

The Colostomy Diaries

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1. Trash Can

These days, I get easily side-tracked. If my brain were an old-fashioned card catalog, right now the drawer would be open to the entry that reads: Feces—Disposal Of.

I work as a Teen Services Librarian for a large public library system. I don't have my own office—the entire back area forms one L-shaped, windowless, fluorescent-lit room. Stacks of books fill every available square inch. My desk hunches at the top of the L, sandwiched between the desk of the children's librarian and the door to the loading dock. The phones ring constantly; knocking on the back door announcing book deliveries interrupts with frequency. The staff bathroom sits ten feet from my desk, and I swivel in my chair with each creak of the door to see who enters or emerges.

As the resident expert on children aged twelve to eighteen, I am often called out onto the library floor. It's a noisy, distracting place to work; the best and worst place to be while anticipating abdominal surgery.

Five years ago, at the age of twenty-eight, I had a rare, benign tumor removed from my large intestine. A few weeks ago, I learned that the tumor has returned. The first time, they were able to remove the tumor while still leaving me with a functioning intestine. This time I would not be so lucky. The tumor sits at the very end of my colon, nestled between my tailbone and my intestine.

"You'll have to have your entire rectum and anus removed," my surgeon told me over the phone as I sat in my living room, an unread newspaper on the table, cherry blossoms blooming on the tree outside my window. "We'll have to put in a colostomy. Permanently." I imagined him sitting at his desk, leaning over the

front of it like an angry judge, long finger extended towards me. *This colostomy will go on your PERMANENT RECORD.*

I will have the surgery in one month, a two-surgeon operation. One of my surgeons is currently on vacation in Greece. I should be there with him, relaxing on the beach, giving my intestine a farewell tour of sorts. Instead, I scramble to make arrangements for a three-month leave from work. Teenagers spend a lot of idle summer time at the library, and we need activities for them once their internet time runs out or we'll have a riot on our hands. I set up monthly movie nights, a henna tattoo workshop, a book-reviewing contest.

I visit the local schools to promote the library's summer reading program, and between school visits, I write out instructions for the librarians who will carry out various tasks in my absence: run the book group, process new books, break up fights, un-jam printers, clean graffiti off tables. I sit at the reference desk watching patrons stream in and out of the library, blithely unaware of my misfortune. Sometimes I try to see how long I can pretend that I am not about to have surgery. It makes coming to work like performing an eight-hour play.

Small wonder, then, that my thoughts turn to my colostomy at this idle moment at my desk. I have talked to the hospital's ostomy nurse about living with a colostomy. She explained to me that my intestine will exit my body at my abdomen, to the left of my navel. I will have what's called a flange—an adhesive disk with a hole in the middle—stuck to my belly. A plastic-lined cloth pouch clips to the flange. Without a rectal muscle, stool will enter the pouch of its own free will. When the pouch is full, I will remove it, bag it up, and throw it away. I will use baby wipes to clean the area before attaching a new pouch. The nurse told me about a process I can perform called irrigation that will minimize the number of times I have to change the pouch, keeping my solid waste disposal to a mostly at-home affair.

But there will be times while I'm away from home when the pouch will require changing. So I think about the staff bathroom

in the library, and, specifically, the trash can in the bathroom. It's tall, sits out of reach of the toilet, and has no lid. Is a trash can without a lid the best place to throw my bagged-up shit? What about the odor? Colostomies aside, I am a fan of trash can lids, especially in a bathroom used by fifty people. I flag down my co-worker, Kim, on her way to the break room. Kim's responsibilities include ordering supplies for our library branch. She is also my sole confidante at work. Three people here know about my colostomy: the branch manager, the assistant manager, and Kim.

"Oh," she said matter-of-factly when I told her the news. "One of my high school boyfriends had a colostomy. I helped him change it sometimes." I told her I would not require her services myself. Now I tell her my trash can idea. She agrees that a lid would be beneficial in this situation, and says she'll go through the office supply catalog right after her lunch break. Problem solved.

An hour later, Kim returns to my desk. Lidded trash cans cost a bundle, it turns out. She had to talk to Denise, our assistant manager, to approve the charge. Denise is a thoughtful, detail-oriented person. On my first day she brought me a bouquet of flowers for my desk. She specializes in untangling the large knots we often get ourselves into while serving our challenging collection of patrons. Any problem that befalls us—a leaky faucet, a rude patron, a difficult research question—Denise is the first one we all call out for.

On occasion, Denise has been known to overthink a problem. Kim explained to Denise why she wanted to buy the new trash can.

"It's for Janet," Kim told her, as though I would get my own special, personalized can. I picture my name painted in festive script on the side, my photograph pasted to the lid. In their three-minute conversation Denise thought of several reasons why ordering a lidded trash can might be an inadequate solution to my problem. I go to talk to Denise myself.

"It's a bodily fluid," she says, "so it requires special disposal."

"What about tampons and pads?" I ask. "What about diapers?" Technically, she tells me, you aren't supposed to throw any of

those things in a public receptacle. This is news to me. But, she tells me brightly, I have a special need, and the library system has to accommodate me.

"We are required by law," she says. She will have to call the director of human resources. She'll get back to me as soon as possible.

A month after my surgery, I am sitting down at the dinner table when the phone rings. I still have a lot of pain and fatigue, but I feel much better than I did at this point five years ago. I can imagine going back to work someday. A friend has come over for dinner, and we are talking and laughing as my husband, Matt, gets up to answer the phone. My library manager, Marie, is on the line. Like Denise, she is warm, friendly, and has an easy laugh. Unlike Denise, she does not enjoy dwelling in details. She likes to cross things off of her list and move on.

"I hate to bother you," she tells me, "but I have a list of questions I'm supposed to ask you." I can see her eyes roll through the phone line. She pauses. "It's about the fucking trash can."

"You're kidding," I say, getting up from the table to go into the other room out of earshot. Apparently, the entire Human Resources Department is on the case of the Trash Can Conundrum. They have a call in to a public health nurse for a consultation. While they await her response, they brainstorm solutions. One bright idea, drummed up no doubt by the newest employee wanting to make a good impression, involves arranging a special trash pickup just for me. My shit would have its own valet. They want to know details in order to facilitate this service: How many times a day will I change the pouch? What kind of bag will it be disposed in? Marie and I are both incredulous. This seems like bureaucratic red tape at its worst: the violation of my privacy, the mistrust the whole investigation implies, the stupidity of nearly everyone involved.

I should never have said anything, just thrown my special trash in the open can and not worried about it. Or maybe I should just go to Target and buy a lidded trash can myself. I imagine a letter I

could write to the director of Human Resources, full of lies she'd never uncover. *They didn't have to put in a colostomy after all. My poop will go in the toilet just like yours.* I picture her face turning a deeper shade of red with each word: Colostomy. Poop. Toilet. Then maybe she would understand how it felt to lie on my couch ten miles from her office and envision the staff meetings—I'm sure there were many—in which they discussed my bodily functions.

After the questioning, Marie tells me some library gossip to make me feel better, and then we hang up. I return to the dinner table, give Matt an I'll-tell-you-later look, and say, "What did I miss?"

One month later I return to work. The public health nurse, when reached, politely told the HR folks they were off their rockers. Our staff bathroom is now outfitted according to her professional recommendations: the same trash can we had before, and, next to the toilet, a smaller can. With a lid.

2. Coming Out of the Bathroom Closet

Having surgery for a recurrent tumor is like having a second child. There's less fuss than there was following my first surgery, when fresh flowers arrived at the door daily and my mother had to keep a schedule to make sure that I had rest breaks between visitors. Friends still come by, but not as many as five years ago. I feel grateful when they do visit, more so if they bring dinner. Today my friends Lee and Treena brought food to cook, and Lee stands at the stove while Treena and I sit on dining room chairs temporarily placed in a corner of the kitchen for my post-surgical recovery. August sunshine drenches the kitchen and we open the door to the deck. A faint breeze wafts in, mixing with the scent of onions frying on the stovetop.

The conversation turns to my surgery. Lee seems curious about the details: How much colon did I have removed? Were they able to reconstruct it as well as they did after the first surgery?

Up until now I've adopted a "don't ask, don't tell" policy about my colostomy. A few close friends and family members

know, but that's it. I haven't yet figured out how to work it into the conversation. Do I do it upon introduction, Alcoholics Anonymous-style? *My name is Janet and I have a colostomy.* Or do I use it as an excuse for irresponsibility? *I'm sorry I didn't get that report done on time. My colostomy was really acting up this week.* I also fear the follow-up questions I don't know how to answer, the different way I assume people will look at me once they know the embarrassing truth about me. Will they fear that shit will come spewing out my abdomen when they hug me? Will they talk about me in my absence, voices laden with pity? *Poor Janet. She has to poop into a bag!*

Perhaps my worst problem is that I am a terrible liar. I don't even know how to tell a partial truth, omitting details to protect my privacy. In most cases, other people's possible feelings bother me. I don't mind people knowing that I have a colostomy, but I worry that *they* might mind knowing. Still, when people ask the right set of questions, as Lee asks now, I feel they can handle the truth.

"They weren't able to reconstruct it like before," I say. "I have a colostomy." I look for disgust in their eyes, but I see only curiosity. I explain that my intestine now comes out near my belly button. The onions start to burn a little and Lee turns the flame down before turning back to me.

"So what about your anus?" she asks.

"It's gone," I say.

"And the hole?" Treena asks.

"All sewn up."

"Huh," they both say in unison. Treena considers this for a few seconds.

"Well," she says with a touch of pity or envy in her voice; I cannot tell which. "No more anal sex for you."

And thus, my truth-telling is rewarded.

3. Do These Pants Make My Colostomy Look Fat?

The dressing rooms at Nordstrom's still have a serene quality at ten o'clock on a Tuesday morning. The room looks spotless—no bits of plastic tags litter the floor, no clothing from previous customers discarded on the leather chair. It reminds me of my grandmother's

house, with her walk-in closet lined with shoes and her ornate dressing table topped with carefully placed combs and face creams. The saleswoman has carried the armloads of clothing I selected off the rack and hung them neatly on hooks. Low-volume Vivaldi plays through hidden speakers.

All of these seemingly frivolous touches of class make clothes shopping a more pleasant task. I am not fashionable, not by a long stretch. I'm not the right shape for most women's clothes: my legs are too short, my belly too round, my breasts too small, and now, five years after my surgery, I have a colostomy pouch sticking out in the middle of my body. Not the model for the low-rise, skin-tight fashion era I dwell in. While I may be fairly open about letting people know I have a colostomy, I work hard to hide the physical evidence from everyone except my doctor and my husband. But does concealment mean that, as a thirty-something-year-old, I have to buy clothes that were designed for an octogenarian?

Five minutes into my clothes try-on session, the saleswoman knocks on the dressing room door.

"Everything fitting okay, Janet?" (I am supposed to appreciate the fact that she learned my name, and I do.) "Do you need me to get some different sizes?"

"No thanks, I'm good." This is always my response, no matter how the clothes actually look.

Clothes shopping presents a pants-waist problem. The top of my colostomy pouch sits stage left of my navel, three inches above it. If I want my pants to cover the pouch, I need them to be high-waisted. The problem then becomes needing a belt so that the pants don't slip down off my waist, exposing the pouch. Belts rub against the flange, threatening the adhesive which keeps the whole appliance in place. Elastic waistbands allow for the most facility of use. But when was the last time you saw someone walking down a fashion show runway with elastic-band pants? Never. I could wear more skirts, I suppose, but I don't like skirts. And don't get me started on dresses.

With my food-stained T-shirt and white running socks worn thin at the heels tucked discreetly in a corner under my backpack, I begin working my way through the clothes. I try on a pair of jeans, a brand called Not Your Daughter's Jeans. I'm not sure if the brand name should make me feel me feel older or younger than I am. I think about my one-year-old daughter. Her jeans have an elastic waistband, so maybe I should look for a brand called Just Like Your Daughter's Jeans. I might feel silly, though, with a pair of pants whose inseams are lined with snaps to facilitate diaper changes.

Another knock on the dressing room door. Am I still doing okay? I am.

In the early days of my colostomy, I tried to solicit sales help. Once I told a saleswoman about my colostomy, so that she could tell me whether or not she could see its shape through my clothing. She seemed thereafter to view me as a leper who was going to leave a small pile of digits on the dressing room floor. Another time I did not share the information, but simply stepped out of the dressing room to get a salesperson's opinion about a pair of pants. Her hand, as if magnetized, went under my shirt and right to my pouch, poking an inch or two out of the top of the pants.

"You've got them on backwards," she told me, fingering the top of the pouch. "I can feel the tag."

4. Gratitude

Naturally, there are occasions when I get pissed about the whole thing. What person would feel lucky to spend her twenties and thirties in and out of hospitals, with a pitiable set of statistics on her chart? Two tumors. Three surgeries. Dozens of probes and scans. Gallons of blood drawn. Countless needles, scalpels, pills, IV tubes.

In the five years between tumors, I did not get a break from my full-time status as a patient. Scar tissue from my first surgery compromised my ability to get pregnant, so I pursued treatments

through a fertility clinic. There were pregnancies; there were miscarriages. The intestinal tumor made its reappearance less than a month after one miscarriage, transforming my imagined summer of belly-swelling and baby clothes shopping into one of surgery and recovery—the worst consolation prize in human history.

After my colostomy surgery, Matt and I began to discuss adoption. Maybe we weren't going to be able to pass on our genetic material. Maybe, given the fact that my first tumor developed when I was a fetus myself, we didn't want to. It would be a lie to say that we did not care about having biological children. But that year off from fertility treatments did help us see that they might not be worth the physical and emotional costs. After all was said and done, they might not even be possible.

We were certain, though, that we wanted to be parents. So when we found an adoption agency we liked, we filled out heaps of paperwork. Then we waited, and waited, and waited some more.

And then they arrived. A boy and a girl, two years apart. They have features that my biological children would never have—they are tall, athletic, rhythmic, high-octane, and dislike sandwiches. But they are every inch my children, and I their mother.

If I blame the tumors for my infertility, I have to thank those same tumors, the surgery, the colostomy, for my two stunning children. Without my biological misfortunes, I would not have Caleb and Helen, which is impossible and horrifying to contemplate. They act as my two blond, blue-eyed, apple-cheeked reminders that every needle poke was worth it.

5. In Public

Sometimes having a colostomy is easier than not having one. As a parent of two young children, I don't have a lot of private time. Caleb and Helen are three and one, respectively. They don't do anything independently. When I leave them in a room by themselves, within seconds one of them is yelling or crying. Caleb lies on top of Helen, or Helen takes the toy truck that Caleb was playing with, and it's instant chaos. They're like the heads of two

warring countries who need a mediator present at all times. When we leave the house, my role switches from political diplomat to sheep herder. Now that Helen can walk, she refuses to be strapped down in a stroller or a baby carrier. The two of them often run in opposite directions, full of delight at birds and bugs at opposite ends of the park. Luckily, I can outrun them. For now.

When solo parenting, trips to the bathroom have to be infrequent and lightning-quick. Sometimes I limit my fluid intake while out with them so that I don't need to use the bathroom. I imagine a trip to a public restroom with both of them when I don't have my hands free to tether them: Helen would unravel the entire roll of toilet paper and Caleb would run from stall to stall, banging on doors. They'd whoop loudly to hear their voices bouncing off the concrete restroom walls. Someone would end up calling a security guard to have us removed from the building.

Luckily, I don't often have to deal with long bathroom trips during the day. Sometimes I feel smug about this, the one big advantage of having a colostomy. All I need to do is put a new pouch on in the morning, while Matt is still home, and I don't need to deal with it for the rest of the day. Almost always, anyway.

Recently, I took Caleb and Helen to the Children's Museum, packing a lunch for us to eat at the food court upstairs. Always entertaining, the food court features good people-watching and plenty of space to run around. A stage sits at one end of the food court, and lunchtime usually brings some kind of amateur entertainment. On this day, a middle school orchestra played Mozart standards. They played out of time and out of tune, and Caleb and Helen gazed at them, riveted.

The younger members of my family don't believe in leisurely lunches, and soon enough Caleb was out of his seat, Helen squirming to get down from her high chair. They act their most feral immediately after lunch, and I scrambled to cram Tupperware containers into the backpack while Helen thrashed in her seat and Caleb tried to rush the stage while the concert progressed. I bent over to pick up my pack, yelling to Caleb to Come Back Right

Now (or some other phrase I swore I would never use with my children that I now use all the time). As I bent down, I noticed that something seemed amiss in my pants. I could feel my pouch, but it was not where it should be (i.e., on my colostomy). Instead, I detected it way over on the right, floating free somewhere near my pubic bone. To my immediate horror, I realized I was experiencing a first: a phenomenon called a Pop-Off. In the middle of a crowded food court, while caring for my two Ape-Children by myself. Heart thudding, I stayed bent over, trying for subtlety as I reached down my pants and attempted to reattach the pouch. I tried a simple snap-and-click motion to clip the pouch back onto the plastic ring, an act I can perform with both eyes closed, one-handed, while chewing gum and juggling fire with my other hand. Only now I couldn't. I did not know why it wasn't working. Maybe the fastener was broken. Maybe panic made my fingers inoperative. In any case, I wouldn't be able to get it back on standing ten feet away from Orange Julius and Pizza Haven. I would need to go to the bathroom to fix the problem. Quickly. It felt at that moment as though stool was pouring out of me like water from a garden hose.

I tried to think of how I could get myself and the kids to the restroom. I only had the front pack carrier for Helen—clearly not an option right now. I looked over at Caleb, almost out of sight behind a crowd of parents grinning at their out-of-tune children performing onstage. I watched as Helen tried to pitch herself over the side of her high chair. Scaling Mount Everest seemed easier than dealing with this bathroom emergency with my kids in tow.

I thought of Matt, sitting in his quiet office half a mile away. I fumbled for my cell phone. *Am I really going to summon my husband so I can go to the bathroom?* I could not think of another option. Fighting back tears, I explained the problem and Matt said he would come right away. He never panics in such emergencies.

"Take a deep breath," he told me. "It's going to be okay." I managed to corral Caleb back to the table, re-interest Helen in her half-eaten lunch. Seven long minutes later Matt strode through the food court doors, a serene smile on his face. We all calmed

down instantly. The kids were happy to see Daddy in the middle of the day. I grabbed my emergency supply kit and headed for the bathroom.

Once inside the stall, I saw that the damage was not as bad as I had envisioned. Minimal cleanup was needed, and the new pouch popped on easily. There was even a lidded trash can right there in the stall. Crisis averted.

On my way back to rejoin my family, I thought about all the ways in which it might have been worse. The location, for example, could have been too far away for Matt to come and rescue us. I could have accidentally left my emergency kit at home, something I often do. My imagined garden hose situation could have been real. And if any of those things had happened, I would have survived them. I thought back to the years when my colon was more complete, and less functional. I'd already endured much graver hardships then—an urgent trip to the world's dirtiest toilet in a Kathmandu bus station, a drunken pants-crapping incident at the Vancouver Folk Festival. Once I had to interrupt a meeting I was facilitating to run to the restroom. This wasn't my first embarrassing defecation incident, nor would it be my last.

As we all walked back to the car I apologized to Matt, but he would not hear it. He enjoyed having a break in his workday, being able to help so easily. Helen rode on his shoulders and Caleb trotted alongside him, singing "Farmer in the Dell."

"I should meet you guys at the food court more often," Matt said, "not just when something like this happens. Not that this will ever happen again," he added quickly, turning to look at me. I laughed. He said that to help me feel better. It might happen again, and if it did, I knew that he would always come to my rescue.

"Never," we said in unison. ☞