Effective Health Care Advance Planning

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Commission on Law and Aging
American Bar Association
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Poll 1

How many advance directives have you drafted?

A. Less than 5
B. 5 to 15
C. 16 or more
“My, oh, my, what a co-inky dinky.”
I. The Law – Very Briefly

II. Why ADs Have Not Worked as Well as Hoped

III. More Effective Advance Planning & Drafting

IV. HIPAA Issues

V. The POLST Paradigm
Key HCDM Cases
Supreme Court

Cruzan v. Director, Mo. Dept. of Health (1990)
• Recognized Liberty Interest in refusing med treatment
• Nutrition & Hydration not different from any other treatment
• Considerable leeway allowed for procedural safeguards, e.g., MO’s “clear & convincing” standard.

• No constitutional right to assistance in committing suicide.
Key Common Law Guidance

• Too many cases to summarize!
• “Most courts have grounded the right to refuse life-sustaining treatment in the common law right to be free from unwanted intrusion on or invasion of bodily integrity, protected through the legal requirements of consent and informed consent to treatment.” A. Meisel & K. Cerminara, the Right to Die (Aspen Pub. 2009 Suppl.)
• My summary: If you know the patient’s wishes, you have to respect them unless a compelling countervailing policy overrides.
District of Columbia case example

*In re A.C.*, 573 A.2d 1235, 1249 (D.C. 1990)

In exercising substituted judgment, court must:

- Determine as best it can what choice that individual, if competent, would make with respect to medical procedures.
- Consider totality of evidence, taking into account patient's past decisions re medical treatment and evidence concerning patient's value systems, goals and desires.
- Give greatest weight to previously expressed wishes.
Typical Standard of Substitute Consent in State Advance Directive Laws

Virginia Code § 54.1-2986

Any person authorized to consent to the providing, withholding or withdrawing of treatment … shall (i) prior to giving consent, make a good faith effort to ascertain the risks and benefits of and alternatives to the treatment and the religious beliefs and basic values of the patient receiving treatment, and … (ii) base his decision on the patient's religious beliefs and basic values and any preferences previously expressed by the patient regarding such treatment to the extent they are known, and if unknown or unclear, on the patient's best interests.
Uniform Health-Care Decisions Act
Standard of Decision-Making

• A surrogate shall make a health-care decision in accordance with the patient's individual instructions, if any, and other wishes to the extent known to the surrogate. Otherwise, the surrogate shall make the decision in accordance with the surrogate's determination of the patient's best interest. In determining the patient's best interest, the surrogate shall consider the patient's personal values to the extent known to the surrogate. Sec. 5(f)
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”
State Statutes you need to know

A. Advance Directive Laws
   • Living Will:
   • Durable Power of Attorney for Health Care
   • Other (DPOA/Health Consent)

B. Default Surrogate law (free standing or in A.)

C. Guardianship Law – HCDM provisions

D. Mental Health Adv. Directive Law (about half the states)

E. Anatomical Gifts Act

F. POLST Law, if any
What Does Your Statute Say About…

A. Required Formalities
B. Oral Directives
C. Prohibited Agents
D. Limits on Agent’s Power
E. Post-Mortem Authority of Principal
F. Determination of Incapacity
G. Medical Preconditions to action
H. Default Surrogate Consent
I. Standard for Surrogate D-M
J. Authority of Agent vs. Guardian
K. Non-compliance consequences
Poll 2

In drafting advance directives, the general practice in my area is to:

A. Draft separate living will and health care power of attorney documents.
B. Draft a combined living will and health care power of attorney documents.
Questions?
II. Why ADs Have Not Worked as Well as Hoped

A great idea but:

- Most people don’t do.
- When they do, a standard form doesn’t provide much guidance.
- When they name an agent, they seldom explain their wishes to agent.
- Even if they do, health care providers usually don’t know about the directive.
- Even if providers know directive exists, it isn’t in medical record.
- Even if in the record, it isn’t consulted.
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.
What ADs *Can* Do

1. **CAN be an important part of a developmental process of advance planning**
   - Especially with respect to appointing/informing a health care agent.

2. **CAN help you stop and think and DISCUSS.**
   - Discussion doesn’t need to be about specific medical decisions, but rather about VALUES & PRIORITIES: What’s important to you in living? What conditions of living may outweigh the value of continued life?

3. **CAN empower and give DIRECTION if reflective of the patient’s voice.**
   - Specific instructions are relevant to foreseeable decisions – as in a care plan, but need not be in AD.
III. More Effective Advance Planning

1. Emphasize the process, not the transaction.
2. Understand your client’s perceptions and fears.
3. Understand your role as Lawyer.
4. Engage your client. Offer a workbook approach, e.g., see **Lawyer’s (& Consumer’s) Tool Kit for Health Care Advance Planning** ([www.abanet.org/aging](http://www.abanet.org/aging))
5. Give priority to appointment of Proxy.
6. Draft beyond the standard form.
7. Stress periodic review of one’s wishes.
8. Have you done your own advance planning?
Drafting Issues

1. Selecting an Agent
   • Help Client think this through…
     Tool Kit for Advance Health Care Planning
     www.abanet.org/aging/publications/docs/consumer_tool_kit_bk.pdf
   • Co-Agents?
   • What is your duty to educate the agent? …
     Making Medical Decisions for Someone Else: A How-To Guide
When you decide to pick someone to speak for you in a medical crisis, in case you are not able to speak for yourself, there are several things to think about. This tool will help you decide who the best person is. Usually it is best to name one person or agent to serve at a time, with at least one successor, or back-up person, in case the first person is not available when needed.

*Compare up to 3 people with this tool. The persons best suited to be your Health Care Agents or Proxies rate well on these qualifications...*

<table>
<thead>
<tr>
<th>Name #1:</th>
<th>Name #2:</th>
<th>Name #3:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Meets the legal criteria in your state for acting as agent or proxy or representative? (This is a must! See next page.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Would be willing to speak on your behalf.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Would be able to act on your wishes and separate his/her own feelings from yours.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Lives close by or could travel to be at your side if needed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Knows you well and understands what’s important to you.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The ideal health care proxy…

1. Meets the legal criteria in your state for acting as agent or proxy or representative?
2. Would be willing to speak on your behalf.
3. Would be able to act on your wishes and separate his/her own feelings from yours.
4. Lives close by or could travel to be at your side if needed.
5. Knows you well and understands what’s important to you.
6. Could handle the responsibility.
7. Will talk with you now about sensitive issues and will listen to your wishes.
8. Will likely be available long into the future.
9. Would be able to 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.
2. Agent’s Scope of Authority/Discretion

- Be aware of statutory limits & post mortem authority
- Be explicit
- Maximum discretion? Do you want agent to be able to override written instructions, if any?
Drafting Issues

Often overlooked—Authority to . . .

- Make anatomical gifts, autopsy, disposition of remains if permitted in your state.
- Hire & fire health care & support personnel.
- Direct care even if pregnant.
- Change domicile.
- Ensure adequate pain management
- Execute releases & waivers (the “carrot”)
- Institute legal action (the “stick”).
- Consent to experimental treatment.
- Delegate d-m during absence.
- Care for pets.
- Determine visitation access by others
Poll 3

The continuing use of narcotic-based pain medications (opioids) will result in:

A. Addiction
B. Physical dependence
C. Increased tolerance
D. All of the above
Drafting Issues

3. Effective Date: immediate or springing?

4. Determining D-M Capacity

- **DC** -- 2 physicians, one must be psychiatrist
  One must examine w/in 1 day preceding cert.
- **MD** – 2 physicians unless otherwise specified
  One must examine w/in 1 day preceding cert.
  If can’t communicate or unconscious, only 1 required.
  PVS confirmed by a neurologist, neurosurgeon, or other physician w/ expertise in cognitive functioning.
- **VA** - 1 physician + either 2nd physician or licensed clinical psychologist after personal examination.
  Recert. required every 180 days.
Drafting Issues

6. Specific Instructions: pros & cons

If you do include specific instructions...

• People change their minds.
• Recent medical history is important
• Focus on quality of life. What’s a benefit? What’s a burden?
• Never say never
• A secondary illnesses can complicate matters
Are Some Conditions Worse than Death?

Name & Date________________________________

This worksheet helps you to think about situations in which you would not want medical treatments intended to keep you alive. These days, many treatments can keep people alive even if there is no chance that the treatment will reverse or improve their condition. Ask yourself what you would want in the situations described below if the treatment would not reverse or improve your condition.

Directions: Circle the number from 1 to 5 that best indicates the strength and direction of your desire. If you wish, you can add additional thoughts on the Comment lines.

1 -- Definitely want treatments that might keep you alive.
2 -- Probably would want treatments that might keep you alive.
3 -- Unsure of what you want.
4 -- Probably would NOT want treatments that might keep you alive.
5 -- Definitely do NOT want treatments that might keep you alive.

<table>
<thead>
<tr>
<th>What If You . . .</th>
<th>Definitely Want Treatment</th>
<th>Definitely Do Not Want Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. No longer can walk but get around in a wheel chair.</td>
<td>1  2  3  4  5</td>
<td></td>
</tr>
<tr>
<td>Comment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. No longer can get outside. – You spend all day at home.</td>
<td>1  2  3  4  5</td>
<td></td>
</tr>
<tr>
<td>Comment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. No longer can contribute to your family’s well being.</td>
<td>1  2  3  4  5</td>
<td></td>
</tr>
<tr>
<td>Comment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
People have personal priorities and spiritual beliefs that affect their medical decisions. This is especially true at the end of life with regard to the use of life-sustaining treatments. To make your values and beliefs more clear, consider answering the questions below. Use more paper if you need more space.

**PERSONAL PRIORITIES/CONCERNS**

1. What do you most value about your physical or mental well being? For example, do you most love to be outdoors? To be able to read or listen to music? To be aware of your surroundings and who is with you? Seeing, tasting, touching?

2. What are your fears regarding the end of life?

3. Would you want to be sedated if it were necessary to control your pain, even if it makes you drowsy or puts you to sleep much of the time?

4. Would you want to have a hospice team or other palliative care (i.e., comfort care) available to you?
Drafting Issues

7. Other instructions:

- Anatomical Gifts
- Pain Control
- Engage principal to greatest extent possible
- Nominate Guardian
- Perhaps designate primary physician
- Eliminate unwanted surrogates (troublemakers)
- Carrots and sticks
- Pregnancy
- Pets
- Personal/environmental/emotional.

See *Five Wishes* at www.agingwithdignity.org
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
Questions?
Drafting Issues

8. Post-execution Logistics

- An invisible AD = no AD
- Still haven’t talked to physician?
- Wallet card
- State AD registries:
- Other Registries:
  - USLivingWillRegistry.com
  - Docubank.com
  - America Living Will Registry: ALWR.com
- Provide a framework for review

*Review 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 significant **DECLINE** in your condition as measured by Activities of Daily Living (ADLs)
IV. HIPAA Issues

Access to protected health information

- **Agent under health care DPA:**
  
  Agent = “Personal Representative”
  
  Doesn’t need HIPA authorization language. 45 CFR §164.502(g)

- **Putative agent under springing power:**
  
  Give HIPAA authorization (42 CFR §164.508) or immediate limited power of access to medical record for purposes of determining capacity.

See:

www.hhs.gov/ocr/hipaa
• *Family members – access under HIPAA:* Privacy Rule at 45 CFR 164.510(b) specifically permits covered entities to share information that is directly relevant to the involvement of a spouse, family members, friends, or other persons identified by a patient, in the patient’s care or payment for health care.

See:

www.hhs.gov/ocr/hipaa
Poll 4

In drafting health care powers of attorney, I deal with HIPAA issues by:

A. Always including HIPAA authorization language
B. Never including HIPAA authorization language
C. Sometimes including HIPAA authorization language.
V. The POLST Paradigm

“Physician’s Orders for Life Sustaining Treatment”

Last 30 years: Policy goal -- standardizing patient communications, i.e., statutory advance directives

Tipping Point: POLST Paradigm – standardizing physicians EOL care orders. Focus on here and now.

Physicians Orders for Life-Sustaining Treatment – requires:

1. Doc to find out patient’s wishes re: CPR, care goals (hospitalize/comfort vs. treatment), antibiotics, ANH.

2. Translate into doctors orders on visually distinct (bright pink) med file cover sheet.

3. All providers ensure form travels with patient to enhance continuity of care.
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.

<table>
<thead>
<tr>
<th>Section A</th>
<th>CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Resuscitate (CPR)□ Do Not Attempt Resuscitation (DNR/no CPR)</td>
</tr>
<tr>
<td></td>
<td>When not in cardiopulmonary arrest, follow orders in B, C, and D.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section B</th>
<th>MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Comfort Measures Treat with dignity and respect. Keep clean, warm, and dry.</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>□ 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.</td>
</tr>
<tr>
<td></td>
<td>□ Full Treatment Includes care above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Include intensive care.</td>
</tr>
<tr>
<td></td>
<td>Other Instructions:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section C</th>
<th>ANTIBIOTICS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ No Antibiotics</td>
</tr>
<tr>
<td></td>
<td>□ Antibiotics</td>
</tr>
<tr>
<td></td>
<td>Other Instructions:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section D</th>
<th>Medically Administered Fluids and Nutrition: Oral fluids and nutrition must be offered if medically feasible.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ No IV fluids (provide other measures to assure comfort)</td>
</tr>
<tr>
<td></td>
<td>□ IV fluids for a defined trial period</td>
</tr>
<tr>
<td></td>
<td>Other Instructions:</td>
</tr>
<tr>
<td></td>
<td>□ No feeding tube</td>
</tr>
<tr>
<td></td>
<td>□ Feeding tube for a defined trial period</td>
</tr>
</tbody>
</table>
## POLST States

<table>
<thead>
<tr>
<th>State</th>
<th>POLST</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>POLST</td>
</tr>
<tr>
<td>Idaho</td>
<td>Physicians Orders for Scope of Treatment (POST)</td>
</tr>
<tr>
<td>Maryland*</td>
<td>Instructions on Current Life-Sustaining Treatment Options (IOCLSTO ?)</td>
</tr>
<tr>
<td>New York</td>
<td>Medical Orders for Life-Sustaining Treatment (MOLST)</td>
</tr>
<tr>
<td>No. Carolina</td>
<td>Medical Orders for Scope of Treatment (MOST)</td>
</tr>
<tr>
<td>Tennessee</td>
<td>Physicians Orders for Scope of Treatment (POST)</td>
</tr>
<tr>
<td>Washington</td>
<td>POLST</td>
</tr>
<tr>
<td>W. Virginia</td>
<td>Physicians Orders for Scope of Treatment (POST)</td>
</tr>
</tbody>
</table>

Plus parts of Pennsylvania, Wisconsin, & other states in development.

* Not a true POLST statute b/c not a doctor’s order
Summary

Process-Oriented Advance Planning

- Don’t do one-stop AD
- 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.
  - Give priority to the power of attorney
  - Use Workbook approach: Value worksheet/Thought-provoking exercises
  - Look at different model ADs
  - Stress that client has to talk to proxy & doctor
  - Don’t draft a one-size fits all form
  - Help educate the agent/proxy

- Periodic review – the 5 D’s.
Questions?