

**Resource Guide for  
Palliative and End-of-Life Care**

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## Fordham University Library Research Guide on Palliative and End-of-Life Care

This is an excellent resource for finding information and references on many areas of palliative care. It is available to all, not just persons affiliated with Fordham.

<http://fordham.libguides.com/Palliative>

## Social Work in Hospice and Palliative Care Network (SWHPN)

[www.swhpn.org](http://www.swhpn.org)

SWHPN was created to bridge the gaps in social work's access to information, knowledge, education, training, and research in hospice and palliative care.

[Journal of Social Work in End-of-Life and Palliative Care](#) is available as a benefit to members.

Membership rates for students and new professionals

## SW-PALL-EOL LISTSERV

The SW-PALL-EOL listserv is an excellent resource for learning about issues that palliative and hospice social workers encounter in the field. To join the listserv, email Terry Altilio at [terryaltilio@gmail.com](mailto:terryaltilio@gmail.com). Terry will send you the application to add you to the Listserv.

## Organizations

American Academy of Hospice and Palliative Medicine (AAHPM): [www.aahpm.org](http://www.aahpm.org)

American Board of Hospice and Palliative Medicine (ABHPM) [aahpm.org/certification/moc](http://aahpm.org/certification/moc)

American Cancer Society <https://www.cancer.org/>

American Pain Foundation [www.painfoundation.org](http://www.painfoundation.org)

American Pain Society. [www.ampainsoc.org/](http://www.ampainsoc.org/)

Americans for Better Care of the Dying (ABCD) <https://www.abcd-caring.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.cancer.org](http://www.cancer.org)

Caring Community <http://www.caringcommunity.org/helpful-resources/models-research/end-of-lifepalliative-care-education-resource-center-medical-college-of-wisconsin-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/](http://www.painandthelaw.org/)

City of Hope, Pain and Palliative Care Resource Center. [www.cityofhope.org/prc/](http://www.cityofhope.org/prc/)

Coalition to Transform Advanced Care (C-TAC) <https://www.thectac.org/>

Collaborative for Palliative Care [cpcwestchester.org/](http://cpcwestchester.org/)

The Conversation Project: [theconversationproject.org/](http://theconversationproject.org/)

End-of-Life Wisdom: [www.endoflifewisdom.org](http://www.endoflifewisdom.org)

Family Caregiver Alliance: [www.caregiver.org](http://www.caregiver.org)

GeriPal: A Geriatrics and Palliative Care Blog [www.geripal.org](http://www.geripal.org)

GetPalliativeCare.org [getpalliativecare.org/](http://getpalliativecare.org/)

Hospice and Palliative Nurses Association (HPNA) [hpna.advancingexpertcare.org/](http://hpna.advancingexpertcare.org/)

Hospice Foundation of America (HFA): [www.hospicefoundation.org](http://www.hospicefoundation.org)

Hospice: [www.hospicenet.org](http://www.hospicenet.org) site for patients and families

Interfaith Center of New York [interfaithcenter.org/](http://interfaithcenter.org/)

International Association for Hospice & Palliative Care  
<https://hospicecare.com/home/>

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

## **Joint Commission Certification for Palliative Care Programs**

[www.jointcommission.org/certification/palliative\\_care.aspx](http://www.jointcommission.org/certification/palliative_care.aspx)

Medicare Hospice Conditions of Participation - Social Work Tip Sheet

[www.nhpco.org/sites/default/files/public/regulatory/Social\\_Work\\_tip\\_sheet.pdf](http://www.nhpco.org/sites/default/files/public/regulatory/Social_Work_tip_sheet.pdf)

National Hospice and Palliative Care Organization (NHPCO): [www.nhpco.org](http://www.nhpco.org)

National Palliative Care Registry [registry.capc.org/](http://registry.capc.org/)

National Palliative Care Research Center: [www.npcrc.org](http://www.npcrc.org)

National Prison Hospice Association <https://npha.org/>

Vermont Ethics Network [www.vtethicsnetwork.org/index.html](http://www.vtethicsnetwork.org/index.html)

## **Palliative Care Journals**

American Journal of Hospice Care

American Journal of Hospice and Palliative Care

American Journal of Hospice and Palliative Medicine

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

Palliative Medicine

## **Advance Directives and MOLST**

### **6 Steps in Advance Care Planning**

6-Steps includes a form and a guide for decision-making about life-sustaining treatment. The web site contains useful information on this topic and links to other websites.

<http://www.6stepslivingwill.org/about>

### **State-by-State**

<https://www.everplans.com/articles/state-by-state-polst-forms>

### **GYST**

Resource for advance directives by state.

<https://www.gyst.com/>

### **State Forms**

MOLST – NY State Form: <http://www.health.ny.gov/forms/doh-5003.pdf>

New York State Advance Directive: [http://www.caringinfo.org/files/public/ad/New\\_York.pdf](http://www.caringinfo.org/files/public/ad/New_York.pdf)

[https://www.ag.ny.gov/sites/default/files/pdfs/publications/Planning\\_Your\\_Health\\_Care\\_in\\_Advance.pdf](https://www.ag.ny.gov/sites/default/files/pdfs/publications/Planning_Your_Health_Care_in_Advance.pdf)

New Jersey Advance Directive: <http://www.caringinfo.org/files/public/ad/NewJersey.pdf>

Oregon POLST website: <http://www.or.polst.org/>

Includes information and videos for professionals, patients and families

Other state advance directives: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>



## Advance Care Planning Resources

Thanks to the following reference for many of the resources on the next pages:

Otis-Green, S., Thomas, J., Duncan, L., Walling, A., Ieto, C., Kung, J., . . . Wenger, N. (2019).

Advance care planning: Opportunities for clinical social work leadership. *Clinical Social Work Journal*, published online May 28, 2019, 1-12.

### Advance Care Planning Decisions

<https://www.acpdecisions.org/>

Angelo Volandes (author of *The Conversation*) offers videos and resources to guide understanding of complex healthcare decisions at end of life.

### Aging with Dignity (*Five Wishes*)

[agingwithdignity.org](http://agingwithdignity.org)

[www.fivewishes.org](http://www.fivewishes.org)

The non-profit Aging with Dignity provides people with the practical information, advice and legal tools including the popular, low cost and easy to use *Five Wishes* Advance Directive, which is available for purchase in multiple languages, including Braille.

### American Bar Association

[americanbar.org/groups/law\\_aging/resources/consumer\\_s\\_toolkit\\_for\\_health\\_care\\_advance\\_planning.html](http://americanbar.org/groups/law_aging/resources/consumer_s_toolkit_for_health_care_advance_planning.html)

<http://ambar.orgagingtoolkit>.

Toolkits for approaching and completing Advance Directives, with links to state-specific Advance Directives.

### American Society of Clinical Oncology (*ASCO Answers: Advanced Cancer Care Planning*)

[http://www.cancer.net/sites/cancer.net/files/advanced\\_cancer\\_care\\_planning.pdf](http://www.cancer.net/sites/cancer.net/files/advanced_cancer_care_planning.pdf)

A free decision-making booklet for patients and families facing serious illness with information and resources about care options, communication tips and coping at end of life.

### Ariadne Labs (*Serious Illness Care*)

[ariadnelabs.org/areas-of-work/serious-illness-care](http://ariadnelabs.org/areas-of-work/serious-illness-care)

Ariadne Labs consolidates evidence-supported videos, tools and resources to support decision making for the seriously ill including a downloadable "*Serious Illness Conversation Guide*."

Serious Illness Conversation Guide

[https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21\\_FINAL.pdf](https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21_FINAL.pdf)

<https://www.ariadnelabs.org/wp-content/uploads/sites/2/2015/08/Serious-Illness-Conversation-Guide-5.22.15.pdf>

## Serious Illness Care Resources

<https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/>

### **Begin the Conversation.org**

[begintheconversation.org](http://begintheconversation.org)

Learn how to take the first steps to begin an ACP conversation. Workbook and toolkit available with information to support community engagement and empowerment.

### **California State University Institute for Palliative Care**

<https://csupalliativecare.org/programs/advance-care-planning/>

Extensive ACP education and materials (including virtual, self-paced courses) for health professionals.

### **Caring Conversations**

<https://www-cache.pbs.org/wgbh/pages/frontline/facing-death/educational-module/decisions-near-end-life/making-your-wishes.pdf>

Step-by-step approach using a workbook to make end-of-life care wishes known.

### **Center to Advance Palliative Care (CAPC)**

<https://www.capc.org/>

CAPC provides a wealth of information to support organizations and clinicians in improving the delivery of palliative care. Educational content regarding ACP is available for CAPC members.

### **Chinese American Coalition for Compassionate Care (*Heart to Heart*)**

[caccc-usa.org](http://caccc-usa.org)

Heart to Heart cards are a bilingual (Chinese/English) communication activity designed to make it easier to understand what people might prefer when their lives are threatened by injury or disease.

### **Choosing Wisely**

<http://www.choosingwisely.org/>

*Choosing Wisely* is an initiative of the ABIM Foundation that seeks to advance a national dialogue on avoiding unnecessary medical tests, treatments and procedures.

### **Coalition for Compassionate Care of California (CCCC)**

<http://coalitionccc.org/tools-resources/advance-care-planning-resources>

Widely used curricula supporting culturally congruent care, ACP and Physician Orders For Life Sustaining Treatment (POLST). Many free and low-cost resources are available, including decision aids, tips for starting ACP conversations, information for professionals and consumers (with tailored resources for pediatrics, faith communities, skilled nursing facilities and long term care facilities), often in different languages. CCCC is involved in public policy, offers educational programs and provides consultation and coalition-building related to ACP and POLST.

## **Coalition to Transform Advanced Care (C-TAC)**

<https://www.thectac.org/>

In Their Own Words: Kathy Brandt and Kim Acquaviva, PhD

In January 2019, Kathy Brandt, a nationally known hospice industry leader, was diagnosed with metastatic ovarian cancer and learned she had mere months to live. Brandt opted for palliative care, forgoing treatments such as chemotherapy or radiation, in order to spend as much quality time as possible with her wife, Kim Acquaviva, PhD, and their 19 year old son. In this video, Brandt and Acquaviva, a nursing professor and end-of-life care expert, discuss their decision and the benefits of palliative care.

<https://www.thectac.org/2019/06/in-their-own-words-kathy-brandt-and-kimberly-acquaviva/>

## **Coda Alliance (*Go Wish*)**

[gowish.org](http://gowish.org)

Offers a fun and non-threatening way to explore people's preferences for care when seriously ill.

## **Consumer Reports (*Advance Care Planning*)**

<http://consumerhealthchoices.org/wp-content/uploads/2017/04/CarePlanningCCCC-ER.pdf>

Free, downloadable patient ACP booklet available in English and Spanish.

## **The Conversation Project Toolkit**

[theconversationproject.org/starter-kit/intro/](http://theconversationproject.org/starter-kit/intro/)

Resources and discussion guide for people who want to talk with their loved ones about end-of-life wishes (available in multiple languages).

## **Go Wish Game**

<http://www.gowish.org/>

Go Wish gives you an easy, even entertaining way to talk about what is most important to you. The cards help you find words to talk about what is important if you were to be living a life that may be shortened by serious illness. Playing the game with your relatives or best friends can help you learn how you can best comfort your loved ones when they need you most. Go Wish can be played by one, two or more people.

Each deck has 36 cards. Thirty-five of the cards describe things that people often say are important when they are very sick or dying. The cards describe how people want to be treated, who they want near them, and what matters to them. One card is a "wild card." You can use this card to stand for something you want that isn't on any of the other cards.

## **Growth House**

<http://www.growthhouse.org/>

Growth House, Inc., gives you free access to over 4,000 pages of high-quality education materials about end-of-life care, palliative medicine, and hospice care, including the full text of several books. We provide education both for the general public and for health care professionals.

### **Heart to Heart**

<https://www.discussdirectives.com/heart2hearts-acp.html>

"How do I start a conversation about my end-of-life healthcare wishes?" "This is really uncomfortable." "What should I say?" These questions were asked over and over again by patients. As a result, the **Heart2Hearts**® deck of cards were invented in order to provide 52 conversation starters.

### **Hello Game**

<https://commonpractice.com/products/hello-game>

Hello is a conversation game. It's the easy, non-threatening way to start a conversation with your family and friends about what matters most to you.

### **My Directives.com**

<http://mydirectives.com>

Free web-based service with guidance for completing an "Advance Digital Directive" with a smartphone app.

### **National Hospice and Palliative Care Organization (*Caring Connections*)**

[caringinfo.org](http://caringinfo.org)

Free resources to help people make medical decisions, with links to Advance Directives for all 50 states.

For patients and caregivers: <https://www.nhpco.org/patients-and-caregivers/>

### **National Institute on Aging (*Advance Care Planning Tips*)**

<https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives>

Free information on ACP in an easy to read format with links to local *Agencies on Aging* and to Advance Directives for all 50 states. Printable wallet card.

### **National POLST (Physician Orders for Life-Sustaining Treatment) Paradigm**

[www.POLST.org](http://www.POLST.org)

Information and patient resources on each state's POLST efforts with recommendations for best practices.

### **Palliative Care Network of Wisconsin (*Fast Facts*)**

<https://www.mypcnow.org/>

Over 350 "Fast Facts" are available as teaching tools, offering clinicians a wide range of information to support ACP conversations.

### **Prepare for Your Care**

[prepareforyourcare.org](http://prepareforyourcare.org)

A website designed to empower people to make decisions, talk with providers and get medical care that is right for them. Prepare for Your Care walks people through the basic steps in ACP and provides prompts and videos to help them get started.

**Respecting Choices**

<https://respectingchoices.org/>

Respecting Choices® is an internationally recognized, evidence-based model of advance care planning (ACP) that creates a healthcare culture of person-centered care—care that honors an individual’s goals and values for current and future healthcare.

**Stanford Letter Project**

<http://med.stanford.edu/letter>

Provides “*What Matters Most*” and “*Who Matters Most*” letter templates to share with healthcare providers and family members.

**UpToDate**

<https://www.uptodate.com/home>

Vast array of evidence-based, clinical decision resources to support medical decision making and ACP activities.

**VeryWellHealth**

4 Questions to Consider When Preparing for the End of Life

<https://www.verywellhealth.com/right-questions-for-advance-directives-2615083>

**Vital Talk**

<http://vitaltalk.org/>

Evidence-based communication skills-building programs to support physicians in having more effective conversations with those facing serious illness.

## Information

Center to Advance Palliative Care (2011). 2011 Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies. Download at:  
<http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>

Family Caregiver's Guide to Hospice and Palliative Care, United Hospital Fund.  
This guide is available in English on the Palliative Social Work Blackboard site and is also available in Spanish, Chinese, and Russian from the website.  
[http://www.nextstepincare.org/Caregiver\\_Home/Hospice](http://www.nextstepincare.org/Caregiver_Home/Hospice)

Family Healthcare Decisions Act (FHCDCA)  
[End of Life Choices New York http://endoflifechoicesny.org/family-health-care-decisions-act/](http://endoflifechoicesny.org/family-health-care-decisions-act/)

New York State Department of Health  
[Fact Sheet https://www.health.ny.gov/diseases/aids/providers/regulations/fhcda/ai\\_fact\\_sheet.htm](https://www.health.ny.gov/diseases/aids/providers/regulations/fhcda/ai_fact_sheet.htm)

New York State Bar Association, FHCDCA Information Center <http://www.nysba.org/FHCDCA/>

Family Health Care Decisions Act  
[http://www.compassionandsupport.org/pdfs/legislation/Family\\_Health\\_Care\\_Decisions\\_Act.pdf](http://www.compassionandsupport.org/pdfs/legislation/Family_Health_Care_Decisions_Act.pdf)

Frequently Asked Questions  
<http://www.nysba.org/CustomTemplates/Content.aspx?id=26462>

Swidler, R. N. (2010). New York's Family Health Care Decisions Act. *NYSBA Journal*, 82(5), 18-27.

Swidler, R. N. (2010). The Family Health Care Decisions Act: A summary of key provisions. *NYSBA Health Law Journal*, 15(1), 32-35.

Upstate Medical University – Center for Bioethics and Humanities  
[http://www.upstate.edu/bioethics/consult/familyhc\\_decisionact.php](http://www.upstate.edu/bioethics/consult/familyhc_decisionact.php)

Guides and Toolkits for Providers for working with family caregivers  
[http://www.nextstepincare.org/Provider\\_Home/#Toolkit](http://www.nextstepincare.org/Provider_Home/#Toolkit)

Morrissey, M. B., & Leven, D. (2014). Palliative care in New York State. New York: Collaborative for Palliative Care.  
<http://cpcwestchester.org/images/PalliativeCareNewYorkStateApril20142ndedition.pdf>

## Reports

Blacker, S., Christ, G. H. C., & Lynch, S. (2005). Charting the course for the future of social work in end-of-life and palliative care: A Report of the 2nd Social Work Summit on End-of-Life and Palliative Care. Retrieved from <http://www.swhpn.org/monograph.pdf>

Institute of Medicine. (2014). *Dying in America: improving quality and honoring individual preferences near the end of life*.

Free download: <http://www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

Reserve in Fordham Library, Westchester campus: R726.8.D95 2015.

Robert Wood Johnson Foundation

<https://www.rwjf.org/content/rwjf/en/search-results.html?u=&k=end+of+life>

World Health Organization. *Palliative care for older people: Better practices* (S. Hall, H. Petkova, A. D. Tsouros, M. Costantini, & I. J. Higginson Eds.).

[http://www.euro.who.int/\\_data/assets/pdf\\_file/0017/143153/e95052.pdf](http://www.euro.who.int/_data/assets/pdf_file/0017/143153/e95052.pdf)

## Facts and Guidelines

NASW Standards for Social Work Practice with Family Caregivers

<https://www.socialworkers.org/practice/standards/naswfamilycaregiverstandards.pdf>

National Hospice and Palliative Care Organization

Clinical Practice Guidelines for Quality Palliative Care, 4th edition

<https://www.nationalcoalitionhpc.org/ncp/>

NHPCO's Facts and Figures – Hospice Care in America – 2018

[https://www.nhpc.org/wp-content/uploads/2019/07/2018\\_NHPCO\\_Facts\\_Figures.pdf](https://www.nhpc.org/wp-content/uploads/2019/07/2018_NHPCO_Facts_Figures.pdf)

NHPCO's Facts and Figures - Pediatric Palliative & Hospice Care in America - 2015

[http://www.nhpc.org/sites/default/files/public/quality/Pediatric\\_Facts-Figures.pdf](http://www.nhpc.org/sites/default/files/public/quality/Pediatric_Facts-Figures.pdf)

## Communication

Sources on Family Meetings - on course Blackboard site

CareSearch – Family Meetings

Conducting a Family Meeting – Memorial Sloan Kettering, 2007

Family Caregiver Alliance - Holding a Family Meeting

Medical Oncology Communication Skills Training Learning Modules 2 - Conducting a Family Conference 2002

Weissman - Edmonton Goals of Care and Conflict Management

Compassus

Guides for Healthcare Professionals and Caregivers

<https://www.compassus.com/blogs/everyday-compassion-blog/posts/414-questions-to-ask-the-doctor>

National Cancer Institute. (2015). Last days of life—for health professionals (PDQ®).

<http://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/last-days-hp-pdq#section/all>

National Hospice and Palliative Care Organization (NHPCO)

Ask Tough Questions

Guide to asking questions of your doctor, health care agent, lawyer, loved one, spiritual caregiver, and social worker

<https://www.nhpc.org/wp-content/uploads/2019/04/asktoughquestions.pdf>

Communicating End-of-Life Wishes

[https://www.nhpc.org/wp-content/uploads/2019/04/Communicating\\_EOL\\_Wishes.pdf](https://www.nhpc.org/wp-content/uploads/2019/04/Communicating_EOL_Wishes.pdf)

Conversations Before the Crisis

[https://www.nhpc.org/wp-content/uploads/2019/04/Communicating\\_EOL\\_Wishes.pdf](https://www.nhpc.org/wp-content/uploads/2019/04/Communicating_EOL_Wishes.pdf)

End-of-Life Decisions

[https://www.nhpc.org/wp-content/uploads/2019/04/End-of-Life\\_Decisions.pdf](https://www.nhpc.org/wp-content/uploads/2019/04/End-of-Life_Decisions.pdf)



How to Talk with Your Loved Ones

<https://www.nhpco.org/patients-and-caregivers/advance-care-planning/communicate-your-end-of-life-wishes/how-to-talk-with-your-loved-ones/>

How to Talk with Your Healthcare Providers

<https://www.nhpco.org/patients-and-caregivers/advance-care-planning/communicate-your-end-of-life-wishes/how-to-talk-with-your-healthcare-providers/>

Talking with Others About Their End-of-Life Wishes

<https://www.nhpco.org/patients-and-caregivers/advance-care-planning/communicate-your-end-of-life-wishes/talking-with-others-about-their-end-of-life-wishes/>

Palliative Care: What You Should Know – guide for patients and families

<https://getpalliativecare.org/wp-content/uploads/2012/09/WhatYouShouldKnowHandoutRevised.pdf>

Vital Talk\_one-page guides: <http://www.vitaltalk.org/clinicians>

Saying goodbye to a patient: <http://www.vitaltalk.org/sites/default/files/quick-guides/GoodbyeForVitaltalkV1.0.pdf>

Addressing Goals of Care: “REMAP”: <http://www.vitaltalk.org/sites/default/files/quick-guides/REMAPforVitaltalkV1.0.pdf>

Defuse conflicts: [http://www.vitaltalk.org/sites/default/files/quick-guides/ConflictsForVitaltalkV1.0\\_0.pdf](http://www.vitaltalk.org/sites/default/files/quick-guides/ConflictsForVitaltalkV1.0_0.pdf)

Talking Map for the Family Conference: [http://www.vitaltalk.org/sites/default/files/quick-guides/FamilyConfForVitaltalkV1.0\\_0.pdf](http://www.vitaltalk.org/sites/default/files/quick-guides/FamilyConfForVitaltalkV1.0_0.pdf)

Discussing Prognosis “ADAPT”: [http://www.vitaltalk.org/sites/default/files/quick-guides/ADAPTforVitaltalkV1.0\\_0.pdf](http://www.vitaltalk.org/sites/default/files/quick-guides/ADAPTforVitaltalkV1.0_0.pdf)

Breaking Bad News Map: “SPIKES”: <http://www.vitaltalk.org/sites/default/files/quick-guides/SPIKESforVitaltalkV1.0.pdf>

NURSE statements for articulating empathy / Three fundamental skills: <http://www.vitaltalk.org/sites/default/files/quick-guides/NURSEforVitaltalkV1.0.pdf>

Start the visit by building an agenda: <http://www.vitaltalk.org/sites/default/files/quick-guides/StartingWithAnAgendaV1.0.pdf>

Fundamental Communication Skills

[http://www.vitaltalk.org/sites/default/files/Oncotalk Fundamental Skills.pdf](http://www.vitaltalk.org/sites/default/files/Oncotalk_Fundamental_Skills.pdf)

## **Mindful language usage: Alternatives to stigmatizing and biased language**

Apatira L, Boyd EA, Malvar G, Evans LR, Luce JM, Lo B, White DB. Hope, truth, and preparing for death: Perspectives of surrogate decision makers. *Ann Intern Med.* 2008;149(12):861-8

Balboni TA, Balboni M, Enzinger AC, Gallivan K, Paulk ME, Wright A, Steinhauer K, Vander Weegle TJ, Prigerson HG. Provision of spiritual support to patients with advanced cancer by religious communities and associations with medical care at the end of life. *JAMA Intern Med.* 2013;173(12):1109-17.

Ira Byock. 1998. Dying well: Peace and possibilities at the end of life. New York :Riverhead Books.

Fallowfield, LJ, Jenkins, VA, Beveridge, HA. Truth may hurt but deceit hurts more: Communication in palliative care. *Palliat Med.* 2002;16(4):297-303.

Hancock K, Clayton JM, Parker SM, Wal der S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Haggerty R, Tattersall MH. Truth-telling in discussing prognosis in advanced life-limiting illnesses: A systemic review. *Palliat Med.* 2007;21(6):507-17.

Keating NL, Landrum MB, Rogers SO Jr, Baum SK, Virnig BA, Huskamp HA, Earle CC, Kahn KL. Physician factors associated with discussions about end-of-life care. *Cancer.* 2010;116(4):998-1006.

Mack JW, Cronin A, Keating NL, Taback N, Huskamp HA, Malin JL, Earle CC, Weeks JC. Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. *J Clin Oncol.* 2012;30(35):4387-95.

McDonagh JR, Elliott TB, Engelberg RA, Treece PD, Shannon SE, Rubenfeld GD, Patrick DL, Curtis JR. Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Crit Care Med.* 2004;32(7):1484-8.

Quill TE, Arnold R, Back AL. Discussing treatment preferences with patients who want "everything." *Ann Intern Med.* 2009;151(5):345-9.

Ramsaroop SD, Reid MC, Adelman RD. Completing an advance directive in the primary care setting: what do we need for success? *J Amer Geriatri Soc.* 2007;55(2):277-83.

Schumacher JD. Narrowing circle of hope. Available from <http://www.nhpco.org>. Accessed 9/11/17.

Workman S, NYT interview, "Plain Speaking at the End of Life." 12/14/11. <https://newoldage.blogs.nytimes.com/2011/12/14/plain-speaking-at-the-end-of-life/?mcubz=3> (accessed 1/16/17)

## **Palliative Care as a Human Right**

Barros de Luca, G., Zopunyan, V., Burke-Shyne, N., Papikyan, A., & Amiryan, D. (2017). Palliative care and human rights in patient care: an Armenia case study. *Public Health Reviews*, 38, 18-18. doi:10.1186/s40985-017-0062-7

Breitbart, W. (2011). Palliative care as a human right: update. *Palliat Support Care*, 9(4), 345-349. doi:10.1017/s1478951511000356

Center for Health and Human Rights. (2019). Chapter 5. Palliative Care. *Health and Human Rights Resource Guide (Vol. 2019)*. Cambridge, MA: Harvard University, Center for Health and Human Rights.

Daher, M. (2010). Pain relief is a human right. *Asian Pacific Journal of Cancer Prevention*, 11 Suppl 1, 97-101.

Gwyther, L. (2014). Palliative care as a human right. *Cancer Control*. Retrieved from <http://www.cancercontrol.info/wp-content/uploads/2014/08/116-121-Gwyther.pdf>

Hess, D. (2017) Privilege and palliative care. In. *Pallimed: Pallimed*.

Smith, G. P., Jr. (2011). Refractory pain, existential suffering, and palliative care: releasing an unbearable lightness of being. *Cornell Journal of Law and Public Policy*, 20(3), 469-532.

The Open Society Public Health Program. (2019). Palliative care as a human right. Retrieved from Open Society Foundations:  
file:///C:/Users/berkman/Dropbox/AAA/Data3/Palliative%20and%20End-of-Life%20Care/Articles%20and%20other%20resources/Open%20Society%20-%20Palliative%20care%20human%20right-fact-sheet-20160218.pdf

## Competencies and Standards for Palliative and Hospice Social Work

Gwyther, L. P., Altilio, T., Blacker, S., Christ, G., Csikai, E. L., Hooyman, N., Howe, J. (2005). Social work competencies in palliative and end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care*, 1(1), 87-120. doi:10.1300/J457v01n01\_06

NASW Standards for Palliative and End-of-Life Care

<https://www.socialworkers.org/practice/bereavement/standards/standards0504new.pdf>

National Hospice and Palliative Care Organization (NHPCO) Social Work Competencies

<http://www.nhpc.org/social-work-competencies>

Canadian Social Work Competencies for Hospice Palliative Care: A Framework to Guide Education and Practice at the Generalist and Specialist Levels

[http://www.chpca.net/media/7868/Social\\_Work\\_Competencies\\_July\\_2009.pdf](http://www.chpca.net/media/7868/Social_Work_Competencies_July_2009.pdf)

Core competencies for palliative social work in Europe: an EAPC White Paper – part 1

[http://www.eapcnet.eu/Portals/0/Clinical/Publications/EJPC21\(6\)\\_Hughes\\_White\\_Paper.pdf](http://www.eapcnet.eu/Portals/0/Clinical/Publications/EJPC21(6)_Hughes_White_Paper.pdf)

Core competencies for palliative social work in Europe: an EAPC White Paper – part 2

[http://www.eapcnet.eu/Portals/0/Clinical/Publications/EJPC22\(1\)Hughes\\_part2.pdf](http://www.eapcnet.eu/Portals/0/Clinical/Publications/EJPC22(1)Hughes_part2.pdf)

## Post-MSW Medical Center-Based Fellowships

PROGRAM	DESCRIPTION
<p>Harvard Medical School, Center for Palliative Care</p>	<p><b>Pediatric Palliative Care Fellowship</b></p> <p>Pediatric Advanced Care Team (PACT), the pediatric palliative care service at Boston Children’s Hospital and the Dana Farber Cancer Institute, is offering a full-time, year-long social work fellowship.</p> <p>PACT is an inter-professional team that supports the treatment of underlying illness while maximizing the quality of life in children with serious medical conditions. Through a family-centered approach PACT promotes healing, comfort and making childhood experiences meaningful. The team includes physicians, nurse practitioners and social workers and works closely with chaplains, communication specialists, psychologists, child life specialists, social workers, etc.</p> <p>As the premier Pediatric Palliative Care Social Work Fellowship in the country, this training program provides the opportunity to participate in an intensive clinical and didactic training experience. The fellow will work closely with our Medical and Nurse Practitioner fellows and will receive social work specific and inter-professional palliative care training. The fellow will have the opportunity to work with patients and their families as well as facilitate and administer the PACT bereavement program. This includes facilitating and administering a parent/sibling bereavement group. There will be opportunities to gain knowledge and experience with related community resources, hospice and bereavement services.</p> <p>PACT provides inpatient and outpatient care as well as support in the community and home settings. The fellow functions as part of an inter-professional team and is responsible for consultation with other medical providers. The fellowship experience includes academic responsibilities such as grand rounds and a quality improvement project.</p> <p>Fellows receive two hours of supervision per week. The fellow will have the opportunity to attend PACT educational rounds featuring inter-professional experts in the field of Pediatric Palliative Care and will participate in the Harvard Medical School Inter-Professional Palliative Care Fellowship Program.</p> <p>All social work fellows at Children's participate in didactic seminars and a fellows’ discussion group.</p> <p>This is an opportunity to work with one of the first pediatric palliative care teams in the country.</p> <p>Compensation is full-time salary plus benefits. Fellowship begins July 1, and ends June 30.</p> <p><a href="http://www.childrenshospital.org/clinician-resources/education-and-training/social-work-training-program/social-work-fellowships">http://www.childrenshospital.org/clinician-resources/education-and-training/social-work-training-program/social-work-fellowships</a></p>

PROGRAM	DESCRIPTION
<p>MedStar Washington Hospital Center</p>	<p><b>Palliative Care Social Work Fellowship</b></p> <p>By the end of the year, the Social Work Fellow will demonstrate competency in a number of domains, including but not limited to:</p> <ul style="list-style-type: none"> <li>• Grief, loss, and bereavement support</li> <li>• Advance care planning</li> <li>• Spiritual, religious, existential and cultural aspects of care</li> <li>• Assessing and treating for total pain</li> <li>• Assessing and completing comprehensive psychosocial assessments</li> </ul> <p><i>Program Highlights:</i></p> <ul style="list-style-type: none"> <li>• Unique interprofessional curriculum taught by expert palliative care faculty</li> <li>• Accelerated development of evidence-based clinical competences with a high degree of supervised independence</li> <li>• Structured training and mentorship from experienced palliative care clinicians, including four social workers</li> <li>• Clinical Supervision for licensing</li> <li>• Clinical rotations across hospice and palliative care settings</li> <li>• Preparation to sit for the Advanced Palliative Hospice Social Worker – Certified (APHSW-C) exam</li> <li>• Stipend and benefits provided</li> </ul> <p>Contact: Anne Kelemen, LICSW,  <a href="mailto:anne.m.kelemen@medstar.net">anne.m.kelemen@medstar.net</a>  <a href="https://www.medstarhealth.org/education/affiliated-hospitals-2/medstar-washington-hospital-center/palliative-medicine-fellowship/palliative-social-work-fellowship/">https://www.medstarhealth.org/education/affiliated-hospitals-2/medstar-washington-hospital-center/palliative-medicine-fellowship/palliative-social-work-fellowship/</a></p>
<p>Montefiore Medical Center</p>	<p><b>Palliative Care Social Work Fellowship Program</b></p> <p>The Montefiore Medical Center Social Work Palliative Care Fellowship focuses on both clinical skills and on preparing the Fellows to play a leadership role. The Fellow participates in orientation and educational opportunities, including weekly didactics, interdisciplinary meetings, journal club, research/quality improvement meetings, complex case discussions, psychosocial oncology rounds, roundtable discussions and grand rounds. The Fellow completes clinical rotations at the Montefiore Palliative Care Inpatient Unit, inpatient consults at Montefiore Medical Center’s Moses, Einstein and Wakefield divisions, outpatient Oncology Clinic, outpatient Palliative Care Clinic, and MJHS Hospice.</p> <p><a href="https://www.einstein.yu.edu/departments/family-social-medicine/education/fellowships/palliative-care-social-work-fellowship-program/">https://www.einstein.yu.edu/departments/family-social-medicine/education/fellowships/palliative-care-social-work-fellowship-program/</a></p>

PROGRAM	DESCRIPTION
<p>Mount Sinai Beth Israel</p>	<p><b>Social Work Fellowship in Palliative and End-of-Life Care</b></p> <p>Mount Sinai Beth Israel’s Department of Geriatrics and Palliative Medicine offers a one-year postgraduate Social Work Fellowship in palliative and end-of-life care. The training program provides experience in multidimensional assessment and interventions with patients and families, in multiple practice sites (inpatient consultation service, an ambulatory practice, an inpatient palliative care and hospice unit, and home-based palliative care) along the continuum of serious illness. A focus on policy and education will be complemented by site visits to the Center for the Advancement of Palliative Care (CAPC). Supervision and consultation is provided by Jennifer DiBiase, LCSW-R.</p> <p>Fellows participate in interdisciplinary rounds, case discussions, journal clubs, didactic conferences and departmental meetings with the focus on the multidimensional nature of palliative and end-of-life care integrating psychosocial, spiritual, cultural and ethical aspects, team and institutional dynamics. Fellows are expected to submit abstracts with the goal of presenting their work at a national conference. Learning is complemented by access to interdisciplinary experts and resources as well as quarterly didactic sessions led by Terry Altilio, LCSW.</p> <p>Designed by Terry Altilio to develop specialist clinicians, leaders, and mentors, the social work fellowship was originally established with a grant from the Open Society Institute Project on Death in America (PDIA)’s Social Work Leadership Award and supported for many years by generous support through the Barbara Zirinsky Fund. The current fellowship position being offered is funded by a bequest from the estate of Barbara Ross. The position is offered on a full-time basis for one year and includes stipend and benefits.</p> <p>Deadline for completed applications is <b>March 13, 2020</b> with fellowship year to begin July 1, 2020. <b>Please refer to attachment for the application.</b></p> <p>For more information about the clinical goals, focus and details of the fellowship, please contact:</p> <p>Jennifer DiBiase, LCSW-R, APHSW-C  Palliative Care Social Work Manager  Mount Sinai Beth Israel  Office: 212-844-1777  Fax: 212-844-1503  <a href="mailto:Jennifer.DiBiase@mountsinai.org">Jennifer.DiBiase@mountsinai.org</a></p>



University of  
Minnesota  
Medical  
Center

### **Palliative Care Clinical Social Work Fellowship Program**

- Palliative Care Program at the University of Minnesota Medical Center provides a rich learning environment for a variety of learners in the medical professions
  - The clinical social work fellowship runs concurrently with the palliative medicine fellowship
  - Clinical rotations with the inpatient consult service are offered to medical students, residents, and fellows in other medical specialties. Specialized training in Palliative Care is also offered to chaplains and students in advanced practice nursing programs. Master of Social Work interns are offered field placement with the service as well.
- Palliative Care Clinical Social Work Fellowship Program
  - postgraduate Clinical Social Work Fellowship in Palliative Care is offered through the Palliative Care Program of the University of Minnesota Medical Center, Fairview
  - fellowship is a training program that is part of a set of comprehensive palliative care clinical services and interdisciplinary professional training services
  - Supervised clinical social work experience is provided on an inpatient interdisciplinary consultation service and in an outpatient palliative care clinic
  - additional learning opportunities are available based on the fellow's experience and areas of professional interest
  - fellow participates in palliative care team rounds and case discussions, teaching rounds, fellow didactics, journal club, palliative care trainings, and department planning meetings
  - program is designed to train leaders in palliative care clinical social work, with an emphasis on advocacy.
  - fellowship is fulltime for 12 months. cycle begins July 1, 2015, and ends June 30, 2016
  - expected that the fellow will choose and develop a clinical project that have direct and/or indirect benefit to patients and families and should include an educational component for other staff.
  - Eligibility: Masters in Social Work degree from an accredited school of social work by the time the fellowship begins
  - applicant must demonstrate interest in the area of palliative care and intent to use the fellowship training not only to increase her/his skills in clinical social work in the area of palliative care but also to contribute to the field and improve services to patients and their families
  - fellow must be licensed to practice social work in the state of Minnesota (at the LGSW, LISW, or LICSW level) before the start of the fellowship.
  - Stipend: 12-month, fulltime fellowship includes a stipend of \$29,000 and benefits, including Paid Time Off (accrued at 7.4 hours per two week full time pay period) and health insurance (toward which the fellow must contribute, amount depending on the option chosen).
  - Applicants... A small group of finalists will be asked to interview for the fellowship in late April/early May. A final decision for awarding the fellowship will be made by mid-May.

Contact: Brooke Kaney, MSW, LICSW  
Coordinator and Clinical Supervisor

Flyer: [https://www.une.edu/sites/default/files/fellowship\\_flyer.pdf](https://www.une.edu/sites/default/files/fellowship_flyer.pdf)

Application: [https://www.fairview.org/fv/groups/internet/documents/web\\_content/s\\_106120.pdf](https://www.fairview.org/fv/groups/internet/documents/web_content/s_106120.pdf)

Department  
of Veterans  
Affairs

## Interprofessional Fellowships in Palliative Care

Department of Veterans Affairs is offering one-year fellowships in palliative care at six sites in 2002. Beginning between July and September 2002, each of the six training sites will be selecting up to four 1-year (or the equivalent) fellows / trainees. At least one, and no more than two of these fellows may be a physician at each of the sites. Each selected site will select one to three associated health (non-physician) fellow/trainee positions in disciplines involved in the practice of palliative care, e.g. nursing, social work, pharmacy, psychology and chaplaincy. The training for associated health disciplines may be for a period of 1-year or less depending on the discipline and the curriculum plan.

The purpose of this VA fellowship program is to develop leaders with vision, knowledge, and commitment to lead palliative care into the 21st century as well as to increase recruitment and retention of these specialists for the Veterans Health Administration. There is no obligation to work for VA after completion of the program. Annual salary varies by site and discipline

- National network of six Interprofessional Palliative Care Fellowship programs was funded in 2002 by the Department of Veterans Affairs
- Provides advanced training in hospice and palliative care to social workers, physicians, nurses, psychologists, chaplains and pharmacists
- Eligibility: Master's Prepared Social Workers from a CSWE accredited program

For further information contact the director of training at the sites listed below:

Palo Alto, California

James Hallenbeck, MD, Director, [James.Hallenbeck@med.va.gov](mailto:James.Hallenbeck@med.va.gov)

Bronx, New York

Judith Howe, PhD, Director, [Judy.Howe@mssm.edu](mailto:Judy.Howe@mssm.edu)

<https://www.nynj.va.gov/docs/greccpallfellapp.pdf>

Los Angeles, California

Kenneth Rosenfeld, MD, Director, [Kenneth.Rosenfeld@med.va.gov](mailto:Kenneth.Rosenfeld@med.va.gov)

Milwaukee, Wisconsin

Marcos Montagnini, MD, Director, [Marcos.Montagnini@med.va.gov](mailto:Marcos.Montagnini@med.va.gov)

Portland, Oregon

Nora Tobin, MD, Director, [Nora.Tobin@med.va.gov](mailto:Nora.Tobin@med.va.gov)

San Antonio Texas

Meghan Gerety, MD, Director, [Meghan.Gerety@med.va.gov](mailto:Meghan.Gerety@med.va.gov)

Hub Site Information

James Hallenbeck, MD

VA Palo Alto HCS

3801 Miranda Ave.

Palo Alto, California 94304

Phone: (650) 493-5000, ext. 63631

Fax: (650) 849-0260

PROGRAM	DESCRIPTION
	<a href="http://www.mywhatever.com/cifwriter/content/33/466.html">http://www.mywhatever.com/cifwriter/content/33/466.html</a> <a href="http://www.paloalto.va.gov/docs/MentalHealth/PsychologyTraining/Palliative_Care_Emphasis_Area.pdf">http://www.paloalto.va.gov/docs/MentalHealth/PsychologyTraining/Palliative Care Emphasis Area.pdf</a>

## Post-MSW Certificate Programs

PROGRAM	DESCRIPTION
<p>NYU</p>	<p><b>Zelda Foster Studies</b></p> <p>POST-MASTERS CERTIFICATE PROGRAM</p> <ul style="list-style-type: none"> <li>• one-year program</li> <li>• provides integrated sequence of courses to combine theory and practice in PELC and to increase practice skills</li> <li>• Social workers with at least two years of post-master’s experience in or related to PELC are eligible to apply</li> </ul> <p>POST-MASTERS LEADERSHIP FELLOWSHIP</p> <ul style="list-style-type: none"> <li>• Goal: to improve palliative and end-of-life care for patients and families, especially under-served populations, through the development of a cadre of MSW PELC leaders</li> <li>• includes one year of one-on-one mentoring from an experienced PELC leader</li> <li>• capstone project is required</li> <li>• Social workers with at least five years of post-master’s experience in or related to palliative and end-of-life care are eligible to apply.</li> </ul> <p><a href="http://socialwork.nyu.edu/academics/zelda-foster-studies.html">http://socialwork.nyu.edu/academics/zelda-foster-studies.html</a></p>
<p>Shiley Institute for Palliative Care, California State University</p>	<p><b>Post-MSW Palliative Care Certificate</b></p> <ul style="list-style-type: none"> <li>• to foster the palliative care workforce needed to care for our aging population</li> <li>• first, and only, fully online Post MSW Certificate in Palliative Care</li> <li>• provides Master’s prepared social workers with the additional knowledge and skills they need to work effectively on a palliative care team in a hospital, hospice or other setting. Three course levels totaling 180 classroom hours comprise the program, each building upon the last.</li> <li>• Continuing Education Hours: 144 Hours</li> </ul> <p><a href="http://csupalliativecare.org/programs/postmswcertificate">http://csupalliativecare.org/programs/postmswcertificate</a>  <a href="http://csupalliativecare.org/postmswannounced/">http://csupalliativecare.org/postmswannounced/</a></p>

PROGRAM	DESCRIPTION
Smith College	<p><b>Palliative Care Post Graduate Certificate Program</b></p> <ul style="list-style-type: none"> <li>• for social workers working in hospice, medical social work, bereavement and in palliative care</li> <li>• draws national and international practitioners who meet on Smith’s campus for two long weekends (Oct.15-18 and April 7-10) during which social work practitioners take courses on: <ul style="list-style-type: none"> <li>○ advanced practice I and II</li> <li>○ leadership</li> <li>○ psychological theories of grief and bereavement</li> <li>○ pain and symptom management</li> <li>○ diversity</li> <li>○ spirituality I and II</li> <li>○ issues in hospice and palliative care</li> <li>○ childhood bereavement</li> <li>○ legal and ethical issues</li> <li>○ practice with gays and lesbians</li> <li>○ cross cultural issues</li> <li>○ compassion fatigue</li> </ul> </li> <li>• Coursework is taught by national leaders in the field</li> <li>• six -month clinical internship in the student’s work setting <ul style="list-style-type: none"> <li>○ participants identify 2 - 3 study cases</li> <li>○ where possible students take leadership in their settings: teaching, creating groups, providing training and presenting at conferences.</li> <li>○ Students receive individual clinical telephonic supervision every other week from outstanding practitioners in the field and also receive group clinical telephonic supervision from an instructor in the program</li> </ul> </li> </ul> <p><a href="http://www.smith.edu/ssw/acad_cont_graduate_elc.php">http://www.smith.edu/ssw/acad_cont_graduate_elc.php</a></p>
University of Maryland, Graduate School	<p><b>Post Graduate Certificates</b></p> <p>Participants can apply to earn a Graduate Certificate titled “Principles and Practice of Hospice and Palliative Care.” The certificate can be earned as the terminal credential, or as part of the Master of Science degree. The certificate is earned by completing the first four courses in the Master of Science degree. There are four additional Post-graduate certificates that may be earned, each 12 credits (four, 3-credit courses) including:</p> <ul style="list-style-type: none"> <li>• Clinical Aspects of Hospice and Palliative Care</li> <li>• Leadership and Administration in Hospice and Palliative Care</li> <li>• Psychosocial/Spiritual Aspects of Hospice and Palliative Care</li> <li>• Aging and Applied Thanatology</li> <li>• Principles and Practice of Hospice and Palliative Care</li> </ul> <p><a href="https://graduate.umaryland.edu/palliative/About-the-Program/">https://graduate.umaryland.edu/palliative/About-the-Program/</a></p> <p><a href="http://www.mlmcperson.com/umb-ms-palliative-care.html">http://www.mlmcperson.com/umb-ms-palliative-care.html</a></p>

PROGRAM	DESCRIPTION
University of Washington	<p><b>Graduate Certificate in Palliative Care</b></p> <p>An interprofessional curriculum designed for practicing healthcare professionals from nursing, medicine, social work, spiritual care, and other discipline seeking specialty training in palliative care. This 9-month certificate is specifically designed for busy working professionals who want specialty training in palliative care communication, interprofessional practice, and system change and program sustainability. The in-depth, applied training is in: 1) Person-centered communication skills; 2) Interprofessional team training; 3) Leadership and program development.</p> <p>Additional information is on our website: <a href="http://www.uwpctc.org">www.uwpctc.org</a>. The application is available <a href="http://uwpctc.org/application/">http://uwpctc.org/application/</a>.</p> <p>Flyer: <a href="file:///C:/Users/berkman/Dropbox/AAA/Data3/Palliative%20and%20End-of-Life%20Care/Fellowships%20&amp;%20Certificate%20Programs/Univ%20of%20Washington%20-%20PC%20Research%20Post-doc/Flyer%20PEDS%20Feb%202020%20(1)%20(1).pdf">file:///C:/Users/berkman/Dropbox/AAA/Data3/Palliative%20and%20End-of-Life%20Care/Fellowships%20&amp;%20Certificate%20Programs/Univ%20of%20Washington%20-%20PC%20Research%20Post-doc/Flyer PEDS Feb 2020%20(1)%20(1).pdf</a></p> <p>Contact Dani Brace, MPH  Program Manager, UW Graduate Certificate in Palliative Care  University of Washington School of Nursing  <a href="mailto:dbrace@uw.edu">dbrace@uw.edu</a>  206-616-1963</p>

## Post-MSW Research Fellowships

PROGRAM	DESCRIPTION
<p>NewCourtland Center for Transitions and Health at the University of Pennsylvania School of Nursing and the Department of Family and Community Medicine in the School of Medicine at the University of Missouri</p>	<p><b>Postdoctoral Fellowship in Hospice and Palliative Care</b></p> <p>The NewCourtland Center for Transitions and Health at the University of Pennsylvania (Penn) School of Nursing and the Department of Family and Community Medicine in the School of Medicine at the University of Missouri (MU) one-year postdoctoral fellowship (with potential reappointment for a second year) with an emphasis on hospice and palliative care research. The fellowship will provide a variety of research experiences relevant to healthcare and social supports provided to seriously ill patients and their families. Fellows will have the opportunity to become involved in ongoing federally-funded studies testing behavioral interventions to support family caregivers of patients with advanced illnesses in addition to receiving mentorship in advancing the fellow's own complementary but independent line of research in preparation for future entry into an academic position.</p> <p>Contact: <a href="mailto:gdemiris@upenn.edu">gdemiris@upenn.edu</a></p>

## Specializations in MSW Programs

PROGRAM	DESCRIPTION
Boston College School of Social Work	<p>Interdisciplinary Palliative Care Certificate (IDPCC)</p> <p>This certificate program aims to provide graduate students from nursing, social work, and theology and ministry with:</p> <ul style="list-style-type: none"> <li>• Knowledge of the core principles of palliative care across disciplines;</li> <li>• Appreciation and respect for the unique and complementary contributions of each discipline in collaborative care; and</li> <li>• Comprehension of the interdisciplinary processes needed to care for seriously ill persons and their families throughout the illness trajectory and across care settings.</li> </ul> <p>The IDPCC certificate would be granted by Boston College (not the respective schools) upon completion of four courses, for a total of 12 credits.</p> <p>There is no field requirement.</p> <p><a href="https://www.bc.edu/bc-web/schools/ssw/bcssw-news/2019/interdisciplinary-palliative-care-certificate-program.html">https://www.bc.edu/bc-web/schools/ssw/bcssw-news/2019/interdisciplinary-palliative-care-certificate-program.html</a></p> <p><a href="https://www.bc.edu/content/dam/bc1/schools/sw/MSW%20Program/IDPCC-Info-for-SSW.pdf">https://www.bc.edu/content/dam/bc1/schools/sw/MSW%20Program/IDPCC-Info-for-SSW.pdf</a></p>
Fordham University Graduate School of Social Service	<p>Palliative Care Fellowship</p> <p>Fellowship includes:</p> <ul style="list-style-type: none"> <li>• Field placement in palliative care or hospice</li> <li>• Career Mentor</li> <li>• Two half-day workshops on ethical issues in palliative</li> <li>• Dedicated Integrative Seminar for Palliative Care Fellows</li> <li>• Free enrollment in continuing education classes in the Palliative Care continuum at Fordham University</li> <li>• Take Palliative Social Work course in the Fall semester and the Grief, Loss, and Bereavement course during the Spring semester</li> <li>• Monthly lunch meetings with Dr. Berkman</li> <li>• Tuition remission</li> <li>• Support for attending SWHPN annual assembly and a local conference</li> </ul> <p><a href="https://www.fordham.edu/homepage/6659/palliative_care_fellowship">https://www.fordham.edu/homepage/6659/palliative_care_fellowship</a></p>



PROGRAM	DESCRIPTION
NYU, Silver School of Social Work	<p>Zelda Foster Studies in Palliative and End-of-Life Care</p> <p><a href="https://socialwork.nyu.edu/academics/zelda-foster-studies.html">https://socialwork.nyu.edu/academics/zelda-foster-studies.html</a></p> <p>A four-year program, the Zelda Foster MSW Fellowship in PELC begins in the final year of the MSW program and continues for three years at the post-MSW level. It includes specialized field placements, two years of post-graduate mentoring, and funding for professional development. Students at NYU Silver entering their final year of the MSW program are eligible to apply.</p>
University of Iowa, School of Social Work	<p>End-of-Life Care Field of Practice</p> <p>The School of Social Work developed its innovative End-of-Life Care Field of Practice to foster social work leadership in the important work of providing services in end-of-life care, palliative care, and bereavement. The coursework prepares students for practice in hospice programs and in hospital social work in pediatric and adult oncology, palliative care units, long term care facilities and other social work settings focused on the needs of individuals at the end of life, their families and bereaved individuals. It is based on the family-centered and community-based principles which permeate the entire curriculum in the MSW Program.</p> <p>Advanced Practicum in End-of-Life Care, Palliative Care, or Bereavement Services is required.</p> <p><a href="https://clas.uiowa.edu/socialwork/graduate-program/end-life-care-field-practice">https://clas.uiowa.edu/socialwork/graduate-program/end-life-care-field-practice</a></p>
University of Louisville, The Kent School	<p>Specialization in Psychosocial Oncology</p> <p><a href="https://louisville.edu/kent/academics/specializations/psychosocial-oncology">https://louisville.edu/kent/academics/specializations/psychosocial-oncology</a></p> <p>This specialization offers:</p> <ul style="list-style-type: none"> <li>• A one-year practicum in a cancer care setting or health care organization</li> <li>• Two integrative seminars concurrent with Advanced practicums (SW 649 &amp; SW 650)</li> <li>• Two psychosocial oncology practice courses &amp; one course in: SW &amp; Human Sexuality, Death &amp; Dying, Spirituality &amp; SW, or Intro to Epidemiology</li> <li>• Opportunity to participate in iCOPE, an interdisciplinary oncology palliative care curriculum</li> <li>• Distance-learning Courses</li> <li>• Certificate in Psychosocial Oncology</li> </ul> <p>Assistance in securing a job after graduation</p>

PROGRAM	DESCRIPTION
University of Washington School of Social Work	<p data-bbox="337 220 779 254">Carol LaMare Scholars Program</p> <p data-bbox="337 304 1230 338"> <a href="https://socialwork.uw.edu/programs/carol-lamare-scholars-program">https://socialwork.uw.edu/programs/carol-lamare-scholars-program</a> </p> <p data-bbox="337 384 1442 541">           The Carol LaMare Scholars Program supports education and research efforts in oncology social work and palliative care for people with cancer and other life-threatening conditions. In the last decade, the program has become a national model for classroom innovation in the field of oncology medical social work.         </p> <p data-bbox="337 594 1481 793">           The program features a robust network of field education placements with local hospice, palliative care and cancer care centers—as well as research opportunities for affiliated scholars. A unique learning component is the yearlong clinical seminar, which provides intensive mentoring for MSW students through case discussion, expert presentations and self-reflective practices.         </p>
Yeshiva University, Wurzweiler School of Social Work	<p data-bbox="337 802 1031 835">Certificate in Gerontology and Palliative Care Practice</p> <p data-bbox="337 882 1198 953"> <a href="https://www.yu.edu/sites/default/files/inline-files/Gerontology%20and%20Palliative%20Care%20Certificate.pdf">https://www.yu.edu/sites/default/files/inline-files/Gerontology%20and%20Palliative%20Care%20Certificate.pdf</a> </p>

## Non-MSW Graduate Programs in Palliative Care

PROGRAM	DESCRIPTION
University of Colorado, Denver	<p><b>Master of Science in Palliative Care</b></p> <p>The Palliative Care Masters consists of 36-credits of coursework designed to be completed in 24 months of continuous study. Students may choose flexible completion options, but note that courses are currently offered once per academic year. All students complete interdisciplinary coursework in palliative care core concepts, communications, teamwork and leadership, community integration, assessment of pain and non-pain symptoms, and diverse topics related to the psycho-social-spiritual-ethical dimensions of patient and family care. Core and track curricula focus on evidence-based practices in diverse palliative care settings. The MS degree is open to students in the following two tracks:</p> <ul style="list-style-type: none"> <li>• MSPC Biomedical Track</li> <li>• MSPC Allied Health Professional Track</li> </ul> <p><a href="https://www.ucdenver.edu/academics/colleges/Graduate-School/academic-programs/Palliative%20Care/About/Pages/palliative-care-masters.aspx">https://www.ucdenver.edu/academics/colleges/Graduate-School/academic-programs/Palliative%20Care/About/Pages/palliative-care-masters.aspx</a></p> <p><b>Interprofessional Graduate Certificate in Palliative Care</b></p> <p>The Palliative Care Certificate is a 12-credit hour courseload for students seeking additional palliative care education, but not ready to commit to completing the Masters degree. Students complete the first 12 credit hours of the MS program over two semesters of study. The certificate is open to students in the following two tracks:</p> <ul style="list-style-type: none"> <li>• MSPC Biomedical Track</li> <li>• MSPC Allied Health Professional Track</li> </ul> <p><a href="https://www.ucdenver.edu/academics/colleges/Graduate-School/academic-programs/Palliative%20Care/About/Pages/palliative-care-certificate.aspx">https://www.ucdenver.edu/academics/colleges/Graduate-School/academic-programs/Palliative%20Care/About/Pages/palliative-care-certificate.aspx</a></p>
University of Maryland	<p>Palliative Care Online Masters and Graduate Certificate</p> <p>The 30-credit interprofessional Master of Science in Palliative Care is completely online and can be completed in five semesters or at your own pace. In addition to the Masters of Science, the University of Maryland Graduate School has five Graduate Certificates that focus in Palliative Care including Clinical Aspects of Hospice and Palliative Care, Leadership and Administration on Hospice and Palliative Care, Psychosocial/Spiritual Aspects of Hospice and Palliative Care, and Aging and Applied Thanatology.</p> <p>These programs have been designed to meet the educational needs of individuals who are currently working or who wish to work in hospice and palliative care and want to gain a deeper understanding of the physical, psychological, spiritual and social needs of patients and families affected by serious illness.</p> <p><a href="https://graduate.umaryland.edu/palliative/">https://graduate.umaryland.edu/palliative/</a></p>

## Classes

### Continuing Education

#### Graduate School of Social Service, Fordham University

#### Check Website for Current Schedule

#### Classes offered online and in-person\* (\*will resume following pandemic)

CLASS	# CEHs
Choice in Dying: Current Legal, Policy and Ethical Issues	4
Clinical Work with Demoralization in Serious Illness	2.5
Grief, Loss and Bereavement – Part 1: Introduction and Framework	5
Grief, Loss and Bereavement – Part 2: Impact of Loss <i>Prerequisite: Part 1</i>	5
Grief, Loss and Bereavement – Part 3: Intervention <i>Prerequisite: Part 1</i>	5
Health Literacy: Assessing and Addressing with Clients	3
Hospice Social Work	3
Cultural Humility in Working with Individuals with Serious Illness	2
Health Literacy: Assessing and Addressing with Clients	4
Communicating with Clients Who Have Life-Limiting or Chronic Illnesses	3
Pediatric Palliative Care for Social Workers	4
A Palliative Approach to Dementia Care	4
Palliative Social Work with Family Caregivers	3
Social Work in Palliative and End-of-Life Care <i>This is a single class scheduled on two Saturdays.</i>	8
Providing LGBT-Inclusive Palliative Care from Diagnosis through End-of-Life	3
The Final Days of Life: The Social Worker's Role	3

California State University, Shiley Institute for Palliative Care  
Offers online webinars.  
<https://csupalliativecare.org/organizations/what-every/social-worker/>

City of Hope  
Interprofessional Communication Curriculum  
  
<https://www.cityofhope.org/ICC>

ALL PARTICIPANTS RECEIVE:  
FREE Registration  
14.5 CEs  
Up to \$600 Lodging Stipend  
Course Materials  
1 Year Online Curriculum Access

Social Work Hospice and Palliative Care Network  
Offers online webinars. Most classes are 1 CE.  
<https://swhpn.mclms.net/en/>

Stanford Center for Continuing Medical Education  
Offers online webinars.  
[https://stanford.cloud-cme.com/default.aspx?P=3000&EID=35110&mc\\_cid=53dd803107&mc\\_eid=096d87374f](https://stanford.cloud-cme.com/default.aspx?P=3000&EID=35110&mc_cid=53dd803107&mc_eid=096d87374f)

## Classes (Not for CE Credit)

### End-of-Life Essentials

The education modules are designed to assist doctors, nurses and allied health professionals working in acute hospitals in delivering end-of-life care. They are free to use. The following ten modules are now available.

1. Chronic Complex Illness End-of-Life Care
2. Dying, a normal part of life
3. Emergency Department End-of-Life Care
4. Imminent Death - How to Respond
5. Paediatric End-of-Life Care
6. Patient-centered communication and shared decision-making
7. Planning end-of-life care - Goals of care
8. Recognising the end-of-life
9. Responding to Concerns
10. Teams and continuity for the patient

## Websites for Adults

American Association of Retired Persons (AARP)

[www.aarp.org](http://www.aarp.org)

Advance Care Planning <https://search.aarp.org/gss/everywhere?q=advance%20care%20planning>

Grief <https://search.aarp.org/gss/everywhere?q=grief>

Palliative Care <https://search.aarp.org/gss/everywhere?q=palliative%20care>

Courageous Parents Network

<https://courageousparentsnetwork.org/>

CPN is a destination created by parents, for parents, to support, guide and strengthen families as they care for a seriously ill child. Here you will find wisdom from fellow parents and pediatric care providers to help you be the best parent you can be to your child and children—and get through each moment.

Anticipatory Grief

<https://courageousparentsnetwork.org/guided-pathways/anticipatory-grief/>

Get Palliative Care

<https://getpalliativecare.org>

Resources for patients and family caregivers, as well as clinicians and policymakers. The website has videos, podcast, webinars, links, and other resources.

I Had Cancer

<https://www.ihadcancer.com/>

“How it Works

Connect

Connect with real people who understand exactly what you mean-whether in your neighborhood or across the world.

Share

Discover thousands of shared experiences and contribute yours to a community of shared strength.

Thrive

Let others fuel you with inspiration and embrace the proof that you are not alone before, during or after a cancer diagnosis.”

Visible Ink

<https://www.mskcc.org/experience/patient-support/activities/writing-visible-ink>

“Visible Ink offers Memorial Sloan Kettering patients the opportunity to express themselves in writing with the individual support of an experienced writing mentor. Our mission is to promote creativity, stress reduction, and personal empowerment for people diagnosed with cancer. While Visible Ink operates under the aegis of MSK, our sole funding is through grants and donations. This program is free to participants. Learn more about giving to [Visible Ink](#).”

## Sources for Children

Doughty, C., & Ruz, D. (2019). *Will my cat eat my eyeballs? Big questions from tiny mortals about death*. New York: W.W. Norton & Co.

Garrett, C. (2019). *My love will follow you there: Calming imagery for children facing death*. Issuu. <https://www.carlagarrett.ca/mylovewillfollowyouthe...>

Glader, S. (2011). *Nowhere Hair: Explains your cancer and chemo to your kids* Thousand Words Press

Long, L. (2015). *Little tree*. New York: Philomel Books.

For graduates, for their parents, for anyone facing change, here is a stunningly heartfelt ode to the challenges of growing up and letting go. A story as poignant for parents as for their kids, from the creator of Otis the tractor and illustrator of The Little Engine that Could.

Age Range: 5 - 8 years

Grade Level: Kindergarten - 3

Mellonie, B., & Ingpen, R. (1983). *Lifetimes: A beautiful way to explain death to children*. New York: Bantam Book.

*Lifetimes* is a moving book for children of all ages, even parents too. It lets us explain life and death in a sensitive, caring, beautiful way. *Lifetimes* tells us about beginnings. And about endings. And about living in between. With large, wonderful illustrations, it tells about plants. About animals. About people. It tells that dying is as much a part of living as being born. It helps us to remember. It helps us to understand.

Mills, J. (2003). *Gentle willow: A story for children about dying* (2nd ed.): Magination Press.

Written for children who may not survive their illness or for the children who know them, this tale helps address feelings of disbelief, anger, and sadness, along with love and compassion. Amanda and Little Tree discover that their friend Gentle Willow isn't feeling very well.

Age Range: 4 - 8 years

Grade Level: Preschool – 3

Nilon, C. (2007). *Chemo cat*: Ravenna Press.

Silver, M., & Silver, M. (2013). *My parent has cancer and it really sucks*: Sourcebooks Fire.

Link to site for ordering book: <http://www.parenthascancer.com/>

Book review: <http://health.usnews.com/health-news/health-wellness/articles/2013/09/20/how-to-help-teens-cope-with-a-parents-cancer>

Available at Westchester Campus Library RC264.S52 2013

Weaver, M., Wiener, L., & Butterley, M. (2019). *The gift of Gerbert's feathers*. Washington, DC: Magination Press.

## Sources for Teens

Helping Teenagers When a Parent Has Cancer

<http://www.cancercares.org/publications/51-helping-teenagers-when-a-parent-has-cancer>

Memorial Sloan-Kettering Cancer Center teen-oriented materials:

<http://www.mskcc.org/cancer-care/patient-education/resources/teens-who-have-parent>

Ness, P. (2011). *A Monster Calls*: Candlewick.

Stupid Cancer

<https://stupidcancer.org/>

Stupid Cancer offers a lifeline to the young adult cancer community by connecting them to age-appropriate resources and peers who get it. Our mission is to empower adolescents and young adults affected by cancer by ending isolation and building community.

When Your Parent Has Cancer: A Guide for Teens:

<http://www.cancer.gov/cancertopics/coping/When-Your-Parent-Has-Cancer.pdf>

## Books for Lay Persons (and Professionals!)

Agell, C., & Ramírez, A. (2019). *Maybe tomorrow?* Scholastic Press.



- Becker, E. (1973). *The denial of death*. New York: Free Press.
- Butler, K. (2014). *Knocking on heaven's door: The path to a better way of death*. New York: Scribner.
- Butler, K. (2020). *The art of dying well: A practical guide to a good end of life*. New York: Scribner.
- 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.
- Callanan, M., & Kelley, P. (2012). *Final gifts: Understanding the special awareness, needs, and communications of the dying* Simon & Schuster.
- Chapple, H. S. (2010). *No place for dying: Hospitals and the ideology of rescue* (1st ed.). Walnut Creek, CA: Left Coast Press.
- Cowan, R., & Thal, L. (2015). *Wise aging: Living with joy, resilience & spirit*. Springfield, NJ: Behrman House.
- Devine, M. (2018). *It's ok that you're not ok: Meeting grief and loss in a culture that doesn't understand*. Sounds True.
- 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.
- Fadiman, A. (2012). *The spirit catches you and you fall down: A Hmong Child, her American doctors, and the collision of two cultures* (2nd ed.). New York: Farrar, Straus, and Giroux.
- Fins, J. J. (2006). *A palliative ethic of care: Clinical wisdom at life's end*. Sudbury, MA: Jones and Bartlett.
- Gutkind, L. (2012). *At the end of life: True stories about how we die*. Pittsburgh: Creative Nonfiction Books.
- Halifax, J. (2009). *Being with dying: Cultivating compassion and fearlessness in the presence of death*. Boston: Shambhala.

- Holland, J. C., & Lewis, S. (2001). *The human side of cancer: Living with hope, coping with uncertainty*. New York: Harper Perennial.
- Hodgson, H. W., & Krahn, L. E. (2004). *Smiling through your tears: Anticipating grief*. BookSurge.
- Jenkinson, S. (2015). *Die wise: A manifesto for sanity and soul*. Berkeley, CA: North Atlantic Books.
- Karst, P., & Lew-Vriethoff, J. (2018). *The invisible string*. Little, Brown and Company.
- Kaufman, S. (2005). *And a time to die: How American hospitals shape the end of life*. New York: Scribner.
- Kleinman, A. (2019). *The soul of care: The moral education of a husband and a doctor*. New York: Viking.
- Kushner, H. S. (2004). *When bad things happen to good people*. New York: Anchor Books.
- Levine, S. (1989). *Who dies? An investigation of conscious living and conscious dying*. New York: Anchor Press/Doubleday.
- Locke, T. (2019). *From scratch*. New York: Simon & Schuster.
- Lynn, J., Harrold, J., & Schuster, J. L. (2011). *Handbook for mortals: Guidance for people facing serious illness* (2nd ed., pp. 320). New York: Oxford.
- Miller, B. J., Berger, S., & Luz, M. (2019). *A beginner's guide to the end: Practical advice for living life and facing death*. London: Quercus.
- Miller, J. E., & Cutshall, S. (2001). *The art of being a healing presence: A guide for those in caring relationships*. Willowgreen.
- Nuland, S. B. (2010). *How we die: Reflections on life's final chapter*. New York: Vintage Books.
- Pantilat, S. Z. (2017). *Life after the diagnosis: Expert advice on living well with serious illness for patients and caregivers*. Philadelphia: Da Capo Press.
- Silver, A. K. (2017). *Second bloom: Poems*. Eugene, OR: Cascade Books.
- Shepard, S. (2017). *Spy of the first person*. Alfred A. Knopf.
- Tisdale, S. (2018). *Advice for future corpses (and those who love them): A practical perspective on death and dying*. New York: Touchstone.
- Volandes, A. E. (2015). *The conversation: A revolutionary plan for end-of-life care* (First U.S. edition. ed.). New York: Bloomsbury.

Waldman, E. (2018). *This narrow space: A pediatric oncologist, his Jewish, Muslim, and Christian patients, and a hospital in Jerusalem*. New York: Penguin Random House.

Warraich, H. J. (2017). *Modern death: How medicine changed the end of life* (1 ed.). New York: St. Martin's Press.

Zitter, J. N. (2017). *Extreme measures: Finding a better path to the end of life*. New York: Avery

## Websites with Resources on LGBT Healthcare

National LGBT Health Education Center

<https://www.lgbthealtheducation.org/>

We provide educational programs, resources, and consultation to health care organizations with the goal of optimizing quality, cost-effective health care for lesbian, gay, bisexual, transgender, queer, intersex, asexual, and all sexual and gender minority (LGBTQIA+) people.

SAGE - Advocacy & Services for LGBT Elders

<https://www.sageusa.org/>

We're a national advocacy and services organization that's been looking out for LGBT elders since 1978. We build welcoming communities and keep our issues in the national conversation to ensure a fulfilling future for all LGBT people.

## Sources on LGBT Community

AARP. (2018). *Maintaining dignity: Understanding and responding to the challenges facing older LGBT Americans*. Retrieved from Washington, DC::  
<https://www.aarp.org/research/topics/life/info-2018/maintaining-dignity-lgbt.html>

ACCESSCare. (2017). Palliative and EOL Care for LGBT People. In K. C. London (Ed.). London: Kings College London.

ACCESSCareA Team. (2017). *"Hiding who I am" The reality of end-of-life care for LGBT people*. Retrieved from  
<https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf>

- Acquaviva, K. D. *LGBTQ-inclusive hospice and palliative care: A practical guide to transforming professional practice*. New York: Harrington Park Press.
- Almack, K., King, A., Suen, Y. T., & Westwood, S. (2019). *Older lesbian, gay, bisexual and trans people: Minding the knowledge gaps*.
- Arthur, D. P. (2015). Social work practice with LGBT elders at end of life: developing practice evaluation and clinical skills through a cultural perspective. *Journal of Social Work in End-of-Life & Palliative Care*, 11(2), 178-201. doi:10.1080/15524256.2015.1074141
- Barrett, N., & Wholihan, D. (2016). Providing palliative care to LGBTQ patients. *Nursing Clinics of North America*, 51(3), 501-511. doi:10.1016/j.cnur.2016.05.001
- Bell, S. A., Bern-Klug, M., Kramer, K. W. O., & Saunders, J. B. (2010). Most nursing home social service directors lack training in working with lesbian, gay, and bisexual residents. *Social Work in Health Care*, 49(9), 814-831. doi:10.1080/00981389.2010.494561
- Bristowe, K., Hodson, M., Wee, B., Almack, K., Johnson, K., Daveson, B. A., . . . Harding, R. (2017). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliative Medicine*, 32(1), 23-35. doi:10.1177/0269216317705102
- Bristowe, K., Marshall, S., & Harding, R. (2016). The bereavement experiences of lesbian, gay, bisexual and/or trans\* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature. *Palliative Medicine*, 30(8), 730-744. doi:10.1177/0269216316634601
- Cahill, S. R. (2017). Research and policy change to improve healthcare and elder services for LGBT older adults. *LGBT Health*, 4(6), 381-383. doi:10.1089/lgbt.2017.0226
- Cartwright, C., Hughes, M., & Lienert, T. (2012). End-of-life care for gay, lesbian, bisexual and transgender people. *Cult Health Sex*, 14(5), 537-548. doi:10.1080/13691058.2012.673639
- Chidiac, C., & Connolly, M. (2016). Considering the impact of stigma on lesbian, gay and bisexual people receiving palliative and end-of-life care. *International Journal of Palliative Nursing*, 22(7), 334-340. doi:10.12968/ijpn.2016.22.7.334
- Choi, S. K., & Meyer, I. H. (2016). *LGBT aging: A review of research findings, needs, and policy implications*. Retrieved from Los Angeles: <https://escholarship.org/uc/item/03r9x8t3>
- Cloyes, K. G., Hull, W., & Davis, A. (2018). Palliative and end-of-life care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and their caregivers. *Seminars in Oncology Nursing*, 34(1), 60-71. doi:10.1016/j.soncn.2017.12.003

- Correoso-Thomas, L. J., O'Mahony, S., & Maingi, S. (2016). Diversity and hospice. In J. Bull & M. Twaddle (Eds.), *Hospice Medical Director Manual* (3rd ed.). Chicago, IL: American Academy of Hospice and Palliative Medicine.
- Currin-McCulloch, J., & Todic, J. (2017). LGBTQ-Inclusive hospice and palliative care: A practical guide to transforming professional practice. In *Journal of Psychosocial Oncology* (2017/11/04 ed., pp. 1-3).
- Harding, R., Epiphaniou, E., & Chidgey-Clark, J. (2012). Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: A systematic review. *Journal of Palliative Medicine*, 15(5), 602-611. doi:10.1089/jpm.2011.0279
- Hospice UK. (2016). *Open to all? Meeting the need of lesbian, gay, bisexual and trans people nearing the end of life*. London: Hospice UK.
- Javier, N. M. (2017). *Culturally competent approach to palliative and end-of-life care for the LGBTQ population*. Paper presented at the New Jewish Home Palliative Care Conference, New York.
- Kcomt, L., & Gorey, K. M. (2017). End-of-life preparations among lesbian, gay, bisexual, and transgender people: Integrative review of prevalent behaviors. *J Soc Work End Life Palliat Care*, 13(4), 284-301. doi:10.1080/15524256.2017.1387214
- Lam, V. (2017). LGBTQ at the End-of-Life: Needs and Challenges.
- Lawton, A., White, J., & Fromme, E. K. (2014). End-of-life and advance care planning considerations for lesbian, gay, bisexual, and transgender patients #275. *Journal of Palliative Medicine*, 17(1), 106-108. doi:10.1089/jpm.2013.9457
- Mahingi, S., O'Mahony, S., Free, D., & Scott, B. (2014). No longer invisible: Creating a welcoming environment for lesbian, gay, bisexual, and transgender (LGBT) patients and families (FR434). *Journal of Pain and Symptom Management*, 47(2), 441. doi:10.1016/j.jpainsymman.2013.12.112
- Maingi, S., Bagabag, A. E., & O'Mahony, S. (2018). Current best practices for sexual and gender minorities in hospice and palliative care settings. *Journal of Pain and Symptom Management*, 55(5), 1420-1427. doi:10.1016/j.jpainsymman.2017.12.479
- Makadon, H. J. (2013). *Meeting the health care needs of lesbian, gay, bisexual, and transgender people: The end to LGBT invisibility*.
- Ng, H. H. (2018). LGBTQ-inclusive hospice and palliative care: Transforming professional practice. *LGBT Health*. doi:10.1089/lgbt.2017.0157

- O'Mahony, S., Maingi, S., Scott, B. H., & Raghuwanshi, J. S. (2019). Perspectives on creating an inclusive clinical environment for sexual and gender minority patients and providers. *Journal of Pain and Symptom Management*. doi:10.1016/j.jpainsymman.2019.11.025
- Rawlings, D. (2012). End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals. *International Journal of Palliative Nursing*, 18(1), 29-34. doi:10.12968/ijpn.2012.18.1.29
- Stein, G. L. (2002). Welcoming elder lesbian and gay patients in palliative care settings. *AAHPM Bulletin*(Fall), 6-7.
- Stein, G. L., & Almack, K. (2012). Care near the end of life: The concerns, needs, and experiences of LGBT elders. In R. Ward, I. Rivers, & M. Sutherland (Eds.), *Lesbian, Gay, Bisexual and Transgender Ageing: Biographical Approaches for Inclusive Care and Support* (pp. 114-134). London: Jessica Kingsley.
- Stein, G. L., Beckerman, N. L., & Sherman, P. A. (2010). Lesbian and gay elders and long-term care: identifying the unique psychosocial perspectives and challenges. *J Gerontol Soc Work*, 53(5), 421-435. doi:10.1080/01634372.2010.496478
- Stein, G. L., Berkman, C., O'Mahony, S., Godfrey, D., Javier, N. M., & Maingi, S. (2019). 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*. doi:10.1089/jpm.2019.0542
- Stein, G. L., & Bonuck, K. A. (2001). Attitudes on end-of-life care and advance care planning in the lesbian and gay community. *Journal of Palliative Medicine*, 4(2), 173-190. doi:10.1089/109662101750290218
- Stein, G. L., & Bonuck, K. A. (2001). Physician–patient relationships among the lesbian and gay community. *Journal of the Gay and Lesbian Medical Association*, 5(3), 87-93. doi:10.1023/a:1011648707507
- Stevens, E. E., & Abrahm, J. L. Adding silver to the rainbow: Palliative and end-of-life care for the geriatric LGBTQ patient. *Journal of Palliative Medicine*, 0(0), null. doi:10.1089/jpm.2018.0382

## **Memoirs**

Awdish, R. (2018). *In shock: My journey from death to recovery and the redemptive power of hope*. New York: St. Martin's Press.

Awdish, R. (2018). *In shock: From doctor to patient - what I learned about medicine's inhumanity*. New York: Penguin Random House.

Coutts, M. (2015). *The iceberg: A memoir*. London: Atlantic Books.

Didion, J. (2018). *The year of magical thinking*. New York: Alfred A. Knopf.

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

Lubbock, T. (2014). *Until further notice, I am alive*. London: Granta.

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

Riggs, N. (2018). *The bright hour: A memoir of living and dying*. New York: Simon & Schuster.

Schwalbe, W. (2012). *The end of your life book club*: Vintage.

Taylor, C. (2017). *Dying: A memoir*. Portland, OR: Tin House Books.

## Articles, Books, Chapters

### Advance Care Planning

- Carr, D., & Luth, E. A. (2017). Advance Care Planning: Contemporary Issues and Future Directions. *Innovation in Aging, 1*(1), igx012-igx012. doi:10.1093/geroni/igx012
- Girgis, A., & Sanson-Fisher (1995). Breaking bad news: Consensus guidelines for medical practitioners. *Journal of Clinical Oncology, 13*(9), 2449-2456.
- Khatcheressian, J., Harrington, S. B., Lyckholm, L. J., & Smith, T. J. (2008). 'Futile care': what to do when your patient insists on chemotherapy that likely won't help. *Oncology (Williston Park), 22*(8), 881-888; discussion 893, 896, 898.
- Kunthur, A., Safar, M., Kyasa, M. J., Makhoul, I., Harrington, S., & Mehta, P. (2010). Addressing end-of-life care—when the patient or family doesn't want to let go. *Fed Pract., 27*(5), 34-36.
- 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. *J Palliat Med, 11*(5), 754-762. doi:10.1089/jpm.2007.0224 [doi]

### Choice in Dying

- Black, K., & Csikai, E. L. (2015). Dying in the age of choice. *J Soc Work End Life Palliat Care, 11*(1), 27-49. doi:10.1080/15524256.2015.1021072
- Wolff, M. (2012, May 20, 2012). A life worth ending. *New York*.  
<http://nymag.com/news/features/parent-health-care-2012-5/>

### Culture

- Berzoff, J., & Silverman, P. R. (2004). *Living with Dying*. New York: Columbia University Press. Chapter 24. Lesbians and gay men at the end of their lives: psychosocial concerns
- Brenner, D. S., Blanchard, T., Fins, J. J., & Hirschfield, B. (2005). *Embracing life and facing death: A Jewish guide to palliative care*. New York: CLAL.
- Bullock, K. (2006). Promoting advance directives among African Americans: A faith-based model. *Journal of Palliative Medicine, 9*(1), 183-195.



- Deshpande, O., Reid, M. C., & Rao, A. S. (2005). Attitudes of Asian-Indian Hindus toward end-of-life care. *J Am Geriatr Soc*, 53(1), 131-135. doi:10.1111/j.1532-5415.2005.53025.x
- Kemp, C. (2001). Culture and the end of life: Hispanic cultures. *Journal of Hospice and Palliative Nursing*, 3(1), 29-33.
- Koenig, B., & Gates-Williams, J. (1995). Understanding cultural difference in caring for dying patients. *Western Journal of Medicine*, 163(3), 244-249.
- Lamm, M. (2012). *The Jewish way in death and mourning*. Middle Village, NY: Jonathan David Publishers.
- Levy, A. (2000). *The orphaned adult: understanding and coping with grief and change after the death of our parents*. Cambridge, MA: Perseus Publishing.
- Stein, G.L. & Bonuck, K. A. (2001). Attitudes on end-of-life care and advance care planning in the lesbian and gay community. *Journal of Palliative Medicine*, 4(2), 173-190.
- Stein, G.L. (2002). Welcoming elder lesbian and gay patients in palliative care settings. *American Academy of Hospice and Palliative Medicine Bulletin*, 3(1), 6-7.
- SUPPORT Principle Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients, *JAMA*, 274(20), 1591-1598.

### **Death, Dying, Grief, Loss, Bereavement**

- 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.
- Christ, G. (2000). *Healing children's grief: Surviving a parent's death from cancer*. New York: Oxford University Press.
- Doka, K. J. (2013). Historical and contemporary perspectives on dying. In D. K. Meagher (Ed.), *Handbook of thanatology The essential body of knowledge for the study of death, dying, and bereavement* (pp. 17-23). New York: Routledge.
- Featherstone, M. (2020). Ghosts in my nursery: The brother I never knew. Yale Review. Retrieved from <https://yalereview.yale.edu/ghosts-my-nursery>
- Kosminsky, P. (2007). *Getting back to life when grief won't heal*. New York: McGraw-Hill.
- Kosminsky, P., & Jordan, J. R. (2016). *Attachment-informed grief therapy: The clinician's guide to foundations and applications*. New York: Routledge.
- Kubler-Ross, E. (1969). *On death and dying*. New York: Scribner.

Kübler-Ross, E. (1970). The care of the dying—Whose job is it? *Psychiatry in Medicine*, 1(2), 103-107. doi:10.2190/p28c-3tv2-d3wm-vw7t

McGoldrick, M., & Walsh, F. Editors (2004). *Living beyond loss: Death in the family*. New York: Norton.

Remke, S. S. (2013). *The insider's guide to grief*: Lowertown Press.

Walsh-Burke, K. (2012). *Grief and loss: Theories and skills for the helping professions*. (2nd Ed.): Upper Saddle River, NJ: Pearson.

## Ethics

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.

Csikai, E.L. (2004). Social workers' participation in the resolution of ethical dilemmas in hospice care. *Health and Social Work*, 29(1), 67-76.

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

Harrington, S. E., & Smith, T. J. (2008). The role of chemotherapy at the end of life: "when is enough, enough?". *JAMA*, 299(22), 2667-2678. doi:10.1001/jama.299.22.2667

Lahey, T. (2018). A harder death for people with intellectual disabilities. *New York Times*.

## Family Caregivers

Reinhard, S. C., Levine, C., & Samis, S. (2012). *Home alone: family caregivers providing complex chronic care*. Retrieved from New York:  
[http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf)

## Family Meetings

Hudson, P., Quinn, K., O'Hanlon, B., & Aranda, S. (2008). Family meetings in palliative care: Multidisciplinary clinical practice guidelines. *BMC Palliative Care*, 7

Joshi. Family meetings: An essential component of comprehensive PC. *Canadian Fam Phys* 2013

Sullivan, S. S., Ferreira da Rosa Silva, C., & Meeker, M. A. (2015). Family Meetings at End of Life: A Systematic Review. *Journal of Hospice & Palliative Nursing, 17*(3), 196-205. doi:10.1097/njh.0000000000000147

### Homeless Persons

Bartels, D. M., Ulvestad, N., Ratner, E., Wall, M., Uutala, M. M., & Song, J. (2008). Dignity matters: advance care planning for people experiencing homelessness. *J Clin Ethics, 19*(3), 214-222.

Song, J., Bartels, D. M., Ratner, E. R., Alderton, L., Hudson, B., & Ahluwalia, J. S. (2007). Dying on the streets: homeless persons' concerns and desires about end of life care. *J Gen Intern Med, 22*(4), 435-441. doi:10.1007/s11606-006-0046-7

Song, J., Ratner, E. R., Bartels, D. M., Alderton, L., Hudson, B., & Ahluwalia, J. S. (2007). Experiences with and attitudes toward death and dying among homeless persons. *J Gen Intern Med, 22*(4), 427-434. doi:10.1007/s11606-006-0045-8

### Hospice

Jackson, K. (2013). Transitions to hospice care: Social workers foster meaningful conversations about dying. *Social Work Today, 13*(4), 22.

Quinn-Lee, L., Olson-McBride, L., & Unterberger, A. (2014). Burnout and death anxiety in hospice social workers. *J Soc Work End Life Palliat Care, 10*(3), 219-239. doi:10.1080/15524256.2014.938891

Reese, D. J. (2013). *Hospice social work*. New York: Columbia University Press.

Social Work Policy Institute. (2010). *Hospice social work: Linking policy, practice and research*. Retrieved from Washington, D.C.:

### Intellectual Disability

McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brandford, S. (2017). "I'm still here": Exploring what matters to people with intellectual disability during advance care planning. *J Appl Res Intellect Disabil, 30*(6), 1089-1098. doi:10.1111/jar.12355

### Interdisciplinary Palliative Care Team

Altilio, T., & Laing, N. (2015). Social work in palliative care. In N. Cherny, M. Fallon, S. Kaasa, R. K. Portenoy, & D. C. Currow (Eds.), *Oxford textbook of palliative medicine* (5th ed.). New York: Oxford University Press.

Association of Professional Chaplains. Standards of Practice for Professional Chaplains in Hospice and Palliative Care  
[http://www.professionalchaplains.org/files/professional\\_standards/standards\\_of\\_practice/standards\\_of\\_practice\\_hospice\\_palliative\\_care.pdf](http://www.professionalchaplains.org/files/professional_standards/standards_of_practice/standards_of_practice_hospice_palliative_care.pdf)

Fitchett, G., Lyndes, K. A., Cadge, W., Berlinger, N., Flanagan, E., & Misasi, J. (2011). The role of professional chaplains on pediatric palliative care teams: perspectives from physicians and chaplains. *J Palliat Med*, 14(6), 704-707. doi:10.1089/jpm.2010.0523

Handzo, G., & Puchalski, C. (2015). The role of the chaplain in palliative care. In N. Cherny, M. Fallon, S. Kaasa, R. K. Portenoy, & D. C. Currow (Eds.), *Oxford textbook of palliative medicine* (5th ed.). New York: Oxford University Press.

Sherman, D. W., & Free, D. C. (2015). Nursing and palliative care. In N. Cherny, M. Fallon, S. Kaasa, R. K. Portenoy, & D. C. Currow (Eds.), *Oxford textbook of palliative medicine* (5th ed.). New York: Oxford University Press.

## International

Economist. (2010). *The quality of death: Ranking end-of-life care across the world*. Retrieved from New York:  
[http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

## MOLST

Lipson, K., & Karmel, J. (2011). Honoring patient preferences at the end of life: The MOLST process and the Family Health Care Decisions Act. *NYSBA Health Law Journal*, 16(1), 35-43.

## Older Adults

Bauerschmidt, T., Liddle, R. (2017). *Driving Miss Norma: One family's journey saying "yes" to living*. Ashland, OR: Blackstone Audio.

Gawande, A. (2007, April 30, 2007). The way we age now. *New Yorker*, 50-59.

Luptak, M. (2004). Social work and end-of-life care for older people: A historical perspective. *Health and Social Work*, 29(1), 7-15.

## Pain

- Altilio, T., & Doran, M.P. (2013). Pain. Encyclopedia of Social Work. Retrieved from <http://socialwork.oxfordre.com/view/10.1093/acrefore/9780199975839.001.0001/acrefore-9780199975839-e-276>
- Campbell, C. M., & Edwards, R. R. (2012). Ethnic differences in pain and pain management. *Pain Manag*, 2(3), 219-230. doi:10.2217/pmt.12.7
- Green, C. R., Anderson, K. O., Baker, T. A., Campbell, L. C., Decker, S., Fillingim, R. B., Vallerand, A. H. (2003). The unequal burden of pain: confronting racial and ethnic disparities in pain. *Pain Med*, 4(3), 277-294.
- International Association for the Study of Pain. (2015). IASP Curriculum Outline for Pain in Social Work. Retrieved from <http://www.iasp-pain.org/Education/CurriculumDetail.aspx?ItemNumber=4956>
- Mendenhall, M. (2003). Psychosocial aspects of pain management: a conceptual framework for social workers on pain management teams. *Soc Work Health Care*, 36(4), 35-51. doi:10.1300/J010v36n04\_03
- Otis-Green, S., Lucas, S., Spolum, M., Ferrell, B., & Grant, M. (2008). Promoting excellence in pain management and palliative care for social workers. *J Soc Work End Life Palliat Care*, 4(2), 120-134. doi:10.1080/15524250802353942

## Pediatrics

- Browning, D. M., & Solomon, M. Z. (2006). Relational learning in pediatric palliative care: transformative education and the culture of medicine. *Child and Adolescent Psychiatric Clinics of North America*, 15(3), 795-815. doi:10.1016/j.chc.2006.03.002
- Freyer, D.R., (2004). Care of the dying adolescent: Special considerations. *Pediatrics*, 113(2), 381-388.
- 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.
- Hoffman, J. (2015, March 28, 2015). Teenagers face early death, on their terms. *New York Times*. Retrieved from <https://well.blogs.nytimes.com/2015/03/28/teen-advance-directive-end-of-life-care/>
- Jankowski, J. B. (2014). Professional boundary issues in pediatric palliative care. *American Journal of Hospice and Palliative Care*, 31(2), 161-165. doi:10.1177/1049909113483539

Jones, B.L. (2005). Pediatric palliative and end-of-life care: The role of social work in pediatric oncology. *Journal of Social Work in End of Life and Palliative Care*, 1(4), 35-62.

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.

NINR. (2015). Palliative care for children: Support for the whole family when your child is living with a serious illness (Vol. NIH publication #15-NR-8003): National Institute of Nursing Research, National Institutes of Health.

Wiener, L., & Sansom-Daly, U. M. (2015). Interventions for children under age 15 living with cancer. In G. Christ, C. Messner, & L. Behar (Eds.), *Handbook of Oncology Social Work* (1st ed., pp. 447-455). New York: Oxford.

Wiener, L., Zadeh, S., Wexler, L. H., & Pao, M. (2013). When silence is not golden: Engaging adolescents and young adults in discussions around end-of-life care choices. *Pediatric Blood & Cancer*, 60(5), 715-718. doi:10.1002/psc.24490

Weir, R.F., & Peters, C. (1997). Affirming the decisions adolescents make about life and death, *Hastings Center Report*, 27(6), 29-40.

### Practice Issues (not included in any of the other categories)

Baile, W., Buckman, R., Lenzi, R., Glober, G., Beale, E., & Kudelka, A. (2000). SPIKES—A six-step protocol for delivering bad news: Application to the patient with cancer. *The Oncologist*, 5, 302.

Chochinov, H. M. (2012). *Dignity therapy: Final words for final days*. New York: Oxford University Press.

Ferrell, B. R., Twaddle, M. L., Melnick, A., & Meier, D. E. (2018). National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *Journal of Palliative Medicine*, 21(12), 1684-1689. doi:10.1089/jpm.2018.0431

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

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

Holland, J. C., & Rowland, J. H. (1990). *Handbook of psychooncology: 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.
- Katz, R. S., & Johnson, T. A., Eds. (2016). *When professionals weep: Emotional and countertransference responses in palliative and end-of-life care* (2nd ed.). New York: Routledge.
- Kolsky, K. (2008). *End of life: Helping with comfort and care*. In National Institute on Aging (Ed.), [https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/end\\_of\\_life\\_helping\\_with\\_comfort\\_care\\_0.pdf](https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/end_of_life_helping_with_comfort_care_0.pdf)  
Bethesda, MD: National Institute on Aging.
- Levine, C., & Murray, T.H. (2004). *The cultures of caregiving: Conflict and common ground among families, health professionals, and policy makers*. Baltimore, MD: Johns Hopkins University Press.
- Lipsky, L. v. D., & Burk, C. (2009). *Trauma stewardship: An everyday guide to caring for self while caring for others*. Oakland, CA: Berrett-Koehler Publishers.
- 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.
- Werth, J. L., Jr., & Blevins, D. (2006). *Psychosocial issues near the end of life: A resource for professional care providers*. Washington, D.C.: American Psychological Association.

## Self-Care

### Self-Care Starter Kit

“The Self-Care Starter Kit<sup>SM</sup> was initially developed for UB Social Work students, but it is our hope that these resources will be useful for students and professionals alike.

Although the kit does not address all that goes into developing the skills of self-care, it does begin the journey.”

<https://socialwork.buffalo.edu/resources/self-care-starter-kit.html>

### [Introduction to Self-Care](#)

An introduction to self-care, its aims, and available resources

### [Developing Your Self-Care Plan](#)

Steps to develop your Self-Care Plan

### [Self-Care Assessments, Exercises and Activities](#)

Assessments, exercises, and activities to supplement the self-care plan

### [Additional Self-Care Resources](#)

Additional self-care resources ranging from inspiration materials to regional resources to an extensive bibliography

### [How To Flourish in Social Work Infographic](#)

This very popular image is a great reminder for all social workers and those in helping-fields, that self-care is important.

## **Social Work**

Altilio, T., & Otis-Green, S. (2011). *Oxford Textbook of Palliative Social Work*: Oxford University Press.

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

Clark, E. (2018). Loss and suffering: The role of social work. *The New Social Worker*. Retrieved from <https://www.socialworker.com/feature-articles/practice/loss-and-suffering-the-role-of-social-work/>

Cox, K., & Steiner, S. (2013). *Self-care in social work: A guide for practitioners, supervisors, and administrators*. Washington, D.C.: NASW Press.

Katz, R. S., & Johnson, T. A. (2016). *When professionals weep: Emotional and countertransference responses in end-of-life care* (2nd ed.). New York: Routledge.

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-products-9781604431711.php>

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

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

## **Spirituality**

Kristjanson, L. (2006). A palliative approach to spirituality in residential aged care. *Journal of Religion, Spirituality & Aging*, 18(4), 189-205.



- LeFavi, R. G. & Wessels, M. H. (2003). Life review in pastoral counseling: Background and efficacy for use with the terminally ill. *The Journal of Pastoral Care & Counseling*, 57(3), 281-292.
- Mallon, B. (2008). *Dying, death and grief: Working with adult bereavement*. Los Angeles, CA: Sage.
- McGrath, P. (2003). Religiosity and the challenge of terminal illness. *Death Studies*, 27, 881-899
- Miller, K. K., Chibnall, J. T., Videen, S. D., & Duckro, P. N. (2005). Supportive-affective group experience for persons with life-threatening illness: Reducing spiritual, psychological, and death-related distress in dying patients. *Journal of Palliative Medicine*, 8(2), 333-343.
- Moss, E. L. & Dobson, K. S. (2006). Psychology, spirituality, and end-of-life care: An ethical integration. *Canadian Psychology*, 47(4), 284-299.
- Murray, S. A., Kendall, M., Boyd, K., Worth, A., & Benton, T. F. (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: A prospective qualitative interview study of patients and their careers. *Palliative Medicine*, 18, 39-45.
- Nakashima, M. (2007). Positive dying in later life: Spiritual resiliency among sixteen hospice patients. *Journal of Religion, Spirituality, & Aging*, 19(2), 43-66.
- Neimeyer, R. A. (Ed.), *Meaning reconstruction & the experience of loss* (pp. 55-73). Washington, D.C.: American Psychological Association.
- Puchalski, C. M. (2008). Spirituality and the care of patients at the end-of-life: An essential component of care. *Omega*, 56(1), 33-46.
- Rosen, S. J. (2008). Introduction. In S. J. Rosen. (Ed.), *Ultimate journey: Death and dying in the world's major religions* (pp. vii-ix). Westport, CT: Praeger.
- Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M. & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132(10), 825-832.
- Stoebe, M. S. & Schut, H. (2007) Meaning making in the dual process model of coping with bereavement. In R. A. Neimeyer (Ed.), *Meaning reconstruction & the experience of loss* (pp. 55-73). Washington, D.C.: American Psychological Association.
- Swinton, J. (2007). *Raging with compassion: Pastoral responses to the problem of evil*. Grand Rapids: William B. Eerdmans Publishing.

Worden, J. W. (2009). *Grief counseling and grief therapy: A handbook for the mental health practitioner* (4<sup>th</sup> ed.). New York: Springer.

Wortmann, J. & Park, C. L. (2008). Religion and spirituality in adjustment following bereavement: An integrative review. *Death Studies*, 32, 703-736.

## Apps

### For Health Care Providers

#### Everplans

Use Everplans to help your clients create, store, and share all of their most important information, and provide them with priceless peace of mind.

<https://www.everplans.com/professional>

#### Health Communication

Now clinicians can have quick and ready access to theory-driven and evidence-based communication tools that are useful in difficult conversations. Endorsed by the End-of-Life Nursing Education Consortium and renowned palliative care physician Diane Meier, this APP provides easy-to-deliver responses when communicating in moments of tension, sorrow, fear, anxiety, awkwardness, and hesitancy. Health Comm guides you to provide compassionate and culturally sensitive care to serious and critically-ill patients and their families.

<https://apps.apple.com/us/app/health-communication/id697289957>

#### Hospice by the Bay Mobile App

- Hospice Criteria – Eligibility, Formulary, Levels of Care, Contact Us
- Prognosis and eligibility information by diagnosis
- Details about the four levels of hospice care
- The Hospice Conversation
- A video to help you start the hospice conversation with patients and families
- A list of clinical articles, updated quarterly, about hospice and palliative care.

<https://hospicebythebay.org/health-professionals/hbtb-hospice-mobile-app/>

#### iPal

This app is intended for clinical use only and should not be used by the general public. The information contained in this app is meant to provide guidance. It should not supersede a healthcare provider's clinical judgment.

Components include: Assess, Manage, Plan, Communicate, Scale

<https://ipalapp.com/>

## MedPal-CNN

MedPal–CNN is an educational tool oriented towards healthcare professionals who care for pediatric patients who have already been diagnosed with a condition that could benefit from PPC. The app is designed to help professionals learn more about PPC and to connect them to diverse resources to learn about management approaches for previously diagnosed conditions. This app is not a diagnostic or treatment tool.

<http://www.medpalcnn.org/en/>

## Palliate Guide

This app is the only offline app that addresses prescribing in palliative medicine using evidence based knowledge. Designed for Hospice and palliative care providers including nurses, residents, internal medicine, family medicine, geriatrics or any provider who treats palliative care patients.

<https://appfelstrudel.com/id/1076219888/palliate-guide.html>

<https://www.imedicalapps.com/2016/02/palliate-guide-app-palliative-care-hospice/>

## Palliative Care Fast Facts

Palliative Fast Facts is the official mobile version of the Fast Facts database, the de facto quick reference for palliative care providers. This app works without an internet connection and is designed to be useful in a clinical setting. Convenience and customization are key--browse the Facts Facts database by search, chronology, or subject; share and bookmark articles that are particularly useful; adjust the text size, background, and font color. The Palliative Fast Facts for Android application was created by Haipeng (Mark) Zhang D.O. at Dana Farber Cancer Institute and Jess Smith (<http://jesskinchen.com/>) at the University of Florida.

<https://apps.apple.com/gb/app/palliative-care-fast-facts/id868472172>

[https://play.google.com/store/apps/details?id=com.jesskinchen.fastfacts&hl=en\\_US](https://play.google.com/store/apps/details?id=com.jesskinchen.fastfacts&hl=en_US)

## For Consumers

### Cake

Explore, document and share all your health, legal, funeral and legacy decisions in an end-of-life plan. Make it easier for family in the future.

<https://www.joincake.com/?redirectedFrom=welcome>

### Everplans

Say goodbye to boxes stuffed with papers, and hello to a whole new way to organize your life. From finances to passwords, use Everplans to store and share the critical information loved ones will need if something happens to you .

<https://www.everplans.com/consumer>

### My Directives

Make your medical wishes known. MyDirectives — free, easy, always available. Families with a plan cope better in a crisis. Don't burden your family with difficult, emotional decisions. Tell them what you want.

<https://www.mydirectives.com/>

### Safe Beyond

The Digital Time Capsule - Emotional life insurance

- Create personalized future messages for your loved ones
- Ensure easy access to all your digital assets
- Secure your legacy forever

<https://www.safebeyond.com/>

### We Croak

Find happiness by contemplating your mortality with the WeCroak app. Each day, we'll send you five invitations at randomized times to stop and think about death. It's based on a Bhutanese folk saying that to be a happy person one must contemplate death five times daily.

<https://www.wecroak.com/>

## Articles about Smartphone Apps

- Agboola, S., Kamdar, M., Flanagan, C., Searl, M., Traeger, L., Kvedar, J., & Jethwani, K. (2014). Pain management in cancer patients using a mobile app: study design of a randomized controlled trial. *JMIR research protocols*, 3(4), e76-e76. doi:10.2196/resprot.3957
- Dhiliwal, S. R., & Salins, N. (2015). Smartphone applications in palliative homecare. *Indian Journal of Palliative Care*, 21(1), 88-91. doi:10.4103/0973-1075.150199
- Greenle, M. M., Morgan, B., Sayani, S., & Meghani, S. H. (2018). Identifying mobile apps targeting palliative care patients and family members. *Journal of Palliative Medicine*, 21(10), 1380-1385. doi:10.1089/jpm.2018.0157
- Heeter, C., & Lehto, R. (2018). Meditation app benefits hospice and palliative care clinicians. *Oncology Nursing News*. Retrieved from <https://www.oncnursingnews.com/publications/oncology-nurse/2018/august-2018/meditation-app-benefits-hospice-and-palliative-care-clinicians>.
- Jamwal, N., & Kumar, S. (2016). Smarter palliative care for cancer: Use of smartphone applications. *Indian Journal of Palliative Care*, 22(1), 108-110. doi:10.4103/0973-1075.173950
- Kamdar, M. M., Centi, A. J., Fischer, N., & Jethwani, K. (2018). Artificial-intelligence smartphone app significantly reduced severity of cancer patients' pain and hospital admissions. Retrieved from <https://www.asco.org/about-asco/press-center/news-releases/artificial-intelligence-smartphone-app-significantly-reduced>
- Meghani, S. H., MacKenzie, M. A., Morgan, B., Kang, Y., Wasim, A., & Sayani, S. (2017). Clinician-targeted mobile apps in palliative care: A systematic review. *Journal of Palliative Medicine*, 20(10), 1139-1147. doi:10.1089/jpm.2017.0070
- Nwosu, A. C., & Mason, S. (2012). Palliative medicine and smartphones: An opportunity for innovation? *BMJ Supportive & Palliative Care*, 2(1), 75-77. doi:10.1136/bmjspcare-2011-000151
- The ASCO Post. (2018). 2018 Palliative Care: Can an AI-Based App Help Manage Cancer-Related Pain? *The ASCO Post*. Retrieved from <https://www.ascopost.com/News/59466>
- Tsemg, D. (2017). How to manage chronic pain with a medical app. Retrieved from <https://www.imedicalapps.com/2017/01/manage-chronic-pain-medical-app/>

## Documentary Films and Videos

Students may watch video via our streaming video database called [Kanopy](#). To access Kanopy:

1. Begin on the library site: [www.fordham.edu/library](http://www.fordham.edu/library)
2. Click on the **Databases** tab; then the link **Databases home and A-Z list**.
3. Click on the letter **K** in the alphabet at the top and then select **Kanopy**.

### The Art of Dying

2009

21 Minutes

Director and Producer: Matthew Hill

"In an intimate and moving documentary, art historian Dan Cruickshank confronts the unavoidable issue of his own certain death, whether soon or far in the future. His mission, in this largely secular age, is to see if art can offer either comfort or explanation in the face of the greatest unknown of all. Confronting death on both an emotional and an intellectual level, Dan relives the sense of loss of close family - his father and grandfather, and the future death of his only child - while also exploring how death has been dealt with through the ages."

<https://www.bbc.co.uk/programmes/b00n1jnn>

### B. J. Miller

19 Minutes

2015

[https://www.ted.com/talks/bj\\_miller\\_what\\_really\\_matters\\_at\\_the\\_end\\_of\\_life?language=en](https://www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life?language=en)

"At the end of our lives, what do we most wish for? For many, it's simply comfort, respect, love. BJ Miller is a hospice and palliative medicine physician who thinks deeply about how to create a dignified, graceful end of life for his patients. Take the time to savor this moving talk, which asks big questions about how we think on death and honor life."

### Caring for Pain - How to Approach Chronic Illness

Diane Meier discusses being with patients in the "everydayness of their pain" and challenges within the medical system to providing compassionate, patient centered care.

<https://www.youtube.com/watch?v=vl8OSTEFpFw>

### Compassion and Support

Brief videos for patients and family members:

#### JoAnn's Story

Start Your Conversation Today. JoAnn shares her story about the importance of having advance care planning discussions, sharing your wishes with your family & loved ones, and completing a Health Care Proxy.

<https://www.youtube.com/watch?v=RXk1Dnb-zzg&list=PLC6705F3E007264F5>

### Bill & Debbie's Story

Share What Matters Most. Talking about death doesn't make it happen. Learn how Bill's mom eased the burden from her family.

<https://www.youtube.com/watch?v=OplXuGWMZKc&list=PLC6705F3E007264F5&index=4>

### Choose the Right Spokesperson

Tricia had a conversation with her family and completed her health care proxy. Find out what happened when she had a stroke at age 37.

<https://youtu.be/G3QvkmZCEgg?list=PLC6705F3E007264F5>

### The Value of a Goals for Care Discussion Prior to MOLST Completion

Physicians, social workers & nurses discuss the value of a family discussion focused on goals for care prior to MOLST completion. This video features: Dr. Tom Caprio, Penny Weller, LCSW, Dr. Joel Potash, & Cindy Bileschi, RN, Dr. Julia Smith, Dr. Alan Roth, Dr. Eileen Chichin, RN, Dierdre Downs, LCSW, Dr. Simon Kassabian & Dr. Bob McCann.

<https://www.youtube.com/watch?v=E7am17KXdd0&list=PL8C8C09B1A5837E08&index=33>.

### Flora's Story about End-of-Life Decision Making

Flora Allen shares her family's story about the death of her father from Parkinson's & dementia. She emphasizes the value of early family conversations. The MOLST form ensured that her father's wishes could be honored. Flora addresses the MOLST discussion process. Dr. Pat Bomba addresses items to consider during end-of-life conversations.

<https://www.youtube.com/watch?v=KleonsdwcDQ&index=37&list=PL8C8C09B1A5837E08>

### Al's Story: Problems with End-of-Life Care Before MOLST

Al Hooke shares his family's story about end-of-life care in a nursing home prior to the existence of MOLST. He emphasizes the value of advance care planning & family conversations and stresses the importance of honoring patient preferences on the MOLST form today.

<https://www.youtube.com/watch?v=yNGPqv40OxU&list=PL8C8C09B1A5837E08&index=32>

### Julie's Story: The Value of MOLST & Family Discussion

Julie Perry addresses her Mom's end-of-life treatment, wishes and the value of the MOLST for her mother and her family. Her mother had emphysema and other health challenges. Her goals were to be around her family, have everyone with her, and die in comfort. Julie's mom was able to make her MOLST decisions herself and had her choices honored.

<https://www.youtube.com/watch?v=vtlpMjYCvDg&list=PL8C8C09B1A5837E08&index=30>

### Belen's Story: En Espanol - Ordenes Medicas para el Tratamiento que Sostiene la Vida

Belen Rivera addresses the challenges in getting her brother's end-of-life wishes honored without the MOLST form. Belen's mother has had a family discussion and completed a MOLST for herself. They keep it taped to the refrigerator and take it with



them whenever they leave the house and make it accessible to all medical professionals. This video is in Spanish with English subtitles.

<https://www.youtube.com/watch?v=qUwEM4WyL0&list=PL8C8C09B1A5837E08&index=29>

Advantages of eMOLST: A Nursing Home Physician's Perspective

Dr. Kim Petrone, a physician at St. Ann's Community in Rochester, NY, shares her perspectives on the advantages of eMOLST.

<https://www.youtube.com/watch?v=jn47FIYsxss&list=PL8C8C09B1A5837E08&index=27>

eMOLST Overview

eMOLST is a web-based version of the current paper-based New York State Department of Health-5003 MOLST form. By moving the MOLST form to a readily accessible electronic format, health care providers, including EMS, can have access to MOLST forms at all sites of care including hospitals, nursing homes and the community. In the long term the eMOLST application and registry should become a statewide service by leveraging connections with SHIN-NY.

<https://www.youtube.com/watch?v=MjL8Qz944IU&list=PL8C8C09B1A5837E08&index=2>

Complicated Grief: Q & A with Dr. M. Katherine Shear

9.28 minutes

2014

<https://www.youtube.com/watch?v=aAEfYSOS8W8>

Consider the Conversation: A Documentary on a Taboo Subject

60 minutes

2011

Producers: Michael Bernhagen and Terry Kaldhusdal

<http://www.considertheconversation.org/>

*Palliative Care Issues: communication, shared decision-making, giving sad news*

Consider the Conversation 2: Stories about Cure, Relief, and Comfort

86 minutes

Producers: Michael Bernhagen and Terry Kaldhusdal

<http://www.considertheconversation.org/>

*Palliative Care Issues: communication, shared decision-making, giving sad news*

Defining Hope

2017

76 minutes

Director: Carolyn Jones

Available to rent on YouTube, Google Play, and Amazon Prime.

“‘Defining Hope’ shows the current state of the end-of-life experience. The film serves as a powerful reminder that ending well looks different for everyone and that we are empowered to make choices that align with our wishes.”

### Defining the Role of the Palliative Care Chaplain

1.46 minutes

8-19-15

The Rev. George F. Handzo, BCC

Producer: Center to Advance Palliative Care

An explanation of how the palliative care chaplain helps patients and families deal with serious illness.

<https://www.youtube.com/watch?v=rao85uGBb10>

### Deploying Mindfulness to Transform the Care of Serious Illness

62 minutes

Diane Meier

<https://www.youtube.com/watch?v=yUbZYzs3IOk><https://www.youtube.com/watch?v=yUbZYzs3IOk>

### Dementia: End of life care

10 Minutes

6-18-11

A video from the Social Care TV YouTube Channel looking at providing end of life care to people with dementia.

<https://www.youtube.com/watch?v=3zKADdgcF14>

### A Dignified End

Produced by Journey Man Productions.

"Obbe Terpstra is 86. He has no terminal illness but his quality of life is deteriorating, he wants to die in a dignified way. This exclusive report follows him as he prepares to commit suicide. 'I want to die. I am not allowed but I want to', states Obbe Terpstra. He watched his wife die of cancer and doesn't want to end up like that. But helping someone commit suicide is a criminal offence. His son, Albert, knows of his plans but hasn't been involved with the preparations. 'He doesn't want us to see him as a drooling old man. He wants us to remember him as he is now.' A month later, Obbe swallows barbiturates. 'He was extremely happy. The atmosphere was like a birthday party,' recalls Albert. By sharing their story, Albert and Obbe hope they will re-open the debate on euthanasia."

<http://www.programsforelderly.com/documentary-death-a-dignified-end.php>

### Dying at Grace

2003

148 Minutes

Produced and Directed by: Allan King

"Allan King's 'Dying at Grace' is quite simply unprecedented: five terminally ill cancer patients allowed the director access to their final months and days inside the Toronto Grace Health Care Center. The result is an unflinching, enormously empathetic contemplation of death, featuring a handful of the most memorable people ever captured on film."

<https://www.kanopy.com/product/dying-grace>  
<http://www.allankingfilms.com/> trailer  
<https://vimeo.com/262831131> trailer  
<https://www.youtube.com/watch?v=qQYx6NFi7RM> trailer

### Dying for a Laugh

Produced by: Picture Wise Productions, Bolton Dying Matters Group, National Council for Palliative Care (NCPC)

"Comedians Ardal O'Hanlon, Jenny Eclair, Dave Spikey, Ricky Tomlinson, Shappi Khorsandi and consultant physician-turned-comic Kevin Jones tackle the biggest taboo of them all in the short film 'Dying for a Laugh'. Joking, reflecting and ultimately considering their own deaths, the comedians hope their involvement will encourage others to talk more openly and more often about death and other end of life issues."

<https://www.dyingmatters.org/page/dying-laugh>  
[https://www.youtube.com/watch?v=VwLH\\_l7uZ-Q](https://www.youtube.com/watch?v=VwLH_l7uZ-Q) trailer  
<https://vimeo.com/23310286> trailer

### Dying in Your Mother's Arm

2020

22.20 Minutes

Director: John Beder

Produced by: Donald Stader, Mark Brady, Rachel Donihoo, Gar LaSalle, Dominic Bagnoli  
A palliative care doctor on finding a "good death" for children in the worst situations.

<https://www.nytimes.com/video/opinion/10000007249913/dying-in-your-mothers-arms.html?playlistId=video/opinion>

### Dying to Live

2019

94 Minutes

Director: Richard Todd

Produced by: Trish Duke.

"Three hours of honest and intimate footage brings us into the homes of patients and families who openly share how they faced the rollercoaster ride from diagnosis through the progression of a terminal disease...they talk about common fears and struggles, how they coped...or didn't, thoughts of suicide, funerals, reactions of friends and family...and more."

<https://www.dyingtolive.com.au/>  
<https://itunes.apple.com/au/movie/dying-to-live/id1446374236>

### Dying to Live

2015

57 Minutes

Documentary about transplant donors and recipients.

<https://www.youtube.com/watch?v=0tYgbtedkss> video  
<https://www.youtube.com/watch?v=SFJ7rznIBdQ> trailer

### Dying Wish

Produced by: Karen van Vuuren & Francesca Nicosia, Dying Wish Media.

Directed by: Karen van Vuuren.

"Michael's "dying wish" was to show others that what is called 'patient refusal of nutrition and hydration' resulted in a gentle death. His own research showed relatively little information on stopping drinking and eating at the end of a terminal illness. What little research he found indicated a more humane end. Michael wanted to dispel common misconceptions that the dying person feels hunger and thirst once they choose this very natural route to an expected death."

<http://www.programsforelderly.com/documentary-death-dying-wish.php>

Empathy: The Human Connection to Patient Care

[http://www.youtube.com/watch?v=cDDWvj\\_q-o8](http://www.youtube.com/watch?v=cDDWvj_q-o8)

The End

NPR

Radio programs on end-of-life issues and death. Text is also available.

<http://www.npr.org/programs/death/trns.html>

### **Roundtable Discussion: End-of-Life Issues**

Monday November 3rd

*All Things Considered*

### **The Story of Helen Payne (Part One)**

Tuesday November 4th

*All Things Considered*

### **The Story of Helen Payne (Part Two)**

Wednesday November 5th

*All Things Considered*

### **The Missoula Demonstration Project**

Thursday November 6th

*All Things Considered*

### **The Place of Palliative Medicine**

Friday November 7th

*All Things Considered*

### **Coping with Death: A Personal Story**

Friday November 14th

*Morning Edition*

### **Roundtable: Grief and Bereavement**

Tuesday November 25

*All Things Considered*

[Do it Yourself Funerals](#)

Monday December 8  
*Morning Edition*

[A Critique of the Rule of the Double Effect](#)

Thursday December 11  
*All Things Considered*

[Doctors and Death](#)

Sunday January 4, 1998  
*Weekend All Things Considered*

[Reincarnation: Tibetan Buddhism](#)

Saturday January 10, 1998  
*Weekend Edition Saturday*

[Death & Society](#)

Sunday January 25, 1998  
*Weekend Edition Sunday*

[Unknown Soldier](#)

Tuesday February 3, 1998  
*All Things Considered*

[Funeral Homes](#)

Tuesday February 3, 1998  
*All Things Considered*

[Slow Code](#)

Wednesday February 11, 1998  
*All Things Considered*

[Burial Society](#)

Sunday March 8, 1998  
*Weekend All Things Considered*

[Alternative Funerals](#)

Tuesday March 10, 1998  
*Morning Edition*

[Who Will Remember Me?](#)

Thursday April 2, 1998  
*Morning Edition*

End Game

2018

40 Minutes

“Facing an inevitable outcome, terminally ill patients meet extraordinary medical practitioners seeking to change our approach to life and death.”

<https://www.netflix.com/title/80210691>

End of Life - Aging Matters

NPT Reports

<https://www.youtube.com/watch?v=uzfcvptgJ2c>

End of Life Wishes

2013

5 Minutes

“Nila J. Webster was diagnosed with stage 4 lung cancer in July 2010. In this video she addresses all types of planning for the end of life, ranging from decisions about complex medical treatments, to completion of a health care proxy, to the notes she has written in advance to family and loved ones. She also covers the practical issues, such as who will care for her cat and which realtor is prepared to sell her house. Nila's attention to every detail gives her peace of mind and ensures that both she and her family will be supported through the end of her life. Nila also speaks about the value of compassionate care in the medical setting. She has recognized that the value of open communication between physicians, patients, and caregivers is in itself palliative. Since her diagnosis, Nila has been invited to be on the faculty of the CME Resiliency Conference sponsored by the Benson-Henry Institute for Mind Body Medicine at Massachusetts General Hospital, where she has spoken about the value of compassionate care. She has also written of her experiences for several peer-reviewed journals, including the Annals of Internal Medicine.”

<https://www.youtube.com/watch?v=FoGHWwti0OQ&list=PL8C8C09B1A5837E08&index=5>

Engendering Empathy

2015

11 Minutes

[https://www.youtube.com/watch?v=HXRIIN\\_tZ4Ww&list=PL8C8C09B1A5837E08&index=7](https://www.youtube.com/watch?v=HXRIIN_tZ4Ww&list=PL8C8C09B1A5837E08&index=7)

Extremis

6-16-16

24.42 minutes

Netflix

“This documentary is a view into the daily dilemmas that occur in an ICU as doctors, patients, and families face the inevitability of death, though they realize it at different time. It’s a fascinating conversation to watch, as any viewers will inevitably realize that they’ll face the same conversations themselves at some point. Nothing can truly prepare anyone for that, but this documentary is a good place to start the conversation.”

## Faces of Palliative Care

7-21-14

45.20 minutes

"Many of us will spend the final days of our lives in palliative care -- but many Canadians are unsure about what palliative care really is. Two years in the making, this moving documentary provides a window into the world of palliative care through the stories of the people who live and die there and the dedicated medical staff who provide care and support. The documentary was produced for the University of British Columbia Faculty of Medicine, Department of Family Practice by Media Services at St. Paul's Hospital in Vancouver, Canada and was shot at a number of different palliative care facilities in that city. "Faces of Palliative Care" shows that today, with new drugs and a collaborative approach to care, palliative care programs can provide comfortable and meaningful end of life experiences for patients and their families.

<https://www.youtube.com/watch?v=p2pv5YLH1B8>

## Facing Death

2010

54 minutes

PBS Frontline Video

Directors: Miri Navasky & Karen O'Connor

"In Facing Death, FRONTLINE gains extraordinary access to The Mount Sinai Medical Center...to take a closer measure of today's complicated end-of-life decisions. In this intimate, groundbreaking film, doctors, patients and families speak with remarkable candor about the increasingly difficult choices people are making at the end of life: when to remove a breathing tube in the ICU; when to continue treatment for patients with aggressive blood cancers; when to perform a surgery; and when to call for hospice."

<https://www.pbs.org/wgbh/pages/frontline/facing-death/> video

<https://www.pbs.org/wgbh/pages/frontline/facing-death/etc/readings-links.html> readings and links

<https://www.pbs.org/wgbh/pages/frontline/facing-death/facts-and-figures/> facts and figures

*Palliative Care Issues:* goals of care, shared decision-making, communication, death with dignity

## Facing Mortality: How to Talk to Your Doctor

February 10, 2015

by Priyanka Boghani

<https://www.pbs.org/wgbh/frontline/article/facing-mortality-how-to-talk-to-your-doctor/>

## Final Call

2007

45 Minutes

Produced by: Journey Man Productions.

"I do not want to be locked up in a nursing home where all you get is bingo and sing-songs", states Ruth Mackinnon. Doctors worry that the popularity of the right to death movement reflects a growing view that to be old and in need of care is to lack dignity and be a burden.... Thanks to medical advances, people can now live on for years after a stroke or heart-attack. Is it naïve and patronizing to discount the feelings of those who

choose death over dependency on others? Or will condoning suicide simply create more stigma about aging and lead to people being pressured to kill themselves? As the population of the Western world ages, the euthanasia debate can only get more topical."

<https://www.journeyman.tv/film/3565>

#### Frontline – Facing Death videos

<https://www.pbs.org/wgbh/pages/frontline/facing-death/>

##### The Big Issues

Excerpts from FRONTLINE's conversations with doctors and family members who were part of this report.

<https://www.pbs.org/wgbh/pages/frontline/facing-death/the-big-issues/>

##### Guide When the time comes, how will you decide?

People with advanced illness may pursue aggressive treatments in the hope of finding a cure. Explore ways to assess the risks and benefits of treatment options.

<https://www.pbs.org/wgbh/pages/frontline/facing-death/educational-module/living-serious-illness/>

Interviews with Physicians about communication with patients, treatment decisions

Jerome Groopman - Chief of Experimental Medicine, Beth Israel Deaconess Medical Center, Boston

<https://www.pbs.org/wgbh/pages/frontline/facing-death/interviews/jerome-groopman.html>

David Muller - Dean of Medical Education at the Mount Sinai School of Medicine, he is also a physician and co-founder of the Mount Sinai Visiting Doctors Program, NYC

<https://www.pbs.org/wgbh/pages/frontline/facing-death/interviews/david-muller.html>

Judith Nelson – palliative care and critical care, Mount Sinai, NYC

<https://www.pbs.org/wgbh/pages/frontline/facing-death/interviews/judith-nelson.html>

Karen Osman – oncologist and hematologist, Mount Sinai, NYC

<https://www.pbs.org/wgbh/pages/frontline/facing-death/interviews/keren-osman.html>

#### A Good Death

2010

45 Minutes

Produced by: Journey Man Productions.

"What do you do when you're told you're going to die? In this heart-rending documentary four Australians face this very question, as they search for that elusive good death. 'I mean we talk about the journey of life ... Well what about the journey of death?' asks one terminally ill patient. Unfortunately, while so often this journey begins



with defiance, the sad reality is that modern death is becoming increasingly drawn out and long suffering often overwhelms people. Palliative care centers like Sacred Heart aim to make this journey easier and provide relief from the pain that usually comes with being terminally ill. But the battle is not against pain alone. In modern society people are reluctant to accept death as a part of life. 'We want to look after them. We want to cure them ... we've set up a situation where it's difficult to die peacefully.' Yet palliative care remains under-funded - it appears helping people die a 'good death' is a service society doesn't recognize."

<https://www.journeyman.tv/film/5023>

<https://www.youtube.com/watch?v=x1btbCxmMCQ>

## Griefwalker

2012

70 minutes

Director: Stephen Jenkinson

"This documentary introduces us to Stephen Jenkinson, once the leader of a palliative care counselling team at Toronto's Mount Sinai Hospital. Through his daytime job, he has been at the deathbed of well over 1,000 people. What he sees over and over, he says, is "a wretched anxiety and an existential terror" even when there is no pain. Indicting the practice of palliative care itself, he has made it his life's mission to change the way we die - to turn the act of dying from denial and resistance into an essential part of life."

<https://www.nfb.ca/film/griefwalker/>

Link for viewing: <https://www.nfb.ca/film/griefwalker/>

*Palliative Care Issues: Stages of grief*

## How Doctors Tell Their Patients They're Dying

2015

5 Minutes

Producer: Frontline

"Doctors who need to break the worst possible news to patients don't just have to overcome their own discomfort about talking about death. They must also overcome the fact that some patients and loved ones aren't prepared to accept the news.

"Frequently, as an emergency surgeon, I'm meeting somebody for the first time and they have no idea they could die from their disease," explains Dr. Zara Cooper, an emergency surgeon with palliative care training. One of her patients at Brigham and Women's Hospital in Boston, Clyde Earle, had been undergoing treatment for advanced cancer for a year. He and his newlywed wife, Audrey, believed he had many more months to live, but it soon became clear he did not. Cooper started the end-of-life conversation. But as Earle's condition worsened, she brought in Dr. Kathy Selvaggi, a senior palliative care physician who specializes in helping patients who are near death. Our short film, below, shows how Selvaggi was able to gently but clearly convey to Audrey that her husband would not be able to leave the hospital. It offers a rare look at how physicians like Selvaggi manage to convey painful truths. "It is a process," said Selvaggi. "And I think it is very hard to come to the realization that you're dying."

<https://www.pbs.org/wgbh/frontline/article/its-very-hard-to-come-to-the-realization-that-youre-dying/>

### How to Die in Oregon

2011

108 minutes

Director: Peter Richardson

“In 1994, Oregon became the first state to legalize physician-assisted suicide. As a result, any individual whom two physicians diagnose as having less than six months to live can lawfully request a fatal dose of barbiturate to end his or her life. Since 1994, more than 500 Oregonians have taken their mortality into their own hands. In *How to Die in Oregon*, filmmaker Peter Richardson gently enters the lives of the terminally ill as they consider whether – and when – to end their lives by lethal overdose. Richardson examines both sides of this complex, emotionally charged issue. What emerges is a life-affirming, staggeringly powerful portrait of what it means to die with dignity.”

<http://www.howtodieinoregon.com/about-the-movie.html>

Link for viewing: <http://www.howtodieinoregon.com/see-the-film.html>

*Palliative Care Issues*: Right to die, Choice in dying

### How to Have an End of Life Discussion

13.46 minutes

Producer: VHA Employee Education System

<https://www.youtube.com/watch?v=JtkgTzCSzqk>

also available at: [vaww.ees.lrn.va.gov](http://vaww.ees.lrn.va.gov)

Delivering difficult news to a Veteran is never easy —especially in matters of life and death. Many providers may not have been taught how to handle these delicate conversations. Learning a strategy on how to have such a conversation can help deliver information accurately and compassionately. This training demonstrates how to deliver difficult news with compassion. We recommend using an approach that follows the acronym: S-P-I-K-E-S., which stands for “Setting”, “Perception”, “Invitation”, “Knowledge”, “Empathy” and “Strategy”. In this program, you will watch a physician use the SPIKES protocol with a Veteran nearing the end of her life.

## In My Time of Dying

2000

58 Minutes

Produced by: KBTC.

"In My Time of Dying explores the way we approach the end of life in America. Medical experts and spiritual leaders are woven together with intimate portraits of people facing imminent death. The result is a unique and important conversation about how we meet death, how we support our loved ones in their time of dying, how we cultivate hope in these times, and how to engage in conversations."

<https://video.kbtc.org/video/kbtc-documentaries-in-my-time-of-dying/>

## In the End

2010

Produced by: Screen Australia. State Government Of Victoria.

Directed by: Charlotte Roseby

"Old people used to die at home, surrounded by their loved ones. Now they are ending up in intensive care, connected to machines and surrounded by strangers. Intensive Care specialist Dr. Charlie Corke is committed to give his elderly patients every chance to get better, but he knows that sometimes the treatment is only lengthening the dying process, causing discomfort and distress. This documentary takes us on a journey of a doctor who is trying to balance his own enthusiasm for medical technology with an acceptance that, after a long and healthy life, it's OK to go. 'In the End' is a beautiful and profound film that follows the journey of patients, their families and their doctor dealing with a modern-day dilemma of our own making. "What makes it so distressing, says Dr Charlie Corke, a senior specialist working in intensive care, is that it takes an immense amount of invasive technology to try and support someone's failed organs. Not just a neat little intravenous drip, but an array of suction tubes, catheters, feeding tubes and breathing tubes surgically inserted. It can also mean sedating patients and tying their wrists to the bed to make sure that in their confusion they don't pull out all the tubes...Charlie certainly doesn't believe in denying anyone treatment, but he asks: 'Just because we have the diagnostic and therapeutic options available, should we always use them?' "

<http://in-the-end.com.au/>

## The Last Chapter - End of Life Decisions

12-28-10

56.48 minutes

<https://www.youtube.com/watch?v=8jKUZ8IS9b4>

Individuals battling end-stage disease reflect on how they want to live their final weeks in The Last Chapter: End of Life Decisions. The one-hour program examines end-of-life care options and the need for advance directives including a living will.

## Last Rights: Facing End-Of-Life Choices

Produced by: Karen Cantor, Chris Gavin. Singing Wolf Documentaries.

" 'Last Rights: Facing End-of-Life Choices,' features physician, Scott Nelson, MD from Cleveland, MS, whose own father, Elbert Nelson, had suffered a terminal illness narrates the film. Relatives of the other three main characters tell their stories about the now-deceased patients: Merian Frederick, of Ann Arbor, Michigan, who was succumbing to Amyotrophic Lateral Sclerosis (ALS), an incurable and fatal disease; Peggy Sutherland in Oregon, terminally ill with lung cancer, and Doug Gladstone in Maryland, dying from liver cancer, spending his last days at home. His wife of 25 years tells about what she sees as a 'typical hospice experience.' The youngest daughters of Peggy Sutherland and Merian Frederick talk about their mothers' hastened deaths – one sanctioned by law and the other illegal. Each shares riveting personal stories about their loved ones' final days and the decisions they made. Expert commentary is woven throughout the film to help viewers understand divergent viewpoints: religious, medical, philosophical, legal, and personal."

[www.lastrightsfilm.org](http://www.lastrightsfilm.org)

## Lessons for the Living

2010

Produced by: Leslie Koren Shani Hashaviah.

Directed by: Lily Henderson.

"Lessons for the Living reveals a unique subculture of Hospice volunteers as they reflect on their experiences and philosophies of life and death. Among them, a teenager escapes from the drama of high school, a hard-edged corporate lawyer searches for meaning and a terminally ill woman faces her own death with unexpected humor and grace."

<http://www.lessonsforthelivingfilm.com/>

## Letting Go: A Hospice Journey

5-24-16

30.10 minutes

<https://www.youtube.com/watch?v=tbH4v-Oktao>

## LIFE Before Death

2016

81 Minutes

Produced by: Moonshine Movies.

Developed in part with the Lien Foundation's "Life Before Death Campaign."

Developed with the assistance of Screen Australia and Film Victoria, and supported by the Lance Armstrong Foundation.

" 'LIFE Before Death' is a multi-award winning documentary series that asks the fundamental question underpinning our mortality. This beautifully filmed journey takes us to 11 countries as we follow the remarkable health care professionals battling the sweeping epidemic of pain that threatens to condemn one in every ten of us to an agonizing and shameful death. Through the eyes of patients and their families we discover the inherent humanity that empowers the best of us to care for those beyond cure. This is an intimate hopeful and life-affirming collection of stories about living well and dying better, advocating for making the most of every moment in our life before death."

The objective of the Lien Foundation's "LIFE Before Death Campaign" is to dismantle the taboos surrounding Death & Dying by encouraging people to openly talk about Death and place the concept of dying in a more positive, empowering light. Life Before Death Campaign hopes to break the silence surrounding end-of-life issues, raise awareness about hospice palliative care, and improve care for the dying.

" 'LIFE Before Death' clips are freely available to any pain, palliative care, hospice and end of life health professionals around the world to download here and use for training and advocacy.

source: [lifebeforedeath.com/movie](http://lifebeforedeath.com/movie)

<http://lifebeforedeath.com/movie/>

<https://vimeo.com/ondemand/lifebeforedeath>

## Live and Let Die

2002

34 Minutes

Produced by: Journey Man Productions

"On average, at least 10 terminally ill people legally die by euthanasia every day in Holland – a figure that would provoke outrage and controversy in most societies. The Dutch claim that doctor assisted suicide is already widely practiced throughout the West, but they just don't acknowledge it. "In other countries they don't talk about it – we do," says Dr Aycke Smook. It is the Dutch policy of tolerance that has allowed euthanasia to, gain broad support. However, unease remains about what the Dutch have done, even amongst those who believe euthanasia should be an option. They are concerned that unless society shows more compassion, the elderly and infirm may begin to feel forced towards euthanasia for lack of alternatives. "We should be very careful not to talk about euthanasia as a normal way to end your life," Clemence Ross of the Christian Democrats.

<https://www.journeyman.tv/film/1257>

transcript: [https://www.journeyman.tv/film\\_documents/1257/transcript/](https://www.journeyman.tv/film_documents/1257/transcript/)

## Living & Dying: A Love Story

2018

44.54 minutes

"Filmed in cinéma vérité style, this powerful film is about so much more than Death with Dignity: it is an invitation to change the end-of-life narrative by embracing living and dying with equal measures of love."

<https://vimeo.com/257939456> watch for free

<https://sharewisdom.tv/living-dying-love-story-documentary/> download

## Living Old

2016

55 Minutes

"With 35 million elderly people in America, "the old, old" — those over 85 — are now considered the fastest growing segment of the U.S. population. While medical advances have enabled an unprecedented number of Americans to live longer and healthier lives, this new longevity has also had unintended consequences. For millions of Americans, living longer also means serious chronic illness and a protracted physical decline that can require an immense amount of care, often for years and sometimes even decades. Yet just as the need for care is rising, the number of available caregivers is dwindling. With families more dispersed than ever and an overburdened healthcare system, many experts fear that we are on the threshold of a major crisis in care. [Explore more stories on the [original website](#) for *Living Old*.]"

<https://www.pbs.org/wgbh/frontline/film/livingold/>

## Love and Cancer at 27

2015

6 Minutes

Allen Chou was just 27 when he was diagnosed with a brain tumor. His girlfriend, Linda Sim, was 25. We usually think of death and dying as problems for the elderly. Usually, when a couple needs to make decisions about how to spend their last days together, they are late in life and can look back on decades of memories. Allen and Linda had only been together for a few years, and though they weren't kids anymore, they were both young at heart. Linda keeps a video of him singing and dancing to Justin Bieber. When they saw a preview for *The Fault in Our Stars*, a film about two young people with cancer, Linda saw herself and Allen in the characters. "I was like, oh my God," Linda says. "It just reminds me so much of our journey together." It wasn't long before Allen's doctor gave them terrible news: He had only weeks to live. Linda climbed into his hospital bed, and they made a decision about how to spend the time they had left together. "I was hoping for a miracle, but ... you have to be rational," she said. You can see what they decided to do in the digital film.

<https://www.pbs.org/wgbh/frontline/article/love-and-cancer-at-27/>

There is also a podcast at this site.

## A Matter of Time

Producer: Solstice Films

"Nurses and volunteers in hospice deal with dying patients everyday. How do they cope with so much loss? How do they face grieving families and dying people in pain day after day? It's not easy. 'But in A Matter of Time' you will find out how they do it."

<http://www.aquariusproductions.com/>

## MOLST Videos

MOLST: Honoring Patient Preferences

2012

32 Minutes

"The Role of MOLST in New York State helps guide professionals through the MOLST process. It educates healthcare providers and first responders about the MOLST program and instructs physicians and other medical personnel on how to properly complete the form. MOLST, the Medical Orders for Life-Sustaining Treatment is an end-of-life care program for New York State and a nationally-recognized POLST paradigm program. MOLST is based on effective communication of patient wishes, documentation of medical orders on a brightly colored form, and a promise by health care professionals to honor these wishes."

<https://www.youtube.com/watch?v=TG-f53clxj0&list=PL8C8C09B1A5837E08&index=13>

Creating a Care Plan to Support MOLST Decisions, from the 8-Step MOLST Protocol

A care plan for in-home hospice care is developed with a patient's family; this plan supports the MOLST decisions and ensures the patient's wishes are honored.

<https://www.youtube.com/watch?v=XdR23cBAAssw&list=PL8C8C09B1A5837E08&index=17>

MOLST Form Completion: eMOLST Section 1 – Discussion

<https://www.youtube.com/watch?v=viJT77aSvVo&list=PL8C8C09B1A5837E08&index=6>

Step 1: Prepare for Discussion, from the 8-Step MOLST Protocol

<https://www.youtube.com/watch?v=b-gBJR9Z4No&list=PL8C8C09B1A5837E08&index=14>

eMOLST Section 2 - Resuscitation Instructions

<https://www.youtube.com/watch?v=vjUQD9huKnY&list=PL8C8C09B1A5837E08&index=8>

eMOLST Section 3 - Life-Sustaining Treatment

[https://www.youtube.com/watch?v=O3\\_Tz5k4LUQ&list=PL8C8C09B1A5837E08&index=9](https://www.youtube.com/watch?v=O3_Tz5k4LUQ&list=PL8C8C09B1A5837E08&index=9)

eMOLST Section 4 - Consents

<https://www.youtube.com/watch?v=VO4Jh0zjvGs&list=PL8C8C09B1A5837E08&index=10>

Steps 2-5: A Goals for Care Discussion, from the 8-Step MOLST Protocol

<https://www.youtube.com/watch?v=VhmzBJTZm5U&list=PL8C8C09B1A5837E08&index=15>

eMOLST Section 6 - Signature

<https://www.youtube.com/watch?v=QhO2a1mJpmg&list=PL8C8C09B1A5837E08&index=11>

eMOLST Section 7 - View + Print

<https://www.youtube.com/watch?v=i7lRefoCQNI&list=PL8C8C09B1A5837E08&index=12>

Steps 6 & 7: Completing the MOLST Form, from the 8-Step MOLST Protocol

Dr. George Giokas uses Steps 6-7 of the 8-Step MOLST Protocol to complete the New York MOLST Form for a patient with his family. The discussion addresses choices related to many aspects of end-of-life care including: resuscitation, intubation & mechanical intubation, feeding tubes, IV fluids, and antibiotics. Step 6 & 7 are: 6. Use MOLST to guide choices and finalize patient/family wishes. 7. Complete and sign the MOLST form. Develop a care plan that supports the patient's decisions.

<https://www.youtube.com/watch?v=Utxaw9eO2mo&list=PL8C8C09B1A5837E08&index=16>

MOLST Form: Review & Renew (Step 8 of the 8-Step MOLST Protocol)

See Dr. George Giokas walk a patient's family through the New York MOLST Form. In this clip he talks about the Review & Renewal section of the MOLST form and explains its use to a patient's family after their father had a massive stroke. He also reflects back on what the family is experiencing and wraps up the conversation with the hospice care plan to support the MOLST decisions.

<https://www.youtube.com/watch?v=s91h6BekdG4&list=PL8C8C09B1A5837E08&index=26>

MOLST Form: Feeding Tube & IV Fluids

See Dr. George Giokas walk a patient's family through the New York MOLST Form. In this clip he discusses "Artificially Administered Fluids & Nutrition" and helps the family choose "no feeding tube" and "no IV fluids" for their elderly father who suffered a massive stroke. The conversation is challenging, as the family members want to make sure their Dad is not hungry or suffering, but at the same time, he always loved to eat and would want careful hand feeding rather than a tube. The family also learns about the challenges with IV fluids - they may not help and could cause their father to become uncomfortable, particularly if fluid is in his lungs.

[https://www.youtube.com/watch?v=\\_dSz3UGAlwI&list=PL8C8C09B1A5837E08&index=22](https://www.youtube.com/watch?v=_dSz3UGAlwI&list=PL8C8C09B1A5837E08&index=22)

Discussing Feeding Tubes & Artificial Nutrition & Hydration

Dr. Joel Potash & Dr. Bob McCann briefly address the benefits, burdens & challenges of artificial hydration & nutrition and feeding tubes.

<https://www.youtube.com/watch?v=6fNcxIh5mxE&list=PL8C8C09B1A5837E08&index=37>

MOLST Form: Antibiotics

See Dr. George Giokas walk a patient's family through the New York MOLST Form. In this clip he discusses "Antibiotics" and helps the family choose "determine use or limitation of antibiotics when infection occurs" for their elderly father who suffered a massive stroke. The family learns about the challenges with antibiotics - that sometimes simple antibiotics may help, but also that infections are very common towards the end-of-life and that antibiotics also have unintended consequences, including yeast infections or diarrhea.

<https://www.youtube.com/watch?v=vqMmZPM4OFg&list=PL8C8C09B1A5837E08&index=23>



#### Discussing Resuscitation (CPR vs DNR)

Dr. Joel Potash, Dr. David Lee & Dr. Manish Shah briefly address CPR and the fact that DNR on a MOLST does NOT mean "do not treat." DNR means allow natural death.

<https://www.youtube.com/watch?v=pCK7AWzqyo0&list=PL8C8C09B1A5837E08&index=36>

#### Thinking In Crisis: Medical Professionals & Families

Dr. David Korones briefly addresses the importance of having advance care planning conversations and making end-of-life MOLST decisions prior to crises.

[https://www.youtube.com/watch?v=Bi8ROyuZ\\_HE&list=PL8C8C09B1A5837E08&index=35](https://www.youtube.com/watch?v=Bi8ROyuZ_HE&list=PL8C8C09B1A5837E08&index=35)

#### MOLST Form: Hospitalization

See Dr. George Giokas walk a patient's family through the New York MOLST Form. In this clip he discusses "Future Hospitalization/Transfer" and helps the family choose "do not send to the hospital unless pain or severe symptoms cannot be controlled" for their elderly father who suffered from a massive stroke. The patient's preference is to remain at home and hospice home care will be used to support this decision.

<https://www.youtube.com/watch?v=FYVO1Z9XFgE&list=PL8C8C09B1A5837E08&index=21>

#### MOLST Form: Resuscitation Instructions

See Dr. George Giokas walk a patient's family through the New York MOLST Form. First he discusses Section A: Resuscitation Instructions and helps the family choose DNR for their elderly father who suffered from a massive stroke.

<https://www.youtube.com/watch?v=vIVKoxp5DRs&list=PL8C8C09B1A5837E08&index=19>

#### MOLST Form: Intubation & Mechanical Ventilation

See Dr. George Giokas walk a patient's family through the New York MOLST Form. In this clip he discusses "Intubation & Mechanical Ventilation" and helps the family choose "do not intubate" (DNI) for their elderly father who suffered from a massive stroke.

[https://www.youtube.com/watch?v=GtjQ\\_8Mp4Ls&list=PL8C8C09B1A5837E08&index=20](https://www.youtube.com/watch?v=GtjQ_8Mp4Ls&list=PL8C8C09B1A5837E08&index=20)

#### MOLST Form: Other Instructions

See Dr. George Giokas walk a patient's family through the New York MOLST Form. In this clip he discusses "Other Instructions" and helps the family reaffirm the choice to keep their elderly father at home, receiving hospice care.

<https://www.youtube.com/watch?v=4MU2-ObAlrM&list=PL8C8C09B1A5837E08&index=24>

#### Creating a Care Plan to Support MOLST Decisions, from the 8-Step MOLST Protocol

A care plan for in-home hospice care is developed with a patient's family; this plan supports the MOLST decisions and ensures the patient's wishes are honored.

<https://www.youtube.com/watch?v=XdR23cBAssw&list=PL8C8C09B1A5837E08&index=17>

#### Hospice Home Care Supports MOLST Decisions, from the 8-Step MOLST Protocol

A care plan for in-home hospice care is developed with a patient's family; this plan supports the MOLST decisions and ensures the patient's wishes are honored. The patient's family shares their perspectives after the plan has been implemented.

<https://www.youtube.com/watch?v=mrfUYGEOOj8&list=PL8C8C09B1A5837E08&index=18>

## The Nurse with the Purple Hair

2017

50 minutes

Director: Sean S. Cunningham

[https://www.amazon.com/Nurse-Purple-Hair-Michelle-Lasota/dp/B072KFWQBY/ref=sr\\_1\\_1?crid=3V59Y5AJOIETQ&keywords=the+nurse+with+the+purple+hair&qid=1561748572&s=instant-video&sprefix=the+nurse+with+%2Cinstant-video%2C121&sr=1-1](https://www.amazon.com/Nurse-Purple-Hair-Michelle-Lasota/dp/B072KFWQBY/ref=sr_1_1?crid=3V59Y5AJOIETQ&keywords=the+nurse+with+the+purple+hair&qid=1561748572&s=instant-video&sprefix=the+nurse+with+%2Cinstant-video%2C121&sr=1-1)

“The Nurse with the Purple Hair is a documentary/educational movie about Hospice Care Workers, the people who take care of the dying. It is meant to honor them and all that they do for us.”

## On Our Own Terms: Moyers on Dying

2000

Four part PBS series by journalist Bill Moyers that focuses on end-of-life care in the US

“This film series explores how society can improve the care that is received near the end of one’s life. Discussions with terminally ill patients in their final days cover frustrations with health insurance and financial issues. Ethical issues include doctor assisted suicide. Possible avenues of making a better system are looked at. The documentary's website provides a wealth of knowledge on topics such as financial guides to help pay for a family member who is dying, advance care directives, the role of family caregivers, how to be with a dying person and much more. For an intimate look, the website features a personal diary of one patient who is dying detailing what he is going through. In addition to his perspective, there are logs entered from his personal friend and nurse as well.”

<http://www.pbs.org/program/our-own-terms/>

[https://www.amazon.com/A-Death-of-Ones-Own/dp/B007TSCL2Q/ref=sr\\_1\\_1?keywords=on+our+own+terms&qid=1561751292&s=instant-video&sr=1-1](https://www.amazon.com/A-Death-of-Ones-Own/dp/B007TSCL2Q/ref=sr_1_1?keywords=on+our+own+terms&qid=1561751292&s=instant-video&sr=1-1)

### 1. Living with Dying

86 minutes

A pediatrician becomes a patient. A sufferer of Lou Gehrig's disease, communicating her treatment wishes through eye movements. Through frank interviews, Moyers exposes the complicated forces behind choices about death.

### 2. A Different Kind of Care

86 minutes

Our cultural attitudes towards suffering are sometimes used as a rationale to withhold medications--attitudes that palliative-care physicians hope to change in order to make dying less frightening and less painful.

### 3. A Death of One's Own

86 minutes

This episode turns an eye to the caregivers, both professional and personal, as they weigh a terminal person's wishes against their own beliefs and responsibilities. Moyers also converses with patients who wish to hasten death to reduce their suffering.

#### 4. A Time to Change

86 minutes

The Balm of Gilead project puts the comfort and care of a hospice into a hospital setting, providing dignified, loving treatment for indigent patients. There, the caregivers help find financial resources for the uninsured and support family members.

#### Palliative Care, a Different Voice in Healthcare: Timothy Ihrig at TEDxDesMoines

2013

13.29 minutes

Healthcare expenditure is the biggest threat to America's economy, due to an aging population and a system in which physicians are often paid based on what they do to their patients, rather than fostering a patient's overall quality of life. Dr. Timothy Ihrig explains the benefits of palliative care that prioritizes a patient's personal values and navigates a serious illness from diagnosis to death with dignity and compassion.

<https://www.youtube.com/watch?v=BI-CnsKyOuk>

#### Palliative care and the human connection: Ten steps for what to say and do.

Diane Meier

2-19-13

<http://www.youtube.com/watch?v=7kQ3PUyhmPQ>

#### Palliative Care: Improving Quality of Life for People with Serious Illnesses

This video explains palliative care in the words of a palliative care patient and several care providers. Discusses the distinction between palliative care and hospice, the interdisciplinary team, reframing the focus of treatment and of one's life for persons with life-limiting illness.

<https://www.youtube.com/watch?v=Y4ZsucFf41Q>

#### Palliative Care from Diagnosis fo Death

2017

Produced by: Primary Palliative Care Research Group

“Many people still associate palliative care with care in the terminal stage of cancer, and patients with cancer remain more likely to receive it than those with other illnesses. It is often delayed until the last weeks or days of life once the illness is advanced and disease focused treatments are no longer effective. However, late palliative care is a missed opportunity to do better for patients, families, and health services. Scott Murray, professor of primary palliative care at the university of Edinburgh, and colleagues set out a rationale for early palliative care based on the three typical trajectories of functional decline towards the end of life (rapid, intermittent, and gradual).”

Quality of Death, End-of-Life Care in America: Inside Out  
2014

Produced by: Anna Bensted, Inside Out, WBUR Boston.

"In this documentary Gotbaum follows several patients in their last months as they confront some of the most difficult decisions of their lives – whether they should pursue aggressive and sometimes painful medical treatments that may extend survival or focus on how to maintain the best quality of life in their final months. She reports on how trends in the American healthcare system influence their decisions and she talks with family members who are often the ones pushing for aggressive treatments."

<http://archives.wbur.org/insideout/documentaries/qualityofdeath/>

<https://www.youtube.com/watch?v=8EehdHsIYZM> trailer

The Self Made Man

2014

60 Minutes

Produced by: Susan Stern, New Day Films.

"Is it ever rational to choose death? On Independence Day at Stern Ranch in central California, 77-year-old solar energy pioneer Bob Stern finds out he is seriously ill - possibly dying. Meanwhile, an elderly in-law is slowly declining on artificial life support in a hospital. Bob decides to cheat that fate and take his own life. His family tries to stop him. Bob sets up a video camera. Daughter Susan Stern (Barbie Nation) tells the story of her father's quirky, inspiring life and the difficult end-of-life choices faced by an aging population."

<http://bernalbeach.com/the-self-made-man/>

<https://www.youtube.com/watch?v=8EehdHsIYZM> trailer

The Space Between

2015

Produced and Directed by: Kimberly Nunez-North and Travis North. Passion Projects.

"...Kenya is one of the poorest nations, with more than half of the country living under the poverty line. Most can't afford medical treatment so they die alone and in pain. For those who can enter the public hospitals, a painful existence awaits them as well: understaffed hospitals with minimal resources and multiple patients sharing a bed. Additionally, most hospitals do not offer Palliative care, an area of healthcare that focuses on relieving and preventing patients' suffering. 'The Space Between'...profiles 4 guests at The Living Room hospice as well as Juli McGowan Boit, a nurse practitioner and HIV volunteer in rural Kenya who was inspired to partner with local leaders to found the hospice."

<http://thespacebetweenoc.com/>

Starting a Conversation about Pediatric Palliative Care

<https://www.youtube.com/watch?v=hKK24Bp1eIQ>

## The Suicide Plan

2012

84 minutes

PBS Frontline

Produced by Miri Navasky & Karen O'Connor

"In this groundbreaking 90-minute film FRONTLINE explores the underground world of assisted suicide and takes viewers inside one of the most polarizing social issues of our time – told not only by the people choosing to die, but also by their "assisters," individuals and right-to-die organizations that put themselves in legal jeopardy by helping others to die."

<http://www.pbs.org/wgbh/frontline/film/suicide-plan/>

*Palliative Care Issues: Choice in dying, Death with dignity*

## Suicide Tourist

1007

56 Minutes

Produced by: Terence McKeown

Directed by: John Zaritsky

Frontline documentary following a Chicago native as he travels to Switzerland in order to take his life with help of a nonprofit organization that legally provides assistance.

<https://www.pbs.org/video/frontline-the-suicide-tourist/>

## Terry Pratchett: Choosing to Die

2011

59 Minutes

Director: Charlie Russell

Documentary about assisted dying.

<http://freedocumentaries.org/documentary/terry-pratchett-choosing-to-die#watch-film> video

<https://vimeo.com/229120539> video

<https://www.youtube.com/watch?v=xsvwhuOSApI> trailer

## Thoughtful MOLST Discussions: Hospital & Hospice Settings

2013

44 Minutes

"This full-length video features Dr. George Giokas using the 8-step MOLST Protocol and completing the New York MOLST Form. The story follows an elderly man and his family when he has a massive stroke after several years of functional decline. The conversation begins with discussions about prognosis and the patient's goals for care and values & beliefs. Then the MOLST is discussed and completed, and a care plan is developed. This video features active listening and discussion techniques to address death, dying, and end-of-life care. Dr. Giokas addresses each of the MOLST decisions that must be made near the end of life including resuscitation, intubation & mechanical ventilation, hospitalization, feeding tubes & IV fluids, antibiotics and other instructions. For more information about MOLST and eMOLST (electronic MOLST completion and the NYS eMOLST Registry) visit [CompassionAndSupport.org](http://CompassionAndSupport.org)"

<https://www.youtube.com/watch?v=gKseJkuuFuk&list=PL8C8C09B1A5837E08&index=3>

## Time of Death

Year: ?

Minutes: ?

Produced by: Showtime.

"What are the final weeks, days and very moments of life really like? 'Time of Death' offers an unflinching, intimate look at remarkable people facing their own mortality. Cameras follow these brave, terminally ill individuals as they live out the end of their lives, supported by family, friends, and dedicated healthcare and hospice workers who gently guide the process. This groundbreaking documentary series provides a tangible, hopeful reminder of the finite nature of our time here on earth."

<http://www.programsforelderly.com/documentary-death-final-call.php>

## Understanding Palliative Care

2013

31 Minutes

<https://www.youtube.com/watch?v=rH3tn-rIV8E>

## The Undertaking

2007

56 Minutes

Produced by: PBS FRONTLINE, Miri Navasky, Karen O'Connor.

"Thomas Lynch, 58, is a writer and a poet. He's also a funeral director in a small town in central Michigan where he and his family have cared for the dead -- and the living -- for three generations. For the first time, Lynch agreed to allow cameras inside Lynch & Sons, giving FRONTLINE producers Miri Navasky and Karen O'Connor rare, behind-the-scenes access -- from funeral arrangements to the embalming room -- to the Lynches' world for this film, 'The Undertaking.' "

<https://www.pbs.org/wgbh/pages/frontline/undertaking/>

University of Buffalo School of Social Work (Producer). (2012, January 9, 2012). *Dr. Pam Miller: Oregon's Death with Dignity Act: Hospice Social Work and End-of-Life Decision-Making* <http://www.insocialwork.org/episode.asp?ep=87>

University of Buffalo School of Social Work (Producer). (2013, May 13, 2013). *Dr. Dona Reese: "A Friendly Face:" Addressing Barriers to Hospice Care for African American Clients by Hiring African American Social Workers* [Retrieved from <http://www.insocialwork.org/episode.asp?ep=119>

University of Buffalo School of Social Work (Producer). (2012, November 12, 2012). *Dr. Allan Barsky: Ethical Issues in End-of-Life Decision Making* [Retrieved from <http://www.insocialwork.org/episode.asp?ep=107>

#### A Very Short History of Death

2015

3 Minutes

Producer: Frontline

Editor: Jason M. Breslow

<https://www.pbs.org/wgbh/frontline/article/a-very-short-history-of-death/>

Vital Talk – videos for clinicians: <http://www.vitaltalk.org/clinicians>

Establish Rapport: <http://www.vitaltalk.org/clinicians/establish-rapport>

Track & Respond to Emotion: <http://www.vitaltalk.org/clinicians/track-respond-emotion>

Disclose Serious News: <http://www.vitaltalk.org/clinicians/disclose-serious-news>

Offer Prognostic Information: <http://www.vitaltalk.org/clinicians/offer-prognostic-information>

Conduct a Family Conference: <http://www.vitaltalk.org/clinicians/family>

Defuse Conflicts: <http://www.vitaltalk.org/clinicians/defuse-conflicts>

Reset Goals of Care: <http://www.vitaltalk.org/clinicians/reset-goals-care>

Bear Witness to the End: <http://www.vitaltalk.org/clinicians/bear-witness-end>

Stay Strong: <http://www.vitaltalk.org/clinicians/stay-strong>

Cultivating Your Skills: <http://www.vitaltalk.org/clinicians/cultivate-your-skills>

#### Why African-American Seniors are less likely to use hospice

2015

7.39 Minutes

Producer: PBS Newshour

<https://www.pbs.org/newshour/show/african-american-seniors-less-likely-use-hospice>

## Documentary Films about Dying in Prison

### Fault Lines Dying Inside: Elderly in Prison

Produced by: AlJazeeraEnglish

Directed by: Josh Rushing

"The US' massive prison population is getting older. Long sentences that were handed out decades ago are catching up with the American justice system. Prisons across the country are dedicating entire units just to house the elderly. During difficult economic times, the issue has hit a crisis point. Estimates are that locking up an older inmate costs three times as much as a younger one. How are prisons dealing with this issue? Who are the prisoners that are turning gray behind bars? Josh Rushing gains exclusive and unprecedented access to jails and prisons across the country to tell the story."

source: [aljazeeraenglish](http://aljazeeraenglish.com)

### Angola Prison Hospice: Opening the Door

Produced by: Open Society Institute Center on Crime, Communities & Culture and the Project on Death in America

Directed by: Edgar Barens

"Half of the 5,000 inmates at the maximum-security Louisiana State Penitentiary at Angola are serving life sentences, and it is estimated that 85 percent of them will grow old and die there. Edgar Barens's documentary examines one of the nation's first prison-based hospice programs, a program that notably incorporates inmate volunteers into the care of other dying inmates."

[www.soros.org](http://www.soros.org)

### One Last Shot

Produced and Directed by: Lisa R. Cohen.

Produced by: Lightworks Pictures in association with KPI, The Oprah Winfrey Network Original Documentaries.

Narration by: Forest Whitaker

" 'One Last Shot' takes viewers inside Louisiana's maximum security prison at Angola, where the average sentence is more than 90 years. The prisoners within its walls are the worst of the worst—rapists, kidnappers and murderers. With prison sentences so long, 85 percent will never again live in the outside world. Instead, they will grow old and die in Angola. "One Last Shot" documents an extraordinary hospice program where hardened criminals care for their dying fellow inmates. In doing so, they embark on a journey that may end in personal rehabilitation.

[www.oprah.com](http://www.oprah.com)

### Prison Terminal

Produced and Directed by: Edgar Barens.

" 'Prison Terminal' is a moving cinema verité documentary that breaks through the walls of one of America's oldest maximum security prisons to tell the story of the final months in the life of a terminally ill prisoner and the trained hospice volunteers—they themselves prisoners—who care for him. The film draws from footage shot over a six-



month period behind the walls of the Iowa State Penitentiary entering the personal lives of the prisoners as they build a prison-based, prisoner-staffed hospice program from the ground up. 'Prison Terminal' demonstrates the fragility, as well as the holistic benefits, of a prison-based, prisoner-staffed hospice program and provides a fascinating and often poignant account of how the hospice experience can profoundly touch even the forsaken lives of the incarcerated."

<https://www.prisonterminal.com/>

Served Out: Aging and Dying behind Bars

Produced and Directed by: Tim Gruber

" 'Served Out: Aging and Dying Behind Bars' documents a world that is made up of inmates that are weathered beyond their years. Many of these men struggle with simple tasks, like remembering the date, feeding themselves or even leaving their bed. Beyond the loss of their physical and mental independence many fight with keeping their hope alive. Forgiveness, hope and a sense of independence are not easily found behind bars. "Hope is all we have. We have to keep some kind of hope if we don't we'll surely perish," said inmate Thomas Jones of coming to terms with a life behind bars."

[www.ackermangruber.com](http://www.ackermangruber.com)

## Movies

### Amour

2012

127 minutes

Director: Michael Haneke

Cast: Jean-Louis Trintignant, Emmanuelle Riva, Isabelle Huppert

“An octogenarian couple struggles to cope after one of them suffers a partially paralyzing stroke, and the other must assume the role of the caretaker.”

*Palliative Care Issues:* caregiver burden, anticipatory grief, loss in later life, death with dignity

### The Barbarian Invasions (Les Invasions Barbares)

2003

99 minutes

Director: Denys Arcand

Cast: Rémy Girard, Dorothee Berryman, Stéphane Rousseau

“This French-Canadian film is an intelligent and cynical look at various aspects of the end-of-life, which focuses on Remy, a radical socialist professor during his final days battling cancer. The story is provocative and controversial and ends with Remy choosing to die by a lethal dose of heroin while surrounded by his family and friends.”

[https://www.amazon.com/Barbarian-Invasions-English-Subtitled/dp/B0091GDBJ6/ref=sr\\_1\\_1?crd=1GQ4YO8XX3JX&keywords=the+barbarian+invasion&qid=1561749826&s=instant-video&sprefix=the+barbarian+inva%2Cinstant-video%2C121&sr=1-1](https://www.amazon.com/Barbarian-Invasions-English-Subtitled/dp/B0091GDBJ6/ref=sr_1_1?crd=1GQ4YO8XX3JX&keywords=the+barbarian+invasion&qid=1561749826&s=instant-video&sprefix=the+barbarian+inva%2Cinstant-video%2C121&sr=1-1)

*Palliative Care Issues:* physician-assisted dying

### Beaches

1988

123 Minutes

Director: Garry Marshall

Cast: Bette Midler, Barbara Hershey, John Heard

The story of two friends from different backgrounds, whose friendship spans 30 years, encompassing the terminal illness of one of them.

Amazon Prime

### Big Fish

2003

125 Minutes

Director: Tim Burton

Cast: Albert Finney, Ewen McGregor, Billy Crudup, Jessica Lange

“A story about a son trying to learn more about his dying father by reliving stories and myths his father told him about himself.” <http://arts.pallimed.org/2008/05/top-10-palliative-films.html>

*Palliative Care Issues:* family dynamics, end of life

### The Diving Bell and the Butterfly

2007

112 Minutes

Director: Julian Schnabel

Cast: Mathieu Amalric, Emmanuelle Seigner, Marie-Josée Croze, Max von Sydow

“The true story of Elle editor [Jean-Dominique Bauby](#) who suffers a stroke and has to live with an almost totally paralyzed body; only his left eye isn't paralyzed.

[https://www.amazon.com/Diving-Bell-Butterfly-Max-Sydow/dp/B00AHAYFRM/ref=sr\\_1\\_1?crid=EGKURVGER14V&keywords=the+diving+bell+and+the+butterfly&qid=1561751026&s=instant-video&srefix=the+diving+%2Cinstant-video%2C126&sr=1-1](https://www.amazon.com/Diving-Bell-Butterfly-Max-Sydow/dp/B00AHAYFRM/ref=sr_1_1?crid=EGKURVGER14V&keywords=the+diving+bell+and+the+butterfly&qid=1561751026&s=instant-video&srefix=the+diving+%2Cinstant-video%2C126&sr=1-1)

### The Doctor

1991

122 Minutes

Director: Randa Haines

Cast: William Hurt, Christine Lahti, Elizabeth Perkins

“Jack McKee is a doctor with it all: he's successful, he's rich, extremely self-centered and he has no problems.... until he is diagnosed with throat cancer. Now that he has seen medicine, hospitals, and doctors from a patient's perspective, he realizes that there is more to being a doctor than surgery and prescriptions, and more to life than serving only his own needs.” [http://www.imdb.com/title/tt0101746/plotsummary?ref=tt\\_ov\\_pl](http://www.imdb.com/title/tt0101746/plotsummary?ref=tt_ov_pl)

*Palliative Care Issues:* empathy, doctor-patient relationship

### The Farewell

2019

100 Minutes

Director: Lulu Wang

Cast: Shuzhen Zhao, Awkwafina, X Mayo |

“A Chinese family discovers their grandmother has only a short while left to live and decide to keep her in the dark, scheduling a wedding to gather before she dies.” IMDB

*Palliative Care issues:* patient self-determination, truth disclosure

### The Fault in Our Stars

2014

126 minutes

Director: Josh Boone

Cast: Shailene Woodley, Ansel Elgort, Nat Wolff

“Two teenage cancer patients begin a life-affirming journey to visit a reclusive author in Amsterdam.” [http://www.imdb.com/title/tt2582846/?ref=nv\\_sr\\_1](http://www.imdb.com/title/tt2582846/?ref=nv_sr_1)

*Palliative Care Issues:* childhood cancer, childhood bereavement

### Fried Green Tomatoes

1991

130 Minutes

Director: Jon Avnet

Cast: Kathy Bates, Jessica Tandy, Mary Stuart Masterson, Mary Louise Parker

“Evelyn Couch is having trouble in her marriage, and no one seems to take her seriously.

While in a nursing home visiting relatives, she meets Ninny Threadgoode, an outgoing old woman, who tells her the story of Idgie Threadgoode, a young woman in 1920's Alabama. Through Idgie's inspiring life, Evelyn learns to be more assertive and builds a lasting friendship of her own with Ninny.”

Amazon Prime

### The Horse Whisperer

1998

169 Minutes

Director: Robert Redford

Cast: Robert Redford, Kristin Scott Thomas, Scarlett Johansson, Sam Neill

“After a riding accident and a death, a young girl and her horse are both left with serious physical and emotional scars.”

Amazon Prime

### Life as a House

2001

125 minutes

Director: Irwin Winkler

[https://www.amazon.com/Life-as-House-Kevin-Kline/dp/B0010T762K/ref=sr\\_1\\_1?keywords=life+as+a+house&qid=1561749539&s=instant-video&sr=1-1](https://www.amazon.com/Life-as-House-Kevin-Kline/dp/B0010T762K/ref=sr_1_1?keywords=life+as+a+house&qid=1561749539&s=instant-video&sr=1-1)

“The story centers around George (Kevin Kline), an architect who decides to build a house on his family's property after he receives a terminal diagnosis. The primary conflict in this story is between George and his teenage son Sam (Hayden Christensen), who eventually heal their estranged relationship by working together on the house. The building of the house throughout the movie serves as a metaphor for finding meaning and purpose at the end of life. Since the father-son relationship is central to this film, *Life As a House* can appeal to both men and women and is suitable for a younger audience, as well (teenage and up). The movie teaches us about the opportunities for transformation that dying can offer and opens up possibilities for a discussion of how to live your life with meaning.”

### Lullaby

2014

117 minutes

Director: Andrew Levitas

Cast: Garrett Hedlund, Richard Jenkins, Anne Archer , Amy Adams

“A man estranged from his family receives word that his father has chosen to take himself off life support within forty-eight hours.”

[http://www.imdb.com/title/tt2210781/?ref\\_=ttfc\\_fc\\_tt](http://www.imdb.com/title/tt2210781/?ref_=ttfc_fc_tt)

*Palliative Care Issues:* Choice in dying, Right to die

### Me and Earl and the Dying Girl

2015

105 minutes

Director: Alfonso Gomez-Rejon

“High schooler Greg, who spends most of his time making parodies of classic movies with his co-worker Earl, finds his outlook forever altered after befriendng a classmate who has just been diagnosed with cancer.” <http://www.imdb.com/title/tt2582496/>

*Palliative Care Issues:* childhood cancer, childhood bereavement

### Me Before You

2016

106 Minutes

Director: Thea Sharrock

Cast: Emilia Clarke, Sam Claflin, Janet McTeer

A girl in a small town forms an unlikely bond with a recently-paralyzed man she's taking care of.

*Palliative Care Issues:* choice in dying

### My Life

1993

107 Minutes

Director: Bruce Joel Rubin

Cast: Michael Keaton, Nicole Kidman, Bradley Whitford

“A terminally ill man prepares for his death.”

[http://www.imdb.com/title/tt0107630/?ref\\_=fn\\_al\\_tt\\_1](http://www.imdb.com/title/tt0107630/?ref_=fn_al_tt_1)

*Palliative Care Issues:* dying young, challenges at end of life

### My Life Without Me

2003

106 Minutes

Director: Isabel Coixett

Cast: Sarah Polley, Scott Speedman, Mark Ruffalo

“Young woman of lower socioeconomic status is diagnosed with cancer and has only weeks to live.”

<https://www.uab.edu/medicine/palliativecare/training/rotation/readings/films>

*Palliative Care Issues*: social disparities, risk and benefit at end of life, legacy building

### My Sister's Keeper

2009

109 minutes

Director: Nick Cassavetes

[https://www.amazon.com/gp/video/detail/0FO2OZO3S6H00I9N1V19ATAIGU/ref=imdbref\\_tt\\_wbr\\_aiv](https://www.amazon.com/gp/video/detail/0FO2OZO3S6H00I9N1V19ATAIGU/ref=imdbref_tt_wbr_aiv)

“My Sister’s Keeper’ follows the fictional story of a family whose lives are ripped apart after their youngest daughter — who was conceived in order to be a marrow donor for her ill older sister — seeks legal action against her parents. A compelling look at how illness affects the lives of both the patient and their loved ones.”

*Palliative Care Issues*: Effect of a child’s illness on the patient and family; ethical issues.

### One Day

2017

Streaming on Viki Global

Trailer: <https://www.youtube.com/watch?v=2joSb0VyvDM>

“In this Korean film, an insurance agent is assigned to the case of a woman who becomes comatose after a car accident. What unfolds is a bittersweet story about love and grief.”

### One True Thing

1998

127 Minutes

Director: Carl Franklin

Cast: Meryl Streep, Renee Zellweger, William Hurt

“A career woman reassesses her parents' lives after she is forced to care for her cancer-stricken mother.” <http://arts.pallimed.org/2008/05/top-10-palliative-films.html>

*Palliative Care Issues*: caregiver stress, end-of-life issues, family dynamics

### The Sea Inside

2004

125 minutes

Director: Alejandro Amenábar

Cast: Javier Bardem, Belén Rueda, Lola Dueñas

“It is based on the real-life story of Ramón Sampedro (played by Javier Bardem), who was left quadriplegic after a diving accident, and his 28-year campaign in support of euthanasia and the right to end his life.”

[https://en.wikipedia.org/wiki/The\\_Sea\\_Inside](https://en.wikipedia.org/wiki/The_Sea_Inside)

*Palliative Care Issues*: Choice in dying, right to die, living with severe disability

### Steel Magnolias

1989

117 Minutes

Director: Herbert Ross

Cast: Julia Roberts, Shirley MacLaine, Olympia Dukakis, Sally Field

“Film follows the lives of 6 women who regular visit a beauty shop, one of whom has severe diabetes and touches on EOL issues related to this.”

<https://www.uab.edu/medicine/palliativecare/training/rotation/readings/films>

*Palliative Care Issues*: dying young, death from chronic illness, loss

### StepMom

1998

125 Minutes

Director: Chris Columbus

Cast: Susan Sarandon, Julia Roberts, Ed Harris

“An unlikely friendship develops when a mother of two is forced to teach another woman to raise her kids. Julia Roberts and Susan Sarandon star.

Amazon Prime

### Terms of Endearment

1983

132 minutes

Director: James L. Brooks

Cast: Debra Winger, Shirley MaLaine, Jack Nicholson, Jeff Daniels, Danny DeVito, John Lithgow

“The devoted, and antagonistic, bond between a dramatic, charismatic widow (Shirley MaLaine) and her quietly rebellious daughter (Debra Winger) is the focal point of this film's exploration of a range of human relationships and their changes over time and under various pressures, including that of serious illness. The major focus of the last part of the film is the illness and death of the daughter from cancer and its impact on her mother, her husband and children, and their immediate circle of friends and lovers.”

<http://medhum.med.nyu.edu/view/10210>

*Palliative Care Issues*: family relationships in the face of serious illness, pain control, dying young

### Truly, Madly, Deeply

1990

106 Minutes

Director: Anthony Minghella

Cast: Juliet Stevenson, Alan Rickman, Jenny Howe |

“A woman dealing with inconsolable grief over the death of her partner gets another chance when he returns to earth as a ghost.”

Amazon

### Tuesdays with Morrie

1999

89 minutes

Director: Mick Jackson

Available from Amazon Prime

“Mitch Albom’s beloved non-fiction book was adapted into a TV movie starring Hank Azaria and Jack Lemmon. This film shows the friendship that forms between Albom and

his former professor, Morrie Schwartz, and the lessons Albom learns from Schwartz — who is dying from ALS.”

#### Two Weeks

2006

102 Minutes

Director: Steve Stockman

Cast: Sally Field, Ben Chaplain, Julianne Nicholson

“In this bittersweet comedy, four adult siblings gather at their dying mother's house in North Carolina for what they expect to be a quick, last goodbye.”

<http://arts.pallimed.org/2008/05/top-10-palliative-films.html>

*Palliative Care Issues*: end of life, family dynamics

#### Wit

2001

99 minutes

Director: Mike Nichols

Cast: Emma Thompson, Christopher Lloyd, Eileen Atkins, Audra McDonald

“A renowned professor is forced to reassess her life when she is diagnosed with terminal ovarian cancer.” <http://www.imdb.com/title/tt0243664/>

*Palliative Care Issues*: patient experience at end of life, death with dignity, doctor-patient relationship



## Additional Movies Not (Yet) Added to the List Above

### Feature films dealing with aspects of dying and death

#### **\* Based On A True Story**

**Dark Victory** (1939) – Bette Davis, Geraldine Fitzgerald, George Brent, Humphrey Bogart, Ronald Reagan (dir. Edmund Goulding). Socialite who is dying gets help from a doctor. Remade for TV as **Stolen Hours**(1976).

**On Borrowed Time** (1939) – Lionel Barrymore, Cedric Hardwicke, Beulah Bondi (dir. Harold S. Bucque). Comedy about an old man who isn't ready to die.

**\*Pride of the Yankees** (1942) – Gary Cooper, Teresa Wright, Babe Ruth (dir. Sam Wood). Classic account of life and dying of baseball star Lou Gehrig with ALS.

**An Act of Murder** (1948) – Frederic March, Florence Eldridge (dir. Michael Gordon). Judge who kills terminally ill wife faces trial in his court.

**Ikiru** (1952) - by Akira Kurosawa

**\*The Eddy Duchin Story** (1956) – Tyrone Power, Kim Novak, Victoria Shaw, James Whitmore, Rex Thompson (dir. George Sidney). Society piano player is dying of leukemia.

**The Bramble Bush** (1960) – Richard Burton, Barbara Rush (dir. Daniel Petrie). Doctor in love with dying friend's wife.

**Love Story** (1970) – Ali MacGraw, Ryan O'Neal (dir. Arthur Hiller). Boy falls in love with girl; girl dies.

**\*Brian's Song** (1971) – James Caan, Billy Dee Williams (dir. Buzz Kulik). Story of Brian Piccolo, Chicago Bears footballer dying of cancer.

**Harold and Maude** (1971) – Ruth Gordon, Bud Cort, Vivian Pickles, Ellen Geer (dir. Hal Ashby). The cult black comedy of a 20-year-old man obsessed with death, and his relationship with 79-year-old woman.

**Sunshine** (1973) – Brenda Vaccaro, Christina Raines, Cliff DeYoung (dir. Joseph Sargent). Couple and their doctor debate the way the wife is dying.

**Murder or Mercy?** (1974) – Melvin Douglas, Mildred Dunnock (dir. Harrey Hart). Court room drama of mercy-killing.

**\*Babe** (1975) – Susan Clark, Alex Karras (dir. Buzz Kulik). Story of athlete Babe Didrikson Zaharias's life and dying.

**\*Death Be Not Proud** (1975) – John Savage, Patricia Neal, Claude Akins, Mark Hamill (dir. James Goldstone). From John Gunther's book about the dying of his 17 year old son from a brain tumor.

**The Gathering** (1977) – Edward Asner, Maureen Stapleton, Lawrence Pressman (dir. Randal Kleiser). Father assembles dysfunctional family for last Christmas gathering before he dies.

**\*A Love Affair: The Eleanor and Lou Gehrig Story** (1977) – Edward Herrmann, Blythe Danner (dir. Fielder Cook). Story of the baseball star who gave his name to the disease ALS.

**\*First You Cry** (1978) – Mary Tyler Moore, Anthony Perkins, Florence Eldridge, Jennifer Warren (dir. George Schaefer). Betty Rollin's fight with breast cancer.

**\*Little Mo** (1978) – Glynnis O'Connor, Michael Learned, Anne Baxter (dir. Daniel Haller). Story of tennis star Maureen Connelly's early death.

**The End** (1978) – Stars Burt Reynolds as a man who discovers that he has an incurable disease and decides to take his own life. The bulk of this darkly comedic film concerns his attempts to find a painless and foolproof way to kill himself aided by a mental patient played by Dom DeLuise.

**Promises in the Dark** (1979) – Kathleen Beller, Marsha Mason, Ned Beatty (dir. Jerome Hellman). Young girl with cancer has compassionate doctor.

**Opname** (1979) – Marja Kok, Erik van Zuylen

**\*The Elephant Man** (1980) – David Lynch

**\*Act of Love** (1980) – Ron Howard, Robert Foxworth (dir. Jud Taylor). Man shoots crippled brother and is acquitted at trial.

**The Shadow Box** (1980) – Joanne Woodward, Christopher Plummer, James Broderick, Ben Masters, Melinda Dillon (dir. Paul Newman). Three terminally ill patients spend a day in discussion at a rustic retreat.

**\*A Matter of Life and Death** (1981) – Linda Lavin, Tyne Daly, Salome Jens, Gail Strickland (dir. Russ Mayberry). Story of Joy Ufema, crusading nurse who modernised ways of treating the terminally ill.

***On Golden Pond*** (1981) – Henry Fonda, Katharine Hepburn, Jane Fonda, Doug McKeon (dir. Mark Rydell). The psychological problems of terminal old age. Henry Fonda and Hepburn won Oscars for their performances.

***Whose Life Is It Anyway?*** (1981) – Richard Dreyfuss, John Cassavetes, Christine Lahti, Bob Balaban, Kenneth McMillan, Kaki Hunter (dir. John Badham). Significant story of seriously injured artist fighting for disconnection from life-support equipment.

***Six Weeks*** (1982) – Dudley Moore, Mary Tyler Moore, Katharine Healy (dir. Tony Bill). Tearjerker about the dying of a six-year-old girl.

***The Ballad of Nayarama*** (1983) – Shôhei Imamura

***Right of Way*** (1983) – Bette Davis, James Stewart (dir. George Schaefer). Elderly couple choose death by car exhaust.

***An Early Frost*** (1985) – Gena Rowlands, Ben Gazzara, Aidan Quinn (dir. John Erman). Emmy-award winning script about son who tells his parents that he is gay—and dying of AIDS.

***Do You Remember Love*** (1985) – Joanne Woodward, Richard Kiley, Geraldine Fitzgerald (dir. Jeff Bleckner). Much-praised story of college professo with Alzheimer’s Disease.

***The Ultimate Solution of Grace Quigley*** (1985) – Katharine Hepburn, Nick Nolte (dir. Anthony Harvey). Black comedy of New York seniors employing a mafia hit man to kill them quickly.

***Dead Ringers*** (1988) – David Cronenberg

***\*My Left Foot*** (1989) – Jim Sheridan

***\*A Woman’s Tale*** (1991) – Sheila Florance (dir. Paul Cox). Australian drama about 78-year-old woman afflicted with cancer who is determined to have “a good death.” (Florance died from her cancer two days after winning Australian Academy Award.

***Dying Young*** (1991) – Julia Roberts, Campbell Scott (dir. Joel Schumacher). A 28-year-old man dying of leukemia hires young woman who undertakes to teach him “the meaning of life” before he dies.

***My Life*** (1993) – Michael Keaton, Nicole Kidman (dir. Bruce Joel Rubin). Dying man videotapes his last days.

***New Age*** (1994) – Judy Davis, Peter Weller (dir. Michael Tolkin). Complex story of self-deliverance and assisted suicide between two thirty-something “yuppies”. Terminal illness is not the cause but rather their exhaustion of life’s illusions.

***The Last Supper*** (1994) – Ken McDougall, Jack Nichol森, Daniel MacIvor (dir. Cynthia Roberts). Chris is a dancer dying of AIDS. He has chosen euthanasia to end his suffering. With the assistance of his lover Val and his doctor, he surrounds himself in his last hours with everything that made his life special and creates his ultimate work of art by choreographing his own death.

***The English Patient*** (1996) – Ralph Fiennes, Kristin Scott Thomas (dir. Anthony Mingella). Oscar Best Picture is a magnificent movie of love and war. Particularly interesting to supporters of choice in dying is that, when close to the end of the story, the nurse quietly administers euthanasia to this dying patient at his request.

***It's My Party*** (1996) – Eric Roberts, Gregory Harrison (dir. Randal Kleiser). Man dying of AIDS and calls all his friends to have a party on his last night alive. Fine drama and dialogue — and it refers in passing to the book 'Final Exit'— but no one should expect to die so long after taking an overdose of drugs.

***Critical Care*** (1997) – Director: Sidney Lumet. The film is a satire about American medicine, based on the novel by Richard Dooling and stars James Spader, Kyra Sedgwick, Anne Bancroft, Helen Mirren, Jeffrey Wright, and Albert Brooks.

***Igby Goes Down*** (2002) – Kieran Culkin, Claire Danes, Susan Sarandon (dir. Burr Steers). The main story is about a brilliant teenager who rebels and flunks out of everything. The opening and closing are remarkable scenes of two brothers helping their terminally ill mother to die with the aid of drugs and a plastic bag. Probably a first for showing this action in Hollywood.

***The Hours*** (2002) – Nicole Kidman, Julianne Moore, Ed Harris (dir. Stephen Daldry). Story of three women who are profoundly affected by Virginia Wolf's novel, 'Mrs.Dalloway'. This excellent film has, as its undercurrent, the reasons for a suicide, an attempted suicide, and a rational suicide. Kidman won an Oscar for her portrayal of Virginia Wolf who drowns herself to escape advancing madness. Moore is the city housewife, bored and confused, who nearly commits suicide. Harris plays the over-the-hill New York poet with advanced AIDS who can no longer bear to live and allows himself to fall to his death out of a window. Screenplay by David Hare from the novel by Michael Cunningham. It helps to have read the Pulitzer Prize novel first.

***Talk to Her*** (2002) – Javier Camara, Rosario Flores (dir. Pedro Almodovar). Emotionally charged drama about the intense friendship between a writer and a male nurse who are both caring for coma-stricken women. Spanish, with subtitles.

***The Event*** (2003) – Parker Posey, Olympia Dukakis, Sarah Polley (Dir. Thom Fitzgerald). An intense relationship drama that takes the form of a mystery, The Event centers around a series of unexplained deaths that occur among the gay community in New York's fashionable Chelsea district. Nick, a district attorney investigating the most recent case, a suspicious, apparent assisted suicide, and her interviews with friends and family of the deceased trigger extensive and intricately interwoven flashbacks that reveal surprising facts about the man's life and death.

***Inside I'm Dancing*** (2004) – Damien O'Donnell

***Planta 4a*** (2004) – Antonio Mercero

***Million Dollar Baby*** (2004) – Hilary Swank, Clint Eastwood, Morgan Freeman (dir. Clint Eastwood). Highly acclaimed by the critics, who nevertheless ignore the 'message' aspect. Despite its inappropriate title and boxing ring background, the underlying theme of this film is assisted suicide and the soul-searching which precedes it. Fine acting all round. Won Oscars.

***The Secret Life of Words*** (2005) – Isabel Coixet

***The Death of Mr Lazarescu*** (2005) – Cristi Puiu

***Away from Her*** (2006) – Sarah Polley

***Il y a longtemps que je t'aime*** (2008) – Philippe Claudel

***Guzaarish*** (2010) – Hrithik Roshan, Aishwarya Rai (dir. Sanjay Leela Bhansali). A paralyzed magician/radio D.J. files a petition in court seeking permission to end his life. This was filmed before withdrawing of life support finally became legal in India (by court decision) in March 2011. In Hindi with English subtitles.

***Biutiful*** (2010) – Alejandro Inárritu

***A Simple Life*** (2011) – Ann Hui

***Contagion*** (2011) – Steven Soderbergh

***The Eye of the Storm*** (2011) – Fred Schepisi

***Intouchables*** (2011) – Olivier Nakache, Eric Toledano

***Hemlock Society*** (2012) – Fictional. The plot revolves around a man who runs a school called "Hemlock Society" which teaches aspirants how to successfully commit suicide. He develops a bond with one of its students, a depressed and dejected woman, and what follows is an unforgettable and life-changing journey for both. In Bengali.

***Side Effects*** (2013) – Steven Soderbergh

***\*I Am Breathing*** (2013) – Directed by Emma Davie and Morag McKinnon. Story of Scotsman Neill Platt dying of ALS with courage and humor.

***Honey (Miele)*** (2014) - Valeria Golino. Fictional story of a young Italian woman who commutes between Mexico and Rome carrying drugs by which terminally ill people can end their lives. Then she has a problem client who is merely tired of life. In Italian with English subtitles. 96 min.

***Un voyage - A Journey*** (2014) - Director and writer: Samuel Benchetrit. Story of a couple who decide on assisted suicide and travel to Switzerland. (in French). 87 min.

***The Farewell Party*** (2014) - Directors: Tal Granit and Sharon Maymon. An Israeli drama film about the use of a euthanasia device. 92 min.

## Made for TV Dramatic Movies

### \* ***Based On A True Story***

***When The Time Comes*** (1987) – ABC-TV. Brad Davis, Bonnie Redelin (prod. Sherry Lansing). Fictional but well-portrayed assisted suicide of dying woman.

\****Murder or Mercy*** (1987) – NBC-TV. Robert Young. Story of Roswell Gilbert’s mercy-killing of his wife who had Alzheimer’s.

\****The Right To Die*** (1987) – NBC-TV. Racquel Welch. Woman with ALS wants disconnection from life support.

***Longtime Companion*** (1990) – PBS American Playhouse. Campbell Scott. Bruce Davison, Patrick Cassidy (dir. Norman René). Moving and witty script by playwright Craig Lucas depicting the growth of AIDS among gay men in New York. Davison nominated for Oscar for Best Supporting Actor.

\****Last Wish*** (1992) – ABC TV. Maureen Stapleton, Patti Duke. Betty Rollin’s story of assisting her mother’s suicide.

\****The Switch*** (1993) – Gary Cole, Craig T. Nelson (dir. Bobby Roth). Larry McAfee is a man paralyzed and dependant on a ventilator. Angry and frustrated with a system that drained him of his insurance money and leaves him in one nursing home after another, he sues for the right to have a switch installed on his ventilator that will allow him to turn the machine off. He wins that “right”. This is an unusually complex (for TV) portrayal of the issues of disability and “quality of life”.

\****You Don't Know Jack*** (2010) – HBO TV Movie. Al Pacino plays Dr. Jack Kevorkian in the 1990s who defied Michigan law by assisting the suicides of more than a hundred persons. Support comes from his sister, a lab tech, the local Hemlock Society president, and a lawyer. The child of

survivors of the Armenian genocide interviews applicants: his sister video tapes them. He assembles a device allowing a person to initiate a three-chemical intravenous drip. The local D.A., the governor, and the Legislature respond. He's single-minded about giving dying individuals the right to determine how their lives will end. He wants the Supreme Court to rule but his legal approach is mistaken. 134 min.

## Television and/or DVD Documentaries

*(Some videos can be purchased on DVD via Amazon.com and YouTube. Video details at [www.IMDB.com](http://www.IMDB.com))*

***Please Let Me Die: The Dax Cowart Story*** (1974) – Robert B. White

***Live and Let Go: An American Death*** (2003) – Jay Niver. DVD.

***Mademoiselle and the Doctor*** (2004) – Janine Hosking

***Final Exit on DVD*** (2006) – Derek Humphry. [Finalexit.org](http://Finalexit.org). Amazon.com. DVD.

***Exit: Le Droit de Mourir*** (2006) – Fernand Malgar. French with Eng. Subtitles.

***Reverend Death*** (2008) – John Ronson. Ch4 UK.

***A Finished Life: The Goodbye & No Regrets Tour*** (2008) – Feature length documentary about Gregg Gour, a 48-year-old gay man with AIDS, who, when given six months to live, takes the road trip of his life, then ends it. Directors: Michelle Boyaner, Barbara Green.

***A Short Stay in Switzerland*** (2009) – Simon Curtis. BBC Films. DVD.

***Choosing to Die*** (2011) – Terry Pratchett. BBC2.

***The Tragic Dilemma of Alzheimers*** (2011) – Derek Humphry. YouTube.

***In Search of Gentle Death*** (2011) – Richard Cote. YouTube.

***The Suicide Plan: The Hidden World of Assisted Suicide*** (2012) – Miri Navasky, Karen O'Connor. Emmy Nominated. Frontline PBS & DVD.

***A Good Death*** (2012) – Wallis Films. Holland. DVD from NVVE Amsterdam. Subtitled.

***Relics*** (2013) – Jennie Allen. A salesman tries to sell his miraculous cleaning machine to an ailing woman and her skeptical daughter, on the day that the woman asked her daughter to help her end her own life. 14 minutes.

**35 Letters** (2014) - Director: Janine Hosking. A terminally ill woman writes to her sister about her final months. Australia. 98 mins.

**The Trouble with Dying** (2014) - Narrated by Christopher Plummer. Director: Ken Simpson. Two women want to control how they end their lives. The opposing argument is also explored. Includes interview with Dr. Richard MacDonald of the Final Exit Network. Canada.



## Blogs

A Pain in the Neck: My Experience with Hodgkin's Lymphoma (& Neuroendocrine Tumors)

<http://apainintheneck.com/2013/06/>

<https://netrf.org/2018/07/10/the-road-to-prrt-a-path-of-self-discovery-and-growth/>

## CAPC

<https://www.capc.org/blog>

The Social Worker's Role in Community Palliative Care: Insights from the Field

February 27, 2019 | By Jeanne Sheils Twohig and Jessica Strong

<https://www.capc.org/blog/the-social-workers-role-in-community-palliative-care-insights-from-the-field/>

## The Conversation Project

<https://theconversationproject.org/tcp-blog/>

## My Cancer Journey

Michael Becker's blog about living with Stage IV head & neck cancer caused by HPV

<https://mdbcancerjourney.com/>

## Podcasts

### [On Being: What Matters in the End—Featuring Atul Gawande](#)

“What does a good day look like?” That question — when asked of both terminally-ill and healthy people — has transformed Atul Gawande’s practice of medicine. A citizen physician and writer, Gawande is on the frontiers of human agency and meaning in light of what modern medicine makes possible. For the millions of people who have read his book *Being Mortal*, he’s also opened new conversations about the ancient human question of death and what it might have to do with life.

### [NPR Life Kit: How to be a Better Caregiver When a Loved One Gets Sick](#)

None of us is prepared to be caregivers — the role is thrust upon us. More than 40 million Americans are caring for an elderly parent or loved one. Here are six tips to make the caregiving burden more sustainable:

- Accept help, and don't be afraid to ask for it.
- Break down caregiving tasks into bite-sized solutions.
- Don't tell your loved one what to do. Ask about the quality of life they want and how you can get them there.
- Be an empowered medical advocate for your loved one.
- Get your legal ducks in order so you can focus on your relationship.
- Make sure to take care of yourself, too.

### [Boston Sunday Review: The Conversation Project & Rev. Rosemary Lloyd](#)

The Conversation Project’s Advisor to Faith Based Communities talks about the importance of having a conversation with your loved ones on their wishes for end of life care.

### [Healthcare Communication—Effective Techniques for Clinicians: How to Prepare for End of Life Conversations](#)

Kelly McCutcheon Adams, MSW, LCSW, talks about IHI's Conversation Ready project and end of life conversations. Learn how systems can become ready; the Conversation Ready principles: Exemplify, Connect, Engage and Steward all of which are the foundation for respect; and the advantages for systems to be conversation ready. The IHI white paper and tool kit are available at [ihi.org](http://ihi.org).

### [NPR Hidden Brain: The Ventilator](#)

Many of us believe we know how we’d choose to die. We have a sense of how we’d respond to a diagnosis of an incurable illness. Hear the story of one family’s decades-long conversation about dying. They found that the people we are when death is far in the distance may not be the people we become when death is near.

## CAPC Podcasts

[Reducing Hospital Readmissions Through Palliative Care](#)

[How to Increase Awareness and Reduce Gaps in Palliative Care for Minorities](#)

[Recipes for Success from Palliative Care Programs \(part one\)](#)

[More Recipes for Success from Palliative Care Programs \(part two\)](#)

[How to Create a Culture of Palliative Care](#)

[Taking a Team to the Next Level with Boston Medical Center](#)

Etc.

## [Stanford Palliative Care Training](#)

[Communication](#)

[Dyspnea: How to Assess and Palliate Dyspnea](#)

[Home Hospice](#)

[Palliative Sedation](#)

[Physician-Assisted Death](#)

[Prognostication](#)

[Transition to Death](#)

[Voluntary Stopping Eating and Drinking \(VSED\)](#)

## Graphic Medicine

- Chast, R. (2014). *Can't we talk about something more pleasant?* (First U.S. edition. ed.). New York: Bloomsbury USA.
- Czerwiec, M. (2017). *Taking turns: stories from HIV/AIDS care Unit 371*. University Park, PA: Penn State University Press.
- Czerwiec, M., Williams, I., Squier, S. M., Green, M. J., Myers, K. R., & Smith, S. T. (2012). *Graphic medicine manifesto*. University Park, PA: Penn State University Press.
- Czerwiec, M. K., & Huang, M. N. (2017). Hospice comics: Representations of patient and family experience of illness and death in graphic novels. *J Med Humanit*, 38(2), 95-113. doi:10.1007/s10912-014-9303-7
- DeFalco, A. (2016). Graphic somatography: Life writing, comics, and the ethics of care. *J Med Humanit*, 37(3), 223-240. doi:10.1007/s10912-015-9360-6
- Dunlap-Shohl, P. (2015). *My degeneration: A journey through Parkinson's*. University Park, PA: Penn State University Press.
- Engelberg, M. (2006). *Cancer made me a shallower person: A memoir in comics* (1st ed.). New York, NY: Harper.
- Fies, B. (2006). *Mom's cancer*. New York: Abrams Image.
- Green, M. J., Myers, K., Watson, K., Czerwiec, M. K., Shapiro, D., & Draus, S. (2016). Creativity in medical education: the value of having medical students make stuff. *J Med Humanit*, 37(4), 475-483. doi:10.1007/s10912-016-9397-1
- Leavitt, S. (2012). *Tangles : a story about Alzheimer's, my mother, and me*. New York: Skyhorse.
- Mackintosh, R. (2011). *Seeds: com.x*.
- Walrath, D. (2016). *Aliceheimer's*. University Park, PA: Penn State University Press.
- Williams, I. (2015). *The bad doctor: the troubled life and times of Dr. Iwan James*. University Park, PA: Penn State University Press.
- Winick, J. (2009). *Pedro & Me: Friendship, Loss, & What I Learned*. New York: Henry Holt.

## **CSWE Teaching Modules**

[Advance Directives and End-of-Life Decision Making: The Five Wishes Teaching Module](#)

[Advanced Directives and End-of-Life Decision Making: The Five Wishes](#)

Dying: A Difficult Subject, a Vital Conversation

[Grief, Loss and Bereavement in Older Adults Teaching Module](#)

[Grief, Loss and Bereavement in Older Adults - PowerPoint](#)

[Loss and Grief Teaching Module](#)

[Loss and Grief Teaching Notes](#)

[Loss and Grief: The Aging Survival Kit - PowerPoint Slides](#)

[Pain Presentation in the Geriatric Population Teaching Module](#)

[Pain from a Cultural Viewpoint – PowerPoint Slides](#)

[Pain Presentation in the Geriatric Population – PowerPoint Slides](#)

## **New York City and Vicinity**

### **Bereavement Resources for Children**

*This was copied from the SW-PALL-EOL listserv. It was posted by Arianne Napier on 8-20-18.*

Arianne J. Napier, LMSW

[Arianne.Napier@gmail.com](mailto:Arianne.Napier@gmail.com)

[347.489.1392](tel:347.489.1392)

### **Calvary Hospital**

Child Group (ages 6-11) Tuesdays from 4-5:30pm

Adolescent Group (ages 12-17) 8-week cycles Thursdays from 4-5:30pm

**Organizer:** Brittany [bdalbow@calvaryhospital.org](mailto:bdalbow@calvaryhospital.org) or [646-771-6604](tel:646-771-6604)

### **A Caring Hand Bereavement Group**

The eleven-week group program is held in the fall, winter and spring for parents/caregivers and children.

**Call [212-229-2273](tel:212-229-2273)** to schedule a required pre group meeting.

Pre group meeting is located 303 Fifth Ave. Room 806 NY, NY 10016.

Groups are held at Harlem Children zone.

<http://www.acaringhand.org/schedule>

### **Comfort Zone Camp**

Comfort Zone Camp is a nonprofit 501(c) 3 bereavement camp that transforms the lives of children who have experienced the death of a parent, sibling, or legal guardian. The free camps include confidence building programs and age-based support groups that break the emotional isolation grief often brings. Comfort Zone Camps are offered to children 7-17, and are held year-round across the Country.

(201) 867-2077/ (866) 488-5679

### **Camp Erin NYC**

FREE, weekend long grief support camp designed to help children and teenagers ages 6 – 17, who have experienced the death of a parent, sibling or someone close to them.

Camp Erin NYC will be from August 25 - 27, 2017.

Ann at [914-552-6919](tel:914-552-6919)/[914-939-5338](tel:914-939-5338) or email [afuchs@copefoundation.org](mailto:afuchs@copefoundation.org)

### **Camp Good Grief of Staten Island**

Camp Good Grief provides a free weekend camp twice annually for children ages 7 to 16 who have suffered the death of a parent, sibling or significant care giver. It is our mission to provide a safe setting for youngsters to grieve the loss of a loved one, an opportunity to share their unique experiences with others who have similar losses, provide feelings of hope and a sense of community, and provide coping skills in a place of creativity where they can express their emotional needs while having fun.

[sunshine@campgoodgriefsi.org](mailto:sunshine@campgoodgriefsi.org)

Tel: [888-507-4474](tel:888-507-4474)

### **Emma's Place**

Emma's Place is Staten Island's only not-for-profit Grief and Loss Center for children and families. Every community deserves grief and loss support.

Children's Bereavement Groups:

\*Every 1st & 3rd Tuesdays

5:30PM - Ages 6-9, 10-14, 15-19

Adult Bereavement Groups:

\*Every 1st & 3rd Thursdays

7:00PM

*\*Please call for registration and for any changes [347.850.2322](tel:347.850.2322)*

### **Hospice Care @ Staten Island**

Bereavement Support Groups

(718) 226-6451

We have support groups for adults and children. Please call to register.

Adults: Every 2nd & 4th Monday, 1 p.m. & 7 p.m.

Children's Group for ages 6–14 meets at the 7 p.m. session only.

## Getting Started in Palliative Care

There are many ways to start a career in palliative and end-of-life care.

### Inform yourself

You may begin by informing yourself about these topics and about the roles of palliative social work. A good overview is an introductory chapter on this topic:

Berkman, C., Stein, G. L., & Glajchen, M. (2018). Palliative and end-of-life care. In J. C. Heyman & E. Congress (Eds.), *Health Care and Social Work: Practice, Policy and Research*: Springer.

This is available at the Fordham University Library Research Guide on Palliative and End-of-Life Care (see page 1). These two books are also excellent resources for learning more.

Altilio, T., & Otis-Green, S. (Eds.). (2011). *Oxford textbook of palliative social work* (1st ed.): Oxford University Press.

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

There are also many excellent videos available online, many of which are listed in this guide.

### Join SWHPN

Join the Social Work Hospice and Palliative Care Network. This is the professional organization for palliative care and hospice social workers. There is a student membership rate.

### Attend Conferences

Find local conferences in your immediate area or region. These are usually one day or part of a day. They are an excellent way to learn more and to meet social workers and other professionals working in palliative and hospice care.

If you are able to attend a national conference, that is also an excellent opportunity to learn a lot and network. These conferences are usually two or more days, although you can attend part of the conference. They are usually located in a different city each year. The SWHPN Annual Meeting is held in March. You can learn about the location and exact dates at [www.SWHPN.org](http://www.SWHPN.org). Many of the organizations listed in this guide also hold annual conferences. Depending on your interests and the location of the conference, you may choose to attend a national conference.



### Join the Listserv

The SW-PALL-EOL listserv is an excellent way to become immersed in issues of importance to palliative and hospice social workers. See page 1 of this Guide for instructions on joining the listserv.

### Volunteer

Consider volunteering in a setting that serves seriously ill persons. Many hospices welcome volunteers as part of their program. You might also consider volunteering at community-based organizations that serve individuals with cancer, such as Gilda's club, or at a nursing home, or other organizations where you live.

### Get a Mentor

If you are a SWHPN member, you may request to be assigned to palliative or hospice social worker through the Mentoring program. Information on this is available at the SWHPN website. It might be also be possible to find a mentor in your area, or to at least make contact with a palliative or hospice social worker in your area to meet and ask their advice relevant to the area in which you live.

### Continuing Education

Take one or more continuing education classes on palliative and hospice care. Fordham University Graduate School of Social Service offers many different classes in the Palliative Care Sequence.

SWHPN also offers a series of continuing education classes designed to help palliative social workers prepare for the Certification Exam, but you may find these classes to be well-suited to your interests and needs.

### Certificate Programs

There are some excellent certificate programs for persons who want an extensive program. These programs are listed in this Guide.

### If you are currently an MSW or BSW student

Take one or more electives in this subject. Many programs have a course that covers death, dying, grief, loss, and bereavement. Very few programs have a dedicated course on palliative

care, but you might find a course on social work in health care settings that would include some of this content. You might find a course on this topic in another department in your university.

Use assignments in any of your courses as a way to become more knowledgeable about palliative and end-of-life care.

Request a field placement on a palliative care team, in medical center working on a service for seriously ill patients (e.g., oncology), in a dialysis center, or in hospice. There may be other community-based organizations that provide services to seriously ill persons.

#### If you are applying to an MSW or BSW program

Consider applying to a program that has a specialization in palliative care (there are three of these – all in New York City) or in psychosocial oncology (there is one at the Kent School, University of Louisville, and one at the University of Washington). If one of these programs is not feasible for you, examine the schools that you are considering to see which have electives and specializations in closely related areas, read the faculty webpages to determine whether there is someone on the faculty with an interest in palliative or end-of-life care. Contact this faculty person to ask them about opportunities in this program for you to gain experience in this field. You might also contact someone in the Field Department to inquire about the possible field placements working with seriously ill persons.