

What She Left Me

By Ellis Avery

When I was diagnosed with a rare uterine cancer called leiomyosarcoma at the age of 39, less than a year after my mother's early death, my rheumatologist told me I had to stop taking Humira, one of the immunosuppressant drugs she had prescribed. Going off my arthritis medication in June of 2012 probably saved my life, but it also heralded the return of my arthritis six months later. Neither osteo nor rheumatoid, mine is an autoimmune condition called Reiter's Syndrome, the medical school mnemonic for which is "Can't see, can't pee, can't climb a tree." Thanks to leiomyosarcoma, I had just been given a 26% chance of five-year survival: I did as I was told that summer and went off the Humira.

During the years I had been on Humira, I had been under strict orders not to consume alcohol; each taxes the liver too much to be combined with the other. "If you stopped drinking, you could try out these drugs," I remember once telling my hard-living mother, without giving a thought to the risk of cancer. "Imagine a life without pain."

My mother, the great bulk of her beached on the couch, did not reply. She finished pushing back a cuticle and took a deep drag on her cigarette, eyes closing in concentration. I waited; the ice in her vodka melted with a quiet hiss: she tipped her head back and pale blue smoke plumed upward.

In the silence with which she replied, I could hear my mother disparaging my father's teetotalling father: *What's the point of such a long life if there's no joy in it?* Drinking and smoking may have abetted the brain hemorrhage that killed her at the age of sixty-eight, but my mother died as she would have wanted to, without losing her independence, without giving up vodka, or cigarettes, or coffee, or chocolate, without compromising the daily pleasures that gave her joy.

Distrustful of doctors, my mother never knew exactly what kind of arthritis she had, but it had struck at age twelve, she said. She did know that her mother had had it too, and her mother's mother before her. My mother left behind twenty-eight pairs of foot-pampering Birkenstocks; my grandmother left behind a brace of gaudy rings that deflected attention from her swollen knuckles. My wheelchair-bound great-grandmother, whose arthritis had wracked her so painfully she spent every winter in the desert, left behind her writing desk, now mine, and a story about her hair, which remained red into her seventies. "When they went to the beauty parlor," my mother told me, "all the old ladies would say, *give me the rinse you gave Lillian McDee*, and they would get the clear rinse. They'd come out so *mad*. Ready to spit wooden nickels." At forty, after my mother's death, a cancer diagnosis, and a hysterectomy, I wouldn't have been surprised to see white hairs among the red, but perhaps I had inherited Lillian's coloring along with the severity of her disease.

In my mother's house, along with her jewelry and Birkenstocks, I found a favorite volume from childhood: D'Aulaire's Book of Greek Myths. Wanting more sisters, I had been especially drawn to Zeus's junior wife Mnemosyne and her nine daughters, the Muses. Mnemosyne is the

goddess of memory: unlike the river Lethe in the underworld that makes the dead forget their lives, Mnemosyne's river makes them remember. In Greek mythology, Mnemosyne's nine daughters preside over Epic Poetry, Love Poetry, Hymns, Music, Dance, Comedy, Tragedy, History, and Astronomy: Memory is the mother of the arts.

Because neither chemotherapy nor radiation had been shown to prolong the lives of leiomyosarcoma patients, I chose not to receive either treatment after my hysterectomy in 2012, hoping that if I stopped taking Humira, the cancer might not come back. A few months after surgery, a CT scan showed no evidence of cancer, but the arthritis came back with a vengeance, flaring in my neck and shoulders. After my doctors prescribed anti-inflammatory drugs that November, I seemed to feel even worse. I had to stop sleeping on my side and start pulling shirts over my head with just one arm. Then, one Saturday in early December, I found it painful to walk the eight blocks to a nearby park. On Sunday, I could only make it to a nearby café. By evening every step was agony. The pain came from a spot on my right foot that had never bothered me before: the big toe. When I woke up Monday morning, the toe was swollen and bruised, despite my not having had an injury. "With Reiter's, the body responds as if to trauma," a rheumatologist had once explained to me, "but there is no trauma."

My foot got worse. My shoulder got worse. After a couple of days, the touch of my foot on the mattress was so painful it kept me awake at night. I could only fall asleep if I propped my foot with pillows, but that hurt my shoulder. I had kept a pair of my mother's Birkenstocks to use as slippers: it took only minutes for the sandal-strap to bite a mark into my swollen toe. When I left the house, my foot had swollen so much it hurt to put on a shoe. It was the last day for months I would try to walk outside like a normal person. At one point that evening it pleased me to notice that, even limping, I'd managed to pass someone on the sidewalk, until I realized it was a father who had slowed his pace to match that of a tiny child.

That night, having compensated gamely for a few days, I felt a tearing pain in the ankle of my opposite foot.

They're such small things—a big toe, an ankle joint—but if they're yours and they hurt, they become huge. Once it became painful to walk, I found myself wondering if the cancer was coming back, as it can, in my feet, which made me think about the hysterectomy I'd undergone just months before. I found myself thinking, *if I cut off my feet, they wouldn't hurt.*

The pain also turned me mean. One day I snapped at a woman and her elderly mother for claiming they'd been waiting for a cab longer than I. "You were here first? Really? You've been here for the past ten minutes? While I've been trying to get a cab?" They huddled together under my onslaught. "Sorry but..." I whined aggressively as I maneuvered into the cab I'd hailed, backing in butt-first, hauling my miserable feet up limply after me. I hated those women. I hated myself.

That's when I recalled something I'd once read about a goddess of pain. Had I done something to offend her? If I said a prayer or slaughtered a dove, would she leave me alone?

I first encountered Loviatar, the Finnish goddess of pain, while playing Dungeons & Dragons between the ages of ten and fourteen. Too shy to actually play with anyone but my little sister, I read everything I could find on D&D, including the *DEITIES AND DEMIGODS* handbook. Loviatar appears in a line drawing by Jim Roslof as a frosty, bare-breasted young woman. Her puffy hairdo made her look mythic on paper, but in real life she would look like an '80s mall-rat. Her weapons were a whip and an icy dagger.

The Dungeon & Dragons version of Loviatar was popular. (Chalk it up to the bare

breasts.) What about the version that preceded her? The Finnish national epic *KALEVELA* presents Loviatar as “the blind daughter of Tuoni,” the god of death, an “old and wicked witch.” Impregnated by the wind, she gives birth to nine sons: Colic, Pleurisy, Fever, Ulcer, Plague, Consumption, Sterility, Gout, and Cancer.

The Finnish Loviatar whom I read about after the arthritis shifted from my eyes to my feet was a frightening but all too familiar figure: blind, old, and stooped. No matter how young you are when it strikes, arthritis makes you feel old. The pain stoops you. That month I left meetings because back pain doubled me over. Some mornings my feet hurt so badly I had to crouch in the shower on my hands and knees.

One day, as I hobbled across the courtyard, I thought about Loviatar: maybe she’s right here, possessing each body in pain. To know her is to be her. Stooped, frail, blind to the beauty of the world, too wrapped up in pain to be kind: does that describe the goddess or those she afflicts? I wondered if my little nephews saw me as a Loviatar-like old lady, tired on the couch and no fun, the way I saw my mother as a child.

Loviatar and her nine sons called to mind Mnemosyne and her nine daughters. Nine muses, nine diseases. Art arises by intention, and requires memory; disease strikes by chance, on an obliterating tide. It takes so much human effort to knit the hand and brush to the work of art; the diseased body unravels according to its own mindless rules.

Like many daughters, the old woman I’m most afraid of turning into is my mother, so it was eerie to find myself calling her forth with the pained gestures I remember her making as well: a careful tilting of the neck, a slow ceaseless seeking of ease. When I tallied up the things my mother left me after her death, I forgot to consider my body, half hers. Sinister double to the works of art—the jewelry, the writing desk, even the Birkenstocks—passed from mother to daughter, our arthritis is a set of instructions our bodies remember and replicate perfectly: in a dark mirror, the goddess of memory is the goddess of pain.

I remembered the way my mother flopped from bed to couch and back: I was doing just that. When I got home from each outing, I could hear my mother’s words in mine: “I just need to sit down with a glass of water before I do anything else.” Most afternoons she would lie beached on the couch, blue smoke rising from her cigarette. It was sobering to think that she had been in as much pain as I.

There was a period in my mid-thirties, not long after I started taking Humira, when cab drivers would ask how many children I had. “I have arthritis,” I explained to an especially chatty driver. “So bad it once caused stress fractures in my feet.”

Before I could tell him that I was afraid of going off my arthritis medications, as I would need to do in order to prevent birth defects, he interrupted. “I can see not wanting to pass that on to a child.”

Sometimes, alone, in the first days after the arthritis crippled my feet again, that December of 2012, I raged at my mother. Why have a child if you (like your own mother, like hers before her) were in so much pain? Had I been supposed to just magically dodge the genetic bullet? Had medical science been going to fix everything? Had the plan been to set me up with a bottle and a couch, just like her? And yet, despite my anger, despite the fact that I wouldn’t have wished this on my worst enemy, it had never occurred to me, as it had probably never occurred to my mother, not to have a child for the *child’s* sake. I had been concerned my medication could cause birth defects; the cab driver had been the one to think the arthritis was *itself* a birth defect. But had I had a child, it would have been with the same love-blind optimism with which I know my mother had me.

I remember my mother's short temper and sour expression, her impatience. I'd been so quick to take those things personally. Things I'd blamed on alcohol I could now see were also due to arthritis: her increased distance, edginess, and emotional messiness at night. The way she organized her errands to end by mid-afternoon. The clumsy way she heaved herself around. Her lack of interest in activities that taxed her joints, like taking walks, or locked them up, like watching movies. She drank, I realized, because everything hurt. She was obese because she couldn't move.

In my fantasy, underneath the alcohol, there was a shy unfledged young person, my mother's real self, buried intact inside my mom. Now I realize that *that* person wouldn't have been my mother's "real" self either: that self, too, had been half-lost, not to alcohol but to pain.

"I can't decide if suicide is the bravest thing a person could do, or the most cowardly," my mother once said as she drove me home from school. At the time, I didn't wonder if she was considering it. Because I was a teenager myself, I assumed she was thinking of the teen suicides we heard about in the news, but she wasn't really one to bring up things we heard about in the news. After the arthritis struck again that December, there were times I could hear my mother's voice in my mind asking, *what's the point of living so long?* When I wondered how many more decades, years, hours of this pain I'd have to take.

"Do you plan how you'd do it?" my friend Cris asked, worried.

"It's a fantasy, not a plan," I said. "It's just a comfort to know that physician-assisted suicide is legal in Oregon, if it comes to that."

Another friend of mine who's in AA told me she thinks about suicide every day. "You're not alone, honey. Even in this."

There's a black humor to it: going off the arthritis medications had probably saved my life, but the arthritic pain was making me wish I were dead. At least I could get to know my suicidal fantasies well enough not to be upset by them: *you again*. And I could work to disentangle those fantasies from others, especially when I realized that I was assuming that if I were dead, I'd somehow also get to be the person I was before the arthritis hit, prancing all over town with my sweetheart. But I don't think death works that way.

It was the darkest month of the year, and I did what I could. I seemed to be sensitive to corn, so I got my anti-inflammatory drugs compounded without it and the most acute pain faded quickly. I made a point of eating more Omega-3s, which had been shown to help with pain and depression. I started doing my daily exercises under a full-spectrum light. I called the acupuncturist who had cured a friend's mother of an autoimmune disease. I began meditating. If a thousand origami cranes could make a wish come true, then every modest act I undertook on my own behalf was a folded crane, a bead in a rosary, a prayer. *I will not let the pain obliterate me*, I decided. *I will drink from Mnemosyne's river. I will dare to hope.*

On night of the winter solstice, I dreamed I could walk without pain. I was outside in the sun; flowers bloomed on the trees. When I woke up, however, I realized that I had been dreaming of flowers that don't grow on trees: forsythia and hollyhock. Was my dream prophetic, or was it about yearning for the impossible?

The grove where I walked in my dream was like the garden where I had taken my mother the year before she died, a lushly planted cloister three short blocks from my apartment. When I woke, I remembered the way my mother had tipped from side to side as she hauled herself forward to the garden, each step costing her. "Walking a mile on city streets isn't the same as walking a mile on the beach at home," she'd mumbled. *You're just saying that to save face*, I'd

thought nastily. *When was the last time you walked a mile?* But as I remembered my dream that morning, my starchy anger ripened into sweet grief. I couldn't walk to the garden now either. We were the same.

In tears, I narrated my dream to my partner, who reminded me of a friend of ours whose psoriatic arthritis had been cured, over many years, by Chinese herbs and acupuncture. "He literally had chunks of skin falling off him, and now he's fine," Sharon consoled me. "You're not alone." It was just the sort of thing I would have wanted my mother to say to me, had she been alive. Had her pain allowed.

Ellis Avery, the author of two novels, a memoir, and a book of poetry, is the only writer to have received the American Library Association Stonewall Award for Fiction twice. Her novels, *The Last Nude* (Riverhead 2012) and *The Teahouse Fire* (Riverhead 2006) have also received Lambda, Ohioana, and Golden Crown awards, and her work has been translated into six languages. Avery edits an urban observations column for Public Books, works one-on-one with writers as a manuscript consultant, and teaches fiction writing at Columbia University. She is currently taking prerequisites to apply to Physician Assistant programs next fall.

© 2015 *Intima: A Journal of Narrative Medicine*