



The ileostomy & internal pouch

Support Group

Registered Charity

Pouch Surgery Experiences – Dr. Diana Stanley

My name is Diana and I thought I would write my story for the website as I know that when I was going through a rough time there were too many stories about how things had gone wrong or people were finding it difficult and not much saying that things work out well in the end.

I am 25 years old and I've had ulcerative colitis for about 12 years. It wasn't diagnosed for a long time as I kept thinking it was just irritable bowel or traveller's tummy after coming back from holiday. It is amazing what you can get used to and think is "normal for you". After I was diagnosed in 2003 and was treated with medication I started feeling SO much better. It was like a new lease of life.

Unfortunately in late 2004 I had biopsies taken during a surveillance colonoscopy that showed there were pre-malignant changes that if left were likely to turn into cancer. I was advised to have a total colectomy and j-pouch formation. At first I was devastated because I had only had 18 months of feeling really great and back on form. Most people having the operation are quite unwell beforehand and can see the benefits of having the op almost straight away, but I had never felt better and didn't relish the idea of going back into hospital and feeling ill again.

I got used to the idea over the next couple of months and went in for the op in February 2005. The op went well and apart from my epidural not working I had an uncomplicated stay in hospital and was discharged a week after surgery.

This is when things started to go wrong! That night at home I started having awful stomach pains and vomiting and nothing was coming through my ileostomy. I had to go back into hospital with an obstruction. I spent ten days having various tests and scans trying to work out what had happened. They kept thinking it would just resolve itself but it didn't. I felt awful and had lost so much weight through not eating and was generally fed up. Then on the Saturday night things got worse and I was taken back to theatre and had to have some of my bowel taken away and a new stoma formed.

It was a long slow recovery from there. I spent another two weeks in hospital. My wound broke down because I was in such a poor nutritional state and it had to be packed daily. Then when I got home I developed an abscess in the top of my wound. At this stage I was at an all time low and was cursing the day I ever had the op. It slowly worked itself out though, and with an amazingly supportive family and boyfriend I got back on my feet. I learnt how to deal with my stoma after a few mishaps and worked out what I could and couldn't eat.

About 3 months later I went back to work part time before the reversal in July 2005. I was a bit apprehensive because I felt like I had just got to grips with having my stoma and it was all going to change again. I also had bad memories of my last visit to hospital, but I figured it couldn't be as bad as last time! And it wasn't.

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Things went fine and I was home within a week. I can't say it was easy at first. I got very well acquainted with the toilet and was scared to leave the house for a couple of weeks and my backside was SO sore!! Quite quickly though things got much better and now two months on I'm getting back to work, I'm going between 3-6 times a day, and sleeping through the night.

Although the last six months have been a difficult time, I now feel I can get back on with my life and I can't really see my pouch stopping me doing anything I want to. I really don't know how I would have got through things without my friends and family who were amazing.

I hope this is of help to people, and proof that things do get better and that you can get back to normality after having pouch surgery.

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