 Advancing Liberty  
Promoting Justice

## Five Myths of Advance Care Planning

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**ABA Commission on Law and Aging**  
**April 16, 2010**  
**National Healthcare Decisions Day**

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**Myth 1:** People should use their state's official advance directive forms

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

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

**Myth 4:** An advance directive means "Do not treat."

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

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**Myth 1:** People should use their state's official advance directive forms

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



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**Conventional Legal 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**

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**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.

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**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

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 **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.

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

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



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 **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

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 **Compare...**

<p><b>If I'm terminally ill...</b></p> <ul style="list-style-type: none"> <li>• I don't want artificial nutrition and hydration.</li> <li>• I don't want surgery</li> <li>• I want antibiotics</li> </ul>	<p><b>What's important to you...</b></p> <ul style="list-style-type: none"> <li>• How have you lived life?</li> <li>• Prolonging life vs. quality of life?</li> <li>• What's a Benefit?/ Burden?</li> <li>• Spiritual dimensions?</li> <li>• Financial issues?</li> <li>• How important control?</li> </ul>
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 **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.

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 **What ADs *Can* Do**

1. CAN be an important part of a communication process in advance care planning
2. CAN help you stop and think and DISCUSS.
  - Less about specific medical decisions, more about GOALS, VALUES & PRIORITIES:
3. CAN empower a proxy and give direction if reflective of the patient's voice & current circumstances.
  - Not the legislature's canned language.

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 **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.

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 **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.




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 **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.

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Proxy and family members play key role in educating professional caregivers

- **Again highlights the importance of the conversations.**
- **Misunderstanding also arise about “Doing everything possible.”**
- **Do “everything possible” to meet the patient’s goals of care.**
  - What are the patient’s goals?
  - That’s what advance care planning with one’s family helps define.

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Isn't this aggressive care?

- Thorough symptom assessment
- Aggressively treat suffering – physical, psychosocial, spiritual
- Intensify patient-physician communication & decision making to establish goals of care (life-prolongation is an appropriate goal)
- Social-emotional, practical support to family
- Assure coordinated continuity of care across multiple healthcare settings
- Coordinate the skills of professionals from medicine, nursing, and social work, plus chaplaincy, nutrition, rehabilitation, pharmacy, and other professional disciplines as needed

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**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.



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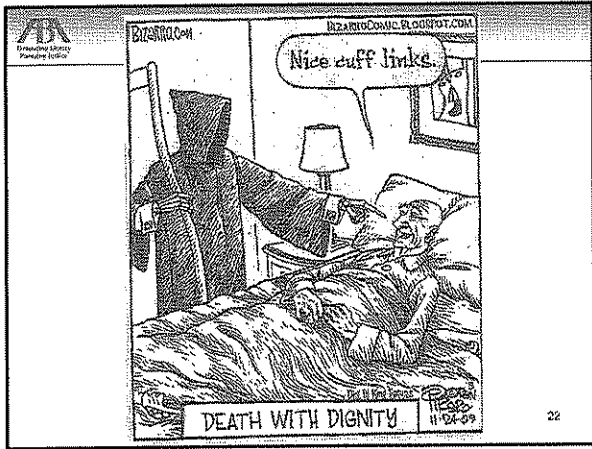
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 American Bar Association  
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### Oral Advance Directives

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.

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### The long view

- **Advance Care Planning is recurring engagement. Documents are static.**
- **Culture change is in our hands.**
- **For individuals, think of the 5 "Ds" to trigger renewed ACP:**
  1. Decade
  2. Death of loved one
  3. Divorce
  4. Diagnosis
  5. Decline

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