

# Advance Care Planning

## Resources

The following resources are associated with the course Advance Care Planning: An Introduction for Public Health and Aging Services Professionals, located on the Web at <http://www.cdc.gov/aging/advancecareplanning>.

**Note:** Links to websites of nonfederal organizations are provided in this course solely as a service to learners. This graphic notice (  ) means that you are leaving a Department of Health and Human Services (HHS) website and linking to a site that provides additional information consistent with the intended purpose of this course. The HHS cannot attest to the accuracy of a nonfederal site. Linking to a nonfederal site does not constitute an endorsement by HHS or any of its employees of the sponsors or the information and products presented on the site. You will be subject to the destination site's privacy policy when you follow the link.

## Care at End of Life

### SUPPORT Study (1995)

In 1995, The Robert Wood Johnson Foundation sponsored the largest study ever conducted on care at the end of life experienced by people who were hospitalized. This journal article, "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)," documents the methodology, findings, results, and implications.

<http://jama.ama-assn.org/cgi/reprint/274/20/1591.pdf> 

### Approaching Death: Improving Care at the End of Life (1998)

*Approaching Death* reflects a wide-ranging effort to understand what we know about care at the end of life, what we have yet to learn, and what we know but do not adequately apply. It seeks to build understanding of what constitutes good care for the dying and offers recommendations to decision makers that address specific barriers to achieving good care. This volume offers a profile of when, where, and how Americans die. *Approaching Death* considers the dying experience in hospitals, nursing homes, and other settings and the role of interdisciplinary teams and managed care. It offers perspectives on quality measurement and improvement, the role of practice guidelines, cost concerns, and legal issues such as assisted suicide. The book proposes how health professionals can become better prepared to care well for those who are dying and to understand that these are not patients for whom "nothing can be done."

<http://iom.edu/Reports/1998/Approaching-Death-Improving-Care-at-the-End-of-Life.aspx>

### When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families (2002)

Although dying is a part of life, a child's death, in a very real sense, is unnatural and has a devastating and enduring impact. More than 50,000 children die each year. This report builds on two earlier IOM reports -- *Approaching Death: Improving Care at the End of Life* (1997) and *Improving Palliative Care for Cancer* (2001). It continues the argument that medical and other support for persons with fatal or potentially fatal conditions often falls short of what is reasonably, if not simply, attainable.

<http://www.iom.edu/Reports/2002/When-Children-Die-Improving-Palliative-and-End-of-Life-Care-for-Children-and-Their-Families.aspx>

### **Describing Death in America: What We Need to Know (2003)**

National expenditures for medical care in the months and days preceding death are enormous. We do not know whether money is buying quality care, optimizing the quality of life of those who are dying, or whether the situation is getting better or worse over time. Although the information that exists "to describe death" at a national level is often quite informative, it is fragmentary.

This report recommends ways to fill information gaps by better using existing nationally-representative data, and through some new measures, in particular, a new, ongoing National Mortality Follow-up Survey. The aim is to allow benchmarking of where we are today as a society, and determine what goals we can set to minimize pain and suffering and maximize the quality of life of all of us who will die in the years to come.

<http://iom.edu/Reports/2003/Describing-Death-in-America-What-We-Need-to-Know.aspx>

### **National Association for Attorneys General End of Life Healthcare Project (2003 and 2004)**

In an effort to help the public sort through the increasingly complex legal and social questions surrounding end-of-life health care, the National Association of Attorneys General End-of-Life Health Care Project has tackled one of the most basic of consumer issues: How can states ensure that its citizens' desires concerning treatment at the end of their lives are honored? What changes in a state's laws or regulations are necessary to ensure that its citizens will be afforded adequate pain relief during their lives and in their waning days? What can Attorneys General offices do to educate constituents about advance medical directives and health care powers of attorney?

Launched in 2002 as a part of Oklahoma Attorney General Drew Edmondson's presidential initiative, the End-of-Life Project has encouraged Attorneys General across the country to take the lead in drafting legislative changes to make medical directives more consumer-friendly, participate in citizen forums and educational efforts, hold listening tours to understand the views of a multitude of stake-holders and review their own jurisdiction's laws and regulations to ascertain where they might hinder the goals of ensuring that end-of-life wishes are carried out, and that a balanced pain policy be pursued. The project published two reports, the first in 2003 titled, *Improving End-of-Life Care: The Role of Attorneys General*, and the other similarly titled report released in 2004, which outlined the challenges of pursuing the project's goals and how Attorneys General might address the various issues raised.

[http://www.naag.org/assets/files/pdf/report-end\\_of\\_life.pdf](http://www.naag.org/assets/files/pdf/report-end_of_life.pdf) (2003) 

<http://www.naag.org/assets/files/pdf/report-2004-end-of-life.pdf> (2004) 

### **Means to a Better End: A Report on Dying in America Today (2004)**

On the heels of SUPPORT, The Robert Wood Johnson Foundation launched Last Acts, a multiyear, multimillion-dollar national campaign to promote improvements in care and caring near the end of life. The Last Acts report rates each of the 50 states and the District of Columbia on eight criteria as a basis for assessing the state of end-of-life care in this country.

<http://www.lastacts.org> 

### **Dartmouth Atlas; End of Life Care Section (2005)**

For more than 20 years, the Dartmouth Atlas Project has documented glaring variations in how medical resources are distributed and used in the United States. The project uses Medicare data to provide information and analysis about national, regional, and local markets, as well as hospitals and their affiliated physicians. This research has helped policymakers, news media, health care analysts, and others improve their understanding of the health care system and form the foundation for many of the ongoing efforts to improve health and health systems across America.

<http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=18> 

### **Advance Directives and Advance Care Planning: Report to Congress, by the Office of the Assistant Secretary for Planning and Evaluation (2008)**

In 2006, Congress requested that the Department of Health and Human Services (HHS) conduct a study on how best to promote advance directives. This HHS report is a product of research by RAND Health, commissioned papers, and roundtable discussions with experts and the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE).

<http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf> 

### **National Priorities and Goals: Aligning Our Efforts to Transform America's Health Care (2008)**

The National Priorities Partnership, a collaborative effort of 28 major national organizations that collectively influence every part of the health care system, is aligning efforts to transform America's health care. The Partners, convened by the National Quality Forum to address the challenges of our health care system, represent multiple stakeholders drawn from the public and private sectors. The Partners have identified a set of National Priorities and Goals to help focus performance efforts on high-leverage areas—those with the most potential to improve health and healthcare—thus, accelerating fundamental change in our health care delivery system.

<http://www.nationalprioritiespartnership.org/uploadedFiles/NPP/08-253-NQF%20ReportLo%5B6%5D.pdf> 

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## **Research on Advance Care Planning**

### **Introduction: Papers from the National Institutes of Health State-of-the-Science Conference on Improving End-of-Life Care (2005)**

In December 2004, the National Institute of Nursing Research (NINR) and the National Institutes on Health (NIH), Office of Medical Applications of Research, along with many cosponsors, held an interdisciplinary State-of-the-Science Conference on Improving End-of-Life Care. The conference panel identified gaps in our current state of knowledge and provided suggestions for future research directions. This supplement presents papers from a distinguished group of scientists with a wide range of backgrounds who participated in this state-of-the-science conference.

[http://www.ninr.nih.gov/NR/rdonlyres/27FB4AE5-8343-4F6F-91A3-93221D9A1FAC/4949/improving\\_eol.pdf](http://www.ninr.nih.gov/NR/rdonlyres/27FB4AE5-8343-4F6F-91A3-93221D9A1FAC/4949/improving_eol.pdf) 

### **End-of-Life and Palliative Care Science: A Needs Assessment of Federal and Private Research Funding Trends, Project Grants, and National Research Priorities**

The NINR was recently awarded funds from the NIH, Office of the Director, Evaluation Set-Aside Program to conduct a needs assessment program evaluation. The project will derive comprehensive analytic data that will be used to identify historical national funding trends in end-of-life and palliative care (EOL PC) research.

<http://www.ninr.nih.gov/ResearchAndFunding/EOLPCNeedsAssessment.htm> 

### **The Quest to Die with Dignity (2008)**

In a study by American Health Decisions, funded by The Robert Wood Johnson Foundation, Americans discuss their views on health care at the end of life. On the basis of in-depth focus group discussions involving 385 Americans in 32 cities as well as two sets of follow-up interviews, The Quest to Die with Dignity identifies how Americans think about death and dying, how they want to be treated, and how they view planning documents such as living wills.

[http://www.georgiahealthdecisions.org/index.php?option=com\\_content&view=article&id=55&Itemid=69](http://www.georgiahealthdecisions.org/index.php?option=com_content&view=article&id=55&Itemid=69) 

### **Agency for Healthcare Research and Quality, Preferences for Care at the End of Life**

Research can help physicians and other health care professionals guide patient decision making for care at the end of life. Findings resulting from research funded by the Agency for Healthcare Research and Quality (AHRQ) are discussed. This research can help providers offer end-of-life care that is based on preferences held by the majority of patients under similar circumstances.

<http://www.ahrq.gov/research/endliferia/endria.htm> 

### **Advance Care Planning: A Systematic Review**

This study examined the research literature on end-of-life care to determine the impact of advance directives, including living wills and do not resuscitate orders, on those at the end-of-life, using studies involving advance-care planning. The evidence provides several key insights involving advance care planning, illuminating strengths of the field, as well as opportunities for research.

<http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=103623376.html> 

### **Research Library**

This website includes a collection of publications gathered over the years and compiled for easy-to-use reference by Respecting Choices, owned and operated by a not-for-profit corporation, Gundersen Lutheran Medical Foundation, Inc.

[http://respectingchoices.org/research\\_library/publications](http://respectingchoices.org/research_library/publications) 

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## **State Efforts**

### **State Initiatives in End-of-Life Care (2006)**

The Center for Practical Bioethics publishes State Initiatives in End-of-Life Care, a policy series that reaches 25,000 end-of-life coalition leaders, policymakers and health care professionals. The publication advances balanced approaches to pain management policy, consumer protection and professional development. Among the more than two dozen articles is Issue 25, Thirty-Five Leaders Map the Future of Reform, which documents responses of 35 recognized and emerging leaders to the question: what must be accomplished in the foreseeable future to ensure quality care for most Americans?

<http://practicalbioethics.org/aging-and-end-of-life-care/state-initiatives-in-end-of-life-care/> 

### **Thinking Outside the Hospice, States Look to Expand Palliative Care Services (2008)**

In the last decade, palliative care has evolved and is now an approach that tries to improve the quality of life of patients and their families facing the problems associated with life-threatening illnesses. This 2008 article from the National Conference of State Legislatures describes efforts of four states that have sought ways to bring palliative care into the mainstream of medical treatment.

<http://www.ncsl.org/default.aspx?tabid=14254> 

### **Planning for End-of-Life Care (2010)**

Since the 1970s, state lawmakers have passed laws that protect individuals' rights to decide the role of life-extending treatments in their future care. Current policies help ensure not only that a broad range of providers and family members understand and can carry out a person's choices, but also that those choices can be easily changed as medical conditions, needs, and desires do. This 2010 article, sponsored by the National Conference of State Legislatures, updates an earlier 2008 publication of state policies.

<http://www.ncsl.org/default.aspx?tabid=21089> 

### **Carolina Geriatric Education Center Consortium**

The Carolina Geriatric Education Center (CGEC) aims to improve the health of North Carolina's older adults by providing evidence-based and culturally competent geriatrics education and training, enabling health professionals to better serve the state's increasingly diverse older adult populations. Its website offers an online Advance Care Planning course and additional resources to help health-care providers apply key steps and principles when developing an advance care plan and advance directives.

<http://clipper.med.unc.edu/acp/>

### **Growth House, Inc.**

Growth House, Inc., offers free access to more than 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 and podcasts. It serves both the general public and health care professionals.

[http://www.growthhouse.org/radio\\_channel\\_education.html](http://www.growthhouse.org/radio_channel_education.html)

### **The National Legal Resource Center**

The National Legal Resource Center is a collaborative effort developed by the Administration on Aging. Its partners are the American Bar Association Commission on Law and Aging, the Center for Elder Rights Advocacy, the Center for Social Gerontology, the National Consumer Law Center, and the National Senior Citizens Law Center. This section provides an overview and highlights resources on medical decision making.

<http://www.nlrc.aoa.gov/>

### **Patient Self Determination Act (PL 101-508)**

The PL101-508 law, passed by Congress in 1990, required many hospitals, nursing homes, home health agencies, hospice providers, and other health care institutions to inform patients of their rights regarding decisions toward their own medical care. Once it became effective on December 1, 1991, adult patients were entitled to dictate their future care if they become incapacitated.

<http://www.libraryindex.com/pages/3133/Advance-Directives-PATIENT-SELF-DETERMINATION-ACT.html>

### **National Healthcare Decisions Day**

National Healthcare Decisions Day is an initiative to encourage patients to express their wishes regarding health care and for providers and facilities to respect those wishes, whatever they might be.

Its website lists participants in this national effort, useful links to participants and other sites, a blog, facts, public resources, media kits, and state and community activities.

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

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## **Role of Public Health**

### **The Relevance of Public Health in Improving Access to End of Life Care (2003)**

"The Relevance of Public Health in Improving Access to End of Life Care" is an article published by National Hospice to help deal with end of life issues.

<http://www.growthhouse.org/nhwg/essay5.htm>

### **Public Health and Social Justice**

The Public Health and Social Justice website includes several slide shows on death and dying, death and dying literature, end of life decision making, and other related topics.

<http://phsj.org/death-dying-and-end-of-life-care/>

## Role of State Health Departments

### **The Role of State Health Departments in Addressing End-of-Life Issues (2004)**

The Association of State and Territorial Chronic Disease Program Directors (CDD) and the Centers for Disease Control and Prevention (CDC) facilitated a process to identify and prioritize public health activities related to end-of-life issues. Concept mapping and a modified Delphi process yielded the five priority recommendations for state health department action. [http://www.chronicdisease.org/nacdd-initiatives/healthy-aging/related-resources/EOL\\_web\\_post.pdf](http://www.chronicdisease.org/nacdd-initiatives/healthy-aging/related-resources/EOL_web_post.pdf)

### **Development of Public Health Priorities for End-of-Life Initiatives (2005)**

Recently, end-of-life (EOL) issues have captured the attention of the public health community. This study reports a project to help state health departments better understand their potential role in addressing EOL issues and developing initial priorities for EOL activities. [http://www.ajpm-online.net/article/S0749-3797\(05\)00310-7/abstract](http://www.ajpm-online.net/article/S0749-3797(05)00310-7/abstract)

### **End-of-Life Content in Comprehensive Cancer Control Plans: A Systematic Review (2007)**

A recent project to define public health priorities for end of life (EOL) recommends incorporating EOL principles in all state, territory, and tribe Comprehensive Cancer Control (CCC) Plans. The degree to which EOL content is currently included in CCC Plans was assessed through a systematic review of CCC Plans, examining keywords, definitions, topics, data, goals, and strategies. Forty-five plans (42 state and 3 tribal) were eligible. Forty-one CCC Plans (91%) included the keyword "end-of-life." EOL goals were most often categorized as use of care, access to care, and awareness of EOL issues among patients, public, and providers. The top EOL strategies were research, provider education, and patient and public education. The results establish a baseline of EOL content in CCC Plans and should help improve assistance in future CCC planning efforts. <http://ajh.sagepub.com/content/24/5/390.full.pdf+html>

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## Role of Aging Services Networks

### **Aging and Ethnicity**

Donald E. Gelfand, PhD, is a professor of sociology at Wayne State University, Detroit, Michigan, and coordinator of the Wayne State University End-of-Life Interdisciplinary Project (WSU-EOLIP). He has conducted and published research on attitudes of Mexican Americans toward end-of-life care. He has also conducted extensive research on issues of aging among variety of other ethnic groups including African Americans, Latinos, Native Americans, and individuals from a variety of European backgrounds. The second edition of his book *Aging and Ethnicity* was published by Springer Publishing Company in 2003. Available at <http://www.springerpub.com/product/9780826174215>

### **The Complete Life**

The Complete Life is a two-part curriculum developed as part of a larger effort to improve end-of-life care in Hawaii. Designed specifically for faith communities but utilized among caregivers, professionals, and paraprofessionals working in the field of aging. <http://hawaii.edu/aging/endoflifecare.html>

### **Senior Connection**

Senior Connection offers several videos on death and dying that provide information to help seniors and their caregivers help themselves. <http://www.seniorconnection.org/video.htm>

## **Palliative Care**

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

CAPC is the leading resource for palliative care program development and growth. On the Center's website are essential palliative care tools, education, resources, and training for health care professionals. These include a state-by-state report card on access to palliative care in the nation's hospitals.

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

### **National Palliative Care Research Center (NPCRC)**

NPCRC is committed to stimulating, developing, and funding research directed at improving care of seriously ill patients and their families.

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

### **National Consensus Project**

The National Consensus Project developed and disseminated two very successful versions of the Clinical Practice Guidelines for Quality Palliative Care (2004 and 2009). These guidelines have served as a foundation for the National Quality Forum Preferred Practices and have become a hallmark within the field guiding policy makers, providers, practitioners, and consumers in understanding the principles of quality palliative care.

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

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## **Hospice Care**

### **National Association of Home Care and Hospice (NAHCH)**

NAHCH is the nation's largest trade association representing the interests and concerns of home care agencies, hospices, and home care aid organizations.

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

### **National Hospice and Palliative Care Organization (NHPCO)**

NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

<http://www.nhpc.org/templates/1/homepage.cfm> 

## Workbooks and Manuals to Help with Advance Care Planning

Several tools are available to help with starting a conversation about advance care planning and with end-of-life decision making, including the following:

### ***Advanced Care Planning: Resources for Caretakers and Health Care Professionals Providing Aging Counseling***

This online Advance Care Planning course was developed by the Carolina Geriatric Education Center (CGEC), dedicated to improving the health of North Carolina's older adults by providing evidence-based and culturally competent geriatrics education and training.

<http://clipper.med.unc.edu/acp/>

***Caring Conversations Workbook***, published by the Center for Practical Bioethics  
<http://www.practicalbioethics.org/FileUploads/FINAL.Caring%20Conversations%20Workbook%202010.pdf>

***Consumer's Tool Kit for Health Care Advance Planning***, by the ABA Commission on Law and Aging

[http://apps.americanbar.org/aging/publications/docs/consumer\\_tool\\_kit\\_bk.pdf](http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf)

***Five Wishes***, was originally distributed with support from a grant by The Robert Wood Johnson Foundation and now available in 26 languages with assistance from the United Health Foundation

<http://www.agingwithdignity.org/five-wishes.php>

***For Health Care Proxies/Agents: Making Decisions for Someone Else: A How To Guide***, published by the ABA Commission on Law and Aging

[http://www.americanbar.org/groups/law\\_aging.html](http://www.americanbar.org/groups/law_aging.html)

***"Good to Go" Toolkit and Resource Guide***, published by Compassion and Choices

<http://community.compassionandchoices.org/document.doc?id=425>

***Loving Conversations***, produced by the American Health Lawyer Association, follows a fictional family through the difficult process of making healthcare decisions for a loved one who did not execute an advance directive.

<http://www.healthlawyers.org/Resources/PI/InfoSeries/Pages/LovingConversations.aspx>

***Respecting Choices***, an internationally recognized, evidence-based program established in 2000 that focuses on the process of advance care planning

<http://respectingchoices.org/>

***The African American Spiritual and Ethical Guide to End of Life Care - What Y'all Gon' Do With Me?*** This guide was prepared by Heart Tones and addresses some of the historical, cultural and spiritual factors that influence African-American's decisions about end-of-life care and planning.

<http://www.hearttones.com/resources.php>

***Thinking Ahead: My Way, My Choice, My Life at the End.*** This workbook and video was created by California advocates with developmental disabilities from three regional centers.

<http://www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm>

## Caregivers and Health Care Surrogates

### Family Caregiver Alliance (FCA)

Founded in 1977, FCA was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. Long recognized as a pioneer in health services, FCA now offers programs at national, state and local levels to support and sustain caregivers.

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

### National Family Caregivers Association (NFCA)

The NFCA educates, supports, empowers, and speaks up for the more than 65 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well being.

<http://www.thefamilycaregiver.org/> and <http://www.familycaregiving101.org/> 

### AARP

AARP has a Caregiving Resource Center with helpful tools, work sheets and tips on how to plan, prepare and succeed as a caregiver.

<http://www.aarp.org/content/aarp/en/home/relationships/caregiving.html> 

### Administration on Aging Caregiver Support Program

The National Family Caregiver Support Program (NFCSP), established in 2000, provides grants to states and territories, based on their share of the population aged 70 years and older, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.

[http://www.aoa.gov/aoaroot/aoa\\_programs/hcltc/caregiver/index.aspx](http://www.aoa.gov/aoaroot/aoa_programs/hcltc/caregiver/index.aspx) 

### CDC's Healthy Aging Program

CDC's Healthy Aging Program provides a wealth of links and resources on caregiving.

<http://www.cdc.gov/aging/caregiving/resources.htm>

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## Legal Issues

### Legal Guide for the Serious Ill: Seven Key Steps to Get Your Affairs in Order (2009)

This guide was prepared by the American Bar Association Commission on Law and Aging for the National Hospice and Palliative Care Organization.

[http://www.healthcarechaplains.org/userimages/Legal\\_Guide\\_for\\_the\\_Terminally\\_Ill.pdf](http://www.healthcarechaplains.org/userimages/Legal_Guide_for_the_Terminally_Ill.pdf) 

### Physician Orders for Life-Sustaining Treatment (POLST)

The POLST Paradigm program is designed to improve the quality of care people receive at the end of life. It 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. The organization's ultimate mission is to facilitate POLST Paradigm Programs in every state.

<http://www.ohsu.edu/polst/> 

### **In Your Hands: Legal Tools for Preserving Personal Autonomy**

Created by the American Bar Association Commission on Law and Aging, this video is narrated by the late Helen Hayes, with an epilogue by her son, James MacArthur. It addresses the legal aspects of planning for incapacity in a clear and positive way, and introduces four legal tools: durable powers of attorney, medical powers of attorney, living wills and trusts.

<http://www.youtube.com/watch?v=pIWgKgZ5Rxo> 

In Your Hands: Legal Tools for Preserving Personal Autonomy (Spanish Subtitles)

<http://get-attorneys.com/education/in-your-hands-legal-tools-for-preserving-personal-autonomy-spanish-subtitles.html> 

### **Making Medical Decisions for Someone Else: A Florida Handbook**

Based on a handbook created in 2006 by the American Bar Association's Commission on Law and Aging, this booklet helps one adult make health care choices for another.

<http://med.fsu.edu/index.cfm?page=innovativecollaboration.publicationspresentations> 

### **Five Big Myths of Advance Care Planning and How to Stay Anchored in Reality**

Slides from this 2010 podcast address the five biggest myths that plague advance care planning, and how to avoid them and how to make advance care planning more effective.

[http://www.americanbar.org/groups/health\\_law/resources/podcast0410\\_advance\\_dir.html](http://www.americanbar.org/groups/health_law/resources/podcast0410_advance_dir.html) 

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## **Advance Directives**

### **U.S. Living Will Registry**

The U.S. Living Will Registry electronically stores advance directives and makes them available to health care providers 24 hours a day via secure Internet or telephone-facsimile. The Registry stores all types of advance directives such as living wills, health care proxies, health care power of attorney, as well as organ donor information.

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

### **State Specific Advance Directive Form**

This links directly to free downloadable advance directive forms and information from state bar associations and other reputable state groups.

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

### **Medline Plus**

This National Library of Medicine, NIH, website offers easy-to-understand information on advance directives.

<http://www.nlm.nih.gov/medlineplus/ency/article/001908.htm> 

### **Advance Directives and Cancer**

This fact sheet provides cancer patients and their families with an outline for thinking about end-of-life care issues and some guidelines for discussion with their doctors, families, and loved ones. This fact sheet is also designed to help patients understand the medical, legal, and personal choices they might face in the future.

<http://www.cancer.gov/cancertopics/factsheet/support/advance-directives> 

## **Cognitive Impairment**

### **Facts and Figures**

This report details the escalation of Alzheimer's disease, which currently impacts more than 5 million Americans. Facts and Figures conveys the burden of Alzheimer's and dementia on individuals, families, local and state government and the nation's health-care system.

[http://www.alz.org/alzheimers\\_disease\\_facts\\_figures.asp?type=homepage](http://www.alz.org/alzheimers_disease_facts_figures.asp?type=homepage) 

### **End-of-life Decisions: Honoring the Wishes of the Person with Alzheimer's Disease**

This brochure from the Alzheimer's Association discusses the issues a family might face when the person with dementia nears the end of life.

[http://www.alz.org/national/documents/brochure\\_endoflifedecisions.pdf](http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf) 

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## **Cultural Diversity**

### **Cultural Issues in End of Life Decision Making**

Braun KL, Pietsch JH, & Blanchette PL, editors. Cultural issues in end-of-life decision making. Thousand Oaks, CA: Sage Publications; 2000.

<http://www.hawaii.edu/aging/endoflifecare.html> 

### **Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians**

H. Russell Searight and Jennifer Gafford. Cultural diversity at the end of life: Issues and guidelines for family physicians. Forest Park Hospital Family Medicine Residency Program, St. Louis, Missouri Am Fam Physician. 2005 Feb 1;71(3):515-522.

<http://www.aafp.org/afp/2005/0201/p515.html> 

### **Facing Death**

HM Spiro, MG Cumen, L Fwandel. Facing death. Yale University Press. 1996.

<http://yalepress.yale.edu/book.asp?isbn=9780300076677> 

## Organizations

### **Alliance of State Pain Initiatives**

<http://aspi.wisc.edu/> 

### **American Bar Association's Commission on Law and Aging**

<http://new.abanet.org/aging/Pages/default.aspx> 

### **American Chronic Pain Association**

<http://www.theacpa.org/default.aspx> 

### **American Medical Association**

<http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/about-ethics-group/ethics-resource-center/end-of-life-care.shtml> 

### **American Pain Foundation**

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

### **American Pain Society**

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

### **American Society for Pain Management Nursing**

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

### **Center for Practical Bioethics**

<http://www.practicalbioethics.org/cpb.aspx?pgID=895> 

### **Center to Advance Palliative Care**

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

### **Duke Institute for Care at the End of Life**

<http://divinity.duke.edu/initiatives-centers/iceol> 

### **Family Caregiver Alliance**

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=401](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=401) 

### **Growth House, Inc.**

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

### **Healthy Aging Program, Centers for Disease Control and Prevention**

<http://www.cdc.gov/aging/caregiving/index.htm> 

### **International Society of Advance Care Planning and End of Life Care (ACPEL)**

<http://acpelsociety.com/> 

### **National Healthcare Decisions Day**

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

### **National Hospice and Palliative Care Organization**

<http://my.nhpco.org/NHPCO/NHPCO/Home/> 

### **National Pain Foundation**

<http://www.makingsenseofpainrelief.org/groups/NationalPainFoundation.asp> 

[http://www.americanbar.org/groups/health\\_law/resources/podcast0410\\_advance\\_dir.html](http://www.americanbar.org/groups/health_law/resources/podcast0410_advance_dir.html) 