

s our population lives longer, healthcare providers are faced with the challenge of supporting quality of care while also honoring self-directed living. One of the most complex decisions for clients and families concerns the use of artificial nutrition and hydration (ANH). These decisions incorporate many factors for consideration. It is critical for providers to compassionately convey the realities of ANH, including potential harms at the end of life. This article offers an overview of ANH along with practical suggestions on how to proactively support clients with self-directed living.

BACKGROUND

Conversations with clients and families about whether to use artificial nutrition and hydration (ANH) in frail elders with advanced disease can be challenging. Ethical principles, case law, and formal opinions of medical and advocacy groups uphold the position that ANH is a medical intervention, and decisions regarding its use fall under the same pattern as informed consent used in all medical decision-making. This includes educating and informing clients and families about benefits and harms to allow client decision-making within the framework



of the client's overall values and specific goals for the intervention.

This requires that providers be knowledgeable about the research findings on benefits and harms of artificial nutrition and hydration, and have the communication skills to convey these to clients and families in an understandable and culturally appropriate manner.

ETHICAL AND LEGAL ISSUES

The ethical issues have been discussed over the past 40 or 50 years, with the current consensus being that ANH practices are medical intervention with benefits and burdens similar to other medical interventions. (See definitions in Table 1.)

Table 1 Definitions:

Artificial Hydration:

Administration of fluid through non oral means; routes include intravenous or subcutaneous (also called hypodermoclysis), rectal (proctoclysis), and enteral.

Artificial Nutrition:

Non oral, mechanical feeding either by intravenous or enteral route. Enteral feedings may be provided through either nasogastric tubes or gastrostomy, esophogostomy, or jejunostomy tubes that are placed either endoscopically or in open surgical procedures. Intravenous nutrition is administered through a central line and often is called total parenteral nutrition (TPN). Parenteral nutrition can also be administered through a peripheral vein.



ethical principles of client autonomy, beneficence, and nonmaleficence. (See Definitions in Table 2.)



Table 2 Definitions:

Client Autonomy:

The right of clients to make decisions about their medical care without their healthcare provider trying to influence the decision. Client autonomy does allow for healthcare providers to educate the patient, but does not allow the healthcare provider to make the decision for the patient.

Beneficence:

A principle of medical ethics according to which a person should do good to others, especially when one has a professional duty to do so.

Nonmaleficence:

Ethical principle of doing no harm.

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To ensure the client is making the decision, providers need to be fully aware of the client/family goals while clients and families need to be fully informed about whether the intended interventions can realistically achieve these goals. There is also the need to be aware of possible side effects of interventions while weighing the benefits of the treatment.

Many medical and advocacy organizations—such as the Academy of Nutrition and Dietetics, the American Medical Association, the American Geriatrics Society, the Alzheimer's Association, the American Academy of Hospice and Palliative Medicine, the American Nursing Association, and others—have position statements on the provision of ANH that also indicate that ANH practices are medical interventions, with possible benefits and predictable side effects. These organizations stress the importance of truly informed consent to allow client autonomy to be possible. This includes informing clients and families of alternative treatments and interventions to ANH.

The Academy of Nutrition and Dietetics shares in a position paper that, "Enteral nutrition may not be appropriate for terminally ill older adults with advanced disease states, such as terminal dementia, and should be in accordance with advanced directives. The development of clinical and ethical criteria for the nutrition and hydration of persons throughout the life span should be established by members of the healthcare team, including the registered dietitian."

The Centers for Medicare and Medicaid Services State Operations Manual Appendix PP - Guidance to Surveyors for Long-Term Care Facilities includes regulatory language regarding use of Feeding Tubes in §483.25(g) Naso-Gastric Tubes (F 322):

Overview: A decision to use a feeding tube has a major impact on a resident and his or her quality of life. It is important that any decision regarding the use of a feeding tube be based on the resident's clinical condition and wishes, as well as applicable federal and state laws and regulations for decision making about life-sustaining treatments.

Considerations Regarding the Use of Feeding **Tubes:** The regulations at §483.25(g) require that the resident's clinical condition demonstrates the use of a feeding tube to be unavoidable. A feeding tube may be considered unavoidable only if no other viable alternative to maintain adequate nutrition and/or hydration is possible, and the use of the feeding tube is consistent with the clinical objective of trying to maintain or improve nutritional and bydration parameters.

The interdisciplinary team, with support and guidance from the physician, is responsible for assuring the ongoing review, evaluation and decision-making regarding the continuation or discontinuation of all treatments, devices, or approaches implemented to care for the resident. Involving the resident, family, and/or the resident's legal representative in discussions about the indications, use, potential benefits and risks of tube feeding, types of approaches, and alternatives helps support the resident's right to make an informed decision to use or not use artificial nutrition and hydration.

In the Dining Practice Standards released in 2011 from the Pioneer Network, relevant research trends include:

- Feeding tubes have not been shown to reduce the risk of aspiration or prolong survival in residents with end-stage dementia.
- Oral secretions and/or gastric content are often the source of aspiration pneumonia or pneumonitis and thus will not be resolved with the placing of a tube.
- Studies in the elderly with dementia have shown little to no improvement in weight. In situations when there was improvement in weight, there was no improvement in clinical outcome for residents. Enteral feeding is also considered for wound care as a means to improve

wound healing, however data over a six month follow up has shown no impact on pressure ulcers or on infections such as cellulitis associated with wounds.

 Percutaneous endoscopic gastrostomy (PEG) and percutaneous endoscopic jejunostomy (PEJ) tubes do not improve a resident's quality of life. Placing a PEG tube in residents with advanced dementia should be strongly discouraged.

So why is it still so hard for healthcare providers to have conversations about ANH with clients and families? Is it lack of knowledge on the part of clients and families? Is it lack of knowledge of interdisciplinary healthcare providers about the evidence-based research regarding provision of ANH to seriously ill frail elders? Is it because of unrealistic expectations of what can be accomplished by ANH on the part of clients, families, and clinicians?

Some say that clients and families have unrealistic expectations and demand unreasonable interventions for their loved ones. Yet, research indicates that when presented with all the relevant facts, clients and families generally opt to forgo more aggressive interventions when benefits are marginal. Conversations are important!

CONSIDERATIONS FOR FACILITY "CONVERSATION PLAN"

It is critical to have an overall facility plan that addresses how "conversations" about ANH will be administered. The following areas are some factors to consider with the overall plan. (See Table 3.)

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Table 3: ANH Plan

- Develop a facility program that identifies overall planning for "having the conversation." Determine how to incorporate information and "conversations" with Admissions, Nutrition Risk Programs, Physician Involvement, Interdisciplinary Team (IDT), Dining Programs, Care Planning, etc. Be sure training occurs throughout the facility for proper implementation.
- Develop a resource folder or notebook that includes client education brochures, research, and resources for helping clients and families make decisions about use of artificial nutrition and hydration. Make the information readily available.
- When having conversations be sure to determine an appropriate setting: These important conversations should occur with the client and/or authorized decision-maker in a private setting that is conducive to comfortable and intimate communication. There should be no interruptions, and the overall tone should be respectful and car-
- During conversations it is important to listen. The clinician should determine what the client and family understand about the disease, and listen to what is important overall to the client and family.
- Use conversation to impart knowledge to the client and family, while clarifying any misconceptions and presenting alternative interventions that can realistically achieve client-specific goals of care, along with known possible harms and benefits of each.

- Allow the client and family to express emotions, while empathizing, and assuring the client and family that support will be there for them.
- Once emotions have settled, have a joint discussion with the client and family about the next steps, and then follow facility protocols to honor their decisions.
- The facility should follow up periodically to determine whether and how client goals are being met by the interventions, and adjust the treatment plan together accordingly.
- Documentation in the medical record should clearly reflect the conversations, nutrition interventions, and ongoing care and services honoring informed choice.



SUMMARY

Discussions about use of ANH in elderly clients with advanced chronic illness should be held with clients and their families considering the client's overall values and goals, as well as the specific goals for ANH, the current clinical status, and likely course with and without ANH, and guided by the current evidence-based research of known benefits and harms of intervention.

This role of the CDM is reflected in the Association of Nutrition & Foodservice Professionals' Position Paper: The Role of the Certified Dietary Manager in Person-Directed Dining, stating the CDM who works in long-term care is expected to seek continuing education and information in order to implement the best practices and recognized standards of practice for elder nutrition care and person-directed dining. The Certified Dietary Manager, in collaboration with the dietitian and the interdisciplinary team, has an essential role both in facilitating this process, as well as in monitoring it for desired outcomes.



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Healthcare professionals must recognize the importance of establishing nutrition treatment goals that are resident centered, and that respect the unique values and personal decisions of the older adult. Section 2 of the Code of Ethics for the Certified Dietary Manager, Principle #10 states, "The Certified Dietary Manager provides sufficient information to enable clients to make their own informed decisions." Having conversations about ANH with clients and families is vital for informed choice, resident-centered care decisions, and quality of life.

REFERENCES

- O'Sullivan Maillet J, Baird Schwarz D, Posthauer ME; Academy of Nutrition and Dietetics. Position of the Academy of Nutrition and Dietetics: ethical and legal issues in feeding and hydration. J Acad Nutr Diet. 2013;113(6):828-833.
- State Operations Manual: Appendix PP—Guidance to surveyors for long term care facilities. Revised February 6, 2015. Centers for Medicare and Medicaid Services Website: http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Internet-Only-Manuals-IOMs-Items/ CMS1201984.html (Accessed April 28, 2015)
- Association of Nutrition & Foodservice Professionals (formerly Dietary Managers Association), The Role of the Certified Dietary Manager in Person-Directed Dining—April 2011 http://anfponline.org/Resources/position_papers.shtml (Accessed April 28, 2015)
- Association of Nutrition & Foodservice Professionals, Code of Ethics for the Certified Dietary Manager, http://anfponline.org/About/CDM_ CFPP_credential.shtml (Accessed April 29, 2015)

ADDITIONAL RESOURCES:

- ALS Association: Information About Feeding Tubes Website: http://www.alsa.org/als-care/resources/publications-videos/factsheets/ feeding-tubes.html
- American Hospice Foundation: Artificial Nutrition and Hydration at the End of Life: Beneficial or Harmful? Website: http://americanhospice. org/caregiving/artificial-nutrition-and-hydration-at-the-end-of-life-beneficial-or-harmful/
- · WebMD: Questions and Answers: Artificial Nutrition and Hydration and End of Life Decision Making Website: http://www.webmd.com/ balance/faqs-artificial-nutrition-hydration-end-of-life-decision-making-medref
- Nutrition411: Facts About Tube Feeding Website: http://www.nutrition411.com/content/facts-about-tube-feeding
- · Nutrition 411: Interdisciplinary Nutrition Care Plan: Tube Feeding Website: http://www.nutrition411.com/content/interdisciplinary-nutritioncare-plan-tube-feeding
- · The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) Guidelines and Standards Library Website: http://www. nutritioncare.org/Library.aspx