End-of-Life Care and Advance Directives

M-2 ICE Ethics Topic for March 19, 2001
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This two-hour class is devoted to exploring end-of-life care for patients who no longer have decision-making capacity. The general philosophy of the ICE curriculum recognizes that patients make health care decisions within their context of familial history, values, beliefs, social situatedness, fears etc. These attributes bring meaning to decisions that patients make in regard to their health care. When a patient loses decision-making capacity, s/he loses the ability to make health care decisions unless s/he has made an advance directive. Such a document guides care-givers in knowing what types of interventions the patient would or would not want; or, it names a surrogate decision-maker who can direct care as the patient would, if able.

If a patient does not have an advance directive (and many don’t), the next of kin is asked to step in to make decisions on behalf of a patient who loses decision-making capacity. This individual is then asked to make substituted judgments on behalf of the patient, i.e. to decide what s/he thinks the patient would want to be done under the circumstance. This responsibility falls first to the spouse. If there is no spouse, the adult children of a patient are consulted; if there are no adult children, then the parents of the patient are consulted; and if there are no parents, then siblings or grandchildren are consulted. In approaching this subject, we encourage a sympathetic understanding of patients/families' experiences and suffering as the context for managing medical interventions and technologies.

Objectives for the class include:

1) Define what an advance directive is including the characteristics of a:
   - Living Will
   - Durable Power of Attorney for Health Care

2) Identify the difficulties of applying advance directives in practice.

3) Identify ways of approaching patients and families concerning advance directives from initiation through completion of documents.

4) Address the uncertainties of advance directives and the necessity of working
through patient preferences in the context of patient’s circumstances at time of death.

## Advance Directives

*The Patient Self-Determination Act of 1991, requires that patients be informed of their right to make decisions about health care, including their right to have an Advance Directive.*

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<th>What is an Advance Directive?</th>
<th>A written document in which a competent patient directs future health care decisions in the event that s/he loses capacity and is unable to participate in future medical decision-making.</th>
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| What types of Advance Directives are available? | **Instructive AD** such as a "Living Will"--this type of AD articulates patient preferences such as:  
- particular therapies or types of therapies  
- transfusions  
- CPR  

**Proxy AD** such as a "Durable Power of Attorney for Health Care"--this type of AD designates a surrogate medical decision maker who will act if the patient is unable because of loss of decision making capacity. The named proxy should have detailed knowledge of the patient's wishes, values and views to be able to make a "*substituted judgment*" as to what the patient would probably want in a given circumstance. |
| Why are Advance Directives Important? | Because they allow patients to have a voice in future medical decision making, even if incapacitated and unable to decide directly.  
AD documents assist others in knowing what the patient would want.  
The "living will" was created so that patients could make known their desires not to have invasive medical procedures performed at the end of life.  
AD documents that name a proxy decision-maker are especially important for patients in non-traditional relationships who wish to designate a partner/person who would not be consulted via legally designated channels about such matters should the patient lose capacity. |
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<th><strong>Are Advance Directives legally binding?</strong></th>
<th>Yes, if completed according to each state's requirements.</th>
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<td><strong>When should a patient make an Advance Directive?</strong></td>
<td>Anytime is a good time. Patient's should be asked early in care if s/he has an AD and where it is. It is recommended that a copy should be given to the primary care physician for inclusion in the chart. Another copy should be taken to the hospital at any admission for inclusion in the record. In any event, persons should talk about their wishes and values in regard to end of life care with those close to them, even if they do not make an AD, so that others are aware of their wishes and values.</td>
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<td><strong>What if a patient changes his/her mind?</strong></td>
<td>Changing one's mind is not uncommon when one is confronted with serious and life threatening illness--the AD can be changed as long as the patient has decision-making capacity. Informed decisions by patients with capacity override an AD.</td>
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<td><strong>When does an Advance Directive take effect?</strong></td>
<td>An AD takes effect only if the patient has lost decision-making capacity.</td>
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<td><strong>What happens if a family disagrees with a patient's &quot;living will&quot; or stated preferences?</strong></td>
<td>This is not uncommon. It is also not uncommon that family members may disagree with one another--some wanting to honor the LW and others disagreeing. These are difficult situations that call upon the physician to help the family/friends interpret via &quot;substituted judgment&quot; what the patient would have wanted in this situation.</td>
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Other quick resources:


The Aid in Dying Communication Project: [http://www.aidindying.com](http://www.aidindying.com) (regarding enhancing physician communication with dying patients and especially patients requesting aid in dying)

The Hemlock Society: [http://www2.privatei.com/hemlock](http://www2.privatei.com/hemlock) (Regarding services for patient requesting aid in dying)
# Two Ethical Perspectives on Physician's Role When Patient Thinking about End-of-Life Decisions

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<th>Ethic of Duty</th>
<th>Narrative Ethic</th>
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<td>Physician-patient relationship</td>
<td>Fiduciary responsibility to serve best interest of patient--recognizes patient's right to self-determination recognizes patient's autonomy</td>
<td>Fiduciary responsibility to serve patient. Physician to serve patient through understanding of patient's life circumstances and social situation</td>
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<td>Patient's Situation</td>
<td>Right to self-determination assumes patient knows what s/he wants and needs and can articulate it to the physician.</td>
<td>Narrative ethic assumes that what patient wants or needs will evolve through shared meanings that are articulated through dialogue with significant others (including the physician).</td>
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<td>Contingent circumstances</td>
<td>&quot;Right's&quot; based approaches to ethics can set up conflict with medical team trying to respond to uncertain and contingent circumstances not covered by LW/DPOAHC documents when patient's expectations are not met.</td>
<td>Narrative ethic is responsive to uncertainty and contingent circumstances. Dialogue with patient/family is important to fine-tune and reconcile patient/family and physician expectations</td>
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<td>Suffering</td>
<td>Patient self-determination model (&quot;Rights&quot;) is not in and of itself responsive to suffering--assumes patient's autonomy as long as cognitively able. By fully assuming that the patient is autonomous, physician may miss the opportunity to be a healer by responding to patient's existential suffering and sense of loss.</td>
<td>Suffering is an integral aspect of life experience that is expressed in patient's narrative to which the physician should be responsive and therefore involved. Dialogue with physician and others can lead to &quot;renewal in loss.&quot;</td>
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**CASE**

Mr. Z, a 40 year old man, from a smaller community in the Midwest had been suffering from progressive weakness and was essentially paralyzed below the waist and confined to a wheelchair. He had lost 50 pounds during the last year. He had prepared a document that stated his wishes for end-of-life care should he be in a terminal condition and unable to make his own health care decisions. He named his close friend and care-giver to act as his Power of Attorney for Health Care. He wanted no artificial means used to support his life if in a terminal state.

The patient was attended by a number of physicians during the period of his illness, but no definitive diagnosis was ever made. Multiple sclerosis was suspected, but unconfirmed. During Mr. Z's last exacerbation, he called his physician and asked Please help me. The patient was admitted to the hospital and his course rapidly deteriorated. He became less and less responsive. His respiratory status was severely compromised and he was placed on a ventilator; his B/P fell and pressors had to be started. Soon the patient was septic and in a coma with periods of up to 45 sec. when he had no pulse. Gilliam Barre was suspected, but not confirmed as was Klebsiella pneumonia. The patient's sibling and friend (with POAHC) insisted that the patient would not want to be maintained using the ventilator and pressors. They wanted these interventions discontinued because they said the patient wanted to die. The doctor argued that the patient asked him to help him. The physician did not think that the patient was terminal and thought that if the medical team could continue...
treating the sepsis and supporting the patient artificially, that the patient might make it.

Form B: Advance Directive

Adapted from: The Five Wishes format from the Aging with Dignity Organization, Tallahassee, Florida

1) Who do you want to make health care decision for you if you can not make them for yourself?

Name
Phone number
Address

If this person is for some reason unable to make these choices for you, name two other people who you would trust to act on your behalf.

Do you want him/her to make decisions regarding (underline those that apply) medical care including tests, medicines, surgery, understanding your health problems/needs, whether or not to keep you alive by maintaining/withdrawing medical interventions; interpret your instructions, wishes, values to medical personnel; arrange for hospital, hospice, nursing home admission, or home care; decide whether or not to take away or not start medical treatments including artificially-provided food or water; move you to another state or location; take legal actions to carry out your desires; apply for Medicare or Medicaid or other insurance benefits, see your personal files, bank records, and act on your behalf in such matters; Other additions/changes desired to include__________________.

2) What kind of medical treatment do you want or not want?

Give general instructions: regarding pain management, being offered food and fluid by mouth, general physical care; life support, i.e. medical devices to help you breathe, food or water by tube feeding/ or other artificial means, CPR, major surgery, blood transfusions, dialysis, antibiotics?
Do you want to limit some aspect of life-support treatment listed above in any way? If so, how?

If you are close to death, or in a coma, or have severe brain damage as determined by your doctor and another health care professional and life supporting treatment would postpone the moment of death, do you want: life-support treatment started; if it has been started, do you want it stopped; if your doctor thinks it might help, do you want to try life-support; if your doctor thinks life-support treatment is not helping do you want it stopped?

3) **How comfortable do you want to be?** List the kinds of physical cares you would want to have performed including general hygiene, hair-washing, care in case of loss of control of bladder and/or bowel; pain management; medications for depression, hallucinations or other psychological conditions, mouth care, environmental cares including visitors, music, having someone read to you, etc.?

4) **How do you want people to treat you.** List ways in which you would like to be cared for emotionally. Do you want someone to always be with you, to hold your hand, pray with you, pray for you, play music for you if so, what kind of music, to let you die in the hospital, to let you die at home?

5) **What do you want those you care about to know about your relationships with others, about the way you d like to be remembered, about your funeral wishes, and any other wishes?**