

Yvonne Linton's Story of Hope



I developed Complex Regional Pain Syndrome (CRPS, also known as RSD), in 2012 at age 48, following removal of a 3.5-centimeter mass in my leg. This was discovered from an MRI that I had requested, due to prolonged ankle pain following a long-distance cycling event. This is a message of hope: how the combination of early specialized physical therapy intervention and nerve block medication helped me resume the activities I enjoy—without pain. The mass was removed from the flexor hallucis longus

muscle in the left ankle, the muscle that triggers the big toe. It was diagnosed as an arteriovenous malformation (AVM). The malformation of arteries and vessels sat on top of my neurovascular bundle that controls the movement in the foot. While great care was taken to pull the nerves aside during surgery, complications resulted, due to trauma to the nervous system. The pain and dizziness was intense upon awakening from surgery. I was given Hydromorphone, a type of morphine, among other pain meds, every five minutes for an hour and a half. After three hours in recovery, I was discharged. I was told the first three days would be the worst, but the pain and sensitivity intensified over the next few weeks.

This is a condition, unfortunately, that is often undiagnosed, misdiagnosed, or even over-diagnosed. While there are different approaches to treating it and there is no one objective test to diagnosis it, key symptoms include: a disproportionate level of pain and swelling and discoloration from poor circulation and an overactive sympathetic nervous system. From the start, my pain level seemed worse than expected. I was told initially this was normal post-operative pain, particularly due to the proximity to a nerve center. The problems worsened with increased mobility, when I began elevating my leg above my heart for shorter durations and less frequency. Initially I was able to walk on crutches, but this became more difficult as the weaker, previously injured leg had to bear all the weight. I persisted in voicing my concerns to those in the medical field, in lieu of waiting until the prescribed follow-up visits.

What follows is a timeline of the 60 days post-surgery: to shed light on the condition and to give others hope. With prudent intervention early on, prognosis can be positive and CRPS can be put into remission. I now do triathlons, century bike rides and even completed a half-marathon.

Day 3: The Tramadol, 50 mg (every 4-6 hours), which was initially prescribed, did little for the pain. The removal of the drainage tube in the ankle provided temporary relief.

Day 8: The ace bandage was loosened and dressing was changed, which reduced the pressure, but pain continued. I was prescribed Hydroco, 5-325 tablets, one per hour, supplemented with 6 Advil per day. I returned to elevating above the heart for all, with 10-15 minutes of crutch time to reduce risk of clots.

Day 9, 10: As the leg swelled, and circulation worsened, the sensation from the knee down felt like a blood pressure cuff tightly squeezing the leg, as if in a vice. I tried low compression socks (15 mmHg) to reduce swelling, and had to take deep breaths to put on due to pain. I also tried alternating hot and cool compression baths with my ankle in a plastic bag, to increase circulation, but even the slight raise or drop in temperature caused dizziness. Seated showers were harsh to the foot due to the pressure of the water. Any jar to the foot sent a shock wave down the leg. Even a blanket felt to the foot, especially the toes, which were hypersensitive. The skin on lower limb was becoming thin, flaky and mottled.

Day 11: The foot was becoming increasingly cold, purple and had little pulse, particularly when not elevated, so I persisted in getting another appointment. The gauze wrap was tightening as the swelling increased. Since the scar was healing well, the sutures were removed and the gauze was not reapplied. The pinky toe was beginning to drop and the foot was beginning to dystrophy to the right.

I was diagnosed with CRPS and instructed to take 5000 mg of Vitamin C, which has shown some promise in treating CRPS, the vitamin L-Carnitine, 500 mg twice a day. I was told to keep moving the foot in order to desensitize it, and to increase partial weight bearing with a post-op shoe, in lieu of the protective boot cast, and to elevate while seated. Frequent movement of foot and ankle was strongly encouraged, and immobilizing was discouraged (including the nighttime splint).



Day 12: Called the on-call doctor and requested nerve block medication to calm down the nervous system, and was prescribed 400 mg of Neurontin. Early side effects included vertigo and sleepiness, but they lessened soon over time. This made exercises more tolerable: wiggling toes, alphabet letters, ankle pumps, and light range of motion. The lower limb was very sensitive. Even floor vibrations could be felt.

Day 15, 17: I began physical therapy (PT). At this point I could barely put my foot on the ground due to the discomfort and tightness in hamstring of left leg. I was still totally non-weight bearing. Even using crutches was difficult due to pain in knees of the weak weight-bearing leg.

Day 18: Visited the Stanford Pain Clinic and Neurontin regiment was increased, from 300 mg to 1500 mg over the next few weeks. Lumbar nerve injection nerve blocks were discussed. At this point I was still non-ambulatory and any drive in the car or wheelchair was jarring to the leg. While they offered evaluations, no referrals were given for therapists. I discontinued treatment for various reasons and returned to my medical group for consistent care.

Day 22, 24: Physical therapy continued. Two sessions a week were suggested. The in-network PT, though well intentioned, was unknowingly aggravating the nerves and mobility gains were temporary. I was unaware at the time she had only seen treated the condition three times. Weight-bearing exercises were introduced before the nerves were ready to absorb it, causing stress to the nerves. The pace was for that of a typical recovery. By evening the swelling and pain would increase to where bone structure and veins were barely visible. The foot was shiny red, with patches of white and even yellow. Toes in both feet discolored. Left calf swelled. The foot was freezing cold and sometimes burning, like frostbite.

Day 29: I sought out a specialized PT, recommended by friends in the medical and naturopath fields, knowing my HMO insurance would likely deny the coverage if an in-network provider had treated the condition before. (My claim was denied after a two-month long appeal, but it was a small price to pay for my recovery). Though in high demand, the PT immediately made room in her schedule for the next day for a thorough two-hour evaluation and booked two months of appointments. The manual treatment from a therapist more experienced with the condition was a completely different experience. The appointments were not jarringly painful, and the symptoms did not flare up afterwards. Sessions were increased to three times per week. Previous exercises were eliminated or reintroduced weeks. Time with the therapist was 30 minutes, but 60-90 minutes was spent one on one with a well-trained aide: reprogramming neuropathways, strengthening core, improving gait on the crutches, and balance. A tens unit was loaned, to stimulate the lumbar spine. Nerve milking exercises were introduced.



Day 35: Results of an ultrasound to check for thrombosis was normal. Visited a physiatrist who recommended elevation to decrease swelling, and walking in water, and more use of compression socks. I was advised to elevate 15 minutes of every hour. He felt 80% of patients he sees do not truly have CRPS, but he was certain that I was in STAGE 1, borderline 2 of CRPS. Toenails and leg hair had stopped growing, and one toenail, weakened with fungus, eventually fell off.

Day 48: Discussed nerve vibrations in glutes and legs, and nerve issues in arm, with a neurologist. I was advised not to taper down on Neurontin too quickly, to avoid relapse of symptoms, as CRPS can wax and wane. Several months of use was suggested. Nerve conduction tests showed nerve damage in the foot.

A Game Ready ice compression machine was rented for three weeks, for left knee and calf. Originally used for 15 minutes following PT sessions, time was increased to two or three times per day, 30-45 minutes per session. This returned warmth to the foot. Swelling and sensitivity reduced, making shoes and pants easier to wear. A doctor's prescription was required. Insurance may not cover it, but well worth it.

Day 60: Walked without crutches! This was partly prompted by ulnar nerve issues and carpal tunnel symptoms developing from extended crutch use. The line of discoloration spread further down the limb with PT, until just at ankle level. Clamminess in the foot diminished and feelings of tightness lessened. Ankle lifts were and toe curls strengthened the foot, first with a slider board, then in a standing position.

Progress was monitored closely and activity was added in gradual increments, so that the nerves would not be aggravated. Within four months of diagnosis, I was cycling over 20 miles and hiking in hills for 75 minutes. While nerve issues remain, these major gains would not have been possible without significant motivation and commitment to therapy, desensitization, medication compliance, and mobility training. The support from friends and family, to cope with the physical and emotional demands of CRPS, made a major difference in the initial days after diagnosis. Fear, stress and worry are never optimal for health, even more so with a disorder of the nervous system. For those suffering from the long-term effects of a chronic pain condition, every effort should be made to optimize one's mental health.



Conclusion

Most PT clinics do not see CRPS often, as it is not very common. Fortunately, I had excellent outside connections, who advocated specialized therapists that treat nerves in a very gentle manner. It is important that recovery and rehabilitation not be treated as a routine post-op recovery. Manual therapy should not be aggressive. Increased activity should be introduced slowly, in small increments. When my in-network

treatment plan differed from what was recommended by those who treat CRPS more often, and symptoms and function did not improve sufficiently over a few weeks, I changed PT's. It was worth the out of pocket expense. With CRPS, results are best achieved if symptoms are treated within the first months of the injury. Exaggerated pain is often considered anxiety-related, but patient stress is greatly reduced when finding optimal care. Recovery times vary for each person, so doctors hesitate to provide timelines (especially with nerve issues). But patients need to rally professionals who provide hope. Pain need not become a permanent condition. The pain has been replaced with an occasional dull ache, due to neuropathy and nerve damage. But thanks to specialized intervention, I am a success story. I was fortunate to receive help early; improvement is still possible if therapy is pursued later, but it takes longer to reverse the damage.