END OF LIFE DECISIONS *

I. DECISION-MAKING PROCESS.

A. Establishing the goals of treatment. This is an important step in the patient's and family's deliberations.

1. In order to make a rational decision as to whether to accept or refuse a given treatment, the patient and the family must consider:

   a. The goals of treatment;
   b. The likelihood the treatment will advance the goals; and
   c. The potential suffering.

2. Possible goals of treatment include:

   a. Cure of disease;
   b. Avoidance of premature death, maintenance or improvement in function;
   c. Prolongation of life;
   d. Relief of suffering;
   e. Optimizing quality of life;
   f. Maintaining control;
   g. A good death; and
   h. Support for families and loved ones.

3. A good way to clarify priorities is to ask: Given what you know now about your disease, what is your biggest concern and what is most important to you?

4. The goals should periodically be reviewed and revised, as appropriate.

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B. Advance care planning ("ACP").

1. ACP is a process by means of which patients and families:

a. Learn about the disease;
b. Anticipate the future;
c. Explore treatment options and the likely benefits and burdens of various treatments; and
d. Begin to make decisions about how they want to be treated as the disease progresses.

2. ACP can include:

a. Completion of formal advance directives, such as:

(1) A Living Will;
(2) A Health Care Power of Attorney;
(3) Establishment of a Do Not Resuscitate (DNR) order; and/or
(4) Establishment of a Do Not Intubate order.

b. Some specific treatment issues should be addressed routinely, specifically:

(1) Resuscitation status;
(2) Mechanical ventilation; and
(3) Medically-administered hydration and nutrition.

II. WITHHOLDING OR WITHDRAWING LIFE-PROLONGING TREATMENT ("LPT").

A. Withholding and withdrawing LPT are ethically and legally equivalent: it is permissible to withdraw any treatment that could have been withheld in the first place.

1. When a patient dies as a result of withdrawing a treatment, the cause of death is the patient's underlying disease.

2. However, the proximity of the act of withdrawing to the death of the patient may create a perception that the withdrawal caused the patient's death.

3. Therefore, it is often much harder, emotionally and psychologically, to withdraw a treatment that to withhold it.

B. It is helpful to recognize that this is merely a special case of the more general question of how one decides to provide or forego any treatment.

1. Whenever a physician or a patient considers whether to embark on a treatment regimen, each typically considers the benefits and burdens of the treatment.

2. If the physician believes the benefits of a treatment outweigh the burdens, he or she is inclined to recommend it.

3. If the patient agrees with the physician's analysis, he or she is inclined to accept the treatment.

4. In the outpatient setting, because the patient has final control over treatment decisions, conflicts rarely become intractable.

5. However, in the hospital, several factors make conflicts over LPT especially problematic:

a. Physicians inherently have more power over the treatment of patients in that setting, and this power differential is often enhanced by the patient's illness.
b. When patients are very ill, surrogates must consent to or refuse treatment, raising the question of their authority to act on behalf of the patient.
c. Decisions about LPT have life or death consequences.
d. Decisions often must be made relatively quickly.

C. One approach is to apply the four principles of Beauchamp and Childress, as each principle provides a possible justification for foregoing LPT:

1. Respect for autonomy is the right of self-rule or self-determination. This would support foregoing LPT if patients refuse to consent to treatment.

2. Nonmaleficence is the requirement to avoid causing harm and to protect patients from harm. This would support foregoing LPT if it were causing undue harm or suffering for the patient

3. Beneficence is the obligation to do good unto others. This would support foregoing LPT if it were not benefiting the patient.

4. Justice is the obligation to be fair, to treat similar situations similarly and to assure an equitable distribution of resources. This would support foregoing LPT if providing it would unfairly deprive others of adequate treatment to which they were entitled (e.g., organ donation or critical care beds).

D. The principles may be in conflict, for example, when a physician recommends against a treatment because he or she believes it to be excessively burdensome or of minimal benefit, but the patient or surrogate desires the treatment; or when a patient or surrogate refuses a treatment that the physician believes is likely to be beneficial and imposes little burden on the patient.

1. Such cases may be further complicated when a surrogate is acting on behalf of an incapacitated patient and there is uncertainty as to what the patient would have wanted.

2. In cases of conflict, ongoing discussion and negotiation is often helpful. Over time, the course of the disease process may become clearer and discussion may lead to improved communication and understanding, such that a consensus can be achieved.

III. MEDICALLY ADMINISTERED HYDRATION AND NUTRITION ("MAHN").

A. MAHN is unlikely to prolong survival and is likely to increase suffering for patients who are actively dying.

1. Stopping eating and drinking is part of the natural dying process.

2. As the organs of the body begin to shut down, dying patients typically lose the desire to eat and drink.

3. Such patients may attempt to force themselves to take food and drink because they or their family believe it will make them stronger.

    a. It is important to acknowledge the powerful symbolism of feeding a loved one and the emotional strain that may accompany a decision to withhold MAHN.
    b. As long as they are able to swallow, patients should be provided with food and drink to the extent they desire them.

4. However, providing MAHN is unlikely to prolong survival and may frequently cause greater suffering.

    a. Dyspnea may be worsened by pulmonary edema and increased oropharyngeal secretions.
    b. Tube feeding may cause diarrhea or other gastrointestinal symptoms.
    c. In particular, patients with congestive heart failure or renal or hepatic failure are likely to have increased discomfort with MAHN.

5. In general, the final stages of death are more peaceful if the patient is permitted to become naturally dehydrated.

6. Thus, the decision to forego MAHN in patients who are actively dying is based primarily on the lack of benefit and the likelihood of increased suffering rather than patient autonomy.

IV. PALLIATIVE SEDATION AND THE PRINCIPLE OF DOUBLE EFFECT.

A. Palliative sedation (PS) consists of sedating a patient to the point of unconsciousness to relieve one or more symptoms that are intractable and unrelieved despite aggressive symptom-specific treatments, usually maintaining this condition until the patient dies. Typically, artificial hydration and nutrition are withheld, as they no longer offer any benefit to the patient and may cause adverse effects.

    1. Because PS is initiated mostly for patients who are imminently dying and suffering from terminal delirium and other symptoms, it is very unlikely that PS shortens the patient's life significantly.

2. In rare cases, PS may be initiated in patients who are alert and cognitively intact, but suffer from one or more severe and intractable symptoms. In such cases, because PS is likely to shorten the patient's life, its use remains controversial.

3. In situations where PS may hasten death, ethical analysis, based on the principal of double effect, is necessary to justify permitting PS while prohibiting physician-assisted suicide and euthanasia.

B. The Principle of Double Effect states that an action which has both a good effect and a bad effect is ethical if it fulfills the following criteria:

1. The act itself is not unethical;

2. The good effect is the intended effect whereas the bad effect, though foreseeable, is not intended and there is no alternative of achieving the good effect while avoiding the bad effect;

3. The good effect is not achieved by means of the bad effect; and

4. The good effect is sufficiently desirable to compensate for the allowing of the bad effect.

C. Thus, PS is ethical because:

1. Sedation itself is not unethical;

2. Although PS may hasten death, death is not intended and comfort cannot be achieved without this risk;

3. Comfort is achieved as a direct result of sedation and not by means of death; and

4. For an imminently dying patient, comfort is more important than prolonging life.

D. In contrast, euthanasia and physician-assisted suicide are unethical because:

1. Killing or assisting suicide itself is generally unethical;

2. Death is intended and comfort could be achieved by other means;

3. Comfort is only achieved by means of death; even though

4. For a terminally ill patient, comfort is more important than prolonging life.