

# Stephanie

*This has given me my life back.*

My name is Stephanie. I'm a patient with an ostomy. I have a unique story because I've had an ostomy twice. I was originally diagnosed in 2000. I was just finishing high school and it was a very sudden onset. Luckily I had a clear diagnosis. Every medication they could throw at me kept things at bay for maybe six months and then my flare was getting stronger and stronger and nothing was helping. At that point my diagnosis was ulcerative colitis and they decided to do a J-pouch. That was a 3-step process and it required a surgery, one, to have my colon removed and then the next one was to have the J-pouch formed and the third one was to have the ostomy reversed.

For a period of about 11 months, I had an ostomy. That was my freshman year of college. That was a very challenging time as I didn't know much about IBD or ostomies. It was just everything was brand new as well as being a college student trying to learn how to manage all this while I'm away from home. I'm not near my doctors that I'm around that have treated me. That was pretty challenging but I did have a great system there, as well the Student Disability nurses, and I had a good roommate. There were things that made it easier but it was still very challenging.

For that surgery when they decided they needed to do the J-pouch surgery, my quality of life was so poor that it was a pretty easy decision for me to make. Everything, getting shots weekly, getting IV Remicade infusions, getting whatever, other pills ... I think I was on 30 pills a day. I had this giant pill box and I'm trying to take it all throughout the day in between classes. At that point I said, "Give me the ostomy. Let's do this because I need to ... I want to be able to function in college." That year I had it and then after those 11 months they reversed it and said, "You're cured, you're done." In my mind mentally I finished the IBD thing. I don't know what that crazy illness was but it just hit me over those 2 years, now I'm done.

That was the case for about 5 years I think. Then I got used to having an internal J-pouch and was thankful I didn't have the ostomy. Still learning what foods bothered me, I still had some limitations but overall I was functioning pretty well. I was able to graduate from college and move back to Chicago and start teaching Special Ed in the Chicago Public Schools. It's a stressful job but I was still able to manage it and go to the bathroom when I wanted to and control things.

Then it happened, I started having some symptoms which I thought were just gynecological symptoms. It ended up being a fistula. I never heard of that term until then, until finally after about two years of it being misdiagnosed by different doctors when they figured out that's what it was, it was kind of a tipoff to learn that that it is closely associated with Crohn's Disease and that I might actually have had Crohn's this whole time versus ulcerative colitis. For a while they had started me on a drug called Humira. That actually closed the fistula right away and then kept it at bay for about two years. It was my magic drug. I was very happy thinking, "Okay. I'm done with this whole fistula thing but still wrapping my head around the fact that this is a lifelong illness and it's very unpredictable but it seemed to keep things at bay.

Then fast forward a couple of years, the medicine started wearing off at least for myself. I started getting these recurrent abscesses. Again, gynecologically I thought maybe this is ... I went first to my lady doctor. You could call it gynecologist and she said, "Oh, this is an abscess and that could be related to the Crohn's as well." As I learned that the fistula had come back and with vengeance, we had to start doing more aggressive treatment. We bumped up the shot I was giving myself to more frequently. I was starting to get a lot more infections. At this point I was working in a hospital setting.

My quality life was definitely decreasing. The fistula was just very debilitating. It's basically like having an extra really, really tiny hole down there. Even if you have a pad or something, it's really horribly debilitating. Your skin is always very irritated. You're trying all these different lotions and topical things but ultimately there's a hole and they need to fix it. They discussed that an ostomy is an option but there are some smaller surgeries. For me to make that decision I

needed to go through the smaller surgeries and fail them ultimately in order to know I need this ostomy. I knew what an ostomy was and I had one before. I just didn't want to jump for that.

I tried a few of the smaller ones like the flap advancement and the plug. Actually those surgeries were making it worse. I would wake up and it was just getting more and more debilitating. Similar to 10 years before that or 15 years before that, it was pretty clear what I needed. I was ready. Mentally, physically, there's really nothing else they could offer me. We've tried all the medications and it's not working. I needed my quality of life back so I decided to do the loop ileostomy to divert everything. They called it temporary so there's some safety in that word where they could always reverse it, which they still can.

I've had my temporary loop ileostomy since December 2012. It's been a year and a half. I'm definitely not reversing it. I've gotten my life back. I realize not everybody's story is as simple but it has literally changed my career. It has changed my relationships. It has changed things for the better in the fact that I have more independence. I'm able to be active again. That was a huge part of my life that was missing. I can play soccer and be able to exercise and swim and do all those things that I wasn't able to because it was just so painful and irritated all the time And working. I own my own business. I also work at a hospital. I'm not getting all those infections from the medications. I'm off of those, all my meds which is a huge blessing. Then I'm also able to pretty much count on being able to work whereas before it was like, "Well, you're in-patient for a month or you need to try this little surgery. You're out for a week and you're having to lead all of your life around your bowel habits.

This is definitely much more control and there's no urgency. There's no awful things that dictated my life for so many years. I also have been really lucky that I haven't had any diet restriction. It's been this wonderful process of learning to have all the things that I've had to leave – fruits and veggies and salads and nuts and seeds and popcorn. I had my list and all my friends knew my list. Now when they see me eating the last year and a half, they're like "You're not

supposed to have that.” They’ll poke you and say, “Wait, wait, wait, you can’t have that.” I’m like, “No, actually I can. Remember I had a surgery. I have an ostomy.” “Oh yeah.”

It just speaks how long I was restricted and had so many limitations. Now, getting the ostomy it’s been such a freeing thing and it’s definitely the decision I feel very happy about. I heard some people say “I wish I would have done it sooner.” Honestly I think the timing was just how it needed to be. I needed to fail everything in order to know I was ready and to have that peace of mind. I really didn’t want to ever doubt it and think like, “Well, if only I had tried one more second opinion, if only ...” I needed to hear from everyone. All signs point to an ostomy. After I did that and I had a very poor quality of life, I was mentally ready to do it.

Right now, I could do a permanent ostomy but I’m choosing just to leave it temporary. There’s no expiration date I found out so that’s pretty good. I’ll keep the temporary ostomy until they find a cure or until the end of my life, who knows, but right now I don’t have to make any decisions and I can just live my life and not have to deal with all the other things that controlled it for so long.

When I found out what this fistula was and then they realized it was Crohn’s, that was probably my darkest time where mentally I really felt like I was done. My expectations were blown onto the water and now I have to start seeing all these doctors again. I was definitely depressed and just really frustrated at the whole experience. I said goodbye to all my nurses and moved on mentally and physically. I didn’t have to go there anymore.

It was definitely a huge blow and just brought up a lot of anxiety over what does this mean. This is life-long and am I going to get another of this? How did I get this? People get this when they have childbirth or horrible trauma or something. It was just so random, one day waking up it was the war. It took me a while to wrap my head around it. It really helped to meet other people who have dealt with it whether online or through different organizations, learning I’m not alone. There are treatments for this.

When I decided to get the ostomy it also really helped to know, “Okay, there’s other young people with ostomies. Okay, there are people who are dating and people who can have kids.” I don’t even know if I want to have kids but I needed to know that that was an option. I’m just getting the education around it to help me calm down and just accept it but it’s definitely a gradual thing, even now as I’m dating someone pretty seriously but it’s still new and learning how to talk about it and how to share that with someone. You can do anything when you have it.

Just being able to have my life back and no eating restrictions and activities, being able to do my soccer like I used to, and running and all those fun things, that’s the hugest part that makes it all worth it. I would definitely say it wasn’t a straight shot of adjustments. I go through waves or cycles of like, “Oh, I don’t really like this.” Usually it has something to do with the fact if I get an infection and I have to try different creams around my ostomy. It’s just a frustrating acute episode but then things settled down and I realized, “Wow! I would not trade this for the world. This has given me my life back.” It’s not as cut-and-dry as I wish I could say, “I love it. It’s amazing” but it really does seem that way when you think about the options you’re presented with and your quality of life. This by far has changed my life for the positive. I would definitely recommend doing it, but again everyone is on their own journey. They have to decide on their own timing.