INTRODUCTION: THE TELEGRAM

Imagine, as I imagine, a community of consumptives, coughing blood in a progressive nineteenth-century mountain sanatorium. Their well-regulated hospital life includes the most modern of treatment protocols: antiquated purging and bloodletting have been replaced by mineral baths, good nutrition, mountain air, and heliotherapy—sunbathing. Yet attitudes have not evolved very far from those of Hippocrates, who, in the fifth century B.C.E., warned colleagues against visiting patients who had advanced consumption (the most prevalent disease of the time), because their inevitable deaths might damage the physicians' reputations.

Through the centuries, there were many theories about consumption's causes—heredity, evil spirits, vampirism, vapors, sewage, swampland odors, and corruption within the body. In the nineteenth century a fashionable conception of the disease was as a spiritualizing struggle between the body and the soul, in which the mortal flesh was slowly consumed in a way that heightened both beauty and creativity. But in the spring of 1882, a German physician identified *Mycobacterium tuberculosis.* Four thousand years of myth vanished in a moment as the bacterium materialized under the microscope. Although everything about the presentation of the disease, from sufferers' glittering eyes to their disappearing flesh, had lent itself to metaphor, science abruptly dissented. Consumption became tuberculosis—a disease, not a state of being. Although the cure—antibiotics—was still half a century away, there was a diagnosis.

In *Illness as Metaphor*, Susan Sontag describes the transformation of consumption into TB as an archetypal example of a process by which diseases are understood metaphorically until their pathology becomes clear. The philosopher Michel Foucault captures this process in postulating that modern medicine began when doctors stopped asking patients, "What is the matter with you?"—a question that invited a complex personal response—and began asking, "Where does it hurt?" instead, a question that focuses solely on biology.

Although these processes are driven by scientific discoveries, social attitudes have to shift in order for science to investigate. Moreover, people have to believe scientific findings before they act upon them. From a distance, one paradigm seems to succeed another in the blink of history's eye, but in their era they surrender slowly, and lives are lived and lost in the interim. Ideas can be slow to catch on: germ theory, for example, had been articulated but not popularized by the time of the Civil War, so soldiers blithely drank from rivers that other regiments used as toilets upstream. And there are always naysayers: bloodletting was discredited years before George Washington was bled on his deathbed by his physicians. Nitrous oxide and ether (the gases used for the first form of surgical anesthesia) had been discovered decades before anyone thought to employ them during agonizing operations.

How did the news of the discovery of tuberculosis arrive at the sanatorium? Did the residents read of it in the newspaper? Did their relatives pay a visit or send a telegram? *It's not you—it's a bacterium! Strange—you seemed so consumptive.* Did the news make them rethink the story of their sickness and realize it had nothing to do with a spiritualizing struggle? Or did they regard the news in the way one takes in scientific advances about black holes or the bones of primitive man—interesting, but personally irrelevant? After all, there was still no cure. Or perhaps the news never reached the sanatorium, and the consumptives perished on the magic mountain, imprisoned not only by disease, but by a host of lonely meanings.

Wouldn't understanding the nature of their suffering itself have been therapeutic? Even in the absence of treatment, epileptics may benefit from knowing that they are not possessed by spirits, and it may help depressed people to know that their condition is not a failure of character. Surely the consumptives would have felt relief, mixed with wonder, to finally know what their disease was—and what it was not. It was not a curse. It was not

an expression of personality or a punishment. For better and for worse, it was and is a disease.

To be in physical pain is to find yourself in a different realm—a state of being unlike any other, a magic mountain as far removed from the familiar world as a dreamscape. Usually, pain subsides; one wakes from it as from a nightmare, trying to forget it as quickly as possible. But what of pain that persists? The longer it endures, the more excruciating the exile becomes. *Will you ever go home?* you begin to wonder, home to your normal body, thoughts, life?

Ordinarily, pain is protective—a finely wired system warning the body of tissue damage or disease and enforcing rest for the bone to knit or the fever to run its course. This is known as acute pain; when the tissue heals, the pain disappears. When pain persists long after it has served its function, however, it transforms into the pathology of chronic pain. Chronic pain is the fraction of pain that nature cannot heal, that does not resolve over time, but worsens. It can begin in many ways—as trivial as a minor injury or as grave as cancer or gangrene. Eventually, the tissue heals, the diseased limb is amputated, or the cancer goes into remission, and yet the pain continues and begins to assume a life of its own.

The doctor assures the patient she is fine, but the pain worsens, the body sensitizes, and other parts begin to hurt, too. She has trouble sleeping; she stumbles through her days. Her sense of her body as a source of pleasure changes to a sense of it as a source of pain. She feels haunted, persecuted by an unseen tormentor. Depression sets in. It feels wrong . . . maddening . . . delusional. She tries to describe her torment, but others respond with skepticism or contempt. She consults doctors, to no avail. Her original affliction—whatever it may have been—has been superseded by the new disease of pain.

Chronic pain is a specter in our time: a serious, widespread, misunderstood, misdiagnosed, and undertreated disease. Estimates vary widely, but a 2009 report by the Mayday Fund, a nonprofit group, found that chronic pain afflicts more than 70 million Americans and costs the economy more than $100 billion per year. Another study in the United States indicates that as much as 44 percent of the population experiences pain on a regular basis, and nearly one in five people describes himself or herself

as having had pain for three months or more. Much of the degraded quality of life from diseases such as cancer, diabetes, multiple sclerosis, and arthritis stems from persistent pain. In one survey, most chronic pain patients said that their pain was "a normal part of their medical condition and something with which they must live." One-third of the patients said that their pain's severity was "sometimes so bad [they] want to die." Almost one-half said they would spend all they have on treatment if they could be assured it would banish their pain.

Yet treatment for chronic pain is often inadequate. In part, this is because it is only in recent years that chronic pain has been understood to be a condition with a distinct neuropathology—untreated pain can eventually rewrite the central nervous system, causing pathological changes to the brain and spinal cord that in turn cause greater pain—though this new understanding is not widely known. Chronic pain is sometimes defined as continuous pain that lasts longer than six months, yet chronic is not ordinary pain that endures, but a different condition, in the same way an alcoholic's drinking differs from that of a social drinker. It is not the duration of pain that characterizes chronic pain, but the inability of the body to restore normal functioning.

"The history of man is the history of pain," declares Pnin, a character in a Nabokov novel of the same name (a name that is itself just one letter removed from the word *pain*). The longing to understand physical pain and to alleviate it has threaded through all of human history, from the earliest records of thought. No single discipline seems adequate to address or represent pain, because every lens through which one tries to examine it—personal, cultural, historical, scientific, medical, religious, philosophical, artistic, literary—fractures pain into a different light.

In the Sanskrit Hindu scripture, the *Bhagavad Gita*, the god Krishna speaks of "life, which is the place of pain . . ." What is pain whose place in life is so central? To unravel its riddles, we must look at the ways in which pain has been understood and interpreted. These understandings seem to fall into three basic paradigms. First, there is what we might call the premodern view, in which pain is never simply a bodily experience, but reflects a spiritual realm suffused with meanings and metaphors, from the pain-causing demons of ancient Mesopotamia who spread their wings

wide, to the Judeo-Christian tradition in which pain begins with the expulsion from Eden. "Thorns also and thistles shall [the ground] bring forth to thee," God condemns Adam—a curse that is transformed, in Christianity, into a means of redemption.

Pain was also seen as a force that could be used for positive spiritual transformation. Pilgrims and ascetics in many different traditions elected to draw closer to God by undergoing painful rites, and martyrs embraced painful death. Belief in pain's spiritual properties made pain the critical instrument of jurisprudence in the premodern world—not only as the appropriate punishment for crimes but also for determining guilt, both through torture and through the curious precursor to the jury trial known as "trial by ordeal," in which the suspects were subjected to painful rituals (such as holding a hot iron, walking on hot coals, or plunging a hand into boiling water). If God failed to protect them from pain, they were deemed guilty.

The premodern paradigm is not entirely obsolete; although it has been supplanted, it has not been expunged. To understand our attitudes toward pain today, we must understand the legacy we inherit from five thousand years' worth of struggle to make sense of this mortal condition. Suffering was—and still is—regarded by many as something that can, must, or ought to be endured. Although it is difficult to believe, the invention of surgical anesthesia (through the inhalation of ether gas) by an American dentist in the mid-nineteenth century was controversial at the time. Many agreed with the president of the American Dental Association, who declared, "I am against these satanic agencies which prevent men from going through what God intended them to go through." The use of anesthesia during childbirth was especially controversial, as it was believed to circumvent the divine injunction to bring forth children in pain. Even after the invention of anesthesia, many surgeons continued to perform surgery without it, including experimental surgeries on slave women who were said not to suffer the same pain as their mistresses.

The premodern understanding of pain was replaced in the mid-nineteenth century by a new biological view of pain as simple, mechanistic sensation: a function of nerve endings that send predictable pain signals to the brain, which responds passively in turn with a proportionate amount of pain. Influenced by Darwin, the biological view of pain saw all pain as protective—serving, usefully, as a warning of tissue damage. The remedy for pain seemed plain: treat the disease or injury, and the pain should take

care of itself. This model prevailed for most of the twentieth century and, indeed, is still commonly held, not only by patients but also by physicians.

While this view has helped us make strides in managing *acute* pain and spurred on the development of anesthesia, it has impeded and continues to impede our ability to recognize and understand *chronic* pain. It cannot explain why some pain continues to worsen of its own accord. Even for acute pain, the model does not suffice, for it cannot explain why in a lab experiment the same heat stimulus may hurt one person more than another, or why injuries that are severe may hurt someone only mildly while mild injuries may be agonizing for others. Moreover, the model cannot explain treatments that target *only* the mind, such as the forgotten nineteenth-century technique of mesmerism (a form of hypnotism), so effective that it enabled surgery to be performed painlessly.

The biological view of pain is in conflict not only with the way man through the ages has regarded pain, but with the way in which pain is *experienced*, not as an ordinary physical function, but as an extraordinary state of being. Unlike the premodern paradigm, the biological model cannot explain the disconcerting flexibility of meaning in pain, or why the meaning of the pain changes the pain itself. Why does the pain of loss of virginity seem to differ so profoundly from the pain of rape, or the pain of sadomasochism differ from the pain of sexual abuse? How can the pilgrims I witnessed in the Hindu celebration at Thaipusam in Kuala Lumpur claim that not only are they not in pain, but they feel *joy* while fishhooks decorate their backs and skewers pierce their mouths?

In recent years, a new, third paradigm of pain has emerged, a synthesis that embodies elements of both earlier traditions. The contemporary model of pain sees it as a complex interaction among parts of the brain. While founded on the same scientific traditions that gave rise to the nineteenth-century view, it has also revealed the truth embedded in the nonscientific, premodern model by showing the way in which pain is inherently meaningful because it is not simply a matter of nerves firing, but an experience created by meaning-making parts of the brain.

Like the consumptives stranded in the half century after science had discovered the nature of their disease but had not yet yielded a cure, those who suffer from persistent pain in our era are caught in an uneasy moment. Pain is one of the most promising fields of medical research today: new tools in the form of advanced imaging techniques are taking the first pictures of the brain in pain, and techniques of gene analysis are identify-

ing which genes are active in the presence of pain. Yet the pain clinic lags far behind the research lab. Patients languish because of lack of access to good treatment and because even the best treatment that exists today is often inadequate.

When we read about the conceptions of pain throughout history—of the ancient Babylonian tablets, for example, that situate the origin of toothache in the making of the world—we are thankful to live in the modern world with modern medicine. What would it be like to have toothache figure so prominently in consciousness that its origin merited inclusion in the story of all creation? When we read of their remedies—a word spell said over a plant poultice—we feel sorry for the Babylonians.

But when others look back on our treatments, they will feel sorry for us—both for the limitations of our knowledge and for our reluctance to use the knowledge we have. They will shiver at the thought that people lived with chronic pain—as we do now when we read the accounts of surgery without anesthesia, an idea so dreadful as to be almost unimaginable. Just as we are amazed that anesthesia could have been controversial, they will be surprised at the way some of the most powerful pain medications we have—opiate and opioid medications such as Percocet and OxyContin—are misunderstood and misused, withheld from those who would benefit from them and given to those who are harmed by them.

Pain takes sufferers' own worlds away and leaves them on a magic mountain of isolation and despair. To understand that chronic pain is a disease is the first step off the mountain of lonely meanings.

Curiously, the progression of my understanding of my own pain mirrored the larger progression of the understanding of pain in history. In 2001, I was given an assignment by *The New York Times Magazine* to write an article about chronic pain. Although I had suffered from pain myself for a number of years, it wasn't until I began researching my article that I gained any real understanding of my condition, what pain is, and what the treatment options are. I had seen a variety of doctors, both good and bad, but I had difficulty distinguishing between the two, changed doctors frequently, and complied erratically with treatment plans. Coming to understand pain as a disease changed my relationship to it, from seeing it as a personal affliction, failure, or curse to seeing it as a manageable medical problem.

For many years, I kept a record of my quest toward healing: a pain diary that documented the meanings I made of pain as it wreathed my personal and romantic life like a choking vine. The metaphors that obscured my medical situation were of my own making. Although my rheumatologist had suggested keeping the diary as a helpful tool, the diary itself became a place for embroidering my pain with pernicious meanings. When, as a journalist, I had the opportunity to read other patients' pain diaries, I was struck by how many others did the same.

While researching my article, I was able to interview the most distinguished pain specialists—researchers and physicians—throughout the country, and I spent time in seven of the best pain clinics, which served such diverse populations as coal miners in West Virginia, cancer patients in New York, and pediatric patients in Boston. I followed the director of each clinic on his or her daily rounds and appointments, studying patient charts and sitting in on difficult case conferences for periods of time ranging from a day to a month. I saw the questions they confront: How do you measure a patient's pain? What if he or she is fabricating it? How do you choose a treatment plan? How do you know which patients will abuse drugs? Are some people genetically more prone to developing chronic pain? What is the relationship between pain and depression? Why are there so many female patients? Most of all, I was struck by the *contrast* between the physician's and the patient's points of view: the difference between patients' understanding of their suffering and doctors' understanding, and the complex nature of the medical encounter.

The Victorians believed in an invisible hierarchy of feeling in which the young were more pain sensitive than the old, females were more sensitive than males, and rich, educated whites (the inventors of the theory) naturally found themselves to be infinitely more pain sensitive than the poor, the unschooled, the enslaved, and indigenous peoples. Surprisingly, modern research has found that physiological pain sensitivity *is* affected by race, gender, and age—but not at all in the way the Victorians believed.

I eventually observed several hundred patients. At times, visiting pain clinics felt like descending into Dante's *Inferno*. Some were crushed in industrial accidents or suffering from degenerative nerve and autoimmune diseases, while others had ordinary complaints such as backaches or headaches that were causing them extraordinary pain. I kept in touch with patients over the course of eight years to try to answer the question: Why did some people get better and not others? Does the answer lie in the

nature of the patients or in the doctors or in the treatment methods used? How does religious faith affect pain, disability, and mortality? Does churchgoing or prayer ameliorate pain?

I met a young woman who acquired chronic back pain from a five-minute demonstration of a chiropractic maneuver which she'd been talked into by a trainer at the gym one day. Over the course of the next eight years, she supplemented her insurance with six figures of her own money, seeing every well-known doctor and trying every type of treatment she had heard of before she found one that worked. Eight years! But she got better.

Pain, like any extreme situation, brings out the best or the worst in people. Pain makes a hero of some: a woman paralyzed by a routine pain surgery for a bulging disk in her neck who coped with her new, much more terrible affliction of spinal cord injury pain. A train conductor who lost three of his limbs when he fell off a train and suffered from phantom limb pain taught his doctor about the mystery of resilience. Yet other patients were suicidal, and others (including myself) found that we were acting in ways unrecognizable to ourselves and collaborating in our pain rather than combating it.

This book is divided into five sections: "Pain as Metaphor," in which pain is seen through the lens of the meanings that have been made of it from ancient times onward; "Pain as History," which traces the discovery of anesthesia in the mid-nineteenth century and the collapse of the religious model of pain; "Pain as Disease," which discusses the state of pain treatment and pain research today; "Pain as Narrative," which follows the experience of patients undergoing pain treatment and the way in which pain changes and is changed by life as it is lived; and finally, "Pain as Perception," which unites the varying paradoxical aspects of pain through the contemporary understanding of how pain works in the brain. Woven throughout is my own story, based on the pain diary that I kept.

Every one of us will know pain in our lives, and none of us knows when it will come or how long it will stay. Although we will one day have effective treatment for the disease of chronic pain, we can never eradicate pain itself, because our bodies require it. Pain is a defining aspect of mortal life, a hallmark of what it means to be human. It often stamps both the

beginning and the end of life. It threatens our deepest sense of ourselves and—portending death—reminds us of the ultimate disappearance of that self. It is the most vivid experience we can never quite describe, returning us to the wordless misery of infancy. It seems to rend a hole in ordinary reality; it is intrinsic to the human body, yet feels alien. And it is the aspect of mortality that we like least; we abhor pain more, even, than death.

Pain is like a poison from whose cup everyone has sipped; there is no one who cannot recall its taste and fear a deeper draught. *Take this cup from us*, we say, while knowing no reprieve is permanent.

This is a book about the nature of that poison—its peculiar taste, its mysterious effects—and its antidotes.