

Jacky, David and son Nick's story

When Nick was diagnosed with Prader-Willi Syndrome at eight months old, the doctors told his parent's, "don't go and look up all the information because it doesn't all apply to your son. But of course, what do you do?" said Jacky. "David went to the library and printed out the sheet on PWS and of course you read all the bad things..."

Nick was Jacky and David's second child. When he was first born, he didn't open his eyes for three weeks. Every day they would go to see him and think maybe this will be the day he wakes up, but no. Despite being referred to specialists and then a paediatrician, it was only when Nick put on a significant amount of weight aged 8 months old that PWS was diagnosed.

Discussing life in those early years, Nick's father, David explains "We tried not to look to the future too much. You have a baby and the baby needs looking after. So, we just took one day at a time. We adjusted to Nick."

In his adolescence, he was the easiest to go out with. My other so-called 'normal' children were a nightmare and gave us all

"I can look at him now and look back over all those years, He has grown up, he's a man now. He can look me in the eye as a man which is marvellous. I remember chasing behind the ambulance when they took him down to Great Ormond Street and we didn't know then what would happen... you shut your mind to the future."

sorts of agro! Nicholas took enjoyment and told you afterwards he enjoyed that, whatever it was even small things. He took pleasure from it which was lovely," said Jacky.

Adolescence and a greater level of independence was however the time the family experienced greater difficulty in monitoring Nick's food consumption. After secondary school Nick went on to college which was two bus journeys away and involved changed in the local train station before going on to college. After practising the journey with him for a month Nick was ready to do it on his own but it led to problems because there was a café at the change over point.

"I don't know where he got the money from, but he was able to go into a café and buy far more food - he wasn't supposed to buy any. He bought a tremendous amount and ate it on the second bus, unbeknownst to me. Until this stage he had been monitored with the food, so it was the start of a really big weight gain," said Jacky.

"That was a problem when he started to have food like that. You try and allow them to have more freedom, but he was possibly a bit too young to have that freedom and that's when Prader-Willi Syndrome cut in and it didn't work," David adds.

One of their proudest moments of Nick growing up was when he completed his Duke of Edinburgh Silver Award after a knee injury the year before ended his first attempt. Jacky explains, "On the third morning, his knee was badly swollen, he went into hospital and they sent him

home on crutches which ended his expectations for that award. Being Nicholas, it was "Never mind, I'll do it next year." He went, everything went fine, and he finally got the Duke of Edinburgh Silver award and I really think that was a great achievement. He was determined. He persevered and was positive he was going to do it."

When Nick's siblings both left home Nick said "right, I'm going too." He stayed for ten years in a mixed disabilities service, which had its pros and cons. He couldn't get complete care and support for his PWS and fell out with staff who didn't understand him. He also struggled with other residents having access to food, which he found unfair. Nick moved to specialist PWS service, Heatherington House aged 36, David explains, "By this time he was a matured adult and ready to move further away from home and live a truly independent life. We are delighted for him."



consensus ●●●

Supporting opportunity, choice and success

Over 90 services across
England, Scotland and Wales.

www.consensusupport.com
0808 223 5320
enquiries@consensusupport.com