

WHAT DOESN'T KILL YOU



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

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Chapter 1

BLOOD

The first time I heard of Crohn's disease, I was in fourth grade. 1997. Mom and my fourteen-year-old sister, Kaetlyn, were talking in the front seats of our Ford Escort after school; I was eavesdropping in the back. A girl in Kaetlyn's class was sick with something called Crohn's disease—"that poor thing," Mom kept repeating, barely above a whisper. "What's Crohn's disease?" I asked. Kaetlyn craned her neck around, slowly and dramatically, eyes in a permanent teenage roll. "*Crohn's* disease," she said, circling her lips around the O, "is where you poop ... until you *die*." I didn't ask any more questions. It was the one of the worst things I'd ever heard.

Fifteen years later, I listened, upright in a hospital bed, as doctors diagnosed me with it.

It was 2012, my second year in New York City. I'd moved to New York in October 2010 from the Midwest for a three-month-long internship at Condé Nast, the storied publisher of *Vogue* and *Vanity Fair* and the *New Yorker*. At the three-month mark, the Condé Nast magazine *Wired* hired me full-time, so what

was supposed to be ninety short days turned into ten years (and counting). I've lived in New York City longer, now, than in any other place. I chose it for the same reasons everyone else does: because it's big and weird and everyone here is smarter and weirder than me. Everyone who moves to New York from someplace you've never heard of has got something to prove: that we're intelligent, that we're creative, that we made it out of our hometowns. When I finished four years at Northwestern, the people I graduated with all had a plan: Google or an ad agency or a newspaper. They each seemed to have an uncle who could get them a job. I had no plan, no prospects, no connections. I moved in with Mom and my stepdad in rural Illinois and wore pajamas all day while I watched *House Hunters*, scrolled job listings, and counted down my student loan grace period. One late summer afternoon just after my twenty-second birthday, I came across what seemed like a fake ad on Craigslist for a public relations internship at Condé Nast (why would one of the world's largest publishers use Craigslist?), specifically working for Chris Anderson's *Wired* as well as a sparse little website

called Reddit that, for reasons no one really understood, was doing bonkers traffic. They invited me to an in-person interview, and though PR hadn't crossed my mind as a career option, I knew it meant working closely with writers and editors. In New York, I stayed with a friend from college whose family rented a two-story penthouse above the now-closed Topshop on Broadway. I'd only ever seen homes like it in movies, but my friend and her family moved about it like it belonged to them. Rich people have a way of moving around the world like that, with ownership. I borrowed a black polyester pencil skirt from Kaetlyn and slicked my hair into a bun because that seemed elegant. In the cab to 4 Times Square, I prayed the internship listing wasn't a con. At the end of a forty-five-minute interview, two intimidating and chic twentysomethings offered me the internship but with a condition: Condé Nast required its interns to be enrolled in college so that the company could give school credit instead of any payment beyond a \$12/day—that's \$240/month—"travel stipend." I had just graduated, so I would have to reenroll. I used \$1,400—most of what I'd saved from my college receptionist job—to buy $\frac{1}{4}$

credit at Northwestern, enough to make me legit for the company's requirements. Mom and my stepdad agreed to help with three months of rent in hopes that the internship would lead to a real job. I was desperate to get to New York because it felt like everyone else my age was building their lives and I'd be damned if I stayed behind any longer in my pajamas. Even \$12 a day felt like progress because that \$12 was in New York Freakin' City. When I moved from Illinois to New York that October, I traveled with just two bags: a tote stitched with my initials, gifted from Mom who monograms everything, and a black suitcase that I bought for \$30 at Walmart. Those bags carried everything I needed—and everything I had, really—to fill my shared apartment, a converted one-bedroom on Ludlow and Delancey on the Lower East Side. I found it, too, on Craigslist, and had corresponded via email for several weeks with my soon-to-be roommate, a fellow Midwesterner and recent college grad who would later become a close friend. My room was seven feet by nine feet and pre-painted bright, almost neon orangey red, with a makeshift plywood platform that I put a squeaky Kmart air mattress on. The shower was in

the kitchen next to the sink and shared its plumbing, so the
tub drain clogged
with bits of macaroni noodles and coffee grounds and
whatever else got rinsed
down the sink. Sometimes during a shower, I'd find myself
standing in ankle
deep swamp water. The toilet was in its own closet with a
narrow window that
overlooked the backyard of the next-door karaoke bar, where
you could listen to
drunk people singing along to Whitney Houston and Bon Jovi
while you peed,
whether you wanted to or not. A vegetable warehouse was
downstairs, and the
smell of rotting onions wafted down the block most days. Our
middle-aged
neighbor smoked cigarettes in the hallway while wearing
tighty-whities and a
hot pink wig. Garbage piled so high in the first-floor hallway,
where the trash
cans lived, that those tenants' front doors got blocked in.
Cockroaches scattered
when you turned on our kitchen light. The room cost
\$750/month and I loved it
well for more than a year, until bed bugs forced me to flee to
Brooklyn.

If I was from Earth, Condé Nast was Mars. Even my four years
at
Northwestern, moving among the children of senators and
diplomats and CEOs,

hadn't prepared me for the world of prestige publishing. A boss's boss told me I was "too nice" to succeed. A creative director grabbed my ass at a company retreat. Friends in ad sales passed along tales of cocaine-fueled parties and affairs between C-titles and their assistants. My colleagues used words like *summer* as a verb and bonded over which posh camp they'd gone to as adolescents. In my hometown, no one went to camp—we detasseled corn, babysat, and hung out at whoever's house had the aboveground pool. And at Condé Nast, people cared a lot about appearance. Though I stayed mostly outside of that bubble working for tech publications, I couldn't help but interact with the fashion set (even Ms. Wintour herself) in the lobby and the cafeteria. I watched them as though we were separated by glass, knowing that we would never be alike—though whiteness and thinness and a maxed-out thousand dollar-limit credit card I used for clothing allowed me to pass unnoticed. My two years at Condé Nast were less about learning how to write press releases or monitor media impressions and more of an education in the ways of a ruling class.

In early 2012, I jumped at the opportunity for an editorship at the famous how-to site Lifehacker. By then, I lived in a boxy two-bedroom in South Williamsburg, right where hipsters and Hasids start to overlap. I was soon making \$49,000 a year plus small monetary bonuses for pageviews, and I felt like I was *rolling in it*. I wanted to upgrade luggage for my Thanksgiving trip back to Illinois, so I walked less than a mile from my apartment to a row of family-run shops where the Satmar store owner helped me choose a practical rolling suitcase. As I handed over my debit card to pay for the bag, searing cramps gripped my abdomen. I grabbed the receipt, rushed out of the store, and wheeled my way home. The pain made it so hard to breathe that I doubled over at crosswalks. “Don’t shit yourself, please don’t shit yourself, *don’t you dare* shit yourself,” I said under my breath. By sheer will and Herculean clenching, I didn’t. But I spent the rest of the night going from my bed to the toilet—bed to toilet—while my intestines tortured me. I’d experienced stomach pain all my life but this was something else. My guts were being pulled like taffy and shredded with hot razor blades. The

cramping felt as though a man with large fists had reached inside my body and was wringing my colon like a damp rag. The next morning, my mouth and throat exploded with throbbing lumps, akin to canker sores on steroids. I swallowed a handful of Tylenol and Imodium and caught my flight to Illinois, sweaty and white-knuckled the whole way. Instead of getting better at Mom's house, I declined further. My family celebrated Thanksgiving while I stayed upstairs, leaving bed only to go to the bathroom ten, twenty, thirty times a day—filling the toilet bowl with nothing but bright red blood and bits of intestinal tissue that floated like scritta paper. Seeing blood for the first time from my body, outside of my body, when it wasn't supposed to be there, was distressing and scary—but more than that, it felt like a total loss of control. I didn't know the source and I couldn't stop it. Every time I went to the bathroom, there was more red. Meanwhile, the pain escalated. It felt like I was shitting barbed wire. I didn't want to eat—even a drink of water had me running to the toilet within seconds. Mouth sores continued to spread and scatter down my tongue and across my tonsils, making it excruciating to speak

or swallow. I started soiling myself trying to walk the fifteen steps from the bedroom to the bathroom. I'd had stomach problems for as long as I could remember, but never with bleeding. As Mom tells it, I cried relentlessly until my first birthday; if I wasn't sleeping, I was crying. Some nights the only way I'd sleep was chest-to-chest with Dad, who used my diapered butt as a book prop so he could keep up with his PhD reading. A pediatrician ruled it colic and said I'd grow out of it. In second grade, I had stomachaches so severe that I'd double over at school. My teacher sent me to the guidance counselor, who asked if I was crying for attention. In fifth grade, I had a bout of illness—abdominal pain and vomiting—that kept me out of school for a month. A CT scan at the local children's hospital was inconclusive. Freshman year of college, another monthlong illness with ER visits and no certain diagnosis. Fear, stress, or excitement led to cramping pain and diarrhea, so early on, I was labeled "sensitive" and a "nervous kid." Mom used to ask if I just had butterflies in my stomach and I'd say, "Not butterflies. Killer bees." Any excessive collegiate drinking made me not just hungover, but

sick for days. My peers got headaches and bounced back with a greasy
cheeseburger, but I'd be vomiting and pooping for at least
forty-eight hours.

During my first year in New York, I'd sometimes get gripping
stomach pain
accompanied by a sore rash on my hands and face.

I got used to it all.

But blood was different. Blood meant something was really
wrong. I'd

planned for everything else, but I had never thought to plan
for blood. I signed

up for every high school extracurricular, graduated at the top
of my class, stayed

out of trouble (for the most part), made it out of my little farm
town, did four

years at Northwestern, moved to New York, secured a full-
time job with a

401(k), and paid my student loans on time. I was going to
work my way up the

media ladder and become the editor in chief of something by
the time I turned

thirty, *goddammit*. But now, I was bleeding uncontrollably
from my butthole.

No.

No.

NO.

"I need to go to the emergency room," I told Mom.

My folks' rural Illinois community, where they settled after
their marriage in

2006, is one hundred miles south of Chicago and thirty miles north of where I went to high school. Thousands of years ago this part of Illinois was quite rugged, but glaciers leveled it into miles of land fit for crops and interstate, gridded and flat like a board game. Now it's car country. Flyover country. Their town has about twelve thousand people and one Catholic hospital out by the interstate. Most residents work there, at the maximum-security prison, or at the manufacturing plant where my stepdad spent forty years. The town has a beautiful 1870s courthouse and pristine square next to dozens of empty storefronts. Opiates are in high demand, and the public schools are suffering from mismanagement and budget cuts. Most businesses have had to install video gambling to stay afloat. But despite the town's problems, people there are friendly, quick to ask how you're doing or lend you a snowblower or bring you a casserole. (Don't be fooled, though: Generations of repressed rage live just below midwestern nice.) I had been to the ER there once before, the time I was sick freshman year during winter break. The emergency department was not at all like the vast

expanses in New York with rows and rows of curtained-off beds and hundreds of people shuffling about. It had ten beds and the same number of seats in the waiting area. One doctor and a handful of nurses. Like the last time I visited, a nurse took me back right away when I told her my symptoms and the doctor saw me quickly. He was in his early thirties, with floppy brown hair and dark-rimmed glasses, and seemed nice enough. He scanned what the nurse had jotted in my chart.

“Bleeding during bowel movements?”

“Yes, rectal bleeding. I’m filling the toilet bowl to the brim with blood.”

“And you’re sure it isn’t menstrual bleeding?”

“Yes, I’m sure.”

“Some women have very heavy periods, you know.”

He insisted on giving me a rectal exam that I was not ready for nor did I

want. I didn’t know yet how to advocate for myself. Instead, I cried. That was

the beginning of relinquishing my body to health-care professionals, a

dehumanization that I’m used to now but will never be okay with. After an hour

and a few more tests, the doctor told me he wasn’t sure what was wrong, but he

suspected some sort of infection. He sent me home with broad-spectrum

antibiotics that did nothing for my symptoms except add vomiting.

The toilet kept filling with what looked like pulpy red juice, and the pain remained unbearable. I'd lost all control of my bowels, so I'd just lie on the bathroom floor, pressing my face into the cold tile. My parents eventually stepped in, taking me back to the same ER where the are-you-sure-it's-not-your-period doctor said I was beyond his capacity. An ambulance shuttled me to a bigger Catholic hospital forty miles away, where I spent several days getting poked and prodded and scoped but didn't mind so much thanks to the warm intravenous painkillers. When it was time to drink a gallon of laxative colonoscopy prep, I got halfway through and couldn't stand to swallow any more. "Keep going!" the nurse chirped each time she checked on me. "You can do it!" I couldn't do it. Mom snuck the other half into my hospital room's bathroom and poured it down the sink. I didn't know then that my life had changed forever. That I'd be able to divide my experiences into before I got sick and after I got sick. The following weeks, months, and years brought short and long hospital stays, good and bad doctors,

countless medications: antibiotics, steroids, anti-inflammatories, blood thinners, enemas, rectal foams, antispasmodics, antiemetics, opiates, suppositories, laxatives, biologics, blood plasma, potassium chloride, medicated mouthwash, antidepressants, sleeping pills, probiotics, benzodiazepines, weight-gain supplements, and antivirals; many side effects: hair loss, joint pain, migraines, hives, throat swelling, mood swings, appetite changes, intestinal blockages, bowel impactions, insomnia, and fatigue; multiple diagnoses, blood tests, stool tests, CT scans, X-rays, colonoscopies, giant hospital bills and fights with insurance companies, and three fecal microbiota transplants (yes, that means someone else's stool transferred to my digestive tract). I became a professional patient, and a good one. I learned that bodies can be inexplicably resilient and curiously fragile. I would never get better, and that would change *everything*: the way I think about my body, my health, my relationships, my work, and my life. When things get rough, people like to say, "this too shall pass." But what happens when "this" never goes away? As I got to know hundreds of chronically ill folks over the coming years

through my work as a journalist and via my support groups, it became clear that chronic illness's physical symptoms are one small part of an intricate puzzle.

We're heroic when it comes to pain—it's the mental Olympics that challenge us:

the depression and anxiety that come along with a malfunctioning body; the defeat of visiting doctor after doctor only to hear it's "all in your head"; the sick, sleepless nights worried about health insurance; the hope of a new treatment and

the crushing loss when it doesn't work; the longing for loved ones to understand

that you're the same you—*except not*; the grieving of a self that doesn't exist

anymore; the PTSD from long hospital stays and invasive procedures; the new

rules of an unrecognizable body; the inescapable loneliness.

Most conversation

about chronic illness—and there isn't much of it, publicly—focuses on the

physical. But forever sickness, I would learn, changes more than bones and

blood. It changes goals, careers, intimate relationships, families, and dreams.

At the hospital, a colonoscopy, biopsies, X-rays, and a CT scan confirmed the

diagnosis of inflammatory bowel disease (IBD). All five sections of my colon—

sigmoid, descending, transverse, ascending, and cecum—and my rectum were

riddled with inflammation and ulceration. IBD (not to be confused with irritable bowel syndrome, IBS) is a chronic disease that causes the immune system to attack the digestive system. There are two kinds of IBD: Crohn's disease, which affects the entire digestive system from mouth to anus, and ulcerative colitis (UC), which is contained to the large intestine (also called the colon). Crohn's and UC can range from mild to severe and will often progress if not treated. Both are notoriously difficult to diagnose, as the symptoms can point to other illnesses, and it isn't uncommon for it to take a long time to get a proper diagnosis. As I wrote in a piece for the *New York Times*, IBD results in what has always seemed to me to be the attempted birth of my intestines through my buttock. Like many chronic diseases, IBD works in patterns of flares and remissions; no one is quite sure what causes either, though there are several theories, and how long each flare or remission lasts varies wildly from patient to patient. I've tried to describe IBD in a way people without the disease might understand: Think of the worst food poisoning or norovirus you've ever had,

then times it by one hundred, for the rest of your life. But even that doesn't come close to capturing the pain. You can't know it until you're there.

An estimated three million people and rising in the United States have IBD, ¹

and most of us are diagnosed before the age of thirty-five.

Though autoimmune

diseases are much more common in women than men (in the United States, 80

percent of the country's 23.5 million autoimmune disease patients are women²), men and women are at about the same risk for IBD. ³ IBD patients try medication

after

medication—including

aminosalicylates,

corticosteroids,

immunomodulators, antibiotics, and biologics—attempting to manage the

disease and, hopefully, reach remission. (Some new research suggests that

patients who don't respond to medication might benefit from stem cell therapy,

which is still in the clinical trial phase. ⁴) Many IBD patients, including 70

percent of Crohn's patients, ⁵ go on to have surgical intervention that might

include having parts of their bowels removed or resectioned.

Some live with

temporary or permanent ostomies—external pouches that collect waste from

rerouted intestines; or J-pouches—internal pouches formed by removing the colon and rectum and connecting the small intestine to the anus.

Now here's where I list all the scary, painful stuff IBD can cause, like

ulceration and bleeding throughout the digestive tract,

diarrhea, vomiting,

dehydration, malnutrition (IBD guts have a hard time absorbing nutrients),

fatigue, fistulas (abnormal connections between organs;

rectovaginal fistulas are

a common topic of conversation in my support groups), bowel perforations

(holes in the intestines), scar tissue in the digestive tract,

fissures (tears in tissue

that often cause bleeding), abscesses, joint pain and arthritis, anemia, eye

inflammation and vision problems, and tooth decay. During childhood, IBD can

cause stunted growth and delayed puberty. ⁶ It can also trigger something called

toxic megacolon, which sounds like a death metal band but is in reality a life

threatening expansion and distension of the colon that traps gas and stool to the

point of rupture. (You know the chest-burster scene in *Alien*?

That was written

by a guy with Crohn's. He died from complications of the disease.) IBD also

increases the risk of digestive cancers, and people with IBD are more likely to struggle with other chronic illnesses including cardiovascular disease, respiratory disease, kidney and liver disease, and arthritis. (Many chronically ill folks have more than one illness, as they often come in twos and threes and sometimes more. Multiple diagnoses are not at all strange in the chronic illness community. Think of it like any structure: If one part begins to crumble, others are likely to follow.) On top of these symptoms, the drugs that treat IBD trigger significant side effects, like hair loss, joint pain, drug-induced lupus, and even cancer.

It's an unfair, heartless, and often debilitating disease. Each patient is unique—chronically ill people, even with the same diagnosis, aren't a monolith. My flare-ups tend to happen like this: First, I start to experience pain and gas. Not regular gas, like everyone gets—painful gas that bloats my belly so badly that I look several months pregnant. Inflammation and ulceration, combined with scar tissue from previous flares, make it difficult for gas to move its way out of my body, so it becomes trapped and extremely uncomfortable. Next comes the blood—initially, just a little on the toilet paper.

Then more. Then a lot, often with clotting. As it increases, so does my sense of dread. Mucus mixes with the blood along with intestinal tissue, and at a certain point I stop passing stool and start passing only that bloody mixture. As the flare progresses, I cannot control my bowels at all. I have accidents. I get sores in my mouth and throat that must be treated with a numbing rinse called “magic mouthwash” that was created for the oral burns experienced during cancer treatment. The 1-to-10 pain scale is highly subjective, but my flare pain hovers around a 7 with some higher bursts; when it gets above that, I go to the ER because it becomes unmanageable without IV opioids and doctor intervention. But I’m at high risk for hospital-acquired infections, so even going to the ER comes with major hazards. It’s frightening that the place I’m supposed to go to get better can make me even sicker. During flares, I get a painful, swollen sensation that feels like someone is playing an off-rhythm drum in my rectum at all hours, day and night. My rectum fills with fluid that makes it feel like I need to go to the bathroom constantly; this is when passing gas becomes a dangerous game of *Will She Shit Herself?* (insert

game show music here). I experience waves of cramps so agonizing that I moan as though I'm laboring. I throw up because of the pain. Because of intestinal narrowing due to new inflammation and old scar tissue, I often get blockages and impactions; blockages occur when the intestine is too narrow for anything to pass through, and impactions happen when stool becomes trapped and immobile. Both cause the sort of pain that makes me leave my body and crawl on the ceiling. The whole point of the digestive system is to get stuff *out*, but impactions and blockages make that impossible. And on already inflamed, scarred-up guts? I don't know the words to describe the misery. More often than not, I also get swelling and stiffness in my joints, nausea, fatigue, and weakness. During flares, my blood panels show borderline or full blown anemia, high inflammation markers like exponentially increased white cell counts and off-the-charts C-reactive protein (CRP), and decreased electrolytes. My flares, so far, have lasted weeks or months; some unlucky IBDers have yearslong flare-ups with little to no relief. I also get "mini flares" that last a few days at a time but remedy themselves, and my disease always flares up

during my period as hormones like estrogen can increase IBD symptoms. I've reached remission twice, and (knock on wood) am currently in the longest remission—almost three years—since my diagnosis. Remission doesn't mean I'm cured or even that I don't have symptoms; it basically means I have no signs of active disease via colonoscopy. That Thanksgiving, in the Midwest, I was initially diagnosed with UC, the form of IBD contained to the large intestine. Later, when I got more comprehensive medical care, that diagnosis changed to "indeterminate IBD," and then Crohn's disease. (I was also diagnosed with celiac disease, an immune response in the small intestine to gluten, a sticky protein found in wheat, barley, and rye that's managed with a strict gluten-free diet. For the sake of not confusing the reader, I will refer to my disease as Crohn's or IBD.) But that November in Illinois, when I dove into research about my diagnosis, I didn't know what "chronic" meant in any real sense. I started taking four large maroon pills called mesalamine every day and tweaked my diet. I didn't need to go to the bathroom as urgently or frequently, and when I did go, there was less blood. I

felt strong enough to fly back to New York, return to my job,
and find some
semblance of a normal twenty-four-year-old's life.

Wishful thinking.

Two weeks passed and my symptoms came back fiercer than
before, along
with new, troubling ones. The urgency and blood were there,
now with violent,
green, mucus-laden diarrhea. Going to the bathroom caused so
much pain that
I'd simultaneously vomit; a few times I couldn't make it to the
toilet, so I shit
my pants while forcefully vomiting into whatever plastic bag I
could grab in
time. My bedroom accumulated tied-off Walgreens bags full of
puke that I was
too weak to carry to the building's trash can, and I threw away
pair after pair of
soiled underwear and pajama bottoms.

One morning before dawn, after being sick for hours in the
apartment's
shared bathroom, as the toilet rapidly overflowed, I realized
that I'd clogged it.

Green diarrhea, blood, and vomit pooled across the bathroom
floor as I panicked
and searched for the plunger, which seemed to have
disappeared. (Turns out we
never had one.) My roommate, a subletter from the internet,
was still asleep, and
at this point I'd managed to keep my illness secret from her. So
I scrambled to

the closest drugstore and returned with a plunger, gloves, a bucket, and bleach.

On hands and knees, I frantically removed the evidence of my rotting, brokenbody.

Along with the diarrhea and vomiting came a high fever, stiff joint pain, and

a distended abdomen that frightened me to look at. My limbs were so thin but

my belly remained swollen. I didn't know whose body I saw in the mirror.

Panicked, I asked Mom to come to New York to help look after me. When she

saw how much I'd deteriorated since putting me on a plane two weeks earlier,

her eyes turned fearful.

"You're coming back to Illinois with me," she said. It wasn't a question—it

was a decision. I tried to argue I wasn't *that* sick. That I could handle it. That the

doctor said I'd have flare-ups and this was probably one of them. That I didn't

look so terrible, did I? We screamed at each other until she left in a taxi, on her

way to the airport without me. It took me less than five minutes to realize I

might die if I stayed.

"Mom, I changed my mind," I cried through the phone. Her cab was waiting

outside minutes later.

As quickly as she'd flown in, she was flying back—this time with a sick kid

who wouldn't remember anything of that flight. "We wandered the parking lot at O'Hare Airport looking for my car and I knew you were so close to giving up," Mom told me. "That was the first time I thought you might die."

A hundred miles of Interstate 55 later, I was back in the central Illinois hospital I'd been so glad to leave.

A stool test revealed that I had an infection called *Clostridium difficile*,

sometimes called *Clostridioides difficile* (as in "difficult"), or *C. diff* for short, a

spore-forming bacteria that's extremely contagious and hard to treat. Common in

hospitals, nursing homes, and other health-care centers where antibiotic use is

high and compromised immune systems are common, *C. diff* releases toxins that

attack the lining of the large intestine. It causes aggressive, foul-smelling

diarrhea, an increased white blood cell count, dehydration, fever, and abdominal

bloating. If it isn't treated properly, *C. diff* can kill you. It infects about 500,000

people every year in the United States and kills 30,000⁷—a historically high

number, thanks in part to increasing antibiotic resistance. To put that in

perspective, car accidents kill about 32,000.

The doctors swiftly isolated me and started a regimen of vancomycin, an expensive antibiotic (\$2,000 per course without insurance) that's a first-line treatment against *C. diff*. It seems counterintuitive that *C. diff* most often happens *because of* antibiotics and is then *treated with* antibiotics, but that's the protocol. Anyone coming into my room, limited to hospital staff and family, had to wear a full-length yellow paper step-in, gloves, and a mask. Common hand sanitizer doesn't kill *C. diff*, so everyone had to scrub with soap and water. A janitor bleached my hospital room toilet every hour, and I was embarrassed every time. (Hospital cleaning staff put themselves at risk every day as they deal with bodily fluids and waste that carry all kinds of dangerous pathogens. Thank them. Be kind to them. Pay them more.) Still, I wasn't worried. The doctors told me that *C. diff* usually goes away with a round of antibiotics and, not knowing any better, I believed them. On Christmas Eve in 2012, I was discharged to my parents' house, where I spent the following days taking vancomycin and obsessively bleaching the upstairs toilet designated mine; my biggest fear was that I'd get my family sick. I was afraid to

touch or hug anyone. I showered until the water scalded my skin and washed my clothing as hot as the machine would go. Though I appreciated Mom's commitment to helping me get better, it was painful to stay in her home. Six years earlier, my stepdad's son had sexually assaulted me when I was seventeen and he was thirty-four. The night it happened, we'd gathered for a "family" dinner—me, Kaetlyn, her boyfriend at the time, Mom, my soon-to-be stepdad, and my soon-to-be stepbrother, Aaron. It was the second time I'd interacted with him so I didn't know him at all, but the dinner table mood was jovial and everyone seemed excited to get to know each other. Mom and Dad's marriage—a cold and eventually violent relationship—had ended in 2001. Dad then sank further into the alcoholism that killed him when I was twenty years old, and Mom became increasingly devoted to Christianity. She didn't date after the divorce, but when she reconnected with my stepdad, a former flame, at a high school reunion, things got serious fast. His wife had recently died after a long illness. The need for companionship was coupled with

the wistfulness of rekindling a youthful romance cut short when he left for the air force. Marriage was decided upon right away. My stepdad—a kind, simple man with a mind for machines and a heart for caretaking—was the opposite of Dad. He had a good job and a cute little home, so I could see why Mom felt safe with him.

At dinner, we soon-to-be siblings bonded over shared musical tastes and cracked a lot of jokes. After dinner, we went our separate ways: me to a high school party and the older siblings to a bar. Before they married, my parents split their time between my stepdad's house and Mom's house, where I lived then with Kaetlyn and my niece, Zoe. I can't remember which house they went to that evening.

When I needed a ride after the party to Kaetlyn's boyfriend's apartment, where we'd planned to stay the night, Aaron said he was happy to pick me up. I could tell he'd been drinking when I got in the car, but I didn't say anything.

Teenage girls often try to be agreeable, even in dangerous situations—a protective mechanism many of us carry into womanhood. And besides, I was used to riding in cars with drunken men like Dad. We got to the apartment, ate

pizza, and went to bed: Kaetlyn and her boyfriend in the bedroom, me on one sofa, Aaron on another sofa across the room. I tucked my flip phone under my pillow, as I always did, and fell asleep. Disoriented, I felt someone's sticky breath on my neck. Then a hand was up my shirt and under my bra. In my brain, I was trying to wake up, trying to call out, trying to reach for the phone under my pillow. Instead, I froze. Aaron's weight was on top of me. His hands were on my breasts. He was kissing and licking my neck. He reached for the zipper of my jeans but fumbled and gave up. I was silent. I closed my eyes tight and tried to keep my body stiff and cold like a statue. And then, he passed out with his full weight on top of me. I tried not to move too much—I didn't want him to wake up—but I struggled to find my cell phone. *Where the hell was it?* I needed to call Kaetlyn for help. I needed to call 911. But the phone wasn't there. (Later, I learned that Kaetlyn had come out for a glass of water and set it on the counter while I was asleep, thinking I'd be more comfortable without it under my head.) Aaron, still fully passed out, slumped off of me and onto the floor. I wanted to scream or run or find a heavy object to bash

his head with. But I was frozen. I stayed awake the rest of the night—eight torturous hours—watching every movement, every breath coming from the body on the floor below me.

When Kaetlyn came out of the bedroom that morning to make us breakfast, she commented that it was odd Aaron was on the floor and not the couch. He laughed it off. I said nothing. When she drove me home, I still said nothing. But when I got in the shower, I fell to my knees and started sobbing.

“What’s going on? What happened?” Kaetlyn asked, peeking through the curtain.

“I ... I ... I don’t know (*sob*)! Aaron ... he ... he tried to ... to get on me

(*sob*)!” I didn’t have the language to explain that I’d been sexually assaulted. Kaetlyn wrapped me up in a towel and told me it was going to be okay, that I

was safe, that I never had to see him again, that she was going to fucking murder

him. I listened from the bathroom as she called Mom, screaming so hard her

voice cracked. Mom said it must be a misunderstanding or that Aaron was drunk

and didn’t know what he was doing. Years after, around the time I moved to

New York, she wrote me a letter arguing that I needed to take responsibility for

“the incident” because I’d been drinking, too (one cup of keg beer at the party).

Mom is a lovable person—friendly and silly, a good storyteller, the best

caretaker when you’re sick. Growing up, Kaetlyn’s and my friends adored her.

But when it came to protecting her daughters, she just ... failed, maybe because

her own trauma got in the way or maybe out of self-preservation. Either way, a

few months after the assault, Mom married my stepdad with none of their

children present.

To this day, my parents maintain a relationship with Aaron.

Mom calls him

“son.” It will never stop being painful. It will never stop being hard to love my

parents—it’s a choice I must actively make. And that means that relying on them

during health crises is all the more complicated. Long-term illness doesn’t fix

families. If anything, chronic illness makes the knotty webs that families weave

even trickier to untangle. Mom loves me *and* she’s hurt me. I want independence

and I need my parents. As the round of antibiotics came to an end, I decided to

travel back to New York again. The infection was almost gone, I thought, and I

needed to get back to my work, my apartment, my life.

When I got back to New York in early January 2013, four days passed before I was in a Brooklyn emergency room with a recurrent *C. diff* infection. I started another course of vancomycin—"Sometimes it takes two rounds," the ER doctor assured me. Two weeks and another hospital stay later: another positive test. See, *C. diff* thrives in already-compromised guts, and mine was full of inflammation and ulceration from IBD—perfect nooks and crannies for bacteria to multiply. An infection that's difficult to treat even in a healthy gut became nightmarish in mine, and folks with underlying illnesses like IBD face a higher risk of death due to *C. diff*. Thankfully, I was referred by a college acquaintance to a bright, capable gastroenterologist at Weill Cornell on the Upper East Side of Manhattan. She was the first to affirm the interrelation of my symptoms and talk to me about the mountainous mental challenges I faced with IBD and *C. diff*. She was up-to-date on new research and treatment options and suggested a fecal transplant, which she could coordinate should antibiotics fail. In reviewing my records, she wasn't convinced that I had ulcerative colitis, so she changed my diagnosis to

“indeterminate IBD.” (It would be another two years before my Crohn’s diagnosis.) She was the first doctor who made me feel safe, heard, and understood. Convinced that vancomycin was not going to rid me of the infection, she switched me to a stronger and even pricier antibiotic called Difcid (\$3,500 for twenty pills without insurance). From January to March 2013, I hung on through what I now think of as “the Lost Winter.” I spent most of my days in close proximity to a toilet. I was afraid of passing the infection on to anyone, so I isolated as much as possible. I did little else but sleep, take Difcid, work from home, and taxi to and from doctor’s appointments. Even a cab ride to the doctor’s office meant taking large doses of antidiarrheal medicine to prevent accidents, but antidiarrheal medication is risky for people with *C. diff* because it traps the bacteria’s toxins in the colon longer—it’s actually better to pass it than to hold it. I sometimes went weeks without going outside, and as winter turned into spring, I grew increasingly unsure whether my life would ever become more than days and nights in a bathroom or bound to my bed. Mentally, I was unraveling.