

"I can't believe you're still conscious!"

My story begins in September 1999. My husband and I already had 3 beautiful sons and very happily found out we were expecting again. I had hoped with all my heart for a little girl that I could treat like a princess. I was very sick in the beginning of that pregnancy and put it down to morning sickness that lasted all day. My first checkup with my obstetrician came at 12 weeks and due to how sick I was and that I was already feeling movement, a scan was performed in his room. He wanted to check that I was only carrying one baby but as I had similar feelings in my 3rd pregnancy, I was not concerned about how many babies were in there. My obstetrician had a good look around in the scan and both my husband and I were relieved to see only one baby. I was told that I would have a proper scan to check everything out around 18 weeks. The earliest I could book into was at 19 weeks and my checkup in the meantime was good although I was still very sick and couldn't keep any food down.

February 1, 2000 came and I was very excited about having the ultrasound. We had decided to find out the sex of the baby and even though my heart wanted a daughter, I was quite prepared to find out I was having another son. The probe was put on my stomach and we could see two circles. I said to my husband "That's a head, but the other one isn't a bottom!" The sonographer laughed and said "Don't you know you are having twins?" I burst into tears. I was excited to be carrying twins but how would I cope with 5 children plus all the worries of a multiple pregnancy? The scan started and I realised straight away that Twin 1 was a boy. I thought out aloud "I still have one chance at having a little girl." The sonographer laughed again and said "Sorry, honey, they are identical". The thought of having 5 sons made me burst into tears again. As time went on, the sonographer got very quiet. She was having trouble locating a separating membrane between the babies plus it appeared that Twin 1 had 4 holes in his heart. I was so scared but that was only the beginning. She said that she would need to get the specialist to have a look at my babies. He came in and said that it appeared our babies were suffering from a condition called Twin to Twin Transfusion Syndrome. Neither my husband nor I had ever heard of it before so he went through the details. We were told that one baby sends its blood to the other through blood vessels in the shared placenta. This makes one baby (the donor) small because all its nutrients are being sent to the other baby. The other baby (the recipient) grows too quickly due to the extra blood being sent to it. The chances of my babies surviving were very slim without treatment - around 10%. The only treatment available was amnio draining of the extra fluid produced by the bigger baby and that left a 25% chance of neurological damage.

We left the medical centre in tears and all the information given to us left our heads as we tried to comprehend what we were told. We spent the afternoon on the Internet searching TTTS but everything we read was from overseas and most of the stories were sad. Many babies had lost their lives due to TTTS. We also had to tell our other sons about the twins and that they were very sick. That was so hard. How do you tell 10, 7 and 4 year old children that their baby brothers may not survive?

The next day, I saw my obstetrician. He was wonderful and as he had tended me in my other pregnancies, we knew each other very well. He said that he would look after me as well as he could and would send me to some of the best TTTS specialists in Australia. Luckily they worked at the hospital where I was to give birth. I was able to make an appointment for the next day and I was given a very thorough scan with some very advanced equipment. The specialist said that it appeared that we had TTTS but only a mild stage at that point. We were also told that there didn't appear to be any holes in Twin 1's heart - the first bit of good news all week. I

was told what to look for and what to do if anything changed. We were to return for another scan in 2 weeks.

Every 2-3 weeks a scan was performed and the news got better and better. Both babies were doing well and we spoke with my obstetrician about a birth plan when I was 28 + 6 weeks. We decided a c-section would be best for the babies and spoke about me having cortison injections to help strengthen their lungs. The plan was to get me to 32 weeks if possible but I was told that if we got to 30 weeks it should be okay. I was so relieved! Only 1 more week and the babies would be okay. I could start to think about having twins and spent the afternoon daydreaming about what it would be like.

I was starting to feel the best I had for months and that night I took my eldest boy to soccer training. I was able to keep food down and was the happiest I had been for a long time. My friends at training commented how well I looked and we chatted about the babies and how much I was looking forward to the birth.

Later that night I started to feel odd. I can't really explain it, I can just say that something wasn't right. It was like Braxton-Hicks but stronger. Not labour pains though. They weren't getting any closer or stronger - it just felt weird. I told my husband and he said to try and get some sleep. The twinges settled and I slept for about 1 hour when they woke me up again. I woke my husband and told him something wasn't right. I wanted him to ring the hospital but he said that they would tell me to relax and not come in. He suggested we go downstairs to the kitchen to have a cup of tea. Even though it was 1am, I agreed. I walked down our stairs and as I put my foot on the tiles at the bottom, I heard a splat and felt a rush of fluid. I assumed it was my waters breaking but when I turned the lights on I realised it was blood. Being a mother, my first concern was the mess and so I automatically walked to the bathroom and sat on the toilet. Then my brain kicked in and I remembered my first aid. I lay on the laundry floor with towels under my bottom. I knew I had to elevate my abdomen to try and stop the bleeding. My husband called 000 and I kept talking to him from the laundry so he knew I was still conscious. He had to call 000 again and finally the ambulance arrived. By that stage I was vomiting but my main concern was for my babies. I just had to save them. The ambulance driver and officer came in and I can remember the driver's face. He went white when he saw the blood and I thought he was going to faint (they estimate that I lost 3 litres of blood and most of it was on the floor). The officer looked at me and said, "I can't believe you're still conscious" and then told me that she thought my babies were dead but didn't try to listen for a heartbeat at all. As I was vomiting she wanted a paramedic to tend to me but the closest one was about 20km away. My husband told her that the paramedic could meet us at the entrance to the freeway on the way to the hospital. That was fine but I told them that the reason I was vomiting was because I hadn't been able to lie flat for 6 months, let alone lie with my head lower than my stomach. I was told to walk to the stretcher (that's right, walk, thank God my husband was there to help me) and then the driver asked "How do I get to the hospital from here?" I couldn't believe my ears as we live right off a major arterial and are only 5 minutes from the ambulance station that they had come from. He also seemed so happy that it was a Code 1 meaning flashing lights and sirens. We met the paramedic but by this stage my vomiting had stopped. I was going into shock though and my legs kept trembling uncontrollably.

We reached the hospital and I was prepped for an emergency c-section. Two heartbeats were found which was a big relief. One was still quite strong although getting slower but the other was under 100 beats per minute. I can't remember a lot from here on but I will do my best. One thing I do remember is how a very kind midwife let me keep nail polish on one of my fingers

because it was such a beautiful colour. My obstetrician turned up to deliver the babies and told me he would do his best to get them out as quickly as possible. As I was wheeled into the operating room, the heartbeats were checked again. Twin 1 was still quite strong although under 100 beats per minute and the other twin was skipping every 6th beat. He looked concerned but said he would do his best. I was put to sleep, after arguing with the anethetist about how hard he was holding the mask over me, and at 3:47am my first twin (*M*) was born. Two minutes later, Twin 2 (*A*) was stillborn. *A* was worked on for 15 minutes with the doctors trying to make him live but it was not to be. *M* was very sick and it took along time to get him stable. When I woke up, I remember being told that *A* had died but I already knew that. Something inside me had already told me. The nurses wanted to take me through NICU to see *M* as they thought he would soon die too but I knew he would pull through. I just wanted to go upstairs to my room.

My husband pushed a crib with *A* in it to my room. I don't remember anymore of that day. I have been told that I held *A* and cried with him in my arms. We took some photos of him. I wish I could remember what it felt like to hold his little body in my arms. Why didn't we take more photos? Why didn't we bathe him? It just didn't cross our minds at all. We sent *A* away later that afternoon before our other sons came up to see us. We thought it would be enough a shock to see me hooked up to blood and drips without them having to see their dead brother too.

The next night we held a Blessing for *A* in the NICU. The nursery was closed so that we could have some privacy and we were able to take photos of *M* and *A* together - well as close together as possible when you have one baby on a vent in a humidicrib and the other in his father's arms. All the children got to hold *A* and we were able to say our goodbyes. An autopsy was to be performed the next day and we were never to see him again. We were given the option of seeing him afterwards but we knocked it back. I wanted to remember him whole and even though we were assured the wounds would be covered, I would've known what he was like underneath his clothes.

M improved slightly and I got to hold him on the day I was released from hospital. He then came down with an infection on Easter Saturday and we nearly lost him. Once he recovered from the infection, there was no holding back and he steadily put on weight. He spent a total of 10 weeks in hospital and was released one week to the day before his due date.

He came home on oxygen and we spent 9 months in total living with 3 cylinders in our house. Whenever I took him out, people would stare at him as if he was an alien. I started to ask people not to stare and also confronted people who parked in Parents' Carparks without any small children. I actually stuck post it notes all over one car saying how rude the driver was, as he shouldn't have been parking there. I can laugh about it now but at the time I was deadly serious.

After *M* came off his oxygen, we uprooted the family and went to San Francisco to live for 3 months. This was to be a healing time for us all and my husband was able to do only a limited amount of work over there. It was like one big holiday and luckily I was able to school the boys via emails to their teachers. While we were there, I face the reality of losing *A*. It was like I hit a big brickwall that I had to climb over. It took a lot of willpower to believe that he was gone and that I would never see him again. I also found that I was worried about my mortality. Until April 12, 2000, I felt invincible but after that day, I learnt how fragile life really is.

We returned home on September 7, 2001, just 4 days short of an event that has changed the world forever. Our memories of living in the US are so happy and carefree. My husband and I were able to visit New York by ourselves for a couple of days in August of that year and it is still so hard to believe what happened.

Soon after we got home, I met (through email) a lovely lady who runs M-BABS, which is the Australian Multiple Birth Association's Bereavement Support. She put me in contact with another TTTS mother whom in turn later told me of a very supportive Internet group run on Yahoo. It is called OzMOST and stands for Aust Mothers of Surviving Twins/HOM. I have found the group to be very beneficial in terms of my loss of *A* and my concerns about *M* growing up as a surviving twin. I am also a member of Austprem Inc, which supports parents of premmie babies. The one thing that I haven't had help with yet is what happened to me. I am a typical mother, always look after everyone else and not yourself. I still cringe when I hear water splat, I hate every month when I get my periods, I refuse to use the toilet downstairs and so I run up to my ensuite all the time. All the little things that bring back the memories of that night. One day I will find the strength to fight it but at the moment I don't feel strong enough to.

There are a couple of positives to this story. *M* is now 3 and doing really well. He is a little behind in his speech but we are working on it and everyday he is improving. He is a very happy little boy and is doted on by his big brothers. I love my husband and my boys with all my heart and without the support of all of them, I hate to think what I may have done. I have also set up a TTTS support group for parents who are diagnosed in Australia (and New Zealand). I founded it with another mum who gave birth to TTTS boys 3 months before me. We actually shared the same obstetrician and hospital and live only 10 minutes apart. We have helped parents from all around the world and are hoping that we can produce a brochure for parents to take home with them when they are diagnosed. We both found a lack of information to be a problem and this is the first thing we want to change. In the future, we want to expand to raising funds for TTTS research but before that we need to become a charity. We are working on that as I speak. With the support of our members and AMBA, I am confident of achieving our goals.

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