Joanna Conroy

Cystic Fibrosis

I have always tried to live a semi-normal life, despite having cystic fibrosis (CF). I was diagnosed with it as a child. In 1976 when I was born, my parents had not even heard of the condition yet, but it soon became as much a part of their lives as it did mine, especially when my younger sister Noelle was born a year later. She was diagnosed with CF first, as she had health issues that necessitated frequent hospital visits. After she was diagnosed, it became clear that the asthma and food allergies my parents thought I had were symptoms of CF.

I felt very isolated from my peers growing up. It was difficult to fit in when most kids had never heard of CF. I distinctly remember always trying to explain my coughing to others and feeling embarrassed by it. The saving grace was that my sister was going through it, as well – so we had each

other. We also have two other siblings (who do not have CF), so Noelle and I never felt truly alone, at least when we were home. We would share a room when we were at the hospital together for what my family would call “tune ups.” At certain times, it was even fun because we would get to meet other kids who shared the same condition, and it became a bonding experience for us all.

Then we got older. We entered our teen years, which can be a challenging time for anyone, let alone when you have CF. Classmates would get annoyed with my coughing, kids would laugh or tease me, in their ignorance. It took a huge toll on me emotionally and impacted far more than just my health. It was hard on my family too, as my other brother and sister who do not have CF felt like my parents were granting my sister and me special treatment. It was difficult for my parents to be protective of us, without seeming to show favoritism.

Sadly, when Noelle was just 18 years old, she passed away from CF. She was waiting for a lung transplant that did not come in time. That was a very dark time for our family. We were all devastated, and I felt like I had lost the one person who truly understood what I was going through. Since her passing, I have tried to live my life as she would have, doing the things I love and not letting this disease prevent me from living my life to the fullest. It has not always been easy, though. In my thirties, I really struggled with balancing daily demands of work with being a mother and wife, and

a good CF patient. I recall once being asked to leave a spin cycling class because I was coughing too much. Those old feelings of shame and embarrassment from my youth came rushing back. I was so embarrassed and mad that I started to cry. My husband told me I should have explained my problem to the instructor, but there are times in my life where I just do not have the fight in me.

My family and friends have been an immense support for me through the years. I have a good group of friends with CF, and we stay in touch by phone and text messages. I also have a good friend who lives close by who also has CF, as does her sister. Just having that listening ear who understands the challenges you are facing can go a long way to providing the support you need to deal with health issues.

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Recently, things have gotten much better for me physically and, therefore, mentally. In November of 2019, I started a new medication that means I no longer need IV antibiotic therapy and my lung function has gone from 58 percent to 75 percent. This has given me a new lease on life as these days I barely cough. I still produce some phlegm, but not as much as before, which has enabled me to finally live a "normal life." The impact that this has had on my emotional state cannot be overstated – for the first time in my life I look to the future with anticipation. Retirement was something I never would have dreamed of before. Now, it's something that I am actively planning for and looking forward to enjoying.

Cystic Fibrosis (CF)

Cystic fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. While there is no cure, life expectancy has steadily improved in the United States. Some other facts about cystic fibrosis are:

- There are now more adults than children with CF in the United States.
- Newborn screening for CF done on blood samples can identify most children before one month of age, which allows for early treatment and disease monitoring.
- CF individuals have abnormally thick mucus, which blocks the airways (obstruction) and leads to repeated infections and damaging inflammation in the lungs. Treatments are directed at trying to prevent.

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