# If I hadn’t had a heart attack when Ellie-Marie’s older sister was born, I wouldn’t have given birth in a specialist paediatric hospital and it is unlikely Ellie-Marie would be here today

**Tuesday 23 January, 2018**

Ellie-Marie was delivered by caesarean on 31 July 2017. I had suffered a cardiac arrest when giving birth to her older sister, Jaime-Leigh, at the beginning of 2015 in Airdale General Hospital, which is close to our home in Keighley. Worried that the same thing could happen again with Ellie-Marie’s birth, a specialist referred me to Leeds General Infirmary (LGI) and despite no complications during my pregnancy, it was decided I would have a planned caesarean at 38 weeks.

After a failed epidural, I was given a general anaesthetic so I was unconscious when Ellie-Marie was delivered, but my partner Darren was present for the whole thing. The birth didn’t go as planned. Far from it. When Ellie-Marie arrived, she wasn’t breathing. It took the doctors over 45 minutes to establish an airway and all that time Darren watched on helplessly, fearing I might never meet get to meet our new daughter. Finally they managed to intubate her, but it was a huge struggle.

An hour later, when I finally gained consciousness, Darren explained what was going on. I was disorientated and distressed. Where was my baby? She should have been right there with me in the room, but instead I was told she was on the neonatal intensive care unit (NICU). I couldn’t comprehend that she was seriously ill. It was me who was meant to be the one at risk, not my baby.

I had to wait a few hours before doctors would allow me to see Ellie-Marie. Darren and a nurse took me to see her in a wheelchair. My baby was in a room on her own with a nurse watching over her, hooked up to a ventilator with tubes and wires all over her tiny body. My heart broke. I felt helpless, I couldn’t even hold her.

At two days old Ellie-Marie had to undergo surgery so that the doctors could determine what was wrong. They suspected she might have a growth in her windpipe or some other abnormality. Fortunately Ellie-Marie didn’t have a growth, but she did have a condition called Pierre Robin Sequence. My heart shattered as a doctor explained just exactly what this meant for our little girl.

Pierre Robin Sequence is a set of abnormalities affecting the head and face, where a number of birth defects appear together consisting of a small lower jaw and a tongue that is placed further back than normal, which in turn obstructs the airway. Most babies with Pierre Robin Sequence are also born with an opening in the roof of the mouth. This explained why Ellie-Marie wasn’t able to breathe on her own and had almost died once the umbilical cord had been cut.

I was devastated. I thought that it was my fault and blamed myself for what was happening to my baby. Although the doctors and Darren tried to reassure me that nothing I had done could have caused Pierre Robin Sequence and that it was a result of genetic abnormalities, I struggled to accept the truth and hated myself for what was happening to my daughter.

I was discharged five days after the caesarean and had no idea what I was going to do about getting to and from LGI to be at Ellie-Marie’s bedside every day. I didn’t want to leave her, but I wasn’t allowed to sleep with her on NICU. And I

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also had my other kids to think about. The next morning, after travelling back to LGI by train, one of the nurses mentioned The Sick Children's Trust to Darren and I and she put our names on the waiting list. Unfortunately, it would be another four days of traveling backwards and forwards before a room became available for us, as there is such a huge demand on the charity's Eckersley House at the hospital.

During that
time, Ellie-Marie turned a week old and was taken into surgery once more to take her off the ventilator. The operation was a success and she was placed on high-flow oxygen. And although Darren and I, along with our two and a half year old daughter, Jaime-Leigh, needed to get a taxi or train to the hospital every day, we made sure we were there so that Ellie-Marie was never alone. However, it was exhausting and emotionally and mentally draining as we were without two of our children, Joshua and Kian, who were being looked after by our neighbour.

On 8 August a
room became available for us at Eckersley House. At the time we had no idea that we would end up staying there until 10 October, over two months later. Jane, the House Manager, showed us around and it was amazing. Jaime-Leigh settled in immediately. She loved the playrooms and all the attention she got from the staff – there was even an outdoor area where she could ride a little bike that was there, which she fell in love with. It meant everything to Darren and me as we couldn't have stayed somewhere that she wasn't comfortable. It became a godsend too, as a toddler doesn't want to be spending 12 hours a day on NICU, so Eckersley House meant one of us could bring Jaime-Leigh back to play, have a nap or have some food throughout the day.

Not only was
Eckersley House good for Jamie-Leigh, but it also meant that Joshua and Kian could come over and they ended up spending a lot of time there with us. It gave them a lot of reassurance because at 13 and 14 years old, even though we told them on the phone we were fine, unless they could physically be there, they weren't convinced!

As the days
passed, it became clear that high flow oxygen wasn't enough for Ellie-Marie, especially during the night when she really struggled to breathe. So at 18 days old the specialist made the difficult decision to perform a tracheostomy. She went back into surgery to have a surgical opening created at the front of her neck so that a tube could be inserted into her windpipe to help her breathe. In under three weeks Ellie-Marie had been in surgery three times.

Over the weeks
that followed we remained at Eckersley House as Ellie-Marie grew stronger on NICU. There was a slight set back when she was six weeks old because she came down with a nasty chest infection and sepsis. Darren was at home in Keighley, as Jaime-Leigh was starting nursery, so I was alone on the ward when I noticed Ellie-Marie had gone grey. I called to the nurse who pressed the emergency call button and doctors rushed to her bedside. Ellie-Marie's tracheostomy tube had become blocked so she was slowly suffocating. Fortunately the doctors replaced the tube and began to give her strong antibiotics.

Without
Eckersley House over that two month period we would have been totally lost. I don't know how we could have coped with everything that was happening to our family and how much we were going through. We met parents whose children had been given a tracheostomy and they were able to reassure us and answer some of our questions. If I was having a bad day there was always somebody in the house I could talk to. Even now, one of the families we met at Eckersley House uses the same day carer that we have for Ellie-Marie. The staff too were simply amazing. Anything you needed, they got for you and even if you just needed to cry or shout, they were there to listen. We will be forever grateful for The Sick Children's Trust. We hadn't even heard of the charity before Ellie-Marie was born.

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Ellie-Marie
still has a tracheostomy tube, but she is doing really well and we managed to have a lovely family Christmas at home. On Christmas morning we all opened our presents and Jaime-Leigh managed to open all Ellie-Marie’s as well as her own – she was so excited! We have an appointment with the specialist at LGI coming up and we have been told Ellie-Marie will need a couple more trips to theatre as time goes on; the doctors need help to make sure her windpipe is large enough and increase the size of the tube, but we are confident she is in the best possible hands and are so proud of how far she has come.

**Sharon**
**Deacon, Ellie-Marie’s mum.**

***About The Sick Children’s Trust***

*The Sick Children’s Trust is working to a future where every family with a seriously ill child in hospital will be able to stay together, just minutes from their child’s bed during their treatment.*

*We believe keeping families together significantly improves the recovery of seriously ill children. We provide free, high-quality ‘Home from Home’ accommodation, as well as emotional and practical support, to families with sick children in hospital in the UK.*

*The Sick Children’s Trust* ***was founded in 1982 by two paediatric specialists Dr Jon Pritchard and Professor James Malpas.*** *Today we have ten ‘Homes from Home’ at major hospitals around the country where families can stay free of charge, for as long as they need whilst their child is undergoing treatment.*

*We support 4,000 families every year, and there is a growing demand for our ‘Homes from Home’ as children must increasingly travel long distances to get the specialist treatment they need.* *www.sickchildrenstrust.org*

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