meeting with the hospital social worker to set up a special care program.

A special care plan will allow you to go into the hospital and be known. Now the Danbury, Connecticut ED has stopped dismissing him as a drug-seeker.

Asking for Help: Why Does it Feel so Hard?

BY ELISA FRIEDLANDER • LMFT

What Does Grief Have to Do with It?

It's that time of year, when we tend to make more space in our lives for gratitude, giving, and even miracles. And considering the unique challenges of this particular holiday season, perhaps we're turning toward these notions even more.

Yet even in non-pandemic times, the holidays can be difficult, especially for those dealing with loss of any kind. Feelings of longing or loneliness are especially highlighted in contrast to seemingly unending snapshots of togetherness on social media and television's portrayal of the ideal.

Part of the fallout that comes from a CRPS diagnosis – and any condition causing high-impact chronic pain – is that we begin to see ourselves through the lens of what we did, and who we were, prior to life with intractable pain. In other words, we become involved in an intimate relationship with grief.

When we ask for help it can remind us (consciously or not) that we're no longer able to do things we could do pre-diagnosis days, at least not in the same way. On a deeper level, needing help can remind us that we've lost a part of ourselves. No wonder the topic of asking for help is so weighted. Who wants to open up to feel that sense of loss? Who wants to be

reminded about something that's so hard to accept?

A Foundation of Self-Acceptance

A friend of mine who, gratefully, does not live with a pain condition, recently lost one of the most important people in her life, her precious aunt. Not knowing how I could possibly help (*do we really ever know what to do or say when somebody dies?*), I reached out to express my condolences, and asked if there was any way I could support her in this time of grief. She responded by saying she finds poetry to be of comfort and asked if we could read some poems together over the phone (if not for the pandemic, I imagine we would have met in-person, somewhere in nature).

As much as I love poetry (and all things related to the written word), it wouldn't have occurred to me to offer to help her in this way, and hearing her request gave me a surprising sense of relief. I couldn't bring back my friend's loved one, or take away that gut-wrenching sorrow, but I could – in a clear and concrete way – give her something she needed.

I also felt a sense of admiration. I don't know if she would have directly asked me for these poetry sessions if I hadn't reached out, but she responded, and did so with clarity and a quality that should always be a priority for people with high-impact pain – *self-care*. Ultimately, my friend's

“Why not find ways to let our loved ones experience what my friend gave me – the chance to help in a concrete, doable way.”

ability to make this request came from a place of self-awareness, as if to say, *“I need the comfort of poetry right now”* and self-acceptance, which might sound like this: *“I’m in a lot of emotional pain... I lost somebody I love dearly”* or, *“As hard as it is, I will feel these feelings of grief”*, or *“I don’t need to go through this alone”*.

Challenges to Asking for Help

Most people have at least some skills to communicate their need for help. So, what gets in the way?

My friend had clarity about what she needed, but her response, and why it was so striking to me, was not the norm. Most people have difficulty identifying what they need from a loved one in the first place (which of course makes asking for help impossible).

Another barrier to asking for help has to do with feelings of vulnerability. As children, we didn't learn how to express our vulnerabilities (much less how to grieve, or how to ask for help). Underneath that vulnerability usually lies a sense of fear, so it's

helpful to ask ourselves, “What am I afraid of?” For some, the fear is about appearing weak; others fear rejection or even abandonment. All of these feelings are amplified by the magnitude of physical pain and other symptoms secondary to CRPS.

We must also acknowledge our societal value of independence (and our hard-wired propensity toward it), and look to our family upbringing and cultural beliefs to understand our feelings and behaviors about asking for – and receiving – help. From that point, we can move to a place of self-acceptance and make choices that are in our best interest. Easy-peasy? Nope, it’s a psychological process made more doable by – you guessed it, getting some help!

Chronic pain also tends to evoke feelings of guilt. If you feel guilty about asking for “too much” from people, consider one of the greatest antidotes to pain and suffering: being of service. Contributing to the world, even in small ways, connects us to humanity and gives us a role in repairing society. When we ask ourselves, “How can I be of service to others?” we show up more presently in all of our relationships and worry less about asking for help.

Like my friend did, we must allow ourselves to grieve and become open to self-acceptance. Only from that place can we become curious about what we need and ask for it, and we can best learn this through mindfulness practices (e.g., meditation, journaling, yoga). Mindfulness practices should be part of our daily lives, as they are the entrances to self-acceptance.

Asking for Help and Needing Help

Ask yourself if one of these statements resonates more:

“I don’t know how to *ask for help*” or

“Asking for help feels *awful* because I don’t want to accept that I need the help?”

However related, distinguishing between these two issues is the place to start. Here are some tips for both that I hope you find helpful.

- Clear communication (begin from a place of “I...”)
- Specificity (ask – in simple terms – for exactly what you need)
- Express gratitude (versus apologizing for needing help)
- Use your resourcefulness (access various means of support so you’re not relying on only one person)
- When it feels particularly hard, shift to asking for help from a place outside of yourself. This, of course, is different for each of us, depending on our beliefs. We might ask:
 - *Please help me accept my pain levels today*
 - *Please help me find self-compassion in this moment*
 - *Please help me be okay with asking for help*

Where we might seek help for deeper inner-wisdom:

- prayer
- poetry
- angels
- nature
- journal writing
- G-d or a higher power
- a loved one who has passed
- the animal world (oh, the wisdom animals have to offer!)
- photographs

- the Universe
- the dream world

People who care about us want nothing more than to take away our pain. So, until a day comes when they can hand us the key to a cure, why not find ways to let our loved ones experience what my friend gave me – the chance to help in a concrete, doable way. These opportunities are sacred gifts, and who doesn’t want an unexpected gift – especially this time of year.

Read a bit about my life at elisafriedlander.com/blog/independence-redefined, and my personal story of how I redefined the notion of independence.

Have you been told that CRPS is not real?

Eleven internationally renowned CRPS researchers have published a recent article in the Journal of Pain Research debunking this absurd assertion.

Their conclusion is, “the level of evidence for the claim that CRPS does not exist is very weak. Published accounts concluding that CRPS does not exist, in the absence of primary evidence to underpin them, can harm patients by encouraging dismissal of patients’ signs and symptoms.”

To access the article visit bit.ly/crpsreal

Food for Thought: Benefits of an Anti-Inflammatory Diet

BY PAMINA BARKOW • CNC

As a clinical nutritionist in a pain management clinic, I see people suffering in varying degrees of pain. Few cases have touched me on a personal level like those with advanced complex regional pain syndrome (CRPS). Perhaps that's because the more the medical field learns about CRPS the more we realize there are variables and unknowns and that often there are more questions than answers. Luckily, there are many indicators that show that changing dietary habits, specifically following an anti-inflammatory diet, can have a significant positive effect on people with CRPS.

What is inflammation?

Inflammation, from the Latin meaning "I ignite," describes the body's biological defense response to remove harmful or irritating events to our bodies and to begin the healing process. Inflammation is initially a positive and necessary response that can manifest as pain, heat, redness, swelling and loss of function. For example, if you fall and hit your knee and then it swells, inflammation is telling your body that your knee needs rest in order to heal.

Chronic inflammation has drastic effects on the body. Moreover, it becomes a self-feeding cycle that prevents the body from working optimally. Chronic inflammation has ties to cancer, diabetes, depression, heart disease, strokes, Alzheimer's, muscle loss, and

many other conditions including pain, nerve damage, and CRPS.

CRPS is often described as injury to a nerve or soft tissue that does not follow the normal healing path. Many physicians agree that the complications and pain stemming from CRPS are due to exaggerated local inflammation. Basically, this means that if you have CRPS, you also suffer from chronic inflammation.

What is an anti-inflammatory diet?

An anti-inflammatory diet focuses on eating foods that heal and naturally reduce inflammation and also reduce triggers of inflammation. It means seeking out fresh greens, vegetables and fruits, giving up processed foods, watching salt and sugar intakes, eating whole grain carbohydrates, increasing intake of legumes and healthy fats, cutting out unhealthy fats, seeking out grass-fed and wild sources of proteins and increasing daily water intake.

Foods in an anti-inflammatory diet are nutrient dense; they provide a high nutrient ratio for the amount of calories. They are easy for our body to break down and extract nutrients from and in turn we get energy and healing agents from them. We call these foods anti-inflammatory foods because they literally promote calming of inflammation in our bodies. On the other end of the spectrum are foods that are difficult to

break down, don't provide much nutrition, and actually increase inflammation in our system. We call these foods pro-inflammatory foods because they add fire to the inflammatory cycle.

Benefits of an anti-inflammatory diet

Following an anti-inflammatory diet provides the building blocks to:

- prevent further nerve damage
- help heal current nerve damage
- increase circulation
- improve sleep
- increase overall health
- restore optimal weight
- improve nutrient absorption
- increase energy
- decrease pain perception
- improve mood
- increase joint mobility
- prevent major and minor illnesses
- strengthen immune system

Super-foods and super-nutrients for those with CRPS

Four primary groups of foods directly fight inflammation:

Healthy fats, especially omega-3s, decrease cholesterol, hypertension, clumping of blood vessels, increase circulation, aid the cardiovascular system and are COX-2 inhibitors (decrease inflammation and pain pathways).

Examples: fish, olive oil, flaxseed oil, canola oil, walnut oil, nuts (especially almonds), and avocados.

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Foods that contain bromelain, carotenoids, flavonoids, and magnesium salicylate work to decrease inflammation in the body. Magnesium salicylate is even classified as a NSAID (non-steroidal anti-inflammatory drug) in high doses.

Examples: artichokes, spinach, sweet potatoes, apples, all berries, basil, mint, broccoli, cucumbers, parsley, onions, tomatoes, and many more.

Foods that contain amino acids glutamine and lysine. Glutamine aids in anti-inflammation, especially in the lower digestive tract, while lysine decreases inflammation by maximizing other molecules' effects of anti-inflammation.

Examples: fish, seafood, poultry, grass-fed beef, bison, soy, lentils, peas, and many more.

Anti-inflammatory herbs decrease inflammation by “altering the levels of molecules that stimulate inflammation.”

Examples: Aloe vera, echinacea, garlic, ginger, licorice, tumeric and many more. In addition, those with CRPS benefit from a daily multi-vitamin, high doses of omega 3s

capsules along with vitamin E (protects the anti-inflammatory powers of fish oil), complex B vitamins, and vitamin C (to increase circulation and blood cell production).

Pro-inflammatory triggers for those with CRPS

There are a number of pro-inflammatory triggers that are particularly important to watch, including:

Unhealthy fats (over-consumption of omega 6s and saturated fats as well as hydrogenated [trans] fats; found in high-fat cuts of meat and whole-dairy products) promote increases in blood cholesterol and LDL cholesterol as well as increases the risk for atherosclerosis, increased triglycerides, increased C-reactive proteins (which lead to inflammation) and decreased HDL (good) cholesterol. They increase the risk of heart disease and type 2 diabetes and contribute to the development of cancer. Trans fats are the worst of the bunch because they provide no benefit whatsoever.

High levels of sugar and empty carbohydrates (high glycemic index foods) provide no nutritional value and are pro-inflammatory. Sugars along with alcohol block absorption of many nutrients including water-soluble B and C vitamins that are crucial for people with CRPS.

Smoking (cigarettes, pipe or marijuana), exacerbates the activity of your body's inflammatory cells... and accelerates the formation of highly toxic and mutagenic substances... fueling inflammation.

Alcohol (regular drinking) raises your body's inflammatory level by increasing oxidative stress and blocks the absorption of essential nutrients (water soluble vitamins in particular).

Lack of sleep (less than six hours of sleep per night) raises pro-inflammatory markers IL-6 and TNF-alpha and C-reactive proteins. Sleep is also the time that your body uses to heal and create new tissue.

Excess weight/overweight not only promotes inflammation but is considered a “state of low-grade systemic inflammation,” which is also a state of chronic inflammation.

Gluten intolerance does not simply manifest as digestive unrest or inflammation but it can cause nerve damage. Therefore, people with any sort of neuropathy, including CRPS, are at higher risk for having this intolerance. I suggest that people with CRPS do an elimination diet (remove all triggers) or some other type of testing to measure food intolerances.

Although CRPS can be difficult to manage, making even small changes to your diet can help you feel better.

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Mast Cell Activation Syndrome and Its Role in Pain

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What are mast cells?

Mast Cells are normally found in our body. They are an important part of the initial defense system. These cells are found in most body tissues and tend to accumulate in tissues that have contact with our external environments, such as mucous membranes, the lining of airways, intestines, skin, and bladder lining, as well as being within the spine and brain. Mast cells contain many granules rich in heparin and histamine. When mast cells are activated they release compounds (also known as mediators) which cause inflammation (redness, swelling, pain). So, for example, if a person was exposed to a trigger (infection, allergy causing agent) or injury, the immune system of the body activates mast cells. These mast cells then head over the affected body part and release mediators that cause inflammation, resulting in pain, swelling and redness.

What is MCAS?

Mast Cell Activation Syndrome (also known as MCAS) is a condition where mast cells are inappropriately activated, leading to a wide array of symptoms. In MCAS, these mast cells start misbehaving. The inappropriate activation of mast cells causes persistent inflammation that is widespread in the body. It is important to note that the number of mast cells are not

increased in MCAS. There is a condition called Mastocytosis where the number of mast cells are increased. MCAS and Mastocytosis are two completely different conditions. This article is about MCAS only.

Signs and Symptoms

MCAS can present differently in people. It is essentially a painful condition because it causes inflammation of tissue. Some of the symptoms are:

1. Rashes: unexplained, random rashes, patches of redness
2. Itching: unexplained itching in random areas of the body. They may complain of an itching sensation deep inside their body. Itching can be triggered by water (usually warm water), sun exposure.
3. Multiple chemical intolerances or sensitivities. They may be intolerant to perfumes, chemicals, foods.
4. Skin flushing after a shower
5. Temperature instability: patients report a sense of being either too cold or too hot.
6. Fatigue: the fatigue is very disabling. Patients report a feeling of 'flu-like' symptoms
7. Sweating: they may have unprovoked sweating, especially at night
8. Gastrointestinal symptoms: may vary from loss of appetite, bloating, nausea, alternating diarrhea and constipation, belly pain.

9. Weight: they may have weight gain or weight loss or fluctuations in their weight without any change in life style.
10. Headaches
11. Acid reflux
12. Hair loss, dry hair
13. Dry eyes
14. Ringing in the ears

However, one aspect of MCAS that is far too often underestimated is the amount and severity of pain it can cause. The prostaglandins released by activated mast cells can lead to significant bone, muscle, and joint pain. Tryptase, another substance released by inappropriately activated mast cells, can further increase pain. Other mediators released during this activation process can lead to headaches, fatigue, brain fog, and muscle cramping. Pain from inflammation is a prominent symptom in patients with MCAS. Mast cells are involved in causing and contributing to inflammation in both chronic and acute pain. MCAS can cause inflammation in almost any tissue including muscle, nerves, joints, intestines.

Mast Cells and CRPS

The immune system in our body is in constant communication with the brain and spinal cord (Central Nervous System). They communicate by 'text message' called pro-inflammatory cytokines (it means 'text messages' that promote inflammation). Over 70% of the brain is made of glial cells. These glial cells pack



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