



*Area Agency on Aging
End-of-Life Resources
Tool Kit
For Professionals*

*Provided by the Kansas Department on Aging
in Conjunction with
the Division of Health Policy and Finance
and the Office of Aging and Long Term Care
School of Social Welfare
University of Kansas*

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Forward

This tool kit is the direct outgrowth of suggestions made by active CARE assessors both in a state-wide survey and also in focus groups. In 2004, all CARE assessors were asked a number of questions about the CARE assessment and hospice referrals. Three hundred and fifty-nine assessors responded and many of them mentioned the need for further professional and consumer information about end-of-life care services and hospice. CARE assessors in both urban and rural areas reaffirmed this request in focus group sessions. Also, the need for a generic one-page brochure specific to Kansas about hospice was requested. This toolkit addresses the identified requests for information on hospice, palliative, advance directives, how to begin the conversation about end-of-life issues, and caregiver needs. In addition, professional standards for the key professional healthcare providers in end-of-life care, and cultural competency information is included. We hope that this tool kit helps to meet the needs of the CARE assessors and other professionals with the AAAs.

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Welcome to our toolkit on End-of-Life/Palliative Care Resources for Area on Aging personnel. Our goal is to provide you with concrete information on available services for persons who are experiencing a serious or life-limiting illness. From your input to both our CARE assessor surveys and our focus group research, you have told us that you:

- ❖ Need more factual information on end-of-life services (hospice and palliative care);
- ❖ Want more information on how to bring up these sensitive areas of discussion (advanced planning and hospice services);
- ❖ Need actual advanced planning information and documents in both English and Spanish; and
- ❖ Would like on-line or hardcopy sources for further information.

You have also expressed to us how hard it is to know when is the “right” time to talk to your clients about end-of-life care. It is extremely difficult to determine (even for physicians) the “right” time. But eventually we all will die and we all need to plan for future care needs regardless of our health status. We may never choose a hospice or palliative care service but it is important for us to know that those services exist and where to find them so that we can make wise and informed choices for our future. This tool kit contains lots of resources for you as practitioners to use and to pass on to your clients.

Each section includes some resources in hard copies and resources that you can download from the web.

We hope that these resources expand your knowledge base, serve your practice needs, and increase your sensitivity to end-of-life care issues.

SECTION ONE: Professional Standards

The following resources pertain to the professional standards in regard to end-of-life care. Knowing these standards and the guidelines on curriculum for the discipline is essential for the health care professional to understand what is expected of them as professionals. It can also help professionals keep abreast of the needs for continuing education in this growing field. This list of resources provides easy access to vital information for the health care professional.

Professional Standards Citations:

(This citations list provides sources for practice and educational standards).

References

FOR SOCIAL WORKERS:

National Association of Social Workers (NASW) (2006). *NASW Standards for Social Work Practice in Palliative and End of Life Care*. Download from www.socialworkers.org/practice/bereavement/standards/default.asp

FOR NURSES:

American Association of Colleges of Nursing (AACN). (2004). *Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care*. Download from <http://www.aacn.nche.edu/Publications/deathfin.htm>

Resources

FOR SOCIAL WORKERS:

NASW. (2005). *Understanding End of Life Care: The Social Workers' Role*. Download from www.socialworkers.org (free CEU opportunity through NASW).

National Hospice and Palliative Care Organization (2001). *Competency-based Education for Social Workers*. Virginia: NHPCO. (This booklet is available from NHPCO for a cost.)

FOR NURSES:

University of Illinois (2004). *Toolkit for Nurturing Excellence at End of Life Transitions (TNEEL)*. Available at <http://www.tneel.uic.edu> (This tool kit can be ordered through this website for a cost.)

National Hospice Organization (1997). *Guidelines for Curriculum Development on End of Life and Palliative Care in Nursing Education*. Virginia: NHO. (This booklet is available from NHPCO for a cost at www.nhpc.org and click on Market Place)

For Any Health Care Professional:

National Consensus Project for Quality Palliative Care (2004). *Clinical Practice Guide for Quality Palliative Care*. NHPCO. (This booklet is available from NHPCO for a cost at <http://www.nhpc.org/templates/1/homepage.cfm>)

For Physicians:

Emmanuel, L.L., Von Gunten, C., Feris, F. Eds. (1999). *The Education in Palliative and End of Life Care (EPEC) Curriculum: The EPEC Project*. Retrieved from <http://www.epec.net/EPEC/webpages/index.cfm>

For Physicians, Medical Students, and Medical Directors:

End of Life: Palliative Education Resource Center (EPERC). Retrieved from <http://www.eperc.mcw.edu/>

For Licensed Practice Nurses:

Hospice and Palliative Care Nurses Association (2003). *Core Curriculum for the Licensed Practical/Vocational Hospice and Palliative Nurse*. Retrieved from http://www.hpna.org/Publications_detail.aspx?ISBN=0-7575-1926-1

For Nursing Assistants:

Hospice and Palliative Care Nurses Association (2002). *Core Curriculum for the Hospice and Palliative Nurse Assistant*. Retrieved from http://www.hpna.org/Publications_detail.aspx?ISBN=0-7872-9924-3

For Clergy and Chaplains:

NHPCO (2001). *Guidelines for Spiritual Care in Hospice*. Retrieved from www.nhpc.org.

For Dietitians:

Position paper on End of Life Care. Retrieved from http://www.eatright.org/cps/rde/xchg/ada/hs.xsl/advocacy_adar0502_EN_U_HTML.htm

References

Section One: Professional Standards

Note: Resources are Located in the Resource Manual

SECTION TWO: Hospice

The following is a brief overview of hospice care and the benefits and eligibility requirements. Included are resources for further information both from national and state resources.

Hospice is the only federally and privately funded service for end-of-life care in the United States. It provides quality, holistic care for people with life-limiting illness. Hospice considers both the person with the life-limiting disease and his/her loved ones/family as their clients and provides services to all of them. The goal is to assist the individual and his/her family to live a quality life until death and for his/her loved ones to be supported in their grief. Hospice is dedicated to provide good pain and symptom management and psycho social support (National Hospice and Palliative Care Organization {NHPCO}, 2003).

Hospice believes that in order to provide good services a team approach must be used and the physical, emotional, spiritual, and social needs of the clients must be addressed. Usually this hospice team includes the person and his/her family and the following health care professionals: a nurse, nurse's assistant, social worker, chaplain, and physician. Volunteers, and other health care professionals as dietitians and others, can be called on if needed (Hastings Center, 2003).

Hospice services can be delivered at home, at nursing homes, at assisted living facilities, and at in-patient hospices. The range of services includes visits from all the above professionals as well as on-call services for nursing interventions 24-hours a day (Hastings Center, 2003).

The goal of hospice is not to cure the disease but to provide comfort care services so that people can live their lives as fully as possible. Current Medicare regulations require people to decline aggressive care services as chemotherapy while receiving hospice benefits. Medicare regulations also require that a physician state that the person has a life-limiting disease. Although a six month prognosis is used, if a person lives longer, there usually are no problems retaining their hospice benefit coverage, as long as the medical professionals can document that the person continues to decline (NHPCO, 2003).

A common myth is that people who have hospice care always die. Approximately 10% of all hospice admissions are discharged because they improve and no longer experiences declining health. Hospice care can help a person stabilize as he/she copes with the serious illness. Moreover, once discharged, the person can always reenroll in hospice at a later date if he/she begins to decline again (NHPCO, 2003).

Hospice is paid by the Medicare Hospice Benefit, the Medicaid Hospice Benefit and most private insurances. The Medicare and Medicaid benefits pay for:

- 100% of the nursing visits and on-call services
- 100% of cost of the nurse's assistant visits
- 100% of cost of the social work visits
- 100% of cost of the chaplain visits
- 100% of cost of the additional health care professional visits approved by the hospice
- 95% to 100% of the cost of the drugs approved by the hospice to keep the person comfortable;
- 100% of the cost of the medical equipment approved to keep the person comfortable; and
- many health care supplies (CMS, 2005)

After the death of the individual, hospice agencies provide support to the grieving family members/friends for up to a year.

Hospice is a CHOICE. The person with the life-limiting disease must choose hospice care and can choose to stop that care and return to aggressive treatments or change hospice providers whenever he/she wishes. The person may exercise his/her choice to discontinue hospice or change providers up to three times without any penalty in benefits. Hospice personnel respect the person's decisions and their right to decide what is best for him/her at this very important time of life. The hospice team approach includes the person and their family as key members of the team (NHPCO, 2003).

Who can I call to talk about hospice services in Kansas?

The Kansas Hospice and Palliative Care Organization can be contacted on the web at (<http://www.lifeproject.org/>) or by phone at 888-202-LIFE (5433). They will give you more information, answer questions, and tell you about hospices in your area.

References

HOSPICE INFORMATIONAL BOOKLETS:

CMS (2005). *Medicare Hospice Benefits: A special way of caring for people who have a terminal illness*. Maryland: CMS.

CMS (2003). *Beneficios de Hospicio Medicare*. Maryland: CMS

Resources

National Hospice Foundation (2003). *Hospice Care: Comfort and compassion when needed most*. Virginia: NHPCO. **This resource is good for professionals and clients.**

NHPCO (2003). *Caring Connections*. Retrieved from <http://www.caringinfo.org>.

References

Section Two: Hospice

Note: Resources are Located in the Resource Manual

SECTION THREE: Palliative Care

Palliative care services are another option to hospice care and can work side by side with hospice. Palliative means simply "comfort care". The healthcare professions have always validated the concept of comfort care in their ethical concept "beneficence", but this concept has grown and been further defined as we have extended life through technological and pharmacological advances. The World Health Organization (1998) has defined palliative care as:

"an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (WHO, 1998, p. 1)

Included in this approach is:

- relief from pain and other distressing symptoms;
- life affirmation;
- awareness of dying as a normal process and neither hastening or postponing death;
- integration of psychological and spiritual aspects;
- support to help patients live as actively as possible until death;
- support for family and friends as they cope during the patients illness and in their own bereavement;
- multidisciplinary team approach to address the needs of patients and their families;
- focus on quality of life not quantity of life;
- implementation of comfort care throughout the treatment process from diagnosis through death (Supportive Voice, 1999).

Palliative care is very similar to hospice in its approach. Hospice philosophy and care are considered palliative care approaches. The major differences are that current hospice care regulations require persons to forego aggressive, curative treatment options; whereas palliative care may not. The palliative care philosophy would encourage health care professionals to integrate comfort care that may include aggressive care treatments to decrease negative side effects and to improve the patient's quality of life. Palliative care units are in many hospitals and are growing in nursing facility care settings.

References

Hastings Center (2003). What is hospice care? *The Hastings Center Report*, 33 (1), 6-13. **Good resource that talks about hospice and palliative care.**

Resources

Stolberg, S. (2000). Cries of the dying awaken doctors to a new approach. Retrieved June 23, 2002 from www.hospicenet.org/html/palliative-pr.html

Supportive Voice (1999). *A vision for better care at the end of life: Five principles of palliative care*. Retrieved from <http://www.careofdying.org/>

References

Section Three: Palliative Care

Note: Resources are Located in the Resource Manual

SECTION FOUR: “Starting the conversation”

Talking about death is hard. It is hard on the person who is ill; his/her loved ones, and the person who is counseling them. These conversations touch emotions that can be painful. Health care professionals understand this and also realize that talking about future care plans, even when they involve talking about dying, is necessary.

Some of the key reasons for these discussions are that:

- people have a right to choose (or not to choose) to direct their health care plans (informed choice hinges on knowing all the options); and
- misinformation or no information is prevalent among patients and their families about many services including palliative care and hospice care services.

Physicians grapple with diagnoses and prognoses. Determining when an illness is life-limiting is difficult especially for non-cancer diagnoses. So trying to “guess” if this person needs hospice or palliative care information is fraught with difficulties (The Practitioner, 2004). The person and his/her family might need this information in the future to address any end-of-life and care planning needs. Starting the conversation is hard. Health care professionals can put off or avoid these conversations because of their own discomfort; or their belief that this is not their professional role; or their desire to “protect” their vulnerable clients, or their own lack of information (Fellowfield & Jenkins, 2004). However, as health care professionals, we have learned to discuss many difficult subjects and this is just another.

One suggestion for starting the conversation is to start with you. Become very self-aware of your own feelings around death. Also, commit to increasing your knowledge base of available resources in your community, and information on both a conceptual and practical level. The first step can be as simple as leaving an informational brochure.

Other suggestions are to:

- Make the setting as “safe” as possible. (Assure privacy, deter disruptions, and if possible, have it in a setting like the person’s home to increase feelings of security).
- If you have established rapport, use past encounters to reinforce to your client that their well being is your first goal. If no rapport is established, just verbalize this.

- Acknowledge up front why you are bringing up the subject. State that your reason is simply to make sure that the client/family knows that if or when these services are needed, there are services that they might want and this is how to access them.
- Be frank that you don't know (and no one knows when a person will die) but that people have a right to die comfortably and with support.
- Listen to what the person/family has to say. If he/she does not want more information, that's their choice. If he/she does want more information still go slow and pause frequently to make sure that he/she is still part of the conversation.
- Answer questions and get needed information if you don't have it.
- Ask if they need more information about basic services or offer to make a referral for them.

Be aware that many times this discussion is the "elephant in the room" and clients and their families may be relieved that someone is willing to discuss advanced planning and dying services with them (Fellowfield & Jenkins, 2004; NIA, 2005; Our Final Journey, 2004; Von Gunten, 2005).

One final thing to remember is that medical jargon and terminology is a "foreign" language to most consumers. So speaking in very simple terms is always best (Morasch, 2004).

The first times that you initiate these conversations will be the hardest. As you become more comfortable talking about end-of-life care plans, you will be less tense and your clients will sense this and also be less apprehensive.

References

- Fallowfield, L & Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine. *The Lancet*, 363 (9405), 312-333.
- Our Final Journey (2004). *Let's talk about it*. Retrieved from <http://endoflifecare.tripod.com/Caregiving/index.html>
- Von Gunten, C. (2005). Fast fact and concept # 038: Discussing Hospice. EPEC. Retrieved from http://www.eperc.mcw.edu/fastFact/ff_38.htm

Resources

- Building Collaborative Solutions (2004). Discussing Sensitive Issues. Retrieved from <http://www.bcsolutions.org/olcdiscussingsensitiveissues.html>

College of London. (no date). Communicating about sensitive subjects (aka breaking bad news). Retrieved from http://www.pcps.ucl.ac.uk/commskills/student_handbook/bad_news.htm

Morasch, L. (2004). I hear you talking, but I don't understand. Presentation for the Molina Healthcare & CA Academy of Family Physicians

NIA (2005). *Talking with your doctor: Discussing Sensitive Subjects*. Retrieved from http://www.niapublications.org/pubs/talking/Talking_with_Your_Doctor.pdf

The Practitioner (2004). A GP guide to breaking bad news. The Practitioner (June 9, 2004), 392+ Retrieved from <http://www.athealth.com/Practitioner>

References

Section Four: "Starting the Conversation"

Note: Resources are Located in the Resource Manual

SECTION FIVE: Advance Directives

Advance directive discussions are a key component of all future care plan discussions in end-of-life care. Advance care directives allow patients to make their own decisions regarding the care they would prefer to receive if they were unable to communicate their preferences. Most advance directives become effective immediately when people have a terminal illness or a life-threatening injury. However, some persons are waiving this "terminal" mandate and just stating if at any time they are unable to communicate their wishes then the document becomes operative. The first part of an advance directive usually allows the person to state "preferences" for care. For example, "I do not want dialysis". The second part of the directives usually is a Durable Power of Attorney for HealthCare Decisions and allows the person to designate someone (usually called an agent) s/he trusts to make decisions about medical care, if the person is unable to make (or communicate) these decisions (American Hospital Association, 2005).

Federal law (Patient Self-Determination Act of 1990) requires hospitals, nursing homes, and other institutions that receive Medicare or Medicaid funds to provide written information regarding advance care directives to all patients upon admission.

Advance care directives can reduce:

- Personal and/or family worry;
- Feelings of helplessness and guilt for family;
- Futile, costly, specialized interventions that a patient may not want;
- Overall health care costs; and
- Legal concerns for everyone involved (Hickman, Hammes, Moss, & Tolle, 2005).

However, advance care directives cannot predict what situations may arise in the future or what new modes of care may be available for situations considered. The key to making advanced directives effective involves completing them and talking with family and named "agents" about what a person does or does not want and how they view their future care. These are not just documents but ways to initiate communication among persons, health care professionals, and key family and friends. Consequently, many advance directive documents are part of a "caring conversation" booklet that encourages these conversations among these key participants (ABA Commission on Law and Aging, 2000; Hickman, Hammes, Moss, & Tolle, 2005).

Advance Directive documents can be changed by the person at any time. They do need to be shared with all the persons involved (agents and medical

personnel) and kept in a place known to all (ABA Commission on Law and Aging, 2000).

References

ABA Commission on Law and Aging (2000). *Toolkit: Conversation Scripts*. Retrieved from <http://www.abanet.org/aging/orderingpage.html#decision>.
In English and Spanish.

ADVANCE DIRECTIVE FORMS:

Center for Practical Bioethics (2004). *Caring Conversations Workbook*. Kansas City, MO: CPB. **In English and Spanish.**

Resources

American Hospital Association (2005). *Put it in Writing: Questions and Answers on Advance Directives*. Retrieved from www.aha.org

Hickman, S. Hammes, B. Moss, A. & Tolle, S. (2005). *Hope for the future: Achiving the original intent of advance directives*. The Hasting Center 35 (6), 526-531.

References

Section Five: Advance Directives

Note: Resources are Located in the Resource Manual

SECTION SIX: Cultural Competency

Talking about future care plans is a difficult task. It becomes even more difficult when the conversation involves persons of differing ethnicities and cultural backgrounds. The American Medical Association has identified three cultural factors that impact end-of-life care with persons of diverse ethnic backgrounds:

- The first factor revolves around how one communicates prognosis, diagnosis, and terminal status;
- The second factor concerns who is or what group is the appropriate decision maker; and
- The third involves advance directives and their appropriateness in some cultures.

When you think about it, it is difficult to discuss these topics with members of the same culture but when you are speaking “cross culturally”, cultural competency is more difficult (Barrett, 2001).

Currently, about one-third of the US population is composed of ethnic minorities and the demographic predictions are that this number will continue to rise. Our medical model is based on a Western way of looking at illness and death. So finding good ways to be “bi-lingual” and value the cultural position of clients is crucial. By paying attention to client’s values, the health care professional can maximize client choice (remember deferring choice to another family member is a choice also), provide the best possible services, and expand awareness of what services are needed by persons of diverse backgrounds (Valente, & Haley, 2002).

One issue around health care at the end-of-life involves “disclosing bad news”, which in some cultures is regarded as impolite, bad luck, or self-fulfilling. Another issue concerns misunderstandings between a Western culture that values individualism and other cultures that see decision making as more of a communal task. Finally, language barriers impact clear communication and impede good end-of-life care (Searight, & Gafford, 2005).

It is the responsibility of the health care professional to learn as much as possible about delivering information and services to ethnically diverse persons so that the best possible services are made available.

References

Barrett, R. (2001). *Recommendations for culturally competent end of life care giving*. Retrieved from www.ama-assn.org/ama/pub/category/6824.html

Koenig, B. (1997). Cultural diversity in decisionmaking: About care at the end of life. Retrieved from <http://www.apa.org/pi/eol/diversity.html>

Resources

Valente, S. & Haley, B. (2002). *Culturally diverse communities and end of life care*. Retrieved from <http://www.apa.org/pi/eol/fsculturallydiverse.pdf>

Building Collaborative Solutions (2004). *Communicating Across Cultures*. Retrieved from <http://www.bcsolutions.org/olccommacrosscultures.html>

Last Acts (2000). *Improving Care for African-Americans near the End of Life*. Retrieved from www.rwjf.org/

Searight, H. & Gafford, J. (2005). Cultural diversity at the end of life: Issues and guidelines for family physicians. *American Family Physician*, 71, 515-522.

References

Section Six: Cultural Competency

Note: Resources are Located in the Resource Manual

SECTION SEVEN: Caregiving Information

Family and friends that care for persons with a life-limiting disease are integral components to successful end-of-life. Supporting the caregivers' physical, emotional, social, and spiritual needs are elements in both a hospice and palliative care model. Studies have reported that good stress management and supportive services can make a difference to caregivers and support them through their loved one's dying process and through bereavement.

References

Turner, J.(2004). *Caregiving at Life's End: Facing the Challenge*. Retrieved from <http://www.americanhospice.org/articles/caregiving.htm>

Resources

Area Agency on Aging of North Central Texas (2005). Caring for the Caregiver: Module 9. Retrieved from http://www.familycaregiversonline.com/family_caregiver_module_9.htm
In Spanish and English. **This resource was created by a AAA for their community.**

Family Caregiver Online (2005). Self-Nurturing Activities. Retrieved from <http://www.familycaregiversonline.com>

References

Section Seven: Caregiving Information

Note: Resources are Located in the Resource Manual

SECTION EIGHT: End-of-life Websites

- Academy of Hospice and Palliative Medicine* <http://www.aahpm.org>
- Advance Directives* <http://www.caringinfo.org>
- Aging Parents and Elder Care* <http://www.aging-parents-and-elder-care.com>
- American Hospice Foundation* <http://www.americanhospice.org>
- Annual Review of State Pain Policies* <http://www.medsch.wisc.edu/painpolicy>
The University of Wisconsin's website provides unrestricted access to a user-friendly database that contains the full-text of all pain policies for each state, a criteria-based evaluation of those policies and other resource materials. This project was supported by the Robert Wood Johnson Foundation.
- Approaching Death: Improving Care at the End of Life* <http://www.nap.edu/readingroom/books/approaching>
- Association for Death Education and Counseling* <http://www.adec.org>
ADEC is one of the oldest interdisciplinary organizations in the field of dying, death and bereavement.
- Barbara Ziegler Palliative Care Education Program
Memorial Sloan-Kettering Cancer Center* <http://www.mskcc.org/zpcep>
- Before I Die* <http://www.wnet.org/bid/index.html>
- Care of Dying* www.careofdying.org/
Committed to bring about cultural change regarding pain and symptom management and relief of suffering for persons living with and affected by life-threatening illness.
- Caring Connections* <http://www.caringinfo.org>
- Center to Advance Palliative Care* <http://www.capc.org>
- Center for Practical Bioethics* <http://www.practicalbioethics.org/>
Comprehensive source for information on both adult and pediatric end of life care; advanced directives; and ethical guidelines.

Disparities at the End of Life <http://www.rwjf.org/news/eoldisparities>

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

Dr. Ira Byock, author of "Dying Well" and past president of the American Academy of Hospice and Palliative Medicine, provides resources including full-text articles, and a "What's New" section

End of Life Nursing Education Consortium (ELNEC)
<http://www.aacn.nche.edu/elneec>

End of Life Physician Education Resources (EPERC)
<http://www.eperc.mcw.edu>

EndLink: Resources for End-of-Life Care Education
<http://endlink.lurie.northwestern.edu>

Griefworks BC <http://www.griefworksbc.com>

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

Hastings Center <http://www.thehastingscenter.org/links.asp>

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

Legacies <http://www.legacies.ca>

Life's End Institute: Missoula Demonstration Project
<http://www.lifesend.org>

Life Project <http://www.lifeproject.org/>
Kansas' grassroots, end-of-life and chronic disease management organization. Focuses on professional development and consumer education/awareness, as well as policy and practice advocacy.

Naropa University School of Extended Studies Contemplative End-of-Life Care: A Certificate Program for Healthcare Professionals
<http://www.naropa.edu/contemplativecare>

National Association of Social Workers <http://www.naswdc.org>

NPR
The End of Life: Exploring Death in America <http://www.npr.org>

National Hospice and Palliative Care Organization <http://www.nhpco.org>

National Prison Hospice Association

<http://www.npha.org>

Nursing Leadership Consortium for End-of-Life Care

<http://www.palliativecarenursing.net>

This new Web site is dedicated to end-of-life care improvements has been created by the Nursing Leadership Consortium for End-of-Life Care. The site allows nurses to share information with other professionals about initiatives and projects related to improving patient care at the end of life. The site features a wealth of end-of-life care resources.

On Our Own Terms

<http://www.pbs.org/onourown/terms>

The full On Our Own Terms companion web site has launched! Offering a broad variety of resources on end-of-life care, visitors to the site can find:

- An indepth assortment of articles, written by experts in the field on aspects of end of life care ranging from management to grief counseling for children;
- A guide to financial planning for end-of-life care;
- A digital diary of a dying patient's hospice experience;
- A debate between two leading doctors over the pros and cons of physician-assisted suicide;
- Resources for art therapy for the dying and their loved ones;
- Audio and video clips from the On Our Own Terms program.

Project on Death in America-Library Catalog

http://library.soros.org/dbtw-wpd/library_pdia.htm

This is the online catalog of the holdings of the Library of the Project on Death in America (PDIA) in New York . The library catalog is provided here for reference purposes. The approximately 600 documents in the PDIA Library collection in New York include primarily books, non-governmental organization reports, and videos concerned with such topics as death and dying, bereavement, grief, mourning, and palliative care. The entry for each document or video includes the Library of Congress call number and/or ISBN to facilitate finding the documents and videos in other libraries, or ordering them from book or video dealers.

Promoting Excellence in End-of-Life Care

<http://www.promotingexcellence.org>

Robert Wood Johnson Foundation

<http://www.rwjf.org>

The Robert Wood Johnson Foundation, based in Princeton, NJ, is the nation's largest philanthropy devoted exclusively to health and health care.

Spiritual Care Program

<http://www.spicare.org>

The National Center for Advanced Illness Coordinated Care

<http://www.coordinatedcare.net>

Toolkit of Instruments to Measure End of Life Care

<http://www.toolkit.htm>