

CHRIS'S STORY

I loved Elsden from the moment I first saw her. When my wife had her twelve-week scan it was like Elsden knew we were looking in and was waving her tiny arms and legs just for us. Having gone through the heartbreak of several failed pregnancies before this one, we breathed a huge sigh of relief when the doctor told us that our baby had a strong heartbeat and that she was "healthy and perfect". We knew next to nothing about Elsden at that stage except that we loved her.

As part of the twelve-week check up, my wife also had a blood test. The results of that blood test showed a high chance of our little girl having Down syndrome and subsequent testing confirmed this diagnosis to be true.

Unsurprisingly, this news knocked me for six. I suppose it was natural to grieve the loss of the child I thought we were going to have but mostly my reaction came from a place of ignorance. Down syndrome was a complete unknown to me. I had never known anyone with Down syndrome, and I had no idea what life with Down syndrome was like. So my mind filled with outdated and incorrect stereotypes. Thankfully we met with the hospital genetics counsellor who gave us an information pack from Down Syndrome NSW. This pack and the information it contained was a lifeline.

By doing a lot of reading and talking with other parents of children with Down syndrome we soon learned that advances in medicine, education and acceptance meant our little girl would live a very rich and rewarding life and she would enrich the lives of those around her – something we now know with absolute certainty. Getting the prenatal diagnosis was actually a blessing, as it gave us time to process the news and our emotions before Elsden arrived. Our initial feelings of disappointment soon passed, and we were then just as excited as any expectant parents would be. After months of scans and appointments, the day of Elsden's birth was one of the happiest of my life. It was amazing to finally meet the little girl we had already learnt so much about. As she was born early and some of her levels were low, Elsden spent her first few days in the Neonatal Intensive Care Unit.



Despite how ominous being in NICU may sound, the notes I was keeping on that first day end simply with 'Not overwhelmed, overjoyed'. As a dad, one of the biggest challenges I found in those early years was getting used to people doing a double take or even staring when they saw Elsden. At times it feels like everyone notices there is something different about your child. However, once you move passed the urge to yell, you soon realise it's human nature for their eye to be drawn to that which they perceive as 'different'. And if people stare, hopefully they will see that what they perceived as different is actually not different at all. If people stare at Elsden all they will see is a little girl doing the things that little girls do.

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I would say to other parents expecting a child with Down syndrome that getting the diagnosis is the worst part. Once you have received that news, the worst part is over. You'll soon find out that most babies growing up with Down syndrome will lead ordinary lives. Just like you and me, all they need are the right supports and opportunities to reach their full potential. That is why reaching out to an organisation like Down Syndrome NSW is so important. That is where you can make valuable contacts and get reliable information.

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For us, as vital as the prenatal and new birth support was, it was just the first step in a lifelong journey. As we move forward, it is reassuring to know that at every stage of Elsden's life Down Syndrome NSW will be there with the support and resources to ensure she lives a meaningful life as a valued and contributing member of her community.

Writing this now, I know my words cannot do justice to all Elsden is and all she brings into our lives. She is still just as the doctor first described her at that twelve-week scan – healthy and perfect.