

**Legal and Ethical Issues**

<p>For patients who <b>CAN</b> make decisions for themselves,</p>	<p><b>Usual standards of informed consent (or refusal) apply. This applies to persons with developmental disabilities who can decide.</b></p>	<p>Like with any other procedure, the physician, nurse practitioner or physician assistant will discuss the pros and cons of a feeding tube with the patient, and, if clinically indicated, the patient 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). If a patient chooses not to have a feeding tube, food and fluids are offered as tolerated using careful hand feeding.</p>						
<p>For patients who <b>CANNOT</b> make decisions for themselves,</p>	<p><b>Patient has completed a health care proxy form or has the ability to choose a health care agent. This applies to persons with developmental disabilities.</b></p>	<p>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).</p>						
	<p><b>Patient has not completed a health care proxy form and the person does not have developmental disability.</b></p>	<p>The legal standard for withholding or withdrawing a feeding tube is currently different depending upon whether the patient resides in a medical facility (hospital or nursing home) or community (e.g. patient’s home, assisted living facility, etc.). As of September 2011, under New York State law “hospital” means a general hospital or hospice.</p>						
		<p><b>If such a patient is in hospital or nursing home or hospice,</b>                  New York State law allows for <b>surrogate decision makers to make decisions about tube feeding based upon “substituted judgment”</b> (what is known about, the patient’s wishes), <b>or</b> if unknown based on the patient’s <b>best interests</b>. Surrogate decision makers in NYS are in order of priority:</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 50%;">1. A patient’s authorized guardian</td> <td style="width: 50%;">4. Parent</td> </tr> <tr> <td>2. Spouse (if not legally separated) or domestic partner</td> <td>5. Brother/sister (age 18 or over)</td> </tr> <tr> <td>3. Son or daughter over the age of 18 close friend)</td> <td>6. Close friend (Must complete a signed statement as a close friend)</td> </tr> </table> <p>Additionally, under this circumstance, two physicians or nurse practitioners or physician assistants must concur that either:</p> <ul style="list-style-type: none"> <li>i. the patient has an illness or injury expected to cause death within six months, or</li> <li>ii. the patient is permanently unconscious, or</li> <li>iii. treatment is inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition</li> </ul> <p>Special requirements exist for an Ethics Review Committee to determine that patient-centered and clinical standards are met:</p> <ul style="list-style-type: none"> <li>i. In a hospital, <b>other than a hospice</b>, if the attending physician or attending nurse practitioner or physician assistant* disagrees with a decision to withhold or withdraw a feeding tube</li> <li>ii. In a nursing home, for all life-sustaining treatment, including a feeding tube, if the clinical standard that the patient meets is “treatment is inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition”.</li> </ul>	1. A patient’s authorized guardian	4. Parent	2. Spouse (if not legally separated) or domestic partner	5. Brother/sister (age 18 or over)	3. Son or daughter over the age of 18 close friend)	6. Close friend (Must complete a signed statement as a close friend)
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		<p><b>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 or nurse practitioners or physician assistants* concur that:</b></p> <ul style="list-style-type: none"> <li>i. life sustaining treatment offers no medical benefit and the patient will die imminently even if treatment is provided, AND</li> <li>ii. the provision of life sustaining treatment would violate accepted medical standards</li> </ul>						
		<p><b>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 patient in hospice in the community follows the same procedures as in the hospital.</b> 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.”</p>						
	<p><b>Patient has not completed a health care proxy form, does not have the ability to choose a health care agent and the person has developmental disabilities.</b></p>	<p><b>Physicians must follow the § 1750-b process as outlined on the MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities.</b> Two physicians must determine to a reasonable degree of medical certainty that <b>both</b> of the following conditions are met: (1) the individual has one of the following medical conditions: a. a terminal condition; (briefly describe); or b. permanent unconsciousness; or c. a medical condition other than DD which requires LST, is irreversible and which will continue indefinitely (briefly describe) <b>AND</b> (2) the LST would impose an extraordinary burden on the individual in light of: a. the person’s medical condition other than DD (briefly explain) and b. the expected outcome of the LST, notwithstanding the person’s DD (briefly explain.) If the 1750-b surrogate has requested that artificially provided nutrition or hydration be withdrawn or withheld, one of the following additional factors must also be met: a. there is no reasonable hope of maintaining life (explain); or b. the artificially provided nutrition or hydration poses an extraordinary burden (explain.)</p>						

*Guidelines are intended to be flexible. They serve as reference points or recommendations, not rigid criteria. Guidelines should be followed in most cases, but there is an understanding that, depending on the patient, the setting, the circumstances, or other factors, care can and should be tailored to fit individual needs. For patients associated with OPWDD a separate process must be followed, see OPWDD checklists.*