

Amber's Story

Six months before having Amber, I sat in my school staffroom (I'm a teacher) reading a piece of writing that to this day I think fate meant I was to read. It struck me so much I talked about it to friends about what an amazing insight it gave. It was 'Welcome to Holland' and when Amber was born it was the first thing that came to mind and the first thing I wanted to read. It still sits in my daughters room, perched on a shelf where I still read it. It changed the way my husband and I viewed what happened to us those 6 months or so later.

Amber was born on 16th November 2006. Despite normal scans and low risk nuchal, Amber was born with Trisomy 21. I remember thinking it sounds better when you say it like that. Better than Down syndrome. She didn't have all the symptoms and so we had to wait a week for blood results to confirm diagnosis. But I knew, and my husband knew. She was floppy and I saw it in her face the moment I saw her. We lived for a week hoping our inner thoughts were wrong and not talking about what if? But we loved her, and the thought of her having Downs syndrome simply made my heart swell and honestly love her more. I felt a protective instinct I cannot explain and began by thinking I'm ok with this, we'll be fine. Then soon after, my husband one day held her, and with tears rolling just looked at me and said 'I don't care'. Then I knew it was the three of us and that was fine, all we needed. Then gradually day by day family and friends were agonisingly told (or texted mostly as it was just too hard to tell people and hear the sadness and shock in their voices). Gradually my tiny circle of protection for her grew and grew as people welcomed her into our world and I began to realise it was never going to be just us, as Amber from the day she was born seems to have drawn people in. Different though our family may be from most I have never felt that we are out on our own.

We took Amber home after 5 days, the hospital had been good on the whole. They were caring but didn't know what to say; though honestly I don't know what anyone could say at that stage. We just had to grieve for the baby we thought we were having. I couldn't bring myself to read all the literature I was given about Downs for some time. I just wanted to be normal, like I was supposed to be. I wanted to get my days of being a new mum back to my plan as much as possible. And that's what we did, just got on with being as normal as we could be. Amber was lucky not to have any additional complications so we could try and get back to our life. As she has got older I've felt it more important for Amber and I to have people in our life who are also leading this slightly alternative path.

We have always tried to be positive from the first day that the bombshell came and mostly we are, though I can't say that from time to time worries and concerns don't raise their head. But we're learning to keep those times shorter.

These days Amber is a funny, intensely curious, active and beautiful child full of life. She has achieved so much and every step has been followed so closely and with so, so much pride. Things are more difficult for her and don't come as easily and so every achievement is magnified (and sometimes every frustration). She

walks (miles when she wants to) and climbs (the furniture) well, she can sign brilliantly (her favourite thing in the world is Mr Tumble) but she is talking more and more and she can read some simple words. All things I never imagined she would be doing by age 3. She delights us with her cheeky sense of humour and delights her brother with all the tickles she gives him.

So I do have high hopes for her future. My hopes are that I (and others) will continue to marvel at her efforts and accomplishments and continue to be surprised at what she is capable of. I was once told by a doctor that my life would be an adventure with Amber. And I like that idea. So... not ordinary, not typical but who doesn't want some adventure in their life? I do and I cant imagine a life without Amber in it.