



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 @rdsa_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-crps-rsd/>.

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.

From One Family to Another- A Pediatric CRPS Journey



By Guest Bloggers Bobby and Lauren Geller

The Gellert's daughter, Zoe, has faced CRPS head on. She has been inspired to do some great things. See what Zoe and the Gellert family are doing and what they learned about pediatric CRPS.

“Dad! You need to come home. The doctor said nothing is broken or torn, but I still can't put my foot on the floor. It feels like someone is sticking a knife through my heel and it's burning inside”.

These were the words of our 11-year-old daughter, Zoe Gellert, who the day before was involved in a crush injury to her right ankle. Zoe was immediately non-weight bearing and was describing pain symptoms that made no sense based on the findings from her X-rays and MRI. She was diagnosed with Complex Regional Pain Syndrome six weeks later. For my wife and I, this

was the first moment in our lives that ‘brought us to our knees’. Having a child that is constantly in pain with symptoms that got worse over time was a devastating situation that immediately threw us into acute survival mode to obtain the best and most immediate treatment for our daughter.

Zoe is very intelligent, passionate and determined – a born leader. Over the past nine months since her injury, Zoe has learned an incredible amount about herself and her disorder. Today, although Zoe is fully functional and playing sports, she continues to manage her daily pain with techniques that she has learned and that she is enthusiastic about sharing with other kids that are suffering. Zoe is committed to creating overall awareness about pediatric CRPS and to raising money to help fund vetted treatment and research projects and to help support parents seeking financial assistance for their child's necessary treatments. Attached below is a detailed video of Zoe's story that we would like to share. We hope that you enjoy it and that it is inspirational for you or someone that you know with CRPS. If you would like to email Zoe, please contact her at zoesheroes@icloud.com. We hope to hear from you!

My wife and I are very grateful that within three months of Zoe's injury she was diagnosed, admitted into the hospital for intensive multi-disciplinary treatment and was released from the hospital walking without any support. However, the feeling of being ‘a fish out of water’ is still very fresh for us. Being thrown into the abyss of CRPS – whether during the pre-diagnosed, treatment or recovery stages – is completely overwhelming. Throughout our research, it was very important to us to consider treatment options that were non-narcotic, non-invasive – but aggressive and appropriate for a child. There were always many things to consider and everyday brought new challenges. So below, we feel compelled to highlight and share what we have learned about pediatric CRPS and what has worked for us and our family thus far in our journey...

Top 20 dos, DON'Ts, SUGGESTIONS AND PRACTICALITIES FOR PEDIATRIC CRPS*

- Do not apply ice
- Do not cast or immobilize
- Do not get a flu shot
- CRPS can spread throughout the body over time without treatment
- Emotional stress can increase the baseline pain endured daily
- Blood tests do not support or exclude the diagnosis – which is clinical and primarily based through observation of a variety of classic symptoms
- Thermography may be the most effective non-invasive diagnostic tool

- If your child must have an IV or get a shot, use the smallest needle possible – sometimes called a butterfly needle
- Discuss with your doctor administering an appropriate dosage of Ketamine along with any anesthesia during surgery
- Your child must be encouraged to stay engaged in everyday life activities while in pain – endure as much daily physical activity or physical therapy as your child can tolerate
- Continually touch, rub and desensitize the affected area – this will facilitate the circulation of blood and oxygen flow and eventually reduce pain
- Recovery is mostly about function over pain – explain to your child that he/she will not hurt himself/herself – if your child can function while in pain he/she will feel in control of the pain and the pain level will be reduced
- Do not ask your child about the pain he/she is feeling
- If your child complains about the pain, be sensitive, acknowledge the pain and distract him/her with homework, chores, physical or social activity – but move on from the conversation
- Your child must accept and surrender to the pain without letting the pain identify who he/she is – do not allow your child to mentally cut off the affected area from his/her body
- Seek a Cognitive Behavioral therapist so your child has someone other than you to talk with about what they are going through and to learn visual pain management techniques
- All family members should be encouraged to discuss with a therapist how they are coping with the affected family member's diagnosis
- Do not allow CRPS to take over the household or to be the main topic of conversation with family, friends and work colleagues
- Consider Osteopathy and Homeopathy as regular, not alternative, treatment options
- Five books to read:
- Get Out of Your Mind and Into Your Life – Spencer Smith and Steven C. Hayes
- Conquering Your Child's Chronic Pain – Lonnie K. Zeltzer M.D.
- The Mind Body Prescription – John E. Sarno M.D
- The Power of Now – Eckhart Tolle
- Fulford's Touch of Life – The Healing Power of the Natural Life Force – Dr. Robert Fulford

* We are parents, not doctors; hence, we are not making any representations or warranties regarding the above information which is based solely on the results of our own research and experiences.

As you saw in the video, Zoe created a GoFundMe site. Please click on the link if you are able to make a tax-deductible donation and/or please share the GoFundMe site on your Facebook page or any other social media outlet. We thank you in advance for your support and for your donation.

We also have an Instagram account – called “Zoesheroes” – that it would be super if you would “like” and follow us on our journey!

With appreciation and gratitude,

Lauren and Bobby Gellert

Original Research

Outcomes of Children With Complex Regional Pain Syndrome After Intensive Inpatient Rehabilitation

Valerie Brooke, MD, Steven Janselewitz, MD

Objective: To examine the effectiveness of an inpatient treatment program on eliminating pain and increasing function for children with complex regional pain syndrome.

Design: A retrospective chart review and follow-up telephone survey.

Setting: A tertiary care hospital.

Patients: Retrospective chart review of 32 children admitted for treatment of complex regional pain syndrome. Nineteen completed the telephone survey.

Intervention: Intensive inpatient physical and occupation therapy in conjunction with psychological counseling, art therapy, recreational therapy, and child life specialists who focused on improving physical function and conditioning, stress management, and the development of self-efficacy related to pain and stress.

Main Outcome Measurements: Resolution of pain and restoration of full function by patient or family report.

Results: All the children had failed various prior treatment approaches: 34% had resolution at the time of discharge; 78% of admissions and 89% of those with follow-up had eventual resolution of pain; and 95% had full restoration of physical function at a median time from start of treatment of 2 months. Seven had recurrence and 5 were able to resolve the recurrence without further intervention from the medical community.

Conclusions: Intensive inpatient rehabilitation is effective for children with complex regional pain syndrome. Additional studies are necessary to compare this treatment with other approaches.

PM R 2012;xx:xxx

INTRODUCTION

Children with pain out of proportion to any initiating injury, or amplified pain, can pose both a diagnostic and a therapeutic challenge for physicians. Some children have autonomic signs such as swelling or changes in skin temperature or color, which lead to a diagnosis of complex regional pain syndrome type 1 (CRPS-1), formerly referred to as reflex sympathetic dystrophy (RSD) [1]. Other physicians have also used the term reflex neurovascular dystrophy (RND) [2-7]. Pain conditions in children without autonomic signs have been referred to as diffuse idiopathic pain syndrome, localized idiopathic pain syndrome, psychogenic pain, psychosomatic pain, pseudodystrophy, growing pains, primary fibromyalgia syndrome, or fibromyalgia [7-15].

Many different treatment approaches have been attempted for these pain conditions in children, including nonsteroidal anti-inflammatory drugs [16-20], steroids [16,19,21-23], prostacyclin analog [12], pamidronate infusion [24], splinting or immobilization [18,20,25,26], transcutaneous electrical nerve stimulation (TENS) [17-19,26-30], sympathetic nerve blocks [6,19,22,25,26,30,31], and spinal cord stimulation [14], all with varying degrees of pain resolution and functional restoration. The most commonly used treatment for children with CRPS-1 is physical therapy (PT). A few studies show the effects of a single treatment modality for the treatment of these pain conditions. Frequently, multiple modalities are used simultaneously, which make it difficult to determine the effectiveness of any single treatment.

The few previous studies of children treated primarily with inpatient or outpatient therapy show rates of long-term full resolution that ranged from 60% to 100% [2,32-34].

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Disclosure: nothing to disclose

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Disclosure Key can be found on the Table of Contents and at www.pmrjournal.org

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Bernstein et al [2] reviewed charts of 23 children with RSD who had been treated with intensive outpatient PT of 2 to 3 PT sessions per day. Twelve patients had resolution of their pain, and 20 patients had full functional restoration after a mean follow-up time of 2.4 years. Blau [32] indicated full resolution of pain and function in 10 children with RSD after PT, with no patient spending more than 2 days in the hospital. The mean follow-up time was 1.1 years.

Sherry et al [33] studied children with CRPS-1 with either home-based exercises or inpatient therapy. Outcomes after a mean of 5.25 years showed pain resolution in 88% and functional restoration in 98%. Sherry did not elaborate on how many patients received inpatient versus outpatient therapy and drew no conclusion as to whether one was better than the other. A later study by Sherry [10] also included children with more diffuse musculoskeletal pain as well as patients with CRPS-1. Treatment consisted of an average of 2 weeks of intensive inpatient or outpatient PT, followed by a 1-hour daily home program performed for another 2-8 weeks. He reported that 80% of children had no pain and were fully functional after 1 month of treatment, with 15% having some pain but full function, and 5% with no improvement at all. At the 5-year follow-up, 90% of patients were free of pain and fully functional.

Lee et al [34] provided treatment of 1-hour weekly outpatient PT with cognitive behavioral therapy for 6 weeks or 3 hours of outpatient PT per week with cognitive behavioral therapy for 6 weeks. At follow-up, both groups had improvements in pain and function, with no significant difference between the groups, which suggests that more hours of PT may not improve outcomes. All the patients contacted at a mean follow-up of 2.5 years had resolution of their pain and restoration of function.

Although some of these studies used inpatient treatment, the studies did not look at this treatment approach exclusively. The aim of our study was specifically to evaluate the outcome of an inpatient rehabilitation treatment program of intensive rehabilitation therapies followed by a home program for children with complex regional pain syndrome.

METHODS

After institutional review board approval was obtained, a retrospective chart review included 33 admissions for inpatient treatment of complex regional pain syndrome at a tertiary care hospital between February 2007 and July 2010. Exclusion criteria limited data collection to first-time admissions, which eliminated 1 repeat admission for a total of 32 unique admissions and subjects for this study.

The diagnosis of CRPS-1 was made by 1 of 3 pediatric physiatrists working at the clinic and hospital with experience in diagnosing and treating children with CRPS-1. The diagnosis was based on symptoms of pain, focal or diffuse, hyperesthesia or allodynia, swelling, changes in skin color or

temperature, decreased mobility or function, effects of prior treatment approaches, and lack of other diagnoses. These signs and symptoms form the basis for the diagnosis of pediatric CRPS-1 as suggested by Stanton et al [20], which include pain out of proportion to the inciting event combined with evidence of neurovascular dysfunction as manifested by dependent edema, dependent rubor, skin mottling, hypersensitivity to light touch, skin temperature changes, altered perspiration, and/or changes in patterns of hair growth. Patients were admitted for treatment based on diagnosis, patient and family willingness to enter treatment, and approval from insurance.

Admission and discharge data for pain and functional status were obtained by chart review. Pain was rated on a 0-10 numerical rating scale, with 0 being no pain and 10 being the worst possible pain. Data on long-term outcomes were obtained by a follow-up telephone survey completed 6 months or more after discharge. The telephone questionnaire included questions regarding the number of recurrences, resolution methods for any recurrences, any further treatment provided after discharge, and pain and functional levels on the day of the telephone interview. The parents were interviewed, unless the child was older than age 18 years at the time of the telephone interview, in which case the patient was interviewed.

Treatment

Inpatient lengths of stay varied depending upon the needs of the child and response to treatment, but all children participated in 5 hours of therapy per day, 5 days per week. The 3 hours of daily PT included timed, high-intensity aerobic activities, lower and upper extremity strengthening, core strengthening, stretching or yoga, and balance or coordination activities. Aerobic activities included the treadmill, stationary bike, step-ups on a bench, sprints, and various nontypical mobility activities. The patients were required to beat the previous day's timed aerobic activities by 1 second before moving to the next activity. Daily occupational therapy included 2 hours of exercises such as push-ups, sit-ups, plank exercises, or using an upper extremity bike. Desensitization exercises, such as brushing, towel rubbing, lotion rubbing, or fluidotherapy, were performed on the affected extremity for 15 minutes twice a day. Also, during the weekdays, the patients performed school activities for 30 minutes, had psychological counseling that taught stress management and pain coping skills, and had 30 minutes of self-directed PT on their own in the evenings. Additional services included art therapy, recreational therapy, and child life therapy. A few children were referred for a psychiatric consultation. Weekend therapy included 2.5 hours of PT and occupational therapy on Saturday, plus 45 minutes of self-directed therapy on both weekend days. Family visitation was limited. Each patient was given an individualized home therapy program

Table 1. *Patient characteristics*

Girls, n (%)	26 (81)
Boys, n (%)	6 (19)
Mean age (range), y	14.3 (8-18)
Mean duration of symptoms before treatment (range), mo	9 (0.5-48)
History of injury or trauma, n (%)	17 (53)
History of psychological diagnosis, n (%)	14 (44)
Perfectionist or overachiever personality traits, n (%)	16 (50)

after discharge, with the expectation to perform 45 minutes each weekday, and 90 minutes on each weekend day, until full functional activity was established.

Either before or shortly after admission, the patients were weaned off any medications being taken for CRPS-1. The patients were allowed to take acetaminophen or ibuprofen for headaches or soreness. The patients were discharged once they had reached their best performance on the above activities and demonstrated an ability to perform their home program.

RESULTS

Patient characteristics are depicted in Table 1. The mental health diagnoses at admission included depression (6 children), anxiety (9), attention-deficit/hyperactivity disorder (3), somatization or conversion disorder (2), eating disorder (1), and posttraumatic stress disorder (2). An additional 4 children were seen by a psychiatrist during their inpatient treatment and were diagnosed with general anxiety disorder (3), dysthymia (2), and depression (2). School absences were recorded for 28 children (88%), which ranged from missing several days due to the pain, to being home schooled secondary to pain and immobility. Five children (16%) had a previous diagnosis of chronic headaches or migraines.

Signs and symptoms on the day of admission, location of pain, and previous treatments are listed in Tables 2, 3, and 4, respectively. All the children had at least 1 prior treatment approach, although typically more. Functionally, 8 children (25%) required the use of crutches for ambulation, and 4 (13%) used a wheelchair, and 3 (9%) were non-weight-bearing secondary to pain. The admission median pain rating was 8.5 (range, 5-10). The average length of stay was 19 days, with a range of 8-32 days.

Table 2. *Signs and symptoms on day of admission*

	n (%)
Pain	32 (100)
Hyperesthesia	27 (84)
Skin color changes	15 (47)
Temperature changes: hot or cold	13 (40)
Swelling	5 (16)

Table 3. *Pain location*

	n (%)
Lower extremity only involved	14 (44)
Neck, back, abdomen, or torso involvement	10 (31)
Upper extremity only involved	5 (16)
Both upper and lower extremity involved	3 (9)

All the children completed inpatient treatment. At discharge, the pain rating dropped to a median of 2 (range, 0-10). Eleven children (34%) had complete resolution of their pain at discharge (Figure 1). No child required the use of crutches or wheelchairs, although 5 (16%) were unable to participate in physical or sports activities. One of these 5 had limitations secondary to focal atrophy, not due to pain, and one had limitations due to hemiplegic cerebral palsy. Nineteen families (59%) were successfully contacted for the follow-up telephone survey. The remaining 13 families were lost to follow-up due to disconnected telephone numbers (3), failure to answer telephone calls (6), or nonresponse to messages (4). The average time to survey follow-up was 21 months, with a range of 6-43 months.

Of the 21 children who continued to have pain on discharge, 14 (67%) had resolution of their pain at a median of 2 months (range, 1-11 months) (Figure 1). Four who had pain on discharge were lost to follow-up. Of the 19 children who participated in the follow-up telephone survey, 3 never had pain resolution, with 2 reported a current pain level of 2, and one reported a level of 6. These ratings were less than their admission ratings, with reductions of 7, 3, and 2. Overall, 25 children had resolution of their pain. This is 78% of admissions and 89% of those with known outcomes.

Relapses occurred in 7 children (37%), including 1 relapse, or flare, in a patient whose pain improved but did not resolve after treatment. Six patients achieved full resolution of the recurrence. Five achieved resolution with home-based exercises learned during their inpatient treatment. One patient required additional outpatient therapy. The child with the flare was admitted for a second intensive therapy program, which resulted in reduction of the pain but still failed

Table 4. *Previous treatments*

	n (%)
Nonsteroidal anti-inflammatory drugs	21 (66)
Outpatient physical therapy	20 (63)
Opiates	17 (53)
Antidepressants	16 (50)
Gabapentin	13 (41)
Benzodiazepines	10 (31)
Cast or splint of extremity	5 (16)
Muscle relaxants	5 (16)
Oral steroids	3 (9)
Local injections	2 (6)
Sympathetic nerve block	2 (6)
Epidural injection	1 (3)

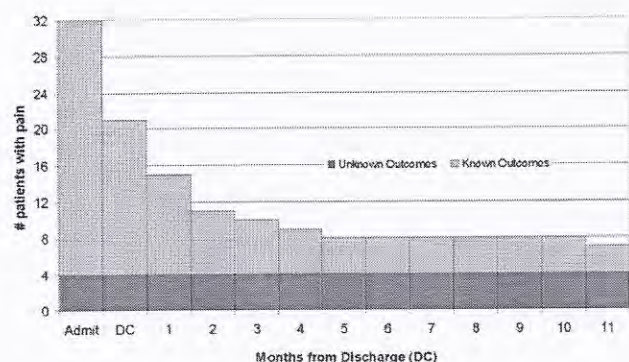


Figure 1. Resolution of pain over time. Bars indicate number of patients with unresolved pain at each time interval.

to achieve resolution. Although counseling was recommended for nearly all the children after discharge, only 5 participated, all of whom had eventual resolution of their pain.

Three children had additional treatment for their CRPS-1 after discharge. One child began with a personal trainer after discharge as well as treatment by a naturopath and an acupuncturist, with eventual full resolution of pain. Two children saw other allopathic physicians after discharge for their pain. One child had full resolution of pain 11 months after discharge and after seeing a pediatric rheumatologist who used the same therapeutic techniques as in this study. The other child saw a pain center physician, attempted biofeedback with no resolution of pain, received a diagnosis of nonepileptic seizures, and never had pain resolution. One child continued with outpatient PT after discharge for focal muscle atrophy. Of the 5 children who reported functional limitations on the day of discharge, 3 children continued to report physical activity limitations on the day of the follow-up survey. However, one was due to hemiplegic cerebral palsy, one to new knee instability, and one to CRPS-1.

DISCUSSION

CRPS-1 occurs in both the adult and pediatric populations, but it differs in several respects. Pediatric CRPS has a 6-7:1 female:male ratio, whereas adults have a female predominance of 2-4:1 [14,35]. Children also tend to have symptoms in the lower extremities 3-6 times more frequently than in the upper limbs, whereas adults more frequently have upper extremity involvement [14,35]. In addition, children tend to have less-pronounced neurologic or sympathetic symptoms [35]. In our experience, children have not developed nail or hair growth changes. Adults have quite variable rates of recovery and frequently have long-term disability, whereas children are more likely to have complete resolution.

Many of our pediatric patient characteristics follow the pattern of previous reports and studies of children with

complex regional pain syndrome, including the female predominance of patients [2,4-6,13,15,16,19,20,23,31-34,36-38], lower extremity involvement greater than upper extremity [2,5,8,13,15,18-20,23,33,34,36,37,39], and not always having an inciting event or trauma [2,3,5,6,15-17,20,23,31,33,34,36,38,39]. Previous reports showed an average age of 10.7 years at onset of CRPS-1 symptoms, whereas others reported median ages of 12, 13, or 14 years [4,23,33,38]. Previous reviews also reported an average duration of CRPS-1 before treatment of 6.3 months, or medians of 2, 4, 5, and 12 months [4,17,20,33,38]. In our sample population, the average age of onset of CRPS-1 was 13.3 years, and the median number of months before inpatient treatment was 9 months, both of which were higher than most previous published reports. The higher duration of symptoms before inpatient treatment could be explained by a delay in diagnosis, attempts at other treatments, or a delay in getting approval for inpatient treatment.

Our pain resolution rate is similar to prior studies on outpatient and inpatient therapy intervention, which ranged from 60%-100% [2,32-34]. Our high functional restoration rate is also similar to these studies but lacks a validated and thorough measure. We found a median time to resolution of pain of 2 months (range, 1-11 months) (Figure 1). For studies that reported time to resolution, the range was 2 weeks to 2.5 years [16,17,20,21,25-29,31,36,40,41,42].

Recurrences of CRPS-1 symptoms occurred in 7 of the 19 children contacted for follow-up in this study. This percentage of recurrences (37%) is not uncommon, and falls within a similar percentage range reported in previous studies [2,3,5,6,10,17,20,26,30,33,36-38,41,42]. Recurrences were found to occur either in the original area or the limb, or occasionally occurred in a new location. Regardless, the skills learned in inpatient rehabilitation were effective in resolving pain and dysfunction in 5 recurrences and kept these children from having to seek out further medical interventions.

Many researchers in previous studies have suggested that there is a strong psychological association in children who have complex regional pain syndrome [2,4,20,23,30,32,37-39]. Despite this association, causality cannot be substantiated, for several reasons. As noted by Bruehl and Carlson [43] and Lynch [44], the previous studies were not prospective trials, and they lacked control groups, had small sample sizes, and did not always have valid Diagnostic and Statistical Manual of Mental Disorders—III (DSM-III) diagnoses, which relied instead on statements of personality characteristics. Our study found the same associations but also had the same limitations. It also was difficult to make any assumptions regarding the relationship of mental health to complex regional pain syndrome, because depression and anxiety can occur as a result of chronic pain. Sherry et al [38] notes this in their reviews, with understanding that a preceding depression can lead to chronic pain or that the distress of a chronic pain syndrome can lead to depression. The high prevalence

of psychological diagnoses in children with CRPS-1 require skilled professionals to treat the mental issues at the same time the therapy is working to decrease pain and increase function.

Three children in our study with known outcomes did not resolve their pain, which limits the ability to compare them with the children who did resolve their pain. However, it is interesting to note the characteristics of the 3 children who seemed to have failed our inpatient treatment program. First, these children had unusual pain distributions. The first one with diffuse pain covering the face, chest, back, and bilateral legs, as well as complaints of chronic fatigue. She had no initiating injury, no known history of a psychiatric diagnosis but did have a history of hyperflexibility. At discharge, this child reported a change in pain rating from 5 to 2, and, at follow-up, a pain rating of 2, which suggests at least an initial response to treatment. At follow-up, she also continued to report functional limitations, including an inability to sit or move for long periods of time.

The second child had right upper quadrant abdominal pain after a resection of a local nodular hepatic hyperplasia. In addition, this child also had autonomic changes in her feet, as well as numbness on her abdomen. She went on to receive treatment at another clinic and was subsequently found to have nonepileptic seizures. Unlike the first patient, she did not report any immediate decrease in her pain; she reported both an admission and discharge pain rating of 8. At long-term follow-up, her pain rating had decreased to 6, although she continued to miss school and participated in very limited physical activities. The third child had back and bilateral posterior leg pain with significant headaches. His back and leg pain, but not his headaches, improved after treatment, with a reported change from 9 to 2. However, his pain did not resolve, and he was readmitted for a second inpatient stay after injury resulted in worsened CRPS-1. His pain improved after the second stay but did not fully resolve.

The limitations of our study are similar to those in earlier studies on children with CRPS-1. The number of study participants is small; there are no control groups for comparison; and not all children participated in the follow-up survey. Even though our rates of resolution of pain and restoration of full function are encouraging, further study is required to determine whether outpatient therapy is more or less effective than intensive inpatient therapy or other treatment approaches.

CONCLUSION

The results of our study suggest that intensive inpatient rehabilitation, which consists of physical, occupational, and psychological therapy, without the use of other medical intervention and followed by a home program, is effective for children with complex regional pain syndrome even when other approaches have failed. Additional studies are necessary to compare this treatment with other approaches.

UNCITED REFERENCES

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Management of Pediatric Patients With Complex Regional Pain Syndrome

Robert T. Wilder, MD, PhD

Abstract: This review summarizes current information about diagnosis and treatment of complex regional pain syndrome (CRPS) in children. Although it has been widely held that CRPS in children is intrinsically different from adults, there appear to be relatively few differences. However, there is a marked preponderance of lower extremity cases in children. Historically, psychological factors have been invoked to explain the genesis and persistence of CRPS in children, but the evidence is not compelling. Treatment outcome studies are limited but indicate that children generally respond to a primary focus on physical therapy. Multidisciplinary treatment reports are particularly encouraging. The general perception that children have a milder course may relate to the potentially greater willingness of children to actively participate in appropriately targeted treatment rather than to innate differences in the disease process itself. Recurrence rates appear higher than in adults, but response to reinitiation of treatment seems to proceed efficiently. Clinical judgment dictates the extent of medication or interventional therapy added to the treatment to facilitate rehabilitation. In many ways, the approach to the treatment of children mirrors that of adults, with perhaps greater restraint in the use of medications and invasive procedures. The rehabilitation of children with CRPS, like that of adults with CRPS, needs further rigorous investigation.

Key Words: complex regional pain syndrome, pediatric

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DEMOGRAPHICS

In children less than 18 years of age, complex regional pain syndrome (CRPS) type 1 develops most commonly in girls, with the incidence rising at or just before puberty.^{1–5} The lower extremity is more commonly affected than the upper, with a ratio of about 5:1. Type 1 CRPS seems to be more common among Caucasian children. I have noted this association in my practice at both Children's Hospital, Boston, and at the Mayo Clinic, Rochester. To exclude sampling bias, physicians at Children's Memorial Hospital in Chicago and Children's

Hospital Medical Center in Cincinnati were also polled (personal report from S. Suresh, Children's Memorial Hospital, Chicago, IL, and K. Goldschneider, Children's Hospital Medical Center, Cincinnati, OH). Although these hospitals have a substantial proportion of minority patients, the same association was seen there. Bernstein et al⁴ also reported this association: 18 of 23 patients in their report were Caucasian, 4 Hispanic, and 1 black. This may not be unique to children, however as Allen et al reported a similar distribution in adult patients: 91% (107 of 118) of their population was Caucasian.⁶

CRPS type 2 is found with roughly equal incidence in both boys and girls and has been noted in children as young as 3 years of age.^{7,8} Interestingly, however, even though brachial plexus injury during delivery is common and can lead to longstanding motor weakness, neonates with Erb's palsy do not generally develop pain in the extremity.

DIAGNOSIS

The diagnosis of CRPS remains a clinical one based on appropriate findings in the history and physical examination. Pain, particularly with allodynia, and signs of autonomic instability either historically or on examination are required to make this diagnosis. The pain should be out of proportion to the inciting event, if any, and is usually distally generalized in the extremity.⁹ Pathologic processes that might explain the pain must be excluded. There are no laboratory tests that can absolutely confirm or exclude this diagnosis.

A group from Belgium including Herregods,¹⁰ Franckx,¹¹ Chappel, and others has argued that disturbed vascular scintigraphy with increased pooling in the initial phase and hyperfixation on bone scintigraphy is necessary on bone scan to make the diagnosis of CRPS. In contrast, most other authors find that bone scans are quite nonspecific for the diagnosis of CRPS. Multiple authors have found that in patients meeting the clinical diagnosis, bone scan may show either hypofixation or hyperfixation or may be normal.^{3,5,12,13} This is not to say that bone scans are not useful in working up the patient with signs and symptoms of CRPS; however, the primary utility is in ruling out some underlying orthopaedic abnormality that might be triggering the neurovascular changes rather than diagnosing CRPS.

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TREATMENT

CRPS in pediatric patients has always been considered different from CRPS in adults. Early large series of CRPS (or reflex sympathetic dystrophy, as it was known at the time) suggested that the syndrome was extremely rare in children.^{14,15} Sporadic early reports of children with CRPS first appeared in the 1970s. Several of these patients had spontaneous resolution.^{16,17} This led to the suggestion that no treatment should be performed for children with CRPS. The rationale was that all treatments carry risks and side effects, and for a self-limited disease these should be avoided.¹⁷ Other authors used treatment strategies very similar to those used in adults, including sympathetic blocks, antidepressants, vasodilators, steroids, and so forth, generally with complete resolution of the disease.^{15,17-19} Between these two extremes was a group of authors recommending conservative treatment consisting primarily of physical therapy (PT) either with^{8,20} or without⁴ concomitant use of transcutaneous electrical nerve stimulation (TENS). The overall impression is that CRPS is more easily treated in children than in adults. This impression is challenged by later reports from Wilder et al,¹ Stanton et al,³ and Greipp^{21,22} showing that a percentage of children will have long-term pain and disability even with aggressive therapies such as sympathetic-chain catheters, and antidepressant and anticonvulsant medications.

Physical Therapy

A recent report by Sherry et al⁵ contradicts this pessimistic viewpoint. Using a program consisting exclusively of PT up to 6 hours per day, without any blocks or medications, they reported a cure rate of over 90%. These impressive results are similar to those Bernstein et al⁴ reported for PT alone two decades earlier. Murray et al²³ also reported similar results using PT as the primary treatment modality: 40 of 46 patients resolved with intensive PT alone.

A major school of thought is that PT is the treatment modality that offers a chance for resolution of CRPS in either adults or children.²⁴ All other therapies, when used, should be prescribed with the goal of facilitating the basic PT regimen. From this hypothesis one would predict that more intensive PT would provide faster and more complete resolution of CRPS. Although nonrandomized trials of intensive PT by Sherry et al,⁵ Murray et al,²³ and others would seem to support this, a recent prospective randomized trial by Lee et al²⁵ does not. In this study patients were assigned to once-weekly or three-times-weekly outpatient PT along with a baseline of weekly cognitive-behavioral sessions. Results for both groups were good, with pain scores decreasing to near zero and function improving, but no statistically significant difference was found between the two groups. This may have been limited by small sample size (13 per group) or because the actual amount of exercise performed may have been similar between the two groups. Curiously, the trend was for more complete resolution in the once-weekly group.

TENS

TENS is a noninvasive physical modality that may provide excellent analgesia for some patients. It has been described in several case reports and series.^{1,26-32} None of these series describe TENS as universally effective, and there are no prospective, blinded trials of efficacy. In view of the modest cost, generally high acceptance by children, and remarkable safety of this device, it is almost always worthwhile giving a trial of TENS as part of a multidisciplinary approach to CRPS.

Biobehavioral and Psychological Treatments

Much has been written about psychological aspects of children with CRPS. Authors have invoked psychological contributions to the disease since the earliest case reports of CRPS in children appeared. Carron and McCue, in their 1972 description of a child with CRPS, stated that they made "the usual referral to psychiatry and for sympathetic blocks."¹⁵ Some authors have even presumed that CRPS is entirely a psychological or psychosomatic disease process.³³ Presumably they are confused because CRPS crosses dermatomes and areas of innervation by single nerves to form a distally generalized stocking-and-glove distribution. The marked allodynia and pain far out of proportion to the original inciting injury, if any, have also caused many practitioners to question whether CRPS has an organic basis or is of purely psychological origin.

There is scarce evidence that children with CRPS are psychologically unique. Sherry and Weisman³⁴ studied 21 families of children with CRPS. These were generally high-achieving, compliant children. They found that in virtually all cases there was significant parental enmeshment with the patient. Beyond that, they found that multiple different stressors were present in these children, including marital conflict between the parents ($n = 12$), significant school problems ($n = 13$), and sexual abuse ($n = 4$). Testing revealed no major psychopathology, except for one child who scored high in somatization. Sherry and Weisman suggested that CRPS is frequently a stress-related disease, and the therapeutic approach must take these psychosocial factors into account. One difficulty with this study is that appropriate control groups were not tested with equal thoroughness. Children with new-onset arthritis were compared in terms of global assessment, but the other psychological tests were not reported for this control group. A healthy control group was not included.

A case series by Brommel et al³⁵ also found psychological dysfunction in children with CRPS. They concluded that the despair of the patients about their reflex sympathetic dystrophy expressed unsolved fears of early childhood. Again, no control groups were studied. Stanton et al,³ in reviewing a series of patients with CRPS, noted that 83% of the patients given psychological evaluations had "significant emotional dysfunction." This was not further defined, although they also noted a great deal of stress in the lives of the patients. In contrast, Vieyra et al³⁶ performed a preliminary study comparing

patients with CRPS to children with migraine headaches and 21 normal controls. Contrary to expectations, no differences in family functioning were found among the three groups. Unfortunately, this work was never published in a peer-reviewed journal. A literature review by Lynch³⁷ in 1992 and recent prospective psychological studies of CRPS in adults also support that these patients are not psychologically unique from others with chronic pain.^{38,39}

In isolated cases, psychological factors may indeed have a predominant role in the etiology of CRPS. Jaworowski et al⁴⁰ reported CRPS in a 12-year-old who developed simultaneously a conversion disorder; her identical twin also developed an identical conversion disorder.

Whether or not psychological dysfunction exists prior to the onset of CRPS, psychological, cognitive, and behavioral strategies are often used as part of the treatment of children with CRPS. Case reports of successful treatment of CRPS with cognitive and behavioral strategies began to appear in the 1980s.^{41,42} There are no prospective placebo-controlled trials of cognitive and behavioral therapies in the treatment of CRPS, either in adults or children. Their use is extrapolated from case reports and prospective series for other pain states, notably headache.^{43,44} Wilder et al¹ reported that 57% of their patients who received such training benefited from it and continued to use this treatment modality. Stanton et al,³ however, found that psychological interventions were not consistently effective. This was felt to be due to the short time for interactions with the therapist during the patient's inpatient admission. Lee et al²⁵ used cognitive and behavioral therapy as part of their baseline treatment of CRPS patients who were randomized to receive one or three sessions per week of PT. Compliance with attending the sessions was good and overall results were good, but the specific effect of the cognitive and behavioral treatments was not broken out. Sherry et al⁵ did not use formal cognitive or behavioral treatments in his series of 103 patients treated with intensive PT, but they did refer 77% for psychological counseling, either individual or family. The results from the counseling were not measured or studied.

Sympathetic Blocks

In previous years many authors have equated sympathetically mediated pain with CRPS. During the 1993 consensus conference that eventually led to the new taxonomy of CRPS, there was widespread agreement that the pain of CRPS could be sympathetically maintained, sympathetically independent, or some combination of both that could change over time.⁴⁵ Sympathetic blocks may help define the proportion of pain that is sympathetically mediated at that time and may be of therapeutic benefit, but they do not confirm or revoke the diagnosis of CRPS. When sympathetic blocks are used in the treatment of childhood CRPS, several authors have proposed the use of indwelling catheters rather than repeated single injections.^{1,25,46} There are several reasons

to prefer this technique. First, accurate placement of a lumbar sympathetic block is facilitated by use of fluoroscopy. Minimizing radiation exposure is appropriate for children. Second, many children and adolescents require heavy sedation or a brief anesthetic for the placement of these blocks. Minimizing the number of anesthetics required is also useful. Third, the goal of the sympathetic block is not to "treat" the CRPS per se, but rather to provide adequate pain relief that the patient can effectively engage in PT. An indwelling sympathetic-chain catheter, when effective, provides continuous pain relief without motor or sensory dysfunction and can be highly effective in allowing PT to proceed. These patients are generally hospitalized. Indeed, one advantage of the indwelling catheter is that it mandates hospitalization, which may allow more intensive PT than is available on an outpatient basis. Single-shot sympathetic blocks need to be coordinated with the PT sessions so that the patient is pain-free during the sessions. Indwelling epidural catheters, although often effective in relieving the pain, cause sufficient motor and/or sensory block that the patient cannot effectively participate in PT. This may be counterproductive, as any immobilization of the limb appears to worsen CRPS. Use of clonidine or opioids along with low concentrations of local anesthetic in the epidural catheters may avoid this problem, but this may not provide adequate analgesia. Several authors who emphasize intensive PT as the sole treatment modality for childhood CRPS actually recommend against the use of sympathetic blocks.^{3,5,23} They have reported success motivating their patients to participate in PT despite ongoing pain and allodynia. Others^{1,25,47} have used blocks to improve compliance in patients unwilling or unable to participate in PT secondary to pain. At present there are no prospective trials directly comparing outcomes in pediatric CRPS with or without sympathetic or epidural blockade.

Medications

There are also no prospective randomized clinical trials of any medications in the treatment of CRPS in children. Case reports and case series have reported success with tricyclic and other antidepressants,¹ anti-convulsants (particularly gabapentin),^{48,49} steroids⁵⁰⁻⁵⁴ (either systemically or as part of an intravenous regional technique),⁵⁵ nonsteroidal anti-inflammatory agents,⁵⁶ and opioids, both systemic and neuraxial. A good deal of controversy exists about drug therapy for this condition. Many authors have found steroids to be of no benefit.^{1,4,57} Those who stress the value of intensive PT suggest that no medications are appropriate.^{5,23} The rationale is that all medications may have side effects and the potential for morbidity. As they are not necessary in the view of these authors, they should be avoided. Sherry et al stopped all medications at the start of the PT program.⁵ A direct comparison of intensive PT with or without any of these medications is lacking.

Neurosurgical Techniques

A few children with CRPS fail to respond to multiple treatment approaches, including the stepwise multidisciplinary approach used by Wilder et al¹ and Lee et al²⁵ and the intensive PT approach used by Sherry et al.⁵ These children and their parents will often seek multiple medical opinions and undergo increasingly invasive and dangerous procedures in their quest for pain relief. Two types of neurosurgical procedures have been used in these patients: spinal cord stimulation (SCS) and sympathectomy. There is moderate evidence supporting the use of SCS in the treatment of CRPS in adults. Retrospective series by Kumar et al⁵⁸ and Kemler et al⁵⁹ and a later prospective series by Kemler et al⁶⁰ all show efficacy in terms of sustained pain reduction of modest proportions. Pain thresholds are not changed by SCS.⁶¹ No series of children undergoing SCS have been reported, although I know of at least a half-dozen children who have undergone SCS for CRPS. Results have been mixed, ranging from modest improvement in pain and function to a worsening of pain, with explantation of the system. SCS has an advantage over sympathectomy in that it is nondestructive and completely reversible.

Sympathectomy, either chemical or surgical, has been reported in children with CRPS. Disadvantages of this procedure include the fact that it is appropriate only for the sympathetically mediated portion of the patient's pain, that it is irreversible and may cause sympathalgia, and that long-term physiologic effects of lumbar sympathectomy on adolescent girls are not well characterized. In a mixed series of adults and children, Bandyk and Johnson⁶² reported an initial 10% failure rate. With 30-month follow-up, long-term results showed a reduction in pain relief overall to 25% excellent relief (pain scores < 3 of 10), and 50% with pain that was moderately reduced from before the block. Wilder et al¹ reserved the use of sympathectomy for patients with impending loss of function from cellulitis complicating massive peripheral edema. The three patients undergoing these procedures did not have improvement in pain scores despite improvement in circulation and edema.

Complementary and Alternative Medicine

Randomized, blinded trials showing the efficacy of acupuncture are also lacking in CRPS. One such study has been performed, but there was improvement in both groups, with no statistical difference between groups.⁶³ There are studies showing a surprisingly high acceptance rate for acupuncture therapy among children.^{64,65} There are also case reports of benefit to this therapy.⁶⁶ It is rational to think that acupuncture, by its mechanisms of raising endogenous opioids and acting as a counter-stimulant to "close the gate" on spinal cord transmission of pain signals, might be of benefit in this disorder. Well-blinded studies are difficult to design, however, so obtaining definitive proof of efficacy may be slow in coming.

Although many patients may have used herbal remedies and nutritional supplements, there are no

studies or even case reports of their efficacy. Most herbal remedies contain active biochemicals. They may indeed benefit some patients, but they may also have significant interactions with any medications that might be prescribed, and may have toxicity in their own right.

CONCLUSIONS

CRPS in children has been widely held to be intrinsically different from that in adults. This has been based on both demographics and a perception that children may have a milder course or a better response to conservative treatments. Other than the marked preponderance of lower extremity CRPS in children and adolescents, the demographics do not seem all that different for children than adults. A female preponderance exists for both groups. Both appear to have Caucasian predominance. Psychological factors are often invoked in pediatric CRPS, including enmeshment of the patient and parents and a degree of overachievement. Although this certainly may play a predominant role in some cases, the available evidence is not compelling that children with CRPS are unique compared with either other children with chronic pain or adults with CRPS. Finally, as regards the perception that children have an easier course than adults do, the evidence is not strong. Certainly, several series have reported children responding to courses of intensive PT alone. Nonetheless, the consensus is that PT is the definitive treatment of adults with CRPS as well as children. I have been unable to locate any series of intensive (5–6 hours per day) PT programs for adult patients analogous to that reported by Sherry et al.⁵ Series using less-intense PT, as reported by Wilder et al¹ or Lee et al,²⁵ give results similar to a stepwise multidisciplinary treatment plan in adults.⁶⁷ The apparent mildness of pediatric CRPS may be due to a greater willingness of children to actively participate in appropriate PT more than to an innate difference in the disease process itself.

The potential for recurrence of CRPS is often of great concern to children with this syndrome and to their parents. Studies have shown a fairly high rate of recurrence in the same limb after successful treatment or spread to another limb concurrent with the initial diagnosis.^{5,25} Recurrence occurred in approximately 30%⁵ to 50%²⁵ of patients, a much higher rate than the rate of 1.8% per patient-year reported for adults.⁶⁸ Although recurrence is common, it generally seems to respond more readily to physical therapy and related treatments than the initial episode.^{5,25} A case report by Tong and Nelson⁴⁸ illustrated that for some children the recurrent bouts of CRPS may be as severe as or even more severe than the original.

In summary, although not definitively proven, PT leading to active normal use of the involved extremity is generally held to be the single most effective therapy in the treatment of CRPS. Children may be willing to participate in PT, despite the associated pain, with proper motivation. In general, however, the clinician's job is to

help provide adequate analgesia to speed progress in PT. A stepwise, multidisciplinary approach is generally in the patient's best interest, starting with minimally invasive modalities such as TENS and biobehavioral pain management techniques. Acupuncture may be useful at this point, too, if there is a practitioner available in the community who has experience working with children. If needed, medications with a proven track record in neuropathic pain management can be added, such as the tricyclic antidepressants (nortriptyline or amitriptyline) or anticonvulsants (gabapentin and others). Children taking these medications need to be monitored carefully for side effects to optimize the risk/benefit ratio. Sympathetic blocks can be useful to accelerate recovery; they are unlikely to be effective monotherapy for CRPS, but they do have a role as a way to help a patient work more actively in an ongoing PT program. Using the above approach, most patients will have an excellent response. For those who cannot sustain improvement despite an ongoing exercise program, neurosurgical techniques such as SCS or, in highly selected cases, sympathectomy may be useful. These techniques are not guarantees of success, and they should be used only as a part of a multidisciplinary program stressing exercise and rehabilitation.

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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

Community Advice

👤 VISIT OUR CLINICIAN SITE

Take Our Chronic Pain Quiz

Introduction to Chronic Pain

Your 1st Visit to a Pain Clinic

The Weight-Pain Connection

Children in Pain

Pregnancy & Pain Management

Non-Pharmacological Pain Management

The BioPsychoSocial Model

Alternative Ways to Treat Pain

Non-Opioid Medication Guide

Gut Health and Inflammatory Pain

Can Diet Relieve Pain?

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

Psychotherapy to Control Pain

Opioids

Starting Opioid Therapy? What to Expect

Opioids & Chronic Pain: It's Complicated

5 Qs to Ask Your Doc

How to Taper off Opioids

Addiction or Dependence: Know the Difference

#NotAnAddict: The CDC Guideline and You

What to do with Leftover Meds

Resources

Anti-Inflammatory Diets for pain

Pain Devices to Use at Home

A Clinical Glossary for Chronic Pain Warriors

Support Groups for Pain

Pain Rehab: What It's Like

Get Involved in Pain Research

When Pain Drives You to the ER

Insurance Woes & Pain Patients

For the Caregiver

50-Plus Resources Every Pain Patient Needs

- 6 Arrange special transportation if traveling on a crowded, bumpy school bus is too difficult.
- 7 For older students, provide a designated handicapped parking space.
- 8 Arrange for the student to meet with the school counselor on a regular basis.²

Special Services for Those Who Can't Go to School

Students with CRPS may qualify for special services, such as a 504 plan or an Individual Education Plan (IEP).

Section 504

Section 504 of the Rehabilitation Act of 1973 is a civil rights law that prevents discrimination against individuals with disabilities from any institution that receives federal funds from the U.S. Department of Education. Some private schools that do not receive federal funding may be exempt from Section 504. According to the United States Department of Education, a student qualifies for Section 504 protection if he or she has "has a physical or mental impairment that substantially limits one or more major life activities."³

"I hate CRPS. I hate the pain I get from it. But, I am done letting it run my life. From now on it is not in charge, I am. Life is to be lived."

—Karen Richards, age 11

Individual Education Plan

An Individualized Education Plan (IEP) is developed in accordance with the Individuals with Disabilities Education Act (IDEA), which governs special education. IDEA has a number of eligible categories, including Otherwise Health Impaired (OHI). The criteria for an OHI designation is "limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (a) is due to chronic or acute health problems...and (b) adversely affects a child's educational performance."⁴

More Information

US Department of Education, Office of Civil Rights

Protecting Students With Disabilities:

<http://www.ed.gov/about/offices/list/ocr/504faq.html>

National Dissemination Center for Children with Disabilities (NICHCY)

Individuals with Disabilities Education Act (IDEA):

<http://www.nichcy.org/Laws/IDEA/>

Disabilities: <http://www.nichcy.org/Disabilities/>

Laws: <http://www.nichcy.org/Laws/>

¹ Sherry D Short and long-term outcomes of children with complex regional pain syndrome type 1 treated with exercise therapy. *Clin J Pain*. 1999;15:218-23.

² Switalski D. Does Your Child's School Have a "Faker's Club"? The CRPS Student's Rights. *RSDSA Review*. 2008; 21:6,7,10.

³ <http://www2.ed.gov/about/offices/list/ocr/504faq.html#protected>

⁴ 34 Code of Federal Regulations § 300.7(c)(9) (hereinafter C.F.R.). [<http://www2.ed.gov/legislation/FedRegister/finrule/1999-1/031299a.pdf>]

Reflex Sympathetic Dystrophy Syndrome Association, 99

Cherry Street, Milford, CT 06460, www.rsd.org, Tel: (203)

877-3790 Toll free: (877) 662-7737 Email: info@rsds.org



Helping Youth with CRPS Succeed School



"At the evaluation meeting, one of your questions should be 'What are WE going to do to help my child?'"

—Dorothy Switalski

Children and adolescents suffering from complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy (RSD), need understanding and support to maintain a sense of normalcy. A student's condition may vary from day to day, and the persistent pain associated with CRPS is invisible, so many health care professionals and school personnel may assume the child is faking and may doubt his or her pain.

If you visit the RSDSA website, there are several stories from young women who, in spite of the terrible pain caused by CRPS, are achieving their goals and living fulfilling lives. Yvonne writes, "My life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life."

We want to help you understand how you can help children who have CRPS, either by simply being supportive or helping make accommodations and modifications in the school environment. Your support and understanding can determine whether our children succeed or fail.



What is CRPS?

CRPS is a neuroinflammatory syndrome characterized by pain in one or more limbs and/or ankles, feet, abdomen, or hands though virtually any part of the body can be affected. The pain, described as burning or sharp, typically appears after a traumatic event, such as a broken bone, sprain, sports injury,

automobile accident, or bad fall. There is often coldness and swelling in the affected limb(s) as well as allodynia (a painful response to a normally innocuous stimulus). The pain is disproportionate to the original injury and is present long after the original trauma has healed. CRPS is more common among pre- and adolescent girls than boys by about 5 to 1. It is usually seen in girls who engage in sports, dancing, or gymnastics.

Although the cause of CRPS is unknown, overuse injuries, trauma, psychological stress, nutritional factors, and hormones are possible contributors. CRPS is thought to reflect overreaction of the autonomic nervous system, leading to transmission of pain signals after the initial injury. As there is no single test for CRPS, the diagnosis is made clinically by patient history, thorough examination, and the results of numerous tests to rule out other serious conditions.

CRPS is not life-threatening, but it can become chronic and even spread to other parts of the body. It can be highly disruptive and interfere with daily activity, leading to as many as 25% of school days missed. Early diagnosis and treatment, with an emphasis on movement, behavioral approaches, and rehabilitation, offer the highest probability of remission, which may be achieved in almost 92% of those treated.

Treatment options

Physical/exercise therapy of the affected body part is the most effective treatment for pediatric CRPS. This therapy

desensitizes and restores function—strength, endurance, and range of motion. Mind-body techniques, such as relaxation, biofeedback, and self-hypnosis, are helpful for pain management and can alleviate the fear of movement often seen in people with CRPS. Psychological interventions to help with coping and emotional responses, and family therapy, to promote adaptive parental/familial responses, can also be valuable. Medications, nerve blocks, and interventional measures, such as a tunneled epidural catheter or spinal cord stimulator, can also be used to facilitate and accelerate progress in physical therapy. A comprehensive coordinated interdisciplinary approach for CRPS management will provide the best results in the majority of children.

Students with CRPS and School

For those students who are able, we recommend the following:

- ✓ Attend school daily whenever possible
- ✓ Permit the student to go to the nurse when needed (may be experiencing a pain flare-up)
- ✓ Limit the use of over-the-counter medications
- ✓ Be allowed to walk in the back of the classroom or in the hallway periodically without disruption to others to stretch and move for pain reduction
- ✓ Establish routines and schedules for learning and extracurricular activities
- ✓ Be as independent as possible in completing assignments
- ✓ Be encouraged to practice normal activities

Other interventions that can be practiced as needed include:

- ✓ Psychological intervention for child and family to assist with adjustment to home and community, behavioral interventions, and emotional support
- ✓ Relaxation techniques and cognitive-behavioral exercises/strategies
- ✓ Monitoring for “overachiever” behaviors, over-scheduling, apathy and reduced motivation and/or initiation, and anxiety, depressed mood, and/or inflexibility.¹

When Students Require Special Accommodations

Some students may not be able to resume activities as normal. Some accommodations that have helped students with CRPS are listed below.

- 1 Because the slightest bump can cause lasting flare-ups of this very painful syndrome, every effort should be made to see that the child is not exposed to the bumping and jostling of school hallways. The student’s desk in each classroom should be positioned away from traffic patterns to avoid inadvertent bumping.
- 2 Determine whether the student needs ergonomic seating/adjustable desk.
- 3 Designate another student as a helper who can carry the student’s books/belongings during the day, help at lunch, and during the changing of classes.
- 4 Because students with CRPS in their upper extremity may have difficulty writing, allow the student to record lectures, use a keyboard with a portable word processor, or use another student’s notes.
- 5 Given that CRPS symptoms can be exacerbated by the cold, allow the student to bring a heating pad. Also, guidelines should be developed regarding whether the child should go outside for recess when it is excessively cold; care must be taken to see that the patient has adequate warm clothing, and is kept out of drafts.
- 6 Allow students to have an extra set of books at home in addition to school.
- 7 Permit the student to leave 5 minutes prior to the end of class to avoid the congested hallways.
- 8 Confer with parents as to whether they wish the child’s classmates to be aware of the syndrome.
- 9 If there is a dress code, the child may need to adapt clothing due to sensitivity to clothing and increased sweating.
- 10 Special accommodations may be necessary for school field trips, including transportation, medication disbursement, and lodging (if an overnight trip).

- 11 Ask before touching the student—a simple pat on the back can cause increased pain.
- 12 Allow a student with CRPS to sit in a quieter area of the cafeteria if the noise is bothersome; however, do not isolate the student from others.
- 13 Students with CRPS are also sensitive to noise and vibrations. Please take this into consideration when fire drills, assemblies, and pep rallies are planned. Allow students to position themselves away from loudspeakers/intercoms—even the classroom bell for beginning and end of class may affect a student with CRPS.

Limiting Stress

Because stress is a known cause of exacerbation of this syndrome, academic schedules and curricula may have to be modified, including:

- 1 Schedule all classes on one level or provide student with key to the elevator.
- 2 Implement flexible homework and make-up policies (homework and tests are a major cause of additional stress).
- 3 If a student is unable to write, modify normal test taking, and allow additional time for tests.
- 4 Reduce school time if necessary (students may be late due to pain flare-ups) and supplement with home-based instruction and tutoring.
- 5 If mobility is impaired, credit the student’s physical/occupational therapy as the requirement for gym (if the school has a pool, allow the student to use the pool during gym).

“My life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life.”

—Yvonne

TREATMENT OPTIONS

Ultimately your physician will prescribe the best program to meet your child's needs, but research has shown that physical therapy can be one of the most effective treatments for CRPS.

Other treatments, such as graded motor imagery, cognitive behavior therapy, or medication may be needed, so consult your physician as to the best course of action.

ADDITIONAL RESOURCES

CRPS is not life-threatening, but it can be highly disruptive and lead to excessive school absences if left untreated. Early diagnosis is key.

Once diagnosed, some students may require special school accommodations, such as ergonomic assessments, additional travel time between classes, revised schedules, and possibly a helper's aide.

Students who find their CRPS too painful to allow them to attend school may qualify for special services, such as a 504 plan or Individual Education Plan (IEP). For more information on available accommodations, contact your school's health services coordinator.



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RSDSA is committed to assisting individuals with CRPS as well as the people who support them

RSDSA offers emotional, financial and medical support to people with CRPS. We can also provide referrals to pediatric rehabilitation programs.

Please visit our website, www.rsds.org, if you are in need or have questions.

If you think you or someone you know has CRPS, please visit your physician and provide him or her with educational information about the disease.

Much more can be accessed through our website. You may also contact us at **877-662-7737**.

Stay connected with us by subscribing to our free monthly e-newsletter, joining our community email news blasts, or visiting our Facebook page.

Visit <https://rsds.org/rsdsa-pediatric-crps-lecture/> to listen to a comprehensive pediatric CRPS lecture presented by Elliot Krane, MD FAAP from Stanford Univ., and the Lucile Salter Packard Children's Hospital.

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WHEN YOUR CHILD'S PAIN WON'T GO AWAY

It could be **Complex Regional Pain Syndrome**



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YOU ARE YOUR CHILD'S BEST ADVOCATE

Your child frequently experiences **severe pain following an accident, injury or other trauma**. It may be accompanied by **swelling, changes in skin color, temperature, or limited mobility**. He or she is suffering, and other treatments have been ineffective. Worst of all, he or she may not be able to tell you what's wrong. **Your child could have CRPS (Complex Regional Pain Syndrome) which is formerly known as RSD (Reflex Sympathetic Dystrophy).**

CRPS is a **neurologic syndrome** characterized by severe and often burning pain. While it **affects nearly 200,000 people in the U.S.**, it is **rarely mentioned in an initial diagnosis**.

There is no gold standard for diagnosing CRPS. Only a careful and thorough exam and review of medical history by your physician can produce the proper diagnosis and recommended treatment. **Pediatric CRPS is typically under-recognized and misdiagnosed by physicians, and you may have to advocate for proper testing.**

**JUST BECAUSE YOU CAN'T SEE IT,
DOESN'T MEAN IT DOESN'T EXIST.
BUT TO RECEIVE HELP,
YOUR CHILD MUST BE HEARD.**

THE FACTS

What is CRPS?

CRPS/RSD is a **rare neurological disorder** that causes severe inflammation in the nervous system.

What Causes It?

It occurs after a **trauma**, such as a **musculoskeletal or nerve injury, surgery or broken bone**. Sometimes there isn't an initiating event.

The trauma causes the **nervous system and immune system to malfunction**. The nerves throughout the body misfire, **overwhelming the brain with pain signals**.

What Are the Affects?

CRPS is devastating. It causes **severe pain, swelling and sensitivity**. Many people are unable to walk, work, go to school, or wear clothes.

Who Can Develop CRPS?

Anyone can develop CRPS, regardless of race, age or gender. However, research shows that it is most common in girls and women.

SIGNS & COMMON SYMPTOMS

This is not an exhaustive list, but symptoms may include:

- A prior trauma (fracture, sprain, surgery, etc.)
- Constant pain described as deep, aching, burning or stinging
- If the pain is getting worse, not better, and if the pain is more severe than one would expect from the original injury it may be CRPS
- Abnormal swelling
- Excessive sweating in the affected area
- Changes in skin color
- Noticeably altered skin temperature in the affected limb
- Weakness in affected limb
- Limited range of motion
- Paralysis or dystonia
(muscle contractions resulting in abnormal positions)
- Allodynia *(pain from stimuli that is not normally painful, such as the touch of fabric or wind blowing across skin)*
- Hyperalgesia *(excessive sensitivity to pain)*
- Hair growth changes
(coarser, darker, rapid growth, loss of hair)



WHAT TO TELL YOUR PHYSICIAN

During your child's exam, ask your physician if he or she is familiar with CRPS. Also tell your doctor or clinician about any sprains, falls, surgery or other trauma your child has had recently. Provide them with information on timing, severity of pain and any other triggers you may notice.

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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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 experienced in treating CRPS. You must become the “captain” or CEO of your team. No one treatment works for everyone. Your first step is to educate yourself. RSDSA’s website has a very informative section, Diagnosed: Now What?

Your treatment goal is to reduce your pain while focusing on improving function. Other members of your team may include physical or occupational therapists, psychologists or counselors trained to help individuals learn how to manage their pain, anesthesiologists or interventional pain specialist (when warranted), and your support people.

Treatments may include: medications, topical medications, interventional therapies such as nerve blocks, intrathecal drug infusion, warm-water-therapy, physical and occupational therapies, psychological support, neurostimulation, IV ketamine or IVIG infusions or, participation in a clinical trial (clinicaltrials.gov).

THE DIAGNOSIS

There is no single diagnostic test for CRPS. Only a careful exam can produce the proper diagnosis.



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

RSDSA offers emotional, financial, and medical support to people suffering with CRPS. Please visit our website if you are in need.

If you think you or someone you know has CRPS/RSD, please visit your physician and provide him or her with educational information about the disease. Much more may be accessed on our website. You may also contact our organization.

**WE ARE HERE TO SUPPORT YOU
- YOU ARE NOT ALONE -**

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Raising awareness of CRPS since 1984

COMPLEX REGIONAL PAIN SYNDROME

LIVING WITH CHRONIC PAIN MORE
SEVERE THAN A CONSTANT
JELLYFISH STING



HOW CRPS CHANGED A CHILD'S LIFE

Once a successful swimmer and a student council member, fourteen-year-old Natalia is now trapped in her body.

After a mild wrist sprain, Natalia's fingers swelled into blood-red sausages. The pain prevented her from even holding a pencil.

Exactly a week after her thirteenth birthday, a neurologist finally diagnosed her with CRPS after many ER visits. In the following months, she was hospitalized more than a dozen times.

Just as she began to show improvement, a car collided with her school bus, and her CRPS spread. Pain covered every inch of her body; Natalia has not walked since.

Her parents have been unable to hold her hand or hug her for over a year.

Natalia's story is not unique. In the U.S. alone, nearly 200,000 people suffer from CRPS, the most painful medical disorder. Like Natalia, these people need help.

To receive help, they must be heard.



THE FACTS

WHAT IS CRPS/RSD?



CRPS/RSD is a rare neuro-inflammatory disorder that causes severe inflammation in the sympathetic nervous system.

WHAT CAUSES IT?



It occurs after a trauma, such as a musculoskeletal or nerve injury, surgery, or broken bone.

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?



CRPS is devastating. It causes severe pain, swelling, and sensitivity. Many people are unable to walk, work, or wear clothes.

WHO CAN DEVELOP CRPS/RSD?



Anyone may have CRPS, regardless of race, age, or gender. However, research shows that it is most common in women.

WORKING FOR A CURE

Since the Federal Drug Administration classified CRPS as a rare disease, RSDSA has been committed to finding a cure.

In 2014, RSDSA established the International Research Consortium, uniting forty-seven CRPS clinics and specialists worldwide to develop better treatments for the disease and to work toward 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 is not normally painful—the touch of fabric or the wind blowing)
- Hyperalgesia (excessive sensitivity to pain)

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.

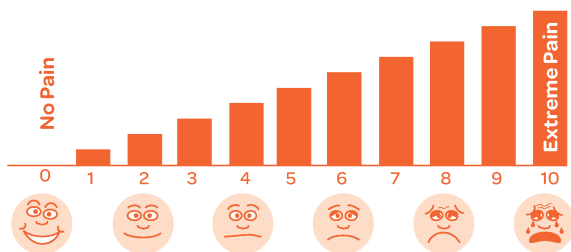
It is OK to ask me about CRPS.

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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rdsa community update

VOLUME NO.7

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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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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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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.

“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.”

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.

Pamina Bakos is a clinical nutritionist, works with her husband Stephen H. Barkow, MD, DABPM, at Orange County Pain Management in Newport Beach and Mission Viejo, California. Learn more about them at painconsultant.com.

Mast Cell Activation Syndrome and Its Role in Pain

BY **PRADEEP CHOPRA** • MD

ASSISTANT PROFESSOR (CLINICAL) OF BROWN MEDICAL SCHOOL AND STEPHANIE CARROLL, RN OF THE PAIN MANAGEMENT CENTER IN PAWTUCKET, RHODE ISLAND

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

around the nerves in the brain. Mast Cells can activate the glial cells to release inflammatory chemicals that cause the neurons in the brain to become inflamed. This is the basis of some of the cases of CRPS-I. Not all cases of CRPS – I are a result of MCAS. Mast cells communicate with glial cells. Chemical mediators such as tryptase and histamine can activate glial cells. Once the Mast cells activate the glial cells, the activated glial cells then release other mediators (pro-inflammatory cytokines IL-1 β , IL-6 and TNF) that cause neuroinflammation of the nerves in the brain, causing a sensation of severe pain. On the flip side, the inflammation as a result of misbehaving Mast cells can be reduced by medicines that inhibit mast cells.

When the skin in patients with CRPS was studied, it was shown to have increased Mast cell tryptase (one of the many chemicals released by Mast Cells). Mast cells in the skin are a major source of chemicals such as cytokines, histamines, and prostaglandins that causes inflammation. They sensitize the nerve endings in the skin.

It should be noted that not all patients with MCAS present with CRPS. In patients who already have pain from an injury, if they develop MCAS, the pain may increase many fold. Unfortunately, pain is also a trigger for MCAS.

For people with MCAS, not all days are the same. There are some days when the mast cells are not as activated, which would show up as relatively low pain days. They may have some days when

the mast cells are misbehaving and overly active. Those days, patients would have a lot more pain. A lot would depend on avoiding triggers, keeping the mast cells stabilized and blocking the effects of inflammatory chemicals released.

Diagnosis

The diagnosis of MCAS is frequently a diagnosis of exclusion. Patients present with array of baffling multi system symptoms. As a result they wind up seeing multiple physicians, who in most cases look at the patient from the lens of their own specialty and not holistically.

Due to the unpredictability of this condition on a day-to-day basis, testing may be unreliable. Consequently, many tests that are routinely ordered may come back as being within normal limits. This does not dispute the fact that many patients have debilitating and disabling symptoms. Yet, there are a number of tests for MCAS that can be performed, including a 24 hour urine collection for N-methylhistamine and Prostaglandin D2. Another test is tryptase levels. The tryptase levels in MCAS is normal in 85% of cases, which makes the test unreliable. Blood tests for histamine, Prostaglandin D2 and Chromogranin A are very difficult. The blood has to be drawn while the patient is going through a flare. The blood has to be chilled immediately. The patient has to be off a lot of medications, including ones that are used to treat MCAS.

For patients who have undergone a gastro-intestinal biopsy (usually done because MCAS affects the

GI system a lot), a specialized stain for mast cells looking at the count and shape of the mast cells may be a far more useful test. In general, the diagnosis of MCAS is based on clinical symptoms and not as much on laboratory findings.

MCAS and COVID-19

MCAS may be a sign of many underlying autoimmune dysfunctions. Patients with MCAS are at increased risk when exposed to COVID-19. As mentioned earlier, mast cells release inflammatory mediators such as cytokines. In patients with severe Covid-19 there is a cytokine storm leading to a state of hyper-inflammation. There is a suspicion that patients who develop a cytokine storm may have had a pre-existing MCAS, either as a full blown condition or as an underlying condition, making these patients more prone to the disastrous effects of COVID-19. Patients who have their MCAS well controlled may have a less severe time with COVID-19.

Management of MCAS

The management of MCAS has to be individualized to each person. A discussion on managing MCAS is very complex and has to be based on the patient's underlying condition, but it can be broadly based on the following steps.

- Anti-histamines.
- Mast Cell Stabilizers
- Avoiding triggers.
- Management of any underlying autoimmune dysfunction.

Ketamine and Low Dose Naltrexone: Some useful tools in your toolbox

BY **CHRISTIAN STELLA PHARM.D** • ABAAHP

As the supervising pharmacist/owner at Precision Compounding Pharmacy, I often come into contact with patients who all commonly suffer from chronic pain disorders. What is profoundly unique about compounding pharmacies, is that we have the ability to formulate and hand tailor a prescription, all with FDA approved raw materials and ingredients. Something to consider though, are the opportunities and specific guidance provided to you when you begin to work with a compounding pharmacy. There is a level of comfortability and a grasp of personal progression upon treating with a compound. This is something not often found in a Retail Pharmacy setting. The versatile nature of compounded medications allows pharmacists to formulate and treat with a myriad of different preparations, all of which meet and reach patient expectations, as well as preferences. Experiences such as the aforementioned, allow us to carefully treat conditions like CRPS on a case by case basis. As a result of CRPS having no specific treatment regimen or medication, it has become extremely common for CRPS patients/warriors to seek out the help and care of compounding pharmacies. At Precision Compounding, we are available at your convenience for consultation and counseling services. Additionally, we have multiple nationwide shipping options.

Extensive pain management experience and research has brought about some groundbreaking treatments of Complex Regional Pain Syndrome, or CRPS, one of them being the use of Ketamine. Ketamine is a rapid-acting, non-barbiturate dissociative anesthetic that was initially approved in 1970 in an injectable form. Ketamine works by blocking a receptor called NMDA (N-Methyl-D-Aspartate) which thereafter stops glutamate from activating excessive brain inflammation. What exactly does this mean for you? Ketamine works to stop the over excitations being caused from pain. As Ketamine is only currently approved as an injectable medication, it remains in the hands of compounding pharmacies to formulate and treat via capsules, creams, troches, suspensions, nasal sprays, etc., all of which are not commercially available through a retail pharmacy. At Precision Compounding Pharmacy, one of our most commonly used compounds is a Ketamine Transdermal formulation. For CRPS/RSD patients, our pharmacists recommend a simple formulation containing 15% Ketamine and 15% Lidocaine. We compound this in conjunction with transdermal pain cream, a highly absorbable base cream. This compound can be applied to any part/region of the body in pain. Lidocaine is a sodium channel blocker that works as a local numbing agent. Although

Ketamine and Lidocaine work very differently in the body, they both help combat localized nerve pain. It is imperative for a patient with a chronic pain condition, such as CRPS, to have something in their toolbox to apply straight onto the affected area when they have breakthrough nerve pain. Transdermal pain creams including these two pharmaceutical active ingredients stay in the local area of application which limits the absorption into the bloodstream. As a result, this curbs the side effects drastically.

Ketamine is also very commonly used in a troche formulation. Troches may seem obscure and unfamiliar, but they are virtually identical to a throat lozenge that you place under your tongue or into your inner cheek. Troches are more frequently used by physicians in pain management, as they deliver the active ingredient, in this case ketamine, right into the bloodstream. Receiving a quick and efficient dosage form is important for a patient that is suffering from CRPS. Ketamine can also be dosed in a rapidly dissolving tablet, capsule, liquid suspension, and a nasal spray.

Another compound yielding profound results in the treatment of CRPS is Low Dose Naltrexone, commonly known as LDN. Naltrexone is commercially available at all retail pharmacies in a 50mg tablet dose, used to treat alcohol dependence and

opiate withdrawal. In the 1980's, Dr. Bernard Bihari, MD discovered that naltrexone can be useful for patients with HIV/AIDS at a very small dose of 3mg. He coined this treatment discovery under the term low dose naltrexone. In using a notably lower dose, the naltrexone hits the opiate receptor and creates a negative feedback mechanism, therefore releasing endorphins. This process is essential and critical in treatment because endorphins are naturally produced to reduce pain. LDN also works by blocking the toll-like receptors which cause glial cell activation. This mechanism is known as the low dose naltrexone anti-inflammatory process. What is important to note here, is the role a compound pharmacy plays in dosing LDN, in efforts of creating these various anti-inflammatory processes. Compound pharmacists and doctors collaborate in formulating naltrexone on a case by case basis, as it is not commercially available at any dose other than 3mg. Patients with CRPS can benefit from treating with low dose naltrexone in various kinds of dosage forms. Some include, but are not limited to capsules, tablets, creams, suspensions, and troches.

Now, let us put the pharmaceutical jargon aside. Your journey(s) with CRPS is something I am a part of. Not as your pharmacist, but as yet another system of support. I have made it a promise and goal of mine in my professional career to help combat the symptoms and struggles of this disease. Each and every warrior story I have come into contact with has left a lasting impact on me and gives me all the more reason to help your

community to the best of my abilities.

Learn more about Precision Compounding Pharmacy at precisionpharmacy.net.

ERs Are a Minefield for People Struggling With Chronic Pain

Dr. Amy Baxter has written a down-to earth, practical guide how to successfully navigate interactions with ER staff when you are seeking relief from chronic pain flares. Here is her introduction: "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."

Read the full article at bit.ly/speakingdoctor

Emergency Department / Urgent Care, Hospital, Dentistry, and HCA Guidelines for CRPS Warriors

The RSDSA team has worked with CRPS Warriors and medical professionals over the years to create guidelines to help improve their care before setting an appointment and before a procedure. These guidelines can be accessed online and can also be printed out and kept handy as a part of one's medical toolbox.

Take a look at our current guidelines:

- Emergency Department and Urgent Care Guidelines for CRPS/RSD Patients: bit.ly/crpserguidelines
- Hospital Guidelines for CRPS/RSD Patients: bit.ly/crpshospitalguidelines
- Dental Guidelines for CRPS/RSD Patients: bit.ly/crpsdentalguidelines
- Healthcare Assistant (HCA), Personal Care Aide (PCA), Certified Nursing Assistant (CNA) Guidelines for CRPS/RSD Patients: <https://bit.ly/crpshcaguidelines>

Living with Chronic Pain: My Path to Freedom

BY **CRPS WARRIOR REBECCA** (LAST NAME OMITTED FOR PRIVACY)

I was injured in a work-related accident in 2011, and sustained significant damage to my leg and ankle. I fractured my fibula, dislocated my knee, tore my peroneal tendon, and damaged my peroneal nerve. Ultimately, in 2014, I was diagnosed with Reflex Sympathetic Dystrophy, now referred to as Complex Regional Pain Syndrome. By 2016 I was begging God to take me.

Throughout the first five years, I did everything in my power to improve, but I couldn't break free from the unrelenting pain. I kept going to physical therapy despite an increase of pain. I tried all of the recommended medications, none of which I could tolerate long term. I did all the standard procedures recommended by my pain management doctors, including injections and nerve blocks. I attempted a series of Ketamine infusions but was forced to discontinue them due to severe side effects. I was devastated because Ketamine gave me miraculous pain relief for the very first time since I was injured. It was a terrible blow, and I began to lose hope that I would ever find relief. I had two surgeries on my ankle, and three surgeries on my knee. Some were successful, some not.

I took steps toward emotional and mental health as well. I tried to continue practicing meditation every morning as this was my routine for over 20 years prior

to my accident. I knew that I had to stay disciplined because if I didn't, that would mean I had completely lost myself on the very deepest level. I tried my best, but pain was a major distraction. I also spent one year seeing a Pain Psychologist every week. This was my saving grace. I was fortunate to talk with someone who understood the hopelessness a person feels when they lose their livelihood, their career and their body as they knew it, to chronic pain. By 2015 the CRPS had spread up my left leg and into my left arm. For the first time in my life I could truly define agony and despair. Although my Pain Psychologist gave me a safe place to express my feelings and to examine the enormous losses I was suffering, my depression and anxiety still held me down. I wasn't able to climb out from under it. With no relief in sight, I truly wished my life would end. My desperation scared me. I didn't trust myself anymore. I thought if the opportunity presented itself, I would choose death. Finally, one day I told my doctor that although therapy had been invaluable, it was not enough. I needed more.

He understood and told me about the Inpatient Pain Treatment Program at Johns Hopkins Hospital in Baltimore. He described the program to me and sent me home with a packet of information about it. There were aspects of the program that sounded perfect for me,

and there were some that would give anyone pause, but I was truly desperate and willing to do anything.

I was terrified the day I admitted myself into the hospital in 2016. The unit was located on a locked floor where I was not permitted to bring any items that could potentially hurt me. The staff was kind, professional and most of all, empathetic. Never once did any doctor or nurse question my level of pain. That made me feel comforted and understood. They operated under the assumption that what we feel is to be taken as truth. No judgements, no feeling criticized or being doubted.

While the medical team worked diligently to find the right combination of medications for me, I was kept very busy with an interdisciplinary program which was designed to treat all aspects of life with pain. It included a host of therapeutic modalities used to educate and develop coping skills for chronic pain patients. Twice daily I attended nurse-led classes where I was constantly learning and developing skills relevant to life with chronic pain. Throughout the weeks I participated in physical therapy, occupational therapy, individual therapy, group therapy, bio-feedback, and learned about cognitive behavioral therapy. I used journal writing and art projects in my personal time as a creative outlet. I ate a healthy balanced diet and

used that time to connect with other patients. I put everything I had into the program and found that I had become so busy engaging in healthy activities that pain was no longer the very first thing on my mind at every moment. Thoughts of pain were still there, of course, but more in the background. I would be amazed every time I would catch myself “not” focusing on pain. I had learned the art of distraction.

I stayed the course, and after two months Inpatient and one month in Day Hospital, I was well enough to be discharged. The combination of medications plus mental, physical and emotional support worked for me. Of course the pain was still there, and still is, but I had learned to separate the physical pain from the emotional pain. I left feeling renewed. Integrating back into normal life, however, was unnerving. Going from such a rigid routine to having total freedom scared me. I didn’t know if I’d continue to be successful without the support I had grown accustomed to. But I was. This had been a life-changing experience. I had truly come to accept myself and my situation, and that changed my entire outlook on my future. I made the decision to carry on with grace and with faith that things were going to be okay no matter what, instead of living in fear and resentment. I understood that I am much more than my diagnosis, that I am an entire being with a life and a purpose.

These are some of the lessons gleaned from my time in the program at Johns Hopkins Hospital:

- The more I do, the more I “can” do.
- We are not alone. There are professionals who do understand and who are determined to help us.
- I can relate to all chronic pain patients, not just those with CRPS.
- Practicing mindfulness reduces stress, which reduces pain.
- Remember to challenge negative thoughts with fact-based evidence and replace those thoughts with positive ones.
- Eliminating alcohol, cigarettes, caffeine and sugar brings some relief.
- The way I feel physically is not a reflection of who I am as a person.
- My label, title, profession does not define who I am, and does not determine my worth. My heart and soul do. And they remain unchanged with CRPS.
- When I accept my situation instead of fighting it, a more hopeful outlook emerges.
- Most importantly *CRPS is not going to kill me, but depression could. So, treat what is treatable.

One of the aspects of the program that I missed the most was group therapy. I was unable to find a local support group, so six months after being discharged, I founded an in-person, patient-led support group which I facilitate in New York. Eventually I moved to Connecticut and started another support group. My goal is to start more groups in years to come. Connecting CRPS patients with one another has become the single most important thing I’ve ever done. I’ve had the pleasure of watching group members help one

another, and improve the quality of their lives. Most are managing well and living full lives despite their diagnoses.

I feel extremely fortunate to have learned so much from my time at Johns Hopkins. The program helped to reduce my pain to a more manageable level, improve my functionality, and leave me with a hopeful outlook. I owe everything to my pain psychologist, Dr. Allen Lebovits, who put me on the path to healing by recommending me for the program. The Inpatient Pain Treatment Program at Johns Hopkins Hospital was nothing short of transformative. The outstanding team of doctors, nurses and staff saved my life. This experience changed me forever and I am forever grateful.

New Suicide Hotline Number Established

The 988 Suicide & Crisis Lifeline — formerly known as the National Suicide Prevention Lifeline — collaborates with more than 200 local crisis centers across the nation to provide the free, confidential service 24 hours a day, seven days a week.

The hotline is operated by the nonprofit Vibrant Emotional Health on behalf of the Department of Health and Human Services’ Substance Abuse and Mental Health Services Administration. Learn more at 988lifeline.org

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

RSDSA UPCOMING EVENTS

WWW.RSDSA.ORG



JANUARY

Facebook Live with Carol Charland-Cliche, Author & Wellness Coach

FEBRUARY

Facebook Live with Apkar Vania Apkarian, PhD on Brain Mechanisms of Chronic Pain

Louisiana Jeepers Jeep Show & Gumbo Cook-Off

MARCH

Pediatric Networking & Fun Event - TBA

YOU CAN PLAN A SPECIAL EVENT WITH RSDSA

You can make a difference in the lives of CRPS Warriors and those who love them by organizing a special event. When you host a special event you increase awareness, build community and raise funds. Invite your friends, family, coworkers and everyone you know to get involved in our events.

You can organize in-person, virtual or hybrid events. Special events can be opportunities for fun, engagement, and education. Every dollar raised supports RSDSA's mission and makes our work possible. Your donations are gratefully received, impactfully used, and profoundly appreciated.

We are here to help you plan your own special event. When you are ready, please contact Jeri Krassner, RSDSA's Special Events Coordinator at jkrassner@rdsd.org or call or text (917)597-7256

Please provide your email, contact number and your location.

Thank you

CAROLYN'S CARDS

Carolyn's Cards is a program led by Carolyn McNoldy that sends cards and other small surprises through the mail to individuals with CRPS and to their caregivers. Carolyn wants to help those feeling isolated or down to not feel alone, and to ensure they feel encouraged, supported, and part of a community. Most importantly, she wants to give them a smile.

The program was inspired by Carolyn's mother who would send her cards when she was down, in a lot of pain, or recovering from surgery as they would help to brighten Carolyn's day. She thought it would be great if she could reciprocate that feeling for others. She started sending cards to the attendees of the first Young Adult Weekend as a way to stay connected to them and show support. Carolyn was surprised to hear how much they genuinely enjoyed the cards. She has continued to add names to her list after each Young Adult Weekend.

If you would like to send a card to a Warrior as the holiday season approaches, please send the person's name and address to carolyns.cards2@gmail.com.

Don't see an event near you?

Contact Jeri Krassner jkrassner@rdsd.org
to discuss planning an event in your area!



Turn hurt into help. Donate today. Call 877.662.7737 or visit www.rdsd.org



**DONATE NOW
ONLINE**

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

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

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