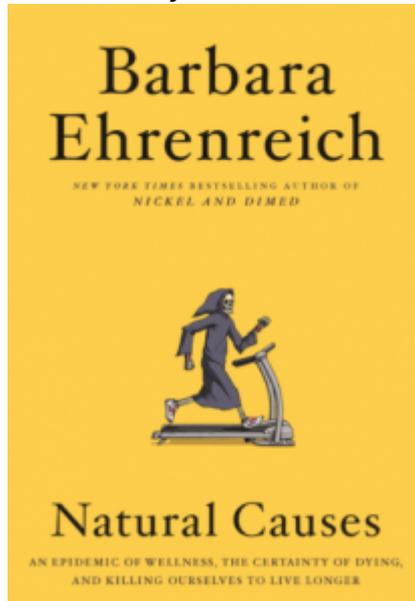


[Alive and Writing: What Recent Memoirs Reveal about Illness and the State of Health Care](#)

written by Guest Contributor | August 2, 2018



Natural Causes by Barbara Ehrenreich

Twelve Books, 2018

256 pages / [Twelve](#)

Everything Happens for a Reason: And Other Lies I've Loved by Kate Bowler

Random House, 2018

208 pages / [Random House](#)

Sick: A Memoir by Porochista Khakpour

Harper Perennial, 2018

272 pages / [Harper Collins](#)

The Family Gene: A Mission to Turn My Deadly Inheritance into a Hopeful Future by Joselin Linder

Ecco, 2017

272 pages / [Harper Collins](#)

I Am, I Am, I Am: Seventeen Brushes with Death by Maggie O'Farrell

Knopf, 2018

304 pages / [Penguin Random House](#)

Transplant, Transport, Transubstantiation by Marjorie Maddox

Wipf and Stock, reissued 2018 (WordTech Editions, 2004)

110 pages / [Wipf and Stock](#)

When I started reading the [first chapter](#) of Barbara Ehrenreich's book *Natural Causes*, I expected to like it. Years ago, her book *Nickle and Dimed*, which *The New Yorker* calls a "[modern classic](#)," got me thinking about my own privilege and about how our options and choices for careers are constrained by our circumstances. Her new book critiques the wellness lifestyle and medicalized death. Like Ehrenreich, I've written about topics like the risks of medical imaging in my book [Tumor](#). Certainly, culture and medicine deserve scrutiny. *Natural Causes* is a well-written, researched set of essays steeped in the personal, just the sort of writing I appreciate. I should be an enthusiastic reader of *Natural Causes*. I'm not.

Ehrenreich writes, "Not only do I reject the torment of a medicalized death, but I refuse to accept a medicalized life, and my determination only deepens with age." That's what my grandfather did. It's definitely the way to go. After surviving the Spanish flu as an adolescent, my grandfather's healthcare decisions were borne out of general good health until he reached his nineties. Ehrenreich's polemic-couched-as-memoir assumes good health.

Of course, she doesn't expect to live forever. Neither did my grandfather, who died at home a few weeks after he called my mother to announce his impending death and subsequently was diagnosed with leukemia. He had no need for the "drastic end-of-life measures" that Ehrenreich—and others like Atul Gawande in his marvelous book [Being Mortal](#)—critique. Importantly, my grandfather had a pension, Medicare coverage, and family support and faced no catch-22 healthcare decisions during his late-life demise. Ehrenreich assumes this is what we can all expect.

For Ehrenreich and for me, getting a screening colonoscopy is a choice. When Ehrenreich emphasizes that decisions should be based on "how we choose to spend the time that remains to us," she assumes an ideal life unhindered by pain, fatigue, or financial worry.

Like Ehrenreich, who has only very recently eschewed the medicalized life, I

dreaded my pre-colonoscopy cleanse, but it wasn't as bad as I expected. The procedure itself didn't, as Ehrenreich claims, "mimic an actual sexual assault." (For colonoscopies, propofol and midazolam are [the most widely used medications](#) for sedation. Neither drug is easily administered outside a clinical setting because they're generally intravenous drugs, so, despite Ehrenreich's shocking, inaccurate allegation, they are not [common date rape drugs](#).) While not all colon cancer can be nipped in the polyp, this type of cancer is sometimes preventable and also treatable, especially when caught early. Discouraging patients' access to health care, as Ehrenreich does, is reckless.

When I'm in my mid-seventies like Ehrenreich, I'll probably forego these screenings too. Ehrenreich has reached the age at which both the [Centers for Disease Control](#) and the U.S. Preventative Service Task Force recommend we forego colonoscopies unless we are at high risk. Likewise, screening mammography is not recommended by the [U.S. Preventative Service Task Force](#) for someone Ehrenreich's age, though one's individual medical history might warrant otherwise. Ehrenreich's choices aren't bold at all. They are masquerades.

Her decisions are cloaked in privilege. My physicians communicate with me at length, my health literacy is high, and my employer-based medical insurance covers a lot of expenses. I am among the [88.1% of Americans](#) who have a place to seek regular medical care. More than one in ten of us don't. Globally, half of us can't afford basic health care, according to the [World Bank and World Health Organization](#). Plus, I'm relatively healthy, despite what might have been considered preexisting conditions before the Affordable Care Act. That's not the case for everyone.

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That's not the case for Kate Bowler, a professor with employer-based insurance who still struggled to figure out how to access and pay for the health care she needed.

At age thirty-five, with a new baby, Kate Bowler was diagnosed with Stage IV colon cancer. In *Everything Happens for a Reason (and Other Lies I've Loved)*, she writes, "I keep having the same unkind thought—I am preparing for death and everyone else is on Instagram." Women her age aren't supposed to get sick, but she had spent three months doubled over in pain. If they do get sick, professors like me and like Bowler expect—and are expected to—to recover. Thinking the problem might be her gallbladder as she waited to have a CT scan, she surmised, "They would find something simple and that would be the end of it. I'd just have to schedule my life around surgery, nothing major." Gallbladder surgery is the worst-case scenario in her mind, an inconvenience more than an illness and one of [the most common surgical procedures in the United States](#), with hundreds of thousands of cholecystectomies performed every year (but with significant [disparities in access based on race and socio-economic circumstances](#)).

Instead, Bowler has cancer, and it has already spread. Cancer is relatively likely for any of us. The [American Cancer Society](#) estimates that one in two

men and one in three women will face a cancer diagnosis at some point in their lives. While it's unusual to be diagnosed with cancer in one's thirties, the risk starts to go up significantly at age thirty-five, according to the [National Cancer Institute](#). Roughly twenty percent of us will die from some type of cancer.

Bowler, often candid in her memoir, acts as if she's "the only one in the world who is dying." Of course, she's not the only one, and that's part of why *Everything Happens for a Reason* is an important book. "Sometime later," she writes, "I will meet a woman with my same cancer and my same life—a husband and a toddler—and she will say the words I was feeling at that moment." Stories like Bowler's are especially powerful because there but for the grace of God go I—or you or any one of us.

Not many people with Stage IV cancer have the time, energy, and skill to write about their experiences, let alone write a book imbued with clear sense-making based on a unique area of expertise. Bowler is a historian at Duke University's Divinity School and an expert on the American prosperity gospel, which professes that health and wealth are bestowed by God on the faithful in big helpings right here on earth. This fascinating backdrop complicates her self-awareness as a cancer patient.

Like Ehrenreich, Bowler recognizes, "Control is a drug, and we are all hooked." But Bowler acknowledges that she—and by extension, many others—"have almost no choice but to surrender." This realization, which she is barely able to admit, flies in the face of the believers of the prosperity gospel whom she has studied for years. "To believers in the prosperity gospel, surrender sounds like defeat. [...] There are no setbacks, just setups. There are no trials, just tests of character. Tragedies are simply opportunities to claim a bigger, better miracle." But death is a cliff she's staring down. In a poignant last sentence, she writes, "I will die, yes, but not today." In the meantime, she needs ongoing treatment and doesn't want to leave her family in financial ruin.

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Porochista Khakpour needs ongoing care as well, though her flares of Lyme disease are intermittent and unpredictable, as has been her insurance coverage and out-of-pocket healthcare costs for many years.

In her intense memoir, *Sick*, Porochista Khakpour chronicles living with Lyme disease, which has a low death rate in comparison with, for instance, the late-stage colon cancer Bowler faces but nonetheless takes an enormous toll. In the United States, roughly 30,000 cases of Lyme disease, which is caused by bacteria transmitted via tick bite, are reported to the [Centers for Disease Control](#) every year, though 14 states account for more than 96% of the cases.

Having lived in the United States since she was a child, Khakpour "was born in Tehran in 1978, infant of the Islamic Revolution and toddler of the Iran-Iraq War." In 2017, the new administration here instituted the so-called Muslim ban, and her home country of Iran was on the new administration's list

of problem nations. (An all-caps tweet from POTUS while I was working on this essay has heightened tensions.) Khakpour explains to a cab driver that she is “not one of the bad people.” *Sick* is a compelling coming-of-age story, full of risk-taking, fascination with drugs, “wrong partners,” suicidal thoughts, and a car accident that almost kills her. Even without Lyme disease, the story and remarkable writing would captivate readers.

Yet all of Khakpour’s life is necessarily molded and remolded by her condition. “I am a sick girl,” she writes toward the end of her memoir. “I know sickness. I live with it. In some ways, I keep myself sick.” She also keeps beginning again, adjusting her life plan, sometimes out of desperation.

In the opening author’s note, Khakpour bluntly states, “Living with this disease has cost me more than \$140,000 so far. Experts put the average cost of late-stage Lyme at somewhere around \$20,000 to \$200,000. The annual cost of Lyme disease in the United States is more than \$1-\$3 billion as of 2017.” She doesn’t know exactly when the wicked tick bit, but Khakpour knows that she will have this disease for the rest of her life and that it will continue to cost her in many ways.

We might assume that a middle-class woman, someone who turned forty this year, has access to good health care in the United States. Instead, Khakpour writes, “For years I had not been able to find a local doctor who would take me when he or she knew Lyme was on the table; even some infectious disease specialists wanted nothing to do with it. But I knew at that point I only had half a year of health insurance left and that I’d have to act fast.” In the course of this memoir, she faces years of medical guesswork and misdiagnosis and many tests, procedures, and medications that insurance won’t cover. After the premier Lyme lab confirms the diagnosis and she is prescribed a costly antibiotic in the final days before insurance under her ex-boyfriend’s policy runs out, Khakpour raises \$9,000 in one week on GoFundMe. That money allows her to see a Lyme specialist who “cost \$280 an hour.” One tick bite that she doesn’t remember results in an often debilitating disease that drains her body of energy and drains her financial resources.

As a result, Khakpour faces years of physical—including psychiatric—ups and downs and related turmoil. “One of the worst symptoms I had was dysphagia—a word I hadn’t known before but suddenly knew well: the inability to swallow.” In a heart-rending section, she researches explanations of swallowing and throws “spoonfuls of applesauce down my throat.” This upsetting description of her efforts to counter the havoc of the disease points to the ongoing effort chronic illness demands. One must become an expert in one’s disease as well as one’s own body.

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This demand for the person who is sick to be her own expert and advocate is most striking in the story of Joselin Linder, for no experts existed for her family’s condition because the genetic mutation had never occurred before.

Joselin Linder details her path to expertise in *The Family Gene*, a riveting memoir about misdiagnosis and the genetic anomaly that threatens her

family—and likely her family alone—with a gruesome affliction. At the age of forty, Linder's father, a physician himself, suffers from swollen ankles, a common enough inconvenience that both his mother and grandmother had suffered. That is the beginning of the end for him. Lymphatic fluid leaks into Billy Linder's lungs and abdominal cavity, ultimately squeezing his organs. He swells even as he is wasting away.

Then, after Billy's death, the same thing happens to his brother, Norman. While Norman is ill, his aunt "Norma had begun to full up with chylous fluid" too, and she declines rapidly. And Norma's daughter—Billy's and Norman's first cousin—has recently had her "mushy" spleen removed after vomiting what looked like coffee grounds. (Later, Valerie has a stroke in her fifties.) Joselin Linder herself becomes plagued with a dangerously low platelet count that she mostly shrugs off. And then her ankles swell.

The telltale sign of this condition is a heart murmur that, in the Linders, signals a variant gene, though it might be innocent in you or me. Both Joselin and her sister have heart murmurs and the inherited variant, which, at least anecdotally, can be traced back to Great-Grandma Mae and possibly Mae's mother, Ester, who purportedly had puffy ankles. Their family history reads like a board game of hit and miss. Billy's sister, Kathy, has not inherited the variant from their mother, Shirley, and Uncle Norman inherited it but did not pass it on to his children. Mae passed the variant on to Shirley, who passed it on to her son Billy, who passed it on to his daughters.

After her father dies and she graduates from college, Linder realizes that she "needed health insurance. It didn't matter that I was only twenty-two and had never really been sick, unnamed genetic variant aside." She fills out the application for insurance, and her mother pays the premium, but "I learned by letter that my insurance application had been rejected." Though only her family and two physicians knew about her heart murmur, her application was denied because, at the time, "the state of Ohio's preexisting-condition code precludes you from getting health insurance." Knowing that she is likely to face a serious health crisis in the future, Linder nonetheless "remained, for the next ten years, without health insurance." When she meets her future husband, she feels "lucky enough that a man like Aaron came into my life when he did, given that I might have settled for pretty much anyone with health insurance who would disregard my complicated health."

Readers can rest assured that chance has not cast the exact same dice for us. In addition, Linder and her sister are ensuring that this inherited condition dies with them. When Linder finds herself pregnant, despite using condoms and undergoing an angiogram that might have left the embryo unviable, she realizes that she is at high risk of bleeding out because of blockages in her liver and that she "could not risk giving birth to a baby who carried this gene." Between them, [the Linder sisters have had three abortions](#), and, through invitro fertilization with pre-implantation genetic diagnosis, Hillary has twin boys without the variant. The family has been systematically tested, and no one beyond the author's generation has the genetic variant—and no one else in the world has reported it.

Linder is taking several medications to stave off complications like stroke, and her physician maintains that women with this anomaly are likely to fare better than men. Linder is especially hopeful that recent research will open up possibilities for her own survival. She ends *The Family Gene* with surprising optimism: "Our bodies are wondrous. Perhaps that's all we ever need to know."

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We each have a body that harbors its own wonder—and its own threats to our very existence. Some of us can meander through our days without the catastrophic looming, but others of us can't.

Maggie O'Farrell conveys deep wonder in her memoir-in-essays, *I Am, I Am, I Am*. In the second chapter of the book, which is subtitled "Seventeen Brushes with Death," she writes of jumping off a harbor wall at sixteen years of age: "My coordination, my sense of spatial orientation is not as it should be." What might be a thrilling, fleeting disorientation for most of us doing something heedless as a teenager is life-threatening for O'Farrell. "A childhood illness has resulted in sustained damage, as neurologists have said, to those parts of my brain involved in movement and balance." She lacks proprioception and must rely on visual clues to know how she is oriented in her surroundings. Underwater, she cannot tell which way is up, which way is air. Despite her unusual situation, she writes, "There is nothing unique or special in a near-death experience. They are not rare; everyone, I would venture, has had them, at one time or another, perhaps without even realizing it." We live precariously, whether we are aware of it or not. "If you are aware of these moments," O'Farrell asserts, "they will alter you."

O'Farrell also writes hauntingly about miscarriage, in an essay first published in [The Washington Post](#) and included in the exquisite *I Am, I Am, I Am*. In another chapter called "Abdomen," she describes childbirth. She prefers a natural childbirth but is concerned that the lingering effects of her childhood encephalitis make this risky. To her surprise, the medical staff suggest that she is lying about her condition. This position between rock and hard place echoes the frustration with the medicalized life that Khakpour and Linder capture as well. In addition, whether it's a [brain tumor](#) or [heart attack](#), women are too often dismissed, leading to delayed diagnosis and treatment. O'Farrell writes, "To be so unheard, so disregarded, so disbelieved: I was unprepared for this. [...] I wanted to run from that hospital and never go back, but how else would the baby be born?" She even questions whether she had the right to allow herself to get pregnant if she "wasn't up to the task of giving birth." After three days in labor, after medication fails to induce delivery, she is granted a Caesarean section, which is marked in her medical record as by her request, "that is, medically unnecessary."

The most heart-wrenching chapter, however, is the last, in which she writes not about her own brush with death but, rather, about her daughter's. "My daughter's breathing is shallow, labored, her lips distended, her skin patched and livid. The delicate features of her face are sunken, swollen, distorted. Her hands clutch mine but her eyes are rolling back in her head."

Her daughter is dying in her arms from severe allergic reaction, and they are lost somewhere in the Italian countryside without a cell signal. Reading, we know O'Farrell survives her near-drowning and childbirth to write the book—but what will happen to the daughter now in her arms?

As a result of an immunological disorder, her “daughter suffers allergic reactions, with varying degrees of severity, around twelve to fifteen times a year.” [Allergies affect millions of people](#); they are the sixth most prevalent cause of chronic illness in the United States and cost billions of dollars per year. While [five percent of the U.S. population has experienced anaphylaxis](#) like that O'Farrell describes, death from this severe reaction is thankfully very rare. As an infant, O'Farrell's daughter developed eczema, her skin “patchy, hot, sand-dry, crêpy with inflammation.” For O'Farrell, motherhood requires extraordinary tending to this child in discomfort as well as vigilance for a long list of allergens and thorough organization of daily activities, medical appointments, and emergency injections. When the GPS kicks in during the crisis in Italy, the family is lucky to be eight minutes away from a hospital, within distance of being saved. Still, O'Farrell writes, “You make sure you say goodbye, properly and with eye contact, every time your child leaves the house.”

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Not everyone makes it to the hospital and is pulled back from the edge of the terminal cliff. Sometimes, efforts that could work don't.

I'm reminded of my own family members we couldn't save, who came to terms with their mortality. Both my parents, who died of cancer, though with aggressive treatment early on, my forty-eight-year-old father lived almost five years after diagnosis and saw his daughters off to college. Or Marjorie Maddox's father, who, as she recounts in the reissued poetry collection *Transplant, Transport, Transubstantiation*, receives a heart transplant from a dead stranger: “His heart is buried / in my father, / who is buried.”

Think about this fact: “Every ten minutes, someone is added to the national transplant waiting list,” according to the [Health Resources and Services Administration](#). If we are well, an organ transplant, an allergic reaction, an errant gene, or a chronic or acute disease seems a distant reality. We can make our healthcare decisions based on our wellness. At the end of the poem “After the Transplant,” Maddox discloses what I've felt as well, even when it's down to palliative care and hospice: “the dying die to soon.” We still want that distance between us and illness, between us and death.

Ehrenreich's point is the opposite, as she claims to have come to terms with being old enough to die un-tragically, not too soon. Though in her mid-seventies, she's relatively healthy, not feeling all that close to death, not in need of an EpiPen or an organ transplant. Maddox writes, in the poem “‘Sudden Death’”:

One day the heart wakes up and says,

'I've had enough' and stops its drone of work,
or maybe pauses just enough
to make us pause,
until it's finally lured into a life
that deaf and dumbly balances on tracks
as flat as monitors.

No one avoids the heart eventually giving out. Immortality is not up for grabs in any of these memoirs. In fact, no matter our age, we're all old enough to die because any of us might develop cancer, be bitten by a tick, develop a never-before-seen genetic condition, or have an allergic reaction that causes our throat to swell shut. Any part of us might either see us through the day or be enough out-of-whack to unravel the daily-ness of our life. This reliability and fallibility of the human body is something Maddox points out in her long sequence of personified "Body Parts." Ribs are "the fine bone line / that saves/ / enslaves / us." The gallbladder is "stoned, / disowned, / thrown with her baggage of bile / on the bloody street [...]." Every body part holds up, until one or more of them don't.

These books—*Everything Happens for a Reason; Sick; The Family Gene; I Am, I Am, I Am; and Transplant, Transport, Transubstantiation*—are each worth reading on their own, for the distinctive story of illness, for the sharp perspective, and for the original voice. If you've seen one, you've *not* seen them all. Each is a really good book in its own right. Together, they are an imperative, a call for compassion for each other. Moreover, they are a call for wide access to personalized health care and individualized decision-making between healthcare providers and patients.

We do not know what the future holds for our bodies. One of us may have the rare "magic" colon cancer eligible for the newest treatment instead of the kind that felled my college friend and a poet friend. Another of us may need continuous access to an EpiPen and GPS to safeguard our daughter's health instead of merely needing a tissue to wipe our own pollen-activated runny nose. Bowler is too poor to pay for out-of-network care herself, whereas O'Farrell is covered by publicly funded health care in the United Kingdom. Our options are hindered and augmented by our circumstances. Together, may we work toward a system that doesn't turn any of us away and from which we are not induced to turn away in frustration. May we each make the best decisions for ourselves and our families to lead the best lives possible, whether in health or in illness, for however long or short that might be.



*Anna Leahy's most recent books are the nonfiction books *Tumor and Conversing with Cancer* and the poetry collection *Aperture*. See more at www.amleahy.com.*