

BARBARA'S CANCER DIARY

Throughout her life Barbara enjoyed excellent health, and she had none of the risk factors for pancreatic cancer except being over the age of fifty. She appeared decades younger than her age; when our daughters were in college, she looked like their older sister rather than their mother. She never abused her body: never smoked, never drank excessively, exercised regularly, had annual physical exams, and always maintained a healthy weight. Perhaps equally important, there was no history of cancer on either side of her family: nearly all her relatives lived to their eighties or nineties, including her parents and their many siblings. Given her health history, we were not worried at first when she began to experience minor stomach discomfort, which we assumed was caused by indigestion or acid reflux. Our concern changed to alarm, however, when she felt a mass in her abdomen a few days before her appointment with a gastroenterologist, to whom she had been referred by her primary care physician.

That was the moment when we began to fear that her illness might be serious, even life threatening. The gastroenterologist was also troubled, and he ordered a biopsy of her liver. And so when Barbara was diagnosed with metastatic pancreatic cancer—a redundancy since nearly all pancreatic cancer is metastatic by the time it is detected—on August 12, 2002, one day after our thirty-fourth wedding anniversary, she was given less than a year to live.

Fear, shock, and horror followed Barbara's grim diagnosis, and for the next several months we were in and out of the hospital, undergoing tests, consultations, and treatments. There is no cure for pancreatic cancer—it is one of the most virulent cancers, with a 99 percent mortality rate, and the standard treatment, chemotherapy, works only for a few months, if that long. As a colleague from another department told me after learning of Barbara's diagnosis, "everyone dies of pancreatic cancer," a statement that we knew too well and did not need to hear again. From the moment of her diagnosis we were on a roller coaster—there is no avoiding this overused metaphor. Unlike amusement roller coasters, in which thrill-seekers know in advance that they are paying for the illusion of danger, we knew that this ride would plunge Barbara lower and lower until its final crash. Barney Glaser and Anselm Strauss use the term

“dying trajectories” to describe the duration of a terminally ill patient’s disease. Barbara’s situation contained elements of two of the three categories used: expected quick death trajectory and lingering trajectory. (The third category is the unexpected quick death trajectory.)

There were, to be sure, a few unexpected highs, when the disease seemed to be retreating, thanks to an experimental pancreatic cancer vaccine that Barbara took for eighteen weeks. The vaccine supercharged the chemotherapy, giving her several additional months of life; but when she was forced to end the chemotherapy after six months, due to a dangerously low white blood cell count, the cancer spread with a vengeance throughout her pancreas, liver, and abdomen. All hope of remission vanished. Slowly and almost imperceptibly our attitude toward death changed from regarding it as a dreaded adversary, to be avoided at all cost, to welcoming it as an ally, signaling the end of the nearly twenty-month ordeal. Ironically, during the final weeks of her life, when all of us were embracing death, the roller coaster inexplicably stopped short of its final destination, leaving us suspended in air.

Barbara did not keep a diary when she was well, except when we were traveling or to record special events, but she began one early in November 2002, shortly after starting the experimental eighteen-week pancreatic cancer vaccine treatment. Her cancer diary records the physical and psychological state of her health along with the day’s activities: what she did, where she went, whom she saw, when she took her medications, and how she felt. The diary contains few psychological, existential, or spiritual ruminations, but it offers us insight into her personality—her love for life, her willingness to pursue any treatment that might offer hope, her connection with relatives and friends, her desire not to burden others, her mystical relationship to dogs, and her delight in the quotidian events of existence. She continued the diary until early January 2004, when, close to the end, she found it impossible to write. Her last entries list her pain level, which much of the time was high. We continued the diary until her death, noting the ever-increasing amounts of morphine during the last weeks.

Nearly every diary entry documents Barbara’s suffering, but her words fail to convey the intensity of her pain. As Elaine Scarry remarks, “Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language” (4). Scarry quotes a passage from Virginia Woolf’s essay “On Being Ill” in which the novelist acknowledges that although the English language can express Hamlet’s thoughts and Lear’s tragedy, it has “no words for the shiver or the headache”: “The merest school-girl when she falls in love has Shakespeare or Keats to speak her mind for her, but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry” (Woolf, “On Being Ill” 194). Scarry also notes that “physical pain does not simply resist language but actively destroys it, bringing about an im-

mediate reversion to a state anterior to language, to the sounds and cries a human makes before language is learned" (4). Scarry makes one more observation that is worth quoting, and which describes my role as Barbara's editor—others must speak for the person in pain: "Because the person in pain is ordinarily so bereft of the resources of speech, it is not surprising that the language for pain should sometimes be brought into being by those who are not themselves in pain but who speak *on behalf of* those who are. Though there are very great impediments to expressing another's sentient distress, so are there also very great reasons why one might want to do so, and thus there come to be avenues by which this most radically private of experiences begins to enter the realm of public discourse" (6; emphasis in original).

Barbara's life changed from the moment of her diagnosis. Her suffering began the moment of her diagnosis despite the fact, paradoxically, that she felt little pain at the time, only slight discomfort. As Eric Cassell points out, suffering and pain are not identical. "Suffering is an affliction of the *person*, not the body" (xii). Moreover, some pain, like childbirth, can be severe but not considered suffering, while suffering can be relieved in the presence of continued pain "by making the source of the pain known, changing its meaning, and by demonstrating that it can be controlled and that an end is in sight" (35). Relieving Barbara's suffering was always a more daunting challenge than relieving her pain. Pain and suffering are subjective phenomena, and, as Cassell explains, "anxiety, depression, and fear increase the experience of pain. It is important to understand that anxiety and its physiologic correlates do not cause the increase in pain; the increased or altered pain is part of the meaning of which the anxiety is also a part" (268). Cassell notes additionally that "suffering always involves self-conflict even when the source appears as external" (287).

Why did Barbara begin the diary? She knew that she was one of a handful of patients receiving the experimental treatment, and she may have felt compelled to keep a record of her responses to the vaccinations. She knew she was living in the shadow of death, but she tried as hard as possible to enjoy her remaining days. Her diary records both the dying of the light and the approach of darkness. She did not agree to have an autopsy after death, as she was asked to do when she signed the medical consent form for the vaccine, but she may have felt that a diary would serve a similar purpose. It is likely that she wanted to leave an account of the ending of her life for those who would be interested in learning more about her. She loved anything associated with the past—antiquing, restoring furniture, looking through old newspapers and magazines, saving childhood treasures—and she may have felt that her diary would one day be a reminder of her own brief existence. As Jason Tougaw remarks in his chapter on AIDS memoirs, silence equals death, and one of the "antonyms" for silence is writing (168). Chekhov's observation in his short story "Lights" supports Tougaw's argument: "You know, when a man of melancholy

disposition is on his own by the sea, or contemplates any scenery that impresses him with its grandeur, his sadness is always combined with a conviction that he'll live and die in obscurity, and his automatic reaction is to reach for a pencil and hasten to write his name in the first place that comes handy" (208).

By writing in her diary, Barbara was keeping alive her memory for those who read her daily entries. Writing is an affirmation of existence, one that we knew would end too quickly. As Robert Nash says, "To write is to demonstrate with a degree of certainty that we truly matter. Is it too extravagant to say, paraphrasing Descartes, that I write, therefore I exist?" (22). Margaret Atwood suggests, in a book aptly called *Negotiating with the Dead*, that "all writing of the narrative kind, and perhaps all writing, is motivated, deep down, by a fear of and a fascination with mortality—by a desire to make the risky trip to the Underworld, and to bring something or someone back from the dead" (156; emphasis in original). She mentions in particular the "quest for a lost beloved" (170) as an important motivation for writing. Writing is a bridge connecting past, present, and future, a way to maintain connection, continuity, and community.

Toward the end of her life, the diary reminded us when Barbara needed the next medication. I skimmed the diary briefly, before her death, hoping to find a passage that I could use for my eulogy; her comments regarding Arielle's wedding gown were perfectly in character. It was only after her death that I read the diary in its entirety. Nearly every entry describes daily suffering, but she tried her best to ignore the pain so that she could enjoy her remaining time.

Barbara did not know that I would use her diary entries in a book about her, but I doubt that such knowledge would have altered the contents of her entries. There is little in the diary that she would have considered private. With one exception, all her comments about relatives, friends, and colleagues were uniformly positive and appreciative. The exception occurred when she visited her elderly parents in Florida for the last time in June 2003. She loved her parents deeply, and was loved deeply by them, but she found it difficult to be with them at times—a reaction with which most "grown-up" children would surely identify. We often said jokingly to each other and to our children, "Shoot me if I ever become like my parents." As I grow older, I have become an easy target for our children, but they would have taken few shots at their mother. David Cook's observation is relevant here: "The perfect mother and the perfect father do not exist in this life, and I am glad for that. No child could stand them or get free from them" (qtd. in Theroux, 248).

To add to her woes, Barbara had a paralyzed vocal cord, which arose mysteriously following the September 11 terrorist attack. This was a stressful time for her, especially because it was during this period that we had to put to sleep our dog Ebony, who developed cancer. The death of a beloved pet was always devastating to Barbara, and I suggested that we purchase another dog,

which helped cheer her up despite her difficulty speaking. We learned that paralyzed vocal chords are caused by throat or lung tumors about 60 percent of the time; the rest of the time, as in Barbara's case, they arise from a virus, which generally disappears after six months. She needed repeatedly to clear her throat to speak, causing her much discomfort, and she could not be heard in noisy places such as restaurants or stores. Her throat surgery in late January 2003 was successful, but her vocal cord once again stopped working normally as soon as she returned to chemotherapy. "Voice has immediately been affected," she writes in the February 14 entry. "Feel like phlegm in throat. Sometimes when swallowing doesn't feel like things can go down quickly. Need to take small sips." After the diagnosis of pancreatic cancer, a radiologist looked at the CT scan taken shortly after she lost the ability to speak normally, and he could see, on the lower bottom of the scan, a suspicious mass in the liver. That mass did not cause the paralyzed vocal cord, but its appearance confirms that the pancreatic cancer predated the loss of her voice.

To understand the cancer diary, one must recognize that all Barbara's assumptions about a benevolent, meaningful existence were, in a single diagnosis, shattered forever. Ronnie Janoff-Bulman captures the shock and bewilderment that accompany a traumatic event: "Nothing seems to be as they had thought; their inner world is in turmoil. Suddenly, the self- and worldviews they had taken for granted are unreliable. They can no longer assume that the world is a good place or that other people are kind and trustworthy. They can no longer assume that the world is meaningful or what happens makes sense. They can no longer assume that they have control over negative outcomes or will reap benefits because they are good people. The very nature of the world and self seems to have changed; neither can be trusted, neither guarantees security" (62).

Existential Anxiety

"The idea of death," Ernest Becker states at the beginning of his landmark book on the subject, "the fear of it, haunts the human animal like nothing else; it is a mainspring of human activity—activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man" (ix). What makes death so paradoxical, Becker adds, is that we are "out of nature and hopelessly in it"; this dualism remains a terrifying dilemma: "Man is literally split in two: he has an awareness of his own splendid uniqueness in that he sticks out of nature with a towering majesty, and yet he goes back into the ground a few feet in order blindly and dumbly to rot and disappear forever" (26).

Barbara's existential anxiety was intense, but it never overpowered her courage. "Courage does not remove anxiety," Paul Tillich remarks. "Since anx-

iety is existential, it cannot be removed. But courage takes the anxiety of non-being into itself. Courage is self-affirmation 'in spite of,' namely in spite of nonbeing. He who acts courageously takes, in his self-affirmation, the anxiety of nonbeing upon himself" (66). Barbara's "courage to be" faltered but never disappeared. "Courage always includes a risk," Tillich continues, "it is always threatened by nonbeing, whether the risk of losing oneself and becoming a thing within the whole of things or of losing one's world in an empty self-relatedness" (155).

I often felt like I was dying during Barbara's illness. Many times I wished I could have died instead of her. One encounters wrenching existential survivor guilt: why her instead of me? A stark description of survivor guilt appears in *Cancer in Two Voices*, in which Sandra Butler reveals how she felt while caring for her partner, Barbara Rosenblum, who died of breast cancer at the age of forty-four. "The guilt of survival. The guilt of comparison. The guilt of randomness—being selected out as the one of us who will outlast the other. The one of us who will live beyond the 'us' that has been the foundation of my life. The guilt of the relief that it is not me" (142).

In *The Gift of Death*, Derrida highlights the impossibility of saving another person from death. "Because I cannot take death away from the other who can no more take it from me in return, it remains for everyone to take his own death *upon himself*. Everyone must assume his own death, that is to say the one thing in the world that no one else can *either give or take*: therein resides freedom and responsibility" (44; emphasis in original).

Barbara and I were fortunate that, with the exception of our freshman English professor and close friend Len Port, who committed suicide two weeks after our wedding, few of our immediate relatives and close friends died during our marriage. Until my father's death in 1998, all four of our children's grandparents were alive and in excellent health. One of the deaths that had the greatest impact on our family was not that of a person but of a dog, Cybele, who was run over by a truck in front of our house in 1977. It would be hard to exaggerate the traumatic implications of this loss both for Barbara and for Arielle. Barbara was so devastated that she vowed never to own another pet. She felt depressed for months, and it was only with the greatest reluctance that she eventually changed her mind.

Cybele's death had a greater effect on Arielle, who was only four at the time. Neither she nor her younger sister Jillian had experienced a major loss before our dog's death, and they did not understand what I was doing when I buried her in the backyard. They looked on curiously as I dug a hole and placed Cybele, who was wrapped in a blanket, in it. Barbara's tears distressed them, but they must have thought that they were observing a game, for they began laughing, and a few minutes later, as we were walking away, Arielle asked me when we would dig up Cybele so that they could play with her again. Follow-

ing Barbara's death, when I reread Kübler-Ross's *On Death and Dying*, I was struck by a passage that described Arielle's response to Cybele's death: "Many a parent will remember remarks of their children such as, 'I will bury my doggy now and next spring when the flowers come up again, he will get up'" (3).

A few months after Cybele's death, Arielle began to "shake," at first only slightly, then more noticeably. One day, when we thought she was having a seizure, we rushed her to our pediatrician, who tested her neurologically and then told us, reassuringly, that she was experiencing "separation anxiety," a response, he thought, to our dog's death. The nervous tics continued throughout kindergarten, elementary school, and middle school, intensifying during periods of stress. About a month after Cybele's death, Barbara told me about a conversation she had with Arielle, who began by asking her whether people die, just as our dog did. When she was told "yes," her next question was whether her mother would die, to which Barbara responded, "yes, but not until I'm very old." Barbara told Arielle what most parents tell their children, the unwritten law of nature that children bury their parents, but as Philip Roth observes in *The Dying Animal*, "The loveliest fairy tale of childhood is that everything happens in order. Your grandparents go long before your parents, and your parents go long before you. If you're lucky it can work out that way, people aging and dying in order, so that at the funeral you ease your pain by thinking that the person had a long life. It hardly makes extinction less monstrous, that thought, but it's the trick that we use to keep the metronomic illusion intact and the time torture at bay: 'So-and-so lived a long life'" (148–49).

Arielle's third question was whether she too would die one day, which Barbara answered in the same way. I was not present when this conversation took place, but I recall how distressed Barbara was when she reported it to me. Curiously, although she experienced a variety of nervous tics throughout her childhood and adolescence, Arielle no longer remembers them: she was amazed a few years ago when we brought up the subject. (Jillian remembers this clearly.) About a year after Cybele's death we bought another Belgian sheepdog, Pandora, who, like our next dog, Ebony, died of cancer. The deaths of the three dogs were almost too painful for Barbara to bear; she could not accompany me to our veterinarian when it was time to put them to sleep.

"We Had Absolute Trust in Each Other"

After Barbara's death, I came across a three-page essay in a manilla folder in our file cabinet that reveals both her grief following Cybele's death and her decision to acquire a new dog, Pandora, nine months later. Barbara wrote the essay, which I had never seen before, in 1988, and it can be understood fully

only by other dog lovers. The letter describes not only love and the inevitability of loss but also the strength of attachment bonds:

It was almost ten years ago when we went to New Jersey to get Pandora, and as I took her in my arms into the car to drive home, I cried, but then they were tears of happiness. That was June 1978. On September 7, 1977, Cybele had been killed. The shock and pain was so great that I told myself that I could never get another dog. The hurt was more than I could bear again. But as the months wore on, although the pain continued, I felt the need that perhaps only a dog lover can understand, to start all over again. I had to say goodbye yesterday to an animal, some would say, but to me she was a beloved friend and soul mate. So now I feel the need to write down my memories of her, some few isolated memories out of so many years to convince myself that her presence was real, that she was here for me to touch, to smell, to care for, and that having her with us was not just a dream. I could look into her eyes and as corny as it might sound we could communicate. We had absolute trust in each other. On our walks I would tell her she was the best dog. She was loving, affectionate, and trusting.

When we brought her home she was six weeks old and a little black fluff ball. We picked her up on the way back from Florida visiting my parents, and when we arrived in Albany our grass hadn't been mowed in weeks. She romped in the grass that towered over her. I remember, soon after we got her, taking a walk in the woods down behind Kraus Road. She was lumbering along, tripped, and did a complete somersault. We laughed watching a new beginning.

I vowed that I would stay detached this time, that this would be an outside dog. She slept on an old yellow blanket in the garage which she took great pleasure in chewing. Spread out, it looked like Swiss cheese. She didn't come into the house. I'd sit in the garage talking to her and she would lift her paw. It was her way of communicating. The plan of detachment lasted until December 1978. Until then the days were busy running back and forth along the back and side fences with [our neighbors' dogs] Ralph, Daisy, Duchess, and Gaby. All the running, though, eroded the sandy soil and uncovered fill which had probably been dumped and covered when the house was built. It remained undisturbed until now. It contained broken glass which we discovered only after Pandora seriously cut the pad on her foot. The first night after her surgery she slept in the house. I remember a fitful night of sleep listening for her every move. The next night she was back in the garage. The following morning I found the bandage partially chewed off and some of the stitches removed. She slept the rest of the convalescent period in the

house. I treated the healing pad with peroxide, and I became emotionally connected.

Barbara's statement that she could look into Pandora's eyes and communicate confirms an observation made by Alina Luna, a former doctoral student of mine, about the adage that eyes are the window to the soul: "Those whom I suspect desire to see the ultimate unseen, the soul, look to the eye as the window into which they may peer to gain knowledge of it. The eye becomes that through which one may glimpse a spiritual plane as well as a physical manifestation of the condition of one's soul" (2). There was nothing corny about Barbara's mystical kinship with her beloved companions; she would do anything for them, and they for her.

Barbara's cancer diary affirms the importance of connection, human and canine. Emotional connection is a theme of women's autobiography, as Judy Long explains in *Telling Women's Lives*. "The female subject often situates herself in a web of relationships, or tells her history in terms of relationships. Relationships are important in women's developmental trajectories, as well as at the point of self-writing. This female emphasis on connectivity is more than a narrative stance. The discourse of connectivity does not arise only in response to the challenge of autobiography; it has deep roots in female culture" (49). Female connection and relatedness lie at the center of feminist theories of development, and two influential books—Carol Gilligan's *In a Different Voice* and Nancy Chodorow's *Reproduction of Mothering*—argue that attachment plays a key role in women's lives. "The basic feminine sense of self is connected to the world," writes Chodorow, while "the basic masculine sense of self is separate" (169). Many empirical studies have demonstrated that women tend to be more empathic than men, and Mary Field Belenky and her associates believe that this greater empathy is the basis for women's "connected knowledge." Judith Jordan and her associates suggest in *Women's Growth in Connection* that empathic attunement and mutual intersubjectivity play a greater role in women's lives than in men's. Throughout her life Barbara was attuned to her family and friends, and her diary entries reveal this connection.

Barbara was always aware, however, of the inevitability of loss, and it made no difference to her whether loss involved a person or an animal; she felt the same grief, the same shock, the same trauma. She knew that she would have to experience the same process of bereavement for every dog we acquired—though she had no way of knowing that she would predecease our present dogs, Caleb and Sabrina. Just as she turned to writing to preserve her feelings of love, loss, and memories of the past, so, too, have I turned to writing for the same reasons—to capture her own special qualities. The most poignant aspect of her letter for me is the sentence, "So now I feel the need to write down my memories of her, some few isolated memories out of so many years to convince

myself that her presence was real, that she was here for me to touch, to smell, to care for, and that having her with us was not just a dream." This sentence characterizes my own efforts to write down my memories of *Barbara*, to convince myself that her presence was real and not just a dream.

I recall thinking when our dogs died that Barbara's grief would not have been greater had one of our children died. This was only a slight exaggeration. But Barbara's diagnosis was of another magnitude, like comparing a storm to an earthquake. From the moment of her diagnosis, we began researching experimental treatments. We knew that the disease is almost always fatal, but we hoped that she would be the exception. A pancreatic cancer Web site states that "pancreatic cancer is the fourth leading cause of cancer death in the United States. According to the American Cancer Society, in 2002, an estimated 30,300 Americans will be diagnosed with pancreatic cancer and approximately 29,700 Americans will die from the disease. Because symptoms are nonspecific, cancer of the pancreas is rarely diagnosed at an early stage leaving surgical removal of the tumor as a treatment option for only approximately 20 to 30 percent of pancreatic cancer patients. The average survival time following diagnosis of patients with metastatic cancer of the pancreas is three to seven months."

Barbara and I agreed, immediately after her diagnosis, to share with each other whatever information we learned about pancreatic cancer, but within a few days she told me that she wanted to hear only "survivor stories," of which there were practically none. She could not bear to read anything about cancer, cancer treatment, or death. I did all the research, using the Internet every day as well as reading articles in newspapers and in cancer magazines. Relatives and friends kept us informed of their own research. There are advantages and disadvantages to patients (or their caregivers) researching their diseases. As a metastatic cancer patient observed in a cancer guide, the advantages are that "it could save your life," "it's empowering," and "you can make a more informed decision." The disadvantages are that "it can be difficult and intimidating," "you might make the wrong decision," "you will have to confront the statistics," which, in the case of pancreatic cancer, are relentlessly grim, and "there might not be any better treatment." During Barbara's illness, I accumulated so many photocopies of articles on pancreatic cancer that they filled the top drawer of my two-foot file case. Each week I asked Barbara's oncologist, Fred Shapiro, about his response to whatever new and exotic treatment I had come across in my reading. We were fortunate that Fred always gave us as much time as we needed, and he patiently answered all our questions. The problem was that the cancer was so advanced that there were no good treatment options.

Throughout her illness Barbara was treated at St. Peter's Hospital, a Catholic facility in which the images of Jesus, Mary, and the crucifixion were ubiquitous. Most of the nurses and staff wore crosses, and they always told us that Barbara was in their thoughts and prayers. At first the religious atmos-

phere seemed foreign to us, but we soon felt comfortable there. Fred Shapiro was, like Barbara, a New York City Jew, and perhaps for that reason we both felt close to him culturally and temperamentally. Fred was, in his appearance and mannerisms, iconoclastic: patients called him by his first name; he had a completely shaved head; he often wore outrageous ties; he played electric harmonica in his own blues band, "MoJo Lightning," whose concerts we attended when Barbara was still feeling well; and he was adored by his nurses and staff. Though he told us early on that he was not a "touchy-feely" doctor, meaning, he elaborated, that his patients do not walk away from him believing that they will all be cured, he was never too busy to answer our many questions or to offer his opinions on the new experimental treatments for pancreatic cancer that I had researched on the Internet. Fred would call us day or night, weekdays or weekends, with the results of the latest CT scans and blood tests, and he empathized with Barbara when she began experiencing disabling anxiety and panic attacks. "I would be a basket case if I were in your situation," he told her, a comment that brought a rueful smile to her face.

Immunotherapy

Much has been learned about this deadly killer, but progress is agonizingly slow. We became aware of immunotherapy through my cousin Glenn Dranoff, a Harvard University Medical School professor who is doing pioneering work on vaccines for melanoma and lung cancer. Glenn is a gentle, kind, and modest person, the rare individual who is both extraordinarily brilliant and self-effacing. Immediately after Barbara's diagnosis, he spoke to a colleague at Johns Hopkins University, Elizabeth Jaffee, who is working on a pancreatic cancer vaccine. Glenn called me up within a few days and said: "I have some news for you, which might cause you to reevaluate your disbelief in God." The news was that a clinical trial of Jaffee's vaccine was being tested at five sites in the country, one of which was at St. Peter's Hospital in Albany—on the same floor that Barbara was receiving weekly chemotherapy. There is so much research going on that even conscientious and devoted oncologists like Fred cannot keep up with all the new developments, and he was unaware that a clinical trial was occurring just a few feet away from his office. The Albany site was treating five patients and was closed, but Barbara was accepted into the clinical trial through Glenn's influence. His news did not convert me into a believer, but he was a godsend to us.

At the time Barbara was accepted into the trial, a patient could not be on any other active treatment, including chemotherapy, since researchers would not be able to determine whether the patient's progress, if any, was due to the vaccine. Fred was initially skeptical of the vaccine, mainly because

he had no experience with it and because he was reluctant to take Barbara off chemotherapy for several months, but he deferred to Glenn's judgment. Barbara and I grasped at any hope for remission, if not cure, and Glenn told us that he thought the vaccine offered the most promising experimental treatment. Both Fred and Glenn consulted with each other and agreed that Barbara would have six weeks of chemotherapy, which might result in a modest shrinking of the tumors, and then begin the eighteen-week vaccine trial, after which she would return to chemotherapy. Throughout this time she would be closely monitored.

The phase II clinical trial into which Barbara was accepted was for patients with inoperable metastatic pancreatic cancer. The theory behind immunotherapy is simple: if the patient's immune system can be heightened, and if cancer cells, which somehow are invisible to the body's immune system, can be clearly marked and targeted, then the body's white blood cells can destroy the cancer. The devil lies in the details. Barbara's vaccine, known as GVAX, is non-patient specific, developed by a private bioengineering firm, Cell Genesys, as an "off-the-shelf" pharmaceutical product. The vaccine consists of pancreatic cancer cells that are irradiated, so that they cannot reproduce, and then genetically altered to secrete granulocyte-macrophage colony stimulating factor, GM-CSF, a hormone that increases the immune system's white blood cells and makes them more active. Because the gene for GM-CSF is inserted into the pancreatic cancer cells, the vaccine is a form of gene therapy. As Glenn notes about GM-CSF-based cancer vaccines on his Dana Farber Cancer Institute home page, "We have shown that vaccination with irradiated tumor cells engineered to secrete granulocyte-macrophage colony stimulating factor (GM-CSF) stimulates potent, specific, and long-lasting anti-tumor immunity in multiple murine tumor model systems. . . . The mechanism underlying the stimulation of anti-tumor immunity likely involves improved tumor antigen presentation by dendritic cells and macrophages recruited to the site of immunization."

Barbara's vaccine treatment called for sixteen injections every three weeks, over a period of eighteen weeks, for a total of ninety-six injections. There were thus six treatments of sixteen injections; the treatment sites alternated between arms and thighs. The vaccine trial would be daunting to most people, not only because of the injections themselves, which felt like bee stings, but also because of the immediate skin rashes they produced, which lasted for days and became inflamed and itchy. Throughout her life Barbara was squeamish about blood, needles, and pain—she had never donated blood for this reason—but she displayed no reluctance to receive the shots. Michele Butler, the nurse and research coordinator in charge of the vaccine trial, told us that Barbara was her best patient, both in terms of her ability to withstand pain and, as it turned out, her body's strong immunological response to the injections.

We never found out the national results of the GVAX pancreatic cancer vaccine trial, though we were told a few months after Barbara ended the vaccine treatment that she was the only Albany patient still alive. In fact, only one of the five Albany patients lived long enough to complete the trial, after which he soon died. Later we learned that subsequent clinical trials allowed patients to remain on chemotherapy while receiving immunotherapy, a recognition that the vaccine in its present form works best in combination with other active treatments.

Barbara felt increasingly ill during the clinical trial. We assumed at the time that the steady growth of the cancer in her liver made her sick, but Glenn told us when the treatment was over that Barbara's nausea, fatigue, and weakness were caused not mainly by the cancer but by her supercharged immune system. "When people become ill with the flu," he explained, "it's not because of the illness but because of the immune system, which is fighting the flu." He did not tell us this during the treatment for fear that it might raise false hope. Scarcely a day went by during this period without Barbara feeling abdominal pains, bloating, anxiety, fatigue, and depression. She generally did not reveal the extent of this discomfort to anyone except to me and, to a lesser extent, our children, but the diary makes clear that she seldom had more than a few hours of relief. During her illness I could see Barbara's fierce determination to live, but this became even more striking as I read her diary.

Barbara was always keenly aware of her body, and during her illness she recorded in detail how the injections affected her health. Her opening entry, dated November 5, 2002, describes her reactions to the first series of injections. "Oct. 25—received the first of 16 injections of vaccine—8 per arm. By the next Friday when Arielle came they were all hard welts which were extremely itchy. Now, the following Tuesday, it looks like 2 on the left are reduced in size. Saturday Arielle and I raked, then went shopping & I was exhausted by 5:00. The next day we drove to Alfred & Sybil [Nadel] in Rhinebeck and I felt uncomfortable—stomach ache—most of the day. Monday slept late, rested after walk & worked about 11:30–2:30—then dinner at the Mankes [our next-door neighbors]. Today feeling very tired from right after breakfast. Is it the vaccine working?" On November 19 she notes her father's eighty-ninth birthday. "Woke up feeling optimistic but then the fear creeps in—feeling well. Legs not too uncomfortable—just a little itchy."

Barbara's body responded immediately to the first set of sixteen injections and to all subsequent injections. This was encouraging because it indicated a strong immunological response. She received the second series of injections on November 15, this time on her thighs, and the November 18 entry summarizes how she felt. "By Friday night thighs became very hot & inflamed. Then by Saturday it was painful to walk. Spent the day lying down. In the evening applied cold wash cloth to thighs to draw off the heat. Saturday night while sleeping the area became very itchy. Sunday was better, not so painful but was

listless and listened to Marylynn's [healing] tape for a few hours & slept a few hours. Went to dinner at the Ryans [dear Albany friends] after taking a shower at 4:45 pm. Felt better there. Had a hard time falling asleep—maybe the decaffeinated tea still had some caffeine. Slept late—almost to 10:00. Went to work about 11:30. Very fatigued & nauseated. Took a Promethazine, which helped nausea. Home about 2:30—after meditation and nap had intense itching on my legs. Took two Benadryls & used cold wash cloths which made it bearable.”

The first CT scan during the vaccine treatment, in December 2002, indicated relatively good results: one of the liver tumors increased only slightly, while the other tumors remained the same size. Barbara and I were disappointed because we were hoping for a miracle—remission—but Fred and Glenn nevertheless were encouraged. From the beginning of Barbara's diagnosis, and until near the end of her life, the detectable cancer was confined to her liver. The August 2002 CT scans indicated a tiny shadow in her pancreas, the presumed primary site, where the cancer had first developed. The first diagnosis was pancreatic cancer, because of the slight shadow in that organ, but when the radiologist, pathologist, and oncologist looked at all the tests, they concluded that the suspicious shadow in the pancreas was too small to be definitively judged cancerous, and so they changed the diagnosis to “primary unknown.” We sent the CT scans to Glenn, who showed them to his colleagues. They concurred with the Albany physicians. The disappearance of the primary tumor is unusual, occurring in only about 1 percent of patients. No one knows precisely why primary tumors disappear spontaneously; it might be, Fred speculated, that the cancer's blood supply dries up.

A smile broke out on my face when Fred informed us, in the middle of August 2002, that the diagnosis was now “primary unknown.” I assumed that any cancer had to be better than the dreaded pancreatic cancer. Unfortunately, neither Fred nor Glenn shared my excitement. They told us that once the primary cancer spreads to the liver, as it had done in Barbara's case, the presumption is that cancer cells are circulating throughout the body, even though they may not be detected by CT and PET scans or blood tumor markers. (Barbara's blood tumor markers were negative every time they were checked, even at the end of her life, when the cancer had spread throughout her abdomen.) When we asked about the possibility of a liver transplant, Fred told us that there were too many tumors, in too large an area, for a liver transplant to be successful. And besides, Fred added, by the time cancer spreads to the liver, the presumption is that it is everywhere. I recall reading an article by a pancreatic cancer patient who used the analogy of placing a chicken in a pot of boiling water and then removing the chicken after an hour or two: what's left in the pot is chicken soup. Presumably, that deadly chicken soup was circulating throughout Barbara's body. Her final CT scan, in December 2003, revealed

that a large mass was now in the pancreas, confirming the doctors' initial suspicion that the cancer began in that organ.

Barbara and I continued to assume, despite the doctors' statements to the contrary, that a diagnosis of "primary unknown" is better than that of pancreatic cancer. We took hope wherever we could find it. We wanted and needed to believe that her immune system momentarily had laid down its guard but now was strong again, battling the secondary cancer in her liver. The initial chemotherapy stabilized Barbara's condition. The CT scans taken in the middle of January 2003 indicated that one tumor continued to grow modestly, increasing from 2×2.5 to 3.5×4 cm, while the other tumors remained the same size. Relative stability was the next best result if we could not have remission.

Until near the end of her life, the psychological challenge of cancer was more daunting than the physical challenge. "Awoke feeling well," she writes on January 2, 2003, "but was afraid to get out of bed"—a fear that she battled daily. Whereas many terminally ill cancer patients are afraid to go to sleep at night, fearing they might not awake, Barbara had the opposite fear, as the January 8 entry confirms: "Woke about 9:30. Felt good and was afraid to get out of bed for fear of feeling badly once up." She expressed this fear in many entries. Nevertheless, she did not let this fear stop her from continuing her life.

Barbara was exposed throughout the twenty months of her illness to a barrage of tests and examinations, including blood tests, liver function tests, CT scans, MRIs, and PET scans. The preparations for these tests sometimes made her ill—the fluid she drank preceding the CT scan invariably produced diarrhea—but she never complained about any of these tests. Sometimes we would laugh dryly when we came across a word whose meaning was counter-intuitive, as when a radiologist described her brain as "unremarkable," meaning, that it showed no evidence of cancer. Words that would ordinarily have transparent meaning suddenly assumed portentous significance, as Janet Hobhouse describes at the end of her novel *The Furies*, when she discovers she has ovarian cancer: "All words were scanned for some double entendre, some secret message from out there. Taxis passed many street signs and you read them, sometimes with irony, sometimes not: Passenger Terminal, No Exit, No Through Road, Road Narrows, Dead End, Complete Stop Ahead" (287).

Maintaining Hope

Maintaining hope in a hopeless situation is perhaps the ultimate challenge for a terminally ill patient. It is a psychological and existential challenge. For the first sixteen months of Barbara's illness, I felt that one of my major roles was to be her cheerleader, and each day I did everything I could to convince her—and myself—that she might be one of the exceptions. "The disease is confined

to your liver," I would tell her, though we both knew that cancer cells were circulating throughout her body. "You're holding your weight, and that's a very good sign," I reminded her nearly every day. "You have excellent genes, and you've always been healthy," I repeated, like a mantra. "You're still feeling well, and Fred and Glenn say that's the best indication of how you're doing clinically," I said truthfully. "You're taking a new pancreatic cancer vaccine, and you've been doing great," I added. She was helping herself in every way possible. She was an exemplary patient, just as she was exemplary in every other way.

Barbara and I both knew about the importance of maintaining hope—hopeful patients do better than hopeless ones. There is growing evidence that the immune system is controlled, directly or indirectly, by the brain. "One of the most widely accepted explanations of cancer," Bernie Siegel writes in *Love, Medicine, and Miracles*, "the 'surveillance' theory, states that cancer cells are developing in our bodies all the time but are normally destroyed by white blood cells before they can develop into dangerous tumors. Cancer appears when the immune system becomes suppressed and can no longer deal with this routine threat. It follows that whatever upsets the brain's control of the immune system will foster malignancy" (68). Many studies demonstrate a link between patients' hopefulness and positive outcomes. Daniel Goleman, a contributing science writer to the *New York Times*, has written extensively on the growing scientific evidence supporting the mind-body connection. In "Afflictive and Nourishing Emotions," he describes a classic research study conducted by Dr. David Spiegel at Stanford University. Women with advanced breast cancer were divided into two groups, both of which received the standard medical treatment. Unlike patients in the control group, those in the experimental group also met for group therapy once a week for a year:

They talked about their feelings concerning the cancer and what it meant for their families. They became very close as a group, with a lot of love being generated in these meetings. They also learned a self-hypnosis technique for pain control.

The researchers then studied the death rate of both groups over the next ten years. After two or three years, the groups started to show differences. The women who had participated in group therapy died less rapidly than those who got only the regular medical treatment. After ten years, the death rate was twice as great in the group that only had medical treatment. (42–43)

The mind-body connection is maddening to catastrophizers, especially when they realize, as Barbara and I did, the self-fulfilling nature of pessimistic thinking. Martin Seligman's theory of depression is that it arises not mainly from genetic or biochemical forces but from "learned helplessness," the belief

that one has no control over his or her life. Seligman concedes that depressed people tend to see reality more accurately than nondepressed people; nevertheless, the latter tend to feel healthier and to be more successful in a wide variety of areas than the former: "Life inflicts the same setbacks and tragedies on the optimist as on the pessimist, but the optimist weathers them better. . . . The optimist bounces back from defeat, and, with his life somewhat poorer, he picks up and starts again. The pessimist gives up and falls into depression. Because of his resilience, the optimist achieves more at work, at school, and on the playing field. The optimist has better physical health and may even live longer. Americans want optimists to lead them. Even when things go well for the pessimist, he is haunted by forebodings of catastrophe" (207).

Seligman suggests that optimism heightens the immune system, encourages people to seek medical help and maintain treatment, and helps them remain connected to others. He devotes the last chapter of his book *Learned Optimism* to a discussion of effective cognitive "talking back" strategies to pessimistic thinking, including "disputation," finding a positive explanatory system for adversity. He concludes by admitting that pessimism has a role to play in life. We must have the "courage to endure pessimism when its perspective is valuable. What we want is not blind optimism but flexible optimism—with its eyes open" (292).

Seligman would doubtlessly acknowledge the grimness of Barbara's situation and the difficulty of maintaining flexible optimism. From the beginning of her diagnosis, Barbara struggled with anxiety, depression, and panic attacks. Apart from seeing our psychotherapist, she was treated by a psychiatrist, who prescribed powerful medications: Ativan and Klonopin for anxiety and panic attacks, Paxil and then Lexapro for depression. She became increasingly dependent on these medications, as she did on morphine, but "dependency" and "addiction" are not problems about which terminally ill patients need to worry. Beginning in December 2003, our physicians told us that we had run out of treatment options, and for the remaining four months of her life, the nature of our hope changed, from hope for remission to hope for a speedy and merciful death.

Barbara was still working in the winter of 2003, though only a few hours each day, waiting for a retirement incentive that soon came. She worked throughout her life, first as an elementary school teacher and then as a computer analyst. She looked forward before her illness to retiring in her early sixties, so that she could devote herself to her many interests and talents, but fate proved otherwise. "I retired as of February 22, 2003," she wrote, trying to be as optimistic as possible. "I hope this is the beginning of an uphill [fight]." She was disappointed that she had to retire but grateful for the farewell party that her colleagues made for her three months later, when she was feeling better: "Today at 10:30 my coworkers made a party for my retirement in-house on the fifth

floor. Jeff and I were escorted up by Pat through the orange alert [a period of heightened national security]. Everyone entering the building had to be pre-approved. A few months ago I couldn't have imagined doing this—between not feeling well and the emotions involved. But now I was prepared and although I was teary eyed the good feelings of all were very special. Ted Hallman [the deputy commissioner of the New York State Department of Criminal Justice Services and himself a cancer survivor] came in especially for it. We shared some hugs—Hugs with everyone! It was a giant receiving line and every hug was positive energy flowing into my body. Jeff spoke to all about my progress. He was wonderful and articulate as always. Tom Meyer presented me with a certificate and spoke very tenderly about my presence on the team. Dawn, Dave O, Cathie Bryant, & Leslie Robbins were there from OTDA—my first 17 years. They presented me with a beautiful Waterford Vase & gift certificate to Joanne's [a fabric store], which will be wonderful therapy!"

Each day in the late winter and early spring was occupied with treatment, medical and otherwise. In addition to the sixteen injections she received every three weeks, she took advantage of other healing techniques. Like a growing number of cancer patients, Barbara availed herself not only of standard and experimental medical treatments but also alternative healing practices, including the complementary therapies that seek to mobilize the body's vital energy. She thus enlisted the help of both "vigorous science," with its Western-based assumptions, and "energy healing," growing out of an ancient Eastern spiritual tradition. She went regularly for acupuncture and massage therapy. She visited our friend Herb Weisburgh whenever possible so that he could mobilize her energy fields through the art of therapeutic touch. Central to Hindu and Eastern religion and philosophy is the belief that there are seven chakras, or energy centers, in the body. These energy fields can be stimulated by the use of mantras during silent meditation. There are seven single-syllable Sanskrit words that correspond to the seven chakras, including the two on which Barbara concentrated, *vam*, the solar plexus, which was the area of the cancer, and *ham*, the throat, the region of the paralyzed vocal chord. "To Herb's for healing touch at 1:00," she writes on April 22. "He had me practice turning on 'switch' & off for energy in top of head chakra & showed me the difference in energy levels of the heart chakra depending on whether I thought of a happy rather than a sad thought which slowed energy." A week later she adds, "Herb creates such a supportive & positive environment. He has the ability to relax me and make me feel that I can conquer this." Every morning and evening she practiced mindfulness meditation, which, as defined by Sharon Salzberg and Jon Kabat-Zinn, is "simply learning to have an open accepting attitude toward whatever arises in one's mind, while watching the movements of the mind. This very simplicity makes it useful as a stress-reducing technique" (107). She also practiced "visualization," a technique in which she tried to mobilize her

immune system. She spent several minutes of each day visualizing white blood cells destroying cancer cells or, alternatively, visualizing serene images such as waterfalls.

Friends did Internet research for her and alerted us to new experimental treatments. “[Our friend] Joyce [Weiss] received an article from Roswell Park [a cancer hospital in Buffalo, New York] about Radio Frequency Ablation—will bring it over.” The next day she read the article and was visibly distressed. “It freaked me out reading it.” She also began “juicing”—drinking large amounts of carrot juice, which she extracted from an electric juicer that we had bought immediately after her diagnosis. She drank so much juice that within a few weeks her skin turned orange. “Everything in moderation,” both Fred and Glenn told us, in gently reproving voices. But moderation in an extreme situation is nearly impossible.

The Healing Power of Music

We also attended as many classical music concerts as possible. Music has always been one of our great passions, and we have spent countless hours listening to classical records, compact disks, and National Public Radio. A stately baby grand piano sits in our living room, bequeathed to us by Barbara's parents when they moved from Brooklyn, New York, to Florida in 1975. Music's healing power is legendary. As Maureen McCarthy Draper observes, “A woman I know who survived pancreatic cancer said that after trying everything else, she turned to Beethoven's last string quartets for consolation. Finally, with this music, she was led to an acceptance and understanding that were necessary to her healing. In addition to inner healing, it happened that her cancer went into remission, and she now works in a hospital as a music therapist” (152). Kay Redfield Jamison writes in her book *Exuberance* that “music activates the same reward systems in the brain that are activated by play, laughter, sex, and drugs of abuse. Brain imaging studies show that pleasurable music creates patterns of change in the dopamine and opioid systems similar to those seen during drug induced euphoric states. . . . Music not only activates the reward system, it decreases activity in brain structures associated with negative emotions” (160).

Bernie Siegel plays classical music in the operating room: “Music opens a spiritual window. When I first brought a tape recorder into the O.R., it was considered an explosion hazard. But we ran it on batteries, and then the nurses and anesthesiologists felt so much better that, if I forgot my music, they'd ask for it. Now there are tape recorders in almost all the operating rooms in New Haven” (50). William Styron reports in *Darkness Visible* that when he had reached the bleakest moment of suicidal depression, prepared to end his life, he was saved by hearing a soaring passage from Brahms's *Alto Rhapsody*. “This

sound, which like all music—indeed, like all pleasure—I had been numbly unresponsive to for months, pierced my heart like a dagger.” The music helped him to realize that he “could not commit this desecration” on himself (66–67).

Why is music so powerfully therapeutic? Draper’s explanation is that music has an “uncanny capacity to suggest . . . universal narrative patterns of exploration and discovery, loss and triumph” (57). Invoking Rainer Maria Rilke’s *Sonnet to Orpheus*, she observes that “grief should walk only in the footsteps of praise, for joy already understands what grief is still learning—life is to be praised” (81). The Greeks, Draper reminds us, knew about the healing power of music—“In the Greek mind, medicine and music were so intertwined that Apollo presided over both realms” (187). As much as I love literature, only music can transport me to otherworldly realms. I feel something akin to an out-of-body experience when listening to the choral movement of Beethoven’s Ninth Symphony or Bach’s *Orchestral Suites*. I do not experience religious awe upon entering a church or synagogue, but I never fail to be spiritually moved when listening to Bach’s *Mass in B Minor*, Beethoven’s *Missa Solemnis*, and the glorious requiem masses by Mozart, Brahms, Faure, and Verdi. Barbara experienced the same musical joy that I do, but unlike me—I cannot read a note of music—she had extensive musical training, even performing in a piano recital at Carnegie Hall when she was a teenager, and so her passion for music was enhanced by technical understanding.

One of the books in Draper’s bibliography, Mitchell Gaynor’s *Sounds of Healing*, piqued my interest, and I was fascinated to learn about the growing scientific evidence of music therapy. A medical oncologist trained in mainstream medicine, Gaynor also uses complementary modalities in his approach to healing and wellness, particularly the medium of sound. “I have long since come to accept nontraditional, holistic approaches as necessities, rather than personal options, that must be integrated with the care and treatment of my patients” (4). The sounds of healing include not only music but also silent chanting during meditation and visualization through guided imagery, all of which, Gaynor notes, have been demonstrated, through the new field of psychoneuroimmunology, to strengthen the body’s immune system. I was intrigued by his discussion of *entrainment*, the tendency in the universe toward harmony:

The seventeenth-century Dutch scientist Christian Huygens noticed that the pendulums of two clocks, hung side by side, would begin of their own accord to swing to the same identical rhythm. The reason that entrainment occurs is that the more powerful rhythmic vibrations of one object, when projected upon a second object with a similar frequency, will cause that object to begin to vibrate in *resonance* with the first object. We human beings also react in resonance with the vibrations and fluctuations in our surroundings, so it follows that our physiological function-