

THE THIEF OF SOULS
AND OTHER ESSAYS ON HEALTH AND ILLNESS

By

Jessamine Price

Submitted to the

Faculty of the College of Arts and Sciences

of American University

in Partial Fulfillment of

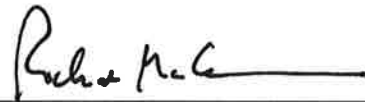
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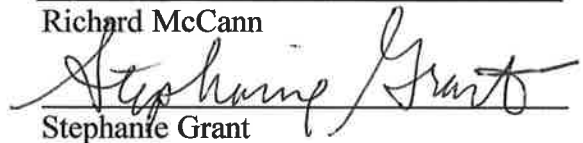
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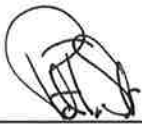
Chair:



Richard McCann



Stephanie Grant



Dean of the College of Arts and Sciences

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Date

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In memory of Cynthia Marie Soroos,
1974–2008

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ABSTRACT

This collection of original essays recounts the author's experiences with unusual illnesses, and investigates what they reveal about the relationship between mind and body. The mind-body connection appears proven by scientific research, but our culture holds tight to Descartes' idea that the self is a mind in control of a body. The complex illnesses discussed here challenge the Cartesian tradition and suggest the body is as integral to the individual as the mind. Although illnesses influenced by the mind were once categorized as "hysterical" ailments, they cause real suffering and contribute to our rising need for health care. The essays here blend memoir with research and discuss repetitive strain injury (sometimes called a form of social hysteria), functional dysphonia (a rare, long-term form of laryngitis), idiopathic dermatitis, "mental" ailments such as psychosis and clinical depression, and the mind-body questions inherent in the challenge of diagnosis.

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Lastly, thank you, Eleanor, for the free medical advice, and Aunt Frances, for valiantly restraining yourself from asking how I'm going to make a living now.

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CHAPTER 1

TO OUTWIT DEATH

I'm not sure when my fascination with travel stories started to fade. They were the first stories I ever heard—the only stories I knew, for a time when I was a child. Before I could read or write, before I knew there was such a thing as fiction or poetry, my parents took turns tucking me into bed at night with these stories. My mother whispered to me about the King of Kings, Ozymandius, and his monument in the desert. My father warned me not to spend hard years prospecting for gold in the Yukon and not to spend too much time sailing the high seas.

I assumed the stories were true since Mom and Dad didn't open up books and read. They just spoke out loud, there in the dark of my small room, sitting on the edge of the bed where I lay with my stuffed rabbit under a circus-colored quilt of orange, yellow and blue. They described such rich details that I never doubted them, though at three and four years old I didn't understand all the words. I did reserve a few doubts about Sam McGee's wintry resurrection in the furnace of an abandoned steamship, but not because I was a preschool rationalist. It was more the way my father concluded McGee's story with glee rather than awe. I thought if I'd frozen to death in an Arctic winter and then come back to life, I'd have something more to say than, "Shut the door, you're letting the cold in!" But I couldn't be sure. After the punchline, Dad would grow solemn and return to that spooky refrain: "The Arctic trails have their secret tales that would make your blood run cold." I imagined my blood running cold.

Mom's stories contained less action and more history, flora and fauna. She described the raucous cry of blue jays in the morning, and the silence of a forest at night in the falling snow. We had blue jays nesting in the large willow oak shading the front yard, so these were familiar things, even though it sounded a little scary to have "miles to go before I sleep." And when she

described things I'd never seen, I accepted them in the same way I accepted the drawings of horse-drawn carriages in Richard Scarry's picture books; here was an adult trying to explain the world to me. So John Masfield's "quinquiremes of Nineveh," tramp steamers and Spanish galleons pulled into port next to Richard Scarry's tugboats and canoes, and Shelley's Ozymandius erected his magnificent statue like any dictator on the evening news. (Nowhere in *Hop Aboard! Here We Go!* did Richard Scarry include drawings of totalitarian statuary, but Walter Cronkite and Peter Jennings fueled my imagination with the grave tones of voice they used to report on Ayatollah and the Soviet Premier.)

If you had asked me which story was most compelling, which one I believed longest into my childhood, it was that story of Ozymandius' decaying statue in the desert. I knew that Mom had lived overseas for a couple years when she was a child—her father had a foreign posting in some distant place pronounced with peculiar, unfamiliar sounds. When Mom told me that she met "a traveler from an antique land," I knew she must be referring to someone she met there, in the Kurdish mountains of Iraq. I pictured an old man in a turban and long robes, bent over a cane, himself an antique, slowly walking across the sand and up to my grandparents' door. Perhaps Mom had lunch with him. Grandma usually made us Campbell's chicken noodle soup followed by sandwiches of crunchy peanut butter and raspberry jam; I assumed he told Mom and her parents his story over a similar feast. Even though it wasn't a happy story, it was an important story he wanted them to know, I wasn't sure why. And now I knew the story, too. The responsibility left me feeling awed and sad.

These parental recitations gave way to other bedtime rituals by the time I started kindergarten and I would only discover the true nature of these tales several years later when Mrs. Bradford introduced my third-grade class to poetry. Strangely, I didn't feel disillusioned.

Knowing that my parents were reciting poems written by other people didn't make them seem less true. Without knowing anything about rhythm and rhyme, I had already sensed that these stories were different from others. Different: if not more true, then at least more important. It was enough that Dad himself seemed pretty convinced of his Yukon dog-sledding days, enough that Mom kept alive the memory of that mighty emperor now fallen. These bedtime stories established the frontiers of my imagination—and the paths of my future travels, too.

When I learned to read myself, I judged the quality of books by how much traveling occurred in them. The best books, like Robert Louis Stevenson's *Kidnapped*, kept the hero on the road from the first to last chapter. Terrible books kept the poor protagonists at home, living dull lives like my own. If I accidentally checked one of these books out of the library, I quickly put it down. I couldn't imagine why a writer would waste time on a story with no traveling.

By high school and college I was also reading nonfiction travel stories—Apsley Cherry-Gerard's *The Worst Journey in the World*, Eric Newby's *A Short Walk in the Hindu Kush*. I read them as handbooks for my own future: this is what it will be like to search for penguin eggs in an Antarctic winter, this is what it will be like to cross Afghanistan on a horse, or the Pacific on a raft, or the Outback on a camel. I wrote my college honors thesis on nineteenth-century travel writers and spent weeks immersed in crumbling Victorian guidebooks and 1990s cultural studies of travel writing hot off the presses. A few days after getting my degree, I set off for my own travels. I started with a year-long job in Yemen—Arabia Felix, the old books called it—and I moved on to backpack from Cairo to Istanbul, visiting every antique land in between.

From that point onward, I've barely picked up a travel book. Perhaps travel narratives lost their appeal for me as soon as I hit the road. I was seeing a real world that was more complicated than the world on paper. Though I still enjoy a good tale of adventure when I can

find one, I have regretfully become a travel lit snob, unimpressed by the new stuff out there. Besides, by the late nineties, travel writing was becoming more and more like sociology instead of exploration. And I wanted more than a cultural education. I wanted to be scared, then awestruck.

Around this time, my desire to read about danger drew me towards illness literature. Stories about sickness and healing. Memoirs of survival, histories of plagues, meditations on the strengths and weaknesses of human cells. The stakes are high in these stories—suffering and survival—just as in travelers’ tales. The field of combat may be close to home, in hospitals and office suites, but the battles still take place in an air of mystery, behind closed doors. Those of us who belong to the kingdom of the well are foreigners in the world of illness, its hospital corridors and chilled operating rooms, those nondescript brick buildings in the suburbs that serve as treasure houses for Space Age weaponry against disease—laser beams, radioactive isotopes, super-conducting electromagnets, the eerily-named X-ray.

###

By coincidence, my changing interests over the past two decades have mirrored trends among American readers. Travel writing had a renaissance in the 1970s and 1980s, when Bruce Chatwin published *In Patagonia* and Paul Theroux's *The Great Railway Bazaar* sat atop the bestseller lists with 1.5 million copies sold. British writer William Dalrymple recalls with some nostalgia that for a time "travel writing was where the action was." Like the best-selling memoirs of today, good travel writing borrowed story-telling techniques from fiction, but promised an

added bonus: truth. In an era when publishers worried about declining sales for literary fiction (are publishers ever not worried about this?), travel writing looked like a winning horse.

But publishing trends come and go. Since the early nineties, travel writing has migrated to a few shelves at the back of the bookstore (even as bookstores have migrated to the internet). At the same time, memoirs—staying-in-one-place, "here I am in America" memoirs—have a growing presence not only on front table displays in bookstores, but also in Hollywood, where odd, unconventional tales like Nick Flynn's and Augusten Burrough's have made it to the big screen. Even travel narratives show the influence of illness memoirs: Elizabeth Gilbert's best-selling *Eat, Pray, Love* recounts a year of overseas travel, but the story is set into motion by the author's depression after a divorce—the triumph of illness lit over travel narrative.

Publishing's embrace of memoir isn't a radical change in direction, since autobiography is an ancient form of writing, after all. But in a genre that runs the gamut from *Running with Scissors* to *Eat, Pray, Love*, we can also find a newer kind of story—the memoir focused on illness and disease. From *Girl, Interrupted* to *The Diving Bell and the Butterfly*: these intimate accounts of suffering would have been unthinkable in the first half of the twentieth century, when illness was off-limits in public conversation. My grandmother, born in 1907, recalled that when she was young no one told her when her grandfather went to the hospital for surgery for throat cancer. She found out years later; at the time, her parents told her and her sisters he had gone to the Caribbean for a vacation. These ancestors of mine treated serious illness as a taboo, never to be mentioned out loud; a public memoir about illness would have struck them as a form of obscenity. Perhaps speaking of illness risked summoning it. Yet today, this sub-genre has grown large enough that it has grown its own sub-sub-genre, the celebrity illness memoir: think Brooke Shields on post-partum depression or Fran Drescher on uterine cancer.

I'm attracted to illness lit for some of the same reasons I enjoy good travel stories. The two appeal to similar emotions, although on the surface a trip across India and a fight with breast cancer appear to be radically different topics. On a deeper level, however, both types of narrative take writers and readers to the borders of contemporary human knowledge. Travel literature hit its stride during the nineteenth century, when the European powers had conquered or co-opted most of the territory on earth, with the exception of Antarctica and the Chinese interior. Readers turned to travel writing to understand this brave new world and the people in it. They also may have found comfort in travelers' tales. In a century rocked by the theory of evolution and its myriad misconstruals, what social Darwinist wouldn't welcome the reassurance that a European could survive in any landscape or culture? Most travel memoirs are, after all, tales of survival. (Though not all: think of Captain Robert Falcon Scott's diary, found with his frozen corpse near the South Pole in 1912, perhaps the greatest piece of posthumous travel writing.) Today, reading the meditative travel writing of V.S. Naipaul or Pico Iyer, it's sometimes possible to forget that danger—or at least suspense—used to be a significant element of travel. The bestsellers of nineteenth-century travel literature provided readers with reassurance that "civilized" people could survive any challenges the globe threw at them. Europeans could enjoy the warm homes and soft beds made available by the Industrial Revolution, yet still be tough when the need arose; they were ready hold their own against the dangers of more primitive environments.

Medical memoirs similarly offer us the reassurance that we're strong enough (clever enough, too) to outwit death, making them a twenty-first century analogue to the nineteenth-century traveler's tale. We are almost numbingly familiar with the image of Neil Armstrong on the moon—the ultimate human travel adventure—but medical stories can draw us in with new, less familiar, ways to think about the limits of survival. The moon might be ours, but what about

the cure for cancer, what about organ transplants, gene therapies, the once-miraculous, now-common "test-tube babies"?

Sometimes I turn to these stories for hope, and sometimes for the shock of the new and unfamiliar. My first encounter with the genre offered both. I discovered the book in the mid-nineties at the used bookstore near campus—a paperback with an eerie black and white cover, a photo of a child standing outdoors with a piece of wrinkled, opaque plastic across her face, as if blown there by a sudden gust of wind: Lucy Grealy's *Autobiography of a Face*. I remember thinking it wasn't the kind of story I usually read. No foreign landscapes, no swashbucklers or pirates, no distant historical period. Why did I feel compelled to buy it anyway? I believe it was the grotesqueness of the premise that drew me in at first: Grealy lost most of her jawbone to cancer while she was still a child, and then spent years undergoing painful medical attempts to reconstruct her face. I hate to admit to my morbid curiosity. What would it be like to lose part of your face? How did she survive middle school, which I felt I barely survived despite having all my body parts accounted for? And that most horrible, yet inevitable, unbidden thought, which I couldn't completely suppress: What does she really look like?

These embarrassing, all-too-human questions drew me in, but most of the suffering Grealy described was very familiar to me, for she tells the story of a child whose parents can't provide comfort. It was the first time in years that a book made me cry. With some literary sleight of hand, Grealy manages to interject a note of hope in her conclusion, but most of her story concerned isolation and pain—and stubbornness and grit. Her survival to adulthood seemed as improbable as any exploration story, a medical and psychological equivalent of Apsley Cherry-Gerard's sledge journey to Antarctica's Ross Sea under the Southern Lights in midwinter 1911. Several years later, when I heard that Grealy had died at the age of 39, I felt as shocked as

the British public must have when they discovered Scott had lost the race to the South Pole and died in the attempt. How could such a heroic person die? But the idea that surviving an illness makes a person "heroic" is a relatively new definition of heroism. I don't know if it's a better or worse definition than more traditional ones.

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Despite sharing a concern with survival, there's one obvious difference between travel and medical narratives. Travel is by and large voluntary, illness a horrifying detour from "normal" life. The victim of disease confronts Job's question: why me? Illness attacks our modern assumption that we're entitled to a statistically-determined average lifespan, the assumption that science has solutions for every ailment and death is a kind of medical failure. But science can only suggest reasons for cancer or diabetes or atrial fibrillation. Science can't guarantee a cure, nor can it answer "Why me?" Man diagnoses, but God disposes. Can there be any common ground between an active journey in search of knowledge and a bodily dysfunction that seems to rob the patient of agency?

Certainly there's a wide difference between taking action and being a victim. But travel lit is full of journeys taken for business, not pleasure. Marco Polo was a merchant looking for new business opportunities when he reached China in the 1200s. Fa Xian, the great fifth-century Chinese traveler, was a Buddhist monk looking for Sanskrit Buddhist texts that could only be found by walking across the Taklimakan Desert and the Himalayas to India. And the entertaining chronicler Eliza Fay set out from London in 1779 because her new husband, a British lawyer, had received a posting in Calcutta. These three very different travelers had good reasons to risk

the hazards of the road. They weren't reckless; they hoped to avoid danger and delay, but danger and delay have been endemic to travel for most of human history. For example, while moving to India, Mr. and Mrs. Fay would find their caravan attacked by bandits in Egypt, and they would be imprisoned by the King of Mysore, and escape captivity with the help of a Jewish-Malayalam merchant, before finally arriving at Calcutta. Starting a new civil service job could be perilous in the eighteenth century.

And it would be wrong to assume that medical narratives inevitably explore the writer's loss of control. The majority of illness stories rely on common metaphors, including the Battle, the Rite of Passage—and the Journey. Writing about one of our most high-profile diseases, breast cancer, Barbara Ehrenreich complains of an "implacably optimistic breast-cancer culture," where "survivors" (never "victims" or "patients") emphasize the "redemptive powers of the disease" that gave them a new appreciation for life. She writes that many of the breast cancer narratives on internet forums resemble "the confessional autobiographies required of seventeenth-century Puritans," with story arcs structured around sudden crisis, painful ordeal and final salvation. This colloquial framework for cancer stories allows little room for anger or existential shock. Rather, the story moves quickly (and pragmatically) to the details of treatment—the wrestling match with the devil, which transforms a patient into a better person—a "survivor." Cancer doesn't lead Job to complain to God; cancer leads Job to greater piety.

In "Welcome to Cancerland," her essay on her own experience with breast cancer, Ehrenreich suggests that we're inclined to think of illness as a spiritual journey, a kind of Pilgrim's Progress. We also think of it as a physical journey. In Cancerland, the landscape is unfamiliar; Ehrenreich finds herself visiting offices drowning in the color pink and photocopies of sentimental, inspirational verse. They sell souvenirs here, too, she says: the pink-ribboned

clothing, accessories and teddy bears that could be seen as commercial exploitation, except that many cancer survivors themselves design and sell these objects, in the interest of cancer awareness and comforting others. Like a souvenir, then, the pink-ribboned teddy bear is a token of having come back from a journey. Above all, Cancerland has a culture of its own. A few decades ago, Cancerland was terra incognita, a place no one spoke about; breast cancer was a horrifying taboo. Today, the more than two million women at some stage of breast cancer treatment form a large community with their own expectations and behaviors ("cheerfulness is more or less mandatory," Ehrenreich claims, "dissent a kind of treason"). Their doctors, too, form a community, one with a distinct argot, the medical language that breaks the body down into lumps and cells and ducts. The language that breaks suffering down into "stages."

Travel lit and illness lit confront the deep fears of their eras. At its height, travel literature dealt with the fear of the foreign, in an era when Europeans were eager to prove the superiority of their civilization—eager but also nervous. The foreign held dangerous appeal. The appeal could be obvious, like the beauty and sensuality of Italy that worries Lucy Honeychurch's chaperone in E.M. Forster's 1908 *A Room with a View* (for the British characters, Italy is undeniably foreign). Or the appeal can be esoteric and unholy—the exaggerated unrestraint of Joseph Conrad's Kurtz in the Belgian Congo. New manners, new customs, new landscapes—they threatened European (and North American) confidence in Progress, decades before World War I delivered that confidence a gut punch. Travel lit showed it was possible to visit other places and resist temptation—to remain, essentially, unchanged. Travelers might even return home having gained knowledge of themselves. The journey away from everything familiar allowed the individual to grow more familiar with his or her own character, those essential personality qualities lying in the bedrock of the brain once manners and culture are stripped

away. While the West was finishing its conquest of the Rest, the old networks of family, religion and community that provided people with meaning for most of human history were simultaneously breaking down; we were in transition to a world where we consider ourselves individuals above all, and family or communal identities are optional. In the past two centuries, travel lit has often provided suggestions for how these newly individualistic humans can navigate cultures or landscapes not their own.

Illness lit similarly shows the individual *in extremis*, and reveals a shadowy outline of what it means to be human. But at the turn of the twenty-first century, the question on our minds is, "What does human mean in an age of powerful technology?" Self-reliance is increasingly unnecessary when human achievements rest more and more on computers and robots, and when human happiness seems to depend more and more on complex medical interventions. A century ago, when my grandmother was a child, her mother forbid her to go to school until fourth grade, in fear of deadly childhood illnesses. Today, a century later, we've almost forgotten how powerfully illness once shaped human lives. We control our own bodies as never before. A few of our successes: inoculations, antibiotics, chemotherapy, psychiatric medications, laparoscopic surgeries, heart transplants, in-vitro fertilization, cochlear implants and prosthetic hands with bionic fingers that flex and grip. Although I know that people of all ages die in accidents, I still find it easy to imagine that I'll live into old age. Most of us do—and early death strikes us as terribly unfair. Someone should have done something.

But even if death is unfair, it remains the endpoint of every life; though doctors may often hold the power of life and death, they cannot entirely prevent the suffering caused by illness and its treatments. Death and suffering challenge our claim to be self-contained, rational individuals. Are we still ourselves when we are in physical pain? Can we rationally choose to

decline treatment if an illness progresses too far? How much ill health can we expect one individual to bear before we offer our support as a society? How much of our character is the product of our biological fate, rather than our inner moral fiber? And how far will we go in using medicine to "upgrade" healthy bodies, not just heal sick ones? Stories about illness give us the chance to think about these questions, which my grandmother would have found inconceivable.

I still love those rare travel stories that are really well written—but illness literature has the power to fascinate me even when it's badly written. I've started getting bored with mystery novels (the bad guy always gets caught), but when I recently picked up a history of the 1518 outbreak of "the dancing plague" in Alsace-Lorraine, I couldn't put it down. The prose style is less important than what I learn about human bodies and behavior. Dr. Abigail Zuger, reviewing a batch of medical memoirs in the *New York Times* in 2010, notes, "After years spent in the company of the sick, I know one thing for sure: there is no story out there that is not a great story." Though most of these books aren't "great literature," she suggests it doesn't really matter. "Should memoirs of illness be held to the same standards as other writing? Or do reader and writer form a different relationship when the health crisis of one becomes the theater of the other, a relationship in which a reviewer has very little business meddling?" Dr. Zuger—perhaps not surprisingly for someone who devotes her life to medicine and writing about it—finds that what she calls "sick lit" is generally a good read, whatever the quality of the writing.

"Sick lit" connects us to the physical frailty inherent in being human—and right here, right now, frailty may be our greatest fear. From the decline of the American economy—the heart and lungs of our society—to the aging of the Baby Boom generation, the question writes itself onto every wall: can we be happy if we don't have our health? Or are the things that make

us happy—chocolate cake, binge-watching a new TV drama, single-malt Scotch—doomed to make us ill?

The year I was born, 1974, was the year that American wages hit their highest point in history, a kind of national health we couldn't appreciate at the time. It was also, to hear them talk about it, among the best years of my parents' lives. They were young, in love and healthy. From the moment of my birth, they imparted to me a sense of nostalgia for a happy, healthy past, which somehow seems to have occurred just before my memories start. When my health breaks down from time to time, it breaks down in peculiar ways—chronic laryngitis, inexplicable pains and incurable rashes—and sometimes I wonder if these are diseases of nostalgia. They are certainly ailments in which the mind and emotions play a role. I have control over many of my decisions and actions, but a simple thing like an emotion defies my control.

The successes of modern medicine have simultaneously made us more aware of its limitations—the ways that our bodies can systematically betray us despite our best efforts, sometimes due to intangible factors like "stress." We are complex organisms who struggle merely to understand ourselves, but we generally wake without astonishment and move through the day as if it's a natural thing to be a living creature in this huge, desolate universe. When we encounter illness, we have an opportunity to reflect on what it means to be so stubbornly alive and yet so delicate. Look on our works, ye Mighty, and despair.

CHAPTER 2

RASH YOUTH

A strange fact: in the womb, the embryonic tissue that grows into your nerves, brain and spinal cord also turns outward to form the skin. Each of the roughly 640,000 sense receptors just under the surface of your skin is still connected directly back to the nerves and brain—640,000 ways for the brain to brush up against the world.

The skin is our largest organ, as well as our most exposed. If you're an average adult, roughly sixteen percent of your body weight is comprised of the skin and its related tissues: hair, nails and the inner and outer layers—dermis and epidermis—crowded with blood capillaries, sweat glands and nerve endings. Compared to your next largest organ, the liver, the skin is some seven times larger. We may sometimes forget that the skin is considered an organ, but even a small piece of skin is amazingly complex. When you flip a coin and catch it, the quarter covers a negligible patch on the back of your hand. But beneath that quarter lie some three million skin cells, among them one hundred sweat glands, fifty nerve endings and three feet of capillaries, our most delicate blood vessels. Many of our internal organs can afford to focus on doing one essential function well—the heart circulates blood, the lungs circulate air—but the skin protects you in dozens of ways. It cools and warms the body, manufactures vitamin D, protects against rain, sunlight, viruses and bacteria, and it contains the thousands of nerve endings telling us where our bodies end and the world begins—sensing pressure, weight, vibration, texture, temperature, wetness, irritation and pain. The small hairs on our skin stand up when we come into contact with static electricity—or when we're moved by a sudden emotion. And when our skin registers sympathetic touches—a mother's embrace or a lover's kiss—our entire emotional

system responds with increased feelings of calm and well-being that can have long-lasting effects on brain development. It's no wonder that healthy skin is a beauty ideal across cultures, because good skin depends on a well-functioning heart, brain, lungs and digestive system.

My skin started to fall apart at the end of sixth grade or the beginning of seventh. The problem started gradually, as a tight feeling around my eyes. My eyelids and the delicate skin just below my eyes grew tender. The area felt almost sunburnt, but I hadn't been in the sun. It was as if my skin was stretched tightly across my face. Perhaps I was dehydrated, I thought; I dabbed on some moisturizer.

The skin around my eyes remained tender and began to bloom pink and red—close enough to the color of a fading bruise that someone asked me if I had had a black eye. For a couple weeks the sunburnt feeling slowly spread. Day by day more and more of my face grew sore: my eyebrows, the sides of my nose, my cheeks and forehead. The nondescript red rash grew to cover the top half of my face, from my cheekbones almost to my hairline.

As the rash spread—and as seventh grade got under way—it changed. The tender, pink surface cells turned white, dry and flaky. They fell from my cheeks and eyebrows in white flurries, like dandruff. As the outer epidermis flaked away, the fluid-rich dermis beneath was left uncovered to the air, and this raw tissue oozed clear liquid that gradually hardened into a scab-like crust. The damaged skin grew thicker over the next week or two, and the moist scales on my face grew into new, pink tissue. And then the new, pink skin began to feel tender—and the whole cycle started again.

This cycle would repeat dozens of times over the next two years. The barrier was failing; my insides were trying to get out. Or was something trying to get in?

###

Skin cells are constantly renewing themselves. The outer layer of the skin, the epidermis, is only .07 to .12 millimeter thick, and its cells are essentially dead and slough off easily.

Beneath its protective coating lies the dermis, one to two millimeters thick and dense with nerve endings, sweat glands, hair follicles, and blood vessels. Our newest skin cells are born at the innermost edge of the dermis, where they begin their life cycle round and plump, full of the strong, elastic protein collagen. Over the next two to four weeks, these cells are pushed toward the surface of the skin by new cells appearing below, and their shape and composition changes. The cells flatten and grow scale-like. Soft, spongy collagen is replaced by the harder protein keratin, the tough fibrous substance that gives shape and structure to nails and hair. A skin cell ends its life unceremoniously, as a bit of dead tissue on the surface of the epidermis, which is brushed away into the environment over the course of daily life.

In a healthy body, we're never aware of this cycle of death and rebirth, so efficiently do new cells step forward to replace the old. We talk of healthy people "glowing," and it is true that well-functioning skin has a specific satiny sheen: not too shiny with excess oil, not too matte with dry or dead cells. Healthy skin renews itself at just the right rate, keeping blood capillaries and nerves just under the surface, but not too deep, ready to sense the world and cool and warm the body. To a certain extent, we can sense good or ill health with a glance at someone's face.

When the health of the skin fails, the reasons can be complex. Chronic rashes generally have an autoimmune component: an overactive immune system often exacerbates skin problems, though it might not be the cause of the initial rash. And rashes are closely tied to our emotions. I didn't realize it when I was starting seventh grade, but doctors estimate that roughly half of skin

problems have emotional triggers. The estimate is much higher if you ask healers who use alternative methods. Integrative medicine expert Andrew Weil writes that skin ailments "should be assumed to have an emotional basis until proved otherwise." Because of skin's complexity, treating skin ailments is also difficult.

I learned that modern medicine couldn't do much for me when Mom took me to see a doctor a few weeks into the painful rash.

"It doesn't look like eczema or psoriasis," the pediatrician said. "Just some kind of dermatitis." The diagnosis sounded impressive, but it wasn't actually a diagnosis. I later learned that "dermatitis" simply refers to any skin inflammation.

He recommended a mild over-the-counter steroid cream. "Don't use it for too long, though," he warned, "Just until it gets better."

When we got home, my dad was shocked. "That's strong stuff," he said to Mom, "I can't believe you're letting her use that."

He turned to me. "Don't use it for long," Dad said. "Or you'll get weird side effects."

The topical steroid immediately stopped the oozing. But my face remained sore and sunburnt-looking. After a couple weeks, I was afraid to use the hydrocortisone cream any more—although it was a very mild formulation. I remembered the doctor's warning and my dad's exaggerated reaction to the small white tube; maybe I had already used it "too long." The box the medicine came in mentioned one side effect I particularly wanted to avoid: rashes.

Topical steroids can ease skin inflammation but they can't reduce the systemic causes of the inflammation. Use a steroid for a few days, and the skin will renew itself quickly. Soon it appears healthy. But the cycle of skin renewal is still off-kilter. Stop using the steroid and the symptoms reappear again almost immediately. My rash quickly returned.

No one could suggest a reason for it, much less a cure. But today I find a possible answer in Andrew Weil's remark about the emotional components of skin disease. The rash began as I was entering a new school, entering seventh grade, and at the time that my mother's troubles were becoming impossible to ignore.

Ever since we had moved to a new town at the beginning of my sixth-grade year, Mom had been angry and unhappy. The move seemed necessary, because my parents had a third child in 1985, and we could no longer pretend to fit into a small two-bedroom ranch house. But the new, larger house meant moving to a new neighborhood and leaving behind the casual friendships of neighbors we had known for a decade. My mom doesn't form friendships easily, and she found it hard in the new neighborhood, where the houses were farther apart and the families busier, less sociable. Perhaps she had postpartum depression. It's hard to say, since the first few months of my sister's life corresponded to the months my parents were making plans to move. Whatever the causes, my mom changed over the course of our first year in the new house.

In the old house, Mom carried out projects that impressed the whole neighborhood: she planted gardens, sewed Halloween costumes, built bookshelves and reupholstered sofas. In the new house, all those were relics of a past life. She didn't plant flowers at the new house, hang suet for the birds, or sit with the neighbors talking. Depression is easiest to describe by the absences it creates: for us it was the absence of Michaelmas daisies and purple iris, the absence of fire-breathing dragon costumes and Christmas rum cake.

At the age of twelve, I couldn't figure out what was wrong, but this wasn't Mom any more, not really. She would suddenly burst into tears while driving us kids somewhere, and she would get angry if we asked what was wrong. It was as if she wanted us to pretend she was invisible. She was always fatigued and spent the afternoons lying on the couch behind the

newspaper. Her apathy alternated with anger, though.

That was the year that on my birthday I suddenly heard howls coming from the kitchen—sounds of fury, despair and grief that belonged in a Greek tragedy. I ran in and found Mom screaming. I threw my arms around her. She was upset because she had dropped a pan of lasagna on the kitchen floor. Some of it had spilled onto the floor. Few human deaths have been mourned as intensely as those two servings of lasagna; I never wanted to hear that shrieking again.

It didn't occur to me that my rash could have anything to do with my worries about Mom. In the mid-eighties, mind-body medicine wasn't a common term and laypeople didn't have much access to medical information. We didn't have any equivalent of today's medical consumer websites; back then, "consumers" were called "patients." In fifth grade, my best friend and I had learned about sex when the teacher wasn't looking, by reading the thick scientific encyclopedias on the bookshelves near our schoolroom desks. If I had wanted to research rashes, I would have gone to the encyclopedias in the library. But my rash didn't have a name, so I didn't know what to look up. And if I had looked up the most common chronic skin problems—psoriasis, eczema, acne and rosacea—I would have merely discovered that "a number of factors" contribute to them, including genes, allergens, environmental conditions and stress, a discouragingly lost list. Our most common rashes have no known cures. Sometimes they respond to steroid creams, exposure to UV light, or oral medications. Sometimes they respond to none of these. Rashes suppressed through medication usually return after a time; some patients suffer off and on for a lifetime. The itching of eczema, for instance, usually starts in childhood and can continue for decades.

We consulted a couple more doctors before giving up. Each spent a moment looking at my tender, inflamed eyelids, and another moment looking at the sore skin on my cheeks. Each

said not to worry about it. Perhaps it's an allergy, they said. Try a new shampoo. It will go away, they said.

My rash caused relatively little pain and itching, and it didn't look like a medical crisis, but its social cost was high. Most teenagers at that age were struggling with embarrassment over acne, but at least acne was familiar. I wasn't sure how to explain why half of my face was a raw, oozing wound.

I'll admit, I find skin diseases repugnant. I know better—for instance, I know it's unfair that leprosy patients were demonized for centuries. Skin diseases don't actually tell us anything about a person's moral strength or state of grace. But I still have strong reactions to the quality of a person's skin. Perhaps this association between health and skin quality even has instinctual components, a visceral desire to avoid contagion.

When I recoil from the sight of a rash, I remember third grade, when my classmates' parents came to tell us about their jobs. The only parent who made an impression on me was the podiatrist, who showed gruesome photos of foot pathologies. I joined the rest of my classmates in a chorus of "Ewww!" and "Gross!" The bunions were okay, I could handle them, but the plantar warts and toenails with fungal infections revolted me. The images stuck in my mind against my will, along with my third-grader's blanket judgment: these people are disgusting. From a few disembodied slides of troubled toes, I drew the conclusion that these patients were people to avoid. They weren't just physically marred but socially undesirable. How could you live a normal life with a wart like that?

Hearing my classmates make pretend gagging noises solidified my sense that we had formed a pact: we never wanted to see these sights again—we would henceforth avoid anyone with a visible skin problem. And now that I'm older and supposedly wiser, I still find the hairs

on the back of my neck standing up if someone with eczema or psoriasis walks onto the subway car where I'm riding. The thought arrives unbidden: "Please don't sit next to me." No matter how much I train my compassion, I think some ancient self-preservation system still flashes a warning: stay back, don't be contaminated.

I didn't want to see that revulsion on the faces of my classmates. I adopted the only strategy I could think of as a 12-year-old: I tried to disappear. If no one looked at me, I thought, no one could see that my face was falling apart. The scheduling computer helped my quest for anonymity, for when my classmates and I moved up to seventh grade, everyone I knew from sixth grade was assigned to different classes than mine. Seven times a day, I walked into a classroom of strangers. All I had to do was ignore them, I hoped.

I didn't make eye contact. I didn't speak to anyone unless a teacher forced us into a group assignment—and then I tried to keep my eyes on the desk. I kept my eyes on the floor when walking through the hallways to change classes. I tried to sit at the back of the classroom or the sides, somewhere on the margins. Incarcerated in the cafeteria during lunchtime, I sat alone at the empty table closest to the adult monitors. During lulls in class when other students joked around with each other, I opened the novel I was reading or the notebook where I was practicing to be a famous writer. In seventh grade I first read Charles Dickens, Alexandre Dumas, Jane Austen and J.R.R. Tolkien—thousands of pages of reading done at lunch and during class. I read everything I could find by Arthur Conan Doyle, including his forgotten historical novels, and ploughed through dozens of forgettable fantasy paperbacks with titles I've long forgotten. I was a traveler stuck in a foreign airport where I didn't speak the language, absorbed in a book during a long wait for the weather to clear. Someday I would get out of here and my life would start again.

At home, Dad often asked Mom why she was upset so often.

She always said the same thing. "I'm fine. I just need everyone to leave me alone."

The answer seemed to annoy Dad, but it usually ended the conversation. Dad retreated: he put in long hours at work and he spent evenings at home in the garage, his head inside the engine of the 1947 Chrysler sedan he was restoring. Even in the middle of winter, when the temperature in the garage hovered around freezing, we could hear the clanking of socket wrenches out there as he dismantled the car piece by piece.

Dad carried his own dark cloud around him in those days. He was stern and serious and scared me a little. Remembering one of the poems he used to recite to me at bedtime, I figured he would be happier living alone in a small cabin on the Lake Isle of Innisfree. He was a shy person, despite his occasional bluster, and he had little idea how to talk to his children as we grew into adolescence. His own father had walked out on his family when dad was eleven or twelve years old. It would be decades before he had contact with his father again, so perhaps my dad was lost in the role of father to teenagers. He studied human behavior in books, but he found it easier to study emotions than to feel them, or sense them in others. During the Rash Years, I mimicked Dad's stoicism, unaware that perhaps my feelings were written on my face.

I missed my mother, the woman she had been before my sister was born and we moved. She was a housewife in the language of the time, but don't picture a generic housewife, please believe me when I tell you she was amazing. Driving down the highway in the summer, she recognized birds from the shapes of their wings as they soared above. ("An osprey! A red-tailed hawk!") She planted the rose bushes in the front yard and the long beds of perennials in the back—Michaelmas daisies, tall bearded irises in deep purple—and the vegetable patch in the sun-drenched side yard. She taught me how to dig a planting bed, mixing dark topsoil and

compost with the dense orange Virginia clay, taught me how to weed and hoe, how to force bulbs in winter and deadhead in summer to keep the blossoms coming. In October, she constructed elaborate costumes from fabric remnants, poster board, small metal brads, pipe cleaners and household utensils. My little brother was a fire-breathing dragon one year, and I was a princess. Another year, she turned my brother into a giant fly with a mask that used metal mesh kitchen strainers to make large, multi-faceted eyes. When I was eight and decided to be a gypsy for Halloween, she spent half an hour on my make-up, painting me an entirely new face—tanned, exotic, older. I looked like I was ready for a production of *Carmen*. No one recognized me that Halloween, not even the neighbors who had known me since I was a baby or my best friend's grandparents who lived around the corner.

She had experience in costuming and make-up. She majored in drama in college, and alternated between costume design and starring in ingénue roles. My dad talked about her college acting career with admiration and envy. The young man who often played opposite her as the male lead went on to be a successful television actor in the eighties. Every week we turned on our TV to watch him play the blond brother on private detective show *Simon and Simon*. Dad liked to give a wry smile and grumble, "I've seen your Mom kiss him on stage many times. I don't know how many times she kissed him off-stage."

Mom never responded to this comment. Her eyes would be somewhere in the middle distance, unfocused, as if she hadn't heard him at all. But her silence just confirmed my belief that she was a star, that she could have conquered Hollywood if she hadn't married and had children. Housewife and mother was simply her disguise.

At school, I was never satisfied that I was invisible enough. The rash was too obvious and disgusting. My thick lavender glasses frames covered hid some of the worst spots on my

eyebrows and the sides of my nose. But the light weight of the plastic frames irritated my skin, making the soreness worse and rubbing the wounds deeper. Twice daily, I washed my face with the mildest of hypo-allergenic cleansers. Sometimes the water irritated the skin, making it feel stretched tight almost to the point of splitting open. Sometimes it made the rash feel better for a few minutes. And every morning, I carefully washed my glasses with mild dish soap. I scraped away pus and dried scabs.

I felt human when I put my glasses back on my clean face, but within a couple hours they would again be sticky with my dissolving cells. No, I couldn't be invisible enough.

Unconsciously, I learned to discourage anyone from talking to me. I developed a collection of scowls and mean glances. I scowled at everyone. Mean girls and geeky guys. The in-group and the out-group alike. Jocks and Dungeon-masters. The bullies and the sweet kids just trying to survive middle school the same as me.

When the sarcastic girl in gym class teased me every morning, I pressed my lips together and refused to reply. Without even realizing it, I rolled my eyes, looked away and shook my head slightly with disdain. One day she got angry and made a strange face.

"I can roll my eyes too," she said. "Is that all you can do?"

Afterwards, I tried to control my reflexive eye-rolling, but I still refused to answer her. I tried not to even look at her. I stared into the distance and imagined a future in which I would be beautiful, glamorous and desirable.

I could remember the day I saw my mother look glamorous. It was the evening of my fifth birthday, and my aunt, Mom's elder sister, came down from New York for the weekend. My aunt brought along an old college friend of hers as well, and together the two New Yorkers looked vaguely foreign in their black slacks and black turtlenecks. My aunt's hair was bobbed

short, into a smooth, glossy globe. As my aunt and her friend talked about their jobs (rather dull) and apartments (rather small), they kept laughing, almost as if they weren't grown-ups. They seemed younger than my mom, not five years older.

After dinner, as someone opened another jug of Martini-Rossi or Ernest Gallo, my mom dug around in a cupboard for an ashtray. The New Yorkers sat cross-legged on the living room floor around the ashtray, and they lit long white cigarettes, still laughing. It was weird to see grown-ups sitting on the floor. Our small ranch house was furnished with things inherited from Mom's New England ancestors—formal, antique stuff: a tall glass-fronted cabinet that stood on the carved, clawed feet of an animal, a creaky wooden Windsor chair with the finish on the arms rubbed off by a century of hands, an ornate rolled-arm sofa. We had furniture for grown-ups to sit on; only my little brother and I sat on the floor. I circled the New Yorkers, impressed. Standing up, I was only a bit taller than they were sitting down. I watched them eye to eye as they gestured elegantly with their cigarettes.

I knew smoking belonged to the adult world—I saw it in the black-and-white movies on Saturday and Sunday afternoon TV, the ones with Humphrey Bogart or Katherine Hepburn, where people lived in cities and talked fast. I couldn't always understand what they were saying, the people in the movies, but I knew from the way they spoke that they were cool, ready to handle crooks, Nazis and Martians, whatever the movies could throw at them.

When my mom joined the two women on the floor, she casually bummed a cigarette. A flame appeared from a lighter, and the paper cylinder crinkled in the heat and caught fire. I saw a glow of embers as she inhaled and a sigh of gray smoke from her circled mouth. She reached toward the ashtray and tapped, tapped.

"Wow, that's nice," she said, with a tone in her voice I hadn't heard before, "I haven't

had one of these in a long time, not since I quit before she was born." She tipped her head towards me where I stood next to them. A few minutes later, I fell asleep in my small bedroom to the sound of grown-ups talking and laughing. My mother was the most beautiful woman in the world, I thought.

Dad subscribed to the theory that women grow up to be their mothers. When he was angry at Mom for being depressed, he rebuked himself for marrying her.

"I met your mother before we married. I should have known this is what you'd be like some day." He liked to expound on this topic when we were driving somewhere in the car together. Mom, my brother and sister and I were a captive audience, and Dad's professorial, scientific turn of mind made his statements sound like lectures. I absorbed every word like it was gospel truth. Mom was like her mother, he said. And it was logical to conclude that I would grow up to be just like my mom.

Puzzlingly, he never explained what Grandma's sins were. I wasn't clear on why it was bad to resemble her. She had a house full of books, which she read to me often when I was a little girl, and I knew that when she was young she had refused to shop for a husband, choosing instead to travel around the world and look at archeological sites. Her only fault seemed to be that she didn't clean her house very often. The coffee table was covered in magazines about history and wildlife, and the rock collection on the windowsill lay under a sheen of dust. And Grandma refused to wash dishes until she had dirtied every single dish and fork in the house. Dirty dishes generally stretched the entire length of her kitchen counter. But if I lived alone, I thought, I wouldn't do dishes very often either. It didn't bother me that her kitchen sometimes smelled faintly of rotting vegetables.

But I think in Dad's mind, Mom's long naps and lack of energy for cleaning the house

were somehow connected to the fact that Grandma didn't like to clean. It was hard to think of Mom's extended bad mood as a disease, depression, because her mood did lighten occasionally. In those days before Prozac advertisements, we had no idea that depression could come in various forms, including "atypical," "reactive" depression that varied from day to day. Easier, much easier, to think of Mom's suffering as something she brought on herself through some sort of character flaw. And when she acted ashamed of her moods, I believed she must be ashamed for some logical reason—she must have been doing something wrong. I didn't know then how shame can wrap itself unbidden around the soul—even though I was weighted down by the shame of my disintegrating skin.

I wanted to avoid being stupid—Dad often said teenagers were stupid—but my attempt at invisibility was no smarter than any other adolescent survival strategy. Acne afflicts the majority of seventh and eighth graders, and self-consciousness afflicts one hundred percent of them. Did my condition really warrant becoming a pariah? Did I look that much worse? I didn't wait to find out. I exiled myself before my peers could, without even realizing what I had done. It was the fault of the rash, I thought—the rash stood between me and the world.

Wait, I told myself. Though Dad's theory made my heart sink, it also gave me hope. If I grew up to be my mom, then I would be happy and beautiful for a time in college. Later, I would be paralyzed with sadness. But before the inevitable decline, I would briefly shine. I did the math in my head to estimate at what age Mom had first become unhappy. How much time did I have left?

Although Mom's unhappiness became obvious when I was ten or eleven, I had first started worrying about her earlier, a year or two before the move. It was a boring afternoon when I was flipping through one of the copies of *Family Circle* or *Woman's Day* that Mom used to buy

in the check-out line at the grocery store. I came across an article about "burn out." Women were working too hard, the author said, trying to be perfect mothers, perhaps working outside the home as well. Mothers needed to take care of themselves. They shouldn't sacrifice themselves for their children.

I was proud in those days that my mom was a housewife, and it hadn't occurred to me that it might be a sacrifice. I had overheard the news stories about "latch-key" children (the media hysteria *du jour* in the eighties), and I felt superior to those poor kids who came home to an empty house after school. But reading this article, I found myself wondering.

Was Mom sacrificing herself? In a sidebar, the article offered a self-test: "Are You Burning Out?" I tried to guess what Mom would answer. Was she angry rarely, sometimes or often? Did she feel a sense of purpose rarely, sometimes or often? I couldn't guess how she would answer. I knew she sometimes lost her temper and she didn't laugh much, but I couldn't go ask her if she was happy. My family didn't talk about things like that.

Lying on my stomach with *Family Circle*, I remembered the vision of my future that I had had two years before, when I was six. I had been riding the school bus with a seat to myself, the way I liked it. That was the year I would stare out the bus windows and imagine building new houses and cities on the empty lawns we passed. The houses in my mind's eye were miniature, designed for stray cats—I was obsessed that year with cats, or maybe it was a fascination with architecture and urban planning. I superimposed an imaginary urban landscape—feline metropoli—on the quiet yards and small houses of suburban Alexandria, Virginia.

And then, for some reason, I found myself thinking about the future. What would I do as an adult? As a little kid, I had had those ritualistic conversations with adults: "What do you want to be when you grow up?" My answer was usually that I wanted to be an archeologist, because I

had heard of archeology. My dad's younger sister was in grad school for archeology and the half-dozen times I'd met her she laughed a lot. My grandmother liked archeology too—after my grandfather died, she spent her sixties volunteering for digs in Israel and Jordan. When I said I wanted to be an archeologist, the people around me smiled with approval. It seemed a good answer. But on the bus that day, I tried for the first time to picture my future, tried to see it in my mind's eye as clearly as the imaginary cat condominiums I was building along Fort Hunt Road.

A clear image came to mind: me, standing alone, folding laundry. That was what my mother seemed to be doing every day when I arrived home from school. People do what their parents do, I thought (what traditionalists we are at six!) or rather Adults do what Adults do. Adult women do laundry. I would thus grow up to do laundry. I didn't ask myself whether I wanted to be a housewife when I grew up. The only adult woman I knew was my mother. So who else could teach me how to be an adult?

I felt a slight disappointment. I didn't know what else I could do. Someone had to do the laundry. Mom had already taught me how to fold the sleeves of the shirts so they didn't wrinkle and how to roll up the socks and underwear neatly. But for a moment, it troubled me.

Now, lying across my parents' bed in our small ranch house at eight, I recalled sitting on the bus thinking about my future in laundry—I was weird when I was six, I thought—and I thought about the laundromat on Route 1 where Mom would let me put one or two quarters in the arcade games while we waited. I looked at the glossy magazine paper saying "Burn out!" and I knew that I didn't want to do laundry and I would burn out quickly in my mother's role. Then I thought, "Let's not think about this too much." I was scared that perhaps Mom was unhappy, because I knew I would be if I were in her shoes.

Now at 12, it seemed unhappiness was just a matter of time. I would use the Rash Years to grow tougher, more stoic, I told myself. I would need that ability to endure.

Meanwhile, none of the hypoallergenic soaps and shampoos I tried helped my skin. In eighth grade, my face hurt just as much as in seventh. I did start talking to a girl in English class who was as strange as I was, and we became tentative friends, or at least comrades-at-arms in the foxhole of middle school. Then I started high school, at a new school, where again I knew almost no one, and I deliberately chose a new personality for myself this time: I would smile at everyone. I was determined to make friends (my first high school friend described me later as "this weird girl who kept smiling at her"). And the rash began to let up, slowly, each cycle getting milder and milder.

I didn't notice at first. Then one day, a couple months into high school, I realized the skin on my face looked almost like everyone else's. Better, in fact, since I was one of the few fourteen-year-olds without acne. I still wore unfashionable clothes that made me look like a kindergarten teacher, and I still wore large round purple glasses, but at least my skin was holding together.

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My skin remains sensitive to imperceptible emotional and environmental stresses. I sat down to write this story with healthy skin, but while writing my right eyelid has grown swollen and tender. The inside corner of my eye feels irritated. A tiny red droplet, a scab the size of a pinhead, sits at the corner of my eye, reminding me of that James Bond movie where the villain bleeds from his tear ducts. Just remembering the rash has summoned it up.

I raise my hands from the keyboard to press cold fingers to my inflamed eyelids. The cold feels good. If I had had any doubt about the research linking rashes to emotions, they would be dispelled by this ghost from the past. In seventh grade, doctors and grown-ups were baffled and couldn't find any reason for the rash; their puzzlement suggested that my skin was simply uncooperative and unruly. But today it strikes me that my skin possessed a powerful logic of its own, and knew my heart better than I knew it myself, perhaps. The cause of my suffering was right there all along, in the fear and isolation weighing me down every day. But no one ever asked.

CHAPTER 3

VOICE DAY

I lost my voice just after I turned fifteen, lost it for ten weeks. Laryngitis itself wasn't new to me, though I'd never had it so long. When I was eleven or twelve, every common cold and flu bug started by heading straight for my larynx. I usually lost speech for a day or two, but by the time I was fifteen I had had two or three bouts that lasted a full week. After my congestion and cough faded away, I would still be whispering my words, as if my larynx was too delicate to keep up with the demands of life.

Voicelessness wasn't new to me either, though I was unaware of it at the time. I was the oldest child of parents who couldn't quite escape the Puritan culture of their upbringing, the culture that gave us maxims such as "spare the rod, spoil the child" and "children should be seen and not heard." My father once said, only half-jokingly, that the mark of a good parent was that none of the kids ended up in jail. His child rearing (and my mother's—she never openly questioned his role as *pater familias*) focused on teaching us (my younger brother and sister and me) to behave. As a child, I was proud of myself for learning how to "behave." Only as an adult did I realize that there are other ways to behave, other ways to grow up. What I mastered as a child was a certain kind of silence: don't make a ruckus when Dad's relaxing on the couch after work, don't goof off in the backseat of the station wagon when he's driving, don't express opinions contrary to his, lest he think you're talking back. Steer away from opinions altogether, that's safest. Talk about science and literature, if you have to. Above all, let him do the talking. Your job is to listen and learn.

My father was easy-going most of the time. He showed his love by fixing our bicycles and teaching us sea shanties. But he also possessed fierce anger that he could turn on without

warning if we said something he didn't like. I watched my words carefully as a child, studying their connotations as a sailor studies the clouds, for he held me to adult standards. (Down the road, my brother and sister got more leniency, as he gradually accepted that children are, after all, not adults.) My mother, on the other hand, kept us quiet with tears. I started to worry about her sad moods when I was eight or nine, but when I was ten, my little sister was born and we moved to a new town, two events that changed something in my mom, taking away whatever stability and peace of mind she had, sending her into a severe depression. No one in my family said the word depression then, however. It was the days before Prozac, and mental illness wasn't in our vocabulary. I did know something was wrong: Mom cried a lot. Simple questions could make her cry—if I asked for a ride to a friend's house or asked what was for dinner. I would do anything to stop her from crying, I thought, and that meant staying out of her way and asking for as little as possible.

When I first started getting laryngitis regularly around this time, I actually minded the sore throat more than the muteness itself. The pain felt like someone had taken a cheese grater to the back of my tongue. A sore throat wasn't a reason to stay home from school, in my mother's book, so I had to go to school, but when the laryngitis started—usually after a couple days of throat pain—she let me stay home. I couldn't do much at school without a voice. I was happy to briefly escape the quiet horror of junior high.

But as my laryngitis began to recur several times a year in high school, my parents revised their policy on school attendance. I didn't have a fever; all my limbs were working. I might as well go to school. I went through the school day silently, nodding or shaking my head, occasionally whispering. I hated being mute, but nobody else seemed to care. Aside from a couple friends, my classmates didn't pay much attention to me: I was the quiet teenage girl with

a baggy sweater and thick lavender-framed glasses who just wanted to be left alone to read my way through the novels of the nineteenth century. Teachers didn't mind, as long as my laryngitis didn't disturb anyone—and even if I had been a troublemaker, it would have been hard to disturb class with no voice.

So when I woke up on New Year's Day 1990, unable to make a sound, I thought I knew the routine. I didn't know I would spend the rest of the winter in silence.

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I will confess that I brought it on myself. It was entirely my fault—at least on the surface. On New Year's Eve, I had a cold and a sore throat but I wanted to spend the night at my best friend Samantha's house anyway. It would be unbearable, I thought, to spend such an important evening at home with my parents, my little brother and sister. It wasn't just any New Year's Eve; it was the last moments of 1989.

"It's going to be a new decade!" Samantha and I would say to each other in amazement back then, the way other teenage girls might get excited about a new pair of shoes or a cute boy. At the age of fifteen, we saw each decade as an epoch unto itself. We remembered the seventies only dimly. Our lives of self-consciousness and self-awareness belonged entirely to the eighties. In the nineties, anything could happen. The Cold War had just ended——what next for the world? And what would happen to us? This was the decade we would learn to drive, go to college, even—impossibly, improbably—become adults. That last possibility was so hard to imagine that even inside my own head, I whispered it.

We had never really expected to grow up. Samantha and I had become friends in fourth grade, around the time we figured out that when the nuclear war with Russia started, we weren't going to make it. Our odds of survival were an occasional topic of playground conversation—we knew not to mention it in front of adults, who got angry or upset when we asked about the coming apocalypse, no matter how many times the topic came up on the evening news and *60 Minutes*. While hanging upside-down on the monkey bars during recess, we calculated. We lived in a Virginia town roughly twelve miles south of the White House, so we'd never have time to evacuate before the bombs hit. We'd have what, a couple hours warning at most? We knew the traffic heading away from the city would be bad. Samantha said it might be better to make a quick end, anyway, so we didn't have to deal with nuclear winter, radioactive fallout and starvation, a theory I found strangely comforting. Perhaps I would never have to deal with adult responsibilities, the budgets and arguments that besieged my parents and wore them down year after year.

But now that the Iron Curtain was falling, anything was possible. Samantha even had a boyfriend. I wanted to start the new decade with friends, people I could talk to, not in the mire of family togetherness. My job in the family was to listen to my parents' complaints and arguments. I wanted a night off. Besides, Samantha lived on the other side of the county, and we hadn't attended the same school since fifth grade, so I didn't get to see her often.

A freezing drizzle was falling outside as I swallowed some cold medicine and begged my mom for a ride to Samantha's. She reluctantly gave in, and I spent the evening with Samantha and a couple other friends, partying like the quiet, intellectual kids we were: we watched videos, ate leftover Christmas chocolates, made banners saying "Happy New Year 1990!" and wrapped

ourselves in polyester sleeping bags on the family room floor, where we whispered in the dark until we fell asleep in the smallest hours of the night.

All evening, I had a catch in my throat that wouldn't budge, despite clearing my throat repeatedly and sucking down boxes of cherry cough drops. My croaking sentences grew fainter in volume. My pitch changed erratically in the middle of words like a twelve-year-old boy with his voice cracking. But I was determined to make my voice work anyway, whether it wanted to or not. Samantha and I couldn't drive yet and she lived some 45 minutes away from me, so we could only hang out together once a month or so. I wanted to celebrate the arrival of a new era in our lives. I wanted to tell her everything I was thinking, with that intimacy found only in the friendships of teenage girls. I stubbornly forced my voice for the rest of the night.

When I woke up on New Year's Day, no amount of force or willpower could draw sound from my abused larynx.

###

The voice box—the larynx of the word "laryngitis"—isn't a box. It isn't even square. The muscles that produce the human voice are two unremarkable half-moons of flesh, which shelter the upper end of the windpipe and meet in the middle. They form an aperture somewhat like a tiny mouth, hidden there inside the throat. These two small vocal chords—"vocal folds" is the scientific term—perform movements every bit as complex and subtle as the whistles, smiles and kisses that our true lips accomplish. These second, hidden lips vibrate to create pitch, in turn giving us singing, the uncertain rising tone of a teenage girl at the end of a sentence, or the screams of fans at a 1989 Guns and Roses concert. They also regulate the speed and quantity of

air we breathe out, allowing the delicate control we need for explosive consonants and complete sentences. Except for a few lizards, mammals are the only animals with vocal chords—and humans are the world’s noisiest mammals, with vocal chords located unusually far down the neck, in the perfect position for producing the animal kingdom’s most complicated, bizarre repertoire of sounds.

When a virus inflames the vocal chords, the muscles swell, distorting and warping the delicate machinery of the larynx. We lose the control of pitch and volume that is one of our biggest evolutionary advantages, the under-appreciated jewel of human anatomy. Though scientists have dozens of conflicting theories about how speech evolved, they agree that high-speed, vocal communication allows us to live complex lives in complex societies, explaining perhaps why humans, not chimpanzees, built pyramids and invented cable television. Humans evolved to talk. Except for contemplative religious seekers, who look for God in silent retreats and meditation, we wilt in silence. Most of us need speech to remain connected to ourselves and others.

###

I still couldn’t talk when I went back to school a week later but my cold was better and I was bored sitting around at home. My friends weren’t too surprised; this wasn’t my first bout with laryngitis. We figured my voice would come back in a couple days.

Does it hurt? my classmates asked, with as much curiosity as concern.

It didn’t, not really, but the frustration of not communicating felt like a physical pressure on my chest. The only chance to talk to friends at school was in the hallways during the five-

minute breaks to change classes, where the noise felt like a physical force: hundreds of voices and the slamming of hundreds of metal lockers meant you had to shout to be heard.

Days went by and my teachers adapted to my new disability. Classrooms were relatively quiet, so occasionally I could have a whispered conversation, even participate for a moment in discussion if I had a patient neighbor who would translate my whispers into speech. And I tried to look at the bright side—the oral report I was supposed to give in French class on Jan. 2 was delayed indefinitely. I enjoyed seeing how my new disability flustered Madame Young, the French teacher with the thick American drawl and thin sense of humor. When I couldn't give my five-minute talk on *le pays Senegal*, the whole plan for the week was *derangé*, she fussed, as if I had chosen silence as a way to resist her uninspired teaching.

My chorus teacher was more resourceful. She installed me in the small windowless room that served as the music library and asked me to organize thousands of pages of jumbled sheet music piled up on tables and in rusting file cabinets.

I loved singing. I would spend many weeks in that room that smelled like choir robes and mildewed paper, listening to the rehearsal outside and wishing I could join in.

###

Two weeks into the New Year, I still couldn't speak. At the doctor's office, a harried and sturdy-looking woman—a pediatrician, since I was not yet eighteen—entered in a doctor's white coat. I sat on the crinkly paper of the examination table with my legs dangling over the side, feeling like an overgrown toddler. My mom sat on a chair in the corner holding her overstuffed purse self-consciously on her lap to hide her large, round stomach.

"Sore throat?" the doctor said with a glance at her paperwork, without looking at either of us. She held up a tongue depressor. "Say Ah."

I thought I would gag on the dry pressure of the wooden stick.

"Not like that. Say Ah."

Finally, she got a look at my tonsils.

"Looks good. A bit red. You just need to rest. Gargle with salt water." She told me it didn't look like strep throat, but I should get a throat culture at the lab upstairs just in case.

That was all. She started to leave.

"Wait!" I whispered as loudly as I could. The effect sounded like a gasp. She looked at me.

"How long?" I said. "How long before I can come back?" I worried the laryngitis would require medical intervention, and I couldn't think of any other way to communicate to her that the situation was desperate.

She gave me a strange look. I wondered if she thought I was nuts. Perhaps because she'd never heard of long-term laryngitis, she didn't believe in it.

"You'll be fine. Gargle with warm salt water twice a day." she said, "And you shouldn't whisper. It's bad for your vocal chords."

After a nurse at the lab scraped a tissue sample from the back of my throat, my mom and I drove home quietly. Mom didn't say anything. I was starting to worry I would never speak again. I felt a little like crying, but there wasn't any point. Crying sounded weird and disturbing with no vocal chords, a gasping, choking noise, not quite human.

###

Weeks go by without my voice returning. At home, my parents handle my mysterious ailment as badly as they handle everything else that decade, absorbed as they are in their personal struggles with anger and sadness. To my mother, the laryngitis is another example of how the world is turned against her; to my father, it's another example of how my mother can't do anything right.

When my mom and I come back from the first doctor's visit with the advice "Gargle with salt water," my father makes it sound like Mom's fault. She needs to see another doctor, he says to Mom. He brings it up night after night. Calling the doctor is Mom's job, like cooking and cleaning. Dad's job is bringing home paychecks. But Mom is terrified to make phone calls—a symptom of her depression—whether to talk to family members or to make appointments with doctors. I haven't been to the dentist in years; none of us have, except Dad, because he schedules his own appointments. My brother, sister and I are Mom's responsibility.

"Did you call today, Nancy?" My dad asks as he slices into a chicken breast at dinner. His voice is stern but I don't notice, because it always sounds like that. His father was an Air Force colonel, and Mom's father was an Army colonel. We all know fathers are supposed to talk like commanding officers.

Mom looks down at her plate and shakes her head. She eats quickly, holding her knife in her right hand and her fork upside-down in her left, like a European. The fork swiftly skewers potatoes, chicken, green beans.

"You're gobbling your food, Nancy," he says. "For Chrissakes, it's not a race. Hold your fork like an American."

My little sister, sitting between them, has barely touched her food. Ever since she could eat solids, she's been a slow eater who spends meals day-dreaming. On the other side of the table, my brother and I look at our plates. I'm mentally trying to absorb all the anger in the room, as if I can heal us all. I hate that my parents give my seventh-grade brother money for his report card grades—I get yelled at for any grade less than an A, whereas he gets ten bucks for a mere B. But I feel sorry for him, too. He finally made a friend at school last year, and then the boy suddenly died. A brain aneurysm on the school bus—abrupt, awful, unstoppable. My brother's presence at my left elbow gives me the same dull ache I feel when I think of my mother at the end of the table or my dad across from me.

I think of this pain as something quasi-magical, a psychic transference. If I feel enough of it, I think, I can use up all the pain in the room, like a flame burning away oxygen. Then my brother and mother will be happy and I can stop worrying about them and get on with my life. I know I can do it, because I'm the strongest person in the family, the only one who doesn't act angry or depressed—even though I feel awful and alone. I'm a good soldier, I think.

"She needs to see the doctor again," Dad says.

"I know," Mom says, in a twisted, pained tone.

I want so badly to go to the doctor, but I hate this argument.

I whisper as loudly as I can across the small kitchen table: "Dad, it's okay." I hiss like a snake.

He gives me a cold look. "Your mother needs to take care of this."

I look back at the yellow vinyl tablecloth and wonder how long until *Jeopardy* comes on. Dinners are better when we turn on the little black and white TV on the kitchen counter and my parents compete to call out answers: "Who is Julius Caesar?" "What is the Battle of Yorktown?"

"What is internal combustion?" My dad is faster, but my mom gets the answers more often. She has an encyclopedic memory for history, literature, art and science. Even today, twenty years later, when she's forgotten several entire years of her life due to the cognitive destruction of clinical depression, she still effortlessly delivers detailed, impromptu lectures about James K. Polk or Anne Boleyn.

"If you don't call," Dad says, "I'll have to do it myself."

"I'll do it," Mom says, looking at her plate, her voice so subdued she almost whispers.

If I were well, dinner would be better. I would ask Dad about work and he would expound on the future of Geographic Information Systems or the irritations of government defense contracting. Maybe I would talk about something I learned in school—grammar or geology or Greek tragedy. I would show how I had memorized the prelude to *The Canterbury Tales* for English class, and my mother would smile brightly, remembering her happy days in high school and joining me (her memory perfect as always) in reciting a long-forgotten language:

*Whan that Aprill with his shoures soote
The droghte of March hath perced to the roote,
And bathed every veyne in swich licour
Of which vertu engendred is the flour...*

But whispering takes as much energy as shouting. I can't take care of them anymore. My helplessness is a physical ache that stretches throughout my body.

###

Before I lost my voice, I appreciated school as a refuge from the cold war at home. In the classroom, I knew how to follow the clear-cut rules for success. My teachers liked me, and no

one needed my emotional support. But with laryngitis, school became frustrating, alienating, strange.

Laryngitis, like depression, is a disease of absence. From the outside, it appears devoid of drama. No ER doctors rush through hospital corridors yelling "Stat!" No ambulance sirens, no helicopters and caring attendants. The suffering is invisible, and you begin to wonder if the experience is even real. The more people treat you as healthy, the more your disability feels farcical.

But as healthy as I looked on the outside, I experienced the world through altered senses. The sound of voices around me changed, grew higher-pitched and distant. My own thoughts grew louder, oppressively so, almost drowning out the talking of others. Because I couldn't participate in conversations, my mind wandered restlessly and uncontrollably. I started missing long stretches of class.

Breathing got harder. Part of me felt very far away, but another part felt all too present—a naked and defenseless captive of some hostile tribe. When I was with others, my legs were always tensed for flight. I couldn't forget my body for a second, couldn't get comfortable no matter how I shifted my body. My throat and chest were carved of wood; I longed to speak but was trapped inside a stiff, unyielding body.

I tried to find humor in the situation. My friend Samantha liked to say, "Where there's humor, there's hope." My classmates enjoyed coming up with silly suggestions for communicating with me: "Let's do charades! How many syllables?" Their attempts to decipher my signals could sometimes move me to laugh a weird, wheezing laugh. Samantha and I tried to have phone conversations. She talked and I hissed into the receiver as loudly as I could. Even

though the doctor warned that whispering would damage my vocal chords, as Samantha pointed out, how could things be worse? Did the doctor not notice that I already couldn't talk? Jeez.

By the time February rolled around, silence was my "thing," a memorable characteristic other than my high grades and grandmotherly taste in clothing. One afternoon as I whispered to a friend at her locker, a lanky girl I'd never met stopped to talk to us.

"Hi. I'm Cat," the new girl said, punching each syllable. She was dressed entirely in black, from her thick black eyeliner to her high-heeled black boots. Some of our mothers still considered black the color of mourning, inappropriate for young ladies. Cat enjoyed shocking the easily shocked.

My friend introduced me, "This is Jessamine. She can't talk!"

I think my friend merely wanted to let me off the conversational hook as quickly as possible, but her odd introduction made chronic laryngitis sound like a lifestyle choice rather than a mysterious ailment of unknown etiology. Cat looked at me strangely. "Really?"

"Yeah," my friend explained. "Since New Year's. No talking at all. That's like, six weeks."

"Weee-ird," Cat said.

Later I learned that Cat, the biggest fashion rebel in school, referred to me forever after as the Girl Who Doesn't Talk, as impressive as black nail polish, in its way. When I recall that long, silent winter, I try to remember how I made an impression on Cat, rather than how I felt like I was slowly dying inside.

###

I felt like a hostage of my ailment, though upon looking back today it strikes me that I was actually a hostage of my parents' failings and my own helplessness. But when I was fifteen, it didn't occur to me to be angry with my parents or myself. Mom and Dad looked at life with suspicion and anxiety, and each of them had taught me in their own, different ways to fear and blame the world. I expected life to be difficult. My imprisonment in silence was just one example of the horrors in store for me, I thought, and my parents were the only ones on my side. Together we were prisoners of our health insurance plan, an HMO that kept costs down by providing as little care as possible, and prisoners of our ailing bodies themselves. Patients could get good care if they made a fuss and demanded it, but my parents believed in "the system," in accepting fate, in following the rules, in never complaining to the Powers that Be. And I was their daughter. I had no idea how to make a fuss even though I wanted to.

Sometime in February, my mom overcame her terror of telephones long enough to make a second call to the doctors' office. The second appointment was as fruitless as the first. The pediatrician shrugged, said he'd never seen laryngitis last more than a couple weeks, but he didn't know any reason to worry. It should go away on its own, he said. You'll be fine.

He wrote me a note for my teachers saying that I had laryngitis, though my teachers had never asked for one. No one would whisper for six weeks just to get out of an oral report on *le pays Senegal*, no matter how stupid the assignment was.

When Mom and I left his office, I thought I would never discover what was wrong, never even find a doctor to acknowledge the problem. I was afraid to say the words aloud, even inside my head: I would never speak again. I would spend life as a nodding shadow at the edge of conversation.

I worried I had polyps. I didn't know what polyps were, but I had heard of opera singers forced to end their careers because of them, so they must be terrible. With no internet in those days to provide quick amateur diagnoses, I didn't know any more than that. Thankfully, I was thus unaware of the other diseases that can cause chronic laryngitis: gastro-esophageal reflux disease, vocal paralysis, laryngeal dystonia, throat cancer. I don't know if my parents knew about these possibilities.

Six weeks turned into seven, then eight.

My parents' worry was real, but so was their sense of helplessness. One Saturday I went with Mom to get errands done. Dad was working overtime or leading a hike with my brother's Boy Scout troop. It was a relief to be alone with Mom away from the house. I thought she was the most beautiful woman I had ever seen, at least until she grew depressed around the end of my first decade. It was hard to perceive her beauty when she was folding laundry with a tense frown or lying on the couch behind the newspaper trying to disappear. She had long, wavy, dark hair—mine was thin and cropped short so I didn't have to think about it—and an oval, classically-proportioned face, like something out of the Italian paintings we regularly visited at the National Gallery. Her lipstick smelled of flowers when she applied it in the rear-view mirror before driving somewhere. When my father told her she was fat, I hated him. Anywhere she went, I wanted to follow and protect her, faintly hoping, too (though I would never have admitted it, even inside my own head) to receive one of her very rare hugs or kind words.

That morning we visited the mall for something, and then stopped at a fast food joint. When it came time for me to order at the counter, I was exhausted. My diaphragm was worn out from the labor of projecting my thin whisper loudly enough to be heard. I was tired, too, of the strange looks from register clerks and strangers.

I touched Mom's arm and whispered to her, "Can you order for me?"

"Go ahead!" she said.

"I can't talk!" I whispered, attempting to add an exclamation point by mere force of will.

"You can do it just fine," she said with irritation.

I was furious. Nothing was fine. Nothing would ever be fine again. She could help me out, just once. I hated her.

I felt my face shiver with the weight of all the crying I hadn't done.

"I can't do it!" I whispered as loudly as I could. I don't know if she could hear me. The clerk at the cash register waited, uninterested and mildly impatient.

My mom looked down at me. Suddenly her face was pleading, her brusqueness replaced by desperation. "There's nothing I can do," she said. Her eyes said: If you start crying, my God, I'll die of shame. There's nothing I can do, nothing I can ever do. I can't even order a slice of pizza for you.

So I put my feelings away and ordered my pizza and we sat down on opposite sides of a plastic table and we both tried and tried not to cry.

I'd like to say that I haven't asked her for anything since that day, but it would be more truthful to say this: that it hasn't occurred to me to ask her for anything.

###

In early March, Mom won the ongoing standoff with Dad over the telephone. My dad gave up pressuring her to call and he argued my case over the phone to our health insurance company himself. It took an hour on the phone (a feat well beyond my mother) for the HMO to

agree to let me see an otolaryngologist—an ear/nose/throat specialist —despite the pediatricians' insistence that I was just fine. I had an appointment on Thursday evening, less than a week away.

As my dad drove me across the Potomac to the doctor's office in Maryland, I was terrified. The doctor would tell me I had polyps, I thought, and I would need surgery. Or my larynx was hopelessly broken. I would never speak again. Although I was glad to finally see an expert, I didn't expect good news. My dad was even tenser than usual, and I expected his pessimistic view of the world would be justified tonight with a tragic diagnosis.

The medical building was dark and still. Everyone appeared to have gone home except Dr. Pryce, a thin doctor in a long, white lab coat, who joked about our similar last names in a soft Welsh accent.

I whispered to him that I hadn't spoken in ten weeks. His cheerful expression didn't alter.

"Let's take a look," he said, holding up a tiny, round mirror at the end of a long metal rod. He used it to glance down my throat for a moment—the length of two heartbeats—then sat back and returned the silver mirror to the front pocket of his lab coat.

"Your vocal chords are fine, excellent. No polyps, no scarring." He looked pleased.

I was horrified for a moment. If the specialist couldn't find anything wrong, I would never be fixed.

The doctor continued. "Let's hear you cough, my dear."

I gave a tentative little hem.

"No, no, no," he smiled, "A great big cough. Like you're choking to death."

I coughed and hacked.

"Ah! Do you hear that?" His eyes shone, though I heard nothing.

He made me cough again and listen carefully. And I could hear it: me, myself. I could hear the faint hum of my vocal chords under the percussions of coughing.

"If you can cough, you can talk," said the doctor.

Pleased with himself, he gave my disorder a complicated name—functional dysphonia—and a simple explanation. Functional dysphonia refers to a tensing of the vocal chords in the absence of the organic pathologies that usually damage the vocal chords, things like cancer or laryngeal dystonia (a neurological condition). Functional dysphonia occurs without obvious physical or anatomical causes, as if the brain stem has simply flipped off the circuit breaker that sends power to the vocal chords.

In my case, the doctor explained, the problem started as my body's attempt to protect my larynx at New Year's. When I continued talking on inflamed vocal chords, I damaged the muscles even more, causing further inflammation. At this point, some primitive part of the brain makes an executive decision and turns off the larynx to allow it to heal. Usually, as soon as the virus goes away and the inflammation subsides, the brainstem switches the vocal chords back on again. But sometimes—on very rare occasions—the brain forgets to switch the voice back on, even though the vocal chords have healed. My brain had forgotten how to talk.

Dr. Pryce directed me through some vocal exercises to gently start the muscles working again. Within fifteen minutes of arriving in his office, I could speak aloud, crudely coughing out my sentences like a terminal tuberculosis patient.

"Well, I'll be damned," my dad said.

By the time we'd driven home, I could speak without having to cough first. And within hours, I could speak without having to think about it. Speaking became natural again. My voice was hoarse with disuse but within twenty-four hours, I sounded normal.

###

For a decade afterwards, I celebrated my own private holiday every March 8: Voice Day. Today I sometimes come down with laryngitis for a day or two, but never longer. I can hear Dr. Pryce in my head reminding me to stay home from work, take it easy, don't whisper or put strain on the vocal chords until they recover.

Though the initial laryngitis may have been partly my fault, for abusing my larynx at New Year's, my voice box was probably healed within two weeks. Roughly eight of those ten weeks of silence were unnecessary. The fear and uncertainty were unnecessary. I owe those extra eight weeks to the apathy of two pediatricians, to our health insurance plan, to my mother's fear of telephones and my father's standoff with the world. Some people might suggest that my own stoicism dragged out the ordeal as well, but short of retaining a lawyer and suing my parents for neglect, I doubt anything could have gotten their attention or penetrated their sense of helplessness that winter.

As my dad and I drove home from the doctor's office, it occurred to me that, as my somewhat more capable parent, he had robbed me of eight weeks of my life. I realized something that would become my guiding principle for years to come: I couldn't trust my parents to help me, even in the toughest circumstances. They were weak, unable to help. I couldn't trust anyone but myself, and an occasional beneficent stranger like Dr. Pryce.

But even as I carved this lesson into my brain, I dismissed my anger about it as quickly as it came. It felt wonderful to talk aloud again. I wanted to talk to my parents, even if it was only about science and literature and not about my emotions or theirs. Blaming them would be

exhausting. I had to live with them for two more years before college and I didn't have the strength to feel anger. I was adept at forgetting my feelings back then. Forgetting them was easy; remembering them later was harder.

Perhaps the laryngitis would have claimed ten weeks of my life even if my parents had put all their efforts into helping me. Even today, internet searches on laryngitis don't yield any information on my rare ailment. In 2011, a case of functional dysphonia in Wilmington, Delaware, actually made the evening news with Diane Sawyer—that's how uncommon it is. The five-minute news item tells of how the young mother of three visited doctor after doctor, who couldn't explain her voicelessness, but attempted various treatments such as oral antibiotics and steroid injections directly into her larynx. After seeing eight doctors in three months, she lost hope she would ever speak again.

Then a tip from a friend led her to drive seven hours and five hundred miles to consult a voice doctor at the Cleveland Clinic. He diagnosed her immediately and cured her within a few minutes. Watching the news footage of this patient re-learning how to talk is like seeing myself as a teenager coughing in front of Dr. Pryce. But I'm glad I didn't visit eight doctors and suffer half a dozen futile interventions before getting answers. My parents' inability to muster up the energy to help me ironically protected me somewhat, given how little known my ailment was. It was pure luck that when I saw a specialist he was experienced enough to help.

It would be well into the nineties before my mother would agree to talk to a doctor about her depression, and the next century before my father would visit a therapist, divorce my mother and begin to shed the grimness that had characterized him for years. And I would leave home at seventeen with the belief that I was a good soldier, the strongest member of the family, a belief that gave me bleak hope, but hope nonetheless. Years would pass before I would learn how to

talk about that winter, about that whole sad series of winters when I was teenager trying silently to tend to my parents' uncontrollable emotions. More years still would pass before I unlearned the lessons of silence.

CHAPTER 4

THIEF OF SOULS

Almost twenty years ago, I developed a strange psychosis, though it would be years before I learned the word for what happened that autumn. I was just back from a gray semester abroad in London and a summer of data entry jobs in East Coast offices that smelled like air-conditioning. I was excited to get back to college and start my senior year. But Septembers rarely lived up to the hopes I pinned on them.

I remember one long, exhausting afternoon I spent pressed to a mattress in my dorm room, unable to move under a great weight of dread. I tried to distract myself, but the only channel the bulky RCA TV could pick up was showing *Apollo 13*: Tom Hanks and Kevin Bacon struggling in the slowness of zero gravity to make it back to Earth.

My heart was probably about to stop, I thought. My next breath would be my last. I didn't care whether the Hollywood astronauts lived or asphyxiated. They bored me. But I forced myself to watch. Hanks and Bacon blathered on about their problems to ground control. I wished they would be quiet. I didn't turn off the TV, however. Hearing my own thoughts would have been worse.

The anxiety I'd felt since starting senior year a couple weeks before had sent out roots and grown massive, finally sending me to bed that afternoon in terror. I was sure I was pregnant and I didn't know what to do.

I had no physical signs of pregnancy. My weight was unchanged, my appetite good, my periods regular. Furthermore, I had never had much interest in the young men at my college, who appeared to come in one of three models: the one with gelled hair, the one in the baseball hat, and the well-spoken one who came out of the closet during freshman year. It would be another

year before I graduated and discovered the world of interesting men beyond New Jersey. That September, I was a virgin.

No earthly way existed for me to be pregnant, and because I was an atheist, I wasn't inclined to contemplate unearthly ways. Yet I was completely sure that I was. The delusion that I was pregnant was fighting against logic for control of my brain.

The delusion had started a couple weeks earlier, with the beginning of the school year at my small, obscure, liberal arts college in the outskirts of New York. Soon after I moved into the dorm, the anxiety moved in too. It gripped my abdomen and chest. My stomach hurt with its weight. My muscles ached with the effort of not screaming, of holding still and acting normal despite the steady flow of adrenaline telling me, "Run! Run!" And then somehow—I don't remember where or how I first had the thought, it grew so subtly—an illogical realization grew in me: the aches and pains meant I was pregnant. That feeling of heaviness came from something living inside me, growing and seeking to be born.

Though I knew the thought was irrational, I went through the same panicked thoughts as any college co-ed: when was the baby due? Was it too late for an abortion? Would I have to drop out?

Sometimes I tried to reason with the delusion. I've never had sex, I told it. I think I'd remember.

Are you sure? It replied. You got pretty drunk at those parties last spring. You blacked out a few times. Jeez, you don't even know who the father is.

This right-hook had Rational Thought staggering on the mat. I did carouse a lot that spring in the U.K. Was I sure I remembered everything? Just in case, I calculated dates. I was in the second trimester and it would be noticeable soon. The baby was coming in January and I

wouldn't be able to finish college. But where would I go? I couldn't, or wouldn't, turn to my parents for help. My dad was quick to criticize irresponsibility. He would disown me, I thought. And my mother was in the ninth or tenth year of a deep, complicated depression. I hadn't asked her for help with anything for years.

If the pregnancy had been real, perhaps I could have spoken up and moved forward one way or another. But the conviction that I was pregnant was made worse by its complete irrationality. I was just rational enough to recognize my irrationality. The quiet, rational part of my mind didn't help, however. Rational thinking told me to just forget about it, get my head straight. Above all, don't tell anyone, rational thinking said. You're not really pregnant, so there's no point telling people you're pregnant, right? Rational thinking said, they'll think you're crazy.

The struggle wore out my body as well as my mind. It was easiest to stay in my dorm room alone. On the afternoon I'm remembering, I skipped dinner not because I cared if Hanks and Bacon made it back from the moon, but because I dreaded the dining hall. It was hard to eat and talk. I couldn't let my friends suspect anything was wrong. I was deeply ashamed.

As I lay there, my heart seemed to be beating too quickly and too loudly. I took my pulse with two fingers against my throat. I had read about panic attacks, and knew they made your heart beat faster, but my pulse was normal. I felt disappointed. A panic attack would have been a physical thing that I could take to a doctor. But if it wasn't a panic attack, I concluded, I really must be crazy.

I tried to just watch the damn movie. I forced my attention to the screen and pretended to root for the heroes. I made myself listen to the dialogue the way normal people do. But I felt completely numb when they landed back on Earth.

That was the week that fear kept me lying awake at night, tense and still, afraid to roll over in bed, afraid even to shift position or breathe too deeply. I was convinced that my sturdy loft bed, homemade from two by fours, was precarious, barely standing upright. Any movement could make it collapse and send me plummeting to the floor, causing me some horrifying injury. An injury to my back or neck, probably. I would be paralyzed.

For several nights, the fear of paralysis settled into my mind as firmly as the pregnancy delusion. I spent the nights in a fevered wakefulness, convinced I had to stay awake and keep still. But to add to my fears, I felt sure that if my roommate ten feet away realized I was awake, she would somehow know everything. She was a good friend, generous and not judgmental; besides, she had her own concerns that fall. She could probably tell I was stressed out about something, but she couldn't read my mind. But I was terrified of her every night. I had to pretend I was asleep in order to fool her.

I'm losing my mind, I thought.

###

Seventeen years would pass before I would realize that I suffered that September from a form of psychosis. The term psychosis carries so much baggage: images of nineteenth-century lunatic asylums, Hannibal Lecter, and the homeless mental patients who still roamed Fifth Avenue and Washington Square Park forsakenly when I was in college. As a medical term, however, psychosis refers to one of the brain's most surprising dysfunctions: the loss of contact with reality. Hallucinations are the best-known form of psychosis, but psychosis can also occur as fixed delusions, mistaken beliefs about reality varying from the mundane to the outlandish.

Psychosis is perhaps the toughest symptom of schizophrenia and bipolar disorder, but it can result from other conditions, as well: sleep deprivation, drug use, head injury, temporal lobe epilepsy, certain diseases, certain medications and half a dozen assorted mental illnesses from anorexia to post-traumatic stress disorder to postpartum depression. Psychiatrists know that even major depression can lead to psychosis if it goes too long untreated. One researcher estimates that 25% of people hospitalized for severe depression also suffer from psychosis, but don't appear in statistics because they hide their delusions from doctors. Even in the psych ward, people don't want to sound crazy.

Researchers struggle to describe what happens to the brain during psychosis, and why. The central mystery of psychosis is its ability to convincingly mimic reality. The hallucinatory voices of schizophrenia can easily sound louder and more real, than the actual voices of family and friends. And psychotic delusions are so resistant to logical argument that psychiatrists refer to them as "fixed delusions," to distinguish a clinical brain dysfunction from a mere "false belief." Fixed delusions are false beliefs that no amount of reasoning or objective evidence can change.

Reading about fixed delusions today at the age of 38, I find it obvious that I was suffering from a kind of mental illness when I was twenty. Yet curiously, it wasn't obvious to me at the time. I had taken freshman psych. I knew that thoughts and emotions come from our brains, and I knew that brains didn't always run smoothly. But the worries running through my mind didn't feel like brain pathologies. They felt exactly like my own thoughts. They spoke in the familiar voice of my own mind, just like every other thought that formed the scaffolding of my identity. If some hostile force could impersonate me and go undetected by my own mind, how could I know that any of my thoughts were truly mine?

The word "psychosis" comes from the Greek word for soul, "psyche," and means "a disease of the soul." The soul: the very thing that allows us to use words like "me" and "mine." The "I" in my mind that narrated my life as it happened—the "I" that narrates this story now, in fact—that "I" itself was somehow broken. Even with my rational mind still occasionally on board, I was unable to perceive that the scared, pregnant part of my mind was wrong, because it spoke with the same voice as the rational "I." My own voice. A civil war was fighting inside my mind. When psychosis stole my reason, it used my own mind to jimmy the locks. This thief of souls can slip past our defenses no matter how tough we think we are, because it comes disguised as the soul itself.

I also had the misconception that mental illness is always incapacitating. When I was ten, not long after the birth of my little sister, my mother had developed a nasty depression that she was unable or unwilling to acknowledge for years. So I thought I knew what mental illness looked like—it looked like my mother's spontaneous weeping at the steering wheel on a routine trip to the grocery store.

I was missing an enormous piece of the picture, however. By thinking of mental illness merely as a set of behaviors, I overlooked for years the emotions and thoughts that accompany it. I proved to myself I wasn't crazy that September by trying to act as usual. In the mornings, I forced myself out of bed in time for my first seminar at eleven. I went to classes, stayed up late doing homework, and hung out with friends watching *The X-Files* on Thursday nights. The charade took all my strength, though, and gave me little comfort.

In the moments when my fear subsided somewhat, I tried rational means to clear up the delusion. Surely, a negative pregnancy test would reassure me, I thought. I drove to a drug store in the next town over—I was terrified of running into someone I knew—to buy an at-home

pregnancy test, which I hid as far in the bottom of my backpack as I could, as if it might try to leap out of the bag and embarrass me in public.

Driving back to the dorm, I debated intensely which bathroom to use. I decided on a women's room down the hallway from my room, but not the one closest to my dorm room. Instead, I chose the one that lay another hundred feet further down the hall. It would be dangerous to use the bathroom closer to my room: there was the risk of my roommate coming in, recognizing my shoes under a stall door and somehow immediately knowing that I was there to take a pregnancy test. She would know everything, although I wasn't even sure what "everything" was anymore. But the danger of humiliation scared me so much that it was hard to breathe.

Unzipping my backpack in the echoing bathroom, I felt sure that the stranger in the stall next to me knew exactly what I was doing. In my nervousness, I had to read the instructions several times over. I waited for the results in dread, knowing the answer would be "yes." When the inevitable "no" appeared, my delusion didn't skip a beat.

The instructions say that it's only accurate 97% of the time. Seventy-five percent if you take account of user error. My delusion reviewed every potential complication from the fine print warnings that came with the instructions. Then it made stuff up. Doctors don't know everything. They only know what average female hormones do. What if you have freaky, abnormal hormones? It sounded convincing. I went back to my room weary and confused. How do delusions evade objective evidence? The only explanation I could come up with at the time, in that mental state, was that the delusion persisted for the simple, obvious reason that it was true. I was pregnant. The test was wrong. The evidence of my body and memories was wrong. Why else would I be so sure of something?

I did know the fear was making me ill, though. In clearer moments I wondered what to do. Researching medical topics wasn't as easy in 1995 as it is now. I looked up "false pregnancy"—pseudocyesis—somewhere, but it didn't describe my problem: I wasn't having any of the hormone changes, weight gain and morning sickness of pseudocyesis. I was only vaguely familiar with the words psychosis and delusion. As long as I continued to go to class and get good grades, I was convinced my mental health was okay.

###

Looking back, my worst agonies only lasted two or three weeks, maybe four, but it's hard to be precise because it felt like months. Occasionally, I became optimistic and resolved to master my fears. In one such mood, I took the bold step of giving up caffeine. I stopped drinking coffee cold turkey, and vowed not to touch the diet Dr. Pepper in the mini-fridge. Caffeine contributed to anxiety, I heard, so quitting would cure me, right?

In early October, I also did something no one in my family had ever done, to my knowledge, except perhaps my aunts who moved to Manhattan in the seventies. I made an appointment at the campus counseling center, a couple of rooms hidden away in a gloomy Victorian. When I rattled the heavy front door and went inside, the front parlor smelled like dust and old wood. I was terrified I would run into someone I knew.

I was relieved when the receptionist in the dim parlor arranged an appointment without asking why. And when I met with the counselor a few days later—in a small, brown attic room where the ceiling sloped deliberately and the other walls sloped accidentally—she turned out to

be a quiet, approachable woman only a few years older than me. Still, it took an effort of will to open my mouth and say something, anything, aloud.

I can't remember how I explained why I was there. Did she understand what I was saying? How strong and weird the delusion was? I suspect I lied. I suspect I told her I was afraid, very afraid, but that I didn't tell her about the mysterious force that had hijacked my thoughts and entire sense of reason. I just talked about my fear of pregnancy, and she asked a quintessential therapist question: Who was I afraid of letting down?

So we talked about my dysfunctional family and the stresses of the summer just past. As I talked, I did feel a slight lessening of the pressure in my chest. The therapist didn't tell me I was crazy, which was a relief. And I was fascinated when she gravely said I had a lot of stressful things in my life. I didn't think of my life as stressful, except right before a research paper was due. It reassured me that she thought I had actual reasons to be anxious. My brain was anxious exactly as it should be. Nothing was wrong with me.

Thanks to the talking—and perhaps to cutting back on caffeine—my anxiety subsided to bearable levels. By the end of October, I realized something inside me was different. I felt lighter. I couldn't remember why I had worried I was pregnant. My delusion had faded—faded enough that soon I could forget about it, pack it away in the back storerooms of my memory. I only visited the therapist three times total. I cancelled my fourth appointment to work on a paper.

Six years would pass before I would visit a counselor again, six years punctuated by long stretches of fear, guilt, despair and crushing physical weakness—symptoms of chronic depression that I refused to acknowledge, or perhaps couldn't see clearly enough to recognize. But I'm lucky in that my first delusion was my last. I suppose I had what psychiatry's *Diagnostic*

and Statistical Manual calls "major depression with psychotic features." It's an awkward phrase, but accurate.

Three people out of every hundred will experience psychosis in their lifetime. In the United States, that means nine million people. Out of those nine million, around six million will have bipolar disorder or schizophrenia, but roughly one million will have what I had—"major depression with psychotic features." One million? Really? Why have I never heard of anyone else having an experience like mine? Few are aware that clinical depression can cause psychosis if it's severe or goes untreated for too long. Even though the complaint sounds petulant to my ears, I can't help wondering, where is my experience shown in *Gray's Anatomy* or *House*? When will common mental illnesses get the same public attention and research funding as common cancers or heart disease?

But I also avoided talking about mental illness for years. My phantom pregnancy was so confusing and shameful that I forgot about it almost entirely. I never thought of telling anyone, even when I consulted therapists and psychiatrists for relief from depression in later years. Then, just last year, I was reading something about psychosis and I discovered that fixed delusions sounded oddly familiar. I already knew where the author was going as he explained that a person can be completely convinced of a belief that is obviously wrong. The notion didn't confuse me; it made perfect sense. So much sense—I realized the reason was that I suffered from a powerful delusion when I was twenty.

I suspect one reason I forgot the episode is that I had no vocabulary for describing what happened. It went against everything I believed about the brain, the mind and the self. You are the captain of your fate, my ancestors whispered to me, you are the master of your soul. You

write your thoughts purposefully, like a hand moving a pen across a page. If you don't like your thoughts, erase them and rewrite.

With this Cartesian worldview, I couldn't frame a sentence to express the suspicion that my thoughts were not my own, that something had moved into my brain and squatted there malevolently. The personal pronouns "I" and "me" utterly failed to capture the multiplicity of voices in my head.

###

The delusion that haunted me at twenty should have made me suspicious of my convictions, including the conviction that I was in excellent mental health. But another eight years passed before I understood that I had chronic, major depression, combined with agonizing anxiety. Ironically, perhaps the most powerful delusion I ever had was the belief that my spells of intense suffering were simply bad moods.

And here we come to the strangest question psychosis raises: can we actually understand ourselves through simple self-examination? I'm relatively smart and I have some real-world evidence of it: I got a tough master's degree at Oxford and I was once a three-day champion on the quiz show *Jeopardy*. But when I go up against the illusions, delusions and denials of my own mind, do I have a chance? The image that comes to mind is a snake trying to devour its own tail.

I'm not alone in finding insight elusive. Psychosis—even a relatively simple, short-lived delusion like mine—is confusing enough that few seek help for it during the first or second episode. And those with schizophrenia, with its complex and distressing psychoses, take an average of nine years to begin medical treatment. That's how hard it is for us *Homo sapiens*—

Wise Men!—to doubt the reality behind our own thoughts. Nearly twenty years later, I still feel rattled when I consider how easily I lost my sense of reality that September.

One possible conclusion is that all mental illnesses interfere with our ability to know ourselves, though not necessarily as dramatically as psychosis. For years, my depression convinced me that sadness and despair are the average emotion and that anyone who goes around happy most of the time is lying. But now I think I was wrong. Was my acute skepticism about happiness that different from the pregnancy delusion?

Perhaps our ability to perceive reality—and to know ourselves—is itself on a spectrum. On one end of the spectrum are people with recurring psychosis. On the other end are those enlightened people who know exactly what they are doing at all times. The rest of us are somewhere on the bell curve in the middle, getting muddled up in our prejudices and worries too much of the time, and occasionally relaxing enough to see ourselves clearly. Sanity is contingent; we all have the potential to be crazy or enlightened.

###

I don't believe suffering will ever make me stronger—I can't stand that cliché of illness literature—but it has made me more compassionate. I'm less quick these days to feel superior to people with schizophrenia or mania, even though their tangled thoughts may seem to place them in a category apart.

Not long ago, when I was answering phones as a volunteer for the information helpline at the National Alliance on Mental Illness, I spoke to a man whose wife of twenty years had developed paranoid schizophrenia. Her delusions of danger led her to flee her husband and five

children for a life of homelessness on the city streets. He knew the laws on mental illness gave him no way to force her into treatment, but he'd do whatever it took to get her the best treatment if she'd just let him, he said. So how could he convince her that she's ill?

Just this morning, he told me, he was sitting by the window in the little diner he opened downtown to be close to the shelter where his wife often stays. Suddenly he saw her face pressed to the glass. She was looking inside intently—as if she wanted to see me or the kids, he said. He bolted out the door as she turned away.

"I love you, honey," he said. "Please come home."

She just looked down. She mumbled something, turned and walked away.

"Why?" he asked me. "Why doesn't she make sense?"

I wanted to tell him that love would conquer all—but I couldn't. Paranoid schizophrenia can cause very convincing delusions. His wife may never doubt her own mind long enough to seek treatment.

All I could give him was a story. I'd never told anyone about the time I had psychosis, but I found myself telling this stranger a thousand miles away. I said, the weirdest thing was how I knew it didn't quite make sense, but I couldn't make it go away. I didn't have control of my mind. No matter how much I argued with the delusion, the lie was still running the show.

His wife in there somewhere too, I thought, but the illness takes up a lot of space. It won't let her love her own family.

Yet strangely, I do have faith in the human brain. If its failures are bizarre, its successes are nevertheless spectacular. I remember that even when I was most confused, some part of myself was still "me"—at least "me" enough that I can tell this story now. If the mind is a mystery, it is surely a holy mystery, one that leaves room for grace.

"She did hear you," I said into the phone. "She knows you love her." I wasn't lying, I told myself. He needed hope and with the brain there's always hope.

Somewhere, I believe, in the brain of this woman I've never met, in a city I've never seen, the thick gray neurons have squirreled away a memory of her family's love. Her brain was the thief who robbed her of her soul, after all—her robbers' hideout is herself. Despite her assurance that the world wants to destroy her, I imagine a day when briefly the veil will lift.

She remembers her husband standing on the corner, his face surprised and raw, hurrying to speak before she turns away. She recalls his words, *I love you, please come home*, and for a moment, the radiance of reality breaks over her.

CHAPTER 5

NOTES OF A HYSTERICAL WOMAN

When you suffer a malady that doesn't exist, you have a choice: the doctors are crazy, or you are. Will you believe the empirical evidence of your senses? Or should you believe the research that says you're just fine?

I ran into these questions when I was 25, during my final six months of a master's degree at Oxford. The mysterious pain that suddenly appeared in my hands and arms behaved like a form of repetitive strain injury (RSI), a controversial diagnosis that spread rapidly in the developed world in the nineteen-eighties and nineties. But when my aches and pains started in December 1999, I had never heard of the "social epidemics" of RSI that hit Australia in the early eighties and Canada in the early nineties. I hadn't read the articles where doctors called RSI "mass hysteria" and compared it to the neurasthenia epidemic of the nineteen-twenties. I didn't know that in 1993 a British High Court judge had declared RSI "meaningless" and blamed it on the "eggshell personalities" of sufferers. I only knew that I was genuinely, suddenly debilitated by continuous pain and mysterious loss of strength from my shoulders to my fingertips.

The pain started a few days before Christmas. I woke up one morning with one of those bad head colds. Along with a fever, fatigue and a stuffy nose, I had the usual muscle aches and pains, though my right wrist was unusually sore even for a bad cold. I thought maybe I had slept with my wrist at a strange angle, tweaking the nerves. Flu alone didn't cause such a steady, sharp ache.

I was at my mom's house for Christmas. My brother and sister still had bedrooms upstairs, but because I'd been nineteen and away at college when my family moved to this house, I slept on a spare bed in the small computer room. It was five years since my family moved in,

and three since my father moved out in a final retreat from my parents' troubled marriage. My brother was away at college much of the year, and I was at grad school on the other side of the Atlantic. With only my mom and little sister living in the big house, the corners were full of cobwebs, and Christmas was more Miss Havisham than Old Fezziwig. My brother cut down one of the evergreen trees growing in the woods around the house, and we set it up in a corner of the living room, hung with Christmas lights. It leaned slightly from years of reaching toward the sun from the uneven mountainside.

Mom's state of mind was much the same as it had been when Dad left three years ago. She presented a kind of vacant good cheer most of the time, but she broke out in anger or tears at unpredictable moments. The year before, she had started sobbing suddenly in the kitchen the morning of Christmas Eve, my birthday.

Weeping, she said, "You only visit because you feel sorry for me."

I felt like she'd put her hand on my chest and shoved me hard. I hadn't said anything to make her think that, but that's how she was in those years, and how she remains: frustrated, sad, unconsciously cruel.

But when I came down with the flu a few days before Christmas, she became Florence Nightingale. Every couple hours she knocked lightly on my sick room door and came in. She smiled, put her hand on my forehead and checked for fever. I appreciated the rare gesture of tenderness.

"Are you hungry?"

She'd return in a few minutes with a tray carrying hot tea full of milk and sugar, with toast or applesauce or yogurt. She looked happier than usual; she was in her element as long as I stayed in bed sleeping.

I spent a couple days in bed, then Christmas came and I got up, took cold medicine and adopted an expression of good cheer for the holiday. The cold was soon better; most of the aches disappeared. But strangely, my wrists still hurt. Not just the right one. The left wrist had slowly grown sore, too, as I lay in bed, though it didn't hurt as much as the right. As the rest of my body recuperated, somehow my wrists grew worse and worse. I felt as if all the muscle soreness caused by the virus had migrated from my legs and back and shoulders to just two points on my body, the two nerves buried somewhere inside the thin bones of my wrists.

The ache was worse when I moved my hands, but it hurt even when I sat relaxed. I hadn't felt anything like this before. But I figured I'd be fine in a couple days, because I hadn't injured my wrists in any way. I was just recovering from a virus.

A couple days later, I flew back to England and got on a train to visit friends for New Year's. My wrists still hurt. The sun sank below the horizon in the middle of the afternoon as the train headed north toward the Scottish border. I sat on the dark train with my hands on my lap in front of me, relaxing my shoulders as much as possible; with my hands vacant, palms up, I looked like I was meditating. This was the least painful position for my wrists. My arms and shoulders had begun to hurt as well. The train was chilly and it felt like the cold had concentrated inside my wrists and was radiating outwards towards my elbows, towards my fingertips. I had bought the latest *Cosmo* at a train station news-stand but I discovered I could only read for five or ten minutes before my hands hurt too much from holding it up. As the ache and feeling of cold increased, my grip strength declined, until I had to put the magazine back in my purse.

When I reached my friends in the old cottage in Northumberland, I found the place warm and welcoming, with a fire going on the open hearth in the living room. But it was a workers cottage built a century or two before radiators and central heating. At night, we crawled up a

perilously steep and uneven staircase to the attic sleeping quarters. The bedrooms were cold, not quite cold enough to freeze water, but cold enough to send us rushing under the covers wearing as much clothing as possible.

This cold had a way of settling in my wrists, hands and arms. I woke up mornings in the cold attic with my wrists and elbows stiff and aching. I wondered if this was what arthritis felt like. I took some more ibuprofen and found the soreness wasn't too bad if I focused on other things. It was the turn of the millennium and we felt a real spirit of celebration. We partied like young people with healthy livers and an overstock of hash and booze. For a few days, the pain was vague and mild.

When I got back to Oxford a few days into the new century, however, the pain continued and grew more and more frequent, without apparent cause or explanation. My attic room in a brick terrace house on Woodstock Road was well-heated by radiators. But still when I woke up in the morning my arms and hands felt stiff and battered. I couldn't attribute the pain to the cold any longer—it had been two weeks since it cleared up. The aching had actually grown worse rather than better: it was more persistent throughout the day, more widespread—up and down both arms from fingertips to shoulder blades—and more acute. When I flexed my joints I felt like someone was stabbing into them with a knife. Sometimes I had shooting pains down my arm from the shoulder to the fingertips.

Flexing my hands to write, to tie a shoelace, or to hold a fork had become not just painful, but difficult. My grip was strangely weak. My fingers didn't want to follow orders. Everyday tasks became hard. I couldn't pick up my mug of breakfast tea with the handle between my thumb and fingers. My hand couldn't pinch the handle firmly enough; my wrist and

forearm couldn't support the weight of lifting it to my lips. Instead, I gripped the mug stiffly between two hands like a child learning to feed herself.

I stopped pushing doors open with a casual hand in front of me; instead, I pushed doors open with my shoulder, cradling my arms so I wouldn't push against them. Chopping onions for cooking took a lot of concentration and determination, because my hands had trouble pushing down on the knife; increasingly I lived on sandwiches, oatmeal and poached eggs. I brushed my teeth for as few seconds as possible, brushed my hair gingerly. Even reading a book was hard. The bowed spine of a paperback acts like a spring to push the book closed, so we unconsciously hold it open by gripping it or pressing it open on a desk. For twenty years I'd held books open without thinking about it. Now even thin paperback novels felt like heavy weights; I could barely lift them, barely force them open. A melodramatic thought crossed my mind from time to time: if this continued, I would soon lose all use of my hands.

###

I met with the college doctor with a mix of hope and cynicism. I didn't expect much from him. My college at Oxford was on the cutting edge of research in fields like Middle Eastern studies and international relations, but kept things modest when it came to food, housing and other student services. St. Antony's was paradise if you wanted to argue with other intellectuals about Israeli politics or the enlargement of the European Union over a cheap pint in the college bar, but it was a let-down if you wanted the fancy food options and gym equipment of an American university. Health services consisted of the doctor who visited the grounds for a few hours a week to dispense antibiotics and advice.

Our college doctor—I'll call him Dr. Winterbottom—had a reputation for being condescending to women. Coincidentally, he had a reputation for warmth and concern towards male patients. The contrast had sparked conflict in the student body the previous year, when the female students wanted to fire him and the male students defended him earnestly, saying we weren't giving the man a fair chance. I saw one of my friends, a phlegmatic Englishman, grow more outraged than I had ever seen him before, as he argued his support for this "excellent chap."

The word "chap" was appropriate. Living in England, first in London and then in Oxford, I rarely ran into the clichés of English life that my generation of Americans grew up seeing on "Masterpiece Theater." But whenever I talked to the doctor I had a feeling I was encountering a monument from the past. He had sandy hair, a bland, slight appearance and wore tweed, like an extra from the BBC's *All Creatures Great and Small*. His marmalade accent, pure middle-class "home counties," wasn't unusual in itself, but he spoke in a shy, hesitating way that made him seem like a visitor from the era of shillings and farthings. He even had a particularly English name that Charles Dickens would have loved to borrow for a character.

We met in the small, dim room that Dr. Winterbottom used twice a week when he visited college. His regular practice was a couple miles away; here, he made do with a desk and a couple plain chairs in an attic of the decommissioned convent that served as the chief administrative building at St. Antony's.

I sat down and told him about the flu, and my aching hands. At this point, the stiffness prevented me from bending my wrists more than a fraction of an inch in either direction. He looked uninterested as he asked me to hold out my hands. He didn't ask me to bend my wrists; didn't take interest in the fact that the joint could only bend twenty degrees instead of the normal one hundred eighty.

"I don't see anything wrong," he said, with finality.

He clearly expected me to leave. I resisted the urge to be polite and pretended not to notice. I told him about the pain again.

He sighed a little, then offered to send me to the Radcliffe Infirmary for X-rays. He didn't think they'd show anything, unless I had arthritis, which he doubted. He implied it would be a waste of time.

But the Infirmary was only a quarter-mile down the road and I didn't intend to lose the use of my hands indefinitely for a diagnosis of "nothing wrong." (I also had a tourist's curiosity to see inside the eighteenth-century Infirmary; I might not have bothered for a hospital with less history.)

When I brought the X-rays back to Dr. Winterbottom a couple days later, he had a look of "I told you so."

"No sign of arthritis," he said. "And you're too young for it anyway." He told me to take ibuprofen and then looked away from me, appearing to forget I was there.

I left his office angry, but my anger had none of the lightness and energy of righteous rage. Instead, it was tainted by the heavy worry that I might be imagining the whole thing. Maybe I wasn't the best judge of what was real or not.

###

Chronic pain is a puzzle for today's Western medicine. Since the discovery of infectious agents two centuries ago, doctors have operated on the assumption that most of our ailments have straightforward causes that they can identify and combat. Find the virus, kill it (or better

yet, inoculate against it), return to health: this battle plan works magnificently against the terrible contagious diseases of the past.

But the martial model doesn't work well for chronic diseases like diabetes and heart disease. And although pain seems to be a straightforward, distinct symptom—the body's warning call that something is wrong—it can accompany complex, chronic illnesses just as it accompanies broken legs and gunshot wounds. In an auto-immune malady like rheumatoid arthritis, pain comes from general, diffuse tissue inflammation, a reaction that is supposed to heal the body, not damage it. A reaction that presents few outward signs. All pain is invisible, in the sense that we experience it alone, inside an individual body. But in chronic disorders, not only is pain invisible, but the causes of pain—and ongoing tissue damage—may also be invisible. Without an obvious injury, the doctor only has a patient's word for it that the pain exists.

For the Dr. Winterbottoms of the world, a patient's experience is not, by itself, enough empirical evidence. Perhaps it's easier for a doctor to ignore the things he can't fix. Dr. Winterbottom usually ignored anything that smacked of complexity, particularly in female patients. During that same year, I had two female housemates who visited him for serious illnesses, only to be dismissed much like I was. The doctor told my friend with acute, daily joint pain that he couldn't offer her a diagnosis or treatment, although on a subsequent short trip home to Switzerland, her doctor there told her she had an obvious case of thyroid disease and needed medication. Another woman I knew began suffering from migraines almost every day, making studies and work nearly impossible. After she spent weeks in bed in agony, Dr. Winterbottom asked her a question that was as amusing as it was insulting: Is it possible, he suggested, that her headaches were "just in her head"?

Time hasn't changed my opinion that Dr. Winterbottom was a bad doctor, not just sexist but ill-informed about complicated, chronic maladies. But I can appreciate his frankness. He made his biases clear: women's ailments, if they were systemic and complex, were "in their heads." Other doctors have dismissed me, but never with such honesty.

Politeness stops most doctors from openly confronting patients with phrases like "just in your head." But most humans, myself included, will sometimes doubt the invisible experiences of others. If I'm sitting in a room that feels overheated and stuffy, and the person sitting next to me complains it's cold and wants to turn up the thermostat, my first response is to argue that they're wrong. I'm stifling; how can you be cold? There's something wrong with you. Put on a sweater.

In his thoughtful essay "The Pain Perplex," surgeon Atul Gawande writes of doctors, "though we want to be neutral in our feelings toward patients, we'll admit among ourselves that chronic-pain patients are a source of frustration and annoyance: presenting a malady we can neither explain nor alleviate, they shake our claims to competence and authority." Chronic pain without a cause, "we're apt to conclude, is all in the head: not a physical pain but a different, somehow less real, 'mental' pain."

What does it mean for something to be "in your head"? The phrase denies a sufferer's experience of reality. We say "it's in your head" to refuse to acknowledge another's sensations. Plenty of things in our heads are real, or at least real enough. We don't tell someone a person in love that he's wrong because love is in his head. But a disease "in your head" is negative, imaginary, a product of hysteria or an "eggshell personality," as the English judge said to the RSI patient standing before him in a highly-publicized 1993 lawsuit.

What makes it possible for doctors to deny pain? And why did I doubt myself when Dr. Winterbottom told me I was mistaken? I was smart enough to be doing Oxford's tough economic and social history program. I was tough enough to get respect from intimidating professors and brash fellow students. I was resourceful enough to have backpacked alone from Cairo to Istanbul a couple years before. And I had at this point forgotten about the fixed delusions I wrestled with at twenty. It didn't make sense to let the doctor's doubts get to me.

One reason I could doubt myself was our everyday assumptions about pain. The first attempt to theorize pain originated with Rene Descartes and despite the passing of three centuries, his model of pain remains entrenched. His ideas should sound familiar: he wrote that pain is a signal from the body to the mind, a signal of injury that travels up the nerves to the brain. The common pains of childhood follow this simple, telegraphic pattern. Ask a few four-year-olds why scraping a knee makes them cry and they'll tell you it's because they have a boo-boo. Damage causes pain. In fact, as a child, I believed that pain happened in precise proportion to the severity of an injury, which was scary since I found scraping a knee bad enough. What happened to the poor kids who broke an arm?

But we've known for decades that Descartes' explanation was wrong. A famous study during World War II discovered that many soldiers with severe injuries reported minimal pain, though civilians would have requested narcotics for similar gunshot wounds and fractured limbs; somehow this particular group of men didn't experience pain as a simple telegram to the brain. The doctor who conducted the study believed the soldiers felt relatively good because they were happy to be alive in the hospital, instead of dead or fighting on the front. A civilian with the same injuries would have to be the victim of some terrible, unexpected trauma, and the horror and shock would intensify the pain.

Evidence like this encouraged researchers to replace the Cartesian theory with gate-control theory in the nineteen-sixties. Gate-control theory argues that a "gate" in the brain determines how much of a pain signal gets through from body to mind. Gate-control theory explains why the soldiers with recently amputated limbs didn't ask for narcotics. Individual pain tolerance varies widely: we are at the mercy of our individual "gate," which decides whether or not a particular stimulus is painful.

I learned gate-control theory my freshman year of college in intro psych. It was also the theory in the textbooks Dr. Winterbottom would have read at medical school. Gate control theory explains the nuances of pain better than Cartesian theory, but it still relies on the idea that an outside stimulus—some kind of injury or sensation—is needed to trigger the original experience of pain. The doctor and I expected pain to work like a kite on a string. If we reel in enough string, we'll find the original injury. We'll fix it, and the pain will go away. Dr. Winterbottom's disbelief resulted not just from his awkwardness with women, but from his trust in an old model of pain. I wouldn't have believed me either, I thought. I was angry at Dr. Winterbottom for his lack of sympathy, but I was also angry at myself, angry at my body for coming up with this bullshit problem. There was no reason for pain, I argued with my muscles and bones, no reason. Why don't you just chill out?

I recently discovered that one of the original theorists of gate-control theory, Ronald Melzack, renounced his own theory in the late 1980s. He started to argue that pain doesn't require an initial trigger. He pointed to new research that pain is a psychological "neuromodule": a complex set of coordinated responses that play out in the brain because something switches those neurons on. These neuromodules can play loudly or quietly, accounting for differing perceptions of pain. And they can play as a result of an external injury, or without any external

stimulus at all. For the unlucky sufferer, the neuromodule gets stuck running in a loop and the experience of pain continues long after the original injury has healed—or the pain continues with no evidence of injury whatsoever.

According to this newest theory, pain is always "in the head," a series of thoughts and sensations. Usually it indicates an injury, but not invariably. Yet pain isn't "in the head" in the sense that Dr. Winterbottom meant; it isn't a sign of an overactive imagination or psychological repression. The long shadow of Freud and his popularizers has encouraged us to think that buried psychological pain—or sexual desires—causes physical ailments, which psychotherapy will resolve. But even the highly motivated Freud had relatively little success in treating "hysterical ailments," suggesting that talking isn't the cure after all. The neuromodule theory suggests an explanation: pain may start in deep, deep parts of the brain, regions remote from our conscious thoughts and memories. Perhaps we can't control our experience of pain any more than we can control our blood circulation or our startle reflex.

Take chronic back pain, for instance. Chronic back pain is a major cause of missed work days in the United States. Its incidence has been rising steadily, even among doctors, ironically. Yet X-rays show that most sufferers don't have injuries to the vertebrae. And despite no evidence of injury, the pain can be excruciating—and sometimes defies the strongest pain killers. How do you explain pain that has no external cause and doesn't respond to intervention? Frustrated doctors sometimes refer these patients to psychologists and psychiatrists, who find that their therapies don't offer much relief either. At present, Melzack's neuromodule theory comes closest to accounting for chronic pain; at least this theory acknowledges that the pain in our heads is real.

I knew nothing about the research into chronic pain back then, but I suspect my difficulties followed a similar pattern. Perhaps I had piled up small stresses for months or years. The flu over Christmas was the last, tiny straw added to the camel's back—a straw that set off the whole set of neuromodules for my arms and hands. A myriad of small straws: the stress of essay deadlines; my tendency to perfectionism (though by St. Antony's standards of achievement, I was practically a slacker); the uncertainty that I would succeed in the cutthroat fight for academic jobs; my mild permanent hangover from hanging out every night at pubs and the college "late bar" after closing time; my tendency to avoid vegetables and seek out dessert; the unaccustomed upper body exercise when I joined the college rowing team the year before; my lifelong avoidance of other forms of regular exercise; my lack of sleep from six a.m. practices on the river; my fierce way of pounding the computer keyboard; the stress of spending the Christmas of 1999 with my unhappy parents; my enormous love for friends and colleagues at Oxford—for the place itself even, its stone walls and scattered gardens and noisy undergrads—and the knowledge that I would leave them in June. A suspicion that the best era of my life was ending. A few or all of these factors may explain why the simple aches of a bad cold lingered to become a chronic problem.

But outside of pain specialists, the gate-control theory still dominates many doctors' thinking. This theory takes a dim view of aches and pains with no apparent cause—or an unproven cause. When an epidemic of RSI hit Australia in the early 1980s, some doctors concluded it was caused by the repetitive motion of typing, based on the circumstantial evidence that it afflicted computer workers. Other doctors pointed out the lack of evidence that computers caused the pain; millions of people worked at computers and a tiny fraction developed RSI. And epidemiologists made waves when they showed that RSI spread through the population in

patterns that suggested it was a form of "mass hysteria." Within a large company like Australian Telecom, the rates of diagnosis varied widely from department to department, although everyone was using keyboards roughly the same amount. Why did some keyboard workers experience disabling pain while others didn't? One well-known study concluded that the power of suggestion was at work. RSI was "contagious" because overworked clerical staff saw it—consciously or unconsciously—as a way to escape frustrations at work. The variations in work atmosphere between departments accounted for the varying rates of disability.

When I saw that Dr. Winterbottom couldn't help, I started my own research, not out of any particular belief in self-healing or patient empowerment, but simply because I was obsessed. The aching waxed and waned, but it was always there. As pain goes, it wasn't excruciating. If someone had asked me to rate it on a scale from one to ten, I would have rated it a five or six. Yet although it wasn't severe, it never stopped—and its unrelenting nature magnified my sense of torment until I felt like I was living in a permanent state of crisis. One corner of my mind was always thinking about my hands, throughout my waking hours. Even at night in bed, I felt a sense of alarm about the pain. It prodded me to stay awake. I couldn't focus on anything else.

Instead of working on my thesis on nineteenth-century Egyptian history, I turned to learning about pain: hand pain, wrist pain, arm pain. A few years earlier, the media had published a flush of articles about carpal tunnel syndrome, which gave me a phrase to start searching on. A little research brought me to the phrase "repetitive strain injury." I had almost every symptom of "RSI." I may have been a little disappointed that my pain was caused by something I'd never heard of; if it had been carpal tunnel syndrome people would have understood what I meant. But I was relieved to read to have a name for my affliction, even if it was a malady that many doctors said didn't exist.

It was the first time I'd looked to Google for health advice, and what I found was patchy, partly because of the debate over RSI as a diagnosis. Mostly I came across personal websites maintained by RSI patients. The personal websites reassured me that I wasn't imagining the pain, the weakness, even the loss of fine motor control. Others besides me were affected by this mysterious constellation of symptoms.

But my fellow sufferers did little to reassure me that I would get better. In the days before wikis and simple blogging platforms, the only people who devoted their spare time to building a website were people with compelling interest in a subject. RSI wasn't just a passing chapter in their lives, it was a life-changing diagnosis. I read of people who lost their jobs, who went on permanent disability, who could barely use their hands despite years of rest and treatment. As I read, the melodramatic thought came to me again: I wanted to be a writer, but I had focused on academic studies instead of writing. Now I would pay the price for my delay—I would never write without pain again.

No one knew the prognosis for RSI, because no one knew the cause. And no one had seen a case of RSI that started with the flu, as far as I could tell. Today, general medical websites reassuringly say that mild cases usually improve on their own. But I was looking at personal websites that talked about surgery, steroid shots and permanent disability. These writers said that they would never be completely free of RSI, even though for some the pain receded at times. And these folks had little treatment to recommend besides rest, improved work habits and a regimen of stretching the muscles involved.

I did find useful advice for how to rest, and how to work and live with RSI. I learned I could download a computer program to operate a mouse without clicking, since that tiny movement of my index finger caused shooting pain. The program would also count my

keystrokes and force me to take breaks at measured intervals before I was in too much pain. I learned that simple drugstore wrist braces would keep my hands in a neutral position at night, but that I shouldn't use them during the day because my muscles would atrophy even more than they had already. I studied illustrations of "ergonomic work stations" and convinced the college secretary to provide me with a better desk and chair than the simple ones in my room, which were designed in the days of writing by hand. I read that I should never, ever use ballpoint pens because of the pressure required; fountain pens were the only way to go.

If I could accept this new identity as a disabled person, and change my work habits, my sleep habits, even my way of holding a knife and fork—if I could do everything differently—I could perhaps reduce the pain. For a week or two, I was angry. I didn't want to change anything. I wanted a new body. I wanted to stay on target: write a master's thesis in the next couple months, graduate from Oxford, go to an elite American PhD program on a prestigious scholarship. I wasn't sure which university or which scholarship, but I had confidence in myself back then in a way I haven't since; I knew my research was good, my colleagues liked me, and my mentors were preparing me to join their ranks in academia. I didn't have time to have a body, much less a hysterical body with imaginary yet agonizing complaints.

By the end of January, my hands were dead weights hanging from my arms. It felt like a burden to carry them around. I sometimes briefly wished they would disappear. Leave me alone, I told them. Give me some relief.

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When I was four or five, I discovered something peculiar. I could sense a voice in my head talking throughout my waking hours, without pause—the sound of my own thoughts, the running narration in every human head—and here's what creeped me out: I couldn't make it shut up. Since it was My Voice, My Mind, I should be able to tell it to be quiet and it should obey me. When I told my legs to walk, they walked. When I told my voice to talk, it talked. My hands and arms and eyelids—everything was under my control.

But when I told my thoughts to stop chattering, they rebelled like unruly two-year-olds. They took my command and repeated it over and over in a continuous commentary on how they should stop, they should stop, they should stop. The louder I imagined myself shouting at them, the louder they shouted back. I was further creeped out when I realized I was perceiving two voices in my head: Me and the Other Me that was disobeying me.

I found my dad sitting in the back room of our tiny ranch house and told him my discovery. I was hopeful he would have a solution, but he just laughed and said I was noticing something important. That's how it is, he said.

"How do I stop it?" I asked.

Those were the days when I thought my dad was the embodiment of human wisdom. His careful, stentorian manner of speech magnified his ideas into Statements of Truth. This was as reassuring when I was a child as it was irritating when I was an adult.

"Some monks in Tibet say it's possible to stop it," he said. "They train for years." He told me that they meditated, focusing on their breath carefully, and sometimes, just sometimes, the voice was silent. I was very young, and he made it sound like a very difficult process. But with that conversation, I began to see the world through Buddhist eyes.

I've never seen my dad meditate, but he enjoyed reading about meditation in the same way he read Scott and Amundsen's memoirs without intending to ski to the South Pole. He was fascinated with one of the strangest metaphysical propositions of Buddhism, the doctrine of annatta, or "non-soul." The non-existence of an individual self, a self separate from everything around it. The emptiness of the thing that seems to us most real.

As I grew older, he expounded the idea to me as we drove to the hardware store and the bank on Saturday morning.

"There is no thinker behind the thought," he would say, overemphasizing every word, then pausing and whistling faintly through the gap in his front teeth. "Think about that. No thinker. People make the mistake of thinking they exist. But only their thoughts exist. And thoughts are always changing. So you can't point to one thought that is You. You're always changing. There's nothing permanent there."

Impermanence didn't shock me, since at eight or nine years old, I'd started to notice the world changes. From that point on, I tried to spot impermanence and emptiness around me. In high school and college, I tried to understand better. I owned two books on Buddhist thought, and I read them over and over. I brought them with me to Oxford despite the expense of transporting books over the Atlantic, and I turned to them now that modern medicine had nothing to offer me.

My room was in the third-floor garret of a Victorian terrace house with low sloping ceilings that made it unsuitable for taller students. The low ceilings brought the rent down; I had the square footage of a "C-class" room, but paid "D-class" rent. From my desk I could watch the busy traffic on Woodstock Road and see over the college wall to watch the comings and goings

in the quad. I sat there stiffly, propping the paperbacks open at a good reading angle that didn't strain my shoulders or neck, and reviewed Buddhism's teachings on pain.

Western medicine couldn't even tell me if I was really in pain or not. Buddhism approached the question from a different angle: it didn't matter if the pain was real or not. In fact, everything, even pain, was essentially "unreal" to the Buddha. Everything was hollowed out inside, empty of permanent essence, existing only in relationship to everything else. We were liberated from pain because pain was liberated from thing-ness.

We can be happy despite our pains, the Buddha said, if we stop being angry at the way things are. By paying attention to the present moment. By observing the impermanence of emotions and sensations. By not defining ourselves by these sensations. There is no thinker behind that thought, no feeler behind the feeling. Let pain come and go. It's just pain; it doesn't have to make you unhappy.

In the first book on Buddhism I studied as a teenager, Buddhist scholar Walpola Rahula wrote, "Being impatient or angry at suffering does not remove it. On the contrary, it adds a little more to one's troubles." I could see that my fear of disability and my worry about what was "real" was making everything worse. Ever since Dr. Winterbottom's dismissal, I found myself arguing with him in my head, "This is real, this is real." I wanted someone to acknowledge my reality. But to feel better, I suspected I would have to believe in a larger reality. It didn't take me much effort to shift to a Buddhist way of thinking that dismissed "real" and "not real" as unimportant categories. I could believe that side by side with my inflamed, sore nerves, there were nerves free of pain, just waiting for their chance at a normal life. I could believe that the pain was impermanent, with tides that rose and fell. I could encourage the pain-free cells and appreciate the moments when pain ebbed a bit.

I don't much like platitudes about positive thinking, but this wasn't be positive thinking. It was neutral thinking, quieting my negative thoughts. Rahula again: "The Buddha says that it is better for a man to take his physical body as self rather than mind, thought, or consciousness, because the former seems to be more solid than the latter, because mind, thought, or consciousness changes constantly day and night even faster than the body." I would pay attention to my aching body to distract myself from worried thoughts. I would focus on the next five minutes.

I could type for five minutes before my fingers grew too stiff and uncoordinated. A bucket is filled drop by drop, as the Buddha said. Five minutes was my drop of water. This was my new work process: five minutes at the keyboard, followed by a five-minute break to pace back and forth in my small room C-class room. Five steps toward the door, five steps back toward the window. I stretched my arms and shoulders and thought out my next sentences as I paced. Then another five minutes to type, a few more lines, and another break.

I didn't know if it was possible to write a thesis this way. But taking a Buddhist perspective had reset my mind. I stopped being angry at my body's disobedience. My mind wasn't a commanding officer; my body wasn't an enlisted soldier gone AWOL. We could perhaps be allies, not adversaries. I stopped calculating how quickly I used to work. That was someone else. Now I was this slow person who had to concentrate to hold a fork. I wouldn't ask myself to do impossible things. I would only ask my hands to type a little, slowly, five minutes at a time.

The pain was in my head and it was also in my body. But immediately after deciding to focus on the present, I felt less frustrated. I stopped bursting into tears in the kitchen while trying to chop onions (to the relief of my housemates). As I adapted to the RSI, I started feeling kindly

towards my arms and hands. I felt sorry for them. I gave my limbs pep talks and encouraged them.

These mind tricks contributed to a slow healing of my hands and arms over the next two years. As I wrote my master's thesis, I found I could type for longer and longer periods of time—ten minutes, then fifteen. In May, I submitted my thesis on time; in June, I took Oxford's intense three-hour essay exams that determined whether I graduated. The pain came and went, but it came less and less often. The next fall I went to New York for a PhD, and found American doctors more helpful than Dr. Winterbottom. In a two-minute conversation, a young female doctor diagnosed me with "nonspecific RSI"—RSI affecting several joints without clear cause—and sent me to physical therapy.

I discovered that there actually were ways to treat RSI. A therapist painfully massaged away the accumulated scar tissue that was constricting the muscles of my arms and hands. She set me to do finger and wrist exercises, bending my fingers to combat the "stickiness" in my tendons, lifting tiny weights to strengthen the muscles in my hands. She also made objective measurements to show how little strength and flexibility I had in my arms, and recorded the improvements I made. After worrying about whether the pain was real or not, I was interested to learn that the restrictions in my movement that pain caused were very real, and measurable.

A year later, my arms were pain-free except for my wrists, which ached deeply on cold days. Finally, a physical therapist noticed that I had benign ganglion cysts—"Bible bumps"—crowding the nerves in my wrists. These cysts don't appear on X-rays, but they are obvious with the naked eye, if you know what to look for; I'm not sure how doctors had failed to see them. The cysts probably contributed to my problems, so a hand surgeon removed them some three years after my initial RSI problems.

Now I can bend my wrists ninety degrees forward and ninety degrees back. A cold day is merely a cold day. Typing is merely typing. Sometimes I begin to feel aches and pains again, but I stop potential relapses quickly with stretching and rest. I'm happy to say what many RSI patients can't: I have been pain free for years.

I look at my health history and I'm surprised to see that it's a history of "hysterical" ailments, those maladies doctors have difficulty even believing, much less treating. Suffering without identifiable cause: skin that breaks down, a larynx that halts operations, a sense of reality that falters, hands that freeze on the keyboard. The Freudian approach to the mind would say they indicate something repressed inside me that seeks to get out. When I lose the ability to talk or to type, is my body protesting the difficulty of finding an audience, either in my family growing up, or in the world at large, as a writer? But the brain, I suspect, is too complex for any straightforward symbolism I'd like to assign it.

CHAPTER 6

AT MY END OF THE WORLD

I can't be the only woman who wants to destroy the world. That's what I thought to myself often that summer in Cairo. Looking out at the city from my balcony in the evenings, I wanted my gaze to light the landscape on fire and burn it utterly away.

I felt like my body was on fire already. Every nerve prickled out an alarm telling me to escape. It felt like the quick warning sensation when flesh touches the flame of a match. But escape from what? Only with the world destroyed would I have relief. Only then would I get rest—would all of us get rest. The destruction I imagined wouldn't be violent but peaceful, so peaceful. The end of the world would free me of those invisible eyes I imagined following me and criticizing. I didn't perceive this anger as an infection, chipping away at me from the inside out.

Depression is the dumbest word in the English language, dumb in every sense, both foolish and lacking in articulateness. It has a hundred different meanings, allowing us to use the word without thinking. Because some use it to refer to sadness, for years I thought depression described an emotional state. After reading a couple books about depression, I then thought it described a state of collapse that made someone catatonic, confined to bed. It took me a long time to realize that the slippery, catch-all word includes an infinite number of troubles, as varied as the millions of connections in a human brain. It took me seventeen years of my own troubles, recurring and receding like tides, to ascribe the word "depression" to them.

It was the last week my July studying Arabic in Cairo, when my friend Tony invited me out for dinner at the vegetarian place. We had gone out together a couple times back in the winter in New York, before coincidentally coming to Cairo for graduate work. Any romantic prospects fizzled out because he was obsessed with protesting the invasion of Iraq and I could

only stand to go to one march per week, but I still enjoyed his conversation. It was exhausting to think of the ten-minute walk to the restaurant—everything made me tired back then—but I forced myself to go, to keep up the facade of a normal life.

The restaurant was dimly lit and air-conditioned. The relief of entering from the bright, hot street reminded me of what I thought enjoyment might feel like. I couldn't quite remember. Tony and I ordered food and I paid close attention to acting normally: hold knife and fork, sip bottled water between each sip of Egyptian wine, make eye contact and nod, say something witty or at least not stupid.

It was easier with Tony than with many. He was reserved and talked at a slow, thoughtful pace. Unlike most of my friends studying the Middle East, he was visiting the region for the first time. I didn't have to pretend to be an expert, as I felt I had to when I was with my fellow PhD students. He listened with interest to my stories of moving to Yemen three days after college graduation and backpacking from Cairo to Istanbul when I was 22. Perhaps I liked his company because he admired me, but his admiration also made me uncomfortable. I didn't find myself admirable at all.

Halfway through dinner, Tony surprised me with the kind of direct question that broke all the rules of genteel conversation I was raised on.

"How are you really doing? You don't seem to be yourself this summer."

I was shocked. He was sincerely concerned. But though I could identify the tone in his voice—yes, that was something called sympathy—I didn't believe it. It was a special effect, which made for a good story but wouldn't hold up beyond the movie screen.

You don't seem to be yourself. Suddenly I saw myself through his eyes: two of me, one happy and capable, the other angry and disintegrating. My capable self was a stranger. She sat

beyond the invisible wall that separated me from the world that summer, with Tony and everyone else, watching me across the table, waiting for my answer with a patient, earnest expression.

I hated patience and earnestness.

"I'm fine. I'm just tired," I said. "That's all."

I couldn't keep the bone-weariness out of my voice, but I had to keep my despair a secret. I couldn't brush Tony off completely, however. I was in a bad mood that summer, it was obvious. I was afraid he wouldn't buy it.

I'm just tired. That's all. I elaborated. The summer classes are over in a couple days, I told him, and then I just need to get some rest. I haven't slept well all summer. I had that case of the flu when I left New York and then I started classes a couple days after getting here, so I haven't had a chance to relax in a long time. I suspect I spoke somewhat sharply and defensively.

Tony, bless him, looked unconvinced but politely accepted my answer. He said something encouraging—I'm here for you, I hope you'll feel better soon—and changed the topic. I returned to the numb ritual of acting human. Raise fork, lower fork, chew, nod, speak.

When dinner was over, I was too tired to carry on. Normally I would have wanted to go out for another drink or two at one of the small pubs dotting the neighborhood. I lived in one of Cairo's wealthier districts, Zamalek, which sits on an island in the Nile—a collection of nineteenth-century villas and Nasser-era apartments, past their prime but spacious and comfortable. By the time I lived there in the early twenty-first century, it was noisy and polluted, but it was still quieter and cleaner than most of Cairo.

I wanted to like living here. I told myself that I did. Zamalek's streets were lined with mango trees that sometimes dropped their ripe fruit smack onto the street as you walked by. In

the early mornings you could hear the junk-man pedaling down Marashly Street on his bicycle looking for cast-offs with a hoarse cry heard from every junk-peddler in Cairo since the colonial era: "*Robbivaaa-kya! Robbivaaa-kya!*"—Italian for "Old clothes! Old clothes!"—an echo of the city's cosmopolitan, Mediterranean past. The cafes and bars were European-style, and welcomed women as well as men. The exchange rate for U.S. dollars was good, so I could afford to eat out and go to bars and take taxis to and from the American University on Tahrir Square. I could live the urban lifestyle that was out of my reach when I was living on a tiny stipend in southern Brooklyn and commuting two hours a day back and forth to New York University.

I was well-prepared for Cairo. I had already studied Arabic for years, including more than a year in the Middle East, and I had adjusted to the unfamiliar pronunciation and vocabulary of the Egyptian dialect. I passed the tricky admissions exam for Cairo's advanced Arabic program, and I had the best luck of my life getting funding for my studies that year. I planned to spend a couple years in Cairo for language study and PhD research, on a path well-trodden for me by friends and colleagues. The year was 2003 and, sadly, funding was good for those of us who started studying the Middle East before 9/11, back when the field was a curiosity. Viewed objectively, the odds were good that once I got my PhD I would snag a tenure-track teaching job where I could spend the rest of my life learning stuff and getting paid for it. I was supposedly in the early stages of a successful career.

To top off what should have been my good luck, many of my friends from N.Y.U. were in Cairo that year for research or study. I didn't even have to look for a place to live because with one email I was able to arrange to rent a room in a friend's apartment.

So when I left Tony at the corner to trudge home in the evening heat, I wasn't brooding about Cairo so much as about this invisible, heavy weight pressing down on my shoulders.

I felt the weight as a physical force that made it hard to stand and hard to walk. It was like visiting a foreign planet where the gravity is twice that of earth—my body seemed to weigh double. I had to fight for every step. And every step left its mark on me in fatigue. Inside and outside, up and down the length of my spine and skin, each nerve cell spoke of pain—not quite physical pain, but not imaginary pain either, something like the shock of a static charge.

I couldn't say when the problem began. In the spring in New York? When I arrived in Cairo in early June? All I knew was that it started imperceptibly, but slowly grew heavier.

Sometimes it was so heavy I had to sit down to rest. At the university on Tahrir Square where I spent the first half of every day, the two-minute walk from my classroom to the exit gate began to seem too far. Fifty steps down the hallway, another twenty down the marble staircase, fifty to cross the hot courtyard in the shade of the spreading mangrove tree. The dusty rattan chairs in the courtyard made a good place for students to socialize, but when I pulled up a chair and sat with my colleagues, it was in order to rest myself before the next 150 steps that would take me to the street, and a taxi home.

Rest wasn't the same as relief. Sitting was only slightly better than standing upright. The pressure pushing me towards the earth continued to bear down. I wanted to slide from my chair and sprawl motionless across the paving stones. Thinking about the next leg of the journey took up half my brain. I could only hear scraps of the conversations around me: someone had a theory about Mubarak's succession, someone was taking the bus to Palestine next week for non-violent protest, someone was telling a story about an earlier, pre-academia life as a professional chef or a soldier or an exotic dancer, someone was proposing to name the courtyard's feral, one-eyed kitten "Al-Jahiz," the "cross-eyed one," after the famous wall-eyed Islamic writer of the Middle Ages.

Nothing could interest me at that moment. I hated current events, I hated non-violent protest, I hated funny anecdotes, I hated the Arabic language and Islamic civilization, and I almost, but not quite, hated stray kittens.

It was easy to tell myself I was "just tired," because it's true I was working hard. We all were. The advanced program required four hours of class per day, followed by infinite amounts of homework. The course was well-known for grinding down even the strongest scholars. Even if I devoted eight hours a day to homework, it was impossible to finish all the readings, vocabulary, compositions, listening exercises and drills in colloquial pronunciation. Since no amount of work would complete the job, the work felt increasingly futile. I could force myself to do four hours of homework, if I took a long afternoon nap first, and then coaxed myself along with chocolate bars. But that was too little, and I was falling behind.

Years later, I can see that it wasn't just the workload giving me trouble. My brain was actually slowing down under that grinding sense of weight pressing down. I couldn't do things I used to do and I struggled to keep up with classmates who I had studied with for years in New York. I wasn't their equal now; I was the dumb kid in class.

Madame 'Azza, the rosy-cheeked professor who was reputed to have never said an unkind word, lost all patience with my new stupidity. One weekend, I spent hours reading and re-reading the short story she assigned. I had read stories in Arabic before, even a novel, and understood well enough, with a child's level of comprehension. But this time, the text was a closed door, as if I had traveled back a decade, to my first semester of Arabic. Holding the photocopied story in my hands, I could still coax sounds out of the letters, but I couldn't find any meaning in the sounds. Sentence after sentence yielded nothing familiar beyond the simplest

words: of, with, for, and. Finally, I saw a verb I knew, then a noun, and I felt hopeful. But in the next sentence, again I knew nothing.

Looking up unfamiliar words in Arabic was an ordeal until recently. (New dictionaries and computer apps make it easier now.) You could easily spend ten minutes surfing back and forth between the green covers of the canonical Arabic-English dictionary to find one single word. I had to be strategic. I couldn't look up every unfamiliar word, so I gambled. But I chose the wrong words to research, because after a couple hours with the dictionary, I still didn't know what the story was about, or where it was set. Even the title puzzled me. I gave up and worked on something less futile instead.

The next day in class, we arranged our desks in a circle in the plain white classroom. 'Azza opened discussion by looking at me.

"Start us off, Yasmeen. What happens in the story?"

I felt ill. Madame already believed I was lazy, I was sure. The silence in the unadorned room was more silent than usual.

I apologized. "I had trouble," I said.

'Azza spoke with a slow, sarcastic imitation of patience. Surely, she said, I could tell the class something.

Looking down at the desk in front of me, I couldn't think of anything to say.

"I read it a couple times. But *mish fahma wala haaga*." I couldn't understand anything.

A long, hostile silence followed. My classmates held still with embarrassment.

Finally, she spoke. "Well, since Yasmeen didn't bother to do any homework, there's no point asking her anything."

As she turned away, I knew the only way to avoid more humiliation would be the destruction of the world. The dissolution of all matter in the furnace of an expanding sun might burn away 'Azza's scorn.

My intellect was failing me, for the first time in a life on the honor roll. But I perceived it differently: I thought the world was growing more difficult around me—growing more difficult for everyone. We were on a continent sinking under rising waters. People asked too much of us. Too much homework. Too much knowledge. Doesn't everyone hate this as much as I do?

Maybe the heat made thinking harder, I thought. I wasn't sure what the temperature was, because I didn't look at weather forecasts. There was no need. Summer in Cairo doesn't bring the possibility of thunderstorms, or cold fronts, or any variation in weather. Rain falls once or twice a year in Cairo, always in the winter. The summer is reliably sunny and hot: daytime temperatures in the high nineties and low one hundreds, mixed with the humid breath of the trees and fields that grow in the narrow habitable zone along the Nile.

My roommates and I lived in an apartment without air conditioning, which kept the rent affordable despite our having the best balcony in Cairo, a hundred-foot-long terrace that curved around the entire eighth floor. To stay cool, we closed the windows and shutters during the day, keeping the sun out. We spent the afternoons napping in front of electric fans in the dark, stuffy apartment, or studying in the posh local cafes that could afford air-conditioning. We came back to the apartment after dark, when we could open the shutters and windows and let a cooling breeze from the desert blow through.

The trick to living with the heat was to slow down. Walk with a dignified saunter. Brace yourself if you have to take a taxi—sit utterly still and surrender to discomfort, since the little black Ladas and Peugeots don't have air-conditioning. If the day grows hotter, slow down more.

Measure your steps, even in the shade, even indoors. Perhaps my brain was adopting the slowness policy, too.

I was annoyed about my conversation with Tony at dinner. I didn't want to go home, but neither did I want to do anything else instead. I thought about ice cream. I had no appetite that summer—I had lost five pounds in the five weeks since I arrived from New York—but sweets still appealed to me from habit. They didn't actually bring me pleasure, but I could remember that I once enjoyed them. When my stomach was growling but the effort of chewing seemed repulsive, I could usually get myself to eat a small Cadbury bar from the import grocery store. Now, I thought, if I took fifty extra steps, I could stop at the fancy ice cream place on the way home.

I ordered paper dish with a large serving of two separate flavors: something with chocolate, and something with blackberries. The two flavors that didn't go together at all, but that's how much I had given up on life.

The apartment on Marashly Street was empty. My roommates had gone to a beach in the Sinai for a few days. I was relieved that my class schedule prevented me from going with them. Travel was effort. But without them the apartment was too quiet.

The sun was setting. I unfolded the French doors to the balcony and propped the shutters open to let in the faint evening breeze. I sat in a dusty rattan chair and ate my half-melted ice cream with its clashing flavors and wished I could destroy everything I saw in the red sunlight: the decaying villa across the street with its roof-top chickens and plaster angels, the apartment buildings opposite hung higgledy-piggledy with satellite dishes and loose wiring, the church tower down the block with its melodious bells, the olive drab of palm tree fronds covered in Sahara dust, the neon brilliance of the Pepsi billboard across the river in Doqqi, shining almost as

brightly as the red sun sinking toward the dusty horizon next to it. Somewhere out of sight beyond the Pepsi billboard were the pyramids. The red sun was sinking toward the Pepsi billboard and the land of the dead, and I could note every detail but I couldn't enjoy any of it. I couldn't even enjoy crafting sentences about it in my head, which sometimes distracted and comforted me. I wanted the world gone.

Not yourself this summer. I was furious. Of course I wasn't myself. But how dare someone ask me about it? Since I was eleven years old, I had had one central goal in life: don't get depressed. I defined depression by the effects it began to have on my mother's life that year: the long silences, the tears, the temper, the inability to plan or make statements about the future. Also, although it was unfair of me, I associated her ensuing years of depression with a failure of will or character. It was hard to think of it any other way. No one talked about depression much in the days before Prozac. So-called "atypical" clinical depression like hers was of little interest to doctors, since it couldn't easily be treated until the invention of new drugs in the late '80s. I could see that in her own mind, my mother felt some outside force was preventing her from acting, but it was hard to believe that something external could change someone so much.

Don't get depressed. Or perhaps I should say, don't appear depressed. I conflated reality with appearances, somewhat naively. I believed that if I could appear happy, I wouldn't be depressed. The popular precepts of positive thinking say as much, don't they? In high school, I made my personal motto, "Life is wonderful," and scribbled the phrase in the margins of my notebooks like other girls wrote the names of boys they liked. I did well in college, and traveled, and met interesting people and spoke to them in foreign languages. I clung to these successes as evidence that I was happy, despite the ache that sometimes hinted at something else. Evidence that I was nothing like my mother.

I hated Tony for asking. I hated him because I knew that, with a forced smile and a sip of wine, I said the same words I heard my mother say over and over for a decade: "I'm fine. I'm just tired. That's all." I hated him for making me repeat my mother's words.

I hated him, too, because I recognized the unfairness of hating him. I recalled the sympathy in his voice. He commiserated without condescension, and his concern was genuine and well-meant.

And I wanted more than anything in the world to be a person no one worried about, a person no one could ever suspect of weakness. Or so I thought until dinner that night. Now I was troubled, and I began to cry while I ate my ice cream. I wanted something else even more than to be strong—I wanted to tell the truth. I hated the prickling in my skin when I said I'm fine. As soon as I said it, I realized it was a lie, and it struck me as the worst kind of deliberate lie, a lie about whatever strange thing was happening to me every moment of the day, the thing that was at the center of my identity that summer.

But if it was a lie, then I wasn't fine, and I wasn't just tired. A good night's sleep wouldn't fix anything. If this feeling of dread wasn't simply collateral damage of fighting to avoid depression, then it was depression itself. And if this was depression, then it followed that the other dark times in my life were depression too. In junior high, in high school, in college, in the working world and in graduate school—oh, I had carried this weight before, though it was heavier now and more dreadful. In the past, it was episodic, but each new episode was longer and more severe. The remission periods were getting shorter. Sitting alone on the balcony it was suddenly clear to me that if I continued to feel like this, the day would come when I would want to die—not soon, but at some point in the future, months, perhaps, or more, but it was the clear end-point of the war inside me. I keep living because of sheer grit, I thought, because I want to

see how long I can keep going despite the meaningless of the universe. But I had a limited supply of grit, and I used some every day. I felt no hope for the future to be better than the present, and without any hope, my grit was eroding away. With this realization, the balcony struck me as a dangerous place, as if my body might—in spite of myself—make a leap for relief at any moment.

Only a half-hour had passed since I left the restaurant, but my life story had rearranged itself completely in my mind while I cried and ate ice cream. I was no longer the person who left behind her sad family for a happy life. I was the person infected with sadness, dragged down by her family history. I was a victim.

Worse than the pain of depression was the agony of having been wrong about myself. How could I have misunderstood myself so badly? How did I become the person who forces a dismissive smile and says, "I'm fine"? The only thing I knew for sure was that I had been wrong about many things.

More than ten years later, it's still painful to remember that summer—the sense of doom, the weight pressing down on me, and above all the conviction that grew on me that evening that I had failed at my life's mission. But the passage of years also allows me to look back and see that my perspective shift that night may have saved my life. I changed course—if this was depression, I would fight it with the appropriate weapons. I had already spent a couple years in therapy in New York, so I would have to turn to something I had always disdained—medication. Within two weeks I had an elite Egyptian psychiatrist and I was taking the pills he prescribed. A few days later the sense of despair had begun to fade away into a strange memory. I have had friends who were not as lucky, who didn't recognize hopelessness or its dangers early enough to

escape—and I have a tiny chink of insight into their suicides—just enough to be grateful that I swerved and avoided what had seemed like an inevitable end-point.

If this sounds like my life turned around easily, the fact is it didn't. I was worn down and couldn't shake a feeling of failure. I eventually dropped out of my PhD program, and groped my way towards other fields, unsure of my future.

But there was something miraculous and strange about that moment when my self-perception changed. There is a painting by surrealist Rob Gonsalves that I can't stop thinking about. A massive gray aqueduct stretches across a blue ocean, framing the puffy white clouds of summer in its arches. As the aqueduct seems to curve closer to the viewer, reaching across the canvas, it grows larger and the archways of white clouds grow larger, too, and the viewer can see something else now. The shape that looked like a cloud glimpsed through an arch is, in fact, the profile of a three-masted schooner heading downwind with full sails set. The slate gray aqueduct we saw outlined against the sky is actually the blue-gray sky in the distance, the backdrop for this parade of tall ships. As with all good optical illusions, it's impossible to say where one image begins and ends. Look to the left and it's clearly a painting of an aqueduct; to the right, sailing ships. Look at the middle, and you have the prickly sensation of a good mystery, something that can't be solved no matter how you look at it. In optical illusions, there's no gray area between black and white. The visual cortex can only perceive one image at a time.

We humans live in the gray areas, so I've always thought. The story of a life can't be reduced to a simple narrative—victim or not-victim, ill or not-ill. But only the smartest parts of my brain love ambiguity. Other parts of my brain want things simpler—and some parts can only perceive simple things to begin with. The narrative I told myself in words was nuanced. It encompassed every subtle emotion, my moments as a victim and moments of take-charge cage-

rattling. But the narrative I told myself in blood and bone was made of bold strokes and absolutes. Something primitive inside was telling me it's either/or. Are you a victim or not? Perhaps the endocrine system writes its stories with hormones: stress hormones for the weak, joy juice and confidence for the strong. Maybe the most important stories are the ones we experience in our cells, maybe without even knowing it.

Neither story I told myself was really the truth: I wasn't a warrior outwitting depression or a victim with a life of suffering behind me. The truth is much more complicated. In many episodes of depression since the age of eleven, my life story has been closely interwoven with the thoughts and feelings of depression. The fact that clinical depression is a malfunction, a disorder, a failure of the body's delicate homeostasis, does not change the fact that it takes up residence at the heart of our self-regard and self-perception. It's an ongoing project for me to learn, like an aikido master using an opponent's momentum, how to defend myself against despair without silencing my own thoughts if they should turn to despair.

I remember my thoughts and feelings that summer so clearly. I want to say I am an entirely different person today than I was then. I'm better at forgiving my weaknesses and those of others. I understand my mother better. I can perceive that we're all victims sometimes and that our influence on the world is never as large as we would like—and this realization doesn't destroy the pleasures of life. But just because I have a more accurate view of myself these days doesn't mean it's an easier view. I don't feel liberated by a psychiatric narrative. I'm less sure of myself than I was a decade ago, more fragile. I'm readier to go home and take a nap when times get tough. I miss the confidence I had when I was convinced of my self-deception, when I lived happily with the lie that I wasn't depressed, when I was alone with my own ego looking down on the world.

CHAPTER 7

THE MEASUREMENT OF PAIN

I wouldn't have called 911 if it wasn't an emergency. It was two hours after midnight on a Saturday night when two EMTs arrived in an ambulance. I opened the door to them like a sleepwalker before sinking down again on the edge of the bed. A moment later an EMT was taking my blood pressure. Then I was slumping over and lying down. If I hadn't been in pain, I would have been sleepy. But lying down was the next best thing.

"C'mon. Get up." The EMT was loud and bossy. "Let's go."

I rose again, slowly, and walked out to the ambulance in pink flip-flops. Most of my brain was focused on pain, absorbing it, feeling it. I was barely aware of my surroundings: the painful brightness inside the ambulance, the smooth, very young face of the EMT making notes on a clipboard. The bright lights made the pain in my back and chest even worse. I squinched my eyes shut. I'd never been in an ambulance before.

The EMT asked questions that I found hard to take seriously. I'd never experienced pain like this and I felt like it should be obvious to everyone around me, obvious that something was horrendously wrong. But I interrupted my shallow breathing to answer each question with a couple words. Age, 37; allergies, penicillin.

"On a scale from one to ten, how bad is your pain?"

This was a new one. In the decade since I had lived with chronic pain, the medical profession had evolved; they had begun to take a patient's experience seriously. The pain rating was now a standard part of the routine. But I wasn't sure how to answer. The question was idiotic. I was in enough pain to call 911 at two in the fucking morning. You figure it out, I wanted to say.

I don't remember what number I told him, but I would hear the question dozens more times in the next two weeks, as doctors diagnosed and misdiagnosed my abdominal pain, as nurses handed me tablets and injected me with intravenous opioids. From the beginning, the question puzzled and irritated me——what was the right answer? We're trapped in these separate bodies; we can't feel another's pain. How am I supposed to come up with an objective rating if I only have my own experience as a reference point?

The question isn't academic. I made three emergency room visits before finding a doctor who took my ailment seriously enough to diagnose me. Although I felt like everyone kept asking me to rate my pain, most of the doctors I met were as uninterested in the answer as if they had been Dr. Winterbottom at Oxford. During the eight and a half days between my first and third trip to the ER, my health rapidly worsened. A simple pain, which turned out to be gallstones, became a complicated one—a ruptured gallbladder poisoning my whole body. Recovering from emergency surgery and five days in the hospital on intravenous antibiotics, I wondered whether I could have done anything differently. With a diagnosis a week earlier, I might have gotten away with a simple outpatient surgery. But the doctors I saw on my first two ER visits failed to diagnose a common ailment. Gallstones aren't even unusual in my demographic, though for some reason the word calls to my mind elderly men with gouty legs. One doctor told me gallstones are the first thing she looks for when an overweight white woman in her thirties or forties comes to the emergency room. So why did not just one, but two, emergency room physicians, one two separate occasions, dismiss me? In the days after I first left the hospital, I wondered if I had been too stoic in the ER. If I had complained more, perhaps the doctors would have taken me seriously. The question about pain ratings was new to me——what did they do with the answer? Did I give the wrong answer when I rated my pain?

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My little sister—a newly-minted family practice doctor—says there's no right or wrong answer. Doctors don't use a patient's pain rating to make a diagnosis. If you have acute stomach pain, for instance, it doesn't matter whether you rate your pain a seven or an eight—the doctor still has to figure out if it's indigestion or appendicitis. The sheer quantity of pain means relatively little. "The rating's just for coding purposes," she says, referring to the complex system of medical coding that turns patient records into abstract letters and numbers for insurance company bureaucracies. From the doctor's point of view, the measurement of pain provides just another data point needed to get reimbursement from insurers.

But from a broader perspective, the pain rating isn't mere clutter on the charts. Only recently has the medical profession come to describe pain as the "fifth vital sign," joining the four standard vital signs used for decades—body temperature, heart rate, breathing rate and blood pressure. Although the measurement of pain is subjective and can't be measured with a machine like the other vital signs, doctors are finding evidence that it plays a role in treatment. Since the nineties, an entirely new medical specialty has developed to focus on pain and its alleviation: palliative medicine. Because hospice patients often call on palliative medicine specialists, I associate the term with cancer, but in practice, palliative medicine is important for an array of conditions. Recent research shows that pain by itself is dangerous, apart from the malady that causes it. Patients in pain heal more slowly than those with effective painkillers. Pain slows people down and keeps them lying in bed where they increase their risk of fatal blood clots. It also prevents us from breathing deeply, which increases the risk of pneumonia in the

vulnerable. Elderly hospital patients are particularly at risk. Proper pain management can make the difference for them between leaving the hospital healthy and moving back home, or leaving debilitated and moving into a nursing facility.

In the nineteen-nineties, medical experts grew concerned about evidence that doctors were treating patients' pain inadequately. They lobbied for a 2001 federal law that requires doctors and nurses to record pain levels as carefully as they record body temperature and pulse rate. The question, "'How do you rate your pain?'" was instantly ubiquitous. But the federal law couldn't force doctors to listen to the answer.

The federal law also didn't specify a universal system for rating pain. A few different methods exist. The method I encountered in the ambulance and hospitals in Washington, DC, was the Numeric Rating Scale (NRS), which asks the patient to rate the pain on a scale from zero to ten, where zero is the absence of pain and ten is "worst possible pain" or "severe pain"—the worst pain you can imagine. Another system is the Visual Analog Scale (VAS), in which patients are shown a visual chart of a continuous line between two end-points and asked to point to the spot where their pain falls in the continuum between no pain and severe pain. The last common method—used with children and the mentally disabled—is to show patients a series of eleven smiley faces that correspond to numerical values and ask them to pick. At zero, he wears a big smile, but at two, his smile wobbles, and at four, his lips are pressed straight across in a line. At six, his brow contracts and his lips turn down at the corners. At eight, his eyes are half-closed and he wears a deep frown. Finally, at ten, tears stream down his cheeks. I try to imagine what it would be like to look like that. I wonder, is there a point where pain triggers a crying reflex? When I was a kid, I cried if I bloodied my knees falling off of my bicycle, but I don't think that counts as "ten pain." In fact, no matter how much pain I might experience at a given moment, I

can always imagine more. "Ten pain" is a theoretical concept that I'll never experience, by definition, like infinity or forever. Poor little smiley face—he's forever frozen on the Wong-Baker FACES Pain Rating Scale as the symbol of the most terrible pain any of us can imagine. And we're a very imaginative species.

###

My sister says I'm over-thinking it. This is why she's a good doctor. She's focused on concrete, immediate things, and "ten pain" is meant to be concrete, not abstract and infinite. Maybe I've already experienced "ten pain," during my ER visits. When I called the ambulance, I couldn't think of anything to compare with this sudden, overwhelming pain. Earlier in the evening I'd felt fine. Over the short course of a couple hours, my body had grown uncomfortable, started to hurt, and entered into a full-out crisis. My lower back was in the grip of a kneading, grinding, restless pain, as intense as a muscle cramp, but spread out over a wide area. I felt like an entire elephant was standing on my lower back, crushing me slowly. No position sitting or standing provided relief. Lying still seemed to intensify the ache somewhat, so I tossed and turned back and forth in bed, moving every few seconds when the pain became unbearable again. The pain continued to grow, accompanied by chills and nausea. My abdomen and chest began to hurt as well. I found I couldn't stand upright. I couldn't take a full breath. I was acutely aware of my lower ribs—they seemed to press tightly against my skin and to weight down on my lungs and other organs.

The tricks I can usually use to distract myself didn't work. I tried to count my breaths, a Buddhist meditation tool. But although I was only aiming to count to four—exhale, inhale, exhale, inhale—I couldn't draw my mind away from the pain long enough to get to four.

"One, two," I thought to myself, then felt mentally exhausted. I couldn't remember what came next, so I started again.

"One, two..." I lost it again. One, two, was as high as I could go.

The fact that I couldn't count to four spurred me to call 911. It was objective evidence that I was unwell. Even though I have perfect blood pressure and no one in my family has heart disease, I wondered if I was having a heart attack.

Within minutes of arriving at the ER, I had to answer the tricky pain question again. I can't remember whether it was a doctor or a nurse who asked, but I remember the particular phrasing.

"What's your pain on a scale of one to ten, if one is a hangnail and ten is the most pain you can imagine?"

Even though I couldn't count to four, I could easily imagine more pain. It would definitely be worse if I actually had an elephant standing on me, so ten was out. I had all my limbs and I wasn't bleeding, so nine, I thought, would sound melodramatic. I tried to pick a number that would convey the seriousness of the situation but didn't sound too whiney. "Seven or eight," I said.

Two hours later, after subduing the pain with a couple tablets of Vicodin and a shot of intravenous morphine, the doctor dismissed me.

"Your heart's good, your lungs are good, your kidneys are good," he said, handing me a prescription for Vicodin. "You've got a back strain and a virus."

I took a cab home just before dawn, slept until three in the afternoon, and woke up feeling okay, as if I'd imagined the whole episode. I felt relieved and a little embarrassed. I couldn't believe I'd called an ambulance for a back strain and a minor virus. I'd never had a back strain before, but I imagined it could be painful. And now it didn't even hurt. The whole thing was a mistake. I didn't want to tell anyone.

Such is the social, contingent nature of pain: when the doctor said I wasn't sick, I thought maybe I'd exaggerated my pain. Perhaps it wasn't "seven-eight." I overrated it because it was the middle of the night and I was tired.

Part of me knew that I wasn't mistaken. It had been the kind of pain Descartes meant when he compared pain to the ringing of an alarm bell—pain that signals an injury. A wiser person might have asked the doctor more questions. But when it was an hour before dawn after a sleepless night, and I was wearing a hospital gown, and the pain and worry had subsided under an injection of morphine, I just felt relief. I wanted to go home. And the habitual beliefs acquired during previous illnesses took over: the habit of assuming doctors don't care, the habit of taking care of myself, the habit of thinking my body doesn't work like anyone else's, since I get those weird, hysterical problems that no one else gets.

It crossed my mind that the severe pain that suddenly appears in the night might be a new variation on an old theme of "ways my body mysteriously fails me." Very briefly, I wondered if I was due for a strange, psychosomatic pain because it was the fourth anniversary of the death of a close friend. In my experience, there's never a simple explanation for illness. Even the far-fetched seemed remotely possible. It was just a back strain and a virus, and some other source of stress had made the pain feel deceptively intense.

A week later, when the same pain recurred, suddenly, again late on a Saturday night, I followed doctors' orders. I treated my "back sprain" with a double dose of Vicodin.

The Vicodin had no effect on the pain, but I took a tiny bit of comfort from the doctor's remark that everything checked out. This was phantom pain, without injury or origin. My job was to endure. I fell asleep shivering around dawn.

###

The next day, I called my sister the medical resident, who lives on the other side of the continent. I hadn't told her about my trip to the ER the week before, because I was embarrassed about mistaking a back strain for impending death. Although it was midday, I woke her up just as she was falling asleep at the end of a 44-hour hospital shift. We didn't talk long, so she could go back to sleep, but in less than a minute, she had a good idea what was wrong. She told me to go to an ER, because a hospital could do the tests I needed.

I felt weak. Could I wait till tomorrow and go to a regular doctor, I asked?

I could sense her weighing the odds when she answered in a deliberative, doctor's voice. "It's not life-threatening right now, but you want to get it looked at quickly," she said, before going back to sleep.

The pain had diminished since the nighttime, but everything felt sore and uncomfortable. I felt feverish. I asked a friend for a ride to the hospital, and I described my "seven-eight pain" again, to a new doctor.

"I don't think it's back pain," I said. "The Vicodin didn't have any effect."

The doctor ordered an X-ray of my spine. The nurse who accompanied him took several vials of blood from my arm; the doctor didn't ask for it yet, she said, but he'll probably want to do a blood count—the most basic way to determine if the body is fighting an infection.

He didn't ask for a blood count, though. He glanced at the X-rays, told me I had a strained muscle in my back, and gave me another shot of intravenous narcotics and a prescription for painkillers—Percocet, this time. I almost felt normal with the narcotics. But I didn't feel strong enough to argue with the doctor. He hadn't looked up from the clipboard once, hadn't seen my face. His manner didn't invite discussion.

When I told my sister, her remarks were unprintable—then, she told me to see more doctors. The next day, I was feverish and my heart was beating twice as fast as usual. I hadn't felt hungry since the pain started. The pain had begun to grow again, but it wasn't the grinding feeling of before. Instead, my internal organs were sore and aching deep inside. They were pool balls, banging into each other and rattling around painfully at jolts in the road on the drive to the hospital. I couldn't stand up straight; my abdomen wasn't big enough for all these pool balls. Their weight pulled me down. I walked very carefully to keep them from bumping each other.

For this third ER visit, I went to another hospital, in a wealthier part of town, where I hoped the doctors would have more time to consider me. I was right. The doctor there looked at my face as we talked, which shouldn't be remarkable, but was. Like my sister, he had a good idea what was wrong after listening to a few of my symptoms. I soon had IV lines in both arms delivering antibiotics and painkillers, and I was admitted for emergency surgery to remove my gallbladder, an organ I'd never thought about once until it failed. But failed it had. The acute agony two weekends in a row wasn't back pain, it was gallstones, and the second attack had

stopped blood from circulating to the nonessential (but useful) little cog in the digestive machine. It was dead now, or dying, and infected. I felt lousy because my insides were rotting.

The laconic surgeon who operated the next day said he was surprised by "how bad things were in there." He dispatched me to intensive care for a night. The pathology report was a tale by Edgar Allen Poe, describing my underappreciated gallbladder as ruptured, hemorrhagic and gangrenous. But I was finally in the hands of good doctors—or I was so sick that doctors couldn't ignore me any longer. After three days of intravenous antibiotics, I woke suddenly in the night feeling the texture of the sheets and the chill of hospital air, and realized the fever was gone.

A simple case of gallstones shouldn't have turned into an epic. But the first two ER doctors didn't pick up on obvious symptoms. It's possible, I thought, that they don't take "seven-eight pain" seriously. If I had said "ten pain" they would have treated me seriously from the beginning. Perhaps some secret doctor playbook says only "ten pain" deserves an expensive abdominal CT scan.

But my sister denies that pain ratings play a role in diagnosis.

"It doesn't matter what number you said," she says. "Those guys were just incompetent." I can't stand to think that mere incompetence explains it. I don't want my destiny to be in the hands of such flimsy fates. I want to know how I can do things better next time. My sister diagnosed me accurately after a two-minute long-distance phone call. Why couldn't the men sitting in front of me?

Although my sister says doctors don't use pain ratings in diagnosis—and research in medical journals warns that pain is too subjective to play a role in diagnosis—still, I wonder. My sister was able to diagnose me without asking me to rate my pain on a scale from one to ten, and

without knowing my other four vital signs either. But she does know that I wouldn't hit her up for medical advice unless it was urgent and that I don't use the word "pain" lightly. She listened to me as a sister, not as a doctor. She took me seriously.

A doctor who mistakes gallstones for a back strain isn't taking me seriously and doesn't understand what I mean when I use the word "pain." He's failed to understand that pain by itself isn't enough bring me to an emergency room. I don't want Vicodin or Percocet. I want to find out which of my organs is failing. Would "ten pain" have conveyed my sense of urgency?

My sister is probably right. I ran into some guys who were too tired from long shifts to listen. They weren't thinking clearly and I probably couldn't change that. Maybe they were like my old doctor in Oxford, and suspect women of exaggerating or imagining their pain. My sister admits she has colleagues who are generally suspicious of all their patients' pain ratings—doctors who believe they can judge a patient's pain better than the patient can. Perhaps I could have rolled into the ER screaming, "Ten pain! Ten pain!" and still received the same dismissive treatment.

But I also saw how reliant these two guys were on their tests. They couldn't listen to my description of the pain, but they knew how to order EKGs and X-rays. They were numbers men, focused on numeric test values to tell them my condition. My pain NRS (numerical rating scale) was another piece of data, another way to keep their eyes on the clipboard instead of my face. Nurses have a saying that "doctors treat the illness, nurses treat the patient." These numbers men risk taking the saying even further. What's to stop them from treating the pain rating instead of the illness?

I've got a collection of unused painkillers in my kitchen now. Percocet, plenty of Vicodin. I could go into business. Ironically, the 2001 law requiring that hospitals track and treat

patients' pain coincided with a rise in the number of Americans addicted to prescription painkillers. The coincidence makes sense to me after seeing how quick my ER doctors were to prescribe painkillers for a "back strain," which is often a mystery pain much like RSI.

I'm glad it's trendy in medicine to take a patient's pain seriously. But in a medical profession strapped for time, the federal mandate to measure pain may provide just another piece of data to ignore in the rush. Ultimately, I don't know if I could have said anything in the ER that would have resulted in an accurate diagnosis. It's hard to argue with the man in the white coat, especially when we're in pain. There is an art to being a patient, just as there is an art to being a doctor, and I have yet to master the secret to being the perfect patient.

REFERENCES

Chapter 1: To Outwit Death

Dalrymple, William. "Home Truths on Abroad." *The Guardian*, September 18, 2009. Accessed October 10, 2013. www.guardian.com.

Ehrenreich, Barbara. "Welcome to Cancerland." *Best American Essays 2002*. Ed. Stephen Jay Gould. Boston: Houghton Mifflin, 2002.

Fa Xian's account. Though I can't find the original book from which I copied Fa Xian's story as a teenager, I suspect it comes from James Legge, tr. and ed., *A Record of Buddhistic Kingdoms Being an Account by the Chinese Monk Fa-Hien of His Travels in India and Ceylon (A.D. 399-414) in Search of the Buddhist Books of Discipline* (Oxford, 1886), pp. 9-36.

Fay, Eliza. *Original Letters from India, 1779-1815*. 1817. New York: Harcourt, Brace and Co., 1925.

Zuger, Abigail. "Compelling Stories, If Not Literature." *New York Times*: June 28, 2010.

Chapter 2: Rash Youth

Ackerman, Diane. *A Natural History of the Senses*. New York: Vintage, 1995 (1st edition, 1990).

Montagu, Ashley. *Touching: The Human Significance of Skin*. 2nd ed. New York: Harper and Row, 1978 (3rd edition, 1986).

Weil, Andrew. *Spontaneous Healing*. New York: Random House, 1995.

Chapter 3: Voice Day

- Davis, Linsey. "Functional Dysphonia: Vocal Cord Massage Brings Back Mom's Voice." *ABC News*. May 16, 2011. Accessed April 28, 2013. www.abcnews.go.com.
- Fitch, W.T. and D. Reby. "The Descended Larynx is Not Uniquely Human." *Proceedings of the Biological Sciences* (2001) 268 (1477): 1669–75.
- "Laryngitis." *Mayo Clinic*. Accessed April 28, 2013. www.mayoclinic.org/diseases-conditions/laryngitis.
- MacNeilage, Peter. *The Origin of Speech*. Oxford: Oxford University Press, 2008.
- Pinker, Steven. *How the Mind Works*. New York: Norton, 1997.
- Roy, Nelson. "Functional Dysphonia." *Current Opinion in Otolaryngology and Head and Neck Surgery*. (2003) 11:144-148.

Chapter 4: Thief of Souls

- Crespi, Bernard, and Christopher Badcock. "Psychosis and autism as diametrical disorders of the social brain." *Behavioral and Brain Science* (2008) 31: 241-320.
- "Psychosis." *National Alliance on Mental Illness*. Accessed January 31, 2013. www.nami.org/psychosis.
- Schatzberg, Alan F. "New Approaches to Managing Psychotic Depression." *Journal of Clinical Psychiatry* 2003; 64 (supp 1); 19-23.
- Svoboda, Elizabeth. "All the Signs of Pregnancy except One: A Baby." *New York Times*, Dec. 6, 2006.

Chapter 5: Notes of a Hysterical Woman

Bakan, David. *Disease, Pain and Sacrifice: Toward a Psychology of Suffering*. Chicago: Beacon Press, 1968.

Gawande, Atul. *Complications*. New York: Henry Holt and Co., 2002.

Marxhausen, Paul. *Computer Related Repetitive Strain Injury*. Accessed Jan. 15, 2014.

<http://rsi.unl.edu>.

Pascarella, Emil, and Deborah Quilter. *Repetitive Strain Injury*. New York: John Wiley and Sons, 1994.

Quilter, Deborah. *RSI Help*. Accessed Jan. 15, 2014. <http://www.rsihelp.com>.

"Repetitive Strain Injury Not Known to Medicine: Law Report." ProQuest Historical

Newspapers: *The Times* (London), Nov 10, 1993. Accessed Jan. 15, 2014.

Scott, Clay. *Repetitive Strain Injury*. Accessed Jan. 15, 2014.

<http://web.eecs.umich.edu/~cscott/rsi.html>.

Chapter 6: At My End of the World

Seckel, Al. *Masters of Deception: Escher, Dali and the Artists of Optical Illusion*. New York:

Sterling, 2004.

Solomon, Andrew. *The Noonday Demon*. New York: Touchstone, 2001.

Chapter 7: The Measurement of Pain

- Angier, Natalie. "Tough Guys, Or Big Babies? How Real Men Deal with Pain." *New York Times*, Sept. 22, 2003. ProQuest Historical Newspapers: *New York Times* (1851-2008). Accessed November 1, 2012 .
- Bryant, Hannah. "Pain: A Multifaceted Phenomenon." *Emergency Nurse* 14.10 (2007): 6-10. ProQuest Central: ProQuest Social Science Journals. Accessed November 1, 2012.
- Krebs, Erin E., Timothy S. Carey, and Morris Weinberger. "Accuracy of the Pain Numeric Rating Scale as a Screening Test in Primary Care." *Journal of General Internal Medicine* 22.10 (2007): 1453-8. ProQuest Central: ProQuest Social Science Journals. Accessed November 1, 2012.
- Schneider, Yale and Larson. "Principles of Pain Management." *Clinical Medicine and Research* (2003) October 1(4): 337–340. Accessed November 1, 2012.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1069064/figure/f1/>.
- Strauss, Robert. "Where It Hurts; State Law Now Requires That Patients' Pain Be Assessed and Treated." *New York Times*, Jan 14, 2001. ProQuest Historical Newspapers: *New York Times* (1851-2008): pg. NJ7.