The four principles of medical ethics:

- **Autonomy** – respect for the patient’s right to self-determination. Preserve patients’ ability to make decisions independently of external control.
- **Beneficence** – the duty to ‘do good.’ Advocate for the course of action that aligns with the patient’s best interests.
- **Non-Maleficence** – the duty to ‘not do bad’
- **Justice** – to treat all people equally and equitably.

CASE:

The patient is a 63 year old with a history of CVA, dementia (BIMS = 9)and failure to thrive. In March 2024 she signed a MOST form indicating that she did not want artificial nutrution by tube. It is unclear if she had decision making capacity when she signed the MOST form. At that time, she chose to remain full code with full treatment but did not want artificial nutrition by tube.

The patient began to decline due to weight loss and was refusing nutritional interventions and refusing to eat. She has had some dementia related behaviors, including anxiety but has continued to refuse nutrition.

The POA lives out of state and decided to send the patient to the hospital for evaluation. The hospital evaluated the patient and had an ethics committee review her case because the POA requested that a feeding tube be placed and the MOST form changed. The hospital placed the feeding tube and the patient returned to LTC with an updated MOST form signed by the POA.

The patient has continued to refuse nutrition and evern covers the PEG tube hole with her hands whenever the nurses attempt to provide nutrition via this route.

1. **What are the ethical considerations we should consider in this case?**
    1. Autonomy – Was this upheld?
    2. Beneficence and Nonmaleficence – some would argue that performing a procedure with no benefits but with potential harms violates both of these principles. Is this always the case?
    3. Would comfort feeding by hand be a more ethical approach?
2. **Should the hospital ethics committee include the LTC facility and primary physician in the decision process? Does this happen?**
3. **Since the MOST form is an order set and NOT an advanced directive, does this give the POA the right to change the MOST form?**

4. **Regardless of cognitive status, the patient seems to not want to eat or use the PEG tube. If a patient does not have the capacity to understand the consequences of not eating, do we have the right to force the patient to take nutrition via the PEG tube?**

What is a MOST form? Is it an advanced directive?

The MOST form (Medical Orders for Scope of Treatment) is a voluntary form that patients can choose to complete, usually in consultation with their healthcare provider, to ensure that their medical preferences are clearly communicated and followed in serious or end-of-life situations. While it is highly recommended for individuals with serious health conditions or those nearing the end of life, it is not legally mandatory.

The MOST form is **not** the same as an **advance directive**, but they are related and often used together in end-of-life planning. Here's how they differ:

1. MOST Form (Medical Orders for Scope of Treatment):

– A **medical order** completed by a healthcare provider based on the patient's wishes.

– It provides **specific instructions** for immediate medical care, such as resuscitation preferences, medical interventions, antibiotics, and artificial nutrition.

– It is designed to be followed by healthcare professionals in emergency situations.

– The MOST form is **binding and immediately actionable** by medical personnel (like a doctor's order), meaning it can directly influence what care is provided at the moment.

– It is usually intended for individuals who are seriously ill or in the later stages of life.

2. Advance Directive:

– A **legal document** that outlines a person's broader wishes about future medical care if they are unable to communicate (e.g., in a coma or severely incapacitated).

– It includes documents such as a **living will** and a **durable power of attorney for healthcare.**

– The advance directive **guides medical decisions in non-emergency situations** and is often more general than the MOST form.

– It allows you to appoint a healthcare proxy to make decisions on your behalf.

Key Differences:

– **Timing and Scope**: The MOST form applies to **current** medical care decisions, while the advance directive addresses **future** situations where the patient might not be able to make decisions.

– **Legal vs. Medical:** An advance directive is a **legal document** that expresses wishes, while the MOST form is a **medical order** that must be followed by healthcare providers.

– **Audience:** The MOST form is primarily for healthcare providers to act upon immediately, while the advance directive is for both healthcare providers and loved ones to follow over the course of future care.

Both documents are important, but the MOST form is often used when a patient’s end-of-life care needs are imminent, whereas an advance directive may be prepared well in advance of such situations. Many people have both documents to ensure their medical care preferences are fully respected.

Ethical Considerations Concerning Use of Percutaneous Endoscopic Gastrostomy Feeding Tubes in Patients With Advanced Dementia – PMC (nih.gov)

Summary:

Multiple studies provide evidence that in most advanced dementia patients PEG tube placement has negligible benefit and may actually cause harm. Families often perceive that the placement of PEG feeding will prolong the patient’s life. They often have very emotional opinions that withholding nutrition is the same as killing the patient. There are multiple social and cultural factors that lead to families pursuing aggressive medical treatment regardless of prognosis or the effect on quality of life.

Typically, by the time a PEG tube is needed for nutrition, dementia is in the severe/advanced stage. The life expectancy of a severe dementia patient is 1-3 years.

PEG tubes in dementia:

Do not prolong survival

Do not improve quality of life

Do not prevent aspiration

Do not promote healing of pressure ulcers

Do not improve labs associated with nutrition

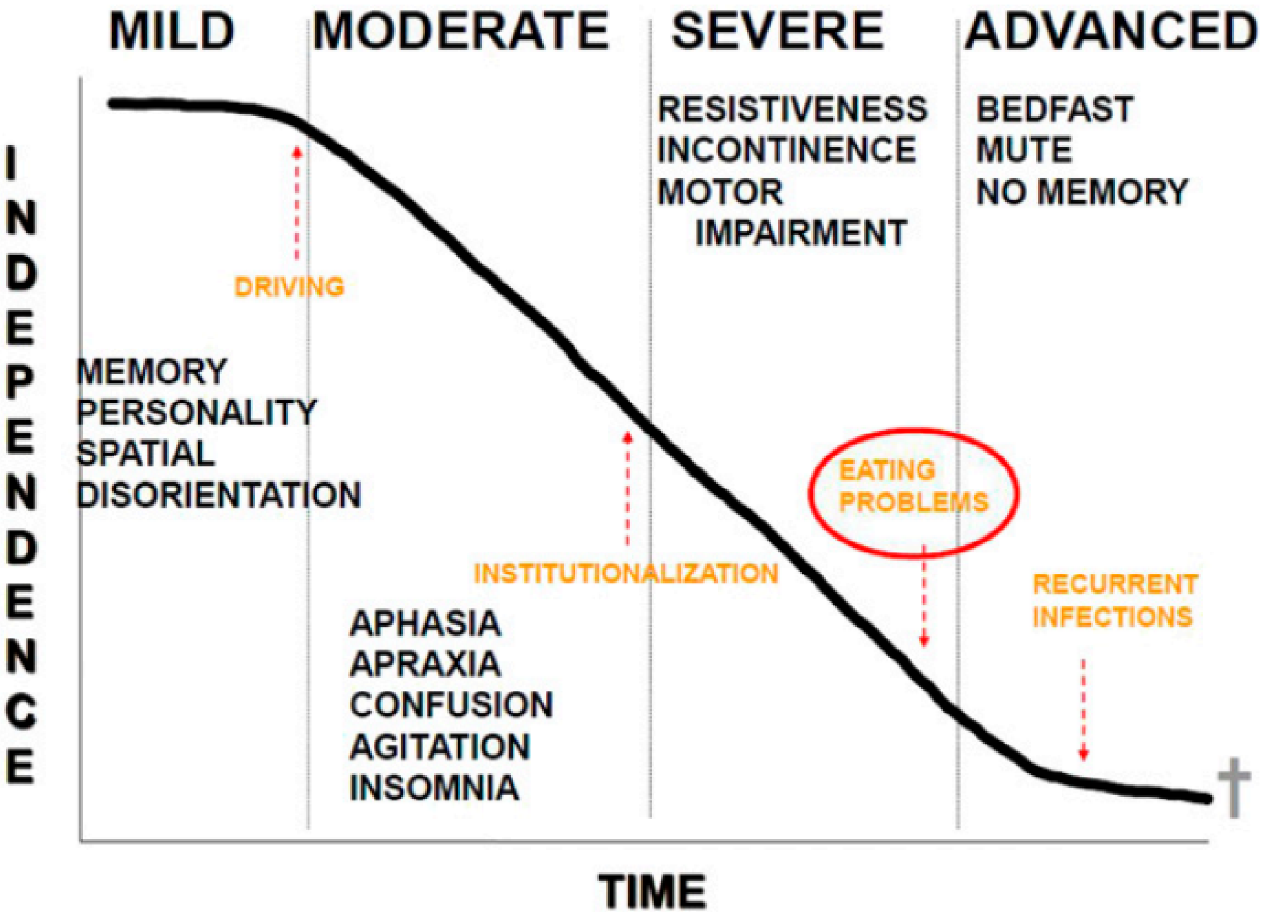

Figure 1. Stages of Dementia. Courtesy of Ladislav Volicer, MD, PhD.

1. In a variety of studies, nutrition via PEG has **not been shown to prolong survival**. In 1 example, no difference in survival was found among 1,386 patients treated with or without tube feedings. A Cochrane Database systematic review of 7 published observational controlled studies in 2009 concluded that there was no evidence of increased survival.

2. PEG also has **not been shown to improve quality of life**, and frequently a PEG tube is placed without regard to this important factor—although quality of life suffers, particularly if restraints or medications are necessary to prevent the patient from removing the PEG

tube. Additionally, when feeding is by PEG, the beneficial human-to-human interaction of oral hand feeding is lost.

3. Feeding via PEG has **not been shown to prevent aspiration pneumonia** either. Patients fed solely in this manner are no longer at risk of orally aspirating fed food or liquid, but they are at continued risk of aspiration from esophageal reflux or oral secretions, and are in fact at increased risk of aspiration pneumonia. For example, 1 study of 104 severely demented patients showed that the rate of aspiration pneumonia more than doubled with PEG feeding.

4. Providing nutrition via PEG also has **not been shown to promote the healing of pressure ulcers or to improve the biochemical parameters that reflect nutrition.** And, if restraints are necessary to prevent the patient from pulling on the tube, the risk of developing pressure ulcers is increased.

5. Potentially burdensome and even life-threatening complications of PEG include infection, hemorrhage, gastric ulceration, stoma (the opening where the tube is inserted) irritation, dislodging and/or clogging of the tube, etc.