



Tina A. Mohr

Ho `omaka ana e ola hou

(Let the healing begin)

By Tina A. Mohr

“Somatoform disorder with underlying depression” read the neurologist’s

summary. Being a licensed massage therapist who had worked in injury care for over 10 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.

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 medication. 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 10 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, my foot slid helplessly on a mini- waterway of slippery soapy fluid draining from inside an open-air shopping mall.

Preliminary Diagnoses. 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 them to myself. Never did I imagine that a slip and fall accident could end up causing the inexorable nightmare I was experiencing.

A couple months after the fateful tumble, I 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 Vicodin® haze, “I’d rather have a baby!” My knee hurt like crazy! It was swollen up to the size of a large Florida grapefruit.

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 telltale sign that recovery might take some time.

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

Continued on page 14

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.

A couple of 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. After leaning to the left and to the right a few times in succession, I realized that the left side of my body perceived the water to be much hotter than the right side. "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.

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 accident. One night near the end of that week at 3 am, 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 it. I was asked to treat her with specialized massage techniques and craniosacral therapy at home to help her be more comfortable. 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 met a neurologist who is a real gem. Instead of a "let me tell you" attitude, he questioned me extensively on my case history, tested me thoroughly, and seemed to be paying attention and listening. This neurologist is an 'old-timer', a gentleman who is perhaps pushing 70 years of age. With plenty of clinical practice under his belt he seemed to be progressive and forward-thinking.

He confirmed the diagnosis of thoracic outlet syndrome, a compression problem of the left clavicle 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 very well have 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. The doctor referred me to a physical therapist in Honolulu who specializes in the treatment of thoracic outlet syndrome and RSD/CRPS. Dynatron STS Therapy was recommended and administered with good success. My pain and related symptoms, particularly the allodynia and hyperalgesia, were relieved with the two-week trial treatment period. My insurance company would not

cover the purchase of a machine for home use; however, I am arranging for purchase of a STS machine and am about to get a unit on my own, as this particular therapy has helped me the most.

I am starting a RSD/CRPS support group and working on legislation for RSD Awareness and Prevention in Hawaii. As a licensed massage therapist who has worked in injury care for over 12 years, I can honestly say my own injury has been the toughest case I have ever had to treat. Having RSD/CRPS has been my worst nightmare, but my best education. My primary goal is to educate in the prevention and treatment of RSD/CRPS and to help others with this disease find answers to overcome the challenge of living with RSD/CRPS. To all those who live with RSD/CRPS, I offer a simple Hawaiian prayer:

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

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Patient to Person - continued from pg. 9

methods. People need to be responsible for their health. Wellness care is essential. And we always focus on abilities rather than disabilities.”

Currently the ACPA has more than 400 active support groups, both nationally and internationally. The ACPA is funded through donations, some grants and member dues. “It’s amazing how much we’ve grown considering the little money we have,” she says.

One of these amazing things is spearheading the Partners for Understanding Pain, a consortium of 45 groups (including RSDSA) which has come together to raise awareness of pain among the community at large. The partners will work to build understanding that pain is a serious public health issue. They will target health care professionals, legislators, business people, individuals with pain and their families. “Pain touches all aspects of society,” Cowan said.

For more information on the American Chronic Pain Society, visit www.theacpa.org or call 916-632-0922; toll-free 800-533-3231.

Mission Statement

Our mission is to promote public and professional awareness of Reflex Sympathetic Dystrophy Syndrome (RSD) and to educate those afflicted with the disease, their families, friends, insurance and healthcare providers, on the disabling pain the disease causes. We encourage individuals with RSD to offer each other emotional support within affiliate groups. And finally, we are committed to raising funds for research into the cause and cure of RSD.

Craftsman and His Tools - continued from pg. 6

but guided more toward helping people get on with their lives and feel better. And become whole people again.

“My campaign always is and always will be this: we have a lot of tools available for any given patient and you have to keep applying the different tools. To start with something very dangerous, unproven and high-tech, like spinal cord stimulation is wrong.”

Posters Available

New 4-color posters entitled, “Anybody Can Get RSD. We did” feature photos of RSDSA members. If you would like some copies to distribute, please call the home office at (203) 877-3790 or send an e-mail to info@rsds.org

Our Future Depends on You

Please remember RSDSA in your estate planning. Our legal title is: Reflex Sympathetic Dystrophy Syndrome Association of America P.O. Box 502, Milford, CT 06460

Bounty of Hope 2003 Fundraising and Awards Dinner

Thursday, November 6, 2003
The Union League Club
New York, NY

Mark your calendars!

Shop On-Line and Help RSDSA

When you shop on-line at www.igive.com, you can designate RSDSA as your charity of choice and a percentage of each sale (up to 12.5%) will be donated. Retailers include CD Now, J. Crew, Avon, and many others.

Log on today for more information!