



The ileostomy & internal pouch

Support Group

Registered Charity

Pouch Surgery Experiences – Neil Johnston

I can't forget the date, late November '96, because :

- (i) It was my wife's birthday.
- (ii) I had a day's fishing on the Nith at Dumfries and lost the biggest salmon I've ever had hold of after playing it for 20 minutes.
- (iii) I didn't feel like eating my bait (Cumbrian term for lunch box) on the river bank - my tummy didn't feel quite right and I wasn't very hungry.

Two days later, after spending umpteen visits to the toilet, I visited my GP and he thought I'd got IBS. He gave me something for it - it didn't work! The following night I had severe stomach pains and drastic diarrhoea, and was absolutely doubled up with pains. Not messing about my wife phoned an ambulance and I was admitted to hospital through A&E.

After numerous telescopes and X-rays I was diagnosed with acute ulcerative colitis. My consultant said we'll keep on top of it with steroids and when the inflammation goes down you can go home. I was on medication for about a week and was X-rayed sometimes twice a day.

On the Saturday morning, with my going-home clothes on, the end of the bed my consultant visited me with the X-ray results. There was me thinking I was feeling better, I was absolutely gobsmacked when he said we're removing your entire colon as an emergency operation on Tuesday. Things were then a daze and I was visited by the stoma nurse who started drawing on my belly where things were going to go. I felt as though I'd been felled by a plank of wood! Things then seemed to happen so quickly I really didn't have time to take it all in. What was a stoma? What's an ileostomy? What's a mucous fistula? By Tuesday night I'd got all three!!

As the days progressed I was learning to manage my stoma and bag and the nurse said when I was competent enough to handle it alone I could be let home. Handling the ileostomy bag was not a great problem for me but let's not pull any punches - it ain't nice, it ain't natural and I wouldn't wish it on anyone, but if you've no choice then so be it. In my case I handled it a lot easier when I was told I would be suitable for a reversal with an ileo-anal pouch, given time.

At the start I had a lot of leaks with the bag. One time in hospital I was so weak I couldn't get out of bed to change it and it blew right off, all over the bed, a mini explosion. The main problem was that the mucous fistula was so close to the stoma, and as it was oozing mucous it would undo the seal on the bag. I regularly had three or four bags on in the space of a morning. I tried two-piece bags, even a small bag on the fistula. Coloplast bags didn't work well for me, I eventually used Hollister bags (American I think) with a small dressing on the fistula and that was the best I could do at the time.

On one occasion in hospital two nurses helped me into the bath and said when I was done pull the cord and they would help me out, when they were helping me out I caught a glimpse of myself in the full length mirror and got really upset.

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I had played cricket for thirty years as an opening bowler and had thighs like a speed skater - what I saw that day really shocked me, collar bones sticking out, skinny legs and arms. It happened again when I got home and my wife was helping me in the bath, I could see she was visibly upset at my scrawny body, I'll never forget the look on her face.

On Xmas day morning my consultant came in the ward dressed in a kitchen apron and served everyone their breakfast, a very nice gesture I thought. As they were short staffed he said if my temperature went down I could go home - it didn't but they sent me home all the same. Everyone that went home that Xmas day had the usual blue box with their bags creams and medications in. I still see them today with their blue boxes at the hospital and know exactly what they've been through. My brother in law brought me home at lunchtime. I stood in front of the fire and broke down, I absolutely bawled my head off, I never thought I'd see home again at one stage.

Things began to improve and I started to put weight on. When I went in hospital on Nov 27th I was 16st 4lbs and when I came home on Xmas day I was 12st 2lbs. To this day I don't put much weight on and now hover around 14 to 15stone, but as I'm 6ft 6in I can carry it no problem.

As I was feeling better we decided we'd go out with our friends for a meal to a nice restaurant, me with a stoma and a fistula, what a mistake! When we'd finished our meal I always had this habit of a quick feel down below to see if everything was ok, it wasn't! It felt quite moist so I went to the loo, what a mess - the fistula dressing had come away, undoing the seal on the ileostomy bag and the bag was down by my knees somewhere, and to cap it all there was no loo paper. I used my white vest to clean myself up the best I could and stuffed it down the loo. I managed to catch my wife's eye, went back to my friends car, got a bin liner out of the boot and sat on it all the way home (he said "Any excuse not to pay!").

After a bath I came downstairs and we all had a bloody good laugh about it. That was the whole point - I could laugh at my illness and talk very frankly about it, so much so that the hospital have used me to talk to other people who are contemplating going through the same thing as I did.

It was nearly 12 months when I returned to hospital to have my pouch built (stage two) and things improved immensely after that (no mucous fistula to deal with) - so much that I went back to my job as a cable jointer with Norweb (now United Utilities) and tried to carry on where I left off, after about 15 months off.

I found my work mates like school kids at times; they could be so cruel to anyone with an affliction. On one occasion I was attending a safety seminar at a hotel in Penrith and during the afternoon session I had to be excused. As I stood up to leave the room someone shouted out, "is your shit bag full?" I laughed at him and asked him if he'd like to change my ileostomy bag for me. He shrank back in his chair with no response, ever since that day at Penrith I was known as "Shit Bag Johnston" but boy did I get my own back on that loud-mouth.

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My job as a high voltage cable jointer involved all hours of the day and night and I was in the depot many a time after hours - well that loud-mouth came into work one morning and found a full used ileostomy bag sitting on his drivers seat in his van (how the hell could I do something like that?). I never had any more problems with him.

I returned to hospital to have my pouch X-rayed a couple of times for the final takedown and twice they said it wasn't ready - the consultant apologised profusely and said it was ok the first time, they had been looking at my pouch stitches and thought it hadn't healed properly when obviously it had.

Final takedown was in April '98 - no big deal really after what I'd been through. I can remember being told that I'd be sat on the end of the bed and feel like the loo and not make it in time, and should expect some little accidents. I was sent home with loads of incontinence pads, the feeling of being bag free was a very moving (no pun intended) experience. I can honestly say I've never had any leaks or accidents, even through the night and apart from two bouts of pouchitis, one in '98 the other this summer (it's learning to recognise it), my pouch surgery has been a total success. I fully understand what has worked for me may not work for others. I realise how very lucky I am to be back to as nearly normal as is possible and for that I am eternally grateful but most of all I am very humble.

I still go once a year for a colonoscopy and my consultant says he's happy enough not to see me but general medical practice says he has to, and I've no problem with that.

I have regular blood tests at my GPs and occasionally have a course of iron tablets and vitamin B12 injections due to no colon to absorb the minerals I require. I take six loperamide a day and have a normal and healthy diet with no restrictions on what I can eat at all from full Chinese meals on a Saturday night to full roast Sunday dinners. I can eat ice cream for England with no effects on my cholesterol at all.

I still play golf regularly, still do my fishing and still attend car shows with my home-built kit car (how the hell did I manage at these shows with my bag on - have you ever tried to empty your bag in a portaloos when you have to sit back to front to empty it, there isn't a back to front in a portaloos is there?). Holidays abroad? - no problems at all, my brother has a yacht based in central Croatia and I go there two or three times a year.

Last year I had a fright whilst playing golf. I'd only played two holes (and was three under par) when I had a brain haemorrhage on the third hole. I was in Newcastle General neuro-surgical wing for two weeks with a burst vein (not an aneurism) in my head and made a full recovery with no further treatment, very scary though.

Thank you for reading my story. My best wishes and kind regards to you all.

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