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The Weight of Every Breath

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** Trigger Warning: This piece discusses chronic illness, medical trauma, hospitalization, and death.**

Emily – Final Journal Entry - 1980

I've never lived through an earthquake, but sometimes it feels like one keeps rumbling inside my chest, shaking loose every breath I try to hold on to. If you told me there was a monster in my chest, trying desperately to get out, I would believe you. The way this monster tries to forcefully claw its way out, I swear I can feel it tearing through the walls of my ribs. I cough as though a wave is crashing into me, with such force that it takes my breath away... literally.

My friends visit me sometimes here, but I miss my house. I miss when Eloise came over to my pink room – my clothes in my closet, my books on the shelves, the smell of home. Now I am in a room with no pink walls, my clothes with me but never quite where they should be, and my books piled on the floor. In fact, I hate that my clothes and books are starting to smell like this place, like antiseptic cleaning products. I mean, I am grateful that Eloise comes to visit me. She always comes with the latest drama at school. Who likes who, who fought with whom... But I can't help thinking about how it feels like my body is fighting against itself. When that thought hits me, I start to zone out while she goes on about the lame fights my classmates are having.

One day, Eloise even brought the prom dress she bought because I needed to see it on her. Oh, she looked lovely. Do you know what else was lovely? The blueberry pie she brought me – A.K.A the best thing to ever exist. I am pretty sureeveryone here knows how much I love pies. Actually, I am 100% sure. Whenever the nurses bake a pie after their shifts, they always bring me at least one slice. Dr. Aamir always tells me about his wife's fantastic blueberry pie... but I told him I will be the judge of what is "fantastic." He has yet to let me try it. I cannot hold it against him.

How can I hold anything against the man who works so hard to keep me alive?

In school, I was horrible at science. Now I think I know about some concepts in more detail than my science teacher. I do not think my science teacher knows about cystic fibrosis, mist tents, and postural drainage to the depth in which I know it. I remember explaining everything to Eloise for the first time. She couldn't wrap her head around it - how I was born with cystic fibrosis (CF), a disease that seriously affects my lungs and digestive system. I had to explain to her the importance of mucus.

How mucus helps keep things clean and working right, just like oil does for an engine. However, for people like me, living with CF, their mucus is very sticky and thick. This causes my lungs to clog up, making me cough until it feels like my body's begging for just one easy breath. Oh, the cherry on top? It is also much easier for me to get chest infections. All that said, I need treatment. I go through these mist tents, which can be best imagined as a little tent that fills up with cool, wet air, like a super gentle fog. People who have cystic fibrosis sometimes use them to help make the mucus (the sticky stuff in your lungs) thinner and easier to cough up. The other treatment I am very familiar with is postural drainage. This is where I lie in different positions, so that gravity helps move the mucus in my lungs to places where it is easier to cough out.

Recently, my parents have had many private conversations with Dr. Aamir. I mean, they always have private conversations, but recently it has been more than usual. It definitely has to do with the fact that I have been feeling much worse. Even when I am sitting still, I cannot catch my breath. My ribs ache like never before, and I taste blood whenever I cough. I know something is severely wrong when my blueberry pie does not sound appetizing anymore.

Dr. Aamir comes into my room a lot more as well. He says some extra fancy words to the nurses, and I can usually recognize the fancy words, but not so many recently. Dr. Aamir has been looking sadder recently as well. Does he hate me now or something? He always used to make funny jokes and usually had a smile on his face.

One thing that has always grounded me has been reading and writing. So, although my mom, dad, and doctor look extra sad, I still look forward to writing and reading

my antiseptic-smelling books. I need to ignore their looks and focus on the next breath, the next chapter I read, and the next word I write. Better yet, I want to occupy my thoughts with what dress I will wear to prom in a few months.

Dr. Aamir – First Journal Entry - 1995

I still remember the first patient I was assigned to as an attending. In fact, I remember it in excruciating detail. Mostly because there weren't many facts available to me.

I think about that little girl who went through so much. Now I only wish she had come into the hospital now... not 15 years ago. Not when I did not know much.

In 1989, a team of brilliant scientists in Toronto discovered the faulty Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) protein. This breakthrough helped us understand cystic fibrosis at its most basic level. From 1989 and onwards, doctors all over the world gradually learned more and more about the disease.

I remember explaining it all to Emily's parents a few months ago. I felt it was only right to share with Emily's parents what we know currently - how CFTR works, why the mucus appears thicker in CF patients, and how modern treatments can change the course of the disease. It's the knowledge I wish I had the first time I met them.

I tried to explain it as clearly as possible without overwhelming them. I told them how a tiny error in our DNA disrupts the CFTR protein. I described CFTR as a door - a door that lets salt and water move in and out. In people with CF, that door is broken, so salt and water cannot move properly. Without the right balance of these components, the mucus in the lungs becomes horribly sticky. But it's not just the lungs; mucus in the pancreas and intestines also becomes thick and sticky.

When I put myself into Emily's parents' shoes, I can hardly imagine their frustration. I would have thought to myself, *Why in the world is mucus the cause of my daughter's death?*

I explained that mucus is normally helpful, as it traps germs and waste, but when it's too sticky, the body can't clear it properly. In addition to this, I also explained how our lungs have these tiny hairs, called cilia, which normally sweeps mucus out, but when the mucus is too thick, the cilia cannot do their job properly. When this thick mucus just sits on top of these tiny hairs our lungs have, they block the airway and trap germs, causing infections.

Now I am here, starting a journal because the patient I could not save, due to the lack of knowledge I had, enters my mind once in a while.
Standing here at Emily's grave, I feel the weight of all the things I could not change. Of what I did not know prior to 1989. At the same time, however, I am reminded of all the progress that has been made. Every discovery, not just the discoveries made about CF, but all evil diseases, brings us one step closer to helping millions of children like her.

My bag feels heavy, as I know it contains my wife's blueberry pie - the one Emily always wanted to try. As I set it down on her gravestone, I can't help but think of every new discovery since then, and every small step forward.

Edited By: Noor Arora