



The ileostomy & internal pouch

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Pouch Surgery Experiences – Dan Jones

My story started back in 1994. I noticed that I was suffering with a slight constipation problem for a few weeks, and then it went totally the other way. I started to notice small amounts of blood, which gradually got worse and worse. Being a typical man, I cringed at the thought of going to the doctor about it because I was embarrassed; at the time, I was 23. It couldn't last though; my parents noticed something wrong and had noticed small amounts of blood and told me to go to the doctor about it. I agreed to go.

The first thing my GP at the time said was “looks like food poisoning” and gave me a set of antibiotics to clear it up. This, as you can probably guess, didn't work and I was back to see him soon afterwards. He wasn't best pleased, but he referred me to the Gastroenterologist at Herefordshire County Hospital who performed a proctoscopy and determined that I had Ulcerative Colitis. He put me on a dose of Prednisolone Steroids and asked me to see how it went. For a while, things seemed reasonable, although I was becoming increasingly tired in general and I started to suffer with severe acne due to the steroids. My vision also changed and now I have to wear glasses for driving as a result.

In March 1995, I got hit with a bout of Gastroenteritis and this was the catalyst for a severe bout of pain and then bleeding. I went back and forth to the GPs, who altered my steroid doses and so on, but I was forced to go back to them again, twice in one day, because I was bleeding so heavily. The second time I went, I saw a Locum Doctor who immediately phoned the hospital and got me booked in.

I spent the next 10 days in a side ward, while they took blood, and filled me up with Hydrocortisone to try and find out how severe it was. I had to have a blood transfusion, and in the end they thought it might be wise for me to meet the surgeon as they were becoming increasingly worried about things. I met Mr Peter Harper, and also my Stoma Care Nurse, Jane Whinney, but because I was so out of it, what they told me was a blur. Mr Harper said that he wanted to check on me over the bank holiday weekend, and see how it went.

On Easter Saturday, 1995, I passed a blood clot about the size of a golf ball, and my surgeon immediately decided that it was severe and told me that he would operate straight away. I was in shock, because I had little time to get hold of my parents to let them know I was having an operation. To be perfectly honest, I had no real idea of what I was facing, but it wasn't because I wasn't told; I was just oblivious to the detail. I had never heard of a stoma before.

I eventually got the Police (who I used to work for) to send a bobby round to let my mum know what was happening and she duly rang the hospital and then came in. Within an hour, I was falling asleep under anaesthetic and remember nothing until the following night when I remember waking up with complete amnesia, but the nurse told me to go back to sleep and it would be fine in the morning. She was right.

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When the bowel is handled as in surgery, it shuts down completely. It can take up to a week to fire back up, and when it did after about 3 days I remember that it was the most severe colic I had ever experienced – very uncomfortable. After a pethadin injection, I was away with the fairies and woke up in the morning much better. From then on, it was upwards and onwards. I learnt how to change and empty the bag, and was out of hospital in about 8 days all in all.

I went home and recovered, and despite the pain of the surgery (which wasn't really that bad) I felt much better than I did with the UC. I was back to work after about 3 months. My surgeon then advised me that I had to have another operation. This came as a complete shock because I thought that it was all over. He explained that I needed to think about the next stage. Either I had to have the rest of the rectum removed and a Pouch installed, or removed and the back end sewn up in an operation called a panproctocolectomy. He explained that there was no going back if I chose the permanent ileostomy. I have to say that I opted not to have the pouch initially as I was worried about permanent diarrhoea, but he told me to think carefully about it - I don't know what changed my mind, but I opted for the pouch.

I was in hospital in January 1996 for the first stage (the pouch creation) and I left the hospital with a temporary loop-ileostomy whilst the pouch healed up. After 3 months I went back and had a small x-ray procedure called a pouchogram, which involved injecting a small amount of dye into the pouch to check for leaks. It was totally painless, and the pouch was fine.

In June 1996, I went in and had the final operation to close the loop ileostomy, and from that point I was able to sit on the loo with the best of them again. The first few months were quite uncomfortable in that the pouch was trying to tell me that it needed emptying all the time, but I held off for as long as possible each time, and it gradually learned who was the boss! Initially, I was back and forth to the loo about 15 times a day, but this decreased as the pouch settled down.

Just over 9 years after my colectomy, I am doing fine. I am now fully active and was able to return to my original trade as an Electrician. I now work in that capacity at a wind tunnel aircraft test centre in Bedford and am doing fine. I joined **IA** very soon after my colectomy and eventually joined the Executive Committee as the National Internal Pouch Coordinator. I remained in this capacity for 5 years.

For me personally there have been good parts and bad. I remember wondering if I had done the right thing once the pouch was connected because I got sore and tired, but now I look back, it was well worth it, for me at least. I can't promise that it will be the same for everyone, but I would advise anyone who is considering it to ask as many questions as you can to help you in the process. Whichever way you decide, I wish you all the very best for the future and maybe you can write your story on here too.

Best wishes and thanks for reading this. It is a little long, but I thought it best to give all the facts.

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