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Apr 22, 2020

When Life Gives You Lymes

People get sick. I suppose I know why, on a certain level. All people get sick sometimes, some people get sick all the time. Some people never get better, some never get worse. The why comes from a bunch of bioscience talk about germs and pathogens and such. I'm no sort of expert in the field, and I'm fine with that. I wonder though, why do mothers get sick at the strangest times, and why can't they get better? I have surely exhausted the question on a multitude of levels.

A 15 year-old girl doesn't know much about life, nor does she want to. I was her. Everything was fine; now I know it actually wasn't. Mom and Dad didn't fight, and I chose to pretend as though we were all happy, but none of us were and that lasted a while. I came home from track practice one day and Dad wasn't there, and he wouldn't be back for some reason I wasn't allowed to know, but I assumed it was a temporary displacement. Assumptions were proved wrong after a month turned into a few more, then a lot more, then too many to even hope anymore. He was around, but not home.

Mom didn't feel good at this time. Well, none of us felt good, but she hurt a little more than any of us.

"I think I pulled both of my hamstrings," she told me one day after she had finished a workout. She had been training for a marathon, but her legs shut down on her and she went to a rehabilitation therapists in order to fix them. My mother spent a month with a physical therapist, but I knew whatever strange exercises they had her doing weren't working because her legs never improved, only worsened. She couldn’t walk some days, and as the time passed, she couldn't breathe either. The muscles in her legs seemed to be intact, besides the fact they were being eaten away by spirochetes—bacteria.

“I know I'm sick, I just know it.” She would say this to me, to herself, to the walls over and over. She saw practitioners and neurologists never heard what she wanted. I never heard what I wanted either: “I’m dying, Paige.”

There was no reason to stay in the hellish hole where everything fell apart for my family and my teenage-self, so my mother and I left. My sister was in college so I didn’t see her much and my mom was in a doctor's office or in pain a majority of the time, so I didn't see her much either. I sat in my room, my new room in my new house, and I talked to no one because I couldn’t make any friends at my new school. I cried for a couple weeks straight but then I realized it wasn’t doing me any good, so I stopped. Or maybe I stopped because I just didn't have anything left to cry. But, my mom didn't stop. She still cried.

The funny thing about Lyme disease is no one really knows what it looks like because it looks different for everyone. The disease is often called an Imitator because it imitates other illnesses like Alzheimer’s, Multiple Sclerosis, Lupus, and the list goes on. My mother, and other “Lymies” alike are no strangers to misdiagnosis, which tacks on a significant amount of time to the treatment process, and the suffering process. It took two years, while my mother was suffering from the symptoms of insomnia, fatigue, depression, anxiety, and chronic pain to hear it from a doctor: “You have Lyme disease,” but we knew long before, thanks to the internet and those WebMD articles that I chose to trust. Insurance companies refuse to treat the disease, because technically it’s illegal. This comes from the annoying fact that doctors only treat Lyme

disease for 30 days, and if the treatment is unsuccessful—more often than not, it is—they stop the treatment. Any further treatment has to be more untraditional, treatments of which most doctors do not approve. Because the effective forms of treatments likely go against some medicinal guidelines, insurance companies deny coverage, and many doctors deny giving treatment to avoid consequences. The CDC chooses not to recognize Lyme Disease after 30 days of unsuccessful treatment, so patients have no way to get additional help. In short, there is a timer on treatment and most of the time, the timer runs out before any inch of progress is made. It took me a long time to learn all of these politics, but being submerged firsthand in the Lyme Disease community for almost 4 years guaranteed that I would become an expert on all of it somehow. At some point, I suppose at numerous points, we had to find detours to avoid the politics which isn't an easy thing to do, and it usually results in taking a much longer route. I was a senior in high school when my mother told me about treatment centers in Mexico. It’s common for those with Lyme to leave the United States for treatment because countries like Mexico are able to give more effective alternative treatments legally.

I dropped my backpack at the top of the stairs and sat at the kitchen counter, next to my mother who was camped at her laptop; I suspected she’d been there for most of the day. “Paige,” she started. I always could predict the direction of conversations by the tone in her voice, especially when she was under the worst influence of the disease’s flare-ups. “I—I think I need to go to Mexico for treatment. But I don't want to leave you.” “Go.” That was all I said, before she could take another breathe to say more. I wanted her to go. I wanted something to change, because I couldn’t watch anymore; waking up before school to find her in the kitchen taking twelve different types of antibiotics that didn’t work, then returning from school in the afternoon to see her lying wide awake on the couch, because she hurt too much to move and too much to sleep. I had heard success stories from people who had gone to the treatment centers in Mexico, namely a clinic in Tijuana which was where my mother had been looking into. The clinic’s specialty is stem cell implantation and making changes to the patient’s diet to improve nutrition. In many cases, patient’s can receive hyperthermia and hypothermia—both ends of the spectrum seem to do a number on the bacteria eating away at the body, kickstarting the immune system.

My mother had many friends who had gone to the clinic in Tijuana and received such positive results, they returned to the clinic every six weeks. I was convinced by my mother’s friends’ feedback; and I think she was too. She packed her PJ’s, bathing suit, and sweatpants and headed for the airport. I didn’t see her again for a month.

She called me everyday, sometimes—most of the time—twice a day. She had said the waiting room was amassed with United States Citizens floating in the same boat as she; Cancer and Lyme patients desperate for treatment which they cannot receive in the US. “We all sat there like ghosts with IV’s in our arms,” she had told me after her return. “But we were ghosts together.”

Her treatment process in Mexico was vigorous, causing her to call at night, telling me she couldn't stop throwing up. I knew the treatment was doing its job; cleaning out the bacteria, getting all the bad out. She knew it was working too, but through the phone each night I could detect the ridges in her voice, hinting at her desire to just quit, to just stop the treatment and come home, but she didn't. She kept calling, and I kept answering, waiting for uplifting responses to reassure me that her trip was worth the expenses and suffering. As the time blended together, I'd forgotten how long she'd been there, but the phone calls granted me better news; not great news, but better than bad.

She received the stem cell treatment and nutritional remedies which knocked out a significant portion of the bacteria, but also knocked out much of the strength she didn't have to spare. This is what the treatment does. It not for the faint of heart, and often times the treatment is so aggressive towards the bacteria in the body that it takes down the host in its wake. During this time spent at the clinic in Tijuana, my mother's body was being sucker-punched from the inside out by powerful stem cells. The stem cell implantation alters the bodily systems, rearranging the immune system. I imagine it to be highly painful to have your insides rearrange down to a microscopic level, and my mother verifies my assumptions.

She returned home in the winter, eager to tell me about her time spent on the Mexico beaches basking in the sun with all of her sick friends, but she wasn't so eager to tell me if the treatment was successful. These types of treatments can take time to show positive results, first showing negative effects, so we waited for her to get better.

After months of my mother feeling her worst slew of symptoms, I asked her if she thought it would be effective to return to the clinic in Tijuana.

“No, I'm never going back there,” she cried to me. “It hurt too bad and it didn't work. Nothing will ever work.”

When you say these things to yourself, you begin to believe it. She said it, then I started to say it too, and it took its toll on both of us. My mom never did go back to Mexico; she remained ill, more ill than she ever had been in the past. Soon, the worst of it passed with flare-ups that came at unexpected times; they would last a few days and then the good days would return.

I wish I could finish this story with a happy conclusion about her full recovery, but I can't, and I am sorry for that. But she hasn't stopped trying to kicking the disease; she continues with antibiotics and herbal supplements, she detoxes her body every night by flushing her colon with coffee and salts, she cannot eat dairy, sugar, gluten, or grains, and with all these routines she still suffers the side effects of depression, insomnia, fatigue, chronic pain, and anxiety. But she is stronger now than she was before she was forced to fight a disease that no one wants to treat, and I am stronger now too from being on the same side of the fight as she.

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