

Advance Care Planning – Selected Resources for the Public

The following resources represent a broad array of materials to assist the public in better understanding advance care planning and related topics such as hospice and palliative care, caregiving, cognitive impairment, and legal issues. While extensive, this list is by no means exhaustive and other quality resources are also available.

Guidance on Completing an Advance Directive

Caring Conversations Workbook

Published by the Center for Practical Bioethics, guide helps individuals and their families share meaningful conversations regarding end-of-life decisions
<http://www.practicalbioethics.org/documents/caring-conversations/Caring-Conversations.pdf>

Five Wishes

Guide on advance care planning available in 26 languages
<http://www.agingwithdignity.org/five-wishes.php>

Consumer's Tool Kit for Health Care Advance Planning

Developed by the American Bar Association Commission on Law and Aging
http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf

The African American Spiritual and Ethical Guide to End of Life Care - What Y'all Gon' Do With Me?

Guide prepared by Heart Tones addressing historical, cultural and spiritual factors that influence African-Americans' decisions about end-of-life care and planning
<http://www.hearttones.com/resources.php>

CRITICAL ConditionsSM

A community education program helping people understand the importance of planning for their end-of-life medical care, this comprehensive advanced care planning program developed by Georgia Health Decisions includes the *CRITICAL ConditionsSM Planning Guide*

<http://georgiahealthdecisions.org>

Thinking Ahead: My Way, My Choice, My Life at the End

Workbook and video created by California advocates with developmental disabilities
<http://www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm>

Loving Conversations

Produced by American Health Lawyer Association, follows fictional family through difficult process of making decisions for loved one who did not have advance directive
<http://www.healthlawyers.org/hlresources/PI/InfoSeries/Pages/LovingConversations.aspx>

Respecting Choices

Internationally-recognized, evidence-based program established in 2000 addressing process of advance care planning

<http://respectingchoices.org/>

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

Online course developed by Carolina Geriatric Education Center that provides evidence-based and culturally-competent geriatrics education and training

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

For Health Care Proxies/Agents: Making Decisions for Someone Else: A How To Guide

Guide published by American Bar Association Commission on Law and Aging

http://www.americanbar.org/groups/law_aging.html

“Good to Go” Toolkit and Resource Guide

Guide published by Compassion and Choices

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

Growth House, Inc.

Offers free access to over 4,000 pages of educational materials about end-of-life care, palliative medicine, and hospice

http://www.growthhouse.org/radio_channel_education.html

National Healthcare Decisions Day – April 16

Initiative encouraging individuals to express their wishes regarding health care; provides variety of resources, including materials for public, media kits, and suggested activities

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

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>

More on Advance Directives

“Speak Up” Video

Highlights the value of advance care planning and provides helpful information on Health Care Decisions Day on April 16

<http://www.youtube.com/watch?v=Bar0qZTUGdw>

U.S. Living Will Registry

Electronically stores advance directives and makes available to health care providers 24 hours a day via secure Internet or telephone-facsimile; also stores organ donation

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

State Specific Advance Directive Form

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

Website of the National Library of Medicine (a part of the National Institutes of Health) offers easy-to-understand information on advance directives

<http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000472.htm>

Advance Directives and Cancer

Fact sheet providing cancer patients and their families with outline for thinking about end-of-life care issues and guidelines for discussion with doctors, family members, and loved ones

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

Hospice and Palliative Care:**National Association of Home Care and Hospice (NAHCH)**

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)

Represents hospice and palliative care programs and professionals in the United States and works to expand access to hospice care and improve end-of-life

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

Caregivers and Health Care Surrogates:**Family Caregiver Alliance (FCA)**

Addresses needs of family members and others providing long-term care at home; offers programs at the national, state and local levels to support and sustain caregivers

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

National Family Caregivers Association (NFCA)

Educates and supports more than 65 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age <http://www.thefamilycaregiver.org/> and

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

AARP Caregiving Resource Center

Caregiving Resource Center offers 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's National Family Caregiver Support Program

Provides grants to states and territories to fund 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

Cognitive Impairment:

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

Brochure from the Alzheimer's Association addresses issues a family may face when the person with dementia nears the end of life

http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf

Facts and Figures

Annual report of Alzheimer's Association detailing burden of Alzheimer's disease and dementia on individuals, families, state and local governments, and the health care system

http://www.alz.org/alzheimers_disease_facts_figures.asp?type=homepage

Legal Issues:

The National Legal Resource Center

Collaborative effort of the Administration on Aging that provides legal support to aging advocacy network and highlights resources on medical decision making

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

Patient Self Determination Act (PL 101-508)

Requires hospitals, nursing homes, home health agencies, hospice providers, and other institutions to inform patients of their rights on decisions about their medical care

<http://www.gpo.gov/fdsys/pkg/GAOREPORTS-HEHS-95-135/pdf/GAOREPORTS-HEHS-95-135.pdf>

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

Prepared by the American Bar Association Commission on Law and Aging for the National Hospice and Palliative Care Organization

http://www.healthcarechaplancy.org/userimages/Legal_Guide_for_the_Terminally_Ill.pdf

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

Podcast slides address five biggest myths regarding advance care planning and how to make advance care planning more effective

http://www.americanbar.org/groups/health_law/resources/podcast0410_advance_dir.html