PREFACE TO THE REVISED AND EXPANDED EDITION

This book tells the story of my nine-year relationship with Gene Weinstein. I was a twenty-four-year-old graduate student and Gene was a forty-four-year-old professor with chronic emphysema when we met in 1975, more than forty years ago. My relationship and caregiving story, which ends with Gene’s death in 1985, is long, sometimes arduous, with dramatic ups and downs, as serious chronic illness tends to be. The writing story that follows this personal tale took place during the nine years following Gene’s death. Writing this account also was challenging, with dramatic ups and downs, as composing a life and minding a career tend to be. Final Negotiations laid the groundwork for the early development of evocative autoethnography (Ellis and Bochner 2000; Bochner and Ellis 2016), the term I now give to personal writing that helps me make emotional and sociological sense of experiences such as these.

The first edition of Final Negotiations was published in 1995. The new Epilogue in this revised edition now affords me the opportunity to review this relationship and caregiving experience and the writing I did about it then. Recalling this time in my history offers a chance for a “do-over” in my mind, as I think about who I was then; how I have continued to be affected by these events and writing about them; and how I might act, think, and feel if I were going through them again now. How many of us get to remember a chapter of our lives in such vivid and excruciating detail? Revising this book also gives me a chance to reconsider and edit portions of the story to make the writing more inviting for readers.
As I read about this period of my life, I occupied dual roles, as I did when living through this experience, and I found myself responding to contrary pressures, even within the same paragraph. At times, I felt that I was “just” a reader of this life on the page or an editor trying to make the prose better; other times, I identified with the protagonist, urging her on, and feeling for her and the situations in which she found herself. Sometimes I wanted her to stand up more for herself, and on other occasions I wished she had behaved better. Often I became the character on the page, and I had to stop to catch my breath at what I had been through and what I knew my younger self would face later in the story. This became especially true as I read and reentered the later stage of Gene’s illness, where the trajectory quickly goes downhill with no relief or bright light offered along the way.

This revision allows me to take a meaningful look back at these two periods in time: the nine years I lived through the dying and death of my partner Gene; then the nine years I reflected and wrote about it in hopes of grasping what it would mean to live a good life in the future. That future is now, and my current positionality offers me and readers a third view for reflection and revisioning (Ellis 2009). What have I learned from this earlier experience with Gene that might help me to live as well now as I might, given the universality of impermanence? How might I cope with, think and feel about illness, grief, and loss in my later years? How might my experience—then and now—offer companionship and comfort to readers who are dealing with loss in their own lives?

Preparing this revised edition also affords an opportunity to honor the role of personal narrative in my life and work. Taking an autoethnographic perspective, I focus on the feeling and thinking self in relationship, narrating particular lived experiences that offer a gateway into understanding social and cultural life. I appreciate how vulnerable personal writing has helped me through difficult times and illuminated human relational experience in ways that detached and distanced writing does not. I celebrate the evolution and diffusion of autoethnography, which has presented opportunities to reveal lived experiences previously shrouded in secrecy; offered hope, companionship, and identification to those who are suffering; and provided insight into human emotions, embodiment, and spirit.

I will return to these ideas in the new Epilogue, which I call “From New Endings to New Beginnings.” The Preface and Epilogue, along with Arthur Bochner’s historical, theoretical, and relational positioning of Final Negotiations in the Foreword, update the frame that surrounds the original story within a story in this book. The primary story stays essentially the same: an account of the relational dynamics and day-to-day experience of caregiving and coping with loss of my intimate partner to disease and death just as I was
starting my professional life in the academic world. The framing story for this text chronicles the writing process and development of autoethnography that took place from 1985 to 1995 when the book was published. To that, I now add recent developments in the rise of autoethnography, focusing particularly on ethics. Then I turn more personally to the living, writing, and revising of this text from my position as an older woman in American society about to enter the post-university phase of my life. I address how writing personal narrative and evocative autoethnography as a meaning-making project has contributed to my thinking about human relationships, identity disruption, and coping with loss.

I've been fortunate to find love again in my life, and I've been in a caring, compassionate, and intellectually stimulating partnership with Art Bochner for twenty-eight years. As he and I age, we've had minor health concerns, but we have been privileged to live relatively healthy and prosperous lives. Yet I know that grief and loss continue over a life cycle and, in the breath of an unprotected moment, they can appear and disrupt our well-put-together lives. Revisiting this dramatic period with Gene leads me to consider how emotions connected with impermanence are, or will be, the same or different at this stage of life from how I felt and thought about them when I was a young woman caring for Gene and writing about our lives. How do my own vulnerabilities and health challenges now affect how I experience grief and potential loss? How does this earlier experience prepare me for and make me fear loss again in later life?

But before I tackle these issues, which currently dwell in my mind, I invite you into the day-to-day experience of a young woman seeking to live as fully as possible with a partner who is chronically ill. The backdrop for the story is the sexual revolution, drug experimentation, feminism, progressive politics, and hippy culture prevalent in the university setting during the 1970s. Seeking to tell an emotionally truthful story for herself and readers, she paints portraits of her interaction with Gene that remind us of how giving and selfish we humans are and how taxing yet meaningful serious illness, caregiving, and dying can be. Sometimes I recognize this narrator as me; sometimes I have to ponder how and why I did what I did. Likewise, you may find yourself resisting identification with her. But possibly you also may recognize some of your own qualities, see parallels in the tensions and conflicts in your relationships, appreciate the love that bound these two people together, and fear the loss that shattered their world every time they thought they had it put together.