

## **TRANSCRIPT: Support**

Ruth, Emma's mother

In terms of support, we live in Oxfordshire, my family live in Scotland, so there is no easy connection there. My parents are quite elderly and Emma's now too big for them to cope with. The support has really just between my husband and myself. Over the years we've become quite self-reliant.

And we have had a lot of support from school and a few close friends and although it's not a physical support, I work part-time and my work colleagues are very supportive and they're always there for a shoulder to cry on, or whatever.

I'm a nurse and when Emma refused to come to school, they just cancelled all my patient clinics right up until mid-January and said, 'It's not a problem, just get on and see how it goes'.

Going to work has been fantastic for me. It's very important for me to go out and be a different person and not just a mum and not a carer, and it's a huge point of social contact for me too and I really don't want to give it up.

The key with school is communication because Emma has no speech. She can't tell you what she's done at school and she can't tell you her worries and concerns either. So, the home-school diary is really quite vital for us, so that we can discuss her day with her when she comes home, and if we've had problems with her at home or we think she's worried about something, we can write it in the diary and let teachers know. And if we have problems, you can come to school and try and hatch out a plan to manage behaviour or sort out something that she's not happy with.

The biggest problem we have with Emma is anxiety at being left, especially with people she doesn't know. A lot of the voluntary organisations can't cope, I think, with that level of behaviour and as a result of that, I've tended to give up and just think, 'Oh, well...'. She does form quite close relationships with classroom assistants, so if we need a babysitter it's usually somebody like that that will come and help us.

In terms of helping Emma to mature, things that could have gone better are being away from her family and, over the years, I've tended to give up because she becomes so upset. But we thought about it and decided that it would be in Emma's best interest to start trying to be away from us, you know, she was seventeen and, obviously, we know that we're not going to be here forever so we thought, well, it could start the ball rolling to a more independent life. We asked for some direct payments to bring people in to look after her at home and it went to the panel and they came back with a very generous offer of respite, which rather took me aback. The respite we were allocated was a Wednesday through to the Thursday, so it gave us two days, and it really wasn't until that point I realised the stress that was in our house, which I hadn't noticed before. The house was quiet. You weren't looking over

your shoulder. You weren't listening. I could actually go to bed and sleep. But she hated it so much. Even though they said she did settle, it was a huge stress for her and a huge stress for me. So we haven't got that anymore and, I don't know, I'm ever hopeful that she will adjust in the future and find somewhere that she would like to be.

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