INTRODUCTION

JOAN BERZOFF AND PHYLLIS SILVERMAN

THE NEED for this book evolved after the death of Joan Berzoff’s sister, an experience that pointed Joan’s career in a new direction. We therefore begin this book with the story of Barbara. In doing so, we honor her memory, and we honor her children with the hope that the book that follows will prevent others from suffering as Barbara and her family did.

JOAN WRITES: I can still remember the dull heaviness I felt when, at the age of thirteen, I heard the news that President John F. Kennedy had been shot. I felt it again when his brother, Robert, was killed, and yet again when Martin Luther King was gunned down. I remember the small details of places I occupied at the time: the crowded train station, the city street, the TV room of a friend whose family I was visiting far from my own. I remember what I was wearing and the crying around me. I remember feeling an inconsolable sadness, a sense of injustice, of impossibility. My world lacked a moral compass; it felt empty, without meaning.

I was seventeen when my father, sick for two years with lymphoma, lay dying in the intensive care unit. In my last visit to him, I feigned good cheer. I remember my mother’s voice, later that night, when the call came that he had died. A health fanatic, a man who walked five miles a day, my funny, caring, irreverent, and devoted forty-nine-year-old father no longer existed. The dullness, the lost compass again: he came to occupy a large empty place in my heart. I pined for him, I yearned and searched for him: among the men who commuted home each day from the city or, in later years, on the streets of Paris, or in Israel, where so many other middle-aged men looked like him.

I was preparing a course in a busy summer at the Smith College School for Social Work when I received a call from my sister, Barbara, my closest friend and confidante. I remember the stickiness of the time of day, the early summer’s smell, her voice, my voice, when my assumptive world changed again. While I chirped on about wanting to conceive a second baby, and, being the consummate little sister, asked her how I could ensure I’d have a girl, her silence became ominous, and I was afraid. She had
had a biopsy, she told me. She had breast cancer. She would be having a mastectomy, and then chemotherapy. Her voice was remote and dull. I began to lose her on that day. She was forty-two years old. I was forty.

In fact, I did become pregnant that year, and my sister, with whom I had spoken daily for most of my life, stopped calling me. I wanted to scream at her, to punish her, but I willed myself not to. I tried to force myself to live in her shoes: three children, a primary identity as a mother, a bad marriage, a low-paying career as a social worker, and the reality that she too might soon cease to exist. Why should she celebrate my life?

When she was forty-seven and her breast cancer was seemingly cured, and after we had long ago reestablished our relationship, this time at an even deeper level, she came up to the country, where I live. We had always spent a month in the country together, she with her three children, and me in a frenzy of teaching full time and parenting my own two boys. She was relaxed; I was always on the edge. She was the comforter, and I the frenetic, overextended, nutty professor.

She had a cough that would not remit, so she tried treating it with acupuncture. It got increasingly worse, although she minimized it. It was not her nature to complain. But when she got so weak that she couldn’t walk up a low hill, she reluctantly visited my internist. He hospitalized her. I arrived at dinnertime with two frozen yogurts in hand (our favorite flavors, no less) and cheerily breezed into her room. My internist asked to see me. I left the yogurts and my sister, and he bluntly gave me the news. Her diagnosis: myelodysplastic syndrome. She had less than two years to live.

I can remember the color of his tie. I can remember the smell of the hospital hallway. I can remember the squeak of shoes, and I remember feeling that this time the world could never right itself. This was the sister who was like my twin: we shared the same humor, the same sensibilities. We both lived in Victorian houses; we were both married to doctors; we shared a history that only she could remember. She had been my constant companion and my most honest friend. I could not lose her.

The next day we took off for the city to meet with her oncologist, who was about our age. The oncologist barely looked at us. She was cold, clinical, factual, and anxious to have the meeting end. She had known the diagnosis for a while but had not told my sister. She told us that the only option for my sister was a bone marrow transplant, and that my sister had better have it fast. She gave my sister a 30 percent chance of survival if she had the transplant. Without it, she had none.

So two sisters who looked like twins, my other half and I, went out to a fancy bistro, dined next to Anthony Hopkins, and checked into a fabulous hotel. As she slept, I wrote. This was one loss I thought I could not withstand. My sister, my friend, who held the light for me, who went first into every life experience, was going to die.

What followed were the frantic calls to all of the medical acquaintances that we knew. The experimental protocols, the alternative medicines, the desperate measures one takes to hold onto life, became daily routine. One spring day, as we walked around the reservoir in her city, I remembering suddenly keening, unable to go forward. I couldn’t envision a world without her: this beautiful, bountiful other.

We ended up at the most prestigious cancer hospital in her city. It was April, and
a year had passed. She was getting transfusions every day so that she could continue to work with the children in her clinic and with the families in her private practice, be present at her own children’s games, events, and play dates, still have the stamina to take short walks. Her first contact was with the hematological oncologist, not with a social worker. My sister recounted her medical history: the lump she had found ten years ago, the doctor who ignored it, the diagnosis of breast cancer two years later, the cure for the breast cancer, the death sentence from the cure. I felt the familiar dullness, yearning, and injustice.

She was hospitalized immediately and had her spleen removed. But that did not help to change her platelet levels, which hovered dangerously between six and four thousand. She was told that she would be dead within months without bone marrow transplantation. She might be dead sooner with one.

My sister was ambivalent about this highly touted cure. She believed she was going to die, and she did not want a high-tech death. She did not want to die alone; she did not want to die in a research hospital. More than anything, she did not want to die physically immobilized or cognitively impaired. She did not want her children to witness her suffering or pain. She did not want her family of origin to become her primary caregivers. She did not want to depend on others; she did not want to be in the complete isolation that the procedure required. She was not sure she wanted to undergo a treatment whose purpose was to bring her to the brink of death and back.

When she expressed her ambivalence to the chief of the Bone Marrow Transplantation Service, his response was quick and imperious. He told her to leave; he had a line of people desperate for his services, and if she didn’t want them, she was wasting his time.

Neither he nor his transplant coordinator, however, had elicited her psychosocial history. Had a social worker done so, it might have revealed that my sister had lost a father to lymphoma at the same age that she was now. A social worker might have learned that when our father died, he left three children, exactly the ages of my sister’s children. No social worker noted that her husband was absent from all of these meetings and that this might suggest marital difficulties and additional psychosocial stresses. No one asked, and therefore no one knew, that she was the primary and absolute caretaker for her children and the designated caregiver in her community of friends. No social worker talked with her about who would take over in her absence. Without a psychosocial history, and without a social worker to interpret her ambivalence to the team, she was viewed by the surgeon as a noncompliant and ungrateful patient.

Ultimately, my sister decided to undergo the transplantation, not because she felt it would save her, but because she felt that by not doing so she might leave a legacy for her children that she had not tried every means to stay alive. Not surprisingly, I was a perfect match as her donor.

She entered the hospital with a number of concerns. First, she did not want to experience the crippling anxiety that had become her constant companion. Second, she did not want to be kept alive if there was no hope for her survival and if life supports were the only means of living. Third, she wanted most of all to protect her children, at all cost, from the reality of what she would encounter. Had there been a
social worker present, a psychopharmacology consult might have been called. A social worker might have recognized my sister’s hopelessness and helped her to find a group, or made a referral to a mental health professional. A social worker might have initiated a conversation with my sister about advance directives. A social worker might have inquired about the ways she was trying to cope, and some of the ways that shielding her children might not serve them best. A social worker might have thought through with her the children’s different developmental needs and how best to address them. A social worker might have suggested a family conference. A social worker might have empathized with my sister as she left her job, terminated her private practice, and wrote letters to her children in preparation for her death.

Had a social worker been available, she might have addressed my sister’s concrete needs: Who would pay for this procedure? Who would take care of her should she leave the hospital? She might have inquired about her spiritual needs: Where did she find comfort and solace and how could it be provided? The social worker might have anticipated her physical needs, her family’s psychological needs, and my needs as the donor.

It might have made a difference to her survivors, after she died, to have had a social worker present to let the team know that when the bone marrow transplantation “failed,” it was the procedure and not the patient that had failed.

On every level—individual, couple, group, family, systemic—it would have been important to have a social worker who could have intervened. But my sister was a social worker, and anyone who worked with her would have to look mortality in the eye, face some of their own existential issues around dying, and be able to bear a range of feelings that would arise, simply by being present.

When our father lay dying, we did not discuss it. In fact, it was considered bad taste, grossly insensitive, to mention death. It was as if by naming death, we would be responsible for it happening. When our father was in the ICU, I remember asking his physician about his chances for survival. I was seventeen and I needed to know. At that time, physicians and medical caregivers did not tell adolescents that their parent was dying. The prevailing view was that neither the patient nor the family member could handle the news and that the adolescent was too young to know. When he told me that my father had a fifty-fifty chance, I knew that he was lying. My father was dying and there was no one in that hospital to tell me the truth, let alone to help me process it.

Now my sister’s children were in the same situation. Unwittingly, my sister and I, two social workers, and two children of a dead parent in adolescence, were complicit in shielding them from the pain of her likely death. She wanted her eldest daughter to go back to college, free of the dread and fear she had felt at the same age. Her sixteen-year-old daughter had stopped eating. She wanted to ease her psychological pain and to protect her from more. Her ten-year-old son was just so young. He didn’t really need to know, did he? Hence when her children came to the hospital to see my sister, and when she was so wasted that she could no longer sit up at all, my mother, the nurses, and I arranged her body to look as if she was sitting, knitting, or sewing. We could not bear the truth. There was no social worker to help her children, or us, to face it, let alone metabolize it.
Within days of the first bone marrow donation, my sister bled into her lungs and was sent to the ICU, where she depended fully on a respirator. One kind nurse took my other sister and me aside, and in a broom closet told us that no bone marrow transplant patient ever survives after such a bleed. But to the world, to the assembled guests in the ICU waiting room, to her children, to our mother, we put on a brave face, acted as if we had hope, and quietly bore the despair, and the dullness, that the world had once again been shattered.

As for being a donor, it would have been useful to have a social worker involved. I lived three states away. I had two young children. I worked full time, and the transplant had been scheduled during my most demanding season: the summer. I needed someone with more expertise than I to help me anticipate not only my physical needs but also my psychological ones. I needed someone to help me size up my commitments and make my sister the first priority. When the first bone marrow transplant failed, I needed to give platelets every other day. This meant finding a driver to take me to the city and finding a place to stay. When bone marrow was extracted from me a second time, no one told me how I was to get across the street after surgery without the wheelchair that I had to relinquish at the door of the hospital. While unrelated donors routinely receive psychosocial counseling, none existed for related donors.

Five months passed in isolation. Every visitor to my sister’s room was gowned and gloved. Our facial expressions were obscured, and our ability to touch, skin to skin, was made impossible. Weeks and months dragged on, and summer turned to fall. My sister never left her room, except for three trips to the ICU. After two bone marrow failures, the team decided that they would send my sister home. They did not say she was going home to die, just that the good news was that she was ready to go home. She was entirely dependent on platelets. She had inadequate physical and emotional support at home. She had no round-the-clock caregivers in place. But no referral to hospice was made, and the opportunity to die with her family and friends around her, dealing with the reality before them, in a safe setting where her physical and psychological needs would be met, never occurred. No social worker was present to advocate to the team on her behalf. Three days later, always anticipating the needs of others, she kindly suffered a stroke that would mean she would never go home. Although the stroke solved the problem of inadequate physical care, it also left her paralyzed and cognitively impaired. She developed a reflex where she repeatedly lifted her arm over her head, smiled a bizarre and clownlike smile, and patted her head. She was diapered; she no longer recognized her children. Her worst fears had been realized. What would it have been like to have had a social work professional to help them, and us, with our grief and loss?

After my sister died, her hematologist wrote the family a lovely letter, as did the bone marrow coordinator. As there had been no psychosocial services prior to her transplant and during the months that she was dying, there were none after she died. Her greatest fears—that she would die cognitively impaired, that she would die without a plan in which her children would be adequately cared for, that she would be paralyzed and kept on life supports—had been realized. Her children’s grief went unacknowledged. My own guilt about not being able to save her life was something...
I carried alone. There was certainly no bereavement follow-up care for her donor or her family.

JOAN'S STORY about her sister Barbara in many ways sets the stage for how we approach this book. What we learn from Barbara’s death and her children’s bereavement brings together the personal and the professional. In her death and dying, as in her family’s subsequent bereavement, there were so many moments when a social work intervention might have made a difference. This book is about the differences that social workers can make in the lives of the dying and bereaved every day.

One theme resonates throughout the rich and multifaceted contributions that make up this book: The authors have emphasized the importance of their own lived experiences in ways that are not always considered in other practice settings. As we worked with their contributions, we came to appreciate even more that there is something in end-of-life care that makes it difficult for workers in this field to leave their own selves at the door. And this is as it should be.

Death is not something that will happen only to others, but something that all of us will encounter. We may not die at a young age, we may not die after a long illness, we may not die as a result of a violent or traumatic death, but we will all die. As we get close to people as their lives end, it quickly becomes clear that we are talking about something that will happen to us too. We will all know grief, as well, as long as we are involved with others about whom we care. We are not talking about “them”; we are talking about all of us. How does this change who we are when we work with the dying?

To be effective, we are forced not only to look at but also to use our own attitudes, values, and fears and feelings about death. We cannot simply adopt a removed or neutral clinical perspective. How do we deal with our common humanity and still be available to help those we are there to serve?

As we tried to answer these questions, we were faced with a need to visit contemporary views of social work theory, practice, and policy. Traditionally, we had been taught that it is important for the well-trained social worker to maintain boundaries between herself and her clients, to be sure that the personal and the professional do not mix. But this work is always personal, and it requires that we examine our practice with a different lens. This is one of the goals of this book.

OUR GOALS

This book is directed to social work practitioners and social work students working in end-of-life care settings. The focus is on practice in settings that are devoted to caring for terminally ill people and their families. However, all social work practitioners need to know about end-of-life care. People come to social workers at various times in their lives, and many will be dealing with dying and grief, even when it is not in the forefront.
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at that moment. Those who work with bereaved children in foster care or in schools, those who work in mental health, those who work with the elderly, to name a few, routinely encounter end-of-life issues. We hope that this book raises practitioners' consciousness, improves their practice, and provides much of the knowledge, values, skills, and attitudes needed to effect changes in our systems of social work care. We hope that this book helps the practitioner in her micro practice, and in being an agent of change in larger systems. We hope that this book encourages social workers to take major leadership roles in the field of end-of-life care: as practitioners, educators, consultants, agents of change, and researchers.

We asked, as we invited practitioners and scholars to contribute to the book, several questions to focus their writing. We wanted to know what in their own clinical experiences informed their practices. We wanted to know about the theories and perspectives that were most useful to those working with individuals, families, and groups at the end of life. We wondered how clinicians who work with the dying and their families sustained hope, worked successfully as members of teams, maintained their clients’ dignity, facilitated communication, and provided access to services, whether those clients were young or old, single or partnered, straight or gay. We asked each of our authors to use examples from their practices, from their own lives as practitioners. What were the settings in which they worked, and what were the issues that must be attended to? What are the gaps? Who benefits from the current system, and who is disenfranchised on the basis of culture, race, gender, sexual orientation, ability, age, or social status?

Joan’s sister’s experience points to some of the profound gaps in the service delivery system. In the years since Barbara’s death, has anything changed?

Sadly, according to a report from the Robert Wood Johnson Foundation of November 2002 on the state of the art for end-of-life care, not much has. In 1995, that foundation produced the SUPPORT (Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments) Report and found that the majority of Americans die alone in institutions, in pain, attached to machines against their wishes. The 2002 report looked to see what had changed since. Although some progress is being made, end-of-life care in this country is still mediocre, at best. Some of the key findings were:

- Seventy percent of Americans say they want to die at home, but only 25 percent of them do.
- Half of all deaths occur in hospitals, but less than 60 percent of hospitals offer specialized end-of-life services.
- There are serious reimbursement issues for hospice, palliative care, and pain management services.
- Most states have only fair hospice use — 12 to 25 percent of deaths include a hospice stay.
- In any given state, at least 25 percent of nursing home residents have pain for at least two months without appropriate pain management.
• Only 33 percent of U.S. physicians are certified in palliative care. The average percentage of nurses certified in hospice and palliative care is 0.44 percent.
• Even though ICU care is often unwanted, 16–37 percent of deaths among Medicare recipients include ICU hospitalization in the last six months of life. A study of cancer patients in ICUs found that 75 percent had pain, discomfort, anxiety, sleep disturbance, and unsatisfied hunger or thirst.
• Half of all dying people experience severe pain.
• Demographers predict that with increasing numbers of elderly people the burden of chronic illness will increase.
• Emotional and spiritual care for families and patients that respects their cultures and traditions are essential parts of the dying experience but are not generally available.

As we study these findings, we see the importance and value of being knowledgeable in the psychological, social structural, and policy domains. We see the need for social workers trained to provide emotional and spiritual care needed at this time in people’s lives. It may not be enough to improve clinical practice. It may require social workers’ using all of their skills and talents to take leadership in changing policy and practice in this field.

Hence another goal of this book is to expand the reader’s perspective about practice beyond the individual person who is dying. The findings from the Robert Wood Johnson Foundation remind us that we cannot simply look at an individual who is dying in isolation from her larger community. Every individual is a member of, a participant in, and a by-product of his or her family and community, with a set of beliefs and values that reflect who the person is and how she came to be that way. The social worker needs to understand the dying person in the larger context in which the person lives: his or her spiritual life, economic reality, and cultural life. Every dying person is a member of a larger community that either affords or blocks access to quality care, based on factors such as class, race, gender, age, ability or sexual orientation, and/or political philosophy as exemplified by the ways healthcare is financed and delivered in this country. Many of those who are dying are marginalized in our society. Prisoners, certain racial and ethnic groups, those for whom literacy is impaired, those with reduced cognitive functioning, those who carry a mental illness, a cognitive or physical disability, a stigmatized status, immigrants for whom English is not their language, children who are bereaved from ravages of the AIDS epidemic, those traumatized by disasters—all of these groups are at the heart of social-work priorities and practice. As social workers in end-of-life care, we must always try to know who a person is in the context of all of these factors and be prepared to advocate on behalf of the most vulnerable clients.

We also need to consider the attitudes, the resources, and the organizational structures of the institutions in which we work. Much of end-of-life care in the United States takes place in hospice programs, many of which are freestanding nonprofit organizations. Some are parts of medical settings and others are for profit. All of these programs rely on a specific reimbursement scheme: the Medicare Hospice Benefit, enacted by Congress in 1982. This benefit can be accessed only by those whom a
physician certifies to have a life expectancy of six months or less. Hospice also refers to a philosophical approach to care for the dying that is holistic and family centered. In Canada hospice-like programs are referred to as palliative-care programs. Palliative care is an approach to care that extends hospice philosophy and practice to a wider range of healthcare settings earlier in the process. Palliative care seeks to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure. It is not restricted to those who are dying or enrolled in a hospice program. It does not preclude the provision of curative treatments. Palliative care provides comprehensive management of the physical, psychological, social, spiritual, and existential needs of people with life-limiting illnesses or who are suffering from chronic pain. The needs of children with life-limiting and incurable conditions for palliative and hospice care are now being recognized. Programs that address the child’s/adolescent’s needs within the context of the child’s/adolescent’s physical condition, developmental stage, family, and community are proliferating. Palliative care and hospice can be seen as part of a continuum of care providing the same interdisciplinary practice, values, and attitudes regardless of the setting. How social workers provide these services forms the nexus of this book.

The quality of clinical practice can never be divorced from the institutional contexts that make the rules and regulations and that control the resources, all of which effect accessibility and the quality of end-of-life care to those whom it potentially serves. This book seeks to help social workers become knowledgeable about who gains access to healthcare in America: Who is included, and who (such as the homeless or substance abusers) is excluded from receiving adequate pain management or Medicaid reimbursements for hospice care? To address this situation, we not only need to be clinicians, but we also must sharpen our skills as advocates of policy change, educators, and consultants. We need to develop a range of roles to be spokespersons for the most at-risk populations as part of the interdisciplinary team that makes and implements policy decisions. We need to become leaders in making systems changes. This is part of our early social work history and mission, and one that must be reclaimed in end-of-life care. In order to understand where we are going, we need to look at where we have been, and the readiness of the profession to grow into this new work.

We must also see that there are adequate curricula to prepare social workers to do the difficult work of end-of-life care, at the BSW, MSW, and post-master’s levels. This includes including content on transference/countertransference, on uses of self, and on the intersubjective spaces between client and clinician. Social workers need to know how to work in a range of settings: bereavement, palliative care, medical social work, nursing homes, prisons, family bereavement camps. Social workers need to be exposed to content on a range of biological diseases. They need to be able to assess and therefore treat the clients whom they meet. They need to learn to be present for the spiritual, existential, and intimate moments in this work. They need to be able to be present to another’s suffering, which requires some attunement to one’s own.

In the first draft of the chapter on the concept of a “Respectful Death,” by Stuart and Lu Farber and Tom Egnew, Egnew wrote a review of the role of the social worker in palliative care. The content of this section so paralleled material we were writing
for this book that we asked his permission to make this aspect of his contribution to their chapter the preface to the book. In it, Egnew critically examines the core competencies and values that social workers need to provide end-of-life care. He looks at practice and at professional education. Rather than paraphrase what he wrote, we encourage the reader to read the preface, for it lays out the important knowledge, values, and skills for the profession of social work in end-of-life care.

Tom Egnew’s review of the state of the profession reminds us of the urgency and importance of listening to the client. We need to recognize that every client is in a process of change, and that the dying person and his or her family need to learn to collaborate with those who care for them, just as we, in the role of caregivers, need to learn to collaborate. Phyllis Silverman’s experience provides us with an example of how this happened for her.

**PHYLLIS WRITES:** My own life as a child and young adult was checkered with many deaths, ranging from the death of a child on our street to the death of grandparents and the death of a dear friend. However, they were always one step removed from me, and I was away from home when the later deaths occurred. My parents worked very hard to shelter me from experiencing their impact. They did not take me to funerals, and they delayed sharing the news of the deaths with me for as long as they could. This is what was considered appropriate at that time.

A question I often ask my students is to think about when they first knew that they would die. Many cannot remember; others feel that in a way they always knew. Others did not think about it until they were teenagers. I asked with whom they could share this. Not all, but many, felt that their parents listened and the conversation was comforting and reassuring. I was eight years old when I first realized that I, too, would die. I was so fearful that I couldn’t sleep for several nights. There was no one to talk to. My solution was to close my eyes when I went by cemeteries, and in many ways I did not open them until I began my work with the widowed in the mid-1960s.

When Joan asked me to join her in editing this book, she saw me as an expert in bereavement with more experience in the death-and-dying world than she had. However, this is only partly true, and then only in a theoretical way. My research, my work in program development, and my clinical experience largely derive from looking out from what I call the other side of the door. I know a good deal about how people die, and about who they were, but I have learned about them by listening to their surviving relatives. I began to appreciate that there was no one good way to die. As a researcher, I learned that the bereaved have profound strengths that they can offer to one another through self-help. What involved me was not the tragedy of their loss, but the opportunity this work created for me to look at people’s ability to cope, to move in new directions, and to find new ways of living in the world without the deceased. I almost did not take the job of working with the widowed because I wasn’t sure I could deal with death and bereavement. To have become involved was probably one of the most
important decisions I ever made. While it doesn’t stop hurting when I experience
other people’s pain, I can live with it and be there for them, for my family and for
myself. I find that I am always learning. This began early on in my relationship with
the widowed I met in my work.

When I first began my work with the widowed, they taught me a very important
lesson. In 1965, bereavement as described in the clinical and research literature was
seen as something that people got over and would get on with their lives in a period
of six weeks to several months. When the widowed women I recruited to work with
me on the widow-to-widow experiment heard this, they couldn’t stop laughing. They
said, “If in two years you have your head turned around so you can look ahead, you
are doing well.” It became very clear to me that they were going to be my teachers,
and this has guided me in my work ever since. I saw that when a theory is not supported
by the real world, there may very well be something wrong with the theory, not the
world. Whenever I think I have it all together or become too confident as a profes-
sional, I hear the laughter at that meeting and I am reminded that I always need to
listen. My professional colleagues have challenged me many times about the impor-
tance I place on what the bereaved can do for each other and themselves, but this
point of view has enabled me to look differently at what I was hearing from the
bereaved and in analyzing my research data. In my work I try to hear what people
tell me and teach me about their situations.

I came to this work with a background in both social work and public health,
having just earned a second master’s degree. I had learned about population patterns
in the need to understand the incidence and prevalence of a problem or disease as
we considered appropriate ways of reaching those who might be in need. This meant
that for any one client seen in an agency there could be many in the community who
might not need “treatment,” but who needed some attention and perhaps a “little bit
of help from a friend.” The widow-to-widow program that we developed was successful
because we were reaching women in their own homes and the help provided was
offered by another widow whose experience was immediately relevant to the newly
widowed. I talked to my colleagues in agencies about services for the widowed that
they might provide. They assured me that they were providing these services as dem-
onstrated by the one or two cases they were seeing. I also learned that the majority of
the widowed I interviewed did not see themselves as needing counseling or therapy
in spite of the pain they were experiencing. I learned that my social-work training did
not provide me with a view of the larger community and the tools to become aware
of those people whose needs the agency could not appropriately meet. My work was
guided by a public-health approach that included a wider range of interventions than
might be provided in any given clinic, among them an acceptance of experiential
knowledge—that is, knowledge gained from lived experience (Silverman 2001). This
was another way of “knowing” that added a new dimension to what I understood as
help and challenged the role of the professional as the expert. I also began to differ-
entiate between the range of mental-health problems people brought to social agen-
cies and those created by life-cycle events that all of us must experience. I am con-
stantly reminded that these are adversities that none of us will escape and that we all
need to be experts in how we manage these periods in our lives and that we will learn from each other.

I don’t think we ever become immune to the pain in the people whom we meet or to our own vulnerability. When I wrote my book on children’s reactions to death, I included a section on how parents and siblings react to the death of a child. I cried my way through each of these chapters. At first I was apologetic that after all these years I should react so personally. The keyboard was a bit moist as I began to understand that unless I could begin to experience some of their pain, I could never hope to offer these people anything. I came to accept my tears as I also realized that I was an observer who was most thankful that I didn’t really understand.

As I worked on the chapters for this book, I became involved in the stories that so many gifted authors have contributed, and I have experienced the pain, the sadness, and the vitality of those who are beneficiaries of their services. I am drawn to this work in a new way, so that my learning and, I hope, my personal growth continue.

**ORGANIZATION OF THIS BOOK**

This book, then, brings together the three aspects of practice highlighted so eloquently in the preface: theory, skills, and attitudes, to which we add personal narratives and the social and contextual issues of policy, research, and leadership. In addition, we have been deeply committed to developing curricula for training for social workers who work in death, dying, and bereavement. Much of this book is based on what social workers need in their training to provide excellence in end of life care.

**DEVELOPING CURRICULUM**

In 1999, the Project on Death in America announced its first Social Work Leadership Award to improve the psychosocial quality of dying in America. Joan was then a teacher of psychodynamic theory and practice and wondered what she knew about death or dying that might contribute to the field. Her husband, himself a PDIA scholar, pushed her to use her lived experience of her father’s and sister’s deaths, and she began to map out both an educational program and a textbook for post-master’s advanced training for social workers in end-of-life care.

G. H. Christ and M. Sormanti had already documented the woefully inadequate preparation that social workers receive in their masters’ programs in end-of-life care. Joan was then given a PDIA Social Work Leadership Award to offer a post-master’s training program in end-of-life care at the Smith College School for Social Work that would address social workers’ needs to attend to psychological, social, and cultural factors and ethical issues in hospice, palliative, and bereavement care. She also began the outline that has now become this book.

The End of Life Certificate Program is in its fourth year, training post-master’s social workers from the United States and Canada in theory, practice, ethics, hospice and palliative care, bereavement, uses of self, cross cultural issues, issues for gay and lesbian clients, spirituality, and legal issues and in leadership in end-of-life care. In
addition to two intensive weeks of coursework over two summers at Smith, every participant completes an eight-month internship and receives clinical supervision in her workplace telephonically, integrating into practice the academic content learned during the summer. Every participant also produces a final paper, some of which are included in this book. Every participant is expected to run a group and to take leadership in the field. Although we wish we had been able to publish many more of their innovative papers, many of the students have already published in journals, presented at national conferences, and taken leadership roles in their end-of-life care settings.

In part, then, this book follows the structure of Joan’s program. We have brought together the voices of those who have taught in the program, those who have studied there, those who are already leaders in the field, and those who have been practitioners whose lives and work have been shaped by personal losses. We have supplemented many of the chapters with scholars and practitioners who are also social-work leaders in the Open Society’s Project on Death in America, supported by the financier George Soros. Additionally, we have solicited many chapters from a range of other outstanding practitioners/scholars in the fields of death, dying, and bereavement, many of whom are affiliated with the International Work Group on Death, Dying and Bereavement.

The book begins with an important aspect of the attitude we bring to our work that focuses on combining the personal and the professional.

THE IMPORTANCE OF THE PROFESSIONAL AND THE PERSONAL

We begin the book with four narratives that are similar to Joan’s, written by professionals in the field who faced extraordinary losses and found ways to give special meaning to them. We begin the book with narratives because we believe that meaning making is an essential part of dying. Creating a coherent narrative is one of the best adaptations to grief and to loss that people make. The contributions of these four authors provide wonderful ways of teaching us about living, and about dying. We begin with David Browning’s reflections on the death of his mother and his own suffering. David is able to reflect upon his own career and his gifts that emerged from that profound trauma. We move to Roberta Hoffman, who was a social worker on the hospital unit where her son was diagnosed with cancer, and where he ultimately died. She talks about the distance her colleagues created, and about, as in Joan’s story, her son’s death, which was seen as the patient’s failing, not the service’s failing him. Ellen Pulleyblank Coffey, a psychologist, writes about making the decision not to terminate her husband’s life support and about the joys and agonies of family life that ensued over the next five years with her husband on a respirator. Les Gallo-Silver and Penny Damaskos, both social workers from New York City, write about being practitioners and people when the World Trade Center collapsed, again reminding us that in living and dying we are all human: sometimes uncertain and often afraid. Each narrative chronicles the role of social worker in end-of-life care. Each story reminds us that dying can be capricious, traumatic, and out of our control. Each narrative offers hope: that out of loss we gain something: a link to the person(s) we have lost, and to our own humanity. Each story reminds us of how we continue our ties to the dying as we
return to living fully, and often with a new focus. Each story is about loss of hope and its restoration. Each story presents the intersection of empathy and compassion that derives from each of our vulnerabilities. By reading these narratives, we experience bearing witness to suffering, and the ways in which facing loss may allow us to be more present. Most of all, these narratives remind us that we cannot fix or take away pain, but we may act as guides and collaborators for those who suffer.

THEORIES THAT INFORM OUR WORK

The second section of the book encompasses a more theoretical and historical approach to practice in end-of-life care. If we are to bring about change, we need to understand the historical and theoretical lenses that have influenced current practice. We need to know about the theories from psychology, ethics, spirituality, sociology, and even organizational behavior that influence death and dying in America.

We begin this section with a chapter by Stuart and Lu Farber and Tom Egnew, who have developed the concept, not of a “good death,” which runs the risk of romanticizing death, but of a “respectful” death. They look at how social workers and physicians learn from each other in the service of their patients or clients. They tell us of core competencies for physicians and for social workers, and they set the tone for a basic approach that we hope to maintain throughout this book: that of learning from the patient and the family. Phyllis Silverman next looks at death and bereavement as universal human experiences over time. Mary Raymer and Dona Reese help us to understand what influenced the development of the hospice movement and the role of the social workers in this development. Carolyn Jacobs integrates psychodynamic and spiritual perspectives in her chapter on the social worker’s journey with the dying. Patricia O’Donnell adds the ethical dimensions of end of life care to the discourse. Inge Corless and Patrice Nicholas provide a scholarly view of the complexity of interdisciplinary teamwork and its centrality in end of life care. Patricia O’Donnell examines ethical issues that surround all end-of-life decision making. Illene Noppe considers, from a social-psychological perspective, the ways in which gender and death intersect. Phyllis Silverman offers complementary developmental models on loss and bereavement, and Joan Berzoff offers a historical view of psychodynamic theories in grief and bereavement, looking at how inner life is shaped by and transformed by loss.

SKILLS: THE BASIS OF GOOD PRACTICE

In the next section on practice, we hope to convey the ways in which the social worker works within a range of modalities, over the trajectory of illness, in a range of settings and with diverse populations. We have sought contributors who explain their clinical work from experience-near perspectives. Our authors use themselves and their stories in ways that bridge the gulf between self and other, to encourage writing in the first person, to model an approach in the field of end-of-life care that we consider essential to quality social work.

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We begin the practice section with Wendy Karger and Allan Levine’s chapter on the trajectory of illness that looks at the impact of diagnosis on every aspect of an individual and family’s life. Felice Zilberfein and Elizabeth Hurwitz’s chapter on clinical practice with individuals at the end of life artfully integrates the biological, psychological, spiritual, and social dimensions in a person who is dying, with the experiences of the social worker. Nancy Cincotta moves the lens to the inner lives of children and their families and how they intersect with the personal and professional aspects of the social worker. Neil and Sue Thompson look at complementary issues in old age. We still read these chapters with great sadness. This is as it should be, because if we are not moved by the work we do, we are likely not fully in it.

A crucial part of providing skilled end-of-life care requires excellent assessments. We hear from Katherine Walsh-Burke on making an assessment that includes mental-health issues: depression, anxiety, or other disorders. Terry Altinio examines how to assess pain and use the skills of the social worker to participate in provision of symptom management. Because pain and symptom management are only a part of quality palliative care, Susan Blacker discusses the multiple roles of the social worker in providing palliative care. Another aspect of quality palliative care is spiritual care, and Barbara Dane provides a clinical view of spiritual practices at the end of life.

Social work practice and palliative care must always be directed toward the most disenfranchised in our society. Hence a number of chapters follow that look at populations at risk who are dying or bereaved. Norma del Rio turns our attention to those whose disenfranchised status based on culture or race may interfere with receiving quality end-of-life care. Shirley Otis Green and Chris Rutland consider dying from the perspectives of the disabled, the homeless, and the addicted, all marginalized at the end of their lives. Bruce Thompson and Yvette Colón introduce the psychosocial concerns of lesbians and gay men at the end of their lives. Gary Stein and Lucille Estalew consider both clinical and legal issues for the disabled, who are often unable to speak for themselves. We know of no other book that has elicited the voices of the disenfranchised dying and bereaved.

With Amanda Sutton and Daniel Liechty’s chapter on groups, we shift the lens to consider a number of modalities: group and family work in end of life care. Sutton and Liechty write about group work with the dying and bereaved; Yvette Colón extends the model, writing about innovative group techniques such as telephone and Internet groups. Susan Blacker and Alice Jordan further expand upon clinical practice in discussing work with families facing life-threatening illnesses in medical settings.

We move the lens again, in a chapter by Phyllis Silverman, to consider bereavement, an essential part of palliative care, to look particularly at what we mean by helping. We also consider, in a chapter by Susan Gerbino and Shelley Henderson, the question of end-of-life bioethics in clinical practice.

Quality palliative care takes place in many settings and requires specific clinical skills. These may include international settings where disasters have occurred, as discussed by Lisa Aronson. Quality clinical social work care may take place in prisons (Sheila Enders), nursing homes (Mercedes Bern-Klug and Kim Ellis), or in bereavement camps for children and families with AIDS (Christian Itin, Susan McFeaters, and Susan Taylor-Brown).
Introduction

Disease processes also have trajectories that are different, and challenges in each of their treatments. Iris Cohen Fineberg helps us experience the world of bone marrow and hematopoietic cell transplantation units and the psychosocial challenges for patients and their families there. John Linder’s chapter on working in oncology offers a window into palliative care with patients who have cancer. We end with his chapter because he provides such a clear intersection of race, class, and gender with individual, group, and family practices in palliative care, again in a voice that is subjective, not objective.

CONTEXT AND LEADERSHIP

In the next section, we examine what else social workers need to know to provide quality clinical care to persons at the end of their lives. Social workers are often on the front lines for making ethical decisions and need to be knowledgeable about legal and ethical issues at the end of life. Both Stephen Arons and Ellen Csikai offer the reader ways of understanding current policies related to advance directives, autonomous decision making, and the right to die. John and Jenny Dawes examine the policies of prisons, in which significant end-of-life care occurs. June Simmons adds the financial contexts to death and dying in America to the discourse.

We go on to examine future directions for social work. Here we have gathered the voices of leaders, and scholars in end of life care to discuss the state of the research in end-of-life care for social work (Betty Kramer and Mercedes Bern-Klug) and the necessity of taking leadership in this field (Esther Chachkes and Zelda Foster). Social workers cannot simply be practitioners; they must become consumers of research, and producers of research. They must take on roles as consultants, educators, and spokespersons for the dying and their families. They must advocate for policy changes, within their institutions and nationally. They must develop new curricula in end of life care.

How do they do this, without burning out? Here we hear from the current president of National Association of Social Workers, Elizabeth Clark, about the future of social work in end-of-life care. But there is another dimension to thriving in and sustaining oneself in this work. We deliberately chose to have our last chapter address self-care for the social worker because we think that this work requires “relentless” self-examination and care. Irene Renzenbrink writes beautifully about her own experiences as a novice in the field of end-of-life care and about the ways in which this work is always personal and demands care of ourselves and of our souls. She embodies the philosophy of the book in suggesting that who we are is crucial to the work that we do, and that we must always attend to replenishing ourselves, through education, supervision, and collegiality, in order to be effective and authentic.

We invite the reader into the lives of so many people: professionals who have suffered major losses and made meaning of them, social workers who work with people dying from particular diseases such as cancer or hemopoietic diseases, social workers who have tried to integrate psychological and spiritual practices, social workers who work with the most disenfranchised, social workers who practice with those at the
beginning of their lives or those who are ending their lives. We introduce the reader to the many roles of social work: in interdisciplinary care, in pain and symptom management, in palliative and hospice care and in bereavement care. We introduce the voices of social workers that have developed innovative programs, such as the Family Unity Camp for families and children dealing with AIDS.

But we also introduce the reader into the lives of people who are dying alone in prisons, on inpatient units, in nursing homes. We introduce a range of very articulate people who teach us about dying: about cultural differences, about existential fears, and about strength and hope.

It is the voices of the dying and bereaved that we hope emerge above the rest. They are our teachers, and as social workers we always learn from their experiences. Many contributors to this book discuss how working with the dying is a privilege. Work with the dying means encountering suffering, mystery, and complexity. Working with the dying compels us to live, and live fully. It requires the best of our knowledge, our skill, our self-awareness, and our appreciation of the multiple contexts in which people live and die.

We hope that this book offers many windows into the worlds of the dying and their families and, of the utmost importance, provides ways to intervene with respect for the ways they have lived, the ways they die, and the legacies they leave behind.

REFERENCES

