


Ethics in Nutrition at End of Life

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 High Calorie Recipes
 Dietitian Side Hustle

Objectives



Upon successful completion of this session, the participant should be able to:

- describe ethics and common **ethics terminology**.
- identify potential **ethics issues** in nutrition at end of life.
- **feel comfortable** with ethical decision making.



Outline

- Nutrition at end of life
- What is ethics?
- Ethics terminology
- Ethics in nutrition at end of life
- Putting it into perspective
- How to use what you've learned
- Conclusion
- Questions





Nutrition at End of Life

END OF LIFE CARE


- The support and medical care given during the time surrounding death.
- Beyond just the moments before breathing ceases and the heart stops beating.
- Days, weeks, and even months before death.

NIH National Institute on Aging website. Providing Care and Comfort at the End of Life.
<https://www.nia.nih.gov/health/providing-comfort-end-life>




Hospice vs. Palliative Care

| | |
|---|--|
| <h3>HOSPICE CARE</h3> <ul style="list-style-type: none"> • End of life • < 6 months life expectancy • Comfort care only • Focus: to provide comfort, care and support for terminally ill | <h3>PALLIATIVE CARE</h3> <ul style="list-style-type: none"> • Any stage of illness • Provided as long as necessary • Curative treatment OK • Focus: to provide relief from the discomforts, symptoms, and stress of a serious illness. |
|---|--|





NIH National Institute on Aging website. What Are Palliative Care and Hospice Care?
<https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>



Nutrition at End of Life

THE DIETITIAN'S ROLE

- Primary goal is comfort & to enhance quality of life.
- Assist in maintaining nutrition and hydration for comfort and enjoyment.
- Advocate for and support patient and their families.

Dietitian Can Help with...


- Nausea
- Diarrhea
- Constipation
- Dry mouth
- Difficulty chewing
- Dysphagia
- Poor appetite
- Concerns with weight loss
- Pressure injuries
- Food access issues
- Support family/caregivers
- Understand nutrition at EOL
- Conflict with eating/drinking
- Issues with feeding tubes



Nutrition Care of the Older Adult

What is Ethics?

- Term often over-used and mis-used
- When high emotions are involved situations, even people, are termed unethical
- Sometimes something is serious, but is it an ethical issue or is it:
 - Legal issue
 - Conduct issue (HR/Employment)
 - Medical issue
 - Spiritual issue
 - Malpractice




What is Ethics?



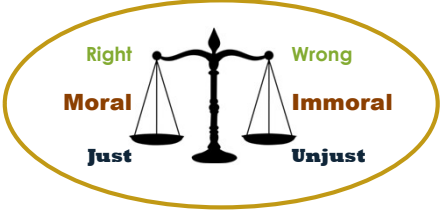

Definition: eth ics
/ 'eTHiks/
noun
Moral principles that govern a person's behavior or the conducting of an activity.

synonyms: moral code, morals, morality, values, rights and wrongs, principles, ideals, standards (of behavior), value system, virtues, dictates of conscience

Source: www.google.com



What is Ethics?

Ethics Terminology

- **Autonomy**
 - Respecting the competent individuals right to choose
- **Beneficence**
 - Taking action for the benefit of the individual
- **Non-maleficence**
 - "Do no harm"
- **Justice**
 - Fairness




Ethics Terminology

- **Benefit/Burden of Care**
 - Weighing pros/cons of options
- **Competency**
 - Ability to do something successfully
- **Informed Consent**
 - Involves disclosure, comprehension, voluntariness, competence and consent
- **Proxy (Surrogate)**
 - Acts on behalf of another



End of Life Documents

IMPORTANT DOCUMENTS

- **Advance Directive**
 - Name varies by state (i.e. living will, healthcare power of attorney)
 - Legal document for healthcare decisions
 - Can indicate who can make decisions for you (surrogate)
- **POLST**
 - Physician Orders for Life Sustaining Treatment
 - May include a section on artificial nutrition

National POLST Paradigm website: <http://polst.org>

Code of Ethics

PRINCIPLES and STANDARDS:

- Competence and professional development in practice (**Non-maleficence**)
- Integrity in personal and organizational behaviors and practices (**Autonomy**)
- Professionalism (**Beneficence**)
- Social responsibility for local, regional, national, global nutrition and well-being (**Justice**)

<https://www.eatrightpro.org/practice/code-of-ethics>

Competence and professional development in practice (Non-maleficence)

Nutrition and dietetics practitioners shall:

- Practice **using an evidence-based approach** within areas of competence, continuously develop and enhance expertise, and recognize limitations.
- Demonstrate in depth **scientific knowledge** of food, human nutrition and behavior.
- Assess the validity and applicability of scientific evidence **without personal bias**.
- Interpret, apply, participate in and/or generate **research to enhance** practice, innovation, and discovery.
- Make evidence-based practice decisions, taking into **account the unique values and circumstances of the patient/client and community**, in combination with the **practitioner's expertise and judgment**.
- Recognize and exercise professional judgment **within the limits of individual qualifications** and **collaborate** with others, seek counsel, and make referrals as appropriate.
- Act in a **caring and respectful** manner, mindful of **individual differences, cultural, and ethnic diversity**.
- Practice **within the limits of their scope** and **collaborate** with the inter-professional team.

Integrity in personal and organizational behaviors and practices (Autonomy)

Nutrition and dietetics practitioners shall:

- **Disclose** any conflicts of interest, including any financial interests in products or services that are recommended.
- **Refrain from accepting gifts or services** which potentially influence or which may give the appearance of influencing professional judgment.
- Comply with all **applicable laws and regulations**, including obtaining/maintaining a state license or certification if engaged in practice governed by nutrition and dietetics statutes.
- Maintain and **appropriately use credentials**.
- **Respect intellectual property rights**, including citation and recognition of the ideas and work of others, regardless of the medium (e.g. written, oral, electronic).
- Provide **accurate and truthful information** in all communications.
- **Report inappropriate behavior or treatment** of a patient/client by another nutrition and dietetics practitioner or other professionals.
- **Document, code and bill to most accurately** reflect the character and extent of delivered services.
- Respect patient/client's **autonomy**. Safeguard patient/client **confidentiality** according to current regulations and laws.
- Implement appropriate measures to **protect personal health information** using appropriate techniques (e.g., encryption).

Professionalism (Beneficence)

Nutrition and dietetics practitioners shall:

- Participate in and **contribute to decisions** that affect the well-being of patients/clients.
- **Respect the values, rights, knowledge, and skills** of colleagues and other professionals.
- Demonstrate **respect, constructive dialogue, civility and professionalism** in all communications, including **social media**.
- **Refrain from communicating false, fraudulent, deceptive, misleading, disparaging or unfair** statements or claims.
- Uphold **professional boundaries** and **refrain from romantic relationships** with any patients/clients, surrogates, supervisees, or students.
- Refrain from verbal/physical/emotional/sexual **harassment**.
- Provide **objective evaluations** of performance for employees, coworkers, and students and candidates for employment, professional association memberships, awards, or scholarships, making **all reasonable efforts to avoid bias** in the professional evaluation of others.
- Communicate at an appropriate level to **promote health literacy**.
- Contribute to the **advancement and competence of others**, including colleagues, students, and the public.

Social responsibility for local, regional, national, global nutrition and well-being (Justice)

Nutrition and dietetics practitioners shall:

- **Collaborate** with others to reduce health disparities and protect human rights.
- Promote **fairness** and objectivity with fair and **equitable treatment**.
- Contribute time and expertise to activities that **promote respect, integrity, and competence** of the profession.
- Promote the **unique role** of nutrition and dietetics practitioners.
- Engage in **service that benefits the community** and to enhance the public's trust in the profession.
- Seek **leadership opportunities** in professional, community, and service organizations to enhance health and nutritional status while protecting the public.

Common Ethical Issues

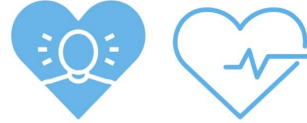
- Tube Feeding
- End of Life
- Social Media
- Sponsorship
- Disclosures/Conflict of Interest
- Research
- Management
- Professional Boundaries
- Billing
- Selling supplements
- Genetic testing
- Etc.



Ethics and Nutrition at End of Life

TWO PRIMARY TOPICS OF DISCUSSION:

- Tube Feeding in Older Adults with Dementia
- Decreased Intake at Very End of Life



Ethics and Nutrition at End of Life

- **Tube feeding in older adults with dementia**
 - Controversy in research
 - Increased kcals; translation to health benefits unclear
 - No evidence that TF prevents aspiration, reduces pressure injury risk, improves function or cognitive ability, or prolongs survival
 - Side effects from tube feeding
- **PEG insertion associated with**
 - Annual inpatient health care costs
 - Hospital and intensive care unit day

-Gandy B, E Sampson, I Jones. Enteral tube feeding in older people with advanced dementia: findings from a Cochrane systematic review. *International journal of geriatric nursing*. 2008;10(5):395-404
-Hwang D, Teng J, Giacolo P, Mitchell S. Feeding Tubes and Health Costs Post insertion in Nursing Home Residents with Advanced Dementia. *JGIM*. 2014;47(5):1116-120

Ethics and Nutrition at End of Life

- Dementia (including Alzheimer's) is a terminal illness similar to incurable cancer.
- Individuals with end stage dementia normally lose interest in food/fluid
- Numerous studies found no evidence that enteral tube feeding provides any benefit
- Nursing facility residents with dementia -associated with poor survival and a significant increase in the use of health care services after insertion.

Ethics and Nutrition at End of Life

American Geriatrics Society position

- When eating difficulties arise, feeding tubes are not recommended for older adults with advanced dementia.
- Health care providers should promote choice, endorse shared and informed decision making, and honor preferences regarding tube feeding.

Clinical Practice and Models of Care Committee. "American Geriatrics Society feeding tubes in advanced dementia position statement". *Journal of the American Geriatrics Society* 62.8 (2014): 1100.

Ethics and Nutrition at End of Life

• Schwartz D, et al:

- Based on current scientific literature... long-term enteral access devices should be withheld in patients with advanced dementia or other near end-of-life conditions.
- Autonomy, patient's culture, religious, social, and emotional value system should be respected.

• ESPEN guidelines:

- The ethical principles "autonomy, beneficence, non-maleficence and justice" are internationally recognized. They are interrelated and have to be applied in the act of medical decision making. [Strong Consensus]

Schwartz D, et al. Gastrostomy Tube Placement in Patients with Advanced Dementia or Near End of Life. *Nur Clin Pract*. 2014; 29(6): 829-840.
Bazzoni F. ESPEN guideline on ethical aspects of enteral nutrition and hydration. *Clinical Nutrition*. 2016; 35(16):1577.

Ethics and Nutrition at End of Life

Artificial Nutrition and Hydration (ANH)

- Roles & Responsibilities RDN
- Withdrawal of ANH
- Advanced Dementia
- Disorders of Consciousness
- Terminally Ill
- Decision Making during Pandemic
- Advance Care Planning
- Etc.



Schwartz DB, Prothauer ME, Malliet JO. Advancing Nutrition and Dietetics Practice: Dealing With Ethical Issues of Nutrition and Hydration. Journal of the Academy of Nutrition and Dietetics. 2020 Sep 25.

Ethics Case Study

- A real-life example.



Artificial Nutrition At End of Life



Question

- What would you do if a patient with dementia had a tube feeding placed despite what was requested on his POLST?
 - A. Nothing, wife can make decisions
 - B. Recommend removal of tube
 - C. Utilize interdisciplinary/ethics team
 - D. Not sure



Interesting Ethics Case...

What about spoon feeding?

- 2016 case in Oregon
 - Mrs. H- early onset Alzheimer's
 - Didn't want measures taken to prolong her life.
- Judge rule: nursing home must continue spoon-feeding
- Continues to evolve with 2018 change in OR law



•Aldous, V. Ashland woman didn't want life prolonged, but state says she must be spoon-fed. Mail Tribune newspaper, September 15, 2016. <http://www.mailtribune.com/news/2016/09/15/ashland-woman-didnt-want-life-prolonged-but-state-says-she-must-be-spoon-fed>

Ethics and Nutrition at End of Life

EATING AT VERY END OF LIFE

- Reduced intake at end of life can be difficult on caregiver/family
- Food = nourishment/comfort = love
- Don't want loved one to suffer (starving, hunger)



Vadivelu N, Kaye A, Berger J. Essentials of Palliative Care. New York, NY: Springer; 2013.

Ethics and Nutrition at End of Life

EATING AT VERY END OF LIFE

- Person at the end of life does not get hungry or thirsty in the same way a healthy person does
- Decrease in appetite and the loss of thirst are natural processes that allow the body to prepare itself for death
- Forcing foods/fluids will not enhance or prolong life-it may be a burden or detrimental

Vadivelu N, Kaye A, Berger J. Essentials of Palliative Care. New York, NY: Springer; 2013.

Ethics and Nutrition at End of Life

EATING AT VERY END OF LIFE

- Starvation is NOT caused by lack of intake, but by the disease process itself
- **Starvation** → **Ketonemia** → **Euphoria, ↑ comfort**
- No food → body uses glucose first → body uses protein → body tries to spare protein → ketone production
- Ketones are a good thing at end of life.

Vadivelu N, Kaye A, Berger J. Essentials of Palliative Care. New York, NY: Springer; 2013.
Fuhman M. Nutrition Support at the End of Life: A Critical Decision. Today's Dietitian. 2008; 10(9):68.

Ethics and Nutrition at End of Life

WHAT ABOUT HYDRATION?

- Water deprivation can reduce pain.
- Many studies show that when mouth moisturizing steps are taken (ice chips, lip balm, moistened swabs), uncomfortable dry mouth can be alleviated without the use of artificial hydration.



Vadivelu N, Kaye A, Berger J. Essentials of Palliative Care. New York, NY: Springer; 2013.
Fuhman M. Nutrition Support at the End of Life: A Critical Decision. Today's Dietitian. 2008; 10(9):68.

Ethics and Nutrition at End of Life

- Reduced oral intake can be a source of anxiety for:
 - Patient
 - Family
 - Health care staff
- Lack of information & misconceptions often present
- Social, emotional, and clinical elements should be considered in the decision making process

del Rio, M. I., Shand, B., Bonati, P., Palma, A., Maltoni, A., Taboada, P., and Neri, F. (2012). Hydration and nutrition at the end of life: a systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff. Psycho-Oncology, 21: 913-921.

Hard Conversations at End of Life

End of Life communication tools

- Identifying concerns
 - Eliciting and recognizing concerns
- Responding to informational concerns
 - "Ask-Tell-Ask"
- Responding to emotional concerns
 - Nonverbal empathy
 - Verbal empathy

McCarthy M. Advance Care Planning: The Dietitian's Role. J of Renal Nutrition. 2015; 25 (5):e41-e43.

Hard Conversations at End of Life

Nonverbal empathy: SURETY

- **S:** Sit at an angle
- **U:** Uncross arms and legs
- **R:** Relax
- **E:** Eye-contact
- **T:** Touch
- **Y:** Your intuition

Stickey T. From SOLER to SURETY for effective non-verbal communication. Nurse Educ Pract. 2011; 11(6):395-398.

Hard Conversations at End of Life

Verbal empathy: NURSE

- **N:** Name the emotion
- **U:** Understand the emotion
- **R:** Respect the emotion
- **S:** Support the patient
- **E:** Explore the emotion

McCarthy M. Advance Care Planning: The Dietitian's Role. J of Renal Nutrition. 2015; 25 (5):e41-e43.

Hard Conversations at End of Life

Mr. A is end of life and no longer competent to make informed decisions. His wife wants to honor his POLST by not initiating artificial nutrition by tube.

• Non-verbal (SURETY)

The RD sits at an angle across from Mrs. A. Her arms and legs are uncrossed and she is relaxed. She makes eye contact and uses touch as she feels appropriate while trusting her intuition throughout the conversation.

Hard Conversations at End of Life

Mr. A is end of life and no longer competent to make informed decisions. His wife wants to honor his POLST by not initiating artificial nutrition by tube.

• Verbal (NURSE)

RD: picking up on nonverbal cues from Mrs. A "You seem upset."

Mrs. A: "I don't want my husband to starve to death & suffer."

RD: "I see you are upset about this." offers education

Mrs. A: "That's helpful. I didn't know that before."

RD: "You have shown a lot of strength through all of this."

Mrs. A: "Thank you. It's hard."

RD: "I want you to know that I support you and we can still work together through this."

Mrs. A: "OK."

RD: "Now, tell me more about what may be upsetting you."

Ethics and Nutrition at End of Life

- Educate- help loved ones understand the patient is dying from the disease process... not from lack of food/water
- Encourage loved ones to find non-food ways of demonstrating love and care
- Allow caregivers to voice their frustrations
- "Your doing a good job"

Ethics and Nutrition at End of Life

FOOD RULES:

Caregiver

Have food available.
Favorite foods.
Mouth care (dry mouth)

Dying Patient

Eat when hungry.
Enjoy food.

Case Study

- A real-life example.



End of Life Discussions

Putting it into Perspective

- **Approach to Ethical Decision-Making:**
 - State the **ethical dilemma**
 - Connect **ethical theory** (terminology) to the dilemma
 - Apply the **Code of Ethics** to the issue
 - Select the **best alternative** and justify your decision
 - **Develop strategies** to implement the decision
 - **Evaluate outcomes** and how to prevent similar occurrences

<https://www.eatrightpro.org/j/media/eatrightpro-files/career/code-of-ethics/codeofethicsdetailresources.pdf?filename=health+4E7736DD04670A71E358F5804E5FE545833AE5B0>

How to Use What You've Learned

- **Keep an open eye and ear for ethical concerns in practice**
- **Reference resources**
 - Local policies and procedures
 - Academy's Code of Ethics and Papers
 - Academy's Ethics Reading List: <https://www.eatrightpro.org/practice/code-of-ethics/ethics-education-resources/ethics-reading-list>
 - Academy's Ethics Opinions: <https://www.eatrightpro.org/practice/code-of-ethics/ethics-education-resources/ethics-opinions>
 - Academy's Case Studies: <https://www.eatrightpro.org/practice/code-of-ethics/ethics-education-resources/case-studies>
- **Know where to go with your concerns:**
 - Facility ethics board
 - Academy ethics board
 - Academy's Ethics Complaints and Violations <https://www.eatrightpro.org/practice/code-of-ethics/what-is-the-code-of-ethics/ethics-complaints-and-violations>
 - Other

Conclusion

We've covered a lot!

- Nutrition at end of life
- What is ethics?
- Ethics terminology
- Ethics in nutrition at end of life
- Putting it into perspective
- How to use what you've learned
- Conclusion
- Questions



Conclusion

Hopefully you should now be able to:

- describe ethics and common **ethics terminology**.
- identify potential **ethics issues** in nutrition at end of life.
- **feel comfortable** with ethical decision making.

Questions

- What questions do you have?

