

Santa Clara University

End of Life Decision Making for Publicly Conserved Persons

A Workshop for Deputy Public Guardians
in Santa Clara County

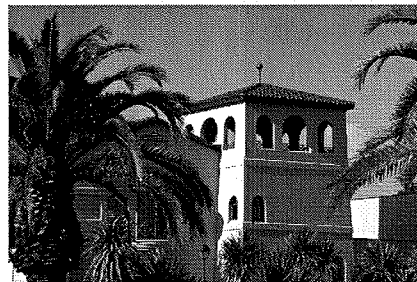
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Markkula Center for Applied Ethics

- Center for teaching, research on-campus & in community
- Established in 1986
- Healthcare/biotech; Government; Character education; Business; Global ethics project
- Leading university-based applied ethics center



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Sponsored by:

The Honzel Family Foundation

Faculty:

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Purpose:

- **To gather information and insight re medical decision making, especially at the end of life, so that:**
 - DPGs can apply ethical standards to medical decision making
 - DPGs can make informed, ethically justified decisions that can withstand rigorous scrutiny.

3 Sessions

- 1. Is it time to die?**
- 2. Decisions at the Ending of Life**
- 3. Client Values and End of Life Decision Making**

Goals for Day one:

- **To understand how the healthcare world works**
- **To understand the time, place, and process of dying**
- **To identify the ethical issues raised in end of life decision making**
- **To discuss a framework for addressing these issues**
- **To describe hospice and palliative care**

Death and Dying

- **End of life care includes:**
 - Preparing for an anticipated death
 - Managing the final stages of a fatal condition
- **Surrogates are being asked to make increasingly difficult treatment decisions about increasingly complicated medical options.**

Death and Dying

- **Death is a natural transition, not a medical or personal failure.**
- **Death has changed from a quick infectious process to a prolonged dying from chronic disease.**
- **Prolonged dying may be worse than death itself.**

Ethics . . .

- raises questions about how we should act and how we should live.
- asks us to justify who we are and how we behave.
- rarely blue or red; usually shades of purple.
- requires us to ask questions of ourselves and others . . .

End of Life Ethics . . .

- ...asks questions about how we ought to act and how we should live.
 - “What standards determine if this action is right or wrong?”
 - “What character traits—compassion, fairness—are necessary to live a truly human life?”
- ...aids us in knowing and doing what is right.

Answering these questions . . .

demands paying attention to values, both professional and personal, both our own and others' (especially the dying person's)

Dying persons must . . .

- **be treated with respect and dignity even when they can no longer participate in decision making.**
 - Treating patients with dignity and respect may involve decisions to limit or stop aggressive treatment; and, . . .

Death is a process . . .

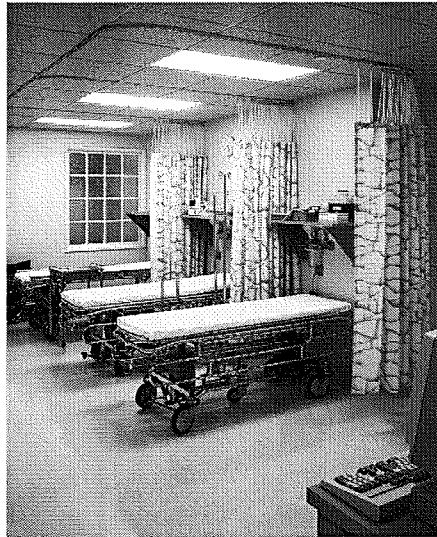
- and different moral obligations exist at different times.
- Proposed ethical standard:
 - Dying like living is a process and attending to the process of dying is a good in itself.

Goals for Day two:

To understand:

- The California health care law and how it impacts health care decisions by conservators
- Some of the medical aspects of :
 - CPR
 - Artificial Nutrition & Hydration
 - Shortness of breath
 - Suffering
- Brain failure, PVS, Brain Death

How & where do people die?



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Protracted Life-Threatening Illness

- > 90%
 - predictable steady decline with a relatively short “terminal” phase
 - cancer
 - slow decline punctuated by periodic crises
 - CHF, emphysema, Alzheimer’s type dementia

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The majority of PG cases involve....

- **Progressive Dementia [“Brain Failure”]**
 - Which is considered a terminal illness.
- **Plus a need for a decision regarding appropriate treatment**

Death and Dying

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- **Death has changed from a quick infectious process to a prolonged dying from chronic disease.**
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Goals for Day three:

- To describe the AHCD.
- To distinguish between ethics and values.
- To define and identify personal and professional values.
- To identify values that govern the conservator-conservatee relationship.
- To understand informed consent.
- To apply values to difficult medical decisions.

What are values?

- Values are inner dispositions or beliefs which actually guide our behavior.
 - central beliefs
 - determine how we will act
- Values and ethics are not the same thing. Ethics is concerned with how we should behave; values with how we do behave.

When values conflict . . .

- we have an ethical dilemma.
- Value conflicts:
 - safety with independence
 - personal with medical
 - religious with medical
 - legal with medical
 - personal with legal
 - conservator with conservatee, family, . . .
 - medical team w/ patient w/ hospital w/ . . .

Ethically justifiable decisions . . .

- are made in light of all that can be known about the conservatee's values, preferences, and, definition of well being.
- protect client autonomy to the maximum extent possible.
- demonstrate respect through shared decision making whenever and to whatever extent possible.
- are timely.

When making decisions:

- Consider the values & wishes of the conservatee / ward
- Consider how your own values inform the decision
- Examine the goals of treatments
- Do not just focus on the interventions

Can wards/conservatees tell you . . .

- If they want prayer
- If they enjoy travel
- With whom they spend their time
- If controlling their bladder/bowels is important
- If they don't want to be a burden

- HELP: *Your Way*, 2004. www.help4srs.org

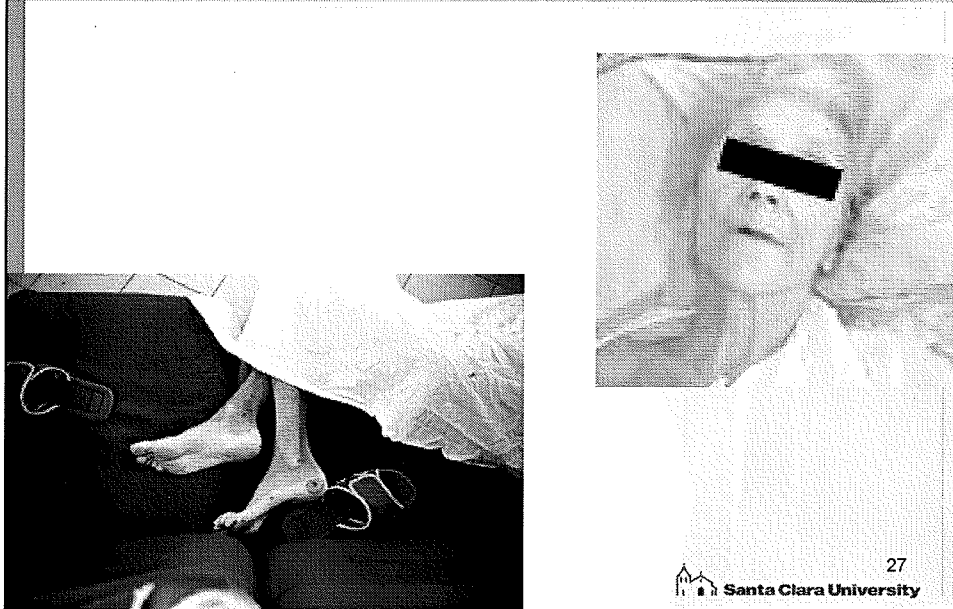
If Yes, then, you can . . .

- **discern some of their values:**
 - **Belonging**
 - **Cleanliness**
 - **Family**
 - **Friendship**
 - **Independence**
 - **Inner harmony**
 - **Security**
 - **Spirituality**

- **Using values along with ethical principles ...**
- **Surrogates can make appropriate choices for the patient**

- **See the cases of Mrs. Doe & Mrs. Long for examples**

Mrs. Doe and Ms. Long



Our Public Guardian's comments:

- "Once we have ascertained values we have an obligation as surrogates to act ethically. This really gets us to where the "rubber hits the road."
- My sense is that once we have been informed and educated on the physical aspects of the dying process and the inevitability of death; we, as conservators, must search our hearts and apply ethical principles to end of life decisions.
- This is what I want to accomplish with these workshops."