

'X marked the spot' and I was off to surgery...

Lisa shares her experiences of colostomy reversal and bowel resection



Lisa Tubbs - getting back on track

At twenty-six I didn't know what a colostomy was! I didn't even realise young people had colostomies as I associated them with older people. I quickly found out I was wrong...

I have suffered from severe Endometriosis for years and was having yet another Laparoscopy to laser off the adhesions attached around my ovaries, bowel, rectum, kidneys and other infected areas. Endometriosis is a condition in women where cells that usually line the womb are found elsewhere in the body, these cells behave in the same way as those that line the womb, so every month they grow during the menstrual cycle and then shed blood. This internal bleeding, unlike a period, has no way of leaving the body and leads to inflammation, pain, and the formation of scar tissue (adhesions). There is no cure and the only way these adhesions can be removed is by laser.

A week after my routine operation all was not well and I was rushed in for an emergency colostomy because a fistula had formed. The doctors formed a temporary stoma to allow time for my bowel to heal on its own as they wanted to prevent having to perform a bowel resection. Although I was informed before the Laparoscopy that there might be a 2% chance I could end up with a colostomy bag (because there was so much endometriosis around my bowel and rectum) ever the optimist and being squeamish I didn't research into it.

Not knowing was probably better in hindsight. Even before the emergency operation I refused to look at any pictures of people with colostomy bags or read about how they worked as I knew I would find it easier to cope looking at it on my own body. They marked my tummy with an 'X marks the spot' and I was off to surgery.

I came round still in denial and not wanting to look under the covers. The nurses were amazing and very supportive which helped me get over the fear. I really felt their empathy which made me feel better and not ridiculous for overreacting. With the best support from my friends and family, I started to deal with it. It was scary to say the least, but you quickly adapt to things thrown your way and realise you can't always prevent things happening to you.

Crying every time I passed wind in front of people was a regular occurrence during the early days. The lack of control was very embarrassing especially being female and very prudish about flatulence. After years of being discrete and private, it was out there for all to hear!

But as time went on, surprisingly I grew quite attached to my stoma. Knowing that it was going to be temporary definitely made it easier to deal with. I wouldn't have been so strong if it was a permanent stoma.

It's very hard for anyone at any age but initially I definitely found it difficult to cope with being young, single and having an active social life. I got braver as time went on and started going out again. I quickly learnt the hard way that drinking too much had a bad reaction in the morning but I adapted by trying other drinks with less fizz.

Buying a new wardrobe to hide the bag was my treat to myself as it helped with my confidence and body image. No one ever guessed I had a colostomy bag as they are quite discreet and by adapting my clothing and wearing magic pants I helped hide it and hold it in.

After six months I had a barium enema to see if the fistula had healed on its own. I was very anxious before the examination because everything hung on the results. If it had healed on its own I would have a simple reconnection of my bowel and the colostomy removed. Unfortunately it hadn't, so I went in for a reversal operation of the colostomy bag and the removal of a large part of my bowel and rectum.

Having a bowel resection is a major operation and recovery is longer but emotionally it is easier to deal with. Coming round from the operation I was in such a daze as it was a lengthy operation. I was very weak and it took me a lot longer to regain my energy and bounce back from it. I was in hospital for a week after the operation as you have to be able to have a bowel movement to confirm that the operation has been successful. (I had a small colectomy at the end of the colon where it joins the rectum (part of the sigmoid colon). That first bowel movement was a massive relief and the entire four bed ward celebrated!

During the first few months you can experience going to the toilet up to fifteen times a day, sometimes with urgency and soreness. Unfortunately the frequency is very different to what you may have previously experienced and after about two years it evens out and your body settles down to what now feels normal. You spend a lot of time in the bathroom so taking up Sudoku or reading passes the time!

Initially after the reversal I missed my colostomy bag as I had become comfortable with using it and I was scared about going to the toilet in the normal way again. Because half of my rectum was removed it got confused, my brain had to re-educate the rectum when I needed go to the toilet because it wasn't compacting the stools. There is a continual sensation of urgency which you have to train your mind to ignore. It took time, and it never goes back completely to how it was before the operations but it's manageable. Going five or six times a day seems normal now.

From keeping my colostomy a tight secret whilst I had the bag I was more open about discussing it afterwards as I was proud of what I had gone through and felt stronger for it. Those that were aware of the bag whilst I had it were understanding and in many cases quite curious and wanted to know more out of genuine interest.

I work in a Design Agency in London and have done the whole way through my journey. Now, a year and a half on I am ready to start getting on with my career as it was on hold for quite some time as you have to put your health first and make yourself feel good.

There were many funny, embarrassing and cringing moments throughout the six months when I had my colostomy bag but you have to try to see the funny side of these things and laugh!

Lisa attended the recent Induction Days and is now a volunteer for CA...