

Paul and Luke's Story

Luke arrived in this world 24 April 1997, some 9 weeks premature and is now a 25 year old young man who loves life and has taken us on a journey we could never have imagined. A few extreme lows but so many more highs and wonderful experiences. He really is a valued member of our family and his community, and our lives are so much richer than we could have imagined.

We now live in Western Sydney, Mum – Judy, Dad – Paul and sister Sarah where Luke enjoys a full and varied program.

Just after Luke was born, I contacted Down Syndrome NSW thinking they may be a good starting point. They immediately arranged a local family with a young boy with Down Syndrome to contact me. We visited them in their home and that really helped us know what to expect and how we should start on our journey. This was hugely encouraging, and I found this, and many other contacts gave me valuable information to help me get to the next step.

It wasn't long before Down Syndrome NSW called me and asked if I could contact a new family and similarly share our experiences. I was taken with how the family valued this interaction, and they stayed in regular contact until we moved from the area.

Down Syndrome NSW was such a support and valuable resource to us especially until Luke was into his school routine, and we had developed our support network. As Luke grew into young adulthood, I renewed contact to have Luke become in the over 18s, Up!Club!. As Luke needed additional support with his diabetes, I decided to take him to the Up!Club! activities as carer. I soon became a volunteer and more recently, this has led me to a new career in disability support.



I think back to some tough moments, like when Luke was born and weighed some 950 grams. The medical teams pulled out every stop to keep him alive over his first days, but he pulled through and went from strength to strength. Then when 4 years old he contracted Diabetes type 1, another challenge for us. Then when 10, he contracted Streptococcal infection and spent 2 weeks in intensive care, again nearly losing his battle more than once over the following 2-weeks, but he finally pulled through. These experiences make him our miracle man!

I knew very little about disability and Down Syndrome, when Luke was born and was quite unprepared. I had to learn many things along the way. We never know quite what to expect and that makes life interesting! But right from the start I found a wealth of support and a whole community in similar circumstances to me. **I discovered how society has evolved from my old-fashion view of sending disabled children off too institutional care and that Luke could enjoy a full and rewarding life as a valued member of the community. We are reminded that we aren't alone.**

When I look back to when I found out my son had a disability, I anticipated it would be an overwhelming burden, but having been handed this gift, I set myself as ready to take on the challenge. The thing I learn from Luke is to live in the present. He only cares about the now and leaves all the worrying and planning to me or someone else. He is non-judgemental and gives unconditional love. His hugs would melt the hardest heart. Luke loves life and is my mission – the reason to get out of bed every day and stay positive.

