

The Vegetative State

Guidance on diagnosis and management

Report of a working party of the Royal College of Physicians



ROYAL COLLEGE OF PHYSICIANS

2003

This guidance has been endorsed by the Royal College of Physicians of Edinburgh and the Royal College of Physicians and Surgeons of Glasgow.

Readers will find the editorial by McLean in 2001 provides a helpful summary of the current medico-legal position, including differences between Scotland and England/Wales.²⁰ In Scotland, local advice should be sought from the Central Legal Office of the NHS in the Scottish Executive.

**Royal College of Physicians of London
11 St Andrews Place, London NW1 4LE**

Registered Charity No 210508

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ISBN 1 86016 186 3

Text edited and designed by the Publications Unit of the Royal College of Physicians
Printed in Great Britain by Sarum ColourView Group, Salisbury, Wiltshire

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Members of the working party

David Bates MA FRCP, (Chair), Professor of Clinical Neurology, Royal Victoria Infirmary, Newcastle upon Tyne

Carol Black CBE MD PRCP, President, Royal College of Physicians (RCP)

Tim Evans MD FRCP, Chairman, RCP Critical Care Medicine Committee;
Professor of Intensive Care Medicine, Royal Brompton Hospital, London

John Forsythe MD FRCS, Director, Transplant Unit, Royal Infirmary of Edinburgh

Elaine Gadd MB ChB MRCPsych, Department of Health

Ian Gilmore MD FRCP, Registrar, Royal College of Physicians

Andrew Grubb MA LL.D FmedSci, Professor of Law, Cardiff Law School

Vic Larcher MA MB FRCP, Consultant Paediatrician, Queen Elizabeth Children's Service,
Royal London Hospital

Lindsay McLellan MB FRCP, Professor of Neurological Rehabilitation, University of Southampton,
Honorary Consultant in Neurology and Rehabilitation Medicine, Southampton General Hospital

Brian McGinnis OBE, Special Adviser, MENCAP, London

John Pickard FRCS, Professor of Neurosurgery, Consultant Neurosurgeon,
Addenbrooke's Hospital, Cambridge

Roy Pounder MD DSC(Med) FRCP, Clinical Vice President, Royal College of Physicians

John Saunders MD FRCP, Honorary Secretary, RCP Ethical Issues in Medicine Committee;
Consultant Physician, Nevill Hall Hospital, Abergavenny

Amanda Swain DipCOT SROT, National Adviser in Acquired Brain Injury,
Leonard Cheshire Foundation, London

Adam Zeman DM MRCP, Consultant Neurologist, Western General Hospital, Edinburgh

1 Introduction

Background

- 1.1 This guidance has been compiled to replace the recommendations published by the Royal College of Physicians in 1996,¹ in response to requests for clarification from the Official Solicitor. The guidance applies primarily to adult patients and older children in whom it is possible to apply the criteria for diagnosis discussed in the body of the document.

Wakefulness without awareness

- 1.2 Consciousness is an ambiguous term, encompassing both wakefulness and awareness. This distinction is crucial to the concept of the vegetative state, in which wakefulness recovers after brain injury without recovery of awareness.^{2–5}

Definitions

The vegetative state

- 1.3 A patient in the vegetative state (VS) appears at times to be wakeful, with cycles of eye closure and eye opening resembling those of sleep and waking. However, close observation reveals no sign of awareness or of a ‘functioning mind’: specifically, there is no evidence that the patient can perceive the environment or his own body, communicate with others, or form intentions. As a rule, the patient can breathe spontaneously and has a stable circulation. The state may be a transient stage in the recovery from coma or it may persist until death. The vegetative state can follow a variety of severe insults to the brain, most commonly traumatic or hypoxic-ischaemic brain injuries.
- 1.4 The terms ‘wakefulness’ and ‘awareness’ require further clarification.

Wakefulness

- 1.5 Wakefulness refers to a state in which the eyes are open and there is a degree of motor arousal; it contrasts with sleep, a state of eye closure and motor quiescence. There are degrees of wakefulness. Wakefulness is normally associated with conscious awareness, but the VS indicates that wakefulness and awareness can be dissociated. This can occur because the brain systems controlling wakefulness, in the upper brainstem and thalamus, are largely distinct from those which mediate awareness.⁶

Awareness

- 1.6 Awareness refers to the ability to have, and the having of, experience of any kind. We are typically aware of our surroundings and of bodily sensations, but the contents of awareness

can also include our memories, thoughts, emotions and intentions. Although understanding of the brain mechanisms of awareness is incomplete, structures in the cerebral hemispheres clearly play a key role. Awareness is not a single indivisible capacity: brain damage can selectively impair some aspects of awareness, leaving others intact. Many brain processes, including some in the cerebral cortex, occur in the absence of awareness.

- 1.7 There is no simple single clinical sign or laboratory test of awareness. Its presence must be deduced from a range of behaviours which indicate that an individual can perceive self and surroundings, form intentions and communicate. As our techniques of assessment are fallible, we can never exclude the possibility of some awareness with complete certainty: this leaves open the possibility that some extremely simple forms of awareness may survive in the VS, including the experience of pain, although the available evidence suggests that this is not the case.^{5,7,8}

The persistent vegetative state

- 1.8 This refers arbitrarily to a VS which has continued for four weeks or more (In the previous version of this guidance¹ this was referred to as the 'continuing vegetative state', to distinguish it more clearly from the permanent vegetative state: we have reverted here to the more widely used term but have avoided the ambiguous abbreviation 'PVS').

The permanent vegetative state (PVS)

- 1.9 When the VS is deemed permanent, a prediction is being made: that awareness will never recover. This prediction cannot be made with absolute certainty. However, as discussed below in para 2.8, the chances of regaining awareness diminish considerably as the time spent in the VS increases.

2 Criteria for diagnosis of the vegetative state

Preconditions

- 2.1 The following preconditions must apply before diagnosis of the VS can be considered.
- 1 The cause of the condition should be established as far as is possible. It may be due to acute cerebral injury, degenerative conditions, metabolic disorders, infections or developmental malformations.
 - 2 The possibility that the persisting effects of sedative, anaesthetic or neuromuscular blocking drugs are responsible in whole or part should be considered. Drugs may have been the original cause of an acute cerebral injury, usually hypoxic, but their continuing direct effects must be excluded either by the passage of time or by appropriate laboratory tests.
 - 3 The possibility that continuing metabolic disturbance is responsible for the clinical features must be considered and excluded. Metabolic disturbances may of course occur during the course of a VS.
 - 4 The possibility that there is a treatable structural cause should be excluded by brain imaging.

Clinical criteria

- 2.2 The following criteria are usually met.
- 1 The key requirement for diagnosis is that there must be no evidence of awareness of self or environment at any time; no response to visual, auditory, tactile or noxious stimuli of a kind suggesting volition or conscious purpose; no evidence of language comprehension or meaningful expression. These are all necessary conditions for the diagnosis.
 - 2 There are typically cycles of eye closure and eye opening giving the appearance of a sleep–wake cycle.
 - 3 Hypothalamic and brainstem function are usually sufficiently preserved to ensure the maintenance of respiration and circulation.
- 2.3 Criteria 2 and 3 are usually satisfied by patients in the vegetative state but, unlike the first criterion, they are not obligatory (thus, for example, a patient with cerebral injuries sufficient to cause the vegetative state might, incidentally, have third nerve palsies preventing eye opening, or injuries to the chest or medulla affecting respiratory function).

Clinical features

- 2.4 It may be helpful to fill out the clinical picture by describing compatible clinical features which occur commonly, features which are compatible with the diagnosis but atypical, and features which are incompatible with the diagnosis.
- 1 **Compatible features** – As well as showing signs of a cycle of sleep and wakefulness, patients in the vegetative state may make a range of spontaneous movements including chewing, teeth grinding, swallowing, roving eye movements and purposeless limb movements; they may make facial movements such as smiles or grimaces, shed tears, or make grunting or groaning sounds for no discernible reason (it would be unusual for a patient to display the entire range of movements). They may react to a number of stimuli: brainstem reflexes can be present (pupillary, oculocephalic (doll's eye), corneal, oculovestibular (caloric) and gag); various stimuli, usually noxious or noisy, can both excite a generalised arousal response, with quickening of respiration, grimaces or limb movements, and cause the extensor or flexor withdrawal of a limb; patients' eyes may turn fleetingly to follow a moving object or towards a loud sound. Grasp reflexes may be present.
 - 2 **Compatible but atypical features** – It is unusual for patients in a VS to follow a moving target for more than a fraction of a second, to fixate a target or to react to visual menace. However, all these behaviours have been described in patients whose clinical features are in all other respects typical of the VS.⁵ Patients have also been described in whom isolated fragments of behaviour, such as the utterance of a single inappropriate word, occur in what otherwise appears to be a VS.^{5,9} These features appear to reflect the survival of 'islands' of cortex which are no longer part of the coherent thalamo-cortical system required to generate awareness.⁶ Epileptic seizures occur occasionally.⁵ Features of these kinds should prompt careful reassessment of the diagnosis, but they do not in themselves negate the diagnosis of the VS.
 - 3 **Incompatible features** – Evidence of discriminative perception, purposeful actions and communicative acts is incompatible with the diagnosis of the VS. Thus a smile in response to the arrival of a friend or relative, an attempt to reach out for an object or the appropriate use of language would all indicate the presence of a 'functioning mind' and the recovery of awareness, although such recovery is sometimes very limited.

Differential diagnosis

- 2.5 The VS must be distinguished from minimally conscious (or 'low awareness') states, states of life-long severe disability with preserved awareness, the locked-in syndrome, coma, and death confirmed by brainstem death testing (see Tables 1 and 2, page 6).
- **Minimally conscious state (MCS)** – The terms 'minimally conscious', 'minimally responsive' or 'low awareness' state refer to the condition of patients who show minimal but definite evidence of awareness despite profound cognitive impairment.¹⁰ Patients emerging from the VS often enter the MCS, which may be the end point of their improvement, or a staging post on the way to further recovery.

- *People with life-long severe disabilities* – Some people with severe intellectual disabilities, commonly accompanied by severe physical disabilities, have limited capacity to respond to the outside world; but those close to them are clear that they do communicate and are aware, and may indeed have a rich internal life. Such people should not be classed as vegetative.
 - *Locked-in syndrome* – Locked-in syndrome results from brainstem pathology which disrupts the voluntary control of movement without abolishing either wakefulness or awareness. Patients who are ‘locked in’ are substantially paralysed but conscious, and can communicate using movements of the eyes or eyelids.
 - *Coma* – Coma is a state of unconsciousness in which the eyes are closed and sleep-wake cycles absent. Coma is usually transient, lasting for hours or days: the VS is one possible outcome.
 - *Death confirmed by brainstem death testing* – This implies the irreversible loss of all brain stem functions: it is followed by cardiac arrest, usually within hours or days, despite intensive care.
- 2.6 The above distinctions are made primarily on clinical grounds. Brain imaging with computed tomography (CT) or magnetic resonance imaging (MRI) often helps to clarify the cause of these clinical syndromes, but the findings on imaging are not specific. Cerebral atrophy is commonly seen in patients in the VS.
- 2.7 Sophisticated techniques used to assess cortical function – positron emission tomography (PET), electroencephalography (EEG), magnetoencephalography (MEG) and evoked potential (EP) studies – can be used to shed light on the physiology of the VS, but are not yet routine diagnostic tools. Their use is not required for diagnosis of the VS, which remains essentially clinical.

The time course

- 2.8 The prognosis of patients in the persistent VS is influenced by age, the underlying cause of the VS and its current duration. People in a VS one month after trauma stand a slightly better than even chance of regaining awareness; in cases of the VS due to non-traumatic causes, fewer than one-fifth of people in a VS at one month recover awareness. The chances of regaining awareness fall as time passes. Beyond one year following trauma, and beyond six months in non-traumatic cases, the chances of regaining consciousness are extremely low. In the very small number of well documented cases, recovery has usually been to a state of exceptionally severe disability.³ Patients in the persistent VS should therefore be observed for 12 months after head injury (traumatic brain injury) and six months after other causes before the VS is judged to be ‘permanent’.

Table 1. Glasgow Coma Scale (GCS).

E	Eye opening	M	Motor function	V	Verbal
1	None	1	None	1	None
2	To pain	2	Extends to pain	2	Grunts
3	To sound	3	Abnormal flexion to pain	3	Inappropriate words
4	Spontaneously	4	Normal flexion to pain	4	Confused
		5	Localises pain	5	Oriented
		6	Normal		

Table 2. The differential diagnosis of the vegetative state.

Condition	Vegetative state	Minimally conscious state	Locked-in syndrome	Coma	Death confirmed by brainstem tests
Awareness	Absent	Present	Present	Absent	Absent
Sleep-wake cycle	Present	Present	Present	Absent	Absent
Response to noxious stimuli	+/-	Present	Present (in eyes only)	+/-	Absent
Glasgow Coma Scale score	E4, M1-4, V1-2	E4, M1-5, V1-4	E4, M1, V1	E1-2, M1-4, V1-2	E1, M1-3, V1
Motor function	No purposeful movement	Some consistent or inconsistent verbal or purposeful motor behaviour	Volitional vertical eye movements or eyeblink preserved	No purposeful movement	None or only reflex spinal movement
Respiratory function	Typically preserved	Typically preserved	Typically preserved	Variable	Absent
EEG activity	Typically slow wave activity	Insufficient data	Typically normal	Typically slow wave activity	Typically absent
Cerebral metabolism (PET)	Severely reduced	Insufficient data	Mildly reduced	Moderately to severely reduced	Severely reduced or absent
Prognosis	Variable: if permanent, continued vegetative state or death	Variable	Depends on cause but full recovery unlikely	Recovery, vegetative state or death within weeks	Already dead

NB: as explained in the text, EEG and measures of cerebral metabolism are not required to make these clinical diagnoses. EEG = electroencephalography; PET = positron emission tomography.

3 Management of the vegetative state

Medical care

- 3.1 Patients in the VS require a high quality of nursing care to avoid the preventable complications of their highly dependent state. Standard measures include adequate nutrition, often via a percutaneous endoscopic gastrostomy (PEG) tube, good skin care, passive joint exercises to minimise contractures, suction where necessary to help avoid aspiration, careful management of the doubly incontinent bladder and bowel, and attention to oral and dental hygiene. Until there is firm scientific evidence that treatment, in terms of specific medical, physiotherapeutic or rehabilitative activities, improves the outcome of patients in a VS, the use of these measures is a matter of clinical judgement. The medical and nursing staff must keep the relatives and carers well informed throughout the course of the VS.

Assessment

- 3.2 Both the initial diagnosis of the VS and the subsequent diagnosis of the permanent VS should be made with great care. There is evidence that the VS has been diagnosed in error.^{11,12} The explanations for misdiagnosis include confusion about the meaning of the term, inadequate observation in suboptimal circumstances, failure to consult those who see most of the patient (especially family members), and the inherent difficulty of detecting signs of awareness in patients with major perceptual and motor impairments.
- 3.3 Thus, when the diagnosis of the permanent VS is being considered, it is essential that the patient should be examined by at least two doctors both of whom are experienced in assessing disorders of consciousness. They should take into account the views of the medical staff, other clinical staff (including clinical neuropsychologists, occupational therapists and physiotherapists with expertise in assessing disorders of consciousness), carers and relatives about the patient's reactions and responses. They should undertake their clinical assessments separately and write the details of their assessments and their conclusions in the notes. They should consider the results of the investigations which have been performed to clarify the cause of the condition. As the patient's physical position can affect responsiveness, it may be valuable to assess the patient in more than one position. It may be helpful for nursing staff and relatives to be present during the examination.

Re-assessment

- 3.4 There is no urgency in making the diagnosis of the permanent VS. If there is any uncertainty in the mind of the assessor, the diagnosis should not be made and the patient should be reassessed after an interval. Structured observation may help to reveal signs of awareness in doubtful cases.^{13–15} The key consideration in making the diagnosis is whether the patient might be aware to some degree: it is always important to seek the views of nursing staff, relatives and carers on this issue.

Final definitive diagnosis and decisions concerning life support

- 3.5 When the diagnosis of a permanent VS has been made by establishing the cause of the syndrome so far as possible, by confirming the patient's clinical state and by the passage of time, recovery cannot reasonably be expected, and further therapy is futile. It merely prolongs an insentient life for the patient and a hopeless vigil entailing major emotional costs for relatives and carers.
- 3.6 In these circumstances, the clinical team, with the help of colleagues when required, should review the evidence formally. When the diagnosis of a permanent VS is considered definite, it should be discussed sensitively with relatives, who should then be given time to consider the implications, including the possibility of withdrawing artificial means of administering nutrition and hydration. At present, in England and Wales, the courts require that the decision to withdraw nutrition and hydration should be referred to them before any action is taken. In Scotland, although the court does not require that it be involved prior to any action being taken, as a result of the Lord Advocate's advice following the Law Hospital case,¹⁶ it would be prudent for a doctor to seek the authority of the Court of Session in order to guarantee that the Lord Advocate would not initiate a criminal prosecution.
- 3.7 A decision to withdraw other life-sustaining medication, such as insulin for diabetes, may also need to be referred to the courts because the legal position is uncertain. By contrast, decisions not to intervene with cardio-pulmonary resuscitation, antibiotics, dialysis or insulin can be taken clinically, in the best interests of the patient, after full discussion with those concerned.
- 3.8 Where a patient has made a valid and applicable advance directive indicating their refusal of continuing treatment, this must be respected. If not, efforts should be made to establish what the patient's views and preferences might have been, to help to make a decision in his or her best interests.
- 3.9 As indicated earlier, one cannot ever be certain that a patient in the VS is wholly unaware, although the available evidence supports this supposition. In view of this small but undeniable element of uncertainty, it is reasonable to administer sedation when hydration and nutrition are withdrawn to eliminate the possibility of suffering, however remote. The normal standards of palliative care should be observed to ensure the dignity of the death.

A note on children and young persons (0–18 years)

- 3.10 Formal diagnosis of the permanent vegetative state in children in the UK is rare. However, there is evidence to suggest that older children (older than circa 10 years) behave clinically and prognostically in a similar fashion to adults. For younger children, in whom survival may be poorer than in older children, greater account must be taken of the child's potentially evolving developmental capabilities. For reasons of this kind, the diagnosis can seldom be made unequivocally under the age of one year. However, there seems no reason why the guidance contained in this document should not be applied to children over the age of ten years, and it can be used with appropriate caution in children between one and ten years.
- 3.11 Where withdrawal or withholding of life-sustaining treatment is being contemplated in children, clinicians should refer to guidance from professional regulatory bodies.^{17–19}

Appendix 1

Checklist for the diagnosis of the permanent vegetative state

The diagnosis of the permanent vegetative state requires prolonged observation, experience in the assessment of disorders of consciousness, and discussion with relatives and with medical and paramedical staff. It cannot be made by following a simple protocol. However, we hope that this checklist will be of some practical help by highlighting the key steps on the way to the diagnosis.

- 1 Has at least one year elapsed since the onset in cases due to head injury?
or
- 2 Have at least six months elapsed since the onset in cases due to other causes?
- 3 Has the cause been established? (It should be established 'as far as possible'.)
- 4 Have effects of drugs been excluded?
- 5 Have effects of metabolic disturbance been excluded?
- 6 Has the possibility of a treatable structural cause been excluded by brain imaging?
- 7 Have two doctors who are experienced in the assessment of disorders of consciousness, independently confirmed that there is no evidence of:
 - awareness of self or environment
 - purposeful movement
 - any attempt to communicate?
- 8 Do medical staff, nursing staff and other therapists agree?
- 9 Do family and friends agree?*
- 10 In case of doubt, has an expert clinical neuropsychological assessment been carried out?

Where the answer is 'yes' to all these questions, the diagnosis of the permanent vegetative state is confirmed.

First assessing doctor:	Second assessing doctor:
Name _____	Name _____
Qualifications _____	Qualifications _____
Signature _____	Signature _____
Date _____	Date _____

* Sometimes, even when all other members of the family and friends of the patient are in agreement, one individual may be unable to agree with the general conclusion that the patient lacks awareness. Any evidence of awareness should be examined very seriously, but in these circumstances the continuing disagreement of one individual with the conclusion of health professionals and others close to the patient is not a bar to the diagnosis of the permanent vegetative state.

Appendix 2

Vignettes illustrating the definitions given in the report

Hour-to-hour and day-to-day fluctuations in responsiveness are common in patients in minimally responsive states and during slow emergence from coma. Understanding the meaning of spontaneous movements and movements occurring in response to stimulation (for example to touch and sound) requires (a) careful observations over a period of several weeks, and (b) considerable experience in their interpretation.

These four brief vignettes are not comprehensive, nor are they a substitute for the formal definitions given in the report, but they are intended as illustrations of how these definitions might apply in practice. These subjects have all been in the state described for 12 months.

1. A man aged 22 with a severe traumatic brain injury and lower limb fractures, with spasticity in all limbs

He was on an artificial ventilator for the first six weeks after the injury, at which time spontaneous breathing and apparent 'sleep-wake' cycles were re-established. When 'asleep', he can be 'woken' by touch or by a loud noise; he blinks repeatedly in response to repeated noise (eg hand claps) for however long they are continued. His eyes are usually directed straight ahead but they sometimes make spontaneous movements; they do not, however, follow the faces of family members who approach and talk to him. He does not chew and swallow food placed in his mouth. When being washed or dressed there is no response but when his spastic limbs are stretched by the physiotherapist, after ten seconds or so a general increase in muscle tone occurs, sometimes accompanied by grimacing and occasionally groaning. Similar levels of responsiveness are seen irrespective of who touches or speaks to him; he shows no evidence of apprehension or discomfort when the physiotherapist first begins to handle him. During periods of urinary or respiratory infection his level of responsiveness usually diminishes, plateauing at the previous level when the infection is over.

Comment: The lack of discriminating responses to environmental or bodily stimuli is consistent with permanent VS.

2. A woman aged 34 who suffered severe brain damage in a near-drowning accident

When 'awake' her eyes are divergent. Usually there is no movement of the eyes in response to sounds, but family members have noticed that when she is 'awake' in calm surroundings, her left eye appears to follow her ten-year-old son when he speaks to her. This response, however, lasts for only a few seconds and after three or four repetitions it disappears; it cannot be elicited again for 30 minutes and sometimes not until the next day. When the patient is unwell with an infection, or if showing frequent limb spasms (which may be a prelude to opening of the bowels and bladder), no eye responses occur. There are no other consistent responses to stimulation but nursing staff have noticed over the past two months an apparent relaxation

in spastic muscle tone in her when they move her arms to wash her, making their task a little easier.

Comment: The combination of discriminating responses to environmental and bodily stimuli with a changing level of responsiveness over the past two months suggests the possibility of a minimally conscious state, and therefore a further two-month period of observation is required.

3. A man aged 38 who was found unconscious after taking an overdose of antidepressant drugs

A year ago, two months after admission to hospital, he had shown early signs of emergence from coma (following people with his eyes, reliably squeezing his right hand to command and occasionally mouthing single words when in apparent discomfort). However, at this point he developed a serious urinary tract infection during which he had a prolonged episode of status epilepticus, requiring anticonvulsant drug treatment. Subsequently only reflex patterns of responses have been seen. Two months ago his anticonvulsant drugs were withdrawn, since when there has been no change in his level of responsiveness.

Comment: The history suggests a further episode of hypoxic brain damage during the episode of status epilepticus. Two months is ample time for any sedative effects of the anticonvulsant drugs to have disappeared and the observed pattern of responsiveness is now consistent with permanent VS.

4. A woman aged 25 injured in a high-speed road accident, resulting in coma and the need for assisted ventilation lasting three weeks

Three months after spontaneous respiration had returned, she started to show movements of the right arm and leg and grinding of the teeth, principally in response to noxious stimuli (eg having a blood sample taken, being stretched by the physiotherapist, or having a foot-drop splint applied in order to prevent calf muscle contractures). At times she would consistently follow certain members of staff and family members with her eyes for periods of up to five minutes but at other times her eyes would remain closed. Ward staff have noticed that each time she has been formally assessed by the visiting neurologist, her eyes have closed within 1–2 minutes of his arrival and she then makes no signs or responses indicating any conscious awareness and her face remains expressionless until after he has left. When the physiotherapist first enters her room she usually grinds her teeth and the limbs stiffen. When in bed or sat in a chair she has not been observed to make any limb movements for which a volitional purpose could be deduced, but in the gymnasium, moving her to an upright position or rolling her over a ball reliably induces an increased state of alertness with more visual tracking and apparent 'protective' volitional (not reflex) movements of the right arm; in this aroused state she might smile when teased by the therapists.

Comment: In this case, eye closure might sometimes represent a volitional withdrawal response to unwanted stimuli. The evidence of consistent discrimination in the range of responses made to different individuals varying with the state of arousal suggests the presence of awareness.

Appendix 3

Information on the vegetative state for relatives, carers and friends

For relatives, carers and friends of people who have suffered a major brain injury and are diagnosed as being in a vegetative state, life will inevitably be stressful and upsetting. Any confusion or uncertainty over what is being done for the patients, what they can and cannot feel, and what the outcome might be, will add to the strain. The information provided here is designed to help clarify these issues.

It may be of some comfort to know that

- rigorous standards have been laid down for the diagnosis and care of people in a vegetative state
- these standards are based on a considerable body of research evidence
- decisions on a patient's care are based on careful assessment of all the available evidence
- the patient's comfort and freedom from pain are top priorities.

What is a vegetative state?

People in a vegetative state show no sign of awareness or of a functioning mind. They are unaware of what is happening to or around them and have no control over what they are doing.

Before doctors can consider making a diagnosis of vegetative state, certain conditions have to be met:

- 1 Every effort has been made to find out the cause.
- 2 Any treatable cause (eg a tumour) has been ruled out.
- 3 Possible effects of drugs have been assessed and ruled out.

Then, in the patient there must be:

- no evidence of awareness of the self or the environment at any time
- no response of any kind suggesting intention, will or conscious purpose
- no evidence of understanding or meaningful expression.

Are brain scans needed to make the diagnosis of vegetative state?

Techniques like electroencephalography (EEG) and positron emission tomography (PET) are not needed to make a diagnosis of vegetative state. However, simple brain imaging should be performed to ensure that there is no unexpected treatable cause (this will generally have been done anyway).

What movements do people in a vegetative state usually make?

In most people in a vegetative state, there are cycles of eye closing and eye opening giving the appearance of sleeping and waking. Most people have normal circulation and can breathe without aid.

Patients in a vegetative state may make a range of spontaneous movements including chewing, teeth grinding, swallowing, roving eye movements and purposeless limb movements. They may make facial movements such as smiles or grimaces, shed tears, or make grunting or groaning sounds for no obvious reason. They may react automatically by reflex responses to various stimuli: for example, they may gag when being fed, or their eyes may move when their head is turned from side to side. Things like noise can also cause a response, such as faster breathing, grimaces or movement of limbs. Their eyes may turn fleetingly to follow a moving object or person, or towards a loud sound, and their hands may appear to grasp objects placed in them. **None of these responses require conscious awareness.**

In addition to occasionally following moving objects or people with their eyes, patients in a vegetative state have also been known to utter a single inappropriate word. Behaviour of this kind should lead to a careful search for awareness, but responses like these may occur because small 'islands' in the brain have survived but they are no longer able to work together to generate awareness.

What can hospital staff do for patients in a vegetative state?

Staff will carefully monitor and record patients' responses on a daily basis.

They will give high-quality nursing care to avoid any preventable complications developing. This care will include things like adequate nutrition (often via a feeding tube), good skin care, joint exercises, careful management of bowel and bladder incontinence, and oral and dental hygiene.

It is generally regarded as good practice to approach patients in a vegetative state as though they do have some awareness, but this is a precautionary measure in case someone should begin to show consciousness.

What can relatives, friends and carers do for someone in a vegetative state?

Those close to the patient can help healthcare staff by reporting their own observations about the patient and also by providing information about the previous personality and experience of the patient, as this will help ensure that staff approach the patient in an appropriate way if consciousness does begin to recover.

There is no evidence that constant stimulation of someone who is in a vegetative state can bring about improvement in the long-term outcome.

What is the outlook for people in a vegetative state?

The outlook for people in a vegetative state is influenced by their age, the underlying cause of the vegetative state and its current duration. Broadly speaking, the longer the state persists, the less chance there is of recovery. At one month after a traumatic brain injury (for example, a car crash), people in a vegetative state stand a better than 50% chance of regaining awareness. At the same stage, only 20% of those whose vegetative state is due to non-traumatic causes (for example, a stroke) recover awareness.

What is a permanent vegetative state?

Beyond one year following trauma, and beyond six months in non-traumatic cases, the chances of regaining consciousness are extremely low. So at this point patients are considered to be in a **permanent** vegetative state. The very small number of people worldwide who have recovered at this stage have been exceptionally severely disabled.

How do doctors make the diagnosis of permanent vegetative state?

First of all, the patient must have been in a vegetative state for at least twelve months if they had a traumatic injury to the head, and for at least six months if they had non-traumatic brain damage (for example, as a result of a heart attack).

Then all possible treatable causes of the state must have been ruled out. The patient then has to be examined by at least two doctors who are both experienced in assessing this kind of disorder. They must conduct their assessments independently of one another, and write their results in the notes. As the patient's physical position can affect responsiveness, the doctors may assess the patient in more than one position. They should take into account views about the patient's reactions and responses from the medical staff involved (eg nurses), from other clinical staff (eg physiotherapists with experience in making such assessments), and from those close to the patient.

If the two doctors think that the patient is in a permanent vegetative state, then they will discuss their opinion with other medical staff, nursing staff, therapists and those close to the patient. If there is broad agreement, then a diagnosis of permanent vegetative state will be made, meaning that the evidence indicates that the patient will never recover their awareness.

The diagnosis of permanent vegetative state will not be rushed. If there is any doubt about it, the patient will be re-assessed at a later date. In doubtful cases, the staff may use structured observation (watching closely for specific time periods at set intervals) to try to see if there are any signs of awareness in the patient.

How are decisions made about withdrawing nutritional support?

When the diagnosis of a permanent vegetative state has been made, it may be decided that recovery cannot reasonably be expected and that continued support and treatment is futile. Prolonging an insentient life would have no benefit for the patient, and would mean a hopeless vigil with major emotional costs for those close to the patient.

In these circumstances, the medical team, with the help of colleagues when required, will formally review the evidence. After confirming the diagnosis of a permanent vegetative state, they will discuss this with those close to the patient, and give them time to consider the implications, including the possibility of withdrawing the means of providing food and water.

At present, any decision to stop giving food and water by tube must be referred to the courts before any action can be taken.

A decision to withdraw life-sustaining medication, such as insulin for diabetes, is also likely to be referred to the courts.

On the other hand, decisions not to use intensive resuscitation in the case of a heart attack, or not to use antibiotics or dialysis, can be taken by doctors, in the best interests of the patient, after full discussion with all those concerned but without going to court.

The legal system in England and Wales differs from that in Scotland where the medical teams will act according to Scottish law.

What about the person's previously stated wishes or advance directives?

If the person has made a valid advance directive which fits these circumstances, indicating their refusal of continuing treatment, including tube feeding, this must be respected. If not, doctors will try to establish what the patient's views and preferences might have been, to help to make a decision in his or her best interests.

A dignified end

If the decision is taken to withdraw life support, every effort will be made to ensure that the person dies with dignity, and that the wishes of those close to the patient are respected, including having all the privacy and time that they require at the end.

Although it is extremely unlikely that the person can feel any pain, he or she will be given sedation if hydration and nutrition are withdrawn. This will eliminate any possibility of suffering, however remote.

Children and young people

These notes also apply to children over the age of ten, although formal diagnosis of permanent vegetative state in children in the UK is rare. In younger children, the brain is at a stage of development where new connections may be forming even in the absence of consciousness. A definite diagnosis of vegetative state can thus seldom be made in babies and young children.

References

- 1 Royal College of Physicians. *The permanent vegetative state*. A working party report. London: RCP, 1996.
- 2 Jennett B, Plum F. Persistent vegetative state after brain damage. *Lancet* 1972;i:734-7.
- 3 The Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state, in two parts. *N Engl J Med* 1994;330:1499–1508, 1572–9.
- 4 *International working party report on the vegetative state*. London: Royal Hospital for Neuro-disability, 1996.
- 5 Jennett B. *The vegetative state*. Cambridge: Cambridge University Press, 2002.
- 6 Zeman A. Consciousness. *Brain* 2001;124:1263–89.
- 7 Zeman A. Persistent vegetative state. *Lancet* 1997;350:795–9.
- 8 Laureys S, Berre J, Goldman S. Cerebral function in coma, vegetative state, minimally conscious state, locked-in syndrome, and brain death. *Yearbook of Intensive Care and Emergency Medicine* 2001:386–96.
- 9 Schiff ND, Ribary U, Moreno DR, Beattie B *et al*. Residual cerebral activity and behavioural fragments can remain in the persistently vegetative brain. *Brain* 2002;125:1210–34.
- 10 Giacino JT, Ashwal S, Childs N, Cranford R *et al*. The minimally conscious state: definition and diagnostic criteria. *Neurology* 2001;58:349–53.
- 11 Childs N, Mercer WN, Childs HW. Accuracy of diagnosis of the persistent vegetative state. *Neurology* 1993;43:1465–7.
- 12 Andrews K, Murphy L, Munday R, Littlewood C. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. *BMJ* 1996;313:13–16.
- 13 McMillan TM. Neuropsychological assessment after severe head injury in a case of life or death. *Brain Injury* 1996;11:483–90.
- 14 Gill-Thwaites H, Munday R. The sensory modality assessment and rehabilitation technique (SMART): a comprehensive and integrated assessment and treatment protocol for the vegetative state and minimally responsive patient. *Neuropsychol Rehabil* 1999;9:305–20.
- 15 Shiel A, Horn S, Wilson BA, Watson MJ, Campbell MJ, McLellan DL. The Wessex Head Injury Matrix (WHIM) Main Scale: a preliminary report on a scale to assess and monitor patient recovery after severe head injury. *Clin Rehabil* 2000;14:408–16.
- 16 1996 SLT848 and 1996 SLT859.
- 17 Royal College of Paediatrics and Child Health. *Withholding and withdrawing life-sustaining treatment in children: a framework for practice*. London: RCPCH, 1997.
- 18 British Medical Association. *Withholding and withdrawing life-prolonging medical treatment: guidance for decision making*, 2nd edn. London: BMJ Books, 2001.
- 19 General Medical Council. *Withholding and withdrawing life-prolonging treatments: good practice in decision making*. London: GMC, 2002.
- 20 McLean S. Permanent vegetative state and the law. *J Neurol Neurosurg Psych* 2001;71(Suppl 1):i26–i27.