The Real Story on End of Life Care Issues in 2009

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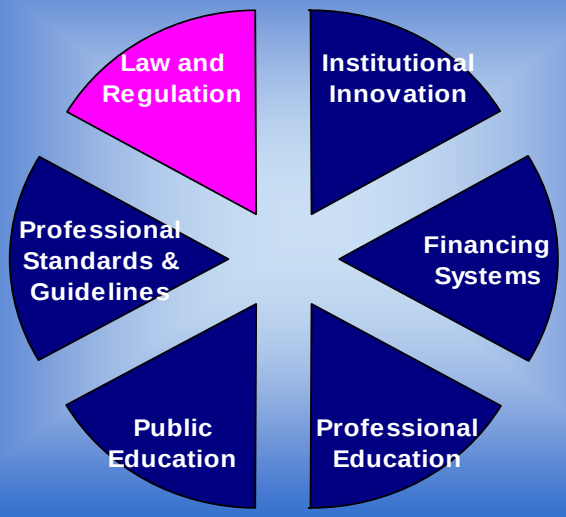
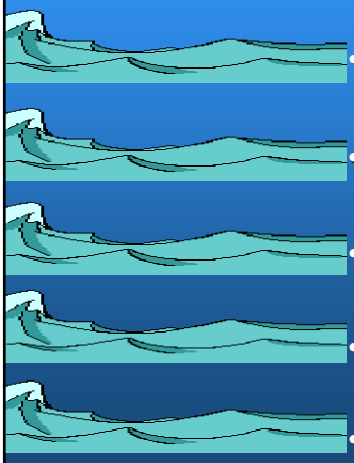
Factors Influencing End-of-Life Care



. . .Spirituality / Family / Workplace. . .

A Quick Legislative History of Advance Planning



- 2000s: POLST/Pt. Plan of Care? Death of Living Wills?
- '90s: Combined AD Statutes & EMS-DNR Statutes
- 80'-90's: DPAHC Acts
- '70s-'80s: Living Will Acts
- 1968: Unif. Anatomical Gifts Act

Default Surrogate Laws: '60s - '00s

Federal Health Decisions Law?

- 1990 Patient Self-Determination Act (PSDA)
- 1996 Military Advance Directives 10 USC Sec. 1044c (pre-empts state law!)
- 2005 - Brief ill-fated foray into review of state court decisions (S. 653 – Bill for the Relief of the Parents of Terri Schiavo)
- Ancillary regulatory areas (e.g., Nursing Home and HIPAA regs) - Defers to state substantive law
- Medicare Improvements for Patients and Providers Act of 2008 (MIPPA) – Welcome to Medicare exam
- 2009 – Health Reform Bill?

The State Statutory Landscape

- **Default Surrogate Laws**
- **Health Care Advance Directives**
  - Health Care DPAs
  - Living Wills
- **Out-of-Hospital DNR Laws**
- **Organ Donation Laws**
- **Guardianship Laws**

Health Care Advance Directive Statutes

- In the 1970s -1980s, states generally enacted multiple laws: Living Will, DPA for Health Care, with overlap from traditional DPAs, & consent laws.
- Today about half the states have combined/comprehensive Advance Directive laws
- 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. Witnessing rules
5. Agent/proxy limitations
6. Diagnostic and certification requirements
7. Limitations on surrogate authority
8. Notice requirements

30 years of research on the legal transactional approach…

1. Most people don't do.
2. Hard to understand the forms.
3. Standard form not useful guidance.
4. People change.
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.

What ADs *Can't* Do

1. Can't provide cookbook directions.
2. Can't change fact that dying is complicated.
3. Can't eliminate personal ambivalence.
4. Can't be a substitute for Discussion.
5. Can't control health care providers.

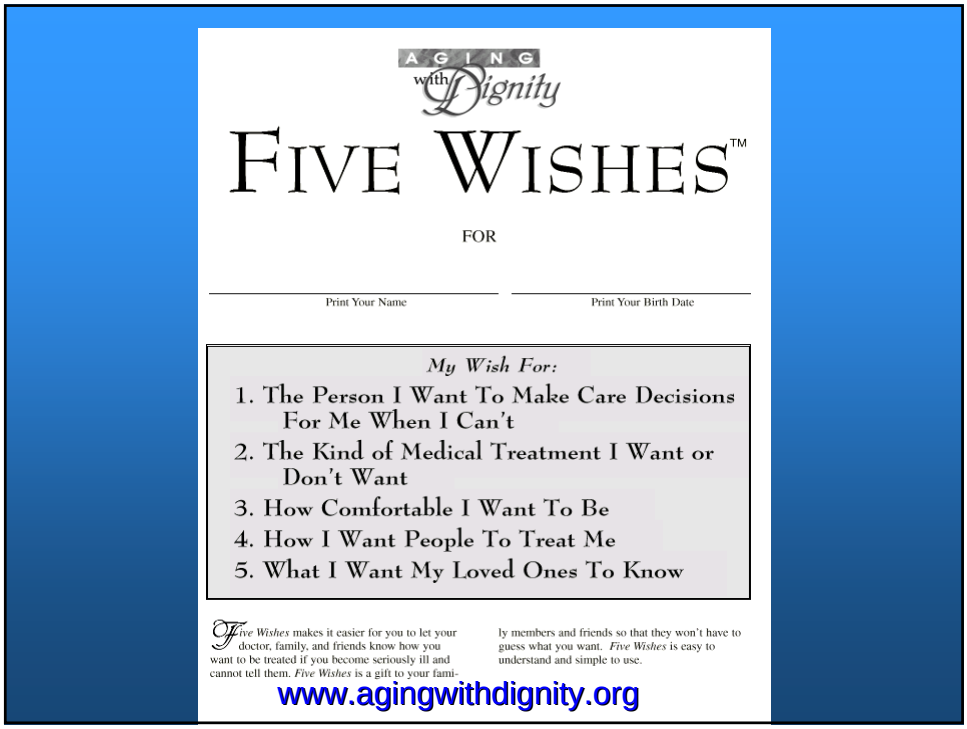
Communications Approach

"Advance Care Planning"

1. Less focus on legal formalities – many routes to the same end.
2. Legal focus primarily on naming a proxy
3. Discussion focused (with proxy, family, health care providers)
4. More broadly focused on goals + values, spiritual questions, family matters
5. Less treatment focused
6. Developmental and iterative in nature (whenever any of the 5 "D"s occur)
7. Conversion of goals to a portable plan of care: POLST

Signs of Change

- 1993 Uniform Health-Care Decisions Act
- Trend toward simplification of state laws
- *Five Wishes* example – 33 to 40 states (1997 – 2007)
- "Oral" advance directives -15 states
- Emergence of workbook approaches
- POLST – a present care planning process intended to be discussion based, resulting in highly visible doctor's orders that follow patient



AGING with Dignity

FIVE WISHES™

FOR

Print Your Name

Print Your Birth Date

My Wish For:

1. The Person I Want To Make Care Decisions For Me When I Can't
2. The Kind of Medical Treatment I Want or Don't Want
3. How Comfortable I Want To Be
4. How I Want People To Treat Me
5. What I Want My Loved Ones To Know

Five Wishes makes it easier for you to let your doctor, family, and friends know how you want to be treated if you become seriously ill and cannot tell them. *Five Wishes* is a gift to your family members and friends so that they won't have to guess what you want. *Five Wishes* is easy to understand and simple to use.

www.agingwithdignity.org

Workbook Approaches

- **Your Life Your Choices – Planning for Future Medical Decisions** (1998 and 2010 online).
- **Caring Conversations** Workbook, published by the Center for Practical Bioethics (1999).
- **Finding Your Way: A Guide for End-of-Life Medical Decisions**, by Sacramento Healthcare Decisions (1998).
- **Critical Conditions - Planning Guide**, by Georgia Health Decisions (1998).
- **Lawyer's Tool Kit for Health Care Advance Planning**, and **Consumer's Tool Kit for Health Care Advance Planning** by the ABA Commission on Law and Aging (2000)

Ongoing ACP…

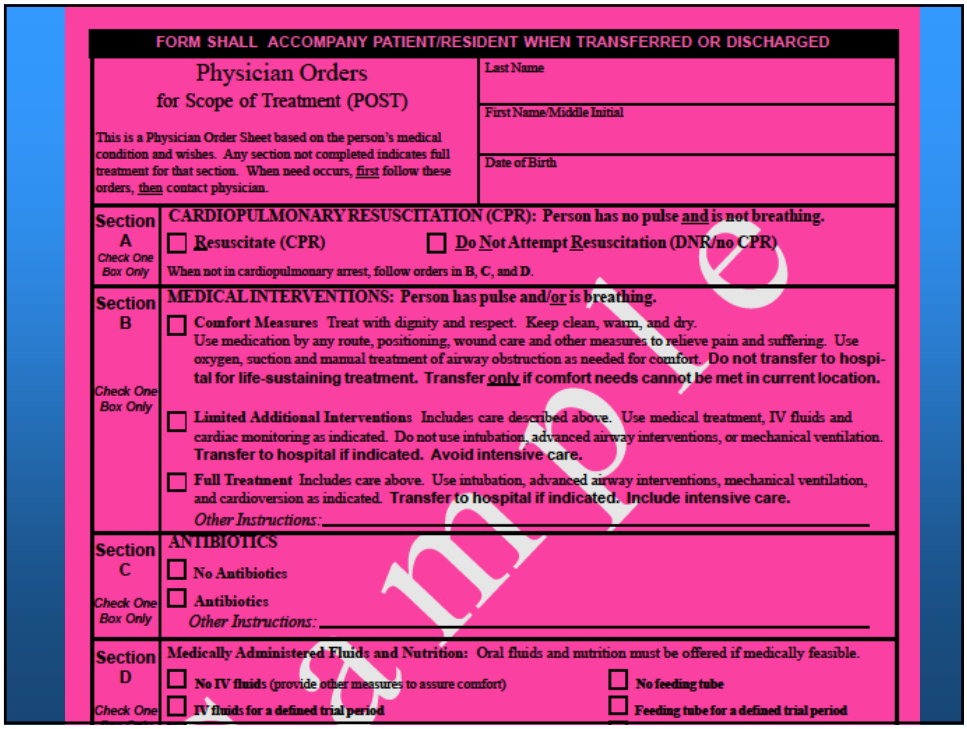
Time to review your AD when any of the 5 D's occur:

1. You reach a new DECADE
2. You experience a DEATH of family or friend
3. You DIVORCE
4. You receive a new DIAGNOSIS
5. You have a DECLINE in your condition as measured by Activities of Daily Living (ADLs)

POLST – Beyond ADs

- **Last 30 years: standardizing patient communications – statutory advance directives**
- ***POLST* Paradigm – standardizing physicians EOL orders. Focus on here and now.**
- **Oregon's *Physicians Orders for Life-Sustaining Treatment* – requires:**
    1. **Practitioner to 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) med file cover sheet.**
    3. **All providers ensure form travels with patient.**

Twelve States have a version of POLST (11/09):
CA, HI, ID, MD, NY, NC, OR, TN, UT, VT, WA, WV



FORM SHALL ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

Physician Orders for Scope of Treatment (POST)

This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. When need occurs, first follow these orders, then contact physician.

Last Name

First Name/Middle Initial

Date of Birth

Section A (Check One Box Only)

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ Resuscitate (CPR) ☐ Do Not Attempt Resuscitation (DNR/no CPR)

When not in cardiopulmonary arrest, follow orders in B, C, and D.

Section B (Check One Box Only)

MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.

☐ Comfort Measures Treat with dignity and respect. Keep clean, warm, and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location.

☐ Limited Additional Interventions Includes care described above. Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. Transfer to hospital if indicated. Avoid intensive care.

☐ Full Treatment Includes care above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Include intensive care.

Other Instructions:

Section C (Check One Box Only)

ANTIBIOTICS

☐ No Antibiotics

☐ Antibiotics

Other Instructions:

Section D (Check One)

Medically Administered Fluids and Nutrition: Oral fluids and nutrition must be offered if medically feasible.

☐ No IV fluids (provide other measures to assure comfort) ☐ No feeding tube

☐ IV fluids for a defined trial period ☐ Feeding tube for a defined trial period

H.B. 3962 – ACP Provisions

Provides Medicare coverage of "Voluntary ACP Consultations" at least every 5 years (§ 1233)

Defined as: optional consultation between the individual and practitioner regarding ACP. May include explanation of:

- **ACP, including ADs**
- **Role of a proxy + Continuum of EOL services/supports**
- **Orders regarding Life-Sustaining Treatment (OLST) if available.**

New Quality Measures (§ 1192) **:** to include "continuity and coordination of café and care transitions for patients across providers and health care settings, including end of life care."

QHBPs (§ 240) must disseminate info related to EOL planning, including:

- **Option to establish ADs and OLST**
- **Information related to other planning tools.**

HB 3962 – Pain Care Provisions

Pain Conference (§ 2561)

Secretary thru IOM, or another entity, shall convene Conference on Pain

NIH Pain Research (§2562)

1. NIH "encouraged" to continue and expand aggressive program of basic and clinical research on the causes of and potential treatments for pain.
2. Secretary to establish Interagency Pain Research Coordinating Committee to summarize advances, ID critical gaps, make recommendations.

Pubic Awareness Campaign on Pain Management (§2563)

Secretary shall establish and implement to educate consumers, patients, their families, and other caregivers.

If the patient's goals are not elicited and given voice, then the phantoms at the bedside shape what happens to us (Nancy Dubler, *Ethics on Call*)**:**

Besides multiple physicians, nurses & family…

- Risk managers
- Financial administrators (DRGs)
- Insurers
- Utilization Review Teams
- Discharge planners
- Hospital counsel & the courts
- Ethics committee
- Death Panels???

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