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## Segmented life of CF

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Anna Novak

### Segmented life of CF

1. I was born with a chronic illness, Cystic Fibrosis. I was diagnosed when I was about three and a half months old. It was on my eldest sister's birthday when my parents got the call from the doctors telling them the test results of my sweat test. My mother said I slept through the night at a week old, and after a week of that, I woke up coughing. A horrible, croup-sounding cough. It was even hard for me to play on the floor without coughing. I was taken to our family doctor and he recommended a sweat test for CF. Patients with CF have a higher salt concentration in their sweat. Mine was high.
2. My parents had to do hand bronchial drainage (BD) treatments on me three times a day. I would do a nebulizer for fifteen minutes beforehand, while watching television, or reading a book. When the neb was finished, my mom or dad would get a receiving blanket to lay on me and would start the treatment. It consisted of literally cupping their hands and pounding on my chest, back, and sides in order to loosen up mucus in my lungs. The treatments lasted about a half hour, with six positions at five minutes each. I remember my dad being the one to do it more than my mom.
3. This was my quality time with Dad. Having 8 siblings at the time, until the next four came along, our parents didn't exactly have a lot of time for each of us individually, especially because they both worked. During my treatments I got to know my dad. We watched television and movies together, sometimes watching what he chose, but other times I got to pick. And during Lent my family didn't watch television, so instead Dad and I would listen to music. I got to know my dad in a different way than my siblings did as we shared movies, TV shows, and music we enjoyed.

4. I most remember time spent with my mom at the doctor's office as she took me to most of my appointments. We bonded in the waiting room and in the office as we waited to see the doctor. We played hangman on the chalk board, or she would watch me as I climbed the giant elephant in the playroom. Sometimes she would read stories to me, or I would draw a picture for her. My favorite days were when we stopped at McDonalds on the way home. I always ordered the same thing when we stopped- chicken nuggets and drink. I remember my mom getting a hamburger and Dr Pepper, every time.
5. I missed more school than most kids, mainly because of frequent doctor appointments. I always wished for the perfect attendance award, but I knew it would never be awarded to me. Looking back, I wonder if the administration thought it odd that I was absent for a doctor appointment every month. It took me a few years until I realized they had me on file, and knew of my sickness.
6. At age five I remember my parents were granted a relief from doing hand BDs, and I got a vest machine. This machine did the work of hand BDs, and was invented by a doctor at the University of Minnesota—the place I go for my appointments. I remember two people coming to my house and bringing this machine upstairs. It was bigger than I was, and super heavy. This was a new and exciting thing for me. Even though I was excited to be getting this giant machine, I acted like any other child at that age and bounced around not sitting and listen to them talk. It was a really good thing my parents were there because they heard all the instructions and were the ones who set me up every time I needed a treatment, which is three to four times a day. As I grew older, I learned how to program the machine and work it so I was able to administer the treatment myself.

7. At age twelve I was admitted to the hospital for the first time. Most patients with CF are hospitalized long before this, and are typically put in once a year in order to get a more focused, structured, and stronger dose of medicines and treatments to help fight off infections. I had been feeling very sick, and my weight was down. My mom had taken me and my five year old brother, who also has CF, to a regular checkup appointment. When my doctor, Dr. Warwick told me he wanted to admit me to the hospital, I started to cry. I was angry, and scared, and disappointed. I missed going to my church's annual Food Fast that year, and it was the first time I was old enough to attend. My mom, brother, and I walked over to the hospital, which is connected by tunnels to the U of M Medical Center. After checking in at admissions, we went upstairs to find my room and unit. I was still upset, and my brother asked me why I was crying. He didn't exactly understand what was going on. Mom tried her best to explain to him as I just sat on the bed feeling sorry for myself. Eventually, a nurse came in and helped settle paper work and to welcome me to the floor. This was not the last time I would be here, by any means.
8. The first hospitalization took place in March. The next one happened a few months later, in August; this one was even scarier. No matter how much I ate or how heavily loaded my food was with calories, keeping weight on and gaining weight was always a challenge. This is typical in patients with CF, but not ideal. Dr. Warwick finally told me I needed a feeding tube. Many CF patients have a feeding tube at some point in their life to help them put on weight. I was scared. I was freaked out beyond anything. I do not know why. I needed surgery to have it inserted, so maybe at first that was what I was afraid of. Looking back, I see no reason to have feared it. Instead, I see why I should have wanted it, and welcomed it. I remember waking up from surgery though, strapped to a bed, with a

tube in my nose to help me breathe. Strapping me to the bed was to prevent me from waking up and trying to pull the tube out. However, waking up and being unable to move my arms scared me and I began to cry. I tried to call out for my mom, only my throat was dry and scratchy, and the tube went into my lungs so that did not help. The nurses understood what I wanted, and they went to get my parents who were waiting for me to wake up from the anesthetic. I was sore for weeks after, and doing a vest treatment was so painful. I knew I was getting better with it when I finished my first cross country running race a month after the surgery. To me, this was such a big accomplishment. Finishing this race meant that I was adjusting to my feeding tube, but also that my lungs were in pretty good shape to allow me to run two and half miles.

9. I weighed myself at least once a week, and loved to see the number go up. It didn't rise very quickly, but by eighth grade I was steady in the 90's every time I got on the scale. Until one night when I stepped on and the scale flashed "103" and I squealed. I stepped off, and then back on again, double checking that it was measuring correctly. It was, as it read 103 again. I ran to my parents' room and knocked on the door. I told them I had finally broke 100 pounds, with obvious excitement. They seemed amused at my joy, and told me that by tomorrow I could be back under 100, as one weighs the most at night. I didn't care though, and I got on the phone and called my best friend to tell her the news. This was a huge milestone for me, and the first sign I could have success in my unhealthy life of CF.
10. I was also diagnosed with diabetes in sixth grade, which was another weight to add on my shoulders. "CF Related Diabetes" the doctors called it, but after a few years, they've decided it is closer to type I. I have been taking insulin since that diagnosis, starting with

injections multiple times a day. I need insulin to keep my blood sugars stable throughout the day, but also I need extra insulin every time I eat, or my numbers will get really high, which is bad. When I was first diagnosed, this still took a backseat to taking care of my CF, and the endocrine doctors didn't explain much to me, believing I didn't need to monitor my diabetes too closely yet.

11. However, by doing this they failed to tell me that when I get sick, like with a cold or flu, my blood sugars will go up, and sky rocket, shooting so high it is dangerous, especially if they stay high for a long period of time. The summer after seventh grade I got the flu, and spent two days in bed or throwing up, drinking only Sprite and eating bits of toast and crackers. I was losing weight so quickly, and because of that I was always cold, even though it was July. Thank goodness for scheduled checkups, though, as I had one for the third day I was sick. I was too tired to walk, so I was put into a wheelchair. I couldn't even muster energy to feel emotion after my doctor took one look at me and placed an emergency call to the hospital to admit me right away. I ended up in the intensive care unit (ICU), where an IV was inserted in my hand and a blood sugar test was run. My blood sugar was so high it was unreadable. I didn't even have the energy to be scared or worried. I spent the next day and a half on an insulin drip to bring my blood sugars back down. As soon as I was well enough to listen, my doctors came in to explain that I was what they call "DKA", which means that because my body has a lack of insulin it is unable to use sugar, and instead it breaks down fat which causes blood to become acidic, and starts to make my organs not function properly. They explained that when I get sick I need to take extra care of my diabetes because my blood sugars can get out of hand. To

drive their point home they told me if I had waited even a few more hours I might not have made it out of that DKA state and I would have died.

12. I spent holidays in the hospital, too, which was quite dismal. Thanksgiving one year, the Fourth of July another year. I have not yet spent my birthday or Christmas in the hospital, and I hope it never comes to that. The hospital always does things to try to cheer patients up around holidays. They have different coloring pages for the kids, visitors such as Santa or football players, and events for families and patients to attend if they are feeling well enough. I was seventeen when I spent the Fourth of July in the hospital, my mom and I made a day of it. She came up around lunch time, carrying a balloon bouquet of holiday-themed balloons. She had swimming goggles, a beach ball, a swimming inflatable shaped like a fish, bubbles, and Fourth of July cups. We bought two bottles of lemonade, regular for her and pink for me, and walked down to the river. There we poured our lemonade into our cups and drank it while sitting in the sun and blowing bubbles, occasionally dipping our feet in the water. After being there for a half hour we needed to head back to my room for a medicine and treatment. We turned on the television and found a marathon of “Jaws” on, which we proceeded to watch. That night we got to join other patients on the top floor and watch fireworks. I was able to see thirteen different cities at once. It was not the most ideal way to spend a holiday, but it was memorable.

13. I never had a “normal” teenage lifestyle. I didn’t go to sleepovers at other girls’ houses, and I rarely had friends spend the night at my house. I didn’t want people know just how different I was from them, and how much work it took to keep myself even a fraction as healthy as they were. My closest friends knew I had CF, and most people knew there was

something going on because of my frequent trips to the nurse, and my prolonged absences at school when I ended up getting hospitalized. Very few of my friends have remained the same through my life. Only two people from my elementary years are still my friends today. High school and middle school was a time to explore who I was, a time for everyone to do so. Friends changed from year to year. I had a group of close friends in high school, but still felt different and high maintenance because of my CF, so I didn't hang out much outside of school. There was a lot I needed to do to stay healthy anyway, and I didn't have much time for hanging out. I was always unsure of who I could trust to tell my secret to because I wasn't sure of how a person would react. No one has ever come out rejected me, or said they are afraid to catch my sickness (even though it is genetic, and not contagious), but I have always had the fear that it could happen. Even if they don't have that outlook, most people don't know what CF is, what it entails, or what it means in terms of me. I don't like to explain, though, again for fear of a lack of understanding and/or rejection. Having friends was difficult because of this, and having a romantic relationship seemed completely out of the question until I met my friend, JC, who was intrigued by CF and genetics in general. He did not treat me differently and came to care a lot about me, and eventually became my boyfriend.

14. In high school I started to see a gradual decrease in lung function- or rather, a bouncing of ups and downs. I was admitted to the hospital a few more times, once or twice a year, and as senior year loomed ahead of me, I wasn't sure how I could survive going to college. Taking medicines and doing treatments three times a day was a hassle, and hard to remember all the time, even with my parents' constant reminder. I worked at it though, even if I was never a perfect patient. I sent off my application to my one and only college



choice- and got in, early acceptance. I was so excited. My parents saw no reason for me not to go, and my doctors said it was doable as well, so my college plans were underway. I knew it was going to be a struggle, but it was a new chapter in my life- one I was eager to begin.

15. In college I experienced more freedom than ever before. I also experienced more responsibility. It was totally up to me now to keep my health in check. I had doctor appointments every time my school had a break, and sometimes when we didn't, I had to miss class. But I was doing it- attending college full time. Throughout my life I never thought I would get to this point. My doctors always talked about how it is hard, and many CF patients take a year or two off, or don't go to college at all. I also always had a fear that death would occur before college, and when I reached this point, I celebrated the fact that I reached yet another milestone in this journey. It was rough going, but I worked hard to keep myself healthy.

16. It didn't always work, no matter how diligent I was about doing treatments and taking medicines. Sometimes my body would get run down, and I needed a break- a short hospital stay to help boost my health back up. Sophomore year of college was different though, and I caught pneumonia twice. Pneumonia is hard on people who don't have CF, but with it, pneumonia is more deadly than normal. I had been lucky to not have caught it until now. My brother caught it when he was little- really little. I remember his lung collapsed because of it, and I was so scared. I recalled that incident as soon as the doctors told me I had pneumonia, and I felt panic rising in me. The doctors assured me it was caught at a pretty early stage, as there were no traces of it in my blood. I spent a week and half in the hospital getting IV medicines and plenty of rest. I returned to college classes

for three days before heading back for a follow up visit. I mentioned to my doctor a pain I had been having in my side. She had an x-ray done and determined there was fluid in my lungs, which was not good. I ended up back in the hospital. By the end of the week I had a procedure done to try to extract the fluid, but to no avail; the substance was too gel-like to be sucked up with their needles. The little bit they did extract tested negatively of all cultures. My doctors were stumped.

17. Meanwhile, I felt worse and worse every day. It got harder to eat as my appetite decreased, and it was much, much harder to breath. By Wednesday I was on full-time oxygen use to help boost my O<sub>2</sub> stats which were low. By Thursday, November 11, 2010 my doctors had come to a conclusion- I needed a lung transplant.
18. This news was delivered to me with my mom and social worker present. The doctors told me they wanted to start the evaluation process for it, and then they told me they would give me time to digest the information. As soon as they left the room I broke into full body sobs, collapsing into my mom's supporting arms, which have always been there for me, and were there now when I needed them most. The doctors had told me this was happening a lot sooner than they expected, as I was barely 20, and often it wasn't considered or needed until 25, at least. I was to go home that weekend for my sister's wedding and return on Monday to begin the process. I would go home with oxygen tanks to get me through the weekend. I told my mom and dad that I did not want any of my family to know about the lung transplant until after the wedding. They asked if I wanted to tell my boyfriend; I wasn't sure yet.
19. By the time I got home that evening, I knew I couldn't keep this secret from him, and decided I would tell him and him only before the wedding. I asked my parents to be with

me when I told him. Friday afternoon he drove to my house from college. I asked him to come into my parents' room so we could talk. I looked at him, and then at my parents, and then back at him and I knew I couldn't get the words out. I started to cry, hard. My mom came over and put her arms around me as she told him the news. He was shocked but supportive. He held my hand, stroked my hair, and told me he was there for me. He told my parents he wanted to be there when this happened, and he would see if he could take a few days off of classes for a family emergency. I could tell they felt a little surprised by how composed he was, and I myself marveled at his love for me. This didn't even seem to faze him as he took it in stride. Later he told me that it surprised him, and shocked him, and he struggled with the idea just as much as I had. It was just as hard on him as it was on me. It didn't stop him, however, from proposing to me the next day. Telling my siblings was a little easier than telling JC, because I knew they didn't have the option to back out from our relationship; they were family, and would be always.

20. I returned to the hospital on Monday feeling happier and more energetic than the week before. It showed in my testing, too. X-rays revealed that the fluid or gel was gone, with no explanation. I was not using oxygen all the time, only when I slept or had been walking around. My appetite was getting better, too. The doctors were completely baffled, and didn't know what to make of it. They conferred some more and decided I did not need a lung transplant at this time, but would still like to start the evaluation process, just in case something like this happened again and it was needed. In order to keep from a sudden relapse, it was determined I would take the rest of the semester off from school and return for spring semester.

21. In 2011, I celebrated my 21<sup>st</sup> birthday, an age I was sure I would never reach. I never had a drop of alcohol before that day, because it is so dangerous for me health-wise. Even now I am very careful with any consumption. I want to live to double this age. Getting here has been a journey, tough and a lot of hard work, but I made it. I am still making it. This is my life through my eyes of Cystic Fibrosis. It is by no means the only struggle I have faced in my lifetime, but they are some of the most significant ones. I am working hard, and fighting for a life worth living.