

# Issues in End of Life Care



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Irene Robitaille Belanger 1913-2003

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# Objectives:



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1. Describe the historical aspects of decision making in the American health system
2. Identify three principles guiding healthcare decisions
3. Discuss the types of advance care planning documents used in the U.S.
4. Apply ethical principles to resolve complex cases

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# How we die in the US (CDC, 2018)



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- 75% of all deaths are attributed to 10 causes
  - The top 3 account for approximately 50%
    - Heart disease (23.4%)
    - Cancer (22.5%)
    - Chronic lower respiratory disease (5.6%)
  - US life expectancy is 78.8 yrs.

# Hospital deaths in 2010 (CDC, 2018)

- 75% of inpatient deaths were 65 and older
  - 27% of those were over 85
- Most common causes
  - Respiratory failure
  - Pneumonitis
  - Septicemia
- Length of Stay: 7.9 days



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# Hospital deaths: What we know



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- Most hospital deaths occur in ICU
  - Deaths are within the first few days (Williams, 2010)
  - Families of older patients perceived a better death experience than families of younger pts. (Lewis-Newby, 2011)
  - Patients with advance directives stating no code have higher APACHE II scores than full code group (Van Scoy & Sherman, 2013)

# Historical Perspectives (Kennedy, 1976; McFadden, 1985)



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- Karen Ann Quinlan April, 1975
  - 9/75: Parents petitioned courts to remove her ventilator and allow her to die “with grace and dignity” after physicians refuse to do so
  - Removal seen as death from natural causes
  - Vent was considered an extraordinary measure but not the feeding tube
  - Died of pneumonia 10 yrs. later



# Historical Perspectives

(Legal Information Institute, 2018)

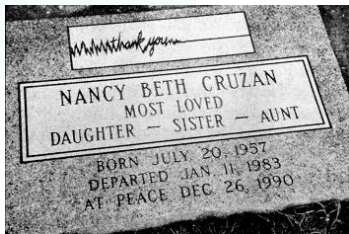


- Nancy Cruzan January, 1983
  - Family petitioned Missouri courts to have feeding tube removed
    - Refused based on lack of “clear and convincing” evidence
  - The case went to the US Supreme Court in 1990
    - Patient Self-Determination Act passed 1991
    - States developed medical proxy laws
  - Case heard again with new evidence



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# Patient Self-Determination Act (American Bar Association, 2018)



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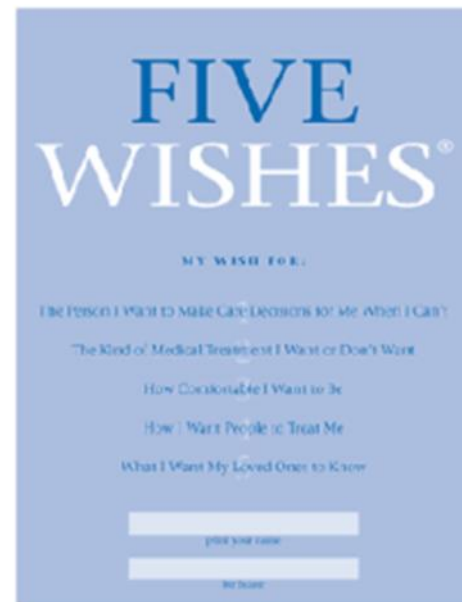
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- Written notice of rights & policies (Dec, 1991)
  - Right of patients to make decisions regarding care
  - Right to accept or refuse medical treatment
  - Right to make an advance directive
- Inquire about the existence of AD and document
- Education of staff
- Must admit and treat patients regardless of presence or absence of AD

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# Types of Advance Directives

- Durable Power of Attorney for Healthcare
- Living Will
- Five Wishes Document (Aging with Dignity, 2018)
- Physician Orders for Life-Sustaining Treatment (POLST)
  - Comfort Measures
  - Antibiotics
  - Artificial Nutrition & Hydration
  - CPR



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# Advance Directives (AD) (NICHE, 2012)

## Elements

- Value neutral
- Used to request or refuse treatments
- Provide guidance

Protection for healthcare providers and families

State statutes determine validity

Not the norm for most adults

- 25% of general public
- 51% of nursing home patients

Most decisions made by surrogates



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# Four Principles

Beauchamp & Childress (2001)



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- Respect for Autonomy
- Beneficence
- Nonmaleficence
- Justice

And two more to consider:

- Fidelity
- Veracity

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# Principle of Respect for Autonomy

(Beauchamp & Childress, 2001)



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- Persons deserve respect
- Persons have dignity
- Basis for privacy & confidentiality
- Grounds for truth telling
- Patient right to self-determination
  - Informed consent
- Patient choice is a right, not a duty



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# Components of Informed Consent



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- “An individual’s autonomous authorization of a medical intervention”
  - Disclosure
  - Comprehension
  - Voluntariness
  - Consistency
  - Communicating a choice

• Beauchamp & Childress, 2001

# Decisional Capacity

## Elements

- Understand and process information about diagnosis, prognosis, and treatment options
- Weigh benefits, burdens, and risks of care options
- Apply personal values to the analysis
- Arrive at decision that is consistent over time
- Communicate decision

The threshold for determination of decisional capacity is an assessment of an individual's ability to make decisions about healthcare and treatment

Jones & Holden (2004)



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# Standards for Decision Making

- Substituted Judgment
  - Decisions based on how the patient would decide
- Best Interests
  - When there's no knowledge of patient wishes
  - Standard for children
  - For those who have never been competent



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# Beneficence / Nonmaleficence



- Obligation to maximize possible benefits and “do no harm”
- Benefit requires a clinician’s “best judgment” discernment
- Beneficence includes protecting, defending, helping, rescuing as well as preventing and removing conditions that will cause harm to the individual
  - Advocacy

Beauchamp & Childress, 2001



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# Justice



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- Fairness in distribution or what is deserved
  - Injustice occurs when an entitled person is denied or an undue burden is imposed without good reason
- To each person:
  - (1) an equal share, (2) according to individual need, (3) according to individual effort, (4) according to societal contribution, and (5) according to merit.

Belmont report, 1979

# Ethical “Hotspots”

- Balance of benefits and harms
- Disclosure, informed consent & shared decision making
- Norms of family life
- Patient-provider relationships
- Professional integrity
- Cost effectiveness & resource allocation
- Cultural differences
- Considerations of power



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# Challenging EOL Situations



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- The family that wants everything done, in the situation of futile care
- The dying patient without capacity who needs treatment but has no surrogate
- The person who refuses treatment but the family disagrees
- Full code order in actively dying

# Ethical Considerations



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- Withholding vs. withdrawing life-sustaining treatment
- Ordinary vs. extraordinary means to preserve life
  - Proportionate vs. disproportionate
  - Risks and benefits (objective)
  - Benefits and burdens assessment (subjective)

# Withdrawal of non-medically beneficial treatment



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- May include ventilator, dialysis, medications, etc.
- Not considered “withdrawal of care”
- Never done with the intention of ending life
- Death results from the underlying condition
- May be determined from AD and/or benefits/burdens determination

# Medically Assisted Nutrition & Hydration (MANH)



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- Used when person cannot swallow/eat
  - When it offers reasonable hope of benefit
  - When it will not pose excessive burden
- May be withdrawn
  - When it causes harm or becomes burdensome  
Increases symptom burden, e.g. aspiration,  
agitation, GI disturbance with skin breakdown

# Case Study



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- Ms. Tate a 54-y/o patient with uncontrolled hypertension is admitted to the Neuro ICU with a diagnosis of CVA with intraventricular extension. She has two daughters who live in California and an estranged sister. Her mother is frail and elderly and lives in a nursing home. She lives with her boyfriend. Decisions must be made regarding her care.



# Resources for Resolving Ethical Issues

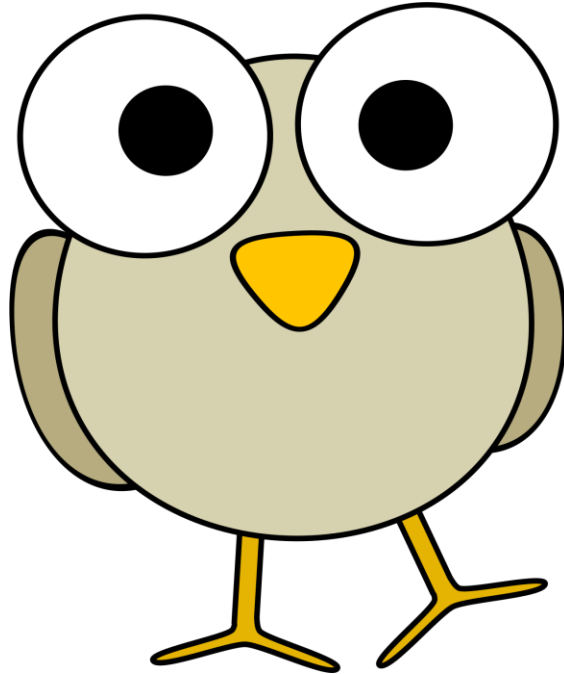


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- Advance care planning
- Institutional Ethics Committees
  - Ethics consultations
  - Organizational policy, DNR/DNI, etc.

# Questions?



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# References:

Aging with Dignity. (2018) Five Wishes. Retrieved from:

<https://www.agingwithdignity.org/five-wishes/about-five-wishes>

American Bar Association. (2018). Law for older Americans: Health care advance directives. (2018). Retrieved from

[https://www.americanbar.org/groups/public\\_education/resources/law\\_issues\\_for\\_consumers/patient\\_self\\_determination\\_act.html](https://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_determination_act.html)

Beauchamp, T. L. & Childress, J. F. (2001). *Principles of biomedical ethics* (5<sup>th</sup> ed.). NY: Oxford University Press.

Centers for Disease Control and Prevention. National Center for Health Statistics: Deaths and mortality. Retrieved from <https://www.cdc.gov/nchs/fastats/deaths.htm>

Jones, R. C. & Holden, T. (2004). A guide to assessing decision-making capacity. *Cleveland Clinic Journal of Medicine*, 71(12), 971-975.



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# References:

- Kennedy, I. M. (1976). The Karen Quinlan case: Problems and proposals. *Journal of Medical Ethics, 2*, 3-7.
- Legal Information Institute, (2018). Cruzan by Cruzan v. Director, Missouri Department of Health. Retrieved from <https://www.law.cornell.edu/supremecourt/text/497/261>
- Lewis-Newby, M., Curtis, J. R., Martin, D. P., & Engelberg, R. A. (2011). Measuring family satisfaction with care and quality of dying in the intensive care unit: Does age matter? *Journal of Palliative Medicine, 14*(12), 1284- 1290. DOI: 10.1089/jpm.2011.0138
- McFadden, R. D. (June, 1985). Karen Ann Quinlan, 31, dies; Focus of '76 right to die case. The New York Times. Retrieved from <https://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html>
- Nurses Improving Care for Hospital Elders (NICHE). (2012). Healthcare decision making. NICHE, New York, NY.



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# References:

Scott, K., Thiel, M. M., Dahlin, C. M. (2008). The national agenda for quality palliative care: The essential elements of spirituality in end-of-life care. *Chaplaincy Today*, 24(2), 15-21.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont Report*. Washington, DC: US Government Printing Office.

Williams, T. A., Ho, K. M., Dobb, G. J., Finn, J. C., Knuiman,, M., & Webb, S. A. R. (2010). Effect of length of stay in intensive care unit on hospital and long term mortality of critically ill adult patients. *British Journal of Anaesthesia*, 104(4), 459-464. doi:10.1093/bja/aeq025

Van Scoy, L. J., & Sherman, M. (2013). Factors affecting code status in a university hospital intensive care unit. *Death Studies*, 37, 768-781. DOI: 10.1080/07481187.2012.699908



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