Palliative Social Work SWGS 6471

Supplemental Resources

Graduate School of Social Service

Fordham University

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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.

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

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

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

<http://www.swhpn.org>

Publishes [Journal of Social Work in End-of-Life and Palliative Care](http://members.swhpn.org/journal)

Membership rates for students and new professionals

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

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

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

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

### [Association of Pediatric Oncology Social Workers](http://www.aposw.org/) <http://www.aposw.org/>

Cancer*Care* [www.cancercare.org](http://www.cancercare.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/)

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/](https://getpalliativecare.org/)

[Hospice and Palliative Nurses Association (HPNA)](http://www.hpna.org/) [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 the Study of Pain.  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/](https://registry.capc.org/)

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

# 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>

**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>

<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>

**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>

Family Healthcare Decisions Act (FHCDA)

End of Life Choices New York <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>

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

Family Health Care Decisions Act

<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>

Guides and Toolkits for Providers for working with family caregivers

 <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>

# Books

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

Available in GSS Palliative Care Library – request from Dr. Berkman

1 reserve copy at Quinn Library

1 reserve copy at WC campus library

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

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

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. (1998). *Dying Well*: Riverhead Trade.

Available in GSS Palliative Care Library – request from Dr. Berkman

Available at Quinn Library - HQ1073 .B96 1997

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.

Available in library at WC campus - R726.8.C336 2003.

**thor**

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

Available at Lincoln Center--Quinn Library - BF789.D4 C25 1997

Available in GSS Palliative Care Library – request from Dr. Berkman

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

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

 Available at Lincoln Center--Quinn Library

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

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

Available in GSS Palliative Care Library – request from Dr. Berkman

Available at Westchester Campus Library L R726 .C83 2006

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.

Available in GSS Palliative Care Library – request from Dr. Berkman

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

Available in GSS Palliative Care Library – request from Dr. Berkman

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

Available at Westchester Campus Library R726.8.H35 2008

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

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

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

Holland, J. C., & Rowland, J. H. (1990). *Handbook of 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.

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

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

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

Available in GSS Palliative Care Library – request from Dr. Berkman

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.

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>

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

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

Available at Lincoln Center--Quinn Library HQ1073 .L48 1989

Available at Westchester Campus Library HQ1073 .L48 1989

Available in GSS Palliative Care Library – request from Dr. Berkman

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

Matzo, M. L., & Sherman, D. W. (2015). *Palliative Care Nursing: Quality Care to the End of Life*: Spring.

 Available at Westchester Campus Library RT87.T45 P343 2015.

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.

Available in GSS Palliative Care Library – request from Dr. Berkman

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

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

 Available at Westchester Campus Library BT732.5.M55 2001

O'Rourke, M. (2012). *The Long Goodbye: A Memoir*: Riverhead Trade.

 Available in GSS Palliative Care Library – request from Dr. Berkman

Available at Quinn Library - PS3615.R586 Z46 2011

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

Available in GSS Palliative Care Library – request from Dr. Berkman

Available at Westchester Campus Library: HV3001.A4 R44 2013

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

Available in GSS Palliative Care Library – request from Dr. Berkman

Available at Westchester Campus Library: HV3000 .R45 2009.

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

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

 Available in GSS Palliative Care Library – request from Dr. Berkman

Available at Quinn Library: RC265.5 .S39 2012

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

Walsh-Burke, K. (2006). *Grief and loss: Theories and skills for the helping professions.* (2nd Ed.): Pearson.

# Graphic Novels

All of the graphic novels are available in GSS Palliative Care Library – request from Dr. Berkman

Chast, R. (2014). *Can't we talk about something more pleasant? A memoir*. 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.

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 ComicArts.

Leavitt, S. (2012). *Tangles : a story about Alzheimer's, my mother, and me*. New York: Skyhorse.

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.

# 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.

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>

# Guides

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

National Cancer Institute. (2015). Last days of life–for health professionals (PDQ®). Retrieved from <http://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/last-days-hp-pdq#section/all>

NASW Standards for Social Work Practice with Family Caregivers

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

National Hospice and Palliative Care Organization

 NHPCO’s Facts and Figures – Hospice Care in America – 2015

 <http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf>

 NHCPO’s Facts and Figures - Pediatric Palliative & Hospice Care in America - 2015

 <http://www.nhpco.org/sites/default/files/public/quality/Pediatric_Facts-Figures.pdf>

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

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

Vital Talkone-page guides: [*http://www.vitaltalk.org/clinicians*](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>

Talking Map for the Family Conference: <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>

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>

# 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 (NHCPO) Social Work Competencies

<http://www.nhpco.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>

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%286%29_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%281%29Hughes_part2.pdf)

# Sources for Children

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

# Sources for Teens

Helping Teenagers When a Parent Has Cancer

<http://www.cancercare.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.

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

# Articles

## Advance Care Planning

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

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

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# Video, Radio, Recordings, Podcasts

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=vI8OSTEFpFw>

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 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=yUbZYzs3I0khttps://www.youtube.com/watch?v=yUbZYzs3I0k>

Dementia: End of life care

 10.11 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>

Empathy: The Human Connection to Patient Care

<http://www.youtube.com/watch?v=cDDWvj_q-o8>

The End

NPR

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

End of Life - Aging Matters

NPT Reports

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

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.” <http://www.slate.com/articles/health_and_science/medical_examiner/2016/09/netflix_s_new_documentary_extremis_shows_the_tension_of_end_of_life_care.html>

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.”

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

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 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

The Last Chapter - End of Life Decisions

 12-28-10

56.48 minutes

https://www.youtube.com/watch?v=8jKUZ8lS9b4

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.

Letting Go: A Hospice Journey

 5-24-16

 30.10 minutes

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

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>

Starting a Conversation about Pediatric Palliative Care

 <https://www.youtube.com/watch?v=hKK24Bp1elQ>

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/>

 Link for viewing: http://www.pbs.org/wgbh/frontline/film/suicide-plan/

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

Understanding Palliative Care

 1-28-13

 31.22 minutes

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

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>

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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>

# 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

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 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 centred 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 realises 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>

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

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>

*Palliative Care Issues:* childhood cancer, childhood bereavement

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

*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 befriending a classmate who has just been diagnosed with cancer.” <http://www.imdb.com/title/tt2582496/>

*Palliative Care Issues:* childhood cancer, childhood bereavement

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>

*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

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>

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

Steel Magnolias

 19

 Minutes

 Director:

 Cast: Julia Roberts,

 “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

Terms of Endearment

 1983

 132 minutes

 Director: James L. Brooks

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

 “The devoted, and antagonistic, bond between a dramatic, charismatic widow (Shirley MacLaine) 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

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

**Graphic Medicine**

Chast, R. (2014). *Can't we talk about something more pleasant?* (First U.S. edition. ed.). New York: Bloomsbury USA.

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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

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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.

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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*.

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