Clinical Pastoral Education Didactic – January 4, 2016
Hospital of the University of Pennsylvania / Penn Presbyterian Medical Center

Do Not Resuscitate Orders, Advance Healthcare Directives, Healthcare Decision Making, and the Role of the Chaplain

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Cardiopulmonary Resuscitation (CPR)

- became standardized practice in the late 60s-70s for patients with no pulse and no breathing (--"patients who are *coding*")

- involves:
  - chest compressions, primarily to circulate the blood
  - intubation and mechanical ventilation to provide oxygen
  - injections of medications to affect blood pressure, heart rhythm, and blood flow
  - shocks to reset the rhythm of the heart's electrical activity

- CPR is the default treatment for anyone in cardiopulmonary arrest, unless the patient exercises the *right to refuse* this treatment

Do Not Resuscitate (DNR)

- **it means do not perform the specific procedure of CPR**
- **a medical order, written only by a physician**

However, in recent years, two other terms have been proposed to be more positive-sounding:

Do Not Attempt Resuscitation (DNAR)

Allow Natural Death (AND)

For “DNR patients,” there are 3 basic categories for the care plan:
(designated at Penn Medicine as)

a) Do everything feasible to *prevent* an arrest
(DNR-A)

b) Place limits on interventions that would prevent an arrest
(DNR-B)

c) Withdraw life-sustaining treatment, do not prevent an arrest, and focus on patient *comfort*
(DNR-C)

If a DNR order is written only by a physician, but CPR is standard practice for anyone in cardiopulmonary arrest, how is a DNR status set?

An Advance Directive

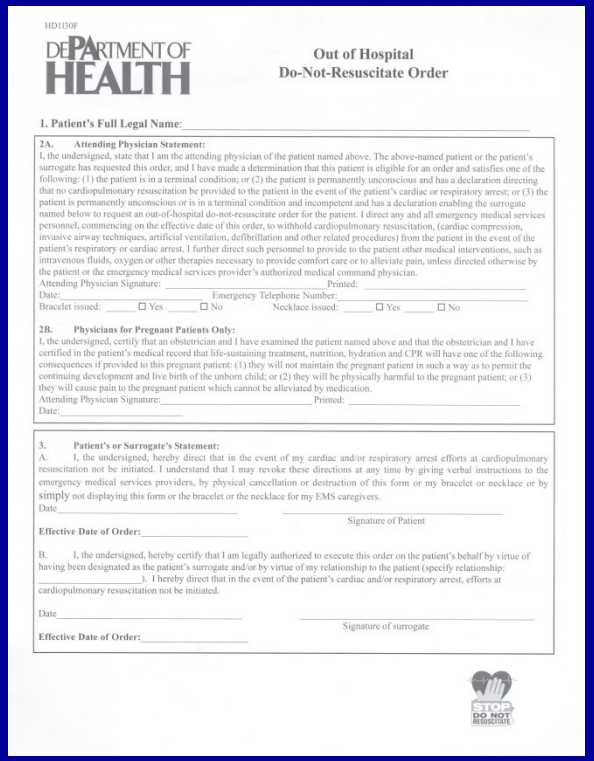
- Set ahead-of-time by a declaration of the patient ("living will")
- Set by someone authorized by the patient to make medical decisions if ever the patient is unable to participate in medical decision-making
- Set by some special process under individual state law

Advance Directives address wishes about CPR, but they've also developed to address *other* kinds of life-sustaining treatments and circumstances

and

Along side of typical Advance Directives, two other forms of documentation have grown up: **Out-of-Hospital DNR Orders** and **POLST** forms

Out-of-Hospital DNR



HD1130F

DEPARTMENT OF HEALTH

Out of Hospital
Do-Not-Resuscitate Order

1. Patient's Full Legal Name:_____

2A. Attending Physician Statement:
I, the undersigned, state that I am the attending physician of the patient named above. The above-named patient or the patient's surrogate has requested this order, and I have made a determination that this patient is eligible for an order and satisfies one of the following: (1) the patient is in a terminal condition; or (2) the patient is permanently unconscious and has a declaration directing that no cardiopulmonary resuscitation be provided to the patient in the event of the patient's cardiac or respiratory arrest; or (3) the patient is permanently unconscious or is in a terminal condition and incompetent and has a declaration enabling the surrogate named below to request an out-of-hospital do-not-resuscitate order for the patient. I direct any and all emergency medical services personnel, commencing on the effective date of this order, to withhold cardiopulmonary resuscitation, (cardiac compression, invasive airway techniques, artificial ventilation, defibrillation and other related procedures) from the patient in the event of the patient's respiratory or cardiac arrest. I further direct such personnel to provide to the patient other medical interventions, such as intravenous fluids, oxygen or other therapies necessary to provide comfort care or to alleviate pain, unless directed otherwise by the patient or the emergency medical services provider's authorized medical command physician.
Attending Physician Signature: _____ Printed: _____
Date:_____ Emergency Telephone Number:_____
Bracelet issued: _____ ☐ Yes _____ ☐ No Necklace issued: _____ ☐ Yes _____ ☐ No

2B. Physicians for Pregnant Patients Only:
I, the undersigned, certify that an obstetrician and I have examined the patient named above and that the obstetrician and I have certified in the patient's medical record that life-sustaining treatment, nutrition, hydration and CPR will have one of the following consequences if provided to this pregnant patient: (1) they will not maintain the pregnant patient in such a way as to permit the continuing development and live birth of the unborn child; or (2) they will be physically harmful to the pregnant patient; or (3) they will cause pain to the pregnant patient which cannot be alleviated by medication.
Attending Physician Signature:_____ Printed: _____
Date:_____

3. Patient's or Surrogate's Statement:
A. I, the undersigned, hereby direct that in the event of my cardiac and/or respiratory arrest efforts at cardiopulmonary resuscitation not be initiated. I understand that I may revoke these directions at any time by giving verbal instructions to the emergency medical services providers, by physical cancellation or destruction of this form or my bracelet or necklace or by simply not displaying this form or the bracelet or the necklace for my EMS caregivers.
Date_____ _____
Signature of Patient
Effective Date of Order:_____

B. I, the undersigned, hereby certify that I am legally authorized to execute this order on the patient's behalf by virtue of having been designated as the patient's surrogate and/or by virtue of my relationship to the patient (specify relationship: _____). I hereby direct that in the event of the patient's cardiac and/or respiratory arrest, efforts at cardiopulmonary resuscitation not be initiated.
Date_____ _____
Signature of surrogate
Effective Date of Order:_____

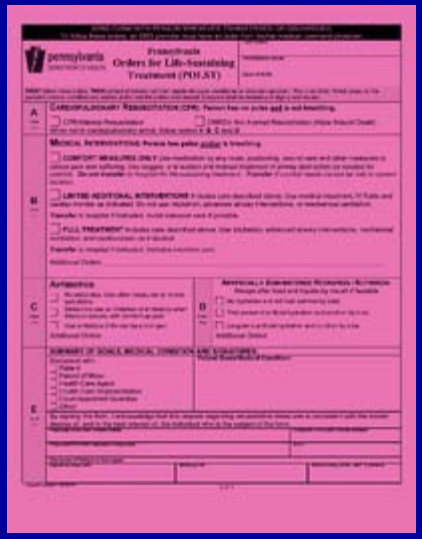
STOP DO NOT RESUSCITATE

Out-of-Hospital DNR

- medical order from the patient's attending physician
- aimed at EMS/first responders
- specific legislation exists in most states (including PA)
- focuses only on CPR

POLST

Pennsylvania Orders for Life-Sustaining Treatment



Known generally across the US as "*Physician* Orders for Life-Sustaining Treatment," but in some states by similar names like "Medical Orders for Life-Sustaining Treatment" (MOLST)

POLST

- grew out of national advocacy for continuity of care in transfers from hospital to hospital and from long-term-care to hospital --conceived as a *paper document that follows the patient*
- short and easily recognizable form, providing clear and standardized language about a patient's wishes
- the existence of a POLST means that the patient or his/her Legally Authorized Representative has worked with a healthcare provider to formalize into a medical order the patient's treatment wishes
- controversial, leading to uneven adoption across the US (e.g., legally ambiguous in PA; once allowed but now not in DE)
- not binding for EMS/first responders in PA

Patients' rights to refuse CPR and other life-sustaining treatments rests upon complex legal developments over time and across states in the US

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

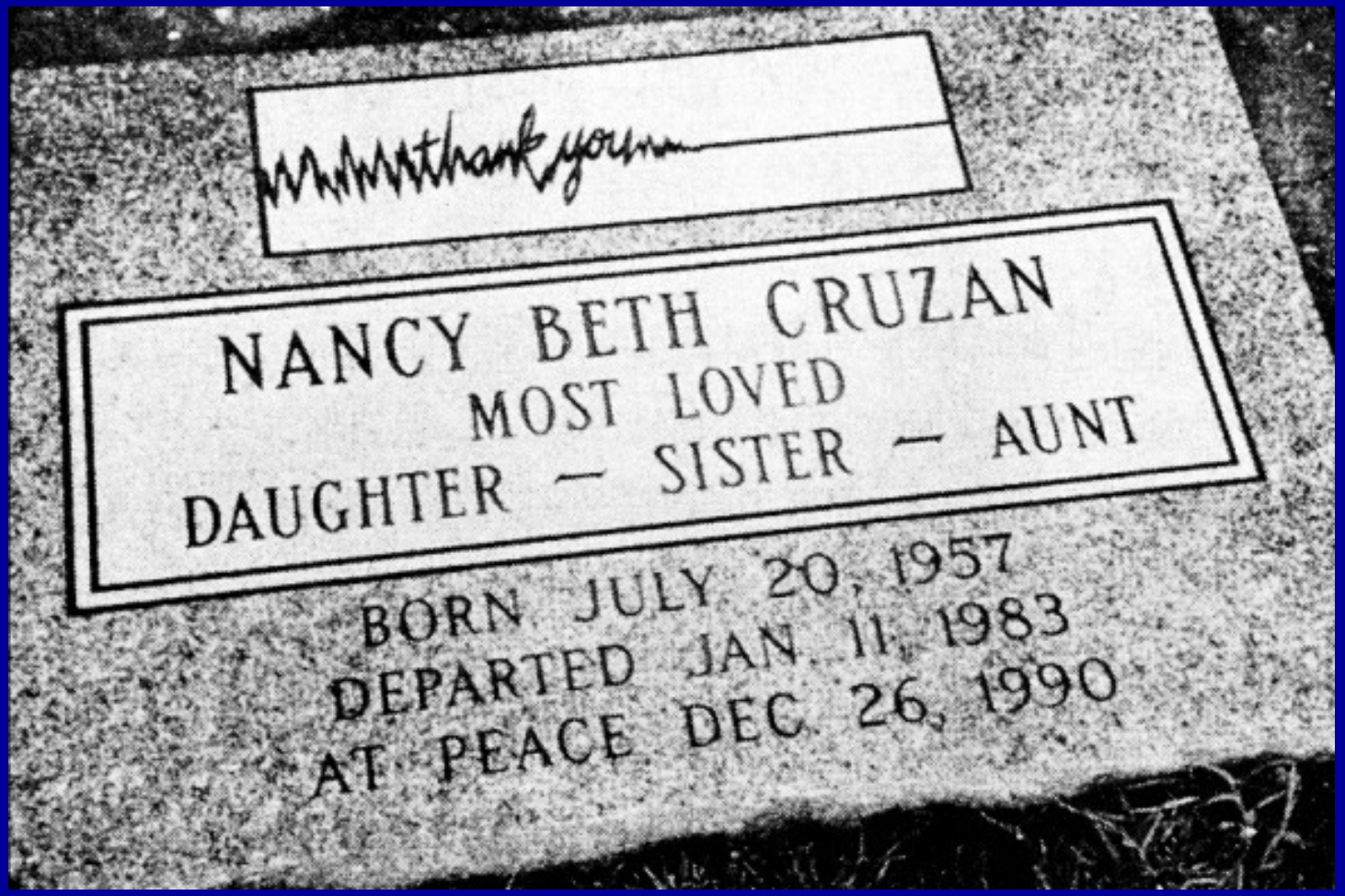
4) Right-to-die cases have proceeded from the 1970s and are ongoing

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.)

The Cruzan Case



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

- Pregnancy
- Nutrition and hydration
- Mental health circumstances
- Minors
- When a Living Will becomes active (medical assessment)
- Portable medical orders for end-of-life treatment
- Rights of incompetent patients to influence decisions

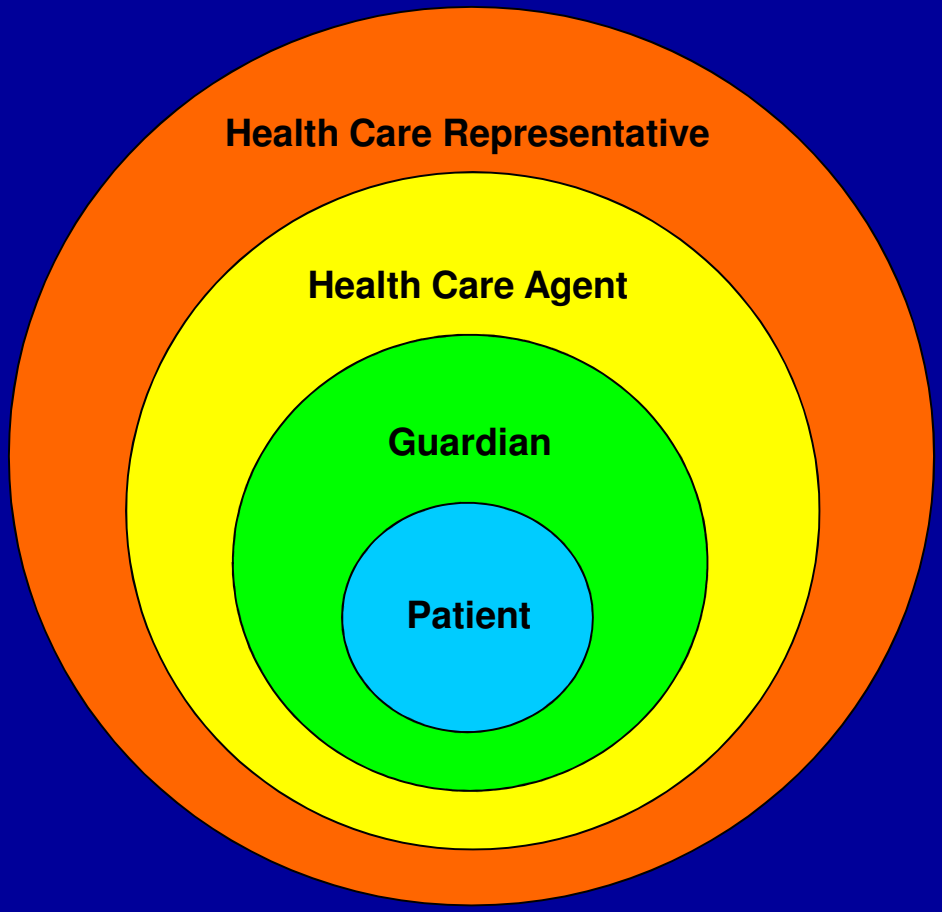
Penn Medicine Policy on the Right to Make One's Own Healthcare Decisions

…[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)

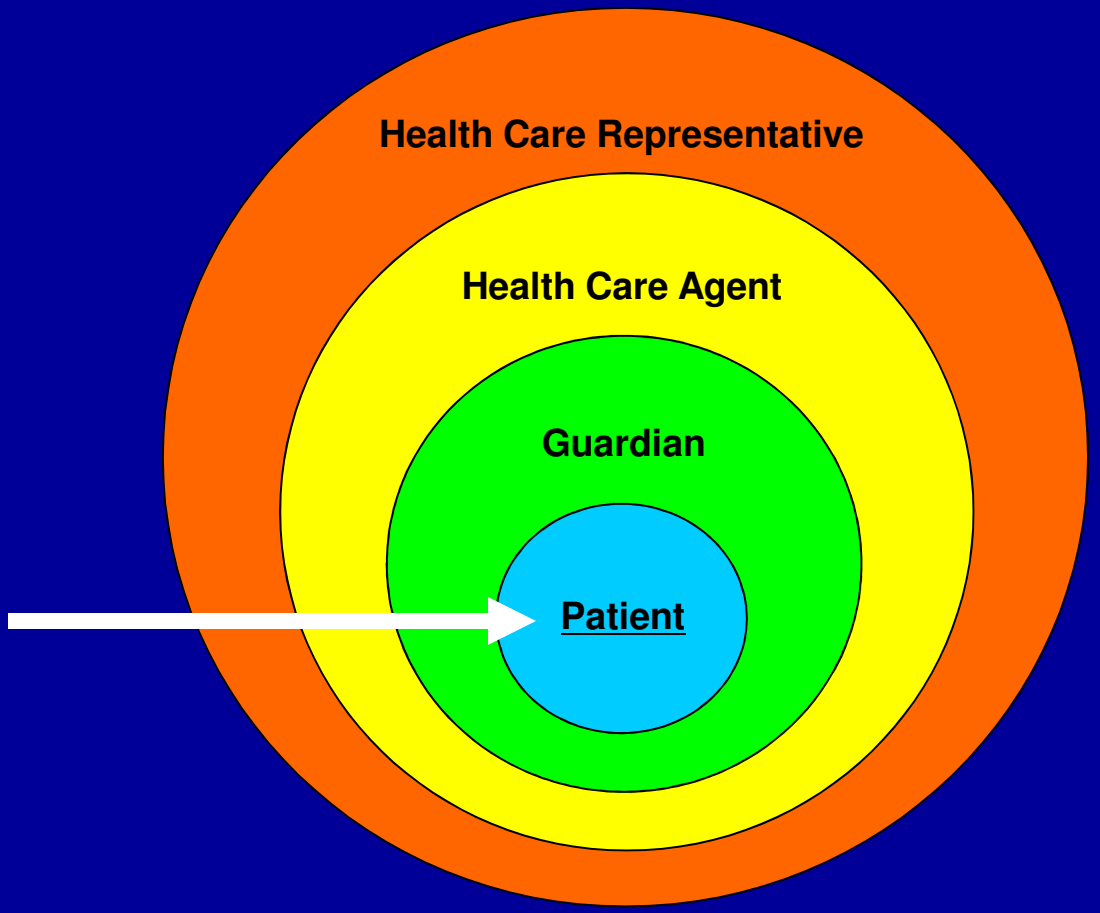
Layers of Protection for Patient Autonomy

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

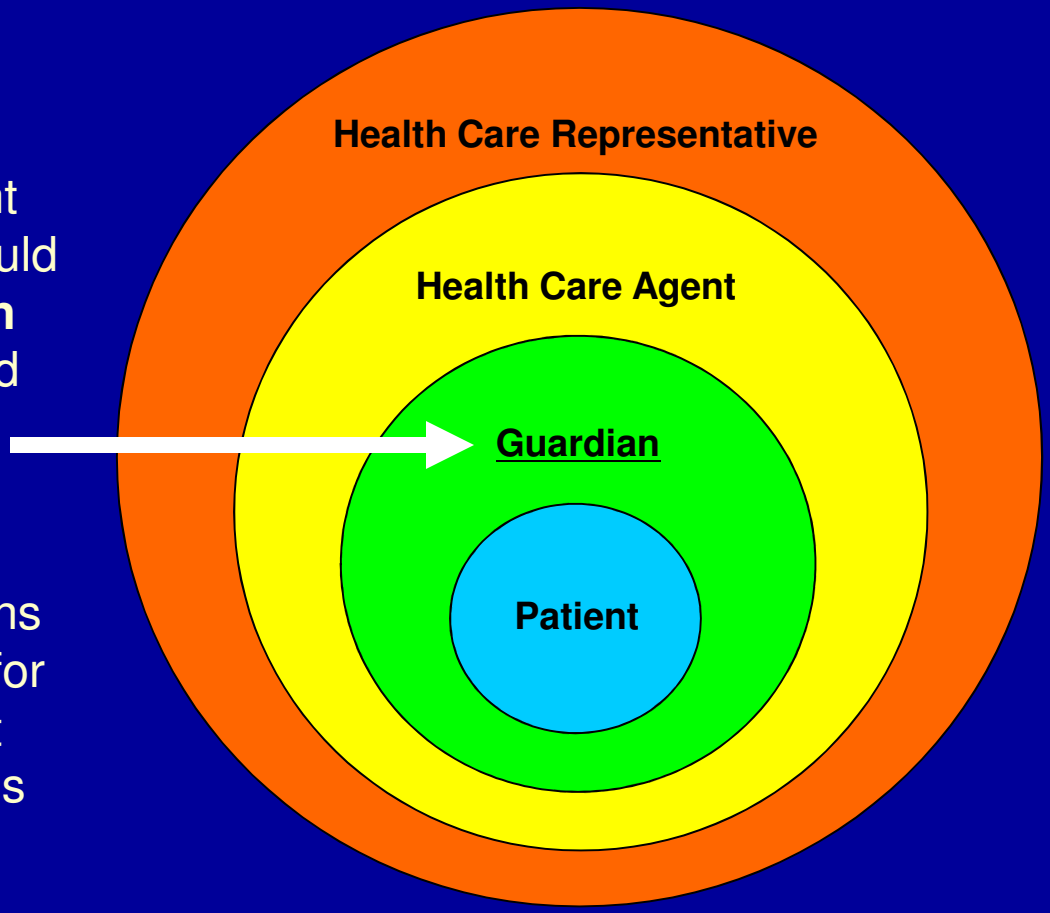
As long as a patient is **competent** to make health care decisions, the care team works directly with him or her on all matters.



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.

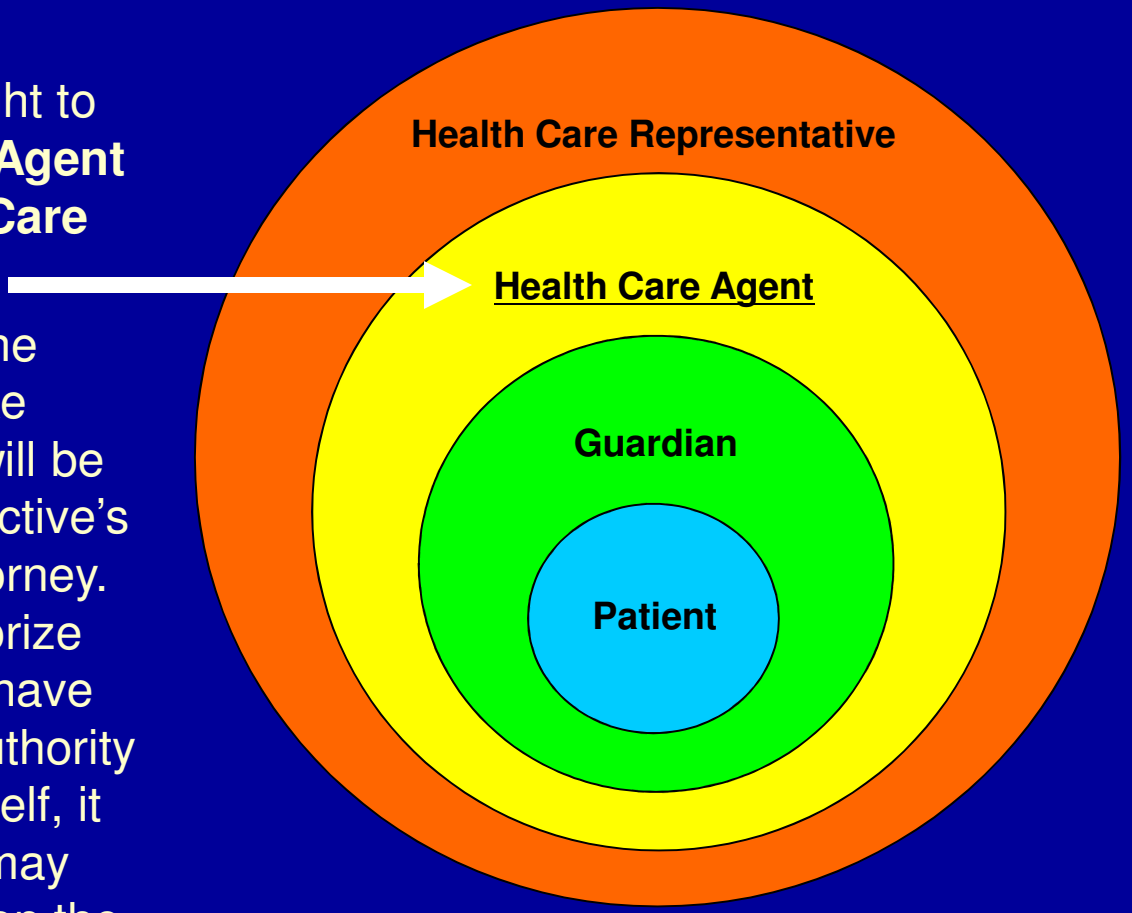
Health care providers should confirm that a court order applies to health care decisions (and is not just, for example, for financial decisions) and that it contains no limits or conditions placed upon the guardian.



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**.

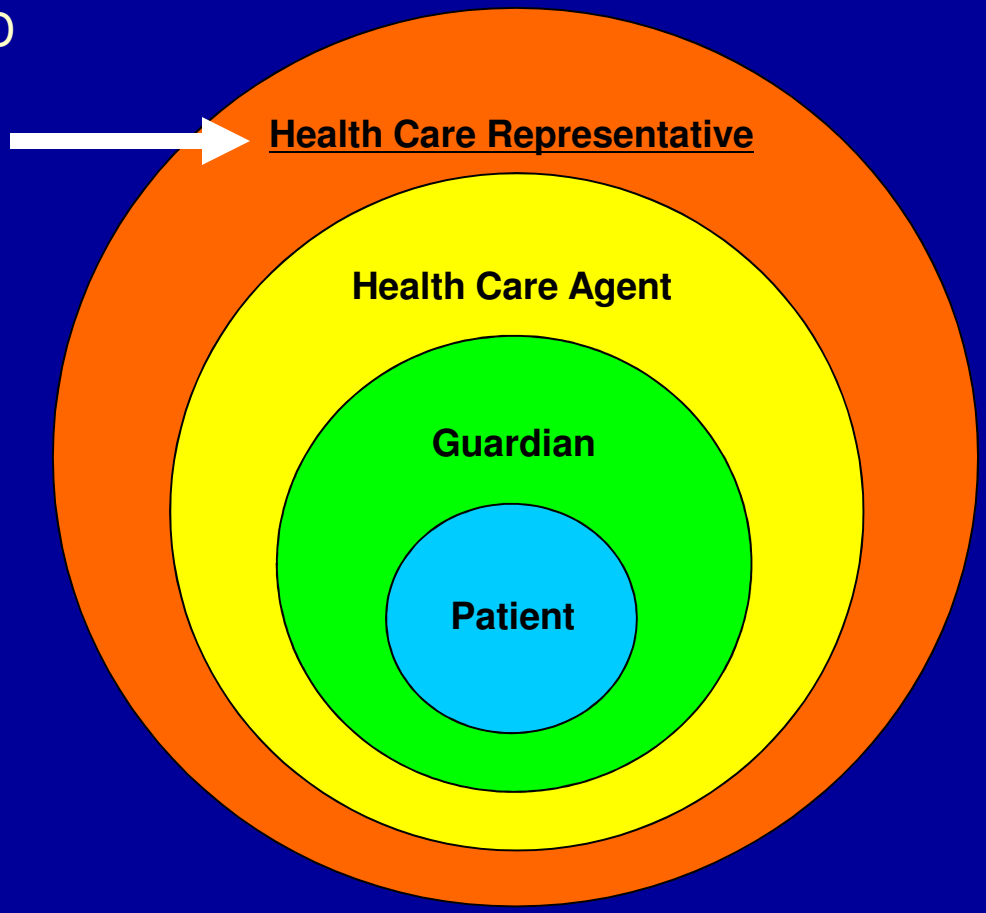
The specific authority of the Health Care Agent to make decisions for the patient will be stated in an Advance Directive's Health Care Power of Attorney. While a patient may authorize the Health Care Agent to have all the decision-making authority of the patient himself/herself, it is possible that a 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 <u>one exception</u>: *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.

To whom does the health care provider look 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.

To whom does the health care provider look 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

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

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

Rights of *In*competent 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.

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* an Advance Directive form in an empowering way.

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.

Ways that chaplains can help the *CARE TEAM* work with the patient's decision-making process:

- Be attentive to how the patient is feeling *pressured to decide*
- Differentiate between the patient's unanswered questions and potentially unanswer*able* questions (e.g., issues of communication vs. issues of prognosis)
- Be sensitive to how the patient may not be able to make a declaration of goals from which a care plan can be *deduced*, but may be able to identify specific wishes from which a care plan can be *built*
- Listen for how the concept of "futility" is being used by staff (vs. a weighing of benefits and burdens)

Ways to Help Surrogate Decision-Makers

The Predicament of Surrogate Decision-Makers

Surrogate/proxy “decision-makers” can find the responsibility very burdensome for many reasons, including:

- the gravity of “holding someone’s life in your hands”
- implications of decisions for family (e.g., emotional, financial)
- fear of blame by family members (now and in the future)
- feelings of guilt (especially of not doing enough)
- feelings of grief, sadness, anticipatory loss
- feeling alone in the process
- working from a position of uncertainty, often under pressure
- dealing with doctors (e.g., medical language, authority issues)
- navigating institutional rules and dynamics
- moral stress (especially pitting *hope* against *suffering*), potentially caused or exacerbated by religious beliefs

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

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 (i.e., pastoral authority should support rather than compromise patient autonomy).

A postscript about CPR:

Whereas the inability to reestablish a heart rhythm through CPR once meant that no further intervention was possible, advances in technology (like ECMO*) are opening up new problems for decision-making, in terms of

1) when to “draw a line” for life-sustaining treatment

2) consideration of potential side effects of extreme treatments for patients who survive

* extracorporeal membrane oxygenation

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