

# Practice parameters: Assessment and management of patients in the persistent vegetative state

## (Summary statement)

Report of the Quality Standards Subcommittee of the American Academy of Neurology

**I. Overview.** The Quality Standards Subcommittee (QSS) of the American Academy of Neurology develops practice parameters for neurologists to use in evaluating clinical disorders. This document is based on a report<sup>1,2</sup> published in two parts, "Medical Aspects of the Persistent Vegetative State," written by the Multi-Society Task Force on PVS.

**II. Justification.** Approximately 10,000 to 25,000 adults and 6,000 to 10,000 children in the United States are diagnosed as being in the persistent vegetative state (PVS). Inasmuch as the Task Force report reviewed the medical facts concerning PVS, the need to develop management standards and guidelines became apparent. The following summary provides practice parameters that outline diagnostic and management standards for adults and children in PVS.

**III. Description of the process.** The Multi-Society Task Force on PVS, established in 1991, was charged with reviewing and analyzing all available data on PVS in adults and children and preparing a report summarizing the medical facts of this condition.<sup>1,2</sup> The Multi-Society Task Force, impaneled from representatives of the American Academy of Neurology, Child Neurology Society, American Association of Neurological Surgeons, American Neurological Association, and American Academy of Pediatrics, gathered and analyzed available information about PVS. An advisory panel of consultants from related medical and allied health fields with expertise in PVS, ethics, and law reviewed and criticized the Task Force report; subsequently, this document was approved by the executive committee of each participating society. The Task Force adopted an explicit approach to the analysis of available data.

A comprehensive literature review from 1972 to 1993 of all MEDLINE references using the terms

"vegetative state" and "persistent vegetative state" was undertaken. Additional case material was sought by publication of a "request for information" in the major neurologic, neurosurgical, and pediatric medical journals. Data concerning outcome of PVS patients from the National Institute of Neurological Disorders and Stroke Traumatic Coma Data Bank were also reviewed. Media and lay press articles from available sources concerning unexpected recoveries from prolonged coma were reviewed and summarized as to their outcomes.<sup>1,2</sup> These data were categorized into three classes: randomized controlled clinical trials (class I), well-designed clinical studies (class II), and evidence provided by nonrandomized historical controls, case reports, or expert opinion and consensus (class III).

Because of the nature of PVS, no class I studies were found. All publications containing valid outcome data at 3, 6, and 12 months about adults and children in PVS 1 month after traumatic and non-traumatic brain injury were identified.<sup>1,2</sup> These studies contained data on 754 patients and used the Glasgow Outcome Scale. Outcomes based on this scale include:

- *Good recovery:* these patients have the capacity to resume normal occupational and social activities, although there may be minor physical or mental deficits or complaints.
- *Moderate disability:* these patients are independent and can resume almost all activities of daily living. They are, however, disabled, as they no longer can participate in a variety of social and work activities.
- *Severe disability:* these patients are no longer capable of resuming the majority of previous personal, social, and work activities. These patients have limited communication skills and abnormal behavioral and emotional responses. They are partially or totally dependent on others for their activities of daily living.

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Reprints of these practice parameters and the Multi-Society Task Force report are available from the American Academy of Neurology office. Address correspondence and reprint requests to Joanne F. Okagaki, American Academy of Neurology, Suite 335, 2221 University Avenue SE, Minneapolis, MN 55414; phone 612/623-2439.

**Table 1. Incidence of recovery of consciousness and function in adults and children in a persistent vegetative state (PVS) after traumatic or nontraumatic brain injury\*†**

Outcome and functional recovery	3 Months (% of patients)	6 Months (% of patients)	12 Months (% of patients)
<b>Adults</b>			
Traumatic injury (n = 434)			
Death	15	24	33
PVS	52	30	15
Recovery of consciousness	33	46	52
Severe disability			28
Moderate disability			17
Good recovery			7
Nontraumatic injury (n = 169)			
Death	24	40	53
PVS	65	45	32
Recovery of consciousness	11	15	15
Severe disability			11
Moderate disability			3
Good recovery			1
<b>Children</b>			
Traumatic injury (n = 106)			
Death	4	9	9
PVS	72	40	29
Recovery of consciousness	24	51	62
Severe disability			35
Moderate disability			16
Good recovery			11
Nontraumatic injury (n = 45)			
Death	20	22	22
PVS	69	67	65
Recovery of consciousness	11	11	13
Severe disability			7
Moderate disability			0
Good recovery			6

\* This table appears as table 3 in the Multi-Society Task Force report.<sup>1,2</sup> Reprinted by permission of the *New England Journal of Medicine*, Multi-Society Task Force on PVS, 330:1572 (1994). Copyright 1994 by the Massachusetts Medical Society. All rights reserved.

† Data were collected from series of patients in a PVS 1 month after injury and do not include individual case reports. Some patients who recovered consciousness died within 12 months after injury or were lost to follow-up. The data for nontraumatic injuries reflect all causes, not just postanoxic injury; for this category alone, the prognosis is poorer than that suggested by the data. Data on functional recovery are for patients who recovered consciousness within 12 months after injury.

- PVS: see definition below.
- Death.

These data were summarized in an evidence table (table 1) and were used to calculate probabilities for predicting outcome (table 2).

**IV. Definitions.** The vegetative state is 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 brainstem autonomic functions.

*Criteria.* The vegetative state can be diagnosed using the following criteria. Patients in a vegetative state show:

- No evidence of awareness of self or environment and an inability to interact with others;
- No evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli;

**Table 2. Probability of recovery of consciousness and function at 12 months in adults and children in a persistent vegetative state (PVS) 3 or 6 months after traumatic or nontraumatic injury\*†**

Outcome	Adults		Children	
	Traumatic injury (N = 434)	Nontraumatic injury (N = 169)	Traumatic injury (N = 106)	Nontraumatic injury (N = 45)
<i>Patients in PVS for 3 months‡</i>				
Death	35 (27-43)‡	46 (31-61)	14 (1-27)	3 (0-11)
PVS	30 (22-38)	47 (32-62)	30 (13-47)	94 (83-100)
Severe disability	19 (12-26)	6 (0-13)	24 (8-40)	3 (0-11)
Moderate disability or good recovery	16 (10-22)	1 (0-4)	32 (15-49)	0
<i>Patients in PVS for 6 months§</i>				
Death	32 (21-43)‡	28 (12-44)	14 (0-31)	0
PVS	52 (40-64)	72 (56-88)	54 (30-78)	97 (89-100)
Severe disability	12 (4-20)	0	21 (1-41)	3 (0-11)
Moderate disability or good recovery	4 (0-9)	0	11 (0-26)	0

\* This table appears as table 4 in the Multi-Society Task Force report.<sup>1,2</sup> Reprinted by permission of the *New England Journal of Medicine*, Multi-Society Task Force on PVS, 330:1572 (1994). Copyright 1994 by the Massachusetts Medical Society. All rights reserved.

† Conditional probabilities were determined from data in table 1. The numbers of patients given in parentheses refer to the numbers of patients who were in a vegetative state 1 month after the injury.

‡ Entries are % of patients (99% confidence interval).

§ A total of 218 adults with traumatic injuries, 77 adults with nontraumatic injuries, 50 children with traumatic injuries, and 31 children with nontraumatic injuries.

¶ A total of 123 adults with traumatic injuries, 50 adults with nontraumatic injuries, 28 children with traumatic injuries, and 30 children with nontraumatic injuries.

- No evidence of language comprehension or expression;
- Intermittent wakefulness manifested by the presence of sleep-wake cycles;
- Sufficiently preserved hypothalamic and brainstem autonomic functions to permit survival with medical and nursing care;
- Bowel and bladder incontinence; and
- Variably preserved cranial nerve (pupillary, oculocephalic, corneal, vestibulo-ocular, gag) and spinal reflexes.

The *persistent vegetative state* can be defined as a vegetative state present at 1 month after acute traumatic or nontraumatic brain injury, and present for at least 1 month in degenerative/metabolic disorders or developmental malformations.

The *permanent vegetative state* means an irreversible state, a definition, as with all clinical diagnoses in medicine, based on probabilities, not absolutes. A PVS patient becomes permanently vegetative when the diagnosis of irreversibility can be established with a high degree of clinical certainty, ie, when the chance of regaining consciousness is exceedingly rare.

**V. Diagnosis of PVS.** PVS can be diagnosed on

clinical grounds with a high degree of medical certainty in most adult and pediatric patients after careful, repeated neurologic examinations. The diagnosis of PVS should be established by a physician who, by reason of training and experience, is competent in neurologic function assessment and diagnosis. Reliable criteria do not exist for making a diagnosis of PVS in infants under 3 months old, except in patients with anencephaly. Other diagnostic studies may support the diagnosis of PVS, but none adds to diagnostic specificity with certainty.

## VI. Categories and clinical course of PVS.

There are three major categories of diseases in adults and children that result in PVS. The clinical course and outcome of PVS patients depends upon the specific etiology:

- A. *Acute traumatic and nontraumatic brain injury.* PVS usually evolves within 1 month of injury from a state of eyes-closed coma to a state of wakefulness without awareness with sleep-wake cycles and preserved brainstem functions.
- B. *Degenerative and metabolic disorders of the brain.* Many degenerative and metabolic nervous system disorders in adults and children inevitably progress toward an irreversible vegetative state. Patients who are severely impaired but retain some degree of awareness may lapse briefly into a vegetative state from the effects of medication, infection, superimposed illnesses, or decreased fluid and nutritional intake. Such a temporary encephalopathy must be corrected before establishing that the patient is in PVS. If the vegetative state persists for several months, recovery of consciousness is unlikely.
- C. *Severe developmental malformations of the nervous system.* The developmental vegetative state is a form of PVS that affects some infants and children with severe congenital malformations of the nervous system. These children do not acquire awareness of the self or the environment. This diagnosis can be made at birth only in infants with anencephaly.<sup>1</sup> For children with other severe malformations who appear vegetative at birth, observation for 3 to 6 months is recommended to determine whether these infants acquire awareness. The majority of such infants who are vegetative at birth remain vegetative; those who acquire awareness usually recover only to a severe disability.

**VII. Prognosis for recovery.** Recovery from PVS can be defined in terms of recovery of consciousness and recovery of function. Recovery of consciousness can be verified when a patient shows reliable evidence of awareness of self and the environment, consistent appearance of voluntary behavioral responses to visual and auditory stimuli, and interac-

tion with others. Recovery of function occurs when a patient becomes mobile and is able to communicate and learn, perform adaptive skills and self care, and participate in recreational or vocational activities. Using these parameters, recovery of function can be defined with the Glasgow Outcome Scale (table 1).

These parameters, as defined by the Glasgow Outcome Scale, were used as outcome measures to calculate probabilities for recovery in adults and children in PVS 3 months and 6 months after acute traumatic and nontraumatic injuries (table 2).

Additional data were collected for patients in PVS for more than 12 months, and these show almost no probability of recovery. The available data indicate that recovery of consciousness from post-traumatic PVS after 12 months in adults and children is unlikely. Recovery from nontraumatic PVS after 3 months is exceedingly rare in both adults and children. The above data are based on class II studies. Several individual case reports (class III) have described a few verified late recoveries of consciousness from traumatic (>12 months) or nontraumatic (>3 months) injury.

**VIII. Survival of patients in PVS.** The life span of adults and children in a PVS is substantially reduced. For most PVS patients, life expectancy ranges from 2 to 5 years. Survival beyond 10 years is unusual. The chance for survival of greater than 15 years is approximately 1/15,000 to 1/75,000.

**IX. Recommendations.** *Diagnostic standard and management guidelines* for adults and children in PVS include the following:

- A. *Diagnostic standard for establishing a persistent vegetative state.* The vegetative state is diagnosable. It is defined as being persistent at 1 month. Based upon class II evidence and consensus that reflect a high degree of clinical certainty, the following is a standard concerning PVS:
  - PVS can be judged to be permanent 12 months after *traumatic* injury in adults and children. Special attention to signs of awareness should be devoted to children during the first year after traumatic injury.
  - PVS can be judged to be permanent for *nontraumatic* injury in adults and children after 3 months.
  - The chance for recovery after these periods is exceedingly low, and recovery is almost always to a severe disability.
- B. *Management guidelines*
  - When a patient has been diagnosed as being in a PVS by a physician skilled in neurologic assessment and diagnosis, physicians have the responsibility of discussing with the family or surrogates the probabilities of the patient's attaining the various stages of recovery or remaining in a PVS.

- Patients in PVS should receive appropriate medical, nursing, or home care to maintain their personal dignity and hygiene.
- Physicians and the family must determine appropriate levels of treatment relative to the administration or withdrawal of:
  1. Medications and other commonly ordered treatments;
  2. Supplemental oxygen and use of antibiotics;
  3. Complex organ-sustaining treatments such as dialysis;
  4. Administration of blood products; and
  5. Artificial hydration and nutrition.
- Once PVS is considered to be permanent, a "Do not resuscitate" (DNR) order is appropriate. A DNR order includes no ventilatory or cardiopulmonary resuscitation. The decision to implement a DNR order, however, may be made earlier in the course of the patient's illness if there is an advance directive or agreement by the appropriate surrogate of the patient and the physician (or physicians) responsible for the care of the patient.

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## References

1. Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state [first of two parts]. *N Engl J Med* 1994;330:1499-1508.
2. Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state [second of two parts]. *N Engl J Med* 1994;330:1572-1579.

## DEFINITIONS

### Classification of evidence

**Class I.** Evidence provided by one or more well-designed randomized controlled clinical trials.

**Class II.** Evidence provided by one or more well-designed clinical studies such as case-control studies, cohort studies, and so forth.

**Class III.** Evidence provided by expert opinion, nonrandomized historical controls, or one or more case reports.

### Strength of recommendations

**Standards.** Generally accepted principles for patient management that reflect a high degree of clinical certainty (ie, based on class I evidence or, when circumstances preclude randomized clinical trials, overwhelming evidence from class II studies that directly addresses the question at hand or from decision analysis that directly addresses all the issues).

**Guidelines.** Recommendations for patient management that may identify a particular strategy or range of management strategies and that reflect moderate clinical certainty (ie, based on class II evidence that directly addresses the issue, decision analysis that directly addresses the issue, or strong consensus of class III evidence).

**Practice options or advisories.** Other strategies for patient management for which there is unclear clinical certainty (ie, based on inconclusive or conflicting evidence or opinion).

**Practice parameters.** Results, in the form of one or more specific recommendations, from a scientifically based analysis of a specific clinical problem.

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 neurologic 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.