Cancer Health™

So, Do You Still...Fart?

May 29, 2018 By Lindsay Norris

Living life with an ostomy has definitely been an adjustment, but when I look back on the last year and a half with this little bag — I've learned there's nothing it can stop me from doing. Since the moment I knew I would be... uhh... re-routed so to speak, I've gotten lots of questions about how this all works.

How do they perform the surgery? I had a robotic Abdominoperineal Resection (APR), in which the distal colon (sigmoid), rectum and anus are surgically removed with laparoscopic abdominal incisions and one large perineal incision. So in English — they removed everything from where the colon turns to go downward and below by using a super cool robot and left me closed like a Barbie from behind.

What is a stoma? The stoma is the small opening in my abdomen which is the new end of my large intestines. My ostomy bag gets fastened around it and I'm good to go! I thought about adding a photo — but decided against it. Since cancer, my oversharing radar is way off so didn't know if it would creep you out or not

Can you control when you go? Sure can't. Sometimes I can't even tell I've gone. It's not all that inconvenient though — typically your same "schedule" remains after surgery (come on, you had to have known what you were getting into reading this post).

How do you change the bag? Every 3-5 days or so I remove my ostomy bag and replace it with a new one. There's special strong adhesive around the bag that locks it on air tight. There are about a million different types of ostomy bags and supplies... one piece or two, closed or open, clamp sealed or velcro, clear or opaque — the list goes on and on. It just took a fair amount of experimenting with samples to find what worked the best for me. (one piece closed mini bag by Hollister, in case you're dying to know)

Does it smell or leak? Generally no, not at all. I have heard of some others having trouble with leaking and odor due to skin breakdown and not getting a good seal — but those cases are rare. In the year and a half I've had the ostomy — I've had one tiny leak. I simply went to the bathroom and changed to my backup bag I always have on hand. No biggie!

Can you do all the same activities you previously could? Of course! I can shower, swim, workout, and wear whatever I want. Sometimes I'll wear a supportive waistband for comfort if I'm going to be active or want to wear something slimmer fitting — but really I have no restrictions.

How do you travel? If I'm flying I just make sure I have a few supplies in my carry on if needed, but there are no problems or restrictions with flying or traveling. An ostomy does, however, sign you up for the ole automatic TSA pat down. It's no big deal — I just explain what I have, they have me pat it down myself, and they wipe my hands with their special solution, and on I go.

Can they still do a colonoscopy? Yes, I still need to keep up with my cancer screening exams — right now I get them yearly. They simply go through my stoma instead of the back end (remember: Barbie). The prep is actually easier with the bag, and no legs falling asleep while sitting on the toilet all night.

Are all ostomies the same? No, there are ileostomies, where the opening comes from the small intestines like for patients that have their entire colon removed or for those who will be able to reverse the osotomy at a later time. And there are colostomies — like mine, that come from the large intestines. The reason I'm not able to have mine reversed is because my tumor was too low. Not enough room between tumor and muscle to save for reattachment.

What's the worst part about having an ostomy? Honestly, the worst thing I can think of is sometimes in the summer or if it's a "change day" it can get itchy. That's it.

I had surgery about 6 weeks after radiation was complete. And to be honest with you, after all the times I had pooped my pants at this point, I was so ready to have an ostomy. The radiation targeted the tumor of course, but I had a lot of muscle damage in the area leaving it difficult to have control. Combine that with the burning diarrhea side effects from oral chemo, and yeah — not fun. I practically skipped into surgery.

The surgery itself went very well. I was first case of the day so it was a super early morning arrival. I was feeling a little weak and dehydrated from the bowel prep the night before but I was ready and in good spirits. I had been counting down to this day since the moment I found out I had cancer and I was anxious to be cancer free. There's always a lot of waiting to do in the pre op area, so it was filled with nervous small talk and phone games. I think Camden and I tagged each other in every single funny internet meme we could find. All the surgeons, anesthesiologists, and nurses had come in to do their final checks and eventually I found myself being carted off with some sleepy medication pushed in my IV and a "see ya later" kiss from my husband — I don't think anything can prepare you for that moment (I knew he was going to have such a long day of waiting and I hated that). I remember the ride down the hallway, me testing my slipping consciousness by the moment. I remember realizing we were in the OR room and being filled with emotion as I heard my song playing (see: blog title). I drifted off to sleep to the sound of the lyrics that had given me hope from the start — a beautiful gift from my friend, Rebecca. Surgery lasted about 6 1/2 hours. I remember my surgeon coming into talk with me when I was in post op, I could tell he was pleased with the outcome. He told me he was confident they were able to remove it all and there were no surprises along the way (having cancer makes you dislike surprises). Between that news and the ice chips I was finally allowed to have — I was a happy camper. I gave my new accessory a quick peek under the blanket, surprisingly wasn't too freaked out at the site (thanks anesthesia), and went back to sleep.

The next 6 days in the hospital went better than expected. My pain was tolerable and I was able to get up and around pretty quickly — by the third day, I could've walked the halls of that unit with my eyes closed. I was even called "the fastest recovering APR they'd ever seen" by one of the surgery residents (he quickly became my favorite resident). The hospital stay overall was uneventful and soon I was resting and recovering in my own bed with a few of the cutest little nurses on duty. A Saturday call from my surgeon confirmed it — all the margins around the tumor on the pathology report were clear (ie. he got it all) and out of the 12 lymph nodes that were removed around the tumor… ZERO had cancer. He also mentioned that the report called my tumor low grade, so maybe not as fast growing as we had originally thought. All in all, about the best report we could have hoped for (other than what we call a pathologic complete response where no cancer cells are found within the area of tumor at all — wishful thinking, huh). I was off work about 7 weeks — I built my way back up to normal diet and exercise, got used to my new ostomy, watched the entire Parenthood series (highly recommended), and was able to recharge and get ready for the next battle in this war. IV chemo.

Mentally preparing myself for life with an ostomy was a challenge but doable. I was thankful my surgeon had laid it all out there right from the start that mine would have to be permanent. I had plenty of time to wrap my head around it. Also, being an oncology nurse — I've obviously taken care of many patients with ostomies, so it wasn't too foreign to me. The pep talk I had given myself before my first bag change was something close to what you tell yourself when you're going to have a new baby… at some point, without meaning to, you're probably going to touch poop… with your bare hands… and it's not that big of a deal. You just do what ya gotta do.

Having an ostomy is simply normal for me now — but that doesn't mean I haven't had a small pity party or two along the way. Every once in a while, something will happen that just reminds me that I'm different. If you don't mind that I jump up on a little soap box for a moment — I'd like to give a friendly reminder that not all "disabilities" are visible. No, I don't necessarily consider my ostomy a disability — but sometimes it requires us to use extra supplies, need a little more space, or have a toilet and a sink together in the same room… so yes, I've sometimes used the family/ handicap single restrooms before if needed. Once was at a Royals game (actually it was my first public outing after surgery) and I got some big mean glares as I came out of the family/ handicap restroom from a mom who was waiting with a few kids. And I get it! A few years ago I if I were waiting for a long time outside a family restroom with my busy toddler and new baby just to see a single (visibly healthy) person walk out — I might've given a similar look. I felt terrible, and didn't have the courage to explain myself — so I just darted off. There are plenty of invisible GI disorders that may require a solo potty — so just give that person the benefit of the doubt if you see it.

It's been an adventure with mixed emotions, but most importantly — I know what this little lifesaving bag represents. A new start, and a chance at a cancer free life. And yes, if you must know — I DO still fart.

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