

Legal and Ethical Issues Related to PEGS/Tube Feeding

For patients/residents who CAN make decisions for themselves:

The usual standards of informed consent (or refusal) apply. Like with any other procedure, the physician will discuss the pros and cons of a feeding tube with the patient, and, if clinically indicated, the patient/resident can agree to have one or not. If they choose to have a feeding tube at one point in time, they can choose to withdraw it at a later date if it is no longer meeting their goals or needs (provided they still have decision-making capacity).

For patients/residents who CANNOT make decisions for themselves:

If the patient/resident has completed a health care proxy form formally choosing someone to serve as his/her health care “agent”, the agent is required to make decisions for the patient according to what is known about the patient’s wishes, or, if unknown, according to the patient’s best interests. The agent can make all end-of-life decisions on the patient’s behalf, but the decision must be based on **“reasonable knowledge” of the patient’s wishes in the case of withdrawing or withholding of tube feeding.** For this reason, it is helpful for the signed health care proxy form to include a statement indicating that conversations have occurred between the patient and the health care agent about artificial hydration and nutrition (tube feeding).

If the patient/resident has not completed a health care proxy form, the legal standard for withholding or withdrawing a feeding tube is currently different depending upon whether the patient/resident resides in a medical facility (hospital or nursing home) or elsewhere (residential home).

- **If such a patient is in hospital or nursing home,** New York State law allows for **surrogate decision makers to make decisions about tube feeding based upon “substituted judgment”** (what is known about the patient/resident’s wishes), or if unknown based on the patient’s **best interests.** Surrogate decision makers in NYS are in order of priority:
 1. A patient’s authorized guardian
 2. Spouse (if not legally separated) or domestic partner
 3. Son or daughter over the age of 18
 4. Parent
 5. Brother/sister (age 18 or over)
 6. Close friend (Must complete a signed statement as a close friend)

Additionally, under this circumstance, two physicians must concur that either:

- i. the patient has an illness or injury expected to cause death within six months, or
- ii. the patient is permanently unconscious, or
- iii. treatment is inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition

Special requirements exist for an Ethics Review Committee to determine that patient-centered and clinical standards are met:

- i. In a hospital, if the attending physician disagrees with a decision to withhold or withdraw a feeding tube;
- ii. In a nursing home, for all life-sustaining treatment, including a feeding tube.

- **If the patient in a hospital or nursing home has not completed a health care proxy form and no surrogate from the list is available, decisions about withholding or withdrawing tube feeding can be made if two physicians concur that:**
 - i. life sustaining treatment offers no medical benefit and the patient will die imminently even if treatment is provided, AND
 - ii. the provision of life sustaining treatment would violate accepted medical standards
- **If the patient has not completed a health care proxy form and is not in hospital or nursing home, the legal standard for making a decision about withholding or withdrawing of feeding tubes is “clear and convincing evidence” of the patient’s wishes.** A prior written statement about feeding tubes or artificial nutrition in a Living Will, completion of the New York State Medical Orders for Life Sustaining Treatment (MOLST) or clear prior oral statements by the patient about his or her wishes may provide “clear and convincing evidence.”

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In discussions with patients/residents and families:

FOCUS ON THE PATIENT'S OWN VALUES, PREFERENCES AND BELIEFS:

- Focus on the underlying disease process as cause of decline and loss of appetite
- Emphasize the active nature of providing comfort care
- Recognize the concerns about “starvation”, inadequate nutrition or hydration and potentially hastening death that many individuals deal with in facing this decision and address these issues
- Clarify that withholding or withdrawing artificial nutrition and hydration is NOT the same as denying food and drink. Health care facilities are required to offer nutrition and hydration orally, without reliance on medical treatment, to inpatients/residents who are able to eat or drink.

UNDERSTAND CULTURAL AND RELIGIOUS VALUES:

- Most cultures and religions recognize death as a normal aspect of life. Most allow for weighing the benefits and burdens of medical treatment including tube feeding
- Explore religious and cultural values that might influence the decision about tube feeding
- When in doubt or unfamiliar about a patient's/resident's belief system, consult with a chaplain or spiritual leader from their own tradition if possible
- Recognize there is variation within a culture. It is best to ask the patient's decision-maker about the patient's values and beliefs.
- Recognize how one's own religious or spiritual feelings affect how tube feeding is discussed with patients/residents and their families, and attempt to minimize the influence these factors might have on the decision-making process.