

Clinical Pastoral Education Didactic – April 27, 2015  
Hospital of the University of Pennsylvania

# Healthcare Decision Making, Advance Directives, and the Role of the Chaplain

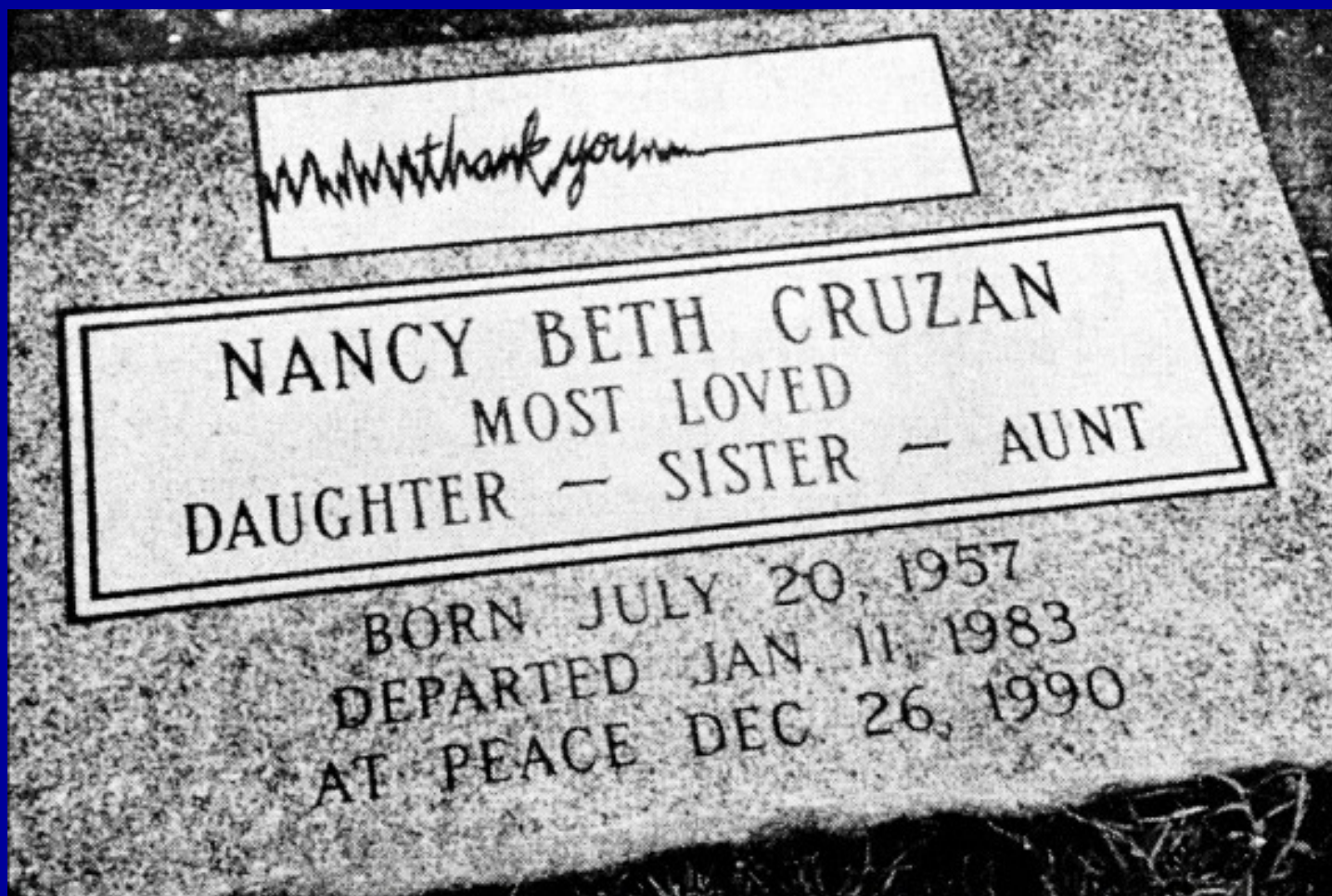
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## **Complex Overlap of Developments in the Right to Make Healthcare Decisions**

- 1) Right of informed consent by a competent patient grew slowly through court cases, 1905-1972
- 2) Legislation around Living Wills (for end-of-life treatment) grew state-by-state, 1983-1992; with federal action following in the 1990s
- 3) Legislation recognizing Durable Powers of Attorney grew state-by-state, 1983-1997
- 4) Right-to-die cases have proceeded from the 1970s and are ongoing

## The Cruzan Case



## Cultural Context and the Medical Technology Factor

“Not long ago the realms of life and death were delineated by a bright line. Now this line is blurred by wondrous advances in medical technology -- advances that until recent years were only ideas conceivable by such science-fiction visionaries as Jules Verne and H.G. Wells. *Medical technology has effectively created a twilight zone of suspended animation where death commences while life, in some form, continues. Some patients, however, want no part of a life sustained only by medical technology. Instead, they prefer a plan of medical treatment that allows nature to take its course and permits them to die with dignity.* As more individuals assert their right to refuse medical treatment, more frequently do the disciplines of medicine, law, philosophy, technology, and religion collide.”

-- Arizona Supreme Court Chief Justice Frank X. Gordon Jr., in *Rasmussen*, 7/23/87. (Italicized section quoted by US Supreme Court Justice William J. Brennan, Jr., in his dissent to *Cruzan*, 6/25/90.)

## **Major Open Points of Contention about the Right to Make Healthcare decisions**

- Pregnancy
- Nutrition and hydration
- Mental health circumstances
- Minors
- Portable medical orders for end-of-life treatment
- When a Living Will become operative
- Rights of incompetent patients to influence decisions

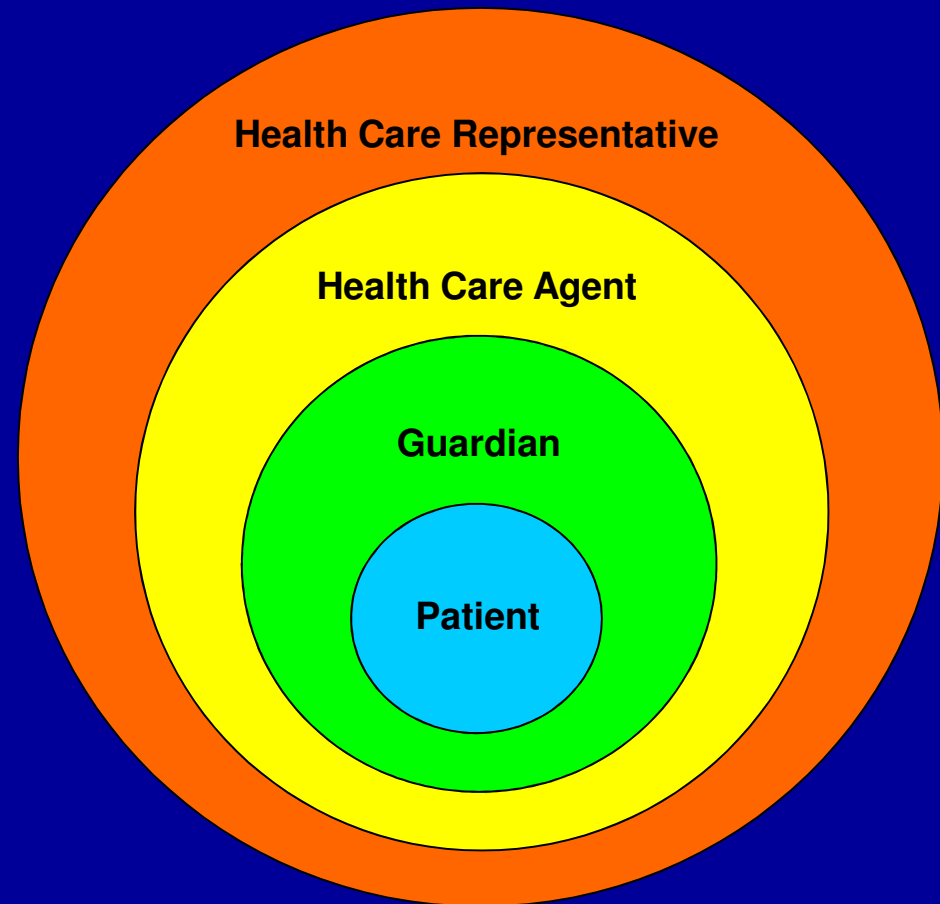
## **Penn Medicine Policy on the Right to Make One's Own Healthcare Decisions**

...[T]o the extent permitted by law, every adult and emancipated minor patient has the right to make decisions about his or her own health care with his or her physician. These decisions may include agreeing to a proposed treatment, choosing among offered treatments, or refusing a treatment. The patient retains these rights even when he or she is unconscious, or lacks capacity, or is unable to communicate his or her wishes or otherwise is incompetent. One of the ways that a patient may exercise these rights is to write and execute a living will, a health care power of attorney, or other advance health care directive (collectively referred to as advance directives).

--UPHS Advance Directive Policy (2014)

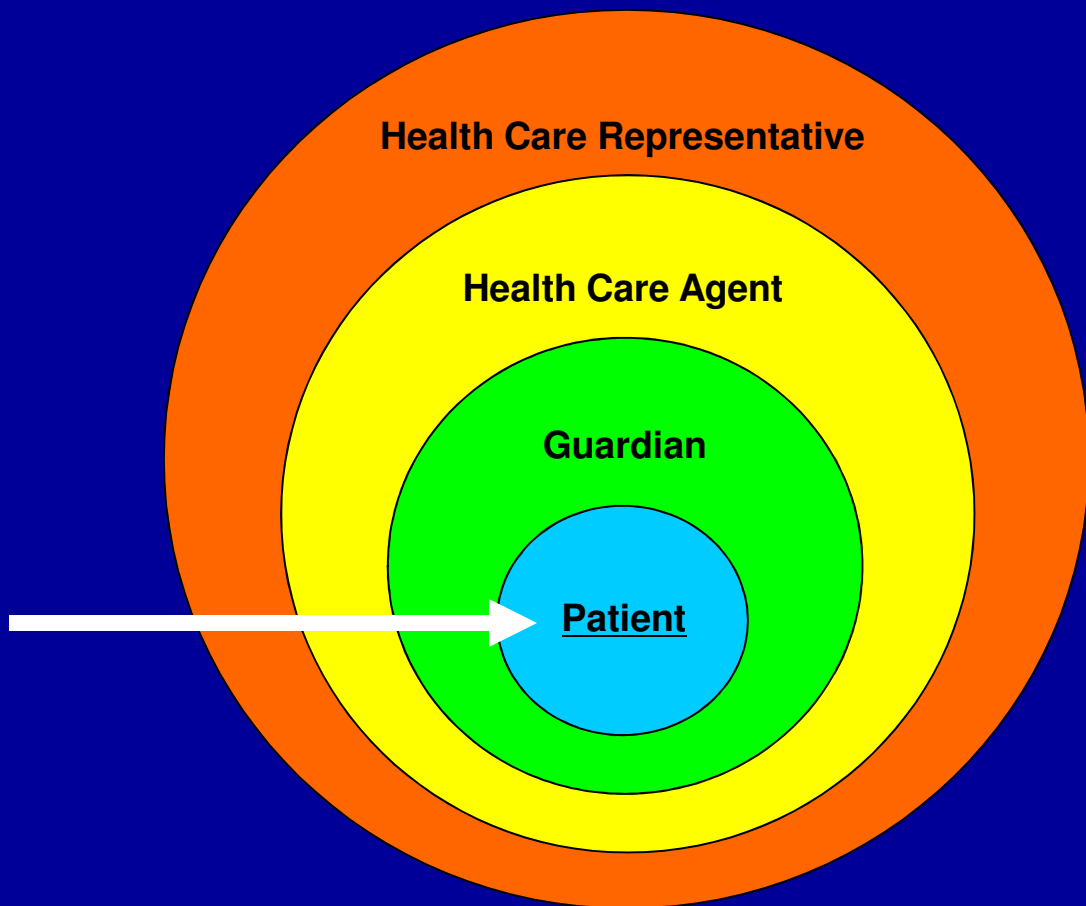
# Layers of Protection for Patient Autonomy

Decision-making is anchored in the rights of a competent patient. However, when a patient cannot participate in decision-making, then a succession of Legally Authorized Representatives may speak for the patient.



# Centrality of the Patient

As long as a patient is **competent** to make health care decisions, the care team works directly with him or her on all matters.

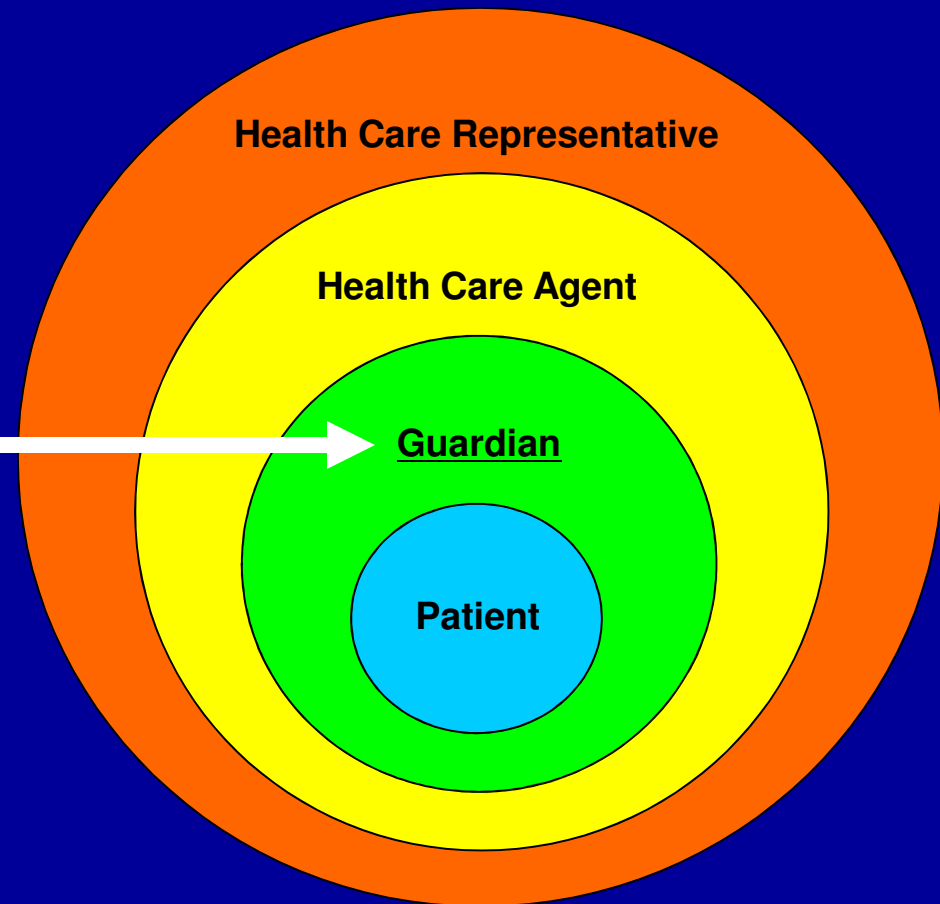




# When a Court Appoints a Guardian

When a patient is incompetent to make decisions, a court could *potentially* appoint a **guardian** whose specific authority would be stated in a court order.

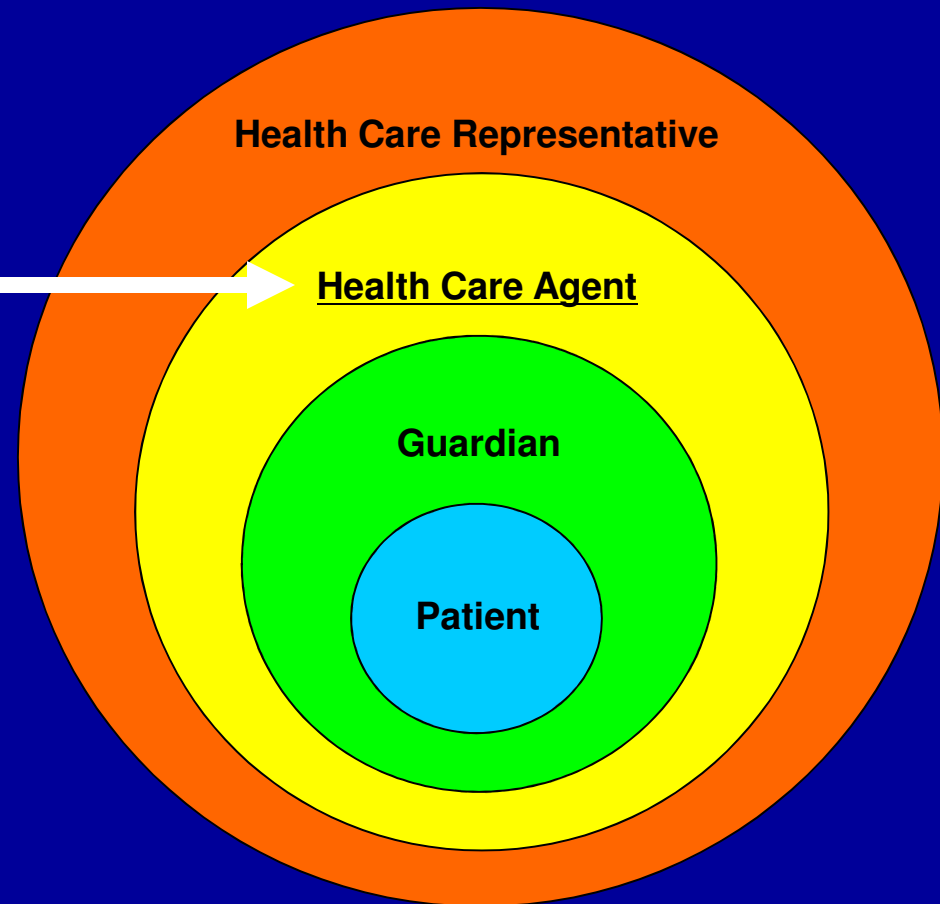
Health care providers should confirm that a court order applies to health care decisions (and is not just, for example, for financial decisions).



# Patient-Designated Health Care Agent

The patient has a legal right to designate a **Health Care Agent** through a *written Health Care Power of Attorney*.

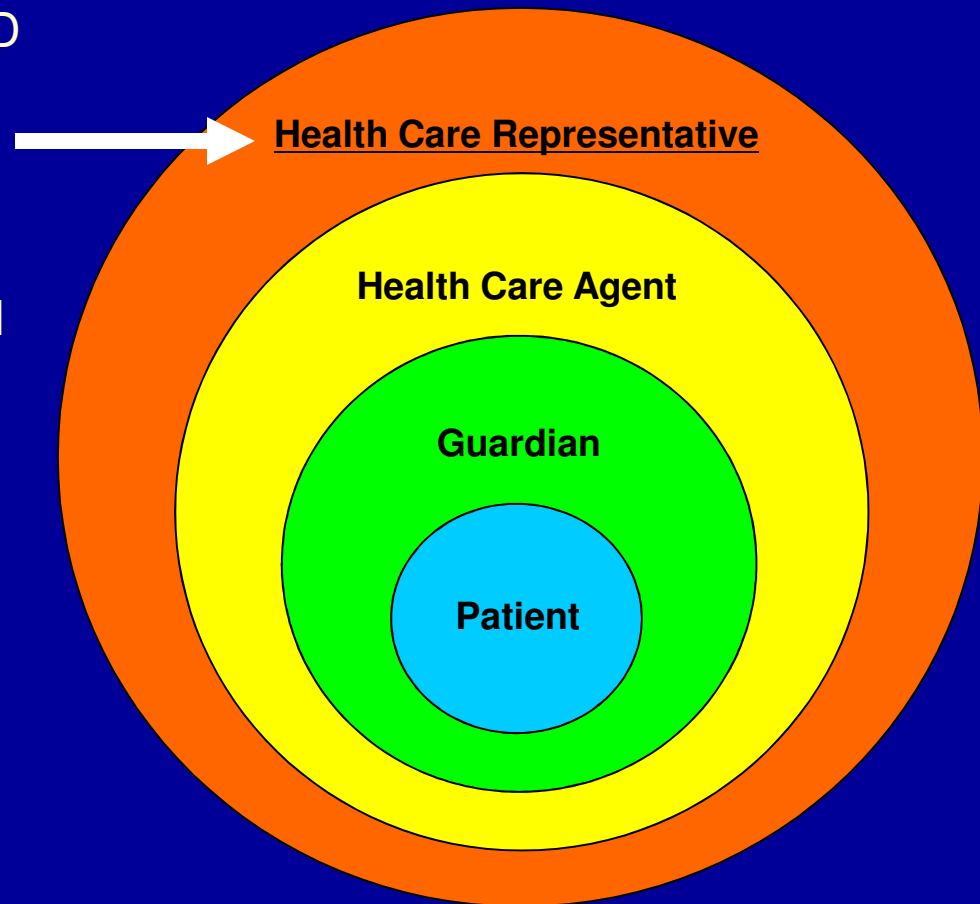
The specific authority of the Health Care Agent to make decisions for the patient will be stated in an Advance Directive's Health Care Power of Attorney. While a patient may authorize the HealthCare Agent to have all the decision-making authority of the patient himself/herself, it is possible that a patient may place limits or conditions on the Health Care Agent's authority.



# Provider-Identified Health Care Representative

When a patient is incompetent to make health care decisions, AND when a Health Care Agent has not been designated by the patient or is not reasonably available, then the health care provider should follow the formal process of identifying who is legally authorized to act as the **Health Care Representative**.

In Pennsylvania, Health Care Representatives may make decisions on behalf of a patient with one exception: *they cannot make decisions to withhold or withdraw life-sustaining therapy when the patient is not in an end-stage medical condition or permanently unconscious.*



# Health Care Representatives in Pennsylvania

If a patient has not designated a Health Care Agent, or if the Health Care Agent is not reasonably available, a physician will identify the patient's Health Care Representative(s) according to a hierarchy of classes of people:

- A. the spouse, unless an action for divorce is pending, AND the adult children of the patient who are not the children of the spouse
- B. an adult child
- C. a parent
- D. an adult brother or sister
- E. an adult grandchild
- F. an adult who has knowledge of the patient's preferences and values, including, but not limited to, religious and moral beliefs, to assess how the patient would make health care decisions

If more than one person is in a class, then decisions are by majority vote.

*[NOTE: No member of the health care team may be a Health Care Representative or a Health Care Agent unless related by blood, marriage, or adoption.]*

## Case #1

**Ms. Thomas** is a 47-year old patient who has been admitted after a stroke and who now requires mechanical ventilation. Tests show that she has suffered significant brain damage, but the care team believes that treatment may allow her to come to breathe on her own and, over time, help her regain some ability to speak, feed herself, and perhaps walk. The patient has been assessed to be incompetent to make health care decisions, but she has an Advance Directive that names **her sister** as her Health Care Agent through a Health Care Power of Attorney. This sister states that the patient "would not want to live this way" and tells the care team that life-sustaining treatment should be withdrawn. The patient has an **adult daughter** who objects and insists on a course of curative therapy.

Who does the health care provider look to for the treatment decision?

- the patient's adult daughter
- the patient's sister

## Case #1

### Answer

For the treatment decision, the health care provider should look to:

...the patient's sister

*It is the sister who has the decision-making authority because the sister has been named as the Health Care Agent through a written health Care Power of Attorney in the patient's Advance Directive.*

*Decision-making authority rests with the legally authorized representative --here, the patient-designated Health Care Agent.*

## Case #2

**Mr. Anderson** is a 55-year-old patient with end-stage kidney disease and who does not have an Advance Directive. He has been admitted to the hospital after a heart attack and has been assessed to be incompetent to make health care decisions. The care team has since worked closely with **his wife** of the last 25 years, and she states that her husband would not want life-sustaining treatment at this point, and her statement is affirmed by **their two adult children**. However, the patient also has a **son by a previous relationship** who has just arrived from out of state. While the son admits that he has had little contact with his father in recent years, he says that "Dad would want to keep fighting" and insists on an aggressive course of treatment.

Who does the health care provider look to for the treatment decision?

- the patient's wife
- the patient's wife AND their two adult children
- the patient's wife AND son by a previous relationship

## Case #2

### Answer

For the treatment decision, the health care provider should look to:

...the patient's wife AND son by a previous relationship

*Without an Advance Directive, decision-making authority falls to the highest CLASS of Health Care Representatives\* --in this case, the wife SHARES decision-making authority with the son by a previous relationship.*

- \*A. the spouse, unless an action for divorce is pending, AND the adult children of the patient who are not the children of the spouse**
- B. an adult child
- C. a parent
- D. an adult brother or sister
- E. an adult grandchild
- F. an adult who has knowledge of the patient's preferences and values, including, but not limited to, religious and moral beliefs, to assess how the patient would make health care decisions



# The Issue of Patient Competency / Incompetency

A patient is determined to be **incompetent** if, despite being provided appropriate medical information, communication supports, and technical assistance, is documented by a health care provider to be:

- 1) unable to understand the potential material benefits, risks and alternatives involved in a specific proposed health care decision;
- 2) unable to make that health care decision on his/her own behalf; or
- 3) unable to communicate that health care decision to any other person.

An individual may be found to be incompetent to make some health care decisions, but competent to make others.

--from Pennsylvania Act 169 (2006)

## Key Questions in Determining a Patient's Competency / Incompetency

- 1) **UNDERSTANDING**: Is the patient able to understand information about his/her condition and the particular decision to be made, including the treatment options (including no treatment at all) and their risks, and their potential burdens and benefits?
- 2) **JUDGMENT**: Is the patient capable of judging how this information relates to his/her values and goals?
- 3) **COMMUNICATION**: Is the patient able to communicate his/her decisions in a consistent and meaningful manner?

--from Appendix 2 of UPHS Policy on Withholding and Withdrawing Life-Sustaining Therapy (2014)

**What rights should be afforded  
to *in*competent patients to affect  
healthcare decision-making?**

# Rights of *Incompetent Patients* in Pennsylvania

(Act 169)

Even if a patient is incompetent to make health care decisions, he/she still has certain rights in Pennsylvania to affect the process of medical decision-making.

Upon the determination that a patient is incompetent to make health care decisions, the physician should seek to inform the patient, if possible, of that assessment. Likewise, when a treatment decision has been made by a legally authorized representative, the physician should seek to inform the patient, if possible, of the decision and who has made it.

An incompetent patient may **COUNTERMAND** any specific decision that would withhold or withdraw life-sustaining therapy.

An incompetent patient may at any time and in any manner **REVOKE** a Living Will.

## Patients' "Wisdom" in Decision-Making and the Gap in Decision-Making Laws

Patient *not*  
competent  
to make a  
decision

Patient *is*  
competent but  
vulnerable to  
suggestion and  
pressures

Patient *is*  
competent  
to make a  
decision

What is the responsibility of health care providers  
to "protect" patients from "bad" decisions?

## Chaplains' Responses to Requests to Assist Patients with Advance Directives

**First**, *continue to be a chaplain*. Continue to follow the patient's lead, and be attentive to spiritual and emotional issues.

**Second**, offer to help the patient *read through* the Advance Directive form.

**Third**, help patients identify *their own questions*, and connect them with further resources.

**Fourth**, encourage patients to use an Advance Directive as a catalyst for *conversation* with key people about values and goals.

## **In Addition to Advance Directives...**

*Physician Orders for Life-Sustaining Treatment (POLST)*

*Out-of-Hospital Do-Not-Resuscitate Orders*

## Supporting Surrogate Decision-Makers

Insights from: Braun, U. K., et al., “Voices of African American, Caucasian, and Hispanic Surrogates on the Burdens of End-of-Life Decision Making,” *Journal of General Internal Medicine* 23, no. 3 (Mar 2008): 267-274.



Themes from Braun, et al., “Voices...”

## **BURDEN OF EOL DECISION-MAKING**

### **Personal Context: Psychosocial & Physical**

- Loss of a loved one
- Taking a loved one's life in one's hand
- Guilt of feeling one never does enough
- Depression
- Role reversal/role change
- Financial
- Caregiving
- Self-neglect of own health from stress of caregiving

Themes from Braun, et al., “Voices...”

## **BURDEN OF EOL DECISION-MAKING**

### **Family Context**

- Being the one in a position of trust who has to make the decisions, sometimes alone without other family members' participation and/or support
- Stress/struggle, especially if family is discordant
- Potential blame by family for (treatment) decisions, and for other decisions (like when to call/not to call family to hospital)
- Feeling the need to be strong for patient, even though [decision-makers] don't feel strong

Themes from Braun, et al., “Voices...”

## **BURDEN OF EOL DECISION-MAKING**

### **Clinical Context**

- Deciding under conditions of uncertainty
  - about outcomes of treatments (e.g., Is continuing continuing treatment sufficiently beneficial?)
  - about patient’s preferences
- Having to decide quickly and/or under pressure
- Feeling a lack of control (e.g., don’t know how to stop intensive care, ventilator, or feeding tubes once started)

Themes from Braun, et al., “Voices...”

## **FACTORS THAT INCREASE BURDEN**

### **Problems of Communication with Doctors**

- Time
- Trust
- Miscommunication:
  - reliance on jargon
  - language barriers

Themes from Braun, et al., “Voices...”

## **FACTORS THAT INCREASE BURDEN**

### **Organizational Factors**

- Discontinuity of care (clinical rotations)
- Restrictive visiting hours
- Desire to assure comfort and quality of life
- Weighing aggressive therapy against chances for functional independence / cognitive capacity
- Uncertainty about the chances of achieving an acceptable functional outcome for an acceptable financial cost

Themes from Braun, et al., “Voices...”

## FACTORS THAT DECREASE BURDEN

- Decision “making” vs. “reporting” a decision
- Trial of intervention
- Social support:
  - family
  - friends
  - congregational members
- Faith / religion / spirituality

## The Question of Prognosis for Surrogate Decision-Makers

A 2010 study at the University of California's San Francisco Medical Center found that *less than half* of decision-makers were affected by the physician's assessment of prognosis. Instead, they relied on their *own* sense of

- the patient as a "fighter"
- the patient's appearance of strength or discomfort
- knowledge of the patient's resilience during past illnesses
- the efficacy of their own presence and support
- belief in divine intervention

--Boyd, E. A., et al., "It's not just what the doctor tells me': factors that influence surrogate decision-makers' perceptions of prognosis," *Critical Care Medicine* 38, no. 5 (May 2010): 1270-1275.

# **Ways to Help Surrogate Decision-Makers**



## Ways to Help Surrogate Decision-Makers

### CLARIFY THE ROLE

Clarify what it means to speak as the person believes the patient would speak (--to bring the patient's voice to the table).

Acknowledge that there may be differences between the surrogate's wishes/values and the patient's wishes/values for treatment.

Avoid or de-emphasize the word *decision*.

## Ways to Help Surrogate Decision-Makers

**AFFIRM THAT NOTHING WILL  
BE DONE TO CAUSE DEATH**  
(as protected under Pennsylvania law)

If necessary, clarify the principle of *double-effect*,  
in the context of the use of pain medication.

If necessary, distinguish the patient's right to withhold  
or withdraw life-sustaining therapy from suicide.

## Ways to Help Surrogate Decision-Makers

### COMPANION THE SURROGATE

Be especially attentive, pastorally.

Offer to be a sounding board as the surrogate thinks through his/her role.

Acknowledge the difficulties of being a surrogate, including the implications for family dynamics.

## Ways to Help Surrogate Decision-Makers

### **SUPPORT THE SURROGATE'S ACTIONS**

Facilitate communication between the surrogate and the health care team.

If life-support is being withdrawn, offer to be present and “represent” the family during the withdrawal (to relieve pressure on the surrogate to be present).

Be attentive to the possible need for careful pastoral leadership at the bedside.

**The Role of a Person's *Own* “Substituted Judgment” in Making an Advance Directive**