

# The fellowship of illness

## MEDICAL MEMOIRS

Jennifer Levin | The New Mexican

In 2020, I underwent two brain surgeries. The first, in July, was to remove a 2.1-centimeter tumor from my pituitary gland. The second, four months later to the day, removed a 1.1-centimeter colloid cyst from my third ventricle. During recovery, I delved into a stack of medical memoirs in an effort to commune with others who have experienced catastrophic illness.

I began Anne Boyer's Pulitzer Prize-winning breast cancer memoir, *The Undying* (2019), at the tail end of August, and then took months to finish it. I interrupted the demanding, high-literary text to devour *Brain on Fire: My Month of Madness* (2012), by journalist Susannah Cahalan in one weekend. Cahalan's story is about her bout with anti-NMDA receptor encephalitis, a rare autoimmune disease that attacks the brain. I'd just finished it and had returned to the final chapters of *The Undying* when I found out that I needed the second surgery — news I had received during a follow-up to the first surgery. The same day, in my series of appointments, I was holding *The Undying* in my hands when an endocrinologist told me I could also look forward to a hysterectomy in the near future. That led me to *Ask Me About My Uterus: A Quest to Make Doctors Believe in Women's Pain* (2018), by Abby Norman, whose chronic trouble with her reproductive organs led her to drop out of college and eventually become a self-taught health writer.

Illness memoirs have the potential to give an artful shape to one's trauma,

as well as support other patients, caregivers, and loved ones when it seems like no one else could possibly understand what they're going through. Such memoirs teach empathy and even inspire further scientific research or better care by medical professionals. And while many people shy away (or even run away) from hearing about the abyss of disease, we are in a historic moment of reckoning with the fragility of our bodies. In 2020, sickness was everywhere. And in 2021, it looks like it will get worse before it gets better. Already, COVID-19 memoirs are being written. As for me, I came back to life during a pandemic.

### 'The moment that pain owns us'

Both of my brain conditions are considered rare. The pituitary tumor secreted growth hormone, resulting in a disease called acromegaly, which affects about 60 out of every one million people. It significantly

shortens life expectancy and causes a wide variety of health problems, including but not limited to excruciating joint pain, hypertension, migraines, insomnia, low vision, excessive limb and digit growth, organ swelling, disfiguring facial changes, severe anxiety, and cancer. The tumor hitched a ride in my head when I was about 11 years old. At just over 5 feet, 4 inches tall, I'm what's known as a tiny giant. Most of my growth is in density. My bones and joints are too big. My skin is several inches thick, which compromises my lymphatic system and

makes it hard to move. To remain mobile this last decade or so, I've done about three hours of lymphatic therapy and yin yoga every day, the latter of which is a form of deep stretching that involves a lot of lying on the floor.

Now, according to imaging and blood tests, I'm in complete remission, save for physical rehabilitation, testing and treatment for residual health effects, and watching — mystified — as 35 years of excess growth attempts to reverse itself.

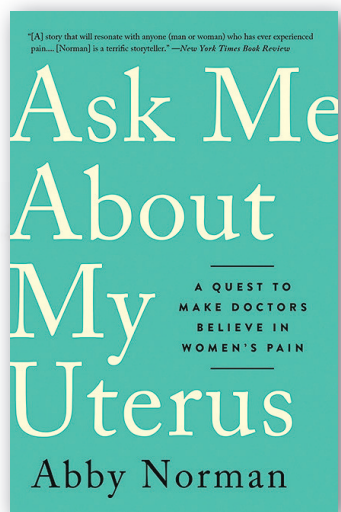
The colloid cyst is something you're born with, and it affects approximately two out of every one million people. It can cause a lifetime of feeling nauseous and achy. Once it grows large enough, it prevents the flow and processing of cerebrospinal

fluid, which can result in hydrocephalus (water on the brain) and, potentially, death. In early November, my surgeon said my death would likely occur in the next few months, as my flow was sluggish at best, creating enormous pressure in the ventricles and a "fetid pool of fluid" in which my brain was sitting. My ventricles were *much* too large for a woman in her mid-40s, he said. (And no, ventricle size isn't related to acromegaly growth.) He kept asking me if I frequently pass out face first, or if I ever wake up with a headache in the back of my neck. No to the first question. To the second: every day of my life.

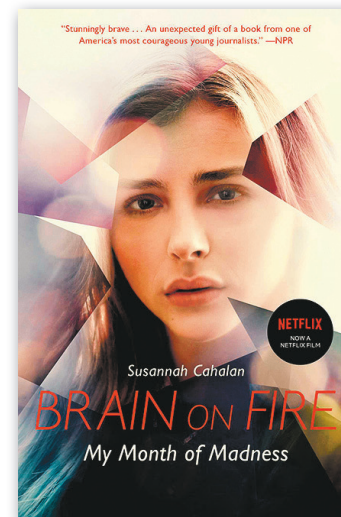
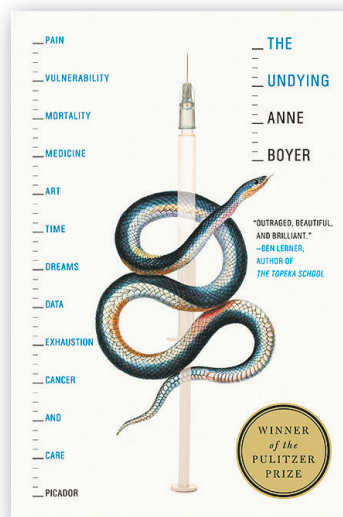
The absence of a distinction in my life between health and illness made *Brain on Fire* fascinating to me because Cahalan could define such a firm boundary between when she was well and when she knew she was sick. She noticed a couple of lesions on her arm, felt flu-like, and found her new mood swings troubling — at least until she ceased to recognize her own erratic behavior. Although her brain was seriously infected, initial consults and tests indicated nothing was wrong. One neurologist said that she was obviously an alcoholic going through withdrawal, even though she hadn't had a drink in weeks.

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Cahalan was in her early 20s when she got sick and wrote the memoir just a few years later. She provides enough information about her personal life and career to give some emotional context to her story, but *Brain on Fire* is mostly about her doctors' and parents' search for an accurate diagnosis while Cahalan wasted away in a hospital bed for a month, first labeled psychotic and then catatonic. Once they found out what was wrong, she was set on the road to recovery. And because of an article she wrote for the *New York Post* about her experience, followed by



I know from the way my personal relationships have been affected that it can be hard to like someone who is in pain all the time. We aren't always nice, or psychologically present for other people. I am particularly guilty of being quick to anger at really innocuous stimulation. This is actually a symptom known as "acro rage" that stems from being in constant pain while being fire-hosed at all times with the growth-hormone levels of a teenage boy.



her memoir, anti-NMDA receptor encephalitis is now more widely recognized, diagnosed, and properly treated than it was during her 2009 ordeal.

That Cahalan couldn't get a respected Manhattan neurologist to see her as more than a 20-something wild child was enraging to me but not surprising. Studies and surveys show that doctors tell women that their pain is psychosomatic far more often than they say this to men. Women are even given fewer post-surgical painkillers than men, even though they report higher pain levels.

Gender bias in medicine is a major theme in *Ask Me About My Uterus*, in which Norman recounts, often in bloody, wrenching detail, her decades-long ordeal with physical distress, as well as the traumatic childhood that may or may not have contributed to her health problems.

Norman was raised by a mother with severe bulimia. She controlled Norman's food intake and growing body. When she was 16, Norman started proceedings to become an emancipated minor. Painful periods were already a fact of her life, but her symptoms became much more serious in college. She missed so many classes that she was asked to take a leave of absence, but she never got well enough to return. She spent the next several years trying to get doctors and surgeons to figure out what was clutching and clawing so furiously at her insides.

Every moment of *Ask Me About My Uterus* is rendered in high relief, without much variation in tone. Norman writes about pain, lust, dancing, and working in a hospital with equal levels of intensity. There's something abrasive about the way she pushes her pain in the reader's face, or describes the profundity of her first sexual relationship, or talks about her own fierce intellect. It can be hard to take at times but, then again, so can a lifetime of parental abuse and neglect, and the all-encompassing pain that often keeps her bedridden. I know from the way my personal relationships have been affected that it can be hard to like someone who is in pain all the time. We aren't always nice, or psychologically present for other people. I am particularly guilty of being quick to anger at really innocuous stimulation. This is actually a symptom known as "acro rage" that stems from being in constant pain while being fire-hosed at all times with the

growth-hormone levels of a teenage boy. It's like never leaving the upheaval of adolescence behind. And I'm constantly hungry.

Norman, in her advocate's zeal, flays herself for the reader in line after line — an approach that terrifies me but from which I couldn't look away.

"Bodily agonies that do not end beget a kind of forced intimacy with pain that, not unlike other intense relationships, can eventually bleed into something tedious and almost unremarkable in its enduring presence," she writes. "Its place in our lives can become ordinary and even, at times, oddly reassuring. The moment that pain owns us is not when it chokes our breath, when it knocks us down, or when it steals our pleasure. Pain becomes our master when we wake up one day and realize we no longer fear it. We come to regard it as not something separate from us, but something of us."

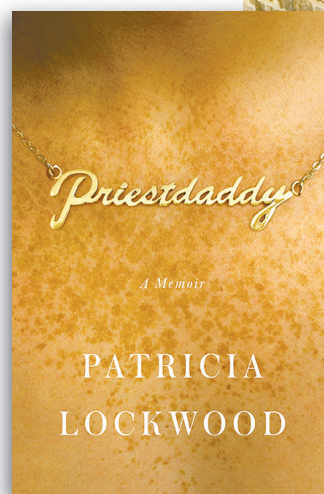
### Unforgivable literature

The lengthy subtitle to *The Undying* only hints at what's inside: *Pain, Vulnerability, Mortality, Medicine, Art, Time, Dreams, Data, Exhaustion, Cancer, and Care*. Boyer is an award-winning poet and essayist whose books include *Garments Against Women* (2015) and *A Handbook of Disappointed Fate* (2018). She survived triple-negative breast cancer, an aggressive cancer that doesn't respond to hormonal therapy medicines or medicines that target HER2 protein receptors. Treatment is old-fashioned and debilitating. Boyer was diagnosed a week after she turned 41. *The Undying* seamlessly fuses her forms, weaving a nonlinear narrative of her treatment with bits of clinical research; reflections on writing by other women with cancer; philosophizing about the cancer industrial complex; slamming the attendant ramifications of expensive, extensive cancer treatment; and many other elements. *New York Times* reviewer Jennifer Szalai called *The Undying* "extraordinary

and furious," a jealousy-inducing turn of phrase for any aspiring memoirist. (I am considering writing a book about my own experience.)

Boyer writes that her book is for the sick, and there is a caustic humor to it that perhaps only those who have been in the trenches will fully appreciate. But she doesn't limit her audience to women with breast cancer. It's relevant to anyone with any cancer (I've had thyroid cancer, twice) and really anyone who has suffered under the pall of serious illness or injury. As I read *The Undying* each day before starting my rehabilitative exercises, I usually found a passage to photograph and post to Instagram, where there are

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## Memoirs, continued from Page 9

many thriving illness communities. (To meet others with your condition, all over the world, all you have to do is follow hashtags for your disease.)

In among her episodic musings of varying length, Boyer captures my own ambivalence about turning my medical traumas into literary fodder. Sometimes, I don't like the idea of turning my sick-but-recovering body into a commodity.

"In literature, one person's cancer seems to exist as an instrument of another person's epiphanies, and sickness takes the form of how sick a person looks," she writes. "At a poetry reading I attended during my illness, a poet is nearly shouting and wailing poems about a cancer she doesn't have, then another poet, and then another ... then a book comes in the mail in which the mother dying of cancer is, now that she is so thin and pale, compared with a long list of famous thin pale beauties. None of this literature is bad, but all of it is unforgivable."

You can read any page of *The Undying* for a jolt of fellowship if you are sick, and to feel almost guilty for your health if you are not. But still, something was missing in this account, and from the others. In them, I didn't find a reflection of my own experience, nor did I meet a voice that truly resonated with me. I wouldn't want to spend any real-life time with these authors, commiserating about our shared misery, such as it is. Sure, I'm angry that it took my whole life to find out that I'm not a hypochondriac, or too weak to handle a normal amount of pain, or that I was somehow making myself sick. I had not one but two brain invaders that were causing me to constantly feel like hell, from the very beginning. For me, the only way to accept this reality is to make a lot of jokes about it. Boyer, Norman, and Cahalan all write with a degree of humor, but I longed for someone to speak to me with open-hearted wit, to offer some absurdity at her own expense.

I found what I was looking for in the critical darling *Priestdaddy* (2017), by Patricia Lockwood, another poet and essayist. *Priestdaddy* isn't about illness, but about an unusual childhood, issues of faith and morality, and creative ambition. Lockwood has a way with words that boggles my mind, because she manages to be simultaneously hilarious and serious, often in the same sentence. She was raised in the Catholic church and oratory is in her blood. I envy her bawdy, nearly blasphemous irreverence. She writes that she wasn't even sure she wanted to write a memoir, because it would mean telling the whole truth instead of dancing around it with poetry. She confronted the issue by wrestling with it in the pages of her book.

"I would write forever, but not about myself, and not about what happened, and never about my most profound and deforming secrets — that I had been raised in an alternate reality, that my childhood sky was green. There were many, many other things to occupy me, I reasoned ... lewd copy for dildo catalogs, for starters. But how long can you outrun your subject, when your subject is your own life?" ◀

*I am honored to have shared some of my health journey with Pasatiempo readers. Although I look forward to reader feedback, I cannot respond to all correspondence. Thank you for understanding.*

**ASK ME ABOUT MY UTERUS: A QUEST TO MAKE DOCTORS BELIEVE IN WOMEN'S PAIN** by Abby Norman, Bold Type Books, 288 pages, \$27

**BRAIN ON FIRE: MY MONTH OF MADNESS** by Susannah Cahalan, Simon & Schuster, 266 pages, \$16

**PRIESTDADDY: A MEMOIR** by Patricia Lockwood, Riverhead Books, 352 pages, \$27

**THE UNDYING: PAIN, VULNERABILITY, MORTALITY, MEDICINE, ART, TIME, DREAMS, DATA, EXHAUSTION, CANCER, AND CARE** by Anne Boyer, Farrar, Straus and Giroux, 320 pages, \$26