

My story The kindness of strangers

When Kerry Parnell and partner Antony learned their baby son Teddy had a rare genetic disorder their life became a terrifying whirl of hospitals and procedures, their sanctuary in that storm was Ronald McDonald House.



A fellow mother smiled and pointed to a table laden with toys. “Take something for your little one,” she said.

I walked over to the table, in Ronald McDonald House, Parkville, on which was piled every kind of Christmas gift a child could dream of. Games, jigsaws, books, dolls – they had been donated by the local fire service for kids in the Royal Children’s Hospital in Melbourne, over Christmas.

I looked at them, feeling awash with the kindness of strangers. Knowing someone cares about you, who doesn’t know you, when your life is unravelling, was profoundly comforting and would stay with me forever.

I remember standing there, bewildered, overwhelmed by the choice. My son, Teddy, was only nine months old, but had spent most of his life in and out of hospital. The only gift I wanted for him was life. But in the end, I selected a wooden train set in the hope my precious, longed-for, only-child, would survive his heart operation and grow up to play with it.

Then at the last moment, I picked up a copy of *Peter Pan*. I still don’t know why I took it, but it was said of Peter, remember, “when children died he went part of the way with them, so that they should not be frightened”. I like to think it’s true: years later, I would read the book about the boy that never grows up to the sisters Teddy never met.

Nobody wants to stay in a Ronald McDonald House, which is an unusual premise for any kind of hotel. But believe, me, if you ever have to check-in, you’ll feel luckier than winning a week in the Hilton.

Ronald McDonald Houses provide accommodation for families with children who have to go to hospital a long

distance from their home. You’ll find them quietly tucked alongside major hospitals around the country if you look for them, which most people don’t, until they need to.

We had to travel from Sydney to Melbourne for specialist heart surgery for Teddy. He had been born with Neonatal Marfan Syndrome, an aggressive form of the rare connective tissue disorder. While most people with Marfan Syndrome go on to live long and healthy lives, the unlucky few with Neonatal Marfan, generally do not, although medical advancements are constantly being made.

For the first 24 hours of Teddy’s life, my partner, Antony, and I thought ourselves ordinary, first-time parents; enraptured with our little boy. How happy we were – but that one day of blissful ignorance would be all we had. After that, as specialist after specialist traipsed into our hospital room describing a cacophony of problems, with his heart, his eyes, his lungs, his spine, I looked at their mouths moving and heard only a clamour in my head. I wanted to scream, “Leave him alone, leave us all alone”.

We started our journey positive – he was beautiful, he breastfed and slept well, maybe we would be lucky. I found other parents of Neonatal Marfan children online in Australia and around the world and they became both friends and medical support team.

“We knew exactly what each other was going through.”

But things began to spiral into terrifying waters and the days out of Sydney Children’s Hospital became fewer than those on the ward, as we bounced in and out with one issue after another. Teddy needed an operation on his mitral valve to have any chance of survival and it was hoped a heart surgeon in Melbourne could do it. It all happened last-minute, just before Christmas. We needed to be there in a few days and could expect him to be in hospital for several weeks. It was only at this point it dawned on us that we needed somewhere to stay, as close to the hospital as possible, where we could cook and wash our clothes. We couldn’t just rent a hotel room – this was no holiday.

Until you are in this situation, you have no idea what to do. If you’re lucky, your hospital social worker will help; if you’re like us, she’ll say, “Oh, I don’t know how you are going to get to Melbourne,” and leave you to it.

Luckily, a friend worked for Ronald McDonald House and explained to me what the charity did. Their subsidised accommodation consists of rooms with shared kitchens and bathrooms and play areas for children. They’re not luxurious, but they are a sanctuary.

Parkville was packed with families, some with children staying with them while they received treatment, some with their other kids making the most of the playrooms. People from every walk of life were there, united with a shared camaraderie – we knew exactly what each other was going through.

The last thing you want to do when your child is in ICU is think about meals, so I was surprised and touched to find volunteers making dinner for residents a few nights a week. Others donated food, cleaning products, toiletries, anything that made life a bit easier. Because again, when your entire existence is spent by your child’s hospital bed, you don’t want to waste a moment going shopping.

It has been years since that Christmas, but I walk the footpath from the hospital to the Parkville house most nights in my dreams. I can still see the room we stayed in, the kitchen we slumped in and feel the heat of that oppressively hot day in early January when I staggered back no longer a mother.

The odds were always stacked against my beautiful boy and in the end, he just wasn’t strong enough to make it. He only had one Christmas; he never saw his first birthday, but the gift he bestowed on both of us was to see life with a clarity we hadn’t had before. Like a veil being lifted from our previous existence, we returned to our house, car, gadgets and clothes, but without the one thing we really wanted. I remember running around the house shrieking, “he’s not here, he’s not here,” in agony. Everything else was simply meaningless “stuff” and has remained so since.

Immediately, I felt a profound need to push my grief

outwards, to use my pain to help others in the same situation. So I started the charity Team Teddy, for families with children in hospital. Like people had touched me in our time of need, I was determined to show someone was thinking of them, they were not alone.

Team Teddy does things like pay for grocery gift cards, we have bought ward recliner chairs for parents to sleep on and every Christmas send Teddy’s favourite cuddly bunnies to cardiac kids in hospitals in Australia and the UK.

We’re also committed to helping Ronald McDonald House which marks its 40th anniversary this year. When our daughter was born a year later, we sponsored a room in the Randwick house, which paid for a total renovation, and took her to the grand opening. We also sent cushions and linen to brighten up other rooms. Even the smallest things – from donating loo rolls or other products on your local House’s wish-list, to volunteering to cook dinner – make a difference.

We’ll continue helping for the rest of our lives. Because, despite what Peter Pan believed, going away doesn’t mean forgetting. **AWW**

For more information about Ronald McDonald House visit rmhc.or.au

Clockwise from right: The clown doctors pay a visit; Teddy spent much of his short life in hospital; Kerry and Antony sponsored a room in Randwick.



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