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A Change in Perspective

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I remember sitting on the couch, breathing in medicine through a mask strapped to my face. The mask was shaped like a fish (to make it more appealing to children, I suppose), and made of a clear, rubbery material. The edges of the mask were rough and scarred where I used to chew on them when no one was looking. Every morning, this was my routine.

On the end table beside me rested my compressor, which rumbled and growled like some sort of monster. A clear tube attached the mask to the compressor.

Beside me was an enormous white box, upon which were pixelated green screen and various buttons. I wore a vibrating vest which was connected to this box by two dark blue tubes, which pumped air into it. Sometimes the tubes popped out of it, and my mother had to push them back in.

The reason for those strange machines? I have Cystic Fibrosis, which is a genetic disease that causes there to be thick mucus in my lungs, which can make it difficult to breathe. The shaking of my vest and the medicine I breathe in help to loosen the mucus so it can be coughed up.

Because of the mucus, bacteria are incredibly dangerous to people with Cystic Fibrosis. Illnesses that would otherwise only mildly inconvenience a regular person can put someone with CF in the hospital.

The only time I was hospitalized was when I was very young.

I remember seeing the IV in my arm. I remember sitting in the hospital bed and playing with my toys. I remember putting stickers on the windows. I remember crying because I would have to get shots in my fingers. And I don't remember anything else, which I am thankful for.

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One day—about two years after my hospitalization—I was sitting at the table with my friend. We were talking and laughing, as young children do, while my mom made lunch for us. My mom placed a bowl of applesauce in front of me. Sprinkled on top were tiny white beads which contained some sort of medicine. I would later learn that they were called enzymes.

As I was eating my applesauce, I noticed my mom putting applesauce in a bowl for my friend, too. I stared in surprise and confusion as my friend began eating it. Hers did not have any of the little white beads that mine did. Why was she eating applesauce, then? Wasn't the whole point of applesauce to take medicine?

I asked my mom about this odd occurrence. She explained that applesauce was just like any other food, and that anyone could eat it whenever they wanted. It took a while for me to wrap my head around this new revelation.

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My mother is a very kind woman, gentle but strong at the same time. She is extremely protective of me; when I was a baby, she hardly ever let me leave the house out of fear that I would get sick, but by the time I was 5, she had started taking me to museums and historical sites all the time.

She was—and still is—an extreme germophobe. She always carries hand sanitizer everywhere she goes. At restaurants she disinfects the table before letting any of us touch it. Whenever anyone comes over to our house, she makes them immediately wash their hands.

To her, touching your face is a crime; I cannot count the number of times she has pulled my hand away, squirted hand sanitizer onto my palm, and instructed me sternly not to scratch my nose.

In public, she often draws me aside, leans in close, and whispers in my ear: "You see that boy in the blue shirt? He has a cough. Stay away from him."

This is especially true at the annual CF walk.

My first walk was when I was five. In the car, my mom explained to me that we were walking to help find a

cure for CF. I understood that well enough; from a young age, I have known that I was different, and that I have to take medicines other children do not need.

Cystic Fibrosis didn't bother me; at most, my therapy and medication were a mild inconvenience. But I was excited for this mystical cure anyway. I was intrigued by the possibility of not needing to do therapy and take medicines anymore. My parents said the cure would be here soon, so by the time we arrived at the walk, I was ready to jump out of my car seat and help cure CF.

The first thing we did was get our special CF shirts; mine was a bright yellow-green, while my parents wore white shirts with the quote "I stride until CF stands for Cure Found."

The whole time we were there, my mom constantly pointed out the other people with CF, all wearing the same green shirt that I wore. People with CF are supposed to stay six feet apart, because it is possible for us to share bacteria, so we are given special shirts to wear at walks so we stand out. Everyone else—the friends and families of the CF people—are the ones that get white shirts.

Despite my mother's warnings, I wanted to talk to someone with CF. I had never spoken to anyone like me, but my mom insisted that I couldn't go anywhere near anyone in a green shirt, so I stood at the edge of the crowd in between my parents.

We spent most of our time at the walk in a large, grassy area, dotted with trees and paths. Music played from loudspeakers, and banners with white, blue, and yellow hung from trees and poked out of the ground. There were hundreds of people there; most had never met each other, and yet all were united under a single cause.

The atmosphere was hopeful and light, and I wanted more than anything to feel like I belonged with this group of like-minded people, but my mom was constantly pulling me away from other people in green shirts and pushing me towards areas where there weren't as many people.

Then, when it was time to start the walk, my mom took my hand and led me down the path. We were at the back of the group; about a hundred people were ahead of us, most of them in white, some in yellow-green.

I did not fully understand what a fundraiser was at the time, nor did I know anything about "raising awareness," so I, being young, assumed that the walk would be like a scavenger hunt; we would collect different plants and grasses to give to the scientists so they could use them to create the cure for CF. As we walked past neatly trimmed trees and tall, brick buildings and ornate street lamps, I often paused to pick up sticks and leaves and anything else I found on the ground. I was convinced that dandelions were the key to curing CF, so I picked any that I saw.

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I was only partially truthful when I said that Cystic Fibrosis did not bother me. It is true that I have never been annoyed by my mountains of medicines, nor have I ever resented my therapy the way some children do.

However, there I one aspect that I do not like: the doctor's appointments.

CF children don't get normal check-ups; instead, every three months, I get to spend three hours (or more) at a specialized clinic, sitting on an examination table in a small, windowless room, lit by ghastly fluorescent lights.

All those rooms look basically the same, no matter where you are; regular, white hospital tiles, a desk in one corner, a couple of chairs, a sink, a rack with various pieces of equipment, a grey box with a biohazard symbol where needles can be disposed of, and charts and signs on the walls. It all gets old pretty quick.

At any CF clinic, there is always a whole team of doctors, dedicated to helping children with my condition. One at a time, these doctors will come in, poke and prod at me with their instruments, ask questions, instruct my mom on whatever new treatment they have come up with, and then leave.

The hospital I remember the best was the one in Hawaii. It was a large building, made of pale pink stone, which sat up on the side of a mountain and towered over Honolulu like a medieval castle. You could hardly go anywhere without driving past it, and when you arrived at or left the island by plane, it was always there to greet you.

The parking lot was huge, perhaps larger than the actual building. And yet, my mother and I always spent about ten minutes or more prowling the lot for a parking space and inevitably having to park halfway down the mountain from the hospital. Then began the great uphill trek to the building itself, which didn't ever seem to get any closer.

Despite my annoyance with my quarterly appointments, I liked all the doctors and nurses at that hospital. Once I got to the examination room, I always began looking forward to talking to them. I remember their names and faces with much more clarity than any of my other doctors.

Hours later when the appointment was over, we would have to trek back down the mountain and try to find our car again. My mom and I once got stranded in that parking lot for twenty minutes because she forgot where we had parked.

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about it too much. CF can be treated, and, despite how tedious the doctors' appointments can be, I am thankful for the doctors dedicated to helping people with Cystic Fibrosis.

I no longer wore my fish mask; instead, I had a mouthpiece which I held in my teeth. I could swallow my enzyme pills whole, instead of having them opened up and poured in applesauce. I took more medicine now, too. One was a sweet tasting pill that melted upon my tongue. Another I had to chew up. I always thought it tasted wrong, sweet like honey, but with the bitter, unnatural flavor of something fabricated in a lab. Still, in a few years, I had gotten used to it.

I feel like I should write more about those years. I could talk about when I got a new "cordless vest," which had a small battery pack and could be worn around the house. I could mention the time when my parents and I were at some event, and I refused to approach the man selling cotton candy because he wore a yellow-green shirt—a color I associated with my condition. I could even tell of the many new medicines I got over the years.

But those stories aren't all that interesting; to me, they were just parts of life, of growing up with a unique condition. For me, they were nothing out of the ordinary.

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But then, at the airport, of all places, my perception of myself was twisted and changed forever.

I was twelve. I was sitting in the waiting area, near one of the gates. Dark, rough carpet lay beneath my feet. All around me were chairs, white walls, wide windows looking out onto the runway, and little shops selling cheap novels and stuffed toys. I was alone with my thoughts; my parents and brother were elsewhere.

Sitting on a table next to me was my compressor, which growled loudly just like it always did. Mist from my mouthpiece clouded around my face. My breathing sounded strange.

It felt odd to do therapy in public. Normally, I did it in my own home, sitting on the couch, surrounded by walls and things I knew well. The airport was unfamiliar; the seats were uncomfortable; the room was too large. I didn't see many people around.

As I stared at the fluorescent lights and seas of chairs, a couple with a stroller came and sat down across from me. The man and woman exchanged a few words, then the man walked off. The strange woman and I sat across from each other.

For just a fraction of a second, the woman and I looked at each other. I remember her clearly; her dark, straight hair, her pale face, the way her hand rested upon the edge of the stroller.

She gave me a small smile. It wasn't a normal smile; it was tight lipped and didn't quite reach her eyes. In her face I saw an odd mix of confusion and pity. She looked as if she knew everything, but at the same time, nothing at all.

And, in that moment, my point of view shifted as I saw myself through her eyes: A strange thing, having to rely on medicines and strange treatments to function. I was an anomaly to be gawked at, with my rumbling compressor and my mouthpiece and the mist clouding around my face. I wanted to tear myself away from the stranger's perspective. I wanted to fall back into the safe little bubble I had lived in for twelve years, but it seemed that my bubble wasn't so safe anymore.

I looked away awkwardly. I shifted back into my own head, but the stranger's perspective did not disappear. It lingered in the back of my brain, a dark stain on my perception of normalcy.

We were trying a bit too hard not to look at each other, this woman and I. She didn't know how to act around me; I could tell by the way she stared pointedly to her right. I wondered what she was thinking; did she know what was wrong with me? Was she worried my roaring compressor would disturb her child? It was clear my presence made her uncomfortable, but in what way?

I pressed myself against the seat, made myself smaller, as if by doing so I could turn invisible. *This is fine*, I told myself, clinging desperately to my own biased sense of normalcy. This was *perfectly* normal. I wasn't doing anything wrong, so why did this woman make me feel like I was?

I finished my therapy. My mom came back. Everything returned to the way it was before—almost.

We ate, discussed plans, and moved on, as if nothing had happened. But that moment, when the stranger and I made eye contact, would be forever burned into my brain. Even now, two years later, I can picture her face clearly.

I wonder if she remembers me. I wonder if she sometimes pauses what she's doing and thinks about that child at the airport, with those strange machines and mist-clouded face. I wonder if she is different, too.

I wonder if I changed her the way she changed me.