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# RSD STORIES

## TOS and RSD

**Story by: Darlene Brownell**

TOS and RSD what does that mean? I will tell you what it means. It's the worse pain that you could ever feel every minute of the day. It causing my pain to spread anywhere it wants to be. I can't move my arms; they feel like there on fire. The doctors would look at me like I was a liar. My shoulders feel like someone was stabbing me all day and night. I can't take it anymore. God just bring me to the light. The pain is so severe, there is no end in sight. Doctor it's not in my head. It's all threw my body. And now it's too late, you didn't catch it early. If you would have listened to me when I said I was in pain. I could have had a change in life, to do the things I planned. Because of you I live in pain, not knowing what the next day will bring. If you caught it right away, I would have been ok. I'm not giving up on this battle of pain I will fight to my dying day for all of us in pain.

The most pain of all is seeing my children growing up as I sit on the side line watching from a far, remembering the days I use to be involved. You took that away from me, Shame on you all. I really hate to say this but I wish you feel this pain, because if you did everything would change. You would act a little faster when someone show's up in your office complaining of severe pain. Instead of dismissing those like you did to all of us.

TOS and RSD suffer's come out of your homes, let's all stick together and fight for are rights, we need treatment other than meds. We need doctors who know what this is. So, we can stop the pain we live with each and every day. Let's fight Comp, Doctors, and Judges that all disagree; that the pain we feel is not real it's only makes you believe that

I.M.E. Doctors need to retire, and get new jobs that require liars. SSD and SSI will fight you too, because we are part of the system just like you. Look out all you people we had enough of the TOS and RSD shuffle.

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## **A Mother / Son RSD Story**

Hello! My name is Cheryl, and my RSD started January 30, 2008. It took months for an actual diagnosis - months of doctor's visits, tests, and anxiety. Once my neurologist diagnosed me, he offered me a variety of medications. I politely refused and chose to fight my battle with acupuncture and physical therapy. Both helped, but I found myself feeling very alone. So little is known about RSD that even my physical therapist (who had the most experience in the clinic) admitted he knew very little. He gave me a few simple exercises, suggested I look a few things up on the Internet, and said that was all he could do. I made progress, actually started walking fairly normal again, but could not seem to conquer the pain and be able to do simple things like take a walk with my family. I refused to give up but sometimes felt frustrated that I wasn't making progress faster.

In early December, I was stunned to learn that my son had RSD as well. He injured his toe which triggered the RSD. I kicked myself for not recognizing the signs, but once his doctor diagnosed him, I could look back and see that it made sense. One of my first questions for my neurologist when I was diagnosed was, "Is this genetic?" He assured me it was not. Now, however, I have to wonder. Watching my son fight his pain was far worse than experiencing it myself. I would have gone through it all over again if I could have spared him the pain.

Fortunately, we live twenty minutes from a fabulous children's hospital that has a rehabilitation program for RSD (although they call it RND). My son was admitted in January and spent three weeks living at the hospital. His rehab was intense to say the least. I was told before he started that the reason there is no program for adults is because adults could never handle what the kids go through. I am incredibly thankful that my son is now fine. Within a month of coming home from the hospital his pain was gone. He still does ninety minutes of therapy a day and even made it through another toe injury with no relapse.

I believe that things happen for a reason. I feel my RSD enabled me to empathize with my son in a way no one else could which hopefully helped him during his toughest days. I also believe that his RSD happened to help me finally heal the way I needed to. Watching him do his rehab taught me what I should have been doing all along. I wish someone would have told me that I needed to push through the pain and use my foot in spite of the pain. Exercising and doing simple desensitization exercises made a huge difference! I would never have known any of this if it weren't for my son's experience. Now I just want to share it with everyone in hopes that I can make someone else's battle with RSD easier. Taking that step, running those stairs, scratching that foot seems too painful to imagine, but the end result is so worth it. Now I can walk with my family and do everything I used to do. There is hope!

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Hello! I am a 32-year-old mother of five beautiful children 10 and under. I was young when I married and was so excited to have children. That is all I wanted. Each pregnancy was very hard and I was mostly in bed. I ended up with a herniated pelvic wall and cystocele. The doctors told me that surgery was my answer. I needed to have a bladder lift and sling to be placed. It is a safe and easy operation for most everyone but me.

I came out of surgery screaming in pain. I thought the pain was a level 20 out of 10! My leg wouldn't move and the doctor was long gone. He said I probably had sciatica so they pumped me full of steroids and morphine. Six hours later they called in the same doctor to fix his mistake. He accidentally stitched right through my sciatic nerve leaving me with drop foot, neuropathy and RSD. I am in constant pain every day and every night.

I pray for God to heal me so I can take care of my children and play with them like I always used to. I was the little fun mommy that jumped on the trampoline and skipped and chased around my kids. I was put on many different drugs including methadone. That really made me sick. I had a pain stimulator implanted. Nothing cut the pain but I was a zombie. I couldn't remember anything. I was nauseous and lost too much weight. The injury was 8 months ago and I am now walking again, but every step is dreadful pain. I push myself; I want to fight this and get better. I stopped taking a lot of the drugs. The Methadone was really nasty to get off of. The doctors said I would feel yucky for 7-10 days.

Wow, that was an understatement! I am now at one month and I still feel sick. I had cold sweats, heart palpitations, and diarrhea. It was so horrible. I suggest that you do not get on Methadone. I have just one more drug to get off of which is gabapentin. I realize it is not helping and only makes me feel sluggish. Sleeping is near impossible with the RSD. It burns on fire and not constant, but pulsates to make it even more unbearable. It is maddening. I still have drop foot and it makes my therapy even harder. I just hope and pray that I can get better someday.

Thank you for reading my story!

Erin

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