

Neurosarcoidosis, you're a bitch

'Drunk say again?' that's what I've been called for months. Mainly by my husband and family as a joke to lighten a heavy mood, to cast off worry about what others have been saying about me. My dad even got me a shirt that says, "AA, it really works." For weeks, most of the parents on the baseball league thought I was drunk, stumbling around, staggering, because of the ultra-dark sunglasses I donned even at night to protect my eyes from the park lights. They didn't know though. They didn't understand.

Neurosarcoidosis is a bitch. It takes what it wishes, when it wishes, and however it wishes. It picks, it chooses, and just when you think you're ok with what it's taken from you, when you've adjusted to the changes, it gets bored and throws something else at you. Like an evil tyrant who gets bored with one form of torment and finally imagines another, it gets pleasure from watching you suffer. Then suddenly one day something is better, you're about to breathe a sigh of relief, but don't. Tomorrow it will screw you another way.

Here's another bitch for you, getting the diagnosis. It takes months, sometimes years, and countless tests, painful tests, and innumerable other diagnoses. Multiple Sclerosis, Lyme disease, lupus, TB, vitamin deficiencies, Guillain Barre Syndrome, cancers, the list goes on and on and so do the tests. It's life-sapping. So you spend countless hours in hospitals and doctors' offices, waiting; and don't forget the MRI's, the CT scans, zapping; the countless tubes of blood, electromyography tests, spinal taps, and blood patches, sucking the life out of you.

But you have to become a bitch yourself. I spent months in my own personal hell, my own metaphoric dark hole, curled up, waiting to die. But on the surface you have to be a bitch, put on a smile, a brave face. On the inside, you're not only wishing it would all just end, or that it would

magically get better on its own and just disappear, but you're fighting with your body. Every step I take, every movement, every bright light, I'm arguing with my body to work, to stand upright, my muscles at the ready. My legs are jelly, for all intents and purposes, so are my eyes and my balance. They're still there physically, somewhere, but I no longer have control over them. I have no control over my body. Neurosarcoidosis is a bitch.

I've adjusted to the new body, I still fight with it every day. I put on my smile and on the bad days I put on my nicest clothes, I do my hair and makeup and get behind a walker, because neurosarcoidosis is a bitch. I deal with side effects of 7, now it's 9 different medications I have to take every day. And now I think medicine is a bitch. My hair falls out, I stay tired all of the time, my mood swings are not only up and down but they go round and round. I am a merry-go-round. The simple cold virus I could handle most all my life up till now could put me in the hospital, and now I have to worry about the possibility of getting cancer because of the medicines. Thank you neurosarcoidosis, you bitch.

I'm not brave, I deserve no accolades like the cancer survivors on T.V. I don't feel like I have fought any beast from hell and come out the other side in glorious victory. I've just gotten through what seemed like an impassable swamp filled with gators and quicksand, and roots sticking up at every turn ready to trip you when you're not looking. It doesn't even feel like my life. And you think I'm brave? The days you don't see me, I'm at home, curled up in bed in the dark, wrapped up in a T.V. show, trying to forget what's going on. Trying to forget what I'm missing out on. Wishing I was just as normal as actors on T.V. always wondering, am I through it yet?

Neurosarcoidosis is a bitch, and I may never be done with it. I may be managing it for the rest of my life. It may get much worse, it may go away. It may strike the base of my brain and kill me, because it's a bitch. I may have to fight it and even fight cancer one day because medicine can be a bitch too. If I

can just wrap my head around this, and realize my initial goals and dreams, find my drive again, you'll see neurosarcoidosis that I can be a bitch too.

Numb

Have you ever been that close to the edge? So close you feel yourself beginning to fall, but you don't, because you step back, because someone pulls you back, because it's not your time. It's dizzying, and terrifying beyond words to know that you're that close to the end. That everything could end in a second. That one loose pebble could send you flying. I've been there, and it didn't feel like it was that close at the time. I became numb to the fear. I became numb to every feeling, I felt no joy, no sadness, not even heartache at seeing my family struggle. And looking back it's scary as hell. What's scarier is how I feel now. I'm alive, and I don't mean I just feel good to be alive. That I am thankful to be alive. It feels like every natural phenomena in the world is tearing through me trying to get out all at once. I feel hurricanes raging, and volcanoes ready to erupt, tornados tearing through my mind racing for the next idea. There are wild horses somewhere deep inside charging me in every direction imaginable. Fireworks explode around me constantly distracting me. I want to conquer everything now, I want to stand on highest points, and scream at the sea in defiance. I want to see every natural wonder and compare it to myself, because I wonder how I'm still here. But I am, and I will not scare as easy now. I will look over the edge and tempt the fate of whatever brought me back from the edge the last time. I will stare it down, and dare anything or anyone to get in my way now. I'm scared of everything I feel now because the feelings are so big, much bigger than I ever imagined feelings and emotions ever could be. There's so much passion that leaves me reeling, and happiness and even a wild anger just under the surface at all times but, at least now, I feel. I am no longer numb.

4 a.m.

Another long day, started at 4 this morning and it's after 11 already. Where did the day go? I woke up and had my coffee, showered and got the kids ready. I fought to get them out the door on time to drop them off at school before I raced 32 miles to get myself to school on time. Let's see, I sat through 2 classes, went to a meeting, and turned in paperwork to request a space app for the next honor society function. Oh wait, I also went and spoke to a professor about a late assignment somewhere in there. Then I ran out of coffee, forced myself to drink water instead. I rushed home to pick the kids up from the bus stop, then it's home for 30 minutes for snacks and bickering before we hit the road again. Softball and baseball practices, at two different fields of course. I needed a time twister so I could be in two or three places at once. Three hours later and we're finally home only to start the begrudging battle of chores and homework and dinner, and laundry, oh my God the never ending laundry!

Did I see Vivian hit at practice? I can't remember now, I think she mentioned something about it at dinner. And poor Zander, I had to miss his practice today, but he didn't let on that it bothered him any. I'll stay at his tomorrow, and then Vivian can be mad I missed hers. If they only knew how little I actually watched because I had my nose stuck in a book.

After dinner, what did we do after dinner? Oh yeah I helped Vivian finish her essay, and then I sat through Zander practicing his trumpet. Geez, please let that kid get better soon. I made them shower, and pick up all their dirty clothes, and finally it was time for them to go to bed. Ah yes, I thought I was finally going to get to relax. Wrong! Put another load of laundry on, and I didn't feel like folding so I just threw the third load of laundry on the couch. I'll do it tomorrow. It's 11:10, if I go to bed now I can get nearly 5 hours of sleep before it starts all over. No, I have that assignment due Friday, if I take an hour now I can be almost finished with it. I'll sit on the couch and watch TV while I do it, then

I can catch up on my shows. I'll multitask. That laundry smells so good fresh out of the dryer. I just want to bury my face in it, and it's still warm. I'll just lay here on it a few minutes and gather my thoughts for this assignment.....4 a.m. again.