

# REVERSING CHRONIC CRPS

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*I wondered how long I could hold out against the torture...I felt the sting of despair...I gave my first scream... another followed shortly after that and from then on every exhalation was a shrill cry. Tears flowed and pain raged like fire throughout my body...I gasped "Stop!", "Stop!"...*  
-- Jeffery Deaver, 2010; *The Edge*

## PART 1

### CONFUSION BEFORE UNDERSTANDING

#### INTRODUCTION

*Complex Regional Pain Syndrome is a multifactorial disorder...CRPS is the result of an "aberrant [inappropriate] response to tissue injury"...Treatment is complicated, involving drugs, physical therapy, psychological treatments, and neuromodulation and is usually unsatisfactory, especially if begun late.*  
-- Wikipedia 2014

CRPS is more than an "injury response" and treatment is not predestined to be "unsatisfactory" even "if begun late". It is vital to understand why some treatment regimens are more effective than others.

At 52 years of age, in December 2007, I was diagnosed with "bilateral lower extremity CRPS Type 1". Five endless years of dysfunction and increasing disability followed. Motivated by an intolerable life and following much trial and error, I revised my treatment plan and my feet finally began to improve in 2012. After another very difficult but rewarding 18 months I was and continue to be completely symptom free.

During the years of pain and torture, it was so very hard to hold on to any hope of recovery. The damage to my nervous system, joints, and circulatory system seemed severe. Gratefully, my worst fears were unfounded as both feet are now pain free and fully functional.

I am not in remission, I am over it. As evidence of full recovery, I present two feet that react and heal in a natural and timely manner. No more hypersensitivity, no more functional disability. No more fear of the slightest twist, turn, bump, or bruise. For a period of months after the pain and swelling was gone my feet were still overactive and the veins were somewhat constricted. As I continued rehabilitation this sensitivity disappeared along with all the other symptoms. My feet are warm to the touch and sweat normally during exertion. Most significantly, injuries now come and go as normally as one would expect.

Chronic CRPS can be reversed. My recovery was not the result of chance. For each specific action taken, there was a definite and observable reaction. Effective as the process was, it was the most difficult and even discouraging experience I have ever slogged through. There is no doubt however; the reward is as immense as the process is difficult.

I searched for ways to attack CRPS at its roots. For example, I found Randomized Bilateral Alternating/Reciprocating (RBAR) therapy provided a major edge towards reversing chronic CRPS. By avoiding all types of repetitive actions and creating a controlled environment of randomized movement and widely varied activities, progress was enabled even when progress seemed most impossible.

It is not simply a matter of learning what to do, and neither is it just working harder. It is searching for the most efficient ways to reverse specific types of maladaptive learning. It is finding ways to rebuild important physical and mental interrelationships. It is carefully working within the constraints created by CRPS.

## **5 YEARS IN A DOWNWARD SPIRAL**

My CRPS started in one ankle and within a few days it spread bilaterally to the ankles, feet, and toes. Both feet were ugly, discolored, swollen, and functionally limited. Hair from the sock-line down was lost and the skin became tight and shiny. Veins contracted and there was a loss of temperature sense and control. The feet were always cold and no longer produced sweat. There was pain, stiffness, and a partial paralysis in the toes...and the trigger for it all was a simple foot massage.

Following my doctor's advice to "keep moving", I tried each day to increase exercise and walking times. Typically there would be progress for a week or so, until the inevitable and destructive flare-up occurred. After each flare-up I restarted the process. In spite of my desperate efforts, the atrophy continued for 5 endless years. Feeling an overwhelming sense of failure, I was trapped in a relentless downward spiral.

Medication seemed ineffective. Pushing harder caused even more flare-ups. With rest and recuperation there was no healing. In fact, lack of movement caused an increase in joint discomfort and a terrible deep tissue pain. I couldn't stop "hurting" my feet...and my feet wouldn't stop "hurting" me.

## **MORE THAN AN INJURY RESPONSE**

*The real voyage of discovery consists not in seeking new landscapes but in having new eyes.*  
-- Marcel Proust

For years I kept a record of flare-up episodes and continually did my best to avoid anything that might trigger another one. This proved to be a fools errand as the list grew larger and larger: turning and twisting, starting and stopping, opening and closing doors, walking in gusty winds, picking up a baby, the feel of cool water, falling asleep with my feet exposed, wearing socks and shoes, sitting too long etc.

How could I be injuring my feet by sitting, sleeping, wearing comfortable socks, or simply putting my feet in cool water? Without question, CRPS is more than an injury response. It is equally clear that movement avoidance is not an effective rehabilitation technique.

## **UNDERSTANDING PAIN**

I had always thought of pain as a straightforward response to pain receptors. This is not true; it is actually a complex construct of the brain. Specialized nociceptive nerves certainly do send information about potential noxious stimuli, but it is up to the brain to determine if and when pain should be felt. Based on a complex mix of associations it is the unconscious brain's responsibility to optimally use pain within the scope of an effective survival strategy.

Although the pain was very real, it was becoming clear that my brain was creating pain unnecessarily and even destructively. The pain was not helping me heal.

## **THE DROPPED CUP INJURY ILLUSION**

While removing a ceramic cup from the dishwasher I fumbled and dropped it. Carefully sliding my feet out of the way, the cup hit harmlessly just beyond my right foot. Relief washed over me. It would have taken weeks to recover from even a glancing blow. To my surprise, within seconds the right ankle began to tighten and there was a dramatic increase in pain. Within minutes both feet visibly increased swelling and discoloration. I was experiencing a flare-up! Somewhere in the depths of my unconscious brain, danger, not relief had registered.

With my sensory sensitivity heightened by CRPS, I knew the slightest twist, turn, bump, or bruise could cause an injury response, but I was dumbfounded to learn that the brain could trigger the injury/immune response with only the *illusion* of injury!

This was a moment of enlightenment. My brain was reacting to what it *thought* happened, not to what *actually* happened. The brain interprets things as it expects and perceives them to be not as they really are. This is the basis of illusion. All this time I had assumed my feet were somehow damaged beyond the body's ability to repair. Here was strong evidence that it was neither my feet nor the regenerative process that was broken; it was the body's command and control system. Giving this, would it be possible to renormalize the brain and reverse the symptoms? Could I heal my feet by changing the brain?

## **INTERRELATED FUNCTIONAL COMPLEXITY**

Systems that have interrelated and complex feedback paths are chaotic by nature; one small change can cause unexpectedly large and surprising results. The multitude of signs and symptoms that come with CRPS is a clear manifestation of how interconnected and tangled the body's functional mechanisms can become.

Mechanisms in the body are like musicians in a symphony. If one player gets lost, it immediately affects the overall harmony, but that is not all. Through the feedback of sound, others may also stumble, one discordant note leading to a cascade of errors. The individual affects the group and in turn the group affects the individual.

I believe CRPS is the brain's natural response to a traumatic and particularly destructive cascade of functional responses; a sequence that ultimately disrupts the brain's adaptive control equilibrium. The interacting functions are individually and collectively pulled along a trajectory towards a powerful and maladaptive attractor. It is not just pain and the injury response that is affected; seemingly disparate mechanisms such as fatigue, touch, and temperature regulation, are also pulled along for the ride.

## **OFF THE ROAD AND INTO A DITCH**

In the body no process works in isolation. Feedback works to stabilize functional mechanisms, but when there are competing requirements ideal stability may be difficult to obtain. Each function is in a constant competitive battle for stability.

After trauma upsets the body's equilibrium, it takes time for the overall process to recover back into an optimal resting state. The return to normality is never the same twice. On the trip back you will hit bumps, cliffs, and ruts along the way. As the healing continues, the body's functions jostle individually and collectively in search of

intermediate states of equilibrium. Ideally, step by step the process continues until total recovery where the body finds itself once again a deep and stable configuration of adaptive equilibrium.

With CRPS the wheels of recovery get stuck in a rut and pulled off the road into a maladaptive ditch. The self-reinforcing nature of CRPS quickly erodes and deepens the ditch into a gully. If you do not get out quickly, it will become a deep energy well with steep walls. CRPS is a physically triggered learning process. This is why early treatment is most effective.

Rehabilitation is the process of climbing out. As you move upwards you must look for the cracks and crevices to grasp onto. At each level it is important to hang tight until you build the strength to move on. There will be times when the rock will crumble under your feet and you will find yourself falling. When this happens you must reach out and find something to slow you down. The key is to catch yourself before you hit rock bottom. Flare-ups are major falls. How you manage them may make the difference between being trapped or clawing your way out.

Chronic illness can certainly be the results of ongoing physical defect, but it is not required. A healing cycle that becomes defective may become both the cause AND the effect of the ongoing debilitation and suffering.

## **ABBERANT SENSORY PROCESSING**

We do not come pre-programmed. Before we can ever hope to move and function effectively, our brain must create an internal world based on probable action/reaction results. The sensations of touch, position, duration, force, and momentum must all be successfully integrated.

If you try to touch your toes, or if someone pinches you or twists your arm behind your back, it typically becomes painful *just before* any apparent injury occurs. Pain is not simply a consequence of injury; it is very often a pre-injury warning signal.

The dropped cup injury illusion proved that the brain could trigger an injury/immune response with *OR* without an injury. Rather than defining CRPS as an “aberrant response to injury”, it is more inclusive and accurate to define it as an “aberrant response to sensory processing”.

Going over my list of flare-up triggers, there is no question that my sensory processing was distorted in sensitivity, time, and space. The CRPS response was triggered by a wide variety of perceptual experiences: injury, pain, stress, inactivity, fatigue, momentum, temperature, constriction, force, weight, range of motion, etc.

The CRPS response was the brain’s confused and misguided attempt to protect me from an exaggerated and even imagined danger. Chronic CRPS is a mix of aberrant processing and the distorted representations it leaves behind.

Each time I got into a swimming pool I immediately felt a warning in my feet that something was “wrong”. My brain was trying to process the perceived change in gravity, resistance, and temperature. It was trying to decide if I had put myself into a dangerous situation, whether action or inaction might have injurious results.

A mismatch between expectation and actual feedback evokes a response. Too little sensory input is as much a problem as too much. Scratchy wool socks were more comfortable than smooth soft ones. With soft socks, my brain was expecting more feedback than it was receiving and I was being tortured as a result of this mismatch.

The overall purpose of the brain is to predict the future; to optimally predict the consequences of action and inaction. My brain was predicting the future inaccurately and even destructively.

## PART 2

### BUILDING AND EXECUTING A NEW TREATMENT PLAN

- *Question everything and everyone...especially your own biases*
- *Test your ideas and follow the evidence...without evidence reserve judgment*
- *Remember you could be wrong and that's OK...unless you refuse to admit it*

#### MOVEMENT RANDOMIZATION

For years I had failed to beat CRPS. "Meditation", "desensitization", "scrubbing", and "repetitive exercises" altogether had not been enough to tip the scale. Meditation was helpful, but tactile desensitization was tortuous and marginally effective. Scrubbing and repetitive exercise seemed to do as much harm as good; triggering flare-up after flare-up. I needed a more effective treatment, i.e., a more efficient learning strategy.

There is little debate about the value of functional restoration. The million dollar question is how to do it in an environment dominated by persistent pain and destructive flare-ups.

Functional restoration includes:

- a) Range of motion
- b) Strength
- c) Endurance
- d) Coordination

With all the ongoing symptoms, accomplishing any of these four objectives seemed impossible. The slightest movement was excruciatingly painful.

Whenever I tried repetitive exercises such as rotating my ankles, my joints would stiffen up and become painful after just three or four rotations. Learning or relearning complex motor skills requires more than a desire to learn, it demands frequent and effective rehearsal and CRPS was blocking my progress.

One day I began to experiment drawing small cursive letters with my toe. I slowly wrote an "a", then "b", then "c". Surprisingly, my ankle did not stiffen up. Ultimately I made it halfway through the alphabet before the CRPS response pushed back.

As a further test, I then switched to capital block letters; "A" then "B" etc. Unexpectedly, the change to straight line stop and start writing, from the more rounded cursive, seemed to reset the brain's resistance to movement and allowed me to finish another 13 letters. You may say "so what?", but to someone hardly able to make 3 ankle rotations...to suddenly be able to make 26 consecutive motions was a breakthrough!

As a final experiment, I had always noted that I could walk longer than I could do typical exercises. I wondered if the brain favors bilateral movement over unilateral movement. I tried alternating feet at each letter to see how it affected exercise duration. The results were dramatic and I was able to nearly double again the time before my ankles began to stiffen and fight back.

My brain seemed to allow the optimal amount of movement when:

1. I was randomizing movements (e.g., writing/scrubbing *abc*s).
2. I was varying activity types (e.g., changing from *abc*s to *ABC*s).
3. I was alternating between feet (e.g., left foot "A" then right foot "A", left "B" right "B" etc.).

These three simple strategies each helped me to tolerate longer rehabilitation sessions (altogether more than 10 times longer than simple repetitious exercise)...but how would the strategies affect the frequency or intensity of the CRPS response? Previously, with repetitive exercises, increasing exercise duration often triggered a flare-up.

I experimented with these three techniques for one week and then for two. Three weeks went by with measurable improvement *AND* without a flare-up! It had been years since more than two weeks had gone by without a flare-up.

Rehearsing randomized movement sequences seemed to “movement harden” my feet; lowering the incidence of flare-up. When sensory processing does not match expectations, the brain is “surprised” by movement and flare-up can occur. By practicing a wide variety of natural movement sequences I was rebuilding important sensorimotor models.

The brain understands the danger of repetitive unilateral stresses and naturally responds to it. With CRPS the response is exaggerated and the brain forcibly pushes back with pain and a premature tightening of joints, muscles, ligaments, and tendons. The first step towards effective physical rehabilitation is to minimize this effect.

*Note: Whether one has bilateral or unilateral pain, rehearsing bilateral alternating/reciprocating actions will result in enhanced balance and coordination (vs. unilateral exercise). The affected side of the brain benefits from the bilateral integration and also from observing the more natural movement of the better side.*

## **MEDICATION’S IMPORTANT ROLE**

Over the years no combination of medications seemed effective. This perceived failure was largely due to a lack of understanding and to unreasonable expectations. Medication can not replace physical rehearsal when it comes to sensorimotor learning. Can you imagine learning to play the piano or ride a bike by taking a pill? That said, medication is useful and in many cases may even be critical to rehabilitation.

The powerful effects of CRPS create a maladaptive learning environment that is very difficult to combat. Finding medications that relieve symptoms, increase motivation, facilitate consistent activity, and minimize the impact of flare-ups, may give you just enough of an edge to make progress.

I came to the realization that stabilizing my medication type and dosage was far more important than finding a perfect combination. Changing medications or even missing a dose can trigger a flare-up, and flare-up is the opposite of progress. With every change the brain struggles to adapt; making the tightrope of progress that much harder to walk.

Once CRPS becomes chronic you have effectively “learned” the disease. A stable drug regimen, properly paired with structured activities, will improve the odds of renormalizing the affected control mechanisms. After symptoms disappear medications can be reduced and eliminated with far less risk to recovery.

## **ACTIVITY/REST AND REPEAT**

For years, I had increased activity as tolerated, and decreased it when forced. My new exercise/activity plan was more consistent as it was based on strict activity pacing. All activity (exercise or life) was duration limited and was followed by a required but limited rest period. Using a timer, I started with 2 minutes of activity followed by 20 minutes of rest. The 2 minute duration was chosen to be just below the threshold of the adverse response.

I repeated this activity/rest cycle over and over throughout the day. This resulted in 8 to 10 rehabilitation sessions/day. This was trying but necessary. Countering the powerful and maladaptive reinforcement of CRPS was the most difficult thing I have ever done. Longer less frequent sessions (1 or 2 per day) had proven to be a rollercoaster of pain and flare-up.

I began each exercise session by writing the ABCs with my toes (cursive and block letters); alternating feet at each letter. Over time, I added more activities, e.g., picking up and dropping objects, passing them back and forth, tipping pillows, dribbling balls, walking, swimming, and even mirror writing the ABCs. All activities involved a forced and focused attention, randomized movement, and bilateral alternating/reciprocating sensorimotor stimulation. Repetitious movement of any kind was avoided.

Functional restoration is far more about renormalizing sensorimotor perceptions than getting into shape. It was necessary to avoid any and all of the typical stress and strains of working out. A simple stiff or sore muscle would

send me into a tailspin. Rather than constantly pushing forward, I found it beneficial to periodically level off the activity duration. This minimized flare-up and gave brain structures time to be reinforced and rebuilt.

Activity pacing and flare-up management are key components of an effective treatment plan. Never do more even if it is a "good" day. Never completely stop exercising no matter how "bad" the day. Flare-ups are inevitable and learning to minimize their impact is essential. Trying to hold fast to my activity duration even in the face of a flare-up was counterproductive, it only intensified the reaction. At the onset of a flare-up, I found that it was prudent to back off to about half activity and begin working back towards the original exercise duration as the flare-up tapered off.

After enduring 8 months of this new treatment regimen, I could finally sustain 90 minutes of activity before resting for 30 minutes. This longer activity/rest period resulted in 3 to 4 rehab sessions per day. I leveled off at this duration for the next 6 months and the CRPS began to disappear from the inside out; first the ankles, then the arch, then each toe one joint at a time.

The probability of successful reversal is directly proportional to the number of adaptive experiences, their duration, and their efficacy. By incorporating a more "learning efficient" physical exercise regimen into a comprehensive treatment plan, I found that it *WAS* possible to heal my feet by changing the brain.

## **A PARTING WORD**

*What is already in the mind can not be removed, but new memories can be layered upon the old.*  
-- Anonymous

Chronic CRPS can be reversed. Moreover, with better fundamental knowledge, I believe I could have done it years ago...likely before it ever became chronic. This is both frustrating and promising to contemplate. With new research and understanding, better trained professionals, and more effective standardized care, I am certain more and more people will recover from CRPS before it becomes chronic...and more and more people will recover even after it has.

Just as one stumbling musician can trigger a cascade of errors, minor trauma can be the first chaotic step towards CRPS and its many devastating symptoms. However, it is important to realize that positive multi-functional cascading behaviors can be just as powerful and far reaching as negative ones.

As my range of motion and exercise duration increased, other interrelated sensory modalities began to renormalize without the need for specific intervention. This made tortuous tactile desensitization therapy unnecessary and redundant. It similarly eliminated the need for temperature and/or constriction desensitization. It is a gift that as part of an overall interrelated functional group, the many symptoms of CRPS tend to improve right along with functional restoration.

Reversing CRPS takes more than hard work. Some treatment regimens are more effective than others. Many small things helped tip the scales. Bilateral randomized movement therapy and strict duration based activity pacing carried the most weight. Ultimately, my individual treatment plan consisted of:

- 1) Meditation
- 2) Stress reduction (delegating responsibilities and minimizing all external forces)
- 3) Activity pacing (duration based)
- 4) Tens sensory stimulation (directly on the toes and feet providing additional sensory feedback)
- 5) A stable medication regimen
- 6) Flare-up management
- 7) A wide variety of RBAR (randomized-bilateral-alternating/reciprocating) exercise spread throughout the day.

CRPS affects all aspects of your life and a successful treatment plan should also. Reversing CRPS requires the dogged execution of a comprehensive, efficient, and effective treatment plan.

Well into the second year after my recovery, I continue to be symptom free and my feet react and heal normally. To reinforce my healthy state, I exercise at least 1 hour/day.