

November 2007

The day I walked into the maternity unit at Kingston hospital for my 13 week scan I could think only about the image I would soon see of my baby. It hadn't crossed my mind that the baby – my 4th and last - would be anything less than perfect. I was blasé; everything would go swimmingly. Besides, I'd been feeling sick as a dog for weeks, always the sign of a healthy baby. And if anything was wrong, it wouldn't make any difference, I would continue with the pregnancy. Easy words which happily tripped off my tongue, such was my certainty that all was well.

I had asked my sister to come along with me to share the day's excitement. We weren't disappointed – the image on the screen was wonderful! Beating heart, 2 arms, 2 legs, a beautiful spine But as the sonographer went about her measurements her smiling face darkened. She wouldn't meet my eye. The measurement for the nuchal fold – the space in the neck - was large, unusually large. My sister asked if this meant something was wrong and the sonographer confirmed that the chances were high. She shuffled uncomfortably and said we should talk to a midwife. I felt winded. It was hard to believe that something could be amiss with this lovely-looking, gently hiccupping foetus.

We were ushered into a side room, me shaking with disbelief, almost faint with fear, leaning on my also shocked but wonderfully supportive sister. A lovely, kind midwife explained that such a reading strongly indicated a chromosomal abnormality, probably a trisomy. A friend of a friend had undergone a trisomy 18 pregnancy the previous year so I had heard of the term trisomy but didn't know that Down syndrome fell into that category. The midwife explained that it could be one of the trisomies, or perhaps Hunters syndrome if the baby was a girl. Of all the trisomies number 21 – aka Down syndrome - was the most 'life-compatible'. I was numb. My ears and head buzzed. The last half hour had changed my life completely. Although it felt like it was happening to someone else.

It was Friday and the lovely midwife fast tracked me for a CVS the following Monday. I wanted to know exactly what was wrong with the baby so that my husband, Andy, and I could re-gather our forces and decide what to do next. I spent the weekend anxiously 'Googling' trisomies and other chromosomal disorders. I cried buckets. My family and friends rallied around with phone calls and texts and messages of love and support. I had been thrust into an alien world and I was scared. Andy was also in shock. He didn't speak much and he certainly didn't want to consult the internet with me, but he hugged me lots.

My sister, who had been an absolute rock at the scan, came with me to the CVS, along with Andy. The staff at St George's were very kind, and very expert. I was terrified, but felt safe in their hands.

The results came 3 days later. I was at work so took the news over the phone. I had started to think that Trisomy 21 would be the worst result – I knew I would probably terminate with one of the other trisomies, not that it would be easy, but DS, I'd always said it wouldn't make any difference. Now that DS had become a reality it didn't seem so clear cut. I was confused and frightened.

Over the next few days my family were amazing. They were very sorry and sad but said that they would completely support whatever decision Andy and I made. It felt good that we wouldn't be judged. At first we didn't rule anything out but having spoken to the DSA and done further research online we both began to feel that we would not end the pregnancy. We were lucky to have had 3 healthy pregnancies and 3 healthy children and it seemed almost churlish to abandon this pregnancy, akin to throwing our toys out of the pram at the first sign of things not going our way! Although I must stress that we are both completely sympathetic to those who choose the other route with this heart rending decision.

The baby's heart was scanned a week later – it was working perfectly – and this sealed our choice. We also found out that the baby was a boy and decided to call him Alfie (Alfred). A cute name and also the name of one of England's wisest kings, and a name to match our two other regal sons, William and James!

After this I threw myself into work, researching DS when I got the chance but mostly just getting on with the hectic pace of 40 hour weeks at the office, commuting and the ups and downs of family life. The fear and grief were still there but most of my colleagues and friends were fantastic, and this helped enormously. I began to think that although this wasn't a box I would have ticked, it didn't have to be all bad. I talked to Alfie about my worries, and Will and James, 11 and 8 at the time, who were wonderfully reassuring. I remember Will saying 'it's only DS Mum, please don't be sad and worried, we'll help you, and it'll be ok'. It gave me such strength.

Alfie was born at home on 6th May 2008. He was floppier than your average newborn but alert and beautiful. He lay on my tummy for an hour before the umbilical chord was cut, looking at me, and around the room, curious and content. I felt a great calmness. Big brother James proudly and tenderly put on his first baby gro.

After Alfie's arrival I became quite desperate to meet mothers of babies or children with DS. Alfie was a lovely laid back baby who fed without problem and had fitted into our family beautifully but I craved meeting people with a link with DS, however small. Then my sister suggested us going on a walk in Bushey Park with the DSA. We did this when Alfie was 4 weeks old and I met a girl called Louise who had a 2 year old daughter, Emma, with DS. Louise was fantastic, taking me under her wing and telling me amongst other things about 21 & Co – bingo! Just what I had been looking for! I went to my first coffee morning a couple of weeks later and found a rowdy melee of Mums, babies and toddlers, chatting, crawling and gossiping over coffee and cakes. The 'established' Mums were so welcoming, and so delighted to meet Alfie and me - we felt like VIPS! The new/newer Mums were as keen and relieved to chat with me as I was with them. I realised that this world of DS, although still strange and daunting, was going to have a big up-side!

Since this happy introduction to 21 & Co, I have regularly attended coffee mornings. They are real oases of advice and support and through them many new and lasting friendships have developed. Having a child with DS binds and unifies us but we are all different people and personalities and I find everyone has so much to offer. Whether further down the line or 'new' you will always find a pearl of wisdom at a coffee morning to uplift or reassure you or make you chuckle. It's empowering to go

back out into the 'typical' world knowing that you have such a regular and supportive group to meet with. I now enjoy welcoming brand new Mums and babes into the coffee fold, and listening to their recent and often raw experiences and fussing over their lovely babies.

Alfie is doing brilliantly. Progress is slow in some areas, but I've realised that he will achieve everything and more, just at a gentler pace. He's a delight to be with, funny and tender and chatty. He boasts an army of fans on the school run, (for James and big sister Zoe), who descend on him every afternoon and jostle for space around his pushchair!

21 & Co is a big part of our life. In September Alfie started attending a weekly speech and communication class run by 21 & Co with 3 of his little friends and it's a joy and privilege to watch all 4 of them develop and grow. In years to come he will move on to a drama and social interaction group, also run by 21 & Co, and then on to a 21 & Co youth club – the possibilities are endless!

The '&Co's also benefit from 21 & Co, just as well as there are 5 in my case! A fabulous family party is thrown in January and it's good to see Dads and siblings getting to know each other. Each child is given a present to take away which makes each child feel special and valued. It means a lot to Andy and I, and my 'typical' children are not overlooked.

I decided to become a trustee of 21 & Co this Autumn to try and give back in an official way some of the support I have enjoyed since Alfie was born. I want to help 21 & Co carry on and increase their amazing work and to reach out even further and wider to those entering or already in the world of DS. Over the past few years I've felt I'd like to get involved in something really good and useful and local, something more than just working and raising kids and helping out occasionally at school - all of which are great in themselves - but Alfie, by having 'something extra', has given me that 'extra something' I craved. And with it extra friends, extra fun, and extra joie de vivre – thanks Alfie!

There are challenging and anxious moments when you have a child with an extra chromosome but it has made my life indescribably richer and fuller. 21 & Co has played a big part in this enrichment. Being involved with such a fabulous and caring group has helped me to accept and embrace the journey that began for me on that Autumn day 2 years ago. And with Alfie on board I am loving the ride!