

Emilys birth story – update

Emmy had an MRI when she was 10 days old. It was clear that she had 3 lesions (areas of damage) to the basal ganglia in her brain. This area is responsible for muscle co-ordination and balance. Although we were prepared to see damage – it would have been a miracle if she had come through everything unscathed, our consultant told us it was a wait and see approach with Emmy. Some babies recovered very well, others not so good. As far as we were concerned, she was OK and out of intensive care so it didn't matter. He told us she might have a few problems holding a pair of scissors..... Another blow was that he recommended we don't have any more children as it would be too risky with the amount of scarring I had. It left me wishing that they had done a hysterectomy then at least I wouldn't have the choice. As it is – if I got pregnant again, I wouldn't be able to carry my baby full term without my life being seriously at risk.

When she was five weeks old we were told in a particularly cruel and callous way that Emmy was showing signs of difficulty. Our community nurse visited us at home to discuss Emmys feeding – or so we thought. He looked at me – and said 'I have two words to say to you – cerebral palsy'.

Of course our world fell apart. In the dark months that followed we got a diagnosis. Emmy has athetoid cerebral palsy which affects every muscle in her body. She is unlikely to ever sit or stand unsupported. Her speech will be affected and she may not talk at all. Intellectually, however, she is unaffected and is a very bright little girl. She is now 14 months old. She is very clever, stunningly beautiful and is doing well. She now rolls over with ease and is now starting to bring her legs up when on her tummy. Her arms still do not do what she wants them to do half the time and she cannot grip very well.

We are heartbroken for her – but a happier little girl you will never meet. She now has full support – physio, occupational therapy, osteopathy, a full range of supportive equipment, chairs, standers etc. She gets measured up for her first pair of supportive boots next week. We have been told she can have pink ones with kittens on them xxxx

On the practical side our house is now up for sale as we need a bungalow so Emmy can have full wheelchair access as she gets older. It's a whole new way to look at the world and a whole new way of parenting.

So trauma upon trauma upon trauma – but we are slowly coming to terms with everything. Some days are easier than others. We do feel robbed of our little girl that should have been and Dan has been robbed of the little sister that should have been running around playing with him.

Please feel free to contact me if this is familiar to anyone – having a child with special needs because of their birth is a hard pill to swallow and we all need support.

We are starting to feel so much better now. We so very nearly lost her and she is teaching us all a lesson in life. We certainly appreciate the little things now and she is our darling, determined, beautiful little star xxxx