"My baby needed a different baby’s heart. A baby needed to lose a life to save my daughter’s life"

Thursday 8 February, 2018

Ella got a new heart after five months in Freeman Hospital. A lot of that time she was on life support and it felt like we were too, but getting a new heart finally brought my baby back to life.

Ella became ill with a chest infection when she was 11 months old. I took her to our local doctor in Douglas on the Isle of Man who prescribed her some antibiotics and sent us home. However, rather than get better she continued to deteriorate. She refused to eat, was breathing rapidly and suddenly started vomiting. Ella’s Dad, TJ, called his mum who rushed over. She recognised Ella’s symptoms as a sign of a problem with her heart and told us to call an ambulance immediately.

My baby was rushed to Noble’s Hospital in Strang and after a chest X-ray, which showed she had pneumonia, a further one showed something a lot more serious. Our daughter looked so small and vulnerable. And all we could do was stand there with the words of comfort from our family members washing over us as we were told Ella had a problem with her heart.

An air ambulance arrived to transfer Ella to Alder Hey Children’s Hospital in Liverpool. I was terrified. There, Ella was diagnosed with dilated cardiomyopathy, which meant her left ventricle (the heart’s main pumping chamber) was enlarged and weakened. We were devastated. For 11 months we had had no idea there was anything wrong with our baby.

The doctor said there was a 30% chance Ella’s condition would remain the same, a 30% chance it could improve by itself and a 30% chance it could deteriorate. After a month being closely monitored in hospital we were sent home, but over the months that followed Ella was readmitted again three times. And each time, I thought I was going to lose my baby girl.

Ella didn’t get better. And it was decided she needed to be flown to Freeman Hospital in Newcastle upon Tyne for a heart transplant assessment. I couldn’t believe it. I knew this sort of thing happened, but never once did I think it would happen to my baby.

Another shock came. At Freeman Hospital it was discovered that Ella wasn’t suffering from dilated cardiomyopathy, her left coronary artery was blocked and had been since birth. She needed to have an operation as soon as possible, but even then it was unlikely her heart could be repaired. It was devastating. Not only were we hours from home - we were a sea crossing away. We had nowhere to stay, we were unable to afford the cost of a hotel and had no idea how long Ella would be in hospital.

Thankfully, as we sat at Ella’s bedside a nurse told us about The Sick Children’s Trust. I didn’t know the charity existed, but we were put in touch with Andrew who manages the charity’s Scott House at the hospital. He came to meet us on the ward and explained that The Sick Children’s Trust would provide us with a room, totally free of charge, just minutes from where Ella was being treated. We didn’t know at that point that we would be staying at Scott House for more than six months, but gratefully accepted the room and moved in. It was a godsend and immediately became somewhere we thought of as home.

Three days after arriving in Newcastle, Ella underwent her first open heart surgery and we waited for her to come out of surgery in Scott House. It was unbearable, but at least we were in an intimate environment surrounded by lovely supportive people who understood what we were going through. When Ella came out of surgery and I saw her lying there I was inconsolable. Nothing can prepare you for that – seeing your child on a life support machine and reliant on another machine to pump blood around her body. It destroyed me.

Ella’s heart was significantly enlarged, but following the operation the doctors hoped it would shrink and begin to function more effectively by itself. However, within a week we were given more devastating news that she had end stage heart failure, her heart was so enlarged one of her lungs had collapsed. Ella’s only chance of survival was a heart transplant. From that point on our lives became a waiting game. Ella had to have another operation to fit her with a tracheostomy tube so that she was able to breathe. And she spent most of her treatment wired up to a life support machine that was keeping her alive.

You can’t begin to imagine the thoughts that crossed my mind during those months. My baby needed a different baby’s heart. A baby needed to lose a life to save my daughter’s life. It was torture, but we had to remain hopeful. Talking to other parents in the same situation at Scott House helped keep our spirits

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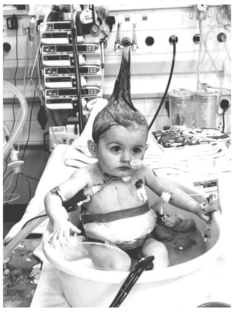

up. It was a tremendous support and we were able to comfort each other – sharing our fears, but also inspiring hope and reassuring one another that good news was just around the corner. Thinking back I remember being in the living room talking about how I was feeling and knowing that those listening understood what I was going through. It was a different story with some my friends back home; they struggled to comprehend and we drifted apart.

Scott House really is an incredible place. It is so close to the hospital and because there was a direct phone line from our bedroom to the ward where Ella was being treated, at night I felt able to relax a little bit, have a hot bath and then, exhausted and drained, tumble into a comfortable bed. Plus, the amazing facilities meant we could wash and dry our clothes, store our own food in the kitchen, cook nutritious meals of our choice and even have family members over. When it was just the one family member visiting they even stayed in our room at Scott House, which saved them money and gave us the additional support we urgently needed. TJ's and my family have been amazing – endlessly supportive they visited us regularly and spent a lot of time with us in both the hospital and Scott House.

On the day we got the call to say there was a heart for Ella, we were ecstatic and terrified all at the same time. She went into theatre that day at 5.30pm and once again we waited, scared stiff, in Scott House until she came out of theatre at 2.30am. Andrew was there with us for the first few hours and he has this amazing ability to lighten every situation. When we heard the news that the operation had been a success it was the best news we had ever received.

From this point on our story is one of triumph! Ella is doing amazingly well – she has recovered from her operation and has even started to walk again. She had started walking before her admission to Alder Hey at the end of May, but she had been in a hospital bed since then so had to relearn. She is chatty, lively and very, very cheeky! She's a completely different child, which means I can be a different mother!

Knowing that other parents we met in Scott House are still waiting for a heart for their child is extremely upsetting, but at least they have the support of The Sick Children's Trust. At the moment Ella and I are living in Newcastle so we can attend her fortnightly appointments at Freeman Hospital, but I am positive that it won't be long before we get back home to the Isle of Man.

Amy Ash, Ella Wiseman's mum.

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