

*This article is as clear an explanation as you are likely to see about what it is like to live with RSD. It is a copy of a speech given at an American school by one of the pupils.*

## Life with RSD

This is the second hardest thing I have ever done in my entire life; the first hardest being directly related to number two.

I want to tell you about the disease Complex Regional Pain Syndrome. In my opinion, Complex Regional Pain Syndrome is the worst disease to ever be named. But then again, I'm biased. In January of 1999, I was diagnosed with it. And like most people, I had never heard those four words together. I quickly created a nickname for my sickness: CRAPS. I highly doubt this, but you may have heard of Reflex Sympathetic Dystrophy (RSD), which is another name for CRAPS.

In the past three years, I have sporadically done research on it, and the more I have learned, the less I like it. Most importantly, I have learned that being able to create the phrase "really stupid disease" from the letters "r," "s," and "d" was more than just a strange coincidence. I honestly believe it was one-hundred percent intentional.

Doctors say that RSD has three stages, but I disagree with them. However, I do believe that RSD and numerous other diseases progress and have stages, but not in the crystal clear, black and white, cut and dry manner that most doctors approach the disease with, therefore I'll just give you the essentials. CRAPS affects the limbs and is oftentimes triggered by an injury, from the stubbing of a toe, to major surgery. The disease affects the sympathetic nervous system – the nerves that are unconsciously controlled. Somewhere in my body, a nerve is out of sync with my brain, thus causing pain and other unnatural, undesired, and uncalled for effects. And because the nervous system is so HUGE, it makes it extremely difficult to find this short circuit. This also explains why there is no cure for RSD, and probably never will be.

A messed up nerve doesn't sound that bad, until you experience it. It's hard to believe that one tiny nerve, even a few tiny nerves, can cause so much grief for a person. I'm not sure if any one of you can completely grasp the horrible, awful, excruciating pain I suffer from every day. Imagine submerging your foot in a vat of boiling oil, never being able to turn down the heat, never being able to take your foot out. That, my friends, is a manageable day.

Some days, it feels like my foot is on fire. Or railroad ties are being shot through it. Sometimes lightning shoots up my calf. I also experience shooting pain, extreme temperature changes, complete numbness, and tremendous swelling. Not to neglect the fact that I can't bend my toes. Unfortunately, I am not limited to one type of pain per day; some days I experience them all, other days just one type.

Anyone who has ever experienced a stinger knows how uncomfortable they are. Multiply that pain level by one thousand, and you're near the parking lot of the ballpark I'm playing in. My foot goes from hot to cold in the blink of an eye. Trust me, it's not fun. Complete numbness probably sounds appealing compared to what I was just describing. In fact, it's just as bad. If my foot goes dead, I don't even know it's there. You try walking without your foot. Not the best game at the party. My foot becomes so swollen that I can't get shoes off or on. The seams tore on a pair of athletic socks last week. That's not supposed to happen; socks stretch. Earlier this school year, I had to leave to buy shoes so I could at least walk normally, without fear of *popping* my foot. The boots I was wearing were so stretched out they

went straight to the garbage. This disease isn't a joke. It hurts so much. Sometimes just the air from a breeze is too much to handle. I've cried myself to sleep countless times, from the painful day I had, and because my foot had to touch a blanket.

To better explain how much it really hurts, I want to tell you about this collection I have. It's a head-less teddy bear collection. Let me explain: a nurse from Bellin Hospital gave me a Beanie Baby before my first surgery. Now these surgeries that I have aren't normal procedure; I don't get to be put under, and the pain medication is minimal. That said, about twenty minutes into the hour-long surgery, I had torn the head off this poor Beanie Baby. Ever since then, when I have purchased a teddy bear or received one as a gift, they get put into this electric blue basket that I have, just waiting to be used. I don't just use them for surgery, though. In case of an emergency, there is one in my car, one at Sean's house, one at Cara's, and most days there is even one in my backpack. My little sister likes to personify and name her stuffed animals, so we had to name mine. I'm not all that creative, so they're just called Squeeze Bears.

I'm not trying to scare you. You can't catch RSD. But just like me, your life can change forever from it. I'm hoping that by being up here today telling you about it, your life will change enough. I sincerely hope that no one will ever again have to experience it first hand. But I know that won't happen.

Guys, I woke up on January 18th three years ago, and I will never be the same. I suppose you could say that for any experience. But how many experiences have you had that make it so you can't do the things you enjoy? I can't dive. I can't roller blade. I can't water-ski. I can't ride a bike. This disease has limited me so much physically merely because I woke up one morning.

The mental affects aren't much better. People kill themselves because of the pain. The suicide rate for people with this disease is 900% higher than for any other group of people. *Any* other group of people. I'm talking your average Joe, your manic-depressives, your prisoners of war, and your white ward "lost causes." *A lot* of people that have Complex Regional Pain Syndrome kill themselves because of the pain. When a doctor diagnoses someone with Reflex Sympathetic Dystrophy, it's like saying, "here are the pills, take them all at once and chase them down with a bottle of vodka to get the all pain and suffering over with right away."

Obviously, the mental affects of CRAPS are quite numerous. Most doctors will stick needle after needle into your foot or arm, inject some crazy concoction, then say "see you next week" when they do it all over again. Between visits to the doctor's office, you swallow pills. At one point, I was taking 125 pills each day. They had me on everything from anti-depressants and seizure medication, to painkillers and sleeping pills, and to counteract the sleeping pills, I took pills to keep me awake. Some of the medications that I have taken in attempt to control the pain include aspirin, Ibuprofen, Tylenol #3, Vicodin, Percocet, Morphine, and Methadone, which is used for heroin addicts. To curb depression, I took Elavil, Prozac, Prazosin, Paxil, and Steroids. As the pain intensity worsened, I took Neurontin and Carbamazepine. It was far from an ideal situation.

For the first year or so that I had RSD, I didn't go to school for any number of reasons: my medicine was adversely affecting me (I was doped up), I was too tired, too sick, at the doctor's, or it just plain hurt too much. I began to get increasingly more stupid. I started doing a lot of things that I would get expelled from Notre Dame for doing, like smoking grass, binge drinking and some other things I'd rather not talk about. I made a lot of dumb choices. They're things that I'm not sure why I did or if I will ever be able to forgive myself for doing. I have the physical and mental scars to prove it. There isn't a day that goes by that I don't think of my choices and the fact that they will affect me for the rest of my life. I screwed up.

But there are the things I can't control that are a result of RSD. To this day, I can't sleep without chemical assistance. I get headaches from the devil and have to take strong narcotics for them. I have track marks from my doctors, and a lump on the side of my foot. I transpose letters and words in my head, sometimes skipping over letters or entire words; I have chemically induced dyslexia. I can be talking to someone, and mid-thought, completely forget what I was talking about. I repeat myself for no reason. I repeat myself for no reason. (I couldn't resist that one.) When writing, I oftentimes mix up tenses or combine words to make new words that you won't find in a dictionary. Things happened during surgeries that should have killed me, and in the end, they will. Because I have RSD and take a lot of medication, I have contracted or developed a number of other diseases.

One of the worst things about RSD is that it spreads. It started in my left foot and crawled up my calf by way of my sciatic nerve. No thanks to my doctors, it was contained to my foot and ankle for over a year. Recently, in the past month, it has spread to my right hand. The one I use for everything, from writing to shifting to breaking boards. My physical therapist is working with me in attempt to strengthen both of my hands, because if and when it gets bad in my right hand, bad to the point where the dystrophy sets in and I can't move my fingers any more, I'll have my left hand to fall back on.

There are a couple of things that I don't understand about people who have RSD. In my opinion, they are easily defeated. A woman in northern California has the disease in her right foot, where it has been contained for over two years. She still has full use of her toes and ankle, but has confined herself to a wheelchair, and gave custody of her three children to her ex-husband, whom she left because he was physically abusive. I just don't get it. I've tried so many things to help with pain, to try to kill the disease, and to try to get my life back. I've had chunks of my spinal cord removed and sterilized. My spine has been injected with everything from Miller beer, to green dye, to ground up fish eggs mixed with milk (which I'm allergic to). I try so hard not to let it defeat me. If there has been an option available to me that could offer relief, I've tried it; but I have never let the opportunity limit me more than the disease has already done. From where I'm sitting, the only way I'll end up in a wheelchair is if I become paralyzed or become unable to bend my knees. Yet, one of my biggest fears is that one day my judgment will become so impaired that I will make choices like this woman did.

Another thing I don't understand about people who suffer from RSD is why they allow it to control their lives. I'm not supposed to walk more than four thousand steps per day and also not supposed attend more than twenty hours of school per week. I am supposed to use crutches in my daily life. Apparently, I don't listen too well. I don't let it control me, and I don't understand how grown adults can let it control them, or how parents can let the disease control their child.

This isn't the life I wanted. This isn't the life any one with CRAPS wanted. But somehow, it happened. I'm not going to kill myself because it hurts, instead, I'll complain and take Vicodin. I don't want to be treated special and I'm not doing this for attention. I think that everyone in this world should know what RSD is in the same way that they know what cancer or AIDS are. The suicide rate for people with RSD is 900% higher than any other group in the world. We need to do something about it. It just is not worth it to look the other way any more.

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