

Resources

Part I. Advance Directives/Patient Self-Determination

Legal Counsel for the Elderly (LCE) American Association of Retired Persons (AARP)

P.O. Box 96474
Washington, DC 20090-6474
202/ 434-2277

LCE has state-specific guidebooks about advance directives. If you want to order a booklet, send \$5 per booklet (for shipping and handling) to the above address. You can obtain up-to-date state-by-state information about advance directives and statutory forms, if they exist, in your state.

AARP, which supports individual autonomy in healthcare decision-making, is conducting community education workshops on medical decision-making and advance directives around the country. These workshops, led by trained volunteers, provide basic information about advance directives and state-specific forms. In addition, workshop participants can return to a later session for assistance in completing their documents. For information about these workshops, call your AARP regional office or AARP at 1-800-424-3410.

Choice in Dying

200 Varick Street
New York, NY 10014
212-366-5540

This national organization provides state-specific advance directive forms and instructions, as well as a number of booklets about healthcare powers of attorney and living wills.

The Medical Directive, by Linda L. Emanuel, M.D. and Ezekiel J. Emanuel, M.D. This directive form has been revised to include six illness situations. For each illness, you indicate whether you would want particular interventions and your goals for medical care. For single copy requests, write to:

[General Internal Medicine Unit](#)
[Massachusetts General Hospital](#)

32 Fruit Street
Boston, MA 02114

Values History Form, by Joan Gibson. This form provides a framework for thinking about medical decision-making issues, and can be used to help communicate your general goals for medical care and your underlying values in medical decisions. For single copy requests, write to:

Joan Gibson, Director
University of New Mexico
Health Sciences Ethics Program
Nursing/Pharmacy Building, Room 368
Albuquerque, NM 87131

Aging with Dignity “Five Wishes”

My wish For:

The person I want to make care decisions for me when I can't

The kind of medical treatment I want or don't want
How comfortable I want to be
How I want people to treat me
What I want my loved ones to know

Aging with Dignity

P.O. Box 1661
Tallahassee, Florida 32302-1661
www.agingwithdignity.org

American Bar Association

1800 M ST., NE, South Lobby
Washington, DC 20036

Alzheimer's Association

70 East Lake St., Suite 600
Chicago, IL 60601
1-800-621-0379

Association for Death Education & Counseling

638 Prospect Ave.
Hartford, CT 06105
203/ 232-4825

Children of Aging Parents

2761 Trenton Rd.
Levittown, PA 19056
215/ 945-6900

Internet Links

State-specific downloadable advance directive forms and state-specific information regarding advance directives can be obtained at www.partnershipforcaring.org

Web site for healthcare providers, good descriptions and case studies.
<http://eduser.vhscer.washington.edu/bioethics/topics/advdir.html>

A nurse and a doctor from Dartmouth Medical School's Center discuss goals of decision making and patient participation in care planning in an article for Evaluative Clinical Sciences.

[\[http://oncolink.upenn.edu/psychosocial/qol/qol_3.html\]](http://oncolink.upenn.edu/psychosocial/qol/qol_3.html)

Last Acts is a campaign to improve end-of-life care by a coalition of professional and consumer organizations. Palliative care, focused on managing pain and making life better for individuals and families facing death, is the focus. This site is for professionals and volunteers working to improve care of the dying. Last Acts can be accessed at www.lastacts.org.

Growth House's mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Growth House can be accessed at www.growthhouse.org.

Information and advice regarding the law in your state may be obtained from the following:

- State Department of Health

- State Office on Aging
- State or Regional Hospital Association
- State Bar Association
- University Centers on Aging

You also can obtain state forms and literature from:

- Your local hospital
- Your local nursing home
- Your state or local office on aging
- Your state's bar association
- Your state's hospital association
- Your state's medical association

Part II. End of Life Care

Pain/Oncology Resources

Agency for Healthcare Policy and Research: <http://www.ahcpr.gov/>

Lists various resources on pain and cancer pain.

American Pain Society: www.aps.org

Good source for current news, legislative activity, and position statements.

Association of Cancer Online Resources: <http://www.acor.org>

A growing list of online resources.

Memorial Sloan Kettering: <http://www.mskcc.org>

Memorial Sloan Kettering Cancer Center's web site provides a wide range of information for medical professionals, patients, their families, and the general public.

OncoLink, The University of Pennsylvania Cancer Resource: <http://www.oncolink.com>

Fast access by disease, specialty, etiology; current clinical trials; more.

Pain & Policy Studies Group: <http://www.medsch.wisc.edu/painpolicy>

All state intractable pain treatment laws, regulations, and state medical board guidelines are available on the PPSG website.

Resource Center for State Cancer Pain Initiative: <http://www.wisc.edu/molpharm/wcpi>

Provides an advocacy network for cancer pain.

Roxane Pain Institute: <http://www.Roxane.com>

Educational materials on cancer and AIDS pain management. Downloadable pain slide show; dates of lectures/seminars; links to patient and professional "libraries."

Palliative Care/Hospice Resources

American Academy of Hospice and Palliative Medicine: <http://www.aahpm.org>

Originally organized as the Academy of Hospice Physicians in 1988, the American Academy of Hospice and Palliative Medicine (AAHPM) is the only organization in the United States for physicians dedicated to the advancement of hospice/palliative medicine, its practice, research and education. AAHPM members are physicians from many medical specialties who are committed to furthering and fostering the practice of hospice/palliative care for the terminally ill and their families. American Academy of Hospice and Palliative Medicine members believe that this organization is the beginning of an organized discipline in the United States devoted to the special areas of palliative care and the management of terminal illness.

ABCD - Americans for Better Care of the Dying <http://www.abcd/caring.com>

ABCD is a non-profit public charity dedicated to social, professional, and policy reform aimed to improve the care system for patients with serious illness, and their families. ABCD is a coalition of citizens and professionals united to ensure that public policy addresses the needs of individuals and families coping with a fatal illness. ABCD will provide an information network, encouraging and supporting public involvement in correcting system deficiencies. ABCD seeks to harness the strength of many concerned people to speak with a shared voice.

The American Nurses Association (ANA): www.ana.org

The national association for registered nurses is a good source for position statements and competencies.

The Association for Death Education and Counseling: <http://www.adec.org>

Bereavement and Hospice Support Netline: <http://www.ubalt.edu>

Public service directory of bereavement support groups.

Center to Improve Care of the Dying: <http://www.gwu.edu/~cicd>

The Center to Improve Care of the Dying (CICD) was founded in the belief that life under the shadow of death can be rewarding, comfortable, and meaningful for almost all persons--but achieving that goal requires real change in the care system. CICD is a unique, interdisciplinary team of committed individuals, engaged in research, public advocacy, and education activities to improve the care of the dying and their families.

Cochrane Collaboration: <http://www.cochrane.org/>

Reviews of research evidence about the effects of healthcare.

Compassion in Dying: www.CompassionInDying.org

Dying Well: <http://www.dyingwell.com/>

Defining Wellness through the 'End of Life': Resources for patients and families facing life-limiting illness.

Eldercare Web: <http://www.elderweb.com>

Welcome to Eldercare Web, one of the oldest and most comprehensive eldercare gateways on the World Wide Web! It's a collection of hundreds of reviewed links to on-line information about health, financing, housing, aging, and other issues related to the care of the frail elderly. This Web site is designed for caregivers, family, healthcare providers, and professional advisors of elderly people with care needs.

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

Monthly guide to Best of the Net sites for life-threatening illness and bereavement.

Hospice and Palliative Nurse Association: www.hpna.org

This is the specialty nursing organization concerned with end of life care.

Hospice Foundation of America: <http://www.hospicefoundation.org>

Information about hospices and hospice care.

Hospice Hands: <http://hospice-cares.com>

Articles, chatroom, links to related sites.

Hospice Web: <http://www.hospiceweb.com/>

Hospice links, information, search for hospice in your area.

Last Acts: <http://www.lastacts.org>

Last Acts is a call-to-action campaign dedicated to improving end-of-life care through the sharing of ideas and solutions by professional care givers, institutions and individuals. The Last Acts Web site includes news updates, a resource center and reports on palliative care, family needs, service providers, education and training, financing and the workplace.

Medical College of Wisconsin Palliative Care Program: <http://www.mcw.edu/pallimed/>

The Palliative Medicine Program is committed to improving care for the dying in America through the development, implementation and dissemination of innovative education and clinical care programs.

National Association for Home Care: <http://www.nahc.org>

National Conference of State Legislatures: <http://www.ncsl.org>

Legislation related to end-of-life issues in states.

Open Society Institute: <http://www.soros.org/death.html>

Oversight Hearing: <http://www.house.gov/judiciary/2.htm>

"Assisted Suicide in the United States" - April 29, 1996 World Wide Web homepage of the House Committee on the Judiciary. This site will keep you informed about Judiciary Committee activities and other important issues facing our nation.

***Oxford Textbook of Palliative Care* by Ferrell and Coyle (Editors), 2002.**

Palliative Care Nursing: Quality Care to the End of Life

A Palliative Care Nursing Textbook by Marianne Matzo (Editor) and Deborah Witt Sherman (Editor).

Project on Death in America (PDIA) Reader: <http://www.soros.org/death.html>

The mission of the Project on Death in America is to understand and transform the culture and experience of dying and bereavement through initiatives in research, scholarship, the humanities, and the arts, and to foster innovations in the provision of care, public education, professional education, and public policy.

The Palliative Medicine Program: <http://www.mcw.edu/pallmed>

Provides a variety of information and educational materials about pain management and palliative care.

"When Death is Sought Assisted Suicide and Euthanasia in the Medical Context"

<http://www.health.state.ny.us/nysdoh/provider/death.htm>

In May 1994, the New York State Task Force on Life and the Law published a 217 page report titled "When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context". Since this particular issue has received so much public attention, the report has been made available electronically on the NYSDOH Web site. The report is posted in individual chapters.

The National Institute on Aging: <http://www.nih.gov/nia/>

The National Institute on Aging (NIA) is one of the National Institutes of Health, the principal biomedical research agency of the United States Government. The NIA promotes healthy aging by conducting and supporting biomedical, social, and behavioral research and public education.

Part III. The Use of Food and Fluids at the End of Life

For More Information Contact USDA's Center for Nutrition Policy and Promotion:

U.S. Department of Agriculture
Center for Nutrition Policy and Promotion
1120 20th St., NW
Suite 200, North Lobby
Washington, DC 20036-3475