



LOVE
is in the care

A Collection of Stories
HONORING
Cystic Fibrosis Caregivers



This book is dedicated to

ALL THE CAREGIVERS

who bring love and compassion to
people living with cystic fibrosis (CF).

THIS BOOK IS MADE WITH LOVE.



At the center of caring is love, a force that drives us to go above and beyond for others. Caregivers to people living with CF demonstrate this daily with their compassion, dedication, and hours spent taking care of loved ones.

This collection of true stories captures never-ending love and devotion, through the good days and the bad. Whether you have CF, love someone with CF, or are just learning about CF, throughout all of these accounts, there's one universal truth—CF caregivers are true heroes.

To CF caregivers everywhere—THANK YOU.

Brendan's Story

NOMINATED BY WIFE, ALISON

California

“Brendan kept us moving forward. He made it possible for me to go back to work and know that our beautiful boys were taken care of with love...”

We didn't know what was in store for us until our first CF Clinic when our son, Devland, was diagnosed at 2 weeks old. While there is no doubt that we were grieving and adjusting to new routines, precautions, and restrictions, Brendan kept us moving forward. He made it possible for me to go back to work and know that our beautiful boys were taken care of with love, absolute attention to detail, and strict adherence to our CF care plan. Our son got a G-tube placed this last January, and even still in October, Devy looks forward to his nightly snuggles and cuddles with my husband. I'll look over in the middle of the night and see Devy's hand tangled in Brendan's beard, reassured by his daddy being right by his side (even if that means my husband barely fits in the bed since Devy is a bed-hog!).

I love their relationship—whether he's sitting and cuddling, doing treatments, reading stories, playing at the park, or pressed as near as he can for sleeping, it's clear that Devy loves his daddy.

My husband, Brendan, makes it possible for me to work a full-time job at night, and for our son to grow up in the safety and comfort of our home instead of a daycare—he provides daily care and outings, and keeps our house moving.





Colby & Erin's Story

NOMINATED BY COLBY'S MOTHER, LORRAINE
Virginia

I am nominating my son, Colby, and his fiancé, Erin. They were both young college students when Erin became pregnant with my granddaughter, Layla. Not only did they both graduate from college with honors, but they threw themselves into educating themselves on CF to provide the best possible care for my sugar baby.

My son was actually accepted into a Doctor of Physical Therapy program, one of 40 students chosen from 800+ applicants due to his hard work striving for his family. His goal is to open his own physical therapy practice in our local area of Virginia Beach for patients with CF (which is mostly only in European countries at this point). I have no doubt he will achieve this goal.

Both Erin and Colby have become very involved in the CF community and organizations since Layla's diagnosis at 2 weeks old. I'm amazed every day at the exceptional care they take and provide to our Layla Love, and because of this she is thriving. She will be 4 years old in April, and I have complete faith she will live a long and full life because of her parents' care and being raised by them.

"I'm amazed every day at the exceptional care they take and provide to our Layla Love, and because of this she is thriving."

Sarah's Story

NOMINATED BY FRIEND, CRYSTAL

Massachusetts

Sarah is a Super Sister—like a superhero, but better. In May of this year, after starting the process of testing to get on the lung transplant list, her sister Amy fell ill with pneumonia and was intubated. Sarah flew to Boston from Ohio that day, and hasn't left Amy's side.

Shortly after Amy was placed in a medically induced coma, doctors determined that she needed to immediately be placed on the transplant list for new lungs. Sarah dropped her entire life (over 700 miles away) to be with Amy, knowing that the transplant would require months of recovery. She quit her job and left her friends. She also said goodbye to her live-in boyfriend. His visa was about to expire, and he would likely need to return home to Iraq in a few short months, which meant Sarah didn't know if she would get to see him again.

Still, Sarah was at the hospital every day. When Amy was in a coma, she would brush her hair and rub her feet. She volunteered to help our fundraising efforts. Other days, she read to Amy from "Harry Potter." On top of learning a dictionary-full of new medical terminology, she also kept all of Amy's friends and family in the loop about her progress each day. For weeks, Amy's health was nose-diving as we all waited for her new lungs. More than once, Amy's heart flatlined while Sarah was in the room. Finally, on Father's Day, Amy was given the gift of life with a new set of lungs.

Since then, Sarah has spent every single day taking care of Amy. She keeps their apartment spotless to avoid infection, manages Amy's strict diet, helps administer medications, runs errands, and takes care of everything Amy cannot. In preparation for Amy's lifesaving surgery, her doctors made it clear that Amy would not be able to be left alone for months while she recovered. While a team of friends and family have come together to support Amy, Sarah is their leader.

I can't imagine how incredibly difficult it has been for Sarah to see her vivacious and independent sister's health place her repeatedly on the brink of tragedy. To spend her entire life the last 5 months dedicated to her sister's care has likely taken a toll on her own body and spirit. You wouldn't know it from her demeanor, though. To say Sarah is an inspiring caregiver is an understatement. We should all hope that in the face of a medical battle, we could have a Sarah by our side.



"Sarah dropped her entire life to be with Amy, knowing the transplant would require months of recovery."



Colleen's Story

NOMINATED BY DAUGHTER, CORRINE

Arizona

My mother is my caregiver. She raised my brother and me as a single mom, and I don't think there is anyone in the world who would do as much as she has for us. My brother does not have cystic fibrosis, but I do. My mom has sacrificed so much to take care of me and make sure I have the right care.

She's made countless phone calls in the middle of the night and demanded help for me when I've been too weak or neglected by certain medical professionals. She's sacrificed hours of sleep holding my hand or supporting me through the pain and suffering. This summer she flew back and forth from Arizona to New York two times within a month to be with me while I was fighting a bad fungal infection.

I think she's inspiring because she keeps pushing forward and teaches me to move forward through everything I go through.

"My mom has sacrificed so much to take care of me and make sure I have the right care."

Peggy's Story

NOMINATED BY SISTER, LUCRETIA

Alabama

I want to recognize my sister, Peggy. For the past 3 years she has put her life on hold taking me back and forth to my clinic visits (and the hospital when necessary) and going through the whole lung transplant process. She could have said no—but she didn't. She has driven from where she lives to where I live pretty much every time I needed to go to the doctor or hospital. On several occasions she has even had to help me pack once she got to me because I didn't have the strength to do it myself. There were times before my transplant that she had to help bathe and dress me because I was just too weak to do it myself.

She has been the one who would stay up all night with me in the hotel because I was having trouble and couldn't get comfortable. I could see the worry and concern on her face, even though she would try to hide it by trying to make me laugh. She has always tried to keep me laughing, even when we were little. When she is not laughing with me she is praying with me, to try and get me through the next second, minute, hour, or day.

She left her dog with family so she could be my caregiver post-transplant, and I know she misses him dearly. Now she has to drive me back and forth to my post-transplant visits and cardiopulmonary rehab.

She inspires me more than she will ever realize, because even when it gets hard she still presses on right beside me. She spends her own money on things I need or want even when she doesn't have to, never really expecting anything in return. She has even done without (which I told her not to do) just to make sure I have what I need or want.

She is so afraid to spend money on herself because I might need something. The only time she will spend money on herself is if I keep insisting or tell her that I am upset or hurt because she is doing without.

She just goes above and beyond to take care of me. She will help me pray for other people, too. If I ask for anything and it is in her power to make it happen, she sees that it gets done.

When I got so weak before my transplant and couldn't think straight or talk fast enough, she was always patient with me until I was able to figure out what I was wanting or trying to say. She helped me remember to write things down when I had questions. She was my protector when necessary and my advocate when I needed one. I was afraid that she wasn't going to be able to speak up in crucial moments—she has always been a little timid—but she really has taken good care of me all this time, making sure that the doctors and nurses were doing what was needed for me.

What she has done for me is just priceless. She deserves to be recognized and rewarded for how great she has been as my caregiver.

“She inspires me more than she will ever realize, because even when it gets hard she still presses on right beside me.”





Landon's Story

NOMINATED BY WIFE, MISTY

Louisiana

My husband, Landon, is more than a caregiver to our son—he is a LIFEgiver.

Everything he does for our son is full of love and life. Landon has never backed down from the challenges of parenting a child with CF and, in fact, he is a master at it. If our son is feeling down or upset, Landon is right there with a joke and words of motivation. He is such a huge provider of strength for all of us. Landon inspires me by never letting the “what-ifs” get to him. He lives in the “today” and makes the absolute most of it. Most importantly, he makes sure our son does, too.

Landon makes the future so bright for our son it makes it possible to believe that his future will be incredible.

“He is such a huge provider of strength for all of us.”

Annetta's Story

NOMINATED BY FRIEND, JESSICA

North Carolina

When Miller was first diagnosed with cystic fibrosis, Annetta wasted no time learning everything she could about the disease and how to give him the absolute best care possible. She learned how to care for a stoma, how to give medications through a G-tube, how to survive 75 days within the stark walls of the NICU, and how to do chest therapy.

Miller's birth was unremarkable, in that he was born happy and healthy. Within days, however, he would need to be transferred to a larger hospital's NICU for a higher level of care.

Annetta, not even fully healed from the bodily trauma that is childbirth, requested she be discharged early—despite her very present pain—to be with her son. She and her husband spent every possible moment with Miller in the NICU, and as their families rallied around them, Miller became known as the baby who always had a visitor!

Annetta, from the very first whisperings of a CF diagnosis, never wavered from an unshakable motherly dedication to her son. As anyone who loves someone with CF knows, CF is not just a day-by-day concern. It is an all-encompassing, second-by-second thought constantly running in the back of Annetta's head. Yet she has walked this season of caring for Miller with grace and unwavering faith. Miller, now 18 months old, is physical proof of her commitment.

From daily medications, dietary changes, vest therapy, doctor's appointments, a rigorous cleaning schedule, and a whole lot of hand washing (!)—Annetta tangibly displays her deep love for Miller. To say that I am inspired by Annetta doesn't begin to cover the depths of how her entire community feels about her; we are inspired, impressed, moved, and encouraged. Miller has been gifted with the very best of mothers, and we know that despite whatever twists and turns CF throws at him, Annetta will be there every step along the way. Through her love, commitment, and advocacy for her son, Annetta makes it possible for Miller to thrive with CF.



“Annetta, from the very first whisperings of a CF diagnosis, never wavered from an unshakable motherly dedication to her son.”

Adam's Story

NOMINATED BY WIFE, SABRINA

Colorado

I met my husband when I was 14 years old, when we happened to cross paths trick-or-treating when I was in middle school. The next year, when I entered high school, we met again and started dating shortly after. I remember Adam asked me about living with cystic fibrosis (CF) and how it impacted me. He had heard rumors that I had CF and that I would die young. He was genuinely concerned and really wanted to learn more. Our high school romance was short-lived—we were very young and Adam would be off to college soon—so we decided to just be friends.

When I graduated from high school several years later, we reconnected and began dating again. Two months later, I was diagnosed with non-Hodgkin's lymphoma and went through chemotherapy and radiation. Fast forward to 14 years later, we have overcome cancer but continue to face the obstacles of CF. Adam chose to spend his life with me despite my chronic illness. We now have a 4 year-old son named Leo and have been married for 8 years.

CF is a progressive disease, and over the past 14 years Adam has learned and experienced how scary and unpredictable this disease can be. There are days where it seems as though CF is not so intrusive—and then there are days where my health seems to suddenly and drastically deteriorate.

Adam took on the role of caregiver when he married me, and he has never made me feel guilty for his sacrifices and time that he has put forth in order to keep me healthy. CF has turned our world upside down. It has the ability to knock us to our knees, but he has never complained about the negative impact that it has on his own life. He is selfless and he is a hero in my eyes.

He has always given me love and comfort when I am weak and disheartened. He has also never pitied me or given up on me. When I feel defeated he reminds me about strength, hope, and our innate ability to conquer the unknown.

I know that being a caregiver to someone living with CF is a hard and harrowing feat to take on. Their pain, emotions, and fears are often hidden because they need to be strong and pillars of hope during the most difficult times. We celebrate the good in life, and he remains steady and calm during chaos—always assuring and reassuring.

We have agreed to not hide CF from our son. When I am sick or hospitalized Adam has to take sudden and long absences from work to care for our son and me. Adam has taught our son to be thoughtful and kind, and I believe that Leo will someday remember these moments and this will shape his life. They bring me clean clothes, flowers, coffee, food, laughter, and hugs. Adam is teaching Leo to be a good person, and that is everlasting.

Adam is a caregiver, but in our world that word encompasses many roles: father, husband, dentist (by day), nurse, friend, motivational mentor, marathon runner, and fundraiser. My life has taken on a whole new depth of love and gratitude because Adam has shown me love and support through immense adversity. The power of love is real.

Adam married me knowing that children may not be a part of our future, so a true miracle happened for us when we found out that we were expecting a baby. My whole life's purpose unfolded when our son, Leo, came into this world. My soul is renewed when I am with Adam and Leo—they are my reason to live; they give me love and, most of all, they give me hope.

My husband has shown me that love is real and hope drives the soul, despite the upheaval of CF.

“He has always given me love and comfort when I am weak and disheartened. He has also never pitied me or given up on me.”



John's Story

NOMINATED BY WIFE, LIANA

Virginia

My husband, John, is a veteran, police officer, and father to two CF-ers. He is always willing to help with both kids and ensures they have insurance that will cover everything. But most of all, he will drop everything and be there 100% when his kids need him. He left active duty military service so that he would be able to always be there but stayed in the reserves so that our children can have the best insurance. He works full-time, does the reserves one weekend a month, and is a full-time student—all this while still being a caregiver to our children.

He provides a stable environment with love and laughter. He encourages our CF-ers to not let their disease define them and makes sure they are getting the best care always.

“But most of all, he will drop everything and be there 100% when his kids need him.”





Jordan's Story

NOMINATED BY WIFE, AMY

Wisconsin

Jordan and I met 10 years ago. From the second date he knew I had CF, but he did not get scared or run away. He wanted to know more.

Since that day, he has been by my side for everything, CF-related or not. He has sat through treatments and hospital stays (he has even worked at the hospital so he doesn't have to be away for too long). He supports me at events like Breathcon and helps so much for the Great Strides walk. He supports me through the little things of CF, and the life-changing things.

He lives with CF as close as he can and I know if he could take it upon himself, he would. He is my strength.

"He supports me through the little things of CF, and the life-changing things."

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