

Kynan's Story

**In memory of Kynan James Turvey
16 July 2004 – 23 September 2004**

My Mummy and Daddy were so happy when they found out that they were having my brother and me. My Daddy had been married before and had a big girl from that relationship who was going to be my special sister (Courtney). I think he thought that at 37 he was getting a bit old so when the doctors said that I was going to arrive with another baby at the same time they thought that was somewhat special and they could enjoy having a family all at once, but little did they know how much trauma I was going to cause them.

A week before my brother Jasper and I were born Mummy had to go in to Calvary hospital as she was covered in some sort of funny rash. While there she had to go and get her 34 week ultrasound scan. This was not done very professionally though and Mummy was not happy. When she got back to the hospital the registrar was also not too happy so another scan was arranged at the Fetal Medicine Unit at the Canberra Hospital. So on Wednesday 14 July 2004 they set off thinking they would get another good look at me and my flat mate.

The scan started really well with a nice Professor looking at us via the sound waves bouncing from us. When he got to me though, he stopped and more closely examined my heart and my limb lengths. He then got a lady to look at me. Then he took Mummy and Daddy into a room to tell them I had something wrong with me and that they would like to get us out of our cosy little house early. He said Mummy had to go straight home and get her bags so that she could be admitted into hospital that afternoon. So they drove home and on the way rang Gran, Grandpa, Nanna and Grandad. Daddy spent a lot of time crying saying things about disability. He sounded a little scared at the turn of events; I think Mummy stayed quiet just wanting to know what was going on.

On Friday morning a Doctor from the Fetal Medicine unit had another look at me to see how I was going and then told Mummy and Daddy that they could see me later that day as he was going to take me and Jasper out of Mummy's tummy.

At 1:51pm, Jasper was born and by all accounts looked very healthy and beautiful. He even got to have a cuddle with Mummy while she was lying on the bed. At 1:52pm, I was born, but the doctors took me away straight away so Mummy and I did not have a cuddle. Daddy was torn as to what to do, he so wanted to be with Mummy but at the same time he wanted to come and see me and see how I was doing, so after spending a little time at the bed with Mummy he came up to the Neonatal Intensive Care Unit to see me and Jasper. I did not see my Mummy until the next day. I know this hurt Mummy and it upset me as well – I had spent eight months with my Mummy and now the hospital would not let me see her because it was too awkward getting the bed she was in into the unit. I did not think this was a very good reason at all!

Anyway, the next day she saw me and where I was going to spend most of my life. However, Jasper was not in the same area as me and I was in a plastic box so we could not have the family cuddle Mummy and Daddy were so much looking forward to.

Throughout the next six weeks, Mummy and Daddy had a lot to cope with. They had to go through the stress of knowing I had Downs Syndrome and then the stresses of the health scares quite often related to us special little babies. There was the Hirschsprungs disease scare and then the leukemia scare. And if this was not enough Mummy and Daddy were then told I had a large Ventricular Septum Defect (VSD), which basically meant that my heart had a big hole in it and was not working properly. A specialist from Sydney came down and told them that I would have to get it fixed in Sydney sooner rather than later. So, as soon as they could get Jasper out of the NICU, plans were made to take me to Sydney to get my hole fixed.

On Monday 23 August 2004, I had my first (and only) plane ride to Sydney. Daddy came with me while Mummy and Jasper drove up in the car. I went to the Children's Hospital in Randwick for my operation and Mummy, Daddy and Jasper stayed in Ronald McDonald House. Whilst in Sydney Mummy and Daddy had to contend with a disagreement between my treatment team as the doctor who came to Canberra still wanted my hole to be fixed straight away but the operating doctor in Sydney only wanted to do a pulmonary artery banding. He won and that was all I had done. Whilst in Intensive Care in Sydney I went blue and the nurses had to give me more oxygen to fix my colour. This was like a warning for Mummy and Daddy although I do not think it truly prepared them for when they saw me on the night I died.

On Monday 6 September 2004, I was supposed to come back to Canberra so Mummy and Daddy had gone home on Sunday; the day before. As it happened though, I did not get back to Canberra until Thursday 9 September 2004, which meant I missed my Mummy's birthday. This was upsetting for her and me, especially now as it was the only birthday I would have ever had with her. If Mummy and Daddy knew I was staying in Sydney they would have stayed too.

When I got back to Canberra, the doctor decided I should go home on an aponea mat, as my breathing was still not too good. So we had to wait for one to arrive. When it did it was not what Daddy thought it was going to be so he made an appointment to see the doctor at 4:30pm on Wednesday 22 September 2004 to talk to her about it. Mummy and Daddy came in to the hospital with Jasper that afternoon and saw me and spoke to the doctor about how I was going home that weekend. Everyone was very excited about me going home, but not half as much as I was, ten weeks in hospitals, although not a super long time, was long enough for me.

However, at 12:50am on Thursday 23 September my Mummy got a call from the hospital saying that my condition had deteriorated and that Mummy or Daddy had better come in. This comment made them very worried and they both jumped out of bed and after a quick phone call to Nanna to look after Jasper they came in to see me. When they got in the door of the NICU they were quite anxious. Their concerns became real as

soon as they turned into bay 4 where I was. Unfortunately I had already died by the time that phone call was made and despite the doctors still giving me CPR I was a horrible white colour. Daddy just told the doctors to stop and let me go.

As I write this, it's Monday 11 July 2005, nearly a year since my brother and I were born. All of my family are trying hard to get ready to celebrate Jasper's birthday but I know Mummy and Daddy are really having trouble being happy for him while they are so sad that I am not there to have a party as well. The last ten months have been a roller coaster for them. They have endured hurtful comments such as:

- it is probably better for him anyway [NO, I would prefer to be living and with my Downs and I know Mummy and Daddy would too];
- at least that is the benefit of having twins [Oh yeah, I was only a back up anyway].

In addition, they have the on-going pain of never being able to see me grow up or see what I could become, but yet they have Jasper, my twin, as a constant reminder that I should be there.

Mummy is pregnant again and I am looking after the new baby (I will not tell you what it is as Mummy and Daddy do not want to know yet and I do not want to spoil the surprise for them). Although, having a new baby after losing me brings about its own complications for them. They are scared, ALL the time that something is going to go wrong with it and they are not looking forward to the next round of "hardly thought about" comments ("Oh well, your family is now complete"). Luckily though, they have Wendy from SIDS and KIDS to help them deal with all of their heartaches and battles, and with her there for them I know they will be alright.

I love you Mummy, Daddy, Courtney and Jasper. I miss you guys and know you miss me too.

Love Kynan J. Turvey xxxx