



The ileostomy & internal pouch

Support Group

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Pouch Surgery Experiences – John Mullins

I first became ill back in 1981, nothing serious initially, just generally feeling unwell. I put this down to being a little run down and didn't really think too much about it. However, over the next few weeks things didn't improve and then suddenly things went downhill very rapidly. I was in tremendous pain, unable to keep food down and spending an inordinate amount of time in the toilet. Nobody was quite sure what the matter was and I was given a cocktail of anti-diarrhoea, anti-sickness and pain killing drugs. None of this had any real effect and I went further downhill. I then started passing blood in my motions. This completely freaked me out, but gave my GP the clue he needed, and he had me admitted to St. James Hospital (affectionately known as Jimmy's) with suspected ulcerative colitis.

I don't really remember much about the first week there. I was given regular jabs of pethidine for the pain and as a result was out of it for most of the time. I had various examinations and eventually my GP's diagnosis was confirmed, though that didn't really help as I had absolutely no idea what ulcerative colitis was. With the disease confirmed the doctors started bombarding me with steroids and 5-ASA drugs, both orally and in enema form. It was also decided that my bowel needed a complete rest so I was 'nil by mouth' for the next few weeks - the only nutrition I got was via a drip. This, combined with my never ending visits to the toilet, caused my weight to plummet and I lost about three and a half stone - I'd always been on the slim side so this weight I could ill afford to lose.

After a while it seemed my symptoms were not improving so, a few days after my twentieth birthday, the surgeons came to visit and the option of surgery explained. Frankly, what I heard horrified me. The thought of spending the rest of my life with an appliance attached to my abdomen filled me with dread, but it seemed it was rapidly becoming my only option. The hospital arranged for a young man of about my age, who had already been through the surgery to come and see me and hopefully answer my questions and provide some reassurance that there was life after this surgery. To be honest, I wasn't that reassured after the visit and was still feeling very depressed, nevertheless the surgery was planned to go ahead a few days later.

Either late on the night before or early on the morning the surgery was due, I can't remember which as I'd not slept for some time and had really lost all track of time, the surgeons gathered at the bottom of my bed and examined my charts and blood results. Talking seemingly amongst themselves I heard one say "I think this one's going to pull through" - obviously my charts and blood work had shown something I wasn't feeling, but in a flash my surgery was postponed. In an instant I felt much better and from then on my recovery was quite remarkable. The removal of the worries of the aftermath of surgery had gone and I could see myself living a normal life once more. It was probably then I realized how my mental state could affect my physical state and vowed never to let this illness affect me in that way again.

Over the next few months as my health improved I was slowly weaned off the steroids and slowly regained my lost weight. I was kept on a maintenance dose of sulphasalazine, and apart from a couple of minor episodes which were dealt with by a short sharp shock of prednisolone treatment, life, whilst not perfect, wasn't particularly bad either. I'd somewhat fallen into a career developing computer games and in 1987 I got married to Angelina who had been with me through my first encounter with colitis and as far as possible tried not to think about my illness and just enjoy life.

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My health remained reasonably good up until 1994 when another flare up led me to be hospitalised once more. This time I managed to stay much more positive and after an intensive course of steroids was well enough to free up the hospital bed and go home. After this flare up my health was very much up and down though I guess I just adapted to it - I didn't really realize how bad it was until a few years later after my surgery.

At the end of 1994, due to work commitments, we moved away from Leeds to Thatcham, a little village just outside of Newbury. A couple of years later we decided to start a family - we didn't expect anything quickly - Angelina had been on the pill for some time and was told not to expect anything for the first two or three months. On top of this I was still taking sulphasalazine which is known to reduce fertility, though this only lasts whilst you are taking the drug. We figured I'd continue taking this for the next couple of months and then ask to be given an alternative until nature had taken its course. This all ended up being quite irrelevant as a few weeks later Angelina excitedly announced she was expecting! Everything was going well until about three weeks before the baby was due, when I found myself in hospital once more after yet another attack. This wasn't exactly ideal, Angelina now had a fifty mile round trip to visit and could possibly go into labour at any time. The doctors did the best they could and got me home a week later, though I wasn't really well enough. A week later Jack arrived after a long and difficult labour. We're forever grateful to Elaine, a good family friend, who helped Angelina through this as I was too ill (so ill, in fact, a bed was provided for me in the delivery room!). I missed out on the first few weeks of Jack's life as I was recovering and Angelina only really coped thanks to the help of friends.

A few months later I found myself looking for work as the company I was working for went into liquidation. Fortunately it was a short search, a phone call to a previous employer to ask for a reference resulted in an instant attractive job offer, and we moved back to the North to a small village just outside of York. A few months later we found we were expecting our second child, and this time I managed to stay well enough to welcome Thomas into the world. Over the next couple of years I had constant trouble with my health, whilst never bad enough to hospitalise me, I seemed to be on a never ending cycle of prednisolone. A bone density scan in 2000 showed that the continuous use of steroids was leeching the calcium from my bones, and as a result we tried long term azathioprine treatment. A few months later after a routine colonoscopy my consultant recommended that I see him in a couple of weeks to discuss some surgical options –my colon ad pretty much reached the end of the road and the question was when, not if I'd need surgery. This didn't come as a huge surprise, I'd long been convinced surgery at some point was inevitable, and decided to focus on the fact that I'd no longer have this illness that had given me so much grief for almost twenty years.

I had assumed surgery meant a stoma, as this had been the only option ever discussed with me in the past and I'd never really looked into it any further. I like to have at least an idea of what my doctors are talking about when discussing things with them so decided now would be a good time to do some research and, being a child of the internet, I hit the Web. What I found quite surprised me, the stoma wasn't my only option, Koch pouches, BCIRs, j-pouches, s-pouches and more seemed to be other choices and these did not involve wearing an appliance. Now the appliance didn't bother me as much as it once did, but the option of being without was something I had to check out. I spent the next couple of weeks visiting forums and user groups for both stomas and pouches. What I found there didn't inspire much enthusiasm. All I heard about were problems, whether it be leaking bags, hernias, fistulae, pouchitis, or 'butt burn' – nobody seemed to be problem free.

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It took me some time to realize that this was exactly what I should have expected to find, after all, here I was visiting support groups. I ought to expect to be finding people looking for such support. I now had a pretty good grounding in potential problems, so decided to look for some hard numbers, fortunately the results of many studies can be found on the web and I spent a good deal of time going through these. Now while it was clear that none of the surgeries are perfect it was almost always preferable to the alternative and the odds were good of a high quality of life afterwards.

A few days later I visited my consultant for what turned out to be quite a short meeting. He explained it was felt I was a good candidate for a j-pouch procedure and arranged for me to meet Mr. Leveson who would be performing the surgery and would explain all the ins and outs. Things moved pretty rapidly from then on, a meeting with my surgeon answered all of my outstanding questions and after agreeing to two stage procedure (colectomy and pouch formation with diverting ileostomy, followed sometime later by takedown) was given a date for surgery there and then. A meeting with my stoma nurse gave me lots more information, a whole host of leaflets and booklets on how to prepare for the surgery and what to expect afterwards. I became something of a knowledge junkie devouring every piece of information I could, I always feel much more in control when I fully understand what is happening around me and now more than ever I wanted to feel in control. In the couple of months I had before the surgery was due I tried to get myself as fit as possible, knowing that this would help in the recovery period, and on the advice of my stoma nurse started pelvic floor exercise.

In early December 2001 I was admitted and despite suffering from a very heavy cold was walked down to theatre the following morning feeling a heady mix of nervousness and excitement. Apparently the operation went well but I spent longer in the recovery room than expected, high blood pressure and a racing heartbeat being the problem, adrenaline still flowing I suppose. Once back in the ward I was asked to let the nurses know once I had passed wind into the bag now attached over the site of my new stoma, this could take anything up to 48 hours I was told. An hour later I felt as though I had a Zeppelin attached to my side, the bowel had clearly started working so now began the process of introducing foods and learning to cope with the new way my body was functioning. Thanks to the care of the nursing and pain teams at York District Hospital the next few days went quite smoothly and seven days after my surgery went home. From then I tried to set myself daily goals so that I could actually see some progress in my recovery and in many ways this actually helped to speed it along. Completing a goal always made me feel that little bit better, of course the inevitable failures could have had the opposite effect but I managed to always look at the bigger picture and look back over the previous few days so I always had the feeling of moving forwards. As a result, come Christmas, I was well enough to enjoy the festivities and was back at work by the middle of January.

Not long after returning to work I went back to the hospital for a pouchogram that showed everything was fine with the pouch and was then informed I would be going on the waiting list for takedown which could mean a wait of up to six months. After the way my initial surgery was organised I hadn't really expected this, but to be honest I didn't really mind. I was feeling better than I had done for twenty years and was quite happy for this to continue. I'd adjusted to life with a stoma much better than I had expected, this may have been tempered by the fact I knew it was only temporary and that this health I'd discovered left me on a permanent high. During April I received a letter from the hospital inviting me in for takedown at the start of May, it was now that something completely unexpected happened, I considered not going through with it!

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This shocked me a bit, I'd never really wanted a bag but here I was seriously contemplating keeping it. I suppose when you've been ill for so long and suddenly you have your health back you don't want to do anything to jeopardize that. Anyway, after some long discussions with my family we decided that as the pouch was already there we really ought to give it a chance. Had my situation, like many others, meant that I had had a stoma formed first and then had to decide whether to go for the pouch I can't honestly say which way I would have jumped.

I went into hospital on May Bank Holiday Monday, and due to being too excited to sleep and being in a bay with three other insomniacs stayed up into the early hours of the morning watching the last few frames of the World Snooker Championships. Early next morning I took a shower and changed my bag for what would be the final time and took a stroll down to theatre (I do like the idea of going to theatre under my own steam, it gives you the feeling of being in control right up until the last possible minute). A short while later I was back in my bed sans bag waiting for the rush of bowel movements I'd been promised, fortunately these never really materialised. I very quickly settled into a routine of six to eight toilet visits a day and within a couple of weeks was sleeping through the night. I was home by the weekend and back at work the following week and recovery from this surgery was a relative breeze.

I've been quite fortunate not to have to adjust my diet much, I already ate many of the foods that are recommended for pouchies. My wife comes from an Italian family so we've always had plenty of pasta and I've long been a lover of Asian cuisine so rice has always been on the menu. There are foods that can give me problems, but I can always avoid those or simply be prepared to face the consequences (I've found I can limit any damage by adding some soluble fibre to my diet, usually some form of psyllium husk). I've also managed to stay drug free, I was initially offered some loperamide to slow down transit times but decided to see how I could manage without before going down that route, I'd taken enough pills over the previous twenty years and if I could avoid them in future that would be a big bonus.

In the four years since my pouch started functioning it has steadily improved, the three to four bowel movements and uninterrupted nights sleep is a much better result than I was expecting. I did have a couple of bouts of pouchitis in the first twelve months, apparently this is quite common, but these were swiftly dealt with by a course of antibiotics and have not reappeared since. One downside has been that I now put on weight much easier than ever before (I guess some of that is simply middle age spread) and as a result started going swimming before work to get some exercise and more recently I've joined the local gym so that I can keep this in check. Of course the most important thing the surgery did was give me back a life I hadn't fully realized I'd lost. I now have enough energy to spend the amount of time with my family that they deserve, and do all the things I simply could not have managed in the past.

I visit my stoma nurse once a year, just for a check up and every three years or so go for a scope. From being a regular face at my GP's I've become a stranger and have a very empty medicine cabinet. Without a doubt the decision to go ahead with pouch surgery was one of my best, and it would not be exaggerating to call it life changing. I never really realized how ill I'd been until I was healthy again and will be forever grateful to Mr. Leveson and his team for giving me back my life.

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(updated 6/5/2010) One for sorrow, two for joy....eight for a wish.

It is just over 4 years since I first wrote the story of my illness and subsequent surgery and recovery and eight years since the actual final surgery itself, so what has happened since then? In truth, in terms of my health, not a lot. I had a bout of pouchitis whilst on holiday in the USA a couple of years ago, and as we only had a few days of the holiday left I decided not to seek help, and all the explanations that would entail, but managed my symptoms and arranged an appointment with my GP for the day we got home. A quick course of metronidazole was prescribed and everything settled down within a couple of days and normal service was resumed. Other than that my pouch has behaved impeccably - I have even managed to avoid the numerous tummy bugs that have gone through our village in those years. It felt quite strange not to be the one hogging the throne during those times.

Pouch function has remained good and if anything has improved slightly, I never worry about where the toilets are and no longer worry nor care how often through the day I need the loo. Confidence plays a big part here - I know that no matter where I am I can manage until I can find a toilet. This means long walks in the Dales are no longer a problem, long haul flights hold no fears, and journeys up and down the motorway are not littered with comfort breaks. Being able to sleep through the night is a huge bonus, it is very rare I need to get up in the middle of the night – though a night out on the beer followed by some dodgy street food might have that effect, but I am sure that was case when I had a fully working colon too. Diet-wise I eat everything I did before surgery and a lot of stuff I didn't, good food is something of a passion of mine and while I know that some foods will have a detrimental effect on my pouch function it is always short lived and never severe and a price I am usually prepared to pay. I now have to keep an eye on my weight - I do not mind this as having spent many years as a '10 stone weakling' due to colitis it is nice to have to fight to keep it in check rather than fight to stop it dropping. I enjoy a drink, whether that be wine, beer or the occasional spirit and have these without any dramas. Of course, overdoing it means a hangover and because of our increased propensity to dehydration these can be a bit severe but these problems can be minimized with care.

The only real setback is that I have just been diagnosed as B12 deficient, which is quite common in those of us with internal pouches. The reasons are not fully understood but it is thought it may be due to changes in the mucosa in the pouch or the changed make up of the bacterial flora. Either way I no longer seem to be able to absorb B12 and my body's own stores appear to be depleted. The deficiency was found as part of my normal annual follow up and treatment is quite straightforward - a series of injections over a couple of weeks gets the body's levels back up and then I may need a boost every three months or so. We will know a little more about this in the coming months as we continue to monitor my levels. While this is not ideal it seems a small price to pay for continued good health and that is after all why I had surgery.

Talking of follow up, I no longer routinely visit the clinics as it seemed to both my stoma nurse and myself to be a bit of a waste of time. Now the blood test form is simply sent to my home and I get that done when convenient and should I have any issues a quick phone call to the stoma care department can arrange an appointment in no time. My hospital has also decided that routine scoping of the pouch is no longer necessary (at least for those whose surgery was due to UC). I have slightly mixed feelings about this - on one hand a pouchoscopy is not a pleasant experience and not one that I will miss but then again there is a degree of comfort to be had from the knowledge that things are being monitored. I do know that should it be necessary, then a scope can be arranged.

I am now looking forward to the next few years, in particular getting into double figures but should it all go pear shaped tomorrow, I would not swap the last 8 years for anything and would do it all again in a heartbeat.

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