

Living with Cali

A BLOG FROM A TRISOMY MOM ABOUT LIVING WITH TRISOMY 18
BY 'JAY'



PART 1 — PREGNANCY, BIRTH AND DIAGNOSIS

With hindsight it's easy to say I always knew something was wrong. Yes, it was my first pregnancy and I am a worrier, but did that account for the deep anxiety that accompanied me through the pregnancy, even when the professionals were telling me everything was fine? At my 20-week scan I remember saying that if everything was OK then maybe, perhaps, I'd be able to start enjoying my pregnancy and believing I would have a healthy baby at the end of it all.

That wasn't to be. Thinking about it now still puts butterflies in my stomach. The Sonographer going quiet and leaving the room. Being rolled onto my side as I felt so sick and faint after they explained that the heart didn't look right, that the brain looked unusual and that they would have to do some tests. They took us to a room clearly designed for parents like us who were receiving bad news, and when it was time to go we left by a different route. That was the first of many different routes for us. For that's what having a child with disabilities has meant for me, always feeling different from the herd of parents with "normal" children. I didn't get to have Cali with me after she was born, I didn't get to breastfeed, there wasn't even any time for me to give my labour aches and wounds time to recover. Whilst my NCT group shared their joys and worries in our Facebook group and organised first meet ups, I was at home with my scrap of a baby into whom I would pour my expressed milk via a nasal feeding tube, learning about apnoea and opening the door to a stream of professionals whose job it was to assist with Cali's expected short life. I found I wasn't even sure that I was Cali's mum, the one whom she was meant to need the most, as there were so many other people turning up to help care for her. Nothing was "normal" or how it should have been.

But let's go back to the 20-week scan. The sonographer had decided that my baby's heart wasn't wired up right. We saw a foetal consultant who cheerfully told us that the heart was wired up fine, but he was worried that it was rotated. We saw a cardiologist who said there was no rotation, but he thought he could see a hole, not necessarily something too serious. I also went for an MRI scan on the baby's brain and they decided that too was OK. Apart from a potential hole in the heart my pregnancy officially returned to being low risk and normal. Yet I continued to worry. As I trudged to work I recited the Buddhist Metta Bhavana meditation to myself, over and over, mostly for the baby, sometimes for myself. "May you be happy, may you be healthy, may you be safe, may you live in peace". I would later sing this repeatedly to Cali through anxious evenings at home and long nights in hospital. I prayed so much, I asked everybody with any link to any religion to pray. I just wanted her to be OK.

So, there I was, praying and worrying. Whilst the other NCT mums were making ouch faces in class at their feisty babies' kicks and rubbing their big bellies I spent most of the classes only half present, the other half tuned into my little bump, trying to feel signs of life. It turned out I was right about the movements, she didn't move nearly as much as other babies. If I'd known her diagnosis at this point I'm certain I would have ended up with an early induction as I would have been told she was in distress, I also believe she wouldn't have survived long if that had been the case. But I didn't know, and so my due date came and went and 13 days later I reluctantly agreed to induction the following day. That night my waters broke, and I went into labour naturally. Eighteen hours later my baby shot into the world breathing but quiet. She'd waited until the last possible moment to exit, which may be one of the reasons she's still with us now, extra time to mature those weak lungs.

Can we stop here a moment? With me, gowned and ready for a c section there was no time to perform. Smearred in blood and meconium with that flush that labour brings to the cheeks. I am cuddled up to my partner C, holding a dark eyed little baby who is tiny, skinny, silent. She is holding my finger. Part of me remains even now in that delivery room because these are the last few moments of my old life and I'm still not ready to let go of it completely. I still haven't been able to quite accept that it was us that got the 1 in 6000 live birth, and then went on to have the 1 in 10 baby that would endure the condition beyond a year.

A couple of days later a vile heart consultant took us to another one of those bad news rooms. He brought with him a ragtag of other hospital workers who leaned against the wall as he casually asked if we'd had any genetic testing. He removed three fountain pens, each with a different coloured ink from his pocket and took his time as he drew a heart to demonstrate our baby's various cardiac problems. He then mentioned our baby had all the markers of Edwards Syndrome; low down ears, crossed fingers and so on, and then he left, and the watchers trooped out after him. I can see us now, huddled together, so vulnerable, 10pm at night, 2 days post-partum, watched by strangers as the process of breaking our hearts began. We didn't look up anything about Edwards Syndrome during that five days whilst we waited for the results. Instead we cocooned ourselves in NICU, me often at the milk pump, C learning how to change tiny nappies, waiting for those precious moments when our little yellow, wired up baby could be placed awkwardly in our arms.

When the results arrived, they were delivered by a much kinder doctor, he told us she had full Trisomy 18, or Edwards Syndrome and that babies with this condition usually only lived a very short amount of time. I asked how long she had and he said he didn't know, maybe 6 months, maybe less. Although he briefly mentioned he thought there might be a teenager that was alive somewhere he didn't encourage us to have any hope. He also told us that any kind of resuscitation would be inappropriate. We clung to each other as the bottom fell out of our world and normality fled to find somebody else more fortunate. We were given a room to share with our tiny scrap and almost immediately I somehow knew her name was Cali. We looked up what this meant. Short for Callista, meaning "most beautiful", named for the Greek Nymph who forms part of the Great Bear constellation whose celestial feet never dip below the horizon. It felt perfect for our little girl with her strangely huge feet. Those feet would never dip below the horizons of our love.

Jay

