



The ileostomy & internal pouch

Support Group

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Robert Anderson Coming to Terms with a New Plumbing System

I was diagnosed with ulcerative colitis in 1992 at the age of 23. I had been suffering with diarrhoea and severe bleeding from the rear for nearly a month before I plucked up courage to visit my GP. I thought, like most others I guess, that the problem would clear up, and I was embarrassed about talking to anyone about it.

How I wish now that I had done something sooner. I had lost nearly 3 stone in weight and in photographs from the time I looked like a walking skeleton. It is odd that one seems not to notice these changes in oneself at the time. It is only looking back or meeting someone one hasn't seen for a while that the differences are spotted.

Anyway, my GP arranged for me to visit the proctologist at Ipswich Hospital and prescribed me something for the diarrhoea. I can't remember how effective that was but within a week I was in hospital speaking to a consultant who diagnosed ulcerative colitis (UC) and arranged for a sigmoidoscopy. I can't remember if he prescribed any prednisolone at that stage or not, but I soon found myself back in hospital, this time lying on my side with a 'telescope' up my rear-end! One thing I do remember was the wonderful feeling of euphoria creeping up my arm as the mild anaesthetic was administered into the back of my hand - one bonus to come from the situation!

By this time I had passed my 24th birthday, and for a young man you can probably imagine this was not how one had planned their life to turn out. Of course I'm equally sure that no one, whatever age or gender, would be particularly chuffed with having one of these procedures.

So the consultant confirmed my UC and from then on I started a love-hate relationship with prednisolone. Large doses brought everything under control – I stopped bleeding, my motions began to firm up, and I had much more control over my bowel actions. However, as we know, one cannot stay on large doses of prednisolone forever, and as I gradually reduced the dosage the symptoms would return. I always dreaded getting down to that 10mg stage because I knew that the symptoms of UC would most likely follow. This yo-yo process of steroid dosage continued for four years before the consultant made an appointment for me to see a surgeon at Ipswich Hospital. The surgeon looked through my records and didn't sugar-coat the pill when he told me that I was facing having to undergo surgery for my condition. I recall crying when that news came. The surgeon and the stoma nurses talked me through the procedure and I was given a video of the surgery to watch. In a way I wish I hadn't seen that – it was like a gory horror movie – but at least I had an idea of what to expect.

That was how I came to find myself in hospital in November 1996 undergoing the first stage of my pouch operation. The first operation was carried out and I woke up on a ward in some discomfort but this soon faded as painkillers were administered. I remember crying again when I looked at what the surgeon 'had done' to me. I had a stoma bag attached to my abdomen and a mucus fistula lower down that I do not recall anyone telling me would be there. It must have been a combination of the medication and my feeling sorry for myself that caused me to be quite weepy in hospital, and I suppose if I am honest some of that was vanity and concern for my body image. I had always enjoyed swimming and keeping fit. I had

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taken up scuba diving and it was difficult to see how this lifestyle was going to work out with a stoma.

I was discharged from hospital and spent the next couple of months at home getting used to the new arrangement for my waste discharge. I was not overly concerned about the situation – it was after all Winter, so there was little scope for baring my stoma to the world. I returned to work at the end of January – I worked then as warehouseman at the Port of Felixstowe – and life continued. I think the worst of it was the mucus fistula that wept quite badly but the stoma bag itself was fine. I had a few leakages at night as I got used to the fitting procedure. As I recall the bag would fill more with wind (a right old Aeolus!) and this would cause it to come loose as I moved around at night.

It wasn't long before I was called back to hospital to have the second stage of the operation. Not a reversal, because I knew that things would not be the same as before I was ill. I had been told to expect my motions to be much like those I had seen from the stoma and that I could expect to be going to the loo up to six times a day and once at night. OK, that sounded reasonable to be rid of the stoma bag and be able to lead something of a more normal life, albeit having to keep one eye on toilet facilities.

Again I went down to surgery – this was in March of 1997 so hardly any time between operations – but this time I woke up with all sorts of tubes sticking out of me. I had a catheter and a tube in my anus and one in my nose. I had IV drips going into my arm and felt like something out of *The Matrix* (although of course that film wasn't released at that time). The surgery hadn't worked too well, and nothing would come out of the tube from my rear. An X-ray revealed that part of the pouch had adhered to my spine or something like that, so I had to go down again to have that sorted out. By this time my surgeon had been through the wall of my abdomen three times so you can imagine it was a bit sore. This time the surgery worked and after a few days as I started eating solids I began to get movement from the pouch and so from my rear. Now I couldn't stop going! My sphincter muscle must have weakened so much it was hard to keep control, and the bed sheets ended up soaked a couple of times. Gradually I was able to hold on long enough to get to the toilet, but often it seemed that as soon as I got off the loo it was time to go again. After a couple of weeks, by which time I think I was going a bit crazy being in hospital, I was allowed home to adapt to my new pouch.

The first months were pretty rough. I still had discharge from where the mucus fistula had been and this took a long time to heal. This kept me off work for about four months. In this time I built up my strength and started walking longer distances and found I was able to hold on until I got to the next toilet. I was still sore though, as I got a lot of anal discharge during this time. I tried several creams to keep the area round my anus clean and non-irritated. There was a lot of itching too just inside the anus. This did get so bad at one point that I seriously considered going back to my surgeon and asking for the stoma bag back! However, I persevered and over time the frequency of my visits to the loo dropped, although I was still going up to ten times a day and a couple at night, and I started to look forward to getting back to 'normal'. Every time I tried to be more active though, whether it was swimming or using a rowing machine, I seemed to get flare ups where I would get bleeding from the pouch and more frequent and loose motions.

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Neither the surgeon nor my doctor could see a relationship between the extra activity and the extra activity of my pouch. Yet it seemed to me that if I sat watching TV or playing games on the computer all day my pouch worked well, but if I pushed myself a bit and tried exercising, it would play me up.

This went on for a few years until my partner, Kristine, and I went to Hawaii in January 2000. This was the first time I remember being confident enough to go out without a piece of tissue paper in my underwear. I was more active – we went snorkelling and hiking across an extinct volcano and I had little trouble with the pouch. I should mention that through all this time I had played the drums in a local rock covers band and this had never caused me a problem. I think it may have helped being a drummer as of course I was seated, not standing like the guitarists. In 2003 I started studying for a degree with the Open University, which is by the way really, except to say that if my UC had continued unchecked I may not even be here to do so.

After the Hawaii holiday I built up what I was able to do. On a trip to Crete in late 2003 we hiked down the Samaria gorge, a trip of ten miles with, of course, no toilets to stop at on the way. In 2005 I joined a gym and started swimming again with no noticeable affect on my pouch. I still have to go to the toilet four or five times a day, generally following meals, so the more frequently I eat the more I go, and usually once at night again depending on what I eat and how close to going to bed. I do still get a little bleeding and sometimes my motions are very watery and I do get sore round the anus at times. I have found that Acriflex works best for this. It heals the soreness and provides something of a barrier for next time I go.

I wouldn't say that life with an internal pouch has been a bed of roses. The first years were very rough and as I mentioned at times I considered asking for a 're-reversal'. But now I know what to expect and how certain foods and drinks will affect me, life does seem better. It is certainly 100% better than when I had UC. I can still see the advantage of a stoma bag, or external pouch, as maybe life is less dictated by when you have to empty it, but I'm not sure how I would have got on walking ten miles in Crete. That was a long time between toilet stops and would a bag have over-filled?

To me I suppose the real advantage is when it comes to swimming. I have the scars of my surgery but that does not prevent me getting in the pool for an hour. The frequency of visits to the toilet can be a problem – especially at work – but I just have to be prepared for that and work around it. I certainly do not consider my internal pouch to be superior to an external one, and I am aware that in years to come I may have to go back to a stoma bag.

I have had my internal pouch for ten years now – how many people have had them for twenty or thirty years, and how they get on, I don't know. Maybe someone else could enlighten us on that question. For now I am glad to be able to do the things I do that I was unable to do when I had UC, or when I had a stoma. If I had to go back to having a stoma tomorrow I would still be happy, just to not have the debilitating ulcerative colitis.

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