



When heartwarming moments are also heartbreaking

Joelle, Lincoln, Harriet & Kayne Dunlop

Cystic fibrosis is often talked about in extremes - either in medical terms, or in moments of crisis. Hospitalisations. Lung function. Breakthrough treatments. Survival.

What we talk about much less is the part in between. The part where sometimes, on the outside, life looks fine – normal, even.

For families and people living with cystic fibrosis, this condition creeps into every decision. What and when to eat; how treatments are scheduled and maintained; whether it's safe to attend a birthday party, church gathering, social event; even planning a trip or holiday.

For most families, these decisions are relatively simple – where will we stay, what do we need to pack, what will the kids enjoy? For families living with CF, there are additional layers of complexity – daily routines that cannot be skipped. It's a different way of living that often goes unnoticed and, over time, creates isolation.

For the Dunlop family, life is as normal as they can make it while living with a chronic condition. Their days hold more decisions and actions before breakfast than many would face in an entire day. When that becomes your normal, you stop noticing the difference.

“When everything is well and everything feels normal, you forget you are living a completely parallel life to friends,” says Joelle, mum to seven-year-old Lincoln, who lives with CF.

Because their normal is different. CF shows up quietly and with early mornings, physio treatments each morning and night, medications several times a day, then school, sport, playdates. Life continues – it's just different.

“It's like when you've got small kids and you're always thinking about car seats and nap times,” Joelle says. ***“That phase of coordination doesn't end. We still have to cater to this thing. Always.”*** And it can be incredibly isolating to have this, but then there is the physical isolation also.

Because isolation isn't a preference. It's about protecting loved ones.

Physical isolation from others wasn't always a thing. Before we knew better, people with CF would come together, build support groups and networks, a village of people who knew and understood what living with CF is like.

However, nowadays and with medical advancements and knowledge, it is clear that the likelihood of cross-infection and “swapping bugs” is too large of a risk to take.



Former paediatric CF nurse Jan reflected on her time at Starship and how isolating CF could be.

“The separation and isolation for young children is extremely hard when they can’t be together,” she recalls. “I remember two young girls of similar age in hospital who, for cross-infection reasons, had to be kept in separate rooms.

Their rooms were just down the hallway from each other; each knew they were in hospital for the same reason and yet they were unable to meet and be together.

They were excited to know someone else their age had CF but sad they couldn’t meet and play together. I asked both girls to write the other a story about themselves or draw a picture, which I could then deliver,” she says. “I will always remember two 8-year-olds knowing someone else their age was dealing with the same issues that they were.”

It is a heartwarming memory. And it is also heartbreaking. The same pattern exists outside the walls of the hospital.

Family weekends away still happen - but treatments still have to be done. ***“We still have to carve out time that no one else has to,”*** Joelle says. While others stay in the lounge, Lincoln slips away. Not because he wants to be alone, but because he’s more aware now. He doesn’t want to nebulise in front of everyone. So even in the middle of togetherness, there’s separation.

It’s what needs to be done. It isn’t dramatic, but it is relentless.

Playdates still happen too. But they come with medication schedules, trust, and risk calculations that other parents don’t carry. Lincoln recently went on his first playdate without Joelle. “When the food came out, Lincoln told the mum he was hungry and that he needed to take his Creon. He sorted it himself.”

There was pride, and there was grief. Because childhood independence hits differently when it’s tied to medical responsibility. Because no parent wants their child to grow up faster than they should have to — even when they’re proud that they can.

“I’m so proud of him,” Joelle Says. ***But I’m also like... you shouldn’t have to be that responsible. I want to be able to do that for him.”***

Isolation isn’t just something Lincoln carries. It’s layered into every relationship around him, and across entire families.

Siblings feel it too. Lincoln’s older sister is always watching, always aware. “Her first thought is managing Lincoln,” Joelle shares. “She tells him when his nebuliser isn’t in properly. She’s always thinking about him.”

Parents carry it - coordinating, protecting, anticipating risks others never see. Extended family carry it too, often unsure how to balance joy and concern when life looks so normal on the surface.

“When we are seemingly so normal,” Joelle says, ***“it’s very difficult for our village to remember that we’ve got all this added stuff going on.”***



Even friendships can feel isolating. Catching up with girlfriends, being asked how you are, answering honestly but briefly.

“I’m great,” Joelle says of those moments. ***“The kids were happy, someone made me a coffee. That doesn’t mean I was good this morning. Or that I’ll be good later.”***

CF doesn’t pause just because life feels manageable in that moment. Isolation in CF doesn’t only come from physical separation. More often, it comes from carrying layers that no one else in the room is carrying.

Treatments that don’t pause for convenience. Cross-infection risk doesn’t switch off in social settings. Decision-making doesn’t stop just because children look healthy.

“There are moments where you’re like, ‘This is amazing,’” Joelle says. “And then you’re like... this is amazing for really sad reasons.”



Another mum, Kareena, reflects on why being open about needs is important.

“CF is very isolating and add in the fact it is an invisible illness,” Kareena explains. ***“Asking visitors to sanitise, wiping down tables at restaurants, avoiding large crowds. It does bring about looks and judgements from those that don’t understand.”***



Those judgements shape behaviour.

“In the early days the fear was too overwhelming and we just didn’t socialise,” she says.

“Now, at six years old, we socialise more - but the fear of picking up bugs is always still in the forefront of our mind.”

And maybe that’s what CF Awareness Month is really asking us to see. Not just the condition.

But the quiet, parallel lives being lived every single day. Where those heartwarming moments are also heartbreaking, and strength is often needed long before anyone notices.

