

TRANSCRIPT: Emma, family life

Ruth, Emma's mother

We tend to do as much as we can as a family. We are limited by her mobility and by her behaviour. We tend to go swimming a lot.

She does like to play badminton but not as you and I know it. We can just about get a rally of four or five. She has her own specific way of playing badminton and it takes three of us to do it but the back garden is no longer good enough, she likes to go to the leisure centre.

She loves going to restaurants but when the foods gone, that's it, there is no further incentive for her to stay there, and the one thing she particularly dislikes is when we're involved in conversation with other people because she can't join in and it becomes very boring for her so she will start to play up.

When she's particularly upset, she will pull hair, lash out, kick, that sort of thing, which in a public place is quite embarrassing and she makes quite a high pitched squealing noise.

And when we just go out to the shopping centre for an hour, you're constantly calming and smoothing and predicting what she's going to do, guiding her away from things. Even if you go into *Top Shop* or *New Look*, there's whole rows of bags of sweet in the clothes shop and you're walking along thinking, 'Oh, oh!', and you'll guide her in a different direction so you don't have an argument over, 'I want the sweets', 'No you can't have them'. So, you're constantly on guard.

Sometimes she doesn't like crowds and it's a bit odd in that we could take her, say, to the *Superbowl* with thousands of people. Initially she might think, 'Oh, it's noisy', but she would walk in and think, 'This is great' - very visual, lots for her to be stimulated by. But if I was to bring her to the school disco, she would get to the door and jam on the anchors. She obviously feels there is an expectation on her to come in and interact, and even though it's all her school friends that she knows, slightly different setting with flashing lights and loud music and it can take us about half-an-hour, perhaps, to get her through the door.

She loves going on holiday but family holidays are difficult. We can't really do beach holidays because Emma is quite hyperactive. She won't sit down for long. She's very easily lost on a beach and has a great affinity for water, so that's a danger. So we have to choose holidays that will fit a younger child, but she can't get into play areas or soft plays, things like that, because she's too big and she's beginning to understand that now, but we're having to go to places where we feel there is enough to keep her occupied, and that's quite difficult.

I think the biggest thing that impacts the family life is sleep deprivation. Emma doesn't sleep well at night, she never has, and she will wake up several times a night. We quite often don't tell her about forthcoming events because she gets excited and she will wake up and want to be reassured that it's still going to happen, which makes things like Christmas very difficult because you can't hide it.

It's quite hard to keep up a social life because she tends to be anxious if non-family members are in the house and, usually, if we're occupied, she sees her opportunity to go and be mischievous around the house and do things she shouldn't do and be into things she shouldn't be in.

When she was younger, we used to have to keep the kitchen, the bedrooms and the bathrooms locked. We used to put things high up on top of the cupboards so that she couldn't get them and she learned quite quickly that if she climbed up on the counter she could get them and that's, obviously, very dangerous. And as she's got older the only two rooms we have locked in the house now are my husband's study so she can't get into the computer, and her sister has to keep her bedroom locked. If Emma gets in there she will tip everything out and when she's caught, she knows she's in trouble and she'll throw things. So you have to be very calm when you approach her when she's surrounded by all her sister's lovely stuff so that it doesn't get thrown and broken but, of course, her sister doesn't see it that way and goes in all guns blazing.

We've replaced several televisions, DVD players, cameras, videos. She's thrown a few, dropped a few, just fiddled around with a few. She's broken the windows in the car just by giving it a kick when she's in a bad mood - that sort of thing.

Family functions, we've been to a few. We haven't taken her to weddings and christenings and things like that because she finds the church quite a stressful place, quite noisy and echoey. We did take her to one when she was about twelve and she ran back in the church - in fact she took her dress off - and that's the sort of thing she will do when she is very stressed and not sure what's going on, and she knows that it's gonna bring several people running. So it's quite often an attention seeking thing too.