Welcome to RSDSA:

The RSDSA is a 35-year old not-for-profit organization. RSDSA’s 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. Being part of our RSDSA community is important. There is power in numbers. We have a community of more than 22,000. But we must increase our community so that Congress, The National Institute of Health, pharmaceutical corporations, and insurers hear our collective voice!

I recommend you sign up for our free electronic e-Alerts if you haven’t done so already at http://rsds.org/joinmembership/ to receive not only the RSDSA Community Update but information on upcoming RSDSA fundraisers and other important information.

Please join us on social medial on Facebook and Twitter @RSDSA.

RSDSA has state-by-state listings of healthcare professionals interested in treating CRPS. Please call us to obtain a listing in your state.

We also have 161 educational videos on our YouTube channel: RSDSA of America.

It is easy to join our community even if you do not have an email. Just provide us with your mailing address, telephone numbers, and we will gladly enroll you. You are not alone in your fight against this horrific disorder. Please donate to RSDSA today (please 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
HELP FIND BETTER TREATMENTS AND HOPEFULLY-A CURE! All proceeds will be invested in RSDSA’s Research Fund

*JEN’S GIFT* is a testimony to Jennifer Abramson’s brief but wonderful and impactful life. Jennifer lived only 31 years; however, she lives on in *Jen’s Gift*. Her goal was to enlighten, transform people’s thinking, and spread faith and hope in the infinite possibilities of this life.

*Jen’s gift will inspire you.* Her wisdom, clever humor and insights paired with her beautiful photos will make you laugh, smile, cry and maybe think about things that haven’t occurred to you before.

May her gift inspire you and may you too be touched by her love and kindness.

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 “Caption 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 doctor feel uncomfortable - it is perfectly okay to be educated about your problem and ask questions. High qualities treaters enjoy questions and are not threatened by knowledgably 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 web site (http://rds.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 & Treatment (http://www.theacpa.org/Consumer-Guide) in particular.
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.
Tips for Managing Complex Regional Pain Syndrome

September 11, 2015 by Jim Ducharme, MD, CM, FRCP

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.
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.
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-crpsrsd/](https://painsandiego.com/2016/11/06/medication-summary-for-intractable-pain-crpsrsd/).

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://rsds.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](https://painsandiego.com) 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.

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.
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/)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/) 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.
Hospital Guidelines for CRPS/RSD Patients Handle With Care!

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

**Tips for Patients**

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

**Tips Medical Professional:**

- When possible, avoid frequent needle sticks or injections as CRPS can cause increased sensitivity to pain (Hyperalgesia).
- If PICC site is available, see if blood can be obtained from PICC instead of using vena puncture technique.
- When possible, use smallest gauge needle and topical numbing cream as many have thin and fragile veins. (EMLA, Synera, Lidocaine).
- When possible, obtain blood work during IV insertion to minimize additional trauma.
- Some are sensitive to rate and temperature of IV fluids, responding better to slower infusion.
- Hypoallergenic materials may be needed for Alldynia (things that shouldn’t be painful are)
- Frequent linen changes may be needed for Hyperhidrosis (increased sweating).
- Avoid ice to CRPS limb to prevent nerve damage
- Patients may not be able to tolerate hospital socks
- Identify affected limb/s to avoid blood drawing, vital signs and or sheets/blankets from touching.
- Before moving/transporting patient, assess for possible limb atrophy (skin, muscles, and bone weakness) and for adaptive equipment and mobility aids.
- When moving/transporting patient avoid sudden movements and or bumps which can increase Dysthesia (Creepy, crawly sensation to touch) and Dystonic movement (abnormal movements, involuntary muscle spasms) & Alldynia (things that shouldn’t be painful are painful).
- A minor/major injury or surgery can require additional pain management plan, IV ketamine should be considered.
- CRPS is a REAL medical condition requiring support, education, and a plan of action.
- **Accredited Courses on CRPS for Practitioners**
  [https://rsds.org/accredited-course-on-crps-for-rds-ph-d-s-and-rns/](https://rsds.org/accredited-course-on-crps-for-rds-ph-d-s-and-rns/)
Complex Regional Pain Syndrome (CRPS), previously known as Reflex Sympathetic Dystrophy (RSD), is a “neuro-inflammatory” condition causing the nervous and immune systems to malfunction, sending constant pain signals to the brain. CRPS is characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rated CRPS higher than childbirth, amputation, and cancer pain. Those with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, and needle sticks.

**Tips for Patients**
- Carry a copy of the RSDSA Hospital and Emergency Guidelines, along with the “I HAVE CRPS” card, to validate and educate practitioners.
- Have your health insurance information.
- Have a list of ALL your allergies, medical history, and physicians treating you.
- Have a copy of ALL your medications, including: dosage and frequency prescribed, vitamins over the counter medications (OTC), and or compounded specialty medications as some may not be on hospital formulary. *Bring your own medication.
- Have a list of ANY active implantable medical device (AIMD): spinal cord stimulators, pain pump, cardiac pacemaker, defibrillators, stents and monitoring devices, etc.
- Have a list of ANY implants: breast, cochlear (ear). Intra-ocular lens (eye), heart valves, contraceptive, hip, heart, valves, etc.
- Have a list of ANY organ transplants and or prosthesis devices.
- Consider having a letter from your doctor and or pain doctor with conditions you are being treating for and your medical routine.
- When possible, bring someone with you, keep a journal.
- Ask hospital staff to always ask before touching, share where you can be touched and or positioned.
- When possible, ask for a quiet, temperature and light controlled area to minimized triggers (allodynia) especially if staying overnight in the Emergency Department. Dark sun glasses may help with bright lights.
- To minimize allodynia (things that shouldn’t be painful but are painful) bring items that are helpful with you.
- Ask the staff to use hypoallergenic items when possible (sheets, blankets, gown, cardiac monitoring EKG leads, paper tape, soap, cream, band aids, etc.)

**TJC provides accreditation to healthcare institutions**

TJC requires each organization to create Pain Policies to Assess, Manage and, Respect the “Patients Right” to pain management.

**Tips Medical Professional:**
- CRPS has both a sensory and autonomic dysfunction resulting in Central Sensitization of pain, causing:
  - **Hyperalgesia** (increased sensitivity to pain)
  - Avoid frequent needle sticks and injections
  - Assess if patient has PICC line access for bloodwork, medications, and infusions
  - Use smallest gauge needle (butterfly) when possible.
  - Numbing cream prior to needle sticks can be helpful as many have thing and fragile veins (EMLA, Synera, and Lidocaine).
  - Obtain blood work during IV insertion minimizes trauma.
  - Adjust rate and temperature of IV fluids if possible, as some respond better to slower and warmer infusions
  - Illness, injury, trauma can exacerbate CRPS symptoms.
  - **Allodynia** (pain induced from non-painful stimulus such as touch, clothing, sheets, temperature, exam, diagnostics).
  - Hypoallergenic materials may be helpful.
  - Patients may not be able to tolerate hospital socks.
  - Bright lights and temperature variations can be painful.
  - Avoid ice to CRPS limb, prevent further nerve damage
  - Use NON- CRPS limp for vital signs when possible
  - Identify CRPS limb(s) to avoid blood drawing, v/s, and or sheets/blankets from touching.
  - Moving and transporting patient: avoid bumps, sudden movements, vibrations and touch of affected area.
  - Noise from monitors, pumps, diagnostics, voices, phones, TV, intercom, can elevate pain.
  - **Atrophy** (skin, muscles and bone weakness)
  - Assess for limited ROM, weakness and need for adaptive equipment and or mobility aids.
  - **Hyperhidrosis** (abnormal sweating pattern)
  - Frequent linen changes may be needed.
  - **Abnormal Skin Changes**
    - Color changes (mottle, cyanotic, red, purple).
    - Skin temperature difference.
    - Hair/nail changes and swelling
  - **Movement Disorders**
    - Assess for motor disorders, involuntary muscle spasms and movements (bradykinesia, dystonia, myoclonus, excessive startle, and tremor).
  - **Dysesthesia** (creepy, crawly, sensation to touch)
    - Avoid using CRPS limb for treatment

**Overview:**

A minor/major injury or surgery may require additional pain management plan, including IV Ketamine.

- Many have secondary conditions (POTS, MCAS, EDS)
- CRPS is a REAL medical condition requiring support, education, and a plan of action.

**Accredited Courses on CRPS for Practitioners**
- [https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/](https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/)
Complex Regional Pain Syndrome (CRPS), previously known as Reflex Sympathetic Dystrophy (RSD), is a “neuro-inflammatory” condition causing the nervous and immune systems to malfunction, sending constant pain signals to the brain. CRPS is characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rated CRPS higher than childbirth, amputation, and cancer pain. Those with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, and needle sticks.

**Tips for Patients**

- Carry a copy of the RSDSA Hospital, Emergency, Dental Guidelines, along with the “I HAVE CRPS” card, to validate and educate practitioners.
- Hand the following to your dentist:
  - A computer printout of your detailed medical history since your 1st episode of CRPS, including the precipitating event.
  - Your treatments for CRPS and treating physicians. List of any allergies—List of current medications prescribed, OTC, specialty compounded medications (dosage & frequency).
  - List of any AIDM (active implantable medical devices) SCS (spinal cord simulators), pain pumps, cardiac pacemakers, defibrillator, stents, and monitoring devices.
  - List of any implants: breast, cochlear (ear), intra-ocular lens (eye), heart valves, contraceptive, prosthesis, etc.
  - List of any organ transplants. Research practices specializing in treating patients with chronic pain conditions (American Dental Association) and willing to learn about CRPS. [http://rdsa.org/crps-and-dentistry/](http://rdsa.org/crps-and-dentistry/)
- Be patient while educating your dental team: dentist, dentist anesthesiologist, periodontist, orthodontist, dental assistants/hygienist, lab technicians, etc.
- To prevent losing YOUR teeth and maintain YOUR overall health, begin with a comprehensive dental evaluation to develop a treatment plan to suit YOUR needs as a CRPS patient.
- Share any dental and oral health issues including:
  - Allergic reactions or sensitivities to dental products or ingredients
  - Burning mouth, dry mouth, erosion, dental decay, chronic mouth inflammation/irritation, orthodontics, muscle issues of the head, neck and jaw, the tongue, or salivary glands changes.
- Develop YOUR daily oral hygiene plan with practitioner including:
  - Type of toothbrush i.e. soft bristle
  - Use of mouthwash and or moisturizing spray
  - Use of floss
  - Adopt a Health dental diet and take vitamins (approved by your doctor)

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**Tips for Medical Professional:**

- 2 Online Accredited Courses on CRPS for Practitioners – Free [https://rdsa.org/accredited-course-on-crps-for-rds-ph-d-s-and-rs/](https://rdsa.org/accredited-course-on-crps-for-rds-ph-d-s-and-rs/)
- CRPS is a REAL medical condition requiring support, education, and a plan of action to minimize further pain.
- CRPS has both a sensory and autonomic dysfunction resulting in Central Sensitization of pain, causing: **Hyperalgesia** (increased sensitivity to pain)
  - Consider anesthesia options including: topical anesthesia, numbing gel, prior to injections, cleanings, X-Rays.
  - Consider anesthesia options including moderate sedation & general anesthesia with long dental appointments or procedures such as a root canal treatment which can exacerbate CRPS symptoms.
  - Extreme gentleness using dental equipment (spit suction, drill, eater spray, dental tooth pick, etc.) to minimize pain.
- **Alldynia** (pain induced from non-painful)
  - Hypoallergenic materials may be helpful with sensitivities.
  - Bright lights can be a patient trigger, sunglasses may help
  - Room temperature may need to be adjusted per patients’ needs.
  - Avoid being in the path of vented air from HVAC systems or fans
  - Avoid ice to CRPS area, prevents further nerve damage
  - Avoid anything bumping into patient.
- Patient position is key to positive outcomes consider utilizing bolsters, pillow, gel support, blankets to support patient.
- Noise from monitors, dental equipment, diagnostics, voices, phones, TV, intercom, etc. can elevate pain
- Shorter treatment sessions may help minimize CRPS flares.
- **Atrophy** (skin, muscles and bone weakness)
  - Assess for limited ROM, weakness for assistance in and out of the dental chair.
  - Assess patient need for adaptive oral hygiene devices
- **Hyperhidrosis** (abnormal sweating pattern)
  - Abnormal skin sweating, skin temperature and skin color changes (mottle, cyanotic, red, purple) may require adjustment of environmental room controls including use of fan for some patients (do NOT place patient in the direct path of a fan).
  - Hair/nail changes and swelling
- **Movement Disorders**
  - Assess the need to alter dental treatment due to motor disorders, involuntary muscle spasms & movements (bradykinesia, dystonia, myoclonus, excessive startle & tremor); use of (bite blocks, positioning the patient, use of sedation or general anesthesia) can be helpful
- **Dysesthesia** (creepy, crawly, sensation to touch)
  - Avoid coming into contact with affected CRPS sites.
  - If more comfortable for the patient & if possible, provide dental treatment standing/sitting

**Overview:**

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

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Revised 03/2/18
FROM HOSPITALIZED CRPS PATIENT TO ADVOCATE: BREAKING DOWN CHRONIC PAIN DISPARITIES (page 7)
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@rsds.org.

SPECIAL THANKS

We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Aetna, Axsome Therapeutics, Baker Family Charitable Trust, Pope/Taylor, Neurologic Relief Center, NoPainHanna.com, Oska and Relax Release Relief.
The Director’s Letter - A Summer Update

BY JIM BROATCH, RSDSA’S EXECUTIVE VICE PRESIDENT, DIRECTOR

JENKINS AWARDS
TOP $100,000
Since 2012, RSDSA, with the financial assistance of the RSDSA community, has awarded over $100,000 dollars in grants via our Brad Jenkins Patient Assistance Program. We have directly helped 167 individuals and families struggling with the financial devastation caused by having CRPS. Weekly, we receive desperate calls to help pay for utility cut-off notices, transportation to out-of-state consultations with CRPS specialists or travel to treatment programs, emergency grants to individuals whose SNAP benefits have been cut, car payments to stop repossessions, help pay for scooters and power wheelchairs, and much more. Just last week, we purchased a used power wheelchair on Craigslist and then purchased a battery & van ramp on Amazon and I personally delivered it to a local family. Need emergency financial help? We will send you an application. Call toll-free 877-662-7737. Every dollar donated to our Jenkins fund is invested directly in helping individuals. Please consider making a gift to our Jenkins Fund by mailing a gift to RSDSA, PO Box 502, Milford, CT 06460 or by clicking here, https://rsds.org/donate/

TREATING THE WHOLE PERSON: OPTIMIZING WELLNESS CONFERENCE IN CHARLOTTE, NC ON SEPTEMBER, 29,
RSDSA is returning to our southeast coast this September. We are partnering with the Stilitano family, founders of Fight the Flame 5K to sponsor an exciting full-day conference: Amberly Largo, author of True Grit and Grace will share her inspiring journey of survival and transformation after a horrific motorcycle/SUV accident. Jenny Picciotto’s riveting interview of Ms. Largo is on page 5. Dr. Robert Schwartz of the Piedmont Physical Medicine and Rehabilitation in Greenville, SC will share his out-of-the box innovative insights which guide his treatment of complex cases of CRPS. Phil Parker, founder of The Lightening Process is will be traveling from England to talk about his three-day program which is helping many people with CRPS(watch Amanda Ashley present about the program at our Arkansas conference: https://www.youtube.com/watch?v=8mDPT-g6bxo Our San Jose conference videos are now posted on our website: https://rsds.org/educational-presentations/

RSDSA COMMUNITY UPDATE
We hope that you enjoy the summer issue of the RSDSA Community Update. Michael Sullivan of the Bay Pain & Wellness Center has written an excellent, helpful article, Rehab of CRPS on the neuroscience of pain and the critical importance of movement. His goal is, “In writing is to convince you that movement, while it may be painful, is good, and to share some strategies for restoring function. His guiding principle is “that if you can do tomorrow what you did today, you are heading in the right
direction. If you can’t do tomorrow what you did today then you did too much. Adjust your activity level accordingly.” Tracy Coral’s interview with Cornell University’s Professor Won highlights a promising virtual reality pilot study in CRPS. Jenny Piccotto’s interview with Dr. Xu of the Cleveland Clinic reports on RSDSA’s international survey on use of IV ketamine to treat intractable CRPS and the development of reference protocols which can utilized to prove the safety and efficacy of IV ketamine for CRPS treatment.

MEDICAL EQUIPMENT

EXCHANGE PROGRAM

RSDSA is creating a program that will facilitate the donation of durable medical equipment such as wheel chairs, shower aids, hospital beds, walkers, etc. We will list the equipment available and where each piece is located. Although we cannot pay for shipping, we will connect the donor and the individual interested in obtaining the equipment.

RSDSA’S ACCREDITED  
MEDICAL EDUCATIONAL  
PROGRAMS

Too many health care professionals have no clue about CRPS and how to treat it. Please help us change this distressing situation. We have developed three free accredited courses on the diagnosis and treatment of pediatric and adult CRPS. Please help us educate health care professionals about CRPS. We can provide you with flyers promoting these courses for distribution in your community.

Here is an online link to the courses, https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/ and https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/

3RD ANNUAL LONG ISLAND AWARENESS WALK EVENT

I invite all metro New Yorkers to gather with RSDSA on September 15 at Eisenhower Park in East Meadow, New York for our third annual fundraising walk event. This year’s walk will take place from 8:00 a.m. until 2:00 p.m. at Eisenhower Park’s 1K and 2.5K paths, which will be reserved for this event. Last year’s event attracted nearly 450 walkers and 50 volunteers and raised $56,000 for RSDSA. Please come and meet others with CRPS and their family members. We will have food, crafts for children, educational exhibits, an incredible raffle, and much more. For more information, register, or to donate, please visit https://rsds.org/event/3rd-annual-long-island-crps-rsd-awareness-walk-event-east-meadow-ny/ or call us 877-662-7737.

5TH ANNUAL COLOR THE WORLD ORANGE DAY IS NOVEMBER 5, 2018

Help us Color The World Orange™ on November 5 by turning the night orange! A number of buildings and landmarks have the ability to turn orange, so let’s request that they turn orange for CRPS/RSD Awareness. In 2017, more than 100 buildings and landmarks around the world turned orange last year.

Want to get involved. Visit Color The World Orange on Face Book: https://www.facebook.com/ColorTheWorldOrange/

Easy Ways to Give

- Make RSDSA your charity of choice on GoodSearch.com and use that instead of Google.

- Use AmazonSmile.com and make RSDSA your charity of choice while shopping online.

- If you’re selling things on eBay, you can give a portion of the profits straight to RSDSA.

- Set up a collection canister in your local grocery store.

- Plan an event with the help of RSDSA by emailing us at info@rsds.org.
Healing From Within
Amberly Lago’s recently released book

BY JENNY PICCIOTTO

True Grit and Grace: Turning Tragedy Into Triumph chronicles her journey following a severe motorcycle accident in 2010. Her life as a professional dancer, fitness trainer, and athlete was shattered when she was stuck by an SUV. The impact broke the bones in her right leg and severed her femoral artery. She was placed in an induced coma while the doctors considered amputation. After months in the hospital and extensive surgeries, she was diagnosed with Complex Regional Pain Syndrome. Her story is one of inextinguishable hope, overcoming insurmountable pain and suffering. She now devotes herself to inspiring others by sharing the lessons she learned on her path toward accepting herself, her scars, and her new normal.

I was honored to have the chance to talk to Amberly, who still appears young, athletic, vibrant, and healthy. She had just finished teaching a fitness class and was recovering in the parking lot with her shoes and socks off, her foot propped up on the dashboard, throbbing and swelling. As anyone who lives with CRPS/RSD can affirm, we learn to put on a brave face and mask the pain inside our bodies. As anyone who lives with CRPS/RSD has can affirm, we learn to put on a brave face and mask the pain inside our bodies. She told me about her road from denial and desperation to claiming her resilience. It is a message she shares with as many people as she can, through social media, her book, interviews, articles, and as a motivational speaker.

Amberly, a mother of two, spent 3 ½ months in the hospital fighting to save her leg. She drew strength from her Texan upbringing, which taught that showing vulnerability equaled weakness. So, she did her best to “cowgirl up.” She stuffed it down and worked hard to regain the use of her leg, motivating herself with the athletic mantra: “No pain no gain.” That approach would only take her so far.

After being diagnosed with CRPS, she would have to unlearn these attitudes and embrace self compassion. “Vulnerability does not mean you are weak,” she tells me. “It shows that you have courage and the ability to grow.” However, arriving at a place of acceptance was a path through darkness and self doubt.

Today Amberly describes herself as a “dignified disabled person.” Learning how to live with CRPS was the most challenging transformation of her life.

Elisabeth Kubler-Ross, a psychologist working with terminally ill patients, pioneered the concept of five stages of grief - denial, anger, bargaining, depression, and acceptance. Her work has subsequently been broadly applied to any major life loss. I asked Amberly how she navigated her path to acceptance, and why it is important to her to share her story with others.

The ultimate lesson all of us have to learn is unconditional love, which includes not only others but ourselves as well. – Elisabeth Kubler-Ross

Amberly’s first response to the diagnosis of CRPS was denial. She searched for a doctor who would give her a different diagnosis. It was inconceivable that she had survived the crash and all of those surgeries only to be facing a life of unrelenting pain. Desperate for relief, she tried anything and everything the traditional and alternative medical communities had to offer including spinal blocks, radio frequency ablation, pain medications, spinal stimulator trial, ketamine infusions, Chinese medicine, dietary changes, and homeopathic medications. The family took out a lien on their home and borrowed money from friends to help cover the costs of her treatments.

When nothing helped, she began a downward spiral. Although she never seriously considered suicide, she found herself thinking that her children could find a better mom; her spouse could find a different wife, one like she used to be, when fitness was her life. Her leg, scarred, riddled with unexplainable pain, no longer felt like it belonged to her. She dissociated from her physical body, and began to hate her leg, the pain, muscle spasms, and scars. She covered it, and tried to ignore the way it looked, the way it felt. “I was in denial for 2 years,” she tells me. “I couldn’t wrap my mind around it.”

The road to acceptance ran through a deep, dark valley. As she tried to tough it out, Amberly sank into...
depression and began isolating. She cut herself off not only from her body, but also from the people and activities that had brought meaning and purpose to her life. She found that a glass of wine relaxed her, and began drinking more than normal. It took yet another tragedy for her to realize that she would have to rearrange her mindset and embrace a new world view to begin the process of healing from within.

When we meet true tragedy in life we have two choices; we can either give up and give in to the pain or use the challenge to claim our innermost resilience and thrive.

– Amberly Lago, “True Grit and Grace”

A couple of years into her struggle, Amberly developed pain in her back, pain that she ignored. It eventually became so severe that it masked her CRPS. Not taking her condition seriously, she nearly paid the ultimate price.

When she went into convulsions, her husband took her to the Emergency Room for treatment, but they immediately redirected her to the Intensive Care Unit. She was diagnosed with sepsis, a life threatening toxic infection, secondary to the kidney stone that had been causing so much pain in her back. The doctors told her that if she had delayed treatment even another day, she could have died.

Amberly describes this moment as her turning point: “It was a huge wake up call. I was scared.” She recognized that covering over her emotional and physical pain, ignoring the messages her body was sending, was not a solution.

 STILL in the hospital bed in the ICU, she began to adopt a new outlook. Her first step was readjusting her attitude toward her leg, accepting the fact that she was going to have to find a way to love and respect her body. She started a gratitude practice, replacing each negative though with a positive one.

“My light was so dim,” she told me, “but when I stopped fighting it and learned to surrender and accept that this is what I have and figure out what I can do to make the best of it, I was able to truly begin to grow.”

Gratitude turns denial into acceptance, makes sense of our past, brings peace for today, and creates hope for tomorrow. ~ Amberly Lago

“I am grateful I have my leg,” she says. “I decided I will love it until it feels better. Our bodies converse with us, whisper, talk, and if ignored, finally they scream. I let my body go until it screamed. I was in the ICU for 3 days and realized I have to listen to my body and have compassion for myself. If my daughter had pain, I would not ask her to ignore it and suck it up. Today, I stop and rest when I need to. I have learned to be gentle with myself. I celebrate the small victories. If I have to stop, that doesn’t mean I can’t, or that I am not successful, it just means I am taking care of myself.”

Amberly describes this experience as the moment she began to embrace her pain and reclaim her passion for life. She searched her heart for the little light that flickered in the shadow of nearly losing her life. She fed that flame by focusing on what she could do, rather than what she was no longer able to do. She began to write exercise and diet plans for friends and family from her hospital bed.

Accepting her new normal meant allowing herself to be vulnerable, giving herself permission to take recovery time, develop her pain management toolbox, and cultivate a strong support network. “When I admitted to myself that I had CRPS I was able to talk about it, to reach out and ask for help.”

Expressing and acknowledging what she was going through felt like a relief from the struggle to bury the painful reality of living with CRPS. In the process, she developed new coping skills such as mindfulness, meditation, self-love, and self-compassion. She began journaling and sharing her experiences on social media and, later, as a motivational speaker. She also returned to the gym and her work as a fitness trainer while still in her wheelchair.

“Working with people is a gift,” she says. “Being of service has given my life purpose, pulled me out of depression. I have a different mindset now. Helping others is the key of happiness.”

These days, Amberly inspires hope and encourages others to claim their own resilience. Her powerful story illustrates the possibility of enjoying life despite living with chronic pain. She encourages everyone to start where they are, be grateful for what they have, and do what they can; to resist the urge to isolate, build community and a support team, and to be gentle to themselves.

She continues to suffer from the swelling, color changes, flares, and fluctuating pain levels that accompany living with CRPS. She still needs to stop, rest, and listen to her body. She counts her blessings every day, practices mindfulness, engages in prayer, surrounds herself with positive people, eats an anti-inflammatory diet, and continues to work with her pain management doctor. She has not found a cure for her CRPS, but she has found that by embracing her pain, she rekindled her love of life, and discovered a path to healing from within.

You can learn more about Amberly Lago at amberlylago.com

By Jenny Picciotto
RSDSA is pleased to announce the publication of Intravenous Ketamine Infusion for Complex Regional Pain Syndrome: Survey, Consensus, and a Reference Protocol, which was published March 9, 2018 in Pain Medicine, a multidisciplinary pain journal. This original research, which was funded by RSDSA, studied the usage of intravenous ketamine for the treatment of CRPS and developed reference protocols for use in future comparative studies.

The first phase of the study was a survey to gather data about what protocols are in use among physicians who currently offer ketamine infusion therapy to their CRPS patients. Then a team of experts convened for a professional conference entitled “Ketamine: The State of the Art and the Science.” Presentations covered the history and pharmacology of ketamine, its use in the treatment of CRPS, a panel discussion, and a day of break-out sessions which kicked off the development of two reference protocols through a process of consensus among clinical experts.

According to their paper, “Ketamine is being used increasingly in intravenous (IV) infusion clinics to manage CRPS pain, but without guidance, standard protocols, or guidelines.” Although “many case series have suggested that IV ketamine infusion is effective in reducing pain in CRPS/RSD,” the lack of rigorous controls and the small size of the studies, in addition to the various protocols followed, have not produced high quality evidence. “The current level of evidence is 2B (i.e., moderate evidence, positive but weak recommendation).”

Complex Regional Pain Syndrome, previously known as Causalgia and Reflex Sympathetic Dystrophy, is a poorly understood, severe pain disorder. According to the National Institutes of Health: The exact trigger of CRPS after an injury is not known, but it may be due to abnormal interactions between the central and peripheral nervous systems, and/or inappropriate inflammatory responses.

Unfortunately, published research studies validating the efficacy of these treatment options are limited and no single drug or therapy (or combination) has shown consistent, long-lasting improvement.

CRPS patients face a complicated array of treatment options, most of which are not FDA approved and/or have been borrowed from other conditions. Because few evidence-based studies have been done, care providers and patients rely on a trial and error approach to treatment. “Formulating an evidence-based approach to CRPS management is difficult given the lack of high-quality evidence supporting efficacy of most available therapies.”

This research is a critical step in the right direction. The “reference protocols, one for inpatient ketamine treatment and one for outpatient ketamine treatment, do not represent guidelines for ketamine infusion for CRPS; rather, they are a reference/orientation by which practitioners can access the consensus of highly experienced practitioners. Importantly, this consensus result can provide a starting point for statistical validation of formal guidelines and a more uniform approach to research protocols that will validate the safety and efficacy of ketamine through controlled clinical trials.”

RSDSA is in the forefront of CRPS research. We are dedicated to funding studies for treatment and a cure.

ABOUT THE AUTHOR

Jenny Picciotto is a writer and CRPS patient who enjoys reading and playing the piano. She was a yoga instructor and massage therapist before CRPS changed her trajectory. She currently lives in Hawaii, where she facilitates the Oahu CRPS Support Group.
Virtual Reality for CRPS

BY TRACY CORAL

What would you think if there were a treatment modality which combined virtual reality with relieving acute pain? Meet Andrea Stevenson Won, a researcher who believes that a facilitated environment, like that provided by virtual reality, offers real hope for those in pain. She is the Director of the Virtual Embodiment Lab at Cornell, where she is an Assistant Professor of Communications with the College of Agriculture and Life Sciences at Cornell. She holds a Masters in Science in Biomedical Visualization from the University of Illinois at Chicago and has completed a PhD in the Virtual Human Interaction Lab in the Department of Communication at Stanford.

Professor Won became interested in virtual reality and how it could be used as a treatment modality for patients living with physical pain. In pilot studies, encouraging results show that virtual reality can help with both acute pain and Post Traumatic Stress Disorder (PTSD). Of particular interest to readers of this newsletter is that Dr. Won’s own pilot studies on pain dealt with the use of virtual reality to treat Complex Regional Pain Syndrome (CRPS) and Persistent Idiopathic Facial Pain.

I had the opportunity to speak with Professor Won, and to learn more about her work. I was anxious to discover what had influenced her to study CRPS. Dr. Won explained that CRPS was a condition close to her heart, as she has a family member who was diagnosed with it at a young age. She also spoke about her mother, a nurse practitioner, whose work focused primarily on non-opiate options to treat pain. Ms. Wong stated, ‘they are my two motivators’.

In essence, virtual reality is a computer gaming system, in which a person can be completely immersed in a three-dimensional environment, and engaged in specific settings during the game. In her lab at Cornell, Professor Won is exploring how physical and social exchanges in facilitated environments affect the perceptions of individuals. In regards to physical pain, virtual reality will distract the mind. The individuals using virtual reality are performing movements during the course of the game which may be extremely difficult to do on a typical day. Won stated “when patients see themselves moving in ways they can’t in real life, their brains use that feedback to create their body image.” Won has stated in a previous article that “visual feedback can effectively change the way people with chronic conditions move. By tricking the brain with virtual experiences, the results could prompt lasting relief in the real world” (Kelly, 2018).

When speaking with Dr. Won, she opened up about how she speaks to her students about CRPS, and the future for virtual reality. “When I am describing CRPS to students, I say that it is a difficult-to-treat chronic pain condition. I explain the reason why we think it might be a target for virtual reality therapy is that it has some things in common with phantom limb pain, which have made both targets for mirror visual feedback. In particular, there are similar changes in the brain that might indicate visual feedback on movement could be helpful. The future for virtual reality is broad, but we really need systematic research before making recommendations.

ABOUT THE AUTHOR

Tracy Coval has lived with CRPS for 15 years, as well as Dystonia and Ehler-Danlos Syndrome (EDS). She is a committee member for the Jenkins Patient Assistance Fund. When she is not doing work for the grant, she is advocating and educating others about cannabis, and how it can be a beneficial treatment option for individuals living with chronic illnesses. In her spare time you can find her painting, spending time with her family and friends, and two dogs.
I would like to see it reach the point where it could be easily and cheaply deployed in homes.” As Professor Won and I were wrapping up our interview, I asked my final question: ‘Is virtual reality currently available for patients who are interested in trying it?’ She responded, “This depends where you live, and what your condition is. Weill Cornell has the PATSS clinic; Stanford has a virtual reality clinic in Psychiatry running a trial for Functional Neurological Disorder (FND); I hope to follow up on a pilot study with Stanford Neuroscience and Pain to run a RCT shortly. There are a lot of people exploring virtual reality, but – it’s not a standard care yet for many conditions, just a promising area of investigation.”

If you have CRPS, you may already realize that exiting treatments do not work as well as we would like. The best hope for improved treatments will come from a better understanding of what is going wrong in CRPS, so that we are better able to fix it. In this column, new developments in our understanding about CRPS, and implications for treatment are reviewed.

Basic scientific research into the cause and mechanism of a condition is important so that appropriate treatments can be devised. Thanks to such research, it is now known that CRPS is caused by inflammation in the nervous system, resulting in increased transmission of pain signals. This knowledge has led to the use of various anti-inflammatory treatments for CRPS; these corticosteroids, high dose intravenous immunoglobulin, anti-tumor necrosis factor, plasma exchange immunosuppressants, such as mycophenolate. Still, these treatments are not universally effective.

A group in France has come up with a different way that may predict ketamine response, involving a test that is generally available, known as three phase bone scintigraphy. This type of bone scan was used in CRPS patients and it was shown that ketamine response correlated with the ratios of fixation of tracer compound in the second and third phases versus the first phase of the scan.

One of the problems with treating CRPS is that there is inflammation in the central nervous system (i.e., the spinal cord and brain), and many agents cannot reach these areas because of the blood-brain barrier, which prevents entry of certain substances into the brain. Normally, this is a good thing as it protects the brain from noxious chemicals, but it also prevents therapeutic agents from entering the brain as well. In previous columns, I have outlined some novel ways that are being investigated to overcome this challenge.

Interesting work from the lab of the late Dr. Ben Barres at Stanford shows that microglial cells (which have been shown to be activated...
in CRPS) secrete factors that increase inflammation, including interleukin 1 (IL-1), tumor necrosis factor (TNF) and one of the first complement components, C1q. They show that it is possible to block the inflammation by treating with antibodies to all three of these substances (anti-IL-1, anti-TNF and anti-C1q) in the lab. Excitingly, antibodies to IL-1 and TNF are already approved for clinical use and are readily available, often referred to as “biologics” that are often used to treat autoimmune disorders like rheumatoid arthritis, and Crohn’s disease. At present, there are no clinically available antibodies to C1q, however.

The problem with administering these antibodies to CRPS patients is that they are fairly large molecules, and do not readily pass the blood-brain barrier. It has been shown in rodents, for example, that if one gives anti-IL-1 systemically in the acute phase of CRPS, there is reduction in pain, but that is not the case in the chronic phase. That is likely because initially, the inflammation occurs outside, in the periphery. By the time CRPS becomes chronic, the inflammation has spread to the central nervous system, where the antibodies cannot reach. However, if the anti-IL-1 is given intrathecally (directly into the central nervous system) in the chronic phase, then there is reduction in pain.

So why not just administer the antibodies intrathecally to CRPS patients? This does involve some risk, including introduction of infection and damage to the spinal cord. However there may be a less invasive way of getting substances into the brain by administering the substances by peri-spinal injection. There is some evidence that this can be done safely, and it has been shown to be effective in treating stroke, and one case of post-operative dementia. This technique has been used only by a few investigators, and is not universally practiced. There are still risks, including infection, which may be heightened since neutralizing IL-1 and TNF impairs the immune system. But if it is proven to be effective and relatively safe, it may open up the possibility of new treatments for CRPS. Would a single agent, like anti-TNF be sufficient, or would there need to be both anti-TNF and anti-IL-1? Would just these two work, as there are no currently available antibodies to C1q? Only further research will tell.

A BETTER WAY TO PREDICT KETAMINE RESPONSE?

Not all CRPS patients will respond to ketamine. Ketamine infusions are time and resource consuming, expensive, and can have unpleasant side effects (but may be worth it if it helps your CRPS). In a previous column, I outlined work done by the Philadelphia group that showed they could predict which patients would respond to ketamine by analyzing the pattern of micro-RNAs in their blood. Micro-RNAs are small molecules that help control the expression of proteins in the cells. However, this type of analysis is not widely available. A group in France has come up with a different way that may predict ketamine response, involving a test that is generally available, known as three phase bone scintigraphy. This type of bone scan was used in CRPS patients and it was shown that ketamine response correlated with the ratios of fixation of tracer compound in the second and third phases versus the first phase of the scan. If this result can be replicated and verified, it is a relatively simple way to predict response to ketamine. It may spare some patients the unnecessary time, expense and side effects of ketamine infusions if they are not going to be effective for them. And for others, it will give them some reassurance that they will likely benefit, and the time and expense will likely be worthwhile.

References.

Five years ago, a group of Charlotte teenagers started an organization that was dedicated to promoting awareness of and raising funds for CRPS. Twelve-year-old Landon had no idea that what he started in 2013 would turn into an annual event that would be ranked as the second largest CRPS fundraising event in 2017. Thanks to our amazing sponsors we had an extremely successful day.

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As of today, Fight the Flame has raised over $110,000 for the RSDSA. Fight the Flame has worked hard to become an active voice in the Charlotte community. They organize and sponsor a local support group for families and individuals in the Charlotte area who are living with CRPS. In addition, every year Fight the Flame awards a CRPS Awareness college scholarship to local high school student. Applicants for the scholarship must educate others about CRPS to be considered for the award.

This year, Fight the Flame will be hosting its 6th annual Fight the Flame 5k Race and 1k Roll & Stroll on Sunday, September 30, 2018 at the McAlpine Creek Park in Charlotte, NC. Those who will not be in the area for the event can also participate as a virtual walker.

Please consider helping us Fight the Flame. You can register for the race, the virtual walk, or make a donation to RSDSA at [https://runsponsor.com/Race/NC/Charlotte/FightTheFlame](https://runsponsor.com/Race/NC/Charlotte/FightTheFlame).

Sydney Eden was a Fight the Flame intern. She just graduated from University of North Carolina at Charlotte with a degree in Health Communications and minor in Psychology. She will be continuing her education at UNC-Charlotte pursing a Master’s Degree in Hospital Administration.
Needle Stick Can Cause CRPS/RSD - What You Need to Know

BY BRIAN POPE, ESQUIRE
POPE/TAYLOR - NATIONAL CRPS/RSD LAWYERS

As an attorney who has been reviewing potential CRPS/RSD liability cases for the last 20 years, I have a pretty good feel of trends in the causes of CRPS. Unfortunately, I have noticed a growing number of people who have contacted me complaining of developing CRPS as a result of an IV needle stick. There are very few actual cases of nursing/medical malpractice that can be brought as a result of developing CRPS from a needle stick.

First, it is always foreseeable that if you are getting a needle stuck into a part of your body, you may develop CRPS as a result. The nurse could do everything by the book in a correct needle stick procedure and you could still develop CRPS. In this case, there is not a potential nursing/medical malpractice case to be pursued. The vast majority of cases I review fall into this category.

However, if a nurse violates the standard of care during a needle stick procedure, then it is a different analysis. The most common needle stick injury I see is when a nurse sticks the needle directly into a nerve, such as the median nerve, and damages the nerve. Usually, when this happens, the patient feels an immediate jolt of “electric” pain and reacts by crying out in pain. Unsurprisingly, there are very few medical records I have reviewed where this reaction is documented, allowing for plausible deniability if there are any subsequent complications from the needle stick.

If there is direct nerve damage due to a careless needle stick, usually the person will follow up with a doctor. The doctor may then do exploratory surgery to determine the extent of damage to the nerve. I have had a few cases where the subsequent treating doctor will take pictures and document the damage done to the nerve. Obviously, these are the best legal cases as the documentation and pictures provide compelling evidence of the damage done to the nerve. This also helps with proving causation in that the needle stick caused direct damage to the nerve, which resulted in the development of CRPS Type II.

Our law firm reviews potential CRPS/RSD cases, whether the CRPS is caused by a trauma (car accident, workplace injury, slip/trip and fall) or medical/nursing negligence (unnecessary surgery/procedure performed incorrectly that damages the nerve). If you have any questions regarding what you think may be a potential CRPS/RSD legal case, please contact our office for a free consultation.

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 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.)
How important is movement to our health and wellbeing? A dark lesson starting in medieval times and running into the mid-1800s is provided by the numerous inquisitions, the most famous being the Spanish Inquisition. For over 700 years torture was used to induce people to confess to their heresies, recant their heathen ways and profess their faith in God. Torture was used to speed up the process. One of the most effective means of torture was the use of constraints to restrict a person’s ability to move. Stocks, barrels, metal cages, ropes and chains were used to prevent movement. The tighter a person is bound, the less they can move, the greater the pain. Complete restriction of movement can lead to excruciating and unrelenting pain within twenty-four hours. People were known to go mad in a matter of days. My apologies if the thought of this alone is enough to make you cringe or feel discomfort (you can thank the mirror neurons in your brain) but this illustrates the importance of movement and highlights that pain is a consequence of immobilization.

One of the many issues that people with Complex Regional Pain Syndrome struggle with is that movement is painful, to the point where they don’t feel they have the choice to be active. Essentially, pain itself becomes the constraint that restricts movement resulting in more pain. As a result of this vicious cycle, CRPS sufferers can get into a downward spiral of functional decline that not only exacerbates their pain but seriously diminishes their quality of life. Fear of movement as a result of pain leads to avoidance of movement. My goal in writing today is to convince you that movement, while it may be painful, is good, and to share some strategies for restoring function. First, let’s look a little more closely at the pros and cons of not moving.

One of our responses to pain is to avoid movement to protect the injured area from further harm. In the early stages of injury this type of guarding is an adaptive response that helps us to heal. Depending on the injury, your doctor may even use immobilization to set up the conditions under which the damaged tissues heal. The simplest example would be casting a broken bone. In deciding how long to immobilize an injury there is always a tradeoff between the time that is needed for the tissue to heal and the deleterious effects of immobilization. Not only can immobilization be painful in of itself, it also is not healthy for many of our tissues. Muscles need to move and work to remain strong and flexible. Moving joints distributes synovial fluid that helps to lubricate and provide nutrition to joint surfaces. Nerves elongate and glide relative to the surrounding tissues when we move. Movement and interaction with our environment activates nerve endings, sending a constant stream of information to our brains for processing that are essential to brain health. Part of the healing process is the laying down of scar tissue as a means of repairing damage. Unfortunately, scar tissue is not very smart and while it strengthens the damaged tissue, it also can form cross-links to tissues that need to move in relationship to each other. The longer these cross-links remain in place the stronger they get and the more they can restrict normal movement. Importantly, movement is also necessary for the final phase of healing, a remodeling process that allows injured tissues to reorganize and gain maximum strength. When we continue to guard against movement after the initial healing process is complete, we are doing more harm than good, and the protective response becomes maladaptive. It is no longer helping us to heal. In short, our muscles, fascia, joints, nerves and brain all need movement to remain healthy and any immobilization, even of an isolated body part, beyond the minimum required for healing is not good for us. The consequences are most extreme when people take to bed rest to cope with their pain. We then add cardiovascular deconditioning, arterial constriction, blood clots and the possibility of pressure sores to the list of adverse consequences. Studies demonstrate that there is no known medical condition that is helped by prolonged bed rest

CRPS/RSD

BY MICHAEL SULLIVAN, PT - DIRECTOR OF FUNCTIONAL RESTORATION PROGRAM
BAY AREA PAIN AND WELLNESS CENTER

How important is movement to our health and wellbeing? A dark lesson starting in medieval times and running into the mid-1800s is provided by the numerous inquisitions, the most famous being the Spanish Inquisition. For over 700 years torture was used to induce people to confess to their heresies, recant their heathen ways and profess their faith in God. Torture was used to speed up the process. One of the most effective means of torture was the use of constraints to restrict a person’s ability to move. Stocks, barrels, metal cages, ropes and chains were used to prevent movement. The tighter a person is bound, the less they can move, the greater the pain. Complete restriction of movement can lead to excruciating and unrelenting pain within twenty-four hours. People were known to go mad in a matter of days. My apologies if the thought of this alone is enough to make you cringe or feel discomfort (you can thank the mirror neurons in your brain) but this illustrates the importance of movement and highlights that pain is a consequence of immobilization.

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When faced with the dilemma that it ‘hurts’ to move and accepting the fact that it is bad for your health and exacerbates pain to not move, I am hoping you will choose the latter. I recognize that this is no small task. So how should you proceed?

**ARM YOURSELF WITH KNOWLEDGE;**

pain neuroscience education is key. Know that pain is not synonymous with tissue damage. In a normal functioning nervous system, pain is an early warning system of potential tissue damage. With CRPS both the peripheral and central nervous system function can become sensitized resulting in pain with non-painful stimuli (alldynia), exaggerated pain with a painful stimulus (hyperpathia) or pain in the absence of any stimulus, i.e. spontaneous pain. To use a smoke alarm analogy, this is the equivalent of every smoke alarm in your house going off when you blow out a single birthday candle in addition to your smoke alarms going off randomly all day and night. With the smoke alarm, eventually you would come to the conclusion that the system is malfunctioning, and if you are anything like me, you would start cleaning them off the ceiling with a broom stick. The smoke alarm is no longer providing you with useful information. The same could be said of the sensitized nervous system. Common sense tells you that touching your hand lightly should not result in a burning sensation, but it does and patterns of activation in the centers of the brain that process this information look about the same as if you were touching a hot burner on your stove. There is nothing imagined about this, it is real. The good news is that you can change this experience.

**LEARN WAYS TO MODULATE YOUR PAIN.**

While knowing how pain is processed is not an absolute requirement to learn pain modulation, most people just don’t take our word for it when we tell them they can make their pain better or worse. The receptors in our body that collect information about actual or potential tissue damage are called nociceptors and the process whereby information about unpleasant stimuli is transmitted to the brain for processing is called nociception. Your brain takes this information, puts it into context of your past experiences, psychosocial factors, your personal beliefs, your cultural identity, your current health and demographics and your spiritual beliefs among other factors and does a threat assessment. Your brain will produce pain in proportion to the perceived threat not necessarily in proportion to the actual threat. If your conclusion is that what you are experiencing is not very dangerous then you will experience less (or no) pain. Thoughts and expectations do matter. If you have catastrophic thoughts and expect that you will never get better your pain will be worse. Your brain will ratchet up the threat assessments unless these thoughts are addressed. A psychologist with experience in chronic pain management is most helpful in addressing these issues.

Nociception need not be present to experience pain. Emotional and cognitive stressors can both produce pain responses in areas of the brain identical to those produced by the nociceptive process. Learning techniques to manage these stressors can down regulate pain. Meditation and relaxation exercises quiet activity in areas of the brain that process pain. Conversely, you can have nociception but not experience pain. There is an abundance of functional magnetic resonance imaging studies that allows observation of brain activity in real time that support these assertions.

**IT’S TIME FOR GRADED MOTOR IMAGERY.**

The ground breaking work being done by Butler and Moseley with the Neuro Orthopedic Institute (NOI) addresses the neuroplastic changes that occur in the brain as a result of the central nervous system being bombarded by nociceptive information. Brain health is promoted through a series of three activities: laterality tasks, imagining/thinking about movement and mirror box therapy. These activities can help to reduce pain and increase motor control for better quality movement. NOI has many good online resources that can help get you started. We generally recommend five minutes of GMIB-10 times per day spread out across your waking hours. If you are going to be working with a physical therapist, make sure the person you are working with has experience with these techniques. Pairing these with desensitization exercises can help with alldynia.
ADDRESS THE BUILDING BLOCKS OF FUNCTION.

Once you have developed some skills to better manage your pain, you are more likely to have success progressing into the active portion of your treatment program. Our goal up to this point in addition to understanding and reducing pain has been to reduce the fear associated with movement by better understanding pain. Given that you will be able to down regulate pain in the event that it increases you will be able to look past those previous experiences of trying to increase your activity level that did not go so well. Gentle exercises to improve joint mobility, improve muscle flexibility and increase cardiovascular endurance are key. Start slow, increase slowly but don’t be deterred by discomfort that you are likely to experience in the moment. As you add more. Activities to your program, the guiding principal is that if you can do tomorrow what you did today, you are heading in the right direction. If you can’t do tomorrow what you did today then you did too much. Adjust your activity level accordingly.

Once you have established a baseline you can start slowly increasing the duration of your cardiovascular activities. Studies demonstrate that cardiovascular exercise helps to regulate health in the nervous system, decrease depression, and reduce stress in addition to promoting cardiovascular health.

In addition to neuropathic pain associated with dysfunction in the nervous system people with CRPS experience a combination of orthopedic consequences associated with the original injury or disuse. Almost universally, one of these consequences is myofascial pain associated with guarding the injured area and adjacent areas. Learning skills to self-manage myofascial pain are essential to reducing pain in the periphery. Releases and stretches are essential to managing flare-ups.

When you are experiencing some success with the above it is time to move on towards addressing specific deficits identified on your physical therapy evaluation. Exercises for building strength, addressing postural imbalances, improving balance, practicing good body mechanics are a good lead in to functional training.

PUTTING THE FUN BACK IN FUNCTIONAL:

Ultimately, everything up to this point is pursued with individual functional goals in mind. What are the most important activities for you to regain quality of life? For some, self-care and the ability to live independently is the most important thing. For others it is playing with their children or dancing with their partner. For some, it is getting back to work and regaining financial independence. Getting back into your normal daily routine involves sitting and standing tolerance, safe ambulation, the ability to transfer from standing to floor and back and may involve components of lifting, carrying, pushing and pulling, fine and gross motor skills. These should all be incorporated where appropriate to meeting your functional goals. Engaging in activities that you enjoy unlocks your body’s natural pain relieving ability and is another step towards a more healthy life.

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.

EVENTS CALENDAR

2018 CALENDAR OF EVENTS THROUGH NOVEMBER

August 25 - CRPS Awareness Day At Dodger Stadium - Los Angeles, CA
September 15 - 3rd Annual Long Island CRPS/RSD Awareness Walk Event - East Meadow, NY
September 22 - Knock Out Pain 5K - Easton, PA
September 29 - Treating the Whole Person: Achieving Wellness, Charlotte, NC
September 30 - Fight The Flame 5K 2018 - Charlotte, NC
October 21 - 2018 CRPS Awareness Walk - Pennsauken, NJ

NOVEMBER IS CRPS AWARENESS MONTH

November 3 - Thompson Park Walk Lincroft, NJ
November 4 - Zumbathon Charity Event in Freeport, NY
November 4 - Fight the Flame 5K in Mentor, OH
November 5 - 5th Annual Color The World Orange

PEER-TO-PEER THOSE IN NEED OF SUPPORT:

If you wish to take advantage of this program, please do the following.

- Please contact LindaLang@rdsds.org
- Please provide your email, phone number and a little bit about yourself.

Don’t see an event near you?
Contact Jim Broatch info@rdsds.org to discuss planning an event in your area!
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.

Treating Complex Regional Pain Syndrome
A Guide for Therapy

Reflex Sympathetic Dystrophy Syndrome Association
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Email: info@rdsda.org
Web: http://rdsda.org

Raising awareness of complex regional pain syndrome since 1984
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 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/sensations, the presence of abnormal guarding or protection postures/movements and active use of the affected extremity during 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 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 Strapping. Manual edema reduction 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 external sources to the extremity. Stimulation of 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 discomfort and guarding 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

Series of exercises consist of affected extremity in a back/forth motion while weight bearing through the extremity.3 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.4 For upper extremity involvement to the hand, a large Veleros® 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 performed standing at a table or chair. Persons with limited wrist extension may benefit from using a handled brush.3 The Dystrophyl® 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, progressively to a handled bag loaded with increasingly heavier weight. Carrying should be performed two or three times a day, whenever the patient is standing or walking.5,6

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. using the unaffected leg) 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 music therapy. Mind/Body 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.

Bracing/Bracing 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 incorporation, to maintain joint position, to 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 may be able to tolerate and participate in AROM, coordination, dexterity, and strengthening tasks. Propriocceptive 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 insensitive situations (as after a nerve block). Pacing and pain management techniques, such as appropriate rest breaks, alternating tasks, thermal or placebo 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, maximize 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 daily activities to achieve optimal function of the affected extremity.

References

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.

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
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

I have Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy Syndrome (RSD).

- Physicians do not know why it 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 pain dramatically disproportionate to the injury.

- More than 140 years ago Dr. Silas Weir Mitchell, a Union Army surgeon, first described the excruciating pain that we know as CRPS.

- CRPS can lead to disability. CRPS can spread.

- 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.

- My skin may swell, sweat, change colors, change temperature, or hurt to the slightest touch.

- Often it is difficult for me to sleep so I may have trouble with attention and concentration.

- I may be taking powerful medications prescribed by my physician with many side effects that may affect how I feel or how I react.

- It is often hard to move easily or keep my body steady.

- Chronic pain, like that caused by CRPS, often leads to depression because we undergo significant, and often negative, life changes.

- I have good and bad days; my pain may even change hourly. Stress increases my pain.

- Presently, there is no cure for CRPS. I always have hope because of the support of my family and friends and ongoing research.
Here's How You Can Help Me.

- My pain is real even though it is 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.rsdso.org and learn all you can.

Pain Scale

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.

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Funded by Kansas City Awareness
Thank you for considering a donation to RSDSA. Your unrestricted gift is vital to RSDSA because it gives us the crucial flexibility to respond to immediate needs and opportunities as they arise. Such contributions also help build a strong RSDSA financial foundation. To fulfill our mission, RSDSA must be able to meet the changing needs of the CRPS/RSD community, in order to continue improving the quality of life for people with CRPS. By making an unrestricted gift, you enable RSDSA to provide financial assistance, conferences, grants, support programs and much more to people across the United States.

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 30 years. We are grateful for your support!