

WHAT DOESN'T KILL YOU



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

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Chapter 2

DOCTORS

Doctors become immediate and central characters in any chronically ill person's story. I always say that for every ten bad doctors in the United States there's one good one, and for patients I've spoken to in rural areas, this *very nonscientific* statistic becomes even more dismal. Away from urban areas, fewer practitioners exist, so there's little to no ability to switch doctors or to get a second opinion without extensive travel. Americans who live outside big cities remain stuck with whoever is geographically convenient. Telemedicine is helping this some, ¹ but a large rural chunk of this country still lacks effective high-speed internet access. ²

I live in New York City, where there's no shortage of doctors. (Fun fact: Crohn's disease was discovered at New York's own Mount Sinai Hospital in 1932.) Research at the highest level takes place here, and some of the best hospitals in the world are no farther away than a cab ride. If I don't like a physician, it's simple enough for me to find a different one who accepts my insurance, for which I can afford to pay \$700/month. My state's health insurance

marketplace is abundant compared to most, and I can't be kicked off my plan for a preexisting condition or because my health needs are too expensive (thanks, Obama). I don't regularly use mobility aids like a walker or a wheelchair and when I'm feeling well enough, I don't have trouble getting around spaces designed for able bodies (which is almost all spaces). I'm white, so I don't deal with the dangerous racism that's prevalent in health care and that leads to worse outcomes—including death—for people, especially women, of color. *Especially* Black women. I'm thin, so I don't receive the brunt of fatphobia or have my symptoms dismissed with a wave of a hand and "you just need to lose weight." And I'm cis, so I don't avoid seeking medical care out of fear of transphobia or being misgendered. I have the privilege—more than privilege, really; I have power—in the ways I'm able to navigate the health-care system. Moreover, IBD is considered a "first world disease." White people and people of Ashkenazic Jewish descent have a higher-than-average risk of getting IBD, and even though IBD is increasing among the Black population in the United States and the United Kingdom, ³ the public image of IBD remains white. This, unfortunately, matters when it comes to fundraising and paying for

research. I will never be the most oppressed person in any room when it comes to being sick. If I had to deal with just one negative bias—leave alone overlapping geographic, racial, gender, or weight prejudices—my health outcomes would surely be worse.

This book isn't about the American health-care system and it's *entirely* about the American health-care system, because chronically ill bodies are at its mercy.

Good health care allows me and people like me to live more independent, sustained lives—and in my country, in my lifetime at least, insurance has been required to access that care. Sometimes I fantasize about what it would be like to be free of the fear of losing my health insurance; how much of my brain space—of this country's collective thinking power—would be uninhibited to focus on other things? We've been fooled into thinking that basic human needs, like access to health care, are indulgences reserved for those who "worked hard enough." I know that health care is a human right and that gets me called *libtard* and *snowflake* and worse. But there's nothing radical about *not* wanting to die for lack of health insurance. What's so radical about wanting to live?

This is the part of the book where I can imagine the Amazon reviews: "Gee,

I was with her until she got all *political*.” This book is about my body, and I don’t live in an apolitical one. Chronic illness is a justice issue. Health justice—the work I do through writing and advocacy—means not only free and accessible health care for all, but secure homes and public spaces, clean water, freedom from police violence (disabled people make up half of cop shooting victims), preventive care, environmental health, gender affirmation and care, and sexual and reproductive autonomy. As the COVID-19 pandemic and protests against police violence overlapped during the spring and summer of 2020, I saw them not as two separate issues but as two branches of the same root. Racism is a public health emergency. Health justice *is* racial justice. Here’s what it’s like in the United States: First, let’s remember that nearly thirty million Americans don’t have health insurance at all, ⁴ a number that’s risen for the first time in a decade thanks to cuts in public health programs like Medicaid and the Children’s Health Insurance Program (CHIP). Women and children report the highest uninsured rates, and an estimated 45 percent of Americans ages nineteen to sixty-four are inadequately insured or underinsured. ⁵ And even for people *with* insurance, deductibles and out-of-pocket expenses

often keep them from seeking care; plus, a lot of plans don't cover dental or vision because teeth and eyes in need of care and correction are, for whatever reason, considered separate from the rest of the body. And though mental health care has improved somewhat under the Affordable Care Act (ACA), one in five people with a mental health condition still aren't getting professional care. ⁶ Less than 50 percent of American adults with clinical depression receive treatment—this could be for a variety of factors including lack of insurance coverage, lack of access to mental health care, the stigma surrounding therapy and medication, or a decreased motivation to seek help. ⁷ And at-home health care for the chronically ill and the elderly is hard to qualify for and even harder to get insurance to cover; caregiving usually falls to the family, whether they're prepared to take it on or not. A 2019 *American Journal of Medicine* study⁸ of 9.5 million newly diagnosed cancer patients found that nearly half lose their entire life savings within two years due to out-of-pocket treatment costs, and 62 percent of cancer patients are in debt because treatment—even with insurance—is so expensive (on top of this, cancer treatment is so invasive that it requires many to stop working). A 2010

JAMA study of 3,721 acute myocardial infarction patients found that many delayed seeking care because of financial concerns. ⁹ That's right: People *in the midst of a heart attack* didn't go to the ER because they were afraid it would cost too much even with insurance. They aren't the only ones: According to a 2019 Kaiser Family Foundation poll, half of American adults said they skipped necessary health care in the last year due to cost, and one in eight said their health condition got worse as a result of missing or delaying an appointment. ¹⁰ What's clear is that the private health insurance system is failing. The few people it's working for are those who profit from its lucrative costs and those who can wield it for exploitation—an insurance holder in an abusive marriage or the bad boss who leverages it against employees. A January 2020 Harvard study looking at government data between 1998 and 2017 reported that even under the ACA, "most measures of unmet need for physician services have shown no improvement, and financial access to physician services has decreased ... [due to] narrow networks, high-deductible plans, and higher co-pays." ¹¹ Further, the study found that the number of adults with health insurance who were unable to see a doctor rose over twenty years from 7 to 12 percent. That's a *60 percent*

increase in people aged eighteen to sixty-four who can't afford to see a doctor even though they have insurance. The study's authors went on to write: "In Canada, only 1 percent of adults 45 years old or older with a chronic disease reported a cost-related unmet health need, compared to 18.7 percent in our U.S. sample." Even twenty years before the catastrophe of the COVID-19 pandemic, the United States had the most expensive health-care system in the world yet came in 72nd out of the World Health Organization's 191 member nations for the level of health that system achieved for its population. ¹² Annually, forty-five thousand American deaths were associated with a lack of health insurance; that meant working-age people without insurance were at a 40 percent higher risk of death—even when taking into consideration socioeconomic factors—than the same age group with insurance. ¹³ And, again, even then, the life expectancy gap between rich and poor Americans was the highest it had ever been: 20 years. ¹⁴ That's right: Wealthy folks have been getting *twenty extra years* of life in large part because they can afford and access health care. Prescription drug pricing offers an especially evil aspect to this baffling, arbitrary health-care system, making necessary drugs like insulin so expensive

that patients ration, go without entirely, or rely on “black market” insulin

exchanges that flourish on the internet. Five years ago, the every-six-weeks drug

infusions I take to manage IBD were billed to my insurance at \$15,000—now

they’re billed anywhere between \$70,000 and \$90,000 and then my infusion

center and my insurance provider do some sort of backdoor negotiating over the

price insurance will actually pay (all the while making me, the consumer, believe

I’m costing the insurance company a whole heck of a lot more than I am).

Ninety thousand dollars. *For the same medication.* I hear similar stories every

day in my support groups from people who’d be nonfunctioning or dead without

access to our doctors and medications. Remdesivir, an antiviral drug used in the

treatment of COVID-19 patients, costs privately insured patients \$3,120 for a

five-day course via the drugmaker Gilead; it takes roughly \$10 in raw materials

to make the drug. [15](#)

It’s no wonder, then, that thirty-four million people in the United States say

they’ve lost a friend or family member due to inability to afford medical care. [16](#)

It’s a particularly American cruelty to make sick people beg for financial help via Go Fund Me while insurance CEOs rake in tens of millions of dollars every

year. What filmmaker Ava DuVernay said about the criminal justice system is true for the health-care system, too: “It isn’t broken. It was built this way.” (If you’d like to read more about the baffling ways our health-care system functions—as it was designed to under capitalism—I recommend *An American Sickness*

by Elisabeth Rosenthal.)

Some groups of people are more at risk than others. Fifty-nine percent of Health Professional Shortage Areas (HPSAs) are located in rural America. [17](#)

These health-care-provider shortages lead to lower rates of preventive screenings, which means illnesses are caught later and become harder to treat.

Less than half of all rural counties have access to obstetric services, and less than half of pregnant people in rural areas live within a thirty-minute drive from perinatal services. [18](#) Rural communities also report slightly higher uninsured rates than urban communities, [19](#) which further reduces access to care. (Not surprisingly, states that expanded Medicaid report better insured rates in their rural communities than nonexpansion states.)

Black mothers are four times more likely to die in childbirth than white mothers, [20](#) and this doesn’t improve as income or education increases. High

profile stories in recent years highlighted these risks: Serena Williams, the most accomplished athlete of our lifetime, came close to dying after giving birth to her daughter because caretakers ignored her symptoms (and her own self-advocacy!) of a pulmonary embolism, a blood clot condition she had a history of. Beyoncé, one of the wealthiest and most famous musical artists ever, suffered from preeclampsia, a sudden, threatening rise in blood pressure that can result in seizures, and ended up having an emergency C-section. Her twins spent weeks in the NICU. The preeclampsia rate for Black women is 60 percent higher than for white women, [21](#) and after birth, Black infants are 2.5 times more likely to die in the first year of life than white infants. [22](#) An August 2020 study from George Mason University that analyzed data from 1992 through 2015 found that Black newborns were three times more likely to die in the hospital when cared for by white physicians. (That mortality rate shrank up to 58 percent when Black doctors were in charge.) Beyond pregnancy, Black women get breast cancer at lesser rates than white women but die much more often from it. [23](#) Similar statistics exist for colorectal cancer, pancreatic cancer, and stomach cancer.

They're also twice as likely to have a stroke versus white women, at younger ages, and with more severe aftereffects. ²⁴ Black people in the United States are twice as likely to live without safe drinking water and three times more likely to die from air pollution-related illness. ²⁵ Black communities suffered more than white ones from COVID-19, and even before quantities of data came in, we knew that Black patients were dying at a much higher rate than white patients. Seventy percent of people killed by COVID-19 in Chicago were Black, though the Black population makes up 29 percent of the city; ²⁶ in Milwaukee, those statistics were 81 percent and 38 percent. ²⁷ (If you want to learn more about the impact of socioeconomic factors on Black health, I recommend reading the racial weathering hypothesis and subsequent research.) Lupus, an autoimmune disease that attacks the body's healthy tissue, is two to three times more common among women of color and kills Black people at a three-times-higher rate than white people. And because of the COVID-related run on hydroxychloroquine, a medication used to treat lupus, patients had a harder time accessing necessary treatment. Communities of color, particularly Black communities, suffer higher rates of

and worse outcomes from asthma, which costs \$80 billion a year in doctor visits, prescriptions, and missed work; [28](#) meanwhile, white people disproportionately create air pollution. Redlining—the economic policy that excludes Black neighborhoods from financial services, like mortgages—has been illegal on paper since the 1970s but is still associated with higher ER visits for asthma. [29](#) (And redlining still very much exists across sectors including health care; for example, insurance companies can participate in the ACA exchange in select areas that they’ve deemed “desirable.” [30](#)) In short, Black people receive inferior health care and suffer from worse health-care outcomes than white patients, whether the illnesses are acute or chronic. As for obese patient outcomes, obese women are less likely to seek screening for gynecological cancers for fear that doctors will discriminate against them due to their weight. [31](#) This often leads to later diagnoses and more-difficult-to-treat, progressive cancers; obese people suffer worse outcomes and higher rates of death across all cancers. (A note on the language here: There’s movement away from using “obese” as the medical term, as it’s based on the flawed body mass index, which suggests that all “obese” people are unhealthy by default. “Fat” is

preferred in most body positive, body acceptance, and body neutrality circles.

After all, “fat” is just a descriptor—the stigma that comes with the word has

been created and reinforced by the people and corporations who profit off weight

loss and fat shame. There’s no more value in “thin” than “fat”

when you remove what we’ve made of those words.) Primary care providers (PCPs) report

spending less time—*28 percent less*, according to one study—with obese

patients. ³² PCPs in that study also reported viewing obese patients as “more

annoying” and said they felt less patience when dealing with heavier patients. A

2016 survey found that 90 percent of emergency departments lacked imaging

equipment suitable for heavier patients, ³³ meaning diagnostic tests aren’t

available for those patients suffering from strokes, blood clots, abdominal pain,

and bodily trauma. Heavy patients deal with a difficult conundrum: Doctors

often assume a higher weight to automatically mean “unhealthy,” but at the same

time, doctors overlook these patients’ true health problems when neglecting to

properly screen them due to weight.

Our health-care system is exceptionally unkind when it comes to the trans

community. According to a 2015 survey of 27,715 transgender adults in the

United States, ³⁴ 23 percent reported avoiding medical care out of fear of discrimination. Thirty-three percent reported a negative experience in a medical setting, including being harassed or outright denied care. Nearly half of trans people report struggling with depression and a third report anxiety. They use drugs and alcohol at higher rates than their cis counterparts, with many reporting substance use as self-medication. Forty percent of trans people report having attempted suicide (*36 percent higher* than the rest of the population). Trans women—especially trans women of color—are disproportionately incarcerated, ³⁵ and 1 in 4 report being denied health-care services while in jail or prison. ³⁶ In mid-June 2020, the Trump administration rolled back health-care protections for trans people under Section 1557 of the ACA, which means providers can deny not only gender-affirming care but *all* care. An already vulnerable population will undoubtedly be hurt further should this rollback be allowed to stand. (As Adam Serwer wrote so poignantly in the *Atlantic*: For this administration, the cruelty is the point.) All these statistics don't just materialize out of thin air. They happen because health-care teachers, texts (a 2017 report on nursing school textbooks found

Black patients listed as more likely to “report higher pain intensity than other cultures” and Jewish patients as “vocal and demanding,” for example [37](#)), and providers can be racist, homophobic, transphobic, xenophobic, fatphobic, and misogynistic, and those prejudices result in poorer health and even death for patients. This is a systemic problem that hurts entire communities—communities that already have a difficult and painful history when it comes to health care.(See: “Tuskegee Study of Untreated Syphilis in the Negro Male,” Henrietta Lacks, J. Marion Sims, forced sterilization, “Mississippi appendectomy,” wet nursing, “husband stitch,” diabetic amputations, homosexuality as mental illness, disparities in schizophrenia diagnoses, beliefs about Black pain tolerance, “gender identity disorder,” gay blood ban, Dr. A. C. Jackson, institutionalization for physical and mental disabilities.) Sometimes this widespread abuse is less overtly violent but just as damaging. As writer Jeneen Interlandi highlighted in a piece for the Pulitzer Prize-winning “1619 Project,” Black Americans were purposely excluded from the New Deal, the Social Security and Wagner Acts of 1935, the Fair Labor Standards Act of 1938, Aid to Families with Dependent Children, and the GI Bill. [38](#) Health insurance was harder for Black people to

obtain, and when they did have health insurance, hospitals were often segregated or white-only. These exclusions negatively impacted, and continue to impact, the health of generations of Black families. (If you want to read more about how

modern American medicine was built on the exploitation of Black people, I

recommend *Medical Apartheid: The Dark History of Medical Experimentation*

on Black Americans from Colonial Times to the Present by Harriet A.

Washington and *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* by Dorothy Roberts.)

The health-care system, even when it functions well, is far from perfect.

We're taught to trust doctors with our bodies, and sometimes abusive

practitioners take advantage of that trust in the vilest ways.

Doctors have

publicly come under fire for rampant sexual abuse (Larry Nassar and USA

Gymnastics), fertility fraud (doctors in the United States and the Netherlands

used their own sperm to inseminate dozens of patients instead of chosen donor

samples), and sexual assault (too many examples to list here).

Once, when I was

hospitalized, a [male] resident doctor came on to me so overtly during an

abdominal exam, while my hospital gown was pulled up just below my breasts

and my underwear rolled down to just above my pubic bone, that I cried.

Another time, a nurse asked if she could pass my phone number along to her

son. During my longest hospitalization in 2015, a [male] doctor called me

“hysterical” for crying and sent a [male] priest to counsel me in my hospital bed.

More times than I can count, physicians did not ask for consent before touching me.

I’m not arguing that all physicians are bad or have ill intentions.

Lots of great

doctors exist, and I still believe that most of them sincerely want to help people above all else. The American health-care system requires that providers work

long hours in stressful conditions, churning through as many patients as they can

like an assembly line. Patients can be demanding, unpredictable, and downright

mean. Still, the burden of professionalism and gaining of trust should remain on

the health-care provider—not the patient, who, in good faith, just wants to feel

better.

I’ve been to more doctors in the last ten years than in the rest of my life

combined. I’ve seen gastroenterologists, endocrinologists, internists, emergency

physicians, pain medicine specialists, infectious disease doctors, immunologists,

and gynecologists, among others. When I was initially diagnosed in 2012 with

UC, the central Illinois-based gastroenterologist acted like the diagnosis was no big deal and didn't explain much about it—just that it was chronic (a word I didn't fully understand), that I needed to take four large maroon pills every day, and that I should follow up with his office. When I had the follow-up appointment, the doctor again told me the disease wouldn't affect my life. I could eat whatever I wanted (wrong), I'd be okay as long as I kept up with the medication he prescribed (wrong), and I wouldn't have to change my lifestyle (wrong). I left that appointment thoroughly confused, as all the books and online forums I'd read made IBD seem life-altering (right). Several weeks following that appointment, when I flew to New York, only to return to Illinois soon after with Mom, a positive *C. diff* test and another hospitalization under my belt, I was back at the diagnosing GI's office to figure out what was happening. I knew I had UC and I knew I had *C. diff* because the doctors told me so, but I didn't understand. What had caused it? Why was this happening to me? How could I get better? Why was I in so much pain all the time? Kaetlyn went with me to the appointment because she could see I was fragile and needed someone else to ask the questions and take notes. She felt I

wasn't getting proper answers from the doctors I'd seen, so she stepped in to serve as my advocate.

The GI who diagnosed me wasn't in, so we saw his practice partner instead. I could tell right away that he didn't take Kaetlyn and me, then twenty-nine and twenty-four, seriously. He made a bad joke about the blessing of my disease being that I could eat Big Macs and not gain any weight ('cause I'd shit them right out, get it?). He delivered the joke as though my disease was lucky: *Don't*

you know women value being thin above all else? I asked about my new

symptoms: joint pain, swollen abdomen, stomach cramps so intense they left me

unable to breathe. He said none of those things were connected to IBD or *C. diff*.

When I began to cry uncontrollably, he blinked at me like a fish peering out of

its tank. I left that appointment wondering if life with my diagnosis was worth

living. It wasn't until I saw the kind, capable GI at Weill Cornell in New York

that I began to make some sense of my illness. (My insurance changed and I

wasn't able to see her in-network anymore, but I still recommend her to anyone

who asks me for an IBD doctor.)

I chose my current gastroenterologist, whom I call "Doc," like any good

millennial: He accepted my insurance, his office was within walking distance of

my apartment, he had good online reviews, and, as a bonus, he was affiliated with Methodist, my preferred hospital. I was in a moderate flare-up in 2014 that needed attention before it spiraled into something worse. Neither Doc nor I had any idea then what the next couple of years had in store—flares, impactions, recurrent *C. diff*, two more fecal transplants, *E. coli* infection, sepsis—but I'm forever thankful that proximity and a five-star Yelp page brought us together.

One thing you should know about Doc is that he's tall. Like six and a half feet tall. When we hug—because we're that friendly now—my head meets his chest. His wide shoulders take up space in a room and people pay attention when he talks. He speaks with a soft Lebanese accent that makes words—even ones like *colonoscopy* and *inflammation*—sound melodic. Doc does not give or take bullshit. But he's also quick to smile and laugh—sometimes when he gets to belly laughing, his eyes crinkle up and all his teeth show, so I can imagine what he looked like as a kid, taller than his friends. Doc takes calls and texts from his patients at all hours. He's always stepping out of the room to explain a test result or medication to someone. (I often wonder just how many people have his cell phone number.)

Doc poses thoughtful questions and listens intently when I answer. When it's my turn to ask, he answers thoroughly and is always saying, "Does that make sense?" to be sure I get it. He never makes me feel rushed, which I appreciate because I ask probably *too many* questions. When he needs to do exams of any kind, he tells me first what they entail from start to finish and asks for consent. When I say no to exams (and I do), he doesn't shame me—he finds another solution. We agree on treatment plans together, and I always leave our appointments with action to take, which makes me feel more in control of my illness. In our conversations over the years, I learned that Doc's wife is also a gastroenterologist and that she has UC. She had to take a year away from medical school because of her illness, and witnessing the effects of her illness made Doc become a GI instead of a surgeon. Though he can't understand what it's like to live with the disease himself, he sees how it affects the person closest to him, and that makes him more understanding and compassionate with his patients. It's personal for him. During my long hospitalization in the spring of 2015, Doc checked on me most evenings before he went home even though the hospital was way out of his

commute. He would pull up a chair next to my bed and listen while I cried.

Sometimes, he would put his hand on top of mine and promise not to let

anything bad happen to me. Doc met with my attending doctors and reviewed

my charts and treatment plans. He gave Mom his cell phone number and told her

to call or text day or night, something she took advantage of often. He consulted

with other doctors and experts about my case and reported back to me about

what he'd learned. Perhaps most important, when I had recurrent *C. diff* in 2015,

Doc sought out Dr. G., the specialist who agreed to perform a fecal transplant

when no one else would due to strict FDA regulations. Both of them fought hard

for me to get the proper treatment, and it's no exaggeration that I'd be dead

without the two of them.

For a while, I believed that the bad doctors I'd had were location-based: Who

but the worst doctors would end up practicing in some nowhereville, anyway? It

was a snobby, shortsighted opinion that I quickly learned wasn't true. Bad

doctors are everywhere, even in the largest and greatest cities in the world.

Though I found excellent, progressive care in New York City, I also encountered

doctors who dismissed my pain, doctors who didn't listen, and doctors who

flirted and acted inappropriately. I had nurses who told me my disease was caused by diet, nurses who left me without care for hours, and nurses who treated me like nothing more than an opiate seeker. My experience as a patient, together with my years as a health journalist and the stories I've heard via support groups, helped me come up with these guidelines for what makes a good doctor (in other words, these are the things you should keep in mind as you choose a physician). When you have a chronic illness, a doctor isn't someone you see once or twice a year when you need a physical or come down with a bug. They are a central part of your life now, and they will play a major role in how well you live with your illness. You will see them often—more often than you'd care to, if we're being honest—so you need to trust and respect them. In an ideal situation, you will even *like* your doctor! But in turn, they need to meet several qualifications: A good doctor respects you. To respect someone means to value their wants, needs, and rights—and though it seems like that should be common sense for any doctor, it isn't. A good physician will take time to listen to you thoroughly, without judgment, even if you're "emotional." They should ask questions that dig deeper into your health

history and symptoms, filling in any gaps of information that might help them treat you. Sometimes these conversations get sensitive, and you never have to answer a question that makes you feel uncomfortable. But a good doctor should create an environment in which you know you're safe to share. Your doctor should not make you feel stupid or behave as though they're smarter than you because you're [fill in the blank: a woman, a minority, poor, etc.]. They should always take your concerns seriously and *never* pass symptoms off as "anxiety" or "you're just stressed" without due diligence. Could it be stress or anxiety? Sure, but that's also an easy way to dismiss serious physical symptoms. And even if it is "just" stress, it's flippant to send a patient along as though that isn't also a real health concern. Along those lines, a doctor should never present weight loss as a panacea for your health concerns. And they shouldn't doubt the level of pain you're in just because you're not writhing around on the floor; chronic illness patients learn to live with a shocking amount of physical discomfort and often go about it looking natural. Physicians should always—with *no* exceptions—honor your name and pronouns, even if they differ from what's on your identification or medical

records. If you don't want to be weighed or you need to step on the scale backward to avoid seeing the reading, they should accommodate your request. If there are certain places on your body or ways that you do not want to be touched, they must comply with your needs. *Your needs come first.* A good doctor explains what they're going to do and why, and they ask for consent before proceeding. One of the worst parts of chronic illness is that you feel like your body no longer belongs to you. Part of this comes from a loss of control due to the disease itself, and part of it stems from the constant poking, scanning, testing, and measuring. Chronic illness requires so many procedures, not only to get an initial diagnosis but also to monitor and manage the disease: colonoscopies, endoscopies, X-rays, CT scans, MRIs, EKGs, ultrasounds, blood tests, genetic tests, stool tests, rectal exams, pelvic exams, abdominal exams, surgeries. The list goes on and on. These things are uncomfortable enough, but when you don't know why you're getting a certain test or exam or what's going to happen during it, it can be agonizing. A good physician explains why you need said procedure and how it will go. What parts of my body are involved and why? Will it be painful? How

long will it take? Will it require any kind of anesthesia, and do I have a choice?

Do I need to prep beforehand? What will the results show, and how long will it take to get them back? How will the results be delivered? Will it require follow up testing? Does my insurance cover the cost? Are there any alternatives to this test?

When those questions have been answered, a good doctor asks if it's okay to proceed. They'll use language like: "Is it all right if I [touch here, do this exam, etc.]?"; "Can I tell you more about [this procedure, why this is important, etc.]?"; "Let me know if you feel unsure or uncomfortable"; and "Tell me at any time if you'd like to stop." You should feel comfortable saying no or asking for a few minutes to compose yourself before proceeding, knowing that your doctor will accommodate your needs. Unfortunately, there are times when you need the test or exam even when you don't want it. (Who *wants* a colonoscopy?) But a good doctor works with you to guarantee you're as comfortable as possible throughout, and that you're informed before, during, and after. A good doctor knows their limits. Listen, egos exist in every profession (hello journalism, my old friend), but they're more prevalent in some than others. Medicine is one of those

professions, and for good reason: These people took a shitload of tests, paid hundreds of thousands of dollars in tuition, and spent, like, fifty more years in school than the rest of us. Their jobs require a level of critical thinking and skill that many do not. Some of that ego is warranted! But it also gets in the way, and that costs the patient. A good doctor is never too proud to ask for a second opinion or seek out an expert when a patient's care goes beyond their scope of knowledge. A good doctor knows that there's no shame in *not* knowing, and they put the needs of the patient above protecting their self-esteem. When a case gets complicated, they should be willing to collaborate with other doctors and seek out experts who know what they don't. Bottom line: A good doctor puts the patient's well-being above all else, always. A good doctor makes the most of their time. Doctors work long hours, packing in as many patients as they can because that's what our health-care system demands. By some estimates, primary care physicians spend fifteen minutes or less with each patient, and research shows that this kind of time stress leads to physician burnout as well as worse patient outcomes. ³⁹ Further research shows that on average, patients get just eleven

seconds to explain their symptoms before their doctor interrupts them.

Physicians are trying to make the most of their time, perhaps, but how much can

they really understand about a patient in eleven seconds? ⁴⁰ A short appointment

might be unavoidable, but a good doctor makes the most of the time they have

with their patient and maximizes the out-of-office time by ordering tests, exams,

etc. If they run out of time with a patient, a good doctor will call the patient later

to be sure all their questions were answered.

No matter how long or short an appointment, you should leave feeling that

your questions were answered—or if they weren't, that you've been referred to a

specialist who *can* answer them—and that you know what needs to happen next.

You shouldn't be more confused after a doctor's appointment than before. And

you should *never* leave an appointment feeling hopeless.

A good doctor is kind to their staff.

This is important not only for nurses, techs, and receptionists, who deserve a

boss who respects them, but also for patients. Simply put, when staffers are

respected, things function better: Appointments run on time, tests get ordered

and completed, follow-up happens as it should, etc. Maybe this is selfish, but I

want to go to a doctor's office with, for lack of a scientific term, a *good vibe*, where I can tell that morale is high and that the people who work there don't hate their jobs, where there's rapport between physician and staff, where the doctor speaks highly of the others in the office and they do the same in return.

When you're a professional patient, you become a fly on the wall in hospitals and doctors' offices, and you overhear *everything*. It's easy to tell when a doctor treats their staff badly—and is that the kind of doctor you want taking care of you?

A good doctor looks at you as a human, not an opportunity. This should go without saying, but a good doctor sees a patient as an individual person to be treated accordingly, not as a financial opportunity.

Doctors maintain relationships with the pharmaceutical industry—this is unavoidable because of the way our system functions—but it's up to a physician how closely they work with Big Pharma and how handsomely they'll profit from it. If a doctor is doling out the same medication to every patient, regardless of the specifics of their illness, you can guess that that doctor is benefiting from writing those prescriptions. While it's illegal to receive kickbacks for writing scripts, it's not illegal for pharmaceutical companies to pay doctors as

“consultants” or “speakers,” and it isn’t illegal for pharma reps to give gifts, trips, charitable donations, or meals to doctors and their staff as a nudge in the direction of the drug or device they represent.

Open Payments, a federal database established under the Affordable Care

Act to monitor the flow of pharma industry money, found that two-thirds of

Americans who’d visited a doctor in the last year saw a physician who had

received money or gifts—but only 5 percent of patients were aware that their

physician received those benefits. You can look up your own doctors by name at

OpenPaymentsData.CMS.gov.

I’ve also found that every good doctor I’ve been to has a personal stake in

the medicine they practice. This isn’t a requirement when choosing a doctor, but

I do think it changes the kind of care you’re going to receive. Doc’s wife has

ulcerative colitis. The doctor who performed my first fecal transplant in 2013

lost his father to colon cancer. Dr. G., the specialist who did my second and third

fecal transplants, told me he chose gastroenterology after watching different

specialists during medical school: “The GIs appeared more friendly, empathetic,

intuitive, and engaging.” Good doctors see their loved ones in their patients; they make choices for their patients that they would make for their own family.

Asking a doctor, “Why did you choose this line of medicine?” will reveal a lot about what drives them and how they view their patients. A good doctor communicates clearly. Some doctors have a better bedside manner than others, a warmth and ease that make it a pleasure to speak with them. Not all doctors maintain this ability, but that alone doesn’t mean they’re bad at their job. Lots of things go into communication—fluency, body language, social cues, etc.—and a doctor can still be good without having all of these perfected. It would be gross to disqualify a doctor just because they don’t make impeccable eye contact, for example. What’s more important is that a doctor communicates clearly, in a way that’s easy for you to understand. Maybe you’re a visual learner and you need your doctor to provide graphs or charts that explain your treatment. Maybe you need detailed statistical breakdowns about side effects, or you like to read double-blind studies. “Explain this to me like I’m five years old” usually works when something is going over my head. Whichever way you take in information best, that’s how your doctor should communicate. And if conversations with your doctor leave you more confused than informed, it might be time to look for a new one.

A good doctor is up-to-date on research and treatment. It shouldn't be the patient's burden to educate their doctor. Part of a physician's job is to stay on top of research in their field, as well as new treatment options—and not just the ones peddled by drug reps. Disease research is evolving and new drugs get approved all the time; I can count a handful of treatments approved for my disease in the last decade. Individuals' chronic illnesses change over time, too—symptoms go away or new ones show up and bodies stop responding to medications that they once did. Diseases aren't treated the same way today as they were even fifteen or twenty years ago. Doctors need to know how to navigate all these changes and how to guide their patients through them. A good doctor acknowledges the connection between physical and mental health. Your doctor should bring up the importance of mental health care as part of chronic illness management, and I'd be suspicious of those who don't acknowledge how depression and anxiety are connected to—I'd even argue *normal symptoms of*—chronic physical illness. A good doctor will help you navigate the mental health side of long-term illness just as they would the

physical, and they should be able to refer you to a mental health professional who understands the burden of chronic illness for therapy and, if necessary, medication.

A good doctor sides with the patient, not the insurance company. Insurance providers don't love chronically ill people. We're expensive, we're always switching or adding new treatments, and we're hospitalized a lot.

Because of this, insurance companies are always looking for ways to cut our

costs through denying medications or referrals to specialists. A good doctor goes

to bat for their patients and appeals the insurance company's decision if it's not

in their patient's favor. Insurance companies are banking on physicians *not*

appealing their decisions, so when they do, they relent more often than not.

Insurance companies tell patients "no" in hopes they won't fight—but you must

always fight. Keep pushing until you get to yes. It's cruel to make sick people

plead for the care they need, but such is the American system. My three best

words of advice for being chronically ill in the United States are:

appeal, appeal,

appeal.

Further, doctors and their staff often know about financial assistance that

insurance companies don't readily advertise. For example, I needed an expensive

blood test that had to be processed by one specific lab. Insurance wasn't going to cover much of the cost, but Doc gave me a financial hardship form that reduced my out-of-pocket cost to almost nothing. Doctors' offices often have savings cards that reduce the cost of prescription drugs, sometimes down to as little as \$5, even for expensive medications. It's always worth asking your doctor if they have financial assistance available.

A good doctor is a woman. I'm not saying this just because women are better and smarter (which *we are*). Hear me out! The research backs this up: In a twenty-year study of half a million heart attack patients, mortality rates were lower for women *and* men when the physician was a woman. ⁴¹ Women patients treated by male doctors fared the worst. Similarly, a Harvard study of 1.5 million Medicare patients found that they were less likely to die or be readmitted to the hospital when treated by a woman doctor. ⁴² Why? Because, according to the research, women doctors take more time to listen to their patients and they're less likely to disbelieve their patients' symptoms. I'm not saying all male doctors are lousy—my current doctors are all men and they're wonderful and I love them. The lesson here isn't to choose a doctor on gender alone but to choose a doctor who

listens and takes your concerns seriously.
Okay, so how do you find one of these good doctors?
One of the first things I tell any newly diagnosed chronically ill person to do, if they ask for my advice, is to join a support group for their specific illness. The internet makes this easier than ever for us folks who don't always feel well enough to go to an in-person meeting. Support groups are helpful for all kinds of things, one of which is asking for a doctor recommendation. Posts like this happen every day in my online IBD support group: "Can anyone recommend a gastroenterologist in the Cleveland area who takes Blue Cross/Blue Shield?" It gets dozens of responses! The internet has also made information about doctors more available than ever. You can find out where they studied, what they specialize in, and what research they've published. As mentioned earlier, you can use Open Network to uncover how much they're benefiting from the pharmaceutical industry; you can also see if they have any serious complaints or disciplinary actions on their public record. For most physicians, you can read patient reviews that offer insight into bedside manner, communication style, and even office wait times. If you're beholden to in-network doctors, work backward: Get the list of doctors in

your network, then do some internet sleuthing to decide who might be the best fit for you. It's worth calling the office to see if they offer free or low-cost consultations as well, so you can meet with—or at least speak on the phone with—potential candidates before deciding on one. This isn't a necessity, but I also recommend finding a doctor who's affiliated with a teaching hospital. Teaching hospitals, sometimes called university hospitals, are connected to medical schools and used to train medical students and residents. Teaching hospitals focus on conducting and publishing research, are better equipped to handle rare diseases and complex cases, and cater to more diverse populations. Recent studies show that the out-of-pocket cost for patients is no higher at teaching hospitals than nonteaching hospitals. (Wait times might be longer, though.) When you've scheduled an appointment with the doctor you've chosen, you should come prepared. Draft a list of all of your symptoms and a list of questions you want to ask the doctor, not just about your illness but about the doctor's experience and approach. It can be hard to remember things when you're not feeling well—pain takes up a lot of brainpower. If you're really sick, it can be helpful to bring a loved one along to serve as a second brain and make sure all

your questions get answered. And always ask about any follow-up appointments or exams/procedures that need to be scheduled. Here's another tip: If a health-care provider makes a choice you disagree with, ignores symptoms you bring up, or seems negligent, tell them to put it in your chart. Say you've requested more testing for abdominal pain, but the physician says it's nothing more than stress and won't proceed further. Tell them to write in your chart that they're denying further care. If there's a paper trail, it usually inspires the provider to be more diligent. This has worked time and time again in my chronic illness circles. Paper is your proof. Now I hope this never happens, but say you experience an unprofessional or abusive doctor. What action can you take? I've outlined your options and what to expect from the process in Appendix I, titled "Reporting a Doctor." Flip to it in the back of the book to learn more. It is more difficult than it should be to find a good doctor under the constraints of miserly health insurance companies, but it isn't impossible. Lean on your chronically ill community for recommendations and guidance and use the good ol' internet to research. Know what qualities and qualifications to look for in a physician and understand the steps to take should a physician become

unprofessional or abusive.

Searching for a doctor who suits all of your needs feels exhausting when you're managing everything else that chronic illness throws at you, but finding

good care is one of the most important ways you can live well with chronic

illness. In many ways, your doctor determines the quality of life you'll live with

incurable/long-term illness, as they're the one guiding your treatment. You have

to trust and rely on them. We have only so much control over our unpredictable,

forever-sick bodies. But we do have control over who we choose to care for

them.