



My Story of Hope and Courage

By Allison Morris

The funny bone.

My journey with CRPS began with a painful bonk to my right elbow's funny bone. I know, not so funny. We all know what it feels like to hit your funny bone. It hurts. You pull your arm in, maybe rub it a bit, you wonder why it hurts so bad, but the pain and wacky sensations usually disappear within a minute or less. I could not recover from this bonk. I had to sit down on my son's bed. My eldest child, 7 at the time, was placed in charge of my 1 1/2 year old daughter. We were upstairs and had very steep wooden stairs. The pain was bad. Eventually it subsided a bit and we all journeyed downstairs so they could play and I didn't need to worry about another injury in the house. The pain was excruciating by now. I could barely move or use my right hand, it was stiff and curling in, a lot like a stroke victim. I was scared and miserable and angry, who hits their funny bone and then gets a shockingly painful arm. I remember not being able to have my children on the right side of me, I needed space, I couldn't even read them a book as it was impossible to turn the pages, even with the book resting on my lap. This was January 7, 2011. Fast forward through winter and spring. I still couldn't use my arm, I could barely get my finger and thumb to touch. I had been doing very painful physical therapy since it happened, trying to get the use back. It was suggested I seek a second opinion. The next MD I saw in May knew immediately I had CRPS. Apparently I had most of the telltale signs. Cold hurt me, weather changes hurt me, wind/breeze/air movement over my arm hurt. Pain and dysfunction completely out of the normal from a funny bone bonk. I was grateful for a diagnosis. I had been a nurse for 14 years and I had never heard of it. My other nursing friends had never heard of it, so what was this? Well, CRPS is the beast trying to take over my body. I tried an acute pain clinic but the nerve block didn't work and scared me, I hated it. Next I tried a chronic pain program. It did help. I learned why my arm hurt so much when just talking about the injury. I learned how to distract myself, how to use adaptive devices to hold forks and spoons. Eating is really hard when you lose your dominant limb. I was back doing physical and occupational therapy and trying to move on, learning to live with this beast.

Summer 2013 I was doing better, not great, but better. I could use normal silverware again. I still didn't like to be touched. I was still in nearly constant pain but for the most part it was tolerable. The normal activities of daily living were still a challenge, my right arm was weak and very sensitive to touch.

In summer 2013, we had planned a family trip to California. We moved from California in 2010 to Boston. We wanted to visit some old friends and then fly onto Australia, where my husband is from. It was during this trip the beast showed its ugly teeth. I thought I had twisted an ankle, stepped funny or just walked too much in bad shoes. My right foot would swell with use, to the point my shoes became too tight. After being elevated, it would improve. The worst of the pain was just above where the toes insert to your foot, crazy. I was praying it would improve and it was just a "normal" injury. Walking through the airport on our return flight, I could not keep up with the family, my husband kept trying to hurry me, but it hurt way too much. I hobbled along and was shocked by the swelling in my right foot when we landed in California. There was severe pitting edema and excruciating, burning pain. I was so scared the CRPS had spread but still had hope it was just a minor injury, it wasn't. July 2013 it spread to my right foot. Within the month, my right leg was warm/hot to touch, swollen and crazy painful. I had an urgent deep vein thrombosis check done. I was actually hoping for a blood clot. The idea of a hospital stay while I got started on anticoagulants sounded like a better option than the CRPS spreading. Not so lucky. Remember, with the CRPS in my right arm I could not use crutches, I could not hold them, I could not tuck them under my arm. I eventually bought a cane and cried a lot. So it is winter now in Boston, where every winter had been worse than the one prior, seriously, really bad luck. I couldn't drive, I could barely walk. I was terrified of slipping on the ice. I was blessed with a physical therapy program at a rehabilitation hospital near our house. They had a pool for aquatic therapy. I believe it was because of aquatic therapy that I am walking now. I learned to walk and regain my balance in the water. I learned floating in warm water was the only way I could finally release some of the tension my body constantly fights. Winter 2013 is when we decided the weather in Boston was stealing any quality of life I had. With every weather warning, freezing rain, thunder storm or breeze, my pain increased. I was depressed, sad, angry, anxious and bitter. I had incredible amounts of guilt over not being the mother I had been. I struggled to get out of bed and face another day of pain, another day of disappointing myself, my friends and family.

My husband and I started having real discussions about moving the family to a warmer climate, with less weather. We were blessed. My husband talked with some co-workers from his old job and they were willing to offer him a job back in Livemore, California. We lived there previously so we knew the climate was good, there are minimal weather changes and we knew people. We knew where to get groceries and our favorite restaurants in town. We settled back into the town of Pleasanton. We have been back 3 1/2 years. Our house has no stairs, except at the entry. A one story house is such a blessing. Most days the weather does not have a negative impact on me. I still have pain daily. I have learned what to push through and when to stop and put my feet up, which is so important to me. I found an aquatic therapy pool for physical therapy, an acupuncturist, a masseuse, a hypnotherapist. I started using an electrical stimulation machine called Vector. It has improved my quality of life. I have more energy, I don't always need an afternoon nap. I still must rest throughout the day. I am not able to work and I prioritize my day as there is only so much I can do. There are no energy reserves. I can't push through, when I try, I feel like I literally hit the wall and the pain circulates around my body.

February 2016, I slipped and hit my left knee. The beast was showing its ugly teeth again. This incidence brought CRPS to my left leg and it has slowly crawled up to my left arm as well. At times my burning pain is bilateral, for example, both thumbs or elbows. The swelling and inflammation is bilateral to the palms of my hands and soles of my feet. The swelling is not always bilateral, another blessing.

Where is the hope you ask?? Let me try and explain. CRPS is taking over my physical body. Some days it is enough to get out of bed, get dressed and drive my kids to school and pick them up in the afternoon. I still struggle with depression and I have more anxiety as I don't know how bad my CRPS will become. My guilt is better. I can walk around the block, not fast, but I can walk. I can hold my kids hands and they can hug me. I am learning to heal myself and believe I can be healed. I am trying every complimentary therapy treatment I can and they help. Most days I can make dinner or at least get it started. I can read my little girl a bedtime story but she comes to me now, slowly and gingerly hopping on my lap. I now have the energy and mental fortitude to help the kids with homework. A couple years ago my body was done for by the time I got them home from school. They had to help each other with homework and fix their own snacks. Yes, this is great for them to do, makes kids more responsible but it's not the same when you "can't" do it. When I can't do it, I feel sad and worthless as a mom. Yes, these are emotions I am working through in therapy and it is improving.

I have started a [website](#). Let's ride this wave, together. It's a combination of what I find helps me with CRPS, the ideas I have from nursing that make a big difference in my life. Such as always positioning my legs on pillows for extra elevation, as well as my arms. My arms just feel better being elevated. It also has ideas for simple meals and how cooking has become therapy for me. I miss nursing, I miss helping others and in sharing my story, hopefully I can help someone else who is struggling through life. I am no longer embarrassed about having a disability. I have a wheelchair that we use for day trips, I hate it, but it means I can still get outside with my kids and husband and enjoy life. If I do have an evening activity, I lessen what I do that day and sometimes the day before, saving up my precious energy. I have so much patience now and have really learned to take life slower. The courage comes because without it, I would lose the physical abilities I have regained and I would lose my mental capabilities, my heart, and my soul. Every day has to be a fresh start. I have figured out what works for me and what doesn't. I can "reset" my mind and body and can sometimes make a fresh start even after an awful morning. I focus on what I can do. My new motto is keep living, keep moving. If you stop moving your muscles atrophy and it is so hard to get them back. I still have weakness in my right arm and hand.

My story of hope is continuous. I am so much stronger now, mentally. I can cope easier, I am happy again. My kids are growing up with compassion and respect, they know when to leave mommy alone or when I need a hug. They have life skills, they can do laundry, make meals and tidy up. They are kids though, so it isn't done without asking. My husband has been my rock through all of this. He understands how awful and debilitating CRPS can be. He holds my hand, pushes me in the wheelchair and brings me a glass of wine or two. I am blessed with such a caring family. There are days when I still struggle and my coping mechanisms don't work, the pain is too much. That is where the web site comes in. I realized my flare ups come in waves, whether it is pain or anxiety and depression. I can't always control it but I learned the flare ups pass. I need to just ride the wave and hang on until the worst of it passes, it always does. Complex regional pain syndrome is a beast. I am learning to live my life, caring for myself and family, loving and laughing again. You can do it too, take your time, keep living, keep moving. Peace.