The Real Story on
End of Life Care Issues
in 2009

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Factors Influencing End-of-Life Care

Law and Regulation
Institutional Innovation
Professional Standards & Guidelines
Financing Systems
Professional Education
Public Education

...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

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.
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
Workbook Approaches

- Caring Conversations Workbook, published by the Center for Practical Bioethics (1999).
**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

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 care 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.

**Public Awareness Campaign on Pain Management** (§2563)
Secretary shall establish and implement to educate consumers, patients, their families, and other caregivers.

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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???