CONCLUSION

WE BEGAN this book with personal and compelling narratives by professional helpers, describing their own experiences with illness, death, dying, and bereavement. We have learned through this process that it is through one's own lived experiences that the greatest knowledge and wisdom may be found. This is a theme that we deemed most important to this book. It underscores the fact that in working with the dying and their families, as well as with the bereaved, it is important to integrate the personal with the professional. The professional who is working in this area is always informed by the personal, and acknowledging this and understanding it is critical to good professional practice; the chapter on respectful death sets a context for the book. We owe respect to the families we serve and to the dying member of that family, as well as to ourselves. And therefore we conclude the book with the Irish admonition to “mind yourself.”

We have learned a good deal from its many contributors in the course of writing and editing this book. We have come to respect the role of social workers in end-of-life care. We see that they are drawn to the field, in part, because it allows them to bear witness at one of life’s most intimate moments. Our colleagues—social workers, nurses, and physicians—come to this field with a desire to support dying individuals and their families in ways that reflect how they lived. Social workers speak of their work with the dying as some of the humblest and yet most spiritual moments of their lives. There are vital lessons that the dying teach us, and there is great value in hearing these anew. Dying people and their families live with uncertainty and ambiguity, and they help us to do the same. As social workers, we cannot take away suffering. But we can witness it, and this then enables us to act as guides, as communicators, as collaborators, and as guardians of our clients’ wishes.

We are committed to practicing with values in accordance with the ethical principles of the profession, particularly as we consider the needs of the disenfranchised. Yet the contexts in which we work with the dying, especially in medical settings, often devalue and marginalize the people whom we serve—and the profession of social work itself. The ways in which clinical practices, medical hierarchies, entitlements, and even interdisciplinary teams are constructed mirror issues of power and powerlessness in the larger society. The allocation of resources such as hospice or palliative care are often based on power arrangements. Likewise, many conflicts between the
Western values of autonomy and independence and the more interdependent values of many other worldviews are unconsciously played out in the field of end-of-life care. We have tried to demonstrate that although death is always an individual and relational event, it also occurs within political, cultural, and social contexts. Because dying is also about access to resources, social workers are always in the foreground of trying to deal with disparities in the provision of care for the dying, whether based on immigrant status, mental illness, substance abuse, status as a prisoner, age, income, or race.

The various chapters in this book remind us that clinical work with the dying does not take place in the fifty-minute hour. It requires the capacity to be present fully, and therefore to stand still. Paradoxically, it also requires a great deal of activity: in interdisciplinary collaborations, leading family conferences, stimulating multidisciplinary dialogues, and advocating for equity in care. We have learned from the contributors to this book that this means more than sitting in a room; it means becoming active listeners. This is what is required of us if we are to be a companion on a journey, a champion for their dying person’s needs, an advocate for death with respect and dignity, deftly handling interpersonal challenges, negotiating impasses, and finding ways to support dying individual and their families’ strengths.

One of the questions we asked is this: How do we social workers remain on the front lines of death, dying and bereavement, actively listening, confronting some of the most complex legal and ethical issues in this country, supporting and empowering individuals and families, and still remaining open enough to face our own mortality at the same time? This takes courage and fortitude. It also takes self-care. Work with the dying can be lonely, and so it is even more essential that forms of renewal be found to sustain one’s sense of hope and purpose. In writing the introduction to this book, we tried to reflect on the range of chapters in the book and what they have to teach. We now see them as a whole, and they point to our obligations and the value of what we as social workers can contribute to this area of practice. We have an obligation to ourselves, to the people we serve, and to our profession. Sometimes renewal and care for the social worker come from doing a job well and reaching to create new initiatives and new partnerships within the community that will change the culture of dying in America.

We have begun a dialogue between the contributors to this book and its readers. It is an opening conversation that we all must continue, professionally and personally, as we move through the years. It is literally a matter of life or death.