

# **The Evolution of Advance Care Planning and Advance Directives**

**Charles P. Sabatino, JD  
ABA Commission on Law and Aging  
February 23, 2012**

# The Crowded Landscape of State Legislation

---

1. **Default Surrogate Laws**
2. **Health Care Advance Directives**  
HCPA / Living Will / Mental Health AD
3. **Out-of-Hospital DNR Laws**
4. **Organ Donation Laws**
5. **Guardianship Laws**
6. **Physician Aid in Dying**
7. **Palliative Care/Controlled Substances**
8. **POLST (MOST in NC)**

# Benchmark Case now 20+ years old

## **Cruzan v. Director, Mo. Dept. of Health (1990)**

- Recognized constitutional Liberty Interest in refusing med treatment
- Nutrition & Hydration not different from any other treatment
- Considerable leeway allowed for procedural safeguards states choose to impose, e.g., MO's "clear & convincing" standard.

Still leaves uncertainty about when a procedural safeguard becomes an undue burden on the constitutional right.

## Federal Law:

- **PSDA (1990):** Hospitals, NHs, HHAs and HMOs in Medicare or Medicaid must:
  1. Give *all* adults at admission written info about:  
(1) patient hcdm rights, and (2) their policies re hcdm.
  2. Ask you if you have AD and document.
  3. Educate staff & community on ADs.
  4. Prohibition: Can't discriminate based on ADs.
- **Military AD (10 U.S.C.A. § 1044c)** is “exempt from any requirement of form, substance, formality, or recording that is provided for advance medical directives under the laws of a State”

# The Original Model of Advance Directives

---

## Conceptual basis:

- Luis Kutner, 1969 article

- Wills & Trusts Model:

An enforceable legal instrument to direct and control property (i.e., your body) when surrogates must act for you (Substituted Judgment Standard of Decisionmaking)

“Legal Transactional Approach”

# Legal Transactional Approach

---

Earmarks: standardized legal formalities to ensure voluntary, knowing & competent execution & implementation— e.g.,

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

# 35 years of research on the legal transactional approach...

---

1. Most people don't do.
2. Hard to understand the legal 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. <sup>7</sup>

# **Advance Directives**

## **- *the Dark Side* -**

See e.g.,

- AHRQ research brief on Advance Directives (2003) at [www.ahrq.gov/research/endliferia/endria.pdf](http://www.ahrq.gov/research/endliferia/endria.pdf)
- Fagerlin & Schneider, “Enough: The Failure of the Living Will,” 34 *The Hastings Center Rep.* 30 (2004).
- Larson and Eaton, “The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act,” 32 *Lake Forest L. Rev.* 278 (1997).
- J. Teno et al, “Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the PSDA and the SUPPORT Intervention,” 45 *J. Amer. Ger. Soc.* 500 (1997).

## Recalibrating expectations: 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.

## Recalibrating expectations: *What ADs Can Do*

1. CAN be an important support to communicating/advance care planning
2. CAN empower and educate an agent.
3. CAN help you stop and think and DISCUSS.
  - Especially if focused on GOALS, VALUES & PRIORITIES rather than treatments.
4. CAN influence care if patient's goals of care are understood and effectively integrated into care planning.

# Advance Care Planning

IOM, Approaching Death, 1997: a broader, less legally focused concept than that of advance directives.

Encompasses not only preparation of legal documents but also discussions with family members and physicians about what the future may hold..., how patients and families want their beliefs and preferences to guide decisions..., and what steps could alleviate concerns...that trouble seriously ill or dying patients.”

# 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. Still needs conversion of goals to a plan of care (POLST)

# Compare...



**Healthy 19 year  
old in college-**

How lives life:  
As if immortal.

Goals: The sky is  
the limit.

Instructions:  
Clueless



**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!

# ACP is Developmental

- Revisit ACP and one's AD at life transitions – The 5 “Ds”:
  - Decade
  - Death of loved one
  - Divorce
  - Diagnosis
  - Decline

# More Effective Advance Planning – a communications approach

1. Emphasize the process, not the transaction.
2. Understand your client's goals, values & fears.
3. Understand your role as Lawyer.
4. Engage your client. Offer a workbook approach, *e.g., Lawyer's (& Consumer's) Tool Kit for Health Care Advance Planning*
5. Give priority to appointment of Proxy.
6. Stress periodic review of one's wishes.
7. Have you done your own advance planning?

# Workbook Examples

- **Finding Your Way: A Guide for End-of-Life Medical Decisions**, by the Center for Healthcare Decisions  
Sacramento Healthcare Decisions
- **Caring Conversations**, Center for Practical Bioethics
- **Good to Go Toolkit and Resource Guide**, Compassion and Choices
- **Thinking Ahead – My Way, My Choice, My Life at the End**, Cal. Dept. of Developmental Services
- **Consumer's Tool Kit for Health Care Advance Planning**  
ABA Commission on Law and Aging
- **Planning for Future Medical Decisions... My Way** (Dept Vets Affairs, 2011 online soon)

# Drafting Issues

1. Know your state law, but don't be overly rigid in interpretation.
2. Selecting an Agent
  - Who's prohibited?
  - Criteria – *Tool Kit for Advance Health Care Planning*
  - Co-Agents?
  - What is your duty to consultation/education?  
See *Making Medical Decisions for Someone Else: A How To Guide; + Tool Kit*

# **Who is the ideal health care proxy?**

## **Tool Kit for Advance Health Care Planning**

- 1. Meets the legal criteria in your state**
- 2. Willing to speak on your behalf.**
- 3. Able to act on your wishes and separate his/her own feelings from yours.**
- 4. Close by or could travel to be at your side.**
- 5. Knows you well & understands what's important to you.**
- 6. Can handle the responsibility.**
- 7. Will talk with you now and will listen to your wishes.**
- 8. Will likely be available in the future.**
- 9. Can handle conflicting opinions between family members, friends, and medical personnel.**
- 10. Can be a strong advocate in the face of an unresponsive doctor or institution.**

# Drafting Issues

## 3. Agent's Scope of Discretion

- Be aware of post mortem authority: autopsy / organ donation/ disposition of remains.
- Be explicit in describing authority.
- Maximum discretion? Do you want agent to be able to trump any written instructions? (Reality: Any written instruction needs a certain amount of interpretation in application).

# Drafting Issues

## 4. Often overlooked– Agent's Authority to

- Make anatomical gifts, autopsy, disposition of remains, if state law permits
- Contract for, hire, fire health care & support personnel
- Direct care even if Pregnancy – NC no restriction
- Change domicile.
- Execute releases & waivers (the “carrot”)
- Institute legal action (the “stick”).
- Consent to experimental treatment (important!)
- Delegate d-m during absence
- Care for pets

# Drafting Issues

## 5. Specific Instructions: pros & cons

**If you do include specific instructions...**

- People change their minds.
- Recent medical condition/history is important
- Focus on quality of life. What does that mean?  
Benefits & burdens are subjective.
- Never say never
- Consider “values history”
- A secondary illnesses can complicate matters

# Drafting Issues

## 6. Other instructions:

- Pain Control
- Engage principal to greatest extent possible
- Nominate Guardian
- Designate primary physician for capacity determination
- Eliminate unwanted surrogates (troublemakers)
- Personal/environmental/emotional. See e.g., *Five Wishes at [www.agingwithdignity.org](http://www.agingwithdignity.org)*

# Drafting Issues

## *Post-execution Logistics*

- Provide guide for proxy.
- Still haven't talked to physician?
- An invisible AD = no AD*
- Wallet card?
- AD registry:
  - <http://www.secretary.state.nc.us/ahcdr/thePAGE.aspx>
  - Others: USLivingWillRegistry.com;  
Docubank.com; MedicAlert.org;  
ALWR.com
- Provide a framework for review– the 5 D's

# HIPAA Issues

## *Access to protected health information by...*

- *Agent under health care DPA ? – Authorized as personal representative, 45 CFR 164.502(g)*
- *Putative agent under springing power ? Authorized but provider has some discretion. 45 CFR 164.510(b)*
- *Close family member/friend? – Authorized but provider has some discretion. 45 CFR 164.510(b)*

See: [www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa)

# Even with a communications approach to ADs, major barriers remain...

AHRQ (2003) Review of the Literature

[www.ahrq.gov/research/endliferia/endria.pdf](http://www.ahrq.gov/research/endliferia/endria.pdf)

- Having AD did not increase documentation in medical chart re patient preferences.
- ADs don't speak language of medicine.
- Medical records too often captive to the venue of care -- don't follow the patient.
- Patients w/ advanced illness most affected.

# **New Idea: Instead of standardizing patients' directives, standardize what providers have to do to know and implement patients' wishes?**

- Already have some experience with this:  
Out-of-Hospital DNR Orders, but...
  - Limited to CPR
  - may or may not follow patients across care settings
  - No obligation to offer an OOH-DNR order to any particular patient

# The POLST Paradigm

## MOST in No. Carolina

An additional, systemic step to bridge gap between patient's goals/preferences and implementation of an actual plan of care.

Four actions required:

1. Discussion: Find out patient's goals/wishes re: CPR, care goals (comfort vs. treatment), N&H, etc.
2. Translate into doctors orders on visually distinct medical file cover sheet.
3. Must follow patient across care settings.
4. Review

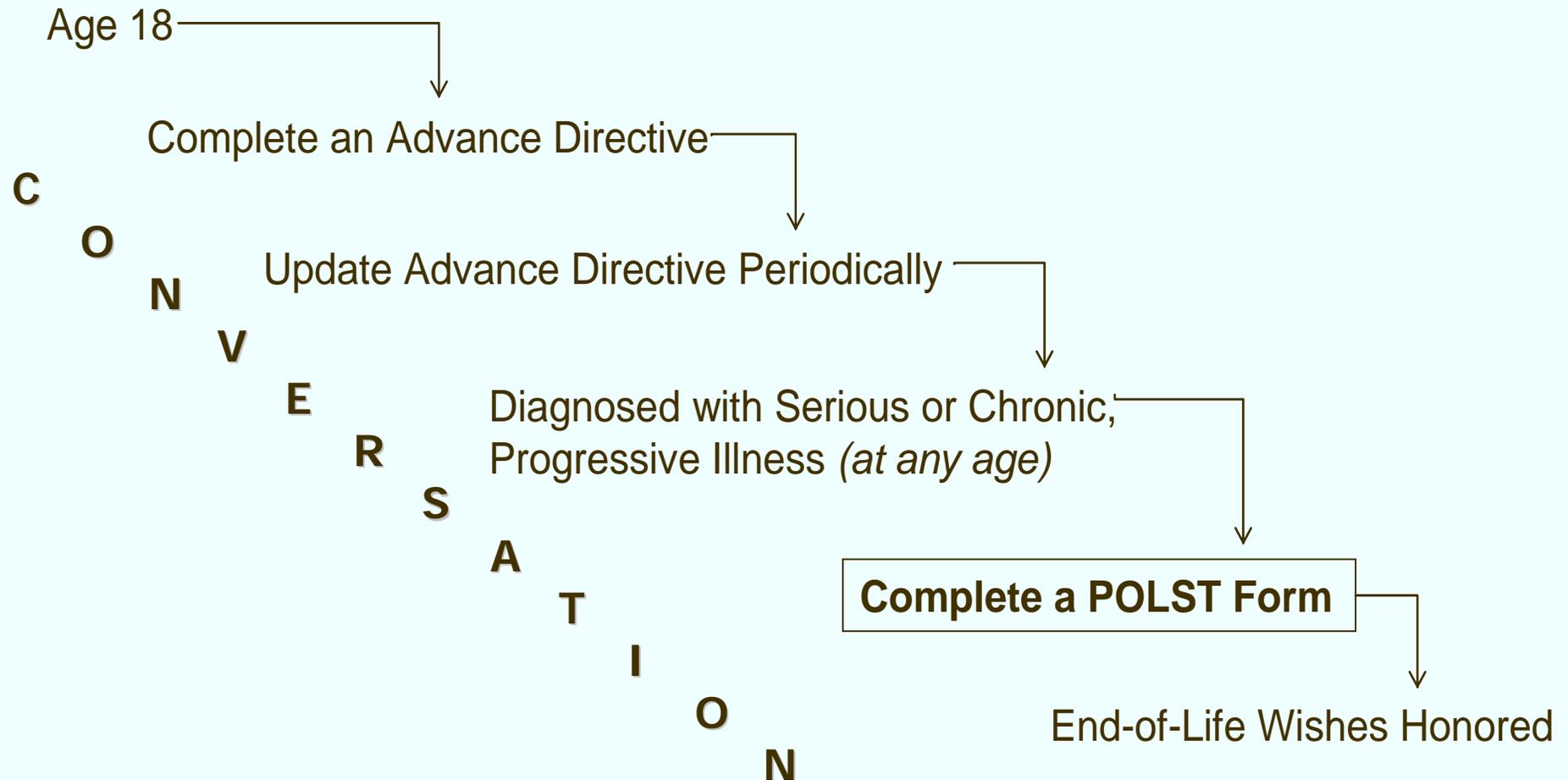


# POLST vs. Advance Directives

	<b>POLST Paradigm</b>	<b>Advance Directive</b>
<b>Population:</b>	Advanced progressive illness	All adults
<b>Timeframe:</b>	Current care/ current condition	Future care/ future conditions
<b>Where completed:</b>	In medical setting	In any setting
<b>Resulting product:</b>	Medical orders	Advance directive
<b>Surrogate role:</b>	Can consent if patient lacks capacity	Cannot do
<b>Portability:</b>	Provider responsibility	Patient/family responsibility
<b>Periodic review:</b>	Provider responsibility	Patient/family responsibility

# Where Does POLST Fit In?

## Advance Care Planning Continuum



Used with permission: Coalition for Compassionate Care of California

HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY



## Medical Orders for Scope of Treatment (MOST)

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 the need occurs, first follow these orders, then contact physician.**

Patient's Last Name:

Effective Date of Form:

*Form must be reviewed at least annually.*

Patient's First Name, Middle Initial:

Patient's Date of Birth:

### Section A

Check One Box Only

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

- Attempt Resuscitation (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.

- Full Scope of Treatment:** Use intubation, advanced airway interventions, mechanical ventilation, cardioversion as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. **Transfer to hospital if indicated.**
- Limited Additional Interventions:** Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation; also provide comfort measures. **Transfer to hospital if indicated.** **Avoid intensive care.**
- Comfort Measures:** 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 unless comfort needs cannot be met in current location.**

*Other Instructions* \_\_\_\_\_

### Section C

Check One Box Only

**ANTIBIOTICS**

- Antibiotics if life can be prolonged.
- Determine use or limitation of antibiotics when infection occurs.
- No Antibiotics (use other measures to relieve symptoms).

*Other Instructions* \_\_\_\_\_

### Section D

Check One Box Only in Each Column

**MEDICALLY ADMINISTERED FLUIDS AND NUTRITION:** Offer oral fluids and nutrition if physically feasible.

- |  |  |
|--|--|
| <input type="checkbox"/> IV fluids long-term if indicated                        | <input type="checkbox"/> Feeding tube long-term if indicated     |
| <input type="checkbox"/> IV fluids for a defined trial period                    | <input type="checkbox"/> Feeding tube for a defined trial period |
| <input type="checkbox"/> No IV fluids (provide other measures to ensure comfort) | <input type="checkbox"/> No feeding tube                         |

*Other Instructions* \_\_\_\_\_

# The Future is Electronic

## Oregon Electronic POLST Registry

- All filed and reviewed in secure electronic Registry.
- Patient may opt out.
- Located at the Emergency Communication Center at Oregon Health Sciences Univ. protected by the OHSU firewall
- Allows health care professionals access to POLST orders *if* the original POLST form cannot be immediately located.

# Oregon Electronic Registry Study

307(1) JAMA 34 (2012)

- 25,142 people were enrolled in Oregon's registry during the first year of operation.
- 86 percent of patients in the POLST program are 65 or older.
- 28 percent wished to receive CPR if needed.
- 72 percent had a "Do Not Resuscitate" order.
- **50 percent of patients who had a DNR order wanted to be hospitalized.**

# Summary

## Process-Oriented Advance Planning

- ❑ Don't do one-stop Advance Directives.
- ❑ Your client probably can't pay you enough to go through the process in depth, so give the client the tools to do the important part:
  1. Give priority to the power of attorney
  2. Include specific wishes cautiously
  3. Use Workbook approach: Value worksheet/  
Thought-provoking exercises
  4. Stress that client has to talk to proxy & doctor
  5. Educate the agent/proxy
  6. Stress periodic review – the 5 D's.

## **Circumstances have changed but the question remains the same as in 1982:**

---

“How to foster a relationship between patients and professionals characterized by mutual participation and respect, and by shared decision-making”

President's Cmsn for the Study of Ethical Problems in  
Medicine & Biomedical & Behavioral Research