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## The Good, the Bad, and the Pouch Surgery

**I have always had trouble with my bowels. One of my youngest memories is that of regularly having to take good ol' syrup of figs (yuck!) and the much nicer orange drinks prescribed by the GP, which I remember contained an extraordinary amount of sugar. I'm pretty sure kids today wouldn't be given those! The difficulty going to the toilet did seem to ease though and my early teenage life passed without issue.**

Roll on to my mid-twenties and in 1997 the man I adored most in the world was diagnosed with terminal lung cancer, and life as I knew it was about to change for ever. Shortly after my dad's death (I was holding his hand as he died), my body went into shock and I became doubled over, seemingly stuck in that position. I could not straighten up or uncurl my fingers. This subsided after about 20 minutes. A few months later, I noticed blood in my very loose, oozy stools but buried my head in the sand and ignored it, thinking perhaps I'd caught a bug and things would be fine.

However, after 5 weeks of this, my weight had plummeted, and I was exhausted. My mum dragged me off to the doctors and I was immediately referred to hospital for more tests. I was diagnosed with ulcerative



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colitis and put under the excellent care of my specialist, Michael Webberley. I was passing loose, bloody stools on average over 40 times daily, and if I could have strapped a toilet to my back, I would have! Every outing consisted of researching the location of every toilet facility, and if there was the slightest chance of there not being a toilet, I would simply stay at home, wanting to avoid the risk of embarrassing "accidents". Eight years followed of repeated anti-inflammatory drugs and the dreaded steroid, Prednisolone.

Whilst Prednisolone is a fantastic drug, the side effects are awful. My weight ballooned from 9 stone to 15 stone over 8 years and I

was ravenously hungry all the time. I just didn't stop eating, despite many warnings from health professionals that my weight was becoming an issue. As I was quite young at the time, the specialist was concerned about bone density, so I was sent for a bone scan and luckily it was all clear, but it did become apparent that I couldn't be on steroids long-term.

Unfortunately, every time I weaned off the steroids the flare ups just kept coming; an alternative had to be found. I was delighted to be prescribed Azathioprine and, although the downside of this drug is monthly blood tests to check my blood cell count, this seemed a small price to pay for coming off the steroids. I was warned that a complication of Azathioprine is possible future kidney problems, but parked that issue to one side in the rush to come off the steroids.

I often wondered where my ulcerative colitis came from. My mother does not remember her father as he died when she was very young, but after speaking with her brother he tells me he believes their father had an ileostomy bag of some sort. My mum remembers him having something strapped to his stomach and always having 'tummy troubles'. This does beg the question - is ulcerative colitis genetic?

I was always told that ulcerative colitis is stress-related. I did have a huge amount of stress at the time of diagnosis and I did notice that all my flare-ups over the years coincided with periods of stress or trauma in my life. I had a demanding job but was struggling with fatigue and even regularly fell asleep in the loos! I remember

attempting to walk my dog during a flare up and had to keep stopping to lie down on the pavement for a rest, having no energy at all.

By 2005, my first marriage had broken down irretrievably and I got made redundant. My stress levels were off the scale. I had a colonoscopy and they found the ulcers had spread to over 95% of my large bowel. My specialist said enough was enough and my medication had stopped working. It was time for the "bag" chat. I was referred to the superb colorectal surgeons Simon Radley and "Kay" at the Queen Elizabeth Hospital in Birmingham, who informed me that the operation was urgent as there was a risk of my large colon rupturing.

Following the first of three operations (sub-total colectomy), I am proud to say that I took to the bag immediately. I soon got the hang of it and the health professionals throughout my journey have all been amazing with their advice and support. I had a few issues with leakages, but soon learned to carry spare clothes in the car together with all the stoma paraphernalia, should I need to change my bag whilst I was out.

In those early days, the stoma nurses were a constant source of knowledge and reassurance and even came to my home on a couple of occasions. I do remember chatting to a friend on the phone one evening and I could feel my bag starting to balloon so I knew I had to empty it soon. I stupidly ignored it and continued chatting away for a couple of hours when suddenly there followed a big explosion with poop everywhere! That took some clearing up, I can tell you! Lesson learned. When you need to go, you need to go!

Suddenly finding myself alone with no husband was daunting and I honestly felt that no-one would ever find me attractive and want to be with me again. Going through surgery without the support of a partner was tough but, finally, a year on, in 2006 I met someone who accepted my stoma without question and was incredibly supportive throughout my 6 stoma years. He saw me through my pouch operation, witnessed a few of my accidents, and luckily understood my sometimes-weird sense of humour (I tend to approach most situations with humour!) After all, I am quite a strong person and I was determined not to let the bag rule my life.

I am quite a strong person and I was determined not to let the bag rule my life, and was fortunate to have a very supportive and caring partner at the time. Despite Simon encouraging me to think about the next step on my path - the internal pouch - I admit to having been apprehensive, as I am also a big believer in 'better the devil you know'. I had adjusted to my stoma and bag so easily; I could hardly imagine having another operation and leaping into the unknown. That, together with the risk of my 'comfy' bag - which had become a bit of a comfort blanket - being taken away was just too much. I had done a lot of background reading on pouch failures, so I decided to wait a while before making the decision. I spoke to many people and read a lot of stories; some good, some bad. My surgeon did remind me that people only tend to write stories about bad experiences, and that each patient is individual.

I had developed a parastomal hernia shortly after my first operation, but by 2010 this had

started to cause pain, so I nervously agreed to bite the bullet and go for the second of three operations and have the ileoanal pouch surgery in August 2011. This operation involved 're-plumbing' my remaining small healthy bowel into the necessary pouch to adjoin it to my back-passage, enabling me to pass poop in the normal way instead of through my tummy.

Whilst nervous and excited at this prospect, it didn't come without its own issues. I was given a temporary ileostomy created from my now-reduced intestines. This caused my new stoma to be inverted and I suffered with many, many leaks and became distressed, thinking I'd made the worst decision ever. Going from a perfectly-functioning stoma to an inverted horror seemed the stuff of nightmares. I was desperately unhappy and pleaded with my surgeon to do the third and final operation as soon as possible. Fortunately, and to my great relief, I was back on the operating table in a little under 3 months to have the bag taken off, stoma removed, and hernia repaired.

It's now been 8 years since my pouch formation, and I can honestly say I've never been healthier and fitter. I take no medication for the remaining few centimetres of diseased bowel I have left. I work full-time as a Sign Language Interpreter, drive over 100 miles a day to my various jobs, attend boot camp regularly, Salsa, and mini-trampolining every week, none of which would ever have been possible before. Simon Radley and his team without a doubt saved my life, and I will always be grateful for the care I received, together with the love and support of my family and friends. I have finally got my life back!