

# WHAT DOESN'T KILL YOU



*A Life with Chronic Illness —  
Lessons from a Body in Revolt*

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## Chapter 3

# THE MOST IMPORTANT POOP OF YOUR LIFE

From my homebound “Lost Winter” of 2013, a February journal entry reads:

*“These days are about waiting for sleep. Waking, waiting.”*

Another from February: *“I remember Dad telling me about a hospital stint in the '70s when he was fighting food-borne hepatitis. According to him, the*

*doctors predicted he'd be there for weeks. He said he meditated for three days*

*and got to go home. Now, I have no idea if this is true or not—Dad was fond of*

*fantasy and exaggeration. But it has me wondering: Could I harness the power of my mind to rid my body of what ails it?”*

Another: *“No one prepares you for the isolation of sickness.”*

From March 9: *“I feel I've finally come undone. Unraveling like cheap thread, piling onto myself...”*

By March, I'd taken two more rounds of Difacid yet was still positive for *C.*

*diff.* The bacteria destroyed my insides while the months of heavy-duty

antibiotics further damaged my immune system. See, the immune cells that live

in the gut make up the biggest part of the body's defense force. As Emeran

Mayer, MD, wrote in *The Mind-Gut Connection*, “In other words, there are more immune cells living in the wall of your gut than circulating in our blood or residing in your bone marrow.” <sup>1</sup> But the work of those cells is disrupted by long term antibiotic use. While the antibiotic’s goal was to get rid of the bad bacteria, it also got rid of my good bacteria—the stuff that helps fight infection and keeps the microbiome healthy. My gastroenterologist knew I was deteriorating, and the only chance at recovery was to repopulate my colon with healthy bacteria. I needed a fecal transplant. The idea is simple: Poop from a healthy person is mixed with saline and transplanted via colonoscopy, endoscopy, or nasogastric tube to the gut of an unhealthy person. During and after a successful fecal transplant, the flora from the healthy stool populates the unhealthy gut with diverse bacteria, overtakes the nasty *C. diff* bacteria, and rebalances the microbiota. (A note on language: *Microbiota* are the microbes that live in the gut. One hundred trillion of them reside in the digestive tract, with the highest population in the colon. They do everything from aiding in digestion and metabolism to regulating the immune

system, and they're in constant communication with the nervous system. No wonder the gut gets the nickname "the second brain."

*Microbiome* is the genetic material of those microbes. The bacteria that populate the gut contain millions of genes, which, in addition to the microbes elsewhere in your body, make the genetic information we carry around 99 percent microbial! <sup>2)</sup> Fecal microbiota transplants have gotten a lot of attention in the last several years, but the "technology" is old—the first medically recorded FMT dates to the 1950s. These days, a donation is sourced from a known donor or from an anonymous stool bank like the nonprofit OpenBiome, which maintains a rigorous approval process for its donors. Under doctor supervision, freeze-dried stool capsules can be ordered online for about \$2,000 before insurance.

FMT is a relatively cheap, simple, abundant, and highly effective treatment against *C. diff*—approximately 80 to 90 percent of *C. diff* patients are cured with one FMT, according to recent studies, and that cure rate goes up even further with more than one FMT. <sup>3</sup> Meanwhile, between 20 and 35 percent of *C. diff* patients fail antibiotic treatment, and 40 to 60 percent will experience a recurrent

infection. <sup>4</sup> A study published in the *New England Journal of Medicine* in January 2013 found that thirteen out of sixteen people treated with fecal transplants were cured of *C. diff* and two of the remaining three were cured with a second transplant. <sup>5</sup> The results were so impressive that the researchers found it unethical to continue the control group on antibiotics, and they received transplants as well.

My gastroenterologist at Weill Cornell coordinated the FMT alongside the doctor who would perform the procedure, another GI at the same hospital whose research focused on infectious disease. He'd just started doing fecal transplants then, mostly for old folks with *C. diff*; at twenty-four, I was one of the youngest patients he'd treated. (Today, he estimates that he's done at least two hundred FMTs.) He suggested I find a donor who was healthy, my same sex, close to my age, under the age of sixty-five, and antibiotic-free for at least six months. Mom had recently taken antibiotics, my stepdad was too old, Kaetlyn was pregnant with her third child (there's no ban on pregnant people donating, but it isn't recommended as pregnancy's changes on the gut flora are not well understood),

and I was too embarrassed to ask anyone else. But the stakes were high, and I'd already secured a hard-to-get transplant appointment for April 2013. My niece, Zoe, a few weeks from turning nine years old then, was the only candidate. (She would also become the youngest stool donor in Weill Cornell's history.)

Kaetlyn was a twenty-one-year-old cosmetology school student when she got pregnant with Zoe. I was fifteen, a sophomore in high school. Kaetlyn interrupted my afternoon chemistry class to show me the sonogram. "It's a girl!" she yelled as she pulled me from the classroom to the hallway, where we jumped up and down, squealing and hugging. It felt like I was getting a little sister rather than a niece. When Kaetlyn gave birth in April 2004, which required Pitocin inducement and several hours of labor, I was the first family member Zoe saw, hovering wide-eyed above the warming table. We've been cosmically linked ever since. Zoe is—and always has been—curious and funny and smart and brave. As a toddler, she had all these -isms, like "wallard" for water, "pal melish" for nail polish, "strawbirdies" for strawberries, and "Danna" for

grandma. We thought they were just cute little quirks until we found out she had been born with sensorineural hearing loss that required hearing aids. You would never know about her disability upon meeting her—she lip-reads so effortlessly and constantly adapts to the world around her. Sixteen years old now, Zoe is set on being a neurosurgeon and with her wild—frightening sometimes—ambition and perfect grades, I think she'll do whatever she decides to do.

My senior year of high school, Kaetlyn and Zoe moved out of our shared house—a crooked three-bedroom with a purple front door and a subprime mortgage that, with help from her siblings, Mom bought just before Zoe arrived—and settled into their own little home, a cute apartment in a complex with a walking trail, a community pool, and a duck pond. Mom began dating my stepdad and spent most nights at his house. Kaetlyn's government benefits went with her and Zoe, so the blocks of cheese and bags of cereal I relied on for many meals disappeared. Unopened bills piled up in boxes below Mom's bed, as if they would go away so long as she didn't open the envelopes. The grass grew

tall and the bank took back the house. But for a moment in time, that shared house had been full of hope. We were a family there, the four of us.

When I needed the fecal transplant, Kaetlyn sat Zoe down to explain why she was the ideal choice and explained how dire the situation was. At first, Zoe refused. She cried and screamed that she wasn't going to do it.

"When you're nine years old and you find out you have to poop into a bag and that poop has to go into your aunt, that's *kiiiiind* of a weird thing," Zoe recently told me. (Now,

she's also taller than I am and old enough to drive.) She laughed as she recounted the story to me at Mom's kitchen table. "I didn't realize the severity of it." Plus, everything is embarrassing when you're nine. But she soon understood

that I might not recover without the transplant, and that she was the best (and

only) one for the job. "I felt proud, knowing that I was doing something

important for someone—someone I care about so much," Zoe said, "even if it was sort of weird."

She carried a burden heavier than any nine-year-old should: First, she'd need

blood and stool tests to verify she could donate. She hollered and thrashed



around so fiercely at the blood draw that nurses had to restrain her. (Kaetlyn later sent flowers and an “I’m sorry” card to the staff.) Then, she’d have to fly to New York with her mom and “Danna” and take the most important dump of her life, which would be collected, taken to the hospital, mixed with saline, and transplanted into my large intestine. She was understandably scared of the whole process, but most of all she was afraid that her poop “wouldn’t save me.”

Before the transplant, I had to gather supplies: colonoscopy prep to clear my bowels for the procedure; Imodium to help me hold in the transplanted stool mixture as long as possible after the procedure; and—this isn’t a joke—a blender. The hospital staff asked for the sample—as fresh as possible, they requested—to be brought in a blender so they could minimize their own poop handling and cut down on the procedure’s ick factor. I ordered one online after reading countless reviews for how well it handled smoothies and protein shakes.

I wasn’t going to risk buying a subpar blender when my life was on the line, you know? (Now that Weill Cornell uses stool from OpenBiome, there’s no need for patients to find a donor or buy a blender.)

April rolled around. Zoe, Mom, and six-months-pregnant Kaetlyn, suffering from hyperemesis gravidarum—a kind of extreme morning sickness that caused her nine miserable months of nausea and vomiting—made it to New York despite one canceled and one rescheduled flight. (The first plane was struck by lightning—how’s that for a bad omen?) We stayed at Weill Cornell’s “hospital hotel,” an apartment-style building for patients’ families, with me in one room and them in another. The rooms looked like any long-term business hotel—kitchenettes and bad watercolors—but they smelled like a hospital’s telltale mix of cleaning products and decay. Zoe brought me a cobalt-blue paper crane that she’d made “for good luck”; it sits on my desk as I write this. Kaetlyn tried to make the trip fun and less scary for Zoe by going to Times Square and the Met. She and Zoe took pictures under the New Year’s Eve ball and in front of Van Gogh’s *Sunflowers*. They ordered in giant plates of pasta and slices of pizza in hopes that those foods would help Zoe “go.” During our conversation at Mom’s kitchen table, Zoe admitted thinking, “We’re in this amazing city and all I’m going to do is *poop*?” (“I would have made that child

drink black coffee and smoke a cigarette if that's what it took!" Kaetlyn joked.)

Meanwhile, Mom stayed close to our lodgings in case of emergency and I drank the colonoscopy prep, waiting for cramps to signal it was time to spend several hours on the toilet, until whatever I passed was clear as water. We all slept poorly that night.

The next morning, Mom called to announce that the "sample" was ready to go, and "the healthiest turd she'd ever seen." Zoe was relieved that her job was over. She and Kaetlyn stayed behind to rest while Mom, tightly clutching the blender box like a chest of precious jewels, walked a city block to the surgical center with me. I was so tired and so nervous that my legs shook, but as we continued, I got to giggling and couldn't stop.

"What if we get mugged right now," I said, "and the thief gets home to find a giant turd in a blender?"

We laughed until we cried.

Mom passed the box along to a nurse and went to the waiting room. She flashed the ASL sign for "I love you," a gesture we'd done since my childhood. I changed into a hospital gown with familiar blue plaid and rolled to my left side

on the surgical bed. As the anesthesiologist inserted the IV and told me to count backward from 10, tears rolled from the corners of my eyes. “This *has* to work,” I whispered, before passing into black. The GI spent an hour snaking the colonoscopy scope through my colon, spraying my diseased guts with the magical poop mixture. While he was in there, he took photos and biopsies that showed significant damage but not enough to warrant bowel resection or removal. Back at the “hotel,” I cried—this time out of relief. My biggest fear then, besides getting someone else sick, was that my colon would be too far gone and have to be removed. I wasn’t ready to live with an ostomy yet—I hadn’t come to terms, after half a year of illness, with what “chronic” would mean for me, let alone the prospect of a lifetime with a waste-collecting ostomy bag. (My ostomy-related fears disappeared over time as I met dozens of IBD patients whose lives were saved by the surgery, and who credit their bags with giving them their lives back.) The morning after the transplant, I felt physically stronger somehow, or maybe it was a renewed sense of optimism fueling the spring in my step. I was ravenously hungry for the first time in months, and Mom watched wide-eyed as I

inhaled a plate of diner eggs and sausage. From December to April, food had tasted bad and had caused massive amounts of pain. I either didn't eat at all or, because I was too sick to grocery shop, ate whatever the drugstore next to my apartment offered: beef jerky, potato chips, gummy candy. It didn't need to inspire me, it just needed to provide calories to count against everything I was puking up and shitting out.

On the walk back to the hospital hotel from the diner, Mom and I passed by Sotheby's auction house. Her face lit up as she scanned the banners advertising an open-to-the-public gem and jewelry show inside. Mom has always been a magpie with an appreciation for all things sparkly. We could never afford fine jewelry, but she loved to bead her own necklaces and find statement earrings at discount stores, dangling gold-fill florals and beaded chandeliers. Costume jewelry inherited from her mother and mother-in-law are among her most prized possessions, not because they're worth anything but because she loves the idea of an old lady (herself, someday) covered in topaz and vermeil. Inside the exhibit, Mom marveled at the giant yellow diamond solitaires and Art Deco

tiaras. A Sotheby's employee saw her admiring a deep-blue sapphire cuff bracelet and took it out of the case so she could put it on. I couldn't believe that one day prior someone else's shit was being sprayed all over my insides, and today I was watching Mom giddily try on a \$75,000 bracelet. Within forty-eight hours of the procedure, I felt markedly better: My taste for food returned, my abdominal pain subsided to a dull throb, my bowel movements began to solidify (do you know the massive relief that comes from seeing a semisolid poop after months of nothing but intestinal sludge?), and my consuming fatigue started to lift. It seemed too good to be true. You might be wondering why, given the clinical evidence that fecal transplants are the most effective treatment, they aren't the first line of defense against *C. diff* over antibiotics. The simple answer? Capitalism. Drug companies can't patent or profit from human feces, but they *can* make vancomycin and Difucid exorbitantly expensive. Even more challenging, the FDA keeps trying to regulate stool as a drug, which requires doctors to complete investigational new drug (IND) applications before they're allowed to do a transplant, delaying lifesaving treatment. But the more complicated answer is that doctors know

exactly what's in the antibiotics that treat *C. diff*. Stool, on the other hand, has countless variables: fungi, good and bad bacteria, protozoa, viruses. No two people have the same gut microbiota, and with that many unknowns comes risk. Doctors have to decide if the danger of *not* performing the transplant outweighs going through with it. For someone like me with inflammatory bowel disease, which increases the chance of *C. diff* mortality, and who'd failed round after round of antibiotics, it was worth it. In 2019, the FDA halted an unspecified number of FMT clinical trials after one death and one invasive infection; the FDA wouldn't offer many details other than both patients were immune compromised and the stool they received was from the same donor. <sup>6</sup> The donor's stool contained a drug-resistant strain of *E. coli*, and whatever screening was done didn't catch that specific pathogen. Now, patients fear that the FDA will crack down on stool banks like OpenBiome, making transplant material harder to access and handing more power to for-profit drug companies. Plus, if the FDA decides not to approve the procedure—or regulates it into oblivion—insurance companies will be less willing to cover

the cost, leaving more patients with an out-of-pocket burden. I was lucky enough to have excellent employer-based insurance, first at Lifehacker in 2013 and again at the *Daily Beast* in 2015, for all three of my FMTs, paying ultimately next to nothing. It's already so difficult to access a proper transplant that some desperate patients try DIY versions. There are dozens of online forums and social media groups dedicated to guiding others through the risky at-home process. There's also chatter of a potential *C. diff* vaccine in development via Pfizer, [7](#) but there's no telling if or when it will be on the market, or who it will be marketed to (the trial is focused on patients aged fifty and up). And of course, "microbiome therapy" start-ups have begun to pop up, seeking to profit from the exchange of human flora and gain favor with the FDA as FMT clinical trials explode for everything from depression to autism. Fecal transplants not only work consistently but, in most cases, quickly. Though research suggests that the gut's microbiota adapts and changes for months post-FMT, symptoms can remedy within days. Through the rest of the spring and into the summer, my insides bloated, gurgled, and moved constantly. I



imagined them rebuilding, like ants reconstructing a stepped-on hill. With a negative test showing the infection gone, I wondered what it would be like to live with *just* IBD. I'd contracted *C. diff* so soon after the diagnosis that I couldn't picture day-to-day life without it. My doctors warned me that *C. diff* could return in patients who've had it, especially in patients like me with underlying disease. I buried their warning somewhere deep in my brain, unable to think about going through it a second time. But two years later, *C. diff* came for me again—bringing me the closest to death I've ever been.