Legal and Ethical Issues Related to PEGS

Legal requirements for tube feeding consent or refusal:

For patients/residents with capacity, the usual standards of informed consent (or refusal) apply.

For patients/residents without capacity, the legal and ethical challenge is to make the decision as the individual would if s/he could speak for him or herself (“substituted judgment”).

Mechanisms to do this include:
- Existence of a prior statement about the issue in a Living Will or other advance care document
- Appointment of a health care “agent” (as identified on a health care proxy form), legally empowered to make the decision based on reasonable evidence of the individual’s wishes
- Use of other surrogate decision-makers (family or close friends) which would require clear and convincing evidence of the individual’s wishes

If there is no appropriate decision-maker, consider obtaining a legal guardian to represent the patient/resident.

If there is family conflict about the patient/resident’s wishes, support and clarification for the decision-making process may be sought by obtaining a legal, palliative care or ethics consult.

In discussions with patients/residents and families:
- Focus on the underlining 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 assisted suicide 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

Understand cultural and religious values:
- Most cultures and religions recognize death as a normal aspect of life. Most allow you to weigh 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
- 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