to describe to me a new sensation she feels across the skin of her chest. It is vague and formless. There are no real words for it. I am attempting to understand how this symptom fits together with a few other recent problems she has reported. Morning vertigo. A funny feeling when she swallows. What picture is emerging here? What does her doctor say? She turns back my questions.

"Let's talk about the chapter you're writing now. What is it called?"

"Silence."

"Let's talk about that."

Like a jury's verdict or an adoption decree, a cancer diagnosis is an authoritative pronouncement, one with the power to change your identity. It sends you into an unfamiliar country where all the rules of human conduct are alien. In this new territory, you disrobe in front of strangers who are allowed to touch you. You submit to bodily invasions. You agree to the removal of body parts. You agree to be poisoned. You have become a cancer patient.

Most of the traits and skills you bring with you from your native life are irrelevant, while strange new attributes suddenly matter. Beautiful hair is irrelevant. Prominent veins along the soft skin at the fold of your arm are highly prized. The ability to cook a delicious meal in thirty minutes is irrelevant. The ability to lie completely motionless on a hard platform for half an hour while your bones are scanned for signs of tumor is, conversely, quite useful.
Whether it happens at a hospital bedside, in a doctor's office, or on the phone, most of us remember the event of our diagnosis with a mixture of photographic recall and amnesia. We may be able to describe every word spoken, the arrangement of photographs on the doctor's desk, the exact color of the office draperies—but have no memory of how we got home that day. Or we may remember nothing that was said but everything about the bus ride. The scene I happen to remember most vividly—and this must have occurred weeks after my discharge from the hospital—is unlocking my door and discovering that my roommate had moved out. She did not want to live with a cancer patient. This was my redefining moment. Fifteen years later, the sight of a bare mattress can still cause me to burst into tears.

In 1995, an estimated 1.2 million people in the United States—thirty-four hundred people a day—were told they had cancer. Each of these diagnoses is a border crossing, the beginning of an unplanned and unchosen journey. There is a story behind each one.

These diagnoses also form a collective, statistical story. When all the diagnoses of years past and present are tallied, an ongoing narrative emerges that tells us how the incidence of cancer has been and is changing. Changes in cancer incidence, in turn, provide key clues about the possible causes of cancer. For example, if heredity is suspected as the main cause of a certain kind of cancer, we would not expect to see its incidence rise rapidly over the course of a few human generations because genes cannot increase their frequency in the population that quickly. Or if a particular environmental carcinogen is suspected, we can see if a rise in incidence corresponds to the introduction of such substances into the workplace or the general environment (taking into account the lag time between exposure and onset of disease). Such an association does not constitute absolute proof, but it gives us ground to launch additional inquiries.

The work of compiling statistics on cancer incidence is carried out at a network of cancer registries, which exist in the United States at both the state and the federal levels. Theoretically, for each new cancer diagnosis, a report is sent to a registry. How a diagnosed person has experienced, reacted to, coped with, remembered, or repressed this stunning event are aspects not included in this accounting, of course. What each report does contain is a coded description of the type of cancer; the stage to which it has advanced; and the geographic region, age, sex, and ethnicity of the newly diagnosed person.

This incoming information is then processed, analyzed, audited, graphed, and disseminated by teams of statisticians. In and of itself, a head count is not very useful. The prevalence of cancer is higher now than it was a century ago, in part because there are simply more people now. There are also proportionally more older people alive now than ever before, and the aged tend to get more cancers than the young. Between 1970 and 1990, for example, the U.S. population increased by 22 percent, and the number of people over sixty-five increased by 55 percent. To eliminate the effects of the changing size and age structure of the population, cancer registries standardize the data. One way of doing this is to calculate a cancer incidence rate, which is traditionally expressed as the number of new cases of cancer for every 100,000 people per year. For example, in 1982, 90 out of every 100,000 women living in the state of Massachusetts were diagnosed with breast cancer. By 1990, the incidence rose to 112 out of 100,000.

These numbers are also age-adjusted. That is, the data from all the differently aged people from any given year are weighted to match the age distribution of a particular census year. Thus standardized, the statistics from various years can be compared to each other. In this way, we know that the 24 percent rise in breast cancer in Massachusetts that occurred between 1982 and 1990 did not happen because the population of New England women was aging. Alternatively, cancer registry data can be made age-specific: the percentage of forty-five- to forty-nine-year-olds contracting breast cancer can, for example, be compared with the percentage from a decade ago.

I have often wondered about the daily lives of tumor registrars, those souls responsible for keeping count of cancer's casualties. How strange it must be to monitor the thousands of cancer reports that flow into the registries every day in the form of paper files or elec-
tronic transfers. Surely I would want to pluck each one from the current and imagine the life behind the name. A seventy-five-year-old black woman from an urban area with advanced-stage breast cancer... or a forty-five-year-old white man from a farming community with chronic lymphocytic leukemia... or a seven-year-old girl with a brain tumor. I would long to sit down and talk with each one. "What has happened to you since your diagnosis? Are you getting good care? Are you surrounded by people who love you?"

As a group, tumor registrars seem like an affable lot—happy to converse about their work. Susan Gershman is the director of the Massachusetts Cancer Registry. Speaking to the public at a small, suburban library one Saturday afternoon, she was cool, well organized, and articulate as she stood in the tiny spotlight of the overhead projector, illuminated by her data. People in the audience took notes. Later, during the coffee and doughnut reception, she mentioned casually that her mother and father had both died of cancer when they were young, and I knew that she must bring a double perspective to her work.

Cancer registries publish their findings in thick annual volumes replete with tables and graphs, much like sports almanacs. My own reaction to these reports follows a particular evolution. At first examination, my eyes disassemble the data. In a graph displaying the age-adjusted rates for ovarian cancer, for example, I initially focus on the points rather than the lines that connect them. I wonder at the individual women whose lives are contained by the little black circles and gray squares that float in a white field of mathematical space. Gradually, as when I am looking at a picture that contains a hidden pattern, another way of seeing emerges from the page. Years of biological training kick in, and my eyes automatically begin to trace the slope of the lines, check the coordinates, imagine how the data might appear if displayed logarithmically.

In many ways, tracking the changing patterns of cancer incidence is not unlike tracking the patterns of ecological change. The statistical methods are certainly very similar—as are the vexing problems.

I once compiled old and current species inventories in order to monitor gradual changes in the composition of a Minnesota forest over several decades. During this time, some species became more common and others more rare. Sometimes I literally could not see the forest for the trees. The graphs constructed from my data showed clear trends often not apparent to me as I walked the deer paths that meandered among the pillars of the ancient canopy pines and through the green tangle of shrubs and saplings below. Without an exact count, I tended to overestimate the presence of rare plants because my delight at discovering them was more memorable than my efforts to note the existence of their more common neighbors. Perception can be misleading.

But I also had reasons to distrust parts of my data. To study time trends over half a century, one must rely on census counts conducted by many previous researchers, including some no longer living. If their system of coding and classifying differed significantly from mine, or if any one of us consistently misidentified certain species, then the changes indicated by my graphs were artifacts of our different techniques rather than reflections of a real biological shift. The seeming disappearance of a species that then suddenly reappeared in abundance five years later was a likely indication of a methodological snafu.

Cancer registry data are cursed with similar problems. We need these data because perception can mislead it. It may seem to us that more and more people are getting brain tumors or that breast cancer is striking women at increasingly younger ages, but what do the numbers actually show? Perhaps people with cancer are now simply more outspoken than their predecessors. The numbers, on the other hand, can also deceive. Earlier detection, changes in the rate of misdiagnosis, and alterations in coding and classifying tumor types mean that apparent rises or falls in incidence rates can be artificial. How to quantify and correct such problems is a recurring question at tumor registrars' conferences and in publications such as Cancer Registry News.

Breast cancer incidence, for example, rose by nearly 25 percent in the United States between 1973 and 1991. During that time, the introduction of mammography changed the way many U.S. women were diagnosed with the disease, presumably because malignancies could be identified before being felt as a lump. How much of this rise can be explained by the increased use of mammograms? To answer
this question, statisticians first look to see whether breast cancer incidence began to rise at the same time mammography became widely available. An internal audit of the data can also show whether groups of women with the highest rates of cancer are those receiving the most mammograms. And, since mammograms purportedly detect cancer earlier, statisticians can check whether the diagnosis of small breast tumors has been increasing faster than the diagnosis of large, advanced ones.

While still a matter of some debate, the most widely accepted estimate is that between 25 and 40 percent of the recent upsurge in breast cancer incidence is attributable to earlier detection. Underlying this acceleration exists still a gradual, steady, and long-term increase in breast cancer incidence that has just recently begun to level off. This slow rise—between 1 and 2 percent each year since 1940—predates the introduction of mammograms as a common diagnostic tool. Moreover, the groups of women in whom breast cancer incidence is ascending most swiftly—blacks and the elderly—are among those least served by mammography. Between 1973 and 1991, the incidence of breast cancer in females over sixty-five in the United States rose nearly 40 percent, while the incidence of breast cancer in black females of all ages rose more than 30 percent. Therefore, the majority of the increase in breast cancer cannot be explained by mammograms.

This kind of analysis is possible only when many years of data are available. Unfortunately, many state cancer registries are new; they cannot look back across fifty years as I could with my tree inventories. The Illinois State Cancer Registry was created in 1985. My own diagnosis, which took place in 1979, is therefore not part of the collective story of cancer in Illinois. Unless I die from the disease, I will never be officially counted among those touched by cancer. The first year of reliable data in the Illinois State Cancer Registry is 1986. Moreover, like many state registries, Illinois's is about five years behind in analyzing and publishing its data. Currently, therefore, Illinois residents have only a four-year picture of cancer incidence in their home state. Studying these time trends is like watching four minutes of a feature-length movie and trying to figure out the whole story.

Regional comparisons are often difficult because cancer registries in neighboring states can vary wildly in their length of operations. For example, Connecticut has the oldest functioning registry, one started in 1941. The Connecticut Tumor Registry provides one of the only truly long-term views of U.S. cancer incidence. Massachusetts, on the other hand, established its cancer registry in 1982. Nearby Vermont is one of ten states that had no cancer registry at all until 1992, when Congress established the National Program of Cancer Registries.

This patchwork of state-based registries is afflicted with another problem that we who count plants never have to worry about. People, unlike trees, move. Lifelong residents of one state, for example, may migrate to another upon retirement and become statistics in their new community. Without a comprehensive national cancer registry—which the United States does not have—state registries must rely on an elaborate system of data exchange. This is especially crucial for my elongated home state of Illinois, which shares a border with five other states. When faced with a serious health problem, many rural folk in the central and southern counties wind up being diagnosed across the Mississippi and Wabash Rivers because they would rather travel to cities in Iowa, Missouri, Indiana, or Kentucky than make the long trek north to Chicago. Illinois recently began trading registry data with its neighbors, thereby considerably boosting cancer incidence figures in its many east and west border counties.

Five state registries also contribute data to the federal cancer registry. The so-called SEER Program (Surveillance, Epidemiology, and End Results), overseen by the National Cancer Institute, does not attempt to record all cases of cancer in the country, but instead samples about 14 percent of the populace. SEER is a child of the War on Cancer as declared by President Richard Nixon and codified as the National Cancer Act of 1971. SEER has been collecting cancer diagnoses since 1973 and currently represents the states of Connecticut, Hawaii, Iowa, New Mexico, and Utah, as well as five specific metropolitan areas: Atlanta, Detroit, San Francisco–Oakland, Seattle, and Los Angeles. Everyone living in one of these states or cities who is diagnosed with cancer becomes a bit of data in the SEER Program registry, and their tumors stand in for all of ours.
Without a nationwide registry, no one can know exactly how many new cases of cancer are diagnosed in the United States every year. Instead, such numbers are estimated by applying rates from the SEER registry to the population projection for any particular year. To generate estimates before 1973, statisticians combine data from older individual state and city registries across the country. In this way, we now have reasonably reliable incidence figures going back to 1950.

Incidence data were not available to Rachel Carson when she first documented what she believed was the beginnings of a cancer epidemic. Instead, Carson focused on rising death rates from cancer. She was most disturbed by evidence that childhood cancer had jumped from the realm of medical rarity to the most common disease killer of American schoolchildren within a few decades.

Some researchers believe that mortality rates—which are also adjusted for age and population size—are still a more reliable indicator than incidence because they are less affected by changes in diagnostic technique. Death, after all, is certain and absolute. Moreover, causes of death, duly noted in all states of the union, have been tallied for far longer than tumors have been registered. We have a much deeper and wider view when we examine cancer trends over time using information gleaned from death certificates.

But mortality is also an imperfect measure of the prevalence of cancer. Not everyone diagnosed with cancer, thankfully, goes on to die from it. If treatment improves, mortality can decline even as incidence rises. This is certainly the case for childhood cancers, which, according to SEER data, jumped in incidence by 10.2 percent between 1973 and 1991 even as the death rate fell by almost 50 percent. Long-term trends show that childhood cancers have risen by one-third since 1950. Using mortality to measure the occurrence of cancer in children today would create a falsely rosy picture. Heroic measures may be saving more children from death, but every year more children are diagnosed with cancer than the year before. Increases are most apparent for leukemia and brain tumors. At present, eight thousand children are diagnosed with cancer each year; one in every four hundred Americans can expect to develop cancer before age fifteen.

Cancer among children provides a particularly intimate glimpse into the possible routes of exposure to contaminants in the general environment and their possible significance for rising cancer rates among adults. The lifestyle of toddlers has not changed much over the past half century. Young children do not smoke, drink alcohol, or hold stressful jobs. Children do, however, receive a greater dose of whatever chemicals are present in air, food, and water because, pound for pound, they breathe, eat, and drink more than adults do. In proportion to their body weight, children drink 2.5 times more water, eat 3 to 4 times more food, and breathe 2 times more air. They are also affected by parental exposures before conception, as well as by exposures in the womb and in breast milk.

The night before Jeannie’s death, I dreamed I traveled on a large boat with many other people. No shorelines were visible. Someone suggested I walk out onto the deck and get some sun. It’s too hot, I said. But I walked out anyway and discovered the weather very pleasant. Someone suggested I go for a swim. Too dangerous, I said. But I dove in, and the water was cool and crystalline. Dolphins circled me protectively. Back in the boat, I asked, Where are we? And someone smiled and handed me a map.

Driving across the Charles River to the hospital the next morning, I took the dream as a sign that I had accepted what I understood now to be imminent. But by the time I crossed the river again that night, I knew I had not and never would.

I wanted time to stop. I wanted all the clocks unplugged and the calendars nailed flat to the walls. It was April. I wanted no leaves to emerge from the buds that blurred the outlines of the trees.

Time had become such a strange commodity in the preceding month. On the surface, it had seemed to speed up as the vague progression of Jeannie’s various symptoms had suddenly accelerated. One day she found she could no longer type. A week later she could not turn doorknobs. The next week, buttons were impossible. Each loss was profound and irrevocable—the ability to write, to walk through a doorway, to undress.
But under the quick surface, in the deep water at the center of every hour and every moment, time was slowing down. Each meal, each conversation, each walk from one room to another unfolded with such deliberateness that an afternoon spent in Jeannie’s apartment was the equivalent of a week.

“You understand this is a terminal event.” A doctor’s voice on the magnetic tape of my answering machine. The dazed drive to the intensive care unit. Each heartbeat visible as data on a video screen. Slow drippings in tubes. An endless night. A blue-black dawn. A nurse’s voice, as though from a distant room: “Okay. These are her last breaths now.”

The whole concept of time was unbearable. I wanted to be back in Illinois in the middle of winter. I wanted to walk across frozen fields. No ocean. No leaves. No boats. She was gone.

All types combined, the incidence of cancer in the United States rose 49.3 percent between 1950 and 1991. This is the longest reliable view we have available. If lung cancer is excluded, overall incidence still rose by 35 percent. Or, to express these figures in another way: at midcentury a cancer diagnosis was the expected fate of about 25 percent of Americans—a ratio Carson found so shocking that it inspired the title of one of her chapters—while today, about 40 percent of us (38.3 percent of women and 48.2 percent of men) will contract the disease sometime within our lifespans. Cancer is now the second leading cause of death overall, and the leading cause of death among Americans aged thirty-five to sixty-four.

More of the overall upsurge has occurred in the past two decades than in the previous two, and increases in cancer incidence are seen in all age groups—from infants to the elderly. If we exclude cancer of the lung and restrict our view to the period covered by SEER, overall incidence rose 20.6 percent between 1973 and 1991, while mortality declined 2.8 percent.

Adding lung cancer to the picture, overall cancer mortality rose by 6.9 percent from 1973 until 1991—a difference that testifies to the deadly nature of this disease. Happily, the decline in smoking is finally affecting the cancer death rate. In a recent study of cancer mortality rates from 1991 to 1995, researchers found a small but decisive decline in overall cancer mortality (about 3 percent) during this period. The single largest factor behind this decline is a decrease in lung cancer deaths.

One-fourth of all cancer deaths are from lung cancer. Because the fatality rate is so high, lung cancer incidence and lung cancer mortality are very nearly the same statistic, and, in the United States, both closely mirror historical patterns of cigarette consumption. (Among American women, who began smoking in large numbers later in the century than did men, lung cancer mortality is still rising.) Overall, approximately 87 percent of the deaths from lung cancer can be attributed to cigarette smoking.

This also means, of course, that 13 percent of all lung cancer deaths occur among people who do not smoke. Thus, although smoking dominates the lung cancer picture, additional mysteries need sleuthing here. And, while smoking remains the largest single known preventable cause of cancer, the majority of cancers cannot be traced back to cigarettes. Indeed, many of the cancers now exhibiting swift rates of increase—cancers of the brain, bone marrow, lymph nodes, skin, and testicles, for example—are not related to smoking. Testicular cancer is now the most common cancer to strike men in their twenties and thirties. Among young men both here and in Europe, it has doubled in frequency during the past two decades. These increases cannot be attributed to improved diagnostic practices. Brain cancer rates have risen particularly among the elderly. Between 1973 and 1991, brain cancers among all Americans rose 25 percent. Those over sixty-five suffered a 54 percent rise.

Mortality and incidence do not always track each other. No cancers are increasing in mortality while decreasing in incidence, but several cancers have increased in incidence even as their death rates have declined due to more effective treatments. According to SEER data, these include cancers of the ovary, testicle, colon and rectum, bladder, and thyroid. There are eight cancers whose incidence and mortality are both on the decline: those of the stomach, pancreas, larynx, mouth and pharynx, cervix, and uterus, as well as Hodgkin’s disease and leukemia. Stomach cancer has been declining for decades,