

## Ulcerative Colitis Katie, Berkshire



Katie was only 10 years old when she first experienced tummy aches and pains. Her GP initially told Katie she was anxious and that she just needed reassurance, but, once Katie's symptoms included diarrhoea and bloody stools, the more typical signs of Ulcerative Colitis, she was referred to an IBD tertiary centre in London.

Katie's mum, Sara, recalls how difficult it was to ask her little girl to swallow a barium meal. However, Sara's even greater challenge was persuading Katie to undergo a colonoscopy to confirm her diagnosis. Sara is herself a nurse and considers that medical staff should be more aware of how to care for children and young teenagers with inflammatory bowel disease in the primary care and district general hospital settings. By contrast, Sara has nothing but praise for the care that Katie received at the IBD tertiary hospital where she says that, "dedicated adolescent wards and nurses make all the difference."

On the occasions when Katie has been admitted to hospital, Sara explains, "it is incredibly stressful for the whole family due to the distance. We both work and we have an older daughter too, so ensuring that we are looking after both our daughters while the youngest is seriously ill in hospital is a major challenge."

Katie, now 15 years old, states that she "hates having Ulcerative Colitis" and unfortunately her experience has been coloured by a serious and rare side effect to one of the normal drug therapies which now limits her treatment options to steroids for relapses. She has a phobia of needles which makes blood tests a challenge, but luckily Sara can normally help out with this.

Katie is now thinking about her future and, at present, has decided that she should not have children because she is concerned about the possible effect of genetic predisposition in Inflammatory Bowel Disease. She is also thinking that she may not be able to take a gap year to go travelling as her older sister did, due to the unpredictable nature of her disease. Even school trips have been difficult to organise due to Katie needing urgent access to toilet facilities, but Katie and Sara did travel to China together earlier this year when fortunately their biggest challenge was arranging medical insurance.

### Messages:

- Inflammatory bowel disease impacts on the lives of the whole family
- Early referral to a paediatric gastroenterology service is essential and specialist adolescent facilities and staff are very helpful
- Psychological support as an integral part of a paediatric and adolescent IBD Service is essential to support young people and their families in adapting to living with a long-term condition.