

Mary and Sarah's Story

PRENATAL AND NEW BABY

When Sarah was born we felt so relieved. She was alert, robust and vocal, and scored well on her birth check. Our Midwife placed Sarah on her Dad's chest, skin to skin, and we were besotted. Soon after, a nurse spoke to us. "We've picked up some of the indicators you're aware of, single crease on hands and spacing of eyes. Your Doctor will see you soon." I knew straight away she was referring to Down syndrome. I thought, Oh, we're in that place. I said to my husband David, "I don't care, look at her, she's beautiful."

Sarah is our fourth child and we were over the moon to be pregnant again. As an older mum at 42, I had a nuchal translucency screening, as a check on our baby's well-being. This gave a high risk result of our baby having Down syndrome. We were cautious when further testing was suggested and declined, considering it too risky. When I was 36 our baby daughter Anna was stillborn, at term; and in the following years I had two early miscarriages. We were very aware of the fragility of life.



>>> Our Pediatrician came to see us. I remember his warm words so clearly - "I am not talking to you with a heavy heart. Sarah will bring you much joy. My role today is to inform you of what Sarah's needs may be so that you leave here more knowledgeable."

We were told about possible health concerns into childhood and adulthood, and to take a proactive approach. We have older children and have experienced a range of services and doctors' appointments. So many questions ran through my mind. What sort of life would Sarah have? Our Doctor enlightened us with possibilities and choices. Sarah could attend regular day care mainly, with a mix of special needs care.

We could enrol her in a mainstream preschool and school, which offers extra support. He explained how to access funding, now the NDIS, and a Carer's Allowance. He spoke of local learning centres, such as Learning Links, and Down Syndrome NSW, and stressed the importance of starting early intervention therapy. Initially, this sounded very clinical to us, but if we were told all of the health risks our older children may have encountered we would've been just as wide-eyed.





I felt overwhelmed and even guilty, as thought in our desire to have another baby, I'd given Sarah a hard life, but then I looked at her in her hospital bassinet, contently sleeping, with a little smile on her face, suggesting "Actually, I'm just fine".

A nurse handed us a folder, she called a Down syndrome Kit. When we opened it we read - Congratulations on the birth of your baby. We took heart in this, and decided to contact Down Syndrome NSW down the track. We wanted to take Sarah home to her brothers, Paul and Michael, and get to know her first, before more discussions. We waited 6wks, but I'm glad we didn't put it off any longer.

Down Syndrome NSW became such a valuable resource for us. The parent support coordinator I spoke with was so helpful and experienced. She had a 7yr old daughter with Down syndrome. I learnt that the organisation was founded by parents. They linked us to information and workshops and invited us to meet with other parents and families. The social groups provided a wonderful network to share knowledge and make firm friendships. I hosted a regular coffee morning when Sarah was a toddler and the friendships we made between parents and children, remain. We have never felt alone. There is support on hand.

I returned to work 4 days a week. Sarah enrolled in the same Daycare and Pre-School her brothers went to. It was an inclusive, beautiful learning environment. We attended an Early Intervention PlayGroup at Learning Links. It combined therapy with fun, and gave a supportive haven for parents to talk, share and laugh. Our Parish Catholic Primary School was welcoming and it encouraged a love of learning in Sarah. We chose a mainstream High School, with a Life Skills class in a supportive school community which challenged Sarah to be her best.

I was once asked, "Does Sarah know she has Down syndrome?" So I talked to Sarah and she replied, just like her friend at school and that someone else has another syndrome. She then asked, "what syndrome do you have Mum?" Sarah doesn't see herself as having a disability, and accepts that everyone is different. She is not suffering from Down syndrome.

A friend shared these wise words - What we want for our children is for them to be happy, loved, loving and good citizens. There's no reason Sarah can't be this. Sarah is now 18 and insists she is an older adult. She voted in the federal election and completed her yr12 HSC in Life Skills. Sarah enjoys her Dance classes and performing and her favourite singer is Harry Styles. Sarah loves her family and is a loyal friend. She has a happy social life and is in a school leavers' employment service program, learning work skills and independent travel. Sarah also has Down syndrome.

We have taken so much pride and joy in Sarah's milestones and achievements, as she has too and admire her emerging strength of character now as an adult. Sarah has many opportunities to achieve and shine, and she is developing resilience. At school she wrote in a letter, "Thank you Mum for giving birth to me and my brothers and sister. Please know I really appreciate you and love you and Dad." Sarah's future is bright.

