

# WHAT DOESN'T KILL YOU



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

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## Chapter 5

### OLD TRAUMA, NEW TRAUMA

I spent my formative years in the rural Midwest, where everyone was nice and polite but thoroughly fucked-up. No one there went to therapy—or if they did, it was with a church leader under the guise of “spiritual guidance.” Though everyone in New York seemed to proudly have a therapist, in my first few years in the city, I still thought therapy was frivolous, something reserved for bored, rich people—or worse, for people I’d watched as a kid on trashy after-school talk shows, guests with compulsive disorders or aversions whose “therapists” made them lick dumpsters or get in a tank full of snakes. Circa 2011, I’d sought out a therapist who specialized in body dysmorphic disorder but bailed after two sessions when she started pushing “exposure therapy.” (At that time, I couldn’t think of anything scarier than looking at myself in a well-lit mirror.) Instead of searching for a therapist better suited to my needs, I’d given up altogether, unaware of how much I’d need help two and a half years later.

In the summer of 2013, as I recovered from *C. diff* and learned how to live with IBD, I scoured Craigslist for a solo apartment. I wasn't sure if I could afford to live alone, but I didn't want to risk sharing a bathroom or being sick for extended periods in a shared space. I was tired of trudging to the bathroom ten, fifteen, twenty times through a roommate's dinner party, or explaining why I was in bed for the seventeenth day in a row. I didn't want my roommate's normal, young-person life to change because I was sick. They should be able to have people over and play music and be loud and laugh and dance. *I* was the weirdo. I needed to find my own space to be alone, incurable, unfixable. My health had improved thanks to the transplant, but I still had daily IBD symptoms—pain, urgency, fatigue—and the lingering fear of the unknown. I wanted privacy. I rented a four-hundred-square-foot studio apartment on the top floor of a classic brownstone off Nostrand Avenue for \$1,100 a month. It had lovely parquet floors and a faux mantel perfect for positioning above a writing desk. I painted the walls a calm blue-gray and hung Dad's old film posters. The building

backed up against a Caribbean bakery, so the smell of Jamaican patties—buttery crusts and rich curried meat—floated in through the windows. A local mosque's call to prayer rang out every dawn while the neighborhood was sleepy and still. I loved that apartment, even if a cunning and uncatchable mouse lived behind the stove and an ice storm caused the ceiling above my bed to cave in.

But while I was physically safe, I was not *well* when I lived there. Living alone allowed me to coddle my worst anxiety-driven behaviors in isolation, like sitting in front of the mirror for hours poking and prodding every pore until my face was swollen and bloody—my brain's attempt at distraction from other stuff, like thinking about my illness and recent hospitalization. Though destroying my skin wasn't helpful in the long run, it kept my mind busy and sidetracked me from dealing with lingering trauma—one of my brain's sloppy magic tricks. And I began working for Lifehacker from home, which meant I didn't leave the apartment for days. Venturing outside put me on high alert. A car horn or a

person brushing past—hard to avoid in Brooklyn—ignited my fight, flight, or freeze response (“freeze” is a third mechanism common in childhood trauma survivors who learned that staying still was a way to tolerate or avoid abuse), leaving me agitated and tired. My mental health nose-dived.

The only person I had any real interaction with was my on-again-off-again boyfriend, Jimmy, who lived within walking distance and came over late nights after his bartending shift. But even then, it was little more than sex and sleep.

Our last breakup had not been amicable and all of our friends knew we were toxic for each other, so our relationship thrived unhealthily on sneakiness and secrecy.

Meanwhile, I was fixated on every motion of my guts, every undulation, every bowel movement. It’s bizarre to observe each liquid or solid or in-between that comes out of you, to become hyperaware—obsessed, even—with your own poop. And on top of that, I was consumed with wondering what caused me to get IBD. Was it because I starved myself from ages twelve to seventeen? Had

unbridled stress made my guts turn on me? Did I take antibiotics one too many times? Could it be punishment for misdeeds? Was it internalized trauma from childhood? After all, adverse childhood experiences (ACEs) increase the likelihood of poor health outcomes. <sup>1</sup> I went over and over the possibilities, all of which were rife with self-blame. I knew the best answer, according to doctors and researchers, was “some combination of genetics and environment,” but that wasn’t good enough for me. I fixated on the cause, because if I had caused it, then maybe I could cure it. In a strange way, my self-blame was a form of hope. But I’d hit a breaking point. I recognize now that I was wrong on all counts about who therapy is for, though mental health care does remain inaccessible for people who could really use it due to the outrageous cost. (To this day, I can’t go as often as I’d like because it’s so costly. In New York City, where everything is expensive, therapy averages \$200 to \$300/hour. Many providers make you pay up front, and even if your health insurance will reimburse you for part of the cost, it can take months

to see any money. When my psychiatrist went out-of-network, I went from paying \$20/session to \$275.) My prejudiced assumptions about therapy and what it meant to seek professional mental health help let me drag my feet for longer than I should have. It took panicking to the point of blacking out and falling down to make me think, "Huh, something might be wrong here." It's a great regret that I didn't seek help sooner. Years sooner. Before my first therapy session, I tried to narrow down what I thought and how I felt before the attacks occurred. My illness and recent hospitalizations were top of mind, as was my fear of the future with Crohn's disease, but I also became preoccupied by my childhood and adolescence, my parents' marriage, and Dad's death. Memories and the emotions attached to them that I'd, consciously or not, buried deep in the vault overwhelmed me. And I kept having this recurring thought: *I have wasted so much time doing things "right," being a grown-up before I was ready, worrying about the future, taking care of mean men, defining myself through work, pretending to want Special K for dinner and*

*angel food cake for birthdays, showing up for some dude's  
crappy band, wearing  
pants at the beach, wearing T-shirts in the pool, laughing at  
jokes that weren't  
funny, agonizing over the curve of my belly and the same two  
zits. So. Much.*

*Time. And now, I'm sick.* That thought turned over and over  
in my brain. I was  
underwater, looking up toward the surface while fully  
aware I couldn't hold my  
breath long enough to reach it. *I'm sick and I will never get  
that time back.*

Could a recent traumatic experience—chronic illness  
diagnosis, life  
threatening infection, fecal transplant—resurface long-  
buried pain? A kind, soft  
spoken psychiatrist in a congenially beige Midtown office  
explained that, yes, it  
was possible. New trauma can bring up old trauma, and  
when your brain doesn't know what to do with it all, it  
panics. *Of course* you're having panic attacks, the  
psychiatrist said. Hot embarrassment rose through my  
cheeks as I spoke, but I  
did my best to explain the past and present compulsions:  
squeezing my muscles  
in certain patterns before sleep, eating bites of food in even  
numbers so no one  
would get lonely in my stomach, focusing on different body  
parts that I thought



needed fixing, my tendency to isolate, and the destructive skin picking. I

revealed my history of disordered eating, my parents' own traumas, and Dad's addiction and death.

It feels strange to dump out a life's worth of ache on a total stranger. You

expect them to point toward the door and say, "I'm sorry, but you are way too

fucked-up for me to help. Please leave." But they just nod, smile, and take notes.

Therapy isn't pleasant—at least, not for me. Maybe some people enjoy it. I still

hate going a decade into the process, even though I can see and feel my progress.

Examining one's multitudes is difficult, lifelong work.

Peeling back layer after

layer to discover the who and what and how of what makes you *you* is painful.

(This isn't to say therapy can't be fun or funny—that's true, too.) What you learn

in therapy about yourself and your relationships isn't always nice. That shit

hurts! It stings, a lot, and sometimes for a long time. But it's *constructive* pain—

the deep, tender kind that comes with growth. Being alive at all is hurty stuff,

and I've found that trying to bury that part of humanness only increases

suffering. Trauma will always hurt, but we can carry it,  
nurture it, uncover it; or  
we can hide it and let it feed.

The overwhelming takeaway from my first therapy session  
wasn't relief, but

guilt. I felt that because my physical health was improving,  
I shouldn't *need*

therapy. That a second chance at life should be enough to  
remedy my mental

illness(es). Other people have it much worse than I do, I  
thought, so why am I

here? *Another white girl with daddy issues and a former  
eating disorder. What a*

*cliché!* I was self-sabotaging. I didn't want to acknowledge  
that my chronic

illness affected me not just physically but also mentally.

And I was afraid to tell

my secrets, giving voice to the fresh and faded traumas I'd  
ignored.

It was uncomfortable, but I kept going back, in part  
because I wished for the

psychiatrist to think I was smart and capable and  
interesting. I fretted over

keeping him *entertained!* (I needed to be the best at  
everything, even therapy.)

But over several more visits, as my defenses softened, my  
psychiatrist explained

how I'd been using anxiety and anxiety-driven behaviors as  
coping mechanisms

since childhood. In a backward kind of way, anxiety diverted my brain from focusing on more painful thoughts, and anxiety-driven behavior (i.e., skin picking) was my attempt at comfort. Children who experience trauma learn to protect ourselves through these types of thoughts and behaviors, until eventually those protective mechanisms don't serve us anymore—but they can be difficult to let go of. My psychiatrist told me to think of it this way: We do what we need to survive. And when we're safe, we must let go of the things we don't have use for anymore. Further, he helped me understand that my childhood had given me a great number of gifts, like resilience, self-reliance, and adaptability. While I felt unequipped to face a lifetime of chronic illness, I was more prepared than I'd given myself credit for. Over the course of these first sessions, my psychiatrist also explained that I likely had PTSD stemming from my chronic illness diagnosis and recent hospitalizations, as well as complex PTSD, or CPTSD, from a childhood with an alcoholic father and from Dad's death. (CPTSD is a newly recognized kind of

post-traumatic stress diagnosis meant to focus on long-term trauma rather than onetime events.) It took several months for me to talk about the sexual assault that happened when I was a teenager. I was scared and ashamed and I didn't know how to say these words out loud: "My stepfather's son tried to rape me while I slept." I tried to minimize it: *At least he passed out. It wasn't "technically" rape. Again, others have had it so much worse.* But when I finally told my psychiatrist, he didn't echo any of this faulty rationality. Instead, he said that he suspected I, like many sexual assault survivors, was dealing with post traumatic stress. There's ample data to support my PTSD from the assault. A US National Comorbidity Survey report found that 94 percent of women experience PTSD symptoms—which may include anxiety, feeling jumpy or irritable, flashbacks, nightmares, hypervigilance, insomnia, reckless behavior, avoiding certain people and places, and trouble concentrating—after a sexual assault. <sup>2</sup> My PTSD was further complicated by the fact that Mom and my stepdad maintain a relationship

with the man who attacked me, and because I had recently grown to rely on my parents more during hospitalizations and bad flare-ups. (I also choose to keep a relationship with them as I love Mom and want her in my life, illness or otherwise, despite her parental shortcomings.) Though I haven't seen my abuser since the night he assaulted me, a translucent connection to him remains intact, which has only been bolstered by my chronic illness and intermittent reliance on my parents as caregivers. After several sessions, I decided to try a daily SSRI for anxiety, obsessions and compulsions, and PTSD, as well as a situational benzo to offset the panic attacks. I no longer need the benzodiazepine, but I'll be on the SSRI for the rest of my life and that's okay. Any fear I once held about losing my creativity to antidepressants dissipated after I realized that I actually functioned at a healthier, more productive level when my brain was medicated. And most days, PTSD isn't an issue. I go weeks, months even, without thinking about it, and then a man will pass too closely in the grocery store or I'll catch a scent similar to

Aaron's nauseating blend of hair gel and whiskey. My body reacts extremely—

heart racing, sweating, shaking, sometimes vomiting—and

I remember: "Oh

right. PTSD." (PTSD due to medical trauma is another kind of post-traumatic

stress common among chronically ill people. I discuss it in Chapter Ten.)

If chronically ill readers come away with one lesson from this book, I hope

it's this: Your body and your brain are not two separate entities. They're a

partnership. What happens to your body affects your brain, and what happens to

your brain affects your body. Taking care of your brain's health should be no less

of a priority than taking care of your body. In a past disease-treatment model,

human bodies were looked at like machines: If one part was broken, that part

could be fixed independently from the rest, and the machine would function

"normally" again. But that model has fallen out of favor as we learn more about

the connection between mind and body and as we discover more about chronic

illness versus acute illness. If you have a chronic illness, find a doctor who

affirms this and a therapist who can help you make sense of your own brain body connections. Some of your mental health support may come in the form of medication; other help can come from talk therapy. (For more information on how to talk to your therapist about medication, flip to Appendix V, “How to Talk About Mental Health Medication.”)

Though medication brought me back from the cliff’s edge, it was only one part of the puzzle. To get a true handle on my mental health I had to begin the slow, painstaking process of figuring out what made me the way I was and what kind of person I wanted to be—now, with chronic illness—moving forward. For me, coping with PTSD and anxiety will likely be lifelong work, but just as I’ve learned what my body needs to manage my physical illness, I’m aware of and prepared for what my brain needs, too.

As you’ve probably picked up on, my childhood home was unpredictable and because of that, I craved control. I shunned anything that made me feel as though I wasn’t in power. My family moved six times and to five states by the time I was in sixth grade. At first it was because Dad got restless and because

good opportunities in academia were coming his way; he was a talented documentary filmmaker and teacher who made movies about late-1970s Rastafari culture and worked closely with Grenada's Marxist-Leninist prime minister, Maurice Bishop, building the country's public school system. Bishop, Fidel Castro, "Brother Bob" (as he called Bob Marley), these were his idols until the end. Before Kaetlyn was born in '82 (and before Bishop was executed in '83), my parents came back to the States where Dad worked his way up the ladder to deanship, mostly at community colleges and state schools. But later, we moved because Dad couldn't keep a job. Mom never seemed to have a say. My parents were progressive in a lot of ways, but not in the man woman dynamics of their marriage where the wife shut up and sacrificed so the husband could excel (and when the husband stopped excelling, he blamed the wife). That's how I understood relationships: men created pain and women silently absorbed it, like photosynthesis. At the turn of the millennium, in the wake of another job loss and Kaetlyn's



own teenage struggle with drugs and alcohol, Mom and Dad moved us to a tiny, rural town in the middle of Illinois closer to extended family. Somehow, Dad convinced Western Illinois University to hire him. The campus was one hundred miles from our new house, so Dad rented a second small house near campus to cut down on commuting. He could drink as much as he wanted to, alone, there—because Dad never drank with other people. Never at bars or parties. Only alone. In the spring of 2001, he didn't show up for work and the cops couldn't locate him. For days, we thought he was dead and waited for the call that his body had been found. But he wasn't dead—he was holed up in a motel. I wrote about his disappearance in my childhood journal, a purple and yellow hardcover embossed with blue butterflies:

*March 1, 2001*

*I have some bad news. Dad is missing. He hasn't been at work for the past two days, hasn't been at his house, hasn't called, and his car is gone.*

*I'm afraid he's dead. I don't know what to do. I am empty in my heart.*

Dad didn't keep the job at Western long. Employment tethered him to some sense of reality, but without it, he was in a free fall. If he was awake, he was drinking. He hid beer cans in his TV cabinet and under the bathroom sink. Sometimes he passed out in the bathtub with the door locked while we pounded on the door, worried that he'd drown. We eventually convinced him to enroll in an inpatient treatment center for alcohol use disorder and depression. He lasted a few days before he decided he was smarter than everyone there and demanded we pick him up and bring him home. That same day, Mom had surgery on a melanoma on the bridge of her nose; what we expected to be minimal was an extensive, face-changing procedure with skin grafts and large stitches. Kaetlyn, still just a kid herself, had to shuttle Mom to and from surgery while coordinating how to bust Dad out of rehab. With Dad unemployed, we could no longer afford the mortgage, utilities, or car payments. Creditors called so frequently that Dad ripped the phones from the walls. He threatened suicide: "When you come home tonight, you'll find my

body,” he warned Mom. “You better not let Tessa come in the house first.” He

was increasingly belligerent, taking out his rage on everyone/ everything from

Mom to the dog to the dinner plates, which he liked to smash on the back deck.

He slapped Mom so hard that I heard her gasp as the wind was knocked out of

her, and I begged her not to call 911 because I was just a kid who didn’t know

any better.

An argument with Kaetlyn ended with her chasing Dad back to his room

with a butcher knife. Barely seventeen, she moved in with her older boyfriend

soon after. I understood why she left, but I was frightened without her. Kaetlyn is

petite but freakishly strong and scared of nothin’, so I always thought if Dad

pulled some serious shit, she’d be the one to stop him. So long as I was in her

immediate orbit, I felt safe. Mom told me to lock my bedroom door at night, as a

precaution, and I did as I was told. Years later during a visit to Brooklyn, she

told me that she worried then that Dad would murder me to get back at her for

being a “bad wife.”

Just before my thirteenth birthday in 2001, Mom signed the lease on a \$500-a-month apartment that she wasn't sure she could afford and prepared to leave Dad. She told him her plans to live elsewhere, and that only increased his threats and violence. Our house was in foreclosure. The repo man kept attempting to take the cars. Two dozen feral cats lived on our deck. Mom and I collected a few things at the house as soundlessly as possible so Dad wouldn't know we were there, but he heard us rummaging around and came out of his room, enraged. He chased us to the car and pried my passenger door open, jumped flat across me, and lunged at Mom. Our three bodies tornadoed together in a spinning pile, limbs flying, voices screaming. He ripped the keys from the ignition and threw them across the yard. "Cunt!" he slurred, punched the car, and stumbled back inside. (I looked up the word *cunt* later on because I hadn't heard it before.) I thought he was going to come back with a knife, so I dashed across the yard for the car keys and raced back to the Mitsubishi. We drove, sweaty and trembling, to my aunt's farmhouse. I sat on the front porch

with my cousin, shucking corn, while Mom called the police. Dad was arrested. I never saw my parents together again. They never spoke again, either. At thirteen, I became their default mediator, hounding Dad for seventy-five-dollar child support checks and asking Mom to return boxes of family mementos. In the wake of Mom and Dad's split, I became concerned with two things: my presentation and my grades. I would be thin and clean and smart. I would maintain a perfect GPA and I wouldn't have sex until I got to college. I would be on Homecoming court and high honor roll. I would be so good and so clean and so smart that no one would suspect that some weeks, my kitchen cabinets were empty. Then, I would choose a university in a major city where I would reinvent myself. Control, as always, was the theme into my twenties. But chronic illness stopped me in my tracks, stripping away any semblance of authority that I had. I'd always felt dominance over my body—to make it smaller, to study it, to punish it—when external circumstances were beyond my grasp. I could rein my body in as needed until I felt calmer, safer. Crohn's

disease removed that power. It made the very thing I used to rein in wild and unpredictable. The phone call was coming from inside the house.

I had my first of about a dozen panic attacks in August 2013, four months after the first fecal transplant. My physical health was manageable as I recovered from *C. diff*, but my anxiety was high, relying on a destructive pattern of isolation, obsessive thoughts, and compulsive skin picking. I woke up every day alone in that small Bed-Stuy studio with a racing heart and a fluttering stomach.

One August afternoon, as I sat at my desk, my heart began beating so fast and loud that I could hear it in my eardrums and see it through my shirt. My vision blurred and my hands trembled as they rested on the laptop's keyboard. Thinking I needed to splash some cold water on my face, I got up to go to the sink. But my cheeks flushed hot and I felt unsteady as I stepped toward the faucet.

My heart pounded even harder. *Am I having a heart attack?* I tried to take a calming breath—in through the nose, out through the mouth, just how Momtaught me before choir performances and class representative speeches—but

drawing air felt sharp and shallow. My sight got kaleidoscopic, like when you press on your eyeballs to “see stars.” *Am I dying?* And then, as fast as I stood up, I fell to the floor. I don’t know how long I was there—maybe thirty seconds, maybe an hour—but when I came to, I crawled to bed and slept through the rest of the day, through the night, and into the following morning. It was as though the life force had been drained right out of me. Some internet sleuthing led me to believe I’d had a panic attack, and when I finally sought out therapy that fall, my psychiatrist confirmed it. I still regret that it took several of these *am I dying?* panic attacks to recognize that I needed help. I needed therapy as a kid, really, and I most definitely should have sought it out as soon as I was diagnosed with IBD. Chronic illness is enough to need professional help. But it doesn’t exist in a vacuum. Pain thrives alongside other pain. As my editor vividly illustrated during one of our conversations about this book, everyone carries around these heavy buckets. One bucket might be a traumatic childhood, another an abusive

relationship, a third the loss of a loved one, a fourth an unfulfilling career. Add to that mix incurable illness, a very full bucket that you must carry for the rest of your life, and it becomes too unwieldy to carry alone. You have to decide which buckets you can set down and which you can lighten. That's where therapy helps.

When Dad died in 2008 during my junior year of college, his death became another heavy bucket. I was relieved, in a way that anyone who's loved an addict will understand, that he was gone, but I still missed him desperately. Dad was confusing because knowing him was like knowing two people: sober Dad and not-sober Dad. If addiction is a disease, which the research supports, then Dad was chronically ill, too. I wish that made the hard stuff—the arrest for physical violence directed at Mom, the emotional terror rained on Kaetlyn, the involvement in men's rights forums, the lying, the stealing—easier to forgive. Even during periods of sobriety, Dad was often arrogant and mean. He was a genius, no doubt, but he wielded his intelligence as a weapon to make others feel



small. He made rude comments about strangers' looks and weight, so from a young age, thinness and beauty were things important to *me* because they were important to *him*. Dad was combative and liked to argue because he'd win; he was smarter and meaner than any opponent. Still, he could be sweet and even goofy. He bought us a karaoke machine and never said we were annoying, even though we were. He let us do his makeup, badly, and he participated in imaginary tea parties, fashion shows, and dance performances. He had a solution for everything; if he didn't have one, he'd research until he did, presenting a perfectly organized, color-coded, highlighted portfolio. When both family cars broke down in the Columbia River Gorge, on the seventeen-hundred-mile move from Oregon to Iowa, we didn't worry because Dad would know what to do. For holidays, he made intricate handmade astrology charts, photo albums, and personalized playlists. He took thousands of photos of us as children and recorded hundreds of hours of home video, always the documentarian. He wrote lovely, poetic letters. When I get sad about the way

things turned out, I try to remember that he loved his children. I know my father loved his children.

Here's something I learned in therapy: I can redefine my memories, traumas, and experiences to work *for me* instead of whitening them out. I don't need reinvention. When I started doing the work of figuring myself out, I actually liked myself—what a *weird* revelation after a life of self-loathing (made even weirder by the fact that a chronic illness diagnosis sparked this self-discovery).

And when I began to see my value, I stopped wanting to be someone else, a far off future self. I claimed all the strange little piled-up bits, even the ones that used to embarrass or hurt me. And it became easier to deal with other challenges, even massive ones like chronic illness, because I can now set down some of those heavy buckets. I'll still carry chronic illness for the rest of my life, but it feels lighter.