PART IV

CONTEXT AND LEADERSHIP
INTRODUCTION: THE CONTEXTS OF END-OF-LIFE CARE

This section brings together chapters that focus less on the dying individual and his or her family and more on systemic and contextual issues that effect practice with the dying. We have mentioned throughout the book that good practice is not measured simply by understanding the social worker–client relationship. It comes as no surprise to us, then, that the social contexts play an important role in assessing the quality of care, a point made most explicitly in this final section. The social worker must have and exercise other skills and develop new roles: evaluating and researching practice, implementing new programmatic ideas, becoming an agent of change, and getting involved in the political process.

From the inception of the profession, social workers have been active advocates for the underserved and the poor, and for those disenfranchised based on disability, age, social class, sexual orientation, and race. Over the years social workers have lobbied and worked to change laws that allowed child labor, discrimination, and limited funding for human services. Many of the “private” problems people have presented with have been located in “public” and societal practices that undermined their capacities for choice, autonomy, and human dignity. There are laws that govern how pain medication may be administered and which medications may be used. There are policies that define who has access to care and its financing. Many problems are rooted in aggressive treatments that treat the disease, but not the person with the disease. There is always an interface between societal problems and personal behaviors, between the way a system is organized and how people respond to it. Focusing exclusively on the clinical aspects of end-of-life care, in the narrowest sense, may not address the serious economic, ethical, and legal constraints at the local and federal levels in which individuals and families are embedded. The chapters in this section consider a variety of these issues.

Modern technology has created its own end-of-life problems, and some of the practices at this point in life are dictated by the legal system. Steve Arons, a lawyer writing from the perspective of the legal system, explains the relationship between the law and healthcare practices, looking at ethical issues in the practice of medicine as limited by the legal system. Arons helps the reader see the issues of advanced directives and physician-assisted suicide from a lawyer’s point of view. This approach is very different from the way a social worker would approach and understand the problem.
Arons introduces the reader to the complexity of current laws that surround end-of-life care and the conflicting principles that underlie them.

Yet we cannot deal with the implications of what our patients wish without recognizing the other constraints on practice. We need to keep in mind, for example, that practitioners on the team who are licensed have the parameters of their practices dictated by the licensing laws of the state in which they practice. Ellen Csikai, from the viewpoint of a social worker, examines how issues related to advanced directives affect social work practice. Social workers need to be aware of state laws and the accompanying regulations that often dictate life-and-death decision making. These impact upon the patient and those caring for and about her. It is not only the laws that are important, but also the regulations that are written by various governmental bodies that support these laws and determine how they are implemented. Social workers need to consider how to be involved in the legislative process; what laws to support, what to work toward changing, how to become involved in developing and implementing regulations, and how they may influence what happens on a day to day basis with their clients.

Another point of interface between social institutions and the individual’s right to death with dignity can be found in Jenny and John Dawes’s chapter on dying in prisons. They address the private/public interface when people who are dying are incarcerated. A prison functions as what Erving Goffman (1967) called a “total institution,” where there is little or no room for individual needs to be acknowledged or met. Goffman’s concept of a total institution helps us understand institutions, not necessarily just prisons, that strip people of their identities. Entering a hospital for medical care, for example, requires that a person assume a new role in which behavior is primarily dictated by the needs of those who are treating and caring for him or her. In spite of any one hospital’s efforts to make the setting more humane, hospitals are still organized so that those who work there can do their “work.” This expectation extends to the way help is organized and how it is available. Any reader who has been hospitalized knows what it means to have to depend on others to meet one’s needs, to be in pain, to feel helpless, as well to undertake the role of “patient,” waiting patiently or impatiently for those needs to be met. Although the personal needs of the patients are important, meeting any one patient’s needs is typically considered in the context of what makes the work of the staff most efficient. Hence the setting provides the context for what needs will be met by whom, and it orders the priorities for what needs to be done, when, and for whom. We begin to see why hospice is so important in providing home care where people can be more in charge of their lives. How much is the prisoner shaped by the institution in which he dies? Dawes and Dawes write of restoring human worth, choice, meaning, respect, and support for prisoners.

In many healthcare settings, the value of personalizing care to meet the emotional, cultural, and spiritual needs of people may not be recognized, in the interest of efficiency and saving money. Social workers have a crucial role to play in making the institutional setting more sensitive and responsive to the social, spiritual, and psychological needs of their patients. Esther Chachkes and Zelda Foster provide vivid examples of how social workers can exercise leadership in their chapter, “Taking Charge.” They
exhort the reader to see end-of-life care as an opportunity, even a mandate, to take leadership.

As we look at the big picture and consider how much assessment plays a part in clinical practice, it becomes clear that we might follow this same model in determining what role to play in advocating for changing systems to be responsive to the needs of patients and families. We need to develop assessment tools for looking at the larger contexts and making plans for appropriate interventions. This requires a return to our social work values, revisiting skills of community organization and community development, discarding those that may no longer be appropriate and building on those that are.

We can begin this type of assessment by looking at the organizational chart of the agency, at how the system is governed, who works in this setting, who makes decisions and where are they made. An institutional assessment also has to include: assessing the sources of funding for any institution, asking who benefits and who loses from such an arrangement, understanding the impact of financing on the kinds of care available, understanding the current legal policies that, for example, encourage or discourage patients and families from having advanced directives or, if they are unable to decide for themselves, having a healthcare proxy. Social workers need to understand the complex societal and legal restraints on pain management and assisted suicide. They need to analyze critically the way health care is financed and practiced, as June Simmons describes in her review of how end-of-life care is financed in this country.

Again there are legal questions: What laws govern resources that are available? For example, in Canada legislation is being introduced to extend palliative care coverage to home care, and the Canadian government is considering providing economic support to those who remain at home to care for the dying person. Assessment needs to understand the nation’s priorities (Ferris et al. 2002). Would it be possible to advocate for family support of this sort in the United States?

Social workers need to ask what flexibility exists in any system, who their allies are, and how to effect change in this setting. They need to develop initiatives that can effect change without only using confrontation as a method. We have many methods in social work: relationships, brokering, and advocacy.

Social workers need to take leadership in providing end-of-life care for those who have been stigmatized or underserved, including those who, for example, may have committed heinous crimes. The assessment has to consider not only a holding environment for the patient and family, but also what a caring environment looks like in a particular setting, considering the community that is served. In asking how healthcare settings can become more responsive to individual and community needs, it is important to consider how to involve lay people or potential patients as partners in any of the planning.

Social workers must also assess the financial resources available to support quality end-of-life services as well as to understand who are its beneficiaries. Such an assessment also needs to include the social worker’s willingness to be involved as a change agent, not only for her clients but also for herself. In their chapter on leadership, Foster and Chachkes observe that what social workers do \textit{least} well is advocate for
Research findings become another element in an assessment of the contexts in which end-of-life care occurs. Social workers must be consumers of research to gain new knowledge about the needs of people are dying and the bereaved, but they must also be producers of knowledge. Betty Kramer and Mercedes Bern-Klug review the paucity of research emanating from social work. Research becomes critical in a human service and healthcare system that is advocating for evidence-based practice. We need to document the work we do and show its value. Kramer and Bern-Klug bring into focus the need and the support that is necessary to do this work, and the various qualitative and quantitative approaches that can be applied. There is no magic in doing research. Many practitioners need to overcome their discomfort with being involved in research and be alert to new work that is being done, often in partnership with other professionals. Social workers need to recognize that this can provide them with greater understanding of their clients and demonstrate the value of what they are doing, as well as provide direction for improving practice. It means stepping back with a critical eye and systematically looking at what is being done.

Social workers need to take leadership roles in program development. Chachkes and Foster provide many examples. Social workers must also be familiar with new program initiatives that solve some of the legal and social system problems associated with the end of life. For example, there are a number of innovative programs to help people make decisions about advanced directives. One of the better known is in La Crosse, Wisconsin (Hammes 1999; Hammes and Briggs 2002). The efficacy of this initiative has been researched and found to be very effective in expanding the population of people who have advanced directives in this small midwestern community.

Part of this assessment is to recognize the need to expand social workers’ knowledge and skill base. Part of the assessment is to identify learning opportunities that can provide the means of dealing with this new understanding. This learning also has to include how to build new alliances to accomplish their goals. Betsy Clark, executive director of the National Association of Social Workers, describes her vision for what social work involvement in end-of-life care will look like in the future. She is represented here because of her extensive experience in working with people at the ends of their lives. She also stands as a reminder that we have an organization behind us to help with our advocacy work, to facilitate developing our voices for change.

This work puts an enormous burden on the person who becomes involved in it. We are asking a great deal of our readers. We began the book with a piece of our personal odysseys as we moved into this field. We end it with Irene Renzenbrink’s personal story, which began as she grew from a young social worker in Australia. She soon learned the importance of being mindful of her own needs and what was needed in a helping system to sustain the helpers. She reviews the literature on self-care and the various labels that are being used for what she calls the need for relentless self-care. Renzenbrink teaches us the importance of what she has learned from the colleagues with whom she worked in Ireland: Mind yourself! And it is with these words that we end the book.
REFERENCES


