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What's Happening to Me?

In August of 2013, my mother flew to San Diego for three days, leaving me home alone overnight for the first time. I was nineteen, but my mother requested that I stay with my father for two of the nights that she was gone. Still, I thought, *this is it: the first step toward my independence*. I had lived at a boarding high school and already completed my first year at the University of Michigan. Yet every time I returned home, my mother regressed into the parent of a child. I was excited to prove to her how well I could handle things on my own. When she was gone, I hopped into my car, rolled down all the windows and opened the sunroof to let the sun pour in onto my head, shoulders and arms. I started my “driving” playlist as I drove down one of the many winding Massachusetts roads flanked by endless trees and headed towards the interstate. I felt light. The wind that blew through the open windows blew through me and invigorated me. I merged onto MA-95 North and drove toward the Massachusetts coast.

I spent two August days at my father's house on the northshore, as my mother had commanded. My father had several appointments in Boston, so I was on my own for most of the weekend. I lounged on the beach in the summer sun, played football with my cousins visiting from New York, read a non-intellectual book and ate fried clams for dinner. When the two days were over, I got into my car, an automatic smile stretching my face. I rolled down the windows, blasted some feel-good music and headed for the bridge off of Cape Ann, Massachusetts.

As I reached the interstate, my smile melted. Something wasn't right. Why couldn't I feel the wheel beneath my hands? Why was the car slowing down? I looked at the speedometer; the

stick hovered steadily over 68 mph. Why *wasn't* the car slowing down? I felt the car losing speed, but the speedometer said otherwise. I passed a station wagon driving in the right lane; my car really hadn't lost any speed. I knew, then, I was imagining it, but I didn't know why. I thought maybe I was hallucinating. Or becoming paralyzed. My head didn't feel light anymore. The wind no longer blew through me, but slammed into the side of my heavy head and rocked it sideways, vibrating it. I closed the windows. Outside, trees whipped past, but I still couldn't feel the car's motion. I tried to focus by squinting my eyes and looking directly at the road, willing myself to see what was in front of me. I thought maybe I had a brain tumor. Hoping for a place to pull over, I drove off the highway and onto the main road of another coastal town, Manchester-by-the-Sea. I found a spot on the side of the road in front of the public high school. Then, I called my mother in San Diego.

"Mom," I blubbered amid a petrified sob.

"What's wrong?"

"I don't know," I cried. "I was driving home, and all of a sudden I felt like I wasn't driving the car anymore. I couldn't feel it moving. I felt like it was going twenty miles an hour, but I was still doing seventy. I tried really hard to focus, but I don't know what's going on." My breathing was sharp and sporadic.

She spoke to calm me down before asking, "Where's your father?"

"He's at work, I think."

"Call him," she said evenly. "See if he can come pick you up and at least bring you back to his house."

"But what about my car?" I wanted the car with me, even when I couldn't drive it anywhere. Without it I would feel stuck. Powerless. Dependent.

“Don’t worry about the car. We’ll figure that out. Just call your father,” she replied.

“Ok.”

We hung up and I called my dad. He had a meeting that afternoon, so he called his wife and stepdaughter to pick me up and drive the car back to his house. Once there, I tried to take a nap. After three hours of futility, I heard the heavy front door close. My dad walked in and asked once again what had happened and how I was feeling.

“Okay. This is what we’re going to do,” he said calmly. “ I’m going to drive your car back to Acton, and then, if you think you can, you’re going to drive me to the train station down the road so I can catch the 6 o’clock train to Boston. Then I’ll get on the train from North Station back to Gloucester.”

I nodded, trying not to cry again.

We drove to Acton in silence as I tried and failed to focus on the road in front of us. We stopped at home so he could carry my things inside, then I anxiously drove him the two minutes to the Acton train station and even more apprehensively drove back home. Then I was alone.

Sitting in my mother’s family room, I second-guessed my autonomy. I had yearned all summer for some time away from my mother; now I felt myself craving for her to come home to me. I hated that I couldn’t handle such a tidbit of independence and that my mother would be able to use this incident as an excuse to never leave me without parental supervision again. Most importantly, I hated that my body had betrayed me. As I was finally gaining some liberation from my parents, it guaranteed that I remained dependent on my parents. For the rest of the summer, I was trapped in my house.

In September of 2013, I returned to the University of Michigan under very self-sufficient

conditions – I lived off campus in an apartment and was responsible for paying rent and bills, buying groceries, and cooking meals for myself. For the first week of my sophomore year, I noticed that I still felt the earth slant suddenly beneath me as I walked; I couldn't walk in a straight line. I got headaches. My eyes had trouble focusing, and my breathing was often heavy. Then, as suddenly as my symptoms struck on the highway in Manchester-by-the-Sea, they stopped. Still, I spent the next two months thinking, *What if it happens again?* Towards the end of October, it did just that. Walking home from buying some ice cream for my Thursday night in, I felt the Earth drop from beneath my feet. I swerved on the sidewalk and then stood still. *Not again.* I walked home as fast as I could, thinking that I wouldn't have time to notice the vertigo. Over the next week, the symptoms grew more frequent and more intense. I tried to explain to my friends what was happening to my body, but it was difficult to explain something I didn't understand. If I wasn't actively complaining about my symptoms, my friends assumed I didn't have any.

As October moved into November, my symptoms grew so unbearable that I was confined to my bed. Classes seemed to amplify my symptoms: the noise, the lights and the people felt suffocating, and I often walked out before a class was over just to breathe. It was impossible for me to focus on class material when I was busy focusing on staying upright and conscious in my chair. I became too scared to go to class – too scared that my heart flutters would turn into a heart attack in the lecture hall or that my throat would close up, and no one would notice that I couldn't breathe. My symptoms remained subdued when I stayed in bed and distracted myself with television. I didn't have to worry about walking to class without falling or sitting through class without breaking an anxious sweat. So for a week and a half, I stayed there and called my mom every day to cry.

I was twenty years old at the time. I was supposed to be the embodiment of health. All around me, college students took their bodies for granted. In the last years of middle school and all of high school, I had combatted illness easily. I was rarely sick besides the inevitable winter cold. However, in college I contracted norovirus, mononucleosis and a basilar migraine within a single year. While the first two illnesses are common amongst high school and college students, the third is not. I couldn't understand why it happened to me. I was a healthy person: I made my own meals, mainly chicken and vegetables, ran four times a week, worked hard at school and watched little television. Why me? And why now?

I had seen two doctors and one psychologist at the university health center by the time I returned to Massachusetts in December of 2013. Neither physician had uncovered anything physically wrong with me, and the psychologist was a graduate student with far more questions than she had answers. Still, however, I couldn't walk without feeling like the world was being tilted beneath me. My heart raced in my classes and pounded in my sleep. Whether sitting or standing, I constantly felt like I was going to fall over. My mother had scheduled an appointment with a neurologist at the hospital where I was born. Around the same time, my father's health insurance coverage ran out. He had been laid off that spring and was working as a consultant, which gave him no benefits, until he could find another full-time position. He purchased new health insurance from a smaller company. However, the office of my primary care physician did not have a contract with the new insurance company and so would not accept it. They couldn't give me a referral to a neurologist. After weeks, we found a doctor that accepted our Neighborhood Health Plan coverage and scheduled an appointment so he could refer me to a neurologist. Finally, two days before New Year's Eve, I was evaluated by Dr. Moore, a

neurologist at Emerson Hospital. I naïvely hoped that all would be instantly resolved by the New Year – that 2014 would automatically give me a fresh start – but I knew, of course, that wouldn't happen.

Dr. Moore perceived no signs of vertigo, seizures, or serious brain damage but ordered an EEG and an MRI just to be sure there were no physical causes for my symptoms. Then he asked me a series of questions.

“When did your symptoms first start?”

“August of this year.”

“Did you get carsick as a child?”

“I never vomited, but I always felt nauseous, and I couldn't read or I'd get really bad headaches.”

“Is there a history of migraines in your family?”

“My mom gets migraines.”

“When you get symptoms, how long do they last?”

“They don't really ever go away. I always have something. When the dizziness or heart flutters get really bad it's usually thirty seconds or so.”

“Have you noticed your symptoms are more prominent in certain environments?”

“Anywhere but my apartment. Usually lots of people and loud noises. I think the headaches get worse at night.”

He paused for a moment looking over these and the previous notes he had taken.

“It seems to me you're having a kind a basilar migraine.”

“A migraine?”

“Yes.”

“But it’s not like a headache. I mean sometimes I get a headache along with everything else, but not always.”

“You can have a migraine without experiencing the unbearable headache. Carsickness as a child is generally the first sign of migraines as an adult.”

A migraine. I couldn’t drive, or walk, or withstand lectures, or sleep because of a migraine? Dr. Moore prescribed a special diet to eliminate tyramine, MSG, red dye number one, and anything that tastes good, as well as a very low dose of a seizure medication that could be used to treat migraines. That night, I took three Topamax pills as he had dictated. I woke up at two o’clock in the morning to the hallucination of a man’s face next to mine. I was sweating. My body was shivering and tingling with electricity. Looking into the dark of my room, I saw green and blue and red lines swirling their way into ambiguous shapes. He had prescribed too many. I woke up my mother who for hours poured water into my mouth and rubbed my back until I fell asleep. The next night, I took one pill only.

In January, one neurologist and one EEG finally cleared me to drive for considerable distances. Dr. Moore assured me that I wasn’t having seizures, and driving was safe. The next day, I got in the car and drove to my dad’s house on the coast. I passed the exit to Manchester-by-the-Sea where I had retreated from the highway five months earlier. My heart pounded in my chest, pulsating all of my limbs. I was waiting for it – waiting to lose control. But I never did.

Several days later, I returned to Michigan, still taking one Topamax pill a day. I walked to my classes without feeling like I was falling over. The sensations of vertigo had subsided. My headaches were shorter and less severe. But, these absent symptoms were replaced by new ones: numbness in my feet, tingling in my hands, loss of appetite, upset stomach and general fatigue. I

managed these for a few days, until one Saturday night proved them too much to handle. I retreated upstairs from a marathon of *Friends* with my roommate to lie down in my bed. Exhausted, I closed my eyes. But sleep never came. I noticed my body was shivering, so I put on a sweatshirt and pulled my comforter over my chin. The shivering wouldn't stop. I turned my head to the side and felt my head falling, but there was nowhere for my head to fall; It remained firmly on my pillow. I couldn't feel my feet, and I picked up my cell phone to call "Home," but my fingers wouldn't move where I wanted. Eventually, I managed to call my mom who called the neurologist who transferred her to the on-call doctor who said I was experiencing side effects of Topamax and to stop ingesting it immediately. My mother asked me some questions, but I could neither think of the answers nor form the words. She asked to talk to my roommate. I handed Sammy the phone and lied back in bed. A few minutes later, I was asleep.

As I moved through the rest of my sophomore year of college, sans medication, I learned how to not eradicate my symptoms, but control them, or at least keep them from controlling me. Despite never receiving an official diagnosis of cause, I began following Dr. Moore's torturous migraine diet, willed myself onto a treadmill for the first time in months and sacrificed watching an episode of *Friends* for an extra hour of sleep. I didn't stay in bed all day skipping class and allowing my symptoms to govern my body. I fought back against them. As the months passed, my symptoms gradually subsided until they were almost undetectable. My days assumed a former routine, and I focused on succeeding in school. Despite remaining dependent on my parents for advice and support throughout this ordeal, I gained more independence from it than I lost. I nursed myself back to health without my parents physically caring for me. I survived my first direct encounter with the healthcare system and learned how to assertively navigate it. I learned how to interpret what doctors say and how to ask the right questions. Alone, I had

struggled through a scary and disheartening experience, but I did not submit to it. Once in November, my mother suggested that I withdraw from the semester, but I refused.

The cause of my symptoms has still not been determined. I will receive an MRI when I return to Massachusetts at the end of my sophomore year. I doubt it will uncover anything, which is both a relief and frustrating. After that, there is little else doctors can do to discover a physical cause. Or so they say. The doctors I have seen do not know what its happening to me. They guess. But there must be other tests for them to run. Other questions to ask. A more educated guess to make. I don't worry so much about identifying a diagnosis when my symptoms are not active. But what if they come back? What am I supposed to do in response?

Last week, I was walking home from one of the last classes of my sophomore year. It was one of the few April days in Michigan that felt like spring. The sun was shining, the birds had finally returned from their southern migration, students were sitting on their porches neglecting their homework and I felt optimistic and excited about the end of the semester. All of a sudden, while walking past my best friends' house, I felt my knees give out and the world drop from beneath me. I stopped on the sidewalk and placed my hand on a tree trunk to steady myself. *Shit*. I closed my eyes, sighed and quickly walked to my apartment.