

“My special needs tot inspired a book”

Rebecca Elliott, 31, from Suffolk, is so keen to educate the world about the positives of parenting a severely disabled child that she's written a children's story about her daughter Clemmie



Rebecca and Matthew had an anxious wait while Clemmie was in a special care unit



I was over the moon when I found out I was pregnant with Clemmie, but things didn't go right from the moment she was born. The birth

was really traumatic, Clemmie didn't cry and looked all swollen. She was whisked straight to the Special Care Baby Unit and I knew something was seriously wrong.

The first few weeks of Clemmie's life were a constant stream of tests while doctors tried to find out what was wrong with her. She was having fits and wasn't responding as she should be. Thankfully, because she was feeding OK, we were allowed to take Clemmie home but she cried constantly and barely slept. She wasn't developing properly and at 6 months old she still couldn't hold her head up and hadn't

attempted to roll over or sit up. She also wouldn't hold eye contact or show any

Clemmie and her brother Toby are the stars of their mum's book

interest in toys or reaching out for things. I knew deep down there was something wrong, but I had been hoping that she was just a bit behind in her development and would eventually catch up.

“At first I wanted to throw things”

It took the second brain scan to finally reveal what was wrong with her. We had a nerve-wracking week's wait before we got the results which were absolutely earth-shattering – the neurologist told us that Clemmie had the second-worse case of brain damage he'd seen in 25 years, resulting in a diagnosis of profound cerebral palsy. It meant she was never going to be able to walk, talk or use the toilet and would eventually be fed with a tube. I never dreamed it could be this bad.

At first I wanted to throw things around – it was an immense shock and not something you can ever prepare yourself for. My husband Matthew was a marvellous support, though – hearing news like this

either breaks you apart as a couple or pulls you closer together and for us it was definitely the latter.

“She'll never be able to join in”

The first few years were tough. I remember taking Clemmie to a nursery group when she was 18 months old and while she was lying across my lap all the other toddlers were whizzing around on trikes. It broke my heart to think that my little girl would never be able to join in.

Looking after Clemmie took up most of my time. I'm a writer and illustrator, but I had to put a lot of work on hold as even things like giving a severely disabled baby a bath takes longer than you'd ever think.

We weren't alone, though, and were lucky with the support we got from charities such as Children Today (www.children-today.org.uk) and social services. We've adapted the house with everything necessary to make life as comfortable as possible for Clemmie, including a special hospital bed, wider



Clemmie, now 5, can't walk or talk



Toby, 2, loves sitting on his big sister's lap

doors and ramps for her wheelchair and a hoist in the bathroom. Clemmie loves the special sensory room we've had built in the back garden. It has lots of equipment for stimulating her senses – she loves following the lights with her eyes.

Our son Toby was born when Clemmie was 3. I was worried about having another baby, but the doctors reassured me the chance of history repeating itself was very slim. Even so, the birth was the most anxious time as I was petrified Toby would be whisked away to the Special Care Baby Unit as Clemmie had been. When I heard him cry for the first time the sense of relief was overwhelming.

Clemmie and Toby have been best pals since day one. Toby is always showering Clemmie with kisses and he loves sitting on her lap in her wheelchair. In fact, everybody who meets Clemmie loves her and she lights up a whole room just by being in it.

“I wanted to show the positive things”

It's that special quality in Clemmie that inspired me to write my book about her. In the back of my mind I'd always wanted to write about my kids – what children's author doesn't? But I also realised that there aren't enough stories that feature severely disabled characters.

I wanted to write something that showed



Each page shows Clemmie's disability in a positive light



Just Because teaches children to accept people's differences

Clemmie's disability in a positive light – a celebration of her differences that would highlight how we enjoy every second with her. The story revolves around Clemmie and Toby's relationship, with Toby explaining how Clemmie is different and what her special little quirks are. I was worried that my agent might find it too sentimental or self-indulgent, but she said it made her cry in a good way.

I spent three months illustrating it while juggling looking after the children. Clemmie's now at a special school during weekdays, plus we get a few hours of help each week from carers and eight nights a

year of respite, which makes things a little easier. I really hope parents and children like the book and it makes them laugh. I also hope it makes the idea of parenting a child with a severe disability a little less daunting.

I've already started work on the sequel, *Sometimes*, due out next year. It's about Toby visiting Clemmie in hospital where they have lots of fun. Next year, I have another book coming out called *Zoo Girl*, which is about a little girl who gets adopted. I know my family will always be faced with challenges – the most recent being Clemmie's operation to put her dislocated hips back in place – but we'll take them all in our stride.

Even though sometimes, if I see a little girl with curly, brown hair skipping along the street I feel a jolt of pain, I wouldn't change our life with Clemmie for anything. ☺

REBECCA'S 5 TIPS FOR PARENTING A DISABLED CHILD

- 1 Join local support groups for disabled children and their parents as even though every disability is different it's good to talk to others in a similar situation.
- 2 Try and keep your sense of humour – you'll have up days and down, but the down days will be a little bit easier if you can have a laugh about things.
- 3 Make sure you are getting all the benefits you and your child are entitled to – not just

financial but also respite care, special equipment and therapy.

- 4 Don't let the disability take over. Get on with normal family life as much as possible. This is especially important if you have other children.
- 5 Don't let yourself worry about the future, it will take care of itself so there's no point fretting about it now. Take one day at a time and enjoy all the great things about your child.

Rebecca Elliott's *Just Because*, is available from 20 August from Lion Hudson (www.lionhudson.com/lionchildrens), and costs £5.99.

