

Position statement: Certain aspects of the care and management of profoundly and irreversibly paralyzed patients with retained consciousness and cognition

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

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. Patients with these conditions remain mentally competent (with 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. (The most extreme example of this tragic condition has been called the "locked-in state" or "de-efferented state.")

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 (eg, ventilators or 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; that the patient has had a consistently held position over time; and that the decision is not merely an impulsive or transient reaction to

the 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 nontreatment. 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 nonparalyzed, 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 profoundly paralyzed patients 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 contribute, as a secondary effect, to respiratory depression, coma, or death.

If a physician has a moral objection to carrying out the patient's decision to remove life-support

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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 and to permit a natural and peaceful death to occur. Such an action is in accordance with the highest ethical standards of medical practice.

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