

Patient Story: "Our story of the frustration we felt in trying to get the help we needed."

Family Profile:



*Jane (Mum)

Contacted PALS June 2020, who were able to support Jane in giving her feedback to the service and seek resolution and appropriate support for Emily.

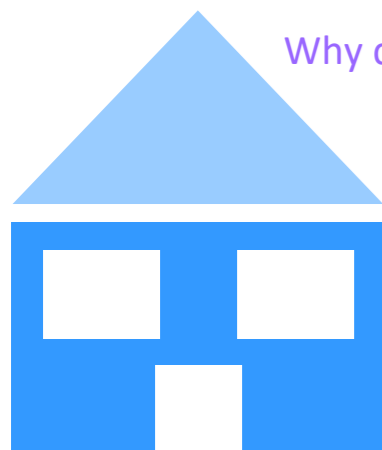
*Emily (daughter)

- Aged 7
- Support for anxiety and eating issues



*Ted (son)

- Aged 11
- Support with bladder and bowel issues



Why did it take so long to get the help my child needed?

Why didn't I know exactly what we were waiting for?

Why was communication so poor?

What happened to the dietician application made by the school nurse?

JULY-DECEMBER 2019

Jane originally made a request for help with her daughter's eating issues in the summer of 2019. She phoned and spoke with the School Nurse about Emily's eating issues. The school was also concerned about Emily's limited diet and completed a referral to the School Nurse at the same time. After meeting with the School Nurse who did an assessment, Jane was told **that they had no concerns but would refer Emily to a Dietician**. Jane and her Family Worker **did not agree** with this initial assessment and believed that more help was needed for Emily. There was confusion as to where the referral had been made as Jane lived on the county border – Jane was told **the original referral was made in the wrong county**. Jane said that the School Nurse was helpful and seemed good at their job but that **no further communication** took place.



DECEMBER 2019-MAY 2020

Over the next **five months**, Jane felt like she was **chasing for help** for both her son with CAMHS and for "the mental health side" of her daughter's mood with **no support** from the School Nursing Team.



MAY 2020

After months of chasing the school nurse, out of the blue **an Assistant Practitioner (Jen Wagner) rang and made an appointment for a phone consultation**. Jen currently meets with Emily at school. Jane is really **happy with the care** Jen has provided and says that communication is really good. Jen has also been able to offer support for Ted whilst he was waiting for an acute referral. Jane said that her overall experience was that she was very satisfied with the care and support although **it took a long time to get the support that her family needed**.

"In the beginning, I felt like I was in the dark about what would happen next and heard nothing back. This was incredibly frustrating."

"I felt there should have been greater depth to the original assessment."

"It seemed like we were trapped in the system..."

