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AMERICAN ACADEMY OF NEUROLOGY

POSITION STATEMENT:

CERTAIN ASPECTS OF THE CARE AND MANAGEMENT OF PROFOUNDLY AND IRREVERSIBLY PARALYZED PATIENTS WITH RETAINED CONSCIOUSNESS AND COGNITION

Report of the American Academy of Neurology's Ethics and Humanities Subcommittee

Certain neurologic conditions result in profound and irreversible paralysis of all limbs and vocal apparatus, often with respiratory paralysis, while entirely sparing consciousness and cognition. These patients remain mentally competent (have adequate health care decision-making capacity), but because they cannot speak or move, they have great difficulty with communication and can no longer actively manipulate their environment.(1)

Physicians have a strong ethical obligation toward preservation of life. However, in some clinical circumstances where the prognosis is poor, this ethical obligation should be carefully evaluated in the context of other goals of medical treatment: patient autonomy, benefits and burdens of treatment, and relief of suffering.

Not infrequently, ventilator-dependent patients with irreversible, end-stage paralyzing conditions will decide to have their life-support systems (e.g. ventilators, artificial nutrition and hydration) removed to permit them to die. Physicians have an ethical obligation to respect these decisions if they are made by competent patients who are fully informed of their prognosis with and without treatment, and who have not been coerced.

Physicians have the duty to ascertain that the patient's decision to refuse treatment has been reached with full knowledge of the consequences and with appropriate consideration of treatment alternatives, the patient has had a consistently held position over time, and the decision is not merely an impulsive or transient reaction to his or her severe illness.

Physicians have heightened obligations due to the profound disability of these patients. Physicians should carefully assess the psychological state, and the cognitive and communicative abilities of their patients, to ascertain that they retain competency regarding decisions made about treatment or non-treatment. In so doing, physicians should make reasonable attempts to enhance the ability of these severely disabled patients to communicate their feelings, needs, and values.

Clinical decision-making for these patients should proceed along the same line as clinical decision-making for non-paralyzed, competent patients, that is, physicians have the obligation to follow the health care decisions competently made by their patients.

Once patients have decided to forgo life-sustaining treatment, physicians have an ethical obligation to minimize their subsequent suffering. This is particularly true of the profoundly paralyzed patient because cognition and sensation may be intact, and they are capable of great suffering. The intent of the treatment is to relieve pain and suffering, not to end the patient's life, but the patient's death may be a foreseeable side effect of the treatment. Under such circumstances, physicians should be willing to administer adequate doses of narcotics (morphine) or benzodiazepines, to reduce dyspnea and other sources of discomfort in recently extubated patients, even if these medications, as a secondary effect, contribute to respiratory depression, coma or death.

If a physician has a moral objection to carrying out the patient's decision to remove life-support systems, the physician should not be forced to act against his or her conscience. The physician is then obligated to transfer the care of the patient to another physician.

These general statements governing decision-making for profoundly paralyzed patients apply to all forms of life-sustaining treatment, including artificial nutrition and hydration. Under the ethical principle of respect for autonomy, competent patients have the right to refuse artificial and imposed life-prolonging treatment to permit a natural and peaceful death to occur. Such an action is in accordance with the highest ethical standards of medical practice.

This statement is provided as an educational service of the American Academy of Neurology. It is based on an assessment of current scientific and clinical information. It is not intended to include all possible proper methods of care for a particular neurological problem or all legitimate criteria for choosing to use a specific procedure. Neither is it intended to exclude any reasonable alternative methodologies. The AAN recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, based on all of the circumstances involved.

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1. The most extreme example of this tragic condition has been called the "locked-in state" or "de-efferented state"

(3/1/93)