

## James's story

I was 33 when we had James in 2005. I'm not an intuitive person by any stretch of the imagination, but for some reason, I worried excessively about my baby having Down syndrome whilst I was pregnant. My nuchal and blood test combined gave me a 1 in 500 chance of having a baby with DS – which I thought was high. However, whenever I questioned midwives or doctors they all said that although obviously someone had to be that one – it was so unlikely to be me as I was only 33. Plus there were absolutely no indicators in either of the scans.

James was born by emergency c section at 11.30pm on 10<sup>th</sup> May. He was very dark as the cord had been around his neck and he didn't cry. I kept repeating 'check his eyes'. I think everyone in the room thought it was the drugs talking! They reassured me that he was perfect. And, at last, for the first time in about 6 months, I relaxed.

Malcy, my husband bought our 3 year old daughter Isla to see her little brother the next morning and we were unbelievably happy. As he left to take her back to her grandparents, a paediatrician came to run some checks on James who still hadn't fed. She said she was taking him to the neonatal ward to run some more checks which worried me. I called Malcy to come back asap. He returned and went to see what was happening. When he came back to our room I told him that I was worried James had DS and he said that he was too. My heart sank. I knew that if Malcy – the voice of reason – was thinking the same as me, I wasn't being irrational.

A doctor, midwife and nurse came to our room shortly after that to tell us they were 99% sure that James had Down syndrome and that they were going to carry out a chromosome test to confirm it. They left us alone to absorb that information with some leaflets and invited us into the neonatal ward as soon as possible where they were going to keep James for the time being to be tube fed.

I felt as if our world had ended. My initial thoughts were that I'd have to give up work, my whole life would change, Isla would get bullied, so would James and very selfishly – that we would be tied to the house, never able to go on holiday on our own when he was older.

Malcy and I went to see James as soon as we could. We called our parents to tell them the news and they were amazing and supportive, coming straight up to see James. We texted our friends who again, were fantastic and took it in their stride. It didn't bother them at all.

I think the turning point for us was a couple of days later. We were told that James was very healthy, his heart was fine and he only had to stay in the neonatal ward until he fed from a bottle. We were so happy there was nothing else wrong and started to accept that although this wasn't what we had planned or expected, it was still fine and we'd just deal with it.

We were completely naïve about DS - I asked a doctor on a scale of 1 – 10 how severely did James have it! And I had such awful, shallow preconceptions about children with DS and the type of people who had children with DS. I'd never been exposed to anyone with any kind of disability.

I was chatting to a nurse one day about how desperate I was to talk to other families with babies who had DS. She disappeared for 5 minutes and returned with a number for Ali who had been in the neonatal ward 3 months earlier with her little boy Jack who had DS. I don't think this was allowed, but I'll be forever grateful to her. I rang Ali who sounded lovely and we agreed to meet up when James came out of hospital.

After 4 weeks James was on the bottle and we could leave. It was such a relief to get a bit of normality in our lives. We met with Ali, Simon, Jack and Ali's mum at Hampton Court for a cup of coffee. It was such a relief to talk to people who knew exactly what we'd gone through. I remember saying to Malcy, that they were the kind of people we'd be friends with in 'real life'! I was so relieved they were normal. (Told you I was shallow!)

After a few weeks Ali mentioned a coffee morning she was going to, run by a support group '21 & Co'. I'm not really a support group type of person so I was a bit reluctant, but went along as Ali was going. I'm so glad I did. As well as meeting loads of lovely mums with toddlers, I also met a couple of other mums who had babies a few days older/younger than James. We'd all been under the same hospitals care, but they hadn't mentioned it to us. So, Malcy and I had felt alienated and unique when we weren't at all!

Malcy and I have made some really good friends through 21& Co and it seems insane that had James not have been born with DS, we might never have met them. There are so many positives of having a child with DS and none of the literature etc really covers that. We became regulars at the events 21 & Co held and they'd helped us so much I felt as though I really wanted to get involved and help more. So, I became a trustee. It's lovely to get stuck in and see so many new parents joining us and getting the same support we did.

Having James seemed like such a life altering experience at the time. And I guess it has been, but in a good way. It really hasn't been a big deal having a child with DS so far. James is adorable (I may be biased), he has a really cheeky sense of humour. He and Isla worship each other and we're all learning to sign. We're incredibly proud of him. He's made such a positive impact, not only on our lives, but also the lives of our friends and family. He's challenged all of our pre-conceptions and exceeded all of our expectations.