



Niraj Patel

Cystic Fibrosis

My journey with cystic fibrosis began with a persistent cough that plagued me throughout childhood. By the time I was 12, I had developed a severe cough that disrupted not just my life at home but also my interactions at school. Teachers were often forced to move me to the hallway during tests because my coughing proved a distraction. Other students did not want to befriend me for fear of contagion.

I was one of those kids who sat at the back of the cafeteria, off to the corner, with just a few friends – only those willing to endure my fits of coughing. Adolescence is already a self-conscious age; my coughing made it doubly so. It was an emotional stressor as much as a physical burden; drawing unwanted attention to me, leading me to miss classes, and causing me to avoid social situations entirely.

During a family visit to the United Kingdom when I was 14, my symptoms worsened with the appearance of blood in my sputum. The sight of it was frightening and led to a rushed trip to the emergency room. I was admitted and isolated, and after a series of tests and scans, I was diagnosed with bronchiectasis and then CF.

For my parents, the diagnosis was not a relief but a call to action. Together with my doctors they implemented a strict treatment regimen, which was a daunting prospect for me as a teenager. I wanted greater freedom and to spread my wings, yet I was told that I would have to be put on a demanding routine of frequent chest physiotherapy and multiple medications. I struggled to cope with all of this as what I longed for most was to be normal.



This emotional turmoil led me to poor decision-making throughout early 20s. I would let treatments slide, drink alcohol, and party knowing full well there would be consequences but choosing instead to do things I thought would make me happy. What I did not realize then was that happiness is inextricably linked to good health. After years of self-neglect, I landed back in the hospital with a severe infection that left me gasping for air. My lung functioning was so low that I was on the verge of a lung transplant.

Laying there in the hospital, I felt 14 again – unable to breathe well, uncertain of the future, and anxious about what was to come. Even worse was the realization that I had done this to myself. Fortunately, the doctors were aware of my condition and able to quickly offer me targeted treatments that led to a fast resolution. I was lucky and I would never take my health for granted again.

It took hitting rock bottom to really help me turn my life around. During that time, I remember thinking a lot about my family, who were impacted almost as much as I was by CF. My parents shouldered a lot of stress having to care for me throughout my adolescence and early adulthood, grappling with the disease as best they could, while putting up with me when I was not as cooperative as I should have been.



Recognizing their efforts really helped me get out of the emotional funk I was in that was causing me to behave so self-destructively as an adult. Better health led me to start thinking about my future. I pulled myself together, got a degree, and landed a well-paying job. I worked my way up the corporate ladder and today am in a much better place than I was several years ago – physically, financially, and most importantly, emotionally.

I also started going to therapy after that second hospital stay, and that has singularly been the best decision I've ever made. It enabled me to see patterns of behavior that weren't serving me well and to connect the dots between physical health and emotional well-being. I recommend it to anyone with a respiratory illness who has ever

experienced what I have felt, as part of a holistic approach to treatment. I hope sharing my story will be a source of inspiration to others, emphasizing both the importance of early diagnosis and the need to bring attention to the emotional and mental health aspects of cystic fibrosis.

As a 32-year-old professional who today is thriving despite having CF, I am grateful for every breath I take. It is a gift made possible by the relentless efforts of the American Thoracic Society, researchers, and medical practitioners everywhere. Thank you. ●

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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