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Grief For A Life I Will Not Live

One's view of oneself is prone to change over time. It is a result of internalized expectations, lived experiences, and idealized versions of the future.

Tick. Tock. Tick. Tock

The clock in the waiting room kept ticking. Why wouldn't it stop ticking?

"Stop bouncing your leg" my mom said as I looked over to her.

Crap. I was doing it again.

Little did I know this one appointment to see if maybe I could escape the shackles of my tree nut allergy would spiral. Little did I realize this would lead to several emergency room visits, multiple specialists, and one summer of medical mysteries.

It was cold outside. Why did I not feel cold? I was burning.

Burning.

Burning.

Burning.

"We think it's possible within a year." I heard him say it. I heard the miracle doctor say it and yet I couldn't believe it. Be able to eat whatever I wanted? No longer would I have to watch the other kids eat cake at birthday parties while I smiled with an empty plate.

If only I hadn't gotten my hopes up. If only I knew what I was getting myself into. If only fifteen year old me had seen– had known– maybe things would be different.

A year. In one year I would be freely eating whatever I want. One year of building a tolerance, an immunity, and I'd be free. One year and I'd be one month from my trip to Paris, where I will eat all that Paris has to offer.

It's been a little over a year.

I was wrong.

My heart was racing. The room was spinning. I was burning. It's January, why am I so hot? I wanted to fall. I felt like I was falling.
Falling.
        Falling.
                Falling.
"Alix?" my mom asked. I caught myself before I could hit the ground. God why was it so hot in here? Why was I so nauseous?

Feeling sick was not– is not– unusual for me. Ever since I was eight years old I've had migraines chronically. Ever since I was nine years old I've had joint pain that no doctor could explain. But the dizziness, the heat exhaustion, the racing heartbeat, that was all new. I was aware something felt wrong. I had always known something was wrong. But I didn't know the scope.

I was itchy. I knew this feeling. I knew it because I had been trained to. I knew it because it was the first sign of trouble. The first sign of death. I knew what to do, I knew not to panic, I knew where to stick the Epi-pen.

I called for my mom.

"Oh my god," I heard my mom gasp. She knew it too, then. I dialed 911. I told him where I lived, my age, what was happening. Just the way I was taught. The steroids weren't working. I was so careful. Why did it go wrong? Why did I react to my dose? Why did I once again face Mr. Death, who had walked with me my entire life?

The doctors had warned me not to get my heartrate up for two hours after taking my daily dose. It would increase reaction risk. But I was resting. I simply got up and then the itching and the nausea poured in. I do know now why I reacted to my dose. Maybe if I had known then I would've saved my family several ambulance bills. But "maybe" doesn't help me now, and it doesn't change the past.

"Have you ever heard of POTS?" I heard the pediatrician at Bryn Mawr Hospital's emergency room ask. I was so tired. I could barely open my eyes. Benadryl does this I reminded myself. Especially hospital grade benadryl.

"I was looking through past charts–" his voice mixed with my mothers as I drifted in and out of sleep.

It was my mother who later explained what the doctor meant. My resting heart rate had been above one-hundred beats per minute for months. My world spun whenever I stood up. I was overheated all the time. Postural Ortheostatic Tachychardic Syndrome. POTS. All of the signs pointed to this illness. But it wasn't the only one. This was only the first hurdle to my idealism of a particular future. A future where I could run, go out with friends every weekend, live from excitement rather than fear.

But do not mistake this for **resentment**.

This is simply **grief** for a life I will not live.

This is where my real story starts, and I must warn you it is messy and painful. Life with chronic illness is never sunshine. It is rain and rainbows. Small wins in a sea of losses.

The office at Children's Hospital was cold according to my mom. I did not feel cold. I never felt cold anymore. I was bouncing my leg. I needed answers. The unknown was not something I was capable of allowing to exist. Everything had an answer. I was determined to find this one. The door opened and my head whipped toward the woman who entered the sterile room.
"Mom, she has recent labs, she doesn't have lupus or arthritis or anything of that sort."

Why was she speaking to my mom? Why was she not speaking to me? I was the patient. I was the one with problems. I was the one sitting on that doctor's bench with the tissue paper. I wasn't a toddler. I was fifteen years old. Why was she treating me like I wasn't even there?

I still struggle with the unknown, as well as accepting that things are out of my control. This process has forced me to allow life to happen to me and realize I cannot stop it. However, when I think back to this visit, I am still angry that I was treated as if I were a fly on the wall in my own doctor's visit.

Five minutes was all it took for the rheumatologist to say I had nothing wrong with me and I was making it up for attention. Five minutes was all it took for me to doubt my own mind. Five minutes was all it took for me to doubt my own body.

"What about Ehlers-Danlos?" my mom asked.
"She's not that flexible" the doctor said as she left the room.

After that visit, I went to the emergency room two more times. It was my high resting heart rate that caused the original visit and the one that followed only three weeks later– well, it was my allergic reaction to my dose, but that was caused by my high resting heart rate. After the second visit, I had to quit oral immunotherapy. It was no longer safe. After the third visit, when my heart rate was so high my mom worried I had an arrhythmia, I knew that my summer would be longer than any other.

I was burning.

I was burning due to my suspected POTS, but also due to my anxiety at being in Children's Hospital once again. A new specialist, a new thing to rule out. Parasites in my stomach, celiac disease, some rare absorption of minerals issue. More things to rule out. More things to obsess over. More non-answers.

Not a thyroid issue, as per the labs.

Not lupus or arthritis, as per the labs.

Not cancer, or diabetes, or anything easy to diagnose.

"We will need a stool sample to be sure."

This doctor was nicer than the last one. She listened to me. She saw I was anxious, but didn't automatically assume it was a psychosomatic issue. That was new for me.

This was the first time I started to feel hope about finding answers. Funny, considering collecting a stool sample was one of the most disgusting moments of my life. But I realized that day that unlike what the rheumatologist said, there is still a variety of things that could be truly wrong. Of course, the results came back showing no parasites, nor celiac disease, nor absorption issues. However, my thyroid labs were suddenly off. There was something there. I want to make it clear that I did not celebrate the fact that something was wrong with me. I celebrated the fact that there was something concretely, visibly, undeniably wrong. No doctor could question me now.

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The labs didn't show markers for Hashimotos or Graves. The world felt like it was crushing me. I was suffocated.

I wanted to ***SCREAM****, but nothing came out. Sure, POTS was diagnosed now after seeing a cardiologist, but there was more there and I was sure of it.*

"There is a specialist who I'm friends with. It's out of pocket, but he might be your last option," my endocrinologist said.

"When can we see him?" I asked, the eagerness couldn't be mistaken for anything but pure worry.

"July, at the earliest."

A whole month of being in my own head.

Another month where I do not know what is wrong.

But there it was… that tiny sliver of light… hope.

"What's his name?" my mother asked.

"Dr. Boris."

I thank the world every single day for Dr. Bardsley, my endocrinologist, recommending Dr. Boris to me. At this point, it had been June, and over half a year of doctors visits and confusion and getting sick every few weeks. I was at my wits end. I just wanted to know what the problem was so I could fix it.

Let this be a lesson: not everything can be fixed.

After a month of compiling years worth of lab results, emergency room visit summaries, urgent care records, and more, today was the day I would finally receive answers. I was still burning, but my yearning for an explanation, a reason, was stronger.

I sat in my room with my mom waiting for Dr. Boris to log onto the virtual appointment.

"Hello! How are you doing?" asked Dr. Boris as he popped into the zoom. He was older than the rheumatologist at CHOP. Middle-aged, if I had to guess based on the gray hairs peaking through his dark brown ones. He had a slight bit of stubble, suggesting he was always working like my own father. Working to help people. People like me. He had kind eyes, understanding eyes, empathetic eyes. He had that twinkle in them that showed he had a natural curiosity, a propensity for solving impossible puzzles. I was an ***impossible puzzle****. Maybe he could solve me. As the pleasantries were exchanged, my heart began racing– not from tachycardia but from eagerness.*

"So… any ideas?" I blurted out.

Crap.

But instead of scolding me, Dr. Boris laughed. He laughed with me. Not at me. That was new.

"Yeah, I have a few. You've been through the ringer, haven't you?"

Suddenly I felt heard. Here was this expert in pediatric POTS and its comorbidities, and even he acknowledged how rough these past few months have been. Pain was not unusual for me, but the added stress made it so much worse.

Dr. Boris tested several different things in this visit. He did a fifteen minute standing test, to confirm POTS. Then he did a beighton scaler for Ehlers Danlos Syndrome, along with questions about family history and other signs. Finally, he asked me to scratch my arm. At the time, I had no idea what he was thinking.

"Scratch my arm?" I asked. It was obvious I was puzzled by his request.

"Yes."

I did, and like always, red angry welts started to appear where I had just scratched. I showed my arm to the camera, confused as to why my mom gasped.

"Just as I suspected. Mast Cell Activation Syndrome."

"What's that?" I asked.

"It is when your immune system, specifically your mast cells, overreact to stimuli. A few years ago you randomly had an allergic reaction and to this day you never knew why, yes?"

"Yes…" I answered hesitantly.

"That would be MCAS."

"So you're telling me I can go into anaphylaxis at any time?" I asked, my pitch rising rapidly.

"Sort of, but not to worry, there are medications that reduce the risk majorly and will keep your mast cells under control." Great, more medications.

"Life is not fair" is what my mother would always tell me when I was younger. In that moment, I felt that statement ring true. It wasn't fair that I had all of these conditions. It wasn't fair I was in pain all the time at only fifteen years old.

It wasn't **fair.**

I had done everything right. I had great grades, strived to be a model student, always tried to be a perfect older sister, and even had time to hope to be a decent daughter. All of my life I strived for perfection in the false hope that it would protect me from harm.

Life's not fair.

Life doesn't work that way. I still struggle accepting that. The day I found out I had not just one chronic illness, but three, was a whirlwind. It was a tornado of relief that I wasn't crazy, confusion as to what this meant for my future, and grief for a life I would never live. I sat in my room, alone, contemplating it all.

How will I tell my friends? Will they think differently of me? Will people coddle me like some incapable idiot? Or will they neglect my limits and become frustrated when I cannot handle as much as them? Will I ever find love? I want to. Who would love someone broken? Why would anyone subject themselves to a life in shackles? I'm forced, but they aren't. I don't want to be a burden.

Burden

Burden

Burden

Everyone knows the five stages of grief. Everyone knows denial, anger, bargaining, depression, and acceptance. What many people don't know is that those five stages aren't exclusive to losing another person. Sometimes they can be felt when you lose yourself– or who you would've been.

I'm not in the acceptance stage. I don't think I will be for awhile. I've gone through denial, anger, bargaining, etc. But my stages aren't linear. Some days I slip back into anger. Others I'm in utter denial. Many people expect me to be **fine** now that I've been diagnosed. Cured, treated, you name it. But I'm not **fine**.

* * *

"How do I stop feeling like I can't breathe whenever I realize I will ***never*** *be* ***normal****?"*

"I wish I had an answer," my therapist said to me.

"I thought getting diagnosed would somehow cure me I think. I thought maybe it would be a magical solution."

"You're an idealist, Alix. And that is a wonderful thing about you– you see the good in all of the bad. But sometimes, there is no magical solution. Sometimes the solution is being able to carry on in spite of it all. You do not need a cure Alix. ***You are not broken****."*

I reread a book shortly after this session. What my therapist said reminded me of a character who struggled in different ways to me, but went through the same emotions. There are many quotes from that book that helped me get through the brunt of the pain. But there is one I repeat to myself every single day.

"I am the rock against which the surf crashes, nothing can break me" (Sara J. Maas).
It is a reminder that despite everything, I am still strong. It is a reminder that strength isn't always physical.

* * *

One's view of oneself is prone to change over time. It is a result of internalized expectations, lived experiences, and idealized versions of the future.

I am going to Paris soon. I won't be able to eat the baked goods like I thought. I won't be able to walk for hours like I dreamed. I might even have to skip a day of activities due to an increase in pain. I thought I knew so many things then.

I know many things now. I know that I have Ehlers Danlos Syndrome, specifically the hypermobile subtype. I know that I have Mast Cell Activation Syndrome. I know that I have Postural Ortheostatic Tachycardic Syndrome. I know that I have lived with these illnesses and somehow managed to get straight As in school. I know that not everyone will be able to handle the fact that I have limitations. I know I'm not visibly sick. Most people would never guess I had these conditions unless I told them. Maybe they would think I look a bit pale, my lips a bit blue, my skin checkered from blood pooling– but they wouldn't know.

Yet I still must remind myself of other things I know. I am not a **burden.** I am not **broken.** I do not need to be **fixed.** There are **good** days amongst the **bad** ones. I cannot spend my life wondering "**what if.**"

Maybe I don't know many things now if I have to remind myself of them. Maybe it's okay to not know things. Other people do not know things. They pretend to, but they don't.

* * *

People do not know what to say to someone chronically ill. When people ask me, "how do you do it?" I know they ask from a place of kindness. But sometimes I want to roll my eyes. What else should I do? Give up? Live a life of regret? I have no other choice– at least in my mind. I'm not an inspiration. I'm not some fawn without its mother wandering into the road. I'm not a fragile porcelain doll. I persevere and I’m strong, but please **don’t** tell me that. **Don’t** pity me. **Don’t** treat me like someone incapable. Its hard enough that sometimes I feel that way myself, I don’t need others adding onto that.

I’m not broken. I do not need to be fixed.

* * *

It's easy to resent myself. It's easy to fall into depression and do the unthinkable to escape my own body. But I’ve never been one to enjoy something easy. I am the person who would purposefully make things more challenging because I was bored. I am the person who would never stop until I got what I wanted. I am the stubborn, persistent, determined, person I have always been.

This is simply another challenge.

Grief for a life I will not live.

Appendix

Many of you are probably asking, what exactly is POTS, EDS, and MCAS? They are complicated chronic illnesses and are often comorbid with one another.

POTS: Postural Ortheostatic Tachycardic Syndrome. POTS is a form of dysautonomia, a disorder of the autonomic system. It involves processes like breathing, heart beats, etc. It causes a disorder of the sympathetic and parasympathetic systems. POTS is very specific, though, in that there are certain requirements that must be met in order to diagnose it. One such criteria is at least a 30bpm increase in heart rate when going from sitting to standing. Symptoms include heat exhaustion, dizziness, fatigue, fainting, and an extremely fast heart rate.

Sources:

“Dysautonomia.” *National Institute of Neurological Disorders and Stroke*, U.S. Department of Health and Human Services,

www.ninds.nih.gov/health-information/disorders/dysautonomia#:~:text=Dysautonomia%20is%20a%20disorder%20of,parasympathetic%20parts%20of%20the%20ANS. Accessed 11 Dec. 2023.

professional, Cleveland Clinic medical. “POTS: Causes, Symptoms, Diagnosis & Treatment.” *Cleveland Clinic*, my.clevelandclinic.org/health/diseases/16560-postural-orthostatic-tachycardia-syndrome-pots. Accessed 11 Dec. 2023.

hEDS: Ehlers Danlos Syndrome, specifically the hypermobile subtype. Ehlers Danlos syndrome is a genetic condition that affects collagen in the body. There are thirteen subtypes total. This condition is underdiagnosed, but still is considered rare. Ehlers Danlos Syndrome affects ligaments, joints, skin, and other connective tissues. Often times, Ehlers Danlos Syndrome causes laxity of the joints causing them to slip out of place and subluxate or even dislocate from minor injuries. Due to this laxity, EDS patients are known to be very hypermobile, which comes with its own host of issues. EDS is very complicated to diagnose, and even more complicated to explain.

Source:

“Ehlers-Danlos Syndrome.” *Mayo Clinic*, Mayo Foundation for Medical Education and Research, 25 Aug. 2022, www.mayoclinic.org/diseases-conditions/ehlers-danlos-syndrome/symptoms-causes/syc-20362125#:~:text=Overview,underlying%20structures%20in%20your%20body. Accessed 11 Dec. 2023.

MCAS: Mast Cell Activation Syndrome. A condition where mast cells, cells part of our immune system, become defective and release activator signals triggering allergic reactions to minor stimuli. Symptoms include anaphylaxis, tachychardia, low blood pressure, syncope, diarrhea, hives, swelling, skin flushing, wheezing, shortness of breath, nausea, and abdominal pain. Mast Cell Activation Syndrome can be a secondary illness to another which causes it or have an unknown cause.

Source:

"Mast Cell Activation Syndrome (MCAS)." *American Academy of Allergy Asthma & Immunology*, www.aaaai.org/conditions-treatments/related-conditions/mcas. Accessed 13 Dec. 2023.