



The ileostomy & internal pouch
Support Group

Registered Charity

Pouch Surgery Experiences – Neil Crozier

I didn't want a pouch. No, I had decided that because of what I had read about pouches that a stoma would suit me better. Then I met Mr Rashed. That was in 2006.

UC had plagued me since 2000 and it had been getting progressively worse and unresponsive to drugs. So I finally reached the decision that surgery was my only option for regaining control of my life. Surgery had crossed my mind before but I had always hoped to find a treatment that worked. Of course it was never going to happen but I had to be certain in my mind that surgery was the only option before consenting to that irreversible step.

To me surgery meant an ileostomy. Through a USA based internet chat forum I managed to get some questions answered about living with a stoma. It was through the forum that I was made aware of the J-Pouch, and was just as quickly advised that living with a pouch meant going to the loo twelve times a day. The J-Pouch idea was swiftly binned.

The main reason that I didn't consider the pouch suitable for me was that my hobby is fishing (alert readers will note the present tense which is an indication of how things are today). Given that my sport entails sitting for five or six hours on a canal, river or lakeside, and often far from a toilet, you can see why a pouch didn't look inviting. Even the stoma nurse that I booked a chat with appeared to agree with my very logical reasoning.

Fast forward to my first meeting with my surgeon – Mr Rashed. “You have been reading the internet” was his immediate reply to my explanation why I wanted a stoma and not a pouch. “The pouch is The Gold Standard for someone like you” was his response to my sheepish admission to having been swayed by the World Wide Web community. So pouch it was.

Things intestinal took a back seat for a while due to my son sustaining an amputation-threatening footballing injury in Germany where he is based with the army. Eventually though in November of 2006 I was admitted for the first stage of my two-stage pouch procedure. This was a bit quicker than I had anticipated as Mr Rashed had only ‘scoped’ me in the October. Having expected the usual NHS waiting list lottery I was told by a nurse “For you there is no waiting list”. I later discovered that this was because Mr Rashed thought my colon looked cancerous. Happily this was proved not to be true. I was also assured by Mr Rashed's secretary that I would be fit enough to walk my daughter down the aisle the following July.

I had read that having been relieved of the diseased colon I would feel healthier almost immediately. A day after the operation, and despite the obvious problems being sliced open causes, I did indeed feel better. Two days after the operation and still with the usual epidural, saline drip, catheter, wound drain, naso-gastric tube and stitches from chest to groin, a physioterrorist arrived and announced that “we” were going for a walk. So I told him where to go in fairly forceful language; I didn't feel *that* much better. Finally though “we” managed to get out of bed and walked about 20 yards up the corridor and back. Apparently that meant I was fit enough not to need his further attention.

My final night in hospital, 7 days after the surgery, will always be remembered as one of the craziest. Imagine a ward of 6 men acting like boys at a boarding school having a midnight feast. Even the ward “Matron” joined in some of the foolish and risqué jokes while doling out the medicines. My only problem was trying not to laugh too much because of the residual pain from the surgery. It only hurt when I laughed.

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Life with my temporary stoma was fine. Six weeks after the operation I was back at the gym and shortly after that felt confident enough to go fishing, oh joyous day. I did take a few months off work and when I returned was told that I looked like I was ten years younger. And that was how I felt. DIY jobs around the house that I had put off previously now actually attracted me with my new found vigour. I found that there was nothing the stoma prevented me from doing.

March of 2007 saw me return to the operating theatre to have my loop ileostomy reversed (“takedown” in pouch-speak) and thus bring the pouch into function. To me, the night before the operation was like Christmas Eve.

Then came the wait for the first rumblings and pouch output that was required before I could go home. Being on a liquid diet I did wonder what they expected the pouch to produce. But eventually everything started to work as it should and I was discharged as fully functioning. I had expected the first few weeks to be like living with UC again. I was not prepared for the level of control that came with my pouch; it was though a pleasant surprise. The first few weeks were wonderful, even though the trips to the loo were a bit more frequent than I would have liked. I managed to go fishing a couple of times but did restrict the time outdoors – just in case.

Then I was hit with what I now know is called “Ring Sting” or “Butt Burn” - so called because it feels as if your backside is on fire. No wonder babies cry when they have nappy rash. Why is it that problems always occur when the shops are shut or you are stuck without transport? I sought an explanation to this misery from the friendly community I had discovered on the IA website chat forums. Frequent baths, Sudocrem or similar, and baby wipes were the recommended and successful solutions. That problem passed fairly quickly and now I am left with a year’s supply of baby wipes and creams. But this was only the start of my problems.

The next few months were miserable. I could quite happily have gone back into hospital and had the pouch removed and a permanent ileostomy created. The basic problem was that I needed to go to the toilet 20 times a day. Having had a very positive experience up to this point I found it very difficult to deal with and became depressed. Being a typical male of the species I tried to tough this out, unsuccessfully. So my wife hijacked me and booked me in with our GP. Having confirmed that I was not suicidal he did prescribe a course of antidepressants. These helped greatly, not only lightening my mood but also because they make you constipated and so cut back on the intimate relationship I was having with my bathroom. It was then that I decided that the bathroom needed complete remodelling.

Luckily I only needed the tablets for about two months. I actually found that I could manage without them by accident. I stopped taking them because I suspected that they were the cause of my fainting while on holiday. Since then I have not felt the need to use them, and I haven’t fainted again.

By November 2007 things had not improved much and were about to get a lot worse. At the end of the month I started to feel as if I had ‘flu or some other infection coming on. So heeding the medical advice that there is nothing you can do to cure a viral infection I didn’t bother to see my GP. Four weeks later, with no improvement in health but having lost about a stone in weight, I was again hijacked. By this time I had started to suspect that the pouch was to blame for my ill health. My GP agreed and suspected pouchitis. This is a condition where the lining of the pouch becomes inflamed, increases frequency of emptying and can cause ‘flu-like symptoms. The condition is treatable with a strong antibiotic.

For a week I wasn’t sure whether I preferred having pouchitis as opposed to the side effects of the antibiotics. I lost a further half stone that week which included Christmas day. Now I have discovered that there is another drug that counters the side effects of the antibiotic.

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Since Christmas 2007 things have been getting better, but slowly. I now suspect, but cannot prove, that I may have had a very low level of Pouchitis for some months. This is despite Mr Rashed not finding any evidence when he examined his handiwork (from the inside) a few weeks after takedown. During the second half of 2007 I would only go fishing where I knew there was a toilet nearby. Now I am confidently fishing all day away from any facilities without even really thinking about it. The strangest thing is though that when I am at home I find it almost impossible to go from morning to evening without the need of a couple of trips to the newly refitted throne room. It appears to be a feature of the pouch that if you have something to occupy your mind it really doesn't cause any problems.

Late in 2008 my wife and I took a trip to the USA. I am happy to report that the pouch behaved impeccably. Particularly impressive given the size of breakfast I was enjoying. After a plate of waffle, scrambled egg, sausage and bacon, plus toast & coffee I was able to go most of the day without needing the restroom. This included going to watch the Miami Dolphins play Oakland Raiders (American football) and a trip to the Everglades. Both trips of several hours, and accomplished without the need for toilets.

Do I regret Mr Rashed talking me into opting for the pouch? Not a bit. Yes the road has been bumpy but life doesn't come with a guarantee. The community that use the **IA** website forums have been invaluable, giving much needed advice as well as inspiration and encouragement, and I thank them unreservedly.

Finally, yes, I did walk my daughter down the aisle and finished the day "dad-dancing" aided by a couple (?) of beers. As for my son, he is on the mend after over 20 operations and lengthy spells of rehabilitation. He hopes to be fit enough to be able to be deployed to Afghanistan during 2009, his mother of course hopes otherwise.

Update – Spring 2009

Two years after takedown. On an average day I probably visit the toilet 8 times including one overnight. However for me the frequency is not an issue. It fits into my life. The main issue is the ability to hold on. If it is not convenient then I know that I can hold for a considerable time. On days I go fishing I have no trouble going from approximately 8am to 6pm without the need of a bathroom. On those days I don't tend to have breakfast but do have a snack lunch.

Mr Rashed told me that it could take two years to fully recover from the surgery. In my case I have used all that time and I still expect to see some more gradual improvement.

The main issue for me is that while I had UC, I would have to plan any outings, even to the shops, around available toilet facilities. Now I don't give that a second thought. I just expect it not to be a problem.

So thank you Mr Rashed for giving me back normality.

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