

Five Myths of Advance Care Planning

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ABA Commission on Law and Aging
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Myth 1: People should use their state's official advance directive forms

Official forms (i.e. usually provided for in state statute) are often cumbersome, don't provide useful guidance, and unnecessary.

To explain why requires a little bit of history.



Health Care Advance Directive Landscape

- In the 1970s -1980s, states generally enacted multiple laws: Living Will, DPA for Health Care, overlapping with traditional DPAs, & consent laws. Treated planning like a legal transaction.
- 1990s to Present, many states combined and simplified advance directive laws to some extent. But still much variation in detail, especially forms.

Legal Transactional Approach

Focus: mandatory legal formalities, procedures, and standardization to ensure voluntary, knowing & competent execution & implementation--

1. **Statutory forms**
2. **Required disclosures**
3. **Prescribed phrases**
4. **Detailed witnessing rules**
5. **Agent/proxy limitations**
6. **Diagnostic and certification requirements**
7. **Limitations on surrogate authority**
8. **Notice requirements**

NIGHT OF THE LIVING WILL



30 Years of Research on ADs

1. Most people don't do.
2. Hard to understand the forms.
3. Standard form not useful guidance.
4. People change mind.
5. Agent/proxy slightly better than clueless.
6. Health care providers clueless about the directive.
7. Even if providers know directive exists, it's lost in space.
8. Even if in the record, it's still lost in space.

Sampling of the Research

- **A. Fagerlin & C. Schneider, “Enough: The Failure of the Living Will,” 34 *The Hastings Center Report* 30-42 (March-April 2004).**
- **E.J. Larson and T.A. Eaton, “The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act,” 32 *Wake Forest Law Review*, 249 (1997).**
- **J. Teno et al, “Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention,” 45 *Journal of the American Geriatrics Society* 500-07 (1997).**
- **D. Orentlicher, “The Illusion of Patient Choice in End-of-Life Decisions,” 267 *JAMA* 2101-2104 (1992).**

Communications Approach

“Advance Care Planning”

1. Less focus on formal instructional documents.
2. Legal focus primarily on naming a proxy.
3. Discussion oriented (with proxy, family, health care providers)
4. More broadly focused on goals + values, spiritual questions, family matters.
5. Less treatment focused, more on quality of life.
6. Developmental and iterative in nature.
7. Conversion of goals to a portable plan of care:
POLST

A form, a form, my kingdom for a form!

1. Make sure your appointment of an agent is on legally appropriate form.
2. Give agent broad discretion to interpret wishes.
3. Any wishes/instructions included should be guidance, not mandates.

Selecting an agent is the single most important decision.

The ideal health care proxy...

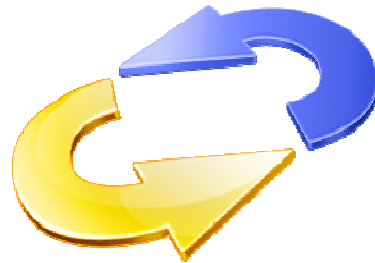
1. Meets the legal criteria.
2. Willing to speak on your behalf & handle the responsibility.
3. Able to act on your wishes, not his/her own.
4. Able to be at your side when needed, now and down the road.
5. Knows your values, priorities, goals.
6. Can listen and talk with you frankly & openly.
7. Able to manage conflict among family & others.
8. Strong advocate in the face of unresponsive doctor or institution.

Myth 2: Your advance directive should include as specific instructions as possible.

Only if you have a crystal ball and a medical degree.



Ambivalence is normal



- Form instructions selected far in advance have not been helpful.
- People change their minds/raise the bar as circumstances change.
- Values, goals, and priorities more helpful to consider

Compare...

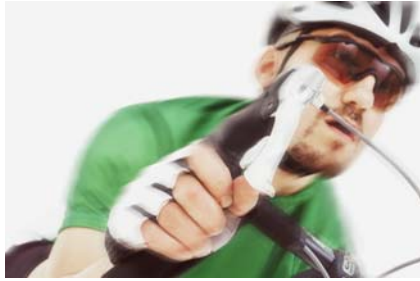
If I'm terminally ill...

- I don't want artificial nutrition and hydration.
- I don't want surgery
- I want antibiotics

What's important to you...

- How have you lived life?
- Prolonging life vs. quality of life?
- What's a Benefit?/
Burden?
- Spiritual dimensions?
- Financial issues?
- How important control?

Compare...



Healthy 19 year
old in college--

How lives life:
As if immortal.

Goals: The sky is
the limit.

Instructions:
Clueless



My mother at 85, with
COPD and cancer--

How lives life: Caretaker
of the universe.

Goals: Comfort and
function.

Instructions: If can't wean
from ventilator, stop!

Use a workbook approach...

- **Your Life Your Choices – Planning for Future Medical Decisions** (Dept Vets Affairs, 1998, 2010 online).
- **Caring Conversations Workbook**, published by the Center for Practical Bioethics (1999).
- **Good to Go Toolkit and Resource Guide**, published by Compassion and Choices
- **Thinking Ahead – My Way, My Choice, My Life at the End**, California Dept. of Developmental Services (2008)
- **Consumer’s Tool Kit for Health Care Advance Planning** by the ABA Commission on Law and Aging (2000)
- **Five Wishes**, published by Aging with Dignity

Myth 3: Advance Directives are legally binding so doctors have to follow them.

- Every state advance directive law permits conscience objections by physician or facility.
- Some obligation to attempt transfer but extent of obligation varies by state.
- Need to engage your health care providers in the conversation ahead of time.



How to convert goals into action?

***POLST* = Physician Orders for Life-Sustaining Treatment**

Primary target group – Patients for whom death in a year would not be a surprise.

Goal – To convert patient’s goals of care into a portable set of medical orders addressing key decisions.

Focus on here and now. Outcome neutral.

Requires:

- 1. Find out patient’s wishes re: CPR, care goals (comfort vs. treatment), antibiotics, N&H.**
- 2. Translate into doctors orders on visually distinct (bright pink) standard form.**
- 3. Ensure form travels with patient.**

See www.POLST.org

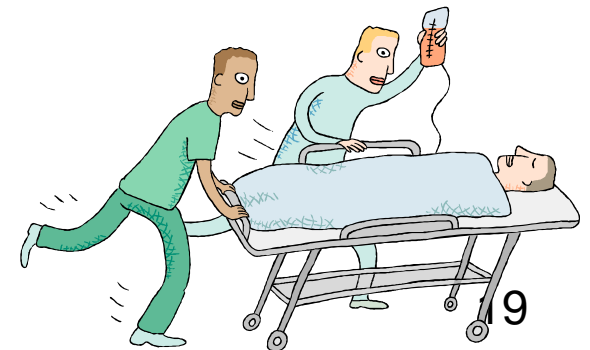
+ A few other states have regional use of POLST

- **CA, HI, OR, WA: POLST**
- **ID, TN, WV: POST = Physician Orders for Scope of Treatment**
- **NY: MOLST = Medical Orders for Life-Sustaining Treatment**
- **NC: MOST = Medical Orders for Scope of Treatment**
- **UT: Life with Dignity Order**
- **VT: COLST = Clinician Orders for Life-Sustaining Treatment**
- **MD:* Instructions on Current Life-Sustaining Treatment Options**

Myth 4: Doing everything possible for dad means keeping dad alive at all costs.

Doing everything possible depends on what the goal of everything is.

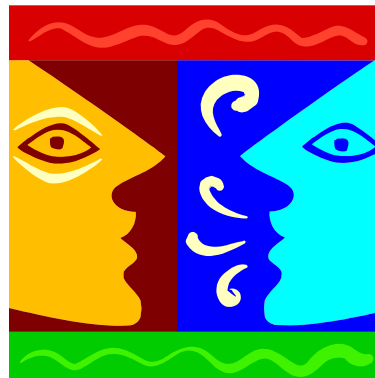
- What are the patient's goals?
- That's what advance care planning with one's family helps define.



Palliative care may be the
most aggressive form of
“everything possible”

Myth 5: A written advance directive is better than talk.

- A written advance directive *by itself* isn't worth the paper it is written on.
- But, it *is* worth the discussion and engagement it is based on.



Oral Advance Directives

States are beginning to recognize that writing is not everyone's most functional mode of communication—

About a dozen states permit your “talk” with your physician, if recorded and witnessed in the medical record, to serve as a formal advance directive.

No Advance Directive?

- In most states, default surrogate laws kick in.
- Usually based on next-of-kin, followed by (in about half the states) close friend.
- May be significant limitations on decision-making authority.
- Multiple decision-makers conducive to disagreement.
- Your health care PoA can exclude loose cannons.

The long view

- Advance Care Planning is recurring. Documents are static.
- Think of the 5 “Ds” to trigger renewed ACP:
 1. Decade
 2. Death of loved one
 3. Divorce
 4. Diagnosis
 5. Decline

Advance Care Planning Myths and Clinical Realities



Richard Payne, M.D.
Professor of Medicine and Divinity
Duke Institute on Care at the End of Life

Myth # 1



**Use Your States Specific
Forms...
Yes, BUT.....**

The Realities—People Do Not Use Them



End-of-life experience - negative image of what people say they want

- 2/3 die in institutions
- Isolated in ICUs (avg. 14 days)
- Unconscious or in pain
- Families are often bankrupted



The Consequences...

*Informed consumers make better decisions
– nowhere more evident than end of life*

- Change the way we experience end of life care
- Save \$100B in next 10 years
- Diminish untold human suffering



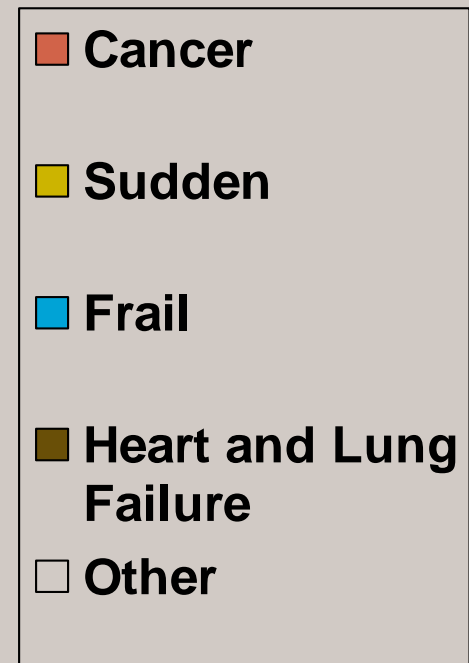
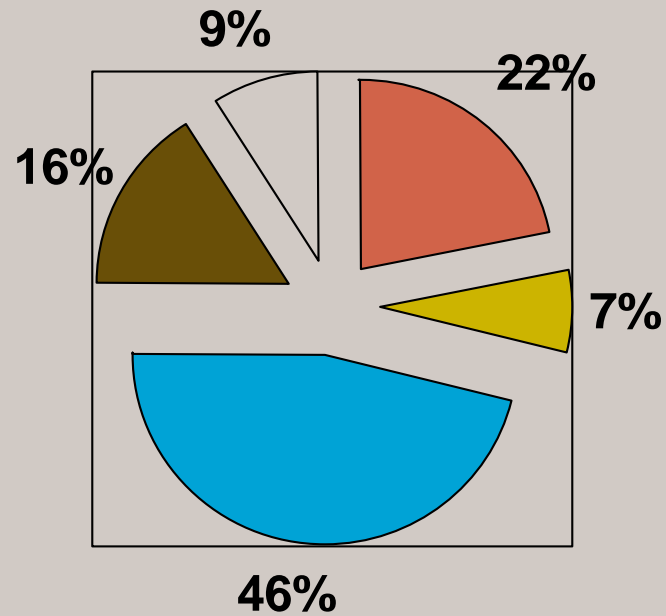
Myth # 2



**Advance Directives
Should Be as
Specific As Possible**

Causes of Death in Elderly

Cause of Death-Medicare Decedents-2002

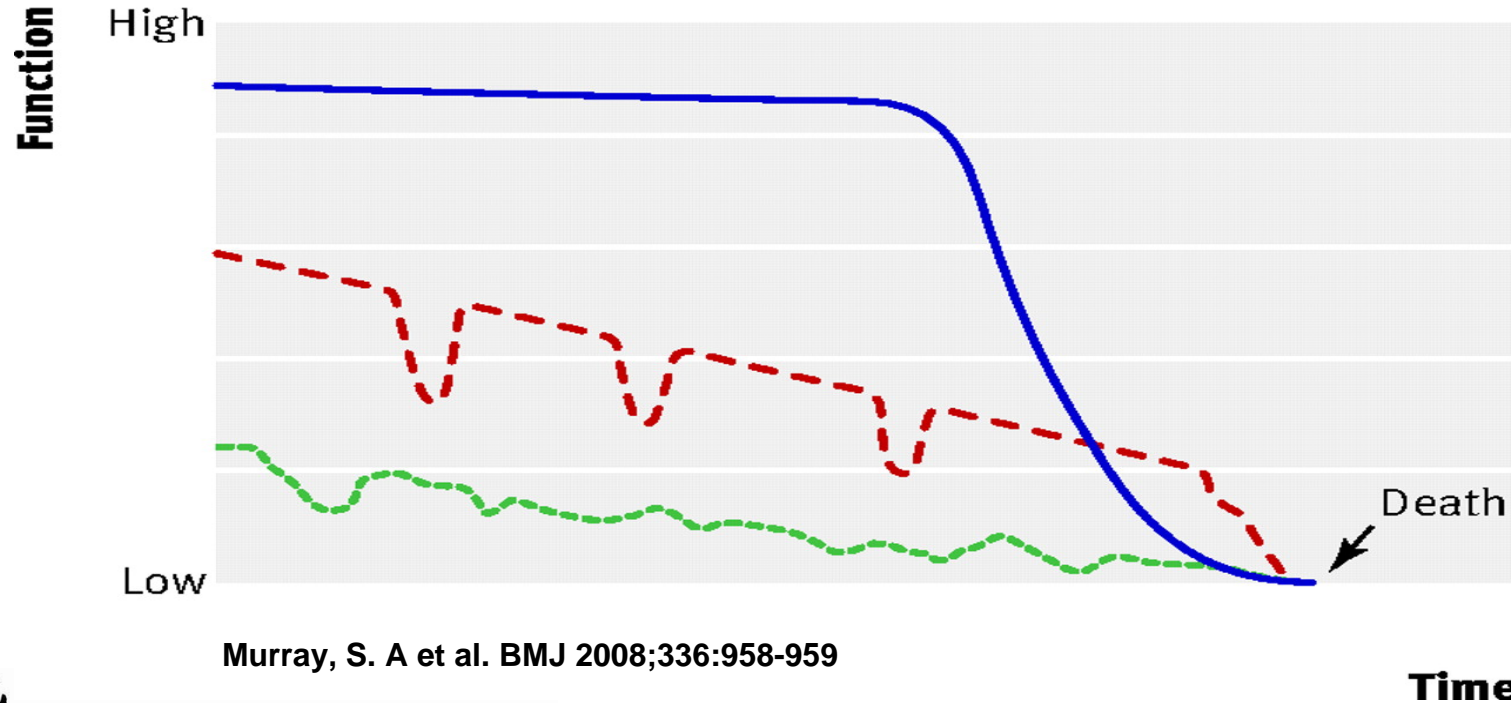


Lunney JR, Lynn J, Hogan C. Profiles of older Medicare decedents.
J Am Geriatr Soc 2002; 50(6):1108-1112.

Figure 1: The three main trajectories of decline at the end of life

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients

- Cancer (n=5)
- - - Organ failure (n=6)
- · - · - Physical and cognitive frailty (n=7)
- Other (n=2)



Murray, S. A et al. BMJ 2008;336:958-959



DUKE INSTITUTE ON
CARE AT THE END OF LIFE

BMJ

What you might say...



- “What is your understanding of...(your current condition, your illness, why you are here)?”
- “What have you been told about your condition/illness?”
- “What have your doctors told you?”

Some Questions to Elicit Values



- “What are your overall goals of care?”
- “I’m trying to understand how you see the big picture. We’ll get to the specifics in a moment. Do you have a major goal in your care? What is most important to you?”
- “If you think about getting very sick, what worries you the most?”
- “Some people want to be kept alive as long as possible at any cost, some focus on being as comfortable as possible, and other people want only modest life-prolonging interventions.”

Advance Care Planning-Clinical Issues



- **Withholding or Withdrawing**
- **Interventions/therapies**
- **Patient/family request to hasten death**
- **Discussing death openly with patient**
- **Disagreements between family members/stakeholders**



Myth # 3



**Doctors Must Follow
Advance Directives**

The Realities of Medical Practice

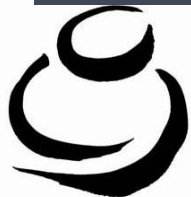
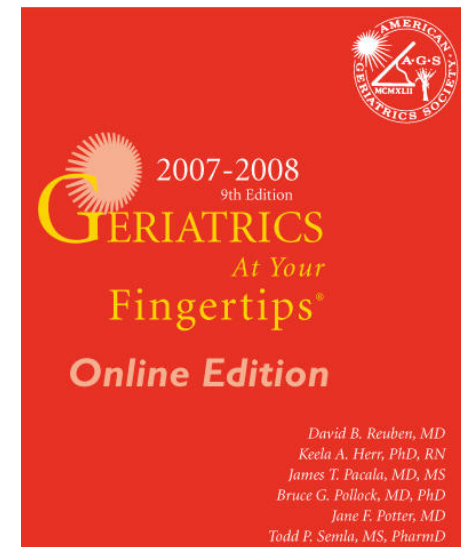
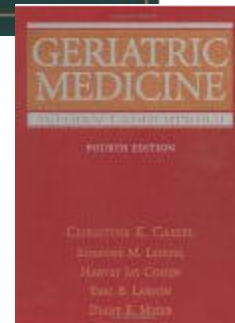
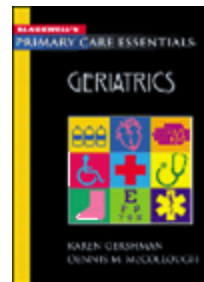
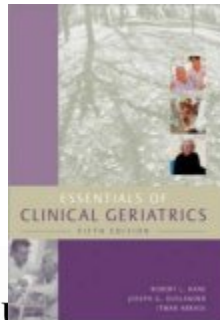
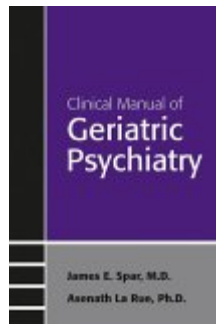
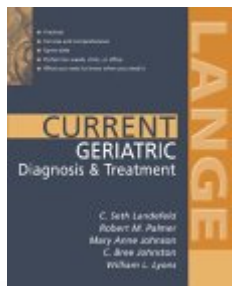
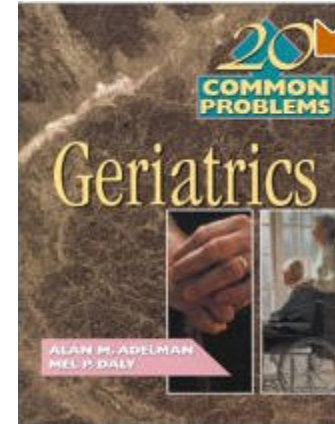
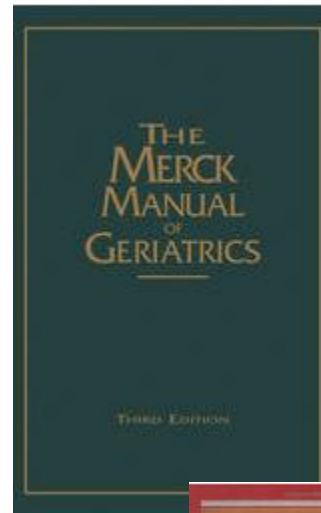
- Prognostication is difficult in micro
- Patient ambivalence
- No ethical obligation to give futile care
- Physician culture



DUKE INSTITUTE ON
CARE AT THE END OF LIFE

Death is Optional?

45% of geriatrics textbooks don't even mention end of life care!



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Myth # 4



**Do Everything Possible
Means Keeping Me Alive
As Long As Possible**

Definition of Palliative Care*

*World Health Organization, 2002

"Palliative care is an approach which improves quality of life of patients and their families facing 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"



DUKE INSTITUTE ON
CARE AT THE END OF LIFE

Palliative Care --What Is It?



- Symptom management
- Emotional support
- Spiritual support
- Care coordination and continuity
- Shared decision-making
- Social support
- Family support/bereavement
- Treatment goal identification

Hospice and Palliative Care



Palliative Care

- hospital based
- quality of life
- all chronic disease

Hospice Care

- home-based
- 6 month prognosis
- bereavement

Myth # 5



**Written Directive is better
than Conversations with
Surrogate or Family**

Goals of Care



- Identify the stakeholders
- Ascertain stakeholders' cognitive understanding
- Assess stakeholders' values
- Elicit 'big picture' goals *first*

Advance Care Planning-Clinical Issues



- Goals and settings of care
- Elect Hospice Benefit
- Full Code or DNR
- Autopsy



“Dying is a spiritual event with medical implications”

-Gwen London, former ICEOL Director



Selected Advance Care Planning Resources

WORK BOOKS TO ASSIST ADVANCE PLANNING

Caring Conversations Workbook, published by the Center for Practical Bioethics, is both a workbook and advance directive. It can be downloaded for free from their web site: www.practicalbioethics.org/cpb.aspx?pgID=986

Consumer's Tool Kit for Health Care Advance Planning, by the ABA Commission on Law and Aging is available for free download at: <http://new.abanet.org/aging/Pages/HealthDecisions.aspx>

Finding Your Way: A Guide for End-of-Life Medical Decisions, by the Center for Healthcare Decisions, Sacramento Healthcare Decisions (1998). Available for purchase at: www.chcd.org/contact-purchasepubs.htm.

“Good to Go” Toolkit and Resource Guide, published by Compassion and Choices. It can be downloaded free at <http://www.compassionandchoices.org/g2g>

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. Available for free at: www.dds.ca.gov/ConsumerCorner/Publications.cfm

The Go Wish Game -- a card game for sorting out values related to end-of-life decision-making, created by the Coda Alliance, a community organization in Santa Clara County, California. It gives you an easy, entertaining way to think and talk about what's important to you if you become seriously ill. Available for purchase at: www.codaalliance.org

For Health Care Proxies/Agents:

Making Decisions for Someone Else: A How To Guide, published by the ABA Commission on Law and Aging, this guide is for anyone serving in the role of health care decision maker for someone else: <http://new.abanet.org/aging/Pages/HealthDecisions.aspx>

SELECTED ADVANCE DIRECTIVE FORMS

Links to state-specific Advance Directive forms prepared by bar associations and related groups can be found on Health Decisions Consumer Information page of the ABA Commission on Law and Aging website at: <http://new.abanet.org/aging/Pages/HealthDecisions.aspx>

Caring Connections is a program of the National Hospice and Palliative Care Organization

(NHPCO). It provides free downloadable state advance directive forms for every state and D.C. with instructions at: www.caringinfo.org/AdvanceDirectives.

Compassion and Choices also provides state specific advance directives at: http://www.compassionandchoices.org/ad_page/

Five Wishes Advance Directive. Published by Aging with Dignity. This nationally used and very popular advance directive focuses on ways of talking about health care wishes and needs. Available for purchase and download from their web: www.agingwithdignity.org. Also available by mail order from P.O. Box 11180, Tallahassee, FL 32302-3180.

A Guide to Living Wills and Health Care Proxies, by Harvard Medical School. This guide and form provides a more medically-oriented advance directive addressing six illness scenarios. For each, you consider possible medical interventions and goals of care. It also includes a proxy designation form. Available for purchase and download from their web site: www.health.harvard.edu/special_health_reports/the-health-care-power-of-attorney-and-living-will

The Halachic Living Will, a directive that comports with orthodox Jewish law and custom: www.jlaw.com/Forms

National Right to Life “Will to Live”:

www.nrlc.org/euthanasia/willtolive/StatesList.html

Jehovah's Witness' health care advance planning information available at:

<http://www.jw-media.org/aboutjw/medical.htm>

Ethical Wills: Putting Your Values on Paper, by Barry K. Baines (Perseus Publishing, 2001). This is a guide to the process of writing and sharing an ethical will, a document designed to preserve a lasting legacy of your most cherished personal values. Ethical wills are not health care advance directives, but they can serve as a valuable supplement to communicate one's values and priorities. Can be purchased at: www.ethicalwill.com

GENERAL END-OF-LIFE CARE RESOURCES

ABA LawInfo.org is a consumer information web site covering multiple topics of interest to individuals and families, including estate and health care advance planning, at: <http://www.abalawinfo.org/fam1.html>.

Handbook for Mortals: Guidance for People Facing Serious Illness, by Joanne Lynn, MD, and Joan Harrold, MD (NY: Oxford University Press, 1999). A comprehensive and readable 242-page guide to dealing with serious, eventually fatal illness.

Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Measures Only and the Elderly Patient, by Hank Dunn . A&A Publishers, Inc. P.O. Box 1098, Herndon, VA 20172-1098 (Tel. 703-707-0169). Web site: www.hardchoices.com

A concise and helpful 48-page booklet on end-of-life decisions concerning resuscitation, food and fluids, hospitalization, and cure versus comfort care.

Caring Connections – This program of the National Hospice and Palliative Care Organization is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. They provide several consumer resources, including state-specific advance directive forms, on their web page at: www.caringinfo.org

The Center for Practical Bioethics, Kansas City, Missouri. A non-profit ethics resource center dedicated to a health care delivery system anchored in respect for patients and their families and guided by ethical discourse. Web page: www.practicalbioethics.org

Compassion & Choices -- A nonprofit support, education and advocacy organization, committed to maximizing the options for a good death, including improving pain and palliative care, enforcing living wills and advance directives, and legalizing aid in dying. Web site: www.compassionandchoices.org