

Riding the Lightning: My Life With Epilepsy, Living With and Without Seizures

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This is a story of a transformation. Arguably, it began decades ago, and even today it shows no signs of being complete, but maybe, just maybe, it will show you that sometimes we need to change into something we never would have wanted so that one day we could grow to become something we never could have dreamed.

On the cusp of the 80s and 90s, nearly 500 miles from where I stand today, a high school junior became another statistic, only he didn't know it yet. It started as a feeling of *deja vu*, and if it had ended there, he never would have thought of it again, but it didn't end there. It was only beginning.

Deja vu was followed by a rising in the stomach. It was progressive, and within days this teenager began noticing other things happening during these increasingly frequent bouts of *deja vu*: lightheadedness, vision losing definition and turning the world into a grey tunnel. If he was walking when one of these episodes struck, his gait became robotic and his feet flapped against the ground with each step. He sucked at the air, trying to control an imaginary flow of saliva trailing from his chin, his hands rubbed against themselves and each other, washing, washing without soap or water. The smell of crushed dandelions across his tongue...

Once, twice, ten times in one day. The episodes were getting worse and more frequent.

He was scared and finally decided he needed help. The 24/7 fight with embarrassment which is the burden of every adolescent on the planet was finally subsumed by the fear of what was taking over the teen's body against his will.

Luckily, my father and I had a very close and honest relationship. He taught biology at my high school, so I figured his science background would be helpful in discovering what was happening to me. We tracked my diet, my physical activity, and the frequency of my episodes

for a couple of weeks and could not discover any correlations. We took pages of notes to the doctor whom I'd been seeing since I was a small child, and after listening to my symptoms, Doctor Wheeler said that he wanted to refer me to a neurologist. He suspected a seizure disorder, which even a 16 year old knows is euphemistic for epilepsy.

I remember the initial eeg and the MRI. I remember trial after trial of medication, I remember the fear, the confusion, and the extra levels of embarrassment when I was burdened by the official, final diagnosis of temporal lobe epilepsy.

A seizure is abnormal electrical activity in the brain, often when groups of neurons begin firing in sync with each other. Epilepsy occurs when a person has two or more seizures that cannot be attributed to something like drug or alcohol withdrawal, or fluctuations of blood sugar or insulin from diabetes. Epilepsy is also not a disease, and it is not a rare disorder. 1 in 26 people will be diagnosed with epilepsy sometime during their life, and 1 in 10 will have a seizure. Most people have never seen the most dramatic type of seizure, called tonic-clonic, but it's the kind that everyone thinks of when they think of epilepsy. A tonic-clonic seizure is the stereotypical "grand mal": all of the person's muscles contract and shake, their face may turn blue or purple, they may produce excess saliva which causes them to appear to foam at the mouth, they may lose bladder or bowel control, and they may appear to be choking while they make involuntary vocalizations with a mouthful of spit. They may bite on or through their tongue or cheek, so there may be blood. Yes, a tonic-clonic seizure is dramatic, but it is not the most common form of seizure. Far more common are partial seizures, which was the type I had at my initial diagnosis.

A partial seizure, also known as a focal seizure, comes in two main varieties. A simple partial, also known as focal-aware, is the classic “petit mal” seizure and may be confused with simple daydreaming, where the person stares off into space for a few seconds, but rapidly “snaps out of it.” The second type of partial seizure is the complex partial, or focal-unaware seizure. Complex because it rarely stays focussed in the part of the brain it originates, but involves surrounding brain tissue as well. Focal-unaware because the patient becomes unaware and unresponsive to their surroundings. One type of complex partial is the temporal lobe seizure. The temporal lobes, located on each side of the brain behind your temples and above your ears, control linguistic memory and time sense, among other things, and their exposed position at the sides of your head make them more susceptible to certain types of damage than deeper structures in the brain. Temporal lobe epilepsy is the most common form of epilepsy.

And it was form I was diagnosed with.

Enough of the dry, clinical descriptions of the types of seizures. Living with seizures was anything but dry and clinical. Especially after we started trying medications to treat them. Epilepsy is more common than cerebral palsy, muscular dystrophy, multiple sclerosis and cystic fibrosis combined. 1 in 3 epilepsy patients do not respond well to medication, and every year in the US 50,000 people die due to epilepsy. That’s one every ten minutes.

I was already a statistic: 1 in 26. I was about to become a second statistic: 1 in 3.

I prayed I wouldn’t become a third statistic.

My initial medications failed, often immediately, usually dramatically. Sometimes a rash spread over my entire body, accompanied by cracking and bleeding in the webbing of my fingers and toes, sometimes uncontrollable vomiting combined with complete lethargy. Nothing worked

the way it was supposed to, so for the next few years I did nothing. I tried to pretend to myself that they didn't exist because I had stabilized at having maybe a couple seizures a week. I learned about my type of epilepsy and I was very open about telling the people with whom I was going to spend any time about the types of seizures I had and what to expect when I had one. I was careful to explain that I never had grand mal seizures, but I might wander around a bit and that I might act drunk. The people who witnessed my complex partials were distressed, but not frightened.

Until the night when I decided I once again needed to seek help.

I had been a student at Cal State Fullerton for a few years. I was living with a girlfriend and I had a job working at Radio Shack. I ignored the fact that I wasn't happy in my relationship, that I hated my job, and that my major in technical theater was going precisely nowhere. What I couldn't ignore was the fact that one night in bed all of my muscles tensed, I fell out of bed, struck my head on the side table, and ended up on the carpet face down where I proceeded to thrash and vibrate for the next 30 minutes. I had never had a tonic-clonic seizure before, so the woman I was with didn't know how to respond. I ended up with friction burns over most of my face from the carpet, a black eye, and a gash across my eyebrow.

Still, it could have been worse. A seizure shouldn't last more than 5 minutes, and a 30 minute seizure is status epilepticus, a potentially life-threatening type of seizure where the brain simply cannot reset itself. It has seizure after seizure with no break between and often the cycle can only be broken by medical intervention. My girlfriend eventually called 911, but my seizure had finally ended before the paramedic arrived.

While my body recovered and healed, while my mind was reeling with the new implications of what had happened to me, my girlfriend accused me; “You told me you never had that kind of seizure!” No, in the 3 years we had been together, in all the years before, I never had. The new stress of my disorder began to erode what little was holding us together, and we split up a matter of weeks later.

Back on the merry-go-round I climbed. It had been years since my diagnosis and many new drugs had been approved for my type of epilepsy. I tried this one, it didn’t work. I tried that one, it didn’t work. I was running out of options. Again. Finally, my doctor told me “there’s this new drug, hasn’t been on the market very long, and there are some risks involved.” I had to sign a release. I was made aware of the risk of acute liver failure, of acute kidney failure, of aplastic anemia, where my bone marrow might just stop working, of the risk of spontaneous death in 1 out of 10,000 patients. I signed the release.

And Felbatol worked.

For months it worked, then for a year. I was able to get my drivers license. Months more... Then once again I began to experience deja vu with a rising in my stomach.

My seizures had begun to break through around the time I met Megan. I had left school shortly after my old girlfriend and I had split up. I worked and rode the medical carousel for the next few years. My new meds were finally working and I decided to go back to school to get my degree. Megan and I met in an English class. Critical Thinking and Writing About Literature. Our friendship began over a shared love of literature, of a common interest in irreverent humor, and, well, the fact that I never had to dumb down my vocabulary to talk with her. We hung out between classes and began spending more and more time together. Our first official date was

March 16, 1999 and were forever afterward inseparable. She knew about my epilepsy early on. I told her as soon as we began spending time together, but it never fazed her. Not even after she witnessed me have a grand mal seizure in the cafeteria and I was carted off by the ambulance. My seizures scared her, but they never scared her away.

My medications were keeping my seizures down to about once a month. We transferred from Fullerton Junior College to UC Santa Cruz, moved to Capitola, and got married 4 years to the day from our first date. We graduated college and moved to Fremont. Megan went to work for Newark Unified School District, and I went to culinary school. I started working for the Cafe at Nordstroms at the Stonestown Galleria, we got pregnant with our first daughter, Johanna, I went to work for Guckenheimer at Sybase in Dublin. We got pregnant with Charlotte. Through all of this, I was still having seizures roughly once a month. I had lost my drivers license years before after having a seizure behind the wheel, so Megan had been dropping me off at the BART station every morning at 4 am, first with one infant in tow, then with two. I had seizures at work after my probationary period was over. My boss started having doubts about my ability to do my job which I had been performing flawlessly for years. My seizures began getting worse. More medications. I had to talk with Human Resources about my rights more than once. One day I contacted Megan from work to ask her to research a portion of the Americans with Disabilities Act and she responded with:

“Have you considered brain surgery?”

I was terrified, but we talked it over, then talked it over with my neurologist. There was a 25% chance that the surgery could eliminate my seizures. The darkness I had been living in for 20 years was now beginning to lighten, but just barely. I had a new hope to hold onto.

Where to begin to talk about surgery? There were tests, there was imaging, there were hours of anxiety about the fact that they were going to saw into my skull and expose my brain, cut out a piece, cauterize the wound, close me up, and expect me to be more functional than I was before. I was okay with it, then I was panicked, okay, then freaked out by turns until a fateful meeting at the Oakland Zoo changed my outlook and my entire future.

I don't know where I'd be today if it wasn't for Jessica Morgan. She was the friend of a friend. Megan and I had decided to take the girls to the zoo one Saturday, so we'd asked another family or two if they wanted to meet us there. One of the women told us "Oh! We're already here! We're meeting up with a friend. She recently had brain surgery too!"

I talked with Jess outside of the giraffe enclosure. She had a vascular issue in her right temporal lobe that had been causing her seizures. She had the same surgical team that I was to have. She had been driving for three months. She had found an old bottle of her pills under the seat of her car and said it had felt so good to throw them away. She was off medication. Her hair had grown back in and completely covered her surgery scar. You couldn't even tell it was there. All my terror evaporated during that conversation. I was still frightened, but it no longer consumed me. I had met someone who had been through the same Hell as me and she had come out the other side. Our conversation became the inspiration for my choices following my surgery; maybe I could be for someone else what Jess had been for me: a guide to a mind free from fear and a beacon of hope.

Tuesday June 23, 2009, the day of my surgery, I began to count, and as the weeks passed, I promised myself that as long as I could write my name I would not forget what it was like to live with seizures. I am now now up to 472 Tuesdays seizure free, and that promise holds strong.

Within my first year seizure free people began coming to me and saying “I know this person. They have epilepsy, and they’re considering surgery.” I began joining epilepsy awareness facebook groups. I looked into the Epilepsy Foundation of Northern California’s annual Awareness Stroll. More people contacted me, friends from school with family who were suffering, old friends themselves, coworkers of family friends, even strangers who couldn't even tell me how they found me. Through shared suffering and shared hope I have become friends with so many people. This past week I got to meet one of the families with shared experiences. Hilary Witt has suffered from epilepsy since childhood. She and her mother, Sissie, have been visiting San Francisco from near Dallas, Texas this past week, so on Tuesday I took Bart out to the city to meet them face to face. This wasn’t the first time I had finally met with someone who was merely a typed line of text battling the terror of epilepsy surgery. Susan Smith, a Bay Area, resident holds that distinction. We had met her and her family years before at an Epilepsy Stroll. Every time I meet with someone, every time I share my story, every time someone contacts me I feel more of a connection with the community I vowed I would serve almost 9 years ago. Connection is important, because epilepsy is a very isolating disorder. There is a centuries old stigma against “the falling sickness.” People suffering from epilepsy have been accused of being possessed by demons;frightened people were convinced you could “catch” epilepsy merely by looking at someone while they were having a seizure; here in the United States, there were laws on the books up until the 1970s forbidding people with epilepsy from getting married or having children. Even now it is one of the most underfunded disorders in medical research. It averages roughly 82 cents per patient, according to the National Institute of Health. Pitiful, considering the World Health Organization calls it “the most common serious

brain disorder worldwide. It has no age, racial, social class, national, or geographic boundaries.” Everyone, from all walks of life, may develop epilepsy, and the names of some of the people who have lived with epilepsy may surprise you: the actors Danny Glover and Hugo Weaving, the musicians Prince and Neil Young, Charles Dickens, Dostoevsky, Lewis Carroll, Edgar Allan Poe, the sprinter Florence Griffith Joyner, President Theodore Roosevelt. The list goes on and on.

I stopped hiding in the shadows decades ago, and I’m even more visible now.

Everywhere I go, my hair starts the conversation for me. I will not stop sharing information, sharing empathy, or sharing hope for everyone who needs it in this fight. I will share my story to anyone who wishes to hear it, because what I’ve shared with you today is merely a sliver of what I’ve gone through. There are millions of us: 3 million in the US, 65 million around the globe. No, I am not alone, you are not alone, and I am doing my part in ensuring that NO ONE is alone with this disorder.

Who I am today is because of who I’ve been, and I would not change one moment of my past, especially my experience with epilepsy, because it was this more than any single thing which has brought me before you today.

Thank you.

BENEDICTION

I am not the scared teenager I once was, but he is still a part of me, and he is the one who reaches out to you now. All of us still have that scared teenager wrapped up inside layers of

experience, but we have never lost them, just as we've never lost the child before them who was frightened of the dark. These people whose hands you hold now, they are just as scared as you, but because of them, you never have to face the dark alone.

Go in peace.

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