



Speaking from Experience *Cystic Fibrosis: Newly diagnosed*

Transcript for chapter 1 of 7: First diagnosed

Gael (her 12 year old son Reuben has CF) - We were absolutely devastated. We'd planned on having a healthy child. We didn't know the future of our child, we didn't really know what CF was. All that I knew was that it was a genetic condition. So, it's a terrible time, in terms of grief. You want to be celebrating the birth of your child, and there you are with all these awful, sad feelings.

Melissa (has a 2 year old son with CF) - It was a real shock. It's one of those things you just can't be prepared for. Ironically, when I was in hospital after giving birth to Ben, the nurse said, "Don't worry, no one ever hears back from these things". Four weeks later, we got that terrible phone call. So it was really difficult, it was a really sad time. Instead of rejoicing this new baby at home, you've got to cope with this serious illness. You're quite scared about what it holds, not only for the child, but for the whole family. What sort of impact it'll have.

Lex and Jo (have a 4 year old son with CF) - We were just, I think, in shock for a fair bit of the time. I run my own business, so I was basically of no value to the business for good part of that first 12 months.

Helen (has a grandson with CF) - I think there was an air of disbelief that this perfect little beautiful, wanted baby could have anything wrong with him. When we heard that he was diagnosed with a life-threatening illness, it was just shattering. We just couldn't believe it. I think it's the sort of thing that just happens to somebody else. We had five perfectly healthy little grandsons and you just expect that the next one will be the same.

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