

## Methods for Minimizing Pain Flare-Ups Survey

- I tried aqua therapy in a warm pool this past year. It helps to bypass my movement disorder.
- Not much minimizes my pain. I figure I'm going to be in pain doing nothing, and if I'm doing something. So I keep on keeping on. I decided to get a Harley Davidson a few years back and I ride to desensitize my nerves in my legs and helps to take my mind off it. Stay active regardless of the pain and reflect on what you accomplished instead of what you didn't. Even the smallest of things deserve your praise. Ketamine infusions are my monthly routine and I have them done now in the comfort of my own home.
- Water therapy is my biggest source of non-medicinal pain relief.
- Moving around
- Warm weather, water therapy, and keeping busy to keep my mind off the pain. Also magnesium supplements to help me sleep better. Lavender lotion at night. Plenty of rest not just sleep but relax and rest throughout the day. It's not just one thing that helps but a lot of little things. Don't let the pain stop you although it may slow you down.
- Pain meds, antispasmodic pills, depression pills, anxiety pills, taking it easy not overdoing it, accepting it. Trusting God through each and every day.
- Nothing SO far, but I keep on keeping on the BEST I can
- I have found that two methods work best for me. I use a light therapy device that I actually bought from an infomercial when I was in desperate pain. I was pleasantly surprised when it actually worked. I can't explain how it works, but uses ultraviolet light and heat. The second item is auricular therapy. This has been a tremendous help and I would encourage anyone to find an auricular therapist. I am lucky enough to have one as a best friend now.
- I have RSD in my right leg which has caused a lot of other problems, so my pain medication is not enough to keep my pain under control. What helps me is to KEEP MOVING! If I can't get out to walk, I pace around my house which is a circle, so I do: "laps" every day. If I am having a "poor" me day and I zone out on the couch or in bed, I notice a HUGE difference in how stiff and sore I am the next day, so it's really important for me to KEEP MOVING!!
- I use hot baths with magnesium, 400 mg magnesium ( buy good vitamins at a health store), vitamin B's, C, alpha lipoic acid, blue spirulina, palmitoylethanolamide, N-acetyl cysteine, turmeric, light exercise, heating pad, light massage, CBD oil, LDN
- I have tried many ways to relieve my pain from hot baths with Epsom salt to pain patches which I was made to get off of. Now I am on Nucynta, which doesn't take away my pain completely but takes the edge off. I live for my heating pad and have gone through many of them over the years.
- I had a neuro stimulator implanted near my spine which has lowered my pain level 1 to 2 points on a good day. I would love to hear how others have battled!
- I participated in a Function Restoration Program at Dr. Massey's Bay Area Pain and Wellness Clinic. It changed my life.
  - I was given profound psychological, physical, nutritional, wellness and daily lessons on how to distract my thought pattern every day.
  - I was given the tools to turn my life around 180 degrees! I have a new view on my life.
  - I look forward to what is next in my life. I use every tool I was taught to live with not against my pain. We no cohabitate in
  - My body as a friend not as an enemy.
  - It is a choice to focus every bit of energy on your pain or make the decision to LIVE MY LIFE!! I am blessed to have an amazing life.
  - I was given the chance to get off high-dose oxycodone through this program. That WAS the biggest change. I no longer was trapped by pills. It is liberating! I am on Suboxone which I have cut in half by choice. It is possible.

- First and foremost: Opiate Pain Medication. This is the most effective way I can possibly manage pain. Yet it is threatened every single day by know-nothing, loud-mouthed people who have never experienced real chronic pain, telling me that prescription opiates, when taken as directed, do not work on chronic pain. Because this is the effective way to manage my pain, I'm assumed to be an addict who overtakes my medication and I am an unequal member of society who doesn't deserve pain relief. We, as a pain community, are being completely and totally ignored and dismissed. This is outrageous!
  - Prayer and faith in God.
  - Exercise and physical therapy.
  - Getting out of bed every morning, getting dressed and actively participating in my day, no matter how difficult it is or how long it takes. I keep to a loose schedule and work on my daily goals. I automatically think of my daily activity and schedule in terms of amount of pain each thing will cause and the limited amount of energy I will have to accomplish it. Because pain requires the majority of my energy just to fight or manage during the day, I automatically think of everything in terms of the pain it will cause and amount of energy necessary. I'm flexible with what I want to accomplish. I try to plan easier days around harder ones. Also essential is keeping a positive attitude and trying not to complain or take my pain out on others. Even though I automatically compute every task in terms of pain vs energy, I do my best not to focus on pain which also helps me with daily goals. I push myself hard.
  - Keep reasonable expectations for myself.
  - Lots of short breaks during the day.
  - I absolutely refuse to think of myself as a victim or as unable to do anything. I rarely use the word, "disabled" because it means limitations in every context. The stronger I am, the better I'll be.
- I lose myself in my work. That doesn't make my life pain free. That requires enough Lyrica to sedate an elephant counteracted by caffeine. With a touch of Tramadol. I keep my dose low as possible as this is a narcotic. Luckily for me it does not cause dysphoria so I can function at the high level my career requires. But when I am engrossed in my work as well as when I'm reading a book or watching a good movie I forget about my disease. However, between 3 and 4 hours after taking my medication, my neuropathy with its burning pain reminds me that it's time for my next dose. So I recommend that you involve yourself in any activities that capture your imagination or your intellect as it has been a time-tested method to relieve pain. No medication is fully adequate. If acupuncture or another Eastern method including yoga works for you, then use it as needed. But don't make pain the centerpiece of your life and you can learn to live with it.
- I try to go outside and enjoy the pretty weather if I can't walk with comfort. Or, I will go to the beach and enjoy. If neither is possible then I will do art, read, or watch a movie.
- I have found that having a hobby or something to be passionate about is healing. Art is my way of focusing on something other than my pain. When I am creating a new sketchbook, stitching on an art quilt, drawing graphite portraits or painting, I get into the "zone" and even though the pain is still there, it gets pushed to the background. It is important to keep moving and this is the only way I can keep going.
- I've found Voltaren Gel to work pretty well. I usually wait until the pain is off the charts so I don't become immune to it, which means it has to work double-time to accomplish anything, but it has proven to be up to the task. My husband uses it for sore muscles as well.
- I am currently taking Baclofen 10mg, Qid and Methadone 5mg in the morning, 7 1/2mg in the afternoon and 5mg at bedtime.
- I try to worry less about my future. Go to Stanford Pain. Did the TMS protocols 4 times. My pain is spreading but still no higher than 3.
- I had Ketamine I.V. therapy back in Oct and Nov 2017 and so, far I've been very blessed that, I haven't had any flare ups!

- First and foremost is the swimming pool or better yet a therapy pool that is heated to at least 102 degrees. I have learned the hard way that patients with CRPS must do all they can to avoid injury at all costs and avoid the dreadful spread of CRPS to other places in the body. Gentle exercise in a therapy pool is the best thing CRPS patients can do. By getting in the pool once, twice, or three times a week and doing basic PT movements you will undoubtedly notice a difference in the way you feel and you will most likely not injure yourself if you just take it easy. Just walk in the water and do basic physical therapy moves that any physical therapist can or should show you. I go to a place call Tier One here in El Paso, Texas and they have a therapy pool with a treadmill in the pool and my physical therapist posts simple water exercises on the wall at poolside. I can go into more detail but I think this is adequate for starters. This advice actually comes from one of the leading lecturers, teachers and researchers in CRPS that I have followed and studied for many years. Also my Phoenix AZ. Barrow institute trained neurosurgeon also recommends this therapy for me because I am in an advanced stage of CRPS that requires intense therapy and I highly respect and regard this conservative doctor who only operates when it is absolutely necessary.
  - Pete Egoscue who developed the Egoscue method of pain relief through proper body mechanics and posture is well worth looking into. There are only a handful of Egoscue clinics in the US so it might be difficult to find an Egoscue certified instructor in your area but it never hurts to study up on this method and see if what Mr. Egoscue has to offer might be helpful to those suffering chronic pain associated with a wide variety of ailments that all relate back to neurology, posture, and the way we maintain the various muscle groups that support our skeletal structure. So I would suggest for starters buying one of Pete Egoscue's books or perhaps checking it out at the local library if nothing else to see if this method makes sense to you as a CRPS patient. If you happen to have access to the web as most of us do, there are many YouTube videos that demonstrate some of the Egoscue moves and method of pain relief. However, since we CRPS patients are generally very fragile a would highly recommended going to an Egoscue clinic even if it means travel because the trainers are very kind and are happy to help you remotely using Skype once they have you in the program. I live in far west Texas and my Egoscue trainer Amanda is in Nashville, TN so I get to see her once a year when I visit Nashville and visit my son who is an ICU nurse at Vanderbilt. In fact, my Son is seeing Amanda because of pain he started experiencing from bending over the beds to lift and help turn patients who are unable to move on their own! He loves his Egoscue now and I think it has made a significant impact on his physical conditioning and pain syndrome that was simply a matter of getting good advice from a highly qualified Egoscue trainer! Egoscue is expensive but I always say that you get what you pay for and if you're serious about dealing with your pain there is almost nothing that gets in the way if you are seeing results, so please by all means do take this suggestion. Yes, it is expensive but seeing results will be ever so rewarding to those who find that proper posture and body mechanics are key to feeling better in day-to-day living.
  - Meditation through bio feedback. This is a very special way to prove that you can in fact reach a deep state of relaxation through biofeedback and that will help you cope with your pain. I started learning biofeedback over 30 years ago in a hospital setting from a PHD friend and physician Jerry who was an expert on meditation and biofeedback. Long story short, I've been using biofeedback for years and the technology has come very far. We now have access to equipment that is state-of-the-art thanks to the highly intelligent folks who developed EM wave technology that costs very little and amounts to the best equipment that I am aware of that you can buy on Amazon or Direct from EM wave on their internet store. I hate to tell anyone to buy anything because it always backfires on me but I'll just say that I bought the EM wave and I am I huge fan, and have no problem recommending it to others as long as they go in with informed consent having read the materials and understand that it's not easy but very rewarding once you master the skill! It takes patience and many of us in pain just don't have that because it's all we can do just to get up and face another day. Buy the machine for a couple hundred dollars (I'm sorry it's expensive but well-worth it) and it connects to your lap top. You use an ear bud attachment and follow detailed instructions and pretty soon you see what the yogis are doing and you will find yourself wanting to beat the machine and go to the highest level of meditation that exists. Personally, I just like the

first level and I have mastered that and can take the graphic from zero to perfect in just a few minutes. It's so easy and so rewarding to get yourself in a deep state of relaxation! They all say "I don't have time for that" but If You are suffering and you are serious about developing coping skills, you will do what it takes to learn how to relax and erase everything from your mind and focus on your mantra, escaping from the cruel and vicious cycle of pain that chronic pain suffers get in through no fault of their own! The mantra is the key and I will tell you mine just so you have an example of what to focus on during meditation. I grew up going to a beautiful private beach in Southern CA. I visualize myself sitting in the sand on that beach during meditation. I take air deep into and fill my lungs with each wave and exhale as the wave crashes onto the beach and the sea foam comes up and covers my feet.

- I've recently added CBD tincture to my medication regimen and it seems to be taking the edge off the "evening" pain episodes and improves sleep as a result. I live in Colorado where cannabis is legal. There is no THC in the tincture I'm taking. I'm just glad I received the recommendation for CBD and wish I had known about it sooner!
- I work out many days in the pool and am still using the DME chair.
- I was given a One Touch laser device which I find helpful. I also use lidocaine cream, CBD oil, and naproxen. Monthly ketamine infusions make the biggest difference, though.
- Dr. prescribed Voltaren Gel 1% that can be applied to either. I also find Salon Pas helpful and take Tylenol. I will be seeing Pain Management Dr.
- I Have Found That Ultram Works Very Well for me. I also get blue ice from family dollar, it's a rub and helps settle the pain.
- HBOT helps a lot with swelling and circulation. I use Lidocaine patches when wearing shoes. Ketamine cream for sleep with fuzzy socks, so sheets can't touch my foot.
- Out of all that I've had done, I would say that the Ketamine infusions gave the most relief, but they were never a permanent solution, as they only lasted anywhere from 4 to 6 months. On rare occasions, a couple of them lasted close to a year. However, as pleased as I was the results, I was still left unhappy; knowing that I would have to once again endure the hellish side effects of the Ketamine in the future. I am by no means a doctor, but I started doing quite a bit of research into alternative treatment. One thing that intrigued me was what I had read about Panax Ginseng. I am; currently 6 months into my Ginseng treatment, and I can honestly tell you that my pain score has dropped from a daily 8 - 9 to a measly 2 - 3. I'm off all of my prescribed medications, and I'm feeling terrific. I actually feel the best that I've felt since I was diagnosed with CRPS. Could it get even better for me, than it is now? I'm not sure. Could I ever reach the all elusive "0" on the pain score? There is one thing that I do know... a pain score of 2 - 3 is absolutely heavenly for me, after staying for so long at 8 - 9, with an occasional "10" that would make you feel as though you were losing your mind.
- I had a pain pump installed last year which has significantly reduced my pain level. I have CRPS in my right foot. First, I had the SCS surgery about 9 years ago. Replaced battery last year. The SCS worked well, it got me into a bearable pain zone. From 8 to 10 pain levels to 5 to 7! It took about 6 months to get used to the SCS. The greatest part of the Pain Pump was getting off the Opioids! I was taking 180 Oxycodone, 20mg per month. My Dr gave me a prescription for Suboxone which I started 2 weeks before pain pump surgery. I had NO withdrawals at all! I was terrified of stopping the Opioids!! A book called "The Secret" has helped me to reprogram my brain to be positive. I highly recommend it.
- Well, this only sort of works! I wrap 'deep freeze gel' patches (Mentholatum co. East Kilbride Scotland) around my wrist and fingers. At night, I do this while resting my wrist on a cool bag that has been in fridge. Distraction from the pain. Cools down the intense burning sensation.
- I am finding Olanzapine helps to minimize central nervous system pain. It's better than an opioid.
- I have been given annual 4 ml infusions of the Bisphosphonate, Zometa for at least the last six years, which has almost eliminated the bone pain. For this it's that good.

- The other big game changer has been the daily use of Cialis, which retails for 1/4 the price of the Viana formulation that's been approved for the treatment of pulmonary hypertension and is basically the same stuff. Put it this way, before going on it, getting through an art exhibition on my feet was typically a challenge. Four days after going on Cialis - maybe four years ago I was able to spend five hours on my feet, going through LACMA on my own. By far the worst of the spasms in my legs have been controlled.
- The other thing that made a difference were "nerve gliding" exercises I was given by a highly trained DPT, after years of bad results with conventional/physiologically orientated PT: strengthening exercises being far worse than nothing.
- Then two years ago I transitioned off OxyContin/oxycodone to "low dose" (4.5mg) Naltrexone along with oral ketamine for breakthrough pain. It took 3 1/2 months for the Naltrexone to begin to cut in, and the worst of the remaining pain has been cut back 80% or more. In addition, my endurance (time active before pain cuts in) has been substantially improved. I dropped the use of oral ketamine within the first year after its "debilitating effects" proved to be more trouble than it was worth. And for the occasional lingering and relatively minor burning pain in my feet at the end of the day, I use a compounded gel with ketamine, gabapentin. and lidocaine works well, even if it's messy.
- Finally, the myocardial small vessel constriction had become a real problem, resulting in frequent trips to the ER (where it was refractory to nitroglycerin patches) and for two years in a row looked like a 30% loss of myocardial tissue on CT angiography. But after 4 - 6 weeks of transcranial direct current stimulation (tDCS) of my motor cortices under the care of a physician, and it was gone, subject to the need for rare booster treatments.
- The major thing that helped tremendously was changing my diet to a whole foods, no processed food diet. Eating a plant based diet minimizes the inflammation which was huge in fighting RSD pain. I was amazed!
- I have a neurostimulator that helps with about 40/50% of the pain. Then I do also take medication. I aquacise as tolerance allows three days a week therapy twice a week for range of motion and strengthening. Crafts take my mind of the pain a lot too. And it very relaxing to do. Online Support groups also help.
- I spent 11 years in pain management and had to come off all meds as they made the pain worse. As a result, I went to a vegan diet and started using ginger and turmeric root (organic, fresh) every day. I also take ginger and turmeric pills. Additionally, I started using organic hemp seeds and hemp milk as hemp is a natural anti-inflammatory. I lost weight and now feel better than I ever did on opioids. I've reclaimed part of my life and would never consider going back to pain meds. I don't even take aspirin. My blood sugar balanced out, my blood pressure is normal and my cholesterol is also normal now. I hope this helps.
- I have been using/applying KT Tape for my back, sciatica, knees, shin, ankle, feet, and hands. Most of the times I find instant relief after applying them.
  - I know I can't sit for a long time, so I try to get up and walk often (every 30 minutes or less sometimes).
  - I lay down several times during the day, to save energy and keep my feet off the floor as well.
  - I've been reading about medical Marijuana and would like to contact RSD patients that have already experienced with this approach.
- The only way that I have been able to live for 17 years with RSDS is by embracing my pain. I had accepted it with love, I do not put resistance to it. My faith in God and the belief that I am an eternal being of love. I meditate at least two times a day for 20 minutes or more and try to smile as much as possible. I have two choices, to live in pain in a bitter way or to live it being happy. I live my life happily even when the pain is at the highest level. As a clinical psychologist, I believe that science works, but there is nothing better than living in the peace of God.
- I use capsaicin for temporary relief at bedtime, and if I'm in air conditioning, I wear cotton gloves.
- Medical Marijuana, Indica only.
  - I vape and ingest Cannabis Oil. Both calm my nervous system like nothing else has. I can rest my entire body, and I sleep deeply.
  - Being in my bed 21 - 23 hours a day. Under the covers, I talk to no one, no one contacts me. Where I live is exceptionally quiet. I am blessed in that way. I have no life, as you can imagine.

- First year, I started with cast(s), tall “boot”, crutches, 6 lumbar sympathetic blocks with physical therapy after, Lyrica, Voltaren cream, and then high dose/4 day ketamine, ketamine cream and troches, oxytocin nasal spray, Mirror Box and TENS unit - all unsuccessful.  
Epsom Salt soak or bath, rest, heating throw, essential oil, cannabis balm & lotion & edibles, regular ketamine infusions, warm water pool exercise, Personal Trainer, LDN, Clonidine, Neridronate, wheelchair, Uggs (especially flip flops), walk-in tub, adjustable bed, Family & hired help. My husband and I moved to a disability-friendly home
- The mind is the strongest part of our human body, and that's where I try to focus on when I'm in pain. I listen to classical music while I'm working in my garden. I manage to reduce my pain if I stay focused on the music and my plants. I also walk every day, mostly at night when it's cool. I have 3 amazing dogs that keep me busy playing with them. I try to control my pain without medication as long as possible. Meditation is very helpful to me. As you can see, I use my mind to control the pain. It took me about a year to see the benefits of this madness. What really helps me cope with CRPS is a positive attitude.
- I try to be positive for little things, the wind, the birds, new dawning, 2 hours with no burning, the laughter of a grandchild, hug from my supportive husband, and talk about the pain, sometimes talk back to the pain. My faith gives me courage, my family are my cheerleaders, think it could be much worse. Live in the moment, never give up.
  - Salonpas pain patch
  - Playing video games to distract
  - Very soft pillows (the ones with the tiny white pellets are best). I use three under my foot to cradle the foot and ankle.
  - Warm microwave bean pack (heated in microwave)
  - And lastly... I find that an occasional Long Island Iced Tea works much better than opiates!
  - Tens unit with variable settings
  - Toe Warmer patches in the winter (cold weather) in my shoes
- I do not use anything for pain control. I do not drink alcohol or take drugs. I eat the best that I can work into my limited income. Breathing, meditation, tapping, enjoying nature, music, movies, art, reading; all are worthwhile activities that help bring joy and fulfillment in my life. I am most blessed with the best medical team and home health care that could ever be bestowed... and a wonderful disability advocate, friends though few, that which claim me are my greatest God-Send; my miracle hard-working Service Dog.
- Palmitoylethanolamide with luteolin ( a supplement called Mirica)
- Physical therapy
- Sauna/ heat
- LDN
- Pacing Activity
- Sleep to reset pain cycle
- Able to sit longer on hip (where CRPS started and spread to right foot, then to left foot) with flat wide chair
- Desensitization and weight bearing multiple times every day for short periods
- OT/PT
- After the first year my feet went from cold to hot! So, now my feet burn, are red and swollen pain-very cold water, gel ice packs, air conditioning set to 69 degrees helps, shade, dunking feet in cooler at soccer games
- First year- feet were icy pain and pale, like the first year or two, warm h2o, heaters, fleece socks and pants, avoiding air conditioning
- Narcotic (nucynta) medicine
- Lamictal (like gabapentin) Med
- Trying many different meds (for example it was the 4th narcotic and the 4th anti-seizure like gabapentin one in the class of medicine that worked)
- SCS game changer but doesn't reach my soles and toes of my feet
- Prayer, Meditation, a Supportive husband, Working out what I can, Wheelchair tennis, Handbiking, Sit ups, Arm weights, Short walk or working each day

- Work adaptations and home adaptations:
- Moved to smaller home with bedroom that is cool, moved 2 minutes away from work, work less hours per day.
- Rest breaks to lie on my stomach and rest my legs, computer on wheels with adjustable height
- Croc shoes
- Facebook support group, CRPS research group. Facebook treatment group ie. SCS, etc.
- Awaiting DRG neuromodulation system
- What has helped me is prayer and meditation, mild massage on shoulder and arm areas, and Counter-Constraint Physical therapy.
- Heated blankets/wraps -- wrapping in soft textures can be very soothing
- Heated therapy pool and/or warm water soaking of effected limb in tubs of water with Epsom salt Gel cooling packs (cold gel, no ice)
- Lidocaine cream (3%) and sometimes Lidocaine ointment 5%
- TENS unit (depending on where applied as some areas are too sensitive)
- Ultrasound treatment (depending on intensity and if skilled therapist)
- Softly running my hand across affected area to sooth it and calm it down
- Steroid injections (combo of Lidocaine, Novocain and other steroids) along various points of injured/aggravated nerve(s)
- Keeping affected limb covered and warm (not exposed to air and light breeze or temperature changes)
- Minimizing movement of affected limb, keeping immobile and protected
- limiting salt and/or sugar consumption
- For many, many years, I took medication. It gave me a good life. Now, I use pain cream to treat an unbelievable amount of symptoms. When the pills were stopped so did my quality of care!
- I have incorporated CBD salve from the drugstore. It really helps. For the muscle cramping in my legs I use Theraworx. People in my family find this very helpful. Moving... is very important. Right now, I have broken big toe and miss the endorphins. I usually walk daily with friends.... talking and walking...best medicine.
- I sleep on an acupressure mat. At first painful but feel it confuses the nerves so I can sleep.
- Laughter...hard to hurt when you are laughing.
- A family member has Parkinson's. He shakes so much, the doctor says he runs a marathon daily. If I am feeling sorry for myself... it happens... I picture his day and mine seems much better.
- I go to a pain center and have a great doc and nurse practitioner.
- In late 2015, I had a (St Jude) spinal cord simulator implanted. I put off the surgery for years because it sounded scary and it wasn't a guarantee. I'm a very thankful I had the surgery, it has changed my life!
- I use LDN (low dose naltrexone) Dextrademorphan, and ketamine. I also do Ketamine infusions when I can afford the stay, and that is far and few between. I do aqua therapy for muscle strength and balance. I do not take any opiates for pain. I try and keep moving even though it hurts, I try and push through flares, that's hard. I also was taught deep relaxation techniques, and bio feedback.
- I am helped by massage three times a week, chiropractic visits once a week and Gua Sha, a scraping technique developed in China. Most of that that helps my pain temporarily by releasing adhesions that have developed. As far as pain control goes, I am on methadone for neuropathic pain which has been helpful. I'm also on several muscle relaxants which also appear to help. For breakthrough pain, I use medical marijuana and an occasional opioid. The opioid isn't very effective, but occasionally it helps. As anyone living in 2018 knows, it has been getting harder and harder to get prescriptions for both the methadone and the hydrocodone. I had fentanyl in the past for pain control, which was much more effective, but it is impossible to get that now for pain.
- I also use distraction, but it is limited in my case by the severity of my pain. Most of the day, my pain level is at least a six or seven, and can get as high as 9 or 10. I was recently diagnosed with breast cancer, and the anti-estrogen I was put on caused horrible shaking chills and a temperature instability which has persisted for over a year after I stopped using it. My oncologist has no explanation for the persistence of

these shaking chills, but I think my unstable autonomic nervous system was tipped over. I had a full course of outpatient ketamine treatment years ago which help the central nervous system symptoms but did not touch the peripheral pain. I think the recent literature shows that only the hospitalized ketamine protocol is effective for the peripheral pain. I'm considering trying ketamine again for the autonomic nervous system chills, but I am unable to find any ketamine centers nearby that will treat me for anything other than depression. Apparently, the pain protocol has gone out of favor. I also tried scrambler therapy last year, but it destabilized my primary injury site.

- First and foremost, I follow suggestions on how to cure a leaky gut. What I eat affects me more than anything. Must be organic. Secondly, for pain is a certain brand of coffee enema as taught at the Gerson Center. This treatment is for stimulating the production of glutathione which is a master antioxidant and detox. If administered daily must accompany with three juices i.e. carrot/apple and green drink with soft lettuces, beet tops, chard, purple cabbage, watercress if it can be found, escarole, and apple. Thirdly, enzymes with meals sometimes along with HCL. Fourth, good water with chlorine removed, fifth—good probiotic—that advice really goes along with leaky gut, sixth—a daily belly laugh. I use movies to get mine.
- Ultracet, low dose only as needed for breakthrough pain above level 5 (note: if upon awakening I know that pain is just starting and will likely escalate, I take the medication early to try to nip in the bud, with some success)
  - Rest!
  - Warmelbow/arm
  - General stress-reducing tools: meditation, prayer, music, lie down, gentle breaths, warm water, etc.
  - Sleep as needed, and always adequate deep sleep nightly (9 hrs. for me)
- Exercise: I use a combination of Pilates, ballet, and yoga in my workouts. Since I have a mobility disability (can't bend my left knee well, stand long, or walk well), my workouts are on the floor. I also use light weights to maintain my strength. And two to three times a week, I use a stationary bike for 10 to 20 minutes. I recommend a Pilates machine for those who can afford it. I completely wore mine out and have struggled to keep up a similar routine on the floor. The machine has some advantages that would require a dissertation to explain.
  - Ice and Elevation: My left leg swells and consequently becomes discolored and painful. I cannot sit in a chair; therefore, sitting with my leg elevated is not only preferable but necessary.
  - Walking: After numerous knee surgeries, my balance is not as good as it once was. So I go to a mall or big store, get a cart, and push the hell out of it. I make sure I visit at times when there are fewer customers so I can haul ass on the straight-away.
  - Smile: Even though it kills you. Be friendly. No one wants to hear about how bad you feel. But if someone is obnoxious, just throw up on his shoes.
- A recent change to a combo of generic Cymbalta and Neurotin improved my pain. Avoiding loud noise or music, and extreme change of temperature (particularly warm to cold) helps, as does avoiding slight motion (long car rides) or a slight breeze. I mostly wear long sleeves. Other things that I use that help, and don't recommend them, but are prescribed by my doctor, are the Fentanyl Patch, and 1 to 3 tablets per day of 30mg Oxycodone HCL. Also, but not prescribed, Hemp Oil 1000 mg. capsules with Omega 3 and 6, 720 mg. twice a day (ordered online).
- I take Neurontin 600 mg 2-3x a day, Cymbalta. Wellbutrin 2x a day, and Inderal 40 mg twice a day for fast heart rate. At night I take Flexeril 15 mg and melatonin 10 mg for sleep. This usually helps me sleep but I have some nights when I can't. I am exhausted most of the day probably due to meds and the disease. I am thankful I have a wonderful husband who shops, cooks, and does the wash
- I went through physical therapy, twice, once for a sprained ankle, and once for Achilles tendinitis. Those gave me back normal range of motion, strength and balance, at the minimum end of normal. I never did not have pain. And being on my feet always caused swelling. I was introduced to essential oils. I put 2 drops of Young Living's Panaway on my ankle, and felt it doing something immediately. For the first time since the injury, I was still on my feet, with no extra swelling, 2 hours after putting that oil on my ankle. Even my parents noticed the difference. I dove in and became a Young Living member the end of June



2014. My kit arrived July 4 -- Independence Day!! Day of Freedom, for sure!!!! Those oils have changed my life!! No, they don't stop the pain, or the swelling, or the spasms, or the parasthesias -- but they help a ton. I've tried going without them... life is unbearable without my oils. I've tried going on field trips, to church, to restaurants, without my oils in my purse, and ended up unable to even stand up...and had no oils with me to help me work through the pain, fear and spasms. So I never, ever, ever leave the house without my oils!!!! I treat them as I treat my Epi-Pen. Where I go, my oils go with me. I've had it written in my vocational rehab paperwork as a must-have accommodation -- I must be able to use my essential oils and nutritional supplements whenever and wherever I need them. My friend's mindset class turned that around nearly instantly!!! It relies on the theory of neuroplasticity, as well. After the first week of daily meeting over Facebook Live with her, I noticed my pain levels had decreased from 7-10 to 5-7!!! And I was sleeping!!!! I began physical therapy in May -- after 2 weeks, my pain levels were below a 5!!! I'm in shock. Instant-Pot also helped for cooking.

- Haagen Diaz; taken orally, as needed for pain control.
- Percocet- this is the most effective method but sometimes it is just not enough which is where the rest of my list comes in. This list is my ongoing routine/combination of things that all play a part in keeping me functional and out of pain. When I have a spike in pain, I refer to these same things as well to see what I can do at that time based on the appropriate timing of medications, but always includes giving myself a nice quiet "time-out" to rest
  - Ketamine capsules - they also help slow down/prevent the spreading of the disease
  - Rest - literally moving as little as possible in a quiet room away from any sort of stimulation to my senses
  - Diet - I found an RSD/Nerve pain diet that helps greatly
  - Mucinex - not only is the main ingredient a pain killer but it helps with the dizziness and facial side effects I have as a result of having RSD In my brachial plexus.
  - Keeping stress to a minimum
  - Cymbalta - helps with my anxiety and is also a nerve pain medicine
  - Vitamin D and B
  - I also had a Pain Counselor for a while who, although she didn't know anything about RSD, helped me learn my triggers so I could keep them to a minimum and treat them accordingly
  - Not doing anything physical to aggravate it or overdoing anything physical on the effected limbs (this included hiring a cleaning lady and a landscaper). Be gentle on yourself!!
  - Oska Wellness electromagnetic device
  - Acupressure, definitely NOT acupuncture
  - Physical therapy only to desensitize the nerves and do traction on my neck
  - Massages at the precise amount of pressure on the touch, not too soft and not too hard
  - Medical Marijuana (ACDC strain that has no THC/no THC Effects)
  - Anti-inflammatory pills
  - Elevating the effected limbs and don't put any type of pressure on them
  - Keeping caffeine limited to one cup a day and quit smoking Compression sleeves in certain situations and for short periods of time
  - Avoid overstimulation on your senses (loud noises, crowds etc.) as much as possible
  - And the most important thing I learned is to NEVER ever use ice where you have RSD!! Not only does it hurt more at the moment but it can also do additional damage to your nerve sheath which will make your condition worse.

- To date, only opioid pain management has worked for me. I have not found a medical strain of cannabis that has proven effective. I do have my medical marijuana card for the state of Illinois.
- The only thing I have found that helped me was my Spinal Cord Stimulator implant for the first years 2-2 1/2 years and medications for break-through pain and gave me back my life until I lost weight due to the chronic migraines and my SCS implant no longer works properly despite all efforts by Boston Scientific engineers to reprogram it for the last 3-4 years. I now suffer from incontinence since increasing the intensity of my SCS does not help but causes that problem. The only other thing that I have found that helps was the several denervation / ablations and a combination of Dilaudid, Fentanyl and Valium. I had the doctors take me off the Fentanyl and Savella (I had horrible reactions to Cymbalta and what was described to me was probably a seizure) because I did not believe they were helping me because I still had pain. I was wrong and did not realize how much the Fentanyl was helping until I was off it.
- Frequency specific microcurrent with the CRPS protocol. Dr. McMakin does a phenomenal job teaching it on YouTube. My 11 year-old pain went from an 8 to a 0 in 45 minutes on her first treatment. We are ecstatic
- Ketamine infusion treatments
- Mindfulness meditation
- Nerve block and pain pump with ropivacaine
- Regular ketamine infusions, weekly exercise in warm pool, heating throw, LDN, wheelchair as needed
- Nerve blocks, epidurals, rest, ice, and muscle meds
- Orgasms... A peaceful mind body and soul
- [My daughter] had gabapentin and baclofen. We had intense therapy 6 times a week... water therapy, myofascial release that was a great help to release pain every day. After 9 months we went to Italy to get the official treatment of Neridronate that is not accepted in the USA
- Mindfulness, yoga, stretching, heating pads, ketamine troches, ketamine infusions, good family support, and a positive attitude!
- Today, I minimized my day by breathing, mindfully. I did the footwork for propels in my life. One at a time. I talked with positive people to help me find a solution to every day bumps in my present life. I advocated for others and myself. I prayed even though I'm not sure about what I was praying to and I stopped taking on the world for my displaced anger about my diseases. Now I am driving to the pharmacy to pick up my medication, not worrying about not having very much money. Then to my therapist, where it is safe to rant and cry because that is her job
- I used the NEVRO HF 10, spinal cord stimulator implant. It's been my greatest blessing since I was diagnosed with RSD/CRPS. On a bad flare day, I use my imagery meditation and focus on my breathing
- Getting off pain meds has helped
- Cannabis and psychedelic medicines, veganism
- Heating pad, Rick Simpson oil, forcing myself to rest, grateful for the warmer weather days
- Vecttor treatments at home. Dr. Rhodes in Houston TX has RSD himself and invented this device for RSD plus other conditions. I also use heating pad
- I pray a lot. I use a lot of distractions. Yes the pain is excruciating but at this point in time I don't really care. I know I'll make it through
- Reiki
- Essential oils. Full nerve block of my entire right leg (pain is bilateral but right is worse) Had numbness for 2 days lingering for 2.5 weeks. Gave me much needed relief. Reduced swelling by 85% which is amazing considering how huge my foot would get. Gave me a break from sensitivity and pain too. Now I am weaning off meds slowly. Praying I keep trending in the right direction
- Sympathetic nerve block, physical therapy every week
- Stellate ganglion blocks- as needed, diet, stay focused on positivity and I meditate in prayer and music
- Keep moving
- Using Vecttor from 10/05/15 I am pain free and meds free from July 2016 in remission
- Ketamine infusion worked well for a year then started wearing off. Clinical trial of neridronic acid started 6.17 Is amazing. Helping mostly postmenopausal women per the research staff I have seen

- An OTC herb combo
- CBD
- Use warm packs, have a warm mattress pad, use Lidocaine patches, and medication. I have now developed nerve pain on my inner knees and I have had 3 blocks whereby my leg is numb for 3 days. Unfortunately, the pain returns and I cannot tolerate anything touching my knees.
  - I also have occipital blocks and cervical plexus blocks. Twice a year, I have epidural blocks for the pain from L4-L5 involvement.
  - I live in a state where I have been on medical marijuana and I take 1/2 lozenges during the evening time when my pain is the worst.
- I am convinced that these surgeries helped reduce the pain. I do not remember whether I was given nerve blocks prior to general anesthesia for the surgery, but prior to the surgeries I underwent numerous stellate ganglion nerve blocks.
 

RSD changed my life. I am now an attorney who has dedicated his career to helping people with CRPS/RSD. I have days on which I am now nearly pain free, and days when I have a great deal of pain. On a bad pain day, I am grouchy and less patient, and I take 800 mg. of Ibuprofen. Sometimes I am able to ignore the pain, especially when I win a case.
- I have a scrub brush that I use in the shower and desensitize my entire body and it hurts like hell but I do it because it helps. It's not easy to bring yourself to doing this. When I'm on fire throughout the body I usually wear really soft clothes and put the heating pad on my head and if that don't work I wear a hat on my head it helps with the air hitting my head. I think I've tried everything over the years. I have it in my head, face, eyes, nose, mouth, and neck down to my torso, arms, legs and feet. So sometimes I try anything I can to get through my tough days. I had 6 surgeries in 2 months' time for stimulators .My Doctors and I are talking about one for the head and face because I still burn really bad in my face and head and the ones I had done don't cover my head and face. I had to buy a house dehumidifier and that helps keep it dry inside. I can't take the humidity at all that's when my flares start and by the time it reaches my head and face I'm out of it because of the severity of my RSD .I do everything I can to stay on my feet. I do walk with a friend when I can that helps as well get more oxygen to the brain. It helps to do that too. I know it's hard for others to do these things but if they can try these things it will help. It's hard for me to but I'll do anything for relief.
- Pain is ever present. I sleep many hours during the day or night, pure exhaustion. (Of course) I stream Netflix to distract from pain. Most importantly I read the news. What is going on in the world? I am appalled most of the time so I use my brain to write letters, call, sign petitions to help people in need. I have hope at least one good seed will plant somewhere and my words will be heard. This makes me happy. I balance out my fears for our Mother Earth and the frightening unknown progression of my CRPS with music as well. My dog is the best helper for my soul, mind and heart!
- Medical marijuana (both oil and vapor)
- Ketamine nasal spray
- Mindfulness
- Hot tub
- YMCA pool (water temp 87)
- Spinal cord stimulator
- Don't overdo (pace)
- Sleep
- Talk with others who have CRPS
- Attend local support group meetings
- Tramadol
- Gabapentin
- Supplements
- Desensitize effected area
- Listen to music
- Light stretches

- Try do things that provide feeling of accomplishment
- I decided to start painting. I don't know where it comes from it's just from within. I paint mostly nature landscapes and when I'm painting I can put myself in a better place. It takes me away for a little while. I also like to get myself out in the garden. Somehow being out there with nature and flowers makes me feel a whole lot better. I feel peaceful digging in the dirt in sunshine...birds singing. When the pain gets bad I vaporize a small amount of marijuana and I can feel the pain leaving my body. My body becomes relaxed and I'm not crazy, stupid, stoned. It's not like that.
- I don't talk about it, ruminate about it, or cry about it. I meditate, exercise the best I can, and try not to be still too long unless I have no choice because the pain is severe.  
In that case, warm water is my savior, especially a jetted tub.  
Finally, diet and weight are key ingredients for a tolerable life. Eating clean foods, eliminating sugars and gluten as much as possible, and maintaining an appropriate weight can be healing. Dr Schwartzman always told me that with all of my RSD related health issues, my lower weight and clean diet were instrumental.
- The Quell device takes my pain level down by one number some of the time. I've had RSD in most of my body for 13 years. I still haven't found a doctor in Memphis to try ketamine on me
- IV Ketamine infusions
- Over the course of eight years, I have slowly gotten my life back. I work full time, go to yoga, socialize-and to the outside world, it would not appear that I struggle with CRPS. I do believe that physicians and patients who are willing to explore new treatments and adventure out into new territory have the greatest chance of recovery.
- I went off all narcotics 9-1/2 years ago (under doctor's supervision). It took about 6-9 months to feel like a person; took another few months to have much reduced pain. I will take Tylenol, usually daily (can't take Asa's) and muscle relaxants when necessary. About 3x/year I get trigger point injections (non-steroidal [used in Europe for decades]), which are helpful. I had a series of three Botox-for-headaches injections. But, diagnosed as RSD headaches, that didn't help, so I carefully take a headache Rx (not often-too often will cause rebound headaches). And I use topicals (some compounds with crazy ingredients) and heat/ice and hot showers-some days, lots of showers; others, just the am/pm.
- I have used nothing but organic turmeric powder in a tea with a little organic cayenne for pain control. An activity I do three times a week is swimming/floating in cool salt water. I went into remission just 11 months after the event I obtained it from; with only a few minor flare ups.
- Therapeutic fascia massage and gua sha on the fascia was administered. Fascia needs to be smooth again and free of toxins. Gua sha (Chinese: 刮痧) is a traditional Chinese medical treatment in which the skin is scraped to produce light petechiae. Practitioners believe that gua sha releases unhealthy bodily matter from blood stasis within sore, tired, stiff or injured muscle areas to stimulate new oxygenated blood flow to the areas, thus promotes metabolic cell repair, regeneration, healing and recovery. Gua sha is sometimes referred to as "scraping", "spooning" or "coining" by English speakers, it has also been given the descriptive French name, tribo-effleurage.[1]
- I minimize pain by the following:
  - paraffin dip then using the paraffin as a therapy ball
  - Tens Unit
  - Infrared
  - hot hands
  - attempt to do biofeedback
  - lidocaine patch
  - tramadol
- I have a spinal cord stimulator implant which has helped a lot. But then my RSD moved to upper body after the implant. I do massage therapy every 2-3 weeks and using horse liniment (purchased at Tractor Supply). My doctor has just added a muscle relaxer 3x a day with my pain medication.

- I manage my pain by using Shaklee products for pain management, plus other food supplements they offer along with; exercise and diet, focusing on foods that cause less or no inflammation and faith. I can walk again! Low to no pain!