

My story Chrissie & Zack

Mental health nurse and mother of five **Chrissie Lowery** talks about her struggle to get the right education for Zack, and how he's inspired her to found her own company.

Around 15 years ago, I managed two residential homes for autistic adults who had varying levels of communication and functioning. Looking for a job change, I then decided to pursue a nursing career and I trained as a mental health nurse. My last position was a clinical specialist nurse, nursing extremely damaged children.

I have five children altogether. I've got Jamie who's 29, Molly who's 16 and then the twins are next, Amber and Zack, 11. Finally there's Jacob, who's nine.

Zack and Amber are my miracle babies. They arrived three months early and survived against all the odds. They had congenital CMV, a virus which is a major cause of special needs, deafness and blindness in children. They were a few years

old when the CMV left them.

They were both behind in their milestones because they were early. They had so many health issues and difficulties, but Zack's behaviour wasn't really an issue until he got to school.

STARTING SCHOOL

At five, Zack started to show difficulty with communication, distress and anxiety at school. He used to say that the classroom sounded like a herd of elephants – which was of course due to his sensory sensitivity. He was obsessed with water, so he used to run off to the bathroom during the school day, and that was a problem for the staff. He couldn't help it. He liked Blu Tack too, but they took it away and he ended up trying to climb up radiators and shelves to get it. In the end, he was excluded because they thought his behaviour was too dangerous.

Unfortunately for us, we lived in a small village with people who had very little knowledge of special needs. Zack was quickly labelled as a naughty child. He spent most of his time at school either rocking under the tables, trying to run away or locking himself in the bathroom.

The headmistress was also the SENCO. In the beginning, she said that Zack might have an anxiety issue, but she didn't follow up on

Chrissie described Zack and his twin sister Amber as her miracle babies



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The school Zack attends now knows how to support him





Chrissie founded Snugglebedz to help other families like hers

→ it. Obviously, I drew on my own work experience. I knew the signs of autism. I could see he had obsessions, that he took a while to hear what you were saying and that you had to repeat yourself. But she didn't listen. I ended up making him some visual communication tools myself. It helped for a while, but I don't think the teachers were on board. I think it was a judgement thing. I'm a single parent with five children. I was really ill at the time as well, with arthritis and fibromyalgia (a condition that causes pain all over the body), and I eventually had to leave my nursing career.

Parents have to go through things like this and battle for their child. But they shouldn't have to. It's hard enough at home.

Eventually, I went to my GP and he quickly referred me to a paediatrician. Zack was diagnosed with autism when he was eight.

He now attends a different school along with his siblings. His current school has an attached centre called Merlin's – so if he feels stressed or uncomfortable he can just go there. The teachers don't put demands on him because he has pathological demand avoidance (PDA). They discovered his PDA straight away

and they know how to get him to work. Since Zack's been there, he's so settled. He is a very different child now – a happy, contented boy who loves life. Outside school, he loves computers, especially Minecraft. When he's older, he wants to be a YouTuber.

A NEW CAREER

When I became unwell, I was pretty much housebound and spent a year on the sofa. The internet became my only contact to the outside world and I joined lots of support groups. During this time I discovered a group where people shared ideas

for items you can make at home to support your autistic child. I taught myself to sew using my mum's sewing machine and my company, Snugglebedz, was born! It has changed my life and has given me a new purpose and focus.

Zack inspired me. He used to be up until four or five in the morning. He would flood the bathrooms and then try and find things to snuggle up with. He's very tactile so he'd fill his bed with toys. Taking them away was a problem, leaving them there was a problem too. He just wanted to snuggle up. He'd wrap himself in his coat because it made him feel safe. I made a bed for him, using his favourite superhero fabrics, and he rolls himself up in it every night. Now, although he won't sleep all night, it's a lot better and he's usually asleep by ten.

I now have a Facebook page and I'm about to launch my website and online shop. I've sold lots of Snugglebedz, some to families who have children on the autism spectrum and/or special needs. I also have a sensory bed, which is in the design stage intended, for special schools, centres and residential homes. I'm applying to go on *Dragon's Den* to secure funding for that. Along the way, I'd love to use my business to raise autism awareness in primary schools and to educate the general population so parents can get early intervention.

THE NEXT CHALLENGE

Zack's happy and settled at his new school but I'm really worried about him going to secondary school. The school that's right for him have just said no because they've got a large intake of children with special

educational needs. There are five children at his school in the same position and we've all been refused. There's no other place for him. I'm going to have to appeal it. I had to do all this appeal stuff when I was ill

“I have to fight for Zack. But I'm a born fighter.”

and it's all going to happen again.

I was led to believe you put the school you wanted on the EHC plan and that would be enough. We've all got together as a group and have talked about it and we'll probably have to go to a tribunal.

I have to fight for myself, I have to fight for Zack. But I'm sure it will be all right. I'm a born fighter. ●

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- Find out more about PDA at www.autism.org.uk/pda or by contacting the PDA society at info@pdasociety.org.uk.
- Would you like to share your story about any aspect of life or work on the autism spectrum? Please email YourAutismMag@nas.org.uk or write to *Your Autism Magazine*, The National Autistic Society, 393 City Road, London EC1V 1NG, and we may feature you in a future issue.