



1

---

---

---

---

---


---

---

---

**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



2

---

---

---

---

---

---

---

---



3

---

---

---

---

---

---

---

---



4

---

---

---

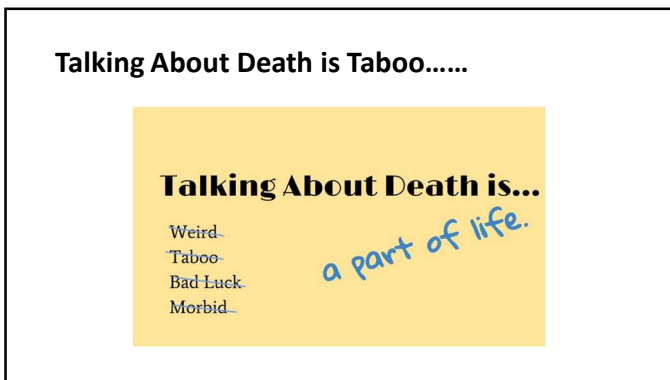
---

---

---

---

---



5

---

---

---

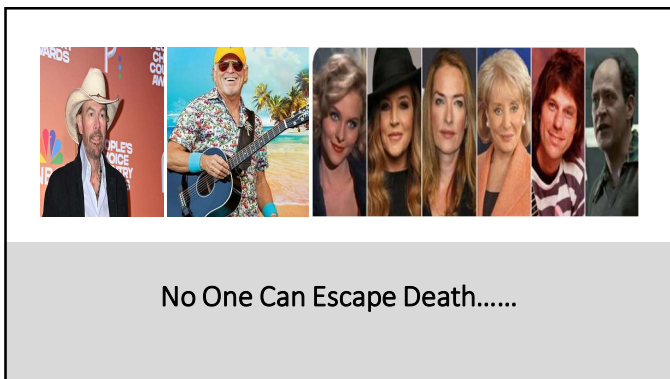
---

---

---

---

---



6

---

---

---

---

---



---

---

---

## Euphemisms

- 200 in English language-practice of using euphemisms to do with belief that to speak the word death was to invite death
- Examples "kick the bucket"

7

---

---

---

---

---


---

---

---

### Reflection Questions.....

What does quality of life mean to you?  
 If you were unable to communicate your wishes due to a medical emergency, what decisions would you want your family or healthcare providers to make on your behalf?  
 What values guide your healthcare decisions?  
 How comfortable are you discussing death and dying?



8

---

---

---

---

---

---

---

---

### 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.



9

---

---

---

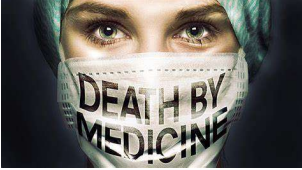
---

---

---

---

---



**Medicalization of Death**

**Definition:**

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

10

---

---

---

---

---

---

---

---

**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.

11

---

---

---

---

---

---

---

---

**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

12

---

---

---

---

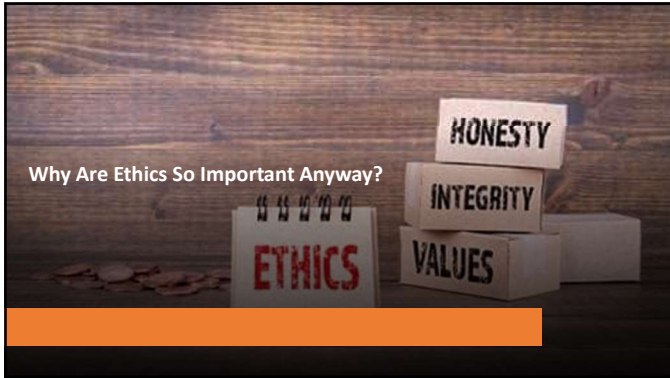
---

---

---

---





13

---

---

---

---

---

---

---

---

### Why are Ethics so Significant?

- Guiding Principles
- Conflict Prevention
- Accountability
- Self-Care
- Respecting Dignity

14

---

---

---

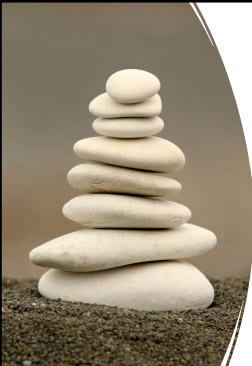
---

---

---

---

---



### Ethical Principles:

- **Autonomy**
- **Beneficence**
- **Nonmaleficence**
- **Justice**

Universal Recognized Ethical Principles

15

---

---

---


---

---

---

---

---



**The Language of Autonomy Resonates with the Language of:**

Respecting one another's choices, decisions, and behaviors, as long as they are lawful, and they do not pose an unreasonable risk of injury to the individual or to others.

- Independence
- Liberty
- Individual rights
- Self-determination

16

---

---

---

---

---



---

---

---

**Ethical Guides and Principles: Autonomy**

- Right to choose and refuse
- Does not entitle person to treatment that is not clinically indicated
- Religious and cultural views may influence individual choices

17

---

---

---

---

---

---


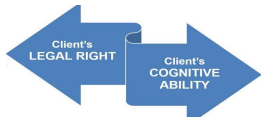
---

---

**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.

18

---

---

---

---

---

---

---

---

**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

---

---

---

---

---

---

---

---

19

**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')

---

---

---

---

---

---

---


---

20

**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.



---

---

---

---

---

---

---

---

21

### What is Distributive Justice?

- Patients are treated impartially, without bias on account of gender, race, sexuality, wealth, etc....
- Usually focuses on who gets medical treatment with specific scarce medical resources.

22

---

---

---

---

---

---

---

---

### Distributive justice

**Ethical Guides and Principles: 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

23

---

---

---

---

---

---

---

---

### 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.

24

---

---

---

---

---

---

---

---

**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.

25

---

---

---

---

---

---

---

---

**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.

26

---

---

---

---

---

---

---

---

**Ethical Dilemma?**

27

---

---

---

---

---

---

---

---

### 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.



28

---

---

---

---

---

---

---

---

 Two white telephone receivers are shown on a blue background, one above the other. The receivers are connected by a coiled cord.
 

**Communication Breakdown:**

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

29

---

---

---

---

---

---

---

---

**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.

30

---

---

---

---

---

---

---

---

### Key Points

Communication Breakdown:	Cultural Differences:	Emotional Impact:
The medical team struggles to understand the patient's desires and values, leading to suboptimal decision-making.	The family's cultural beliefs clash with the recommended medical care, creating tension and confusion.	The patient and family members experience heightened emotions, making clear communication even more challenging.

31

---

---

---

---

---

---

---

---

### Resolution:

<p><b>1</b></p> <p><b>Open-Ended Questions:</b></p> <ul style="list-style-type: none"> <li>Ask open-ended questions, allowing patients and families time to share their experiences and feelings.</li> <li>Listening actively and empathetically is essential.</li> </ul>	<p><b>2</b></p> <p><b>Family Meetings:</b></p> <ul style="list-style-type: none"> <li>Facilitate family meetings to clarify goals of care.</li> <li>Discuss the patient's condition, values, and therapy options.</li> <li>Ensure accurate information is provided.</li> </ul>	<p><b>3</b></p> <p><b>Ethics Committee Consultation:</b></p> <ul style="list-style-type: none"> <li>Consider involving the ethics committee to navigate conflicting cultural beliefs and communication challenges.</li> </ul>
---	--	---

32

---

---

---

---

---

---

---

---

### Effective Communication: Key Strategies

<b>Establishing Context</b>	<ul style="list-style-type: none"> <li>Create a supportive and empathetic environment</li> <li>Make sure patients and families feel heard and understood.</li> </ul>
<b>Attentive Listening</b>	<ul style="list-style-type: none"> <li>Show empathy and validate feelings</li> </ul>
<b>Creating Safety</b>	<ul style="list-style-type: none"> <li>Make sure patients won't feel judged for sharing their fears and anxieties</li> </ul>
<b>Goal Planning:</b>	<ul style="list-style-type: none"> <li>What are their preferences regarding treatment options</li> <li>Quality and comfort vs. Quantity</li> </ul>
<b>Honesty:</b>	<ul style="list-style-type: none"> <li>Be transparent and avoid using vague language.</li> <li>Be straightforward even if it is difficult to hear</li> </ul>

33

---

---

---

---

---

---

---

---



**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.



34

---

---

---

---

---


---

---

---

**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.



35

---

---

---

---

---

---

---

---

**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.

36

---

---

---

---

---

---

---

---

**Ethical Complications**

**Conflict Between Autonomy and Non-Maleficence:**

Mrs. Rodriguez's autonomy clashes with her children's desire to prevent harm (non-maleficence). They worry that allowing her to die at home without aggressive medical interventions might lead to unnecessary suffering. The tension between respecting her autonomy and ensuring her well-being creates a dilemma.

**Benevolence of Family and Professional Caregivers:**

Mrs. Rodriguez's family members and healthcare providers genuinely want what is best for her (beneficence). However, their understanding of "what's best" may differ significantly from her own wishes.

37

---

---

---

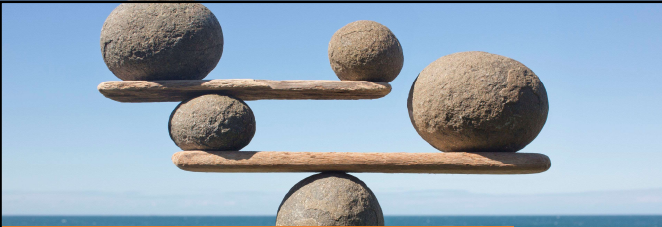
---

---

---

---

---



**Balancing**

- Mrs. Rodriguez's daughter, who acts as her primary caregiver, also has autonomy.
- Balancing her autonomy with her mother's autonomy adds another layer of complexity.

38

---

---

---

---

---

---

---

---

**Decision-Making Capacity**

**Does the patient have the capacity to make self-directed decisions?**

- Patient must be able to.....
  - Understand the relevant information about proposed diagnostic tests or treatment
  - Appreciate their situation (including their current medical condition, treatment options, and consequences of their decision)
  - Use reason to make decisions
  - Communicate their choice

39

---

---

---

---

---

---

---

---

**The Five Statutory Principles**

**1 Presume Capacity**  
Start by thinking the person can make the decision

**2 Support individuals to make their own decisions**  
Do all you can to help the person make the decision

**3 The right to make unwise decisions**  
You must not say a person lacks capacity just because their decision seems unwise

**4 Decisions in best interest**  
Use a best interest checklist if the person can't make a decision

**5 Least Restrictive option**  
Check that the decision made does not strip the individual's freedom more than needed

**The 5 Principles**

40

---

---

---

---

---

---

---

---

**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

41

---

---

---

---

---

---

---

---

**Refusal of Life-Sustaining Treatment Scenario**

**Scenario:** An informed adult patient who is a **Jehovah's Witness** refuses blood products, even when facing a life-threatening situation.

42

---

---

---

---

---

---

---

---

**Refusal of Life-Sustaining Treatment:**

**Dilemma:**

- Balancing the patient's religious beliefs with the duty to provide life-sustaining treatment.

**Resolution:**

- Efforts to persuade the patient should be made, but ultimately, the patient's refusal should be honored.

43

---

---

---

---

---

---

---

---

**End-of-Life Pain Management Misconceptions**

**Unconsciousness:** • Some believe that unconsciousness in dying patients is unnatural or problematic.

**Tradeoff:** • There's a misconception that managing pain may compromise consciousness or shorten life.

**Legal restrictions:** • Concerns about legal limitations on pain management.



44

---

---

---

---


---


---

---

---

**Ineffective Symptom Management**

 Ensuring effective symptom control while respecting patient autonomy can be difficult.

 Balancing pain relief with potential risks requires thoughtful decision-making.

45

---

---

---


---

---

---

---

---



**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.

46

---

---

---


---

---

---

---

---



**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

48

---

---

---

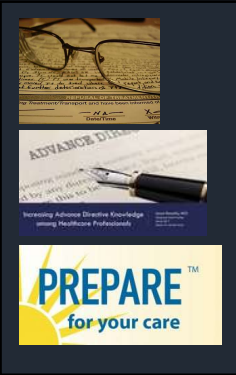
---

---

---

---

---



**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.

49

---

---

---


---

---

---

---

---



**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.

50

---

---

---


---

---

---

---

---



**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.

52

---

---

---

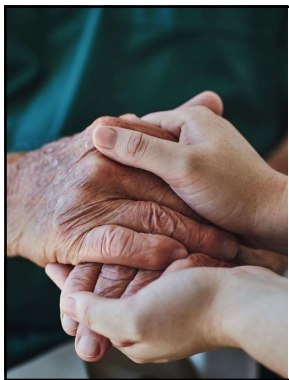
---

---

---

---

---



### 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.

53

---

---

---


---

---

---

---

---



### 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.

54

---

---

---

---

---

---

---

---



### 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.

55

---

---

---

---

---


---

---

---

#### Ethical Issues: End of Life

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



56

---

---

---

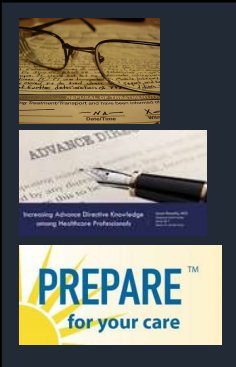
---

---

---

---

---



### 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.

57

---

---

---

---

---

---

---

---

### 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.

58

---

---

---

---

---

---

---

---

## Life Support

Pros:	Cons:	Ethical Dilemmas:
<ul style="list-style-type: none"> <li>• <b>Sustains life:</b> Provides hope and potential solutions.</li> <li>• Some patients make a <b>full recovery.</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Prolongs dying process:</b> In cases where recovery is unlikely, life support may only extend suffering.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Morally wrong to let someone die:</b> Supporters argue against withholding life support.</li> <li>• <b>Morally wrong to keep someone alive without consent:</b> Opponents emphasize autonomy and dignity.</li> <li>• <b>Judicious use of medical resources:</b> Balancing the benefit of life support against resource allocation.</li> </ul>

59

---

---

---

---

---


---

---

---

### Ethical Issues Surrounding CPR/Resuscitation

- Decisions to attempt resuscitation should consider known patient preferences and goals of care.
- Patient receives CPR that does not work or results in a poor quality of life.



60

---

---

---

---

---

---

---

---

### Case Scenario

A critically ill patient who is nearing the end of life. The medical team faces a decision regarding whether to discuss CPR with the patient and record their decision.

What are the conflicting aspects of this situation?

61

---

---

---

---

---

---

---

---

### 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.

62

---

---

---

---

---

---

---

---

### Ethical Guides and Principles: Euthanasia

**Ethical Dilemmas:**

- **Personal Autonomy:**
  - For terminally ill patients, loss of independence and the inability to engage in meaningful activities can make life unbearable. Thus, euthanasia provides a release from such suffering.
- **Compassion:**
  - Respecting patient wishes, offering them a compassionate "remedy".
- **Moral Dilemmas:**
  - Euthanasia raises agonizing moral dilemmas.
  - Is it ever right to end the life of a terminally ill patient experiencing severe pain and suffering?
  - Under what circumstances can euthanasia be justifiable?

63

---

---

---

---

---

---

---

---

## 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.

64

---

---

---

---

---

---

---

---

## 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.

65

---

---

---

---

---

---

---

---



66

---

---

---

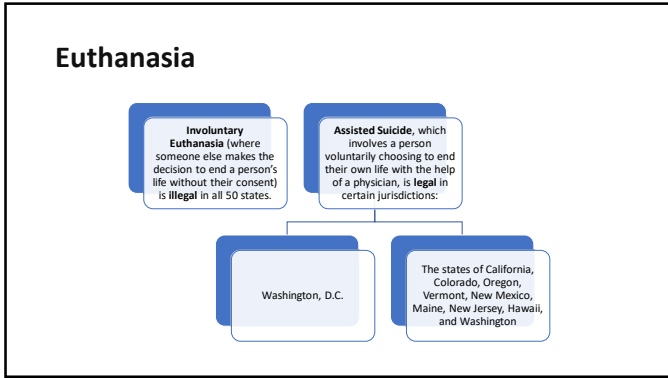
---

---

---

---

---



67

---

---

---

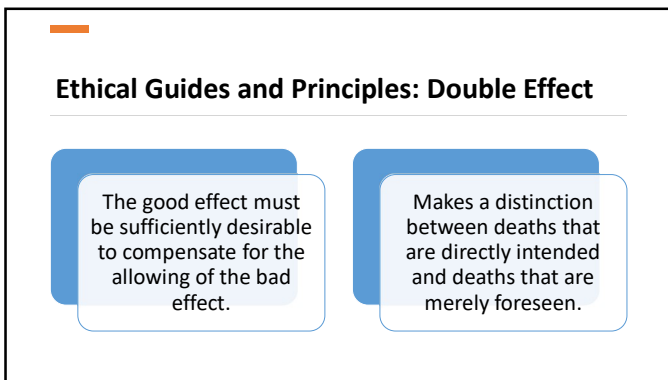
---

---

---

---

---



68

---

---

---

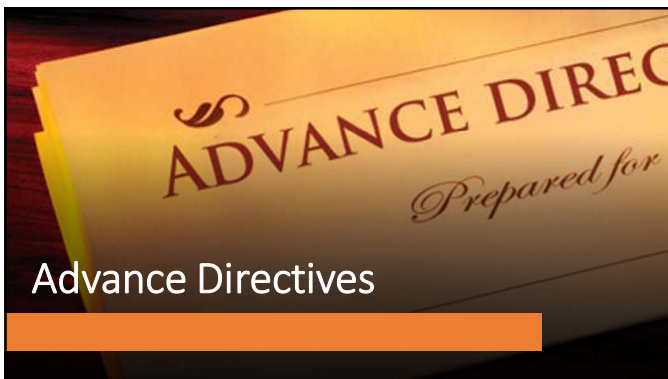
---

---

---

---

---



69

---

---

---

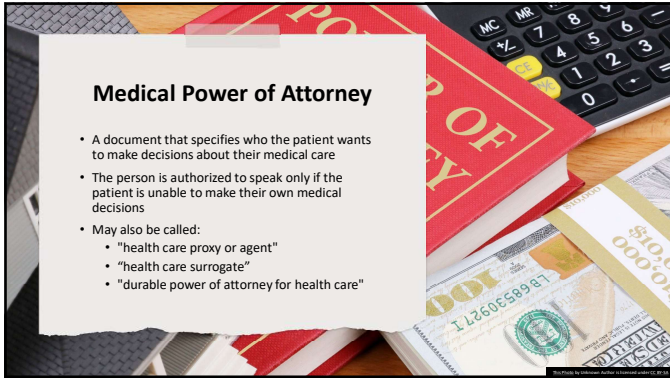
---

---

---

---

---



### Medical Power of Attorney

- A document that specifies who the patient wants to make decisions about their medical care
- The person is authorized to speak only if the patient is unable to make their own medical decisions
- May also be called:
  - "health care proxy or agent"
  - "health care surrogate"
  - "durable power of attorney for health care"

70

---

---

---

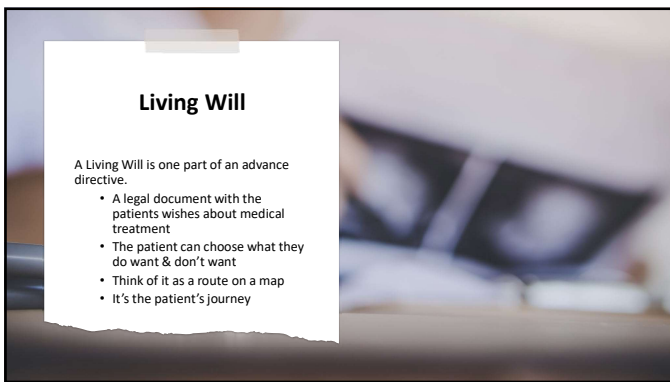
---

---

---

---

---



### Living Will

A Living Will is one part of an advance directive.

- A legal document with the patients wishes about medical treatment
- The patient can choose what they do want & don't want
- Think of it as a route on a map
- It's the patient's journey

71

---

---

---

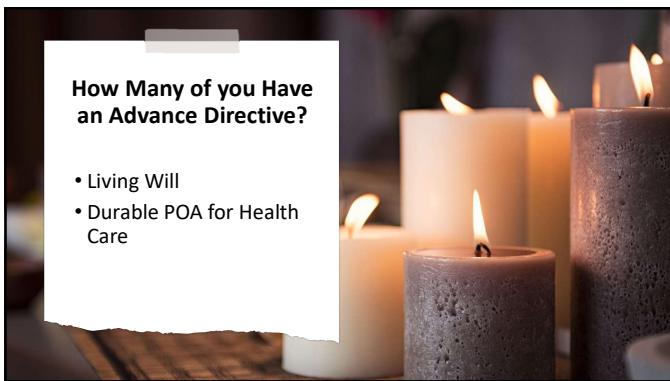
---

---

---

---

---



### How Many of you Have an Advance Directive?

- Living Will
- Durable POA for Health Care

72

---

---

---

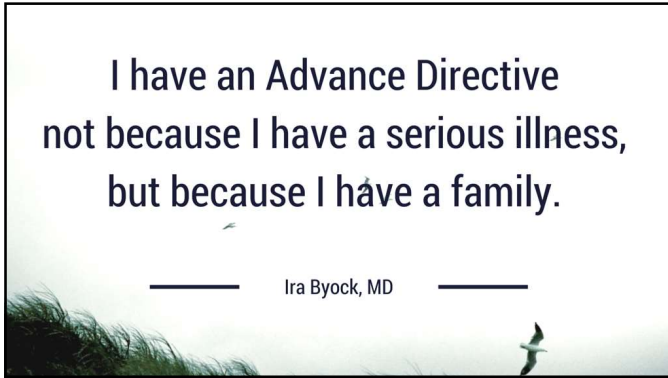
---

---

---

---

---



73

---

---

---

---

---

---

---

---

### What Percentage of Americans have an Advance Directive?

- Approximately **36.7%** of Americans have completed some form of **advance directive**.
- 29.3%** have completed a **Living Will**
- 33.4%** have designated a **Health Care POA**

74

---

---

---

---

---

---

---

---

### Why do so Few American's not have Advance Directives??

- Perceived Unimportance**
  - Belief that it is not necessary; not fully understanding the importance
- Avoidance of Death or Serious Illness**
  - Talking or thinking about death can be emotionally challenging leads to postponing
- Fear of Burdening Others**
  - Fear of causing emotional distress to family; not wanting to burden their family
- Lack of Knowledge**
  - Lack of knowledge prevents them from acting

75

---

---

---

---


---

---

---

---





**Myths about Advance Directives**

- Advance directives means "Do not Treat."
- Appointing a health care POA means giving up control.
- Attorneys are necessary to execute advance directives.
- Physicians and health care providers do not have to honor advance directives.
- Families can freely make decisions in the absence of advance directives.
- Advance directives are only for old and sick people.

76

---

---

---

---

---

---

---

---

**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.

77

---

---

---

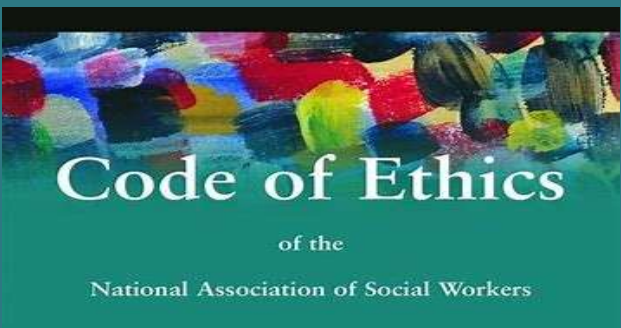
---

---

---

---

---



**Code of Ethics**  
of the  
National Association of Social Workers

78

---

---

---

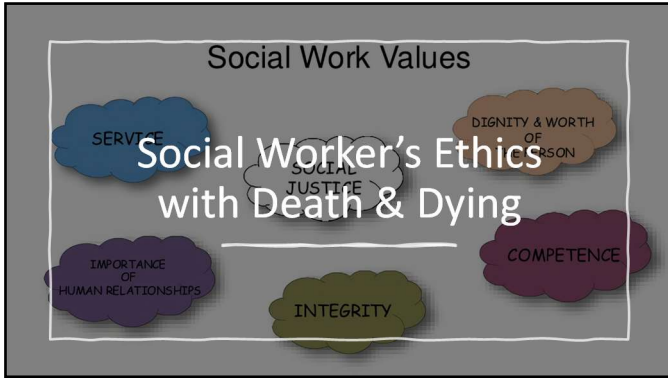
---

---

---

---

---



79

---

---

---

---

---

---

---

---

### Social Work Ethical Principal: Service

Emotional Support and Active Listening:

- Social Workers.....**
- Offer a listening ear and emotional support to patients and their families during this challenging time.
- Validate feelings, address fears, and help individuals cope with the emotional impact of a terminal illness.
- Guide or connect patients to available resources and assist in accessing medical specialists, legal support, transportation and other necessary services.

80

---

---

---

---

---

---

---

---

### 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 ethnic diversity.
- Strive to ensure access to information and equality of resources.

81

---

---

---

---

---

---

---

---

### 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.

83

---

---

---

---

---

---

---

---

### 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...

87

---

---

---

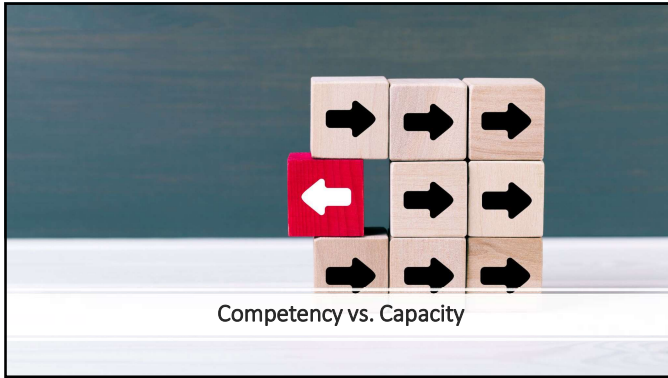
---

---

---

---

---



88

---

---

---

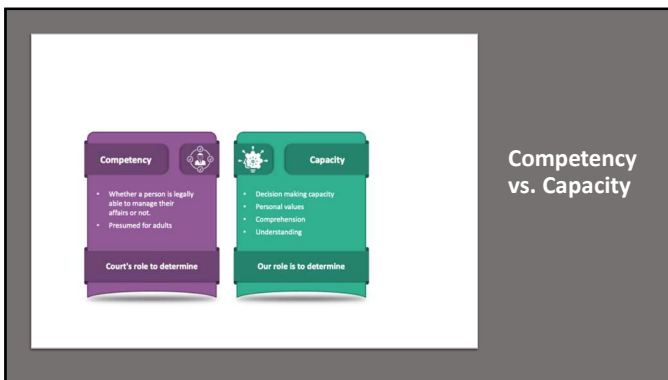
---

---

---

---

---



89

---

---

---

---

---

---

---

---

**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



---

---

---

---

---

---

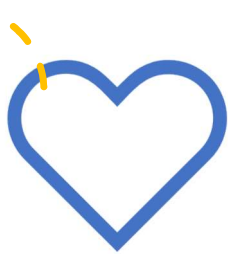
---

---

91

### Capacity to Comprehend Example

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



---

---

---

---

---

---

---

---

92

### Competency

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



---

---

---

---

---

---

---

---

93

### 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

94

---

---

---

---

---

---

---

---



### 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.

95

---

---

---

---

---

---

---

---

### 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.



96

---

---

---

---

---

---

---

---



**Voluntarism: The Forgotten Capacity**

The ability to make free and authentic choices without internal or external coercion which prevents or impedes the exercise of self-determination.

**Example:** A veteran with post-traumatic stress disorder refuses a request from his primary care physician to participate in a research study.

97

---

---

---

---

---

---

---

---

**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

98

---

---

---

---

---

---

---

---

**Ask a Family Member**

The daughter might tell you her mother has always been obstinate, but being uncooperative and cantankerous were new characteristics, more than likely associated with her diminished capacity.

99

---

---

---

---

---

---

---

---



100

---

---

---

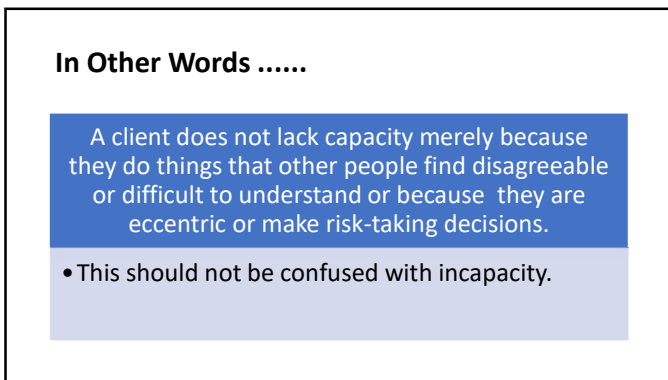
---

---

---

---

---



101

---

---

---

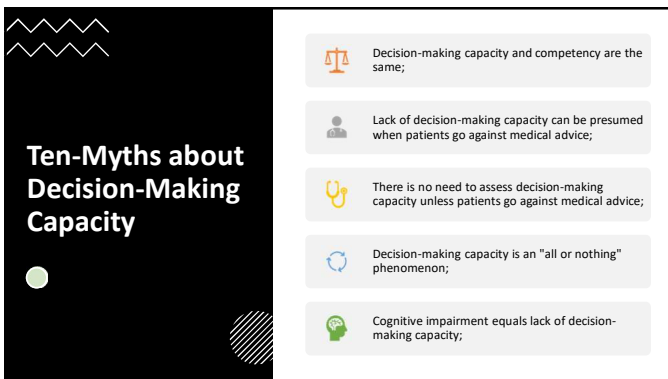
---

---

---

---

---



102

---

---

---

---

---

---

---

---

### 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.

103

---

---

---

---

---

---

---

---

### 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).

104

---

---

---

---

---

---

---

---

### 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?

105

---

---

---

---

---

---

---

---

**Questions to Consider?**

- Can the patient make decisions and/or able to express preferences?
- If not, is there evidence of previously expressed preferences? Who is the appropriate decisionmaker?
- If no known preferences, then consider beneficence, non-maleficence, best interest.

106

---

---

---

---

---

---

---

---

**Logical Point about Capacity**

Worries about capacity sometimes go away when the patient accepts their medical providers recommendation for treatment but not their ability to accept it.

e. g., Being concerned about a patient's ability to refuse treatment for chemotherapy but not their ability to accept it.

107

---

---

---

---

---

---

---

---



**Court Cases-It's What Started it All.**

108

---

---

---

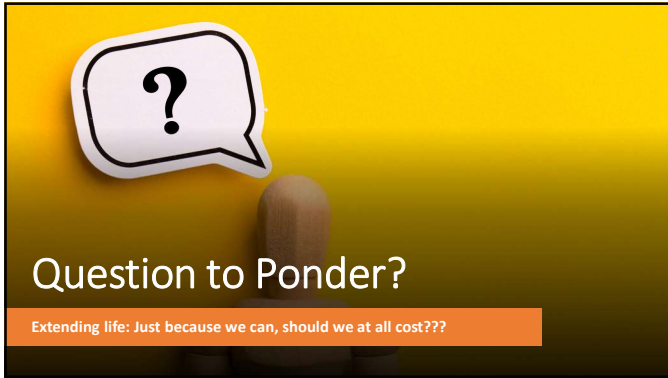
---

---

---

---

---



109

---

---

---

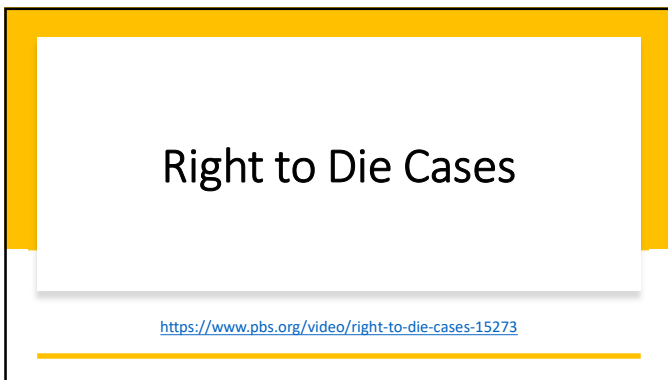
---

---

---

---

---



110

---

---

---

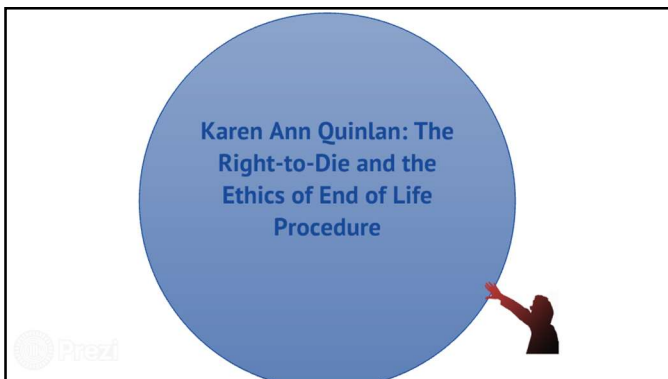
---

---

---

---

---



111

---

---

---

---

---

---

---

---

112

---

---

---

---

---

---

---

---

**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

113

---

---

---

---

---

---

---

---

**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.

114

---

---

---


---

---







---

---

---



## Significant Outcomes of her Case

-  Advanced Directives
-  Creation of Ethical Committees in Hospitals, Nursing Homes, and Hospices
-  Creation of the Health Care Proxy
-  Established substituted judgment
-  Influential in determining Catholic beliefs
-  Karen Ann Quinlan Center of Hope Hospice

115

---

---

---


---

---

---

---

---



Nancy Cruzan - 1990

116

---

---

---

---

---

---

---

---

**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 obligated 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

117

---

---

---

---

---

---

---

---

**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

118

---

---

---

---

---

---

---

---

**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.

119

---

---

---

---

---

---

---

---

**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.

120

---

---

---

---

---

---

---

---





121

---

---

---

---


---







---

---

---

**Case of Terri Schiavo: Central Issues**



-  Who gets to decide when there is no advance directives?
-  Terri had not legally identified who should make such decisions.
-  This case shows the challenges of not providing an advance directive.
-  Advance directive will deter any interference with personal choices, autonomy and liberty interests.
-  Advance Directives uphold the voice of patients even if they have lost abilities to communicate.
-  Advance Directives help to ensure self-determination.

122

---

---

---

---

---

---

---

---

**Ethical Considerations:**

**Ethical Decisions in the Schiavo Case**  
 Uncertainty, conflicts and priorities

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

123

---

---

---

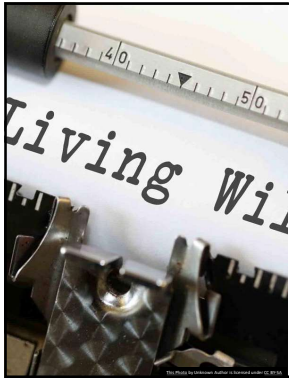
---

---

---

---

---



**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.

124

---

---

---

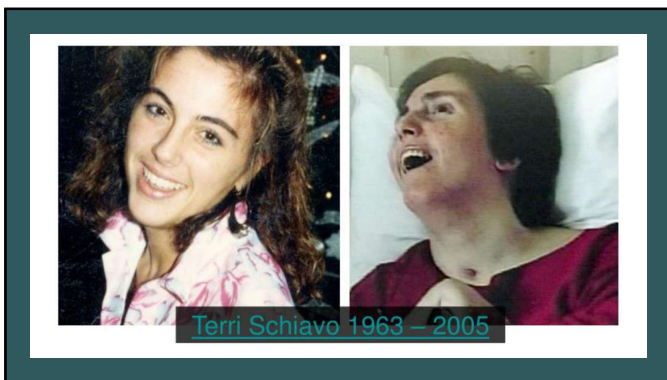
---

---

---

---

---



Terri Schiavo 1963 - 2005

125

---

---

---

---

---

---

---

---



October 2003

126

---

---

---

---

---

---

---

---

## 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

127

---

---

---

---

---

---

---

---

---

---

## 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

128

---

---

---

---

---


---

---

---

---

---



## The Patient Self-Determination Act 1990:

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

129

---

---

---

---

---

---

---

---

---

---

**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.

130

---

---

---

---

---

---

---

---

**Key Provisions:**

<b>Informed Consent:</b>	<ul style="list-style-type: none"> <li>Healthcare providers must <b>inform patients</b> of their rights under <b>State law</b> to make decisions about their medical treatment.</li> </ul>
<b>Advance Directives:</b>	<ul style="list-style-type: none"> <li>Providers are required to inquire whether a patient has executed an <b>advance directive</b>. They must also <b>document the patient's wishes</b> regarding medical care.</li> </ul>
<b>Non-Discrimination:</b>	<ul style="list-style-type: none"> <li>Providers cannot discriminate against individuals who have executed an advance directive.</li> </ul>
<b>Implementation of Wishes:</b>	<ul style="list-style-type: none"> <li>Legally valid advance directives and documented medical care wishes must be <b>implemented</b> to the extent permitted by State law.</li> </ul>
<b>Education:</b>	<ul style="list-style-type: none"> <li>Providers must offer <b>educational programs</b> to staff, patients, and the community on ethical issues related to patient self-determination and advance directives.</li> </ul>

131

---

---

---

---

---

---

---

---

**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.

132

---

---

---

---

---

---

---

---

**Why it Matters?**

The PSDA ensures that our voice is heard in critical healthcare decisions.

It promotes transparency, respect for patient autonomy, and adherence to documented wishes.

133

---

---

---


---

---

---

---

---



**Ethical Dilemma's**

---

**Case Studies**

134

---

---

---

---

---

---

---

---

**Case Study 1:  
Mrs. Clark**

---

135

---

---

---

---


---

---

---

---

- 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

136

---

---

---

---

---


---

---

---

### 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



137

---

---

---

---

---


---

---

---

### 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.



138

---

---

---


---

---

---

---

---



### 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

139

---

---

---

---

---


---

---

---

### Shared Decision-Making

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



140

---

---

---

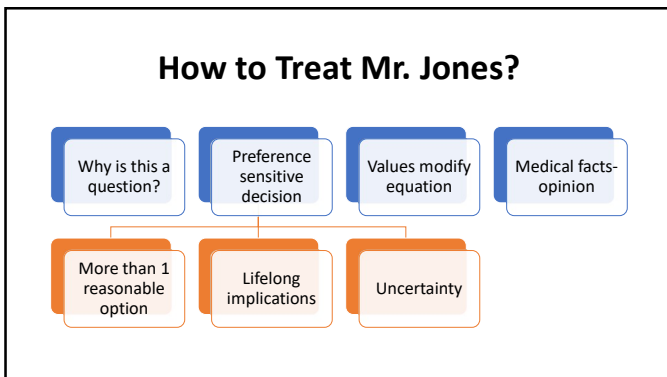
---

---

---

---

---



141

---

---

---

---

---

---

---

---



**Other Questions:**

- Do we have to put him on a ventilator
  - Are we killing him?
- Who decides?
- Does he have advance directives?
- Why is there no info. on the SNF chart?
- What is his quality of life?
  - Is it a life worth prolonging?
- Who can find his family and talk to them?
- How can we treat his suffering?
- Should we admit him to the ICU?

142

---

---

---

---

---

---

---

---



**Ethics Guide Decision-Making**

- Ethical principals and a systematic approach should be used to facilitate decision-making.

143

---

---

---

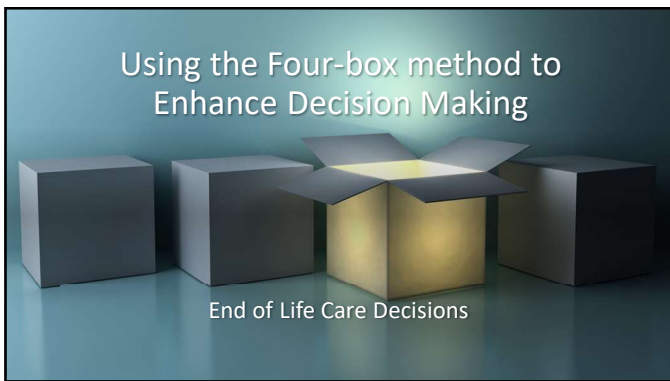
---

---

---

---

---



**Using the Four-box method to Enhance Decision Making**

End of Life Care Decisions

144

---

---

---

---

---

---

---

---





145

---

---

---

---

---


---

---

---

### 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**



146

---

---

---

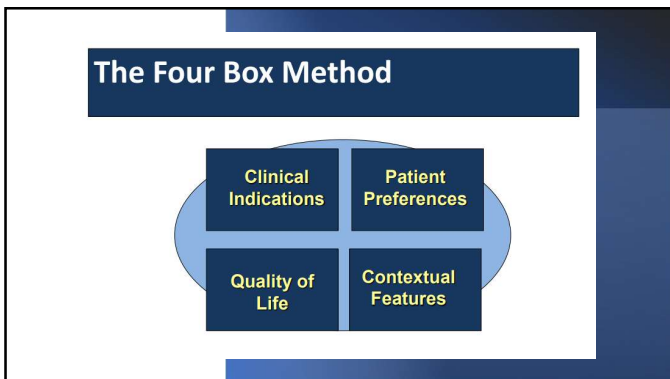
---

---

---

---

---



147

---

---

---

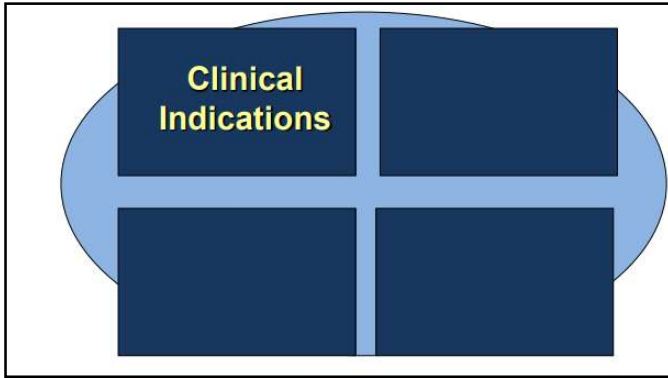
---

---

---

---

---



148

---

---

---

---

---


---

---

---

**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?



A magnifying glass with a yellow handle is positioned over a purple background filled with white question marks of various sizes.

149

---

---

---

---

---

---


---

---

**Beneficence and Non-Maleficance**

Obligation to determine what is medically indicated (beneficial).

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



A blue semi-circle graphic on the left side of the text boxes.

150

---

---

---

---

---

---

---

---

### Futility Considerations with Bonnie:

Patients with advanced Dementia are susceptible to pressure sores and pneumonia.

Patients with advanced dementia tend to be bed-chair confined and have incontinence.

Research indicates actually that tube feeding causes more pneumonia than hand feeding a patient with advanced Dementia.

Inserting a feeding tube will not stop this process.

Pneumonia is a complication of tube feeding,

151

---

---

---

---


---

---

---


---

### Case of Bonnie:



**Physiological**

Can we provide a medical benefit to Bonnie with the feeding tube?  
Does the benefits outweigh the risks?  
Will this improve Bonnie's quality of life?  
Will this improve her cognition?



**Quantitative**

Less than 1% chance of treatment success

152

---

---

---

---

---

---

---

---

### 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.

153

---

---

---

---

---

---

---

---

### 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

154

---

---

---

---

---

---

---

---

### Suffering



Studies suggest most dying patients do not experience hunger/thirst



Hunger/thirst relieved with small amounts of food and ice chips, not feeding tubes



Terminally ill patients who refused food/water do not demonstrate signs of discomfort

155

---

---

---

---

---

---

---

---

### Potential Harm

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

156

---

---

---

---

---

---

---

---

**Likely Beneficial**

- Support for reversible problems
  - Dysphagia related to CVA (still maintains a good quality of life)
  - Critical illness
- Nutritional support during oncology treatment
  - Chemotherapy – Optimizing nutrition for therapy
- Allow time for accurate assessment of recovery
  - Traumatic brain injury
- Chronic disabilities with tube feeding providing quality
  - Parkinson's disease

157

---

---

---

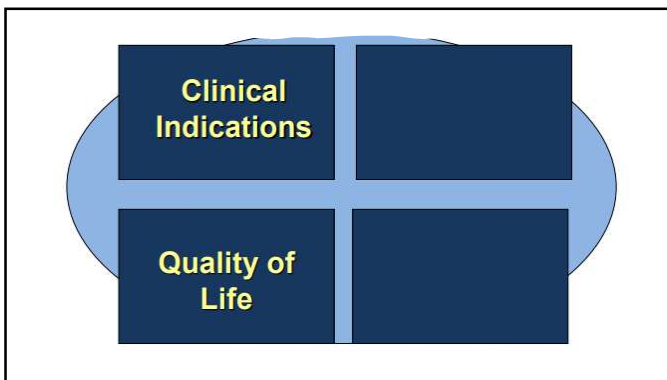
---

---

---

---

---



158

---

---

---

---

---

---

---

---

**Quality of Life (QOL)**

- What constitutes quality?
- Whose definition? –What is the expected QOL with and without treatment: physical, emotional, social, spiritual?
- Are their additional resources to optimize quality?

159

---

---

---

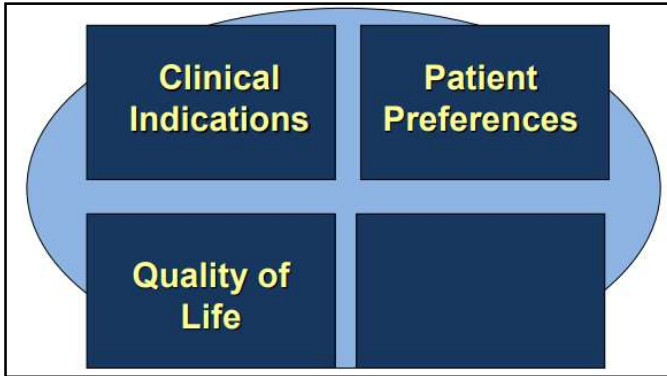
---

---

---

---

---



160

---

---

---

---


---


---


---

---

**Legal Right to Choose and Refuse**

 Our Constitution guarantees liberty and privacy

 The right to refuse end-of-life care was guaranteed with the passage of the federal Patient Self-Determination Act (PSDA)

 Decisions must be based upon the elements of informed consent (veracity)

161

---

---

---

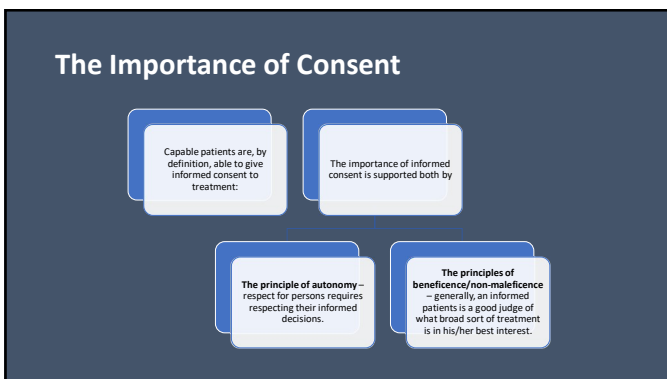
---

---

---

---

---



162

---

---

---

---

---

---

---

---

### Benevolence Toward Incapable Patients

An assessment of capacity helps us figure out what matters morally.

In the case of an incapable patient, we no longer have recourse to the **principle of autonomy**.

The **principles of benevolence/nonmaleficence** require that incapable people be protected from making decisions that are harmful or that they would not make if capable.

163

---

---

---

---

---

---

---

---

### A Better Idea

- Make plans while you are still competent
- Execute your advance directives:
  - Living Will
  - Medical POA
  - Trust

164

---

---

---

---

---

---

---

---

Clinical Indications	Patient Preferences
Quality of Life	Contextual Features

165

---

---

---

---

---

---

---

---

### Contextual Features: Family Factors



166

---

---

---

---

---

---

---

---

### Contextual Features: Cultural Factors



167

---

---

---

---

---

---

---

---



168

---

---

---

---

---

---

---

---





### 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.

169

---

---

---

---

---

---

---

---

### 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

170

---

---

---

---

---

---

---

---

### 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.

171

---

---

---

---

---

---

---

---

### 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.




---

---

---

---

---

---

---

---

172

### 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.

---

---

---

---

---

---

---

---

173

### 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.




---

---

---

---

---

---

---

---

174



### 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.

175

---

---

---

---

---


---

---

---

### 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.



176

---

---

---

---

---

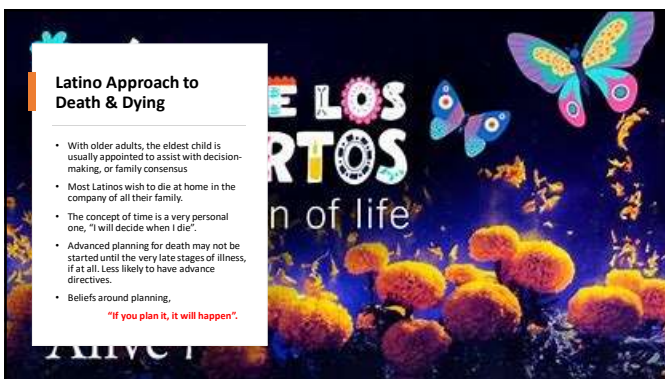
---

---

---

### 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".



177

---

---

---

---

---

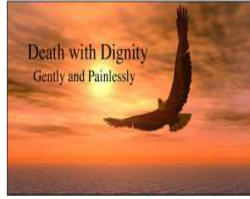
---

---

---

### 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.




---

---

---

---

---

---

---

---

178

### 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.

---

---

---

---

---

---

---

---

179

### Conclusion..... What can I do??

#### Pain Management and Comfort:

Prioritize pain control and comfort. No one should suffer needlessly.

#### Advance Care Planning:

Encourage patients to create advance directives.

#### Legal Considerations:

Provide compassionate care while respecting the law.

---

---

---

---

---

---

---

---

180



181

---

---

---

---

---

---

---