BREAKING BARRIERS FOR CYSTIC FIBROSIS

TODAY'S DEDICATION

DAY 8: FRIDAY 8th SEPTEMBER 2023

Caz

Born in 1967, Caz's mother had a difficult time convincing doctors there was something wrong with her firstborn, despite numerous bouts of pneumonia, signs of pancreatic insufficiency, and salty skin. Labelled a "manic mother" her mother's intuition pursued an answer.

Finally, in 1971 Caz was diagnosed with Cystic Fibrosis.

Her parents were told she would be lucky to make it to her 10th birthday.

Little was known about CF in 1971, apart from the fact that it was a life-limiting disease. Treatment was limited to nebulised mucomyst and postural drainage physiotherapy, twice daily. Physio was performed over 4 pillows on the ground as there were no physio tables in those days.

Despite celebrating her 10th birthday, doctors continued to tell her parents that she wouldn't survive to 13, 16, 18, etc.

At the age of 16, I suffered a stroke that paralyzed my left side. I had to learn to walk again and give up my dream of becoming a Hansard Reporter. A pneumothorax (collapsed lung) at the age of 22 took away valued lung function. That same year my CF physician suggested I see the transplant team from St. Vincents in Sydney to discuss lung transplantation. I felt like I had been slapped in the face. With limited lung function, I was still holding down a part-time job and had an active social life.

I met with the transplant team in November 1992 and was told that if I did not have a transplant, I would be dead within 2 years.

I knew all too well how CF stole lives however, as my parents never treated me any differently to my brothers and enabled me to lead a "normal" life, hearing those words "two years" had a profound effect on me. Speaking to a very wise friend about the transplant, she said "If I was given a second chance I would take it" .....and take it I did.

Mum and I moved to Sydney to await the ultimate gift, the gift of life.

Over the two years, my lungs deteriorated. Haemotosysis and infection played havoc with my lungs. I was on oxygen 24 hours a day and slept with a V Pap machine.

On the 8th of November 1994 I was admitted to Royal Prince Alfred Hospital with palpitations and increasing shortness of breath. My weight plummeted to 42kgs. I was given IV antibiotics but was not responding to these. I couldn't shower myself without the help of my mother. I

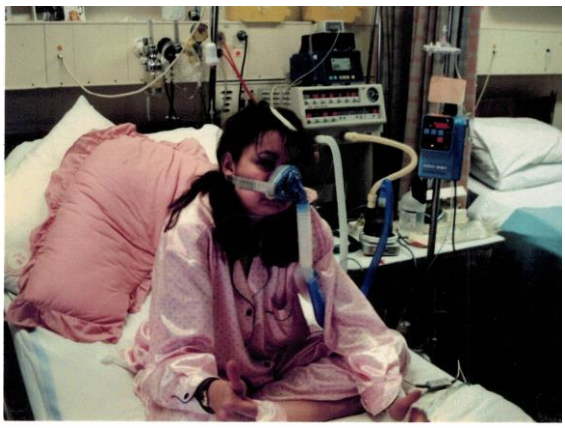
couldn't even make it to the toilet without soiling my pants. Here I was 27 years old and all my dignity and sense of hope for life was being viciously stripped from me. Even the simple task of brushing my teeth would render me breathless. I barely had the energy to breathe. I would simply sleep all day petrified that when I closed my eyes I wouldn't wake up. I suffered excruciating headaches as my carbon dioxide level was getting dangerously high day by day.

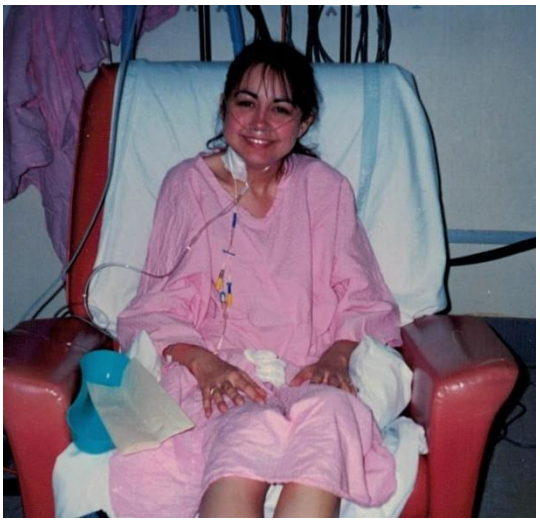
A few days later I was put on a respirator. My physician spoke to Mum, unbeknown to me, and said "We've pulled out all the stops for Caz, there's not much more we can do. I just want you to know that she probably won't make it to transplant." How does a parent deal with that? I knew that I had never felt so crap in all my life, but I certainly didn't think this was the end of my life. I mean how does one know?

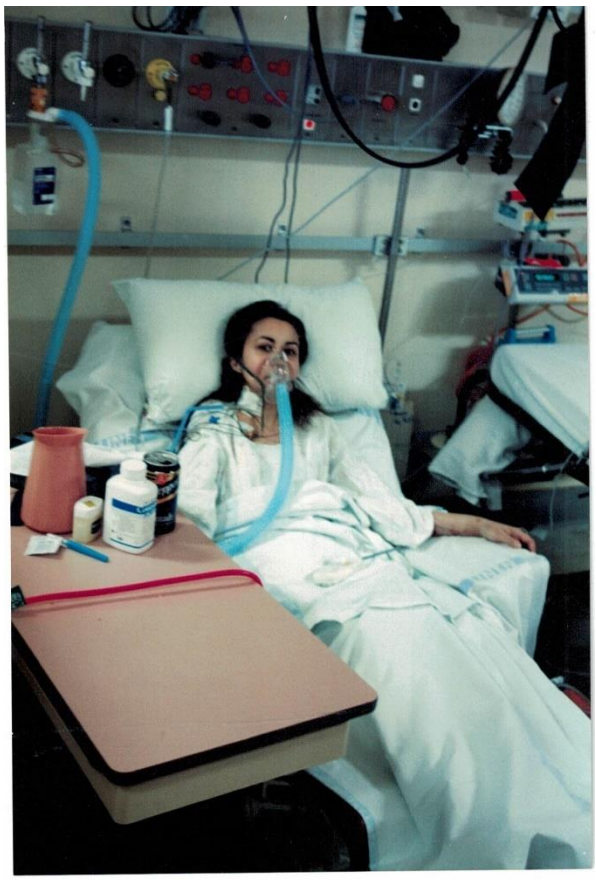
No one says when you are about to die.

Finally, just 12 hours before my predicted demise, I received my call. A call that would ultimately change my life and soon I would receive the ultimate gift, the gift of life. This was not a cure by any means, I was merely swapping one set of problems for another. Pneumococcal pneumonia, fractured hip, and various other bones, chronic sinusitis, and copious amounts of medications. The list is endless.

On the 21 November, I will celebrate 29 years with my "new lung" and celebrate I will.









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