

# Eloise's Story



*2 months old and at home*

**We're pregnant! My husband, Andy, and I were about to start a family and we were ecstatic. We'd done everything we could to make sure we were both reasonably healthy and I was taking all the right vitamins and folic acid to make sure the new baby was going to be fine. In fact it never even crossed our minds that there might be something wrong with our soon to arrive bundle of joy. At least, not until we went for a routine 20 week scan.**

We were both so excited to see the pictures but as soon as the scanner said that she wasn't quite able to get one of the images she needed and was going to get someone else to have a look we immediately knew something was wrong. Another scanner came in and then they went to get the consultant. The atmosphere in the room had suddenly changed; we were no longer excited expectant parents but just two very frightened people.

The consultant at Aberdeen explained to us that day that it looked like our precious little baby had a heart problem. It was most likely something called Hypoplastic Left Heart Syndrome, but they would know more after we visited Glasgow's Yorkhill Hospital.

We had to wait a few days for the appointment to find out if this was true or not. At Yorkhill Dr Richens very carefully explained that the left side of the heart hadn't formed properly and wasn't going to. He also said we had three choices: 1) to continue with the pregnancy, hope it went full term and then go through a series of major operations, 2) to abort the pregnancy or 3) to continue but do nothing and allow the baby to pass away naturally within a week.

I also had an amniocentesis to see if there were any other problems, but thankfully this showed no other complications. My only memory of that was hearing the doctor say "No, I think we'll need the 5 inch needle today" - I didn't need any sedative after that!!

For us, we could only think about doing everything we could for our baby and giving it every chance we could. This was the hardest decision we've ever made as we knew that whatever happened we would have to live with our own feelings and, if all went well, deal with a 'special' child. We'd never imagined that this would happen to us - it always happens to other people doesn't it?

For the remaining 18 weeks of the pregnancy we had lots of scans and visits down to London to see the specialists at Guys and St Thomas'. Although we live in Aberdeen we had the choice of Birmingham or London for the surgery and with my family living in Surrey it seemed the best option.

My due date just happened to coincide with the exact week everything was being moved from Guys to the new Evelina hospital, so it was decided to induce the baby 2 weeks early and do the first surgery at Guys and then move the baby across to Evelina once she was stable.

Early on 9th October 2005 Eloise Ann came into the world kicking and screaming! We were warned that she was unlikely to cry when she was born and that they'd have to put a ventilator tube down her throat to help her breathe. But as soon as they heard her they decided not to bother! I briefly held her before they took her away to look after her in NICU. Andy went with her while I recovered from the delivery with my mum.

Later that day I was able to see her and hold her properly for the first time. She looked so perfect and tiny that it was impossible to believe that inside there was anything wrong.

*I'd only known her for a few short hours and yet she was the most precious thing in the world to me.*

I didn't get much time with her as I was tired from the birth and we thought we had a couple of days before the 1st operation. But later that day they told us she was so strong that it would be better to do the surgery the next day and not wait until it had been previously scheduled as she may get weaker. Although this was the right thing to do, it was incredibly difficult to only have spent half an hour with her before she was due to be operated on, especially when we had been told there was a high chance of not surviving.

The following morning we were able to take her to the anaesthetic room and were with her as she went to sleep. I have never felt so wretched in my life watching her quietly go to sleep in my arms, not knowing if we'd see her again. I'd only known her for a few short hours and yet she was the most precious thing in the world to me.

The hours that followed were long and hard. I was taken to the maternity ward, but they very kindly put me in a separate room so I wouldn't be surrounded by other new mums and their babies. We tried to keep busy and focused on other things, like learning to use a breast pump to start expressing milk for her when she would be able to drink. After what felt like an eternity we got the call that Eloise had successfully made it through the Norwood Stage 1 operation and we were able to see her in intensive care. She'd spent a record short amount of time on bypass (which is good!) and was doing really well.

When we saw her in PICU she was just as beautiful and I didn't really see all the tubes and wires coming out of her, I just knew she was still with us and doing great. We'd been shown pictures of other babies so were prepared for what we were going to see, but as the days passed and a tube was taken out or a drug was reduced we could really see her again. The nurses were fantastic and really looked after us as well as Eloise. I was still recovering from the birth and trying to express milk every three hours so I was

quite tired, but when they gave me her to hold for the first time it was amazing. When she was allowed to take some of my milk through her NG tube they let us do it which was fantastic. And when she finally came off the ventilator and we could see her nose again and hear her tiny voice... words can't describe how I felt.

She finally left PICU after 10 days and we went up to Rothschild ward in Guys. It was really scary to suddenly go from the one to one nursing we'd got used to on PICU to the ward where there wasn't someone watching her every moment. Then a day later we were moved over to the new Evelina hospital.

There were still workmen finishing off things but I think Eloise was the second patient onto Camel ward! We stayed on Camel for another 10 days and we were then told she was doing well enough to go home, via Glasgow. Katie Chou came with Eloise and I on the train up to Glasgow and helped us settle in at Yorkhill. We were only supposed to be there for a couple of days so the staff could get to know us as that would be our 'local' heart specialists and where we would be going for follow up clinics.



*Just a few hours old*

Unfortunately Eloise developed a wound infection which rapidly deteriorated. After another 10 days we were transferred by air ambulance back to Evelina for further treatment. A course of strong antibiotics cleared it up after a while and we were finally allowed home to my parents in Surrey.

I was really unsure about taking her 'home' as we'd had so much medical support for so long I was convinced I wouldn't be able to cope. Apart from not knowing anything about young babies, let alone heart babies, Andy had to go back to work, I was still expressing milk all through the day and night, feeding her and sorting out her medication. Somehow we struggled through and it slowly got easier and almost normal! We stayed at my parents for another month and then were let home to Aberdeen - all by ourselves! A very scary time!

Once Eloise got to 4 months we were back down at Evelina for her first MRI to see how the stage 1 had gone and when they were likely to do the 2nd stage. We were under the impression that she'd be about 8 months old before she would be operated on so were rather shocked when Dr John Simpson told us 'Great news, she can have it next month!'. This didn't seem like great news to us as we'd only just managed to start doing normal things with our baby. But, again, it seemed that she was strong enough and thriving well so it was best to do it sooner than anticipated.

Taking Eloise for the anaesthetic was, if possible, even harder this time. In a strange way she'd become a real person to us rather than the 'bump' or the unknown baby we'd just 'met'. Even though they assured us that the risks were significantly less for this operation you still couldn't stop worrying or being scared you'd never see her again.

A long 3 hours later we were able to see her in PICU. She was just as puffy and full of tubes as before but I still didn't see them. I was just overjoyed to see her again and know that everything had gone alright. She was out of PICU after 48 hours and back on Camel ward. This time we were a bit more prepared for the change of pace and Eloise was discharged back to my parents after 7 days. Eloise and I spent another month with my parents and then went home.

Everything was going really well for Eloise and we were settling into our normal routines and doing the normal things families do. The medications were even becoming second nature to give!

At the beginning of June, when she was 8 months old, Eloise suddenly starting crying, not eating or sleeping, being very irritable yet lethargic. We took her to Aberdeen Children's Hospital where they initially told us she had some unknown tummy problem. Her liver was incredibly enlarged but we were assured this wasn't anything to do with her heart. Our usual paediatrician who has an interest in hearts was away on holiday at the time so we couldn't ask for his advice. We persuaded them to talk to Evelina who immediately told them that an enlarged liver was a sign of heart problems and to transfer her down to London.

In the weeks running up to this Eloise had started to put on weight a lot quicker than normal, but as we were actively trying to increase her weight with the dietician we didn't think anything of it. When we arrived in London we realised just how puffy she'd got. They told us she was in heart failure but they didn't know why. In the following week she had every test I think they could do, including both an MRI and an angiogram within 2 days, both under general anaesthetic. It was during the angio that Dr Eric Rosenthal saw a clot on the aortic root within her heart.

The general consensus was that a part of this clot had broken off and gone down one of the coronary arteries blocking the heart muscle itself from receiving blood. This meant that the right side of her heart, which was doing the work of the whole heart, was unable to function properly.

We were told that unless the clot could be broken down the only option for her to survive much longer was to have a heart transplant. She was immediately put on Warfarin in an attempt to help her body remove the clot naturally and various additional medications to help her heart beat stronger.

She did improve a bit and we were allowed back home to see if the Warfarin would help. This meant weekly visits to get her blood levels checked and a medication regime that was even more intense. Each of her medications had to be given at different times during the day and each had to be given an hour apart. This meant she was being given a drug pretty much each hour of the day from 7am to 11pm. Plus feeding, changing, bathing and all the other normal baby things! We got the hang of it after a while and celebrated her christening and first birthday at home together.

In November when Eloise was just over a year old she started getting puffy again and even more lethargic than she had been. She was very bright and alert but her body just didn't want to do anything. Eating became a daily battle to get just a few spoonfuls in and even milk was difficult to drink. Again we

went to Aberdeen and our pediatrician, Dr Booth, said that it was likely that it was now time to think about a transplant.

We were air ambulated down to London again and Dr Simpson agreed that the Warfarin wasn't helping and the heart really couldn't cope at all. Within a few days Eloise had been put on the transplant list and we just had to wait.

We'd talked previously about what we'd do and again we'd both decided that we had to do whatever we could for Eloise, no matter how difficult. We both lived with Eloise in her room on Camel ward as, if and when the call came, she would be taken immediately to Great Ormond Street Hospital and the transplant would take place - and if we weren't there we'd have to make our own way. We spent Christmas and New Year at Evelina, although they did let us out to surprise all the grandparents for Christmas Day!

We were very lucky that we only had to wait 7 weeks for a suitable heart. We never wished for a new heart as we knew that would mean someone else going through the worst thing imaginable to us - losing a child - but if it had to happen then we would be eternally grateful. I am still amazed that someone went through this and yet was still able to think of others and give them the gift of life. It's incredibly humbling.

One evening in January 2007 the nurses on Camel ward told me I had a phone call. I just thought it'd be one of our friends calling to see how we were doing. It wasn't. It was Kate, the transplant co-ordinator from GOS. The emotions that went through me when she said they might have a suitable heart ranged from complete shock to elation. I didn't know what to do or say, other than start crying with happiness and fear whilst trying to tell Andy what was happening!

Within an hour we were at GOS waiting and waiting and waiting. At 8pm it was confirmed that a heart was being donated, but it wasn't until 11pm that they confirmed it was suitable for Eloise. By 12.15am she was back in theatre (once again we had to send our little girl into the unknown all by herself). While the heart was being transferred to London the surgeons were trying to undo all the previous surgery to make it possible to put a normal heart into her!

At 8am the following day we were told that the transplant was a success and that she was not only in the Critical Care unit - but she was pink! We went to see her and for the first time ever Eloise had pink soles to her feet and her fingers and lips were pink. I hadn't realised just how blue she'd been!

She woke up and was taken off sedation within 48 hours. Immediately she was putting things in her mouth, wanting to eat and pointing at everything around the room. Although still very groggy and sore, we'd never seen her this active before. Her first bottle of milk she drained in about 4 minutes - previously we barely got anything in her over half an hour! It was unbelievable and totally wonderful.



We were originally told that she would be in hospital for about 4 weeks, but our little fighter was discharged after just 10 days. Once again, back to my parents in Surrey! She was already trying to do things she'd never done before and feeding her was a pleasure – she wanted to try everything! Within a few weeks she started trying to stand and 'cruise' around the furniture. She'd never had the strength before. It was very obvious that although her body hadn't let her do much, she'd been watching what everyone else did and taking it all in for future reference.

Now 6 months after transplant she's walking and has pretty much caught up on her same age friends. It's almost like they just replaced her batteries!

Life will always be a little different for us, we have to be a bit more careful about catching any bugs, if she gets ill we will have to be extra cautious, she'll need lots of clinics, biopsies and tests, not to mention the mundane things like travel and insurance hassles. But these all pale into insignificance when she gives me a hug.

The past two years have been exceptionally difficult but we've been lucky in the support we've had from the excellent medical staff, our own families and each other. I wouldn't wish what we've been through on anyone, but there is no right or wrong choice to make – you just have to do the right thing for you and yours.

P.S. Eloise has just competed in the British Transplant Games in Edinburgh, in the under 5's ball throw, obstacle course and 25m run!

**Sarah Lowrie**