

Chloe's Story



Our little boy Henry is a gorgeous, cheeky chap with a gleam in his eye and a love for life. He also has DiGeorge Syndrome (22q11 deletion), a genetic disorder which in Henry's case resulted in four specific problems with his heart, collectively known as Tetralogy of Fallot's.

The condition was diagnosed at our 20 week scan and we were immediately referred to Evelina London Children's Hospital where a Cardiologist did another detailed scan. Everything was explained clearly and sensitively, and a support worker sat with us to discuss the diagnosis and our options going forward. We decided not to have an amniocentesis - a medical procedure where amniotic fluid is sampled and tested - as the result wasn't going to alter anything in our minds and we wanted to continue as normal, as much as possible.

We had more scans than a normal pregnancy and attended the ECHO antenatal class at St Thomas' Hospital, which was really informative. Along with all the usual advice on feeding and changing, we found out about things we'd need to know as parents of a heart warrior. We visited the maternity ward and the NICU (neonatal intensive care unit) which was quite difficult: seeing the reality of what would soon become a familiar place was hard to take in but reassuring as it was such an amazing facility with brilliant staff.

I was induced at 38 weeks and our beautiful baby boy arrived assisted by a specialist Tower's midwife at St Thomas' Hospital. Every care was taken to ensure I had as normal and supported a labour as possible, with Henry being constantly monitored. There were a lot of additional staff in the room, including the NICU doctors, but nothing can distract from the moment you're passed your baby to hold for the first time, and staff made sure we could have that incredible moment. Henry was checked over by specialist doctors, then taken to the NICU for further monitoring. Just five days later we were allowed home as Henry's heart was coping well.

We spent 6 months at home ahead of his surgery, during which time his heart and weight were regularly monitored. It was a really nerve wracking time, but the cardiac support workers were always available to phone for advice and we also had the reassurance of the ECHO Facebook group, and attended ECHO events to meet other heart parents and children.

When the time came for Henry's surgery we stayed in Gassiot House, next to St Thomas', which was affordable and convenient and allowed us to focus on Henry and what was to come. He had a pre-assessment on the day before, which included blood tests, x-rays, echocardiograms and an ECG (electrocardiogram, which checks the heart's rhythm and electrical activity). We also met with the surgeon to discuss everything, and signed the consent form at the end of a long and tiring day.

The following morning we arrived at Savannah Ward where we were given a gown for Henry and then took him down to theatre. This was the most difficult part. We stayed with him until the anesthetic kicked in, then we had to leave. Some people wait in the parents' room, but we chose to go for a walk around the hospital grounds and the staff took our mobile number so they could keep us posted.

Henry's surgery lasted nearly 5 hours, and we went to meet him straight after on PICU (Pediatric Intensive Care Unit) where he received one to one care until he was well enough to move back onto Savannah. Whilst Henry was in intensive care we stayed in the Evelina parents' rooms so that one of us was always there with him.

During this period, the biggest help we had was time - time with family and friends to visit and let us talk, time to take a shower or time to go outside. It's an intense experience and you don't want to leave your child's bedside, so being able to stay close by really gives you peace of mind. After a week at Evelina, Henry was well enough to come home.

In preparation, we got lots of microwave food in so we didn't have to think about meals. We also bought Henry some clothes from [Wrap Fairies](#) as they're easier to use after surgery than ordinary baby grows, and we got him a [Warrior Bear](#) as a comforter. Both of these organisations are not-for-profit and raise money for children's charities - little things like this made a huge difference.

The whole experience was difficult emotionally; no one wants to see their child go through surgery, but the staff were amazingly supportive and you will get through it. It's incredible to see the fight and strength of your little heart warrior, and we're so grateful for all the kindness and support we received from the Evelina and from ECHO.