

DYING *to* TEACH

~ A MEMOIR OF LOVE, LOSS, AND LEARNING ~



JEFFREY BERMAN

DYING TO TEACH

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A MEMOIR OF LOVE, LOSS, AND LEARNING

Jeffrey Berman

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For Clark Dougan, Priscilla Claiborne, James Peltz, and Jane Bunker,
My Editors and Friends

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ON THE ANNIVERSARY OF HER DEATH

(in memory of Barbara Berman)

You expected she would
have been gone by March,
but instead, dying was tenacious,
and hung on, making
her belly distend, as if it was
suddenly ripe, again
with daughters.

Today, two years later,
a cruel April wind
roars and carries off the seared
blossoms that now
flood my yard,
like heaves of snow, glinting
with atomistic hooves of gold—

The earth was not ready for them, either.
It would rather toss,
and give away,
but on this day, let's think of her
not in pain, or horror,
but as this flight of ivory petals,
ferrying fro heartbeats
swift as beaming wings.

Yes, let's think she has flown away
somewhere, like them, indelibly,
where the flesh of trees no longer bleeds
and nothing left is visible,
to disappear.

—Judith Harris

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INTRODUCTION

Most of us have a “life script,” a set of assumptions, conscious or unconscious, changing or constant, publicly expressed or not, about the story of our lives, including our endings. Central to my life script, which I shared with my family and friends, was the belief that I would predecease my beloved wife, Barbara, by twenty years. I never viewed this fantasy as morbid or unrealistic, though it might have been self-centered, as fantasies often are, in that I was not only the center of attention in this dying drama but also spared from the grief of watching a loved one suffer. Barbara’s gene pool was excellent, unlike mine, which is average; from this I concluded that she would outlive me by several years. Far from depressing me, the fantasy that I would predecease my wife was consoling. I wanted to believe that Barbara would die at a ripe old age, her beauty, grace, and dignity intact. Years ago I recall a colleague’s wife telling me that her husband’s dying words were that she meant the world to him, and in my fantasy I imagined expressing the same words to my wife, who has been the center of my universe from the moment we met in our freshman English class in 1963.

Life has a nasty way of smashing assumptions. I was right that Barbara and I would affirm our undying love for each other, for better for worse, for richer for poorer, in sickness and in health, to love and to cherish, till death do us part. I did not anticipate, however, that she would die of cancer at the age of fifty-seven.

Barbara’s diagnosis shattered our “assumptive world,” which Colin Murray Parkes defines as a “strongly held set of assumptions about the world and the self which is confidently maintained and used as a means of recognizing, planning and acting. . . . Assumptions such as these are learned and confirmed by the experience of many years” (“What Becomes” 132). Barbara and I shared several fundamental assumptions before her illness, including the three that Ronnie Janoff-Bulman proposes are “at the core of our assumptive world”: the belief that the world is benevolent, the belief that the world is meaningful, and the belief that the self is worthy (6). After her diagnosis, Barbara and I could no longer believe that the world is benevolent. We knew intellectually that “bad things happen to good people,” as Harold Kushner states in his best-selling

book, but we did not believe that misfortune would befall us in our fifties. We were always optimistic about our future, delaying many gratifications so that we could help our children through college and professional school. Then we would “enjoy ourselves.” That future never came. Barbara’s diagnosis changed irrevocably our perspective on the world. It was as if we now saw life through opaque sunglasses: everything that had been luminescent was now sinister, dark, and shadowy. Suddenly the world became irrational, contingent, and unpredictable. Like Job, we couldn’t understand why this had happened to us. What had we done, or not done, to deserve this catastrophe? Our own self-worth was called into question. No longer could we believe in the illusion that we were in control of our lives. We knew that we would be devoted to each other to the end, but we didn’t know whether we had the strength and courage to confront a situation that struck terror in our hearts. How could we maintain hope in a hopeless situation, help each other when we each needed help?

Before Barbara’s illness I never imagined I would write a memoir of our life together, nor did I envision that I would write her eulogy as she lay dying. There are many reasons why I felt compelled to write about Barbara, including the wish to memorialize her. Writing seemed the best way to do this. I have long believed in both the “talking cure” and the “writing cure.” My last four books have all affirmed the value of personal writing and personal teaching: *Diaries to an English Professor* (1994), *Surviving Literary Suicide* (1999), *Risky Writing* (2001), and *Empathic Teaching* (2004). An overwhelming majority of my students have found it therapeutic to write about difficult personal issues. No subject is more difficult to write about than death, the greatest of life’s mysteries, the enigma that preoccupies us increasingly as we grow older. The one experience that is impossible for us to understand, death is the “undiscovered country,” as Hamlet exclaims, “from whose bourn / No traveller returns” (3.2.56), and though we may try to imagine death, there is no way to confirm our speculations. Like my students, I turned to personal writing as a method of problem solving, in my case, to celebrate Barbara’s life and to help me grieve her loss. I often share my writings with students, discussing how aspects of my life bear upon their own; consequently, it made sense to disclose my life with Barbara during her final months.

Dying to Teach explores my efforts to hold onto Barbara precisely as she was letting go of life. Her dying and death called into question all my beliefs, and I struggled to hang onto anything that would give me strength as a husband, father, caregiver, and teacher. In terms of John Bowlby’s attachment theory, writing about Barbara was a way to remain close to her while I was simultaneously detaching myself from her. This paradox is, I believe, the basis of all relationships, which must inevitably end in loss. *Dying to Teach* is about my lifelong love for Barbara, the shock and horror we felt when we found out about her terminal illness, and what we both learned about love and loss from this

experience. Sharing this event with my students, I was able to teach them what I was learning and to learn from their own experiences with death.

Education is reciprocal: teachers learn from their students just as students learn from their teachers. Teaching has always been less of a job to me than a calling, a way of life, a passion, and I have been fortunate that so many students have made a difference in my life, just as I have tried to make a difference in theirs. In *Dying to Teach* I pay tribute to the woman who was, and is, the love of my life, and I explore the impact of her life and death on my students, who have been the center of my work. Freud defined psychological health as the ability to love and to work; writing about my love and work kept me psychologically healthy, or at least functioning, during this dark time.

Throughout *Dying to Teach* I describe the many people who helped us during Barbara's illness, including our daughters and sons-in-law, Arielle and David Albert, Jillian and Alex Willscher, and Barbara's sister, Karen Anuar, along with the doctors and nurses who took care of her, especially her two oncologists, Fred Shapiro, and my cousin Glenn Dranoff, a Harvard researcher who led us to a clinical trial for an experimental pancreatic cancer vaccine. We were also helped by our psychotherapist, Edward Dick, and the hospice nurse, Geraldine Breitenstein.

I have been teaching for thirty-five years, and many of the stories I read with my students contain one or more characters who die. Indeed, it is difficult to find a novel or a play in which a character does not die, either on stage or off. Most of my experiences with death have come through literature, and these fictional encounters with death are both similar to and different from Barbara's experience. As soon as she was diagnosed, I began to read nonfictional books about dying and death in an effort to understand what would happen during the coming months. Many of these works can be characterized by the words that are inscribed on the medallion that Tolstoy's dying judge, Ivan Ilych, wears on his watch chain: *respice finem*: reflect on your end (132). Some of these books were classics, such as Elisabeth Kübler-Ross's *On Death and Dying*, that I had read and written upon decades earlier but that now assumed greater urgency. I also began reading memoirs, including John Bayley's *Elegy for Iris*, a moving tribute to his wife Iris Murdoch, whose literary career was cut short by Alzheimer's disease. A memorable passage describing Bayley's changing relationship to his wife foreshadowed my own shifting relationship with Barbara: "Already we were beginning that strange and beneficent process in marriage by which a couple can, in the words of A. D. Hope, the Australian poet, 'move closer and closer apart.' The apartness is a part of the closeness, perhaps a recognition of it; certainly a pledge of complete understanding" (44). Some books were too difficult to read during Barbara's illness but became valuable after her death, such as Donald Hall's *Without*, the poetry volume memorializing his wife and fellow poet, Jane Kenyon. Anna Quindlen's novel *One True*

Thing was almost too wrenching to read because it raised an issue that haunted me months after Barbara's death: euthanasia.

Chapter 1, "Barbara's Cancer Diary," records, in her own words, her responses to her illness and her efforts to make the best use of her remaining time. Physical pain brought her to the first of several physicians, culminating in the dreaded words "terminal cancer," but psychological pain was the more formidable adversary until the final months of her life. Barbara's illness created an instant divide, separating the happy years before diagnosis from the anguished months following diagnosis. And yet Barbara was unusually sensitive to the specter of death throughout her life. This can be seen in a remarkable handwritten letter—apparently to herself—that I found in one of our file cabinets after her death. Written in 1988, the letter describes her despair when our first dog, Cybele, was killed; her decision never to acquire another pet; and then her change of mind when she purchased our second dog, Pandora. Barbara's willingness to give her heart to another life, be it human or canine, reveals her acceptance of the inevitability of loss and grief—an acceptance that Arielle, Jillian, and I similarly reached at the close of her life.

Chapter 2, "Barbara's Death," explores the similarities and differences between real and fictional representations of death. Literature often shapes our understanding, or misunderstanding, of death; my own knowledge of dying and death before Barbara's illness was influenced more by literature than by real life. Many of the novels and plays that I taught or read immediately before or after Barbara's diagnosis took on new meaning for me after her death. Margaret Edson's 1999 Pulitzer Prize-winning play *Wit*, Ernest Hemingway's *Farewell to Arms*, and Anna Quindlen's *One True Thing* all focus on an aspect of dying or death that casts light on Barbara's ordeal. After her death I found myself "talking back" to the authors of these texts, telling them what they had grasped, or failed to grasp, about our experience.

Chapter 3, "My Eulogy for Barbara," opens with the first draft of my eulogy of Barbara, which I wrote in January 2004, when we were told that she did not have much time left. The eulogy describes how we met, the kind of person she was, our marriage, and how we responded to her diagnosis. Writing the eulogy was my first attempt to make her into a "character," explaining why she was so important to her relatives, friends, and colleagues, as well as describing how we were similar and different. I also discuss the eulogy as a literary genre, with its own formulaic characteristics. Eulogists confront many challenges: they must speak for the dead without falsifying their characters, exploiting their lives, or rendering them into narcissistic versions of themselves. The eulogist has only a few moments to do this. Maintaining composure is itself a daunting challenge, especially in the case of premature death.

Chapter 4, "An Optional Writing Assignment," discusses my students' responses to hearing the first draft of the eulogy, which I read aloud to my writ-

ing class in March, a month before Barbara died. The eulogy had a profound impact on my students, intellectually and emotionally. Several stated that it was the most powerful classroom experience in their lives. They not only viewed me differently after hearing the eulogy but they also felt that my self-disclosure encouraged them to write about their own experiences with death. The eulogy narrowed the distance between teacher and student, allowing everyone to learn from each other. With this heightened self-understanding came increased empathy for others.

Chapter 5, "The Other Eulogies," contains the final draft of the eulogy that I read during Barbara's funeral on April 9 along with four other eulogies. There are important differences between the first and final draft of my eulogy, differences caused by the relentless metastasis of the disease. Some of these changes, which I could not anticipate months earlier, were so agonizing that I could not acknowledge them, not even to myself, until after Barbara's death. The other eulogies, written by Jillian, Arielle, Karen, and my dear friend Jerry Eckstein, are not only revelations about Barbara's life but also fascinating to read: funny, serious, truthful, and heartfelt.

Chapter 6, "Students Reading about Barbara's Life," focuses on my students' responses to reading an early draft of this book containing their reactions to hearing the eulogy. Students now learned about their classmates' reactions to the eulogy. Some students were more affected by my daughters' eulogies than by my own, probably because they were closer to my daughters' ages and could imagine losing a parent but not a spouse. Just as writing became a form of grief work for me, so did several students predict that my eulogy would help them to mourn future losses. They became more aware of the fragility of life, pondering the implications of my statement that our family's attitude toward death changed from regarding it as a dreaded antagonist to welcoming it as an ally. As one remarked, "Reading [this essay] has made me face some of my fears." And yet not all students wanted to face their fears—one, in fact, objected to hearing the eulogy and then reading about it. Teachers must be careful when discussing traumatic subjects in the classroom, lest students be themselves traumatized. The teacher's challenge to students, like the writer's challenge to readers, is to narrate stories that are not *too* painful.

Chapter 7, "Life after Barbara," describes how our family has grieved her loss, which remains the most catastrophic event in our lives. The chapter opens with a discussion of the "language of condolence," the difficulty of finding the right words to express sorrow. "After great pain a formal feeling comes— / The nerves sit ceremonious like tombs" (Dickinson 365). After Barbara's death I began to understand, for the first time, Emily Dickinson's poetics of grief in her poem "After Great Pain." That formal feeling was of numbness, not quite an indifference to life, nor simply an acceptance of death, but a feeling of death-in-life. Time is not a healer, as most people believe, but working through grief

takes time. Barbara's death subverted my assumptive world, and I needed to discover a new set of assumptions. I wanted not to "move on" with my life or to "achieve closure"—two popular descriptions of the bereavement process that strike me as glib—but to learn to live with Barbara's death. Living with death allows us to acknowledge the continuing presence of absent people, the ways in which they remain alive to us. They have left us, but we have not left them.

Upon completing *Dying to Teach*, I sent the manuscript to the students in Expository Writing who heard me read my eulogy for Barbara in March 2004. The appendix contains their responses to the completed book.

Why would anyone write about the most wrenching experience in life? Dave Eggers explores this question in his highly autobiographical novel *A Heartbreaking Work of Staggering Genius*. After describing how his father died of lung cancer and, a few weeks later, how his mother died of stomach cancer, Eggers uses a self-interview format to reveal the writer's conflicting sides:

So why are you here?

I want you to share my suffering.

You don't seem to be suffering.

I don't?

You seem happy.

Well, sure. But not always. Sometimes it's hard. Yeah. Sometimes it's so hard. I mean, you can't always suffer. It's hard to suffer all the time. But I suffer enough. I suffer sometimes.

Why do you want to share your suffering?

By sharing it I will dilute it.

But it seems like it might be just the opposite—by sharing it you might be amplifying it.

How do you mean?

Well, by telling everyone about it, you purge yourself, but then, because everyone knows this thing about you, everyone knows your story, won't you be constantly reminded of it, unable to escape it?

Maybe. But look at it this way: stomach cancer is genetic, passed more down the female side of our family than otherwise, but because according to [my sister] Beth and me my mother was done in by dyspepsia, the dyspepsia caused by swallowing too much of our tumult and cruelty, we are determined not to swallow anything, to not keep anything putrefying down there, soaking in its juices, bile eating bile . . . we are purgers, Beth and I. I don't hold on to anything anymore. Pain comes at me and I take it, chew it for a few minutes, and spit it back out. It's just not my thing anymore. (209–10)

Eggers's theory of the origins of his mother's stomach cancer is questionable, but what is beyond question is that he affirms what may be called a purgative theory of writing, in which artistic expression brings with it psychological relief—what I have called in my book on Joseph Conrad the idea of “writing as rescue.” Eggers must convince himself throughout his postmodernist novel that he is not exploiting his parents' deaths for the sake of art, a fear that anyone who writes about a real person's suffering or death must similarly confront.

One of the paradoxes of writing a book about a spouse's recent death is that the writer must not only bring the deceased back to life, in the process re-experiencing the trauma associated with dying and death, but the writer must then rebury the dead at the end of the book, thus repeating the loss. Reading Barbara's cancer diary in its entirety for the first time after her death, I felt acutely again how much she and our entire family suffered throughout the twenty-month ordeal. Why, then, would any writer go through such a painful process again? Simply because writing about Barbara's life and death was more helpful than harmful for me. I needed to recall as many details of her life and death as possible both to honor her memory and to help me grieve her loss. “Mothers typically are the chroniclers of a family's narrative history,” states Hope Edelman (200), and this was especially true of Barbara, who rarely forgot anything. As I revise these words, eighteen months after her death, I struggle with two conflicting fears. The first is that for the rest of my life I will remain obsessed with Barbara, thinking about her from the moment I wake up to the moment I fall asleep—not to mention dreaming of her at night. The second fear is that I will forget about Barbara as time passes, and that such forgetting will constitute a betrayal of her memory. I suspect that many bereaved experience these conflicting fears.

Words, no matter how loving or consoling, cannot bring a dying person back to life, nor can they by themselves diminish suffering, but words are finally all that we have, and they can rescue a person from oblivion. *Dying to Teach* demonstrates how all the members of our family used language not only to express our devotion to Barbara but also to keep her memory alive. I have vivid memories of only one of my grandparents; the other three died when I was very young. Our grandson, Nate, was seven months old when Barbara died, and his only knowledge of her will come from our spoken and written words. Perhaps the most heartbreaking moment of Barbara's illness occurred when she held Nate for the first time. There is no word in the English language that captures our conflicting feelings—those of sorrowfuljoy, a neologism that is more accurate than “bittersweet.” The more we speak and write about Barbara, the more Nate and our future grandchildren will learn about their grandmother's life.

The title “dying to teach” captures many of the ambiguities of this book. How much agency does one have when one feels compelled to do something almost against one’s will? I have resolved, on the one hand, to tell the story of Barbara’s life and death and her impact on my family and work. Yet I have felt driven, on the other hand, by an inner force that I cannot resist. Control is important to me, and therefore it is wrenching to give up all control when watching a beloved spouse die. I want to believe that I have controlled every aspect of this book, but it would also be true to say that this book has controlled me. I wrote it, but it wrote me. I can’t recall the moment or day when I started this book. Its existence is both an act of will and an example of following one’s obsession. I did not feel the same joy that I experienced writing my earlier books, but I did feel, surprisingly, pleasure, along with the satisfaction that I was honoring Barbara’s memory and perhaps helping readers understand her life and death. *Dying to Teach* is not a “how-to” book, but I hope that it will enable readers to understand how our family’s experience with death may help other families when they find themselves in our situation.

Dying to Teach reflects a caregiver’s need to explain to others and to himself the mystery of death. I needed to learn as much as possible about what was happening to our family. I needed to know. It is impossible, however, not to feel ambivalent about certain kinds of knowledge. As I write in *Empathic Teaching*, “The central ambiguity in Robert Penn Warren’s novel *All the Kings Men*—‘The end of man is knowledge’(9)—can be read in antithetical ways: knowledge is the goal of life but certain types of knowledge may be fatal” (15). The greatest terror we felt during Barbara’s illness was at the beginning, waiting with our children for the telephone to ring with the results of her liver biopsy. It was a time of pure dread, when we both thought we would die literally of fright.

Barbara knew exactly what was happening to her, and no one withheld anything from her, but unlike me, shortly after her diagnosis she did not want to know the specifics of her disease. She wanted to hear only survivor stories, of which there are almost none, and it became increasingly difficult for her to read, which had been a lifelong passion. From the beginning, however, she made a heroic effort to teach her husband and children everything they would need for life without her. She was, in a terrifyingly literal way, dying to teach us everything she could for our survival. We were simultaneously caring for and teaching each other until the day of her death.

I was also dying to teach my students about what was happening. I have long believed that one must teach a subject to understand it. Nowhere is this more evident than the subject of dying and death. Anything that does not kill you, strengthens you, Nietzsche observed wryly, and for many people, the thought of death is paralyzing. Virginia Morris quotes the British sociologist Geoffrey Gorer as saying that the subject of death has become as unmention-

able today as sex was during the Victorian age (112). In an age that is obsessed with youth, and in which, unlike in previous ages, 80 percent of people die in hospitals, nursing homes, or other institutions, we have become divorced from the reality of death and its centrality to life. As Howard Spiro remarks, “Once, when grandparents, parents, and sometimes children—too often children—died at home, everyone knew death first hand. Death is as common as birth, but it went into hiding in our twentieth-century hospitals” (xv). Countless stories focus on love and loss, but surprisingly few books explore how college teachers can help students survive and record their own unavoidable losses. Such books need not be depressing or morbid; they may, indeed, be life affirming.

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I

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