

## CARING FOR PATIENTS IN PERSISTENT VEGETATIVE STATE (PVS)

The bitter legal battle over Terri Schiavo's feeding tube has triggered renewed concern about appropriate care for patients in persistent vegetative state (PVS). However, media coverage of the Schiavo story has not always been clear about PVS as a clinical condition or about the long-standing ethical and legal consensus on withdrawing life-sustaining treatment in PVS.

### What Is Persistent Vegetative State?

In 1994, the American Academy of Neurology's Multi-Society Task Force on PVS defined the *vegetative state* as a clinical condition of "complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brain-stem autonomic functions."<sup>1</sup> The task force defined *persistent vegetative state* (PVS) as a vegetative state present one month after acute brain injury, or lasting at least one month in patients with degenerative or metabolic disorders.

Patients in PVS are unconscious, but have sleep-wake cycles. When awake, they may appear to be alert, yet they are not aware of their surroundings. This distinguishes them from patients in coma, "who are unconscious because they lack both wakefulness and awareness."<sup>1</sup> And unlike "brain dead" patients, who have lost *all* brain functions, including brain stem functions, patients in PVS retain autonomic brain stem functions—most PVS patients do not require mechanical ventilation, for example. PVS is also clinically distinct from the "locked-in syndrome," in which patients retain consciousness and cognitive function but are unable to communicate or to move because of severe paralysis of the voluntary motor system.<sup>1</sup> Diagnosis of PVS is based on repeated physical examinations over time; neurodiagnostic tests, such as electro-encephalography or cerebral metabolic studies, may provide supporting information.

Patients in PVS retain sufficient brain stem function to survive for extended periods with

DIAGNOSTIC CRITERIA FOR PVS
• No evidence of awareness of self or environment
• No evidence of ability to interact with others
• No evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli
• No evidence of language comprehension or expression
• Sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical and nursing care
• Bowel and bladder incontinence
• Variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes
Multi-Society Task Force on PVS 1994.

appropriate medical and nursing care. They require daily skin care and attention to personal hygiene, along with range of motion therapy to slow the formation of limb contractures, and artificially administered nutrition and hydration. Therapies that require patients to follow commands or otherwise participate in their rehabilitation cannot be used with patients in PVS.

Prognosis is poor for patients in PVS. This condition is considered "permanent," meaning that the likelihood of recovering any degree of consciousness is extremely small, if it persists 12 months after traumatic brain injury, or 3 months after a nontraumatic injury, as in the case of Terri Schiavo.<sup>2</sup>

### Caring for Patients in PVS

Caring for patients in PVS can be emotionally demanding.<sup>3</sup> These patients maintain irregular sleep-wake cycles; most show reflex eye movement, but they do not actively track moving objects or move their eyes voluntarily. PVS patients usually can move their limbs or trunk; some utter grunts or other vocalizations, many vary their facial expressions, and some may even smile or shed tears, but these actions are not voluntary or purposeful.<sup>1</sup>

To someone who is not familiar with the condition, however, patients in PVS can appear to be making deliberate gestures or to be at least minimally aware. Thus, it can be very difficult for family members or loved ones—and even, at times, for health care professionals—to understand that the patient is not, in fact, aware of his or her surroundings and is not responding to the presence of others.<sup>4</sup> Although family members often say they understand the diagnosis, 90 percent also assert that the patient has some awareness.<sup>5</sup>

Initial aggressive treatment may be appropriate because of the time needed to make a diagnosis of PVS with a high degree of medical certainty.<sup>6</sup> Once the diagnosis has been established, difficult decisions must be made about what level of care is appropriate, including decisions about withholding or withdrawing life-sustaining treatment. Families and surrogates facing such decisions should receive appropriate psychosocial support.<sup>2</sup>

### Withholding or Withdrawing Life-Sustaining Treatment

Ethical and legal consensus holds that the right to refuse treatment, including artificially administered nutrition and hydration, extends to patients in PVS.<sup>7</sup> When a patient has indicated in an advance directive that he or she would not wish to receive life-sustaining treatment in these circumstances, that directive should be followed.<sup>8</sup>

When the patient has no advance directive, treatment decisions fall to his or her health care agent (durable power of attorney for

health care) or authorized surrogate, who may make the decision to withhold or withdraw treatment on the patient's behalf.<sup>8</sup> The decision should be based on the patient's wishes, if they can be ascertained. If the patient's preferences are not known, decisions should be based on the patient's best interest.

Many people find the decision to withdraw artificially administered nutrition and hydration from patients in PVS particularly upsetting. They worry that the patient will suffer during the dying process. This is not the case, however. By definition, patients in PVS do not have the capacity to suffer because they lack self-awareness.<sup>2</sup> Moreover, research has shown that self-aware hospice patients who voluntarily refuse nutrition and hydration do not experience "bad" or painful deaths.<sup>9</sup>

Others are concerned that withdrawing artificial administered nutrition and hydration may violate religious teachings. Although some religious traditions do have specific teachings relating to life-sustaining treatment, interpretations are often complex and misunderstood. Pastoral counseling should be available to help families and health care agents grappling with these difficult decisions.<sup>10</sup>

With so much public misperception surrounding PVS, health care professionals need to help families understand the clinical realities and implications of the diagnosis. Clinicians also need to provide a supportive environment that gives families time to come to terms with the emotionally charged decisions they are asked to make for a loved one in PVS.

### References & Resources

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