CHAPTER 1

Overview of Serious Illness in Social Work

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LEARNING OBJECTIVES

- Discuss the importance of serious illness care for social workers.
- Introduce social work practices in working with adults with serious illness and their family members.
- Describe key concepts, including the ecological perspective and the contexts of illness.
- Present ethical issues in serious illness practice and relevant standards for these ethical issues.

SOCIAL WORK PRACTICES

- Promote self-determination through early care planning, including advance care planning, starting early in the illness course and continuing through the end of life.
- Provide emotional and psychological support to adults with serious illness and their family members.
- Engage as effective members of healthcare teams.
- Advocate, empower, and promote social justice for people faced with serious illness.

Key Terms: advance care planning; advanced illness; chronic illness care; chronosystem; end of life; exosystem; formal support context; hospice; illness context; informal support context; macrosystem; mesosystem; microsystem; palliative care; person-centered care; serious illness

Social workers, particularly those who work in healthcare settings, play a pivotal role in advocacy and social justice for persons from diverse cultures who are experiencing the life challenges associated with serious illness. The social work profession is particularly concerned with advocating for people with diverse values and beliefs, gender identities, and racial and ethnic backgrounds, and the profession holds a special interest in addressing social inequities and social justice issues. This includes people with disabilities, isolated elders, persons with unmet needs, those who lack informal or formal supports, and persons who have difficulty accessing services due to challenges such as low income; poverty; and gaps in healthcare, social connections, or supportive care. These individuals face barriers to services, primary care, and medical referrals in addition to food and housing insecurity. These factors can contribute to reduced quality of life and poor health outcomes, particularly at the end of life.

In this book, we focus on enhancing the knowledge, competencies, and skills needed to help social work students and practitioners, chaplains, and other healthcare personnel in multiple service settings support and advocate for diverse groups of persons with serious illness. By reading this book, social workers and other healthcare providers will come away with a set of perspectives and guidelines that they can put into practice in varying contexts in which serious illness issues are likely to emerge.

In this first chapter, we clarify the role of social workers for adults facing issues related to serious illness. We begin by defining serious illness and describing distinct types of serious illness trajectories. We introduce key social work practices relevant to serious illness and the diverse ways that social workers may be involved in serious illness care. We then describe several terms relevant to serious illness, including palliative care, hospice care, and person-centered care. We discuss theoretical perspectives as they concern serious illness, including the ecological perspective and a conceptual model highlighting the three contexts in which people experience serious illness. We introduce ethical issues based on the principles established through the revised *Code of Ethics* (National Association of Social Workers [NASW], 2021) and the *NASW Standards for Social Work Practice in Palliative and End of Life Care* (NASW, 2004). We conclude by explaining the approach of the book, providing an overview of the book chapters, and summarizing the key chapter elements.

SOCIAL WORKERS WHO ARE INVOLVED WITH SERIOUS ILLNESS CARE

We recognize that the concept of serious illness is most relevant for the work of geriatric social workers and those collaborating in the delivery of primary, palliative, hospice, and end-of-life care and treatment. However, greater knowledge of best practices related to serious illness can also enhance the knowledge and competencies of social workers in diverse fields such as adult protective services; community-based social services provided at Area Agencies on Aging; and those providing services for unhoused individuals, people in correctional facilities, and individuals with disabilities. Issues related to serious illness are also relevant for social workers in macro practice roles who are involved with healthcare research and legislative advocacy.

DEFINING SERIOUS ILLNESS

Clinicians and researchers have often used the term *end of life* to refer to the time immediately preceding death, but a lack of consensus on this term has contributed to ambiguity and sometimes confusion in care planning efforts. Recognizing this complexity, Hui et al. (2014), based on a comprehensive review of the literature, defined the end of life as "progressive life-limiting disease with a prognosis of months or less" (p. 87). This book has a broader focus, as it includes a discussion of adults with serious illness who may or may not be at the end of life. *Serious illness* has been defined as "a health condition that carries a high risk of mortality AND either negatively impacts a person's daily functioning or quality of life OR excessively strains their caregivers" (Kelley & Bollens-Lund, 2018, p. S7). This definition, established through a consensus panel of palliative experts, has also been adopted and promoted by the Center to Advance Palliative Care (Block, 2019). Although some groups continue to use the term *advanced illness*, which refers specifically to serious illnesses associated with functional decline in which available treatments are becoming less effective (i.e., American Hospital Association, 2022), several groups, including the National Committee for Quality Assurance (2018) and the Coalition to Transform Advanced Care (n.d.), are now using the term "serious illness" as part of educational and policy advocacy efforts.

In this book, we follow the aforementioned Kelley and Bollens-Lund (2018) definition of serious illness. However, we recognize that each adult facing serious illness experiences these challenges in their own way based on their illness trajectory, their access to and use of formal health and social services, healthcare disparities due to racism and socioeconomic challenges, and the availability of informal services and supports.

It is important to recognize that there can be considerable overlap between *serious illness*, as defined here, and *chronic illness*, defined as non-communicable conditions lasting one year or more that either require medical care and/or limit activities of daily living (Centers for Disease Control and Prevention, 2024; World Health Organization, 2023). A chronic illness can include conditions such as rheumatoid arthritis, multiple sclerosis, or chronic fatigue syndrome that are unlikely to be cured and that are often associated with progressive functional decline (Fennell et al., 2013). In some ways, cancer can be considered a chronic condition, particularly when people are confronted with distressing symptoms and their quality of life declines over an extended period (Paleczna, 2018). However, the multiple and complex trajectories of cancer that include both chronic and acute episodes, and the variability in mortality associated with cancer types, have led others to conclude that cancer cannot be considered a chronic condition (Tritter & Calnan, 2002).

The important distinction between chronic and serious illness is that the latter is defined as having a high mortality risk, while chronic illness may or may not be associated with high mortality. In making these distinctions, it is important to attend to what Tritter and Calnan (2002) refer to as the "user experience of cancer," which highlights the role of an individual's unique perspective on their illness trajectory, prognosis, and quality of life challenges. The social worker's role in chronic illness care includes attending to persons in their social environment, providing self-management support, and interfacing with health systems (Fennell & Rieder Bennett, 2013). For social workers, chronic illness and serious illness care have many similarities, suggesting that many serious illness competencies are applicable to both chronic and serious illness conditions.

Serious Illness Trajectories

There is often no clear demarcation as to when serious illness begins. For example, regarding the part of the serious illness definition that concerns high mortality, there is a commonly used assessment tool known as the "surprise question" in which physicians ask themselves, "Would I be surprised if this patient died in the next 12 months?" Despite the wide use of mortality prediction tools such as the surprise question, predicting mortality can be challenging, particularly in situations in which people are faced with non-cancer conditions such as organ failure (Chu et al., 2023; Downar et al., 2017). Social workers support people with serious illness and their family members as they navigate the healthcare system amid this uncertainty, promoting quality of life even when the length of remaining life is unclear.

The trajectory of serious illness also has many variations. Some people have a period of high functioning followed by a steep decline. Others may experience a frailty trajectory in which their functioning declines over a prolonged period. With the frailty trajectory, function decreases gradually, and improvement becomes less likely over time. Some persons with conditions such as heart failure or chronic obstructive pulmonary disease experience an organ failure trajectory in which treatments lead to temporary improvement, but functioning continues to diminish (Ballentine, 2018; Duffy et al., 2007; Field & Cassel, 1997). Regardless of their illness trajectory, all individuals with serious illness deserve compassionate, culturally competent care that is person centered and focused on maintaining and enhancing their quality of life.

Key Social Work Practices in Serious Illness

According to NASW (n.d.-c), the mission of social work is to "enhance human well-being and help meet basic and complex needs of all people, with a particular focus on those who are vulnerable, oppressed, and living in poverty" (para. 1). NASW defines *social work practice* as

> the professional application of social work values, principles, and techniques to one or more of the following ends: helping people obtain tangible services; counseling and psychotherapy with individuals, families, and groups; helping communities or groups provide or improve social and health services; and participating in legislative processes. (NASW, n.d.-b, para. 1)

The mission and definition of social work as applied to serious illness suggest several key social work practices (see Table 1.1). First, social workers who understand serious illness can advocate for self-determination by **promoting early care planning**. As we discuss in chapter 3, facilitating discussions about goals and preferences for care

Table 1.1: Key Social Work Practices in Serious Illness

Concept	Social Work Practices
Self-determination	Advocating for self-determination by promoting early care planning
Emotional and psychosocial support	Providing emotional and psychological support to persons with serious illness and their family members
Teamwork	Engaging as effective members of healthcare teams
Advocacy, empowerment, and social justice	Advocating, empowering, and promoting social justice for people faced with serious illness

early in the illness course and providing for written expression of preferences through living wills and appointments of healthcare proxies is consistent with patient-centered care and the promotion of social justice, a core ethic in social work. As noted by Bernacki et al. (2014), people differ with respect to the amount of desired involvement of family and friend caregivers during their illness. Social workers promote the ethic of self-determination when they provide people with serious illnesses with the opportunity to identify the individuals whom they wish to have involved in care and support.

Second, social workers can play a significant role in **providing emotional and psychosocial support** for persons with serious illness and their family members. In chapter 2, we discuss the role of social workers' psychosocial expertise in promoting communication among patients and family members (National Academies of Sciences, Engineering, and Medicine, 2022). As part of their capacity to provide emotional and psychosocial care, social workers have played a significant role in reaching out to family members of persons with COVID-19, demonstrating the profession's role in community-based outreach and support (Poulin et al., 2021; Turner et al., 2023). This suggests the importance of promoting biopsychosocial competencies among social workers to strengthen their effectiveness in these roles (Taels et al., 2021).

A third essential role for social workers is **effectively engaging as members of interdisciplinary healthcare teams.** As we discuss in chapter 2, social workers play an important role in educating these teams and promoting and supporting overall team functioning (National

Academies of Sciences, Engineering, and Medicine, 2022). These practices are particularly important during times of crisis and team stress, such as during the COVID-19 pandemic (Cox, 2020; John A. Hartford Foundation, 2013; Parker-Oliver et al., 2005).

A fourth and final role for social workers is **engaging in advocacy, empowerment, and social justice**. All social workers need to recognize and address health issues that have disparate impacts on vulnerable individuals due to their race, gender, sexual orientation, or socioeconomic status. The social work profession, as documented in the NASW (2021) *Code of Ethics*, is particularly concerned with attending to social justice issues, including the interrelated issues of marginalization, discrimination, social disparities, and vulnerability in healthcare settings. The onset of serious illness further exacerbates and impacts these challenges and is therefore of immense importance. These factors impact persons with serious illness and their caregivers, who often have difficulty in navigating their daily lives and find challenges accessing quality healthcare, especially as their illness progresses.

We address ways of attending to social justice throughout the book. For example, in chapter 4, we elaborate further social justice issues as they pertain to racial and ethnic diversity, highlighting the role that healthcare social workers play in advocacy, promotion of human rights, and support related to reducing health disparities and enhancing healthcare access (NASW, n.d.-a). In chapter 7, we discuss social justice for persons with serious illness with respect to addressing elder abuse and neglect (Auerbach & Mason, 2010; Bern-Klug, 2010; Cox, 2020; Csikai & Black, 2009). The role of social determinants of health (SDOH) is discussed in chapter 8, where we explain how social workers can promote social justice by advocating for people with serious illness who are facing socioeconomic challenges. This social justice work can take place in a variety of settings, including emergency departments (American College of Emergency Physicians, n.d.; A. S. Wallace et al., 2020); long-term care (Bern-Klug, 2010; Kusmaul et al., 2017); and at the micro, mezzo, and macro levels of practice.

What Is Palliative Care?

Palliative care is an important treatment modality to address the needs of people with serious illness throughout their course of illness (Coalition to Transform Advanced Care, 2023). Palliative care “seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure" (Berzoff & Silverman, 2004, p. 40). A palliative approach does not necessarily exclude treatments focused on disease or cure, and many people who seek this approach will continue to consider various treatments as they also seek approaches focused on comfort and the alleviation of suffering (National Institute on Aging, 2021b). Despite the many advantages of a palliative approach, racial health disparities have prevented many persons with serious illness, particularly those who are African American, from receiving this form of care (Bazargan & Bazargan-Hejazi, 2021).

What Is Hospice Care?

The National Institute on Aging (2021a) defines *hospice* as care that "focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life" (para. 1). Although hospice is like palliative care in terms of services offered, hospice care has specific program requirements. For example, for an individual to be eligible for hospice, a physician must determine that they have six months or less to live "if the illness runs its natural course" (National Hospice and Palliative Care Organization, 2022, p. 41). When persons with serious illness or their proxies elect hospice care, they no longer receive curative focused care. Most hospice services are provided at home (National Institute on Aging, 2021a) by multidisciplinary teams that include social workers, nurses, chaplains, physicians, and volunteers (National Hospice and Palliative Care Organization, 2022). Hospice is provided as a Medicare benefit and may also be available through Medicaid or through private insurance for those under age 65 (National Institute on Aging, 2021a). Despite the many benefits of hospice, there has often been historical mistrust of this form of care, particularly among African Americans (Cuevas & O'Brien, 2019; Washington et al., 2008).

What Is Person-Centered Care?

Person-centered care, as described by the Health Foundation (2016), is a collaborative approach in which persons with illness themselves are the key drivers of healthcare choices and approaches. In a person-centered care approach, healthcare and social work care providers focus on helping people to develop and draw on their own knowledge and skills and to have the confidence to make their own informed healthcare decisions (see Figure 1.1).

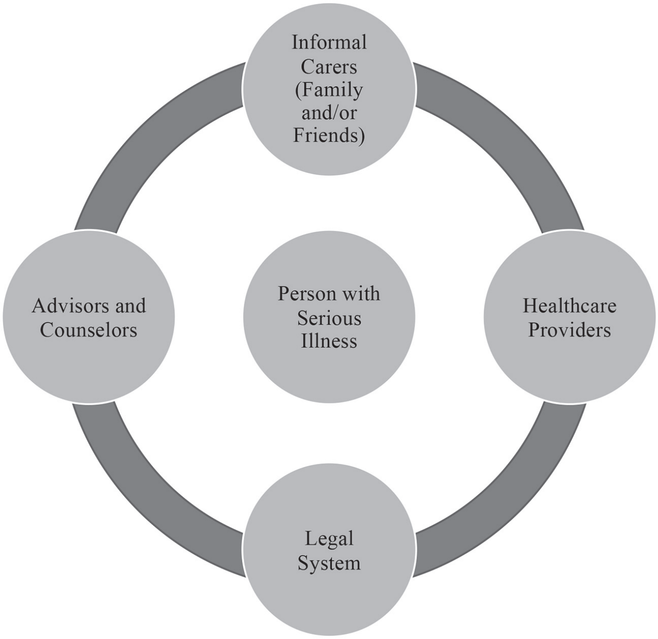


Figure 1.1: Person-Centered Care

CONCEPTUAL PERSPECTIVES ON SERIOUS ILLNESS

The person-in-environment perspective brings attention to the ways that people are in a "mutually influential relationship" with their physical and social environments (NASW, 2016, Guiding Principles Section). The ecological perspective (Bronfenbrenner, 1977, 1994) further elaborates on these relationships, while a perspective focused on the contexts of serious illness (Hopp & Popkin, 2018) guides social workers toward consideration of the context of formal and informal carers as well as the context of the serious illness itself. These perspectives are described in the following two sections.

The Ecological Perspective

Bronfenbrenner (1977), in his widely cited approach to research on human development, suggested that human development continues throughout our lifetimes through ongoing adaptation to the microsystem, the mesosystem, the exosystem, and the macrosystem (Guy-Evans, 2020). The *microsystem* includes an individual's interactions with the immediate environment, including family members, friends, and individual healthcare providers. The *mesosystem* can be understood as the interaction between two or more microsystems in an individual's environment. An example of the mesosystem is the interaction between a family and members of the healthcare system such as physicians and nurses. The *exosystem* refers to people, systems, and policies that people with serious illness do not directly interact with but that influence care, such as organizational policies and hospital supervisors who can influence the context in which social workers deliver services. For example, people with serious illness may be indirectly impacted by factors such as the social worker's caseload size and organizational documentation requirements, as well as the amount of respect, professional autonomy, and discretion that is accorded to them. The *macrosystem* includes issues in the larger society, such as SDOH (discussed in chapter 8), culture, ideologies, and social welfare policies that influence persons with serious illness through their impact on available resources and support.

Social welfare policies impact services and support offered through multiple levels of government at the federal, state, and local levels that affect factors such as service delivery, advance care planning, and potential options for medical assistance in dying (Zworth et al., 2020). Policies focused on hospice services, such as Medicare coverage through the Centers for Medicare and Medicaid Services and innovations in hospice eligibility and treatment (Harrison & Connor, 2016; C. L. Wallace, 2015) are of particular importance in potentially expanding comfort-oriented care for persons with serious illness. At the judicial level, the *Jimmo v. Sebelius* decision (Centers for Medicare and Medicaid Services, n.d.) mandates that skilled nursing care be available to maintain or prevent declines in functioning, even if such care does not result in functional improvement. This allows individuals with serious illness to benefit from essential services that can help them to maintain their current level of independence and quality of life.

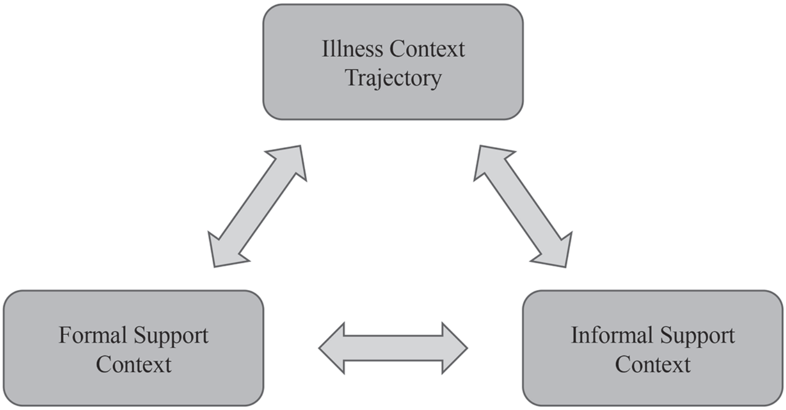
The *chronosystem*, as described by Bronfenbrenner (1994), refers to the time dimension of human development, including events such as changes in family structure, life transitions, and historical events. Applied to the situation of persons with serious illness, the chronosystem could include events such as the COVID pandemic that influence the incidence of acute life-threatening illness, the availability of healthcare services and support, and the working conditions that social workers faced in dealing with the pandemic. The chronosystem could also include widespread changes in the macro environment, such as policies and executive orders promoted by the Trump administration in 2025, that impact the vulnerabilities, resources, and stress experienced by persons with serious illness.

Social workers have adapted and expanded Bronfenbrenner's theory to incorporate feminist (Besthorn & McMillen, 2002), postmodern (Dybicz & Hall, 2021), and critical (Fook, 2002) theory perspectives. These theoretical perspectives have in turn informed the ecology of practice (Ungar, 2002), which attends to the power and privilege of social workers and the way in which marginalized persons describe their own experiences in social-ecological systems.

The Contexts of Serious Illness

In the transition to serious illness, a person and their family will begin to experience their lives differently than before. Figure 1.2 (Hopp & Popkin, 2018) displays the different contexts in which individuals experience serious illness.

The *illness context* includes the trajectory of illness, which refers to the rate and pattern by which functioning improves or declines over time (Lynn & Adamson, 2003), as well as to the objective and subjective nature of symptoms during the illness course. We can view the illness context in terms of various aspects of the individualized, lived experiences of the illness process. This context includes aspects such as the nature, duration,



Note: From *Advanced Illness Care: Understanding and Integrating Diverse Perspectives from Client, Family, and Health Care Perspectives* (PowerPoint slide #5), by F. P. Hopp & S. Popkin, 2018, Wayne State University School of Social Work Office of Continuing Education and Professional Development.

Figure 1.2: Contexts of Serious Illness

and severity of symptoms; changes in functioning that may occur during various stages of illness; the degree to which these changes respond to different medical treatments; and the overall duration of time between illness and death. The illness context also includes how individuals react to and cope with the changes associated with becoming ill.

The *formal support context* refers to the availability and use of formal, paid health and social services providers. The formal support context includes paid providers of services who address service needs associated with the illness context. For example, the availability of a primary care physician may determine whom people turn to for medical advice when they are not feeling well. Those who have not received preventive services and have experienced years without going to a doctor for a checkup may need more help to connect with formal services. Individuals experience availability or access issues through past encounters with medical care and social services.

The *informal support context* refers to support received from family, friends, neighbors, and religious groups. The informal support context includes unpaid caregivers who take on various supportive roles for persons with serious illness, including those roles and activities that sustain those with serious illness as their physical functioning declines and as they or their loved ones perceive that they have difficulty in caring for themselves.

Cultural expectations influence patterns of informal support. For example, factors such as trust and mistrust of formal care providers (Cuevas & O'Brien, 2019), support from religious congregations (Koenig et al., 2001), and gender norms related to expectations of different forms of assistance (Swinkels et al., 2019).

When providing serious illness services, social workers can play a pivotal role in working collaboratively with persons with serious illness by attending to all these care contexts and working to develop and support programs and practices that meet the needs of diverse individuals facing illness-related challenges.

ETHICAL ISSUES RELEVANT TO SERIOUS ILLNESS

Social work values and ethics play an essential role in guiding practitioners toward equitable and culturally competent care provision. The NASW (2021) *Code of Ethics* promotes the best practices for working with individuals, families, groups, and communities and leads the profession toward practice and scholarship that address vulnerable populations. The *Code* *of Ethics* highlights the primary importance of cultural competency as it concerns persons from diverse cultural backgrounds. The emphasis on cultural competence in the 2021 revision reflects the importance of culturally informed skills. These skills, informed by knowledge of our own racial, ethnic, and cultural identity as well as the perspectives of other groups, should be used to guide community-focused advocacy aimed at enhancing inclusion, empowerment, and care access. Social workers should endeavor to enhance their understanding of the role of cultural beliefs and practices, improve their knowledge of social diversity and oppression, and practice cultural humility (discussed further in chapter 4) through critical reflection. Social workers are encouraged to consider how the growing use of internet-based services will impact persons from varying educational backgrounds and strive toward greater inclusion with respect to electronic services to address the digital divide (Mubarak & Suomi, 2022).

The *NASW Standards for Social Work Practice in Palliative and End of Life Care* (NASW, 2004) extend the work of the NASW (2021) *Code of Ethics* by emphasizing critical issues for working with persons with serious illness, including the role of bioethics, palliative care knowledge, assessment, treatment planning, cultural competence, professional attitudes, self-awareness, and empowerment and advocacy. These professional ethics and standards guide social workers to advocate for people with diverse values and beliefs, gender identities, and racial and ethnic backgrounds, and social workers should have a special interest in addressing social inequities and social justice issues. This includes advocacy on behalf of people with disabilities; older adults who are isolated; persons with unmet needs; those who are lacking informal or formal supports; and persons who have difficulty accessing services due to challenges such as low income, poverty, and gaps in healthcare, social connections, and/or supportive care. These individuals face gaps and barriers to care, services, primary care, and medical referrals, and may face food insecurity and challenges finding safe, accessible, and affordable housing. All these factors can reduce quality of life and create poor health outcomes, particularly as individuals face serious illness challenges.

Social workers, in collaboration with other professionals, can play a key role in advocating for social justice for persons from diverse cultures facing illness challenges. Social workers often “start where the client is” by building rapport and applying social work values, competencies, and ethics. By drawing on a person-centered and strengths-based perspective, with attention to the care of the entire person and their role in the larger structures of family, organizations, and the larger policy context, social workers can provide vital advocacy and support for persons facing serious illness.

THE APPROACH OF THIS BOOK

Several books provide excellent and comprehensive material on hospice and palliative care in social work (Altilio & Otis-Green, 2011, 2021; Reith & Payne, 2009; Sumser et al., 2019). We seek to extend this work by adding a focus on serious illness as a phase that many of us will experience, whether we seek hospice, palliative care, curative approaches, or a combination of both palliative and curative care. Consistent with a person-centered perspective, we refer to "persons with serious illness" and "people with serious illness" interchangeably throughout the book. We also use the terms "patient" and "client" when appropriate to describe people receiving care in health and social services settings.

Given the increasing emphasis on person-centered healthcare, we focus on the human dimension, emphasizing the importance of the biopsychosocial/spiritual assessment as a means of better understanding people with serious illness in their life experiences, their social environment, and their spiritual values and beliefs, which we discuss in chapter 2. To further illustrate this human dimension, we include case studies and/or personal narratives of illness in many of the chapters. Several coauthors contributed case studies, and we are grateful for and honored by their valuable contributions to this book.* Our book is also innovation focused, and we share resources and best practices related to several different dimensions of serious illness care.

BOOK OVERVIEW

This book focuses on enhancing the knowledge, competencies, and skills to help social work students and social work practitioners in multiple service settings to support and advocate for diverse groups of persons with serious illness. By reading this book and considering the best practices, guidelines, and principles that emerge from reading the case studies and

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*With the exception of Markus Whitehead's narrative in chapter 4 (in which Whitehead shares the story of his late wife), the case studies in this book are composites and were written based on our professional experiences.

narratives of persons experiencing serious illness, we expect that both emerging and experienced social workers will come away with a set of perspectives and guidelines that they can use in varying practice contexts in which serious illness issues are likely to emerge.

The first section of the book is an introduction to social work practice for persons with serious illnesses. This section includes the present overview chapter and chapters on serious illness and interprofessional practice (chapter 2) and serious illness and ethics (chapter 3).

The second section of the book focuses on diverse perspectives on serious illness in terms of racial and ethnic diversity (chapter 4), strategies for addressing diverse family perspectives (chapter 5), gender and sexual orientation diversity (chapter 6), diversity with respect to vulnerability to abuse and neglect (chapter 7), and serious illness as it concerns persons experiencing socioeconomic challenges (chapter 8).

In the concluding chapter (chapter 9), we provide a summary and implications for social work practice in serious illness. We also review recent developments, such as the COVID-19 pandemic, discrimination due to immigration status, the lack of access to health insurance and affordable home- and community-based services, the increasing importance of antiracism advocacy, and emerging policy innovations in the field.

RESOURCES

We suggest the following resources for further reading and reflecting on the issues discussed in this chapter.

The Blue Chair Movement: Shirley Roberson, a friend of coeditor Faith Hopp, was a passionate advocate for person-centered care, the importance of human dignity, and the imperative to listen to the voices of persons with serious illness. She died from stage IV cancer in January 2022. In this video, "May Her Memory Become a Revolution: Honoring Shirley Roberson and Launching the Blue Chair Fund," posted by the Coalition to Transform Advanced Care (CTAC News, 2022), she provides an inspiring story of resilience and strength amid the challenges of illness. (https://www.youtube.com/watch?v=QQ7W8f6jjHg)

Project on Death in America: From 1994 to 1997, the Open Society Institute provided funding to support innovations in research, scholarship, humanities and the arts, care provision, education, and public policies. In this 2004 essay, "Transforming the Culture of Dying: The Project on Death in America 1994–2003," they make recommendations for transforming palliative care through training, healthcare provision, and funding mechanisms through innovative programming and support. (https://www.opensocietyfoundations.org/publications/transforming-culture-dying-project-death-america-1994-2003)

Journal of Social Work in End-of-Life & Palliative Care: This is the only professional journal for social workers in serious illness/end of life care with articles from social workers all over the world, covering a variety of relevant issues. (https://www.tandfonline.com/journals/wswe20)

Coalition for Social Work and Health: This organization focuses on enhancing healthcare quality and outcomes through transformational efforts aimed at improving health equity. (https://www.socialworkandhealth.org/)

Association of Oncology Social Workers: This international nonprofit organization aims to improve the lives of people with cancer and those of their families and caregivers by enhancing psychosocial services. (https://aosw.org/)

REFLECTION AND DISCUSSION QUESTIONS

1. Review the "Blue Chair" video and think about a healthcare setting where you work or receive healthcare. How do you think your colleagues or healthcare providers would react to Shirley Roberson's advocacy approach focused on the importance of listening? What changes do you think healthcare providers need to make in these settings to enhance person-centered, culturally appropriate care?
2. Think about your own experiences with serious illness, palliative care, and/or hospice as they impacted you, your friends, and your family members. What did you learn from these experiences and how do you think this impacts your work in the field?
3. Reflect on the contexts of illness shown in Figure 1.2. How can social workers engage in support and advocacy in each of these contexts?

REFERENCES

Altilio, T., & Otis-Green, S. (2011). *Oxford textbook of palliative social work.* Oxford University Press.

Altilio, T., & Otis-Green, S. (2021). *Oxford textbook of palliative social work* (2nd ed.). Oxford University Press.

American College of Emergency Physicians. (n.d.). *Social work and case management in the emergency department* [Policy Resource and Education Paper]. Retrieved August 24, 2025, from https://www.acep.org/siteassets/new-pdfs/preps/social-work-and-case-management-in-the-emergency-department.pdf

American Hospital Association. (2022). *Advanced illness management strategies—Part I.* https://www.aha.org/ahahret-guides/2012-12-11-advanced-illness-management-strategies-part-1

Auerbach, C., & Mason, S. E. (2010). The value of the presence of social work in emergency departments. *Social Work in Health Care*, *49*, 314–326. https://doi.org/10.1080/00981380903426772

Ballentine, J. M. (2018). *The five trajectories: Supporting patients during serious illness*. California State University Shiley Haynes Institute for Palliative Care. Retrieved August 24, 2025, from https://dl.icdst.org/pdfs/files3/e05db244c15801597e435c8fc4fd4039.pdf

Bazargan, M., & Bazargan-Hejazi, S. (2021). Disparities in palliative and hospice care and completion of advance care planning and directives among non-Hispanic Blacks: A scoping review of recent literature. *American Journal of Hospice & Palliative Care*, *38*, 688–718. https://doi.org/10.1177/1049909120966585

Bernacki, R. E., Block, S. D., & American College of Physicians High Value Care Task Force. (2014). Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Internal Medicine*, *174*, 1994–2003. https://doi.org/10.1001/jamainternmed.2014.5271

Bern-Klug, M. (2010). *Transforming palliative care in nursing homes: The social work role*. Columbia University Press.

Berzoff, J., & Silverman, P. R. (2004). *Living with dying: A handbook for end-of-life healthcare practitioners*. Columbia University Press.

Besthorn, F. H., & McMillen, D. P. (2002). The oppression of women and nature: Ecofeminism as a framework for an expanded ecological social work. *Families in Society*, *83*, 221–232. https://doi.org/10.1606/1044-3894.20

Block, S. (2019). *Moving towards universal access to high-quality serious illness care.* Center to Advance Palliative Care. https://www.capc.org/blog/

palliative-pulse-palliative-pulse-september-2017-moving-towards-universal-access-high-quality-serious-illness-care/

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32, 513–531. https://doi.org/10.1037/0003-066X.32.7.513

Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husén & T. N. Postlethwaite (Eds.), *International encyclopedia of education* (Vol. 3, 2nd ed., pp. 1643–1647). Elsevier.

Centers for Disease Control and Prevention. (2024). *Chronic diseases in America*. Retrieved August 24, 2025, from https://www.cdc.gov/chronic-disease/about/index.html

Centers for Medicare and Medicaid Services. (n.d.). *Jimmo v. Sebelius settlement agreement fact sheet.* Retrieved July 21, 2025, from https://www.cms.gov/medicare/medicare-fee-for-service-payment/snfpps/downloads/jimmo-factsheet.pdf

Chu, C., Engels, Y., Suh, S. Y., Kim, S. H., & White, N. (2023). Should the surprise question be used as a prognostic tool for people with life-limiting illnesses? *Journal of Pain and Symptom Management*, *66*, e437–e441. https://doi.org/10.1016/j.jpainsymman.2023.05.003

Coalition to Transform Advanced Care. (n.d.). *Strategic plan + goals.* Retrieved July 21, 2025, from https://thectac.org/strategic-plan-goals/

Coalition to Transform Advanced Care. (2022, December 22). *May her memory become a revolution: Honoring Shirley Roberson and launching the Blue Chair Fund* [Video]. YouTube. https://www.youtube.com/watch?v=QQ7W8f6jjHg

Coalition to Transform Advanced Care. (2023, July 7). *C-TAC advocates for hospice reform in comments on recent proposed CMS hospice rule.* https://thectac.org/asset/blog/c-tac-advocates-for-hospice-reform-in-comments-on-recent-proposed-cms-hospice-rule/

Cox, C. (2020). Older adults and Covid 19: Social justice, disparities, and social work practice. *Journal of Gerontological Social Work*, *63*, 611–624. https://doi.org/10.1080/01634372.2020.1808141

Csikai, E. L., & Black, K. (2009). Advance care planning in the delivery of adult protective services. *Journal of Social Service Research*, *35*, 311–321. https://doi.org/10.1080/01488370903110811

C-TAC News. (2022, December 22). *May her memory become a revolution: Honoring Shirley Roberson and launching the Blue Chair Fund* [Video]. YouTube. https://www.youtube.com/watch?v=QQ7W8f6jjHg

Cuevas, A. G., & O'Brien, K. (2019). Racial centrality may be linked to mistrust in healthcare institutions for African Americans. *Journal* *of Health Psychology*, *24*, 2022–2030. https://doi.org/10.1177/1359105317715092

Downar, J., Goldman, R., Pinto, R., Englesakis, M., & Adhikari, N. K. (2017). The "surprise question" for predicting death in seriously ill patients: A systematic review and meta-analysis. *Canadian Medical Association Journal*, *189*, E484–E493. https://doi.org/10.1503/cmaj.160775

Duffy, S. A., Copeland, L. A., Hopp, F. P., & Zalenski, R. J. (2007). Diagnostic classifications and resource utilization of decedents served by the Department of Veterans Affairs. *Journal of Palliative Medicine*, *10*, 1137–1145. https://doi.org/10.1089/jpm.2006.0256

Dybicz, P., & Hall, C. (2021). An introduction to the postmodern paradigm: Relevance for social work practice. *Social Sciences & Humanities Open*, *4*, Article 100206.

Fennell, P. A., & Rieder Bennett, S. L. (2013). Chronic illness. In *The encyclopedia of social work* (21st ed.). Oxford University Press and the National Association of Social Workers. https://doi.org/10.1093/acrefore/9780199975839.013.56

Field, M. J., & Cassel, C. K. (Eds.) (1997). *Approaching death: Improving care at the end of life.* National Academies Press. https://doi.org/10.17226/5801

Fook, J. (2002). *Social work: Critical theory and practice.* SAGE.

Guy-Evans, O. (2020; updated May 6, 2025). *Bronfenbrenner's ecological systems theory*. Simply Psychology. https://www.simplypsychology.org/bronfenbrenner.html

Harrison, K. L., & Connor, S. R. (2016). First Medicare demonstration of concurrent provision of curative and hospice services for end-of-life care. *American Journal of Public Health*, *106*, 1405–1408. https://doi.org/10.2105/AJPH.2016.303238

Health Foundation. (2016). *Person-centred care made simple*. https://www.basw.co.uk/resources/person-centred-care-made-simple

Hopp, F. P., & Popkin, S. (2018). *Advanced illness care: Understanding and integrating diverse perspectives from client, family, and health care perspectives.* Wayne State University School of Social Work, Office of Continuing Education and Professional Development.

Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., De La Cruz, M., Kim, S. H., Kwon, J. H., Hutchins, R., Liem, C., & Bruera, E. (2014). Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": A systematic review. *Journal of Pain and Symptom Management*, *47*, 77–89. https://doi.org/10.1016/j.jpainsymman.2013.02.021

John A. Hartford Foundation. (2013, March 28). *Social workers and their integral role in interdisciplinary team care*. https://www.johnahartford.org/blog/view/social-workers-and-their-integral-role-in-interdisciplinary-team-care/

Kelley, A. S., & Bollens-Lund, E. (2018). Identifying the population with serious illness: The "denominator" challenge. *Journal of Palliative Medicine*, *21*, S7–S16. https://doi.org/10.1089/jpm.2017.0548

Koenig, H. G., Larson, D. B., & Larson, S. S. (2001). Religion and coping with serious medical illness. *Annals of Pharmacotherapy*, *35*, 352–359. https://doi.org/10.1345/aph.10215

Kusmaul, N., Bern-Klug, M., & Bonifas, R. (2017). Ethical issues in long-term care: A human rights perspective. *Journal of Human Rights and Social Work*, *2*, 86–97. https://doi.org/10.1007/s41134-017-0035-2

Lynn, J., & Adamson, D. M. (2003). *Living well at the end of life: Adapting health care to serious chronic illness in old age*. Rand. https://www.rand.org/pubs/white_papers/WP137.html

Mubarak, F., & Suomi, R. (2022). Elderly forgotten? Digital exclusion in the information age and the rising grey digital divide. *Inquiry: A Journal of Medical Care Organization, Provision, and Financing*, *59*. https://doi.org/10.1177/00469580221096272

National Academies of Sciences, Engineering, and Medicine. (2022). *Caring for people with serious illness: Lessons learned from the COVID-19 pandemic: Proceedings of a workshop*. National Academies Press. https://doi.org/10.17226/26596

National Association of Social Workers. (n.d.-a). *Health*. Retrieved August 24, 2025, from https://www.socialworkers.org/practice/health

National Association of Social Workers. (n.d.-b). *Practice*. Retrieved July 21, 2025, from https://www.socialworkers.org/Practice

National Association of Social Workers. (n.d.-c). *Why choose the social work profession*? Retrieved July 21, 2025, from https://www.socialworkers.org/Careers/Career-Center/Explore-Social-Work/Choose-the-Social-Work-Profession

National Association of Social Workers. (2004). *NASW standards for social work practice in palliative and end of life care*. https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3D&

National Association of Social Workers. (2016). *NASW standards for social work practice in health care settings*. https://www.socialworkers.org/Practice/NASW-Practice-Standards-Guidelines/NASW-Standards-for-Social-Work-Practice-in-Health-Care-Settings

National Association of Social Workers. (2021). *Code of ethics of the National Association of Social Workers*. https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Highlighted-Revisions-to-the-Code-of-Ethics

National Committee for Quality Assurance. (2018). *Serious illness care: Person-driven measures for accountability*. https://www.ncqa.org/wp-content/uploads/2018/07/20180306_Report_SeriousIllnessCare-1.pdf

National Hospice and Palliative Care Organization. (2022). *The Medicare regulations for hospice care, including the conditions of participation for hospice care 42 CFR 418*. https://www.nhpco.org/wp-content/uploads/Medicare_Hospice_Regulations-with-2021_Updates.pdf

National Institute on Aging. (2021a). *Frequently asked questions about hospice care*. https://www.nia.nih.gov/health/frequently-asked-questions-about-hospice-care

National Institute on Aging. (2021b). *What are palliative care and hospice care?* https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#hospice

Paleczna, M. (2018). Cancer as a chronic disease—A psychological perspective. *Nowotwory Journal of Oncology*, *68*, 28–32. https://doi.org/10.5603/NJO.2018.0006

Parker-Oliver, D., Bronstein, L. R., & Kurzejeski, L. (2005). Examining variables related to successful collaboration on the hospice team. *Health & Social Work*, *30*, 279–286. https://doi.org/10.1093/hsw/30.4.279

Poulin, V., Provencher, V., Mélodie, N., Shea, V., Aubin, G., Beaulieu, M., Bier, N., Fortier, J., Giroux, D., Levasseur, M., & Lord, M.-M. (2021). Challenges and strategies to adapt the provision of support services to older adults and caregivers during the COVID-19 pandemic: The perspective of community organizations. *Canadian Journal on Aging*, *40*, 591–603. https://doi.org/https://doi.org/10.1017/S0714980821000507

Reith, M., & Payne, M. (2009). *Social work in end-of-life and palliative care.* Lyceum.

Sumser, B., Leimena, M., & Altilio, T. (2019). *Palliative care: A guide for health social workers*. Oxford University Press.

Swinkels, J., Tilburg, T.V., Verbakel, E., & Broese van Groenou, M. (2019). Explaining the gender gap in the caregiving burden of partner caregivers. *Journals of Gerontology Series B: Psychological Sciences & Social Sciences*, *74*, 309–317. https://doi.org/10.1093/geronb/gbx036

Taels, B., Hermans, K., Van Audenhove, C., Boesten, N., Cohen, J., Hermans, K., & Declercq, A. (2021). How can social workers be meaningfully involved in palliative care? A scoping review on the prerequisites and how they can be realised in practice. *Palliative Care and Social Practice, 15*. https://doi.org/10.1177/26323524211058895

Tritter, J. Q., & Calnan, M. (2002). Cancer as a chronic illness? Reconsidering categorization and exploring experience. *European Journal of Cancer Care, 11*, 161–165. https://doi.org/10.1046/j.1365-2354.2002.00345.x

Turner, N. R., Freitag, C., Johnson, I., Parsey, C. M., Ramirez, M., & Berridge, C. (2023). The role of trust in older adult service provision at the onset of the COVID-19 pandemic. *Journal of Gerontological Social Work, 66*, 739–762. https://doi.org/10.1080/01634372.2022.2164821

Ungar, M. (2002). A deeper, more social ecological social work practice. *Social Service Review, 76*, 480–497. https://doi.org/10.1086/341185

Wallace, A. S., Luther, B., Guo, J., Wang, C., Sisler, S., & Wong, B. (2020). Implementing social determinants screening and referral infrastructure during routine emergency department visits, Utah, 2017–2018. *Preventing Chronic Disease, 17*, Article 190339. https://doi.org/10.5888/pcd17.190339

Wallace, C. L. (2015). Hospice eligibility and election: Does policy prepare us to meet the need? *Journal of Aging & Social Policy, 27*, 364–380. https://doi.org/10.1080/08959420.2015.1054234

Washington, K. T., Bickel-Swenson, D., & Stephens, N. (2008). Barriers to hospice use among African Americans: A systematic review. *Health & Social Work, 33*, 267–274. https://doi.org/10.1093/hsw/33.4.267

World Health Organization. (2023). *Noncommunicable diseases*. https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases

Zworth, M., Saleh, C., Ball, I., Kalles, G., Chkaroubo, A., Kekewich, M., Miller, P. Q., Dees, M., Frolic, A., & Oczkowski, S. (2020). Provision of medical assistance in dying: A scoping review. *BMJ Open, 10*, Article e036054. https://doi.org/10.1136/bmjopen-2019-036054