

# Journey to getting an ostomy and back

*I know there are many out there for whom an ostomy bag is only a temporary stop of the journey. That's why I'm so glad Lindsey is willing to share her story about living with an ostomy bag and now having her colon reconnected.*

## **Lindsey's story**

I will never forget the day that my doctor looked at me and said, "Lindsey, I think it is time that you consider getting a colostomy bag". At the time, I had been diagnosed with Crohn's Disease for 13 years. Sure I had flares, it comes with the territory. But never had I flared this badly. After trying a last-ditch effort with more steroids and other medications, I was sent to a consultation appointment with an Ostomy nurse. That day was a game changer for me. I saw my first stoma and it began to set in with my "practice bag" that part of my insides would soon be on the outside of me. My mental health was spiraling downward with my physical health.

I was literally devastated at the scheduling of surgery and I had no idea how to process what was going to happen to me. I was not involved with any support groups and didn't know a soul with any sort of diversion bag. Feeling very much alone, coming to the decision to get my ostomy bag was one of the biggest battles with myself to date. I had full support from my husband, family and friends but I just couldn't shake the thought, "Who would ever elect to poop out of their belly?" I felt that no matter what my decision was – bag or no bag – I would have always wondered what would have been if I had chosen the other choice.

But for me, I eventually got the other choice. On February 9<sup>th</sup> of this year, I had my ostomy bag reversed. What was the one thing that I was most excited about you ask? Well, farting of course! I actually asked my doctor after surgery when I will be able to trust a fart again. He laughed and reassured me that in time, it will come. In a way, I underestimated the reversal surgery. My rectum was very malnourished from not using it for almost two years. Some of the symptoms that I experienced were rectal spasms, urgency, multiple trips to the bathroom, anxiety over leaving the house and pain at my incision sites.

By the time I had my reversal surgery, I had three major abdominal surgeries under

my belt with not a single complication. This time was different. One of my incisions became infected and it resulted in a trip to the trusty ER. They had to re-open parts of the incision site which resulted in two open wounds. Both open wounds needed to be packed with gauze twice a day. It by far was not my favorite thing in the world, but slow and steady wins the race. Although we were seeing progress with the infection and healing of the surgical sites, I continued to lose a lot of blood and my persistent symptoms didn't let up.

Confused as to whether to get my GI back in the game... or stick with my surgeon's advice, that all of these symptoms were normal... I went with my gut. All it took was one phone call to my favorite nurse and an honest conversation about what I was experiencing. My doctor at the University of Michigan got me a record-breaking colonoscopy date within a week. Sadly, he found ulcers and a narrowing in the intestine, and also discovered that the last 25 cm of my rectum/colon are severely inflamed with active Crohn's. I began to go all the way back through the grieving process. This reversal surgery was supposed to be a good thing and we were all convinced that I was healthy enough to go through with this. No one could have ever predicted what cards were dealt next. Now my Crohn's is back full force and I am trying to navigate my way through this winding journey. I don't know what the future holds for me or my bowels but I do know that if one day I end up with my colostomy bag back, it won't be nearly as hard as the first time. In fact, I might actually welcome that trusty bag!

Looking back on my nearly two years with my ostomy, I wouldn't have changed it. Although it was a literally a life changer, I was able to meet some of the best people who are currently in my life. Having my ostomy opened doors and allowed me to grow as a person in ways that I would have never dreamed of. My desire to help others, especially those with IBD is so strong that I can feel it in my bones. My husband and I started a Facebook page to help patients and their caregivers who deal with IBD. We believe that education is power and that this silent disease deserves a voice!

Always know that no matter what hand life deals you, you will come out the other end stronger and wiser for have lived through it. I look forward to seeing where life takes me next!