Thriving beyond diagnosis – Chantelle's Story

Cystic Fibrosis has been part of my life since the day I was born. I was diagnosed at birth because my brother, David, who was born four years before me, also had CF. We also have an older brother who is a carrier, and I have a twin sister who is a carrier as well.

When my brother and I were born, my parents were told we might only live into our teenage years. Over time, there have been huge medical advances, better understanding of CF, and new treatments that have continued to push life expectancy higher. Watching those changes happen has been incredible. Being diagnosed with CF and growing up with a shortened life expectancy made me look at life differently.

For me, that meant trying to cram as much life as possible into every moment. Family has always been one of the most important things in my life, so getting married and having three children, has been a huge milestone, something I thought might not even be possible.

What made that milestone even more special was that my brother, who also had CF, had children around the same time. We got to raise our kids together, something we truly never expected we would have the chance to do

The biggest challenge I've faced with CF has been losing my brother to the disease last year. David and I had been on this journey together since day one, and because of that we shared a very close bond, we understood each other in a way few others could. Losing someone you love to the same disease you are fighting every day is one of the hardest things to process. It has been a huge mental shift, and it's a challenge I know I will continue to face for many years.

The biggest turning point in my CF journey has definitely been gaining access to Trikafta. From the moment I took my first dose, my life changed, not only for me, but for my whole family too. So much of the daily worry and many of the difficult challenges we used to face have been lifted. It has allowed me to live a much more normal life over the last three years. Living with CF now compared to earlier years is a huge difference.

Although I now have access to Trikafta and CF is more in the background, it doesn't mean I can ignore it completely. I still need to exercise regularly to help keep my lungs healthy. I still take a number of pills every day that are important for my overall health. I still need to listen to my body when it tells me to slow down and rest for a few days.

One thing people often don't realise is that CF never really takes a day off. Even when things are going well, there is still constant management happening behind the scenes.

Chantelle and David

> **"Before Trikafta, CF controlled almost every part of life. Now it sits more in the background, but it never fully disappears" says Chantelle.**

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> ***"Many people with CF are also fighting an internal battle, struggling with the fact that their body can't always keep up with other people their age."***

Ella, Benji, Chantelle, Cory and Charlie

CF has always had an emotional impact on my life. One of the hardest parts is the guilt that sits in the back of my mind, the feeling that my husband and children have a sick wife and mum.

My biggest fear for the future is not being there to see my children grow up.

There is also a lot of past trauma that comes with growing up with CF: long hospital stays, needles, being separated from family, and living with the fear of death from a young age. Those experiences stay with you.

CF doesn't just affect the lungs, it affects the whole body. It can impact the sinuses, digestive system, joints, bones, and many other organs, as well as our mental health. A lot of people with CF don't necessarily "look sick," but the ongoing battle is relentless. There are no days off from medications, treatments, or looking after your health.

Many people with CF are also fighting an internal battle, struggling with the fact that their body can't always keep up with other people their age. There can be missed social events, holidays, celebrations, and everyday moments because the body is too exhausted or because they are in hospital fighting yet another infection. I think people often underestimate how much CF affects mental and emotional wellbeing, not just physical health.

I want people to understand that CF is still a serious, lifelong condition even with incredible advances like Trikafta. While newer treatments have changed lives, they are not a cure. There are still daily medications, ongoing health concerns, emotional struggles, and uncertainty about the future.

Awareness and support still matter deeply, especially for those who cannot access modulators because of their specific mutation type.

For myself and my family, my hope is to simply to live without constant worry, to have more carefree moments, and to have a normal life expectancy.

Most of all, I hope to be here to watch my children grow up.

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