

# Mia's Story

**Pregnancy should be an exciting time for parents looking forward to their new arrival. My pregnancy started off really well, no morning sickness or any complications until we got to our 21 week anomaly scan.**

The sonographer explained that the baby was laying awkwardly so asked me to go for a walk and jump about to see if the baby would wake up and move, but after 20 minutes of jumping around and pacing the floor the baby continued to be stubborn. So a second appointment was arranged for next week. I was not too at worried as I was aware that this is a common occurrence and the sonographer herself was not too bothered.

So two weeks later I went back for the scan, I was on my own for this one as my partner Ab, had to travel to Dubai on business. While being scanned I was calm and confident that everything was fine, even when I saw the sonographer staring intently at the monitor and looking pensive I remained unconcerned. I was healthy; my family was healthy, what was there to worry about?

It was only after she made her excuses and left the room that doubt started to creep in. Why has she gone outside? Has she seen something on the monitor? Who is she talking too? My mind started to race. What seemed like an age, but was no more than a few minutes before she returned and said that, she had seen some anomalies on the scan, stated that she wanted me to arrange an appointment with a specialist at Kings College Hospital in London. That was it my world exploded. I bombarded her with question after question; some silly, some I could not or would not have expected her to answer. She remained polite despite the grilling I was giving her, while offering words of comfort and support telling me that there are many variations of normal hearts and the appointment was precautionary.

One negative thought after another started to flood into my mind, each one becoming more worse than the previous one. The appointment at Kings College was for the following Friday on the weekend before the Spring Bank Holiday. That Bank Holiday Monday I would officially be 24 weeks limiting any options that might have. I phoned Ab and he was on the next flight home, ensuring that we were both together for this appointment. To add further angst to the day the clinic was running late and we were kept waiting for some time.

Eventually we were called into the scanning room, to be greeted not by one doctor, but by six of them. It was only the shock on our faces that led them to explain that as it was a teaching hospital, the people present were in fact trainee doctors, and did we mind if they observed the scan. I was so uptight about the whole situation at this point that I was not bothered I just wanted to know what was wrong with our baby.

We were then introduced formerly to the professor; a lady who was going to conduct the scan, and for the second time that week, I was prepped for another ultrasound.

This scan took around half an hour, and it was quite surreal lying with my belly exposed while six people all crammed around the bed looking at me and the monitor muttering medical words that I absolutely no idea what they meant.

After the scan the professor said someone would take us to a consultation room and she would follow shortly discuss her findings. It's funny how you pick up on the smallest detail when you're in fright or flight mode, and I immediately noticed that the sign on the consultation room actually said counselling room. Now I knew something was seriously wrong. Ten minutes later all my fears were confirmed and our world caved in. The professor said that our baby; which was a girl had a congenital heart defect known medically as 'double outlet right ventricle and tetralogy of fallots'. She explained what it meant, and told us there was also a very likely that the baby would have an additional chromosome defect or some other form of disability.

Some blunt conversations were had and our options limited and stark. She offered us the option of a termination, but said we would have to decide quickly as the cut off point would be the Tuesday when I would be 24 weeks. We both needed some time to think so we went for a walk so that we could be alone and discuss ours and our baby's future. Such a big decision, such little time, and we still knew next to nothing about what was wrong with our baby's heart other than it was abnormal. We both knew that termination was not at option. The baby had been very active inside me for a number of weeks and to me she was my baby and her kicking was suddenly to my mind, her telling me 'listen I'm doing OK in here, don't let me down'. There was so much to take in, and really no time to take it in. While they did their best to explain the seriousness of the condition, how it happens, what they can and can't do, mortality rates at birth, disabilities and longevity of children with the condition, I just could not comprehend it. God I didn't even know how a normal heart worked how could I understand an abnormal one (boy I sure do now). I just couldn't take everything in, we came home and the whole bank holiday weekend was spent scanning the internet to find out everything I could.

That's how I found Echo. I posted a message and had such positive response, it was nice to speak to people who had been in my situation and come through the other side and understood all my emotions and fears. The support I have received from Echo has been fantastic.



The rest of my pregnancy continued as normal except that I had more scans than other mums to be, and

god knows how many blood tests. Babies with this condition are not allowed to go full term and an inducement date was set for the 6th September when I would be 37 weeks. But this pregnancy had another turn to take, and I suffered some preeclampsia three weeks before, resulting with me being admitted to St Thomas's Hospital where I stayed for the rest of my pregnancy. This, on top of everything else was all I needed. I was suitably looked after and remained well albeit from the high blood pressure, headaches and swollen legs. I felt more sorry for Ab and my Mum who made the long slog up to Central London from Slough every day.

As the induction date neared it became a synchronised operation to get me into labour, when a cot was available in the Paediatric Intensive Care Unit, This was more problematic than I thought, it seemed that as soon as a cot was free, a new born baby in some regional hospital would need the same care that my baby was going to need, and as they were already here they took the cot.

However good planning paid off, and I was finally induced on the 8th September two days later than intended. But it seemed my body was still not ready and refused to play. It was decided to leave me for 24 hours and try again. Poor Ab was sent home, only to be recalled as soon as he opened the front door. He arrived just in time, Mia was born in double quick time, with only the gas and air for pain relief. And I so wanted an epidural!

So here she was, our gorgeous girl Mia born in the early hours of the 10th September weighing a healthy 7lbs 6ozs. I was able to cuddle her for a minute or so and before she was taken to of to Neo Natal Intensive Care Unit with Ab in tow. Yes... the cot in the other P.I.C. Unit had already gone because of my refusal to play and another poorly child.

During my pregnancy we were advised that she would probably need to have a BT shunt operation performed within the first few days of her life. But to everyone's surprise Mia's saturation levels were in the mid nineties. So after six days of monitoring and establishing Mia's feeding routine we were discharged, and were told to return to the Evelina for check ups every 6 weeks. The Consultant wanted to wait for Mia to deteriorate, before starting any repair or remedial surgery, this he predicted, could be at around the six months mark.

Whilst at home Mia was gaining weight and doing well until 11th December 2007 when the Community Nurse came round to check Mia's blood saturation levels and was concerned that she looked really blue, She measured her sats and they were 55% and dropping, I should state that Mia father is Asian and Mia skin colour is slightly darker even so I had not even noticed any significant colour change, and it had only been two weeks since our last consultant appointment where her sats were still in the nineties. We were taken by Ambulance to our local Hospital and Mia was given lots of oxygen while the doctors liaised with Evelina Hospital. They decided that Mia needed to be in the Evelina as soon as possible and that there was a cot available. An ambulance transfer needed to be arranged and Mia needed a medical team to travel with her as she was so unstable. This took some hours to arrange. I had not been comfortable with Mia while at the local hospital. Her condition is so delicate and the doctors did not appear to understand how or what the condition was. I actually think that they really wanted rid of us as well. Anyway we eventually arrived at the Evelina at 10pm at night and the welcome was so different and appreciated. I felt so safe and I knew Mia was now in the best place to be cared for. Mia had an echo as soon as we arrived and although not conclusive, the Registrar told me not to worry, for they would continue to do more tests the following day to see what was happening.

The nurses made me up a bed next to Mia in the High Dependency Unit and the following day Mia underwent various tests to ascertain what was causing her saturation levels to be so erratic. The Consultants have a Wednesday meeting to discuss patients in their care and Mia became a hot topic at this meeting. A decision was made to do a Septostomy procedure, basically to make an enlarged hole in the septal wall of Mia's heart to increase the blood mix and hopefully improve the oxygen levels in her blood. This was done by cardiac catheterisation, but proved not to be successful and Mia returned to the ward with similar poor saturation levels.

The only other option available for Mia at this time was to do a BT shunt between two of the blood vessels that flow from the heart to the lungs. This option was discussed with us by the medical team and was seen as the only option. The surgery would be performed by Mr Anderson who came to speak to us on the evening of the 20th December and explained the procedure and risks.

Mia was due to undergo the operation at 8 a.m. the next morning. It was so awful to starve Mia the night before, and even worse carrying Mia down to theatre the following morning, she just kept looking at me. A Mother can never feel so guilty.

The operation started late as Mia spiked a temperature and her saturation levels dropped. Luckily it was not serious and surgery began at 9 a.m. What seemed to be the longest wait of my life was over at 1.30 p.m. We got a call to say that everything had gone well and we could go and see Mia in intensive care. I was distraught when I saw how poorly our baby girl looked. All the tubes and drips were overwhelming, but despite all that for the first time I saw my daughter pink. I left her hours earlier all puffy and mottled, but here she was actually pink, Both Ab and I could not believe the difference.

Mr Anderson came to see us and explained that he was pleased with the operation. Now Mia made her own efforts, within 24 hours she was off the ventilator, a few hours after that the chest drains were removed, then one by one the all but one essential drip were removed and within 48 hours she was back on the ward, bright and alert and pink.

Mia was now actually over oxygenating, as the size of the shunt was a little too big for her body mass, and there was some concern as the pressure of this on her tiny lungs could lead to heart failure. This however was a necessary risk and could be controlled by drugs. Mia would need to grow into the shunt and it had to last until she was able to undergo the major reconstructive surgery that would be performed in around eighteen month's time. A strict medicine regime would be required to keep this perfusion overload at bay.

Mia's spent her first Christmas with her extended family recovering on the ward, and on the 29th December was allowed home; although this time we had to get used to setting up a medicine routine and supplementing Mia diet with high energy feeds to get some weight gain.

Since being home Mia has given me a few scares with colds and temperatures and we have spent a few nights in our local hospital. But on the whole she is doing really well and growing into her shunt. We are still unsure what the next stage will be for Mia but hopefully will know more after an MRI scan in a few months time once she has grown into the shunt more.

I think that is the hardest bit of living with a complex heart condition, dealing with the unknown all the time (and having a daughter that refuses to take her medicine). But the joy Mia brings to me is

unbelievable, she is such a happy and contented baby to look at her you would never know she had anything wrong.

Today we have just got back from swimming, something that when I was pregnant I never thought I would be able to do with a 'heart baby' I know that we will have a lot more ups and downs to come, but seeing Mia giggling with excitement makes all of the heartache and worry worthwhile.

**Laura Court**