

Arrogance can lead to an unexpected amount of pain

I was an extremely sick baby. I was constantly throwing up, underweight, and I was unable to receive the nutrients I needed. My parents did not know what they could do to help me and what could possibly be wrong with me. When I turned two years old, my parents could no longer stand seeing me constantly sick and took me in for routine testing. Shortly after the tests my parents received a call and were told that my diagnosis was celiac disease. They were prepared to tackle this health issue and finally understood what was causing my sickness. A few days later they received another phone call from the same doctor saying that on top of the celiac disease I also have a chronic lung disease, cystic fibrosis. This turned my life and my parents' life in a completely different direction. My parents were filled with different emotions and introduced to unexplored territory. They were not properly told the extent of my illness and how to treat me. They had to learn about everything that comes along with this life-changing diagnosis.

My parents learned how to treat me and worked to give me the healthiest life possible. Before I was old enough for the medicine, I take now they would pat me on the back and break up the excessive mucus forming on my lungs. They did everything in their power to make sure I was in the best health I could be in. I was relatively healthy throughout my entire childhood and regularly active. Compared to my peers with CF, I was above average in my PFT's (Pulmonary function test). I was able to go about my life the way I wanted and was able to play multiple sports. Being active helped with my lung capacity and improved my condition.

I remember when I was eleven years old, my PFT's suddenly dropped. I was not feeling well for a few weeks. I did not like feeling like I was not a healthy person, I always wanted to be in my best health. Since I grew up in a tiny town with limited doctors, I had to travel an hour to see my regular physician that specialized in cystic fibrosis. I was taken to the doctor and my state of health meant I needed to be hospitalized. Little did I know this hospital stay would change my outlook on doctors for a long time. This hospital stay is not something I enjoy talking about and it is a very depressing story. My PFT's were identified to be a lot lower than normal because of some bacteria in my lungs. They were not sure what it could be from, but my doctor's assumption was some body of water. My doctor's course of action to cure the bacteria was to administer Bactrim. My mother protested this treatment plan since I had previously had an allergic reaction to this antibiotic. The doctors disregarded my mother's wishes and gave me the medicine anyway. Very soon after I took the Bactrim, I sat up in my hospital bed. My body needed to throw up the poison it was fed. I spent the entire night awake and my body trembled. I was exhausted, in pain and kept vomiting all over.

I sat in that cold hospital bed, receiving the same medicine repeatedly that caused my body agony. My mother asked the doctors to give me a different medication, she knew the Bactrim was what caused me this unnecessary pain. My doctors believed my body was just trying to reject the medicine because it was something new, and the problem was not because I was

allergic. I was administered another dosage and the same thing happened. I had come into the hospital feeling sick and now I was in worse health than before. I was throwing up nonstop, the smell of stomach bile filled the room. Each member of my family pleaded with doctors to find a different solution. They knew how I normally acted towards new medicine, and this was not a normal reaction for me. The doctors continued to preach that they knew what was best. The doctors decided they were going to put the Bactrim through my PICC line, directly into my blood stream. The PICC line was a way for me to get the medicine into my body without being able to throw it up. I was not sure if this was going to work but these were the doctors I trusted so I thought they were doing everything to help me. That night I woke up in a cold sweat, my body was itchy, but it felt like the itchiness was underneath the skin. I am miserable, I had a headache, everything hurt. At this point I felt like I was on the brink of death. I was bawling my eyes out telling my mother how scared I was and telling her how I thought I was going to die. Seeing the distraught look on my mother's face hurt me even more, I knew how badly she wished she could help. I just wanted the pain to stop, any way possible. I was laying there in a bland hospital room in polarizing pain. I remember my mom leaving my bedside to have a conversation with my main physician. As I sat there, I could hear my mother sharing some harsh words and opinions with my doctors. She clearly let them know how upset she was with my care and explained how she was not afraid to sue. Everyone in my family showed their discontent with my care and voiced their opinions to my doctors. For five days I was at the point where the only peace I would get would come with death. I was fearful and weak, never moving from the isolated room. After what felt like an eternity my doctors realized this was ineffective and took my mother's threats to heart. Finally, I was administered a different medicine that allowed me to start getting better. I was no longer a weak little eleven-year-old boy. I started to feel stronger and regained my hope for life. I had enough strength back to crawl out of my hospital bed and got to see some new scenery with my brother's assistance. I played video games in my hospital room and felt as close to normal as I could. My health improved and I was at a point where I could be discharged. My bacterial infection that should have been treated in three days became a twelve-day stay. My PFT's increased but they were not at the level they used to be.

The whole hospital experience left a bitter taste in my mouth. The feeling of being ignored repeatedly changed how I viewed my doctor for a good amount of time. I still have a lot of respect for that doctor but will always be confused why he would not listen to me or my family. After many years have passed, I still feel a great amount of sadness with this medical situation. It affected me greatly, since the doctors acted with extreme arrogance. I am currently living a healthy life and have above average PFT's. I am able to participate in college sports and continue to improve my lungs by running. The experience taught me how important it is to not just listen to doctors when you know something is harming you. I know that advocating for myself can save me from an abundance of pain. If I am ever put into a situation like this again, I will think back to how careless some people can be without understanding all the information.