

BECKY WYATT

SIZE 6

Audio Producer: Robbie MacInnes

My name is Becky. I'm what's known as a parent carer or unprofessional carer. I said to my sister "I'm known as an unprofessional carer," and she said "What does that mean?" And I went "Well, it's not a career choice, I'm just a mum," and she went "You are never just a mum." I was like "Okay, I'm not just a mum."

Connor's nine and he's very cheeky. He's non verbal, so he'll say "gah" - granddad. "en," which is his sister Erin. He will point and he will say "Look look look look look." He'll say "Stuck!" you know, if we put him in his chair and we haven't taken him out for a while... The rest of it are little hand gestures and things like that but sometimes I think he just points, if we've got something and he wants that thing too, we would just carry on like that.

He's quite a laid back little boy. At a birthday party recently there was a Mickey & Minnie Mouse, quite low-rate Mickey & Minnie Mouse. Erin was up and she was cuddling them and having a photo taken. Connor was sort of just watching them and staring and not really sure but then when they left the room a minute later he was waving like saying goodbye and he carried on saying goodbye for half an hour afterwards. He was pointing at the door where they were, just waving to the door where they'd gone.

They call it 'Global Developmental Delay'. Which means he's not developed on a lot of areas. I think it's just a word they use because they're not quite sure, what Connor is. We're still not sure with Connor. So the doctors have classed this as two different conditions with Connor: one is the global developmental delay and one is his epilepsy. I think a lot of it is down to his epilepsy, I think a lot of it is memory and epilepsy. Because I think a lot of the time, when Connor has a seizure, it takes away a bit of memory from him. He used to say car and cat and he used to tie his shoe-laces and we'd say "ONE," and he used to go "TWO," do you know, I mean - all these things sort of just stopped. We did go for a period where he was having quite a few seizures and we used to call it 'sofa day' because he would, he would have up to 19 seizures on the day.

We didn't really notice anything was different about Connor until he was probably about eighteen months old, and before that he was a little bit below on some of these milestones, but they - so many people used to say to me "Well he's a boy, he's a boy. So, okay, this is usual, that's fine." I mean, we weren't worried about him at all, not that we're worried about him now, but you know, and then, eighteen months old, he sort of cried - I remember him crying in his cot and so I went through to get him as usual, sort of sat down with him and sort of comforted him, and then when I looked down, he was just staring blankly. So I went through to my husband - "I think, is something the matter? I'm not quite sure," - sort of laid him in the middle of us. You know this is something not right, and then he started having a full blown body seizure. So that, they call it tonic-clonic. I panicked like crazy, ran around the house going "Oh my God!" My husband phoned the ambulance very calmly. Very calmly phoned the ambulance and explained and he said "Right, go downstairs, put the light on so they know where we are," 'cause it was five o'clock in the morning obviously,

“and then put some clothes on, or get changed, because they’re going to be coming to the door,” so I was running around panicking as usual and then they came. And the ambulance drivers were really great and they basically said “Well a lot of children have these. It’s a way of them cooling you know, cooling their systems down. Don’t worry about it too much,” but he just kept on seizing and he actually seized in total for an hour and a half, full body.

Conversation with daughter

-Are we going to talk about your brother? You used to wear your nurse’s outfit, didn’t you, when Connor was poorly?

-Yeah.

-And you used to look after Connor when he was poorly, didn’t you?

-Yeah.

-What would you do for Connor when he was poorly?

-Get a cushion, get a wipe and a blanket.

-Stroke his hand? He’s not so bad now is he?

-No.

His big passion at the moment is throwing balls. He has, like, a couple of tennis balls and he’d throw them up the stairs and then he’d point and you have to go and get them and then he’d throw them again. So he stands there and he will throw and throw and throw until he looks absolutely exhausted, and he sometimes aims directly at his sister, because she makes this fantastic screaming noise - very dramatic is Erin, so he thinks “Great, I love that noise!” So he aims at his sister - so she is quite good at dodging. And she knows when he’s going to do it as well because you can see this little cheeky look in his eye and he aims at his sister because she screams and he goes “Oh I love that.” That’s when we sort of say no, you know, you have to basically get his eye contact, look me in the eye and he wouldn’t look at mummy’s eyes. So we know we’ve actually got eye contact with him. I’m quite firm with him to start saying sorry, and he’ll go to his sister and he’ll stroke her arm and that’s saying sorry. Probably five minutes later he’s probably aiming the ball at her again, but she would tell you “Mum he’s done this! Mum he’s done that! And usually, when, you know, you do your teeth or something, halfway through doing your teeth you’ll hear MUM! and you think, oh no what’s happened now, you’re running up and down the stairs just check that. What’s he doing. It’s pretty constant, he’s quite a little terror. Yeah, he’s 24/7. We have a baby monitor in the room, so it is through the night as well. We adjust our whole family life around Connor. I think, sometimes, when, like, if you read something on Facebook and someone goes “Oh I just nipped to so and so” spontaneous. I think I put a rant on there the other day, because somebody had put something about spontaneous, and I’ve gone “Oh, to all those people who just jump in the shower, this is how I got in the shower today. Ian was at work, I was desperate for a shower. So I filled the bath up half with water, put Connor in one end of the bath, I had a shower in the other end of the bath. Erin was in there with us as well. She was on the toilet and I washed my hair as quickly as humanly possible. You know, I mean, and it’s, it’s like, oh yeah, just a simple task is made twenty times more difficult because you have to be aware. Oh, we’ll just get a babysitter - oh no, we can’t do that. Oh, shall we book a holiday abroad? Oh no, we can’t do that. But, yeah, you can’t go on a train, wouldn’t dare put him on a boat ’cause he’ll want to throw things over the side. We do try and take him to, like, if we go to restaurants or things like that, but we always have to say can we get somewhere with a booth and then we can sort of trap him in. He goes to a Saturday Club that has gone up from three pounds up to five just recently. A bit of a big jump. And then they also do the holiday clubs as well and that is it, like a 10 to 3, and that’s just gone up from 15 pounds up to 20, which is quite a big hike really, so.

Some people have said quite a lot of Lincolnshire isn't a massively supportive county, I think we probably access as much as we possibly can. Because we need to. The school is fantastic. They have speech and language therapists, educational psychologists...I have met a really nice group of ladies, actually, that I met at Connor's old school, when we did, like, a behavioural course together. And we've actually founded a charity. We're called 'Umbrellas'. There's six of us and we've all got children with different, sort of, some have autism some are Down's Syndrome and there's Connor, who's like an enigma, we're not really sure. And there's nowhere really in Lincoln that we can all go as families. And there's places they can go on their own, but there's no way we can all go as a big family. So we're starting to fundraise, we've been fundraising for a couple years now to purpose build somewhere that people with learning difficulties and their families can go because there's nothing, so we've decided, you know, what we'll do ourselves - as if I don't have enough things to do! Otherwise there's nothing and all our children. They're all similar ages, actually, and they're all boys, always seems to be in the boys, and once they get older and older there's less and less things, especially in Lincoln, so why not just build a place where people can go to. We're quite determined.

Nottingham is just an hour's drive away and we go to a lot of his appointments at QMC and they do say to us "Oh if you're in Nottingham you could access this," but we're not, so obviously we go there and we have all his treatments for epilepsy at Nottingham, but we can't access any of the actual support, and at Lincoln we don't really have, like, there is like one ward for children. There's not a children's hospital. So it's, they don't quite know what to do with Connor because all his treatment is specialised. And for more provisions I think the children's health in Lincoln would be great and a lot of them are being taken away, unfortunately, and there's a lot people that live in Lincoln, so I think they've, we've, kind of been forgotten about slightly.