

Ethical & Legal Issues in Clinical Practice: End-of-Life Issues

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This Presentation is Approved
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Learning Objectives

- Describe the ethical, legal, cultural, & psychosocial issues pertaining to end-of-life care
- Describe issues confronting caregivers when they are involved in end-of-life care

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Legal Issues Pertaining to Death

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Determination of Death

- **Uniform Determination of Death Act (accepted by most states)**
- **Purpose: to provide a comprehensive & medically sound basis for determining death in all situations**
- **Determinants of death**
 - ❖ **Cessation of circulatory and respiratory**
 - ❖ **Cessation of brain function**
- **State Law – Not Federal**

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Case Study: Jahi McMath

- 2013 declared brain dead in CA
- Alive again in NJ
- 2018 dead in NJ

➤ Legal Case

- ❖ Lewis, A., Pope, T. M., & Bonnie, R. J. (2020). Dead in California, alive in New Jersey. *Neurology Today*, 20(1), 7–9.
https://journals.lww.com/neurotodayonline/fulltext/2020/01090/dead_in_california,_alive_in_new_jersey_.7.aspx

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Determination of Death

- Clinical signs of brain death
 - ❖ Apnea: test done by RCP
 - ❖ PaCO₂ ≥ 60
 - ❖ PaCO₂ ≥ 20 Baseline
 - ❖ Absence of cough, gag reflex
 - ❖ Absence of pupillary response
 - ❖ Absence of corneal reflex
 - ❖ Positive doll's eyes
 - ❖ Absent response to pain

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Determination of Death

- **Coma: does not respond to external stimuli**
- **Persistent Vegetative State (PVS)**
 - ❖ Irreversible cessation of higher functions of brain
 - ❖ Involuntary (autonomic) bodily functions present
 - ❖ No reasonable expectation of reversal

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Autopsies

- **Coroner's cases: varies among states**
 - ❖ Homicide, suicide
 - ❖ Natural deaths
 - No signed death certificate
 - Sudden, unexpected deaths
 - Drug-related
 - Potential public health threat
 - Incarcerated individuals

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Right-to-Die

- State laws vary
- Uniform Rights of Terminally Ill Act provides guidelines for states
- Physician-assisted death
 - California
 - Colorado
 - District of Columbia
 - Hawaii
 - Maine
 - Montana
 - New Jersey
 - New Mexico
 - Oregon
 - Vermont
 - Washington

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Case Study: Brittany Maynard

- Background:
 - 29-year-old newlywed from California
 - Diagnosed in 2014 with glioblastoma multiforme (aggressive brain cancer)
 - Prognosis: ~6 months to live with severe decline expected
- End-of-Life Decision:
 - California did not allow physician-assisted death at the time
 - Moved to Oregon to use Death with Dignity Act
 - Met legal requirements: physician confirmations, written & verbal requests, competence checks
- Public Advocacy:
 - Shared her story through videos and Compassion & Choices
 - Became national symbol of the right-to-die movement

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Lessons Learned: Brittany Maynard

- **Patient Autonomy:**
 - Maynard's case highlighted the importance of respecting patient choices in terminal illness
- **Advance Care Planning:**
 - Showed the need for clear legal frameworks to support end-of-life decisions
- **Public Advocacy:**
 - Her openness increased national awareness of physician-assisted death options
- **Legislative Impact:**
 - Directly influenced California's End of Life Option Act (2016)
- **Healthcare Practice:**
 - Reinforced importance of communication, dignity, and compassion in end-of-life care

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Right-to-Die

- **Patient Self Determination Act of 1990** requires healthcare facilities to provide written information to patients about their rights to
 - ❖ Make medical decisions
 - ❖ Advanced directives

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Advanced Directives

- Detailed instructions regarding a patient's wishes for end-of-life treatment
- Patient must be competent to generate advanced directive

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Advanced Directives

- May include any or all the following
 - ❖ Circumstances under which treatment should be discontinued
 - ❖ When heroic measures should or should not be taken
 - ❖ Directions for organ donation, autopsy, or alternative treatment

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Advanced Directives

- **Durable Power of Attorney:** designates individual(s) to act on another's behalf in all legal matters
 - ❖ Takes effect when the grantor loses ability to make decisions
 - ❖ Acts as health care proxy
 - ❖ Acts as power of attorney for end-of-life situations

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Lessons Learned: Terri Schiavo

- **Advance Directives are critical:**
 - Schiavo had no written directive, leading to years of conflict
- **Legal & Ethical Principles:**
 - Substituted judgment vs. best interest
 - Courts upheld patient's autonomy
- **Family Dynamics:**
 - Conflicts between spouse and parents intensified the case
- **Political Overreach:**
 - Legislative & executive intervention prolonged dispute
- **Healthcare Practice:**
 - Reinforced importance of communication & planning in end-of-life care

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Case Study: Nancy Cruzon

- **Background:**
 - 1983: Nancy Cruzon (25) in car accident → severe brain injury
 - Persistent Vegetative State (PVS) for years
 - Maintained by feeding tube
- **Family & Doctors:**
 - Parents requested removal of feeding tube
 - Treating physicians supported withdrawal
- **Outside Intervention:**
 - Missouri state officials & right-to-life groups opposed
 - Argued no clear evidence of Nancy's wishes
- **Legal Battle:**
 - Cruzan v. Director, Missouri Dept. of Health (1990)
 - U.S. Supreme Court ruled states may require 'clear and convincing evidence' of patient's wishes

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Lessons Learned: Nancy Cruzon

- **Outside groups may intervene**
- **Written advanced directives**
- **Patient autonomy**
- **Medical futility**

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Do-Not-Resuscitate Order

- Order issued when a patient specifies that no CPR should be performed
- Patient must be competent
- Different procedure exists in each state

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Do-Not-Resuscitate Order

- Often abrogated by others
 - ❖ Family
 - ❖ Physicians

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Do-Not-Resuscitate Order

- **Bases for abrogation**
 - ❖ **Incompetence of patient**
 - ❖ **Reversibility of condition**
 - ❖ **Ignorance of DNR status**
 - ❖ **Panic**

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Do-Not-Resuscitate Order

- **Bases for abrogation**
 - ❖ **Incompetence of patient**
 - ❖ **Reversibility of condition**
 - ❖ **Ignorance of DNR status**
 - ❖ **Panic**
 - ❖ **Emergency call: no choice for EMS, depending on state law**
 - ❖ **Denial of patient's rights to DNR status**

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Resuscitation Types/Levels

- Everything but chest compression
- Everything but intubation
- Medications only
- Comfort measures only
- 2 from column A, 1 from column B
- Token resuscitation (slow codes)

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Euthanasia

- Active euthanasia: conscious act that results in death
 - ❖ Legal? In the Netherlands
 - ❖ Legal in Colombia
 - ❖ Physician-assisted suicide: Legal in U.S.
 - California
 - Colorado
 - District of Columbia
 - Hawaii
 - Maine
 - Montana
 - New Jersey
 - New Mexico
 - Oregon
 - Vermont
 - Washington

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Euthanasia

- **Involuntary euthanasia**
 - ❖ Ethical concern: euthanasia could be extended
 - ❖ Vonnegut, K. (1968). *Welcome to the Monkey House*. In *Welcome to the Monkey House: A collection of short works* (pp. 217–248). New York, NY: Delacorte Press.
 - ❖ Katrina incident

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Euthanasia vs. DNR

- **Killing vs. removing obstacles to death**
- **Heroic measures often only prolong the dying experience for all concerned**

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Hospice

- **Facilities to care for dying patients - home or facility**
- **Focuses of care**
 - ❖ **Pain control**
 - ❖ **Symptom control**
 - ❖ **Emotional support: for all**
 - ❖ **Not curative or rehabilitative**
 - ❖ **Not euthanasia or assisted suicide**

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Palliative Sedation

- **Definition:**
 - **Intentional lowering of consciousness to relieve refractory symptoms at end of life**
 - **Goal is comfort, not hastening death**
- **Indications:**
 - **Refractory pain, dyspnea, agitation, delirium**
 - **Considered when no other treatments are effective**
- **Ethical Distinctions:**
 - **Different from euthanasia: intent is symptom relief, not causing death**
 - **Doctrine of Double Effect: relief justified even if life is unintentionally shortened**
- **Key Takeaway:**
 - **Compassionate, ethically supported practice**
 - **Used in hospice/palliative care to maintain dignity and comfort**

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End-of-Life Decisions

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Factors That May Affect Decisions

- **Religion**
 - ❖ Most religions do not forbid DNR, life support withdrawal
 - ❖ May refuse sedation, pain medications

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Factors That May Affect Decisions

- **Religion**
 - ❖ **Jewish law forbids hastening of death**
 - **May influence physicians**
 - **Discontinuation of life support**
 - **Autopsy**

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Factors That May Affect Decisions

- **Issues influenced by culture**
 - ❖ **Communication of bad news**
 - **Some cultures dispute right to informed consent**
 - **Informing patient may be considered cruel**
 - **Informing patient may be considered self-fulfilling prophesy**

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Factors That May Affect Decisions

- **Issues influenced by culture**
 - ❖ **Locus of decision-making**
 - Patient does not decide
 - Illness is family event
 - Family may be the collective decision-maker

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Factors That May Affect Decisions

- **Issues influenced by culture**
 - ❖ **Minority attitudes about advanced directives & end-of-life care**
 - Mistrust for healthcare system
 - Less likely to have advanced directives, DNR status
 - Less likely to be organ donors

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Factors That May Affect Decisions

- **Age of patient**
 - ❖ Asians revere elderly & want aggressive care
 - ❖ Parents: difficult to let children go
- **Finances**
 - ❖ Families may be collecting social security, retirement, etc.

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Grieving

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Kubler-Ross' Grief Stages

- Denial & isolation
- Anger, rage, & resentment
- Bargaining & guilt
- Depression or sadness
- Acceptance

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Worden's Task-Based Model of Mourning

- Accept reality
- Process the pain
- Adjust to the World
- Enduring connection → New life

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Morbid Grieving

- Persons may get 'stuck' in a stage
- May never finish grieving

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Complicated Grieving

- Absence of crying
- Hyperactivity
- Somatic symptoms
- Hostility
- Wooden affect

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Grief Over Child

- **Loss of future**
- **Finances**
- **Siblings**
- **Failure to bond (neonates)**
- **Guilt: about everything**

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Issues Confronting Practitioners

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Pulling the Plug

- Legality: valid order
- Sources of difficulty
 - ❖ Therapist perceptions
 - Religion, culture
 - Reversibility of condition: terminal?

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Pulling the Plug

- Legality: valid order
- Sources of difficulty
 - ❖ Therapist perceptions (religion, culture)
 - ❖ Conscious, cognizant patient

**"I wonder how many people looked up
& saw me as their last person, ever."**

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Pulling the Plug

- **Sources of difficulty**
 - ❖ **Therapist perceptions (religion)**
 - ❖ **Conscious patient**
 - ❖ **Family conflict over discontinuation**

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Pulling the Plug

- **Legality: valid order**
- **Sources of difficulty**
 - ❖ **Therapist perceptions (religion)**
 - ❖ **Conscious patient**
 - ❖ **Family conflict over discontinuation**
 - ❖ **Procedural: terminal wean or extubation**

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Futile Procedures

- **Ethical issues**
 - ❖ **Prolongation of suffering**
 - ❖ **Resource misallocation**
 - **Financial**
 - **Time**
 - **Scarce resources, e.g. blood**
 - ❖ **Motivation for procedures**

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Denial of Right-to-Die

- **Legality: are the orders legal?**
- **Ethical issues**
 - ❖ **Our role in denying patient's rights**
 - ❖ **Motivation behind denial of rights**

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Resolutions & Defenses

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RTs Have Company

- **Nurses**
- **Physicians**
- **Social workers**
- **Chaplains**

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Personal Impact of Ethical Conflicts

- Frustration
- Burnout, malingering
- Depression
- Anger
- Negative attitudes about blood, organ donation

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Defense Mechanisms

- Arcane humor
- Religious faith
- Philosophy
- Talking about issues

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Possible Resolutions

- **Education about issues & alternative viewpoints**
 - ❖ **Promote comprehension**
 - ❖ **Eliminate anger**
- **Regular conferences about issues**
- **Rotating assignments to healthier units**

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Summary & Review

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Summary & Review

- **Legal issues**
 - ❖ **Determination of death**
 - ❖ **Autopsy**
 - ❖ **Right-to-die**
 - ❖ **Euthanasia**
 - ❖ **Hospice care**

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Summary & Review

- **Factors for end-of-life decisions**
 - ❖ **Religion**
 - ❖ **Culture**
 - ❖ **Patient age**
- **Grieving**
 - ❖ **Stages**
 - ❖ **Complicated grieving**

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Summary & Review

- **Issues confronting practitioners**
 - ❖ Pulling the plug
 - ❖ Futile procedures
 - ❖ Denial of right-to-die
- **Resolutions & defenses**
 - ❖ Personal impact
 - ❖ Possible resolutions

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The End



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