



The ileostomy & internal pouch

Support Group

Registered Charity

Pouch Surgery Experiences - Diane

Hi! My name is Diane, 50 years old, and I am a Pouchie. I suppose I am a good example. I was thinking about this last night - I have been having trouble since I was 20 years old. I was told first it was spastic colon, then years later IBS, until I got to the point I gave up going to the docs to be told there was nothing wrong with me, I saw a person (!) who said there was nothing wrong with me - it was just the way my body wanted to be, in the loo 15 times every day and night.!

Luckily I then got a new GP who hit the roof at this comment and sent me to another nice man who did a colon examination and said I had UC. He started me on medications, which worked for a while but after a bout of flu I went downhill very fast and was admitted to hospital on steroids via a drip for 2 weeks. This seemed to help for a while but did not last, and I was told I would have to accept that I would have to have the colon removed, but he thought it would only be a partial removal.

I then saw a brilliant doctor (Mr. Woods) and he did a other check and agreed it would have to go, but he suggested going to Brighton or London and having the removal and pouch constructed in one go, and a stoma for a while.

Whilst waiting for the appointment to come through I again got very ill and could not eat anything at all, and was vomiting. I went to see a diet nurse in the local hospital and I could not even get there. I was so weak I had to be taken in a wheelchair. Over the next weekend I was so bad I could only get out of bed to go to the bathroom - I could not go downstairs as I could not get back up to the bathroom - I could not go to work, look after my family, I suppose I thought I was dying! Oh boy, did I lose weight? - 13 stone to 7...I could not wait for the Brighton or London hospitals to get in touch.

I then phoned Mr. Woods and went to see him on the Tuesday, and was admitted there and then, with the op on the Thursday night. This was April 2001. I had the normal tubes etc. which was not too bad. By the following Thursday I felt like a new woman, even though I had a stoma sticking out of my belly.

I went to Brighton in the September and had a pouch constructed but had another stoma. This one was flush with my skin and was not a lot of fun - the skin was eaten away, and I could not get a bag to stay on. This was not very nice, but I got through it. I then had a reversal in the November and have not had many problems since then apart from butt burn which, touch wood, is not bad now. I have got used to looking after myself better, pouchitis twice, but that is better than what I went through for years. The pain of UC will always be remembered. I can't remember the pain of childbirth, but I will always remember the pain in the dead of night all my own being so scared, how I will..

I am so well now and putting weight back on, grrr! But never mind at least I am here to bore you...

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