

SPEAK, MALADY

An autobiography of cancer

By Adam Baer

Discussed in this essay:

The Emperor of All Maladies: A Biography of Cancer, by Siddhartha Mukherjee. Scribner. 571 pages. \$30.

The procedure was offbeat, even for someone whose malignant lymph nodes and chest masses had melted away thanks to aggressive radiation fifteen years ago. After removing my glasses, I reclined on a narrow motorized

chair, especially for my unique face—surgically taped onto my head, pulling my hair. (The making of the mask was nearly spa-like: for forty minutes I lay breathlessly meditating as people tended to my complexion, wrapping my head in what felt like hot

plastic, notwithstanding occasional fasciculations caused by my peripheral neuropathy. The techs had assured me that even if I moved a little—by swallowing, say—the machine would know how to adjust (“The beam is aligned with physiological markers set by an X-ray taken immediately beforehand”), but I was still worried about spillover: if the particles were to overshoot their mark, they could damage healthy tissue surrounding the malignancy—in my case, inconveniently located right in front of my brain stem. I had been allowed to select the Internet radio station and had requested Classic Rock, which I was enjoying as my chamber echoed with the Beatles’ “Help” and Pink Floyd’s “Brain Damage.”



plastic plank suspended over a chasm in the hospital floor, in the cylindrical belly of a colossal white Kubrickian particle accelerator. I wore a tight-fitting mask—made from webbed plastic molded spe-

Adam Baer lives in Los Angeles. This is his first article for Harper's Magazine.

strands of sticky papier-mâché.) Inside the machine, I heard a circular whir, a motorized grinding, a sigh like a bus releasing exhaust. Protons programmed to follow the convolutions of my tumor's every twist and turn shot into my head at three spots: my temples and above the third eye. I tried to stay totally mo-

For nine weeks last summer, I underwent a custom course of proton-beam radiation at Massachusetts General Hospital. I live in Los Angeles, so I sublet a strange Beacon Hill tenement. For my 7:30 appointment each morning, I would cross Cambridge Street with a fresh shift of scrubbed-up residents and hospital personnel.

Wearing my glasses, beard, and New Balance sneakers, I was frequently mistaken for a colleague. Summer students of all kinds flooded the city. My parents drove the four hours up to take their overgrown kid grocery shopping, out for chowder, to big-box stores for portable plastic furniture.

The tumor in my head, a partially cartilaginous lesion in the clivus bone known as a chondroid chordoma, was atypical: mine in particular made me, according to my doctor and his excited radiologist, odder than one in a million. Ironically, my medical history was considered irrelevant: stage IVB Hodgkin's disease in long-term remission, massive amounts of sub-lethal chemotherapy, a stem-cell bone-marrow transplant, growing up on Long Island, degenerative neuromuscular symptoms, severe hormonal imbalances, heavy loads of radiation to the neck and chest. The Boston radiologist's exhaustive and innovative imaging of the chordoma had picked up shape and depth that earlier MRIs, performed at sophisticated facilities in New York City and Los Angeles, had missed. This wasn't exactly happy news—I now knew the tumor was larger than previously thought, that a neurosurgery six months prior had been more like a biopsy—but it was useful information nonetheless. Initially, several doctors had guessed the growth to be benign, before seeing the pathology, obtained when two skilled Manhattan surgeons drilled into my skull and sucked some mushy gray matter out through my nose, as a bonus fixing a deviated septum I didn't know I had.

The godfather of chemo was just like me. Sidney Farber came from earthy Polish Jewish stock, grew up in the state of New York, and spent time in Boston, now home to the renowned cancer center, Dana-Farber, that bears his name. Sidney and I were raised in budget-conscious but educationally ambitious families, and we both helped put ourselves through college as performing violinists. Of course, Sidney attended Harvard Medical School and became a pathologist, whereas I did not—but we've both been called natty dressers, and anyway, let's not split hair cells.

I learned of these biographical symmetries from the formidable new book by writer-oncologist Siddhartha Mukherjee: *The Emperor of All Maladies: A Biography of Cancer*. Mukherjee's project is literal: he sets out to personify the disease(s) we call cancer, following its life as civilization came to know it better: its terrifying and mysterious infancy (solid tumors poking out from porous skin sacks; bloated white blood cells visible to the naked eye, leaking from autopsied veins); its means of action ("activated proto-oncogenes and tumor suppressors," or "jammed accelerators" and "missing brakes"); the history of our attempts, linguistic and experimental, to define the bafflingly expansive disease category; the financial and political forces that have guided research; the "military history" aspect, i.e., our efforts to fight the disease (from Marie Curie and blunt surgeries to chemicals made from Madagascar periwinkle to the artificially intelligent drugs of our genome era); the cancerous themselves (the way a feeble, elderly female patient reminds Mukherjee of those "tiny insects or animals that you read about in natural history textbooks"). While not uncompassionate, the tone is somewhat emotionally disconnected, as I have learned some oncologists have to be; still, the project's level of assiduous exactitude is exactly what we expect from a good doctor. Mukherjee also writes well. His literary flourishes—etymologies (*oncology*, from the Greek *onkos*, "burden"), allusions to Shakespeare and Sontag—reflect and justify his ambition.

The Emperor of All Maladies has enjoyed an ecstatic reception, but its place in the zeitgeist is more complicated for some of us: those for whom cancer is not phenomenon but phenomenological. I can't attend a social function in bookish Los Angeles without someone whipping out his *Emperor*. At a holiday party last December, months after I had returned from my radiant Boston summer, my wife and I stood in a house overlooking West Hollywood from atop a scruffy canyon, and I could see, even through the

sheen of secondhand smoke, the twinkling lights of the Cedars-Sinai hospital complex down on Third Street. A music executive who had "really wanted to be a doctor" had read Mukherjee's book digitally, on his Kindle: "That way I can always have it with me." I responded with my surefire cancer e-book joke about the massive amount of malignancy I carry around in analog form. A bright young entertainment blogger, who had also just read the book, asked whether I was "on Gleevec," the pioneering leukemia smart-drug that keeps some patients alive for a surprisingly long time. Upon discovering I'd had Hodgkin's, she reminded me that this particular lymphoma was once classified, on HBO's *Curb Your Enthusiasm*, as the "good one to get."

Who can blame these cancer fans? I, too, appreciate projects that treat a difficult subject with rigor, although I'll confess to harboring a bit of prejudice toward thing-biographies. It's the enormity of these subjects—whether the dictionary or the ocean—that makes me wary of the way any attempt to sum them up can serve to diminish them, simultaneously reducing and inflating their significance with accounts that seem definitive. Necessarily, they generalize experiences; their form of fastidiousness brands and even deadens their subjects. Apparently, the pioneer of radical surgery, William Stewart Halsted, loved purebred dogs and Parisian cobblers. It's not exactly that I feel excluded from a *Biography of Cancer*. I fit in, just as the guy who plows my parents' snow fits into the *Biography of Salt*.

Mukherjee's book skews most inclusive when he gets lyrical about cancer cells' *joie de vivre*. It's there in the subtitle, and the theme recurs throughout, almost like . . . lupus? "Cancer's life is a recapitulation of the body's life, its existence a pathological mirror of our own. . . . Down to their innate molecular core, cancer cells are hyperactive, survival-endowed, scrappy, fecund, inventive copies of ourselves."

AD PAGE TK

WALTER KARP

Buried Alive

Essays on Our Endangered Republic



A CONTRIBUTING EDITOR TO HARPER'S MAGAZINE FOR 11 YEARS BEFORE HIS DEATH, WALTER KARP WAS A JOURNALIST AND POLITICAL HISTORIAN WHOSE WRITING IS CHARACTERIZED BY INCISIVE COMMENTARY ON GOVERNMENT AND A FIERCE LOVE OF DEMOCRACY. BURIED ALIVE INCLUDES THE BEST OF KARP'S ESSAYS SCRUTINIZING AMERICAN POLITICAL AND SOCIAL ISSUES (THE PRESIDENCY, POLITICS, THE PRESS, CENSORSHIP, EDUCATION, AND THE LESSONS OF LIBERTY) WITH FORCE, ELOQUENCE, AND INDEPENDENT THINKING. PREFACE BY LEWIS H. LAPHAM.

Order today through
www.harper.org/store

Published by Franklin Square Press
ISBN 978-1-879957-04-6
Softcover \$14.95

FRANKLIN
SQUARE
PRESS



Distributed through Midpoint Trade Books

Mukherjee calls cancer cells “desperate individualists” who live “territorially, cannily, and defensively, at times teaching *us* how to survive.” Cancer’s “quest for immortality mirrors our own”; “if we seek immortality, then so, too, in a rather perverse sense, does the cancer cell.” (I for one don’t seek immortality; I’d just like a flying car and to die at an average age from something obvious; not least, as Mukherjee also reminds us, because that’s what cancer really is: a disease of aging.) He also calls cancer a “desperate, malevolent doppelgänger,” which mildly discomfits this *Twilight Zone* fan, given that my younger brother, who looked just like me as a baby, grew up to be extremely strong, six inches taller, and a hell of a lot healthier (does that make me his nefarious doppelgänger? Is my bad left ankle my OCD sister?).

Yet for all of Mukherjee’s immortality talk, he still speaks of curing cancer, when, in fact, his own investigation into this relentless, beguiling antihero has suggested it can never really be destroyed, that it will grow resistant even to new smart drugs that target its specific genetic pathways. In this way, *The Emperor* taunts us with the sweetness of an end to a story that has no true conclusion. I don’t believe I have been or ever can be “cured” of “cancer,” despite what Mukherjee tells one leukemia patient, and what my own pediatric oncologist, a short, truculent Hungarian man, told me at eighteen after my first round of effective chemo.

No one can be *cured* of a malignant disease (if we are to adhere to the true definition of that word). Black-and-white data-people, the scientifically religious, may, in conversation, say someone is “cured” of cancer, but in those instances they are disrespecting language and fact. Today, the goal with my chondroid chordoma is to slow or stop its growth, to outlive its potential disturbances of vital structures (such as my brain stem and facial nerves). For two months, my head absorbed heavy doses of daily radiation in an effort to stop the thing from grow-

ing too large down the road. My newest tumor—made of notochord cells that, in the earliest stages of life, build everyone’s spinal cord—has been called by certain doctors “a benign chordoma,” an oxymoronic term, since the definition of *chordoma* is, essentially, “a type of cancerous bone tumor” (“benign” refers to the tumor’s growth rate, slow because the lesion is partially cartilage). You can cure salmon and heal cuts, but cancer has no permanent off switch. You can only put it on hold, like an iPod. The power is always on, because it is your power: malignant, benign, and everything in between.

According to Mukherjee, and indeed anyone trawling medical message boards, the cancer patient is a storyteller, a “narrator of suffering.” If every cell is a life, then every one has a unique tale. In that spirit, I offer up herewith some of my more unusual, cutting-edge experiences. Call it a living biography, a review.

Born in 1950, I’d be dead. Of course, I might not have come down with a malignant disease to begin with, given the chance that environmental factors encourage the mystery virus that may have caused my Hodgkin’s. But in this evidence-based biography, let’s not descend into conjecture. Chemo, radiation, and surgery are boring. The real divertissement arrives after conventional treatments. You sign all kinds of terrifying pro forma documents that permit doctors to try to kill things growing within your breast, testicle, marrow, skull, prostate, liver, cervix, brain (personality).

You don’t think about the secondary cancers, so why should you think about the extremely odd late effects that may appear after treatments? The answer is: Because they will happen to you. And when they happen, they may not mimic what a doctor has seen before. As a member of the first generation of young adults able to avail of the new, effective cancer treatments of the 1980s and ’90s, I am something of a poster child for late effects. Take, for example, my autologous

stem-cell bone-marrow transplant, an intervention that became popular and successful in the 1980s (and is now also given to multiple sclerosis patients), which required me, at twenty, to undergo a process called apheresis, wherein my own baby white stem cells were extracted, for two days, from a catheter port installed in my neck as I sat in a sticky vinyl recliner. Said cells were then frozen while different, high-dose, “sub-lethal” chemotherapies obliterated my immune system to the point where my white blood cell count officially measured zero. For this procedure, I was sealed in a HEPA-filtered Bubble Boy room, replete with commode and unfailingly brave mother in pink booties, for a month, to prevent infection while the cells were given a chance to regenerate and create a New Me.

The stem cells took, grew; I developed an immune system again, went on, “cancer-free,” some would say. But the aftereffects were even more debilitating than the first few courses of chemo. I could hardly climb five stairs in my parents’ noiseless home without feeling like I needed a nap. My condition and stamina would improve, and six months later, I climbed Aspen Mountain, although with a terrible nosebleed. Ten years on, either the cancer, the chemo, or this procedure—which can, as one Dana-Farber oncologist recently told me, change the way your immune system behaves—led to my current chronic and degenerative mystery condition, which some people call an “idiopathic peripheral neuropathy”: in my case, ongoing, full-body nerve damage that renders you numb, little by little: weakens your muscles, dries your skin, slows down or speeds up your autonomic functions (pulse, breathing, digestion), fucks with your balance, causes stabbing muscle cramps and Lou Gehrigesque fasciculations nose to tail.

Up until 2005, I had been living a normal life, though my normal included thyroid medication, feeling frightened about more medical problems, the smearing onto my

skin in gel form of masculine hormones, regular visits to oncologists, check-up MRIs, conversations with those who cared (or didn’t). Then I sprained an ankle that didn’t heal right and began to lose feeling, strength, and muscle mass. I would see a twitch in my arm but not actually feel it. I sensed stinging insects under my skin. The left side of my lip would quiver rapidly; a second later, a chef’s knife might fillet my right hamstring before my left hip jerked ever so slightly to the left in an involuntary krump move. My leg muscles were decreasing in size, along with the thickness of my neck and arms.

Lymphoma patients often experience progressive nerve damage—it could be the gene that led to the lymphoma in the first place, or misdirected T cells. In the past few years I’ve seen more than twenty prominent specialists—hematologists, neurologists, rheumatologists, immunologists—to diagnose this as yet unnamed numbing, weakening beast. Along the way came the discovery of my chordoma, so my doctors and I got at least one answer, even if it wasn’t the one we were looking for.

I have a particular fondness for my 2008 trip to the Mayo Clinic, which I undertook, one balmy winter, on the recommendation of a nationally lauded USC neurologist who had thrown up his hands at my case and sent me not to someone specific but to a hospital on ice. There wasn’t much of the group-assessment style of treatment one hears about in association with Mayo; instead, I was assigned to a young doctor who told me I’d undergo a few days of tests before we met to learn his findings and opinion. Test. Test. Lunch. Test.

One uncommonly memorable assessment was the measurement of autonomic nerve function via the capacity to sweat. Here’s how it happens: First, you are stripped naked, save for a loincloth over your genitalia and a pair of sunglasses, and strapped to a table with wires taut over a few choice areas. Soon, a thermometer enters your mouth and

**FPO
PAJAMA GRAM
4/C
AD TK
020**

stays there for a good hour. During this hour, you're cooked. The technician covers you in a saffron powder and slides you into a large cabinet outfitted with overhead infrared lamps and digital cameras. Like a massive, naked, hairy, possibly delicious Big Bird, you are roasted in a convection oven until your internal temperature exceeds 101 degrees Fahrenheit. The saffron powder eventually turns purple on the parts of your body where your autonomic nerves work.

After the procedure, I took the longest shower of my life, noxious merlot raining down my powerfully lumpy extremities as I scrubbed myself, only to emerge ruddy still. "Take a dip in a chlorinated pool," advised the technician. The Mayo had none, so it would have to be, in this Minnesota January, the Motel 6.

Because of its location, my chordoma resists traditional radiation dispensation, instead requiring super-targeted high-dose methods, among which the leading candidate proved to be the proton-beam variety (instead of X-ray photons); my luck, an exotic choice left out of *Emperor* and other popular cancer biographies.

Developed at Harvard and Massachusetts General Hospital in the 1960s, proton therapy is attracting renewed interest as research suggests its effectiveness in irradiating treatment-resistant malignancies in areas that require extreme precision. It's used most notably in sensitively located head-and-neck tumors (the bone in front of your brainstem, say), in prostate cancer, and in children. The main drawback is the nearly \$100 million price tag of such particle accelerators; proton therapy has to date only been available at a few locations in the United States. New York City and Los Angeles, both bastions of top-notch cancer care, lack proton-therapy centers, although there is a new node at the University of Pennsylvania, and some radiation oncologists do not prescribe proton therapy because they cannot offer it at their own facilities. Most hospitals have instead sought an aggressively market-

ed, less capital- and real estate-intensive form of radiation therapy: "intensity modulated radiation therapy" (IMRT) or radiosurgery. IMRT and other similar techniques utilize traditional photon beams but with a three-dimensional targeting method. The result: more precision and the ability to deliver higher doses than standard radiotherapy.

Proton beams can be shaped more precisely than photons; the particles gain momentum as they travel through tissue to their targets (the tumors), where they stop—never exiting the body. This both loads higher doses into tumors more safely and preserves healthy tissue and structures around the malignant masses. IMRT and similar therapies also target their beams sharply, but the X-rays slow down as they move through the air and then your skin and then the tumor and into realms beyond (the aforementioned "spillover effect," a term I like about as much as "cure").

The literature suggests proton therapy is the better choice for my type of tumor, and I had a choice between Massachusetts General Hospital and Loma Linda University, an Adventist medical center an hour east of Los Angeles. I went to UCLA for guidance. Did they refer patients like me to the nearest proton facility, or would they recommend my flying to Boston for ten weeks? Their answer wasn't A or B, but C: "Choose us." UCLA owns a Novalis-brand IMRT machine—Novalis is regularly and vaguely advertised, like herpes suppressants, during morning news shows—the radiation oncologist explained, and he could treat my tumor with "comparable" results, even if compelling backup data wasn't yet available. "We'd have to begin offering proton therapy if our competitors like Cedars-Sinai buy a machine," this doctor told me. "Until that happens, we don't need it."

Say thank-you, repeatedly; try not to express any anxiety or doubt; suppress stomach quirks and bad behavior; and for Science's sake (as well as that of ever getting another appointment or fair assess-

ment), don't write anything about your medical experiences unless it's flowery praise. These are just some of the rules, only implied yet iron-clad, when your life is in the hands of an oncologist, or team of them, some of whom you'll love, some of whom might save your life, all people who must adhere to their own code of silence, the more explicit, legalistic Health Insurance Portability and Accountability Act.

Somewhere in between the highly skilled doctor imparting the history of the internal rhythms that govern and power your body and the patient who has learned to remain, in all social encounters (medical and non-), gracious and "chill," as they say in L.A., there's another conversation. It's the one going on among cancer autobiographers, and it's typically off the record, as it tends to make outsiders squeamish, scared, or sad.

For most of us, cancer—if we must call it one thing—is simply one running line in the polyphony that is a life. Disease is raised to melodic status only if you choose to bring it out in your performance; I prefer to relegate it to the realm of the poor viola.

Believers in cure almost always obscure or ignore the mysterious and degenerative late effects of both treatments and the cancers themselves, the stuff you, the patient, will always carry with you, the stuff they never really tell you about, because no one walks away from an infusion of platinum with just a little more shine in his hair—even if your white-cell count is considered "normal," which is, in itself, nothing more than a constantly changing number in a range of scores, nothing definitive, just like there is no truly "normal" way to run, speak, feel. Infirmary and health are fluid states.

When I tell people, especially those whose curiosity has been conferred by recent cancer primers such as Mukherjee's, about my chordoma, their first question is, understandably, whether I'll get better. Its incurability is a bit of a conversation stopper. "Even now with all this stuff they can do?" "Do you hate it? I

mean, it's invading your head." "How can you live like that?"

I explain that I don't think of my tumor as something alien invading

my head; it is my head, a part of me. And I like myself, exquisitely treated and uncured, at least most of the time. ■

tures and fashion choices of the pretty young woman she only recently was. When Mary (Lesley Manville) remarks that it's lovely to be cooked for—that "you don't really bother when you're by yourself, do you?"—Tom (Jim Broadbent) and Gerri (Ruth Sheen) respond intuitively, with offhand reassurances intended to dispel the momentary chill cast by their friend's involuntary yet calculated allusion to her loneliness.

"You're looking well," says Tom.

"You're nice and slim," says Gerri. "Unlike me—middle-aged spread."

"Shut up," says Tom, kissing his wife. "You're perfect. Gorgeous in every way. And you know it."

Lingering on Gerri's face, the camera records a mix of emotions: sympathy, pity, chagrin, a flicker

LONELY ISLAND

Mike Leigh's intimate cinema

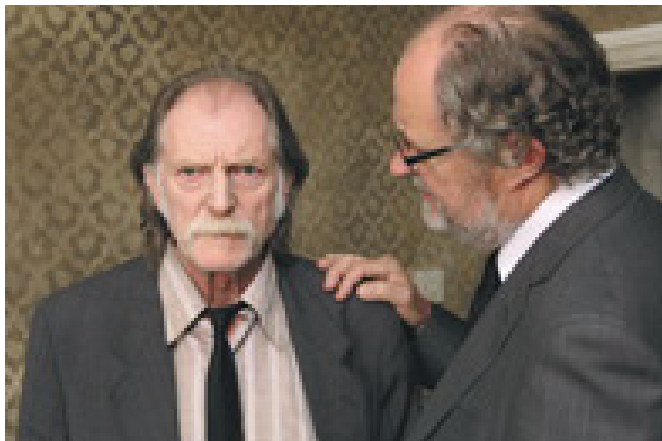
By Francine Prose

Discussed in this essay:

Another Year, by Mike Leigh. 2010. Sony Pictures Classics. 129 minutes.

Near the beginning of Mike Leigh's most recent film, *Another Year*, a married couple named Tom and Gerri

home. As Tom and Gerri prepare the meal with the effortless choreography of the long and companionably wed, Mary flutters around



invite Gerri's coworker Mary to dinner at their suburban London

Francine Prose is a contributing editor of Harper's Magazine. Her novel My New American Life is out from HarperCollins this month.

the kitchen like a bird trapped in a house. For Mary, this prison is her solitary plummet into middle age, a fall she is attempting to arrest by grabbing on to the flirtatious pos-

of guilt for her own good fortune, perhaps even mild irritation. Tom's spontaneous, reflexive display of affection has shattered Mary's eggshell gaiety. (As in