

## A World with CRPS as Your Constant Companion

I live in a world with Complex Regional Pain Syndrome (CRPS) as my constant companion. While on deployment to assist the Hurricane Rita recovery effort I contracted an antibiotic resistant (MRSA) bone infection (Osteomyelitis). The Osteomyelitis/MRSA and 2 subsequent surgical procedures resulted in the development of CRPS -- also known as Reflex Sympathetic Dystrophy Syndrome (RSD).

Physicians don't know why it develops, but CRPS is a nerve disorder that usually occurs after a traumatic injury, surgery, sprain, fracture, infection or a period of immobilization. CRPS/RSD is said to be the most painful chronic disease that's known today. On the McGill Pain Index it (Causalgia) scores 42 out of 50.

How does that compare to other types of pain and/or chronic pain conditions? Arthritis pain is ranked about 18, Non-terminal Cancer pain at 24 and Chronic Back Pain is at 26. Natural labor and delivery of a 1st child is about 35. With a score of 40, the pain associated with the amputation of a digit is closest to matching the intensity of CRPS/RSD.

Now, imagine for a few minutes that we've traded places.

Imagine that this is your new world. You begin and end every day with CRPS as your constant companion.

**In your new world...** the lightest breeze, touch, vibration, movement or exposure to cold causes excruciating pain. If asked, you couldn't honestly tell someone when you last experienced a pain free day, or when your pain level had dropped below an 8 (on a scale of 1 to 10) for any significant length of time (two hours or more).

**In your new world...** you know it makes your spouse feel helpless to see you in pain and be unable to help. You force yourself to smile, laugh, and hide the pain as much as possible. You face your friends, family and the rest of the world with your mask firmly in place.

**In your new world...** you wake up in the morning and are unable to use your hands to sit up—they will no longer support you. In order to get up you have to carefully scoot to the edge; roll off onto the floor, onto your knees—while trying to minimize the vibration to your hands and arm. The fingers on both of your hands are stiff; your dominant hand is locked in a curled position—you now have a claw—the same arm feels as though it has been filled with white-hot coals, while simultaneously soaking in a glacier fed river.

**In your new world...** when your spouse is home, your 1st cup of coffee in the morning is delivered. You slowly—being as gentle as possible—wrap your hands around it. You're sitting, grasping your coffee cup like a toddler being weaned off a bottle—but, who cares? You know it will loosen up the joints in your hands a bit.

**In your new world...** Your spouse is gone, so if you want coffee, you have to make it yourself. The question isn't the "no brainer" it used to be. You have to decide if the additional pain will

be worth it... and if so, while waiting for it to brew; one hand gets a paraffin bath (dipped in hot wax). Your dominant hand and arm will have to wait until the coffee finishes brewing to get some relief since you wear a pressure garment on it 24/7.

**In your new world...** while enjoying that 1st cup of coffee, you contemplate the day ahead. For every 10 to 15 minutes spent on a task, it will take 2-3 hours for the pain to return to the pre-exertion level. You've learned that you have to prioritize tasks and pace yourself. You haven't learned to accept your limitations, and will occasionally push yourself further than you should when there's a critical task that must be completed.

**In your new world...** you've always been fiercely independent, often to a fault. You find it demoralizing to ask for assistance with the tasks that you used to consider trivial, like opening: a straw in a plastic wrapper, a single serving creamer or sweetener, taking the lid off a soda bottle; or zipping up a winter coat.

**In your new world...** instead of "living" a very active lifestyle, you "exist" in a sedentary world where you need assistance with, or are unable to complete, many of the essential tasks of daily life. Dressing yourself unassisted is quite the challenge, and not always possible. Garments with zippers, snaps, buttons, and hook & eye fasteners have been eliminated from your wardrobe as much as possible.

**In your new world...** your first concern as you review a menu is what you can eat with little or no assistance. You rarely order anything that can't be cut with a fork because you just can't bring yourself to ask your spouse to cut your meat for you.

**In your new world...** you're seeking a new doctor to coordinate your care—your current physician isn't on the new insurance provider's list. As you call around attempting to locate a PCP that is experienced treating your condition, the 1st thing you're told is that they won't write prescriptions for pain. Even after telling them that you're fine with that, you're all ready seeing a pain management specialist; they still feel the need to reiterate their position.

**In your new world...** you've been on numerous medications for the pain, and have experienced a variety debilitating side effects which have included: loss of cognitive function, inability to concentrate, weight gain, dizziness, uncontrollable muscle movement, tremors, hair loss, elevated blood pressure, etc. There are two things that you haven't experienced since CRPS became a part of your life...

1. A night with more than 4 hours of uninterrupted sleep; and
2. A day without pain

**In your new world...** at an 8 you're breathing your way through the pain, absurdly grateful that you retained some of the Lamaze classes you took 20+ years ago.

**In your new world...** an 8 ½ is when the pain is so intense you're nauseated and not entirely

sure you'll be able to keep yourself from spending a good portion of your time worshipping at the porcelain throne.

**In your new world...** a 9 is when you force yourself to stay silent, you shift the book you were attempting to read so your face is hidden, tears are streaming down your face, hoping that no one will notice.

**In your new world...** a 10 is lying on the floor, curled in fetal position, unable to move or speak as tears stream down your face... Knowing that all you can do is lay there and endure. The only alternative is unacceptable. You refuse to give up!

**In your new world...** it's time for your day to end. You took the sleep aid about 4 hours ago; you're beginning to feel it try to pull you under. You've learned that the frustration of not being able to fall sleep will increase your stress level, making falling asleep more difficult. You lie on the sofa with your back pressed tight against the back; several pillows are wedged around you to prevent your body from shifting during the night. If your position changes, it will cause the pain to flare and wake you up. Your body must have this rest.

**In your new world...** a brief review of your day flits through your mind as you drift off. You didn't manage to accomplish everything that you wanted to, but completed what had to be done. You still feel a little guilty, but you force the thought away. You need to rest.

Thank you for trading places with me for a little while. While you spent time imagining yourself in my world, I spent my time remembering what it was like to live in yours. My time in your world reminded me that there's still hope. I have hope.

**I have hope...** that as your return to your world, you'll take with you the understanding that you could substitute Fibromyalgia, Lupus or one of several other chronic pain conditions for CRPS — this would be their world as well.

**I have hope...** that the next time you encounter someone who lives in my world, that you'll show them compassion, understanding, and kindness.

**I have hope...** that you remember how difficult it was to put on that mask, to protect family & friends from feeling helpless. To protect them from experiencing the same devastating effects to their sense of self-worth as we have.

**I have hope...** that you the short time you gifted me with by trading places, is the only time you'll spend here.

**I have hope...** that you remain healthy, happy and whole.

**I have hope...** that my world never becomes yours.