

A bumpy road – but I'm here!

Julia Spanswick

When I was 25, I started having problems with diarrhoea and blood in my stools. I was diagnosed with ulcerative colitis.

For the next 4 years I struggled with the disease. I was on and off of steroids and other medicines, and had periods of time in hospital to rest the bowel. During each hospital stay, there was discussions about the removal of my bowel, but because I was so young, they wanted to avoid it. Eventually, I was spending more and more time in hospital, I was getting weaker and going to the toilet on average 30 times a day and losing lots of blood during each motion. One occasion, I collapsed at home and did not have the strength to get myself up off from the bathroom floor.

When I was 29, my health had really deteriorated, I had a TPN line fitted and I was told that my colon had to be removed to save my life. I was devastated that I was going to have a bag. I told my soon-to-be husband that I would totally understand if he didn't want to stay with me, as I felt I would look like a freak. Looking back on it all, it seems crazy that I felt that way, but it was how I felt. But on the



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flip side, I knew I was losing my battle, as I was attached to machines in hospital, my hair was falling out and I didn't want to die. My fiancé, was totally supportive and said he didn't care about the stoma and he just wanted me to live, so that he could marry me nine months later (our wedding was booked). So it was agreed that the operation had to happen, and quickly. I was given blood transfusions and vitamin injections to try and build me up for surgery. I was marked up for a stoma, and down I went.

When I came round after surgery, it was my fiancé who saw my stoma first, as I wasn't interested in looking at it. My reaction was "I don't want it, so I don't want to look at" and when I was told I should name it! Well, you can only imagine what I wanted to name it! In time, obviously, I had to look at my stoma and I was amazed at how this thing moved on its own. But in the following days, I eventually got my head around it and was grateful for it, as it had saved my life, and I knew that without it, I wouldn't have made it. So for my wedding nine months later, my hair had started to grow back, and I had named my stoma Ruby, I was full of life and loving life. On our honeymoon, I was parascending off the back of a speed boat in Mauritius in a bikini (with a swim skirt) living life to the full and I loved having control, which I hadn't had for a very long time.

I ate everything and made sure I chewed my food well (I had one blockage with apple peel once, where I pulled the peel out of the stoma... that was a bit freaky!).

I still had my rectum, which had UC, so I had to use suppositories to keep it calm, as well as seeing to my stoma. My surgeon, Mr Ward said he would like to perform J-Pouch surgery on me. My initial thought was, why should I go through surgery again and risk having to sit on the loo all the time, when for the first time in years, I

was in control. My family thought I was mad not to consider getting rid of the bag, but it was my decision. With my husband, we came to the conclusion that we had nothing to lose and if the J-Pouch surgery didn't work, I would know what life was like with a stoma and I was now well and strong and able to recover a lot quicker from surgery.

So one year after I had had my colon removed, Mr Ward created a J-Pouch and I was given a loop stoma to rest the J-Pouch before reconnection. My loop stoma was a nightmare and I had terrible burns around the stoma site, as it was a lot closer to my skin. I had one day standing in the shower without a bag letting warm water fall onto my stoma for relief, as I couldn't get a bag on. My lovely stoma nurse, Sue, sorted out a cone bag for me and this helped massively, but after 3 months with the loop stoma, I was pleased to see the back of it and had surgery to close the loop stoma.

To begin with, I kept on going to the toilet. My nightmares of UC came back to haunt me, and my bottom was so sore, as it wasn't used to being wiped, so Sudocrem became my friend! I came to the conclusion that I was going to control this J-Pouch rather than 'it' controlling me. So every time I had the urge to go, I held on and worked on my pelvic/sphincter muscles. And it worked. I go to the toilet on average 2 or 3 times

a day. I very rarely get up in the night to go to the toilet and I don't have any leaks. I built my fitness gradually at first and then attended exercise classes, pilates and did power walking.

My ambition in life to was to become a mother and we were unsure as to how it would go, so with Mr Ward's approval, we started trying for a baby, and eight months after surgery, I fell pregnant. I felt so healthy, when I was pregnant. I had a great pregnancy and my obstetrician kept a very close eye on me, as he was aware of my set up, and its potential complications. It was decided that I was not to have a natural birth and that I would have a C-Section.

This was to avoid any problems with the J-Pouch and also not to damage my sphincter muscles, as this could have led to leakage or incontinence. Towards the end of my pregnancy I did have a bit of difficulty draining the J-Pouch, so I had my C-Section performed at 38 weeks with Mr Ward in theatre so he could have a look at everything to make sure everything looked ok. He was delighted to be asked to attend the birth, as he said it made a nice change from looking up bottoms! Our daughter Isabella was born in the November and we had our son Harry two and a half years later at 38 weeks, again by C-Section. This pregnancy again was problem free.



Julia (left) with her daughter

My J-Pouch has been terrific and I have great control. I have had to have my tail end stretched twice, as it became narrowed, so I now use a rectal dilator twice a week to stop any future narrowing. Five years ago, I had elective surgery to free all the adhesions following some admissions into hospital due to blockages. Unfortunately, I have had two further blockages following this operation, one resulting in emergency surgery, where the surgical team warned me that I could end up with a stoma once again. After the surgery, I remember reaching down to check and felt relieved when there was no stoma. Before the last blockage, I was able to eat anything and just remembered to chew very well, but unfortunately due to my adhesions, I have been advised to stay on a

low fibre and low residue diet. It has been three and a half years since my last blockage (shhh!) So I'm a burger and chips girl and no salads for me. But hey, if it works for my body, then I'm happy with that.

I am fit and really well. I have just had a routine health check, which showed that I am in great health, cholesterol levels and full blood count were perfect. You should have seen the nurse's face, when I told her I haven't got a colon, her eyes nearly popped out of her head! I have now added 'Bounce' to my exercise regime and love it. Considering the bouncing up and down on a mini trampoline, I have no leaks and my J-Pouch copes just fine. Pilates is a massive help to me too, to keep my core and mind strong.

Of course I wish that this hadn't happened to me, but it has and it has made me a stronger person. I am so grateful to my fantastic surgeon, Mr Ward (my angel), all the nurses, who have cared for me. Without them all, I wouldn't be here, enjoying being a wife and a mother and to be able to live my life to the full. My J-Pouch has been so successful, because I built my health back up and remained healthy, active, and maintained a positive attitude.

Once I got my head around it all, I knew that it would be OK and I was determined that my life and



Julia exercising

health would go on from strength to strength. IA supported me by sending me a visitor during my darkest time and now I am a visitor for IA, giving something back. I also give my patient perspective talk to professionals, so that they have a better understanding, and can then offer the support of IA to their patients. I am so passionate about IA, that I have now taken a year out of work, to volunteer full time to spread the good word of IA and to build good relationships with our local hospitals and doctor surgeries. I hope that this will make sure that everyone who leaves hospital following surgery to remove their colon, will have the knowledge of IA's support.