

Simon James

Friday July 10th 2009: 00.10 – 1.10am

by Stacey

Finding out I was pregnant was the best news we could have had, as we had been trying for a year. Like every other pregnancy, we were thrilled that we were going to have our own baby. We went for our first dating scan late, at 15 weeks at Nottingham City Hospital. Everything was fine. We went for our detailed scan late, at 22 weeks and this was the first time we heard that something was not quite right. Our sonographer had found a choroid plexus cyst (tiny air bubble) in our baby's brain, so she started to check for anything else. Choroid plexus cyst's are common in babies and if the sonographer can't find any other markers to say there is something wrong, then the cyst is ignored. But our sonographer then noticed that our baby had a cleft lip and informed us that we would need to speak to one of their specialist sonographers. We were placed in a small room tucked out of the way of everyone else.

That's when I looked at my partner Lee, and said, "This isn't good!" I thought that if there was really nothing to worry about then why had we been put in one of these rooms? Soon a hospital midwife came to chat to us and said that she could arrange another scan in a day or two so that specialists could find out more, but I asked if it would be possible to be seen today. There was no way I could go home not knowing what was happening. We would have to wait a couple of hours, but we could be seen. Lee and I went out of the hospital and just held each other crying tears of worry. We reassured each other that a cleft lip and palate was something we could get over and deal with. We reassured each other that at least it wasn't worse. We tried to eat lunch and then returned a couple of hours later to have yet another scan with more specialists in the room.

It was confirmed. Our son had a cleft lip and possible cleft palate. Our specialist sonographer looked for anything else and she couldn't see anything. She felt that she needed to warn us of other complications that could occur. She told us that the cyst and the cleft on its own is not something to worry about they are treatable.

But if anything else was found then there could be the possibility of Edwards. This was the first time we had heard of Edwards' syndrome. I asked her to explain what it was and she tried to dance around telling me the truth, but I insisted. That's when she told me that Edwards babies just don't live. At that moment my life stopped! Lee and I went home in a daze, not saying a word to each other. In my head I was trying to process what was happening, but I just couldn't. I decided that as long as nothing else was found then all will be OK. We can get through this. And deep in my heart I thought, if they find anything else I will have to have an amnio test done. An amnio test was offered to us already, but I said no. If my baby only had a cleft lip and palate I would love him anyway. I didn't need any more tests to know that.



Two weeks later (24 weeks) we had another scan to try and get a good look at his face. We managed to see his cleft lip clearly and it was only small. This was good news. Then our specialist started to look for other things. The room went quiet. After about 5 minutes I could tell by her face that she had found something. She then began to explain to us that our baby had a very small VSD (hole in the heart). That was it. I knew I couldn't avoid it any longer. I was going to have to face an amnio. Because Nottingham didn't have a paediatric cardiologist, we had a consultant referral to a heart specialist at another hospital. Two days later we visited Leicester Glenfield hospital. The heart specialist came in on her day off to see us. She explained that, yes, there was a hole and it

was in between the two main arteries of our baby's heart.

The artery to his lungs was bigger than it should be and the artery to his body was too small. She was worried that if it didn't get any bigger it would be dangerous. She told us that it was operable and he would require open heart surgery at three days old. But then she took a more serious tone and strongly advised we have an amnio test done to rule out Edwards' syndrome. She made it very clear that if the baby had Edwards' syndrome then they would not be so eager to operate, as the babies usually aren't strong enough for surgery. If our baby didn't have Edwards then they would have everything on standby, ready and waiting for him. She said it would be best, so that afternoon I rang Nottingham City hospital and said I wanted the amnio.

I was booked in for the amnio at twenty five weeks. I never want to go through that again. It was painful but I knew it had to be done for the baby's sake as well as my own. After it was done I felt I had done everything I could possibly do to help our baby and now it was all in the hands of the powers that be. We had the amnio on a Wednesday and were told that we could have the results by Friday. We arranged with the midwife that she would phone us when Lee was back from work so I wasn't alone. The call came. As soon as the midwife asked if I was sitting down I knew it was bad news.

"Stacey, I'm so sorry. Its full Edwards". I just passed the phone to Lee as I screamed at the world. The midwife told him that she would call back in a few days to arrange the next steps with us.

Our world was destroyed. We cried for hours and hours. I can't even remember how we got through the next week. We were offered a termination, but it would mean that I would have to go through early labour. I was told that 95% of Edwards babies terminate themselves before 3 months pregnancy and that the 5% that made it had a 10% chance of making it into this world. I was already twenty five weeks into my pregnancy (5 months).

He had made it this far.... so who was I to stop him now? We decided to let nature do what it

needed. So for six weeks we knew we were not going to be able to keep our baby and that we must enjoy him while we could. The only way I was able to carry on was to say and think....

"My baby is born to be an angel. I'm carrying an angel who wanted a brief time here with us on earth". It may sound silly, but it was the only way of keeping my sanity.

Monday July 6th 2009

I had an appointment at the hospital with the anaesthetist on this day... But just before leaving my home I nipped to the loo and noticed I had a show. By the time I got to the hospital I had started to get regular cramps. Like period type cramps. After seeing the anaesthetist I was taken to the delivery suit to be monitored. I was internally examined at 4pm and my cervix was not doing anything. So a swab was taken to see if I was in labour. My test came back positive. I was in early labour. The doctors wanted to re-examine me at 9pm to see if my cervix was doing anything. They checked and it hadn't moved so I insisted I go home so I could pack my hospital bag and return in the morning.

Monday night was awful. I was getting bad cramps every 3-4 minutes and didn't get to sleep until I passed out at 3am.

Tuesday 7th - Thursday 9th July 2009

I woke up still in pain and the cramps were continuing. I rang the hospital and asked if I could return to be rechecked. I was booked in for 10:30am. Again just before leaving the house I nipped to the loo and found that I was bleeding. It wasn't gushing or flowing... Just when I wiped myself.

I walked around the corner of my street, with Lee in tow carrying bags galore. I decided to ring the hospital just to let them know I was bleeding. The midwife told me to stop where I was... 'Hang up and dial 999'. I did this and within three minutes the ambulance arrived. I was strapped in the back with Lee and was taken to the hospital. I got the blue's & two's too.... Very exciting. But I wish they wouldn't make you sit backwards in the ambulances. What is wrong with sitting us the right way?

Anyway... I was in the hospital within 10 minutes. After being examined on the delivery

ward I was told I would have to stay for 24-48 hour observation and was given a private room on the labour ward. So basically, through Wednesday and most of Thursday I was poked and prodded. Tests galore. Pain killers galore. In the end the doctors said that I was showing signs of infection somewhere in my body but they couldn't work out where. I didn't feel unwell, I had no temperature and they were sure that there was no infection in my womb... So it was a mystery. And because I was neither getting worse nor better, they really didn't know what to do with me. I sent everyone home late Thursday evening and told them not to come back until I was being wheeled into the delivery suit in labour!!!

Soon after everyone left my cramping pains returned at regular intervals and the painkillers were doing nothing. I decided to do laps around the ward because walking was better than laying in bed. I walked for hours. I even got chatting to a lovely young girl who had been admitted that day. She was alone in a ward room so I walked laps around her room while we chatted. She was so nice... And I never got her name. By 10:30pm I just couldn't take it anymore and headed back to my room. I walked in my room and had the overwhelming urge to squat. As soon as I did my waters broke and that was it.... The cramps turned into contractions.

The midwives managed to get me back on my bed between contractions... But there wasn't much of a gap. I rang Lee, my mum and best mate to say.... "Get here quick". Lee arrived within 10 mins so I was still in my room getting ready to go down to the labour suit. But my contractions were only 2-3 minutes apart at this time.

I got down to the delivery suite and was examined by 11pm. I was 3cms dilated. I started screaming for my epidural (!!!!) because I was warned that Simon's birth would be quick. I was given gas and air and had the biggest laughing fit ever!!! I was telling everyone off saying, "Its not funny, don't laugh!", but I was the only one laughing. As the epidural was being prepared I was in absolute agony. How Lee managed to cope through my screams of anguish and pain I don't know. I had moments of wailing and tears because I was so upset that I was going to have to say goodbye to my baby. When the epidural

started to take affect things slowed slightly. I would highly recommend having one. You can still feel everything but the pain is vastly reduced. My mum was then allowed in. It was about 11:30 pm now.

I was still getting contractions but I absolutely refused to push yet. Lee was putting his full weight on my right hand so I had to push him upright. I was focusing all my pushing into my hand.

At 11:55pm I was re-examined and I was fully dilated. My midwife then told me it would be OK to push but I just didn't want to. I didn't want to loose my baby but I knew there was obviously no stopping this! Three pushes and his head was out. One more and Simon arrived. It was Friday 10th July 00.10 hours. Simon gave one cry, a sound I will never ever forget. We all cried with joy. Simon opened his eyes and reached out once. The cord was cut and he was whisked to one side. Lee stayed by his side the whole time. The doctors checked him over and said his breathing was good and his heart was beating well. Lee cut the cord again and Simon was wrapped up and placed in his daddy's arms. Lee sat beside my bed.



The midwife was still struggling to get my placenta out. There was a chance that I would have to go into surgery to have it removed, but I wasn't going to allow this. I didn't want to miss any time with my baby. Having surgery would mean that my baby could die without me. My midwife placed me on a new drip to help make my placenta come. Then we were left alone with our baby. Lee passed him to me and I did nothing but cuddle and kiss him, hold his hand, look at his feet. His thighs were massive, just like his dads. Adam was brought in and held his brother briefly. Then as I held him again the rest of the family were allowed in to see him

very quickly. Once everyone left Simon was re-examined and the doctors confirmed that his heart was failing.

Lee and I held him together on the bed. I held Simon's head close to my lips and between kisses I said..."Thank you sooooo much for being so strong and brave and letting us love you while we could. We love you so very much and we always will....but you don't need to stay any longer than you need to. Its OK, we know you love us and its OK to leave us. We love you."



And with that I was blessed to see a shadow lift from his face....and I knew he had gone. It was 01:10am exactly. Ten minutes later the doctor re-examined him and confirmed that he had passed. Simon was placed back in my left arm and in my right lay Lee's head sobbing with utter grief!!! I just lay there, consoling Lee whilst feeling relieved that my baby suffered no pain.

After this I was able to birth my placenta and the midwife let me see it so we examined it together. She told me that it was not a healthy placenta and pointed everything out to me.

Simon was laid in a crib with new clothes and belongings. I was cleaned up and the whole of the family was let in so we could announce that Simon had passed. They all got to hold him and cry.

The rest of the morning was spent getting showered. Together, Lee and I then cleaned and dressed Simon's body. The midwife helped take feet and hand prints and locks of hair and even

arranged tea and toast for Lee and me. At about 6am we were all cleaned up and the whole of our families were allowed back in. We all had tea and toast and there was lots of holding and passing Simon around. It was sad, but a peaceful kind of sadness.

Everyone left and Lee and I were returned to the labour ward with a private double room and bathroom. Lee slept for a few hours while I lay on my bed cuddled up with Simon. I even fell asleep with him a while, which was lovely. I left to get some breakfast and chatted with all the ladies who had got to know me during the week. They all knew my story and were just lovely with me. After an hour or so I returned to my room and when I looked at Simon, something had changed. He was starting to not look like my little boy any more. I tried holding him. But it really didn't feel right, he just wasn't my baby anymore. I knew this meant it was time for me to leave, before this feeling got any worse. But it took the hospital hours to let me go. Constantly coming up with forms, medicines or people I should speak to before I left. I hated it. I just wanted to go home. But when that moment came I had to fight the overwhelming feeling that I was abandoning my baby. It was horrid. I got home and fell asleep for an hour. I woke up screaming, because he was no longer there in my tummy and I had left him behind. Lee held me until I passed out again. Since then we have both missed him terribly.

Two weeks later we had Simon's funeral. It was everything we could have hoped for. It was so beautiful and peaceful. After the service we all wrote notes of love and tied them to a bunch of balloons and let them go.

Life since has not been easy. One day you are fine and things are normal. Then the next everything feels wrong and you just have to cry and cry. We have photos and a memory box for Simon but I find it hard to look through it because at the end of looking at all his things, I am angry that I am holding a box and not my baby.

Lee and I are already trying for baby number two. It may seem too soon to some, but we are not trying to replace Simon. Simon will be our first son and with us in our hearts forever.