

DOWN SYNDROME NEW SOUTH WALES

Melissa and Samuel's Story

PRENATAL AND NEW BABY

Early Years

Being a new parent comes with its common set of challenges for most families, but for parents whose children are diagnosed with Down syndrome, the start of their journey can feel particularly daunting. What should be a time of celebration and joy can sometimes be overshadowed by the cautionary messaging from healthcare professionals.

While there has been progress in recent years, there are still instances where healthcare professionals may struggle to deliver accurate and supportive information to parents upon the diagnosis of Down syndrome. In some cases, the news is delivered in a way that may emphasise the challenges rather than the potential for a fulfilling life. Unfortunately, the initial communication from healthcare providers can be framed in a negative light, using language that conveys sympathy or apologies instead of celebrating the birth of the child.



For Lee and Melissa, reflecting on the birth of their son Samuel, now 10 years old – a skilled ball player, bike rider and lover of music, they consider themselves lucky to have had an extremely supportive midwife who encouraged them about their baby's capabilities. In the early days, when Samuel was only a newborn, Lee and Melissa were visited by a team member from Down Syndrome NSW to offer support, guidance and celebration for the birth of their beautiful son with Down syndrome.

This first hospital meeting would start a much longer journey for Samuel's parents, who continued to contact the team at Down Syndrome NSW at all stages of Samuel's life. Throughout the years, they found a strong sense of community; connecting with other families, attending educational webinars and social events, and receiving guidance when new challenges came up.

Parents like Lee and Melissa know how important it is for parents of newborns with Down syndrome, to get access to support and connect with their community as soon as possible in those early years. Like many of the families Down Syndrome NSW work with every day, they experienced firsthand the benefit of medical professionals learning to say Congratulations, instead of sorry, and providing parents with accurate, up to date information to support their journey.

As Samuel grows up, with his parents beside him, Down Syndrome NSW will be with them along the way.

"I know Down Syndrome NSW are advocating on our behalf in the wider community to improve the lives of all with Down syndrome."