Final Negotiations

A Story of Love, Loss, and Chronic Illness

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**FINAL NEGOTIATIONS** tells a story within a story. The central narrative gives a detailed account of attachment, chronic illness, and loss in my nine-year relationship with Gene Weinstein, a sociologist who died in 1985 from emphysema. The framing story chronicles the process of writing the personal narrative and contextualizes its meanings. The result is a multilayered, intertextual case study that integrates private and social experience and ties autobiographical to sociological writing (Broyard 1992; Butler and Rosenblum 1991; Frank 1991; Haskell 1990; Krieger 1991; Linden 1993; Mairs 1989; Murphy 1987; Paget 1993; Quinney 1991; Ronai 1992; Roth 1991; Yalom 1989; and Zola 1982a).

My goal in this and related work (Ellis 1993, in press; Ellis and Bochner 1992) is to make sociology an intimate conversation about the intricacies of feeling, relating, and working. Some friends and colleagues have reacted to the intimate quality of the text by asking why I would “risk” divulging personal details about my life that show my flaws, disappointments, and bad decisions as well as my strengths, achievements, and good judgments. Although I appreciate the significance of these risks, I have not been swayed from my conviction that the sociological imagination can touch on the complexities, ironies, and ambiguities of living only by showing the bad as well as the good, what has been private and confidential as well as what is public and openly accessible, what makes us uncomfortable as well as what makes us comfortable.

Written as “experimental ethnography” (Marcus and Fischer 1986), *Final Negotiations* intersects two recent burgeoning interests in human studies research—autobiography (for example, see Bateson 1989; Berger 1990; Friedman 1990; Goetting and Fenstermaker 1995; Heilbrun 1988; Higgins and Johnson 1988; Jackson 1989; Merton 1988; Okely and Callaway 1992; Personal Narratives Group 1989; Rosenwald and Ochberg 1992; Stanley and Morgan 1983; Steedman 1986; Williams 1991; Women’s Studies
International Forum 1987) and narrative (for example, see Bruner 1986b, 1990; Coles 1989; Gergen and Gergen 1993; Josselson and Lieblich 1993; Kleinman 1988; Kreiswirth 1992; Maines 1993; McCabe 1993; McCloskey 1999; Parry 1991; Polkinghorne 1988; Richardson 1990a; Riessman 1993; Rosenwald and Ochberg 1992; Sarbin 1986; and Turner and Bruner 1988), bringing social science closer to literature (Benson 1993). Consequently, this work takes an unorthodox form for social-science research in its narrative structure, its self-conscious focus on emotional experience, and the reflexive position I assume as both narrator and a main character of the story. As with all narrative accounts, mine is partial, historically situated, and mediated (Bruner 1986a; Clifford 1986). I try to show this experience as I remember it, as a life being lived in a particular moment, place, and culture, rather than as a model for how life should be lived everywhere by everybody.

"The beauty of a good story is its openness," as Robert Coles (1989, p. 47) says, "how you take it in and use it for yourself. How you, as a reader, respond to my story as you read and feel it is an important part of this work. I coax you to be open to your feelings as you take this narrative journey. Some of you may prefer to feel with me, as in watching a true-to-life movie; some may be reminded of and feel for the parallels in your own relationships, as in reading an engaging novel; some may prefer cognitively processing the feelings expressed, closer to a traditional social-science reading. My goal is to engage you in aspects of relationships that usually are neglected or overlooked in social-science inquiry. It is my assumption that this kind of "knowledge" comes from actively getting close to the text, rather than from being a passive spectator observing from a distance (Dewey 1980; Jackson 1989).

Although scholars who study personal relationships say it is important to understand the dynamic qualities of intimate bonds, most research "freezes" the fluid motion of relational processes" and "transforms the passionate process of 'falling in love' into a cooler, more rational state of being that substitutes product for process" (Bochner 1990, p. 3; Shottet 1987, p. 242). These researchers usually operate under the tacit assumption that it is more important to be true to the practices of rigorous social science than to the practices of lived relationships. Conversely, I have chosen to examine my own relationship in-depth in order to show a thickly detailed chronicle of how people get together and manage attachments or pull apart, and how they feel during these processes. This strategy moves closer to lived particulars of what happens in relationships than the traditional social-science research practices that categorize, generalize, and abstract from snippets of the experiences of others. My story provides enacted episodes of the dialectics of close relationships; that is, it shows how the contradictory pulls of private and public life, adventure and security, instrumentality and affection, independence and interdependence, expressiveness and protectiveness, and attachment and loss are played out in ordinary and extraordinary circumstances (Bochner 1984; Rawlinns 1992). The relationship story shows the ambiguous, complex, and contradictory aspects of my connection to Gene as we interacted in our day-to-day lives, confronted epiphanies, managed attachment and loss, and struggled to make our life together meaningful. The result is a narrative that attempts to be true to the practices of relationships, taking the reader inside our experience as if it were happening now, instead of using our life mainly as "data" for preexisting sociological hypotheses.

Final Negotiations is addressed to social scientists interested in narrative research, medical sociology, and relational processes, as well as readers engaged by the complexities of attachment, chronic illness, and loss. Medical and social workers seeking to comprehend the experience of chronic illness for patients and caregivers, as well as those who want mainly to understand relationships, may want to turn now to the relationship story in Parts II, III, and IV. Interpretive social scientists and ethnographers will find a discussion of methodological and contextual issues of how this story was constructed in Part V, which may be read in sequence or at any point after reading Part I.

Contextualizing My Project

Why have I chosen to tell a personal story to sociologists and other students of relationships who in this century have not encouraged the idea that personal experience or narrative prose is a way of "knowing"? Certainly I did not learn this way of investigating lived experience from the academic model of social science I endured, first as a graduate student in sociology and later as a professor. To make the shift in my research orientation understandable, I will describe events in my work and personal life that led to the writing of Final Negotiations.

In 1974, after completing my undergraduate education, I spent a year as a social worker. My work was with abused and homeless children and adults unable to hold their families together. What I learned upon returning to school as a graduate student in 1975, however, seemed to have little to do with my experience in the public world. I had gone into sociology as an undergraduate because I was drawn to writers like Erving Goffman (1959,
1971), who excelled in opening readers’ eyes to the world in which they lived. I had hoped to continue the same study in graduate school and learn more about my life and the social world around me.

In search of a real-world connection, I worked on a comparative study of two isolated fishing communities in the Chesapeake Bay (Ellis 1986), which allowed me to live with the people I studied and to participate in, observe, and describe their day-to-day lives. This seemed preferable to a library project or a secondary data analysis, where I would not meet the people I studied or be involved in their lived experience.

While in the communities, however, I often experienced conflict between remaining uninvolved and distant, as I had been trained, and participating fully; between recording only my “objective” observations of fisher folks’ actions and speech and noting my sense of their emotional lives, a process that required my engagement. Often distance won out over involvement because of my concern about meeting the requirements I had learned for being a neutral social scientist.

When I returned to the university to write my dissertation, I struggled with the constraints of detached social-science prose and the demand to write in an authoritative and uninvolved voice. Though I worked hard to follow these principles, professors I admired still reprimanded me for having “gone native” and for being too sympathetic toward my subjects.

My dissertation was organized around “legitimate” sociological topics—social structure, family, work, and social change. Within this framework, I discussed “hard” sociological concepts, such as personal attachment, locus of social control, reciprocity, public conformity, civic status, individualism, communitarianism, career, and periphery. Yet, it was difficult to capture the complexity of the lives of the fisher folk using these categories, and I often felt unsure of the distinctions I was forced to make. To me, these theoretical concepts seemed as vague, subjective, and ethereal as emotional experience. I wish now that I had placed more emphasis on how the people felt, which was my primary interest.

I also wish now that I had been more present in my writing about the fishing communities. Mostly, I describe “them,” the fisher folk, interacting with each other, as though I am off in the corner, invisible. In reality, most of what I learned came through my interactions with the people, especially their reactions to me. But those exchanges and the effects my presence might have had on what the fisher folk said and did took a back seat. I agonized over speaking in the first person, having been told it was “unprofessional” and that readers would then conclude I had not been neutral and distant (see Krieger 1991).
lived experience was secondary to abstraction? Even though our jealousy paper was based on peoples’ stories, the final version was written abstractly so that peoples’ everyday experiences were camouflaged. Wasn’t there something worthy about showing lived experience in and of itself? Wasn’t there something valuable about evocative detail? simile and metaphor? Didn’t “like a dentist’s drill hitting a nerve” tell readers more about the jealous flash and get more reaction than “extreme, intense pain” or “blended emotion” (Ellis and Weinstein 1986)? Wasn’t there something valuable in readers’ seeing themselves in our work and reacting with feeling to what we wrote?

Several events happened in my life during the next few years to impact my work. First, my younger brother was killed in 1982 in an airplane crash on his way to visit me (see Ellis 1993). At the same time, Gene entered the final stages of chronic emphysema. Mocking my fears and hopes, flashbacks of live TV footage of passengers from my brother’s plane floundering in the Potomac River were interrupted in real life by Gene choking and yelling for me to untangle his oxygen hose. Suddenly, the scientifically respectable survey of jealousy I was working on seemed insignificant (cf. Krieger 1991).

Instead, I wanted to understand and cope with the intense emotion I felt about the sudden loss of my brother and the excruciating pain I experienced as Gene deteriorated. My presentation of self as a cheerful optimist was challenged. What was happening to our relationship—to Gene, to me—as we reversed roles, as our world narrowed, as our identities were called into question, and as our human condition threatened every shred of meaning we had constructed as a couple in love?

In early 1985 I was promoted to associate professor; meaning my work had passed the standards set by colleagues in social science. Now I could better afford to challenge the boundaries of what counted as legitimate sociology, an endeavor that became a passion after Gene died a few weeks later. Then, with the advent of a section in the American Sociological Association called “Sociology of Emotions,” many sociologists began to consider emotions a proper arena of research. Nevertheless, it was disappointing to see many of them fall into the same trap as “rational-actor” sociologists, as they busily handed out surveys, counted and predicted emotions, observed facial muscles contracting on videotapes, categorized people, and abstracted from lived experience. I feared that emotion was in danger of becoming simply another variable to add to rational models of social life. What about emotion as lived experience and interaction? I vowed to resist the rationalist tendency to portray people exclusively as

The Writing of the Relationship Story

The writing of the relationship story began in 1984 during the last year of Gene’s life when I started to keep daily field notes about our personal relationship. My narrative about writing this story continued until the manuscript was accepted for publication in 1995, ironically duplicating approximately the length of my relationship with Gene—nine years. This metastory, begun here and taken up again in “Negotiating the Story” and in “Endings,” represents my encounters with the process of writing the text, a text that I constructed and that, in turn, constructed me.

The notes that I kept for eight months prior to Gene’s death and for two years afterward included thoughts and feelings; verbatim conversations between Gene and me concerning meaning and death; day-to-day descriptions and analyses of events; stories of contacts with physicians, support staff, and friends; and details of grief and grief work. My goals in making these notes were to document my feelings, thoughts, and interpretations as the events occurred and to write eventually about my experiences. As an ethnographer, I followed the rules for keeping ethnographic field notes and tried to be rigorous and systematic.

As soon as I began to write from the notes, I realized that I could not talk about loss without showing attachment. This led to recreating through memory my chronological history with Gene by first recording major events during the relationship and then connecting them. Interviews with family and friends; physicians’ records and nurses’ notes; tape recordings of conversations; diaries, calendars, and travel logs contributed to my systematic recollection of this period. I also had the advantage of many years of interactive sociological introspection with Gene about the illness process (Ellis 1991a).

I felt I had to write about this experience. Not only did these notes and recollections serve as an anchor preventing me from being swept away by this epiphanic event, but it also seemed important to describe and bring meaning to this experience for me as a person who will lose other loved ones and for others who will go through similar losses. As a sociologist, I thought it was imperative to personalize and humanize sociology and try to deal with the complexities of relationships as we live them.

I knew this would be a difficult task, but I had no idea how difficult. It
was complex enough that, once again, I became an ethnographer of my own experience, keeping notes on the details of the actual construction of the text. Thus, after the relationship story, I used these notes to tell the writing story, emphasizing how the text was conceived and reconceived—initially as science and then as interpretation, first as realist ethnography and then as an evocative narrative.

Part VII brings the stories of the relationship and the writing together. Here, I integrate the two stories, examining in particular the dialectical tensions of "endings." Finally, I discuss this work as an identity- and meaning-making project, circling back to the initial inspiration for the book.

The Relationship Story

The relationship story is divided into three parts. The first two chapters show Gene and me negotiating our attachment through a maze of jealousy, attraction, love, and arguments. Chapters 3 through 8 reveal a rocky period of negotiating stability and change as Gene's health grows worse, our relationship becomes stronger, and we change roles. The bulk of the relationship story is contained in Chapters 9 through 16, as we come to accept Gene's demise yet try to work out how to live a full life in spite of it and struggle not to define Gene as "dying."

I present the relationship story primarily in the present tense, which invites the reader to share in the immediacy and intensity of the interaction, dialogue, and emotionality. Seeking to provide perspective for readers to analyze my experience and contemplate their own, I express my personal reflections, sociological observations, and general descriptions in past tense. Chapter 1 starts with my first meeting with Gene, where the complex process of attachment begins as we enter into our first negotiation.
“HI, I’M CAROLYN ELLIS, a first-year graduate student here.”

Revealing his weakness for women—especially young ones, Gene looks up with a gleam in his eye. “Oh, you did come. Ed told me about you.”

Wondering if it was my intellectual ability he had heard about from my former professor at William and Mary, I reply, “He told me about you too. So did Gina.”

“Ah, yes, Gina,” Gene says wistfully. “But they didn’t tell me you were so good-looking,” I continue, ignoring his response to Gina, to whom I knew he had been engaged, and displaying openness to more than a mentor-student relationship.

Gene’s face brightens as he takes my hand and says seductively, “Sit down and tell me about yourself.” His style of asking questions, listening to answers, and following up on details makes me feel interesting, and I become animated.

Seeming not to mind that we are the only people at the Sociology Department party engaged in an illegal activity, Gene passes me a marijuana joint. After a few tokes, he suggests a walk to a nearby dock. On the way there, he holds my hand lightly. The sounds of his labored breathing, silenced only slightly by the spraying of his oral nebulizer, are masked by my racing pulse and the aura of marijuana.

“You should know that I am here with another woman, but we’re no longer a couple. I’m free to do what I please.”

Amid conversation, he quietly kisses me, softly, undemanding. The lack of desperation coupled with the intensity I feel are like experiencing a storm at its center from inside a safe enclosure. Gene would later admit to similar feelings: “My life had been crazy since my son died. Joyce and I had broken up. And there you were—attrACTIVE, soft, telling me I was good looking. The electricity that came from running my hands along your bare sides made me want to stay there forever, doing what we were doing.”
That was not to be. Suddenly, "Gene, Gene, I need your keys," commands a voice from the darkness. Joan, a colleague and close friend of Gene's and one of my professors, steps into view. As we quickly move apart, she says to Gene, "I have to take your date home." I am forgotten as they argue heatedly about the virtue of Joan's intrusion. Tears of humiliation stream down my face as I slip away unnoticed.

I met Gene in 1975 at the end of my first year in graduate school. I was a twenty-four-year-old graduate student in a sociology Ph.D. program in New York; he was a forty-four-year-old professor there. I had gone to SUNY at Stony Brook specifically to study strategies of interpersonal negotiation and control with Gene, but he had been on sabbatical when I arrived. Although I then worked on a study of isolated communities with another professor, I knew my academic talents and personal interests intersected with Gene Weinstein's social-psychological approach to human interaction, and I eagerly looked forward to working with him later on.

Gene made quite an impression when I finally met him. I found him good looking, although not in the traditional, magazine-cover way. A tall six-foot, one-inch frame, wide shoulders supported by an iron-rod straight posture, and a barrel chest made him look much bigger than his 160 pounds. The touch of gray in his thick, naturally Afro hair called attention to the generous size of his head, face, ears, lips, and nose. Set off from his nose by two deeply indented triangular lines, his rounded, puffy cheeks presented a moon face that glowed with expression. His crooked, decidedly Jewish nose interrupted the symmetry. Lines danced around his deep-set eyes, more piercing still because of the bushy eyebrows that curved around them and, in the middle of each eye, rose to a point. The eyebrows questioned while the eyes penetrated. Immediately I felt I could keep no secrets from him.

From having read Gene's work, I had an inkling of his intelligence; from listening to other professors, I sensed he occupied an important, mediating position in the Sociology Department; from student rumors, I suspected his adventurous but kind spirit; from the "energy" between us, I assumed his reputation as a "womanizer" who dated students was accurate. Given the commonness of such relationships in 1975 and my own history of friendships with professors, this image made Gene more, not less, attractive. I craved the exhilaration that came in learning in an intimate relationship, and rose to the challenge of being considered an equal. I was not concerned then about using my appearance and youthful exuberance as currencies of exchange, since they seemed to be valuable bargaining chips for a woman. Attractiveness got me an audition, a chance to play and hone my intellectual role. At the time I met Gene, the script was already in place. I did not consciously calculate or plan this exchange. But much of how we act, I know now, becomes routinized; our motives are hidden, even from ourselves; our reactions become automatic, scripted. Whatever the case, my anxieties about "measuring up" interpersonally and intellectually created heightened emotion that I translated easily into romantic attraction.

"Hello, this is Gene. I hope it's OK to call. I'm so sorry I put you in that embarrassing situation."

Since meeting Gene two days before, I have fantasized about him continuously, alternately glowing with excitement and wincing from embarrassment. How did he get my parents' telephone number, I wonder as I respond, "Everything is OK now."

"Is it?" he asks softly. "I was concerned. You were crying when you left."

"I was worried about what Joan thought, and crying from confusion and guilt."

"You shouldn't have felt guilty. You didn't do anything wrong. I'd like to take you to dinner to make up for that evening."

"But you're in New York and I'm in Virginia. That's over 400 miles."

"I don't mind driving."

We made plans to meet two days later in Washington, D.C., on the steps of the Lincoln Memorial. Although I had never driven in a big city, I found the Memorial and waited with my small terrier, Poogie, for Gene to arrive. When he walked toward me, my feelings of excitement were muted by how much older he looked than I remembered. His out-of-style leisure suit—baggy in the seat and emphasizing his lack of rear—hung loosely. What am I doing here?

Later, Gene would confess to a similar reaction: "You were dressed in a tacky outfit that was too tight. That and your little dog made you look like a kid. I thought 'she's so much younger than I remember. And a lot heavier too."

Awkward at first, we discuss how to spend our time. "How about a walk in the park while we talk?" Gene asks, taking Poogie's leash. I nod. The dog scampers one way, then the other, wrapping Gene in bow-tie fashion. I acknowledge that Poogie is accustomed to running freely, and pay only slight attention to Gene's shortness of breath.

"We could have a picnic," he offers. "I have wine and cheese in the car. Or go to a museum."

"A picnic would be nice," I say, wanting us to be alone.
"Can you stay in Washington tonight?" I shake my head yes as he continues, "No obligation now. I'll understand if you want to have the afternoon together and then go your way."

We spent the afternoon in a hotel, laughing, and sharing stories about our lives. Making love was tender, yet passionate, and the intensity of my excitement and the attention he paid to me were new. Later, when we went to a French restaurant, the menu was unfamiliar and expensive, and after a short lesson in French cuisine, Gene ordered for us.

Back in our room, he says apologetically, "I need to treat my lungs. It's not a pretty process, so I'll do it in the bathroom." As I undress, the continuous humming of a motor provides background for periodic spraying and hissing sounds.

Afterward, we talk about his disease for the first time. "I have emphysema, and I have to 'pump out' my lungs each night with an electric nebulizer filled with normal saline and a bronchial dilator."

"The emphysema makes you cough and short of breath?" I ask, acknowledging that I have noticed these symptoms. His illness appears to be minor, and intrudes little into my fantasy.

As Gene prepares to leave the next morning, I say, "I'll miss you, and I hope to see you again." I am concerned that I won't see him until I return to graduate school after summer vacation four months later.

"Think of our time together as a gift from life," he replies, ignoring my implied question.

"I will." Then I try again. "I might be coming to New York in the middle of summer to look for a place to live."

"I'll be in England for a month. I'm traveling with a friend, part of my foreign empire."

The phrase "foreign empire" grates on me and I wonder if I am now included. Was last night just a one-time fling to make up for our initial meeting? If so, surely he feels different after our time together.

"Let's have our picnic before we part," Gene suggests.

"Welcome back. It's good to see you," Gene says as he hugs me. It's the third day of the fall semester and I've run into Gene in the Sociology mail room. When he doesn't linger, I am disappointed, but, since he asks about my old boyfriend, I assume our hesitant communication comes from my acknowledgment that Rick has moved to Stony Brook with me.

Like a high-school girl with a crush, I try to run into Gene at school. Usually surrounded by students or with his friend Joan, he is pleasant but distant. I am assigned randomly along with five other graduate students as Gene's teaching assistant. Attending his classes and constructing and grading his exams provide chances for interaction, but our conversations are brief and task oriented.

"The German nation is divided into East and West Germany," Gene says in a thick German accent as I come into his first undergraduate class. What is going on? Obviously, some of the undergraduate students wonder too as they shuffle in their seats. A few calmly take notes. Finally, one brave student raises a hand and says, "Isn't this a sociology class?"

"Oh, so je veut sociology?" Gene switches accents and starts talking about the sociological perspective. Continuing his performance, he explains sociological concepts of "working consensus" and "definition of the situation," pointing out that in every interaction we have to agree about what reality will be honored and answer for ourselves the question, What's going on here?

"I want to talk to you." I say to Gene as I enter his office. "Rick has gone and I want to see you."

"What happened?" he asks. "He's only been here a month."

"Our friendship wasn't enough to sustain our relationship."

Rolling his desk chair to where I sit, he takes my hands in a fatherly fashion and says, "No, this is not a good idea." Surprised, I ask, "Why not?"

"It wouldn't be fair. First, I'm seeing someone else in New York City every weekend. Second, I'm twenty years older than you."

"Nineteen and a half," I kiddingly remind him.

"And third," he continues, without being amused, "I'm a professor and you're a student and that's sure to make problems."

I calmly respond, "I don't care if you're seeing someone else, I'm not asking you to marry me. I don't have a problem with age. And I don't think the status difference will be an obstacle, if we don't let it. I've dated professors before."

He is silent, thinking, still holding my hands. Since he doesn't seem convinced, I prepare to argue my case. Then, quietly, he says, "Why don't you come over tonight and we'll talk about it." I smile.

His speech that night about needing to have no strings if he continued seeing me did not interfere with the champagne and lovemaking that began the most intense romance of my life, and the most problematic one.

"Why don't you like group conversations?" Gene asks.

"Because they take on the character of least common denominator. You
end up talking in a superficial way about what most people know about, or a few people hug the conversation.”

”I like group conversations.”

”Of course, that’s because your style is to ‘hold forth,’ for which you need an audience. I like to dig deeply into what I’m interested in, and you can do that only in one-on-one conversation. Or in large groups, because there you can break into pairs.”

We spent most evenings in such discussions—foreplay for the lovemaking that followed. Gene said he found my insights as fascinating as I found his, and he liked what he called “my eye,” which was the ability to pick apart the most common interpersonal episode and talk on different levels about “what is really going on here.”

We loved talking about group process and interpersonal relationships, and other people’s emotions, motives, and strategies. But addressing these aspects of ourselves provided our favorite topic. His interest peaked when I told him how people perceived him and why.

”You intimidate students.” I say.

”Really, I don’t think of myself as intimidating.”

”Well, you are. Your voice is loud and overpowering and sometimes you make them feel stupid. Remember when you were talking to Cathy and she asked you how to determine class?”

”Yes. Why?”

”You said to her ‘that’s a really complicated question. You don’t realize how difficult.’

”Yeah, I was trying to tell her she shouldn’t feel bad for not knowing.”

”But, instead, she felt stupid because you indicated that she didn’t even know how complicated the question was. It’s your tone, sort of all-knowing, that’s intimidating, as well as your booming voice.”

Perhaps this was a way to tell Gene that his aggressive manner sometimes intimidated me too, especially whenever the topic veered from interpersonal relationships to historical or more macrosociological issues. I wanted to learn from him, yet was afraid to admit to what I didn’t know. Would I be less valuable if he thought I was not “smart enough?”

Given my background, my apprehension was understandable. I had grown up in a Protestant, rural, working-class area in the Blue Ridge Mountains. The intellectual, metropolitan, Jewish-influenced culture I confronted at Stony Brook presented a formidable but exciting challenge. Since Gene epitomized this world, I was more than willing initially to let him play Pygmalion and mold me into his version of a “cultured sociolo-

gist.” Gradually, through talking about my insecurities, I became comfortable with our teacher-student exchanges, and I learned more formal sociology around the kitchen table than I encountered in classes. Gene didn’t seem to mind that it was one-sided. “Nor,” he assured me, after my confession, “do I think you are dumb.”

Gene intimidated many people, even some who loved him, but the same elements that intimidated also drew people to him—his self-assurance, comfort in any situation, and ability to talk intelligently about most topics. Always ready for a good discussion and intellectual argument, he took up a lot of space—both physically and psychically. He earned attention and validation for his intelligence by listening closely and asking probing questions, allowing others to proclaim their wisdom. Challenging every statement with his darting, alert eyes, he was in control, directing the story even when someone else spoke. His ability to frame and analyze intellectual and practical problems meant that many, even some who were put off by his aggressiveness and need for power and control, sought him out.

As I did. I became intellectually dependent on Gene, my toughest critic, needing his approval of my ideas. If he said my work was good, I believed him. If he didn’t, I worked until he approved. This feedback offered an invaluable push then; later I would see it as holding me back.

”Hi, Gene, this is Carolyn. Could we have dinner tonight?”

”Sorry, but I’m tied up.”

Two weeks later, I call again. ”Just to talk,” I say.

”Sorry, I have company.”

I resented Gene’s control over when we got together and what we did. Although he acted as fascinated by our relationship as I, he never asked to see me more than one night a week, and I always accepted his invitation.

”Hi, would you like to have dinner tonight?” he asks at 6:00 P.M.

”I would love to,” I say, putting my half-eaten dinner into the refrigerator.

I could not understand Gene’s need to control the expression of his feelings. Even in bed, he would not say he loved me. Yet, he seemed to crave our lovemaking and relished that I was having new experiences. “Have you ever felt this way before?” he asks.

”No, I’ve never experienced loss of the boundaries of my body before. I soar into another reality, where there’s only blackness and energy, over and over.”
"Do you experience this with other men now?" he asks hesitantly.
"Not quite like with you," I reply, "but sex in general is different from before." I wonder, but don't ask, what it is like for him, the "teacher."

"One of the things I really like about you is that you're so undemanding. You don't ask for more. You just seem to enjoy what we have. I've never had that before," Gene says, repeating sentiments he has expressed previously. "You're gravy."

I smile, but feel uneasy that these characteristics are so important, and resent that he is trying to reinforce my behavior. Yet I am delighted that my ease about the relationship is drawing him to me. I know that one rarely, if ever, gets more in a relationship by demanding it—especially not over the long haul. "Don't ask for more time," I admonish myself. Instead, I say casually, "I like my freedom and I enjoy seeing other men." Does he flinch? I don't tell him that there are others only because I can't have more time with him. Besides, making myself look valuable, independent, and attractive to others is a good strategy. Soon Gene starts seeing me two nights a week.

"Look at the individual petals," Gene says, as we lie in the grass amid the blooms. "Each flower is different, delicate."

"Yes, the field unfolds in blended color," I reply, as I lay back with my eyes shut. "The sun shining on my body makes me feel like I am having multiple orgasms."

"You are," he says, leaning over to kiss my eyes.

"In the throes of romance, love is a high-arousal and high-interpretation emotion," Gene says, as he lectures to our graduate class in social psychology. "It is unclear whether we experience symptoms as consequences of the definition or define ourselves as being in love because of the symptoms."

"Love may not be the same for everyone or the same for each person all the time. But in each situation, we label feelings as love because it makes sense to do so. Enough of the details fit the love frame."

"At times we may be more willing or needful to define ourselves as in love. But it is hard to know sometimes whether we are in love with the role (in love with love) or the person. Is our claim to being in love valid? Are we loving just to get love back?"

"Love provides new mirrors for our sense of self. We narrow the gap between what we are and what we want to be by falling in love with a person who can reflect back to us an image of ourselves we value, or get us further away from one we devalue."

"I will not evaluate your exams in my class," Gene declares when I meet him at his house after class. "Two other professors have agreed to do it. Nor will I be on your Ph.D. committee or evaluate you in any way."

I understood, but was disappointed with the B I received in his seminar, my favorite graduate class, especially given the work I put into it and the anxiety I experienced from wanting to impress him.

"So you're leaving your toothbrush here now," Gene teases with a half-smile on his face. Although he pretends to be joking, the hidden message is that I do not live in his house.

"Oh, I'll be sure to take it home," I reply, and then don't.

Most of the time Gene's actions belied his words concerning my place in his life. Although he verbally held me at arms' length, he now invited me to his house on weekends and most evenings. I never had felt so connected to anyone, and a piece of my heart wanted more. Or, more accurately, I wanted him to want more. Was this to validate my worth? Was this because the love I wished for was not obtainable and therefore more desirable? Or did I want to change the power imbalance, which I found infuriating and exhilarating at the same time?

On the other hand, I was worried about the consequences of getting more. Having some idea now of the extent of Gene's illness, I was hesitant about becoming more involved with this older, sick man. What did I want? Sometimes I questioned the value of the relationship in exchange terms—I was getting a great deal now, but wouldn't there be diminishing returns in the future?

Confronting the cold economic model of relationships made me flee to the romantic notion of pure love. Then I compromised, telling myself I had the best of both worlds: intensity and love, yet no future demands or commitments. I felt better then, for a little while. In spite of my feelings for Gene, I was caught up in the ideology of the sixties that considered commitment and monogamy to be bad words. People should stay together only as long as they both wanted. This simplistic thought would haunt me much later.

"Get a cart," Gene commands, the first time we enter a grocery store together.
"We don’t need a cart for a few items," I reply.
"Well, we might get more than that."

It soon became apparent that leaning on a cart made walking easier for Gene. Sometimes I felt impatient and even embarrassed to be seen with a much older man who appeared sick and short-of-breath. At the same time, I argued with myself that age and health discrepancy should say nothing about my self-worth—or his.

From a distance, I see Gene on his way to class, moving more quickly than usual, chest heaving, his face betraying the struggle of the short but slightly uphill walk. His destination is a wall at the halfway mark, approximately a block from his classroom. Once there, he leans over, resting on his elbows, a position that, I learn later, makes it easier to breathe. I want to approach him, but I am unsure if, in that condition, he will be glad to see me. What will I say to him? I feel envious of the students who easily stop to talk to him as he sits on the wall to rest. His expression changes quickly from agonized to animated as his breathing slows and he holds court for the students who surround him.

Although there were 600 people in his introductory sociology class, Gene managed to elicit discussions that played off the provocative lectures he gave spontaneously, without notes. He became my role model for the kind of teacher I hoped to be. In Gene’s classes, I was able, unobserved, to watch him for fifty minutes, three times a week, and slide into fantasies about the time we had spent together.

Yet, even here my fantasies confronted a contradictory reality. Projecting his voice without a microphone to 600 people took energy and sometimes required that he stop for deep breaths or to cough. Spraying his inhaler sometimes helped and other times seemed like a prop or a pause between paragraphs. After one particularly rough day, another assistant said to me, "I wish he would just die and get it over with." Her comments forced me to come face-to-face with how bad his disease appeared to others.

"Maybe you should pull over," I say to Gene, who is coughing uncontrollably while driving. My calm voice belies my fear.
"No, I’ll be OK in a minute."

He must know what he’s doing. But he’s choking, and now turning gray. Pull over, goddamn it. I scream silently.
"It’s a ‘clump,’ a mucus plug," he explains between coughs from deep in his gut. "It’ll come up and then I’ll be OK."

The car weaves into the oncoming lane. "Maybe I should drive," I suggest, controlling my alarm.
"No, I’ll be fine."

The coughing continues, the mucus that thwarts his breathing rattles. He works—cough, cough, clear the throat, gag—and finally, five minutes later, he swallows the loosened mucus. I, too, almost gag, before my anxiety turns to relief.

Exhausted, he still manages a smile. "See, I’m fine now."
"Do you get those often?"
"Just once in a while. But they’re sons-of-bitches."

I learn much about clumping the next few months. Because of constant inflammation, Gene’s lungs produced a flood of mucus to combat irritation. That and the pus from the infections he got sometimes covered the air sacs and membranes of his lungs. Then, because of the buildup of carbon dioxide, he felt like he was suffocating and drowning, and he coughed furiously to get the mucus to release, which would allow him to breathe comfortably again. If he were "well," the clumping might happen once every two or three times I was with him, and be minor. If he had an infection, he could have six or seven a night, or, during a serious infection, the clumping sometimes went on continuously.

Since panic restricted Gene’s breathing further, it was important that he stay calm during these episodes, preparing for the violent coughing that finally forced the mucus into his mouth. Sometimes he worked as long as ten minutes on a plug before it loosened and allowed his pale gray color to change immediately to pink.

Initially, I grew numb as I waited for the emergency to be over. Once I understood the process. I joined in the fight. "Relax, baby, it’ll release soon. OK, give it a try. No, not this time. OK, rest. Deep breaths. OK, maybe now. We’ll get through this." I hold his hand, rub his back. Imagining what it must feel like, I hold my breath, letting it go only when his mucus plug is displaced. His struggle becomes my struggle too, and feels better than numbness. Later, when he is worse, I will welcome the numbness.

"I think the time has come," Gene says when he can breathe freely, "for me to show you what to do in case I don’t come out of one of these."

"See this needle and vial of adrenalin?" he instructs, "I always keep one in the car and one in the bathroom medicine cabinet. If I ever seem to be suffocating, stick me with this." He could die. I realize, feeling both close when he talks openly about his disease and fearful of the meaning of the information.
"I'm going to Alaska," Gene announces when I arrive at his house. "To see my daughter, Beth. We'll go from Seattle to Alaska on a ferry and sleep in sleeping bags on the deck. Then travel hippy-style around Fairbanks and Mt. McKinley National Park."

"Are you sure you'll be OK?"

When he says, "Of course," I wonder if he always knows his limits.

He returned from his trip ecstasy about his adventure but with a cold that made him sicker than I had ever seen him. His coughing railed with never-ending mucus plugs. Later, I would define this as the first drop in his health that I witnessed firsthand. Neither of us was prepared.

I stand helplessly, on alert, regretting that I have gone ahead with this surprise birthday and welcome-home party. After opening each present, Gene chugs codeine cough syrup in hopes of silencing his rattling cough. We ignore the fact that codeine will stop the expectorating of mucus, perhaps causing more damage. As he had said earlier in the evening, "The codeine might get em through the night and that's all that matters right now." This was my first experience with weighing long-term difficulty against short-term problem solving.

"Oh, a wine stein, I get it," he says, laughing and appreciating the pun of the present. The laughter renews his cough.

"Bad cold, huh Gene?"

"Yeah, a bad one," Gene responds, pointing to his chest. But Gene's attempts to normalize the situation fail to cover the sorrowful, tense feeling in the room as people realize the extent of his problem yet try to act normally.

For the first time, Gene and I function publicly as a team, trying to carry off the charade together. "God, I feel awful," he says quietly to me. "Should I take more cough syrup?"

"Yes, here," I say, and then turn to explain cheerfully to someone that Gene caught a cold from sleeping outside on the ship to Alaska. This training for learning to grab the moments between agony and fear would come in handy later.

I alternated between embarrassment, caring and concern, and numbness. When my tear took over, I was glad we were not in a committed relationship. Was this a glimpse of what was to come?

"I can't let anyone see me like this again," Gene says forcefully when we arrive home. "Do you have any idea what it does to the image people have of me? They don't see me as a whole person when I'm this sick."

"Come on, Gene. These are your friends." I flinch at his anger and want to assure him no damage has been done. They worry about you, but this hasn't changed the way they see you."

"How can they see me as an influential person at work when I'm this sick? I have to hide it."

"Tonight didn't look as bad as you think," I respond. "People see you as having a cold, it's something you'll get over. Everyone is sick sometime."

As I try to convince him and myself, Gene continues to insist that he will not let this slipup in identity maintenance happen again.

Gene faced one set of identity concerns while I faced another. He said he wanted to be seen as a "whole" person. The irony was that he really only wanted to be seen in terms of the healthy and robust part. I couldn't help but wonder how our friends had seen me. On the one hand, I liked being seen as a caring person. On the other, I wondered whether people thought Gene was using me as a caretaker. Was I seen as a love-struck young woman? What about my identity as a student and professional? Did acquaintances wonder why I was with someone who was "not a good catch"? Did it lower my value in their eyes? Gene's deteriorating health had raised a new problem: how to preserve our identities in the outside world while coping with the disease and our relationship.

Gene continues getting worse, and I stay with him the next few days, until he says, "Don't come over today,"

"But who will take care of you? You need someone."

"I'll be fine. I have to be able to take care of myself. I'm worried about all the time we're spending together and I don't want to need you like this."

You'll be sorry, you bastard, I think angrily. Then I feel some relief that I am not yet fully responsible for his care. But what if he gets into real trouble?

After only one day, Gene asks me to come back. When he opens the door, he looks like my picture of a tuberculosis patient—beet over, weak, skinny, pale gray. "I feel better when you're here," he admits quietly.

I fix something to eat and then get his medicines. "Look, when you're better, we can cut down on time. But not now. I want to be with you and help you. Just accept it. No strings."

During the next two weeks, Gene rarely slept at night and spent days kneeling on the floor, leaning over a chair. "I can breathe better that way," he explains, as I ration the cough syrup and marijuana that provided relief, with a cost.

Gene readily admitted that no one could care for him the way I did. I tried to let him make decisions for himself, yet be available if he got into a jam. I never had felt such giving love before. We grew closer, and I trusted
Gene's looks of love, even without the words. Sometimes it upset me that for Gene our increased closeness might come out of need. But maybe love always comes from need. What makes this particular need any different? Becoming more and more involved in this relationship, I experienced the complexity in being drawn to his vulnerability.

Although amazed at how much I wanted to help him, I was scared, more than ever, of this disease and its potential. Where did our relationship go from here? I reassured myself that this deteriorated state was temporary. Unaware of how little power I had in combating the disease, I was determined it was not going to control our relationship, or me.

Finally, the crisis passed, leaving Gene a little shaken, more breathless, and less mobile. Most people probably failed to notice his deterioration, but we couldn't ignore it. Our lovemaking was less varied; more and more the top position became mine. When Gene failed to return to his condition prior to the Alaska trip, we were forced to come face-to-face with the "progression" of the disease. "I have a progressive disease," he laughs cynically. "Progressive—what an absurd way to describe it."

The power margin in the relationship was narrowing, but the costs of equilibrium ironically exceeded its rewards.

"I WON'T HAVE TIME to see you during the meeting," Gene announces. "I'll be busy with old friends." The meeting he referred to was the annual American Sociological Association conference, which provided an occasion for sociologists to give papers, talk about their research, and renew friendships.

Since Gene and I had been seeing each other every night for seven months, his proclamation surprised me. At first, I rationalized that our relationship wasn't going to work anyway, I didn't want a long-term relationship with a sick person. That I was free to see other people however, failed to cheer me. Why did I live my life waiting to be with him?

Then I released the anger I had stored during the last few months. "I no longer accept that you control when we are together and when we aren't. I am not your toy to toss aside whenever you feel like it."

"But I've always said I need my freedom."

"And I need more consideration."

"What kind of consideration?"

"I mean the way you treat me in public. Like just another person or another student. I am not just another person."

"But you have no right to be angry. I never promised you anything. Don't you get a lot out of this relationship?"

"And don't you?"

"Yes, but there are other people in my life. You get your time."

"Well, 'my time' is no longer enough."

The day after the conference, Gene called, as though nothing was different, and invited me to his house. I went, but I showed little enthusiasm. During the next few weeks, he worked hard to please me, buying presents, calling more than usual, and being loving and considerate when we were together. He invited me to drop by his office, a place that had fi