



HEALTHCARE HOSPITALS

How Down Syndrome care changed a mother's journey



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Julie Fisher, a 50-year-old mother of four and author from Langwarrin Victoria, would never have expected the journey she would go on when her son Darcy was diagnosed with Down Syndrome in 2006.

Tough as it was, when Julie found out during her pregnancy that Darcy would be a special child, she was determined to learn how she could provide the best care possible for her son.

Now 13 years old, Darcy is a thrilled, active teenage boy who loves to dance, play basketball, football and go bowling. However, Darcy still requires assistance with everyday self-care tasks, including brushing his teeth, bathing, dressing and going to the toilet. Darcy's sensory issues around food also mean that Julie must assist him in eating at all mealtimes.

Despite the extensive amount of care Julie provides around the clock, Julie struggles to think of herself as a carer. The way she sees it, she's only done what she could so her son got to experience everything that his brothers have.

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Julie said, “It’s taken me a long time to identify myself as a carer. As a parent, I think it is a bit strange, identifying fully as a carer because when your children are young, it’s natural to care for your kids in every way possible. I only really started to feel like a carer when we attended early intervention sessions for Darcy and when we had many hospital visits with the aspiration to eradicate the fluid in his lungs so he could breathe properly. It was a scary time.”

Being a carer means that I do have to make extra considerations for my son that most parents never have to think about for 13-year-olds, Julie said. For example, “I have to help Darcy bathe, brush his teeth, put on socks and shoes, climb up and down the stairs, et cetera. He also needs my support with going to the toilet because he’s incontinent. This means I am his guide, teacher, advocate, voice, defender and his mum, all at the same time.”

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The advent of COVID-19 has posed new challenges to Julie’s daily care for Darcy. Darcy’s immune system is relatively weak, so Julie has had to keep him home at all times. The support worker Darcy is familiar with couldn’t help as much either due to the restrictions. As a result, Julie had to focus more on Darcy’s wellbeing all the while finding herself in a precarious situation with her employment. Luckily, Darcy’s brothers at home have been able to offer some support by keeping Darcy entertained when he’s bored, for example.

Having had a thorough reflection on her journey as a carer for her disabled son while writing her first book, titled *The Unexpected Journey*, Julie truly understands what it means to love and care for someone with a disability. She describes the unspoken contribution unpaid family and friend carers are making to society as profoundly impactful.

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Julie is incredibly proud of her son and everything he has accomplished. She adds: “Watching him enjoy life and the things we do with him is a true motivator. He is an amazing little boy who gets so much enjoyment from accomplishing things he’s been trying to do. I get an overwhelming sense of pride and joy, watching this young man blossom.”

Julie understands first-hand the support that’s needed for not only her son but for herself and many other carers.

“To me, the support network is vital. I think it is so helpful to have connections with other people going on the same journey as you. Much like a group for first mums, when you first start having your family, it’s crucial on many

different levels, be it advice, a shoulder to cry on, days out together.”



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