

**RSD: Really Scary Disease**  
**Withstanding the trials and tribulations of RSD/CRPS**

*Healing can happen but a proper and timely diagnosis is essential.  
 Attitude is everything along with an uncommon blend of patience, persistence,  
 faith, hope, instincts, insistence and an unrelenting quest for answers.*

Tina A. Mohr

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“*SOMATOFORM DISORDER WITH UNDERLYING DEPRESSION*” read the neurologist’s summary. Being a licensed massage therapist who had worked in injury care for over ten years, I knew all too well what the doctor’s words meant. It was his professionally ‘polite’ way of saying, “It’s all in her head.” Now I understood why he had quickly shuttled me out of his office. My mind drifted back to his offhanded comment. “I think you’ll be ok,” he dismissed, nodding to me reassuringly. Now, retroactively, I understood that cheesy grin. Even at the time, I wanted to believe the doctor. I wanted to believe that I would be “ok”. It had been a year since my accident. I thought after one year, for sure, I would be have been fully recovered.

As I sat reading the doctor’s report, I questioned myself. Somatoform disorder? How could this pain and these problems be something I was imagining or making up? Depression? I didn’t *think* I was depressed, at least not until I read this doctor’s diagnosis. Why would I need or want to manifest this hideous, burning pain and these weird symptoms in my left arm, hand, leg and foot? Could this pain and these bizarre symptoms be something I ‘wanted’? Could it be that I was kidding myself? Could it be that I was trying to make a bigger deal of my slip and fall injury just to get attention or make a legal case? Searching deep in my psyche, the honest answer to these questions was an unequivocal and resounding ‘NO’; in fact, if anything, I thought I was being a real trooper, a really good sport, about being injured.

I always thought of myself as having a high pain threshold. Years earlier I had given birth to twins and not once did I even think to ask for pain meds or anything of the sort. I was one of those lucky women who viewed having a baby as an athletic event, but not painful. As a former competitive athlete, I was used to overriding pain. As a medical massage therapist specializing in injury care, I had spent a good part of the last ten years of my life helping people get out of pain. I could deal with this injury, I thought; I was an ‘expert’ at helping people get out of pain. I knew the protocol to address my initial orthopedic injuries and I followed them to a tee.

When the accident happened I was out of town and attending a professional conference. Returning to my hotel just after the conference I was walking alone on a public sidewalk just after midnight. With no warning that I was about to precariously plummet onto the pavement, my foot slid helplessly on a mini waterway of slippery soapy fluid draining from inside an open-air shopping mall. I hadn’t seen the sudsy stream ominously trickling from inside the building onto the sidewalk. No orange ‘caution’ cones were set out to warn passers-by. Poor lighting did not help matters either. Bam! Before I knew it, I felt a strong slam. Face down on the sidewalk I was trying to figure out what had

happened. What did I hear? A sound of a motor seemed to come from a distance. I slowly lifted my head off the pavement and turned my face in that direction. I squinted trying to focus. It was then that I saw the late night janitor operating a large floor-cleaning machine inside the shopping area.

I don't much remember the actual fall. Once I was on the ground, though, I knew I had hit hard. It was all I could do to scrape myself off the sidewalk and stand up. It took me a while to get my breath, to orient myself. It would take me much longer to ultimately realize the bigger picture—what was really in store for me.

After those first couple weeks, I returned to work part time but with some difficulty. Just the same, I was determined not to let the injury get the better of me. I treated myself as I had so many patients I had worked with over the years. I rested and moderated my work schedule. Gradually, I did more and more, trying to return to work full time, but with difficulty. Why did every thing seem so hard? I did not want to admit to the pain or the problems I was experiencing; I did not even want to admit it to myself. Never did I imagine that a slip and fall accident could end up causing the inexorable nightmare I was experiencing. At that point, optimism was my closest ally.

A couple months after the fateful tumble, it was advised that my left knee was definitively in need of orthopedic medical intervention. A left lateral meniscal tear was diagnosed and surgery was recommended. "You'll bounce back in no time," I was told. Unfortunately, that wasn't exactly how I would describe my experience. The first time I got up on crutches the day after the surgery I vaguely recall muttering to myself in a Vicodan haze, "I'd rather have a baby!" My knee hurt like crazy! It was swollen up to the size of a large Florida grapefruit. My husband had just left for a business trip to Japan a day or so after my surgery. Time and rest, I thought, would help me recover. I took it as easy as a mother with her husband out of town could and hobbled around on crutches to do the things I had to do. My daughters were of tremendous help and offered lots of hugs and reassurance.

At my post surgical follow-up visit, the doctor told me he had also done a 'lateral release' to help reposition the patella to help normalize my 'kneecap'. The lateral release, he clarified, may explain the extra degree of pain and swelling. Gradually, with physical therapy, little by little, my knee improved. The pain I was still feeling was a tell-tale sign that recovery might take some time. I had this odd numb feeling in my lower leg and a weird burning feeling on the outside of my knee. It felt quite strange, but again, I was optimistic. "What do you expect post-surgically?" I thought. I tried to convince myself it would all be just fine. I looked forward to a gradual but complete recovery.

Weeks later, I was at a restaurant with my family. I picked up a glass of ice water with my left hand. A stinging cold pain made me put down the glass immediately. "Wow, *that* glass is *cold*," I said. I picked up the glass with my right hand but it felt a 'normal' cold. I touched the glass again with my left hand, "Wow!" I said again! The glass felt so much colder to my left hand than to my right hand. It actually hurt to hold the glass in my left hand. "My arm had been numb after the fall and now the nerve was repairing", I thought to myself. "After all, I *did* hit my elbow and had a big abrasion. Maybe the nerve

is healing and it's just sensitive", I thought to myself. Even then, though, I think I knew better.

A couple days later, I was in the shower. I leaned to my right. "Whoa!" the water got burning hot. "Who flushed a toilet in the other bathroom?!" I thought. I tried to duck out of the way of the cascading water. Soon I leaned back into the water and it felt 'normal' hot again. I leaned again to the left. "Whoah!" the water got burning hot again! I leaned to the right and it once again felt 'normal'. After leaning to the left and to the right a few times in succession, I soon realized that the left side of my body perceived the water to be much hotter than the right side of my body. "That's weird!" I thought. Little did I know that this strange phenomenon was the beginning of something that was destined to change my life; the onset of a real problem that would persist, haunt and torment me.

Weeks later I was in a parking lot walking past a large refrigerated ice truck. As I walked near the giant truck, my left arm and face began to sense a strong vibration. The oscillation from the motor of the truck seemed magnified in my arm and face. I backed up a few steps away from the truck and the sensation disappeared. Again I walked forward and I could again feel the strange sensation in my left arm and face. Was I imagining things? What was this strange twist? It was only much later I realized that it was, in fact, an eerie portent of what lay ahead.

Still in pain but still optimistic, I had gradually over several months time returned to work full time. It was the first week I had worked a full time schedule since my slip and fall accident. One night near the end of that week at three in the morning, I awoke with a startle. "What was that?" It felt as though something on my left arm was crawling and burning. There was a deep, almost throbbing and fiery ache in my arm. It was *very* painful. Then a breeze crept in through the open window by my bed and immediately accentuated the pain. In a drowsy daze I thought, "Boy, this is just like RSD." I tried to go back to sleep but the pain was too intense. Unable to sleep, I awoke. My arm was killing me. I gently massaged it then wrapped it in a blanket to keep it warm and protected.

I had studied Reflex Sympathetic Dystrophy (RSD) in massage therapy school. I remember cringing when my teacher was describing the symptoms. It sounded just horrible. Then in the first year of my massage therapy career I met a woman who had the dreaded disease. She had injured her hand while working with a printing press at a copy center. Unrecognized and left untreated, the disease progressed to the point that she had constant, intractable pain. At one point in her life she had been a vibrant Tahitian dancer entertaining at Disney World. When I met her she lay in bed barely able to move or function. She needed full time home health care and eventually an implanted morphine pump. I was asked to treat her with specialized massage techniques and craniosacral therapy at home to help her be more comfortable. She was very appreciative and continually thanked me for the help I offered her. I only visited her a few times. I have always had tremendous compassion for her even though I have not seen her in years. Then I could not even begin to imagine or fathom her pain.

By the winter of 2000 I learned that I slept best with my left arm in my down ski jacket and my left hand protected with a winter glove. Hawaii winters are relatively warm but my left arm and hand found even the slightest rumination of a whisper cool breeze to be unbearable and my arm and hand begged to be well protected. The same sensation, though to a lesser degree, began to appear in my left foot and gradually crept up into my lower left leg. The intrinsic muscles in my left hand atrophied and my hand felt clumsy. Initially, I was sent to an arm specialist who x-rayed my elbow and reported the elbow to be okay. He advised SSEP nerve conduction testing and a cervical MRI. The nerve conduction testing of both left extremities came out normal. My cervical MRI showed problems but they did not exactly correlate to the subtle atrophic changes in my left hand.

To this day I don't exactly know why that first neurologist tossed me off as a "Somatoform Disorder" when my hand was 'disappearing'. I suppose it was because the nerve conduction tests had come back 'normal'. It took nearly another year for my left lateral forearm to atrophy; it almost halfway disappeared until one doctor agreed with me that maybe we should look into this situation more closely.

I was referred to an orthopedic surgeon who recommended a triple laminectomy and advised that my neck was unstable with some degree of cord compression at three levels. About that same time my family lost our medical insurance coverage which seemed like a curse but may have been a blessing in disguise. Instead of having the surgery immediately, further medical care was delayed. I relied on chiropractic, massage and acupuncture, which helped relieve some of the pain some of the time.

I recall a conversation with a friend of mine, Marion, who is a retired psychologist. She at one time had taught on the Ph.D. level at a well-respected university. I have always loved talking to Marion about life and all sorts of things and consider her to be an extremely wise woman.

"I don't want to be paid to be a victim!" I insisted to my friend, Marion, who was urging me to seek legal counsel.

"You've got it all wrong," she replied, "You don't get paid to be a victim—you get paid so you don't *have* to be a victim."

"Gee, I never thought of it that way," I mused.

"Denial is a great tool when you need to use it," she added, "but you're not being realistic about how much this injury has affected you. You're being way too nice about this. This problem has really affected your life!" she added.

Her words echoed in my mind. That was, perhaps, the first time I really acknowledged that I was really having some serious problems. This injury had affected not only me, but also my children, my husband, our family income, our stability, my livelihood and much more. "Maybe I should seek legal counsel," I had thought. Maybe my friend was right.

It was not until months later, when I got medical insurance re-established I saw a well-respected neurosurgeon for a second opinion. He advised not to have surgery telling me that neck surgery would not help the problem I seemed to have. His testing revealed, of all things, a possible right brain injury. I was referred to a second neurologist. Now I felt I really *was* beginning to lose my mind.

A brain MRI was recommended. The brain scan revealed ischemic changes in the periventricular regions of the parietal lobes. It was advised I get yet another neurological opinion. I was sent to Stanford to see a third neurologist in Palo Alto, California. My husband and I dutifully flew to California hoping for the best but fearing the worst. As we approached Stanford Medical Center, the huge adobe style complex reminded me, for some strange reason, of pictures I had once seen of Texas' historical fortress, the Alamo. A huge clock tower added a modern flair. This all seemed like some strange dream.

“You’ll just love the doctor!” His secretary had told me when I had called from Hawaii to make my appointment in Palo Alto. I still do not exactly know how or why this woman would have surmised that I would just “love” this doctor. In fact, I found him to be quite starchy and rigid, as cut and dried as a textbook. I am all for good medical expertise and following protocol but this guy seemed more concerned with the fact that I had consulted an attorney for legal counsel rather than the degree of pain I was in or that my arm was atrophied. He conjectured that the ischemic changes in my brain may be “old and static” and there seemed, in his opinion, to be no single unifying neurologic basis for my problems. He offered some perfunctory advice and made some decent recommendations but I walked out of this office with more questions than answers. After giving due consideration to some of his comments, I concluded that I thought he was “old and static” and what I really needed were some satisfactory answers to my questions.

Why were my left extremities so painful and sensitive with a burning cold sensation? Why was this feeling spreading to the left side of my face and up into my hairline? Why did it feel so cold in my left lung when I took a deep breath? Why was my left eye burning and so oftentimes dry? If it wasn't neurologic could it be a vascular problem?

Soon I found myself at the office of a well-respected vascular specialist in Hawaii. This doctor really took his time and asked very distinct questions. He performed thorough testing and then confirmed that it appeared I indeed had a problem—thoracic outlet syndrome and possibly other complications. The vascular specialist referred me to yet another neurologist. The vascular specialist then quietly explained that the other neurologists I saw did not ‘believe in’ thoracic outlet syndrome (TOS), that it was sometimes a controversial diagnosis and that my condition fell into a rare 4% of TOS cases. I am not sure what exactly he meant by that, but this was a doctor that I innately seemed I could trust. Eventually I learned that the doctors I had seen previously generally worked for insurance companies. Now I got the picture and I was beginning to learn to go with my instincts.

Shortly after that, I scheduled an appointment with neurologist number four whom the vascular specialist had recommended. This time I met a truly rare doctor who is a real gem. Instead of a “let me tell you” attitude, this neurologist questioned me extensively

on my case history, tested me thoroughly and seemed to be authentically paying attention and listening. This neurologist is an 'old-timer', a gentleman who is perhaps pushing seventy years of age. With plenty of clinical practice under his belt he seemed, at the same time, to be progressive and forward thinking.

He confirmed the diagnosis of thoracic outlet syndrome, a compression problem of the left clavicle (collar bone) that he deemed to some extent to be both neurologic and vascular and that may be contributing to the left arm weakness and atrophy. He noted left supraclavicular swelling. He also suspected late stage Reflex Sympathetic Dystrophy and concurred that from some of his testing that I may have very well had a mild traumatic brain injury. For the first time, I began to feel that there was a doctor who really understood that I authentically needed and wanted help and that I was not just some whacko.

About this same time is when I first became aware I was having seizures. I do not remember them but they scared the living daylights out of my 8-year-old twin daughters. Four times my daughters witnessed me having weird episodes where I would make strange growling noises with my eyes rolling around and my tongue hanging out. All four times it happened just as I was going to sleep or when I was asleep. I had no awareness or recollection of these one to two minute episodes. All I remember are moments of hearing the frantic voices of my daughters pleading, "Mommy, mommy...wake up!" as I seemed to awake from a groggy sleep. My husband was working nights to bring in extra income to make up for the work I was not able to do. He missed these strange encounters, which was probably just as well. He worries so and hates to see me suffer; yet at the same time he has been and remains a constant source of support.

I was referred to physical therapy in Honolulu to see Dawn Isa, a P.T. who specializes in treating both Thoracic Outlet Syndrome and RSD/CRPS. Dawn helped me quite a bit and her compassion, understanding and reassurance alone helped heal more than just my physical symptoms. She lifted my spirits with her true sense of caring.

It was my doctor's recommendation of a relatively new therapy called Dyantron STS--Sympathetic Therapy--that proved to be what helped me most, though. My doctor asked Dawn to administer a 10-day trial of Sympathetic Therapy. It wasn't easy for me to arrange to be gone from my family. The Dyantron STS machine was on the island of Oahu and I live on the island of Hawaii, also referred to as the "Big Island". I had to stay in Honolulu on Oahu and be away from my family. My husband and friends juggled the kids. I went to Honolulu for the STS therapy for almost two weeks of treatment. That was a turning point for me!

With the STS therapy, for the first time in over two and a half years, the burning pain, allodynia and hyperalgesia plus a host of other symptoms virtually disappeared with treatment. By day number four of the treatments I could get in a swimming pool without feeling like the left side of my body was in a glacier fed pool. I could actually go into air-conditioned buildings, or near the frozen food section in a grocery store, without wincing in pain. I could drive in a car with the window open and the wind didn't send me through

the roof of the car. The sun shining on my left arm and face no longer felt like an oven was cooking my skin. Did I have a chance at beating this disease? For the first time ever, I felt ever so encouraged.

My doctor and therapist were pleased with the results and presented my case to a hospital staff meeting. The results were phenomenal. I learned that I was in the lucky percentile of patients that get great results from STS therapy. Studies show that about 30% of patients that use the STS unit get full relief; another 30% get marked but not complete relief; and for some people the STS therapy is not successful. For whatever reason I seemed to fall in the 30% of patients who get virtually complete relief with the Dynatron STS unit, I am very thankful. The doctor recommended to my insurance company that I get a Dynatron STS home unit. Was I ever excited—maybe I had a chance to really have a life again!

Getting a Dynatron STS unit approved by my insurance company proved to be another nightmare. The managed care company overseeing approval rubber-stamped a non-authorization almost immediately. The managed care company's form letter entitled *'Notice of Non-Authorized Services'* stated "Service is not medically indicated." What? How could something that helped me so much not be medically indicated? Who were these clowns?

After a month of requesting additional information from the managed care company and getting no substantive information other than the rote answer that "Service is not medically indicated" with the excuse of "lack of medical efficacy", I thought I would go nuts. I went to a psychiatrist as I felt like I was starting to really lose it. As it turned out, I was having side-effects from the Topamax I had been put on in the interim of getting a STS home unit. Topamax and I don't go together too well. While it managed some of my pain, I was a bit wacky on that stuff. My kids later told me I was "really cranky on the stuff" and I noticed they were being invited to their friend's homes for lots of overnights. My husband tip-toed around me and my aggressive behavior. Eventually, I was able to go off the Topamax much to my family's relief.

Thankfully, the managed care company did an about face and finally approved the STS home unit. Apparently, the aggressive letters I faxed them every day while I was popping Topamax worked. The psychiatrist assured me I did not have a somatoform disorder. A psychiatrist specializing in pain management who I had seen for a second opinion assured me that my biggest problem seemed to be that I had been in too much pain for too long. Thankfully, the psychiatrist supported my efforts to get an STS home unit backing my neurologist's recommendation that it would be most effective for me. These doctors' opinions fueled my efforts to convince the managed care company to authorize the prescribed STS home unit. I sunk my teeth into getting the STS home unit like a junkyard dog. I don't think the managed care company had ever seen the likes of my unremitting efforts. Sometimes it's tough being tough; being tough, though, is sometimes necessary. My husband said my behavior was obsessive but applauded me for wrangling the managed care company into seeing things my way. Desperate times require desperate measures.

Through my trials and tribulations with RSD/CRPS perhaps the one thing that intrigued me most was something I found in Webster's New World Dictionary. In one of my obsessive letter writing binges to the managed care company, I actually looked up the definition of the word "patient" in the dictionary. To my chagrin I read the following:

"patient: *pa' tient* **adj.** || < L *pati*, **1** enduring pain, trouble, etc. without complaining **2** calmly tolerating delay, confusion, etc. **3** diligent, persevering  
-**n.** one receiving medical care"

At that moment, I was proud of myself and my efforts. I was proud of the way, even in my moments of darkest despair, that I had pursued answers to my questions. I was even thankful for the harsh lessons I had learned. I vowed at that moment to help other patients with RSD/CRPS to find their answers. Each of us has our own answers.

I have realized that healing happens on many levels. Different things work for different people. Personally, my drug of choice happens to be kittens... yes, kittens. Pregnant cats seem to adopt my family and kittens have been, at times, prolific around our house. I could feel really junky and then watch these little creatures play and tumble. That always seemed to give me an endorphin high and make me smile. Of course, our two basset hounds and adopted dog named 'Oreo' are good medicine, too. Animals just have a way of knowing when you don't feel well and they help you cheer up. Through my ordeal, they have been steadfast friends.

With RSD/CRPS a proper and timely diagnosis is essential. Unfortunately, I ran into a few doctors who did not understand. I am thankful, just the same, to find those who did care enough to really listen and all those who have offered help and reassurance.

To all those who suffer with RSD/CRPS I offer my condolences, understanding, love, support and free kittens plus a simple Hawaiian prayer:

*Ho`omaka ana e ola hou.*  
(Let the healing begin)