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Learning Objectives:

- Explore Social Work Values that relate to quality end of life care, namely Importance of Human Relationships, Inherent Dignity and Worth of the Client, and Competence.
- Explore the NASW Ethical Standards that relate to cultural awareness, the right to self-determination, and protecting vulnerable clients.
- Ethical Dilemmas at end-of-life
- Diversity/Religious Considerations
- Discuss and review the different types of Advance Directives

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Talking About Death is Taboo……

Talking About Death is…

~~Weird~~
~~Taboo~~
~~Bad Luck~~
~~Morbid~~

a part of life.

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No One Can Escape Death……

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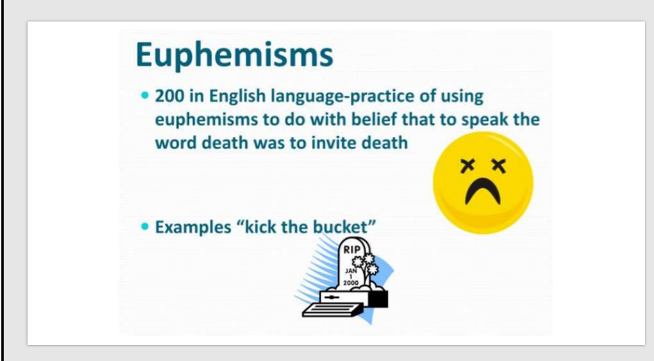

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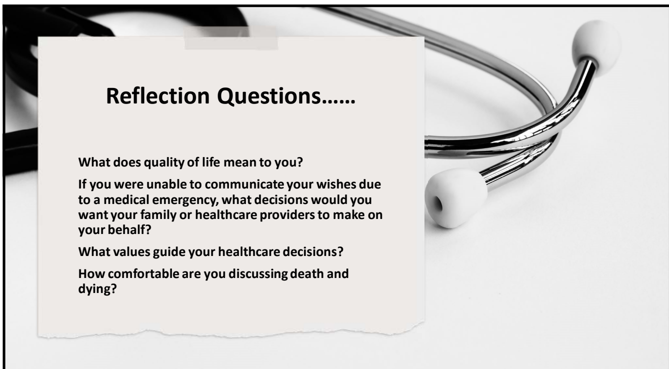

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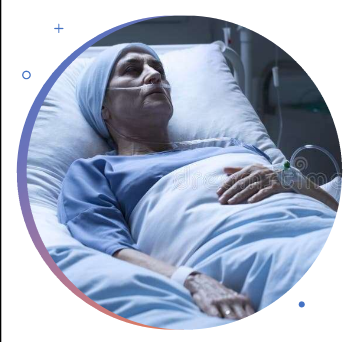

View on Death…..

- In the United States end of life tends to be medicalized. Death is often viewed as a failure, rather than as an expected stage of life results in people dying in institutions, cut off from their loved ones and comforts.

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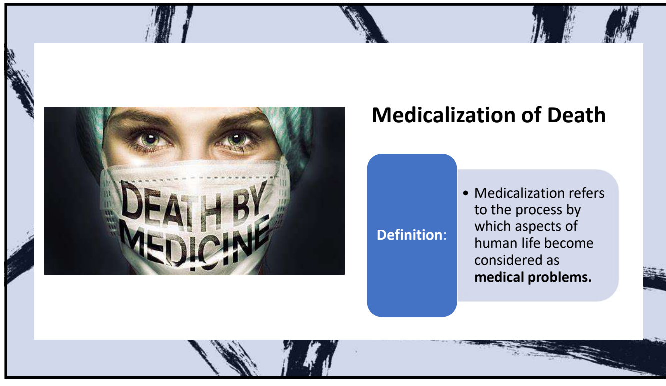

Medicalization of Death

Definition:

- Medicalization refers to the process by which aspects of human life become considered as **medical problems.**

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Why Does it Matter?

Excessive Interventions:

- Unnecessary interventions at the end of life.
- Increasing use of futile or inappropriate medical treatments near the end of life.
- Increased suffering and consumed resources that could be used elsewhere.

Human Connection:

- By providing our time, attention, and compassion during the dying process, we connect with individuals and their families.
- This is the core of human relationships.

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Impact……

Hospitalization:

- Death now occurs more frequently in hospitals rather than homes, distancing individuals from familiar surroundings and loved ones.

Reduced Family Involvement:

- Families and communities are less engaged in the dying process than they used to be.

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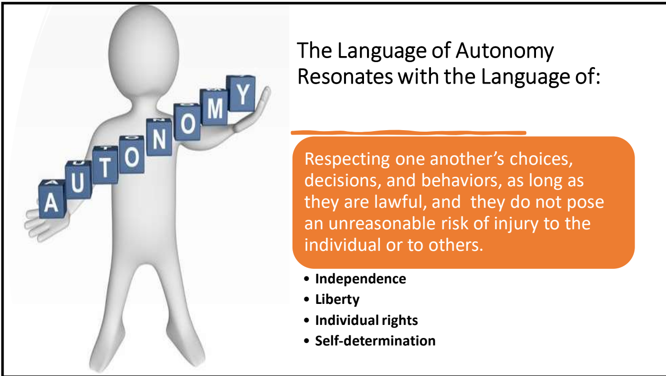

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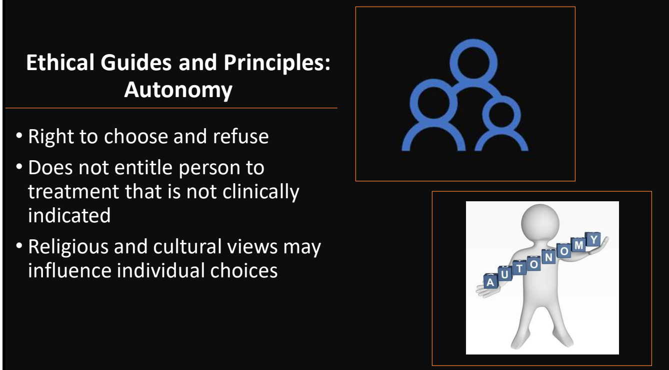

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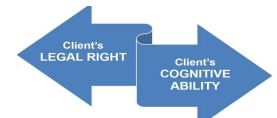
Why is Honoring Client/Patient Autonomy Difficult?

Client has a legal right to behave in a particular way, it may be difficult for the medical professional in their duties as a to honor this right if you believe the individual is acting foolishly or irrationally.

The client must have the cognitive ability to understand, reason about, and appreciate the nature and likely consequences of his/her behavior to exert their autonomy.



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Principal of Beneficence

Beneficence……

- **is to produce benefit, to do good, to always act in the best interests of the patient**
  – whatever is done or said must be for the patient's good
  – includes being honest with patients, which in nearly all circumstances will be of benefit to the patients
  – patients should not be subjected to unnecessary investigations

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Principal of Beneficence

– patients should not be subjected to unnecessary or futile therapies
– applies not only to physical good but also to psychological, social and existential well-being
– must be distinguished from paternalism ('doctor knows best')

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Ethical Guides and Principles: Nonmaleficence:

- Do no harm
- Not sharing treatment options which you disagree with, but which are beneficial to the patient.
- Take measures for treatment that results in harm in a terminally ill patient.
- It is only justifiable if the act is for a greater good than the intention of harming the patient on purpose.

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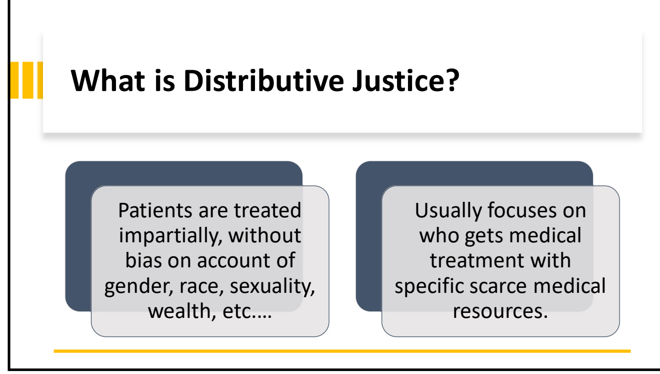

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Ethical Guides and Principles: Justice

Distributive justice

- Society uses various rules and principles (moral, legal, and ethical) to decide how to distribute in a just manner its benefits and burdens
  - process is called 'distributive justice'
- distributive justice becomes an important issue when a resource is limited and when there is competition for it

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Distributive Justice: Example Organ Donation

Equal Access:
- Everyone should be able to access it equally
- Length of Time
- Age of recipient

Reasons for Equal Access:
- Access to the waitlist for organ donation.
- Selling an organ is an autonomous decision, but a market that increased healthcare disparities violates distributive justice principal.

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Example:

– For example, one of the first instances to allocate a scarce medical resource was in the 1960s with the availability of dialysis for people in chronic kidney failure. Since the demand exceeded the supply because dialysis was expensive and not accessible on a large scale, it meant not all people who needed it could receive it. So the principle of JUSTICE was applied. AND who gets the treatment or not is the ethical question at hand.

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Questions to Consider

- Dying people should **always** be told the truth.
- End-of-life care is a human right.
- Everything possible should be done to keep people alive at all cost.

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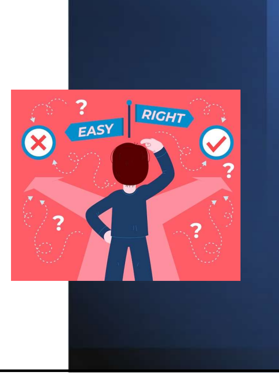
Identifying and Dealing with Ethical Challenges and Dilemmas

- An ethical dilemma is regarded as a state of uncertainty or perplexity; requiring a choice between two equally or unfavorable options
- What "if" questions is one way of identifying ethical dilemmas in advance.



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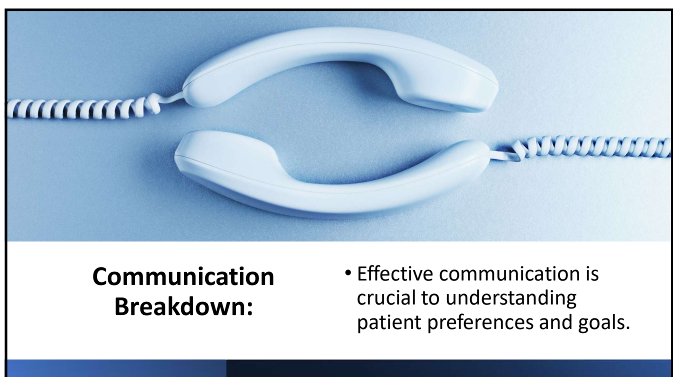

Communication Breakdown:

- Effective communication is crucial to understanding patient preferences and goals.

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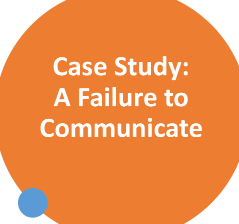

Case Study: A Failure to Communicate

- A cancer patient nearing the end of life. The patient's family members come from a different cultural background, and there are significant misunderstandings between them and the medical team. The patient's wishes and preferences are not adequately conveyed due to language barriers, differing cultural norms, and emotional distress.

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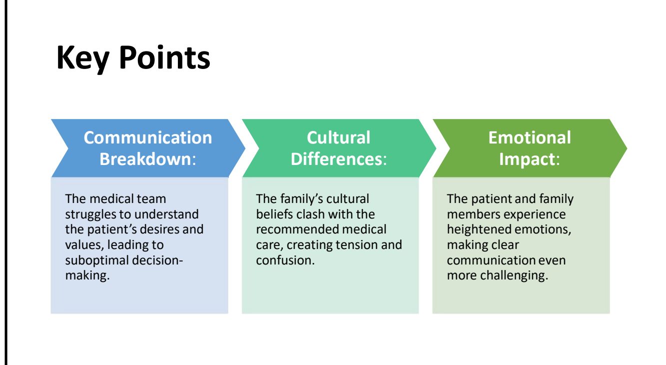

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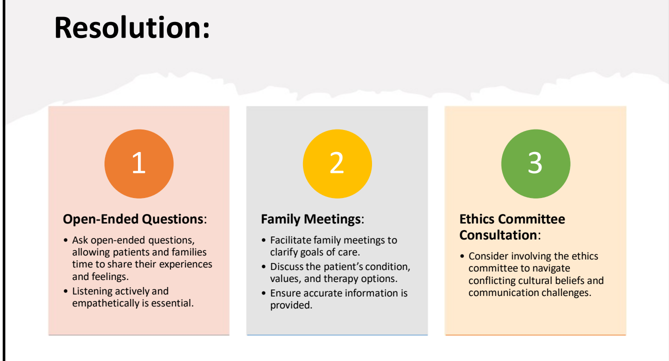

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Effective Communication: Key Strategies

Establishing Context	• Create a supportive and empathetic environment • Make sure patients and families feel heard and understood.
Attentive Listening	• Show empathy and validate feelings
Creating Safety	• Make sure patients won't feel judged for sharing their fears and anxieties
Goal Planning:	• What are their preferences regarding treatment options • Quality and comfort vs. Quantity
Honesty:	• Be transparent and avoid using vague language. • Be straightforward even if it is difficult to hear

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Respect for Autonomy: End-of-Life

- End-of-life care, patients may not want to continue their treatments.
- Families don't want it and elongate the care duration. They don't give a second thought about the advance directives of the patients.
- Direct attack on the patients' autonomy, which is ethically and morally wrong.

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Compromised Patient Autonomy

- Sometimes patient autonomy is compromised due to cognitive decline or family dynamics.
- Balancing patient wishes with medical recommendations can be ethically challenging.

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The Case of Mrs. Rodriguez

- Mrs. Rodriguez, an 80-year-old woman with advanced cancer, is nearing the end of her life. She has expressed her desire to remain at home, surrounded by her family, during her final days. However, her adult children are deeply concerned about her suffering and want to explore all available medical interventions to prolong her life. They fear that honoring their mother's autonomy by adhering strictly to her wishes might lead to unnecessary suffering.

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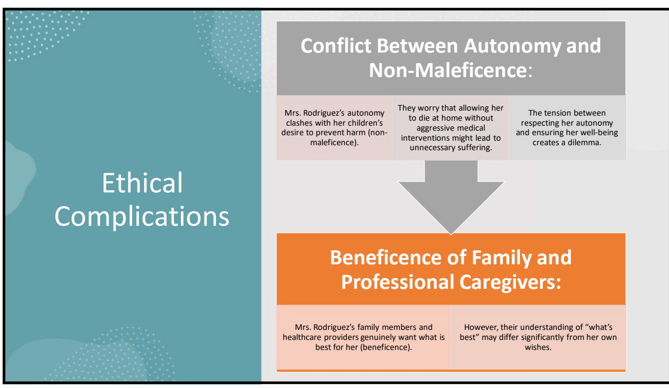

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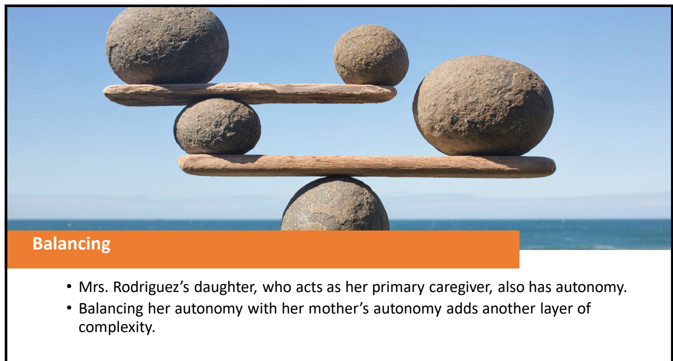

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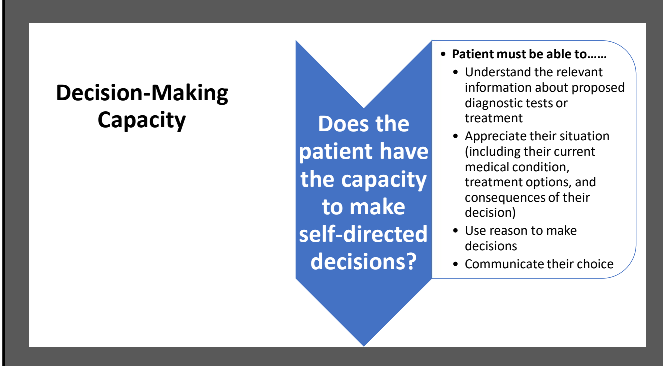

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Informed Consent

- Process of ensuring the patient has the opportunity to make a free and meaningful choice.
- Informed consent requires:
  - **Agency:** Capable of deciding
  - **Liberty:** Free from coercion/controlling influence
  - **Information:** Adequately informed

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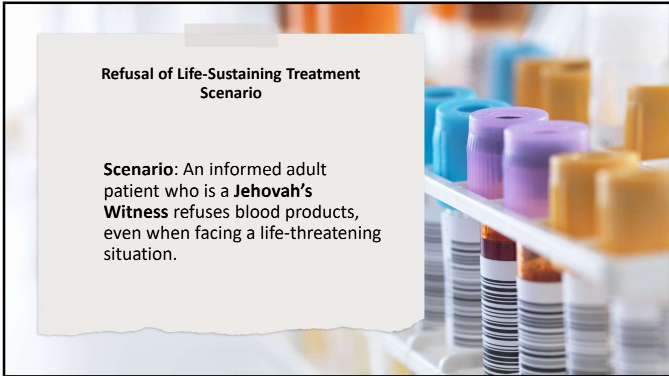

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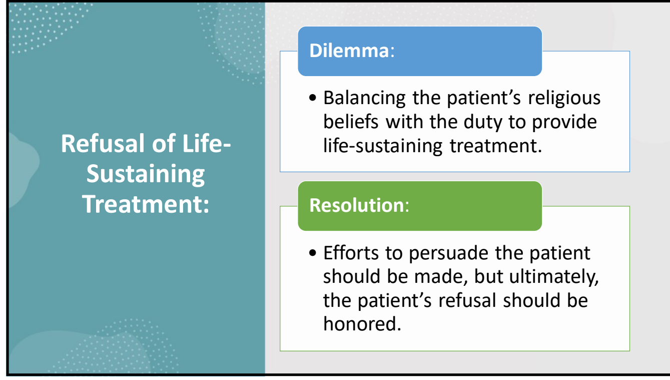

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Ineffective Symptom Management

- Ensuring effective symptom control while respecting patient autonomy can be difficult.
- Balancing pain relief with potential risks requires thoughtful decision-making.

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Non-Beneficial Care

- Deciding whether to continue or withdraw interventions when they no longer benefit the patient is ethically complex.
- Should consider quality of life and patient values.

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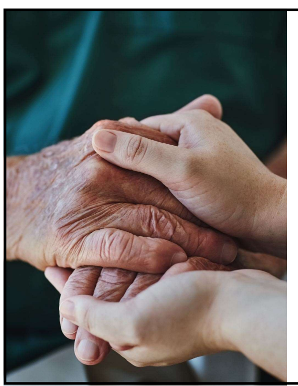

The Case of Non-Beneficial Care:

- 80-year-old male with advanced Dementia, history of CVA, bed confined, and low blood pressure. Unresponsive to medical interventions.
- Advance Directive states that life prolonging treatments that will only artificially extend life without meaningful interactions with family should be withheld.
- The medical team believes that his current situation aligns with his directive, so they propose stopping dialysis treatment.
- The daughter (DPOA) disagrees and wants to bring him home.
- A Nephrologist second opinion confirmed that continued dialysis or further treatment would be non-beneficial.

47

Surrogate Decision-Making

Surrogate Decision-Making:

- Respects patient autonomy, and
- Protects patients from harm.

Three Standards Apply to Surrogate Decisions:

- Expressed wishes
- Substituted judgment
- Best interests

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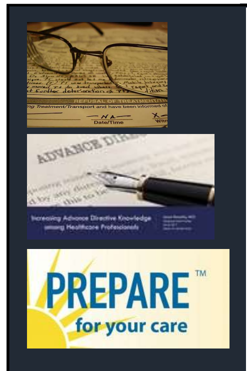

Advance Directives

- Advance Directives empower patients to maintain control over their healthcare decisions even when they cannot actively participate.
- Ensure continuity of care and uphold the fundamental principles of autonomy and fidelity in medicine.

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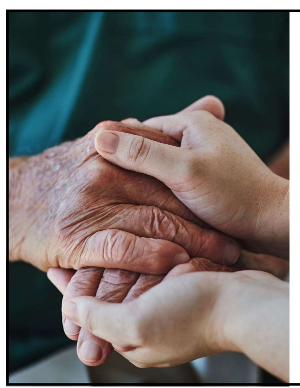

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Fidelity: Context of End-of-Life

- Unwavering commitment and loyalty to providing compassionate and dignified support to individuals nearing the end-of-life.
- Being faithful to the patient's well-being, dignity, and peace.

51

Evolution of Futility:

The safe harbor came after Quinlan 1976. Now called inappropriate care or Non-Beneficial care.

Once there was a safe harbor for withdrawal of care, doctors became comfortable with it.

You didn't die in a hospital without getting CPR first.

In the **1970's,** doctors would not remove life support even if the family ASKED for it.

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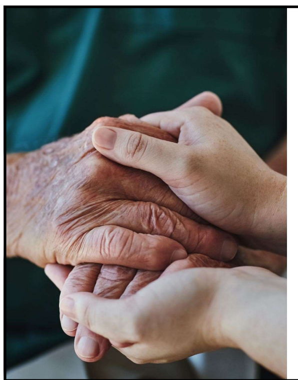

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Shared Decision Making

- Involving patients and families in decision-making is essential.
- Ethical dilemmas arise when preferences differ or when patients lack capacity to participate.

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Surrogate Decision Making: Case Examples

- Elderly female patient who is diagnosed with advanced Stage IV Lung Cancer with four children who disagree about continuing life-sustaining treatment.
- Elderly female patient with advanced CHF whose cultural norms dictate that her husband makes all decisions for their household. The husband's decision is to continue life-sustaining treatment at all cost which conflicts with her wishes.
- Ethical analysis involves selecting the appropriate surrogate when conflicting family members hold equal rank.
- Conflicts may arise between surrogate decision makers and cultural expectations.

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Ethical Issues: End of Life

- Advance Directives
- Cardiopulmonary Resuscitation (CPR)/DNR
- Withdrawing/Withhold Life Support
- Euthanasia
- Double Effect

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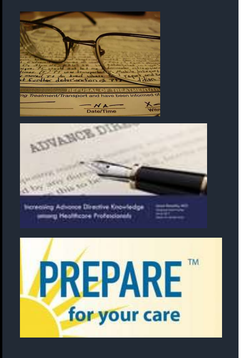

Advance Directives

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- Ensure continuity of care and uphold the fundamental principles of autonomy and fidelity in medicine.

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Ethical Issues with Advance Directives

- Determining that a patient is incompetent to make personal decisions is one of the first issues when addressing advance directives. Courts and medical personnel can assist in the determination of competency to make decisions.
- Ensuring that the patient has made their wishes known and that others are supportive of the patients choices is a second ethical hurdle when making life choices . Making sure that when the patient becomes unable to make choices the advanced directive will be followed is a top priority.
- When families do not agree with the decisions that the patient or proxy have made related to health care needs can pose a large problem for both the patient, healthcare providers and other family members.

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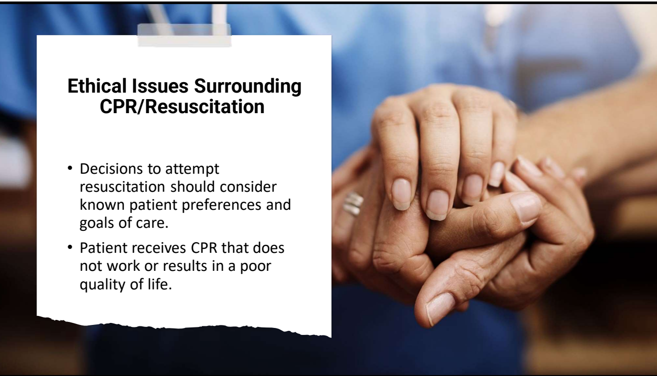

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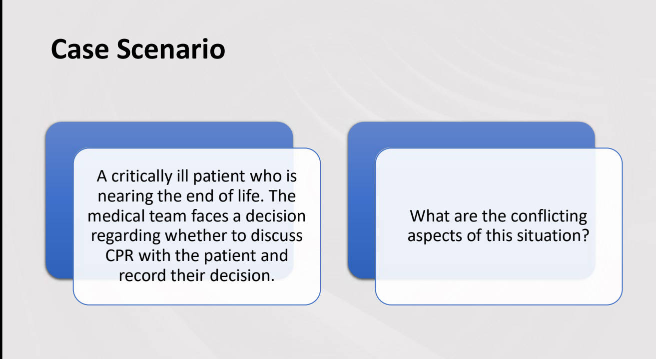

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Pros/Cons to Discussing CPR

Not Discussing CPR:

- Choosing not to discuss CPR with the patient and not recording a decision, the patient may receive CPR that doesn't work or results in a quality of life that is unacceptable to them.
- The patient's wishes and preferences regarding resuscitation might remain unknown, leading to potential harm.

Discussing CPR:

- Engaging in a conversation about CPR with the patient and documenting their decision, it ensures transparency and respects the patient's autonomy.

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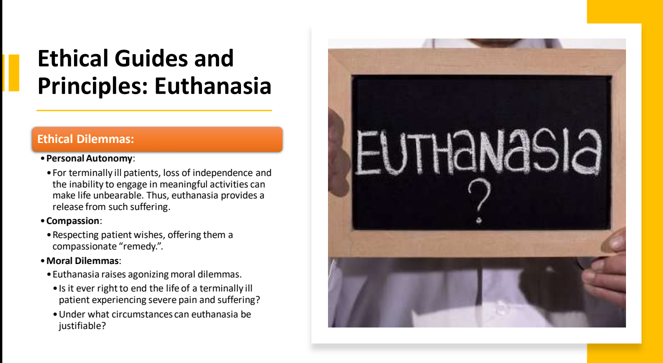

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Ethical Guides and Principles: Euthanasia

Ethical Dilemmas:

- **Religious and Societal Views**:
  - Various faiths view euthanasia as a form of murder and morally unacceptable.
- **Slippery Slope**:
  - Accepting voluntary euthanasia could lead to involuntary euthanasia and the killing of people deemed undesirable.
  - They fear a slippery slope where the boundaries blur.

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Case Study: Brittany Maynard

- **Brittany Lauren Maynard……**
  - An American activist with **terminal brain cancer** who decided that she would end her own life "when the time seemed right." She was an advocate for the legalization of **assisted suicide** for the terminally ill.
  - In April 2014, her cancer was elevated to Grade 4 **Glioblastoma** with a prognosis of six months to live.

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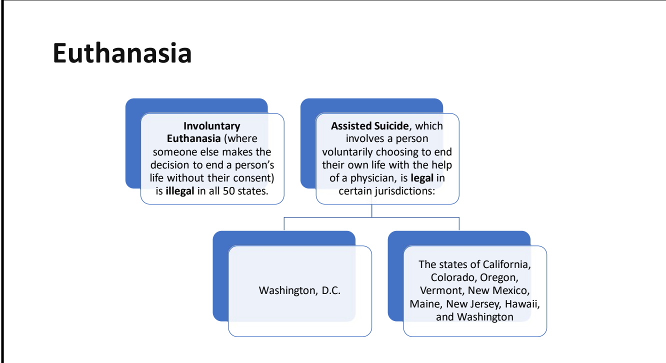
Euthanasia



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Ethical Guides and Principles: Double Effect

- The good effect must be sufficiently desirable to compensate for the allowing of the bad effect.
- Makes a distinction between deaths that are directly intended and deaths that are merely foreseen.

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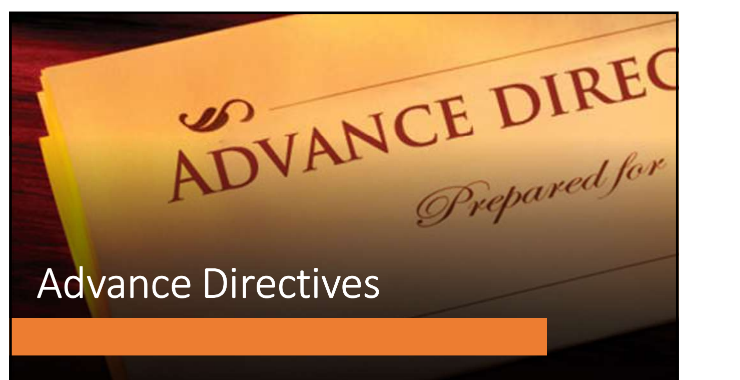

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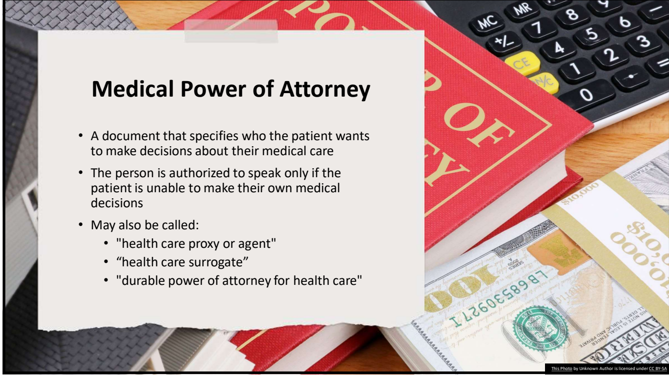

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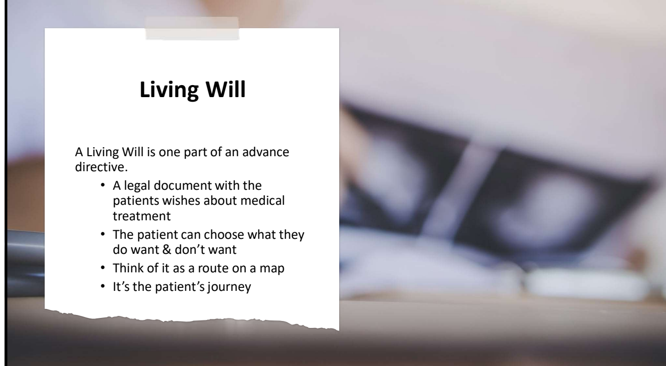

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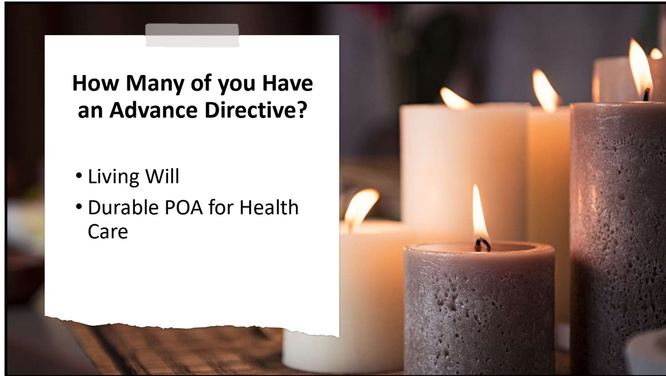

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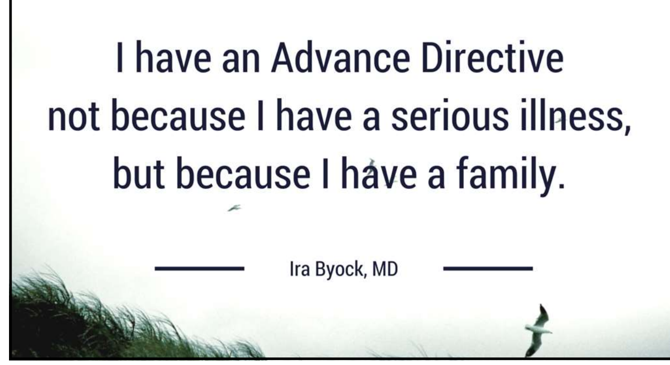

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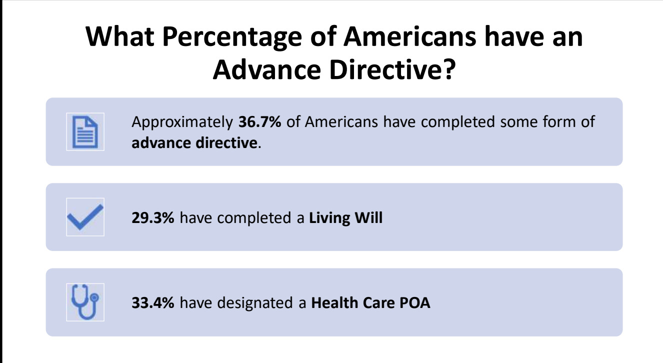

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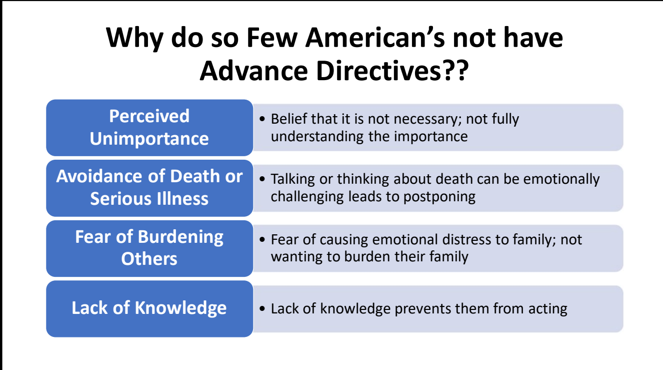

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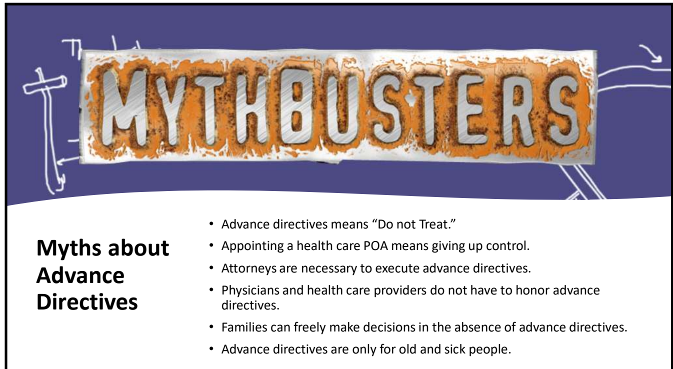

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Why do so Few American's have Advance Directives??

Complexity of Forms

- Can be overwhelming and our clients may need assistance in completing

Limited Time with Healthcare Providers

- Busy doctors not allowing time to have in-depth conversations with their patients about advance directives.

Cultural and Ethnic Factors

- Cultural backgrounds can influence attitudes toward end-of-life decisions. Minorities, for example may be more suspicious of healthcare providers intentions.

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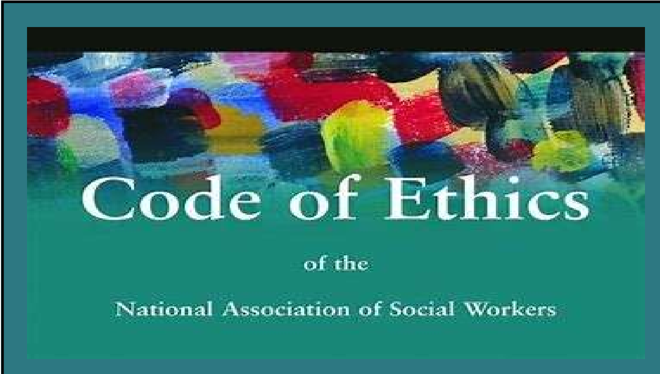

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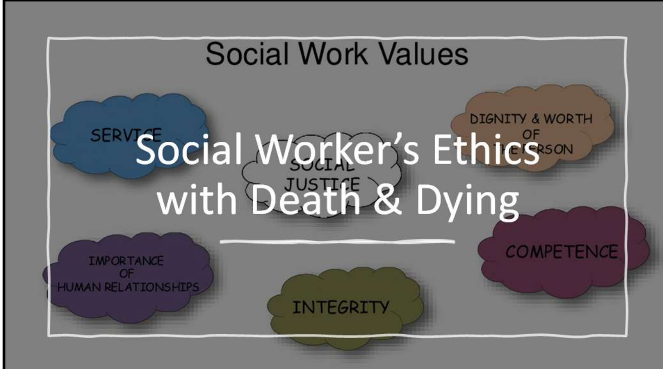

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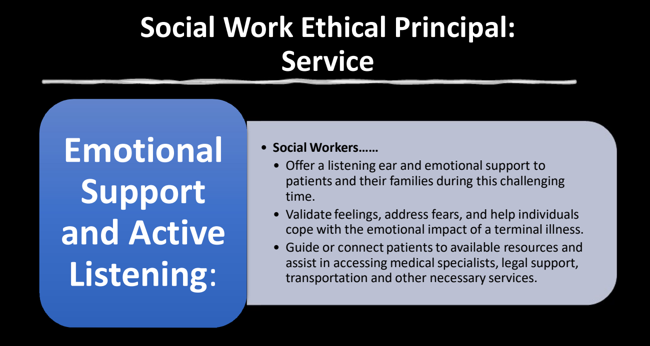

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Social Work Ethical Principal: Social Justice

Social Workers……

- Challenge social injustice.
- Pursue social change, particularly with and on behalf of vulnerable and oppressed individuals.
- Social change efforts are focused primarily on issues of poverty, unemployment, discrimination, and other forms of social injustice.
- Promote sensitivity to cultural and ethic diversity.
- Strive to ensure access to information and equality of resources.

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Social Work Ethical Principal: Dignity and Worth of the Person

Social Workers……

- Treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity.
- Seek to enhance clients' capacity and opportunity to change and to address their own needs.
- Seek to resolve conflicts between clients' interests and the broader society's interests consistent with the values, ethical principles, and ethical standards.

82

Social Work Ethical Principal: Importance of Human Relationships

Social Workers……

- Recognize the central importance of human relationships.
- Understand that relationships between and among people are an important vehicle for change.
- Engage people as partners in the helping process.
- Seek to strengthen relationships among people in a purposeful effort to promote, restore, maintain, and enhance the well-being of individuals, families, social groups, organizations, and communities.

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Social Work Ethical Principal: Integrity

Social Workers……

- Behave in a trustworthy manner.
- Are continually aware of the profession's mission, values, ethical principles, and ethical standards and practice in a manner consistent with them.
- Behave in a trustworthy manner
- Act honestly and responsibly and promote ethical practices.

84

Social Work Ethical Principal: Competence

Social Workers……

- Practice within their areas of competence and develop and enhance their professional expertise.
- Continually strive to increase their professional knowledge and skills and to apply them in practice.
- Should aspire to contribute to the knowledge base of the profession.

85

Social Work Ethical Principal: Boundaries

Social Workers……

- Set limits for safe, acceptable and effective behavior.
- Avoid conflicts of interest; sexual relationships and physical contact with their clients.

86

Social Work Ethical Principal: Conflict of Interest

Social Workers……

- Should not engage in dual or multiple relationships with clients or former clients in which there is a risk of exploitation or potential harm to the client.
- Should take steps to protect clients and are responsible for setting clear, appropriate, and culturally sensitive boundaries…

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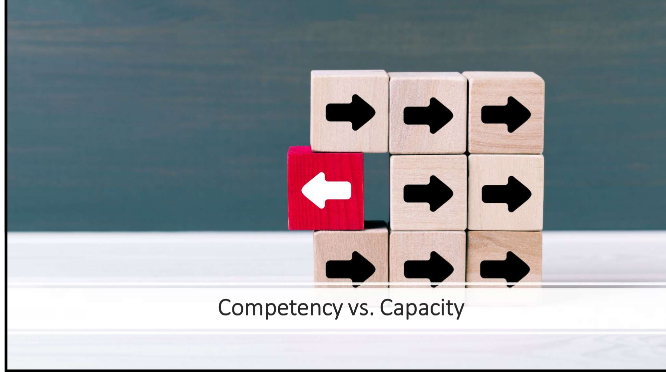

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Decision-Making for the Incapacitated Patient

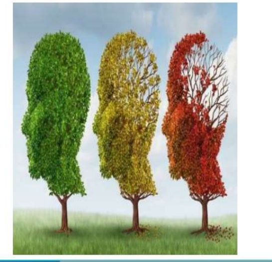
What happens when a patient does not have Advanced Directives in Place? (i.e., Durable POA for Health Care)?

- The consent of the appropriate individual or individuals is given after consultation with the patient's attending or consulting physician and after receipt of information that is sufficient to satisfy the requirements of informed consent.
- The appropriate individual or individuals who give a consent are of sound mind and voluntarily give the consent.
- If a consent would be given under division of this section, the attending physician made a good faith effort, and used reasonable diligence, to notify the patient's adult children who are available within a reasonable period of time for consultation.

90

What is capacity?

Capacity is defined as the person's **ability to understand**, at the **time** a decision is to be made, the **nature and consequences** of the decision to be made by him or her in the **context of the available choices** at that time



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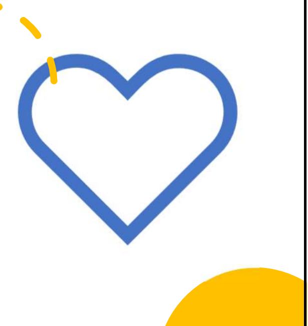
Capacity to Comprehend Example

- **Example:** An anxious patient being consented for cardiac surgery can repeat the information the clinician explains in his own words.



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Competency

- Decided by a court/judge
- Expected to be permanent
- Chronic alteration

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The 5 Cs of Decision Making Capacity

- know the context of the decision at hand
- know the choices available
- appreciate the consequences of specific choices
- is consistent in their decisions
- can communicate their decisions

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Capacity to Reason

- The ability to rationally manipulate the facts given and arrive at a logical conclusion.
- **Example:** A schizophrenic patient with delusions of persecution can tell their physician that they would rather receive a medication that is effective 85% of the time than one that works 15% of the time.

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Capacity to Appreciate

- The ability to make authentic choices which reflect one's life history, culture, religion, values and prior significant decisions.
- **Example:** A 55-year-old woman who has been a devout Christian Scientist her entire life, refuses to see a doctor when she becomes jaundiced, vomits and has abdominal pain.

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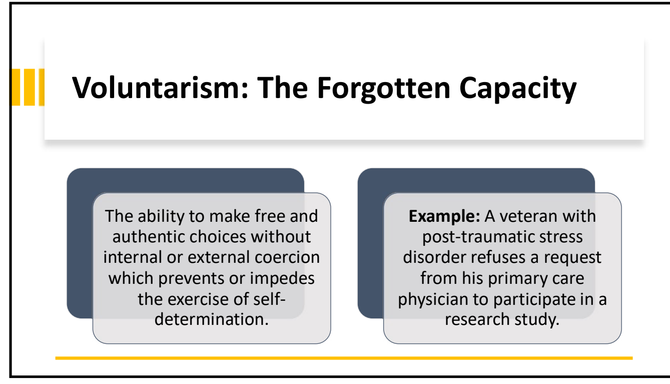

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The Importance of Knowledge

Is the client uncooperative, cantankerous, and obstinate because her memory and mental functions are impaired, OR is she a woman who has spent a long lifetime being uncooperative, cantankerous, and obstinate?

KNOWLEDGE = POWER

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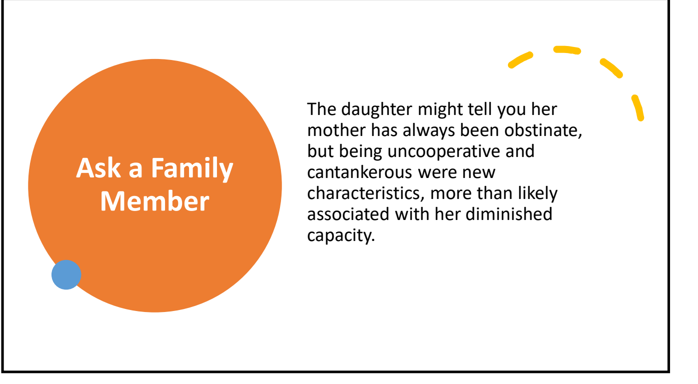

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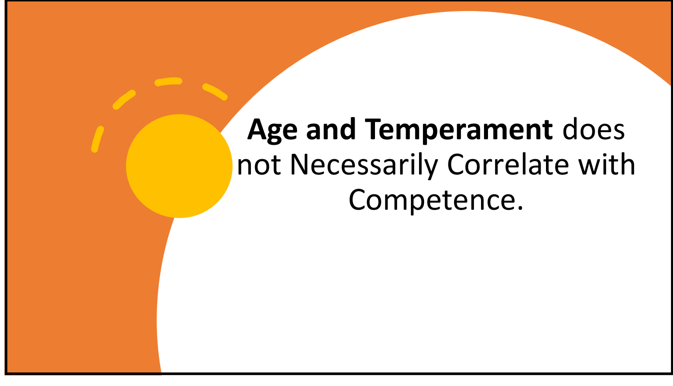

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In Other Words ......

A client does not lack capacity merely because they do things that other people find disagreeable or difficult to understand or because they are eccentric or make risk-taking decisions.

- This should not be confused with incapacity.

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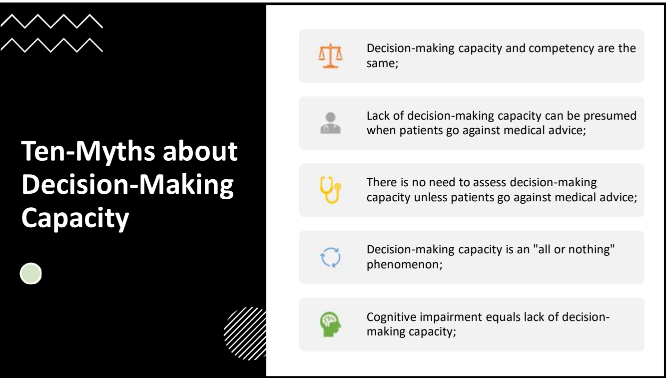

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More Myths……

- Lack of decision-making capacity is a permanent condition;
- Patients who have not been given relevant and consistent information about their treatment lack decision-making capacity;
- All patients with certain psychiatric disorders lack decision-making capacity;
- Patients who are involuntarily committed lack decision-making capacity; and
- Only mental health experts can assess decision-making capacity.

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Ethics of Capacity Evaluations

- Should give the patient the best chance of demonstrating capacity (e.g., examine in morning).
- Should ensure capacity not reversible.(e.g., B12, delirium, infection).
- Should improve/internal capacity if possible (antipsychotics, abstinence).
- Should bolster external capacity if feasible (social support, APS).

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My Patient Lacks Decisional Capacity: What is Next?

- Does the patient have an advance directive?
- Did the patient appoint a proxy or surrogate decision maker?
- **Legal Next-of-Kin:** If no AD or surrogate then the following order is utilized: Spouse, adult child, parent, adult sibling, grandparent, friend?
- Do they need a guardian?

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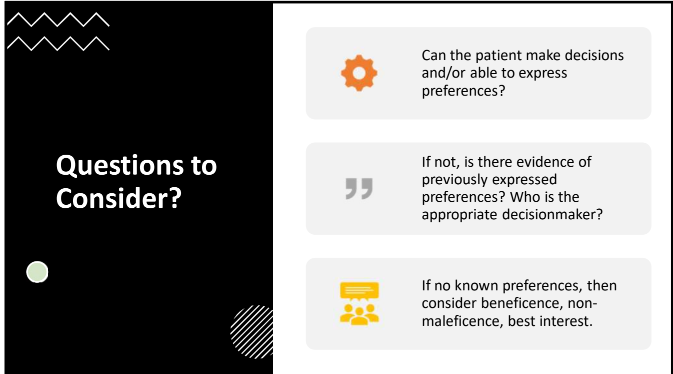

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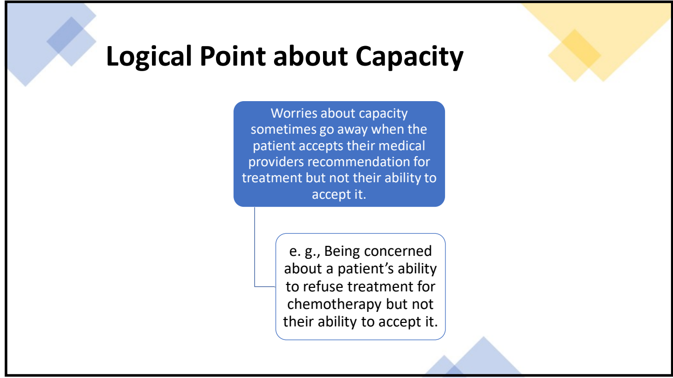

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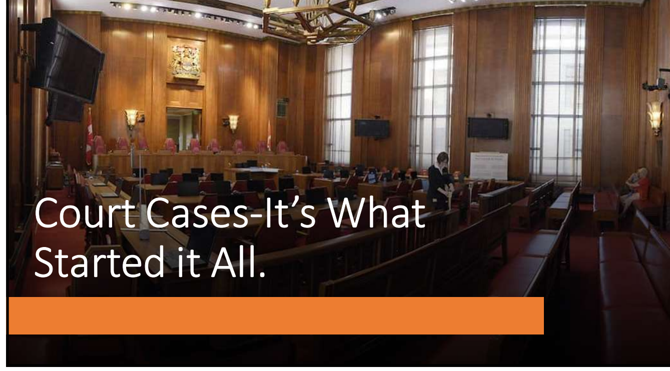

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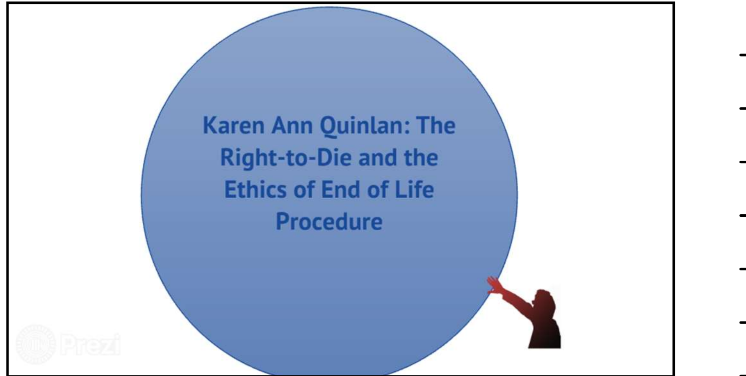

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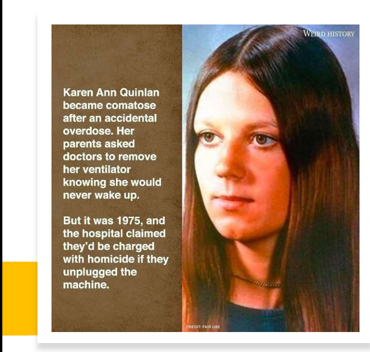

Karen Ann Quinlan -1975

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Ethical Considerations:

- **Paternalism**
  - Karen's physician's felt strongly that the best decision for Karen was to keep the ventilator in.
- **Locus of Authority**
  - The decision was between Karen's caretakers and her family.
- **Patient Autonomy**
  - Karen was unable to exercise her autonomy, but it was still respected
- **Nonmaleficence**
  - Doctors valued ethical steps; it was unethical to let someone die if they have the power to prevent this.
  - Physicians swore by the Hippocratic Oath to "do no harm".
- **Beneficence**
  - The duty to help others

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Ethical Considerations:

- **Euthanasia**
  - Believe that withdrawal of ventilator is euthanasia which is murder.
- **Utilitarianism**
  - Quinlan family valued the end goal: let Karen die peacefully.
- **Malpractice Concerns**
  - Departure of normal standards of medical practice.
- **Legal Concerns**
  - It is illegal to terminate a patient's life if she does not meet the definition of brain dead.

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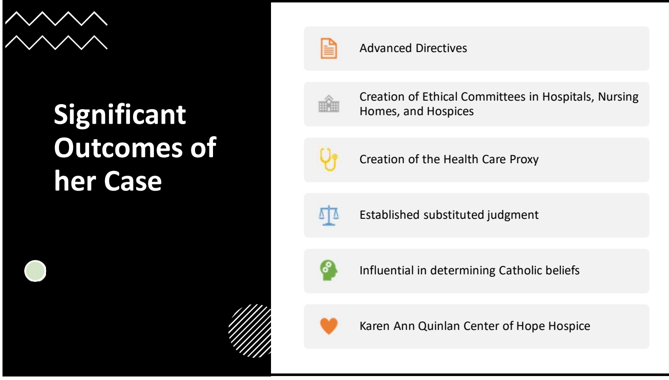

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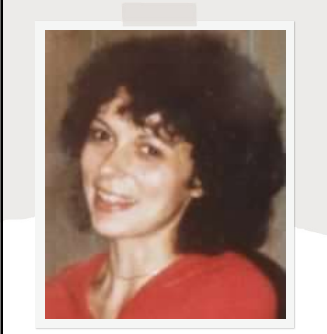

Nancy Cruzan - 1990

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Case of Nancy Cruzan

Mid-1980s

- A young woman named Nancy Beth Cruzan fell into a PVS after a devastating anoxic brain injury
- The family requested that artificial nutritional support and hydration be discontinued
- The Missouri Supreme Court ruled
  - Guardians did not have the authority to terminate life-sustaining medical treatment on the basis of indirect or hypothetical reasoning about what the patient would have wanted
  - Surrogate treatment decisions must be based on clear and convincing evidence of what the patient would have wanted
  - If there is no clear and convincing evidence of a patient's wishes, the guardian is obligatec to act in the patient's best interests, and for the Missouri Supreme Court, this meant the continuation of life and of medical life support

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Case of Nancy Cruzan (continued)

- The Cruzan family appealed to the United States Supreme Court
- The Court ruled that U.S. Constitution confers a right ("liberty interest") to refuse medical treatment, even life-prolonging medical treatment (including artificial nutrition and hydration)
- However, it also held that states did not violate this constitutional right by requiring clear and convincing evidence of the patient's wishes when the patient lacked decision-making capacity
- The Cruzan case marked the end of a period of legal consolidation because this was the first time that the U.S. Supreme Court had addressed end-of-life medical decision making in the light of the Constitution and established a right to refuse medical treatment

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What does the Nancy Cruzan case mean for us today??

Advance Directives:

- Underscored the importance of **advance directives**.

Clear and Convincing Evidence:

- Established the standard of **"clear and convincing evidence"** for withdrawing life-sustaining treatment.
- Medical providers must have substantial proof that the patient would refuse treatment under the current circumstances.

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What does the Nancy Cruzan case mean for us today??

Medical Futility and Quality of Life:

- Highlighted the concept of **medical futility**—when further treatment is unlikely to result in meaningful improvement.
- Emphasized the importance of considering the patient's **quality of life** when making end-of-life decisions.

Legal Safeguards:

- Many states enacted laws to ensure that patients' wishes are respected.
- Laws provide a framework for decision-making, including provisions for surrogate decision-makers and guidelines for withholding or withdrawing treatment.

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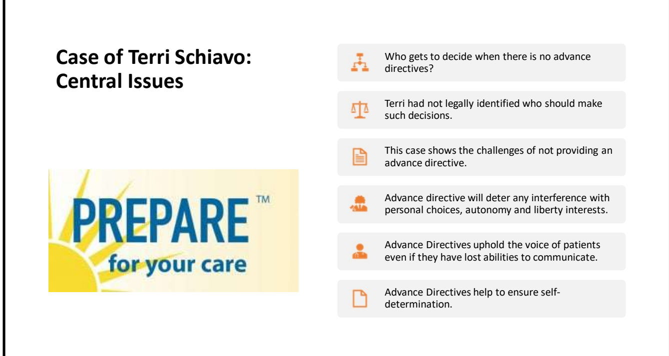

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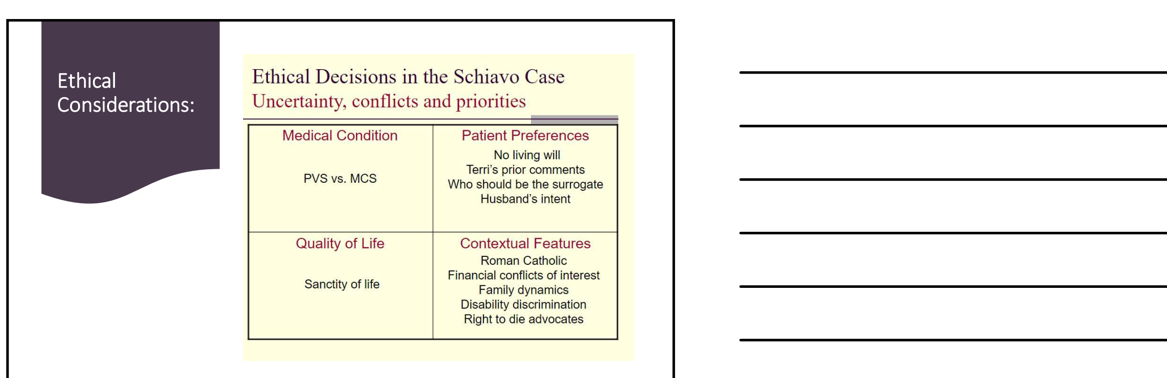

Medical Condition	Patient Preferences
PVS vs. MCS	No living will Terri's prior comments Who should be the surrogate Husband's intent
Quality of Life	**Contextual Features**
Sanctity of life	Roman Catholic Financial conflicts of interest Family dynamics Disability discrimination Right to die advocates

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Legal Battles

- Legal battle between her husband and her parents lasted from 1998 to 2005.
- Lack of a living will a major contributing factor to this legal battle of appeals to determine what Terri's wishes would have been regarding life prolonging procedures.

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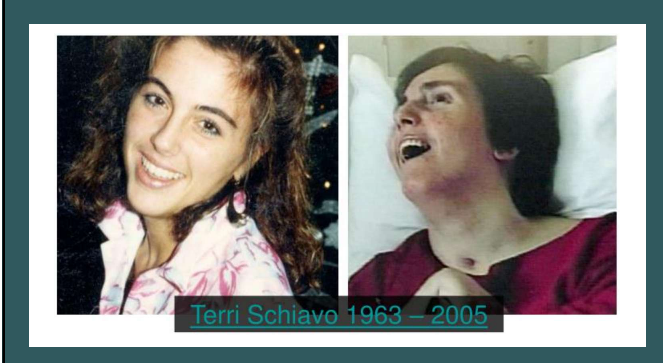

Terri Schiavo 1963 – 2005

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Right to Life Movement

Keeping Terri alive became a focal point for the Right to Life movement:

- MULTIPLE appeals, motions, hearings, etc.
- Florida legislature
- Florida Governor Bush
- Florida and U.S. Supreme Court
- Congressional Republicans
- President Bush

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End of Life Issues

Background

A little background…

- End-of-life issues: patient autonomy, quality of life at the end of life, and withdrawal of life-sustaining treatments
- In 1990, Congress enacted the Patient Self-Determination Act:
  - Accept a patient's right to either refuse or accept medical treatment,
  - Safeguard the patient's autonomy and preserve self-determination
  - Protect patients against maltreatment
  - Foster communication between patients and their physicians
  - Protect physicians from litigation in end-of-life decision making

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The Patient Self-Determination Act 1990:

What is it and What Does it Mean for Me Today?

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Purpose and Scope:

The PSDA applies to hospitals, skilled nursing facilities, home health agencies, hospice programs, and health maintenance organizations.

Its primary goal is to **empower patients** by ensuring they are informed about their rights and have the ability to make decisions regarding their medical care.

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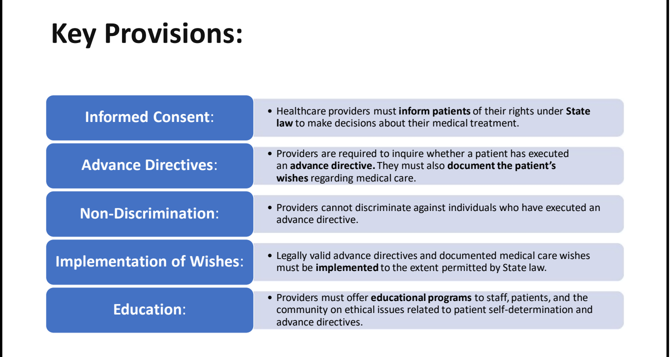
Key Provisions:



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Our Rights Today

As a patient, the PSDA reaffirms our **right to autonomy and self-determination**. You have the authority to:

- **Accept or refuse medical treatment**:
  - You can make informed choices about the type and extent of medical care you want.
- **Execute an advance directive**:
  - This allows you to express your preferences for medical treatment in case you become unable to communicate your wishes.

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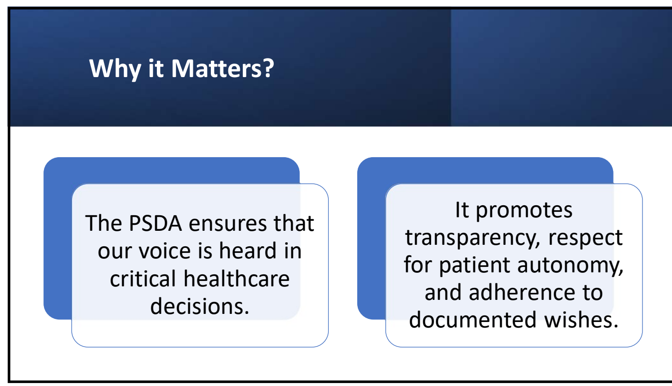

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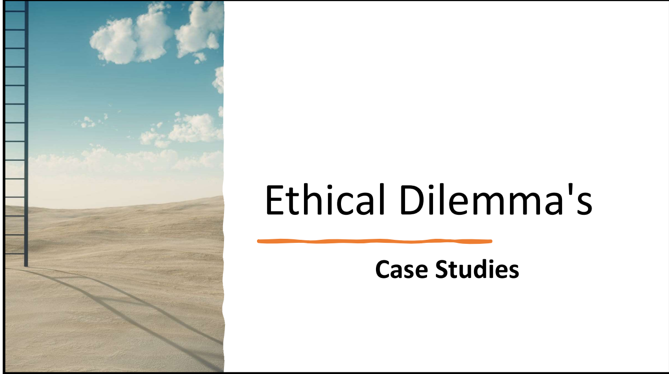

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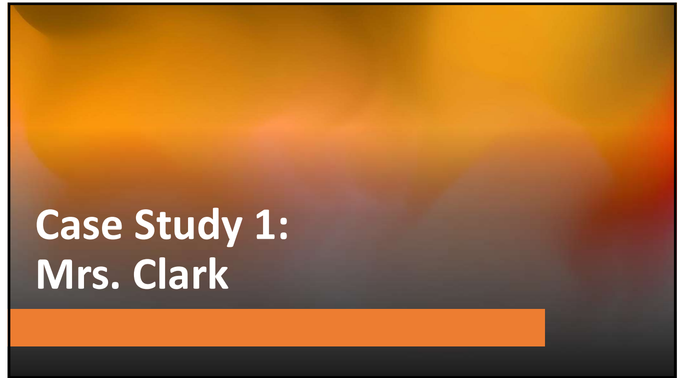

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- 73 year old woman
- Hypertension, tobacco use
- In ER with chest pain, dyspnea
- ECG shows acute anterior MI
- Recently retired paralegal
- Lives with husband
- Treated appropriately by ER
- Plan for cardiac catheterization
- Mrs. Clark refuses

Case Study: Mrs. Clark

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Treatment Refusal

- Mrs. Clark refusing cardiac catheterization in setting of acute anterior MI
- Refusal is the *beginning* of a conversation
- Risks/Benefits
- Reasons for refusal
- Husband arrives in ER, reassures Mrs. Clark
- With family support, decides to proceed with cath

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Case Study: Mrs. Miller

- 87-year-old, female patient with Alzheimer's Disease. Has developed aspiration pneumonia and she is struggling to breathe.
- Lacks decision making capacity about intubation.

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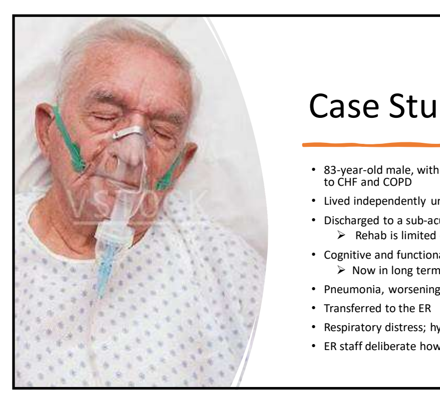

Case Study: Mr. Jones

- 83-year-old male, with recent history of 5 hospitalizations due to CHF and COPD
- Lived independently until his hip fracture 9 months ago
- Discharged to a sub-acute rehab setting
  - Rehab is limited due to advanced disease process
- Cognitive and functional decline
  - Now in long term care
- Pneumonia, worsening despite oral antibiotics
- Transferred to the ER
- Respiratory distress; hypotensive
- ER staff deliberate how he should be treated

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Shared Decision-Making

- Patient and clinician work together to develop plan of care
- Mr. Jones can mumble yes/no to simple questions

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How to Treat Mr. Jones?

- Why is this a question?
- Preference sensitive decision
  - More than 1 reasonable option
  - Lifelong implications
  - Uncertainty
- Values modify equation
- Medical facts-opinion

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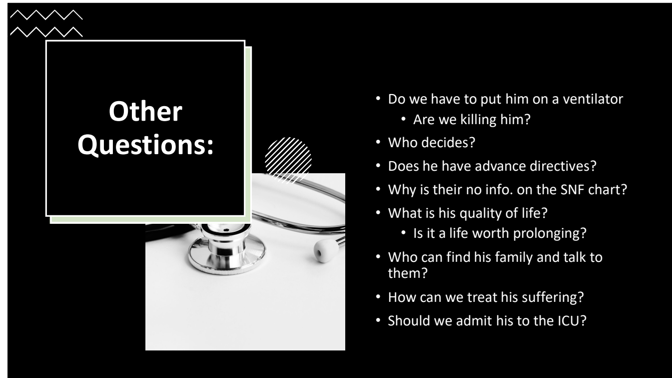

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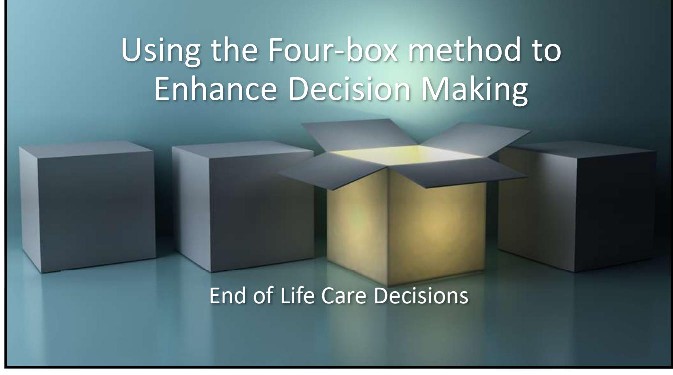

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Case of Bonnie

- 85-year-old female with advanced dementia
- Resides in Nursing Facility
- Bed/chair bound
- Limited verbal, dependent all ADLs
- Disoriented to Person, Place and Time
- No longer recognizes her family
- History of Aspiration pneumonia
- Advanced CHF (end-stage)
- 75% of IBW (Ideal Body Weight) indicating **severe nutritional failure**
- Failed swallowing evaluation
- PEG (feeding tube)?????
- **That is the question**

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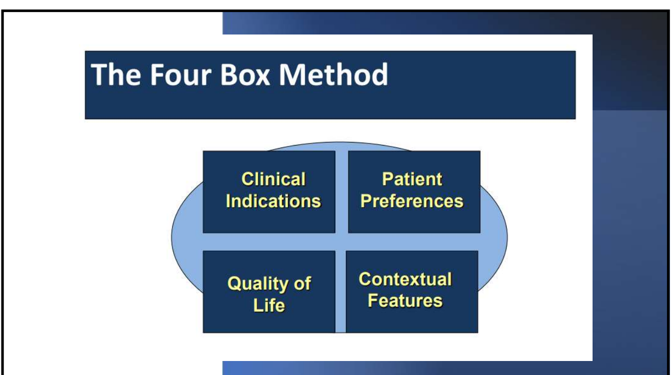

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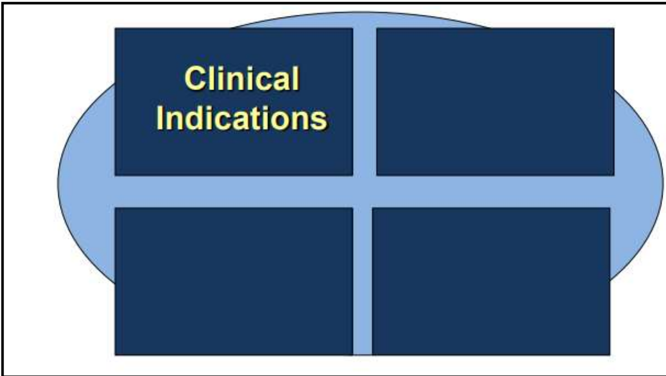

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Ethical Questions to Consider

- What is the goal of care?
- What is evidence that the feeding tube may achieve the goal?
- What is the potential harm of providing/not providing the PEG?
- What are the alternatives?
- What are the risks?
- Is a time-limited trial warranted?

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Beneficence and Non-Malfeasance

Obligation to determine what is medically indicated (beneficial).

No obligation to provide non-beneficial (“futile) treatment.

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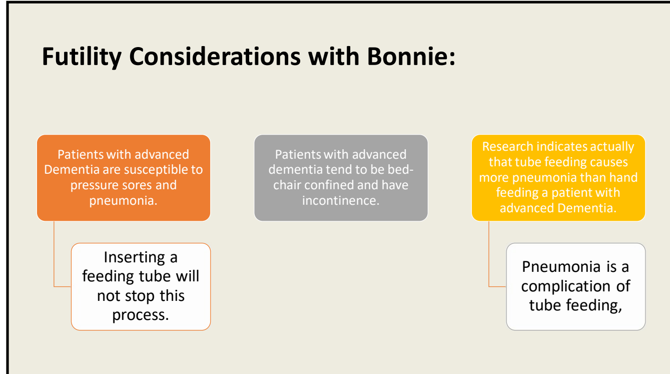

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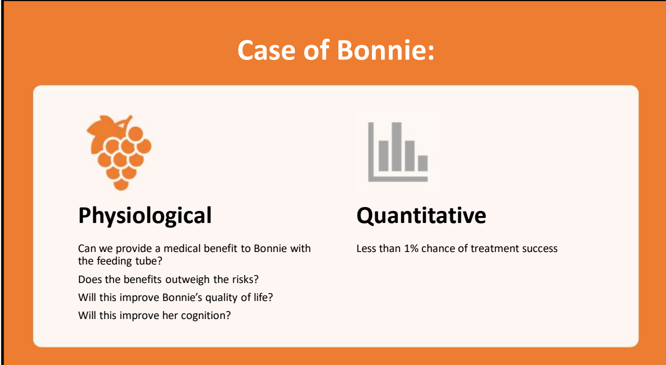

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Case of Bonnie

Lethal Condition

- Bonnie has underlying health conditions of advanced CHF that will not be changed by the feeding tube and death will occur within weeks to months.

Qualitative

- Cannot achieve an acceptable quality of life. Bonnie will remain totally dependent on intensive medical care. She will still be at risk for aspiration pneumonia and skin breakdown. Bonnie will still not recognize her family and she will remain bedbound.

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No Meaningful Benefit in Advanced Dementia

No…..

- Increased survival compared to hand feeding
- Difference in survival between early and later insertion of feeding tubes
- Lower risk of aspiration
- Increased healing of pressure ulcers
- Difference in weight loss
- Evidence of increased comfort, functional status or quality of life

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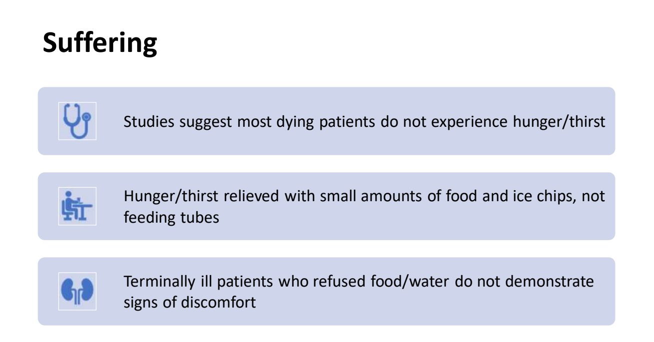

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Potential Harm

- Nausea/vomiting
- Diarrhea
- Pulmonary congestion
- Edema
- Increased urination
- Infection
- Immobility/Use of restraints
- Trauma due to dislodgement
- Bleeding
- Earlier death?

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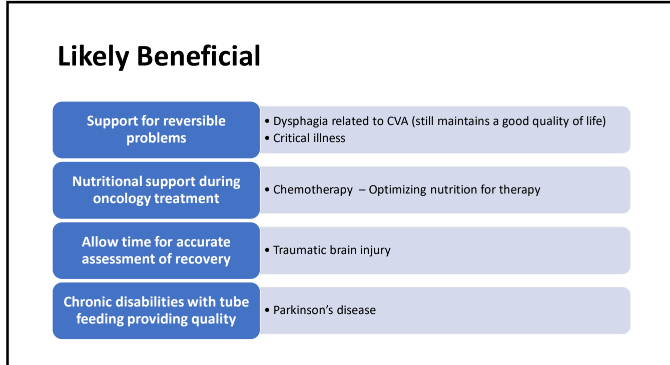

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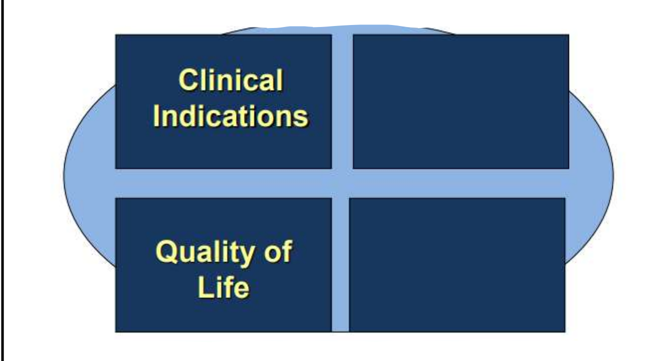

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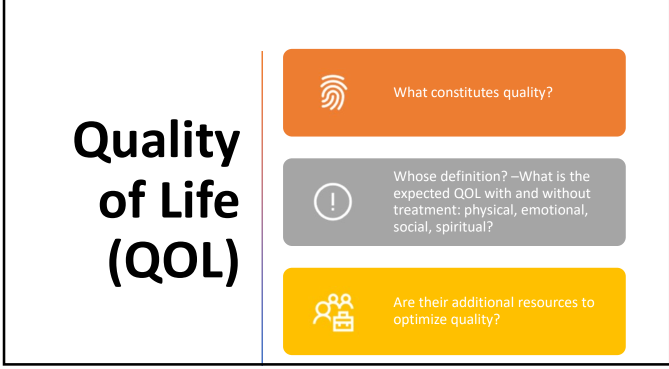

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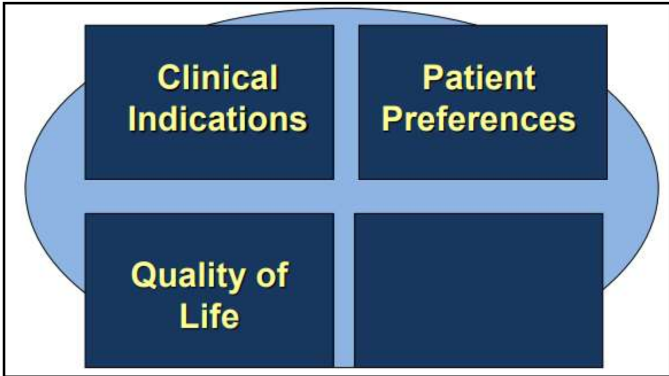

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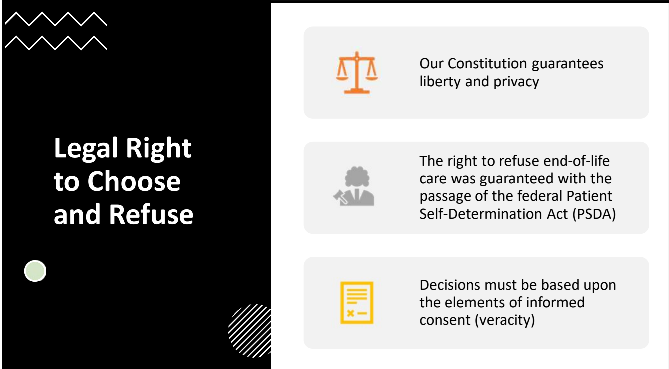

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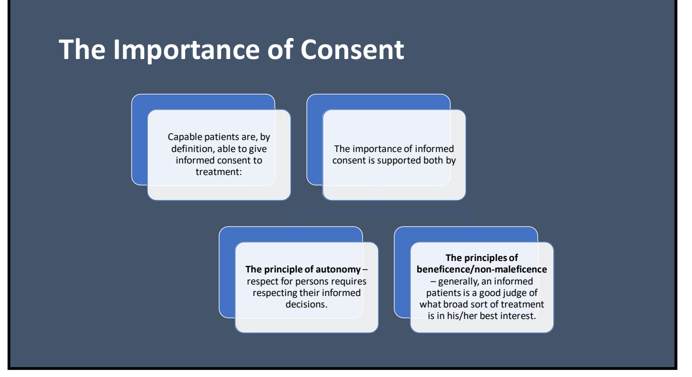

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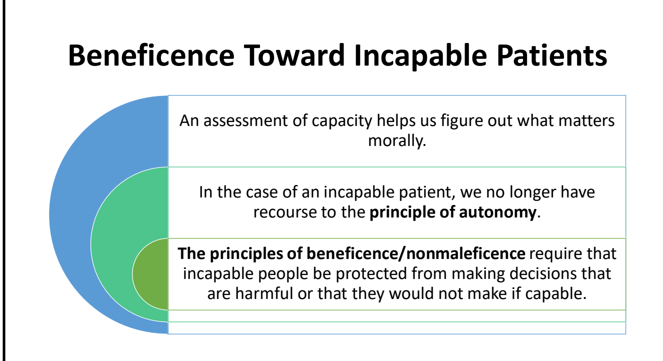

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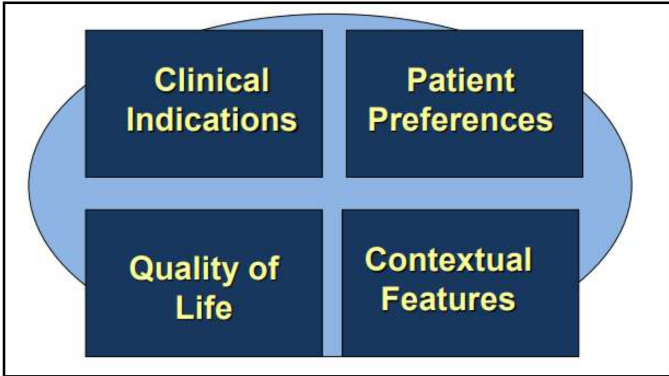

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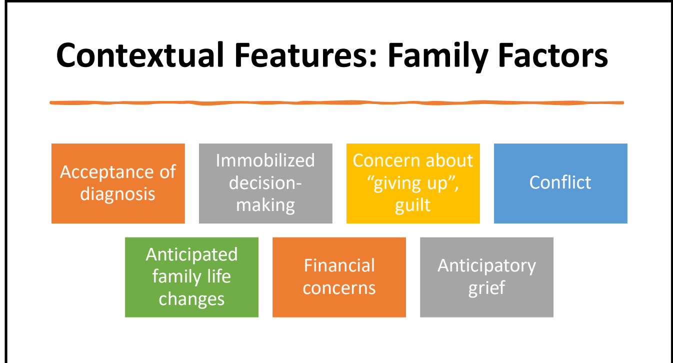

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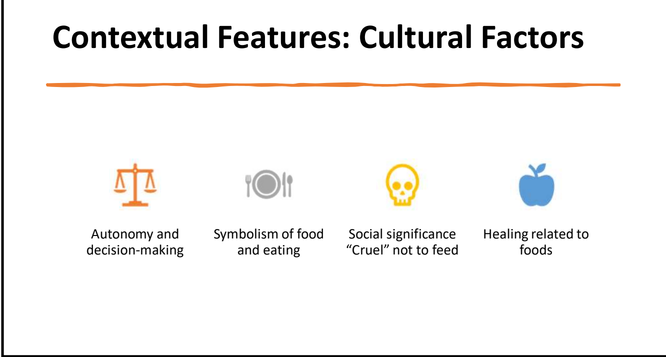

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Cultural in End-of-Life

Culture fundamentally influences how individuals make meaning out of illness, suffering, and dying, and therefore influences medical services at the end of life.

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Cultural and End-of-Life Medical Care

Cultural differences in:

- Truth telling
- Life-prolonging technology
- Decision-making styles
- End-of-life experiences, beliefs, and expectations are linked to cultural values

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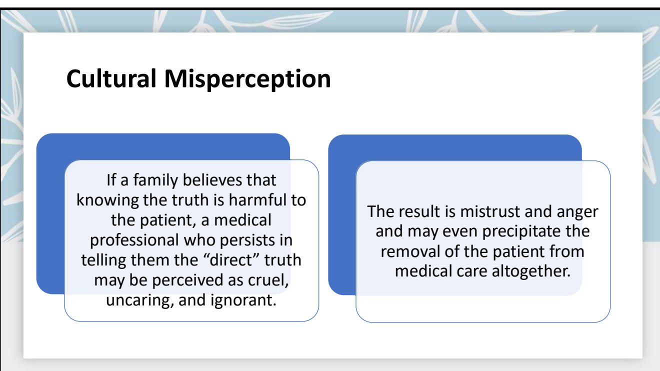

Cultural Misperception

If a family believes that knowing the truth is harmful to the patient, a medical professional who persists in telling them the "direct" truth may be perceived as cruel, uncaring, and ignorant.

The result is mistrust and anger and may even precipitate the removal of the patient from medical care altogether.

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Cultural Negotiation

- The clinical encounter often requires a negotiation between the cultures of the medical professional and the patient/family unit to reach mutually acceptable goals.
- In the end, addressing and respecting cultural differences will likely increase trust, leading to better clinical outcomes and more satisfactory care.

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African American Approach to Terminal Illness

- The withholding of life-prolonging treatment, the removal of nutritional support, and the possibility of limited or no resuscitative efforts are seen as another attempt to limit access to healthcare.
- Advance care planning is also regarded with distrust and suspicion that care will be diminished in some way.
- African Americans prefer the use of life-sustaining treatments at the end of life.

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Asian & Pacific Islander Approach to Terminal Illness

- It is perceived as unnecessarily cruel to directly inform a patient of a cancer diagnosis.
- Less likely to sign their own do-not-resuscitate (DNR) orders.
- Reverence for aging family members perceived as vulnerable. Special status of the elderly in Asian culture includes a value that they should not be burdened unnecessarily when they are ill.
- Asian patients and their families may not want to discuss the possibility of death due to a belief that direct acknowledgement of mortality may be self-fulfilling.
- Illness is considered a family event-family based medical decisions.

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Chinese American Beliefs on Death & Dying

- Some believe that a death in the home brings the family bad luck.
- Others believe that the patient's spirit will get lost if death occurs in the hospital.
- Family members make use of special amulets or cloths. Some families prefer to bathe the patient themselves.
- They may believe that the body should be kept intact; organ donation and autopsy are uncommon.

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Latino Approach to Death & Dying

- Death is not an end but a continuum of life.
- Most important decisions are made by consensus rather than individually.
- Extended families care for loved ones who are ill
- In some cases, patients prefer to be given bad news in the presence of their family; in other cases, families prefer that health professionals not inform the patient about the prognosis of terminal illness.
- Life-sustaining measures are less acceptable.
- The head of the household, usually a man, will make the decisions.

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Latino Approach to Death & Dying

- With older adults, the eldest child is usually appointed to assist with decision-making, or family consensus
- Most Latinos wish to die at home in the company of all their family.
- The concept of time is a very personal one, "I will decide when I die".
- Advanced planning for death may not be started until the very late stages of illness, if at all. Less likely to have advance directives.
- Beliefs around planning,

"If you plan it, it will happen".

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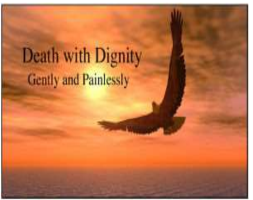
Native American Approach to Death & Dying

- Words should be carefully chosen because once spoken, they may become a reality.
- Will not even discuss advance directives or anticipated therapeutic support status with patients because these verbal exchanges are considered potentially injurious.
- Acknowledgement of mortality may be self-fulfilling.



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Conclusion…… What can I do??

Empathy and Compassion:
- Our patients are not merely just cases.

Transparency:
- Honesty is our greatest ally when discussing prognosis or treatment options, be transparent, use clear language, listen actively, and address their concerns.

Shared Decision-Making:
- Involve patients and their families in decision-making. Respect their values, beliefs, and cultural backgrounds.

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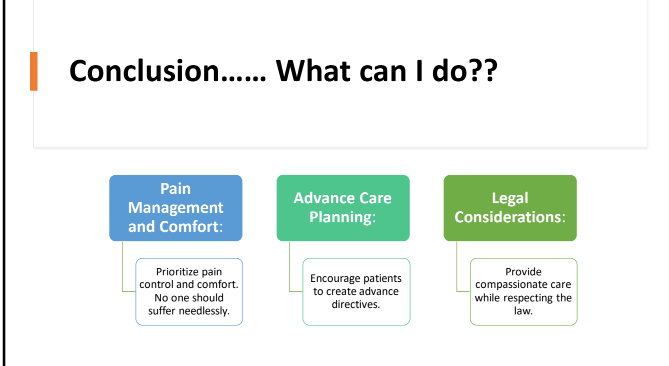

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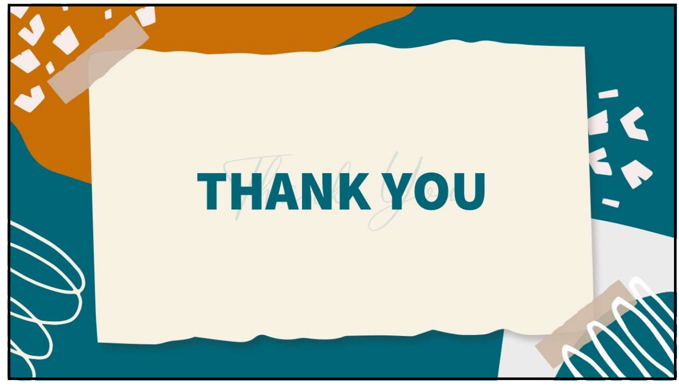

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