

When I was twelve years old, I experienced my first indication that my body was different than that of other people. I dropped in the middle of a run on Sugarloaf Mountain. That was the first time I had ever fainted, and I did not take it too seriously. I was alarmed by the loss of vision, nausea, and falling unconscious on the side of the trail, but part of it seemed peaceful to me. My whole world stopped for a couple minutes, and my body gave in. I did not try to fight it, I just collapsed. That moment has been a defining one for me. With every struggle that followed, I have had the same approach, and the voice inside my head always said, “do not fight it, listen to your body.”

I had noticed in the years leading up to that first faint that I would black out when I stood up. I did not analyze it, as it seemed normal to me. I had grown used to not being able to see, and I did not tell anybody often or make a big deal out of it. It did not scare me; it was just simply what happened when I stood up.

After I fainted that day, I noticed a change in my body— small at first. My blackouts began to last for longer periods of time— two seconds at first multiplied into four, then before long I was blacking out for twenty seconds at a time. I began to faint more. As these symptoms became increasingly severe and new symptoms arose, I started to seek medical treatment. I began seeing a cardiologist and a neurologist. My weeks began filling up with tests— stress tests, EKGs, tilt table tests, blood work, MRIs, CT scans, etc. I sported a fashionable heart monitor. I’ll never forget when one of my 8th grade teachers tried to give me detention for having an “electronic device” out in class. I can still see the look of embarrassment on his face when I told him it was recording my episodes.

The older I became, the more symptoms I started to experience— chronic migraines, nausea, fatigue, blurred vision, and more. All of the tests performed came back with reassuring news that I did not have any serious terminal illness or organ deformation, but disappointing news that I was left without any answers. I started to become discouraged when no doctor could tell me what was wrong with me, or offer me any solution to get better. The only thing that I knew was that I had low blood pressure and a low heart rate. Taking blood pressure medication, drinking water, and adding salt to my diet was frustrating advice to be given over and over to treat such frightening symptoms.

As the years went on, I became severely ill. I rarely attended school, I dropped out of my athletics, and the things that brought me joy became scarce. I felt alone— with the exception of my Mom, my dogs, and my bottles of gatorade (for electrolytes). The days turned into weeks, which turned into months, which turned into years of me lying in bed. As time went on, the weaker I became, the severity of my symptoms increased, and the more anxious I became that something more serious than just “low blood pressure” was going on.

My cardiologist diagnosed me with POTS (Postural Orthostatic Tachycardia Syndrome). Think of “postural” as posture — sitting, standing, lying down... every which way your body can position. Think “orthostatic” as upright posture. Think “tachycardia” as a rapid heart rate. Think “syndrome” as, well, syndrome— a group of symptoms that occur together. Put it all together and you get me: the chronic fainter.

I met with a doctor at Boston Children’s Hospital to confirm my diagnosis, and to seek additional advice. When I met with him, I felt like a guinea pig. Every time I visited

Boston, he would give me a different program to try. He did not quite know what to do with me, and almost shrugged his shoulders -- he was not interested in me. He frustrated me for two reasons. First, he always said to me, "Well, you look really good! You can't possibly be feeling as lousy as you describe." When he told me that, my heart always sank. I felt as though he did not believe that I was experiencing such severe symptoms. It seemed that he overlooked me. Little did he know that when I woke up that morning, I slowly lifted myself up to eat cereal and drink gatorade in my bed. A half hour after that, I tried to stand up. I made it to the bathroom, and spent another half hour putting on makeup and getting dressed so that I was not ashamed to go out in public, and people would not be afraid of me.

The other reason that he frustrated me is that he used to tell me, "Well, we can't have you driving cars or flying planes." This upset me more than him telling me that I looked good, and accusing me of faking. I had goals for my life. I was going to be able to drive a car if I wanted to. And if I wanted to become a pilot, I was not going to give up that hope, either. I refused to give up my hopes and dreams to have a full life. I needed a doctor who believed in me and was going to encourage me to live life to the fullest, as opposed to telling me what I cannot do. I always left Boston Children's Hospital feeling like a defeated guinea pig whose symptoms were not validated.

My symptoms reached new heights when I came down with Mono. I learned that such an illness can turn the nervous system into hysteria. The longer I was ill, the friends that I once had disappeared. I felt as though I was always disappointing friends because I could never follow through with plans. People stopped reaching out to me. Boys told me they would never date me because they were afraid of me. I always told them I was not contagious, but they were still grossed out by an invisible illness. I became depressed and struggled with anxiety attacks.

When I was a sophomore in high school, I began receiving IV treatments. Being hydrated in the emergency room was the only thing that gave me relief. I had treatment at home three times a week, but that only gave me immediate relief. I stopped that treatment after a month. In addition to IV treatment, I tried hypnosis, acupuncture, meditation, yoga, counseling, physical therapy, osteopathic manipulation, and more. I had two counselors... one who was a cognitive behavioral therapist for my anxiety and depression, and another who taught me meditation and yoga.

Junior year of high school came, and I was still in bed. I was rapidly losing hope, and gave up on going to school. My vice principal looked at me one day as I was recovering from fainting in the nurses office and said, "Why do kids like that even bother coming to school?" He did not take away my determination to persevere, but he really hurt me. I was on crutches for sciatica, which became chronic pain as a result of POTS. I was in bed most of every day. I was terrified that there was something seriously wrong with me. At that point, I was blacking out for hours on end, and fainting an average of nine times per day. With each fainting episode, I fell into a deeper and deeper slumber from which I had difficulty waking up. I was burnt out and terrified.

I started to give up on the possibility of graduating high school. It did not seem possible that I could make up all that I had missed. Then, that fall of junior year, all of my hope came back. My Mom and I discovered the Mayo Clinic's Pain Rehabilitation Center (PRC), and heard stories of kids just like me who were able to turn their life around with the help of the Mayo Clinic's experts. It was the only hope I had. We

immediately contacted them, and were let in to the program. My Mom and I packed up everything, left our family, and moved into a hotel in Rochester, Minnesota that November. I graduated a month later in December.

The Mayo Clinic had me in classes from 8am - 5pm every day, and forced me to do a social activity with the other patients after classes. My days consisted of physical therapy, occupational therapy, recreational therapy, learning neuroscience, anger management, stress management, biofeedback, diaphragmatic breathing, nutrition classes, drug addiction information sessions, relaxation, spirituality counseling, and more. My nurses and therapists taught me how to get my life back, and be able to do everything I wanted to do. The physical therapists pushed me to do high impact cardio to strengthen my heart. My favorite days at the program were "look good feel good Thursdays" when we had to dress up and do our hair and makeup. The specialists taught us that looking good is something beneficial that we can do for ourselves to strengthen the positive neural pathways we are trying to form to feel good. I still dress up on Thursdays.

I graduated the PRC feeling empowered and strong. I came home, and felt like myself again. My Mom would always joke around when I started to giggle (I am also a chronic giggler) and she would say, "She's back!" I was really back. I never missed a day of school again due to POTS. I made up all of high school, graduated the following year, and now attend college. I have never missed a day of following my program from PRC since.

I immediately contacted my cardiologist and Maine Medical Partners to try and start a program like PRC. The concepts and treatments were so simple, they just all needed to be linked together in an interprofessional setting. We just needed PTs, OTs, nurses, counselors, and guest speakers.

Maine Med did not embrace my ideas, as they told me they did not have the funding for it. I get calls from people in my community and my cardiologist to help people who are struggling with POTS, chronic pain, or anxiety and just need to learn some simple skills.

I am not cured, and I still struggle daily, but I am good at pretending to be a normal person. I take great pride when people tell me that they would have never guessed that I was sick. I know that I will be able to have a full life, because I am living one now. I am a full time student, I am able to exercise every day, I am driving cars (no planes yet), and I have had a boyfriend for a year and a half... and he's never been afraid of me (at least he hasn't admitted it).

I am fascinated with my body, and I am inspired to teach others about it. I want to encourage those who are struggling with chronic illnesses that they can have a full life. Most of all, I want to be an image of hope for those who feel like they are losing their own.