WURZWEILER SCHOOL OF SOCIAL WORK
YESHIVA UNIVERSITY

PALLIATIVE CARE: SOCIAL WORK PRACTICE WITH SERIOUS ILLNESS
SWK 6825/SWK 8825
SPRING 2025

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Office Hours: TBA

COURSE DESCRIPTION:

This course will provide a comprehensive study of issues related to palliative and end-of-life care. Palliative care is an exciting, relatively new specialty in health care social work, and presents dynamic practice opportunities for social workers with a knowledge base in this arena. This course will integrate an interprofessional approach to caring for individuals facing life-limiting and serious chronic illness and their families. Readings, class discussion, and student research will include medical, psychosocial, legal, and ethical perspectives. This course is a required course for students in the Certificate Program in Gerontology and Palliative Care, but is open to all students. There are no prerequisites for this course, but it is highly recommended that students take Social Work in Health Care (SWK 6241) as background prior to enrolling in this course.

Objectives:

Students will be able to:

- Identify their personal attitudes towards serious illness and the end of life.
- Develop a self-care plan to prevent any adverse impacts of working in palliative care.
- Explain the concepts of hospice and palliative care as a compassionate and effective approach to serious illness care.
- Articulate an understanding of the basics of pain and symptom care.
- List the roles of social work on the interprofessional team, and how those roles are distinct from (and similar to) the activities of other team members.

- Express an appreciation for the vital roles of family caregivers in caring for family members facing serious illness and the end-of-life.

- List reasons for the importance of advance care planning and advance directives in the provision of palliative care.

- Discuss how cultural perspectives impact the provision of hospice and palliative care.

REQUIRED TEXTS:

Sumser, B., Leimena, M.L., & Altilio, T. (2019). Palliative care: A guide for health social workers. New York: Oxford.
List: $55.00 ISBN-10: 0190669608

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). Handbook for mortals: Guidance for people facing serious illness. Second edition. New York: Oxford University Press. (Available as an e-book from Yeshiva Univeristy Library)
List: $18.72 ISBN-10: 0199744564

RECOMMENDED REFERENCES:

Altilio, T. & Otis-Green, S. (Eds.)(2011). Oxford textbook of palliative social work. New York: Oxford University Press.
List: $138.00 ISBN-10: 0199739110
<u>Note:</u> This 2011 version is available as an e-book through the Yeshiva University Library. It has been updated, as Altilio, T., Otis-Green, S., & Cagle, J.G. (2022). Oxford textbook of palliative social work, 2nd Ed. New York: Oxford University Press.

Berlinger, N., Jennings, B., & Wolf, S.M. (2013). The Hastings Center guidelines for decisions on life-sustaining treatment and care near the end of life. New York: Oxford University Press.
List: $39.95 ISBN-10: 0199974551

Berzoff, J. & Silverman, P.R. (Eds.)(2004). Living with dying: A handbook for heathcare practitioners. New York: Columbia University Press. List: $96.50 ISBN-10: 0231127944

Brody, J. (2009). Jane Brody's guide to the great beyond: A practical primer to help you and your loved ones prepare medically, legally, and emotionally for the end-of-life. New York: Random House.
List: $22.81 ISBN-10: 1400066549

Byock, I. (2012). The best care possible: A physician's quest to transform care through the end of life. New York: Avery/Penguin Group.
List: $16.00 ISBN-10: 1583335129

Didon, J. (2007). The year of magical thinking. New York: Knopf. (Available on e-reserves)
List: $14.95 ISBN-10: 1400078431

Hitchens, C. (2012). Mortality. New York: Twelve.
List: $22.99 ISBN-10: 9781455502752

Kastenbaum, R.J. (2018). Death, society, and human experience. 12th ed. Upper Saddle River, NJ: Prentice Hall.
List: $128.00 ISBN-10: 1138292400

Levine, C., & Murray, T.H. (2007). The cultures of caregiving: Conflict and common ground among families, health professionals, and policy makers.
Baltimore, MD: Johns Hopkins University Press.
List: $25.00 ISBN-10: 0801887712

McPhee, S.J., Winkler, M.A., Rabow, M.W., Pantilat, S.Z., & Markowitz, A.J. (eds.) (2011). JAMA evidence: Care at the Close of life: Evidence and experience. New York: McGraw Hill Medical.
List: $70.00 ISBN-10: 0071637958

METHODS OF INSTRUCTION:

Lecture, discussion and interactive exercises will be used as the principle means of learning. Students are expected to attend class, do the assigned reading prior to class, participate in class discussion, and hand in their assigned materials on time. Students will integrate material from field practice into their class discussions and assignments. Guest faculty may be invited to provide a broad interdisciplinary perspective.

GRADING:

Grades will be computed on the following basis:

Mid-term paper – 30%
Final paper – 50%
Meaningful class participation – 20%

Participation will be judged on the quality of a student's involvement in the classroom, characterized by attention to the learning process, contributions to the learning climate, questions asked, opinions stated and how defended, sensitivity to the feelings of others, an awareness of his/her unique input within the classroom setting, and classroom presentations. This is a cumulative assessment based on the entire period of the course.

More than two absences may result in a lower grade for the class.

Students with disabilities should identify themselves to the instructor at the beginning of the semester so that any needed special considerations can be made to accommodate the student.

PLAGIARISM

The Wurzweiler School of Social Work does not condone plagiarism in any form and will sanction acts of plagiarism. A student who presents someone else's work as his or her own work is stealing from the authors or persons who did the original thinking and writing. Plagiarism occurs when a student directly copies another's work without citation; when a student paraphrases major aspects of another's work without citation; and when a student combines the work of different authors into a new statement without reference to those authors. It is also plagiarism to use the ideas and/or work of another student and present them as your own. This explicitly includes the use of AI, which is not recommended. However, if AI is used in any class assignment, students must cite and reference any AI generated material; failure to do so is regarded as plagiarism.

It is not plagiarism to formulate your own presentation of an idea or concept as a reaction to someone else's work; however, the work to which you are reacting should be discussed and appropriately cited. Any student who can be shown to have plagiarized any part of any assignment in this course will fail the course and will be referred to the Associate Dean for disciplinary action that may include expulsion.

MID-TERM ASSIGNMENT: Due at Session 7

Select one of topics below for in-depth discussion. At least five scholarly references, in addition to your texts, should be used; websites may be used, but they do not count towards the five scholarly references. The paper must be in APA format.
Page length: 8 pages

Some possible topics are:

a. Obituary and death anniversary notices – what is their essential message? What

need(s) do they meet on the part of the bereaved? On the part of society? What effect do they have on the reader? On society as a whole? Should the practice be encouraged or discouraged? Why?
b. Widows – Discuss the realities of the plight of widows around the world. Begin your research by looking at the subjective experience of a widow you know well or to whom you have ready access. Think about the customs, statistics, and relevant laws effecting widows around the world and in the US.

c. Bereavement – What are the common representations of bereavement we see in the media? What images of grief do we see in the movies? Magazine/newspaper articles? News reports on TV? What differences do you think the terrorist attacks on September 11 are having on the ways the nation views and understands the grief process?

d. Disenfranchised grief – Discuss the multiple types of disenfranchised grief in this culture. What are they? Why are members of these particular groups not supported in their grief as others are? What can be done to eliminate the sense of ostracism felt by those who are disenfranchised as a result of the death of someone they love?

e. Madison Ave. culture -- Consider the messages of Madison Avenue advertising and the youth worshiping culture in which we live alongside the level of violence in movies and TV, and the depictions of elderly in all of the above. What are the essential messages conveyed in all of these about the value of elderly persons and those who are ill?

f. Near-death experiences – What is meant by the term "near-death experience?" What information is circulated on the internet about this phenomenon? What impact do you see it having on patients and their families?

g. Hospice – What is hospice? What role does a hospice play in a terminally ill patient' life? What is palliative care? How widespread is palliative care in US health care practices today? How many people die on hospice services today? Are hospice service equally distributed across all segments of society? Why or why not?

h. Suicide and suicide prevention – Discuss suicide and suicide prevention resources. What resources are readily available to the general public concerning suicide and its prevention? How do you evaluate them? In your view, is there a "rational suicide" that we need not "prevent?"

i. Other topics must be pre-approved by your professor.

FINAL ASSIGNMENT: Due at Session 12

Select one of the below topics for in-depth analysis. At least five scholarly references, in addition to your texts, should be used; websites may be used, but they do not count towards the five scholarly references. The paper must be in APA format.

Page length: 8-10 pages

Topics:

a. Cultural Perspectives – Select a culture or community with which you are unfamiliar. Discuss the cultural meaning of illness and death, including the culture's rituals surrounding death and the mourning process. You may be creative, but discuss your ideas with your professor.

b. Alzheimer's Care – Explore the ethical issues faced by families/surrogates making end-of-life decisions on-behalf family members with Alzheimer's Disease. Include a description of the biological process of this disease. Give special consideration to the ethics of withholding or withdrawing artificial nutrition and hydration (food and fluids).

c. Advance Care Planning – Research whether or not advance care planning has been an effective tool for documenting individual wishes regarding end-of-life care. Consider the tools that are used for advance care planning, including the POLST approach. What has worked and what has not. Explore challenges presented by cultural perspectives, or practices around family decision-making (as opposed to decisions made by individual patients).

d. Other topics must be pre-approved by your professor.

COURSE OUTLINE

Session 1 – Introduction to End-of-Life Care

- Professor and student introductions
- Course overview
- Attitudes & experiences about death - Self inventory: Can we talk?
- Our bucket lists

Session 2 – Talking about Death

- Attitudes and experiences about death - Self inventory: Can we talk? (continued)
- Introduction of curative and palliative care, using Wit as an illustration
- Examples from literature and film (Didion, Hitchens, & Wit)

Required viewing prior to 2nd class:
Wit (2001), Mike Nichols (Director)

Required readings:

Didon, J. (2005). The year of magical thinking. New York: Knopf, pp. 3-41.

Hitchens, C. (2012). Mortality. New York: Twelve. Chapter 1, pp. 1-9.

Sessions 3 - 4 – Understanding Hospice and Palliative Care

- Principles of palliative care
- Distinguishing/integrating palliative care from hospice
- The interdisciplinary care team
- Social work roles and the interdisciplinary team
- Examples from literature and the humanities

Viewing:
Letting Go: A Hospice Journey

Required readings:

From Sumser:
Mulkerin, C.M., Ch. 1: The convergence of social work practice: Integrating health social work and specialized palliative care, pp. 17-30.

Center to Advance Palliative Care (May 2020). America’s care of serious illness: A state-by state report card on access to palliative care in our nation’s hospitals, 2019.

Download from: https://reportcard.capc.org/wp-content/uploads/2020/05/CAPC_State-by-State-Report-Card_051120.pdf

Glajchen, M., Berkman, C., Otis-Green, S., Stein, G.L., Sedgwick, T., Bern-Klug, M., Christ, G., Csikai, E., Downed, D., Gerbino, S., Head, B., Parker-Oliver, D., Waldrop, D., & Portenoy, R.K. (2018). Defining core competencies for generalist-level palliative social work. *Journal of Pain and Symptom Management, 56*(6), 886-892.

National Hospice and Palliative Care Organization (2023). NHPCO: Fact and figures, 2023 Edition. Download from: https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2023.pdf

Recommended:

Harper, B.C. (2011). Palliative social work: An historical perspective. In Altilio, T. & Otis Greene, S. (Eds). *Oxford textbook of palliative social work.* 11-20.

Session 5 – Pain and Symptom Care

- Medical terminology
- Major symptoms and treatment
- Life-sustaining/life-prolonging interventions
- Behavioral symptoms, including anxiety and depression
- Issues of specific populations (children, substance users, HIV, oncology)

Required readings:

From Sumser:
Altilio, T., & Leimena, M.L., Ch. 3: Physical aspects of care, pp. 52-70.

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). Handbook for mortals: Guidance for people facing serious illness. Second edition. New York: Oxford University Press, Chapters 7, 8, and 9; pp. 87-149.

Lamas, D.J. (February 6, 2022). Who are we caring for in the I.C.U.? New York Times. Download at: https://www.nytimes.com/2022/02/06/opinion/intensive-care-patient-hospital.html?searchResultPosition=8 (Links to an external site.)

Van Pelt, J. (2012). Pain care advocacy in an era of opioid abuse. Social Work Today, 12(5), 16.

Recommended:

Cagle, J.G. & Altilio, T. (2011). The social work role in pain and symptom management. In Altilio, T. & Otis-Greene, S. (Eds). Oxford textbook of palliative social work. 271-286, Section III, Chapter 25.

Session 6 – Psychological Aspects; Effective & Ethical Communication

- Resilience and meaning
- Psychological distress
- Truth-telling
- Informed consent
- Delegating decision-making to family members
- Social work and physician codes of ethics

Required readings:

From Sumser:
Onderdonk, C., & Thornberry, K., Ch. 4: Psychological aspects of care, pp. 71-96.

National Association of Social Workers (2017), Informed consent, Section 1.03. Download from: https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English.

American Medical Association (2020). Informed consent. Download from: https://www.ama-assn.org/delivering-care/ethics/informed-consent.

Recommended:

Altilio, T. (2011). The power and potential of language. In Altilio, T. & Otis-Greene, S. (Eds). Oxford textbook of palliative social work. 689-694, Section VIII, Chapter 75.

Gardner, D.S. (2011). Palliative social work with older adult and their families. In Altilio, T. & Otis-Greene, S. (Eds). Oxford textbook of palliative social work. 397-414, Section IV, Chapter 37.

Session 7 – Cultural Perspectives

- Role of culture in end-of-life care
- Unique cultural concerns
- Diversity within cultural traditions
- Religion and spirituality - Bias and discrimination
- Health disparities

Viewing:

The Farewell (2019). Director, Lulu Wang.

Required Readings:

From Sumser:
Colon, Y., Ch. 7: Cultural aspects of care, pp. 148-164.

Koenig, B., & Gates-Williams, J. (1995). Understanding cultural difference in caring for dying patients. Western Journal of Medicine, 163(3), 244-249.

Gonzales-Ramos, G. (2007). On loving care and the persistence of memories: Reflections of a grieving daughter. Chapter 2. From C. Levine & T.H. Murray (eds.). The cultures of caregiving: Conflict and common ground among families, health professionals, and policymakers. Baltimore: Johns Hopkins University Press.

Stein, G. L., Berkman, C., Acquaviva, K., Woody, I., Godfrey, D., Javier, N. M., O'Mahony, S., gonzález-rivera, c., Maingi, S., Candrian, C., & Rosa, W. E. (2023). Project Respect: Experiences of seriously ill LGBTQ+ patients and partners with their health care providers. *Health Affairs Scholar*. 1(4), 1-9.
https://doi.org/10.1093/haschl/qxad049

Recommended readings:

Bullock, K. (2006). Promoting advance directives among African Americans: A faith-based model. Journal of Palliative Medicine, 9(1), 183-195.

Leung, P.P.Y. & Chan, C.L.W. (2011). Palliative care in the Chinese context: An integrated framework for culturally respectful practice. In Altilio, T. & Otis-Greene, S. (Eds). Oxford textbook of palliative social work. 573-578, Section VI, Chapter 62.

Stein, G.L., Berkman, C.S., O'Mahony, S., Godfrey, D., Javier, N.M., & Maingi, S. (2020). Experiences of lesbian, gay, bisexual, and transgender patients and families in hospice and palliative care: Perspectives of the palliative care team. Journal of Palliative Medicine, 23(6), 817-824. DOI: 10.1089/jpm.2019.0542.

Volandes, A. E., Paasche-Orlow, M., Gillick, M. R., Cook, E. F., Shaykevich, S., Abbo, E. D., & Lehmann, L. (2008). Health literacy not race predicts end-of-life care preferences. Journal of Palliative Medicine, 11(5), 754-762. doi:10.1089/jpm.2007.0224

Sessions 8-9 – Health Care Decision-Making & Advance Care Planning

- Primary role of communication

- Social work role in advance care planning, facilitating communication, and conflict resolution
- Surrogate decision-making
- Understanding documents
- Doing your own plans
- Do-not-resuscitate orders
- Organ donation

Required readings:

From Sumser:
Smolinski, K.M., Ch. 9: Legal and ethical aspects of care, pp. 192-225.

Stein, G.L., Cagle, J.G., & Christ, G. (2017). Social work involvement in advance care planning: Findings from a large survey of social workers in hospice and palliative care settings. Journal of Palliative Medicine, 20(3), 253-259, doi: 10.1089/jpm.2016.0352.

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). Handbook for mortals: Guidance for people facing serious illness. Second edition. New York: Oxford University Press, Ch. 11, pp. 167-178.

Schaeffer, J. (2013). Supporting end-of-life decisions: The social worker's role in advance directives. Social Work Today (Special White Paper Report)

Fins, J.J. & Maltby, B.S. (2003). Fidelity, Wisdom & Love: Patients and Proxies in Partnership. New York: Weill Medical College of Cornell University.

Institute for Healthcare Improvement and The Conversation Project (2021). Your Guide to Choosing a Health Care Proxy. Download from:https://theconversationproject.org/wp-content/uploads/2020/12/ChooseAProxyGuide.pdf

Morrison, R.S. (2020). Advance directives/Care planning: Clear, simple, and wrong. *Journal of Palliative Medicine, 23*(7), 878-879. **Article is available on Files page.**

In re Quinlan, 70 N.J. 10 (NJ 1976)

Recommended:

Bullock, K. (2011). Advance directives from a social work perspective: Influence of culture and family dynamics. In Altilio, T. & Otis-Greene, S. (Eds). Oxford textbook of palliative social work. 625-636, Section VII, Chapter 69.

Sessions 10-11 – Assisted Suicide and the Right to Die

- Understanding distinctions between assisted suicide and euthanasia
- Understanding distinctions between assisted suicide and foregoing life supports
- Terri Schaivo and disorders of consciousness
- Legal background
- What social workers may do with requests for help in dying

Required Readings:

Washington v. Glucksberg, 521 U.S. 702 (1997).

Oregon Health Authority/Public Health Division (2023). Oregon Death with Dignity Act: 2022 Data Summary. Download at: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year25.pdf

Kozlov, E., et al. (2022). Aggregating 23 years of data on medical aid in dying in the United States, *Journal of the American Geriatrics Society*, 70(10), 3040-3044.

Hartocollis, A. (2009, December 27). Hard choice for a comfortable death: Druginduced sleep. The New York Times. Download at: https://www.nytimes.com/2009/12/27/health/27sedation.html

Session 12 – The Critical Role of Family Caregivers

- Appreciating the roles and responsibilities of family caregivers
- Who are family caregivers?
- What family caregivers do
- Cultures and values implicated in home care

Required readings:

From Sumser:
Conceicao, S., & Swenson, G., Ch. 8: Care of patients and families at the end of life, pp.165-191.

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). Handbook for mortals: Guidance for people facing serious illness. Second edition. New York: Oxford University Press, Ch. 5, pp. 54-68.

Reinhard, S.C., Young, H.M., Levine, C., & Kelly, K. (2019). Home Alone Revisited:

Family caregivers providing complex care. Retrieve from: https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf

Surpin, R., & Hanley, E. (2007). The culture of home care: Whose values prevail? Chapter 6. From C. Levine & T.H. Murray (eds.). The cultures of caregiving: Conflict and common ground among families, health professionals, and policymakers. Baltimore: Johns Hopkins University Press.

Session 13 – Pediatric Palliative Care

- Special needs of children
- Decision-making by minors
- Family approaches
- Innovative service models
- Social work roles

Required readings:

From Sumser:
Altilio, T., et al., Ch. 10: Special issues in children and older adults, pp. 226-252.

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Session 14 – Impact of Covid-19 on Palliative Care

- Intersection of the Covid-19 pandemic and palliative care
- Special need for advance care planning
- New roles for spiritual care
- Grief considerations

Required reading:

In Tosone, C. (ed) (2021). Shared trauma, shared resilience during a pandemic: Social work in the time of COVID-19 (Cham, Switzerland: Springer). Carol Tosone, Ch. 36: Shared trauma: Group reflections on the COVID-19 pandemic, pp. 347-353.

In Tosone, C. (ed) (2021). Shared trauma, shared resilience during a pandemic: Social work in the time of COVID-19 (Cham, Switzerland: Springer). Nicholas Santo, Ch.14: Reflections on the HIV/AIDS crisis, COVID-19, and resilience in gay men: Ghosts of our past, demons of our present, pp. 127-133.

Delisle, S., Heller, F.E., & Blinderman, C.D. (2020). Prolonged critical illness and demoralization: Curative factors in hospice care in the age of Covid-19. Journal of Hospice & Palliative Nursing. 22(6), 428-431.

Wallace, C., Wladkowski, S., Gibson, A., and White, P. (2020). Grief during the covid-19 pandemic: Considerations for palliative care providers. Journal of Pain and Symptom Management, 60(1), e70-76.

Session 14 – Self-Care for Caring Professionals

- Protecting ourselves against burnout
- Supporting bereaved staff
- Family and professional caregivers

Required readings:

Clark, E. J. (2011). Self-care as best practice in palliative care. In Altilio, T. & Otis-Greene, S. (Eds). *Oxford textbook of palliative social work.* 771-778.

RESOURCES

From Sumser, General Resources, pp. 259-265

Berkman, C. (2023). Resource guide for palliative and end-of-life care. Download from: http://www.palliativecarefordham.com/uploads/9/3/7/2/93725736/resources_for_palliative_social_work_-_6-23-23.pdf

BIBLIOGRAPHY

Books

Acquaviva, K. D. (2019) *LGBTQ-inclusive hospice and palliative care: A practical guide to transforming professional practice*. New York: Harrington Park Press.

Altilio, T. & Otis-Greene, S. (Eds) (2022). *Oxford textbook of palliative social work.* NY: Oxford.

Berlinger, N., Jennings, B., & Wolf, S.M. (2013). *The Hastings Center guidelines for decisions on life-sustaining treatment and care near the end of life.* New York: Oxford University Press.

Berzoff, J. & Silverman, P.R. (Eds.) (2004). *Living with dying: A handbook for heathcare practitioners.* New York: Columbia University Press.

Bishop, J. P. (2011). *The anticipatory corpse : medicine, power, and the care of the dying*. Notre Dame, Ind.: University of Notre Dame Press.

Byock, I. (2012). *The best care possible: A physician's quest to transform care through the end of life.* New York: Avery/Penguin Group.

Byock, I. (2014). *The four things that matter most - 10th anniversary edition: A book about living*: Atria Books.

Byock, I. (1998). *Dying well*: Riverhead Trade.

Cairns, M., Victoria Hospice Society, T., & Thompson, M. (2003). *Transitions in dying and bereavement: a psychosocial guide for hospice and palliative care*. Baltimore, MD: Health Professions Press.

Callanan, M., & Kelley, P. (2012). *Final gifts: Understanding the special awareness, needs, and communications of the dying* Simon & Schuster.

Christ, G. (2000). *Healing children's grief: Surviving a parent's death from cancer*. New York: Oxford University Press.

Christ, G. H., Messner, C., & Behar, L. (Eds.). (2015). *Handbook of oncology social work* (1st ed.). New York: Oxford.

Csikai, E. (2006). *Ethics in end-of-life decisions in social work practice*: Lyceum Books.

Dunn, H. (2009). *Hard choices for loving people: CPR, artificial feeding, comfort care, and the patient with a life-threatening illness, 5th Edition* (5th ed.): A & A Publishers.

Ellison, K. P., & Weingast, M. Eds. (2016). *Awake at the bedside: Contemplative teachings on palliative and end-of-life care.* Wisdom Publications.

Halifax, J., & Ira, B. (2009). *Being with dying: Cultivating compassion and fearlessness in the presence of death*. Shambhala

Heiney, S. P., & Hermann, J. F. (2013). *Cancer in our family: Helping children cope with a parent's illness* (2nd ed.). Washington, D.C.: American Cancer Society.

Holland, J. C., Breitbart, W. S., Jacobsen, P. B., Lederbarg, M. S., Loscalzo, M. J., & McCorkle, R. S. (2010). *Psycho-oncology*. New York: Oxford.

Holland, J. C., & Lewis, S. (2001). *The human side of cancer: Living with hope, coping with uncertainty*. New York: Harper Perennial.

Holland, J. C., & Rowland, J. H. (1990). *Handbook of psycho-oncology: Psychological care of the patient with cancer* New York: Oxford.

Hooyman, N. R., & Kramer, B. J. (2008). *Living through loss: Interventions across the life span*. New York: Columbia University Press.

Jenkinson, S. (2015). *Die wise: A manifesto for sanity and soul*. Berkeley, CA: North Atlantic Books.

Kaufman, S. (2005). *And a time to die: How American hospitals shape the end of life*. New York: Scribner.

Kalanithi, P. (2016). *When breath becomes air*. New York: Random House.

Kolsky, K. (2008). *End of life: helping with comfort and care*. In National Institute on Aging (Ed.), *https://d2cauhfh6h4x0p.cloudfront.net/s3fspublic/end_of_life_helping_with_comfort_care_0.pdf* Bethesda, MD: National Institute on Aging.

Lauria, M., Clark, E., Hermann, J., & Stearns, N. (2012). *Social work in oncology: Supporting survivors, families, and caregivers*: American Cancer Society. http://acs.bookstore.ipgbook.com/social-work-in-oncology-products9781604431711.php

Levine, C., & Murray, T.H. (2007). *The cultures of caregiving: Conflict and common ground among families, health professionals, and policy makers.* Baltimore, MD: Johns Hopkins University Press.

Levine, S. (1989). *Who dies? An investigation of conscious living and conscious dying*: Anchor Press/Doubleday.

Lynn, J., Harrold, J., & Schuster, J. L. (2011). *Handbook for mortals: Guidance for people facing serious illness* (2nd ed., pp. 320). New York: Oxford.

Matzo, M. L., & Sherman, D. W. (2015). *Palliative care nursing: Quality care to the end of life*. Spring.

McCue, K., & Bonn, R. *How to help children through a parent's serious illness: Supportive, practical advice from a leading child life specialist* (2nd ed.). New York: St. Martin's Griffin.

McPhee, S.J., Winkler, M.A., Rabow, M.W., Pantilat, S.Z., & Markowitz, A.J. (eds.) (2011). *JAMA evidence: Care at the Close of life: Evidence and experience.* New York: McGraw Hill Medical.

Miller, J. E., & Cutshall, S. (2001). *The art of being a healing presence: A guide for those in caring relationships*. Willowgreen.

Morrissey, MB, Lang, M, & Newman, B. (2019). *A Public Health Strategy for Living, Aging and Dying in Solidarity*: *Designing Elder-Centered and Palliative Systems of Care, Environments, Services and Supports.* London and New York: Routledge.

Morrissey, MB*.* (2015). *Suffering narratives of older adults*: *A phenomenological approach to serious illness, chronic pain, recovery and maternal care.* London and New York: Routledge.

O'Rourke, M. (2012). *The long goodbye: A memoir*: Riverhead Trade.

Pantilat, S. Z. (2017). *Life after the diagnosis: Expert advice on living well with serious illness for patients and caregivers*. Philadelphia: Da Capo Press.

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Briefings in Palliative, Hospice, and Pain Medicine & Management
Journal of Hospice & Palliative Nursing
Journal of Pain and Symptom Management
Journal of Palliative Care
Journal of Palliative Medicine
Journal of Social Work in End-of-Life & Palliative Care
Palliative and Supportive Care

Key Organizational Websites

American Academy of Hospice and Palliative Medicine (AAHPM) www.aahpm.org

American Pain Foundation   www.painfoundation.org

American Pain Society. www.ampainsoc.org/

Association for Death Education and Counseling (ADEC): http://www.adec.org

Association of Oncology Social Work http://www.aosw.org/

Association of Pediatric Oncology Social Workers http://www.aposw.org/

CancerCare   www.cancercare.org

Caring Community http://www.caringcommunity.org/helpful-resources/modelsresearch/end-of-lifepalliative-care-education-resource-center-medical-college-ofwisconsin-milwaukee/

Caring Connections: http://www.caringinfo.org

Center to Advance Palliative Care (CAPC): http://www.capc.org

Center for Health Law Studies, St. Louis University American Society of Law, Medicine and Ethics. www.painandthelaw.org/

City of Hope, Pain and Palliative Care Resource Center www.cityofhope.org/prc/

Collaborative for Palliative Care cpcwestchester.org/

The Conversation Project: theconversationproject.org/

End-of-Life Wisdom: www.endoflifewisdom.org

Family Caregiver Alliance: www.caregiver.org

GeriPal: A Geriatrics and Palliative Care Blog www.geripal.org

Hospice and Palliative Nurses Association (HPNA) hpna.advancingexpertcare.org/

Hospice Foundation of America (HFA): www.hospicefoundation.org

Hospice: www.hospicenet.org site for patients and families

International Association for the Study of Pain
www.iasp-pain.org/AM/Template.cfm?Section=Publications&Template=/CM/HTMLDisplay.cfm&ContentID=2307

Social Work Hospice & Palliative Care Network (SWHPN) www.swhpn.org

The Society for Social Work Leadership in Healthcare (SSWLHC) www.sswlhc.org