

The permanent vegetative state: practical guidance on diagnosis and management

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Patients who survive catastrophic brain damage may be left permanently unaware—in the permanent vegetative state. Many doctors are likely to manage these patients at some point in their career.¹ The diagnosis has been the subject of reports prepared by official bodies.²⁻⁶ It has been defined as “a clinical condition of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation, and shows cycles of eye closure and opening which may simulate sleep and waking.”⁴ A wide range of causes has been reported, but head injury is probably the most common.^{5,6}

The diagnosis of permanent vegetative state is of particular importance; once it has been made, active medical treatment may be stopped. In the leading English case of Bland in 1993, the House of Lords held that artificial nutrition and hydration (for example, feeding by percutaneous endoscopic gastrostomy tube) constituted medical treatment and that if a patient was permanently unaware of self and environment, it was lawful not to continue such medical treatment.⁷ Up to October 1998, court approval to stop active medical treatment had been given for 18 patients.

Criteria for diagnosing permanent vegetative state have been drawn up by various groups.²⁻⁶ Although these criteria are the result of collective thought and wisdom, they are not always helpful in clinical practice. In contrast to the diagnosis of brain death, where a few specific clinical criteria can determine the state,⁸ the diagnosis of permanent vegetative state depends on providing evidence of a negative: a lack of awareness. The criteria developed have included incidental but irrelevant clinical observations (for example, response to ice water caloric testing⁶). Furthermore, they have failed to focus on the fundamental question of awareness, which has led to difficulties in some of the cases that have come before the High Court.⁹⁻¹¹ It has also become recognised that (un)awareness is part of a continuum.²

Clinical evaluation of awareness

A structured, systematic clinical approach to the assessment of awareness is shown in table 1. It starts from the premise that the patient seems to be unconscious and has been so for at least six months. The three major sensory systems (auditory, visual, and somatic) and the motor system are assessed to establish that some sensory stimuli can enter the central nervous system and that the motor pathway out is functioning, and that there is no evidence of:

- Sustained, reproducible, purposeful, or voluntary behavioural responses to normal or noxious visual, auditory, or tactile stimuli
- Language comprehension or expression
- Any spontaneous meaningful motor activity (including voice).

Summary points

The diagnosis of the vegetative state can be made only in a patient shown to be unaware of self and environment

Published research varies in relation to prognosis and permanence—currently, the vegetative state is considered permanent by 12 months at the latest

In England and Wales, stopping artificial nutrition and hydration requires the approval of the High Court

The patient is represented legally by the official solicitor

The question for the court is whether continued treatment will be in the patient's best interests

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Visual awareness

The visual system is the easiest to test. To check whether intact motor output is available, the examiner should observe whether the patient has spontaneous eye movements (the eyes often rove about spontaneously) and eye opening and closing. Then pupillary reflexes to bright light must be checked to establish whether there is an intact primary sensory pathway. Next the examiner should look for visual fixation—active looking at or for objects. Patients in a permanent vegetative state may occasionally look towards noise or new visual stimuli, but any greater visual exploration of the environment should raise concern that they have some residual awareness. Visual tracking of large objects moving in the visual field may occur in patients in the permanent vegetative state, but this should always prompt careful evaluation of the state. There should be no response such as eye closure to direct visual threat. The limited evidence from humans suggests that this requires complex cortical processing.¹² A response implies awareness of threat, although this need not suggest self awareness in the absence of any other evidence.

Auditory assessment

Auditory assessment involves using voice and other noises. The examiner should first establish whether sudden loud noise causes a general startle response. If so, the examiner should give simple, unambiguous instructions to undertake some simple movement such as closing eyes, looking left, or moving an arm. Spontaneous movements may complicate the interpretation, and prolonged observation may be needed to establish whether any apparent response is coincidental. It is also important to establish what responses there are or

Table 1 Clinical assessment to establish unawareness

Domain observed	Stimulus	Response	Implication
Auditory awareness	Sudden loud noise	Startle response	Primary auditory pathway intact Motor pathway intact
	Meaningful noise (bell, knock, etc)	Non-specific response, including localisation	Primary auditory pathway intact Motor pathway intact
		Specific and reproducible response	Evidence of awareness
	Spoken commands	Obedied	Evidence of awareness
Visual awareness	Bright light to eyes	Pupillary responses	Evidence of intact primary visual pathway
	Large moving objects	Tracking movements	Evidence of intact primary visual pathway Evidence that might be aware
	Visual threat	Blinks/other avoidance	Evidence that might be aware
	Written command	Obedied	Evidence of awareness
Somatic awareness	Painful stimuli to limbs	Local or generalised non-specific response	Evidence of intact primary pathway (not of awareness) If facial response, evidence of intact spinal pathway
		Coordinated response to remove pain by another limb	Evidence of awareness
	Painful stimuli to face	Local or generalised non-specific response	Evidence of intact primary pathway
		Coordinated response to remove	Evidence of awareness
	Routine sensory stimuli (care, etc)	Local or generalised non-specific response	Evidence of intact primary pathway
		Coordinated response to assist in process	Evidence of awareness
Motor output	Spontaneous	Non-specific, undirected activities	Evidence of intact primary pathway
		Goal directed activities	Evidence of awareness
	Responsive	Non-specific, undirected activities	Evidence of intact primary pathway
		Goal directed activities	Evidence of awareness

have been to other noises (for example, telephones, music, and familiar voices).

Somatic sensory system

The somatic sensory system is first assessed by using painful stimuli, looking for local and generalised responses to confirm intact input and output. Establishing whether the patient can abstract meaning from other somatic sensory stimuli is more difficult. The examiner should ask whether any cooperative motor response has been seen during routine nursing and other care and should observe responses to touch and other stimuli.

Motor activity

Some motor activity—both spontaneous and in response to sensory stimulation—is normal. It would be extremely unusual not to see focal and generalised motor responses (such as limb movement, facial grimacing, or yawning) to painful stimulus. If movement is minimal, the examiner should consider whether there is other neurological damage such as spinal cord injury, peripheral neuropathy, or drug toxicity.

Use all available evidence

Medical assessors must not restrict themselves to direct formal examination of the patient. A patient's behaviour may vary throughout the day and over longer periods, and some stimuli will arise only infrequently. Consequently, all available sources of evidence must be used; all written records including nursing notes should be reviewed and staff who have been in close contact with the patient over some time should be interviewed.

It is particularly important to interview family members. They may have observed behaviour that indicates awareness, and their opinion on the patient's level of awareness must be sought. It is also important to ask them what they believe to have been the likely

wishes of the patient, and what their own views are on the appropriateness of stopping medical treatment. Finally, the clinician should explain the situation and procedure to the family, and answer all their questions.

Observation versus interpretation

When obtaining evidence from other observers or from written material, it is vital that the examiner distinguishes clearly between observed behaviour and interpretation of the behaviour. Thus, family or staff should be asked directly what behaviour was actually observed. The examiner may then ask for their interpretations, which may show further observational evidence. However, interpretations made by observers may well be biased and the assessor should make her or his own interpretation.

Determining unawareness does not require any particular investigations. There is no specific structural neuropathology underlying the permanent vegetative state.¹⁵ However, investigation may be needed to eliminate plausible, treatable causes for the current state.

Experience is needed

Errors in the diagnosis of the vegetative state do occur.^{14 15} It is vital, therefore, that any doctor who assesses a patient is careful in his or her assessment and has appropriate expertise and experience. If there is any doubt about the diagnosis or conflict between different sources of evidence, re-examination at another time or prolonged observation, or both, must be undertaken.

Permanence

The full assessment of a patient extends beyond simply establishing unawareness. It is vital to be certain the situation will not change and cannot be altered. Therefore it is important to establish how the brain was

damaged and that there are no continuing reversible causes that may cause or worsen unconsciousness. The common causes of the permanent vegetative state include traumatic brain injury and diffuse cerebral anoxia,^{5, 6, 15} but any cause of acute generalised brain damage may lead to the permanent vegetative state. The examiner must consider whether any drugs being administered may be causing the vegetative state and, if there is any doubt about the diagnosis, might wish to re-examine the patient after these drugs have been withdrawn. Some diagnoses, such as the development of hydrocephalus, are occasionally overlooked. It is accepted that in some cases of permanent vegetative state no definitive cause can be discerned.^{9, 16}

The evidence in relation to prognosis has been reviewed.^{5, 6} It is generally accepted that recovery from the vegetative state rarely occurs after 12 months,^{5, 6} although recovery after this period has been reported.^{17, 18} In some cases, such as in patients with anoxic brain damage, a shorter period of six months is considered to indicate permanence.⁴

The legal process

Most medical interventions depend for their lawfulness on the consent of the patient. In many situations consent is implied by the patient's cooperation with treatment. Patients who are unaware cannot make decisions about treatment. It is lawful to treat these patients if the treatment is in their best interests.¹⁹ It is also lawful to stop providing artificial nutrition and hydration to these patients—but only with the approval of the High Court.^{7, 20} In principle, any interested person may initiate this process, although it will usually be clinicians or family members (table 2).¹⁶

The British legal system is adversarial in nature. Consequently, there must be an applicant who wishes to stop artificial nutrition and hydration, and a defendant. The applicant is usually the organisation (NHS trust or health authority) currently paying for the medical care. The doctor responsible for the patient must take the first step by contacting his or her employing authority, whose legal advisers will begin to prepare the necessary paperwork. Even if it is not the applicant, the organisation responsible for care will be required to participate in the legal process.¹⁵ The defendant is the patient, who is obviously not able to instruct solicitors to act on his behalf. He or she will

therefore be represented by the official solicitor, an independent official with a staff of about 100 civil servants, who represents incapacitated patients in court cases throughout England and Wales. The first legal step is for the applicant's solicitor to contact the official solicitor's office. One of the official solicitor's in-house lawyers will conduct the case on behalf of the patient.

The evidence

The applicant must produce evidence to establish that:

- The patient is unaware of self and environment
- There is no reasonable prospect of improvement
- Continuation of medical treatment (including artificial nutrition and hydration) is not in the patient's best interests. (Note that it is simply necessary to show that there is no benefit in continuing medical treatment.)

The applicant's medical evidence usually consists of reports from both the doctor who is treating the patients and an expert in the field—often a neurologist or specialist in (neurological) rehabilitation. Evidence of the family's views is usually required.

The court case

The official solicitor will examine the applicant's evidence and conduct inquiries with the patient's family and carers. It remains important for the official solicitor to obtain independent evidence, and he will almost always commission an independent expert to prepare a report. We know of one case in which experts on behalf of the plaintiff initially suggested that the patient was in the permanent vegetative state, but in which it was later argued (and disproved) that the patient wished to stop treatment.^{21, 22}

The official solicitor files a report with his recommendations on behalf of the patient. There is then a hearing in open court, but the identities of the patient, hospital, and staff directly involved are protected. In all the cases that have gone to a final hearing, permission has been given to stop feeding. It is not clear how the court would decide applications where there was evidence of some awareness (however minimal). In all the reported cases, the court was satisfied that the patient had no awareness, although in at least two cases the patients did not meet the criteria of the Royal College of Physicians.^{9, 10, 16}

Table 2 Legal process

Person or organisation	Action	Comment
Clinician, family, or other	Consider stopping treatment	Family and clinician to discuss
Doctor	Inform responsible organisation	May first consult informally official solicitor
Organisation responsible	Identify and inform solicitor	Usually NHS trust or health authority May consult informally official solicitor
Applicant's solicitors	Commission separate formal medical assessment and report	Confirmation of clinical state
	Inform official solicitor and issue application to court	Official solicitor represents the patient
	Attend directions appointment at court	To establish timetable for enquiries and final hearing and to establish reporting restrictions
Official solicitor	Commission formal medical assessment and report	Confirmation of clinical state
	Contact and talk to family members	Views are taken into account, but are not paramount ¹¹
	Discuss areas of concern with experts and applicant	If doubt is present
High Court (Family Division)	Hearing: evidence presented and judgment given	Continue reporting restrictions
Clinicians	Organise cessation of treatment	Usually in hospital side room, but can be elsewhere
	Organise support to family and nurses	
	Give patient any symptomatic treatment needed	For example, anticonvulsants

Subsequent management

The management of the patient after court approval rests with the doctor responsible. The usual and recommended process is as follows. The patient may be moved to a different location. The gastrostomy (or nasogastric) tube should be removed. There is no need to start intravenous fluids, but it is reasonable to maintain intravenous access if drugs (for example, for epilepsy) are thought to be necessary. Drugs for any symptoms can be continued (for example, anticonvulsants and antacids). Arrangements must be made to provide the staff and family with emotional support. The family should be given free access to the patient. The patient is likely to die within 14 days.

Competing interests: None declared.

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*A memorable teacher***Reasons to be thankful**

Big Bob Torrance is dead. I last saw him in 1990. Knowing that he was to retire and that, fortuitously, the Physiological Society was meeting in Oxford that summer, I went to the meeting. At a similar meeting, under his tutelage, I had made my fledgling scientific presentation 20 years earlier. As I walked through the familiar front door of the physiology department, Bob was the first person I saw. I had not seen him for over 15 years. Within three minutes it was as if I'd just come into the laboratory to report last night's experiment.

I was a perfect research student for him. My mouth was exactly at the height of the hearing aid microphone he wore in his shirt pocket. He was the perfect research supervisor. He suggested things and then went away, returning only when I needed help. Our laboratory contained a large preparation area, a shielded room for the experiments, and two offices. One office, occupied by the senior of the two students Bob usually had working with him, was light and airy with an outside window. The other had only a window on to the corridor. But it had more book space and shelves, and an all important blackboard. This was Bob's room. There were piles of journals and books and old experimental records, some on shellac coated smoked paper. The board was covered in Bob's thoughts. I would join him and others, crowded into the little room, as we discussed bicarbonate ions and oscillatory stimuli, and ideas for future experiments.

The original purpose of my research was to investigate a possible efferent inhibitory pathway to the carotid body. About a year into the work I had one of the only truly original thoughts that I have ever had (the other one was wrong): part of the evidence for this pathway was an artefact of the experimental technique. Further investigation supported my idea. I submitted the paper with Bob's name on, but he took it off: it was my idea, my work, and therefore my paper. That was just one of the many, many things that Bob taught me by example.

He taught me to write: the first draft of that first paper was 7000 words long, but with his help the final version was 3000 words that said more than my original 7000. He taught me to trust: there were days when I was less than diligent, and he let me know. He persuaded me to stick with my original intention and qualify in medicine. I almost applied for a lectureship in physiology, but Bob suggested that I do that only if I was prepared to accept teaching people who would end up earning far more than I ever would. He was medically qualified, and was happy teaching those who would earn more, which includes me.

The best medical school is the one you go to. The best research supervisor should be the one you have. Mine certainly was. I cast my mind back and I hear him coming through the corridor side door towards our laboratory, humming tunelessly, and walking with his unmistakable slapping shuffle. He comes in and asks about last night's experiment. We go to the blackboard and talk it through, and I am reminded that he did have one fault: his handwriting was nearly illegible. But his words and thoughts were crystal clear, and I am eternally grateful.

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We welcome articles of up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.