

## WILLIAM'S STORY

At 12.11pm on the 18<sup>th</sup> July, 2003 at Frances Perry Hospital we welcomed our third child, William into our family, a little brother for Ben, 5 & Sam, 1.

William has had many hurdles to cross since arriving in this busy world. He was diagnosed with Aortic Stenosis when he was 24 hours old. William has had 3 operations in his short little life so far. His first operation at 3 and a half weeks was a balloon valvuloplasty to hopefully widen the narrowing of his aortic valve. This did not work as well as what the doctors thought and William ended up in ICU for a week. His second operation at 8 weeks was a heart bypass to try to repair his aortic valve and give us some more time so he could grow stronger before they had to replace it completely.

The surgeons told us William would get between 8 months and 4 years. William returned to the hospital at 8 months to have the valve replaced by his pulmonary valve and a donor valve was inserted where his pulmonary valve was - this is called The Ross procedure.

When I was asked to tell our story I wanted to tell it from our family's perspective, what we went through as a family and how we coped.

What an amazing road we have been down. From having a family who were hardly ever at the doctors to a family with a sick little boy plus having to juggle 2 other children at home under 5 was a huge task in itself.

Our eldest child Ben was quite aware of what was happening. What an amazing little boy he was through this time. I spent the majority of William's first 12 weeks of life in the Children's Hospital, therefore Mum was not home often to tuck him into bed or read his bedtime story. Ben was attending 4 year old kinder at the time. I remember thinking how fantastic the staff at the kinder were with him. Ben started Prep in 2004; therefore Ben had only been at his new school for a month when we were told that William would need his 2<sup>nd</sup> bypass. I was so concerned for Ben as I couldn't be there for him at school as much as I would have liked. He really is growing up before our eyes. His nature is one of love and caring for his two little brothers.

Then there is little Sam who at the time was only 13 months old, so really was still a baby himself. He grew up so quickly. At the time it was hard as I didn't even see Sam take his first steps. He walked into the hospital with his Dad and the tears just didn't stop on my behalf. What a huge milestone and I had missed it!!! Sam was going to daycare 2 days a week and the staff had told us that he had become very clingy and cuddly. I remember feeling so guilty that I wasn't there to give the cuddles that he needed. Since William has returned home from his last operation, he and Sam have developed such a neat relationship. They do everything together and get up to a lot of mischief from digging in the dirt outside, to having races with their bikes.

Our extended family all pulled together as one to help. It was really fantastic. Darren & I are both from large families and William has brought us all so much closer together. Ben & Sam spent a lot of time in between our family's houses so Darren & I could concentrate on William getting better. How tired Darren & I were. They really were long days in the hospital and often very frustrating. Just when you think William was progressing really well, we would face yet another hurdle.



Spending time in the hospital you meet lots of different people who are going through exactly the same thing as you. It's so nice to talk to the other parents. We all seemed to help one another. We have met so many lovely people, from the volunteers and Heartkids representatives who come in and offer their support whether it's giving a bottle or giving your baby a cuddle while you go and have a coffee; the nurses who I believe are the unsung heroes - they are like counselors, friends, & doctors all rolled into one; the PSA's who always make sure you have everything you need; to the Playroom co-ordinator who would come and grab Ben & Sam and get them drawing or painting. This really opens your eyes up to what beautiful people there are in this world.

The community as a whole also was there in our time of need. When William came home in between his first and second operation the Maternal & Child Health Nurse, Wendy Thornton, visited us on a weekly basis to weigh William and see how we were coping. This continued when he arrived home after his second operation. What an amazing lady she is.

Just to have someone to talk to and a shoulder to cry on.

When William returned home from his 3<sup>rd</sup> operation he was 8 months old and seemed to have been traumatized by his experience in hospital. He wouldn't let me out of his sight. This made our home life very hard as I couldn't leave his bedroom until he was asleep. I thought we have to do something about this, for his sake and ours. We took William to the Mother Baby Unit at South Eastern Private Hospital. What a great decision this was. William was suffering from anxiety. The help and support I received was amazing. After a 5 night stay there, William and I returned home and our lives started to return to normal.

William and his brother Sam now attend childcare which they both love. William is treated just like any other child and has a permanent smile on his face. He can't wait to get to childcare to play with all the kids and toys. We still have an Emergency Plan in place at the centre in case anything should happen.



We still have the scheduled cardiac checkups (but they have been extended to 3 monthly), the never-ending doctor's visits (as William seems to pick up any bug that is in the air), the short hospital stays due to these bugs, and the 6 monthly dentist visits (a preventative measure because heart kids need good dental health), but all in all who can complain when you look at his smiling face.

Our lives now are amazing and so fulfilling. We now have 3 healthy boys, but one little boy called William who will always remain a very special little boy. William has just taken his first steps last week. He loves his brothers so much and enjoys the company of others.

Written by William's Mum, Louise, November 2004

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ACRONYMS EXPLAINED:

PSA	-	PATIENT SERVICES ASSISTANT	ICU	-	INTENSIVE CARE UNIT
IV	-	Intra-venous	PAP	-	Continuous Positive Air Pressure

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***WILLIAM'S MUM, LOUISE, KEPT A DIARY OF HER FEELINGS AS WELL AS THE DAILY EVENTS. SHE SHARES WITH US SOME EXTRACTS FROM WHEN HE WAS IN HOSPITAL.***

**William's 1<sup>st</sup> Operation: Balloon Valvuloplasty (3 weeks old)**

*Friday 15<sup>th</sup> August, 2003* You had your last breast feed at 5.30am. You smelt so good, because the nurse had given you a bath at 5.00am and then woke me up to feed you. At 9.00am they came to get you to take you to theatre. Mum & Dad walked with you to the waiting area and then kissed you goodbye as they took you through to theatre. I will never forget watching you being wheeled away in your cot. You were only 3 weeks old and you were about to face the biggest challenge of your life.

Your father and I, tissues in hand, decided to wait in the parents waiting room, even though your operation was to take at least 3 hours. The surgeon said that when they were finished they would call our name over the intercom. Four hours later, the doctors came and got us from the waiting room and asked to sit down in this tiny little room. My heart was going a hundred miles an hour. They told us that they had a few hiccups when beginning the operation and that they had to administer CPR for 5 minutes. They said that you were OK but they had decided to transfer you to Intensive Care and the next 24 hours would be critical. We would be able to see you in 1/2 hour.

I had tried to prepare myself as we were told you would have a lot of tubes coming out of everywhere. No matter how much we prepared ourselves mentally, your father and I were very emotional when we saw you for the first time. We were even scared to touch you. We asked permission to touch your hand and they said that was fine. Oh William, you are such a strong little boy. We love you with all our heart. You hang in there!!!

*Sunday 17<sup>th</sup> August, 2003* The ICU Unit Manager came and spoke with Mum & Dad this morning. They are worried because you have been making strange movements with your arms. They suspect that you may be having seizures. He said they were organizing for you to have a CAT scan. You were wheeled from ICU down to where they perform the CAT scans. Dad and I sat outside the room waiting for you. It took about 1/2 an hour and this was once again another scary moment for your Dad & I. The doctor came out of the room and told us that everything looked normal. I can't tell you William how much I wanted to throw my arms around that doctor and give him the biggest cuddle.

*Tuesday 19<sup>th</sup> August, 2003* Today was an amazing day! I got to hold you for the first time since your operation this morning. They sat me in the chair beside your crib and moved all your tubes and wires so I could nurse you. I cried my eyes out!! Your little eyes were looking straight up at me, that moment was priceless.

**William's 2<sup>nd</sup> Operation: Bypass Surgery to Repair the Aortic Valve (8 weeks old)**

*Saturday 31<sup>st</sup> August, 2003* You woke up this morning at home with sweat all over the back of your head. I was very concerned. Dad & I had decided to monitor you throughout the day and if we weren't happy we would take you to the hospital. Your breathing throughout the day had really increased. Your tummy was going up and down so fast. I decided to take you straight to emergency. The Cardiology Fellow saw you straight away and said that the x-ray showed that your heart was enlarged and that he wanted to admit you straight away for close monitoring. He said your case would be presented at the meeting tomorrow morning and then we would know what was to be done.

*Monday 1<sup>st</sup> September, 2003* Dr Penny came and spoke with Mum & Dad and told us that the leak from the valve was very bad and that you had to have open heart surgery as a matter of urgency. Dr Brizzard told us they had two options, either to repair the valve or to replace it completely but they wouldn't know which way they were going to go until they had opened you up and had seen how severe the damage was. Your father and I were so upset at the thought of you having to have open heart surgery but realized if you didn't have it, we probably would be saying goodbye to you next week! Why us? I keep asking.

*Sunday 7<sup>th</sup> September, 2003* Today is Fathers Day. I left Dad at the hospital with you and took Ben to a birthday party. Sam and I went shopping for Dad's Father's Day present. We picked Ben up after the party and came back to the hospital. We got Dad a digital camera for Father's Day. You had had a good day with Dad. Dad took Sam & Ben home at 4.30pm. At your 9pm feed we tried you with a bottle. You took a few sucks which was great. At 9.30pm I headed back to my room as Lucy's parents (you are 6 weeks apart and she is in the ward with you) had cooked me dinner. It was so nice to have a proper meal!!! We even had a glass of wine. How well I slept that night.

*Wednesday 10<sup>th</sup> September, 2003* Dad dropped Mum at the hospital today and then dropped Ben & Sam at Auntie Molly's for the day. The doctors decided to feed you through the naso-gastric tube for the next few days so you could rest. They explained that at 4am you went very pale and were quite agitated. You vomited 3 times throughout the day. We spoke with Dr Penny this afternoon. He told us that it was going to be a very slow process and we would take it day by day. Dad & I left the hospital at 5.30pm to go and pick up Ben & Sam from Auntie Molly's. We had dinner at Auntie Molly's & Uncle Brad's.

At about 7pm I rang the hospital to see how you were doing. Nana & Grandpa had been in to visit you. Danielle (nurse) answered the phone and said that they were about to contact us. She said you weren't doing very well and the ICU team was on the way up. You had gone a pale grey colour and were having trouble breathing. Dad & I left the kids with Aunty Molly and rushed straight to the hospital. It took us 12 minutes from Balwyn to get to the hospital.

They were having trouble finding a vein to put an IV drip in. The doctors and nurses were all around you. They took me in to see you. They were trying to give you an echo at the same time. You had lost all your colour. I was so scared!!! They did a chest x-ray as well and then you were taken straight to ICU. Once they had put the oxygen nasal prongs back on you, you seemed to really pick up again. They restricted your feeds completely. You were on heavy sedation to let you rest. Dad & I left the hospital at 11pm and went and got the boys. What a day!!! One step forward, two steps back!

**William's 3<sup>rd</sup> Operation: Bypass Surgery to Replace the Aortic Valve - The Ross Procedure (8 months old)**

*Sunday 7<sup>th</sup> March, 2003* It's now 3 days since your operation, and when I arrived at the hospital at 9am they were concerned about you. Your heart rate had increased and you were breathing really hard. They had the ICU doctors up to look at you at 11.30am. They put nasal prongs back on you and started giving you Lasix to get rid of the fluid. You wouldn't have anything to eat or drink. By 1pm they were really worried about you so the ICU doctor came back up and had another look at you. They decided it would be best for you to go back down to ICU so they could keep a closer eye on you. They took blood samples from you. You had a high temperature and you were very distressed. They doctors came back to us and said you had developed some sort of infection and you were not coping too well. They decided to put CPAP on to help you with your breathing. You were not happy with this in!!! They started giving you morphine straight away. Your Dad & I were beside ourselves because you were so upset. We hate seeing you like this. You soon relaxed. Your Dad & I were exhausted. They told us to go home and get some sleep. We left the hospital at 10pm and drove home. I rang many times during the night to make sure you were OK.

*Tuesday 9<sup>th</sup> March, 2004* They took your CPAP short tube out today. They turned your morphine off. We finally got a smile from you. You were transferred back to the ward tonight. You were so happy once you got back up to the ward. You were laughing and giggling with the nurses. You didn't like one of the medications they had started you on. You kept vomiting it straight back up again. I left you at 10pm. You were sound asleep. Good boy.

*Friday 12<sup>th</sup> March, 2004* The doctors are so happy with your progress. Maybe you might come home tomorrow. Fingers crossed!!! Dad came to the hospital this morning. You slept for 3 hours so your father was happy. He got to sit and read the paper. I came to the hospital this afternoon. When I arrived you were still asleep. You woke 5 minutes after I arrived. You should have seen the smile on your face when you saw me. It was priceless! Amanda & Nana came in to see you tonight. You were in such a good mood. Laughing and giggling. It's so nice to see you happy.

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