

Living with Reflex Sympathetic Dystrophy, RSD: “Never Give Up On Hope” By Brenda Refior



Before I had RSD, I was a strong and happy person who loved life to the fullest. When I was nineteen, I tried out for an Olympic handball team at the Colorado Springs Olympic Training Center. I was accepted and asked to go to the Lake Placid training camp, but this conflicted with my wedding plans. I was young and felt that all of life was ahead of me, and decided not to go to Lake Placid. However, I continued to play sports and worked as much as I could.

In July 1983, I married and couldn't have dreamed of a more beautiful wedding. A couple of years later, I started working for the local school district as a bus driver. I loved the kids and the people I worked with, and driving a school bus never got boring. But it was on a trip driving that school bus taking kids home at 5:30 at night that my life changed forever.

Stopping at an intersection, I pushed down on the accelerator, and five large sparks, fire and smoke covered my feet. I pulled over quickly, undid my seatbelt, and evacuated 25 kids from the bus.

Grabbing the fire extinguisher, I sprayed the bus as it filled with smoke, covering my body in white foam, as it floated back on me. Looking like a phantom ghost, I ran to check on the kids.

Since they hadn't all grabbed their jackets, I jumped into the back of the smoky bus and retrieved them. No one stopped as I tried to flag down cars for help – they surely must have thought I was a ghost! Finally, police transferred the kids to a 7 Eleven where parents picked them up. I rode to the bus barn with the head maintenance supervisor. It was the most uncomfortable car ride of my life.

After receiving muscle relaxers for my aching arm, neck, back and stomach, I spent days getting worse. Most of the time, my hand was marbled and turned shades of blue and purple. It was colder than ice, yet it burned on fire, like thousands of little hot needles. Throughout this time, I continued to drive a school bus, received some commendations, and, I found out that I was pregnant!

My health got worse. My stomach burned and cramped, the diarrhea was unbearable, and I thought I was going to die.

I ended up having an emergency gall bladder operation, and just two weeks later, an early C-section and exploratory surgery to see why I was having so much pain. They did not find anything.

A year later, my husband found me passed out on the bathroom floor. He rushed me to the hospital where I had major surgery. The doctors fixed a hiatal hernia, found a detached colon, (probably detached two years before when I put out the fire in the school bus), and took my appendix for the heck of it.

While in surgery, I flat-lined and they had a time bringing me back. I had a misty vision of four beings dressed in white. A strong voice said, "You will be judged, and you will judge yourself." I thought of things that I knew were wrong that I had done to people in the past. I had to feel not only what it felt like to them, but also how it affected other people in their life. I just knew I had no chance to get into heaven. Then I got to see the good in my life. I felt the feelings of people I had been kind to or had helped, and I saw the ripple effect on other people in their life. I felt like I had made it to heaven, and I was so happy; I really can't explain the feeling. Then the strong voice said, "You are not done. You still have something to do. You need to go back." The next thing I knew, there was a nurse in the room and I told her what I had experienced. I asked her for a pencil and paper so I could write it down. This vision gave me faith, hope and inspiration.

Finally, in 1988, Dr. Toni McLellan, an expert on Reflex Sympathetic Dystrophy, diagnosed me with RSD. It was agony living with this pain for two long years, and nobody knew what was causing it. There was little known about RSD at the time. In the summer before I started my new job, I was strongly encouraged to spend a full month in Saint Francis Hospital's Pain Therapy Program. There were two others in my group. I received pain meds and muscle relaxers right away. The other two were taken off their meds. It really scared me! I found out that one of them held up a pharmacy so he could get pain meds. He said he did it to make the pain go away, but he kept overdosing. Was I going to be like them in the future? Here I am on meds, great...! We swam in the morning and did physical therapy in the afternoon, and, in between, I had psychotherapy.

Bedtime was 9:00. I felt terrible that my two-year-old,

Rachael, could only see me for a few precious moments a day. That was heartbreaking, to say the least. It was the longest month of my life.

I was in pain for two more years, and, once again, I thought I was going to die. My stomach burned and cramped, I had diarrhea and I couldn't stop throwing up. I experienced sweating, passing out, and lengthy hospitalizations. I was no longer allowed to keep my job driving the school bus. It was making my right arm, neck and back pain worse. I missed driving and the kids so much. I loved that job. I was

really down. I felt like I was inadequate and no good to anybody. I was offered a job in special education and I had to jump into it with everything I had, just to make myself feel like I was worth something.

While I hated to work and leave my daughter daily, my new job as a special ed. aide boosted my self-esteem. I worked there for three years and came to really love that job; the kids came to respect me. One young man I saw after school putting a butcher knife up his sleeve told me he was going to “take care of” the guy who had stolen his girl. I told him, “Listen, I’ll do my best to see that you don’t get into trouble over this at school, but you need to give me the knife.” In the end, he trusted me, listened to me, received a one-day suspension, and his uncle thanked me.

I suffered through a lot of pain working as an aide at the school. RSD was taking a toll on me. I’d work and then go home and crash. I would be in so much pain that I would come in the door after working all day and not be able to do anything at home. Poor Rachael wanted to spend time with me, but all I could do was take my meds and sleep. I joined one of the first RSD support groups in town for help. It scared me to join this group, being the youngest by sixteen years. All the ladies put their meds on the table and asked me, “What are you taking?” I kept quiet. I stayed with the group for two years, but found it a little intimidating and depressing. One woman, Shelley, had so much pain in her fingers that she could not move them. I promised myself that no matter how much pain I was in, I would work my limbs so I wouldn’t lose mobility. Let me tell you, the pain is so bad when your fingers and hands start to lock up, but you just do have to move them, because you won’t be able to use them otherwise.

Despite making a difference at school, my pain and exhaustion continued. RSD was taking a toll. The disease stole the job from me. I couldn’t do anything at home. This pain is like when one of your legs falls asleep and you have a painful tingling, achy, electrical feeling. The pain is extreme and lasts, not just seconds, but sometimes years! After four years of agony, I was willing to try a stimulator implant in my neck that would transmit an electrical current to the spinal chord. First, they put it on the Wrong Side! A month later there was a second surgery...even worse pain. I just felt like dying. This disease had robbed me not only of my health and job, but also of my ability to take care of myself. Thank goodness for my grandmother who was in her late eighties. She would say to me, “Let’s walk the mall. I need exercise!” So, we would walk the mall - and I thought I was helping her out! She was a wonderful woman.

Two years later, I discovered a doctor who agreed to take the stimulator out. I awoke from surgery and was able to use all my limbs – Thank God! I continued to see my psychiatrist who had me on meds, but I found real therapy in drawing and making mandalas, dream-catchers and presents. It gave me a sense of pride that I was able to give something I made to someone I loved.

Today, I go to a doctor who prescribes medicines that actually work. I'm able to concentrate better and control the pain better. My pain level is half what it was in my worst times. Sure, I have good days and some days my pain level is 5 to 7 on the pain scale, but I can handle that. My family and friends help me through the hard times, and now, I'm able to help them.

My faith in God and Jesus keeps me going all the time. It's my faith and the memory of a promise that there is something more I have to do that gives me hope. There's a reason I'm here right now, and it feels important for me to share my story. I want to tell others with RSD not to give up. Have a vision that supports you. My vision gave me hope. Never give up on hope.

Keep on going, no matter what. Don't sit and lie down and die. Get up out of that chair, out of that bed. Keep yourself going. You've got to keep yourself going, and trust in God to help you make it through.