

## One Day at a Time

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Imagine you are a four-year-old little girl, lying on the grimy cement floor in the garage under your father's car. You are terrified that your parents will find you. You are aggravated at the fact that you have to receive another shot. They never stop. You hear the garage door creak open and the lights flicker on. Cringing, you curl up into a ball behind the tire, clutching onto it with your delicate fingers. The footsteps are light and you recognize it must be your mom. She calls your name and you hold your breath. You watch her feet travel over between the two cars. She bends down checking beneath the first, then turns her head to the left to find you. Your eyes meet and both immediately begin to fill with tears. You scream and kick as the tears stream down your tiny cheeks and she carries you inside. Your dad pins you down to the ground, begging you to stop fighting the injection. This is only the beginning of a long journey that will consume your entire life. You are living with type 1 diabetes and there is no escape.

An origin is typically described as a place where something or someone is derived from. My origin is not a place, but rather a chain of events. Most people focus on defining themselves through their finest qualities. However, I believe that my identity is best explained by one overarching event that happened early on in my life, but continues to impact me to this day. In addition, it is the lifestyle I have come from. It is my origin. Throughout my life, I have faced a multitude of medical obstacles. Complications started at the age of three when I started experiencing common symptoms of leukemia. I can specifically remember my family doctor with his back facing me holding onto my mom by the shoulders. I will never forget my mother's reaction. Overcome by emotion, tears steamed down her face uncontrollably. She began convulsing and lost control of her body. My doctor screamed for the nurses as my mom blacked out. I started crying, telling my mom everything was going to be okay, and she was going to get better. What I couldn't understand was that I wasn't going to be okay.

Less than an hour later, I found myself on the longest car ride I had yet to experience. My mom was sitting in the passenger's seat still crying as my dad drove us to Riley Hospital for Children. They told me I was going to a big doctors office with lots of

people who were going to help me get better. I didn't understand what was going on. Everyone kept telling me I was sick and going to get help, but I didn't feel sick at all. I watched the city traffic and tall buildings pass by while we drove in silence. When we arrived they were waiting for us, practically ripping me away from my parents. Everything happened so quickly, before I knew it everyone was a blurry mess of tears. I was screaming and flinching from needles and IVs left and right. I was passed along from room to room to receive shots and have my blood drawn. I didn't see my parents until I was finally put in a permanent hospital room. I was crying from all the painful shots, but I couldn't understand why everyone around me was crying. I kept asking if the doctors were hurting them too and when it would all stop.

Thankfully, I was instead diagnosed with a rare autoimmune disease called idiopathic thrombocytopenic purpura instead of leukemia. ITP leads to excessive and uncontrollable amounts of bruising and bleeding due to low platelet levels. Platelets are the cells that help to clot your blood. A normal platelet count registers around 150,000 platelets. A patient with ITP usually has a reading of around 20,000 platelets, but mine was closer to 5,000 platelets when I was diagnosed. At this point, internal bleeding begins to occur without any sort of injury to the body. If I had hit my head on anything during this time I would have hemorrhaged and bled to death. Essentially, once all the damage was done, ITP had caused my own immune system to no longer recognize my body's pancreas cells as its own. Similar to when a transplant is performed, my body couldn't accept my pancreas. However, we wouldn't find this out for six months.

The original treatment plan I received was not strong enough to fight off the ITP. Only two weeks after being released from the hospital I was rushed back to the University of Chicago for extremely low platelet levels. After an ineffective first treatment of low dose steroids, my body responded poorly to the second treatment. The second steroid treatment I had received was too strong for me. I suffered multiple seizures from the second treatment attempt. After my seizure episodes, I was restricted to a bed until I was considered stabilized. When I was finally released from the hospital I was required to go for daily blood tests. Eventually, the lab work was stretched out to weekly tests. I still dreaded doctor's appointments and blood tests no matter what. Often the blood work would make me faint because the draws were so large and so often.

As a preschooler, I loved going to school. Playing in the sandbox with my friends and story time were some of my favorite activities. When I initially got sick with ITP, I was heartbroken at the amount of school I had been missing out on. I didn't get to play with my friends and I wasn't allowed to go to birthday parties. I couldn't participate in anything that would wear me out or potentially cause internal bleeding. I was robbed of my childhood. I was practically confined to my bedroom for months while my body worked to return to full strength. The autoimmune disease drained all of my energy as I suffered from chronic fatigue. Some days I would never leave my bed because I didn't have the energy to, even after sleeping for an entire eighteen hours. I was deprived of a childhood filled with fun, but it was beyond anyone's control.

Just after my fourth birthday, I found myself back in the hospital. This time was a different story though. The autoimmune disease I had received treatment for only six months ago had nearly destroyed my pancreas. It was damaged to the point where it could no longer manufacture any insulin and my body didn't even recognize it as my own. This was the day that changed my life forever. I was diagnosed with type 1 diabetes and became completely dependent on insulin.

At the age of four it was difficult to understand that my entire life was changing. I knew I was sick to begin with, but now I was sick with something new all over again. I didn't understand what diabetes was or how my life would never be the same. Type 1 diabetes is a chronic medical condition usually found in children and young adults. Only about five percent of people have type 1 diabetes in comparison to type 2 diabetes. Some factors that contribute to being diagnosed with diabetes are genetics, while others are related to exposure to certain viruses. In my case it was due to the ITP virus. Having type 1 diabetes results in no insulin is produced. Insulin is a hormone that is needed to convert carbohydrates into energy. Without insulin injections high levels of sugar remain in the bloodstream making the person vomit or even black out in extreme cases.

I thought I would be better after the doctors "fixed me" or I stayed in the hospital for a while. Despite all the money and years that have been put into research, type 1 diabetes has no cure. It is possible to live a comfortable life with diabetes if it is well managed with proper treatment, but there aren't many pain free treatment options. Six times a day I had to test my blood sugar by pricking my finger with a needle and testing the blood glucose

level on a specific glucose-monitoring device. Twice a day my father would have to hold my shaking body down as I screamed, kicked, and cried in constant fear of receiving insulin shots from my mother. I even started hiding under beds, in cabinets, and like earlier mentioned, even under cars in our garage.

Life at home became stressful for my parents. Financially, I was eating them alive. Mentally, they were beat down and broken. Emotionally, they couldn't handle it. I often remember hearing crying across the hallway late at night while I laid in bed and my parents spoke to each other in their bedroom. Nobody understood the pain they went through when I was falsely diagnosed with leukemia, actually diagnosed with ITP, and now diabetes.

Eventually, my body started to rebound. I was able to attend most of kindergarten and enjoy the summer before first grade. I was excited to finally be a "normal" kid and go to school five days a week. I wanted to make friends and play outside at recess. I was ready to learn in a classroom instead of in my bedroom at home. However, my parents had fears about me being so young and a newly diagnosed diabetic away from home for a full day of school. After a long and hard thought out decision, I ended up back at Riley Hospital for Children, but for a positive and exciting reason. I was receiving an insulin pump and wouldn't have to receive shots anymore. With the insulin pump I would only have to change a miniscule catheter every three days. The catheter secreted insulin into my skin and then into the blood stream by entering into the pump how many carbohydrates I had consumed and what my blood glucose reading was. It would change my life forever.

Three years after my initial diagnosis, at the age of seven, I was placed on the insulin pump. It was a life changing decision that relieved stress on both my parents and myself. Instead of receiving two shots a day I had one shot every two to three days. Initially, doctors discouraged my parents from putting me on an insulin pump at such a young age. My parents argued that they would be in constant control of the situation. In a way they were, but they quickly began teaching me how to operate my pump. I was able to learn the basics that were essential for me to know, even at the age of seven. Over the years, they pushed more and more of the responsibility on me until I was finally able to accept all responsibility for my diabetes.

Now I am responsible for testing my blood sugar at least six times a day, regulating carbohydrate to insulin ratios, calculating corrective doses, and changing the catheter apparatus every two to three days, and ordering my medical supplies. I can say that having diabetes has been a constant battle, a battle that took away a large portion of my childhood. I spent weeks in hospitals and multiple days at doctor's appointments. I was forced to mature fast enough to accept a great deal of responsibility. I cannot consider my journey with diabetes an accomplishment as of right now, because there are no current cures. Although I cannot consider my situation an accomplishment, as I am still fighting diabetes, I can consider it an origin. Diabetes has helped to build who I am. Until a cure comes along, my story with diabetes will continue to be written. One day I hope for a happy ending.

Morgan likes Piña Coladas and getting caught in the rain. She's not into yoga, and has half a brain. . . . In all seriousness, She is a freshmen nursing major at Valparaiso University with a love for recreational writing and slam poetry. Morgan has grown up speaking and writing about her experience with a multitude of medical conditions. She is always thankful for the opportunity to tell her stories to others through speeches, writing, and poetry.