

HOW DOCTORS THINK

CLINICAL JUDGMENT AND THE PRACTICE
OF MEDICINE



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To Anne, Keith, Lucy, Maggie, Ellen, Eric, Will, Jesse,
Paul, Sallyann, Megan, Samantha, Ben, Anna, Lisa,
Aaron, Jacob, Elijah, Debra, Michael, Hunter,
Hannah, Beth, and Tom—for whom
I'm thankful all year round.

CHAPTER ONE

Medicine and the Limits of Knowledge

Every living thought represents a gesture made toward
the world, an attitude taken to some practical
situation in which we are implicated.

—JOHN DEWEY

I SET OUT to write a book about clinical judgment: how, given the uncertainty of its knowledge, medicine is taught and practiced and how its identification with science affects both patients and physicians. Before I was well into it, my 28-year-old daughter found a breast lump and had an excisional biopsy.

Physical symptoms are read narratively, contextually, and interpreted in cultural systems. A physician's diagnosis is a plot summary of a socially constructed pathophysiological sequence of events. The lump is there. It is a sign, caught *in medias res*, a clue to a natural history that is unfolding. Science describes and explains it and determines what can be done about it. But the importance of that lump, the acts its discovery entails, and what those acts will mean are social and cultural matters. Although for turn-of-the-millennium North Americans, culture is shaped by—of a piece with—Western scientific medicine, within that culture, as Lynn Payer pointed out, there are significant national variants. The French like breasts, she observed, and not surprisingly, surgeons in France regularly performed lumpectomies long before the English and Americans, who like randomized clinical trials.¹ Is there a fixed, invariant truth about breast cancer and its treatment, a reality that has nothing to do with culture? Certainly there are scientific facts, refinements in knowledge, improvements in care. Mastectomy is no longer the automatic treatment regardless of tumor and breast size. But women in the United States

who 20 years ago were led to have modified radical mastectomies rather than lumpectomies were not duped by their surgeons. Then everyone—patients, surgeons, families—felt more secure trading breasts for what they were convinced was a higher degree of certainty: “They think they got it all.” American medicine moved very slowly to investigate the alternatives because the choice was posed as a matter of life or death.²

“Invasive ductal carcinoma, moderately differentiated . . .” a pathology lab in Beijing and New York City might both report. But would it be the same? Breast cancer is not common there. Do the Chinese like breasts? One imagines that the meaning of breast cancer in that half of the world might have more to do with maternity and women’s social citizenship than sex and the self. The therapy might differ—if not the primary treatment, then the treatment of side effects. The United States has “the best medicine in the world.” But, just as U.S. surgeons adopted the German practice of giving valium preoperatively (once it was clear the benefits went beyond calming the patient to lessening the measurable side effects of surgery), might the Chinese know something that U.S. medicine could usefully borrow?

Millions of woman-hours are spent anguishing over the possibility of breast cancer, lump or no lump. Mammograms are never truly routine, even for women fortunate enough to afford periodic screening. Some manage to stay busy until the report is in, even busy enough to neglect to call to be sure the results are negative. But for many the test is a final exam that poses ultimate questions about the relation of self and body, about death and the meaning of life. The obvious answers to these questions are answers in the aggregate. They are common knowledge: we are embodied selves in a strongly gendered, body-conscious society, and those bodies—we ourselves—will die. A mammogram suggests that the ultimate questions also have particular answers and that it may be time to work them out in our own lives. A biopsy leads us to discover, like Tolstoy’s Ivan Ilych, that the syllogism ending “Causa is mortal” could just as easily be written with our own name.

When the results are normal, we go back to normal too. We are reimmersed in our ordinary lives and their more immediate concerns.

I wanted to shield my daughter from all this. She was only 28, married not quite a year, absorbed in interesting work. I quoted her the statistics for lumps, the age-weighted probabilities. If not quite negligible, they are minuscule. And besides, this happens. “Large-breasted women often have lumps,” I said, putting it in the big, epidemiological picture. I didn’t want her to have both a suspicious lump and a mother who teaches in a medical school alarmed about it.

The night before the biopsy I dreamed she lay inert and faded in a hospital bed. I sang to her; but she was too sick to bear it and shook her head weakly. Awake, I understood it as a dream about her younger sister, just out of college and on her own, and the interesting problem of being a good mother to adult daughters. Don’t infantilize, I decided it meant.

Two days later the surgeon left a message on her answering machine: he’d call her the next day. But what time? “He could at least have said the report was okay,” she said.

I had spent the last 20 years puzzling out what doctors do, and I summoned up a narrative into which his nonmessage fit. “He needs to make you a speech, wants to be sure you go on following these up,” I said. “Besides someone probably once told him surgeons shouldn’t communicate by answering machine.”

She called the next day: “It’s not a fibroadenoma. It’s real cancer.”

My perspective on medicine has changed since then. Although some of what I knew about medicine and the uncertainty of its knowledge was helpful, much of it I completely forgot. Friends were the real help—some in medicine, some out, some licensed respassers like me. The ground of ordinary life opened up, and I fell through to the breast cancer world, an alternate reality. Colleagues appeared at my door and on my computer screen to talk about their wives, their sisters, themselves. On the sidewalk of my very urban campus, people passing asked with a special emphasis, “How are you?” or waved crossed fingers from the other side of the street. They meant breast cancer; all references were to breast cancer. It was October, breast cancer month, and statistics were everywhere.

Young women don’t do well. Their cancers are as lively and energetic as they are. Most are estrogen-receptor negative, which means that tamoxifen—the only therapy that, if not quite benign, is at least not dangerous in itself—for them is useless. And if a devout agnostic pleads with fate that bone and brain scan be clean, that the lymph nodes that surgeons continue to remove be cancer-free, and that plea is granted, then how can she not be grateful for the best odds a 28-year-old can have? Stage I: a 75% five-year disease-free survival rate, improved by chemotherapy to 82%. I rejoiced. I am thankful nonstop. Still, 82% is terribly uncertain.

The perception of statistics is notoriously subjective.³ In the 1980s I kept a folder of articles and stories labeled “Sick Docs,” and my favorite was by a physician who believed he would die of his cancer. The five-year disease-free survival rate for his disease was 90%, and still he felt doomed. Then one day he realized that he “had decided, having been in the top 10 per cent of

everything I did, that I would be the one in ten to die of this tumor."⁴ After my daughter's diagnosis, the story wasn't charming anymore. I complained to my physician colleagues about breast cancer's relatively rotten statistics. A one-in-five chance of recurrence in five years—who knows beyond that—and, with microcalcifications all through the biopsied tissue, a second, equally strong chance—a new toss of the coin, unbiased by this occurrence—of a new cancer down the road. This was the best they could do?

It was the best they could do.

The best it can do is, at its best, what medicine does.

We make a great, even dangerous mistake about medicine when we assume it is a science in the realist Newtonian sense we learned in high school—even that it is, as Lewis Thomas described it, "the youngest science."⁵ The words are noble and the aspirations praiseworthy, but assuming that medicine is a science leads to the expectation that physicians' knowledge is invariant, objective, and always replicable. Although biological research now provides the content for much of medicine, clinical knowing remains first of all the interpretation of what is happening with a particular patient and how it fits the available explanations. Such knowledge is still called an opinion; the skill used in arriving at that opinion is called judgment. In this, physicians resemble lawyers and judges, and medical rationality resembles jurisprudence. Both professions are engaged in practical reasoning, which, as Aristotle observes, is shared with practitioners of navigation and moral reasoning.⁶ In these realms, knowing is particular, experiential, and conventionally agreed upon. Although areas of agreement may be large, even international and transcultural, physicians, lawyers, and moral reasoners nevertheless rely on skill and judgment that are taught and practiced, improved and clarified case by case.⁷ Without a doubt, biology provides essential knowledge and promotes valuable technological advance, but medicine, like other practices—engineering, architecture, law—has a body of experiential, detail-driven wisdom. In this, clinicians are far more like naturalists or archeologists than like biochemists or physicists.

Meanwhile, the lump was undoubtedly there, and it was cancer.

She would die if it stayed.

Or would she?

Bernie Siegel, Andrew Weil, Caroline Myss, and Christian Science promise that mind and spirit can alter flesh, and I do in part believe it. But I wouldn't want to bet on it until I had to, not for my child, not on faith alone. The chances don't seem strong, especially if such faith is not already part of one's everyday practice. In life as in medicine, as I once heard a venerable surgeon say, "you have to proceed with the guidance of the knowledge you trust."

My folk belief and hers, as George Engel observed of our time, is Western scientific medicine.⁸

What should be done for a 28-year-old's breast cancer? It's widely held to be different from breast cancer in older women, but no one knows entirely how or why. Because there are very few cases in young women, research is difficult. Breast cancer for thirty-somethings is more frequent but still rare. There is occasionally a thirties bar, a mere sliver, on age-distribution graphs, but never one for the twenties. As a result, breast cancer in very young women is treated like other breast cancers. For the time being this makes sense. There is no reason (yet) not to, and besides, there is nothing else to do.

Surgery then. Lumpectomy and radiation? Or a modified radical mastectomy? Mastectomy with or without reconstruction? What sort of reconstruction after the never-quite-proven failure of silicone? Immediate reconstruction so as to minimize the sense of loss and mutilation? Or a delay so as to deal with the sense of loss and mutilation? Opinion varies.

Breast cancer long ago crossed the postmodern divide. Patients and their families have access to the statistical uncertainties of its treatment and prognosis, and because the therapeutic choices bear different weights in different lives, people with breast cancer undergo a sudden, staggering education aimed at enabling them to choose well. A friend who studies the discourse of breast cancer called with advice ("Discourse?" my daughter e-mailed, "Great! Hello, I'm Fred, I'll be your tumor this year . . ."); "You are entering a real thicker. Your heads will swim with minutiae you never wanted to know."

The possibility of a lumpectomy depends on the relative size of breast and tumor.⁹ There are no clear choices beyond that. No rules, not many obvious bets. Just preferences and available clinical proficiency. Chemotherapy, indeed everything, depends on the stage of the disease, determined not only by tumor size but also by metastases and the presence of cancer cells in the lymph nodes beyond the breast in the armpit and upper arm. Positive nodes are the clue to a not-yet-identifiable metastasis: tumor cells have left the breast, ready to colonize. And the meaning of negative nodes? Researchers now think malignant cells have been leaving the tumor all along, but, if the nodes are negative, not in such numbers that they've taken hold—or not in an identifiable way.

The number of positive nodes counts a great deal. Once Halsted's radical mastectomy took all the nodes; the less severe, modified radical mastectomy leaves enough arm tissue for most people, after rehabilitation, to approximate normal movement. While lumpectomy with radiation to the tumor site proved to be as effective as the modified radical, the surgical excision of nodes went on impairing people who have had breast cancer. Negative or

positive, out they came. Here, as in the rest of medicine, it has been difficult not to do everything that can possibly be done if it might prolong life. Clinical research regularly focuses on paring down a treatment either in its severity or in the descriptors caught in its predictive net so that (ideally) it can be given to fewer people in milder doses for a shorter time. Every possible node was once taken, then every node along the axillary vein, now only 10 in an *en bloc* resection, or increasingly, just one "sentinel node." Scaling back in this way took a long time. It was no doubt hard for a surgeon to leave a node that might be cancerous, but it is, after all, primarily a sign of disease and chemotherapy will eliminate it. And for many people, the axillary surgery has been the most disabling consequence of breast cancer: swollen arms, easily infected scratches. Even the removal of only 10 nodes means a permanent increase in the risk of infection from cuts and scratches and a prohibition against carrying any more than 15 pounds: a suitcase, a heavy briefcase, a couple of grocery sacks, a baby.

And microcalcifications? They used to be seen only in patients undergoing mastectomy, and when mammography first revealed that they exist in the absence of tumors, they were regarded as precursors of cancer and removed. Now they're left, watched, even in women under 35, whose dense breast tissue makes keeping track of them by mammogram uncertain. The meaning of the calcifications has changed. They are not "precancerous" now, but a risk factor: 20% of those who have them go on to develop breast cancer.

But she already has breast cancer!
The calcifications are still a predictor. The dice will be rolled again. They'll "watch it!"

Some women, exhausted with waiting, losing bits of tissue to biopsy every year or two, chose prophylactic double mastectomy. But no mastectomy ever takes out all the breast tissue. Men have breast cancer.¹⁰ People who have never had cancer find a lump on the chest wall: those who have had a mastectomy find recurrences in the scar.

As recently as the 1980s, if a tumor were small with no metastases and negative nodes, chemotherapy was thought to be unnecessary. But some people with small tumors had unexpected metastatic recurrences years later, and the cells from the new biopsy matched the old cancer. No one knows what the cancer cells were doing all that time. They were not "just circulating"; they were there somewhere, quiescent. No one knows what made them begin to grow again. Guidelines were changed in 1988. Now almost everyone with the most common kind of breast cancer, no matter how small, is treated with chemotherapy. It's not the tumor that's treated. By then it's gone. What is treated is the possibility that the cancer cells have left the tumor and migrated to the rest of the body. That's why it's called "adjuvant" treatment. It's a

hedged bet: the chances of recurrence receive chemotherapy. The rest of the body is unfortunately in the way.

If consensus has been reached about who needs chemotherapy, there are nevertheless bewildering choices among chemotherapeutic agents and regimens. For my daughter, the decisions included timing. Should the chemotherapy come before radiation? After? Split around it? Four choices, and all that was known statistically about their consequences for longevity, fertility, and side effects (including subsequent, iatrogenic cancers) were laid out for her and her husband by a young oncologist who not only tolerated their need to understand what they were embarked upon but also encouraged it. Together they made a chart of the options: the standard, Cytoxan-Methotrexate-5-Flourouracil (CMF) every three weeks for six months, the newer, more caustic alternative, Adriamycin-Cyroxan (AC) every three weeks for three months, and two longer, experimental protocols, whose effects, under study, were not known. They added a fifth—no chemotherapy—for reference.

The thicket of nightmare possibilities, some of them contingent on others, puts breast cancer in the category of disease Lewis Thomas described as characterized by "halfway retechnology": high cost, elaborate and uncertain therapy, "at the same time highly sophisticated and profoundly primitive." For such diseases, Thomas observed, diagnosis and treatment involve highly trained personnel, special facilities and equipment, and enormous expense. The aim is not prevention or cure but "making up for the disease or postponing death."¹¹ The thickness of Susan Love's *Breast Book*, the lucid, authoritative guide to breast cancer and its treatment, is evidence of the mounds of information that a person may be called upon to reckon with. Although Love describes current areas of research and their goals, the book is inevitably out of date even as successive editions are printed.¹² Internet breast cancer groups help—and not only with the facts. They are especially recommended for younger people, who are better represented there than in face-to-face support groups. Besides, as my daughter observed, parodying the cartoon about the Internet, no one can see that you're bald.

The drive for information led her and her husband to their town library, where they read textbooks and got by heart the *New England Journal of Medicine's* recent summary article on breast cancer. By the time I got there before her surgery, they knew all the pathophysiology and had a good grasp of the pharmacology and sound instincts about the social customs. They had asked me to find in the medical library three studies the oncologist mentioned: a description of the chemotherapy regimen they chose, a study of birth defects in the children of cancer patients (insignificant for the drugs used to treat breast cancer), and the study that established that pregnancy does

not accelerate tumor growth. I didn't go to the library for days. When I did, it was with a friend, then a resident, who coached me through the loss of what little faculty I had had with on-line searches. The abstracts printed out were brutally plain: real lives aggregated into bare numbers. But they were no worse than a sentence glimpsed in a woman's magazine doing its Breast Cancer Month duty: only 65% of young women with breast cancer survive five years. When finally I went to the stacks, I read everything and found no comfort. Cancer cells have been studied by every characteristic they are now known to possess in a search for better predictors or a clue to new treatment. Estrogen and progesterone receptivity and DNA are just a start. High S-phase fractions, aneuploidy, HER-2/neu negativity, and estrogen-receptor negativity characterize breast cancer in young women. Bad as they are, they do not entirely add up: "Higher mortality in young women is not completely accounted for by the known prognostic factors." Studies continue, proliferate like the cells themselves. Bound together into volumes on library shelves, they are a massive reminder of the tentativeness of current scientific knowledge. Once breast cancer is understood right down to the bottom—etiology, diagnosis, therapy, and prognosis—it will take up a page and a half in a textbook. Still, the scientific journals were somehow reassuring. They're working on it, I told myself.

And they are. The nightmare thicker can be cleared. Much of it is, after all, the temporary uncertainty that comes from lack of knowledge at Thomas's "halfway" stage: what we know we don't know, answers to the questions even I might think of. This is not the uncertainty that finally must be confronted, however. What's even harder to think about is how uncertainly any of these numbers apply to one particular woman.

I walked, meditated, read Larry Dossey's clinical assessment of prayer.¹³ I wrestled with the statistics: she's young and strong, she found it early, her doctors and nurses and technicians are very good, she had no nodes! But to no avail: 75% and 82% are numbers in a study of similar women, all of whom caught it early, all with stage I tumors, all receiving exactly the same therapy from physicians and nurses well-trained enough to undertake the studies. And "young" was not an advantage. I came to hate the walk from the hospital parking garage to my office. In that short block, my efforts at acceptance faded, and my hope of humbling myself—in a way that might alter fate—before the indifferent splendor of the universe dropped away. "Higher mortality in young women is not completely accounted for by the known prognostic factors" went round and round in my head. That is the science, such as it is, and in a medical school it demanded daily acknowledgment. Not that my physician-colleagues reminded me. They were far too kind.

I had gone over to the other side. I watched them shift, sometimes in the middle of a conversation, to regarding me as one of those others: a patient, a patient's mother. I battered them angrily with the facts of illness, vulnerability, medicine's imperfection.

Some of the imperfection is society's. While we often speak of medicine and society as if they were entirely distinct, encapsulated "influences" on one another, they are inseparably enmeshed. The United States took a long time to acknowledge breast cancer. It was a shameful secret until the 1970s, when Rose Kushner wrote *Why Me?*¹⁴ and Betty Ford and Happy Rockefeller called press conferences in startling succession to talk about their diagnoses. They urged women to do self-exams and get mammograms but above all to regard breast cancer as a disease and not a failure of womanhood. Since then, the disease rate has risen from one in eleven in the early 1980s to almost one in eight. The increase feels like an epidemic. What the civil rights movement taught women about equal pay for equal work the gay community taught about research funding: politeness can be fatal. Until the infusion of funding in the early 1990s thanks to Congresswoman Patricia Schroeder and National Institutes of Health director Bernadine Healy, a sizable proportion of breast cancer research was conducted in Italy. The multicenter studies that established lumpectomy and radiation as an alternative to mastectomy were, in part, conducted there. The Cytoxan-Methotrexate-5-Fluorouracil regimen, standard chemotherapy for two decades, was developed there; so was Adriamycin, a poison named poetically, possessively, for the Adriatic. Meanwhile, in the United States, medicine was slow to give up the Halsted radical mastectomy, slow to adopt the breast-conserving lumpectomy, slow to devise new chemotherapy regimens, then slow to limit the number of nodes removed for staging, now slow to develop new tests. Breast cancer cells must shed *something* into the bloodstream, I'd challenge a colleague. Why isn't there a test?

The question of cause consumed me. What had gone wrong? A gene had mutated, cells had proliferated unchecked, but what had caused that? The possibilities—genetic inheritance, environmental and dietary carcinogens, stress—were numerous and slippery at best. My daughter's paternal aunt had died in her forties of ovarian cancer, but no genetic mutation thus far accounts for what is probably a coincidence. Our neighborhood in the 1980s had logged a case of breast cancer in every one of its ordinary-sized blocks of single-family houses, but so prevalent is breast cancer in the United States that this information is a better sign of a close-knit community than of an environmental cause. International studies have implicated the American diet. As an adult, my daughter ate relatively little fat, but her special treat as a child

had been her baby sitter's own childhood favorite, stewed chicken necks and rice, until we learned the necks were the site of injections of diethylstilbestrol (DES), the growth hormone. She had spent seven years in New York City at increasingly stressful work, but she had no known occupational exposure. The cause that seemed most likely was iatrogenic: she had ingested radioactive iodine for Graves' disease two years before. The technician who administered it wore mask and gloves, and she herself was counseled not to touch anyone and to double-flush the toilet for three days afterward. Yet studies have not shown that this treatment increases the risk of breast cancer. Was it some combination of these things? Surely there was a cause that, if removed or reversed, could have kept her safe.

If the causes of breast cancer are inaccessible, what is known about encouraging recovery, preventing recurrence? She reduced the meat and fat in her diet even further, ate more broccoli, cauliflower, and tofu, and developed an unlikely taste for soy milk. She went on exercising, learned biofeedback. Friends suggested meditation, visualization, prayer. Anxious for something, anything, that could be controlled, I imagined that the difference between the four in five who stayed well and the one in five who suffered a recurrence might be that the four had mothers who had faith: faith in God or, failing that, faith in medicine. What if some communicable maternal serenity in a mysterious way we don't yet understand strengthens the younger woman? Her mother *knows* she will be all right and so she is. In the days after the diagnosis, when the scans were still to be done and the positive node count was still weeks away, I spent a good while walking on the nearby beach. I had better sense than to ask Why me? Indeed the burning, terrible question was Why *not* me? Why my daughter? But whatever the question, the answer is eternally the same. I imagined it rumbling from beyond the horizon of Lake Michigan like a late summer squall: Why not? Only Job's answer was left me: to repent "in dust and ashes" of my question and its audacity. Still, at odd moments, doubled over, I found myself bargaining for her life, offering my body parts, my life, the hope of grandchildren, at last even her body parts. When I mentioned this odd new pastime, she wrote back, "As long as you're appealing to higher powers, don't compromise."

At the heart of the quest for certainty is a longing for control. Or, to look at it the other way around, we disguise the need for control as a need for knowledge. We don't have control. Nor are we likely to achieve it. We work hard to provide stability—the illusion of certainty—for our children. Parenthood is largely a matter of turning over this task to them, of preparing them for the gradual assumption of responsibility for their own lives. But

we have no control. If we did, there would certainly be no breast cancer for 28-year-olds. But there might be no teenage driver's licenses, no camping expeditions across the country, no trips to China.

She had a lumpectomy, chemotherapy, radiation. The usual. Or, as Odette keens through the first act finale of the Bill T. Jones/Arnie Zane dance suite, *Still/Here*: slash, poison, burn. I sat next to her as the Adriamycin snaked into her body. It is an antibiotic so toxically opposed to life that the nurse didn't let it drip along with the rest of the mix—saline, Cytoxan, Zofran, Decadron—but sat to push it slowly into the plastic tubing that ran into her arm. If a drop leaked it would destroy her flesh to the bone. I aligned myself with her so exactly that if by miracle it could have entered me instead it would have done it. It did not. A good friend, an internist whose daughter-in-law had just finished chemotherapy for breast cancer, wrote:

Fear takes turns with rage and longing and magical thinking.

Think of red Adriamycin as a magical potion.

E-mail turned it into a piece of a poem and I posted it where I could see it every day.

In the absence of magic, in the absence of certainty, I did other things. I requilted her childhood comforter, a project I had put off since it fell apart when she was 11 or 12 (it had been mine before that) and put off again from her departure for college through the first apartment of her own and then past her marriage. Until then. Once I sang to her as she lay inert with Ativan, the sledgehammer sedative she took for the violent nausea and vomiting. She was falling asleep, and I was trying to live out my premonitory dream in a way that didn't add up to dying. As cold weather closed in, I thought a lot about the myth of Demeter, a story that I had always believed belonged to her daughter Persephone: a young woman leaves home to see the world and assume her life as a sexual being; her mother gets upset. Now I saw it as Demeter's story after all. Wild with grief and rage at her child's abduction to the underworld, she decrees that there will be no spring until Persephone is returned from the clutches of Hades. I found Chicago's gray, cold weather strangely comforting.

Through the fall and winter, the *New England Journal of Medicine* regularly included ads for Kytril, the second of the new, "miracle" antiemetics. The first, Zofran, had changed the use of Adriamycin from a nearly intolerable treatment to (with Cytoxan) a real alternative to the old six-month-long warhorse, CMF, and here was an improvement. The Kytril ad was beautiful: two and a half pages, dense study results, and a picture of a golden, glorious sundial promising—what? Emergence into the sunlight? Sunny summer days?

I tore it out and pinned it above my desk as a promise that biomedical knowledge is advancing and that she'd be all right.

But she wasn't all right. She took the miraculous drug (\$78 a pill) along with Ativan, the sedative of choice for detoxifying alcoholics, and the tranquilizer Compazene, but she had total-body nausea and vomiting that, while far short of the esophagus-rupturing damage Adriamycin is capable of, was still terrible. Despite adjustments in dosage, it worked even less well the second time, and her husband drove over icy rural Connecticut roads 15 minutes before the nearest pharmacy closed to buy Zofran, the "old" wonder drug, now reduced to \$29 a pill. \$740 spent on antiemetics in five hours. "What do people without insurance do?" my daughter exclaimed, knowing the answer: Zofran worked little better. With the third round of chemo, Compazene was replaced with a drug that unfocused her eyes and numbed her lower jaw. The vomiting went on.

Before the fourth round, I resolved to find some marijuana. Stephen Jay Gould wrote very little about his stomach cancer in the 1980s, but he described the experimental treatment he finally undertook, an early trial of Adriamycin. It made him so violently ill for so long that despite an adamant, lifelong resistance to any sacrifice of his rationality, he decided to smoke marijuana, and it enabled him to finish the treatment. I asked around and was promised some for my daughter. A generous ounce came stuffed into the spine of a recently published, respectable scholarly book by Lester Grinspoon and James B. Bakalar that argues for its medical use.¹⁵ My friend wrapped the book in innocent homemade gift paper and tied it with a raffia bow.

Scientific research has cast doubt on marijuana as an antiemetic. Certainly the legally synthesized pill form called Marinol has not been shown to work. To be reliably therapeutic, pot must be smoked. The fantastic recipe for a hashish-laced confection in Alice B. Toklas's *Autobiography* and its mundane brownie variant deliver the dose too slowly and in an imprecisely controlled amount. Smoke, by contrast, works immediately and is easily adjusted. But it needs to be started before chemotherapy, and two days before I was to leave, four days before her chemotherapy, snow began to fall. Would the plan work? Would I get there in time? Physical certainty is no greater than certainty of clinical knowledge. In a year of failing airlines, I had a ticket that was still good. The plane would surely head in the right direction, almost certainly land. But, besides the snow, who knew what else might intervene: a traffic jam, a slip on the ice, a cold or flu I could pass on to my daughter in her immuno-compromised state. What in life is ever certain until it's pared down so small that it can be controlled? So small that we might not think it

matters. That biomedical science can approximate that experimental control in a human body is a source of wonder. And gratitude, of course.

The wild card was a record-breaking blizzard. My flight was canceled. Airports throughout the East were closed for days. I felt sure I could drive there—less than a thousand miles. It was only snow, after all. But I had a saving suspicion that this was the operative choice, that I was equally likely to end in a snow bank. I decided instead to trust that the snow would stop in time, that runways and roads would be cleared. While the snow fell, I carefully unwrapped the book, peered into the spine, and read every word, even the chapters on glaucoma. Two days later, almost as soon as the first runway was plowed, I made my way through Newark Airport. It was the morning of my daughter's appointment, and I had the goods on my middle-aged professorial person, along with 8 ounces of redolent candied ginger, a friend's recipe for ginger snaps (reputed to quell nausea), and a pound of pungent coffee beans for my son-in-law. The drug dogs, if they were interested, didn't stand a chance. Two lanes of the interstate were open, one in the right direction. While I made my way toward the hospital, the oncologist was explaining to them why she hadn't been given Marinol and that, if she used marijuana, she should omit the Ativan, not the miracle antiemetic. We wouldn't have known. The last difficulty was that my daughter, despite her inner-city public high school diploma and an excellent liberal arts education, had somehow never learned to smoke. But she had married a preacher's kid with briefly exercised but first-rate bong-making skills, and she let us coach her, never getting high, always choking, but not vomiting anymore either. "It's time for your pot," I heard myself saying once and added a quick, ironically maternal "dear."

It worked. "It keeps the nausea down where it belongs," she reported to an older sister three days later. "Almost controls it."

She has done well. She went on working, taking a few days off for surgery and each chemotherapy and a half day to be fitted for the radiation mold and marked for the lasers. Friends, so recently assembled for their wedding, came and called, sent flowers and lucky objects, wrote and e-mailed. Before chemotherapy, her husband cut her long hair twice—first to shoulder length, then just below her ears. Then she went with a friend to a hairdresser and came away with a half-inch buzz cut. The effect was dazzling. As planned, the family assembled at their new house for Thanksgiving. She asked for hats and was given a closetful. Her bald head, on a lifelong science fiction reader, was shockingly beautiful. She observed. She thought. She learned. She sent regular e-mail reports—"The Baldness Bulletin"—to family and her friends. She was cut but scarcely mutilated. She recovered from the poison.

The burning left small, inextricable tattoos but no scars. April came. Her hair, beginning to grow back, approximated that dazzling buzz cut. Strangers asked her how she dared to do it, how she knew she'd look so great with such short hair. It had been an expensive hairstyle. Her energy, her creativity slowly returned. She and her husband were told to wait to have children, but they were young as parenthood is measured now. When the last treatment was done, the tulip bulbs they had sent me just before it all began were on the point of blooming. Spring.

Back at my writing table, computer on, notebooks open, I was afraid to read, really read, anything I had ever written about medicine's uncertainty. This book was mostly thought out, some of it written. I would easily have given it up in exchange for the certainty of her cure; I would deny everything I know about uncertainty if that could revoke its truth. But it also seemed that not to write the book would be a challenge to fate: a kind of hubris, still hoping for control. Instead, I have written it slowly, aware of the crisis of knowing that awaits those physicians who glimpse the disjunction between their idea of science and the medicine they practice. My hopes for medicine's science are challenged by what I know about medicine's practice. Research will increase our knowledge of breast cancer, I have no doubt. My daughter donated an aliquot—they still use that old-fashioned word—of blood to a study of the disease in very young women. We will know more: we already know more in the time since she made her choices. Will we know more in her lifetime? In time to save her if her cancer recurs? There's the question.

No one knows.

The practice of medicine, even in the era of postmodern cultural studies, is irreducibly material, real. The body is there: alive, beyond construction or representation, although unknown without those human acts. Bodies bear our identity, are our selves; they are socially constructed but not out of nothing. Bodies are language, mute appeal for recognition, for attention and care. Knowledge may be contingent, and existence may be too, but bodies are given: needy, playful, pleasurable, healthy, ill. They are interpreted, treated, sometimes cured. In its response to a suffering human being, medicine works upon the body, attends the person, at its best buoys the spirit. There is always the hope of going on, of knowing more.

Knowing in medicine, a science of individuals, is a two way, bidirectional matter. What can be drawn from the individual experience? Can it be generalized? Abstraction from the particular case is always a problem in medicine. What did her sudden loss of energy 10 days after the first chemotherapy mean? Why did her hands bruise easily for a long time afterward? The usefulness of established abstractions is a puzzle too: how does general, scientific knowledge

apply to her particular case? Why did marijuana, which has been declared ineffective, stop her nausea when two well-studied antiemetics with Food and Drug Administration (FDA) approval did not? Regular scans determined that Adriamycin didn't damage her heart. But what about other damage? The radiation that cures cancer causes it too. The statistical chances of developing leukemia after exposure are known rad by rad. What are her chances? How do they compare to those of an eastern European under Chernobyl rainfall?

When we know more, will we have control? And for everyone? There will always be mistakes, delays, and, worst, the persistent assumption that a lump in a 28-year-old's breast—or a man's—is surely nothing to worry about. Tumors will be more and less accessible: breasts will vary in size and density. The red Adriamycin now and then will leak. Women will vary in their willingness to be tested and, so long as the cost of tests stays elevated to amortize the oversupply of mammogram machines, in their ability to pay for it. Judgment calls on breast signs are still unstudied. Radiologists, for example, will differ in the interpretation of scattered calcifications: some will be "insufficiently suspicious"; some will cross a line and be biopsied. What constellation of bright specks becomes sufficiently suspicious? Where, what is that line? For which physician? With regard to which women?

Biomedicine will know much more: about the etiology, the genetics, the immunology, about timely and nonmutating diagnosis, effective treatment, cultural variants in diagnosis and treatment, and the psychosomatic components of the disease. Medicine will even learn more about the sensitivity and specificity of radiologists' interpretations. We may adopt a therapeutic practice from another country or discover for ourselves a prophylactic herb—or, who knows, go on eating broccoli to good effect. Someone may demonstrate, as David Spiegel was believed to have done for support groups, that meditation or prayer increase life expectancy for the seriously ill.¹⁶ Society may even learn to celebrate, as Audré Lorde challenges us to do, the one-breasted woman.¹⁷

All we learn will work better than what we know now. But it will never be certain knowledge. Medicine will never know everything for every case, and the knowledge physicians have will not always translate into effective action. It won't be control—nor even, in and of itself, power. I once teased a not-quite-40-year-old friend who had had a bone marrow transplant for breast cancer for worrying that her hands were a little stiff in the morning: did she think coming through all those deadly chemicals, all that suffering, would keep her from getting older? Not aging was the *other* possibility, the fate she had so far avoided. The rest of life's chances remained.

What acceptance of uncertainty I managed that year I learned from the younger generation. Ten days after the diagnosis, my daughter reported an

odd happiness: "At first I felt like it didn't matter what happened to me because all of a sudden I had this fatal disease. Maybe I should learn to rock climb because I wouldn't be so scared to die. After all, I'm going to anyway, perhaps sooner than expected. That was sort of interesting. Now I feel more like I should take Very Good Care of Myself—not because I feel fragile or accident prone, but because now that it looks like I'll get through all this pretty well, it would be a shame to get hit by a bus covered with Snapple ads on Third Avenue."

Just before the surgery, well before the physical toll began but with the therapeutic course more or less mapped out, her husband said, "The odds just seem to sharpen life's chances. They're bearable." He paused. "I'm thinking hard about the Quaker advice to be thankful in all things."

Beyond the search for accurate predictors, uncertainty remains—to say nothing of blizzards and the bus tearing past on Third Avenue.

For now, breast cancer is forever. Five-year disease-free survival is just that. There is no cure. I follow the biological research, now wonderfully energized by an infusion of funding. I admire the work of Hollis Siegler, who has made the postmastectomy body the theme of her art, and of Matuschka, who bared her scarred chest on the cover of the *New York Times Magazine* and dared us to look away.¹⁸ The genes BRCA-1 and BRCA-2 have been located and pathogenic mutations identified. Research has established that a normal, unmutated BRCA gene produces a protein that reduces tumors in mice. What all this means for my daughter I can scarcely bear to think. More is known now, but medicine is not simply these scientific discoveries. Further discoveries will not grant certainty to a particular patient. Far from being an objective observer of medicine, for a long time I alternately raged at it and wanted to give up all I know in exchange for simple trust.

She has had the best medical care there is. But the best treatment for breast cancer is still primitive, barbaric, and uncertain. Some day the women who have survived it will regale their granddaughters with accounts of the weird things done back at the turn of the millennium. How can I have faith in those treatments? Someone whose child is in peril and who knows too much about medicine is challenged by a version of the awful awareness that physicians somehow manage to overcome or ignore. It is the irony of medicine. Medicine is not a science; physicians must act. They must do the best they can, even when it is inadequate, even when they don't know all there is to know, even when there is nothing to do. So must we all.

CHAPTER TWO

The Misdescription of Medicine

To say that all human thinking is essentially of two kinds—reasoning on the one hand, and narrative, descriptive, contemplative thinking on the other—is to say only what every reader's experience will corroborate.

—WILLIAM JAMES

IF MEDICINE IS NOT A SCIENCE, WHAT IS IT?

Once in the mid-1980s, at a clinical research conference I attended every week, I observed aloud that medicine has the methodology, the rationality, of the social sciences. I meant to make a useable point about my colleagues' approach to some matter at hand, but it was quickly brushed aside as the mistake of a clueless outsider. Lucky thing. I was near the beginning of three years of clinical observation. Although I was a faculty member in the medical school, they regarded me (quite rightly) as a learner. Only the National Science Foundation grant funding my research guaranteed that I was worth setting straight. I did not know then that the eminent medical historian Henry Sigerist, himself a physician, had made the same observation. "Medicine," he said, "is not so much a natural as a social science." I've wondered since whether it would have made much difference if I had been able to cite Sigerist on the spot. My colleagues were clinical researchers concerned with establishing a solid academic reputation for what was then a new whole-patient, primary care specialty, general internal medicine. Although they undoubtedly revered the great men of medicine, I suspect they would have dismissed someone who had written in the 1940s and 1950s, before the advent of truly advanced, technologically sophisticated medicine.