

PATIENT STORIES

From Patient J.A., transplanted in 2015: *At the time of your call, pre-transplant physical preparation ends and all your hard work will now be put to full use. Upon awakening, your new life awaits, impatiently hurrying you to your first walk – no oxygen – still groggy from the operation. You will quickly adjust to your new drug regimen and heed your brain’s demand that you get up and move – how far doesn’t matter. You may suffer episodes of rejection but you will get through them. For my physical health, the lung transplant team watched over my new lung, keen on identifying and treating quickly rejection or infection at the earliest signs. For my psychological health, I found a lung transplantation Facebook page with lung transplant warriors from around the world eager to share their experiences addressing every imaginable rejection issue. You will find comfort and wisdom in these postings. At first you will measure physical progress in days but in time you will stop short at the thought of how normal your life has now become. The three legs of the stool I now stand upon will forever evoke in my heart deep and genuine gratitude for my donor, my wife and caregiver and my transplant team.*

From patient B.S., transplanted in 2014: *I received my lung transplant for Cystic Fibrosis in 2014, at the age of 27. It was not an easy decision. In fact, I was completely shocked and angry when my doctor brought up the idea. I had become so used to my routine of being hospitalized every few months for an infection, getting treated, and feeling better for a short period of time before ending up back in the hospital. I thought this was how my life was going to be. I was used to this, and I was very afraid of having a transplant. Looking back, I know that this was the best thing to ever happen to me. I was able to marry the love of my life and adopt a cat together; I have my own house. I am able to travel. I have not one, but two fulfilling jobs that I love. I even workout, and enjoy it! Getting a transplant has been like getting a second chance at life. A chance to do all the things that I dreamt about but was never able to because my health held me back. Before transplant I felt like I was living for my lungs, and now I feel like my lungs are living for me.*

From patient K.S., transplanted in 2016: *The day that every little girl dreams about, the day that I thought I would never see being diagnosed with Cystic Fibrosis at 4 years old, but after my double lung transplant in 2016 that little girls dream became a reality. My husband and I got engaged shortly after my transplant and quickly began planning a wedding. We set the date for 18 months out from our engagement, because we wanted to focus on getting through the first year of transplant successfully.*

The first year went off without a hitch, and wedding plans were in full swing! As the big day approached we thought nothing could go wrong, but deep down I knew that wasn’t going to happen. As the week of my wedding arrived so did difficulty breathing and extreme exhaustion. I called my doctors and they brought me in for an emergency bronch “just to be safe”; the results came back that I had an infection and I was in A1 rejection.

I woke up on the morning of my Rehearsal dinner feeling dizzy and out of sorts, my labs quickly revealed that not only was I severely dehydrated and that every other possible level came back either up to high or down to low. The doctors called me and told me to drink as much as I physically could in three hours and then come back to get retested. My bridal luncheon consisted of my bridesmaids and I counting water bottles and opening gifts! The doctors called back and decided that drinking wasn't going to be enough and I should instead come in for 2 liters of fluids. It takes about 4 hours for 2 liters or fluids to go through an IV, and I only had 2 hours before I had to be at the church for my Rehearsal. The doctors were amazing and worked around my schedule; however, I did end up walking down the aisle at my Rehearsal in a workout T-shirt and leggings due to lack of time. I ended up leaving the Rehearsal dinner early to finish getting the rest of the fluids, but when I woke up on my wedding day nothing was going to get in my way!

The wedding went off without a hitch! My doctors had given me some medication to help make the pain and breathing a little better so I could dance the night away. I was able to marry my best friend and celebrate with all my friends and family!

The next morning I woke up and my doctors, my husband, and I decided that the honeymoon would have to wait. We canceled our trip to Greece and London and I was admitted to the hospital for the next week. With rest, and three weeks of IV's my husband and family were able to help me get back on my feet.

Two months after the wedding I was finally cleared to travel with the stipulation that I had to stay close enough they could fly my home quickly if anything went wrong. My husband and I settled on Cuba where we had an amazing honeymoon with no phones, no internet; just an amazing country to explore.

CF and transplant have taught me that things can change on a dime and you never know when or what is coming, but if you surround yourself with positive people and amazing doctors you will be able to make it through anything.

From Patient A.L., transplanted in 2017: *I remember being evaluated for lung transplant, and being asked to name two caretakers. I wasn't completely sure why I needed TWO. My husband had been handling my care for years up until now, why would I need anyone else? I ended up enlisting my mom as my second caretaker, but didn't think we would really need her. Immediately following surgery, it became apparent why you need two people. While my husband had years of experience taking care of me and my CF needs (and he was excellent at it!) the demand on the caretaker for the first couple of months after surgery absolutely around the clock.*

A perspective from S.P, lung transplant in 2004: *My life post-transplant has been more than I ever thought possible. I've been able to raise my kids and be present and active in their lives. I've watched my oldest graduate high school and my youngest train for a career in the military. I've earned my Bachelor's degree and am currently working on my masters. I hike, play with my fully vaccinated dog, and spend time as much time hanging out with my goofball husband and kids as I possibly can. I'm able to be there*

for my aging parents and have had the privilege of being the caregiver instead of a patient. I haven't been on home oxygen in 14 years! I'll admit that life isn't perfect, after all, I am still a patient, I just traded a terminal illness for a chronic one, but it is good. Hospital admissions, bronchs, and infections will always be a part of my life, but the further out I am from transplant, the fewer I've had. It's difficult to convey how life changing a transplant can be for every person involved. It's hard and continuous work, but, for me, it has been more than worth it.