



Bridgewater State University

## Virtual Commons - Bridgewater State University

---

Honors Program Theses and Projects

Undergraduate Honors Program

---

8-18-2022

### Blood Sugar: A Collection of Essays on the Highs and Lows of Diabetes

Annalisa Morganelli  
*Bridgewater State University*

Follow this and additional works at: [https://vc.bridgew.edu/honors\\_proj](https://vc.bridgew.edu/honors_proj)



Part of the [Nonfiction Commons](#)

---

#### Recommended Citation

Morganelli, Annalisa. (2022). Blood Sugar: A Collection of Essays on the Highs and Lows of Diabetes. In *BSU Honors Program Theses and Projects*. Item 557. Available at: [https://vc.bridgew.edu/honors\\_proj/557](https://vc.bridgew.edu/honors_proj/557)

Copyright © 2022 Annalisa Morganelli

This item is available as part of Virtual Commons, the open-access institutional repository of Bridgewater State University, Bridgewater, Massachusetts.

Blood Sugar  
A Collection of Essays on the Highs and Lows of Diabetes

Annalisa Morganelli

Submitted in Partial Completion of the  
Requirements for Departmental Honors in English

Bridgewater State University

May 9, 2022

Sarah Fawn Montgomery, PhD., Thesis Advisor

Date: 4/15/22

Heidi Bean, PhD., Committee Member

Date: 4/13/22

Lisa Litterio, PhD., Committee Member

Date: 4/25/22

## Critical Introduction

As soon as I began working on this thesis project, I knew that I wanted this collection to focus on the different aspects of my life that have been affected by me having type one diabetes. The diabetic experience is one that has been underrepresented—and arguably, misrepresented—in popular media. Admittedly, I had never read a diabetes-focused memoir, as I had never encountered one before. However, as I started my work on this project, I read various chronic illness focused nonfiction books, such as *Sweet Invisible Body* by Lisa Roney, *Needles* by Andie Dominick, and *Sugar High* by Alexandra Park. These works provided great insight into the intricacies of living with an incurable condition, such as diabetes, and how those intricacies affect every area of one’s life. Some facets of these books resonated strongly with my experiences, while others were rather unrelatable for me. The four non-fiction essays in my collection aim to add my personal experience to the existing literature, showing that while diabetics may have similar experiences, these experiences can also be vastly individualistic. Additionally, while I share my own stories, I explore the general chronic illness experience and how ableism and misunderstanding impacts larger societal systems such as healthcare and the educational system.

The first essay in this collection, “Eyes Closed,” focuses on the social isolation that can occur from living with a chronic illness. As I share different examples of times that I was socially ostracized or isolated as a result of my condition, I argue that chronically ill children—whether they have diabetes or another condition—are often placed in similar positions. I write, “Like most other chronically ill kids, my peers lacked understanding around my condition. I find myself wondering if they inadvertently learned this behavior from their parents, who didn’t seem interested in trying to understand either” (13). I am arguing that this isolation was not necessarily a result of outright cruelty, but rather stems from a societal misunderstanding of what it is like to

live with a chronic illness. Additionally, this ignorance tends to be passed from parent to child, as I—and many other chronically ill individuals—have received misunderstanding from children and adults alike. My aim is to show that despite the harmless intentions that an individual may have, these negative interactions have a serious impact on the chronically ill child.

A major recurring theme within chronic illness nonfiction books is the feeling of social isolation and loneliness. Throughout my collection, but most specifically within this essay, there are many moments of someone not understanding or making ignorant comments about me having diabetes. This thematic element can be seen in *Reflections on A Life with Diabetes*, edited by Diane Parker and Dr. Ruth Mark, a collection of poems and prose surrounding the diabetic experience. This book places a strong focus on how illness can be entirely isolating, both in terms of society not understanding, and in one isolating themselves as a result of that misunderstanding. Additionally, in this book, there is a cohesive thread throughout many of the works from the different writers that contributed to this anthology. There is a section specifically devoted to works about being diagnosed that emphasizes how the moment of diagnosis is a key moment of feeling different from their peers. One writer featured in this collection named Cinda Thompson writes, “‘for life’ was my sentence, and the implication seemed to me to be a life that would now be ‘different,’ even separate from ‘the rest’” (Thompson 15). I touch upon this concept of feeling different in my own work, saying that “From the moment that I was diagnosed the summer before kindergarten, I found myself existing in a category separate from my peers, feeling like my disease had labelled me as ‘other’” (13). With this quote, I am arguing that outside of negative comments and social interactions, diabetics and other chronically ill individuals are inherently made to feel as if they are outsiders. By bluntly addressing these feelings, I am actively working to break down the stigmas that cause them. Writing this essay

allowed me to reject the isolation that I've felt throughout my life and give other chronically ill people who have experienced that feeling a moment of connection and unconditional understanding.

In the second essay, "Education in Absentia," I argue how my experiences in the educational system were deeply affected by academic ableism from teachers, administrators, and even classmates, who did not understand my chronic illness. Throughout this essay, I share how I was often mistreated for my diabetes-related absences despite the fact that I had proper documentation. I write, "Most importantly, they would've known that diabetes-related absences were inevitable, and should not only be excused but also accommodated. It could be that they read my file, and just decided that the doctor's words didn't matter, and they knew best about what I needed" (23). With this sentence, I am reinforcing the idea that not only did my school not understand my condition, but they also did not care to properly inform themselves about my situation, as they felt that school attendance came before anything else. I am also furthering the concept that chronically ill and disabled students are often set up to fail in the educational system when educators do not respect their necessary accommodations. This is a concept with which I am entirely familiar, as no matter how much academic success I had—even as an honors student—I continued to be reprimanded for needing to use my accommodations at school.

Navigating diabetes or chronic illness in an educational setting was present in some of the non-fiction books on my reading list, and absent from others, mostly due to the writer being diagnosed at a later age. The book *A Bottle of Rum Can Cure Diabetes* by Wendy Wagner places a significant prominence on how her teachers treated her in response to her condition. In her memoir, Wendy Walker discusses how she had a teacher who refused to listen when she tried to explain diabetes, and furthermore, would not let her manage any of her diabetes care in class.

When her mother called the teacher to intervene and explain, the teacher responded by laughing and responding, “it’s not like she has a real disease” (Wagner 34), showing how little some teachers care to help their chronically ill students. Interestingly, Andie Dominick chronicles an entirely opposite experience in her book *Needles*. Her teachers ignore her absences, forgive her missing work and give her credit anyway, and show deep sympathy for Andie’s condition. My overarching experience lies somewhere in the middle of these two writers. I write, “The majority of my teachers were graciously accommodating” but “there were also teachers who mastered the art of singling me out” (29). Through my second essay, I am expanding upon this quote from Wagner’s book, showing how those negative educational experiences were extremely detrimental to my own educational experience. Furthermore, I am using juxtaposing my negative school experiences with my positive college experience to show the impact that proper treatment and accommodations can have on a chronically ill or disabled student. It is my hope that this essay will inform and guide educators, leading to real change and better treatment for students who need to utilize accommodations at school.

In the third essay, “Wilted,” I discuss how the medical system can exacerbate body image issues and disordered eating issues for a vulnerable audience. Women and diabetics are two groups that already have higher rates of eating disorders, and having a care team that is solely focused on weight—especially during childhood, a time where weight gain is not only expected but necessary—promotes this issue. As Marya Hornbacher writes in her memoir *Wasted: A Memoir of Anorexia and Bulimia*, “I have never been normal about my body. It has always seemed to me a strange and foreign entity. I don’t know that there was ever a time when I was not conscious of it” (Hornbacher 13). This quote encapsulates the intersection of chronic illness and disordered views about the body: there is a persistent focus on the state of one’s physical

body when they are constantly forced to be thinking about it. This idea is one that I explore throughout “Wilted”. The chronic illness community tends to have much higher rates of body image issues and disordered eating. It is my hope that this essay will not only make people reconsider the way that patients are spoken to about food and their body, but will also reach out to individuals who may be struggling with these issues in silence.

A notable theme that persisted throughout the chronic illness memoirs that I read was presence of the doctor-patient relationship. Becoming a perpetual patient is a unique experience in that it becomes a major part of one’s identity. Every moment of the day, you have no choice but to be managing a symptom or actively anticipating the arrival of the next one. In reference to this transformation, I write, “You weren’t sick, and now you are. You were a person, and now you’re a patient. Who were you before? Who are you now? Will you—could you—ever feel the same again?” (36). This concept is present in Ellen Samuels’s piece “Sick and Well Time,” featured in *Brevity Magazine*, which discusses what it’s like to live with a chronic illness. She writes, “On a good day, am I sick or am I well? [...] And if I can’t figure it out myself, how can I expect anyone else to understand?” (Samuels). This sick/healthy dichotomy—which can be confusing and difficult to process, especially soon after diagnosis—can cause the patient to feel inadequate, leading to complete faith in their doctor. I explore this concept further in the essay, saying that “I trusted [my doctor], and more importantly, I trusted her words” (45), despite how that trust was not necessarily warranted. Here, I argue that because I trusted in her care and guidance so much, I took her words as law. Therefore, when she said something negative about my body or my food intake, that doctor-patient relationship dynamic caused me to completely follow whatever she told me.

As it was previously aforementioned, disordered eating is a major issue within the diabetic community, as well as the chronic illness community in general. When an individual has a condition that is so focused on food and the body, and are also misled by the medical system and societal expectations, there can be extremely negative consequences. Unfortunately, this means that this theme is highly present within chronic illness memoirs. In Lisa Roney's memoir, *Sweet Invisible Body*, she chronicles the body image and eating issues that she faces as a result of living with type one diabetes. On this topic, she writes that "[her] goal as female and diabetic gradually turned into being the champion of restraint, of walking the fine line between too much and not enough" (Roney 116). I expand upon this idea in my own piece, writing that "Chronic illness typically demands the pursuit of genuine health—wholesome and nutritious foods, balanced exercise, hydration, and rest when needed. Being a teenage girl is a whole different beast" (43). With this passage, I am arguing that the care needs of my condition and the societal expectations of my body were often in conflict. As a diabetic teenager, I often struggled to conjoin these two expectations, which I explain in conjunction with specific anecdotes from the doctor's appointments that contributed to my negative patterns of behavior. There is often the expectation that the doctor knows best, but even the medical community makes mistakes. Medical sexism and medical ableism are two major issues that run rampant in not only my own personal experience, but also the experience of many patients. Listening to the patients who have been affected by these issues is the best way to figure out what needs to be changed and how it can be done.

In the fourth essay of this collection, "Wish Upon," I share my personal journey of learning how to accept my chronic illness and the technology that goes along with it. As evidenced by each of my essays in this collection, being diagnosed with a chronic illness changes



every single aspect of someone's life. Whether it is attributed to the inaccurate societal stigma about diabetes, or the major adjustment period after receiving an incurable diagnosis, it can be extremely difficult for someone to process how much their life has changed. On this topic, I write, "It wasn't fair that my body attacked my insulin-making cells. It wasn't fair that doctors couldn't fix it. If they could fix a shattered arm or an aching throat, why couldn't they do anything to fix a faulty pancreas?" (53). Here, I argue that accepting a chronic illness feels so impossible because of the concept that there is not a cure. As children, we hold the belief that everything can be fixed with medication and time. With a chronic illness or disability, that is not the case, and there is a struggle of trying to accept the so-called "new normal".

Struggling to accept one's diagnosis is a common theme in chronic illness memoir. This is a reoccurring theme throughout Alexandra Park's memoir, *Sugar High*. Alexandra Park is an Australian actress who was diagnosed with type one diabetes as an adult mere months before she was planning to move to Los Angeles. Due to these sudden lifestyle changes coming all at once, Alexandra struggled to accept her newfound condition. In reference to her having to inject insulin at mealtimes, she writes, "a sudden wave of depression washed over me. I was struggling to wrap my head around the fact that I would have to do this every time I ate any food for the rest of my life" (Park 29). This feeling is a common motif in the last essay of this collection. Receiving a diagnosis inevitably means that there is going to be a significant change in daily life, and with no clear end in sight, it can be easy to fall into depression or anger over the situation. Regarding my own situation, I write "I was furious, and confused, and tired. I didn't know how—or truthfully, want—to talk about any of it. Burying that heavy, indescribable exhaustion felt easier" (54). Here, I argue that I felt so many overwhelming emotions over not being able to

accept my life with diabetes that I was unable to even process any of them, and instead, internalized those feelings for a long time.

In the last essay, I argue that chronic illness is not always a negative thing. Most of the time, chronic illness and disability is portrayed through the lens of an abled audience. Stories surrounding illness are usually a narrative of unrelenting suffering or a tale of inspirational hope. Throughout this collection, but specifically in the concluding sections of the final essay, I argue that my condition has not made my life completely miserable. In Elissa Washuta's collection of essays, *My Body is a Book of Rules*, she details her journey with her mental health. Eventually, she comes to a point in her life where despite the fact that she still struggles, she has developed a deeper understanding of who she is and how her brain works. My journey with my feelings about my diabetes has followed a similar journey. I write, "Being a diabetic is inextricable with who I am as a person. I can't imagine who I'd be without it all" (59). Here, I argue that my diagnosis has not hindered who I am as a person, but rather, has shaped who I am as a person. Even though there was pain and struggle in that growth, I appreciate the person that I have grown into. Additionally, in this section, I acknowledge that "despite my love and appreciation for the way my condition has changed me, I'd still jump at the chance for a cure. I think that's understandable" (61), reasoning that acceptance and appreciation does not counteract a desire to not have diabetes. Here, I argue that life with diabetes—or chronic illness or disability—is not always either inspiring or horrific. Rather, there is a balance of moments that make us proud and moments that cause us pain.

Before I began writing the essays for this collection, I was admittedly intimidated. While I had loved my creative non-fiction workshop and was excited to tackle this project, I was uncertain in myself as I hadn't written anything of this magnitude before. I knew the basic topic

of each of the essays I wanted to write—and the stories that I wanted to feature in those essays—but I didn't know how it would all turn out. However, once I actually got started with this process, I found that sharing these stories came very naturally to me. As someone who has had diabetes for the majority of their life—about 17 years—I felt empowered by getting to share my experiences, clarify misconceptions, and reveal things that someone without diabetes would never think of.

When I finished writing the essays for this thesis project, I was extremely proud of the work I did. As it was previously mentioned, there is a considerable lack of type one diabetes essays and memoirs. Being able to add to the existing literature, provide comfort and understanding to fellow diabetics, and inform non-diabetics about the diabetic experience is an exciting prospect. Two of these essays have already been accepted for publication, and I am pursuing publication of the remaining two essays as well. Additionally, I am considering using these essays to seek admission to an MFA program. Ultimately, I feel that this collection is successful in expanding upon the diabetic experience and sharing the intricacies of living a life with chronic illness.

## Eyes Closed

I am reveling in the afterglow of a sleepover. Being fourteen comes with little freedom—except for the uncontrollable, undeniable magic of a middle school sleepover. This morning, my body wakes before I do. Eyes still closed, I feel my arms gently stretching towards the new day, moving only centimeters but releasing the tension from a night slept cramped up on a couch. My feet shift subtly, brushing against the cool leather of the cushion. The unraveled edge of a wool blanket pulled from the back of a hallway closet scratches the bottom of my chin, but I don't mind. I'm just about to open my eyes when I hear them.

He is the boy with swoopy brown hair that he's always flicking out of his eyes. He is the boy who I spend hours dissecting the newest episodes of American Horror Story with. He is the boy who I do all of my science homework over FaceTime with, both of us grumbling over the stages of mitosis and wondering why it's relevant. She is the girl with blonde hair that she always wears in a high pony-tail, accented by hot pink fabric fashioned into a headband. She dons a matching outfit with me on our middle school's twin-themed spirit day. She spends countless hours at my house, the two of us talking about everything and nothing all at the same time. She is who I call my best friend.

I hear his voice before I hear hers.

“Yeah, so Annie woke me up at like, two in the morning and was like, ‘I'm 41 and I took two glucose tablets, but I still need to eat’. And so, I got her a granola bar, and all I could hear for like, an hour was her crunching on it”, he says to her in a hushed whisper. They laugh and laugh and laugh for what feels like hours. Tears prick my still-closed eyes, and I picture them taking turns holding my heart in their hands and crushing with casual cruelty.

I think back to the night before, to when I woke up sweating and dazed. After over a decade of balancing highs and lows, I can usually predict my blood sugar like a magic act. Watch, as the Amazing Annie guesses her number; keep your eyes locked onto her, don't even blink, or else you could miss it! Look at her silent prayer as she awaits that blinking screen—will it be a perfect 110? Will it be a nauseating 350? Or perhaps, will she shock and awe her adoring audience with a dizzying 60?

But this night, diabetes played dirty, sabotaging my performance and sneaking up on me in the false sense of security that sleep brings.

With shaking hands, I reached over to my supply bag and performed my monotonous ritual—the one that has left the soft pads of my fingers peppered with clusters of miniscule scars. I load my needle into the spring loaded poker, drag an alcohol pad across my skin, and plunge the lancet into my finger, summoning up a perfect bead of blood to load into the test strip.

A few beats, and the screen flashes, a cool blue light flooding the room. “41,” it tells me. I chew two gritty purple tablets and wait, hastily hoping for the influx of sugar to reach my bloodstream and pull me out of this heavy place.

Five minutes pass, which turns into 10, which bleeds into 15. I check again, only to find that the number has barely risen. The dreaded “low anxiety”—a jarring feeling of panic—buries itself into my brain. My body roars at me in desperation while ravenous hunger tugs at me from every direction, begging me to eat something, anything, everything. Though I view my body as my enemy all too often, she shows time and time again that she will ruthlessly protect me at all costs.

I tiptoe over to my friend, and gently nudge him awake. He grumbles, still in the dreamy in-between of sleep and wake, but ultimately obliges, guiding me to the dimly lit kitchen while I incessantly apologize for trying to survive.

He goes back to sleep, and I eat my Nature Valley bar alone in the pitch black basement.

In the morning, my eyes stay closed until my friends go upstairs to eat breakfast. Once I'm certain that I'm alone, I gather my things, wordlessly pluck my insulin from the fridge, and leave while they giggle and carefully flip chocolate chip pancakes.

Gathering all my courage, I make a group chat and text them later that day. I heard you, I say, I heard you and it hurt me.

“Oh, sorry,” they respond. “That’s not how we meant it.”

In a private text, my other friend washes her hands of her involvement.

“I didn’t say anything,” she reasons. “All I did was laugh.”

I picture them both waving goodbye with perfect fingers that bear no marks.



From the moment that I was diagnosed the summer before kindergarten, I found myself existing in a category separate from my peers, feeling like my disease had labelled me as “other”. Like most other chronically ill kids, my peers lacked understanding around my condition. I find myself wondering if they inadvertently learned this behavior from their parents, who didn’t seem interested in trying to understand either.

While birthday parties were usually a source of glee and excitement for other kids, I began to dread them. I hated having to stop and check my blood every 30 minutes after swimming or jumping around in the bounce castles, knowing that the fun would always be cut short. I hated the feeling of sitting at the table while my peers gobbled down cookies and cake

and ice cream and juice boxes. I hated having to sneak away with my mom to get an insulin shot to avoid my peers' horrified looks and subsequent comments about how they could never do what I do. Eventually, I begged my mother not to make me go. It was easier to stay home—and stay alone—than to feel like an outlier. Nothing thrust my differences into the light like an elementary school birthday party.

To combat some piece of my desired isolation, my mom started packing sugar free Kool Aid Jammers in her purse to casually slide over to me when other parents inevitably had nothing for me to eat or drink. This was nothing new for her; she made it her mission to create a sense of normalcy and comfort for me when it came to social events. On Halloween, once I had trudged back to the house with a stuffed pillowcase in hand, she organized my loot, using her pink and white acrylic-tipped nails to split the pile, and then bought each piece back for 50 cents each. I can still feel her hazel eyes reflecting into mine, searching for a sign of contentment. In those little moments, she had the power to fix everything. But beyond that, no matter what my mom did for me, the voices of my peers and their parents echoed loudly.

“Ugh, sorry.” I would hear the birthday kid's parents say to my mom. “We didn't even think to buy anything for her.”



In elementary school, every moment of my day felt like it was co-opted by managing my condition. My days were marked by visits to the nurse's office—once in the morning, once before snack, once before lunch, once before going home for the day, and whenever I felt like I needed to. Every day, before my lunchtime check-in, my teacher allowed me to select a friend to take with me. I joyfully cycled between the same three or four friends in my class, relishing in

these little moments of control over the uncontrollable, until the other students in my class began to revolt.

“Why don’t we get to go?” they complained to my teacher in front of me. “If they get to go with her, we should get to go with her too.”

Just like that, it wasn’t up to me anymore. I had so little that was mine, that I could choose about my illness, and now that had been yanked out of my grasp. My disease had officially been commodified, turned into something that the abled kids in my class got to consume when they wanted to and forget about immediately after. Instead of making my pick for who I wanted to bring with me, I now had to move through my class list, each day bringing a different student to let them marvel at me like a circus act. Some kids stood close and watched in peculiar fascination of what I was doing. Others stood at the other end of the room, face wrenched up in disgust, making commentary about how vehemently they hated needles and blood and how happy they were that they didn’t have to do what I did. Regardless of their reaction, they never truly understood the importance of the moment.

“Wow,” one classmate said to me, with a mixture of disbelief and misguided jealousy. “You’re so lucky that you get to eat Skittles in here.”



By the time I was in sixth grade, I was managing the majority of my diabetes care, which came with its own set of responsibilities and freedoms. That September, my friend and I made plans to attend the annual Relay for Life event. It was the first year that we were allowed to go without parental supervision, and we were delighting in this sweet glimpse of maturity. We laced up our sneakers, sprayed on overly generous amounts of Bath and Body Works warm vanilla sugar body spray, lined our eyes with rings of smudgy black eyeliner and set off to circle the



track. We lapped the path over and over and over, talking and laughing and trying to impress the boys from our math class that we had met up with.

We had been walking for almost an hour when I began to feel it in my eyes. I usually feel it in my eyes first—sometimes, when my blood sugar drops, it feels like my eyes could free fall all the way backwards into the sockets. At first, I kept walking. I ignored my sinking eyes and the cold sweat and the feeling that the earth was rippling beneath my feet. I wanted to take my tremulous hands and grab and stretch the moment that I was existing in, making it last as long as I possibly could. This was a moment in which I had felt decidedly adult—I was no longer in elementary school, instead feeling like I was entering my own coming-of-age movie, similar to those that I had watched hundreds of times. I willed my mind to believe that that sickly feeling in my stomach came from the nerves of trying to impress a middle school crush, not from a sudden and startling lack of glucose flowing through my body.

But diabetes works on its own schedule. It didn't matter what I wanted in that moment. It doesn't matter what I want in any moment. My body rules my choices in a way that those without chronic illness don't experience. It goes far beyond temporary discomfort. If I have to stop, I have to stop. If I have to act, I have to act. It is not a choice; it is a commandment. When my blood sugar beckons, I obediently answer it's call at breakneck speed. I took a deep breath, pulled my friend to the side of the track, and asked her if we could stop walking for a moment while I checked my blood.

She sighed, still keeping her eyes on the boys as they half-heartedly lingered near us and re-tied her laces while I drew blood. Just as I expected, the number reflected how low I felt.

“Could you sit here with me while I come up?” I asked her, resting on the curb. I folded into myself completely, desperate to combat my wobbly legs and woozy head in any way I

could. It wasn't just that I didn't want to be alone—I was scared to be alone. Those lows can take away my ability to think clearly and move around, leaving me stranded.

“Well, I wanted to walk with Evan and he's starting to walk again,” she said, tilting her head over towards the boys who had in fact started to walk away, apparently deciding that our three minute respite was far too long for their liking. “I'm just going to go walk with him, okay? You're fine, right?”

She had already started to walk away before she finished her sentence. Even if she hadn't, I already knew that I wasn't going to say anything to her.

I didn't want to be a burden. This was the underbelly of diabetes that I tried to keep hidden from my friends whenever I possibly could. This wasn't like trips to the nurse that could get them out of the last five minutes of a boring social studies lecture, or extra candy packed in my bag that I could share. It wasn't packaged away neatly, unaffected their lives. So, I did what many people with chronic illness do. I cleaned up the mess myself and pushed it away from where everyone could see. I ensured that their comfort would always come before my safety. I sat resigned and alone, picking the peeling rubber edge of my sneaker and mentally kicking myself for even asking her to stay with me instead of going with them.

“Yeah,” I said, watching her move further and further out of my line of sight. “I'll be fine.”



I've spent hours living in the past, unearthing these memories, scrubbing them raw to look at them as clearly as I can, and asking myself why I put up with any of it. I think back to myself, saddled with a newfound responsibility and freshly diagnosed only two months after I turned five, wishing that I could play like everyone else. I think back to how I desperately

wanted people to understand. I think back to how I chose my own discomfort over anyone else's. I think about how I thought it was easier to be alone. I think back to the hollow feeling that I was burdening my friends and peers simply by existing.

I used to resent how my illness made me grow up so fast in comparison to my peers. I doubted that anyone would ever understand how I felt or what I go through. So instead of standing up for myself, I took the punches and forced tight smiles onto my face to mask how I was feeling. I've since learned that this is a common experience for those with chronic illness and disability. We tend to expect misunderstanding from strangers and the outside world, but furthermore, we grow to expect that we'll receive it from those we love the most.

I've heard something from almost everyone: friends, family, teachers, strangers. Some people try harder to understand than others, but it's still a disconcerting feeling, wondering if anyone will ever truly get what it feels like.

But then something happens. Sometimes, it's at the grocery store. Other times, it's at the mall. Once, it was even in the middle of a party. I see a pump proudly protruding on someone's arm, or hip, or stomach. I tilt myself towards them, showing off the egg-shaped machinery adhered to my own body. Sometimes we speak, sometimes we never say a word out loud. That isn't important—what's most important is that knowing look between us, the one that says, "I understand". We've never met, and it's likely that we'll never meet again, but there is a deep bond between us, forged by our shared experiences. I know that they've spent hours chasing highs and lows. They know the kinds of comments I've heard from people.

From an outside perspective, these moments probably seem insignificant. A stranger would simply see two people nodding and gesturing towards each other, and then moving on

with their day. But it is so much deeper than that. It is community, it is connection, it is everything.



I wake up, grab my phone off of my night table, and open my Instagram feed like usual, only to be greeted with a picture of my old middle school friend. He's cut his hair—now, it's short and spiky instead of falling right above his eyes—but I'd recognize him anywhere. He's dressed in a hospital gown, looking gray and gaunt. When I read the caption, I feel like I've been transported directly to the Twilight Zone. I scan the words over and over, begging my brain to process the words right in front of me.

“I found out I have type one diabetes,” he declares, laying out the story of the recent unexplained illness that led to his diagnosis. I open the comment section, and it's flooded with messages of encouragement and love. For a moment, bitterness swirls within me, resenting that someone who hurt me was getting the social validation around his illness that I so badly craved.

And then I remember. He has now unwillingly joined a club that no one ever imagines they'll be a part of. Eventually, he will face the same ignorance and mistreatment that I and every other chronically ill person has felt, likely from those who vow that they'll be there for him through it all. I bury my stubbornness and swallow my pride and scroll through my contacts to find his phone number.

“Hi. I know we haven't talked in a while, but I wanted to reach out,” I tell him. “Obviously I know a lot about diabetes so if you ever need anything or just want to vent to someone who gets it, I'm here for you.”

Hours pass before my screen lights up, signaling his reply.

“Annie, I completely forgot you had diabetes!” is how the message starts.

I put my phone down and close my eyes.

## Education in Absentia

I'm in the principal's office of my middle school, sitting uncomfortably in a scratchy upholstered chair that's littered with old coffee stains, waiting for my name to be called. I'm drumming my fingers against the metal arms of the chair, bouncing my leg up and down on the carpet, fidgeting with the seam of my sweatshirt. I've never had a detention. In fact, I've never done anything to warrant a detention. I keep my head down, do my work, never talk back to a teacher, and actively avoid involving myself in anything remotely risky. I don't belong here, and it's clear that I don't know how to act in this situation. Yet, in the middle of history class, a phone call came, specifically summoning me here. The only possible explanation that I can come up with is that someone is hurt, or worse, dead, and this meeting is a way to break the news to me. I catalogue my loved ones in my head: Is it Nana? Auntie? Mom? Dad? My sister?

Just as my mind begins to devolve into a downward spiral of panic, the wooden door cracks open. My vice principal, Ms. Walsh, steps into the doorway, gesturing me into her office.

I've never spoken to Ms. Walsh before, but I recognize her. She spends the lunch periods going from table to table, asking students about their classes and extracurriculars. I've often seen a flash of blonde hair and patterned fabric zipping around the cafeteria, moving with purpose, whether to make small talk or bust a student on their cellphone. She's popped into my theatre class a few times—a course that all seventh graders are required to take—but she just stands at the back of the auditorium, silently watching and overdramatically pantomiming her praise.

“Annalisa Morganelli? You can come in now,” she smiles softly at me, like this is normal, like we've had this interaction a thousand times and everything is fine. My hands are clamming up and my heart is beating so loudly that I can barely hear her speak.

As I enter her office, my vice principal sinks into her cushioned seat and methodically adjusts a stack of freshly-printed paper. She plucks a red pen from a vibrantly painted ceramic cup, draws circles around some of the text near the bottom of the first page, and then slides the sheet towards me.

“See this number?” she says, tapping her pen against the paper. “This is how many times you’ve been absent just this year. Could you explain the reason for these absences?”

My feeling of dread is instantly replaced by a heavy feeling of discomfort. Everyone is alive, but I know where this is going.

“Um, yeah, okay. I’m a type one diabetic and sometimes my blood sugars can make me feel sick which keeps me up all night,” I explain, hearing my voice crack a little as my throat goes bone-dry.

“Right,” she gives me her soft smile again, “I understand that. But there are other kids with diabetes who don’t miss nearly as much school as you do.”

I’m not quite sure how to respond to this. In an alternate universe, perhaps I have some steely grit where I stand up for myself and explain that diabetes isn’t one size fits all. Diabetes is notoriously finicky; when I was little, my mom used to explain my condition to those who had no experience with chronic illness by telling them it was like nailing Jell-O to a tree. While diabetics may experience the same broad situations, the illness is so complicated that comparison is futile. There are too many variables, too many uncontrollable factors, that can affect someone’s life.

Maybe in another universe beyond that one, I say something else that would really get me a detention. But in this universe, I concede.

“I know,” I say, mirroring that smile. “I’m sorry.”

She nods her head gently. I can tell she thinks she's done her job adequately and solved the issue by pulling this apology out of me, like I've finally atoned for the mortal sin of missing more school than she deems appropriate.

“Well, okay. We just don't want you to miss too much class, right? It's really important for you to have that in-class instructional time. So, if there's ever a day where your diabetes isn't that bad, just try to come in, okay?” Ms. Walsh tells me as she scribbles her signature onto a small green excusal slip that I am to give to my history teacher when I get back to class.

She stands and guides me back to the door. As I walk down the hall, it is not lost on me that I've missed over twenty minutes of class to be told that it is my fault for missing too much class.



By the middle of my seventh grade year, my school had not let up on my inadequate attendance. The principals continued to call me down to the office to discuss how my diabetes should not be impairing my ability to come to school. To this day, I'm not sure if they ever bothered to read my paperwork before scolding me. If they had, they would have known that I was supposed to be allowed to go to the bathroom at any time, head to the nurse's office as needed, and eat and drink in the classroom. Most importantly, they would've known that diabetes-related absences were inevitable, and should not only be excused but also accommodated. It could be that they read my file, and just decided that the doctor's words didn't matter, and they knew best about what I needed.

Interspersed between these office visits, we received threatening letters from the superintendent's office. They were clear warnings, written in absolutes: if my parents did not ensure that I didn't miss any more school, the truancy officer would be making a visit to my



house. It was stark and unforgiving—they were making it obvious that they were ready to punish me for not coming to school because of my diabetes. Worst of all, these letters implied that my parents, who always stayed up with me all night battling the fallout of a broken insulin pump, were failing me.

“Let him come,” my mom would say to comfort me when one of these routine letters made its way into our mailbox. “I’ll make him a cup of tea and we’ll have a nice talk.”

They never sent one, but I was always waiting for it to finally happen. I imagined that one day, I’d hear a heavy-handed knock reverberate through the house, and then see an officer through the glass panes of our front door. I feared that my verbal warnings would finally manifest into a physical punishment, not only for me but for my parents. I had no clue what the punishment would actually entail if it were to actually happen. Would they get a verbal warning? Maybe a fine of some sort? Or, the worst of all, was getting arrested a plausible possibility? The thought of it tied hard knots in my stomach.

While I felt beaten down into silence by these encounters, my parents maintained their status as my biggest advocates. After my second office visit that year, they called and demanded that it was time for the principal to have a meeting with them. They operated as an undefeatable team. My mom is the social butterfly, an extrovert to her very core, who can find connection with anyone that she meets. My dad is the analyst, quiet but always listening, known for making a spreadsheet for any and every situation that should arise in our lives. They invited each of my teachers—science, history, English, and math—and ensured that the nurses would be in attendance. My dad printed out copies of every piece of paperwork related to my diabetes and filed them into a crisp manila folder.

When they arrived, everyone was crammed into a semi-circle around the same wooden desk I had been sitting in front of not even a full week before.

“Mr. and Mrs. Morganelli, you have to understand that grades suffer when students miss as much school as Annalisa does,” Ms. Walsh told them, signaling a manufactured empathy through her eyes.

“Show us her grades then,” my mom challenged, already anticipating what was to come, while my dad exhibited his stoic support.

Ms. Walsh instructed my teachers to tell my parents my current grade in each of their classes. Their answers came in rapid succession.

English: A+. History: A. Science: A. Math: C+.

My parents later told me that Ms. Walsh seemed a bit flustered by this report. Apparently, she had never cared to check my grades before warning me that I would be on the verge of failing.

“But look,” she said to them. “She has a C+ in math.”

“Annie always has a C+ in math, which has nothing to do with her attendance,” my parents replied. “I think this meeting is over now.”



I’ve always fixated on academic success. In elementary school, I’d eagerly rip open my report cards before I got home, not to cover up poor grades but rather to gaze proudly at the columns of “E” for excellent. In middle and high school, I pursued excellence through numbers—anything less than a 90 felt like an abject failure. Admittedly, my downfall was math class; it was a dizzying performance of equations and variables that I could never seem to get just right. From math book problems to blood sugars to my weight to absences, numbers had a

unique tendency to rule my life. Even still, I stayed after school for extra help, got a math tutor, and spent hours sitting at the dining room table with my dad while he tried to explain how I could solve each problem. I tried, and tried, and tried.

My work often paid off. Excluding math class, I got the grades I wanted, a sweet resolution that fed my anxiety-induced perfectionism. My drive didn't go unnoticed, and I was named as student of the month during my sophomore year of high school, thanks to a glowing nomination from my favorite English teacher.

Even so, I never quite felt like a good student.

Good students didn't miss as much school as I did. Good students didn't have a pile of late slips in their locker for the times that their bodies were so exhausted that they couldn't pull themselves out of bed to get to first period. Good students weren't called down to the office to discuss how much class time they missed. Good students didn't have a hefty packet of makeup work to do after a particularly difficult week.

The acceptable definition of a "good student" was simply not compatible with my existence. I felt that any shred of success that I had was automatically undercut and erased by the days that I stayed home. The administration at my middle and high school treated attendance as the crux of all academic achievement. They refused to account for my continuous effort or the extra time that I put in to stay on top of all my work. If someone isn't able to fulfill their cookie-cutter expectations of success, even with "impressive" grades, then it must mean that they are a failure in the school system.

Upon reflection of my own experiences, I've started to think of the other students with chronic illness and disability who have been punished for their personal requirements for success. In November of 2021, a hearing and visually impaired graduate student at American

University was denied an in-person transcriber, despite the fact that her automatic transcription technology wasn't functional. Each week, she was attending two and a half hour lectures that she was not able to learn anything from. Another student at Stanford University who has POTS and chronic fatigue syndrome was left in an impossible situation when the 8,100 acre campus's golf-cart service for disabled students was no longer an option for them due to increased demand. As a result, the student was forced to miss classes in order to protect his well-being. What happens to students like them when they are told that they will never experience success like their abled peers? What happens to the students who are set up to fail from the moment they enter a school system? What truly makes a so-called "good student"; is there even such a thing?

Despite how I feel now, back then I felt that I could be chronically ill or the good student that my school system wanted. That decision had already been made for me.



My punishments extended beyond the principal's office and into the classroom. My peers couldn't seem to grasp why I wasn't there, were never taught about what was keeping me home while they were spending ample time in class. They acted like my nonattendance was an orchestrated rebellion, like I was playing an interminable game of hooky. What they failed to understand was that I wanted to be in class. On those mornings where I was still recovering from an insulin pump failure or depleted from stubborn low blood sugars, anxiety would build up in my chest until I felt like it was caving in entirely. It wasn't missing the day itself that made me feel dizzy, but rather the day after.

The day after being absent was always the worst. There was always someone who would say something about me not having been in class. Sometimes, it felt strangely comforting, like

people noticed when I was gone and were eagerly awaiting my return. Other times, it felt like I was on trial, and the jury of my peers was speaking their mind.

Once, when I returned to school after having a virus that made my blood sugars skyrocket, a casual friend greeted me when I entered the classroom. We had two or three classes a day together, and our desks were positioned adjacent together in all of them, so my absences were typically on her radar. She was someone who I considered to be a “school friend”; we could talk for hours in the halls, but we rarely communicated at all once the bell signaled that the day was over.

“Annie, you’re back,” she said to me, as more of an observation than anything else. She examined the chips in her crackle nail polish, jingled the row of Alex and Ani bracelets on her arm while she adjusted a lock of her deep brown hair, and started lightly doodling hearts and swirls in the empty margins of her agenda book. Looking back up at me intently with furrowed brows, she said, “I feel like you miss so much school. How are you ever going to make it in college?”

I don’t remember what I said back to her. Maybe it was a noncommittal shrug, or an abridged story to defend myself, or a laugh so that I could feel like what she said didn’t matter. I knew she meant no ill intent—she was someone whose parents didn’t allow her to miss school unless she had thrown up that morning. She genuinely wanted to know how someone like me could miss school more than the average person and still succeed when the stakes are raised.

Still, that question stuck with me. I hadn’t thought about college at this point, I was only a freshman in high school, but something deep within me wondered if my classmate was right. If my high school could barely accommodate my needs, how would I ever be able to be a successful college student? What if I missed too many classes and received an automatic failure?

What if a professor cold-called me, and I had missed the previous lesson, and I was ostracized in front of everyone?

My experience with my teachers up to this point in my life was vastly varied. The majority of my teachers were graciously accommodating. One of my teachers was a diabetic herself, and always understood when I had to duck away to check my blood or pop a glucose tablet into my mouth. Another teacher had a diabetic brother, and never minded when I left his class five minutes early to check my blood before lunch so that I would have enough time to eat.

But there were also teachers who mastered the art of singling me out. Towards the end of my sixth grade school year, Mrs. Smith, my biology teacher, made a highly coveted deal with my class. Mrs. Smith was a strict and traditional teacher who often mentioned to us that she was one or two years away from retirement. If you ran into class at 7:26am when the class began at 7:25am, you were marked as late without a chance for explanation. If anyone ever dared to forget their textbook in their locker, they were undoubtedly going to receive a detention. Having chewing gum was an offense of the highest degree in Mrs. Smith's eyes, and she wasn't afraid to dole out some public shaming for it. During passing periods, she stood with her arms crossed and her feet firmly planted into the ground, scanning the crowds, while other teachers chatted amongst themselves.

We knew that this deal was a once in a lifetime moment. She didn't give her reasoning for it; maybe it was a celebration for us coming to the end of our first year of middle school or maybe it was a celebration for her that she wouldn't have to deal with us anymore. Regardless, we listened intently: the deal stated that if everyone came to school tomorrow, then she would rearrange her teaching schedule and bring us a box of doughnuts on Friday in place of a lecture. The class exploded into chatter, promising that we'd all be there the next day, looking from

student to student and making each other guarantee that they'd show up. That night, I went to sleep dreaming about iridescent rainbow sprinkles and sickeningly-sweet strawberry frosting.

The next morning, I woke up and felt my stomach twist. I checked my blood and the screen signaled "HIGH", meaning that the number was somewhere over 500, too high for the meter to properly read. I checked for ketones, those vicious acids that build up when there is a serious lack of insulin in the bloodstream. They cause a laundry list of symptoms: headache, nausea, exhaustion, all-consuming thirst, and beyond. When left untreated, they cause diabetic ketoacidosis, which can cause serious complications like swelling of the brain or coma. I knew that I had them before the ten-second countdown on the loading screen had even finished.

My first thought wasn't the ever-present concern about the possibility of DKA that most diabetics have. It wasn't about my aching head, or my dry mouth, or the overwhelming wave of nausea that was washing over me. It was about the doughnuts. I was going to be the absent one; my chronic illness was the reason that the party was off. It wasn't just about me anymore, but it had instead become a collective punishment that directly was attributed to my diabetes.

That afternoon, while I sipped sugar-free Arctic Blue Gatorade and checked my blood incessantly, someone from my class posted on my Facebook wall.

"Truth is: you're nice, but you didn't come to school today. So, we don't get the doughnuts tomorrow."

It made my chest tighten, like all of the oxygen had seeped out of the room in that split second. There was nothing for me to say—it was the truth, wasn't it? I liked the post and commented back, thanking my classmate, and tacking on a smiley face at the end. At least they said I was nice.

When I made my dreaded return the following day, my teacher stood in front of the class and pulled up a PowerPoint about Gregor Mendel's genetic experiments. There were a few groans in the class as she organized her discussion notes. I tried to sink into my chair, as deep as I could, hoping that maybe I would just melt into the floor and fade away from sight.

"We didn't have perfect attendance yesterday," Mrs. Smith said to the class. I could feel the eyes around the room drilling into me. Worst of all, I noticed a prolonged glance from Mrs. Smith herself. "So today, we'll be doing the lecture that I've prepared as I originally planned."

In my memory, I was the only one who had been absent that day. But, honestly, I'm not sure if I actually was. There might've been one or two other kids who missed that day, who were also sinking into their chairs, who also had read Facebook posts on their walls over and over the night before. But my mind has erased that possibility and latched onto the idea that I was entirely to blame.



When I first entered college, the words of my old friend weighed me down like an invisible chain around my neck. I wondered if it was only a matter of time before her words rang true, if maybe my diabetes really would hold me back from thriving in my college courses. I scanned each syllabus for the attendance policy, systematically highlighting how many absences each course allowed in fluorescent yellow ink. Some professors allowed three absences, some five, and others didn't take attendance at all. Instead, it was your responsibility to make sure you were caught up and doing well in the course, whether you were physically in class or not.

My head was spinning. My friend was wrong, and so was I. College gave me a different opportunity than I had experienced previously. While middle and high school guilted me, college guided me. For most of my classes, attendance was important but not the be-all-end-all. Beyond



that, my schedule had suddenly become flexible. In high school, if I didn't feel good in the morning and needed to sleep in, I missed nearly the entire day. In college, breaks between classes allow me to rest and do what I need to do for my health while still attending. Because of this accommodation, I rarely—if ever—miss classes now. Being in college has not only allowed me to succeed, but has also given me the chance to revel in my success.

But I'm one of the lucky ones. After high school, the accommodations that work for me came along merely because of how colleges classes are structured. For other students, this structure is yet another problem. Some students may struggle with sitting in a classroom for three hour blocks. Other students may find that class time offerings regularly conflict with their necessary doctor's visits. In terms of the coronavirus pandemic, many chronically ill and disabled students who are immunocompromised have found themselves displaced at their universities as online courses are being removed as an option. As a whole, middle schools, high schools, and colleges alike continue to fail to provide adequate accommodations to their disabled students.

There are a wide range of issues that affect different students with different disabilities. In some places, ramps are dilapidated and rendered entirely useless, leaving students with wheelchairs unable to get to class. Many students have spoken up about the lack of ramps in general, rendering the campus inaccessible for them. Elsewhere, automatic door-opening buttons are out-of-order. Maybe braille is inaccurately written outside a classroom, or teachers refuse to provide large-font books, or students are not given extra test-taking time when they need it. Some students need to stim, or fidget, or move around and take breaks. Professors may disallow the use of audiobooks, or assign books that don't even have an audiobook component, meaning that the student has no way to read the book. Many students are afraid to disclose their situations

in the first place due to a palpable lack of understanding; a student at Johns Hopkins shared that her professor told her that her accommodations were unreasonable. Or, like me, students are punished for when they physical health takes precedence over physical time in the classroom. There is so much to be fixed that sometimes it feels like a Sisyphean task. Regardless of the magnitude of changes that need to occur, a school being ill-equipped to accommodate its chronically ill and disabled students is one of the greatest failures of modern academia.

Chronically ill and disabled students want—and deserve—to succeed like their fellow classmates. They want to thrive in an academic setting. They want the chance to redefine what we as a society consider “the good student”. If schools and universities start giving them the opportunity to, they will.



Over the past few months, I’ve spent a lot of time thinking about my experiences in the educational system. I’ve told my stories to my friends and family members, sometimes rehashing situations we’ve talked about a million times, and sometimes sharing a splintered memory that I hadn’t even realize had been tucked away in the corner of my mind. I watch as their faces fall, and twist, and distort, bewildered by what I’m telling them.

One of these conversations with my mom segued into a thought about my grandfather. His leg was amputated when I was only three years old—all of my conscious memories of him feature his wheelchair, his arms reaching out to greet us in the doorway, and the prosthetic leg that he rarely wore thrown somewhere in the room. I remember him visiting him in the hospital a few days after his operation, clinging to Mom’s side and pulling on Dad’s hand, and listening to him explain it to me in child-like terms, telling me not to be confused or afraid. After becoming disabled, he made the decision to involve himself in advocacy—he spent the next couple of years

fighting for disability rights. On the morning that he unexpectedly died in 2011, he was getting ready to attend a meeting to discuss accessibility for wheelchair users on city buses.

With age, I have gained a newfound appreciation for my grandfather's actions. The combination of that and my own personal experiences makes me want to fight harder for chronically ill and disabled students out in the world. I sometimes wonder if sharing my stories could help open doors to change, if perhaps I could somehow assist in making things better for the next group of kids coming through the school system.

Sometimes I feel empowered in my desire to advocate because of my experiences at school. Sometimes I'm furious that it happened, that there are so many people suffering in a place that is supposed to nurture and educate, that we even have to advocate for something so intrinsically necessary. I'm not sure of the right path to take, or how to fix such a layered issue, or if I even have the power to do so.

I just never want another kid like me to get blamed for not having doughnuts

## Wilted

Two months after I turned five years old, I had a mandated pre-kindergarten physical where my mom mentioned my recent insatiable thirst and incessant exhaustion. I had been spaced-out and not acting like my typical self in the previous weeks, so fatigued that I was sleeping in until 11 am on the days that I didn't have to wake up early for preschool. The doctor brushed it off at first—it was July, it was hot, I was spending a lot of time playing outside. My mom wasn't too worried at first either—I was going through a growth spurt, and we had just gotten a new fridge with a water dispenser that seemed to fascinate me. The doctor decided to order a basic test just to assure that I was completely fine.

Less than an hour after we arrived home, my mom's ringtone filled the room, a haunting harbinger that signaled the trajectory of the rest of my life.

"You need to bring her to the hospital now," the doctor told my mother over the phone in a tense, hushed tone, "The results came back, and she might have type one diabetes."

One of my earliest memories is sitting in my hospital bed while nurses streamed in and out of the room every hour or so, poking and prodding at my tiny uncalloused fingers. I kept thinking that each time would be the last, until yet another rosy-cheeked nurse dressed in teddy-bear themed scrubs would stroll in, needle primed in hand. I got so tired of them puncturing holes into the tops of my fingers that I locked myself in the bathroom attached to my hospital room and had to be lured out by my parents, only convinced by my mom promising that she would let me wear her clicky high heel shoes if I came out. It's a defining moment of my life, reminding me that the four years I lived without diabetes almost feel like they didn't really happen, that this has always been my identity. There has never been a "before" for me—my entire being has occurred in a state of "after". No matter the age, when you receive a diagnosis,

your life is suddenly fractured into two distinct pieces. You weren't sick, and now you are. You were a person, and now you're a patient. Who were you before? Who are you now? Will you—could you—ever feel the same again?

Not long after my hospital stay, I met her: Dr. Griffin, a short woman with light brown hair that fell to the bottom of her back. She had round glasses that she was almost constantly fidgeting with as she reviewed my chart, and was usually wearing a tan-colored cardigan, a floor length skirt, and athletic sneakers that could efficiently get her from room to room around the hospital. As I quickly learned, she was going to be my endocrinologist. An endocrinologist, they told me, is a special doctor who knows all about the pancreas. The word felt foreign in my mouth when I repeated it back. Endo-crin-ologist.

The first time I stepped into her office, my eyes were drawn to the enormous mural on the wall. Golden yellow sunflowers, slightly askew, blown over by the wind coming in from the west. The other rooms around the hospital had murals too—pirate ships and snowball fights and sinewy ballerinas twirling in place—but these sunflowers captivated me like no other.

We sat across from each other, me, sandwiched in between my parents; her, in a shiny black swivel-chair next to her computer. I felt secure tucked between them, noticing a hint of my mom's perfume in the air—the same fresh, flowery smell that she sprayed on my stuffed animals when I had a nightmare—and absentmindedly clasping and unclasping my dad's watch.

“Annie, do you want to play with my stethoscope?” she offered. I gingerly took the cold, metallic instrument from her hands. It was the ultimate gift to a five-year-old: something exclusive and special, only for the chosen few to wield. I had spent the remainder of July in a state of perpetual confusion about what was going on, but I knew that it was about me; I heard my name sprinkled throughout conversation, interjected with “autoimmune disease” and “no

cure”. But all that mattered to me was getting to hold that stethoscope, so shiny that I could see my warped reflection in the bends of the metal. While the adults discussed blood sugars and carbohydrate intake, I pressed the chestpiece against my mom’s heart, and then my dad’s, and then my own. I closed my eyes and listened to the thumping sound. Steady and constant, my concrete sign that my body was still on my side in some way.

My diagnosis was a medical mystery. Most type one diabetics are not diagnosed until they are in the throes of diabetic ketoacidosis—when their blood sugar is so high that acids have started to build up in the blood and destroy them from the inside out. In the months leading up to an eventual diagnosis, they tend to become skin and bone, seeming to be inexplicably ill, teetering on the edge of death. The normal blood sugar for a non-diabetic person is in the range of 90 to 110, sometimes gently gliding slightly upwards or downwards depending on the last time they ate. Conversely, many type one diabetics have a blood sugar of 500, 800, 1,000, or beyond at the time of diagnosis. I was the outlier: diagnosed unusually early, a picture of health except for my basic symptoms that could’ve been attributed to a multitude of reasons. After my diagnosis, my medical team made an unusual decision: I wouldn’t start insulin yet, but rather, I would live under the restraints of a strict, low-carb diet.

Eggs. Peanut butter. Vegetables. Protein. Regimented, structured, orderly.

When other kids brought in cupcakes to class for various celebrations, my teacher would solemnly walk to the cabinet, and pull out a puppy sticker or Hannah Montana themed pencil that my mom had pre-purchased for me instead. At birthday parties, while plates stacked with thick-crust pizza and fluffy white cake were gleefully passed around, I snacked on roasted almonds and sipped from tiny water bottles flavored with Crystal Light. Kids in my class looked

at me with confused wonder in their eyes, bewildered by the fact that I wasn't partaking in their joy.

“Don't you want cake? Why don't you have anything on your plate? Do you not like it? Are you going to have some?” they asked.

I sat there quietly, feeling grotesquely Martian among my peers. I never knew what to tell them when they asked; the answers to their questions were something that I barely understood myself.

A little less than a year later, I started insulin. My mom said she couldn't take it anymore; her heart ached when she saw the way I cried after I got home, wanting so desperately what I just couldn't have. Being on insulin meant that I could eat more than lean proteins and low carb snacks as long as I got a shot before. Being on insulin meant that I could have pizza, and cake, and just about everything else the other kids were having. Being on insulin meant feeling a little more normal.



I went to see Dr. Griffin every six months, like clockwork. As I got older, inevitably, so did the mural. While I sat in the pleather-cushioned chair in her office, I noticed little cracks in the paint—subtle, but undeniably present. Harsh sunlight streaming in through the open windows faded the vibrancy of the colors from golden to a dull yellow. It was markedly different than it had been, but still beautiful in a comforting way. It was like my favorite pair of sneakers; soles worn out, and laces unraveling, and canvas muddied. It was like my favorite book; pages dog-eared, and quotes underlined, and spine cracked from midnight re-readings. It was my mural.

Eventually, she stopped offering me her stethoscope. It was expected—I was twelve, free floating somewhere in the in between of childhood and the teenage years. Like most twelve-

year-olds, I was desperate to be taken seriously, to be treated with an air of cool indifference. I sat up straight in the chair, ever-so-attentive, soaking in everything she told me. She fiddled with her round glasses, crossed one leg over the other, and clasped her hands together.

“Annie,” Dr. Griffin held an unwavering gaze on me, “you gained about two pounds since the last time I saw you. It’s fine for now, but don’t gain any more weight.”

The words catapulted themselves into the air and sunk into my chest like a round of bullets. In rapid succession, I tried to cycle through everything I thought I knew about my body. I was lanky, towering above almost all of the girls in my seventh-grade classes. My blood sugars were consistently in a healthy range, only sometimes temporarily raised by hormonal changes from the oncoming tidal wave of puberty. All of my health markers were ideal. Up until this point, I had never considered my weight to be an issue—but now it had become a source of chastisement. Before that moment, my body image and my physical health lived in vastly different planes of existence. After that moment, it seemed as if the two had become inextricably linked. If I gained weight, not only was I failing to uphold an acceptable image in my head, but I was letting my doctor down. I didn’t argue, or disagree, or try to question her orders. Instead, I took her words and cradled them delicately in my hands. Who was I to think otherwise? She was the doctor; I was the patient. If she said it, it must’ve been true. It had to have been true.

“Okay,” I vowed to her, “I won’t.”

After that appointment, it was like a switch had flipped in my mind. Every time I grabbed a flimsy cardboard box to check for the carbohydrate count—precious information for a type one diabetic—I felt my eyes drift higher, higher, higher to the calorie line. I grabbed product after product from my pantry, flipping and scanning and adding. Each label felt like a punch to the gut. It was all too much, I was all too much, why didn’t I know that before she told me?



Two weeks later, I went on my first diet. I counted and counted and counted until I didn't have to count anymore. I had it all memorized.

Having an unhealthy relationship with food feels like getting out of bed the morning after a sleepless night. It's all-consuming, and maddening, and hollows you out into a shell of yourself. I was exhausted when I convinced myself that I wanted a chalky protein bar for breakfast. Counting out exactly 12 almonds to pack with my lunch drained me. Making macaroni and cheese with chickpea pasta, Greek yogurt, and reduced-fat cheese left me with dark rings under my eyes.

Eggs. Peanut butter. Vegetables. Protein. Regimented, structured, orderly.



When I think about the doctor's appointments that I went to during the peak of my disordered eating, there is a certain level of detachment that takes place. The feelings that those memories evoke are too raw, too omnipresent in the world, too much of a reminder that I couldn't protect the past versions of myself who didn't know any better. When I slide into those memories, I can feel the invisible string between my brain and my body snap, each side pulling me in a separate direction, each calling me to follow one and ignore the other. I have to consider it from a different perspective, as if I could float out of myself and watch it all from above.

Before every single endocrinology appointment starts, a nurse comes out to the waiting room and calls your name. By age 13, this procedure is second nature. She sits you down and wraps a blood pressure cuff around your arm, watching it tighten like a python entrapping its prey until the machine finally beeps and the blood rushes back into your fingertips. She tells you to take your shoes off, orders you to stand tall against the wall with your head straight, and records your height into your file. These numbers are essentially meaningless to you.

And then she makes you step on the scale. It's exactly what you've been waiting for. The scale you have at home was purchased sometime in the early 2000s, and shows the wear and tear of time. You can never be sure how accurate that scale is, so you both relish and fear the moment that you get to step onto that medical grade metallic platform. As you creep towards it, it feels like a punishment and a reward all at once.

The number always shows in kilograms. You wonder if it's because they don't want patients to know or obsess about their weight, especially since it's a children's hospital. But that's silly, you think to yourself, because googling a kilogram to pound converter is laughably easy. Besides, even if you couldn't figure it out yourself, Dr. Griffin would tell you. She always tells you.

When you type the numbers into that converter, your fingers shake with impatient, uncontrollable energy and you can feel your heart pounding against your ribcage so quickly that you almost swear you can hear it. The page loads, and as it turns out, you have finally succeeded. Your weight is lower than it was at the last appointment.

You walk into Dr. Griffin's office with a different energy today. You feel like you're bursting at the seams, eager for when you can go home and tell everyone about your accomplishment. When she confirms to you that you have lost weight, you can't stop a smile from plastering itself onto your face. She congratulates you on a job well done, and you finally feel like you've done something right, and you can ignore all of the bad feelings swimming around in your head for at least an hour.

She asks you the same questions that she always does. What are you eating? When are you eating? How many carbs are you eating? Are you exercising?

You answer each question, including even the most minute details like the good patient you are. She is pleased with your answers about food, but you admit that outside of gym class, you are not exercising.

“If you keep up the way you’re eating and add in exercise,” she angles her swivel-chair in your direction and gives you a tight-lipped smile, “the weight will just melt off.”



When I was 16 years old, I stopped looking in the mirror.

Every morning followed the same basic routine: first, I stepped into the bathroom, lights off, averted my eyes from my reflection, and brushed my teeth. Then, I walked over to my dresser, plucked out a sweatshirt that was three sizes too big so that I could cover every inch of my body, and pulled it over my head, narrowly avoiding a glance in the floor-length mirror nestled in the corner of my bedroom. I took every precaution I could to avoid seeing myself—if I didn’t see it, I could erase myself for a little longer. I wouldn’t be forced to crawl back into the corners of mind and confront the ugly thoughts that constantly looped in the background of my mind headfirst. I thought that if I could avoid the mirror, I could outrun the reality of my existence.

Finally, before I left for school, I went to the kitchen and packed my lunch for the day. I used to eat a peanut butter and jelly sandwich for lunch nearly every single day. I loved everything about it, from the seedy multigrain bread my mom always bought, to the sweetness of the (sugar-free) grape jelly, to the salty crunch of chunky peanut butter. I loved that my dad brought a peanut butter and jelly sandwich for lunch every day when he was in school, and how it felt like a longstanding tradition between the two of us. I loved the routine, the simplicity, the familiarity.

But when I was 15, I had another regularly scheduled appointment with Dr. Griffin. We sat in the same chairs, by the same table, in the same room that we had been meeting in for ten years.

“Annie,” she said to me, in that way she always did. “What do you usually have for lunch?”

To a casual listener, it sounded like an innocent question. But I knew. I had years of careful training at this point—my ears could pick up the subtle shift in the air. There was always a specific intonation in her voice before she delivered her blow, something that would make hot tears roll down my cheeks the whole forty-minute drive home.

I told her. A peanut butter and jelly sandwich, with a side of fruit, and sometimes I bring another snack if I’m hungry, but really it depends on—

“That’s too much. If you want a sandwich, you should only use one piece of bread.”

I had already stopped ordering hot chocolate on Sunday mornings when my family went to our favorite local breakfast spot. I had already stopped bringing a bag of cheddar-flavored Goldfish to school for a mid-day snack. I had already chosen an Angel Food cake on my birthday instead of the marble cake that I really wanted. The more I tried to fulfill Dr. Griffin’s wishes, the more I fed into the expectations of being a teenage girl. Being chronically ill and a young woman is a complicated dichotomy. There is a near constant erasure taking place, a war being waged on the body from all fronts. The medical system will handle the brunt of the work, reducing patients into numbers and diagnoses and paychecks. We as patients handle the rest, whittling down the rest of ourselves into nothing to appease our doctors and nurses and peers and crushes. Chronic illness typically demands the pursuit of genuine health—wholesome and nutritious foods, balanced exercise, hydration, and rest when needed. Being a teenage girl is a

whole different beast. Women—especially teenage girls—are expected to diet, to stay thin at all costs, to be in the physical prime of their lives. We are raised on hundred-calorie cookie packets and Diet Coke and Splenda. We are fed lines like “a moment on the lips, forever on the hips” and “nothing tastes as good as skinny feels” and carry them with us wherever we go. We survive on the idea that we are only our bodies and pray that we’ll receive the admiration that we are trained to desire.

No matter how hard I tried, nothing I did was enough for me to gain Dr. Griffin’s coveted stamp of approval.

I stared at the wall. The sunflowers looked more wilted than ever.



When I was 19 years old, I decided to switch endocrinologists. Quite honestly, the idea had never struck me until my mom brought it up one day in passing. My parents had come into appointments with me when they managed the majority of my diabetes care, but as I took over most of the responsibilities, I began going in alone. While they didn’t see most of my experience firsthand, they knew what Dr. Griffin was like. Before I started going to appointments alone, there had been a few occasions where Dr. Griffin had criticized my family’s decisions too. Regarding my care, she judged my parents for letting me pick what kind of insulin pump I wanted, saying that I wouldn’t make the right choice. In terms of our personal lives, she questioned why our family decided to do foster care, telling us that it simply wasn’t a good idea and that she didn’t know why we were doing it. While I struggled to stand up for myself, my mom was able to shut her down with ease. She is bold and extroverted and welcoming, able to talk to anyone and make a friend anywhere we go—but she will defend me and our family at any cost.

“We’re letting her pick because she doesn’t get a choice about having to take insulin, but we want to give her a choice about *how* she gets her insulin,” she would say, locking her hazel eyes directly onto Dr. Griffin, while her highlighted shoulder-length hair rustled around her shoulders. “And we don’t have to explain or justify our decisions.”

They knew that Dr. Griffin was blunt to a fault and number-focused in her treatment, but I don’t know if I ever properly communicated the gravity of the situation until I had begun to process it myself in adulthood. Somehow, it had never even crossed my mind that that I could permanently sever the ties between us, that I could cut the cord of a 14-year long doctor-patient relationship. For most people, it seems unfathomable that one should have a say in the doctor-patient relationship. It’s easy to get lost in the fact that the doctor has spent years and years in medical school, investing hundreds of thousands of dollars to specialize in learning how to treat whatever plagues you. We are trained to obey our doctors from the moment we are born; be a good girl for the doctor and you’ll get an extra sticker at the end. It feels natural to assume that they deserve total authority and control. The truth of the matter is that the doctor-patient power-dynamic is deeply skewed. Doctors may have spent decades studying the body, but the patient is the one who knows best about their own situation.

I’ve realized that part of my mind kept Dr. Griffin frozen in time in that special place, where she was the woman who gave me her stethoscope and let me listen to my heart. But that reality only existed for a moment in time. She was that woman, but she was also the woman who had a devastating impact on the way that I view myself. I trusted her, and more importantly, I trusted her words. I came to her new and intact, a lump of fresh clay. And she molded me, guiding me to tear off pieces of myself until I didn’t really look like me anymore. I tried so hard for so long to get it just right, but my edges were always too sharp or too rounded out. I don’t

like the version of myself that I was when I was hyper focused on getting it all right, the one who was misled and irritable and spent far too much time thinking about daily calorie allotments and whether or not I would permit myself to eat dessert.

When I made the switch, it almost felt too painless: just a five-minute phone call and a request to meet with someone else.

The older I get, the more the lines have blurred. I don't know if I would have struggled so much if Dr. Griffin never told me the things that she did. I don't know if self-hatred was bubbling within me anyway, if perhaps it was inevitable, and Dr. Griffin just helped to expedite the process. I often find myself wondering: did she realize she was cruel or was she simply just too clinical? Did she know that her words would embed themselves into my mind so deeply that I can watch them play out like a film scene? Would she care if she did know?

Some people may think I gave her words too much weight. Some people may think that a doctor's bedside manner is irrelevant as long as they are able to provide good medical care. But shouldn't good medical care include the mental well-being of a patient? If a doctor doesn't listen to their patient, or consider that their words hold a deeper impact due to that doctor-patient power dynamic, are they really providing good medical care? How many girls and women are brushed off, told that their pain is nothing, told that they're being overdramatic? Doctors not listening to their patients can have deadly outcomes; every year in the United States, there are approximately 40,000 to 80,000 deaths attributed to diagnostic errors. Furthermore, women are given less pain medications post-surgery than men despite reportedly having higher pain levels, on average spend more time in emergency room waiting rooms, and typically take longer to be diagnosed than a male counterpart. When my mom visited a new doctor to address symptoms of brain fog and fatigue after being diagnosed with an autoimmune disease of her own, he asked her

if maybe the issue was really just anxiety or depression. Does any of that sound like good medical care?

Sometimes I don't know who to blame or how to blame or even if I should blame. Instead, I have recently found myself trying to make peace with my body; she has endured misplaced blame and unjust treatment for far too long. On my worst days, I still can't stand to see her, and I can feel the 16-year-old version of myself desperately clawing her way to the surface, willing to tear flesh and shatter bones to make me listen. But on other days, I stand right in front of the mirror and look at her—really look at her. It's a peaceful moment that has stemmed from such violence, us sitting together in silence, apologizing to each other without having to even say a word.

A few weeks after I stopped seeing Dr. Griffin, I read a statistic that type one diabetics are twice as likely to struggle with disordered eating. It makes sense when you think about it, as the disease is so centered around food and control and numbers being perfect. Depression and anxiety rates are higher for type one diabetics too, which can contribute to an additional increased rate of body image issues and eating disorders. And, of course, some people are naturally predisposed to these afflictions regardless of diabetes. I've decided that the specifics don't truly matter. There are so many possible reasons that fellow diabetics would struggle with their body image that it's nearly impossible to narrow it down to a singular catalyst.

And yet I can't help but wonder if they all had a Dr. Griffin too.

My new doctor—Dr. Torres—is a tall woman with a soft accent and black hair cropped to the edge of her chin. Her office is plain, with solid-colored blue walls. I miss my sunflowers, but she has never made me cry.



## Wish Upon

Not long after I was diagnosed with diabetes, in the early months of the school year, I was invited to the sixth birthday party of a student in my kindergarten class. The details of the actual event are fuzzy in my memory, faded away into oblivion—I can't remember whose birthday it was, or where the party was held, or what happened for most of the time that I was there.

What I do remember is the party favor. It was a little clear plastic bottle filled to the brim with purple, pink, and silver glitter. The top was sealed off with a removable cork plug. The mom who planned the party went around the room giving each girl a vial of her own until we were all clasping them in our hands with the utmost reverence.

“This is magic fairy dust,” the birthday girl's mom told us in a hushed voice, like she was letting us in on the best kept secret in the world. She angled her own bottle under the light to display the radiant shimmer to her awestruck audience. “That means you can make a very special wish on it, and whatever you wish for will come true.”

This dazzled us. We were all five, or freshly six, years old. We knew magic was real: we had seen all the movies, read all the books, and heard all the stories. What was so special was that we had never had magic of our own—it had always been reserved for the princesses who needed their beast to turn back into a prince, or their pumpkin to turn into a carriage, or their mermaid tail to turn into a pair of legs. Before, magic had always been controlled by an enchantress, or a fairy godmother, or even an evil sea witch. But now magic belonged to us, tucked into the center of our smooth palms, waiting to be unleashed into the world.

I don't quite know what the other girls wished for. Maybe some of them wished for dolls, or stuffed animals, or a tea set. Maybe others wished for a trip to Six Flags, or Disneyworld, or Hawaii. Or, maybe, some of them wanted a puppy, or a pony, or a unicorn. I'll never know what

they picked, but I'd like to think that my guesses aren't too far off. The only thing I can say for certain is that I knew what I wanted my wish to be. I plucked the cork out, spilled the glitter into my hands, closed my eyes, and willed my wish to happen.

Later, when I got home from the party, I couldn't wait to show my mom and sister my new prized possession. More than that, I couldn't wait to tell them about my wish. I knew that they'd be overjoyed when they heard about it.

"Look," I rolled the bottle around in the same way the mom at the party had, making sure that they could see every gleaming particle. "Look at this. It's fairy dust. Magic fairy dust. That means that my wish will come true."

They played up their interest, pantomiming shock and awe to appease my childhood wonder.

"What did you wish for?" my sister asked me, a playful smile on her face. Undoubtedly, she was expecting that I would wish for something similar to what I think the other kids wished for. I was a Barbie doll fanatic, and always had a running list of dolls that I dreamed about owning. She was probably prepared for a rambling spiel about the Magic of Pegasus Barbie, or Fashion Fever Barbie, or Beach Girl Barbie, or...

"I wished that I wouldn't have diabetes anymore," I told her, excitedly, still rolling the bottle around and waiting for the magic to kick in at any moment.

I don't think I noticed the devastated looks on their faces at the time. I was too lost in my fantasy—or rather, what I assumed was surely soon to be my reality. I was prepared for a life of no more finger pokes, no more strict diet, no more eating peanut butter crackers even when my stomach was so full it felt like it was going to burst open because I had to stabilize my blood sugar.

When reflecting on this moment about 16 years later, my mom and my sister told me they didn't quite know what they should say to a child naively trying to make a wish. They didn't want to crush my delicate heart, to be the ones who had to rip away my childhood innocence by telling me that magic wasn't real, and not only that, but my chronic illness was very much not going to go away because I wished on cheap glitter from the craft store. But really, they had no choice.

My mom pulled me into her lap and did her best to break the news to me. Holding my hand tight in hers, she lovingly explained that the stuff in the vial was not magic fairy dust; it was just the same kind of stuff that I used when I wanted to make my artwork fancier while I was doing arts and crafts at the kitchen table. I could not wish away my type one diabetes; diabetes didn't have a cure right now, remember?

For hours I was inconsolable.



The first year after my diagnosis was a whirlwind.

Due to my age, my parents carried the brunt of the responsibility. They diligently checked my blood every few hours, measured my food into pre-determined portions that followed my low-carb food plan, and, once I finally started insulin, calculated each dosage meticulously. I can only imagine how it must have felt for them, trying to balance it all and process their own feelings about my brand-new condition at the same time. It must have kept them up all night during those early days, wondering how my life would be now that it had forever changed course, how I would manage it all on my own someday, how they would make sure they did everything right to keep me healthy. If they could have, they would have wished it all away too.

Indisputably, being diagnosed in this day and age doesn't hold the same worries that it once did. Before insulin was discovered, diabetes was a guaranteed death sentence. Now, thanks to Dr. Frederick Banting—inventor of insulin—it's usually demoted to a life sentence. Still, for diabetics and those who love them, there's always a modicum of fear brewing deep inside. It almost feels unspeakable. What if I do everything right and something goes wrong anyways? What if I can't afford my insulin someday? What if I became a statistic? The truth is that that's the reality for many diabetics. Insulin is reasonably cheap to produce—costing about three to four dollars per vial—but is sold at about 100 to 300 dollars per vial. Depending on someone's age, sex, weight, and carbohydrate intake, they may use about three or four bottles per month. As it stands right now, about one in four diabetics admit to rationing their insulin due to the profound increase in costs.

Despite the fact that I wasn't in charge of my care, I was aware of all of the changes in my life. I couldn't understand why all of this had to happen to me. Had I done something wrong? Only months ago, I had been learning about letters and numbers and the colors of the rainbow in my preschool class. Now, I had to learn about what a carbohydrate was, and what the pancreas does, and why my pancreas doesn't do it. I remember the day I went to kindergarten with a freshly-printed copy of the book "Taking Diabetes to School" tucked away in my princess backpack, waiting to explain to the other kids. I sat up at the front of the class while the teacher thumbed through the book and read aloud. I wished that I could be like the rest of them on the alphabet-themed rug, sitting with crisscrossed legs and having bodies that didn't launch an unexplained attack on itself.

Diabetes invaded my life in countless ways. Amidst the sea of my stuffed animals was now a bear named Rufus. Rufus wasn't like any other teddy bear that I had; all the others were

from Build-A-Bear, cute and shiny and decked out in overpriced tutus and headbands. Rufus was plain, covered in light brown fur, except for the square, colored patches that covered some parts of his body. There was a giant green patch that covered his belly, a red patch on each hand, and a blue patch at the top of each leg. He was made specifically to teach young diabetics to learn how to inject needles into their skin. Sometimes, to help me practice for my future, my mom would fill up my orange-tipped syringes with water, and guide me on how to carefully wipe the spot with an alcohol pad, gently pinch the skin, insert the needle (not too fast, but not too slow either), and plunge. When I played with my toys during this period in my life, half of the time I was creating rich, dramatic storylines with a slew of glamorous dolls, and the other half of the time, the lines between child and patient were imperceptibly blurred.



The second year that I had diabetes was somewhat better than the first. I continued to adjust to my new reality—as much as you possibly can adjust when you’re dealing with a lifelong autoimmune disease that you’ve developed before you’ve learned your multiplication tables. Nevertheless, I hated that feeling of being different than everyone else.

Checking my blood became more irritable than painful. I started to build up callouses on my fingertips at this point, a sign that my hands had finally started to adapt to having a needle pushed into them four or five times a day. But I didn’t like that I was the only one who had to do it. Headstrong and stubborn, I came to the decision that if I was going to have to check my blood, so was nearly everyone that stepped foot into my home. They were just going to have to do what I did.

“Can I check your blood?” I would ask, innocuously. “Please? *I* have to do it all the time.”

Unsurprisingly, most house guests were unable to deny a six-year-old with big round eyes and scars forming all over her own fingers, so even the most needle-phobic people let me do as I please. I loved it. I wasn't the outlier anymore. It felt like second prize to not having to check my blood at all, but second prize was more than enough for me in those moments.

Despite these few moments of respite, there were nights where it felt like my whole world was shattering around me. When everyone had gone to bed, I fell into a spiral of anguish and anger. I was only one in my whole family with diabetes. I was the only person in my class with diabetes. It wasn't fair that I got it. It wasn't fair that my body attacked my insulin-making cells. It wasn't fair that doctors couldn't fix it. If they could fix a shattered arm or an aching throat, why couldn't they do anything to fix a faulty pancreas? None of it was okay, none of it was going to be okay, none of it would ever be okay.

On one particularly difficult night, I got out of bed and walked over to my white wicker bookshelf—the one that was stacked so tightly with books that it looked like it was going to crumble to the ground at any moment. I reached into the middle shelf, sliding over copies of Junie B. Jones books, and pulled out a sea-shell shaped notepad. I had gotten the notebook at the Dollar Store the week before and I thought it was the most beautiful thing I had ever seen. The shell was a cool purple shade, and the ridges were filled in with a blue glitter. I thought that it would be perfect to doodle in, or write songs in, or design extravagant dresses in. But on this night, it had one express purpose.

With the seashell notepad in one hand and a pink glitter gel pen in the other, I crawled back into my bed, pulled the sheets up, and leaned against the white metal bedframe. Uncapping the pen, I flipped the book open to the first page and started writing.

*I hate diabetes. I don't want diabetes. Why do I have diabetes?*

After I finished filling each page with huge, heavy-handed writing, I would rip the page out, fold it up as many times as I possibly could, and then throw it down into the space between the bed and the wall. Burnout tends to be inevitable when it comes to chronic illness—there is never a single moment in which you get to stop and take a break. I didn't know how to handle those big feelings when I was only a year into having diabetes. I was furious, and confused, and tired. I didn't know how—or truthfully, want—to talk about any of it. Burying that heavy, indescribable exhaustion felt easier. So, I wrote and ripped and tossed until the notebook was completely empty.



By the time that I was entering my third year with diabetes, I went from insulin shots to an insulin pump. The decision was life changing; the pump calculated boluses on its own, only had to be changed every three days, and gave me more freedom in my diabetes care. I wasn't reliant on my mom or dad to inject me; instead, I could type the number of carbs I was consuming into my controller, press a button, and get my insulin painlessly.

The only issue was that my Omnipod, the insulin pump I chose, looked enormous in my eyes. In reality, the dimensions of the Omnipod are 1.53 inches by 2.05 inches by 0.57 inches. It's egg-shaped, an opaque white color, and tubeless. That's why I chose it—the other pumps had so much tubing hanging out the side, just waiting to be caught on a doorhandle or, worse, noticed by a peer. The pod attaches to just about anywhere you want on your body, provided that there is a bit of fat. Lean tissue is acceptable, but can lead to an occlusion in the cannula. Most people follow my bear Rufus's lead, sticking their pump to their arms, thighs, or stomach.

When I first got my Omnipod, I stuck it to my hip area, just below my back. I could conceal it there, pull my shirt down to hide the protrusion so that no one would be able to ask me

about it. The Omnipod website suggests that the site of insertion should be rotated to promote insulin absorption. I kept it there from the time that I got my first pod to the time that I turned 17. I cared far more about keeping my pod as concealed as possible than I did about maintaining the efficacy of the system. I had to have the insulin, I had to have the pump to get the insulin, but I didn't have to let anyone see it happen.

Eventually, I decided that it was time to move my site. I was entirely motivated by the state of my skin; it was constantly being broken down by the pod's harsh adhesive and slathered in Aquaphor to revive it. The thought of putting my pod on my stomach was a non-starter. What if I wanted to wear a tight shirt? Everyone would see the outline. My legs weren't factored into the equation either. Though that adhesive was more than sufficient in breaking my skin into an angry, itchy, red mess, there were plenty of times that it ripped right off. I could just imagine falling asleep, rolling over too hard, and feeling the harsh pull of the cannula—the little tube that pumped insulin into my body—out of my skin. My only other option was to put it on my arm. So, I tried to ignore the fact that shorts-sleeve weather was rapidly approaching, peeled the sticker off the pod, glued it to the back of my arm, and clicked the button. It was on.

About two weeks later, I was standing in the auditorium during choir class. The day had been perfect as far as high school days go—the air was balmy and sweet, the kind of weather that makes you want to sit outside and breathe it all in. It was last period, the day finally ending after hours of analyzing novels, balancing chemical equations, and trying—but usually failing—to figure out what “x” equaled. I was wearing a t-shirt, something I had bought at the bookstore of a college I had visited, fresh off the high of the possibility of the future. While I looked over a sheet of music, absentmindedly trying to figure out the harmony, I felt a tap against my pod. Not my arm, not my shoulder, not my hand. My pod.



“So, sorry, you totally don’t have to answer if you don’t want,” a freshman asked me.

“But what’s that thing on your arm?”

It took me a second to gather myself. I didn’t know this freshman at all—we had never spoken beyond introductions and pleasantries. What right did this stranger have to touch my pod like that? What right did he have to ask me that question? And most of all, why is it always my job to teach people anything about diabetes when Google is so readily available? But still, I knew he was harmless, albeit clueless. And as much as I hated feeling spotlighted about my diabetes, I hated ignorance more. So, I swallowed my pride and gave him the answer he wanted.

“It’s an insulin pump,” I told him with the biggest smile that I could possibly muster on my face. If this exchange was uncomfortable for me, I wasn’t going to let it show. “I’m a type one diabetic.”

When he heard those words, his face paled. He backed up slightly, increasing the distance between us, and incoherently muttered an apology.

“Oh, no, I’m so sorry, I’m sorry I asked, sorry, sorry, sorry,” he rambled, and I kept smiling that big uncomfortable smile.

“It’s fine. It’s really fine,” I assured him.

On my drive home that day, I reviewed the exchange in my head. If he was going to ask, why did he have to make me feel so hollow when I answered? How was it fair that someone I didn’t know at all could confirm my fear—that people were weirded out or disgusted or afraid—and then move on with their day like it was nothing? I resented the power that he—that other people—had over me and how I felt about myself. I had always felt like that, like I had to wear the right clothes and say the right things and style my hair the right way. I wasn’t perfect, rather far from it, but I wanted nothing more than to blend into the crowd seamlessly. A cruel comment

about my shirt was crushing, but fixable. I could toss the old shirt, buy a new one, wear it like the first one had never existed. A vicious whisper about my eyebrows was humiliating, but easily resolvable. I could trim, pluck, shape, perfect. An isolating comment about my diabetes was the ultimate devastation. No matter what I wore, no matter what I did, there was nothing I could do to fix that but wish in vain.



If you ask any type one diabetic, there is a roughly 100 percent guarantee that they will have heard at least one of the following lines:

1. But you're not fat, how do you have diabetes?
2. Did you get it from eating too much sugar?
3. I could *never* do what you do.
4. Should you be eating that?
5. My grandma/grandpa/cousin/neighbor/dog has diabetes, too.
6. My grandma/grandpa/cousin/neighbor/dog lost their foot because of diabetes.

Navigating the world's views about diabetes can feel like a fruitless effort. While there are plenty of people who are willing to invest time and effort into learning about diabetes, there are people who will never understand my reality, who will never care enough to inform themselves, who will unwittingly make me feel like "other" in less than a minute after disclosing that I have diabetes. Those comments used to tear me apart when I heard them back in elementary, middle, and high school, knowing that those people would always see my diabetes, and therefore me, through a warped lens.

I've thought about my identity a lot in the past few years. For a long time, I would avoid saying that I had diabetes unless it was absolutely necessary. I was as subtle as I could possibly

be around people I didn't know well, checking my blood under tables and burying my pod under layers of clothes and trying my hardest to laugh at diabetes jokes when they inevitably arose in conversation. I didn't want to be a diabetic, and as hard as I wished things would change, that wouldn't happen. My parents did a great job in making sure that I knew diabetes was not the only thing about me. They reminded me that I was kind, and smart, and brave, and funny. They told me that having diabetes did not define me—yes, I have diabetes, but I also have brown hair and brown eyes and a beauty mark on my left cheek. They instilled in me that I was a person with diabetes, not a diabetic. I'm immensely grateful for their guidance, and in some ways, they were right. I am kind and smart and brave and funny. My hair is brown, my eyes are brown, and I do have a mole—sorry, Mom, a beauty mark—on my left cheek. But I am a diabetic.

There's plenty of discourse surrounding person-first language versus identity-first language. Person-first centers on the fact that a person is a person first, while identity-first centers on the diagnosis. Advocates of person-first language want to reiterate that someone is more than their condition while advocates of identity-first language feel that their diagnosis being a major part of their identity is not an inherently negative thing. There are multilayered benefits and drawbacks to both, and ultimately, there is not one right answer. It all comes down to each individual's personal preference.

In the early 2000s—when I was diagnosed—person-first language was the standard and identity-first language was considered offensive. My parents followed suit and raised me with a preference for person-first. They did this with the best possible intentions. The general consensus in this time was that using person-first language would maintain a level of individualism outside of the condition. The idea was that saying that someone was a person before they were their condition would hopefully help to remove unfair and inaccurate stereotypes. My mom and dad

always wanted me to know that having diabetes wouldn't stop me from doing anything I wanted to do in my life, so only using person-first language to refer to me made complete sense to them.

As I've gotten older, I've come to my own understanding about the matter. Though I tend to use terms interchangeably, I gravitate more towards identity-first language. For as long as I can possibly remember, stretching back as far as I possibly can in my own mind, I have been a diabetic. The idea of a life without checking my blood and changing my pod and balancing the highs and the lows is entirely unfathomable to me. Through every vital moment of my life, every first day of school, every discovery of a new dream, I have been a diabetic. Being a diabetic has entirely shaped who I am as a person. Diabetes has made me responsible. Diabetes has made me thoughtful. Diabetes has made me insightful. Diabetes has made me empathetic, and mature, and passionate. It has opened my eyes to injustice in the world—like insulin being the sixth most expensive liquid in the world—and given me the drive to want to address that injustice. Being a diabetic is inextricable with who I am as a person. I can't imagine who I'd be without it all.

When I catch a glimpse in the mirror and see the pod hanging onto my arm, it reminds me of everything that I've become. Who would I be today if I didn't live through all the long nights awake, all the doctor's visits, all the misguided comments, all the beautiful moments of connection and understanding? How would I move through this world if I hadn't spent those nights tucked in the middle of my parents' bed, both of them rubbing small circles on my back, while I cried and cried and cried about how it just wasn't fair? Would I be where I am today if I didn't feel those moments of bursting pride when a friend knows exactly what my blood sugar is supposed to be?

I think that even if my diabetes was cured, I'll always be a diabetic.



When I was in college, 14 years after I was diagnosed, I was going through the giant Rubbermaid boxes full of stuff from my old room that are stored in our garage. I moved twice in two years, and packed away most of my childhood belongings as fast as I possibly could, trying to work efficiently to get it all over with. Most of the things in those boxes were stored in the attic at my old house, and I hadn't seen them in a quite a while, so when I got to rustle through them again, I was thrilled. One of the gigantic boxes is filled with my old childhood books, most of which I had gleefully purchased at the Scholastic Book Fair or at Borders bookstore with my dad. Another box is filled with toys and dolls. There are an exorbitant number of Barbies and Bratz dolls, all dressed in mismatched patterns or gowns that I fashioned out of fancy paper napkins and colored rubber bands. Yet another box sitting in the corner of the garage, placed right underneath the windows, is filled with random decorations that had been in my room throughout the years. There is a decorative beaded pillow, 3D movie theater glasses, and the gray boombox that my sister gave me when she got her first iPod so that I could play my Taylor Swift CDs. I shuffle through the boxes, pulling out item after item, thinking about how these things that seemed so insignificant now had been so vital to my life.

That's when I come across a wooden box. Most people would see it as quite unremarkable; the finish is starting to deteriorate, the color is faded, and it is undeniably simple looking. But I know how special this box is the very moment I see it. When I was five, maybe before I was diagnosed or maybe after, I decided that this box would be the keeper of all of my dearest possessions.

When I open the box, its contents are unsurprisingly useless to my adult self. The entire inside of the box is filled with breakable plastic rings that I won at the arcade, one half of a set of silver friendship necklaces, Lilo and Stitch temporary tattoos, and a fuzzy koala keychain. And

there, nestled right in the center, is a little clear plastic bottle filled to the brim with purple, pink, and silver glitter. It looks just as magical as the day I got it.

I don't make a wish on it this time. I know better now. Magic is kept within the movies, and books, and stories. Maybe that's what makes it so magical, that its exclusive to these little worlds that we get to slip in and out of through the power of words. The real world is too big and harsh and cold to have that magic. We need to have magic out of reach, something to hope for, something to escape to when our fingers hurt, and our skin is broken down, and we can't stop wishing we had a different body.

Besides, I don't know exactly what wish I would make nowadays. I could always ask for a new phone or a European getaway or world peace. Maybe I'd ask for insulin monopolies to be taken down so insulin would be affordable. Or, yes, maybe I'd ask for diabetes to not exist at all. Despite my love and appreciation for the way my condition has changed me, I'd still jump at the chance for a cure. I think that's understandable. It's a running inside joke between diabetics that the cure is five years away, but I stay cautiously optimistic that one of these next five years will make that joke obsolete.

Until then, I know that this is my life. It's been far from easy, but over the past few years, I've learned more than I could've ever imagined. I've learned to accept my scarred fingers and my broken down skin and my mostly useless pancreas. I've learned to wear my pod with pride, for all to see. I've learned to answer (or deflect, if needed) questions, both ignorant and well-intentioned. I've learned to develop a deeply beautiful acceptance and—as some may argue—a morbid appreciation for my disease. I've learned that I should surround myself with people who love and support me—and therefore my diabetes. I've learned that my self-worth can't be defined by other people's words.

Those boxes are still sitting in my garage. If I wanted to, I could go outside, pull the door up and secure it in place, and step inside that room. I could feel the hard concrete under my feet, and open the windows to let a little air in, and listen to the hum of the freezer. I could dig through box after box to find that glitter again. I could dump the whole bottle into my hands and wish and wish and wish. I know it wouldn't work, but maybe it would feel right—close some sort of loop that I opened on the first day that I got it and made my first wish. Like I said, I've learned a lot of lessons since that day I first got that glitter. Most importantly, I've learned that learning these lessons is sometimes incredibly painful, but it's also incredibly worthwhile.

I only wish I could've done it sooner.