

My Journey to Becoming an Ostomate

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My first memory isn't faking sleep so that my parents would carry me to my bed. It's not playing with dolls or even the birth of my baby sister. My first memory is clutching my stomach and writhing in a pain that felt unknown and scary to me. It's telling myself not to tell my mother, because it felt like it had to be a secret. Something I shouldn't bother her with.

Right now, I'm a 26-year-old woman with what you may know as a "poo bag". You might know it as something elderly people have to deal with. Something you might have heard vague details about, or it might be something you never knew existed.

My large intestine sits on the outside of my body, and I shit into a bag. Sounds pleasant right?

The truth is, this "poo bag" is something I had tried to run away from since I was 12 years old. Worst case scenario, the end of my life as I knew it.

Let's rewind a little. That scary pain I mentioned earlier, was the beginning of the end of the normal life I thought I'd have. When you're a child, you think you'll finish school someday, party, go to university, fall in love, get your heart broken, finish your dream degree, get your dream job, find your soul mate and have the perfect wedding. Maybe have a couple of children and grow old. You never think of all the shit that goes wrong in between those things.

I'll spare you the dramatics, my situation has not taken away all of those things. Only some. I kept my pain a secret for too long, something I wish I hadn't done. When I could no longer hide it, and I looked malnourished and severely sick, my parents caught on.

Eventually, I was diagnosed with severe Crohn's disease. Everyone loves to say that Crohn's is "incurable, but treatable". And that is true, but it changes you as a person and sits on your shoulder for the rest of your life. Sometimes, you'll have days or months where you forget it's there. If you're lucky, years! Sometimes it's too loud, and all you want to do is scream in its face and ask it to spare you some mercy.

The first time I almost surrendered and let my disease have its way with me was when I was 14, in the middle of a 3-week hospital stint and given 2 options.

Option number one: have surgery to create a stoma: aka the poo bag I mentioned earlier. First thought, not happening. I'm 14, I haven't even started living yet, how would ending my life as I knew it benefit me? "You can put a cap over the stoma, so you'll still be able to wear a bikini and be a normal teenage girl" my surgeon at the time said. A cap? Fuck no.

Option number two: try a drug that hasn't been tried on someone with the same level and area of my disease. It's experimental and comes with a catch, it's been known to potentially cause cancer.

Fuck me, I'm 14.

The choice was not mine, but I was beyond grateful to find out my father chose the new medication route. No shit bag! Dodged that bullet.

That medication put me into remission. I was free from this nightmare. Or so I thought.

I was in clinical remission, why am I still shitting my pants at the age of 16?

Turns out, I had a prolapsed bowel. The option of a stoma was again presented to me. No thanks, I'd rather my bowels fall out of my rectum and have to push them back in myself than shit into a bag.

I continued to suffer in silence, I even think I put on such a good performance that I believed it myself. I don't need a shit bag, that's for elderly people. No one would date me if I had one.

I went a decade living my life in half. I was functional to a degree. I would leak blood and mucous, shit myself after 5 seconds of warning that I needed a bathroom, yes. But I didn't look sick.

It wasn't until I started to shit myself in my own home that I realised I couldn't do it anymore. That's a lie, the 2 or 3 people I trusted with knowing the true details of my situation urged me to consider my options. THEY knew I couldn't do it anymore.

The ironic part was, I had met friends along the way that had stoma bags. And I admired them, advocated for them, and supported them. They were brave. Some of them made the decision themselves, and some of them woke up from emergency surgery, their stoma bag saving their life.

But having one myself? No fucking way. I wasn't strong enough. Nope, I needed a second opinion.

The day of the appointment came, and I was confident my new surgeon would agree with me. I'm too young, my quality of life isn't that bad. I have other options. I will not be bullied into getting a stoma bag just because my surgeon thinks he's God and wants the first chance he can get to cut me open.

My new surgeon said that he was sorry, but he agreed with my primary surgeon. "You'll know when you need one, you will be begging your doctor for one. Give him a call when you're ready"

I thought, okay, well I'm definitely not begging for one, so it's not time yet. "Isabella, you shit your pants at work, at home in the kitchen, at social gatherings, in your car, and leaving the house is not an option anymore" the rational side of my brain said. Doesn't matter, I'm not begging so it's not happening.

"I'm going back to work on Monday." I told my boyfriend. I hadn't had an accident in 2 weeks, I was ready. The morning of, I washed my hands after my third "just to be safe" poo and got into the car. My boyfriend drove. I had made the 25-minute trip without shitting myself, we pulled up a block outside of my building. I did it. It was going to be a good day.

I felt a rush of anxiety mixed with excitedness.

Fuck.

Fuck fuck fuck.

I failed to mention before, having a prolapsed bowel wasn't as simple as shitting myself just when nature called. It happened when I experienced any strong emotion. Joy, anger, sadness, excitement, anxiety. The list goes on.

I was shitting my pants. In the car. My shift started in 3 minutes. I screamed and cried. I couldn't walk into work. I was not better. I was covered in poo.

"Bel, I think it's time"

I knew what that sentence meant.

I sat in the back seat, tears streaming down my face, shaking. I called my boss and told her I couldn't come in. I can't remember if I made up an excuse or told her the truth. Either way, she was understanding.

"I'm sorry, I'm so sorry" I kept telling my boyfriend. He didn't deserve an incontinent 25-year-old girlfriend.

I thought about what he said. "Bel, I think it's time." I called my mum and told her what happened, she said the exact same thing.

Usually when I heard that sentence, or anything remotely similar, I'd nod along and think "yeah fucking right".

This time was the same, for about 10 minutes.

Crohn's disease and its complications were once again sitting on my shoulder, screaming in my face. This time I couldn't ignore it. I don't know why, considering shitting myself, crying, calling in sick and apologising to my loved ones was a common song and dance for me.

Something in me, I don't know what it was, if it were my own thoughts, an angel, or if I had just finally come to my fucking senses, said "what if you just had the surgery and dealt with it?"

Huh? Interesting.

I said that out loud, to my boyfriend. He went on a tangent about how I was strong enough, that I couldn't live like this anymore, that we could do it together. What he was saying turned into white noise as I began to actually seriously think about my options for the first time.

All the other times in my life that I "considered" having surgery to give myself a stoma were just a song and dance to appease everyone around me. This was the first time I was seriously considering it, for me. For my quality of life. A real option.

When we got home, I showered and freshened up and sat on the couch. I was in pain just like I always was after this happened to me. Emotionally and physically. The sun was golden and beaming in from the window. It lit up my whole apartment and I felt a weight come off my shoulders.

"What if I just did it? Have the surgery?"

I booked an appointment with my surgeon.

It wasn't that easy though. I constantly went back and forth between "What if I just fucking did it" and "yeah fucking right!"

I decided then and there, I need to document this process from start to finish. I needed to post the journey online, so people would know my reality and I couldn't run away. And maybe, I'd help someone else like me along the way.

My only option left was that dreaded shit bag. I was scared shitless. I did what I said I would do, and filmed my first appointment with my surgeon to actually book the surgery in. To make a date. That was a huge step.

I lied to my surgeon, and myself, and said I wanted to wait 5, maybe 6 months. I had a concert coming up that I did not want to risk missing. The concert part was true, but really, I was just procrastinating. Half of me, fuck, even more than half wanted to give myself time to cancel.

I posted the TikTok, and a few more explaining my situation. If worse came to worst, I'd deactivate my account the day I cancelled the surgery and act like it never happened. I'd continue living my life, shitting myself along the way. Who cares?

I don't know how, but I was brave enough to talk about shitting myself online. This felt like the only way to keep myself accountable and go through with this harrowing decision that I had made.

As time went on, people started actually watching my videos. I felt like half of me was lying. Every day was the same "I can do this, no I can't" song and dance. I had a date for the surgery, but it felt like that day wasn't actually going to come.

My surgery was booked for May 5th. In February I called to bring the date forward as I once again, shat in the back of my car on the way to IKEA. My new surgery date was April 21st.

March approached fast, and suddenly I realised my fate was coming closer and closer. Next month. Four weeks. Fuck sake.

At the end of March my videos went semi viral and I gained a lot of followers. 10 thousand to be exact. There was no backing out, I was actually doing this. People were watching the journey.

The month leading up to surgery were the darkest days of my life. Fear in its purest form. I knew the surgery was major on the body. I was no stranger to hospitals, general anaesthetics, and everything in between, but this was my first major surgery. And it had a long recovery time. I knew that.

I never slept, I was angry at everyone around me, I was having serious heart palpitations and I was scared beyond anything else.

When I said I was angry at everyone around me, I genuinely was. It sounds so selfish, and I'm ashamed to admit it. When anyone who complained about work, their love life or anything else to me, I would sit there and think "fuck you, try knowing you're about to live the rest of your life with a poo bag." I know that is selfish, I've chalked it down to one of the stages of grief. I had been in denial for a decade, now came anger.

I even had people tell me I was lucky that my boyfriend stuck around for this, that he could have easily left. I'm the lucky one? I thought.

The concert I mentioned earlier came and went. I named the event “my funeral”. My last outing before my new harrowing chapter began. Morbid, right?

I shat myself in the mosh pit.

I had between 10 and 7 days until surgery, I can't remember. When I was alone, I'd scream bloody murder and consider running away. Where to? Don't know. I was NOT in my right mind.

My online videos kept me strong, distracted and my followers gave me comfort. It wasn't all dark, there was some light too. I was actually going to do this, and I hadn't cancelled the surgery.

The day before, my mum was on her way. A four-hour trip. The phone calls started coming in from family members and close friends, wishing me luck. I could not even speak words on that day. I felt paralysed by fear.

I'm not sure many people understand fear in its purest form. I know some do, and I'm one of them. I'm not God, I'm not someone who has had THE hardest life imaginable, and I know many people have had it worse than what I'm describing here. But for me, fear in its purest form was not being able to think beyond every single second that came and went. Those last days before surgery were some of the darkest, I know.

“You'll look back on this and be so thankful you did it”

“You are strong”

“You will be fine”

Those were some of the things people told me in those phone calls. I could not even respond if I tried. My voice did not work.

I didn't sleep a wink that night, which isn't surprising. I woke up and can only remember dry reaching on the trip to the hospital.

I thought of an escape plan, dry reached again, thought of jumping out of the moving car, dry reached again.

We pulled into the hospital drop off, and of course, when any big emotion washes over me, I fucking shat myself. It's like the angels said “you fucking need this surgery, and you're going to fucking do it.”

Very funny guys.

The nurses cleaned me up, and I was numb to everything at that stage.

My new “stoma nurse” came in to mark me up for surgery, which means marking my belly with a marker, so the surgeon knows where the stoma needs to be. This was important because the right spot matters when you have a stoma. I couldn't care less where it was going to be, I was just trying to stay alive.

“It’s time to go” my nurse said, and I was about to be wheeled off. I said bye to my mum and boyfriend and cried my eyes out. We started the trip down the hall to theatre and I heard them both fall apart behind me. I had not realised they were trying to keep strong for my sake.

You might think this is the part of my story where it gets to the peak of its dramatics, but for me it’s when things start to get better.

I didn't expect this, but everything from this point onwards, for the day at least, lifted. My nurses held my hand, my surgeon made jokes and laughed when I told him I was naming my stoma “Stomas The Stank Engine”.

I woke up from surgery comfortable and at peace. It was nothing like I had spent months preparing myself for. I chose not to look at my stoma. I was wheeled back to my room with my boyfriend and my mum waiting for me. I actually felt good. What the fuck?

I was drugged, obviously, but it was the first moment of bliss I had felt in a long time.

Slowly, I started realising it was nowhere near as hard as I thought it was going to be. It was extremely hard, do not get me wrong. But my life was not over. My heart kept beating and I felt hope for my future and my quality of life.

There were obviously bumps in the road and learning to live with a stoma is not an easy thing to do. But as I lay in my bed, writing this, funnily enough recovering from my second ostomy surgery...I want people to know that the things you believe you aren't strong enough to deal with are the things that can sometimes save your life.

I still have to remind myself of this on hard days.

Stoma stereotypes suck, and I have to live in a world where the one thing that gave me my life back, is viewed as ‘disgusting’ and sometimes even a death sentence. I thought those things myself in the

past. Some days that really gets to me, but I am committed to spreading awareness now. Life doesn't have to stop when it takes a turn you never saw coming.

People keep their stoma a secret, because of these stigmas. And I hate that. People use a fake name on public ostomy forums, and for what? I can't imagine having to hold this all in, and why should I have to?

I shit out of a hole in my stomach, so what? To stay alive, every single person on the planet has to shit. I do it a different way. And it has its advantages too. No toilet breaks, no accidents.

And let's face it, my butt is always clean.

I changed as a person on the 21st of April 2023, in the best way. Do I sometimes mourn the life that my illness stole from me? Absolutely. Do I wish some days my body looked different? Absolutely. But I can't change these things, and I will no longer let my situation eat me alive.