

The **Vegetative State**

The strange and harrowing sight of a person being awake but unaware with no evidence of a working mind – characteristics of the vegetative state – provokes intense debate and raises profound questions for health professionals, ethicists, philosophers and lawyers. This unique account by an unrivalled expert in the field, who himself collaborated in coining the term ‘persistent vegetative state’, surveys the medical, ethical and legal issues that surround this controversial topic. The medical definition and criteria for diagnosis are discussed, as are its frequency and causes, and possible outcomes. These range from some recovery to death, with some surviving indefinitely in a vegetative state, which some people believe is a fate worse than death. Ethical arguments discussed include the conflict between sanctity of life and respect for the autonomy and best interests of the victim, and between killing and letting die. Legal issues are explored with details of landmark court cases from the USA, Britain and elsewhere. This well-informed and carefully constructed account will be a benchmark for medical specialists, ethicists, lawyers and philosophers.

Bryan Jennett has had a long and distinguished career with unrivalled insight into the vegetative state. As Professor of Neurosurgery at the University of Glasgow his research was instrumental in defining the condition, and in coining the term ‘persistent vegetative state’. Since then he has continued to write extensively on this subject, to lecture widely around the world, and has been an expert witness in a number of key court cases.

The **Vegetative State**

Medical facts, ethical and legal dilemmas

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Foreword

Professor Bryan Jennett has led the world in understanding the devastating unconscious condition termed the vegetative state. New forms of bedside, physiologically oriented ventilators and other supportive devices for maintaining lives around the world started to develop in the late 1940s. Much of this technology was grouped in critical poliomyelitis centres, but after 1955, as polio epidemics became prevented by vaccination, only a few institutions world wide developed critical-care programmes that received all kinds of severely ill patients. These centres required doctors specially trained to handle both medical and surgical crises, but unfortunately it took some years for small hospitals to understand the importance of transferring critically ill patients rapidly to such centers in large teaching hospitals. At this point, in the late 1960s, Professor Jennett and his associates were developing and testing their own, now famous, Glasgow Coma Scale (GCS) for traumatic brain injury. Their first goal was to estimate the acute findings of the GCS with the patients' current symptoms and signs. They then compared the initial scale against the patients' ultimate outcomes. The quality of outcome in patients who were immediately referred to the Glasgow University Hospitals was greatly better than those who remained to be treated in smaller hospitals. It was an astonishing success. But even with the best treatment some severely ill patients whose lives had been saved were left with severe permanent brain damage.

Knowing of this work I had the rewarding opportunity of discussing with Professor Jennett, both in New York and Glasgow, the significance of GCS scores and outcomes and how they could be modified to evaluate severe medical illnesses and medically related catastrophic accidents. Following visits to Glasgow and other large UK hospitals, as well as some in the USA, we gained support from the US National Institutes of Health (NIH) to study the prognosis of coma resulting from asystole, asphyxial stroke and other severe dysfunctional medical conditions, as well as from

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traumatic brain injury. During these fruitful years Professor Jennett and I coined the term ‘the vegetative state’, which has become rapidly understood by the medical profession.

As Professor Jennett emphasizes in this fine monograph, the judicial systems of both Britain and America relatively quickly came to understand the public’s emotional and cost-conscious reaction to vegetative loved ones. Following the lead of American courts, British judges placed the responsibility of maintaining or withdrawing medical care for permanently vegetative patients in the courts. With the advantage of the general homogeneity of the British people, the judges in the UK have been able to review the law progressively and to agree individually with doctors and families how best to deal with such hopelessly unconscious patients. In the USA, there is a much greater heterogeneity in religion, in widely spread global ancestry, and even in currently spoken languages. This, together with different laws in different states, has made it more difficult to reach a national consensus on these matters.

As well as correlating a mass of medical information, Professor Jennett has presented us with a valuable dissertation on ethical issues, their specific qualities and their strong relationships with the law in many countries. The book is a treasure chest of the associations that exist between ethics, customs, language, homogeneity of population, and strong relationships to science and to religion.

We thank him for his sensibility and will read him many times over.

Fred Plum, MD

Preface

The life-sustaining technologies associated with resuscitation and intensive care make it possible now for many patients to survive an episode of acute brain damage so severe that it would previously have proved rapidly fatal. Some such rescued patients make a good recovery, some survive only briefly, whilst others are left with permanent brain damage of varying degrees. In its most severe form this damage leaves the patient without any normal function in the cerebral cortex, and therefore bereft of thought or perception. Although these patients have periods with their eyes open, and are thus apparently awake, they show no evidence of being aware of their surroundings or of having a working mind. They are said to be in a vegetative state. For some this is a temporary state that is followed by some degree of recovery, but others are left permanently vegetative and they can survive like this for many years if life-sustaining treatment and nursing care are provided.

In the 30 years since this state was first described it has provoked intense debate among health professionals, clinical scientists, moral philosophers and lawyers. It is the strange combination of being awake but unaware with no evidence of a working mind that is so disturbing and puzzling. When a patient is left permanently vegetative this is widely perceived to be an outcome of medical intervention that is worse than death. The controversial question then arises as to whether it is appropriate to prolong their lives indefinitely by further medical treatment. Many cases have come to court for judicial review of a decision to withdraw life-sustaining treatment, initially in the USA but recently also in Britain and elsewhere. Certain high profile cases have reached the highest courts – *Cruzan* in the US Supreme Court and *Bland* in the House of Lords. Several cases have provoked eager media interest. This has led to an unusual degree of public awareness of this condition and there are said to be over a thousand web sites devoted to it. The issue of how such patients should be treated is seen as having wider

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public policy implications, particularly in relation to the debate about euthanasia. As a result there have been position papers from doctors, moralists and lawyers in several countries about the dilemma posed by vegetative patients, and the attitudes of doctors towards them in different member States have been surveyed in a research project of the European Commission. However, the vegetative state is relatively uncommon, with few professionals and fewer of the public ever having encountered such a patient.

It therefore seemed timely to review what is known medically about the vegetative state and how prolonged survival in this state is viewed by doctors and others in society. The early chapters consider how its nomenclature has evolved, and review the extensive medical literature on how it is diagnosed, how often it occurs, the causes and nature of the underlying brain pathology, and the prospects for recovery and survival. Attitudes to the permanent vegetative state are considered next, and a brief account is given of its medical management. The later chapters deal with the ethical and legal issues that have arisen in various countries when deciding how to deal with permanently vegetative patients, with detailed accounts of some landmark cases that have reached the courts in several countries. The medical and legal reports and ethical commentaries on this subject are widely scattered in specialist journals. The opportunity has been taken to bring these together in order to provide an accessible source for professionals in the different relevant disciplines and interested members of the public, who wish to broaden their perspective.

Acknowledgements

Charlotte Boulnois and Alistair Shields of the Central Library, Southern General Hospital, Glasgow were most helpful and resourceful in obtaining articles from a range of journals far beyond their regular repertoire and I am most grateful to them. Professor Hume Adams kindly vetted the chapter on pathology for me. My secretary, Madeleine Younger, brought her usual consummate skills to initial drafts of this text.

I acknowledge permission to reproduce Dr Beernink's poem from the *Lancet*, Table 2.3 from the *Annals of Neurology*, Tables 2.8, 2.9 and 2.10 from the *Journal of Neurology, Neurosurgery & Psychiatry*, and Tables 3.17 and 3.18 from *Advances in Pediatrics*, John Wiley and Son.

An appeal to doctors

It adds fresh terror to traffic to know that an accident may make you an unconscious hulk lasting for years, a sorrow to any who love you, and a trouble to all concerned, wasting valuable nurses and resources. At best you could die in the end unconscious, at worst recover some degree of awareness and live indefinitely, deprived of all those powers which distinguish us from the lower animals. The ability to prolong life may be a curse instead of a blessing.

From a letter in the *Lancet* from a Cambridge University physicist.

Thompson GT. An appeal to doctors *Lancet* 1969; 2: 1353

Traumatic decortication

Always the blinds were pulled in your room where you waited,
Patient as a pupa, for a diaper change or a turn
Onto last week's bedsore. Your sightless eyes would burn
White in the dark while your soul crouched in the corner.

Monthly that winter your mother came and repeated
Her convictions that you, 'would soon be looking better',
And proudly numbered the gooks you'd killed before
The shrapnel buried you mind in Asia's mud.

For a year synthetic life had been pumped to your blood
Through dozens of tubes. Each day the residents
Were pleased to see your heart and lungs were clear –
Organs serving no intelligence.

Then one morning we found your BIRD^a unplugged.
The corner
Was empty. I opened the blinds. Spring was near.

^a(BIRD is a respirator)

From 'Ward Rounds', a book of poems about particular patients, by Dr K.D. Beernink, 1970.

Lowbury E.J.L. Ward rounds. *Lancet* 1970; ii: 924

Abbreviations

AAN	American Academy of Neurology
ALERT	Against Legalized Euthanasia – Research and Teaching
AMA	American Medical Association
ANA	American Neurological Association
ANH	Artificial nutrition and hydration
BMA	British Medical Association
CBF	Cerebral blood flow
CPR	Cardiopulmonary resuscitation
CT	Computerized tomography
DA	District attorney
DAI	Diffuse axonal injury
DNR	Do not resuscitate
EEG	Electroencephalogram
MCS	Minimally conscious state
MP	Member of parliament
MRI	Magnetic resonance imaging
NHS	National Health Service
PEG	Percutaneous endoscopic gastrostomy
PET	Positron emission tomography
PMP	per million population
PVS	Persistent or permanent vegetative state (in legal chapters, always denotes permanent)
VS	Vegetative state