

10 August 2023

In March of this year, a remarkable mother from our close-knit community opened her heart to share a poignant piece, a reflection on her journey as she approached the two-year mark since Cystic Fibrosis became part of her life. The response we received was overwhelming, as her words touched the hearts of many.

We're thrilled to announce that this incredible mother has once again chosen to grace us with her words. With immense courage, she's sharing her next piece, a continuation of her journey. While she wishes to remain anonymous, her hope is that her story will serve as a guiding light for others navigating similar paths.

If you'd like to read her piece from March and draw inspiration from her unwavering strength, please follow the link <u>HERE</u>.

Her second piece is below. Let's come together as a community to support, uplift, and connect. Kindly share this with those who might find solace and encouragement in her words.

Parenthood can be quite daunting.

There are so many different thoughts that flood your mind on a daily, even hourly basis, especially when it's your first child.

After two children, I thought to myself, "One more can't be that much different from the other two. He'll simply slip right into our routines and our home."

Alas, CF entered our world, and in the moments following his diagnosis, I felt our world completely change.

My surroundings seemed different. The sound of traffic outside almost went silent, replaced by the thumping of my heart.

I told myself, "It's wrong... it's an error. We'll look back on this day soon and say - wasn't that a doozy." But then reality kicked in!

This was real. It wasn't an error. We had to set aside everything we once knew and embark on a new journey.

We were new parents again.

All our plans were thrown out the door.

This was particularly challenging at the beginning of a pandemic. However, the lockdowns and masks with a newborn with CF were our little silver linings.

New routines were created, and a new found strength in our family was formed.

We spent most of our time in the early days informing family and close friends about our news, always reassuring them that we were fine and things would be okay. Yet, during the early morning feeds, we both questioned our own comforting words. Was it going to be okay?

A crystal ball would have been handy. "Tell us, magic ball... is everything going to be okay?"

One thing we didn't anticipate was the well-meaning comments trying to "comfort" us. "He can always have a lung transplant," or "He doesn't look sick... He looks normal... he'll be fine."

Though these comments come from a place of warmth and support, they can be hard to hear for parents grappling with a 3-week-old baby's diagnosis.

The most supportive action for a parent with a child with a medical condition, no matter what it may be, is simply understanding.

No comments need to be made. No stories of "I knew or know a person with CF..." need to be shared, particularly considering each CF patient and their symptoms are unique. In my opinion, and based on my experience, the most supportive care to offer is to understand, and maybe check in now and then. The days can be heavy at times, but with the right support from family and friends, they are much easier to bear.

As parents, we have already exhausted nearly every resource in reading up on information and connecting with others dealing with CF. Therefore, having a network of support to just listen, understand, and learn can be the biggest support of all.

Battling CF as a parent can be exhausting. There are days with many wins, like good swab results and weight gain. Then there are days where you want to scream! Battling such comments and feeling isolated should not be part of the fight.

Understanding the disease and the situation of a family member or friend can not only provide support but can also make them feel like they are not alone, especially when it comes to social events.

Many families have to skip events due to a child that is unwell or perhaps it's during cold and flu season and you're desperately trying to avoid another cold in the house. Declining an event is never easy, however it definitely helps when there is understanding and support around the decision made.

So, if you're reading this and know a CF parent, or person with CF, know that offering them understanding and a listening ear can be the best comfort, support, and inspiration of all.

If you are a CF parent, know that you are not alone. Although each CF journey is unique, the CF community, family, and friends can be extremely supportive. Reach out, chat, and remember, even the hardest days don't last forever.

With each day that passes, we inch closer to further medical advances and hopefully, one day a cure.

Onwards and upwards.