Rendered visible

It wasn't always this way. If I was the object of others' staring in the past, I could assume it was because of my 6-foot stature, so rare for a woman, people in the street would tell me. Once, in high school, I was swimming at a local community pool in Maui during spring break, trying to get back in shape for swim season in the wake of a hospitalization. A photographer there asked if he could use a photo of me swimming for a fitness magazine. I chuckled, noting the irony, but still taking my healthy appearance for granted, assuming it would last as long as I did.

For so long, while cystic fibrosis took its toll on my lungs, my pancreas, my bones, my liver, my intestines, and my stomach, the illness was invisible. It was so invisible that I could have written pieces on the difficulty of trying to get disability accommodations while looking perfectly healthy, the frustrating process of making the severity of my disease known to the skeptics on the other side of the negotiation. Those skeptics were the people who would ensure that I got through school without failing out for excessive absences and tardies; they were the people who would let me board early on airplanes, but rarely without a disapproving glare; they were the people who could either grant me the ability to work without compromising my health, or deny it.

Though having an invisible illness presents its own unique set of challenges, now, I pine for the days when I could still walk down the street and blend in. I pine for the days when I could choose to hide my disease if it was convenient.

Now that my disease is visible, it creates walls between me and those around me. The IV pumps in my purse connected via long plastic tubing to the medi-port in my right chest are an instant spectacle. The nasal cannula connected to my oxygen tank, oxygenating my blood in ways my own body can't, is another spectacle. In short, wherever I go, I am a spectacle, and it's tiresome.

The night of the 2016 presidential election, I went to an election party thrown by one of my best friends. There were about thirty people there, packed tight into a San Francisco apartment. People stand on their feet at these types of things; that is so hard for me, these days, even with oxygen. I meet people and I see the way their eyes jump from nasal cannula to oxygen tank to medi-port to IV tubing, the way pity swells inside of them as they realize that this is my life. I know many are wondering – does she have cancer?

There are other signs, less obvious than the equipment to which I'm tethered, perhaps noticeable only to a keen eye. The subtle thoracic kyphosis, which worsens by the year. The edema in my ankles, a sign of mild heart failure. My disproportionately large ribcage and upper torso compared to my chicken legs and noodle arms. Clubbing, common in CF, characterized by curved and bulbous fingertips and toes. My pale skin, a trademark of the iron-deficiency anemia my

doctors are too afraid to treat because iron can feed the infection in my lungs. My labored breathing, so loud it can't possibly be ignored. My periodic winces, from pleuritic chest pain or stomach cramps or migraines. The dark brown staining around my teeth, a result of the enamel being destroyed from months of frequent vomiting. The bald patches on my head, which only became noticeable after I'd become anemic and malnourished. Blue nails, deprived of oxygen. The blank look in my eyes when I can't follow a conversation because of the THC pills I have to take for appetite stimulation and nausea. The coughing spells that often hit when I laugh, which are painful and sometimes lead me to avoid laughter altogether.

Soon, I may have to undergo a procedure to place a GJ-tube (gastro-jejunal feeding tube). This is a tube that bypasses the stomach and feeds liquid nutrition directly into the small intestine, ideal for patients with a lot of nausea and vomiting. I can't eat enough to keep up with my body's nutritional requirements. It will be yet another piece of medical equipment, surgically implanted into my body, just like my medi-port. It will help save my life, but it's yet another way my previously invisible illness is rendered visible.

All of these identifiers are walls that separate me from meaningful interaction with the people around me. People do not know what to say. I don't blame them; I wouldn't either, were the roles reversed.

I pine for the days before those walls existed. I pine for the days before I had to tug my leash around, the 25-foot tubing connecting me to my home oxygen machine. I pine for the days when I could play a beach volleyball match, and people would just assume I had a cough or a cold. I pine for the days when I could swim, surf, hike, even just *sit* there, *comfortably*. I pine for my invisible illness, now that it has turned visible.