

# Joyce, Andrew and daughter Lydia's story



**For Lydia's parents, Joyce and Andrew, the year leading up to her diagnosis was a year full of anxiety. They passionately loved Lydia, who was their surprise third child and wanted to do the best for her, so it was a great relief to finally get the diagnosis of PWS although they didn't know what that meant.**

As soon as we knew what we were dealing with, we had a food regime within the household and that worked really well. We didn't have biscuits. If we had sweets it was smarties and Lydia would have one smartie after her tea. She never had more because they were the rules and she followed the rules pretty well. She would negotiate - "If I have this that means I can't have that?"

In early childhood, Lydia didn't express a desire to be friendly with other children, she was among other children but not necessarily joining in their play.

From age eight to 16, Jacky says that Lydia's school experience was mixed and the family faced a lack of willingness on the part of some staff who insisted on giving chocolate bars as a reward.

"When Lydia was younger she had a great sense of humour. She would suddenly decide that one of her siblings had been naughty and I can picture it now – she's dragging her brother who is 11 years older and saying, "Come out here, sit on the stairs, you've been naughty." He is collapsing with laughter and saying, "I didn't do anything!" She had us all in stitches and we all used to say, "What did we do for fun before we had Lydia."

By the age of 12, they became aware that Lydia's access to a social life was pretty non-existent unless they initiated it, so, with the support of some wonderful friends they set up a charity for young people with learning disabilities which provided a social club and some holiday activities and that made a big difference to Lydia to be with another group and not just dependent on us.

By the time Lydia was 14, her brother and sister had been to university, graduated and were leading independent lives and they had cars. Lydia's mum remembers her saying 'when I am older, I will have a car and it will be red and I'll drive to Tesco and do the shopping.'

"And I used to explain to her well driving is quite difficult, and some people don't like driving and sometimes it's easier to get the bus," Jacky said.

For Jacky this has always been the great sadness - that the things that have been open to her brother and sister have not been open to her.

"It was always our hope that Lydia, just like her brother and sister, would move into an independence that was appropriate for her...that we could get Lydia settled into an independent life while we were still there to support her emotionally."

Lydia's parents initially avoided looking at specialist PWS services as they wanted her to be in a place where not everybody was the same and different people mixed together because 'life's like that.' It soon became apparent that none of these places were prepared to instigate any form of regime around food which meant

her weight would go out of control. Andrew explains, "it had only been through Joyce's constant application of the regime that Lydia had always stayed a decent size."

Reluctantly they began looking at Specialist PWS services and Lydia moved in to Smythe House, 13 years ago, aged 22. It was a much more emotional wrench than Joyce and Andrew anticipated... but their driving force was that they wanted her to have a life and realised she wasn't going to get that by staying with them.

She now has a marvellous life, "actually in the last couple of years in particular, it is harder to get her home. We'll say Lydia are you coming home on the train, you've got a hospital appointment and she'll be saying 'I'm not coming home, I have things to do,' Joyce laughs. "So, she's become very independent in her choices which is good, it's wonderful that's what you want, accept when it's a hospital appointment which can take six months to get!"



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