

Mandy and daughter Katie's story



When Katie was tested for PWS at 12 weeks old, the results came back negative and the family got on with their lives. Then, age two and a half, they got the news that left them devastated. Katie's mum Mandy said, "At the time we didn't know anything...they really couldn't give us any guarantees as to her future life."

As Katie's condition wasn't obvious at the time, the family made the decision not to label her and to "let her be Katie." However, by age 10 her weight became harder to control and by age 13, she was diagnosed with diabetes. "Our whole world caved in because her father has diabetes and it is exceptionally difficult to control," said Mandy.

Her teenage years were really the turning point when it became incredibly hard for the family. Mandy says, "I definitely think behaviour was a problem going into puberty. It meant her behaviour became more and more unmanageable.

Despite these challenges, Katie lived at home and attended a main stream school until she was 17 and took her qualifications. "She did pretty well, so we were really proud of her, but we knew

"She lost two stone, put it back, lost three stone put it back, but to see her change and be active again...there are so many proud moments, but this is up there because the stakes were so high, and we knew that if this didn't work then our options were small. It's been an extraordinary journey."

long term it wasn't an option to keep her at home because it was becoming harder and harder to control. I felt she needed other people around her who also had special and additional needs - she needed a different level of support that we as a family couldn't give her," explains Mandy.

For this reason, Katie went to live at a residential facility in Manchester where she stayed for 13 years and met her fiancé (who she has now been with for 14 years) but Mandy explains, "they were not equipped to deal with PWS in the same way as Consensus Gretton, so it became harder and harder and she became more and more unwell."

"The staff there however willing they were just didn't have the right experience and it wasn't their fault, it's just PWS is so specialised that unless you were extensively trained in it is really very hard to control," says Mandy.

In 2017, the situation reached crisis point. "A year and two months ago they told us Katie wasn't going to make it. She was 16 stone. Her heart was in heart failure. She was very, very ill and her whole body was water logged. They told us it was palliative care." Katie's cardiologist started her on a new course of treatment in a last ditched attempt to save her life and thankfully it worked, with Katie losing three stone in three weeks!

It was at this point that Mandy began looking at Consensus Gretton specialist services. "We knew that in the previous year between September and December, she had gone from being able to walk and breathe to being in a wheelchair and on

oxygen, and we knew her life expectancy was very limited if we didn't move her, so I was pretty desperate and I knew Consensus Gretton was the place that was going to save her life."

Since moving to Consensus Gretton's, Holland House aged 30, Katie has lost almost half her body weight and is now 8 stone 11 pounds and is enjoying a much more healthy and active life. "Children with PWS, you devote your life to them because you have to, so to be able to pass that mantle on and say to someone else, I feel comfortable with you doing my job, is very special," said, Mandy.



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