

Abbie

Why me, how come, what for?

We are about to get up close and personal. You are going to get to know me on the inside, literally. I share a lot of similarities. If I could draw a Venn diagram with my fifth grade students, we would definitely have a lot in common. We could do a three circle. We could get really complicated. I teach fifth grade. I enjoy kickboxing, reading, and long walks on the beach. I feel like we've gotten to know each other. I was diagnosed when I was 20, in college. I was doing my student teaching and all of the sudden it's diarrhea and blood and all these stomach pains. I'm like, "Whoa! This student teaching is intense!" You think you have the flu and you think, "Well, maybe it will go away." And it never does.

I saw some doctors locally and, I hope nobody tells them, but they didn't really know what was happening. I was 20. "Little girl has a stomach ache. Try this. Try this. Oh, that's not working? Try this. What about this one?" They whipped me through the medicine so fast I had a half a bottle of everything and nothing was actually working.

I happened to fall upon Dr. Rubin's name where I was student teaching, which was divine intervention, I think. She had Crohn's and she was seeing Dr. Rubin. I was like, "I really don't want to go up there. When you have to go to Chicago, to those doctors, something must really be wrong with me." I was scared and I didn't drive in the city then and I didn't know where I was going.

I got up there. I eventually got bad enough to where I needed to go see him. I saw Dr. Rubin and I guess from that point on life changed. He was like, "Well, yeah. You've been on a lot of medicine, so we have a limited amount to work with because they whipped you through those so fast." We found a combination of things that were working, and he actually had me on a maintenance plan. New idea, right? I didn't have that before. That worked for a while. I'd get sick and then we'd go back and we'd try something else.

But after about ten years, in 2010, I ran out of medicines. Nothing was working anymore. I'm teaching fifth grade. I'm in the bathroom ... you know, you can't leave them. You're not supposed to leave them in there alone, but I've got to go. I was calling teachers to come over and it was happening like three times a day. Then it was happening a couple days later, and now I'm up to six times a day.

Eventually I'm in and out of the bathroom 20 times a day, I'm waking up at night. I can't sleep through the night. I'm not getting any sleep. I'm wasting away to nothing. I was down to like 92 pounds. I was tired. I was just exhausted, and Dr. Rubin's like, "All right. Come in. We'll check it out. We'll go in. We'll take a look." I actually wrote a little something after all three of my surgeries that I'd like to share with you. My official diagnosis is ulcerative colitis, was, was.

It's called "Why Me, How Come, and What For?"

"Abbie, the colonoscopies show that it is your entire colon and rectum, and it is severe. Because the steroids aren't working and you've been through nearly all of the medicines and therapies, I believe it is in your best interest to have the entire colon removed. There is a series of three surgeries." That was the moment I couldn't hear her anymore. This coming from a doctor who I couldn't remember her name because I had just met her. My mind was instantly clouded with, "Where's Dr. Rubin? Does he agree? What does he think? I need to talk to him. I've never had surgery on anything before. How could this be? I thought the pain felt different this time. What about work and my students? Will insurance cover this?"

Similarly to my hospital stay three years prior, I was expecting to refill some fluids, take a look under the hood, have an oil change that would last another three thousand miles. IV fluids, steroids, colonoscopy, and three surgeries? I never expected they would have to junk the entire engine and rebuild a new one. Dr. Rubin uttered this surgery once upon a time ten years previously when I was 21 and meeting him for the first time. He referred to it as, "an absolute last resort" and reassured me that there were some other therapies for my 8 to 10 cm of ulcerative colitis.

Up until that moment with a stranger on January 25, 2010, the word "surgery" had never been mentioned again. Because of the confidence and trust that I had built with Dr. Rubin over these ten years, I believed him when he confirmed, "All the steroids you have been taking aren't touching the inflammation. I'm not convinced we can get you back into remission, and if we do, there's a 25 percent chance that this last medicine will work and no telling for how long."

Then he revealed that the first surgery of removing the colon would cure me. No more bleeding. No more steroids. No more pills. No more enemas. No more suppositories or toxic medicines. No more risky IV treatments every six weeks. No more, literally, gut wrenching, knee buckling pain. Surgery, or surgeries, were my only option.

Over the next nine months there were good days and bad days. Dr. Rubin told me, "You'll have bad days, and that's okay. Just don't get stuck there, between your ears." As usual, he was right. There were days of joy, days of relief, days of frustration, and days of grief, days of anger, days of normalcy, and days of pain-free living.

I won't take you through every meticulous detail, but there were surgeries. There were pains. There were ER visits. During my surgery there were complications. There was some hair loss, believe it or not. There were home IVs, there were bills, and there were tears, but most of all, there were remarkable doctors and nurses, supportive family members, my mother-in-law is here today, loyal friends, and an amazing husband to pull me through.

I'd love to say that I was tremendously tough, astonishingly brave, and extremely positive through it all, but that wouldn't be the whole truth. There were many times I felt weak, scared, and a bit sorry for myself. Right now what I feel is thankful. Thankful for the advances in medicine and thankful that my pain is gone because my disease was curable. I don't know all of the fancy medical terms. They'll handle that, but before this experience, I didn't even know that my appendix was attached to that large colon I had removed. I didn't even know. Whoops! I'm like, "Oh, you took that too? All right." I do know, by the end, all of the king's horses and all of the king's men could put Abbie together again!

It really did take all the doctors and nurses communicating together to make my puzzle complete. Now that the clouds are gone, I can see the good in this adventure. I am cured, and my husband really did mean, "in sickness and in health." I have learned that I can persevere and I'm fortunate. I have to believe that this isn't something that happened to me. This is something that I was chosen for. I can see that sharing my story and supporting others through this life changing process is my "why me, how come, and what for?"

It must be the teacher in me that I had to write it down, what I was thinking and what I was feeling, so that I could tell others, because I didn't have those connections. Because mine was so, "You're in on Monday. Surgery Wednesday." It happened so fast I didn't have time to research. We didn't have smartphones. I couldn't Google in 2010. I'm lying in the hospital bed and I could just ask questions and know what they told me and take it as it comes.

No surgery is a piece of cake, and I didn't have to decide. It was kind of decided for me. "This is where you're at. You're out of options." You have to learn a whole new vocabulary, like "ileostomy," and people are like, "What surgery did you have?" "Ina- ... um ... ileoanoastamosis? They took out the whole colon." There's this pouch in here that they built out of my small intestine, and I can go to the bathroom like everyone else" is the gist of what I can tell people.

Because I was so sick going in, that's what caused a lot of my complications. There was a time when my whole system shut down for 21 days and I was in the hospital for 21 days. I couldn't eat and I was on IVs and TPN. It was complicated, and it wasn't the three step procedure plan. But as life goes everywhere, nothing follows the plan, ever.

I just couldn't heal right. The pouch couldn't heal right. My stoma site never healed right. My hair, a lot, not all of it, but a lot of my hair ... I had significant hair loss. It was just, I was so sick going in. In hindsight, I shouldn't have waited so long. My stoma never worked. I always had a red rubber tube to keep it open, and I did have food blockages. My body didn't like it.

Nine months after surgery I couldn't even climb my own stairs. I was so weak and just malnourished. I think I was down to 86 pounds. My husband had to carry me. I couldn't get my

leg out of the car. He had to help me get out of the car. Yet nine months after my final surgery, I did a mudathlon, which is 40 obstacles in mud and it's a 5K. I was with all my friends from work. All these teachers were running, and it took me a long time and working out to be able to be healthy enough to get there.

People ask me which surgery was the hardest. Definitely the second. The loop ileostomy was tricky, because it's not like an end ileostomy. It's kind of the middle. It was just uglier. It wasn't as cute and pretty as the little end. It was messier. There was two of them. One is closed off and then you have the other one next to it, so the bag was a little trickier. Your track is so much shorter, so I would get dehydrated faster. I had less time to absorb nutrients. I'd eat a hard boiled egg and in 40 minutes it was a hard boiled egg. Not much happened. Right now in life, I don't think about it until I use the bathroom. It's the consistency of kind of like a baby's stool. I do use baby wipes and there is a cream because sometimes it gets sore. You get a little diaper rash.

For the second surgery you're under anesthesia longer, so that was a little bit harder too. You still come out with an ostomy. It's not like anything really happened that you know about, that you can see happened. I got such relief from the first surgery, after the colon was out, and I did consider, "I could live like this. I don't need to go through another two surgeries." Do you take the risk? My husband said, "Abbie, you're ..." at the time I was 31. "Don't you want to go to the pool?"

But it's a risk. Any surgery is a risk. I felt a little guilty, a little selfish, a little vain, to try to go ahead and have the followup surgeries, but now I can say I'm glad I did. But everyone is different. Yep, and everybody's body is different. People ask me would I do it again, and I would say yes, because I've learned to respect the pouch.