

Crohn's Disease Aideen, County Down, NI



Aideen is 28 years old and lives with her family. When she is well enough she works in her mum's Post Office. Diagnosed with Crohn's Disease when she was 15, Aideen's first experiences of her illness were highly unfortunate, since she was admitted to an adult ward, where lack of support, excessive use of steroids and awful experiences with naso-gastric tubes left Aideen with panic attacks and a hospital phobia.

On New Year's Eve in 1998, Aideen developed a fistula from her small bowel, which caused her severe pain and needed surgery. Despite an operation, the fistula rumbled on for two years and because of Aideen's fear of hospitals, she refused to be admitted for further surgery. The fistula finally burst and she had to accept admission and surgery.

In 2003, Aideen developed excruciating pain in her left hip which turned out to be another fistula. This time the fistula was drained for six months which left Aideen bed bound in hospital. Finally Aideen's doctors removed her large intestine (colon) and

performed an ileostomy, leaving her with a permanent stoma ('bag'). For many patients a stoma can make a huge improvement to the quality of their lives, sadly this was not the case for Aideen, who experienced another fistula under her stoma in 2005.

Eventually, Aideen was referred to a tertiary centre where the fistula was drained and she spent six weeks on a specialist liquid diet to restore her nutrition and rest her remaining bowel. She was then hospitalised for six months when two further fistulas developed. Only at that stage was Aideen aware of being considered for treatment with infliximab, a biological treatment that has been available in specialist centres for a decade. Unfortunately due to infection in her fistulas it was not clinically appropriate at the time. She was started on the immunosuppressant azathioprine. By Christmas 2005, she was allowed home, but only after she had agreed to a further resection and relocation of her stoma in January 2006.

In 2007, with chronic fistulising Crohn's Disease, Aideen underwent further surgery to move her stoma. In 2008 her doctors again considered treatment with infliximab, which works for about eight weeks, but funding issues meant that she was only eligible for three infusions. Subsequently Aideen switched to adalimumab, which controlled her bowel inflammation, but, unfortunately, she had a strong adverse reaction to this. Aideen is nevertheless very happy with the care she receives from her Gastroenterologist. Her Stoma Nurses have assisted her in managing her condition and provided much-needed moral support.

Messages:

- Crohn's Disease can have a devastating impact on the lives of some patients, especially if they are young
- Specialist care and access to the best available treatment at an early stage are vitally important
- Some people with Crohn's Disease need multiple operations.