My Little Warrior

Tracey Azzopardi

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Going to be a mum

I was always focused on my career. After six years from working overseas in Hong Kong, Shanghai, and London, I came home to Sydney to have a baby. Having a baby was the one thing that I had always wanted. At 43 and after four rounds of IVF with an anonymous donor, I was ecstatic to find out I was finally pregnant. I was going to be a mum.

23 Weeks~The roller coaster begins

Where to begin. It was still early. I hadn't yet started ante-natal classes or visited a maternity ward. I still had plenty of time to get ready for childbirth, or so I thought. Little did I know it was the start of an unexpected roller coaster journey of uncertainty and emotions.

While on my way to work 23 weeks into my pregnancy, I didn't feel right so I visited my obstetrician. Several hours later with ruptured fetal membranes, my doctor explained that it was vital I deliver at a hospital with a neonatal intensive care unit. Thankfully Westmead Hospital had a bed because later my baby would need the Grace Centre for Newborn Intensive Care at the Children's Hospital at Westmead. I was transferred by ambulance to the Westmead Hospital which was only one street away and taken to the delivery suite.

The following day I had an ultrasound. I could not see the monitor that the three doctors were looking at. Clearly, something was wrong. My baby had moved from being ready to deliver to being transverse and the umbilical cord wrapped around my baby's arm. My baby could not move. That afternoon one of the Fellows from the Newborn Intensive Care Unit (NICU) came to sit with me. She was a kind and gentle doctor who took the time to listen and help me understand what was going on and the options available. The doctor explained the probability of survival and the ramifications of a delivery at such an early age. We were at 23 weeks and one day, and every day counted.

What was going to happen next? I was told that one of three things would happen: contractions would start, my baby's heartbeat would slow, or infection would set in as there was not much amniotic fluid. I was started on antibiotics and my baby's heartbeat was checked three to four times a day. Thank goodness for my mum who was with me every day. Confined to bed, I hung on to hope and stayed focused on the positive.

Delivery at 24 weeks

Seven days later while lying in the hospital bed, I experienced rigors and within minutes, several members of the medical team surrounded my bed. Antibiotics, steroids and vitamin K were injected, blood tests were taken, and I was put on oxygen. My

Tracey Azzopardi with her daughter, Matilda

obstetrician and I had a very quick discussion. As much as I wanted to experience childbirth, the only thing that mattered was giving my baby the highest probability of survival, which meant my baby being delivered by emergency caesarean. Before I knew it, I was in the theatre and there were people everywhere.

It's a girl!

I woke midday the following day. The nurse asked me if I knew where I was and I said yes. Then I asked, "My baby...is my baby alive?" Her answer was yes. I then asked, "What did I have?" She responded with "you had a girl." It was a surreal and joyous moment that I will never forget.

Meeting my baby

Taken by wheelchair to meet my daughter, I was excited and scared at the same time. She was born at 24 weeks and 1.5 hours weighing 590 grams and required resuscitation and intubation at birth. Being wheeled into the NICU and meeting my baby was overwhelming as she was in a humidicrib and there were wires and tubes everywhere with multiple pumps and machines beeping.

Too fragile to hold, for the first three weeks of Matilda's life, Tracey placed her hands gently on her through the crib's doors

My baby was so tiny. It was hard to believe. The nurse explained containment holding and where I could place my hands on my daughter. Needless to say, I did a lot of containment holding.

Picking a name

Upon meeting my baby girl, giving her a name was an easy choice...Matilda. The meaning of her name is quite significant and means might and strength in battle. This tiny human had many battles ahead.

On-going challenges

In the following four weeks after Matilda's birth, she faced serious breathing and lung issues. Her x-rays showed lungs that looked like they were covered in clouds and she was given two rounds of steroids to clear them. Matilda's heart valve had not switched over until a day after her second round of treatment. Everything seemed to take a little bit longer.

Too fragile to hold, for the first three weeks of Matilda's life I placed my hands gently on her through the crib's doors. After three weeks, I held Matilda for the first time for one hour. It was our first skin to skin and it was sensational. As Matilda got stronger, I was able to hold her for longer periods. Skin-to-skin or Kangaroo Care was the most precious time I had with Matilda. Transferring Matilda out of her humidicrib was done with extreme care. It took a bit of organising and required three nurses. As soon as I would arrive in the morning, I would touch base with Matilda's nurse, find out how she was overnight, and what was scheduled for the day. Together the nurse and I would figure out the best time for skin to skin. During skin to skin, Matilda's breathing would always be at its best with minimal desats. I made it my mission to do as much skin to skin as possible. Our record was 6.5 consecutive hours. Typically, I would usually do 3 hours each day.

Surgery

On day 28 I arrived to find out that Matilda needed a surgery consult. All I heard was the word surgery. They were going to cut my tiny baby open. Preparations were underway without delay

and Matilda was transferred to The Grace Centre for Newborn Intensive Care at the Children's Hospital, Westmead in Sydney. A battery-operated motor was attached to the humidicrib to power the CPAP and pumps, and Matilda was transferred via a tunnel that connected the two hospitals.

Grace is a surgical NICU, and without a doubt one of the best in the country. Upon admission, tests, x-rays, examinations and so on, a surgical team arrived. The medical team was standing two deep around Matilda's humidicrib. Then the surgeon arrived and examined Matilda and there was rigorous discussion. He introduced himself and explained that after examining Matilda he could not guarantee, however was quite sure he knew what was going on and that there were no tests to confirm it. The only thing that could be done was to go in and have a look. I listened carefully. The surgeon was very clear. There was no doubt how serious it was as Matilda was so distended. She was 28 days old and weighed 790 grams and had already been through so much, yet needed this surgery urgently. Once the surgery was over the surgeon confirmed that Matilda had NEC or necrotising enterocolitis and showed me a diagram. In total, 28 centimetres or approximately a third of Matilda's bowel was removed.

Progress measured in baby steps

Post-surgery the darkest green bile kept coming out of Matilda's oral venting tube for weeks. One of Matilda's neonatologist kept reminding me, Matilda runs on her own time table and we need to patient with her. I'll always be grateful for the generosity of his understanding and ability to explain things and manage my high expectations. Two weeks after Matilda's surgery, she started on one millilitre (ml) of breastmilk over four hours. Every two days we slowly increased her milk by 0.5 mls per hour. It was a slow progression. When Matilda's target was reached, we then had to transition from the four-hour cycle via continuous pump to regular feeds every four hours that I would be able to do via gravity feeding at home.

Taking each day as it comes

Two steps forward and one step back was the term commonly used. Taking one day at a time is the only way to go and not

get ahead of yourself. I refused to go online and read blogs etc. If I had a question, I would put it in my phone and ask the appropriate person on Matilda's medical team. Attending morning and afternoon rounds meant I was always up to date and knew what was going on. It was important to learn how the NICU worked, who was who, and how to find out information or escalate concerns.

A month before coming home, Matilda's nose was finally big enough to have the smallest size nasogastric tube (NG) fitted. Without any tubes in her mouth, during skin to skin with the support of the Speech Therapist and Lactation Consultants, we persisted in encouraging Matilda to latch on and breastfeed. They would put the stethoscope behind her ear, counting how many sucks and swallows she had. Matilda was sucking, but rarely swallowing. Our plan was to keep trying. I really wanted to breastfeed believing it would be the best thing for Matilda's gut and growth as she was still very tiny. My persistence was worth it as I breast fed Matilda until she was 17 months when Matilda was able to use a sippy cup.

Developmental rounds and individualised developmental care

I would be so disappointed if I missed the Developmental rounds. There were usually three specialists who would assess each baby and give recommendations to the nursing team. What may seem like something small to some, the recommendations for Matilda had a significant impact on her.

I was approached about carrying out an assessment to review and develop an individualised developmental plan for Matilda. This was exciting. Anything that we could do to help Matilda to make her as comfortable as possible and that supported her progress was a great thing. A group of professionals going through training observed a nurse and I doing Matilda's cares. As I was shown, I would always start from Matilda's head and work my way down to her feet.

The written report I received following the observation was brilliant. When changing Matilda's nappy and undoing the Velcro tabs, her body would flinch and her facial expression would change. When these observations were shared in the report and I read it, I modified the way I changed Matilda's nappy. The report provided instructions for all of Matilda's team to follow. One of the trainees on the Developmental team suggested I prepare a shorter version of the report as if it was written by Matilda. It was then attached to the end of her bed for all of her nurses to follow.

Reflections from our NICU experience

There was a night or two when I got all the way to the car park and had to walk back to the NICU. Leaving your baby is a challenge. The best thing to do is focus on getting home, eating and sleeping, staying as healthy as possible and seeing and holding them the next day.

Helping my daughter's voice be heard

Being Matilda's advocate and voice...that is what mums do, right? It is a balancing act. Being respectful of the medical team

is really important. At the end of the day or evening, you have to leave the NICU and leave your baby in the care of this team and trust is really important.

Going home

After spending 161 days (5 ½ months) in the NICU, Matilda was discharged in early December 2017 weighing 3.3kg. For ten months following discharge Matilda required home CPAP and was connected to a mobile corometrics monitor for obstructive sleep apnoea whenever she was sleeping.

The year following discharge was full of appointments and therapy. The combination of attending a feeding clinic, physiotherapy and occupational therapy were all very beneficial. We put everything we had learnt in the NICU into practice at home. She will have glasses in the near future. Matilda has Chronic Lung Disease and will continue to be monitored. Whilst Matilda is delayed and in the low average range for her language, cognitive and gross motor skills, we continue to focus on these areas and I have no doubt that she will continue to improve. She is making great progress with her fine motor skills. Matilda loves books and has them everywhere. We do a lot of reading.

Tracey says Matilda is a very resilient, determined, happy and joyful child

Gratitude

There is no doubt Matilda is alive and doing so remarkably well today due to the care she received from the moment I found out she would be arriving early, and throughout her entire journey. I remain forever grateful and indebted to every person who cared for Matilda and for their amazing skills, patience and empathy. They were a dedicated team of people who worked together and truly cared for Matilda.

Matilda is now two and a half and is a very resilient, determined, happy and joyful child, who has made amazing progress and continues to thrive. She is truly loved and I am fortunate to have such an amazing daughter.

We thank Tracey Azzopardi, Matilda's mother, for sharing her story, and Matilda's journey with us.