

# Kate and daughter Alex's story

**Alex was diagnosed with Prader-Willi Syndrome (PWS) at nine months old. For Kate, her mum, the initial feeling was shock and devastation. Her thoughts immediately fast forwarded - "Right well, she probably won't go to University. Where will she live? What will her life chances be?"**

23 years on, Kate is so proud of the confident and happy young woman Alex has become, making choices about her own life and living independently of her family at Smythe House, a specialist PWS residential setting with six other individuals with PWS, all of whom are great friends and feel like an extended family to Alex.

Kate says, Alex was a "happy baby, docile and relatively easy. When she came home we had to learn to tube feed her, she didn't learn to crawl but bum shuffled. Gradually she progressed, hitting her milestones - but late. She was also slow to talk so we learned Makaton to help her better communicate."

"Alex as one of four siblings is easily the one who is the most thoughtful, who is the most generous and the most organised. She will be the only child who gives me an early Mother's Day card, an early birthday card, an early anniversary card. And that sense of Prader-Willi being ordered and organised, definitely has a lot going for it."

In her early years, Kate found introducing Alex to other children with PWS was a positive step as she was able to spend time with a group of peers who were understanding and accepting and often had different PWS challenges than she had. Kate explains, "It gave us a vision for the future as well as giving Alex a real sense of community."

During adolescence her issues with food got more challenging and the family found that putting locks on the kitchen and on the pantry helped as it made Alex less anxious and allowed them to give her more freedom. Around this time, Alex began to ask a lot of questions about what her future life would look like. Will she get married? Will she have children? And Kate had to explain to her that not everyone gets married and not everyone has children which Alex was very understanding and accepting of.

While Kate says Alex was "not in the least bit academic" she was very hardworking and diligent at doing her homework, even if it meant falling asleep at her desk completing it. It was while pursuing further education that Alex experienced her first taste of independence. She attended a three-year programme on horticulture and animal care at Derwen College. It was a wonderful transition for her and she was delighted to win an award from her college for overcoming her disability which gave her a huge sense of achievement. The only downside was that she put on a considerable amount of weight. Being the only student with PWS it was hard for her to have sufficient dietary control even with support from her college carer's.

Seeing the huge weight gain that happened at college was a significant turning point for the family in realising they needed to find a specialist PWS setting where Alex would get the sense of community of other people like her, get the dietary support she needed with carers who understood the syndrome and how to give her the happiest and healthiest life chances she could have.

Alex now lives at Smythe House, a specialist residential PWS service in Kettering. Kate says since finding her independence, Alex "doesn't like to come home that often," (which Kate sees as a good problem!) Kate is thrilled that Alex is being a normal adult and "enjoying all the wonderful liberties of independence, including cutting her long beautiful hair and getting her ear pierced" - although she now hopes she won't get a tattoo!



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