

## Stephen's Story



The youngest of five boys, our son Stephen was born in September 2009. It was during our 18 week scan it was picked up that he would have a cleft lip and palate. Prior to the scan our thoughts were only focused on whether the new baby would be a boy or a girl - we never expected anything to be wrong - so as a family we went through an immediate change of perspective!! Even though I had come from a background in disability services, I did not know much about what a cleft palate was, and what having a child born with a cleft lip and palate would look like. So, in the months before Stephen was born, I read lots of journal articles, looked at as many photos on the internet as I could find, and read through stories written by parents and families who also had children with clefts. The biggest help for me came from all the beautiful stories and photos that parents had put together, sharing their journey and experience of parenthood, and what having a child born with a cleft lip and palate meant to them. Their stories brought me great comfort and I felt part of a community that shared and supported each other through a common bond.

Before Stephen was born I worried about a lot of things... What would I do when I saw him for the first time? How severe would his cleft lip and palate be? What would his brothers think? What would other people say? How would his feeding go? It's funny but I didn't need to spend so much time worrying!! From the first time I saw Stephen I loved him, he was precious and beautiful, I had felt him growing inside me, and now he finally lay in my arms, adored and wanted and loved unconditionally. He was a brother, a son, a cousin, a nephew, and a grandson. He was just beginning his life and it was filled with opportunity and possibility and hope. Although Stephen was born with a cleft lip and palate, it was at this moment that I realised that he was not defined by it. And his big brothers didn't worry at all, they just told their school friends "my new baby brother has a big hole in his face, but when he gets bigger the doctor will sew it up"!!



When Stephen was just a few weeks old, we went to the Royal Children's Hospital to have him fitted with a NAM (nasolabial moulding), which he wore until his lip repair surgery. Wearing a NAM just became another part of our new "normal". It really helped with his feeding, and he did much better with his bottle when he wore it (we used the special needs feeder, formerly the Haberman Feeder, with regular baby bottles) and it made a significant difference in closing his cleft lip and palate before surgery. Every so often his skin would become a little rashy from the tape, but we would just keep trying different ones and used lots of Dermaveen!!



As he got older, Stephen did flick the NAM out of his mouth with his tongue (which did invite some quizzical looks by people in the supermarket!!) but a little denture glue helped keep it in place!! Travelling into the RCH each week and seeing the very lovely orthodontists became much looked forward to, and sitting in the waiting room chatting with the other parents and seeing their children with cleft lip and palates, was something we missed going after Stephen's surgery!!

In the week before Stephen's lip repair surgery, we had some professional photos taken, as I wanted to remember him as he was before his surgery, and wanted something that Stephen can look back on when he is older. His cleft lip and palate makes up a special part of who Stephen is, and as a family we are proud of that, and trust that he will be too.



When Stephen was 6 months old, he had his cleft lip repaired. Handing Stephen over to his surgeon was such an anxious moment, as so much trust is placed in the hands of another. We knew that the face of our son was about to be changed forever!! The surgery went really well and was a great success, and we are thankful for the skill of our surgeon, his compassion as a medical practitioner, and his empathy and humanity as a person. We are profoundly thankful for his care, and see him as one of the many pieces that come together to form a picture of who our family is. Holding Stephen in recovery was an emotional time for my husband and I, as after his lip repair he did look so different!! His mouth was a little swollen but he now had a beautiful little nose and a lip that joined together held in place by the smallest and delicate of stitches. Stephen spent one night in hospital and came home to be admired by a

wish I had a dollar for every time someone said “it’s amazing what can be done these days”, but it’s true, it is *amazing* how superb cleft lip and palate surgery is today!! For several months after Stephen’s surgery people would comment on the difference that it made (in the supermarket, at playgroup, at the park...) and continues to make in his life today. One of the worries that I had before Stephen was born was that I would feel isolated, but having a child born with a cleft lip and palate has been the opposite experience; it has opened many doors and provided countless opportunities for people to come up and start conversations. Complete strangers would want to know what his name was, and want to talk about the families they knew who also had children with cleft lip and palates. I found that their questions were always without judgement and that their well wishes were always genuine.



When Stephen was 9 months old, he went in to have his second surgery, this time to repair his cleft palate. Again, the same plastic surgeon (not to forget the whole medical team!!) did a beautiful job repairing the cleft palate. Stephen spent two nights at the RCH, and as we were able to get his pain management under control and he was feeding well, Stephen came home. However, it did take longer for Stephen to recover from the palate repair surgery and for him to feel comfortable, than compared with the lip repair. So that Stephen didn’t put things in his mouth and damage the newly repaired palate, he wore arm splints for about 6 weeks. Although it wasn’t long before Stephen was tearing open the cupboards and throwing out the Tupperware and generally wreaking havoc. It also wasn’t long after his surgery that Stephen was drinking all by himself from a regular baby bottle, and for us, it’s these things, so often taken for granted, that become real achievements!!



The next big milestone for Stephen was his first birthday, and as time has gone by so quickly, he is just about to celebrate his second!! Stephen is a very action-packed toddler, madly racing after his older brothers and desperately wanting to join in all that they do. He takes the batteries out of the remote controls, puts Lego down the ducted heating, draws on the table, wears my shoes, and is obsessed about socks, cars, books and balls. Stephen chases the chickens in the garden and tips out their water. He stands on all the vegies in the veggie patch and throws the clothes pegs off the decking. He talks non-stop and wants to read books about trucks and liggers *all* the time. Stephen loves to eat but won’t let anyone feed him and throws his food on the floor when he has had enough. He is independent and resilient, he is funny and is full of laughter, and he is cuddly and loves to snuggle in bed with his blanket and teddy.



As a family we are blessed to have another beautiful and boisterous son, who was born with a cleft lip and palate, but is not defined by it. When speaking with others, the most confusing thing that I find happens these days, is that my past-present tense constantly changes!! *Yes* Stephen *was* born with a cleft lip and palate, but *no*, he doesn’t have one *now*, he has *had* his surgery and his cleft is repaired, and although Stephen *did* have a cleft (and there may still be ‘work to be done’ in the future), *now* he is just like any other happy and healthy toddler!! As a person, Stephen is an individual, made up of so many things, and being born with a cleft is a special part of who he is and who he is to become in the future!! I hope that Stephen will always be proud of the many parts that make him whole and to reflect upon his many blessings. I am proud to be a parent of a child born with a cleft lip and palate, and to be part of a wider community of people who support and encourage each other.



As a family, we are also much more aware of people living with cleft lip and palate conditions other countries. We are thankful for Stephen’s surgery and we choose to support the work being done overseas by amazing and truly inspirational surgeons and all those who volunteer their time. It’s a joy to be able to pay our blessings forward, and to help other families in the same way that others have helped ours!!

