PROTECTION OF AUTHOR’S COPYRIGHT

This copy has been supplied by the Library of the University of Otago on the understanding that the following conditions will be observed:

1. To comply with s56 of the Copyright Act 1994 [NZ], this thesis copy must only be used for the purposes of research or private study.

2. The author's permission must be obtained before any material in the thesis is reproduced, unless such reproduction falls within the fair dealing guidelines of the Copyright Act 1994. Due acknowledgement must be made to the author in any citation.

3. No further copies may be made without the permission of the Librarian of the University of Otago.
DECLARATION CONCERNING THESIS

Author's full name and year of birth:  
SAMUEL GEOFFREY BLOORE
(for cataloging purposes)

Title of thesis:  
THE MEDICAL, ETHICAL AND LEGAL ISSUES SURROUNDING THE MANAGEMENT OF PERSISTENT VEGETATIVE STATE PATIENTS

Degree:  
MASTER OF BIOETHICS AND HEALTH LAW (MBHL)

Department:  
BIOETHICS

I agree that this thesis may be consulted for research and study purposes and that reasonable quotation may be made from it, provided that proper acknowledgement of its use is made.

I consent to this thesis being copied in part or in whole for

i) a library

ii) an individual

at the discretion of the Librarian of the University of Otago.

Signature:  

Date:  
17/11/04

Note: This is the standard Library Declaration Form used by the University of Otago for all theses. The conditions set out on the form may be altered only in the most exceptional circumstances. Any restriction on access to a thesis may be permitted only with the approval of -

(i) the appropriate Assistant Vice-Chancellor in the case of a Master's thesis;
(ii) the Deputy Vice-Chancellor (Research and International), in consultation with the appropriate Assistant Vice-Chancellor, in the case of a PhD thesis

and after consultation with the Director of the University Consulting Group where appropriate.

The form is designed to protect the work of the candidate, by requiring proper acknowledgement of any quotations from it. At the same time the declaration preserves the University's philosophy that the purpose of research is to seek the truth and to extend the frontiers of knowledge and that the results of such research which have been written up in thesis form should be made available to others for scrutiny.

The normal protection of copyright law applies to theses.

September 1998
THE MEDICAL, ETHICAL AND LEGAL ISSUES SURROUNDING THE MANAGEMENT OF PERSISTENT VEGETATIVE STATE PATIENTS

SAMUEL G. BLOORE

A THESIS SUBMITTED FOR THE DEGREE OF MASTER OF BIOETHICS AND HEALTH LAW (MBHL) AT THE UNIVERSITY OF OTAGO, DUNEDIN, NEW ZEALAND

1ST JULY 2004
ABSTRACT

The persistent vegetative state (PVS) has emerged as one of the most challenging dilemmas in clinical medicine. It is a condition that necessarily follows a brain insult, resulting in total unconsciousness with partially preserved brainstem function. The irony of the condition is that, although PVS patients have lost all capacity for consciousness and cognition, their bodies usually remain in good health. With active treatment and nasogastric feeding, survival for many years is not uncommon. The economic and opportunity costs of their care is significant. Clinicians have reported that recovery of consciousness after twelve months in PVS is exceedingly rare; beyond this, patients are said to be in irreversible PVS (iPVS). In the last decade it has become increasingly accepted that withdrawal of nutrition and hydration is an appropriate way to end the life of one such patient.

The enigma of a ‘living non-person’ has received much attention in medical, ethical and legal commentary. Most is devoted to defending or damning the subjective, substituted judgment and best interests standards as they are used to justify treatment withdrawal. The main failing of the subjective and substituted judgment standards is that they are founded on prospective autonomy. As it will never be of consequence to the iPVS patient whether or not their wishes are followed, the principle of autonomy no longer applies to them. Similarly, the best interests standard focuses on what the interests of an iPVS patient are and who should decide them, rather than asking the question: Can a permanently unconscious patient have interests?

The theme of this report is that iPVS patients are neither persons nor corpses, but a separate unique group who should be recognised and treated as such. The underlying principle in determining legitimate goals of medicine is that without proven, presumed or prospective benefit, the pursuance of an outcome is difficult to defend. In the case of a permanently unconscious patient, it is impossible to justify continued feeding at the expense of real benefit to other sentient patients. Furthermore, as iPVS patients are not persons, much of the emotionally-charged discourse surrounding euthanasia does not belong in discussions of nutrition withdrawal. In their case, ‘Exactly what is dying?’ becomes a more important question than ‘How will they die?’

This report suggests that the decision to withdraw nutrition and hydration should be routinely made by the healthcare team once iPVS has been diagnosed; in accordance with ‘good medical practice’. It is a decision based on the unique status of the iPVS patient, the impossibility of any present or future benefit to them, the subsequent futility of ongoing treatment, and the recognition that medical professionals are required to distribute health care in a wise and fair manner. It calls on parliament to legally recognise
iPVS patients as a unique group, qualifying neither as corpses nor citizens. In so doing it must repeal the applicability of criminal and common law principles to iPVS patients, replacing them with legislation endorsing specific guidelines for their management.
ACKNOWLEDGEMENTS

STAFF AT THE BIOETHICS RESEARCH CENTRE, UNIVERSITY OF OTAGO

Prof. Grant Gillett – my supervisor, whose advice and accomplishments in both clinical and ethical disciplines of medicine continue to inspire.

Prof. Alistair Campbell – whose vision established the Centre, and whose undergraduate lectures whet my appetite.

Prof. Don Evans – whose warm assistance, despite my numerous crises and delays, has been nothing short of Samaritan.

Vicki Lang – who deserves this degree more than I do! Truly the mortar that holds this thesis (and, I suspect, the whole Centre!) together. A huge THANK YOU!

OVERSEAS STAFF WHO GAVE INTERVIEWS TO A NAÏVE AND INQUISITIVE STUDENT

Prof. Sheila McLean – Director of the Institute of Law and Ethics in Medicine, University of Glasgow

Prof. Robert M Veatch – Professor of Medical Ethics, Department of Philosophy, Georgetown University, Washington DC.

Dr. Jim Howe – Consultant Geriatrician, Airedale General Hospital, Steeton, West Yorkshire

Dr. Bryan Jennett – Emeritus Professor of Neurosurgery, University of Glasgow

OVERSEAS STAFF WHO ALSO DONATED FOOD AND BOARD TO THAT SAME STUDENT

Dr. William J. Winslade – James Wade Rockwell Professor of Philosophy in Medicine, Institute for the Medical Humanities, University of Texas Medical Branch

Prof. Alexander McCall Smith – Professor of Medical Law, University of Edinburgh

Dr. Keith Andrews – Director of Medical and Research Services at the Royal Hospital for Neuro-Disability, Putney, London

FAMILY AND FRIENDS

The large tribe of Bloores – Dad, Mum, Jessie, Ruth, David and Michael. Thanks for your financial and moral support over the last decade!

The even larger tribe of flatmates – Albany St, Gloucester St, Montreal St, Manchester St... I honestly don’t think a single one of you thought I’d get this finished... 😊

God – Who needs no introduction...or maybe He does for some of you... My own encounter with Him 2 years ago has resulted in a pleasant improvement in the way I do ethics and the way I do life... Hardly surprising...since He authored them both!
# CONTENTS

**ABSTRACT**

**ACKNOWLEDGEMENTS**

**CONTENTS**

**INTRODUCTION**

**SECTION 1: THE MEDICAL ISSUES**

1.1 **Persistent Vegetative State**

1.1.1 Variations in Nomenclature

1.1.2 Persistent vs. Permanent

1.1.3 Terms used in this Report

1.2 **The Causes of PVS**

1.2.1 Acute Injuries

1.2.2 Degenerative and Metabolic Disorders

1.2.3 Developmental Malformations

1.3 **Pathological Features of PVS**

1.3.1 Diffuse Laminar Cortical Necrosis

1.3.2 Diffuse Axonal Injury

1.4 **Diagnosis of PVS**

1.4.1 Clinical Observation

1.4.2 Neurological Investigations

1.4.2.1 Electroencephalography

1.4.2.2 Neuroimaging

1.4.2.3 Evoked-Response Studies

1.4.2.4 Cerebral Metabolic Studies

1.4.2.5 Cerebral Blood Flow

1.5 **Differential Diagnoses**

1.5.1 Whole Brain Death and Brain Stem Death

1.5.2 Coma

1.5.3 Locked-in Syndrome

1.5.4 Akinetic Mutism
1.5.5 Minimally Conscious State 16
1.5.6 Dementia 17
1.5.7 Other Conditions 17

1.6 Prospects for Survival 18

1.7 Prospects for Recovery 19
1.7.1 ...from PVS caused by Traumatic Injury 19
1.7.2 ...from PVS caused by Non-Traumatic Injury 20
1.7.3 ...from PVS caused by Degenerative or Metabolic Disease 21
1.7.4 ...from PVS caused by Developmental Malformation 21
1.7.5 Prognostic Guidelines 22
1.7.6 Are These Guidelines Certain Enough? 24

1.8 The Incidence and Cost of PVS Patient Management 25

1.9 Treatment of the PVS Patient 26
1.9.1 Medical Care 26
1.9.2 The Role of Rehabilitation 27

1.10 Withdrawal of Nutrition and Hydration 29
1.10.1 Physical Effects 29
1.10.2 Pain, Suffering and Consciousness 30

1.11 Summary of Medical Issues 32

SECTION 2: THE ETHICAL ISSUES 34

2.1 The Ethical Status of an iPVS Patient 34
2.1.1 The Significance of Personhood 35
2.1.2 The Significance of Biological Function 36
2.1.3 Ethically Recognising this Unique Group 37

2.2 The Ethics of Feeding iPVS Patients 39
2.2.1 Medical Treatment vs. Necessary of Life 39
2.2.2 Ordinary vs. Extraordinary Care 41
2.2.3 Medical Futility 42
2.2.4 The Goals of Medicine 44
2.2.5 Benefits and Burdens 45
2.2.5.1 Improvement in Prognosis 45
2.2.5.2 Preservation of Biological Life
2.2.5.3 Alleviation of Discomfort
2.2.5.4 Bringing Comfort to Friends and Family
2.2.6 Justice
2.2.6.1 Quality Adjusted Life Years
2.2.6.2 Is it Fair to Distribute Resources to iPVS Patients?

2.3 Autonomy and Surrogate Decision-Making
2.3.1 Autonomy
2.3.2 The Subjective Standard
2.3.3 The Substituted Judgement Standard
2.3.4 The Problem with Prospective Autonomy
2.3.5 The Best Interests Standard
2.3.5.1 The Best Interests of an iPVS Patient
2.3.5.2 Can an iPVS Patient Have interests?
2.3.5.3 A Wider Definition of Interests
2.3.5.4 Ascribing Mental States to the iPVS Patient
2.3.5.5 Honouring Prior Wishes
2.3.5.6 Acknowledging Religious Beliefs

2.4 Further Criticism of Treatment Withdrawal
2.4.1 Discrimination Based on Quality of Life
2.4.1.1 Quality of Life
2.4.1.2 Discrimination Against the Disabled
2.4.2 Patients in ‘Near PVS’
2.4.3 Is Withdrawing Treatment from iPVS Patients Euthanasia?
2.4.3.1 Passive Euthanasia
2.4.3.2 The Mode of Dead
2.4.3.3 Death of a Person

2.5 Summary of Ethical Issues

SECTION 3: THE LEGAL ISSUES

3.1 Are iPVS Patients Legally Alive or Dead?
3.1.1 Joe v Joe
3.1.2 Auckland Area Health Board v Attorney General 77
3.1.3 Airedale NHS Trust v Bland 79
3.1.4 United States Law 80
3.1.5 Legally Recognising this Unique Group 81

3.2 The Legal Right to Medical Treatment 82
3.2.1 Health and Disability Commissioner Act 1994 83
3.2.2 Applying the Code to an iPVS Patient 84
3.2.3 Human Rights Act 1993 85

3.3 The Legal Right to Refuse Medical Treatment 87
3.3.1 Consent 87
3.3.2 The Incapacitated Patient and Implied Consent 87
3.3.3 The Right to Refuse Treatment After it has Commenced 88
3.3.4 Have iPVS Patients Forfeited this Right? 89

3.4 Advance Directives 91
3.4.1 Living Wills 91
3.4.2 Durable Power of Attorney 92
3.4.3 Practical Difficulties with Advance Directives 92
3.4.4 The Current New Zealand Position 93
3.4.5 Advance Directives and the iPVS Patient 93
3.4.6 Advance Directives in Other Conditions 94

3.5 The Right Not to be Deprived of Life 95
3.5.1 The Law of Homicide 95
3.5.2 Section 151 (1) Crimes Act 1961 96
    3.5.2.1 Cause of Death 96
    3.5.2.2 Necessaries of Life 97
    3.5.2.3 Lawful Excuse 99
3.5.3 Good Medical Practice 99
    3.5.3.1 The Bolam Test 100
    3.5.3.2 Rogers v Whitaker 100
    3.5.3.3 Futility 101
    3.5.3.4 Justice 102
3.5.3.5 Best Interests 103
3.5.3.6 Consulting Family and Ethical Bodies 103
3.5.3.7 Good Medical Practice and Lawful Excuse Summarised 104
3.5.4 Section 164 Crimes Act 1961 104
3.5.5 Section 157 Crimes Act 1961 106
3.5.6 Section 155 Crimes Act 1961 106
3.5.7 Miscellaneous Sections of the Crimes Act 1961 107

3.6 The Need for Specific iPVS Legislation 107
3.6.1 Legislation Granting iPVS a Unique Legal Status 109
3.6.2 Legislation Protecting and Guiding Doctors 110
3.6.3 Legislation Addressing the Effects in Other Legal Areas 110
3.6.4 Advance Directive Legislation 111

3.7 Summary of Legal Issues 112

SUMMARY AND RECOMMENDATIONS 116

APPENDIX 120

REFERENCES
SECTION 1: THE MEDICAL ISSUES 121
SECTION 2: THE ETHICAL ISSUES 125
SECTION 3: THE LEGAL ISSUES 130
INTRODUCTION

"Perhaps there are those who believe that it is a great medical step forward that we can indefinitely sustain the lives of those who have lost their human potential, or who believe that the sanctity of life is enhanced by large numbers of permanently unresponsive bodies... I think, on the contrary, that technology got the better of them once more. Medical science is very clever in making us feel guilty about accepting the end of human life; in its hubris it has led us to think of death as a curable condition, or at least indefinitely postponable. Human life had value before technology came along, and if death is an insult to the human condition, that insult requires a spiritual, not scientific, remedy."

While the formal study of medical ethics as a discipline is relatively new, its existence is not. As the writings and teachings of ancient philosophers testify, the principles which are now accepted as the basis for modern moral theory began to evolve before the birth of Christ. The earliest and certainly the most celebrated attempt to canonise a code by which doctors should conduct their practice was that of Hippocrates. Within the Hippocratic Oath are found the basic principles of beneficence, non-maleficence, peer review and confidentiality – all of which still command adherence from medical practitioners today. The Hippocratic Oath also forbids engagement in a number of specific behaviours deemed to be immoral: euthanasia, abortion and relations with a patient. While society’s attitude towards these actions may have changed over centuries, they remain among the most controversial and debated issues in medical ethics. They share their difficult characteristics with new issues that have arisen over the years to challenge the medical profession, often demanding its immediate attention. Some have been resolved rapidly; others, despite exhaustive deliberation by international ethical committees and regulatory bodies, have continued to evoke disagreement for decades. The Persistent Vegetative State patient is one such puzzle. In comparison to the time-old issues of abortion and euthanasia, Persistent Vegetative State is a relatively new problem as its existence has only been possible through recent medical developments.

In the 1950s the invention of machines capable of assisting ventilation allowed the prolonged survival of patients who would previously have died. Subsequently, in intensive care units around the world, critically ill patients could have their cardiorespiratory function artificially maintained while their bodies recovered from serious injury. A number of ethical developments followed. First, it became clear that the current definition of death, based on irreversible cessation of cardiorespiratory function,
was no longer adequate. It was recognised that, with the aid of a ventilator, these functions could continue for some time despite irreversible damage to the areas of the brain that controlled them. In 1968 a committee of the Harvard Medical School advanced a proposal that the traditional cardiorespiratory criteria be replaced with a brain death definition. These developments led to the majority of countries throughout the world adopting brain death criteria by the early 1970s.

Secondly, clinicians were documenting the emergence of a separate patient group. Surviving the initial insult of a severe brain injury, these individuals retained integrity of their brain stem and therefore spontaneous cardiorespiratory function. Properly fed and cared for, these individuals could achieve survival times of many months, if not years; long after artificial ventilation had been withdrawn. Faced with the challenge of naming this unique group, who were neither brain dead, nor in a coma, Jennett and Plum proffered Persistent Vegetative State (PVS) in 1972. The medical community was quick to adopt the title and it is still used today to describe this unique syndrome of cyclical wakefulness without cognition.

Obviously, naming the condition has proved easier than solving the considerable dilemmas that it poses. For the last three decades medical experts, law courts and ethical commentators the world over have attempted to resolve the issues surrounding the treatment of a permanently unconscious, but otherwise well, patient. What exactly is the condition? Is it always or ever reversible? Are these patients persons? If so, do they have rights as such? How can they exercise those rights? What legal privileges and protection are they offered? What medical treatment do they need? How can society justify giving it to them while conscious patients go without? Is it morally defensible to withhold treatment? Is doing so the same as euthanasia?

Ethical commentary and legal rulings exist which ask and argue every question and viewpoint imaginable. This led to some inconsistency in treatment over the years as different groups struggled to make decisions on a case-by-case basis. However, in the last decade it has become increasingly accepted that withdrawal of nutrition and hydration is an appropriate way to terminate treatment in the case of an irreversible PVS patient.

The medical profession in New Zealand watched the developments overseas without the security of its own official policy. Following an appeal to the New Zealand Medical Council by clinicians for such a statement of position, it commissioned the Bioethics Research Centre from the University of

---

b Ad Hoc Committee of Harvard Medical School to Examine the Definition of Brain Death. A Definition of Irreversible Coma. *Journal of the American Medical Association* 1968;205:337-40
Otago to prepare a report on the treatment of PVS. Published in 1993 it contained a summary of the main medical, ethical and legal issues surrounding the condition (in particular the withdrawal of nutrition and hydration from such patients). Closing with a series of guidelines for medical professionals, the report also suggested legislative changes that might be made to assist staff and families during this difficult time.

Unfortunately, the report did not fully explore the unique ethical status of an irreversible PVS patient and the multitude of subsequent clinical and non-clinical implications. Instead it chose to focus largely on how the decision to withdraw nutrition and hydration should be made. It attempted to justify the action by employing bioethical theory already applied in other clinical scenarios. The report proposed greater reliance on advance directives by medical teams faced with the decision of whether or not to continue treatment for a PVS patient. It suggested promoting the need for individuals to give prior written instructions (an advance directive) as to how they would want to be treated should they enter a PVS, with legislation endorsing the same. It also called for the legal recognition of decisions made by a designated proxy, or close family member, on that patient's behalf. The report emphasised that such legislation "...would aim to enhance the autonomy of the patient by applying the patient's known values to circumstances in which the patient is unable to express his or her desires." In the absence of any information pertaining to a patient's prior wishes, it encouraged decisions to be made in the patient's best interests. Eighteen months later, the New Zealand Medical Association published its Policy Paper on Persistent Vegetative State. It was essentially a truncated version of the Bioethics Centre Report with similar recommendations and similar shortcomings. Again the focus was upon employing advance directives in the decision-making process, with little emphasis on the diagnosis and sequelae of irreversible PVS.

Any review of PVS policy needs to return to the clinical definition of exactly what PVS is. It is obliged to be frank about the expected medical costs and outcomes. It should address the possibility of a return to consciousness and recommend time frames outside which such possibility is infinitesimally small. It must get to the heart of what a complete and irreversible loss of consciousness means in terms of personal existence. It should examine the very goals of medicine and explore the nature and intention behind providing medical care. It needs to highlight the

---

4 Report for the Medical Council of New Zealand by the Bioethics Research Centre, University of Otago. Persistent Vegetative State and the Withdrawal of Food and Fluids. 1993. Copies available through the Bioethics Research Centre, PO Box 913, Dunedin, NZ.

* New Zealand Medical Association Public Issues Advisory Committee. Policy Paper: Persistent Vegetative State. 10 August 1994. Copies available through NZMA, 26 The Terrace, PO Box 156, Wellington, NZ. (The following year the NZMA approved a further policy paper on Advance Directives, copies of which can also be obtained from the NZMA.)
inconsistencies involved in current ethical commentary; in particular the reliance on advance directives, surrogate decision-makers and ‘Best Interests’ theory. Instead it should provide alternative moral justification for withdrawing treatment from this unique group of insensate individuals. Lastly, a thorough review should examine whether these objectives can be achieved within the existing legal framework and suggest statutory changes that will lubricate the process.

This essay attempts such a review.
SECTION 1: THE MEDICAL ISSUES

Debates cannot take place until the moot is defined. Likewise, discussion in medical ethics and medical law should not commence without a prior understanding of the medical facts. Parties engaging in such discussion, especially if holding different viewpoints, will not find satisfactory solutions unless they first ensure that the objects of their attention are clearly outlined. Therefore, any comprehensive report on the ethical and legal issues surrounding persistent vegetative state (PVS) should start with a detailed description of the condition and its consequences, costs and complications. In 1991 the American Academy of Neurology commissioned a Multi-Society Task Force on PVS comprised of eleven neurologists and neurosurgeons. Aided by a panel of medical, ethical, and legal consultants, its objective was to issue a consensus statement summarising all published material on relevant clinical issues surrounding PVS. The resulting two-part article, published in 1994, is widely recognised as the most comprehensive review of the topic.1

While legal opinion and ethical commentary are often heavily influenced by authors’ own convictions, modern medicine requires that clinical findings be evidence-based. Peer-reviewed publications attempt to ensure that this is so. The forum for opinion-sharing is not to be found in the clinical defining or diagnosing of a patient’s condition, but in the subsequent medical, ethical and legal treatment of that patient once those initial definitions/diagnoses have been made. Thus Section 1: The Medical Issues draws largely from that Task Force article and on appropriate papers that have been published since.

1.1 Persistent Vegetative State (PVS)

In 1972, having discovered “...a syndrome in search of a name...” Jennett and Plum coined ‘persistent vegetative state.’2 Quick to gain popularity, the term is now employed by medical professionals worldwide. It describes “...the condition of patients with severe brain damage in whom coma has progressed to a state of wakefulness without detectable awareness.”3 In 1990 an American Medical Association Council4 defined the vegetative state as:

“...a state of unconsciousness (i.e. Loss of self awareness) where the body cyclically awakes and sleeps but expresses no behavioural or cerebral metabolic evidence of possessing cognitive function or of being able to respond in a learned manner to external events or stimuli.”4

Four years later the Multi-Society Task Force Report published a similar definition:

---

1 American Academy of Neurology
2 Jennett and Plum
3 American Medical Association Council
4 Council on Scientific Affairs and Council on Ethical and Judicial Affairs
"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 brain-stem autonomic functions. The condition may be transient, marking a stage in the recovery from severe acute or chronic brain damage, or permanent, as a consequence of the failure to recover from such injuries. ... We define such a state [PVS] operationally as a vegetative state present one month after an acute traumatic or non-traumatic brain injury or a vegetative state of at least one month's duration in patients with degenerative or metabolic disorders or developmental malformations."  

It proceeds to give a detailed description of the clinical signs present in PVS, as these signs set the condition apart from similar states of altered consciousness.  

1.1.1 Variations in Nomenclature  

Much confusion surrounds the nomenclature of the condition – from disagreement as to what the letters PVS stand for, to the sporadic use of different terms altogether. This section attempts to clarify these differences and then outlines the terminology that will be employed for the remainder of the report. A 1995 meeting of international experts in the field prompted the comment:

"The mere fact that by the end of the two days some 21 different terms had been used for various low level states of cerebral function...indicate[d] the difficulty with even providing an acceptable definition for the syndrome."  

Although persistent vegetative state (PVS) is the most widely known and used term to describe the condition, there are many alternatives that can be found in some of the literature on the subject:

- **Higher-Brain Death**: This term highlights the fact that the cerebral hemispheres of a PVS patient no longer function. It is most often used by those who would like to see a higher-brain-oriented definition of death (i.e. the definition of death broadened to include PVS).  

- **Apallic Syndrome**: ...archaic term for a condition that is now considered equivalent to a persistent vegetative state.  

- **Neocortical Death**: A name given to patients with the features of persistent vegetative state and, in addition, an absence or significant decrease in electroencephalogram activity. "The terms ‘neocortical death’ and ‘apallic state’ have limited usefulness and should be abandoned, because they do not represent distinct clinical entities."  

---  

\(^a\) See 1.4.1 Clinical Observation.  
\(^b\) See 1.5 Differential Diagnoses.  
\(^c\) Organised by the Centre of Medical Law and Ethics (King's College, London) and the Royal Hospital for Neuro-disability (London).
• ‘Uncollected Corpses’ ‘Non-persons’: Examples of the emotive attempts by some to label the condition. The use of such terms is not encouraged because of their vague and value-laden nature, and the subsequent scope for misinterpretation.

1.1.2 Persistent vs. Permanent

Despite the precise definitions of persistent and permanent vegetative states by Jennett and Plum, confusion has arisen over the exact meaning of the word ‘persistent.’

“The adjective ‘persistent’ refers only to a condition of past and continuing disability with an uncertain future, whereas ‘permanent’ implies irreversibility. Persistent vegetative state is a diagnosis; permanent vegetative state is a prognosis.”

Jennett and Plum were keen to see criteria established that allowed accurate identification of a permanent vegetative state, but concluded that “…until then ‘persistent’ is safer than ‘permanent’ or ‘irreversible.’”

“A permanent vegetative state...means an irreversible state which, like all clinical diagnoses in medicine, is based on probabilities, not absolutes. A patient in a persistent vegetative state becomes permanently vegetative when the diagnosis of irreversibility can be established with a high degree of clinical certainty – that is, when the chance that the patient will regain consciousness is exceedingly small.”

The ‘P’ in PVS has always been an abbreviation of ‘persistent.’ Perhaps it is this very PVS acronym that has continued to confuse the issue. While acronyms are very useful for people who must use them on a day-to-day basis, they can mislead those who are unfamiliar with the jargon. For whatever reason, many people outside the health profession (and some within it) attribute PVS with a ‘permanency’ that it may not possess.

Attempting to clarify the nomenclature, the American Congress of Rehabilitation Medicine issued an official position paper in 1995. It resolved that the ‘P’ should be dropped altogether, leaving VS or ‘Vegetative State.’ The international panel of experts meeting in London in 1995 came to the same conclusion – a move that does little to remedy the situation.

A patient is in a vegetative state the moment he enters the ‘awake but unaware’ condition defined above, but not in a persistent vegetative state until he has been ‘awake but unaware’ for one month. The two are not the same. Just as similar adjectives are prefixed to clinical conditions for temporal perspective (e.g. acute pancreatitis or chronic renal failure), so ‘persistent’ gives an indication of the
PVS patient’s history. It has been argued that referring to a precise time period with vegetative state is more accurate – ‘He has been in a vegetative state for three months...’ However, there is no reason why such specific statements cannot continue to be made using the already well-documented term – persistent vegetative state.

1.1.3 Terms used in this Report

Further name changes will only add to the confusion. A large majority of literature refers to this condition as persistent vegetative state. The time to use ‘vegetative state’ is in the first month, before the condition can be said to be persistent. Permanent vegetative state should be discarded altogether. Instead irreversible persistent vegetative state describes those patients in which the prospects for a return to consciousness are exceedingly small. Therefore the following terms are employed throughout this report.

- Vegetative state or VS: Refers to a patient who has been in a vegetative condition for less than one month.
- Persistent vegetative state or PVS: Refers to a patient who has been in a vegetative state for longer than one month, but who still has an appreciable chance for recovery.
- Irreversible persistent vegetative state or iPVS: When referring to a patient who has been in a PVS under such circumstances and for such a length of time that “…the diagnosis of irreversibility can be established with a high degree of certainty.”

1.2 The Causes of PVS

PVS is caused by damage to the brain that results in the cerebral hemispheres being destroyed or isolated, while leaving all or part of the brain stem intact. There are three groups of disease process that give rise to PVS:

1.2.1 Acute Injuries

This category is made up of traumatic injuries (e.g. motor vehicle accident, gunshot wound) and non-traumatic injuries (e.g. cerebral ischaemia due to cardio-respiratory arrest, intracerebral haemorrhage).

---

6 Anecdotally, the most vocal supporters of change were those working in PVS patient rehabilitation. They believe many PVS patients to be capable of some recovery and therefore ‘persistent’ does nothing for the morale of staff who are trying to bring about that improvement. These health professionals need to remember that ‘persistent’ as a prefix provides definite information only up to and including the present; not beyond it.

7 Thus avoiding an identical acronym, PVS; rather, iPVS.

8 Those circumstances and time periods will be discussed in 1.7 Prospects for Recovery.
"The clinical course after the acute insult usually begins with coma (with eyes closed) for several days to weeks, during which time the acute illness stabilises and the stunned but ultimately viable brainstem and lower diencephalon resume function. By this time, most patients are able to breathe spontaneously and no longer require ventilatory assistance. After the interval of coma, spontaneous opening of the eyes, random eye movements, blinking, and limb movements occur, along with sleep-wake cycles. In a few patients, the vegetative state occurs immediately after the insult, without an initial period of coma."\(^{17}\)

1.2.2 Degenerative and Metabolic Disorders

Degenerative and metabolic disorders often cause the nervous system to deteriorate to a point where the patient enters an irreversible PVS. Examples of such disorders are: Alzheimer’s disease, Parkinson’s disease, Creutzfeldt-Jakob disease and organic aciduria. These conditions are often progressing so rapidly that the patient dies before the one-month criterion for ‘persistent’ vegetative state has been met. For the purposes of this report (i.e. whether withdrawal of food and fluid from such patients is clinically, ethically and legally appropriate) a deteriorating vegetative state is analogous to iPVS.

"The early stages of such disorders are marked by progressive impairment of intellect, memory, language, motor skills, and social behaviour, yet many patients retain some degree of awareness of themselves and their environment. In later stages, awareness disappears, marking the start of a vegetative state."\(^{18}\)

As some disorders (especially infectious, metabolic and toxic encephalopathies) can be temporary, it is crucial that these possibilities are eliminated before establishing that the patient is in PVS.

1.2.3 Developmental Malformations

In this category, rather than a disease process inducing unconsciousness, severe congenital abnormalities of the nervous system prevent the development of awareness or cognition. Anencephaly (failure of the brain to form)\(^{1}\) is the most well-known example of a malformation associated with ‘developmental’ vegetative state.

"On the basis of our understanding of development, the diagnosis of the vegetative state may be difficult to make in infants younger than three months, except in the case of infants with anencephaly. Newborns and young infants have a limited ability to show higher cognitive functions before this age. ... The concept of the vegetative state cannot be applied to pre-term infants because of developmental immaturity and, to a lesser extent, the lack of consistently

\(^{1}\) See Appendix for a full list of the causes of PVS.

\(^{1}\) See 1.7.4 Recovery from PVS caused by a Developmental Malformation.
recognisable sleep-wake cycles. ... Recognition of the vegetative state in infants and young children also depends on the ability to distinguish between voluntary and involuntary responses."^{15}

1.3 Pathological Features of PVS

The set of circumstances that result in a patient entering PVS are unique in almost every case. Even when those circumstances would appear very similar (e.g. two near-drownings) there will be inconsistencies (age of the patient, length of time they were without oxygen). The time period between the brain insult and death also determines how advanced the neuropathological disease processes will appear at autopsy. Add to this the fact that "...in patients with chronic neurologic conditions, other complicating factors, such as severe atherosclerotic disease, may independently injure the brain..."^{20} and it is not surprising that the believed anatomical basis for PVS differs somewhat from case to case. The Task Force writes:

"Allowing for the above limitations, two major patterns have characterised most detailed reports on the neuropathology of a PVS due to acute traumatic or non-traumatic injury. We are not aware of any systematic investigation of the neuropathologic characteristics of patients in whom a PVS was due to degenerative, metabolic, or developmental disorders."^{21}

1.3.1 Diffuse Laminar Cortical Necrosis

This pattern is found in those cases where oxygen supply to the brain tissue has been interrupted.

"The principal finding is an extensive multifocal or diffuse laminar cortical necrosis with almost invariable involvement of the hippocampus. These abnormalities may be accompanied by scattered small areas of infarction or neuronal loss in the deep forebrain nuclei, hypothalamus, or brain stem."^{22}

Those who undertook a detailed examination of Karen Quinlan's brain stated that, although the neuropathological findings were multifocal and complex, "...contrary to expectation, the most severe damage was not in the cerebral cortex, but in the thalamus."^{23} They went on to claim that this "...supports the hypothesis that the thalamus is critical for cognition and awareness and may be less essential for arousal. Taken with emerging information about the part that the thalamus plays in

---

1 After a cardiopulmonary arrest and coma in 1975, Karen Quinlan entered into a PVS. Although her parents sought, and eventually won, permission from the courts to discontinue mechanical ventilation in 1976, Karen survived another nine years in a PVS. This celebrated case prompted widespread discussion that ultimately led the United States to develop medico-legal guidelines for the care of such patients - see 3.1.4 United States Law.
cognition and reports of thalamic dementia, these findings point to the role of the thalamus in the pathogenesis of PVS."

1.3.2 Diffuse Axonal Injury

This is a phenomenon that often occurs in cases of acute head trauma.

"At the moment of impact, shearing forces sever the white matter fibres in wide areas of the white matter, thereby isolating the cerebral cortex."

"Sometimes a diffuse axonal injury is accompanied by small primary brain-stem injuries, as well as secondary damage to the brain stem that results from transtentorial herniation soon after the injury. In patients with an axonal injury complicated by acute circulatory or respiratory failure, diffuse laminar necrosis may also be present."

1.4 Diagnosis Of PVS

Diagnosis of PVS is essentially made on the basis of clinical evaluation and knowledge of the circumstances that gave rise to the state. While there are a number of complex neurological investigations that can be carried out, these should only be employed to add weight to what is essentially a diagnosis of careful observation and neurological examination.

1.4.1 Clinical Observation

A regime of repeated neurological examinations should be carried out over an extended period of time, ideally by more than one consultant neurologist or neurosurgeon. The aim of these examinations should be to confirm whether or not the clinical features of PVS are present. In addition, long periods of observation are often needed before PVS patterns can be confirmed. For this reason it is important that clinicians are in regular discussion with families and nursing teams, who spend far more time in patient contact.

The Task Force goes into some detail when describing the clinical features of PVS:

"The vegetative state can be diagnosed according to the following criteria: (1) no evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioural responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension or expression; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes. The
distinguishing feature of the vegetative state is an irregular but cyclic state of circadian sleeping and waking unaccompanied by any behaviourally detectable expression of self-awareness, specific recognition of external stimuli, or consistent evidence of attention or intention or learned responses.

Patients in a vegetative state are usually not immobile. They may move the trunk or limbs in meaningless ways. They may occasionally smile, and a few may even shed tears; some utter grunts or, on rare occasions, moan or scream. These [reflexive] motor activities may misleadingly suggest purposeful movements, yet these responses have been observed in patients in whom careful study has disclosed no evidence of psychological awareness or the capacity to engage in learned behaviour. As a result of the relative preservation of brain-stem functions, most patients in a vegetative state retain good to normal reflexive regulation of vision and eye movement. Sustained visual pursuit is lacking in most patients. They do not fixate on a visual target, track moving objects with their eyes, or withdraw from threatening gestures. However, patients in a vegetative state often have inconsistent primitive auditory or visual orienting reflexes, characterised by a turning of the head and eyes toward peripheral sounds or movements. In most patients, the gag, cough, sucking and swallowing reflexes are preserved.\(^1\) Except for a lack of co-ordination in chewing and swallowing, gastrointestinal function remains nearly normal.\(^2\)

1.4.2 Neurological Investigations

While neuro-diagnostic tests alone cannot confirm a case of PVS, when used to complement clinical observations they can provide useful supportive information. In particular, while normal results don’t exclude the possibility, abnormal results definitely increase the likelihood that a particular case of PVS is irreversible.

1.4.2.1 Electroencephalography: Electroencephalograms (EEGs) can vary widely between individual cases. As well as occasional reports of ‘flat’ EEGs “...in approximately ten percent of patients in a vegetative state, the EEG is near normal late in the course of the illness...”\(^2\) In most patients in a PVS, EEGs show diffuse generalised polymorphic delta or theta activity. This pattern is usually not attenuated by sensory stimulation, except occasionally by noxious stimulation. [C]linical recovery from the vegetative state may be paralleled by diminished delta and theta activity and the reappearance of a reactive alpha rhythm. This phenomenon is inconsistent and does not predict future recovery.\(^2\)

\(^1\) Preservation of these reflexes protects the PVS patient from contracting life-threatening lung infections. Without this intact reflex, survival times would be greatly reduced as in the case of a coma patient - see 1.5.2 Coma.

12
"The presence of EEG spindle activity after hypoxic or anoxic injury did not indicate a favourable prognosis, but the absence of spindles or EEG background reactivity was associated with a poor outcome [death or PVS]."10

In summary, when the appropriate clinical features are present an abnormal EEG is strongly suggestive of iPVS, while a normal EEG does not eliminate the possibility that the patient is in iPVS.

1.4.2.2 Neuroimaging: Involves scanning the brain using Computer Axial Tomography (CAT or CT) or Magnetic Resonance Imaging (MRI). Although neuroimaging can neither confirm or eliminate a diagnosis of PVS, it is helpful in exposing neuropathological features common to the condition – for example, "...diffuse or multifocal cerebral disease involving the gray and white matter"31 and/or "...ventricular dilatation and cortical atrophy..."32 Taking repeated images over time will reveal any progression of these abnormalities, the existence of which reduces the likelihood of neurological recovery. While a normal brain scan in the early stages indicates a better chance of a return to consciousness than an abnormal one would, it does not exclude the possibility of iPVS.

1.4.2.3 Evoked-Response Studies: Somatosensory Evoked Potentials (SSEPs) have proven to be the most useful of the evoked-response tests. The absence of SSEPs in coma patients has been an accurate predictor of a poor outcome in some studies.33

"The bilateral absence of such responses one week after the insult is highly predictive of failure to regain consciousness (i.e. of death or survival in a vegetative state.) Patients without SSEPs, however, may recover at least minimal cognitive activity, especially if the coma is traumatic rather than anoxic."34

"If a CT scan excludes the presence of extraaxial fluid collections or brain stem haemorrhage, the presence of normal SSEPs suggests a 93% chance of a favourable outcome, whereas the absence of SSEPs predicts a 92% chance of an unfavourable outcome."35 1

Brain-stem Auditory Evoked Responses (BAERs) and other evoked potentials are of limited diagnostic or prognostic value.36

1.4.2.4 Cerebral Metabolic Studies: A technique that involves positron emission tomography (PET) measurements of glucose metabolic rate in the cerebral cortex. Tests have shown that patients in a PVS exhibit a much lower metabolic rate than normal subjects.

"These PET results demonstrate a profound reduction of cerebral glucose metabolism in vegetative patients. The changes involved not only the cerebral cortex but also the basal nuclei and the cerebellum, with which these higher centres normally interact. Furthermore, no

1 This was a paediatric patient study.
metabolic overlap occurred between vegetative patients and either normals or persons who were
locked in."

"Global cerebral metabolic rate of glucose was 6.72 mg/100g/min. in [ten normal, age-matched]
subjects. It was significantly reduced to 3.70 in coma, to 3.45 in VS, and to 2.33 in PVS
patients."\(^{38}\)

"When compared with normal values obtained in 16 normal, age-matched subjects, mean
cerebral glucose metabolism was drastically decreased (approx. 50%) in vegetative cases."\(^{18}\)

Notwithstanding these results, there will have to be further studies undertaken before PET scans of
metabolic rate can be relied on to give an accurate prognosis. This is especially so in cases involving
children, whose normal cerebral metabolic rates are substantially lower than those found in adults.\(^{40}\)
In any case, the enormous costs of PET techniques has meant that they are limited to research studies.

1.4.2.5 Cerebral Blood Flow: A number of methods are used to obtain information on cerebral
blood flow (CBF): xenon-133, radionuclide-imaging using hexamethyl propylenamino oxime
(HMPOA), or a similar PET technique to that used to measure glucose metabolism. CBF has not
proven to be an accurate diagnostic or prognostic feature in PVS patients: results have been more
variable than those of metabolic studies.

"Measurement of CBF immediately after an acute neurologic injury does not predict a
vegetative outcome in either adults or children. Once a vegetative state exists, however, CBF is
likely to be reduced. ... Some studies, however, have found normal cerebral blood flow in
patients in a PVS."\(^{41}\)

"This greater variability of CBF than cerebral glucose metabolic rate could reflect either
dissociation between parenchymal flow and metabolism as observed in cases of acute coma or
different patterns in response to injury which are known, for example, to include
neovascularisation."\(^{42}\)

1.5 Differential Diagnoses

There are a number of situations where severe brain damage, isolation, or even death, can give rise to a
condition with similar features to PVS. It is important that these alternatives are eliminated before
confirming the diagnosis and making decisions accordingly.

"An accurate diagnosis is critical. Errors in diagnosis have occurred because of confusion about
the terminology used to describe patients in this condition, the inexperience of the examiner, or
an insufficient period of observation."\(^{43}\)
1.5.1 Whole Brain Death and Brain Stem Death

It was the suggestions of a Harvard Ad Hoc Committee that led to a majority of countries throughout the world adopting a whole brain definition of death by the early 1970s. The committee gave three diagnostic (and a fourth, confirmatory) clinical signs that satisfy this whole brain definition.

- **Unreceptivity and unresponsivity**: A total unawareness of externally applied stimuli and complete unresponsiveness; for example, no groan, withdrawal of limb, or quickening of breath.

- **No movements or breathing**: No spontaneous muscular movements or spontaneous breathing.

- **No reflexes**: Pupils fixed and dilated, ocular movements and blinking are absent, as are corneal, pharyngeal, and (in most cases) tendon reflexes.

- **Flat EEG**: An isoelectric EEG is of great confirmatory value.

Thus a person who is brain dead has not simply lost the capacity for consciousness. All neurological signs and functions of the brain have irreversibly ceased. Over time there was a realisation that, just as the brain is the organisation and integration centre for the body, in the same manner the brain stem is the organisation and integration centre of the brain. Therefore, “...death of the brain occurs when the organ irreversibly loses its capacity to maintain the vital integrative functions regulated by the vegetative and conscious-mediating centres of the brain.” Increasingly, existence of brain stem death has been regarded as adequate. This does not require a flat EEG, as the cortical cells (whilst isolated and unable to function normally) are still living. “Clearly PVS does not satisfy all the criteria for either brain stem or whole brain death, since brain stem functions continue.”

1.5.2 Coma

The differences between coma and PVS are more subtle. “Coma is a deep, sustained pathologic unconsciousness that results from dysfunction of the ascending reticular activating system in either the brain stem or both cerebral hemispheres. The eyes remain closed, and the patient cannot be roused.” So coma patients do not exhibit the distinguishing feature of PVS – a circadian sleep-wake pattern.

“Because there is often concomitant impairment of the cough, gag, and swallowing reflexes, the comatose patient will be more susceptible to fatal respiratory infections, a reason why comatose patients do not experience the long-term survivals associated with PVS.” Within four weeks of losing consciousness, almost all comatose patients will either recover, lapse into a PVS, or die.
1.5.3 Locked-in Syndrome

In locked-in syndrome, the patient retains consciousness and cognition, but loses the ability to move voluntarily due to interruption of descending motor pathways. These mute, tetraplegic patients "...are entirely awake, responsive and sentient, although the repertoire of response is limited to blinking, and jaw and eye movements." They can usually employ these small movements to establish limited communication. Careful clinical examination is needed to detect these minimal responses, and thus prevent an incorrect diagnosis of PVS being made.

1.5.4 Akinetic Mutism

"Akinetic Mutism is a rare syndrome characterized by pathologically slowed or nearly absent bodily movement and loss of speech. Wakefulness and self-awareness may be preserved, but the level of mental function is reduced. The condition characteristically accompanies gradually developing or subacute bilateral damage to the paramedian mesencephalon, basal diencephalon, or inferior frontal lobes."

1.5.5 Minimally Conscious State

Earlier this year an international Neurology Workgroup published criteria for the definition and diagnosis of the minimally conscious state (MCS). Such patients have severe impairment of consciousness and cognition, but are not brain dead, comatose or in a vegetative state as they demonstrate a limited (but nonetheless detectable) level of awareness. The inconsistency and insufficiency of published findings made it impossible for the Workgroup to establish evidence-based guidelines:

"Therefore a consensus-based case definition with behaviourally referenced diagnostic criteria was formulated to facilitate future empirical investigation. ... The minimally conscious state is a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated."

The inherent difficulty in quantifying 'minimal' has angered disability advocates and prompted some clinicians to ask, "...whether it is justifiable to carve a new syndrome out of a continuum of diffuse neuronal damage."

"One scientific question is the boundary issue: what are the boundaries of this clinical state and with what confidence can they be measured? The lower boundary between MCS and

---

" See 2.4.2 Patients in 'Near PVS'."
PVS is the presence of awareness. The upper boundary between MCS and lesser states of
diffuse cognitive impairment is necessarily indistinct and merges with them...

A second scientific question is the level of confidence clinicians ever can achieve about the
precise level of awareness of a severely brain-damaged patient. ... Assessing another's
awareness is purely inferential and depends on a subjective interpretation of the quality and
quantity of their responses to various stimuli.\textsuperscript{56}

The Workgroup agreed that the upper boundary for MCS is indistinct, "...and it is precisely for this
reason that functionally based criteria for emergence from MCS were proposed."\textsuperscript{57}

"We agree... that consciousness is 'intrinsically unknowable'; however, even arbitrary
boundaries are required to ensure that researchers can consistently identify a particular
clinical population. ... We hope that by clarifying these disorders, clinicians and the public
will be better equipped to engage in a more informed debate."\textsuperscript{58}

1.5.6 Dementia

Synonymous with Organic Brain Syndrome, dementia is "...an irreversible organic brain disease causing
memory and personality disorders, deterioration in personal care, impaired cognitive ability and
disorientation."\textsuperscript{59} While arousal functions usually remain normal during the initial deterioration,
advanced dementia can lead to total loss of wakefulness, self-awareness, and learned behaviour. At this
point, the patient is in PVS. Therefore 'dementia' should only be used in reference to the state of the
patient before this level of incapacity is reached.

1.5.7 Other Conditions

There are a number of other conditions, whose appearance can resemble PVS: for example acute
polyneuritis, myasthenia gravis, and catatonia. As for all the differentials mentioned in this section, a
thorough history, careful clinical observation and practical neurological investigations are crucial in
preventing misdiagnosis.

All subsequent discussion and recommendations in this report apply only to patients in true PVS.
It assumes that careful diagnosis has already taken place and all differentials have been
excluded.\textsuperscript{6}

\textsuperscript{6} It also assumes that the requisite period for irreversibility has elapsed before the patient is labelled \textit{iPVS} and treatment
withdrawal initiated – see 1.7.5 Prognostic Guidelines.
1.6 Prospects for Survival

PVS patients are not terminally ill. Given nasogastric feeding and adequate hospital care such patients can survive for years and even decades. The Otago Bioethics Centre report identified three criteria that affect the length of survival – age, economic and institutional factors, and the natural robustness of the body. However, larger studies would suggest that the much-publicised examples of longevity are in the minority. The task force states:

“Despite the preservation of hypothalamic and brain-stem function, the severe neurologic injury necessary to produce the vegetative state in adults and children reduces the average life expectancy to approximately two to five years. Survival beyond ten years is unusual. … Overall the available data (based on 251 patients in four large series) indicate that the mortality rate for adults in a persistent vegetative state after an acute brain injury is 82% at three years and 95% at five years. … Reported causes of death include infection, usually of the pulmonary or urinary tract; generalised systemic failure; sudden death of unknown cause; respiratory failure; and other disease-related causes, such as recurrent strokes or tumours.”

These survival times prompted reaction from others who felt that the report had been unnecessarily negative.

“My colleagues and I followed a cohort of 27 persons who remained in the locked-in state for more than one year. Their five year survival rate was 81%. The cohort includes a person who remains alive 18 years after injury. I am aware of a few patients with this syndrome who died only after they chose not to be treated for treatable medical conditions. I suspect many of the patients in the studies cited by the Multi-Society Task Force may have died as a result of conscious or subconscious neglect by care givers or a decision by their families not to have them treated.”

“In treating more than 100 patients in a vegetative state at a specialised coma-care facility for five years, I saw only a handful of deaths. Thus, I believe that aggressive medical management and rehabilitation can result in much longer life spans than those indicated by the Multi-Society Task Force.”

In replying to these comments, two members of the Task Force agreed that aggressive treatment would likely result in longer survival than limited treatment. However, they emphasised the lack of studies accurately assessing such a proposal and the job of the Task Force: “…to collect and summarise medical and neurological facts”. While their response encouraged future research in the area, its following statement puts the issue of PVS patient survival into perspective: “More important
than life expectancy is the point at which irreversibility (permanency) can be established with a high degree of certainty.

1.7 Prospects for Recovery

Recovery from PVS can be seen as having two dimensions: recovery of consciousness (reliable evidence of awareness of self and the environment, voluntary responses to stimuli, interaction, etc.) and recovery of function (communication, the ability to learn and to perform adaptive tasks, mobility, etc.). While a patient can return to consciousness without recovering function, recovery of function always requires a prior return to consciousness. In this section a distinction is made between those who recover consciousness only (severe disability), and those who go on to recover some level of function (moderate disability or good recovery). There is a difference between a minute chance that a PVS patient will only regain minimal sentience and an equally slim chance that he will be able to return to work. However, in later discussions on food and fluid withdrawal, any distinction is discarded. Once someone regains awareness, to any degree, they cease to be in PVS—they need not meet any functional standard in order to be found non-vegetative.

The Multi-Society Task Force report contains the most extensive collection of findings available on emergence from PVS. Although nearly every case of PVS is unique, the report focused on two features that have an appreciable effect on recovery prognosis: (a) whether the acute insult is traumatic or non-traumatic, and; (b) whether the patient is an adult or a child.

1.7.1 Recovery from PVS caused by Traumatic Injury

Traumatic injury includes motor vehicle accidents, gunshot wounds or other form of direct cerebral injury.

- **In Adults:** Information was available on 434 patients in VS one month after a severe head injury from seven studies.

  "Recovery of consciousness varied with time. Three months after injury, 33% of the patients had recovered consciousness; 67% had died or remained in a vegetative state. Recovery had occurred in 46% of the patients at 6 months and in 52% at 12 months. Recovery after 12 months was reported in only 7 of the 434 patients (1.6%).[67]

  Six of the seven who reportedly recovered consciousness after 12 months were from the same study.[68] The Task Force believed the condition of three of them had actually improved before

---

6 While many would agree that the latter chance was worth taking, far fewer would agree that the former was—see 2.2.5.1 Improvement in Prognosis and 2.4.2 Patients in 'Near PVS'.

5 See Appendix.
one year. Since their report, at least one other publication has described the recovery of a long-term PVS patient. Its authors tell of an emergence from 'permanent vegetative state' more than 15 months after the patient's injury and write: "To our knowledge only one other well documented case of late improvement after permanent post-traumatic vegetative state has been reported."

Among the 52% of Task Force patients who had recovered consciousness at 12 months, 28% had severe disability, 17% had moderate disability and 7% had a good recovery.

"For the entire group of 434 patients, the incidence of a good recovery beginning 6 to 12 months after injury was less than 0.5 percent."11

Of the seven patients who recovered consciousness after 12 months in PVS; six remained severely disabled and one had moderate disabilities.

- **In Children:** Six studies supplied information for review on 106 patients.

  "The prognosis for recovery of consciousness after a traumatic injury is slightly better in children than in adults. Of the 106 children in a vegetative state one month after a severe head injury, 24% had regained consciousness within three months. At one year...62% had recovered consciousness. None of the children recovered consciousness after 12 months."72

  The percentages of children experiencing the different levels of functional recovery were comparable to those of the adults. Of the 62% that had recovered consciousness at 12 months, "...35 percent...had severe disability, 16% had moderate disability, and 11% made a good recovery."73 Of these results, more good recoveries had occurred after six months in PVS than the adult group.

1.7.2 Recovery from PVS caused by Non-Traumatic Injury

Non-traumatic injuries include hypoxic ischaemic encephalopathies (cardio-respiratory arrest, near-drowning, suffocation, etc.) and cerebrovascular injuries.5

- **In Adults:** Patients in a non-traumatic-injury-induced PVS have a poorer prognosis than those whose PVS is caused by a traumatic insult.

  "Recovery of consciousness after a nontraumatic injury is unlikely. Of the 169 patients with such injuries, only 11% had recovered consciousness three months after injury; 89%..."72

---

4 They also question the impressive recoveries reported by Keith Andrews from the PVS Rehabilitation Unit of the Royal Hospital and Home, London. Those recoveries will be discussed in 1.7.6 Are These Guidelines Certain Enough?


5 See Appendix.
remained in a vegetative state or had died. Six months after injury, only two additional patients had recovered consciousness. One year after injury, 15% of the 169 patients had recovered consciousness. ...

"Recovery of function in the 15 percent of patients who regained consciousness was extremely poor. Only one patient had a good recovery. Two additional reports of individual patients with good functional recovery after non-traumatic injury have been published. In both patients, improvement began within two months after a hypoxic injury. There have been reports of five other patients who began to recover from a vegetative state more than six months after a non-traumatic injury. Two had moderate disability, and three had severe disability." 74

- **In Children:** The data available on children in PVS as a result of a non-traumatic insult was limited. Three studies supplied a total of only 45 patients for review.

  "Recovery of consciousness in children, as in adults, was primarily observed within the first three months after injury. By that time, 11% of the patients had regained consciousness; by one year, only an additional 2% had recovered consciousness. ...

  "Apparent recovery of consciousness after one year has been reported in several children in a vegetative state after a hypoxic-ischaemic injury. However these children recovered a level of function described as socially responsive, meaning that they smiled in response to the presence of other people but without other evidence of awareness. ...

  "The prognosis for recovery of function in children with a non-traumatic injury is somewhat better than that for adults. Of the 13% of children who recovered consciousness, 6% had a good recovery, and the other 7% had severe disability..." 75

1.7.3 Recovery from PVS caused by Degenerative or Metabolic Disease

Patients with true PVS due to a degenerative or a metabolic condition have no possibility of recovering consciousness.

"Some patients may temporarily lapse into a vegetative state when systemic illness causes a reversible depression of neurologic function. This possibility must be considered before determining that a patient's vegetative state is irreversible." 76

1.7.4 Recovery from PVS caused by Developmental Malformation

Anencephaly (failure of the brain to form) is the only condition that can be immediately recognised at birth as being PVS. "The complete absence of the cerebral cortex in anencephalic infants precludes consciousness." 77 Other developmental causes of PVS have prognoses almost as bleak.
“Infants and children with brain malformations severe enough to cause a developmental vegetative state are unlikely to become conscious; those who do are in most cases severely disabled....

Other malformations diagnosed at birth may result in a vegetative state. If the patient remains in a vegetative state at three months of age, the prognosis for any improvement is quite poor. Lack of evidence of consciousness in such infants by the age of six months almost completely precludes the potential for future improvement.”

1.7.5 Prognostic Guidelines

According to the Task Force report, recovery of consciousness after 12 months in PVS is unlikely in adults and children who have suffered traumatic injuries. Correspondingly, in adults and children who have been in PVS as a result of a non-traumatic insult, recovery of consciousness is rare after three months. It recommended the following:

"On the basis of these probabilities, a persistent vegetative state can be judged to be permanent 12 months after a traumatic injury in adults and children; recovery after this time is exceedingly rare and almost always involves a severe disability. In adults and children with non-traumatic injuries, a persistent vegetative state can be considered to be permanent after three months; recovery does occur, but it is rare and at best associated with moderate or severe disability.” (Also, that there was no chance of recovery from PVS caused by a metabolic or degenerative illness, and an exceedingly small chance of improvement in the case of an infant still in PVS at six months.)

National medical bodies worldwide have to a large extent, accepted these recommendations. An American Academy of Neurology subcommittee published ‘Practice parameters’ for the assessment and management of PVS patients in 1995: “The vegetative state is diagnosable. It is defined as being persistent at one 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....
- PVS can be judged to be permanent for non-traumatic injury in adults and children after three months.
- The chance for recovery after these periods is exceedingly low, and recovery is almost always to a severe disability.”
A Working Group convened by the Royal College of Physicians in the United Kingdom was more conservative in its recommendation concerning non-traumatic PVS. In 1996 it published the following:

"In patients who are in a continuing vegetative state following causes other than head injury there is very little hope of recovery of sentience after three months and none after six months. In patients who are in a continuing vegetative state after head injury the chances of recovery after six months are extremely low and, after 12 months non-existent. ... Thus, the diagnosis of the permanent vegetative state should not be made before six months following non-head injury brain damage or 12 months following head injury."81 (Underline added.)

Here in New Zealand, the Medical Association published a policy paper in August 1994.82 In preparing the paper, it drew largely on a report by the Bioethics Research Centre at University of Otago: "PVS and the Withdrawal of Food and Fluids".83 While neither of the documents give specific time frames after which a patient should be considered to be in iPVS, both include a set of (similar) guidelines. Those from the NZMA policy paper which relate to prognosis are as follows:

2. While the diagnosis and prognosis are uncertain, nutrition and hydration should be continued. This may have to be for a period of several months, or a year or more.
3. Where there are possible legal implications, as where the patient is in PVS as a result of an illegal act, nutrition and hydration should be continued until the legal situation is clear.
4. Where the diagnosis and prognosis are clear then a decision as to whether nutrition and hydration should be continued must be reached.86 (Underline added.)

For New Zealand clinicians in search of some practical assistance, ‘...a period of several months, or a year or more...’ is too imprecise. Unlike the American and United Kingdom equivalents, the NZMA guidelines fail to offer the security of a recommended and endorsed time frame.

This report recommends that the following specific guidelines be adopted in New Zealand:

1. PVS should be considered irreversible (i.e. iPVS) after 12 months in the case of traumatic injury.
2. PVS should be considered irreversible after 6 months in the case of non-traumatic injury.
3. PVS should be considered irreversible if caused by a degenerative or metabolic disease.
4. PVS should be considered irreversible if an infant is anencephalic or has shown no signs of consciousness by 6 months of age.

23
1.7.6 Are These Guidelines Certain Enough?

For some the above time frames will not seem certain enough. One correspondent wrote after the Task Force report, "...the time required before the discontinuation of treatment should be placed at 36 months. Research shows virtually no verified recovery of any kind after this time had elapsed." Such an attitude, however, is contrary to the manner in which care is provided in all other areas of medicine.

"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, i.e. when the chance of regaining consciousness is exceedingly rare."\(^{86}\)

The misgiving that the Task Force had over reports of late recovery from PVS was the apparent lack of detail in recording diagnostic testing or time frames.

"Several reports in the popular media have described dramatic recovery from a persistent vegetative state. ... Unusual cases in the medical literature or popular media are poorly documented, the nature of the patients' neurologic condition is unclear, or the timing of the entry into the vegetative state is extremely atypical."\(^{87}\)

A centre that claimed some remarkable recoveries in the early 1990s was the PVS Rehabilitation Unit of the Royal Hospital and Home in Putney, London - headed by Dr. Keith Andrews.\(^{88}\) In 1996 it published an article of a retrospective study in which 17 of the 40 'vegetative state' patients observed over a period were considered to be misdiagnosed.\(^{89}\) These findings prompted the editorial commentator to observe:

"Such an apparently high rate of misdiagnosis raises important concerns about the accuracy of the diagnosis of the vegetative state and related syndromes of severe brain damage. It also demands a critical review of the study's methods. ...

In my experience rehabilitation units often develop 'unique' ways of communicating with patients that only they can master. ... Until such validation [results reproduced at other rehabilitation centres] occurs, I must view [this publication's] buzzer system with some scepticism. ...

Both the multi-society task force on the vegetative state in the United States and the working group of the Royal College of Physicians in Britain stated that these neurodiagnostic studies
[CT, MRI, EEG and PET] have some use in diagnosis. It is unfortunate that Andrews et al. did not make use of them.  

All of the patients in the study were admitted to the Putney Royal Hospital with a referral diagnosis: "...diagnosed by the referring clinician as being in a vegetative state." Patients were presumed to be in PVS on their arrival and enthusiastic rehabilitation was commenced before the diagnosis was confirmed. Thus it is not the accuracy or honesty of the centre’s reporting that is questionable; rather the state which such patients were in before their remarkable recoveries. It is disappointing that the cases were never confirmed using accepted criteria before the reports were widely published.

None of the reports, papers or guidelines discussed in this section preclude future publication of facts to the contrary. As in any area of medicine, published peer-reviewed findings that support an alternative approach will prompt swift changes to management guidelines. Two members of the task force write:

"After considerable deliberation, the members of the task force concluded that it was necessary to distinguish clearly the permanent vegetative state (in which the chances of recovering consciousness are extremely remote...) from the persistent vegetative state (arbitrarily designated as a vegetative state present one month after the initial traumatic or hypoxic-ischaemic event), in which studies demonstrate that full recovery of consciousness and other neurological functions can occur. We hope that this document will encourage the reporting of more data, either individual case reports or systemic studies of large numbers of patients, that will support or refute the predictive probabilities contained in the report."  

1.8 The Incidence and Cost of PVS Patient Management

The number of PVS patients in New Zealand is unknown. When overseas studies attempt to estimate the incidence in their country, the figures vary widely. For example, in the United States:

"The most commonly cited estimate of the number of PVS patients in the United States is 5,000-10,000. This estimate is based on epidemiological studies from Japan showing approximately 2,000-3,000 patients in this condition in that country, and an extrapolation of that data to the United States considering our population double that of Japan and our more advanced (and more indiscriminately applied) life-support systems."  

"A 1992 research study found 3% of the 1,611 patients in four Milwaukee nursing homes in PVS. 3% of the 1.3 million nursing home residents in the United States translates to 39,000 patients in PVS."  

---

1 Witnessed by the author of this report during a visit to the Royal Hospital and Home, Putney, London in 1995.
"According to estimates, however, in the United States there are 10,000 to 25,000 adults and 4,000 to 10,000 children in a PVS."

Estimates of the financial costs incurred in maintaining a PVS patient are also many and varied. In 1988, a range was given at $US2000/month to $US10,000/month. This did not include the extremely high costs of initial resuscitation and intensive care. The task force states:

"The costs of caring for patients in a PVS are difficult to estimate. The costs of hospitalisation care for the first three months is estimated to be $US149,200. The estimated cost of long-term care in a skilled nursing facility ranges from approximately $US350 per day [$10,500/month] to approximately $US500 per day [$US15,000/month]."

As with the incidence of PVS, little is known about the costs of its management in New Zealand. The Bioethics Research Centre report gives the only published estimate:

"In New Zealand the costs would probably run from $NZ3,000 to $NZ12,000 per patient-month depending on the level of care and the institution involved."

A Workgroup this year estimated the lifetime costs of severe traumatic brain injury:

"Projected average per person lifetime costs of care alone for severe traumatic brain injury range from $US600,000 to $US1,875,000. A single case...reported in-hospital lifetime costs of $US6,104,590."

1.9 Treatment of the PVS patient

There are two aspects of ongoing treatment for a PVS patient: the medical care required for the patient to survive, and; rehabilitation therapy the aim of which is to stimulate recovery. They will be considered separately in this section.

1.9.1 Medical Care

The level of treatment administered to the PVS or iPVS patient will be largely determined by which stage of the condition they are in.

"There are four levels of treatment: high technology rescue treatments, such as mechanical ventilation, dialysis, and cardiopulmonary resuscitation; medications and other commonly ordered treatments, including antibiotics and supplementary oxygen; hydration and nutrition; and nursing or home care to maintain personal dignity and hygiene."

All of these levels are indicated at the time of injury, as the eventual outcome is unknown. It is quite appropriate to employ all available technology while a chance of recovery exists.
"Aggressive medical treatment is appropriate at the onset, when the prognosis remains uncertain. This will include adequate hydration and nutrition (through a nasogastric tube or gastrostomy), protection of the airway, attention to posture and contractures, and care of the bowel and bladder."^{102}

Once it becomes clear that a patient has entered a PVS, but before the condition has been diagnosed as irreversible, the treatment will depend somewhat on the policy of the institution and on discussion with the patient’s family. Many hospitals would agree, after consulting the family, that Do-Not-Resuscitate orders should be in place for such patients. **There is no contradiction in requiring the continuation of nutrition and hydration to an otherwise healthy body over this period, while choosing not to aggressively salvage organ systems should they fail.** It is during this period that advance directives would be most appropriate.\(^8\) Whatever the treatment decision regarding resuscitation and medications; nutrition, hydration and nursing care should continue.

"Doctors who look after vegetative patients frequently agree with families and nursing staff to withhold antibiotics and cardiopulmonary resuscitation."\(^{103}\)

"Much of the management of PVS patients is a good standard of nursing care - the prevention of pressure sores, control of bowel and bladder function, management of tracheostomy tube (if present), prevention of pneumonia, and avoidance of contractures. These are basic, but fundamental, to the care of the patient."\(^{104}\)

Following the diagnosis of irreversible PVS, a decision to withdraw treatment should be made. It must involve the withdrawal of all treatment including nutrition and hydration. Nursing care should continue until the patient passes away.

"At all times the patient’s dignity and hygiene must be respected. ... Appropriate nursing care can prevent the most common signs of acute dehydration, such as dryness of the skin and mucous membranes of the mouth and eyes. Facial swelling from prolonged administration of artificial nutrition and hydration decreases as the patient becomes progressively dehydrated; during the last few days of life, facial features may assume a more normal appearance. ... Except for dryness of the skin and mucous membranes, it is not readily apparent to family or health care professionals that a patient in a vegetative state is dying of acute dehydration."\(^{105}\)

### 1.9.2 The Role of Rehabilitation

Some groups are convinced that the active rehabilitation of PVS patients improves their outcome. Such rehabilitation is usually in the form of a Coma Stimulation Programme. Dr. Andrews writes:

\(^8\) See 3.4.5 Advance Directives and the iPVS Patient.
"Coma arousal programmes are attracting interest. These use stimulation of vision, hearing, touch, taste, and smell, starting at a simple level and then building up to more complex stimuli as the conscious level improves. There is still much to learn – for example, whether familiar sounds are more effective than noise or unfamiliar sounds. Similarly, with the duration of stimulation: at the Royal Hospital it is our impression that short bursts of less than a minute, repeated intermittently with periods of silence over quarter of an hour, are all that patients in a PVS can tolerate."\(^{106}\)

"There has also been an increase in the interests of using deep brain stimulation with electrodes... with promising results. There are, therefore, a number of new treatment programmes which have the potential for improving our approach to PVS and give greater opportunities for treatment and rehabilitation. They have, as yet, to be fully evaluated but early experience is showing some promise."\(^{107}\)

"One problem is the possibility of self fulfilling prophecy - the prognosis is poor, therefore no treatment is given, therefore the prognosis is poor."\(^{108}\)

Wilson et al found that multimodal stimulation brought about very minimal, but statistically significant, improvements in four patients – compared to a unimodal programme.\(^{109}\) According to Pierce et al, PVS patients subjected to multi-sensory stimulation for 8 hours a day had an 11% better outcome than the ‘control’ group.\(^{110}\) In a study conducted by De Young and Grass, patients in PVS were stimulated every 15 minutes for up to 11 hours a day – only 4% did not improve.\(^{111}\)

Such publications have met with scepticism. A large number contain methodological problems; many of the remainder produce results, the significance of which are statistical rather than clinical.

"Sensory stimulation... has a long and venerable history dating from Hippocrates who wrote ‘the patient in a state of coma should be spoken to in a loud voice, splashed with cold water and exposed to bright light’. Is the result of regular, sequentially applied, multi-modality sensory stimulation, however, likely to provide any material benefits other than those accrued by the relatives and nursing and paramedical staff who feel themselves involved in an apparently active mode of treatment as opposed to one that is inherently passive? Although there may be theoretical justification for such programmes at a neuronal level... controlled prospective studies are still lacking."\(^{112}\)

Despite including most of the studies mentioned above in its review, the Task Force report states:

"Therapy aimed at reversing the persistent vegetative state has not been successful. ... Direct electrical stimulation of the mesencephalic reticular formation, nonspecific thalamic nuclei, or dorsal columns has been attempted experimentally in patients in a vegetative state, with claims of recovered consciousness in a few instances. The quality of the recovered state was
not described in detail, however, and these approaches remain experimental. Reports of improvement with coma stimulation programs have been published, but there are no verified controlled studies reported in peer-reviewed journals. Overall, there is no published evidence that coma sensory stimulation improves the clinical outcome in patients in a persistent vegetative state.\textsuperscript{113}

1.10 Withdrawal of Nutrition and Hydration

Withdrawal of nutrition and hydration has been thoughtfully recommended (by the medical profession, overseas and here in New Zealand)\textsuperscript{114} as the most appropriate method to bring about the death of an iPVS patient.\textsuperscript{7} This section outlines the physical and physiological changes of such withdrawal and the current evidence surrounding any pain or suffering that it inflicts.

1.10.1 Physical Effects of Withdrawing Nutrition and Hydration

The physical changes that take place in the acutely dehydrated patient are listed in the University of Otago’s Bioethics Research Centre Report:

“\begin{quote}
These effects can include dry mouth, parched lips, tongue swollen and cracked, sunken eyes, lining of the nose cracked, dry scaly skin hanging loosely from the body, dry lining of the stomach causing vomiting, dry brain cells which in some patients cause convulsions (but may well not do so in PVS), and hyperthermia.
\end{quote}”\textsuperscript{115}

While indeed the signs of dehydration in this worst-case scenario sound macabre, almost all of them can be prevented or ameliorated through the continuance of good nursing care and symptomatic intravenous medication (e.g. anti-emetics or anti-convulsants).\textsuperscript{w} At a cellular and organ level the

\textsuperscript{v} Later this report claims that it is the subject of any act or omission that is of relevance in determining its moral rightness or wrongness. Section 2: The Ethical Issues and Section 3: The Legal Issues discuss in detail the need to ethically and legally define iPVS patients as a distinct group of individuals; neither persons nor corpses. Recognised as such, the ending of an iPVS patient’s life by lethal injection would be as ethically justifiable as the withdrawing of nutrition and hydration. However this report recognises that, to some within the medical profession (and many more outside it), such an act of injection would intrinsically violate many of the taboos surrounding active euthanasia. Widespread misunderstanding and speculation would follow (not to mention the fuelling of pro-euthanasia support) regardless of how well the unique nature of the iPVS patient was explained – see 2.4.3 Is Withdrawing Treatment from iPVS Patients Euthanasia?

\textsuperscript{w} Such nursing care and medication is continued, not because the patient is aware of their appearance or suffering, but rather that their dignity (and that of their loved ones) be preserved. While an iPVS patient remains unconscious even while vomiting uncontrollably, such an episode is very distressing for friends and family.
pathophysiological consequences of dehydration progress. The Task Force report outlines some of the end-stage developments that may take place:

“When artificial nutrition and hydration are withdrawn, patients in a persistent vegetative state [irreversible] usually die within 10 to 14 days. The immediate cause of death is dehydration and electrolyte imbalance rather than malnutrition; patients in a PVS cannot experience thirst or hunger. Some patients die from intercurrent acute illnesses, such as pneumonia. Others may die from underlying cardiac or renal disease when medications are also discontinued. …

When dehydration leads to systemic hypotension, some patients in a vegetative state slip into a coma, whereas others continue to have periods of wakefulness and sleep-wake cycles until they die.”

The University of Otago’s Bioethics Centre Report is more conservative in its estimate of survival after nutrition and hydration withdrawal, stating that death has usually occurred after 30 days. However the critical question regarding nutrition and hydration withdrawal is not: ‘What is the mode or the length of the dying process?’ nor is it; ‘What are the clinical signs that the healthcare providers observe?’ rather; ‘Can the patients experience any of the symptoms of starvation or dehydration during the process?’

1.10.2 Pain, Suffering and Consciousness

Not everyone is convinced that entering a PVS results in a complete lack of pain perception. Following the publication of results from an iPVS patient autopsy (which, contrary to expectation showed that “…the most severe damage was not in the cerebral cortex but in the thalamus”) one commentator referred to this finding, suggested that there was a case for the storage of memory in the cerebellum and continued:

“It may be hearsay to suggest that persons in a PVS can perceive pain, but in view of the fact that more than a third of patients (25 of 68) in one series who recovered from post-traumatic coma could recall or relate experiences that occurred during coma, the issue remains open.”

The issue does not remain open for the members of the Task Force who replied to this correspondence:

“The correlation of the vegetative state and unconsciousness rested on the medical view that the cerebral cortex is the primary locus of ‘conscious awareness’. We realise that a minority
of neurologists remain unconvinced of this, and an even smaller minority continue
to maintain that patients in a vegetative state can experience pain or suffering. Members of
the task force were aware of occasional cases of the vegetative state arising from
predominantly thalamic damage. Our report notes that relatively selective thalamic necrosis
may follow acute global ischaemia. The autopsy findings...do not refute the basic
assumption of the primary locus of consciousness.”

Indeed the medical profession would not have accepted such a method of allowing iPVS patients to
die were not a large majority of its representatives convinced that it inflicted no pain or suffering.
Reports from the Royal College of Physicians, the American Medical Association and the University
of Otago’s Bioethics Research Centre all contain assurances the PVS patients are unconscious and
cannot experience pain. “[T]he crucial issue is that, despite the signs of loss of food and fluids, the
patient cannot experience any of the symptoms of starvation and dehydration.”

Such assurance is based on findings like the following:

“The PVS patient’s rCMRGlu [regional Cerebral Metabolic Rate of Glucose] measurements
of the cerebral cortical regions necessary for sentience are reduced to an extent similar to
those of normal people who are placed under deep general anaesthesia, who all would agree
cannot experience pain and suffering.”

“Another concern is that withdrawal will cause the patient to suffer unpleasant physical
sensations. The Institute of Medical Ethics sought to agree with the American view that there
is no remaining neurological mechanism to make pain or suffering possible... There is
therefore no case for yielding to the sloganism of starvation.”

After reviewing this publication and many others in its discussion on diagnosing unconsciousness,
the Task Force wrote regarding pain and suffering:

“The term ‘nociceptive’ refers only to the response to noxious stimuli, not to the experience
of pain. ... Nociceptive stimulation elicits well-known, unconscious postural responses, as
well as other motor, autonomic, and endocrinologic reflexive responses. None of these,
however, can evoke the experience of pain and suffering if the brain has lost its capacity for
self-awareness.

As noted in the first part of this article, extensive clinical experience, the results of positron-
emission tomographic (PET) studies, and neurologic examination support the belief that

---

31 The focus in this section is on iPVS patients, as they are the only ones for whom withdrawal of nutrition and hydration is
carried out. However, the distinction between PVS and iPVS patients is purely one of prognostic assessment. In terms of
functioning and perception, their deficits are identical.
patients in a PVS are unaware and insensate and therefore lack the cerebral cortical capacity to be conscious of pain.”122

It is this view that has also been accepted as most convincing by the majority outside the medical profession. Most courts have agreed with medical experts promoting a ‘lack of pain and suffering perception’ theory, as the following statement in *Airedale NHS Trust v Bland* exemplifies:

‘Counsel for the Official Solicitor opened this appeal by saying that the President ‘had held that it was lawful for a doctor to starve his patient to death.’ This is emotive language and by that I do not mean that this is not a proper case for emotion. It certainly is. By emotive language I mean language that evokes emotional images which are false, which have no application to the present case. The use of the language is intended to evoke images of cruelty, suffering and unwelcome death. Such images have no part to play in arriving at an answer to the problem, already difficult enough, which this case presents to the court.”123

1.11 Summary of Medical Issues

Persistent Vegetative State (PVS) is a clinical condition of total unconsciousness with partially preserved brainstem function. Accordingly such patients, although unaware, breathe spontaneously and exhibit a cyclical sleep/wake pattern. The condition is caused by brain injury that results in the destruction or isolation of the cerebral cortex while leaving all or part of the brainstem intact – it is not equivalent to coma or to brain death. There is variable sparing of cranial nerve reflexes: most importantly cough, gag and swallow, which protect the PVS patient against fatal respiratory infections and contribute to their prolonged survival times. However, they are not even minimally conscious.

The exact pathological changes in the brain depend on whether the insult is acute trauma, non-traumatic hypoxia, a degenerative process or a developmental abnormality. The diagnosis is essentially one of clinical observation and neurological examination, although various investigations can add weight to those findings. There must be no evidence of the patient possessing cognitive function or exhibiting a learned response to stimuli. It is absolutely crucial that alternative diagnoses are excluded, as other severely debilitating conditions can mimic PVS. It is therefore recommended that the patient be examined at various stages, preferably by more than one specialist in neurology.

---

* Twenty year-old Anthony Bland sustained serious injuries in the disaster at the Hillsborough football ground in 1989. He was in an iPVS for more than three years. His doctors and parents sought permission from the courts to lawfully discontinue all life-sustaining treatment. See 3.1.3 *Airedale NHS Trust v Bland.*
PVS patients are not terminally ill. With appropriate feeding and medical care there are reports of patients living for many years. The prospects of a return to consciousness are less favourable. Following a traumatic injury, fewer than one percent of patients recovered any cognition after 12 months in PVS. In cases of non-traumatic injury, no one has come out of a PVS after six months. Consequently, based on reliable findings to date, those are the time frames beyond which PVS can be said to be irreversible PVS. (Referred to throughout this report as iPVS.)

The number of PVS patients in New Zealand is unknown. Indeed attempts by overseas commentators to estimate the incidence in their own countries vary wildly from paper to paper. The cost in healthcare dollars was broadly estimated in 1993 at between $NZ3000 and $NZ12,000 per PVS patient per month. This range is a reflection of the vast differences in treatment required from case to case; from simple nursing cares and nasogastric feeding to prolonged periods of ventilation, dialysis and pharmaceutical therapy. Any significant benefit of coma stimulation programmes has yet to be proven in controlled trials.

Withdrawal of nutrition and hydration has been thoughtfully promoted by clinicians as the most appropriate method of causing an iPVS patient to die. The subsequent cause of death is usually electrolyte imbalance and dehydration. The obvious physical manifestations of acute dehydration can be minimised with continued nursing care. All but a small minority of healthcare professionals are satisfied that, lacking the primary locus for consciousness, PVS patients are unable to experience pain and suffering. Consequently, medical bodies and law courts alike have been quick to criticise those who have used unnecessarily emotive terms such as ‘cruelty’ and ‘starvation’ either out of ignorance or a deliberate attempt to mislead.
SECTION 2: THE ETHICAL ISSUES

Whether or not withdrawing nutrition and hydration from iPVS patients is acceptable can only be answered after negotiating a complex maze of ethical issues. In Section 2: The Ethical Issues both the moral significance of nutrition and hydration and the implications of their withdrawal are discussed with respect to the iPVS patient. The goals of a medical intervention are discussed and the question is asked whether feeding can ever be said to be futile. The moral justifications for making a decision to withdraw treatment are addressed, as well as who is entitled and responsible for making it. Finally, comparisons and contrasts are drawn between: i) withdrawing nutrition and hydration from an iPVS patient; ii) discriminating against the disabled, and; iii) euthanasia. Firstly though, the ethical status of an iPVS patient is determined, as this will provide the position from which other issues can be approached.

2.1 The Ethical Status of an iPVS Patient

This has prompted much debate among ethicists. Some hold fast to the belief that ‘...with the breath of life in their nostrils, and blood coursing through their veins...' iPVS patients fulfil criteria to be living. Their opponents claim, as these patients have lost the potential to be persons, they no longer exist and “…something that no longer exists clearly cannot be alive.” Those somewhere in the middle feel that iPVS patients fail to satisfy the requirements for living or dead. While the fundamental differences in what people see as ‘counting for life’ dictate that there will always be some disagreement, the ambiguity is largely because, as the 1993 Bioethics Research Centre Report states, “…the problem with our ethical perception of the PVS is that the patient does not fit a category with which we are familiar.” That report goes on to identify three categories of patients:

1. The conscious competent patient: These patients are in possession of all their faculties and as such, are legally and ethically entitled to make their own informed choices regarding treatment. The attending health professionals are then obligated to comply with those wishes, even to the point of withdrawing nutrition and hydration.

2. The conscious incompetent patient: Comprised of those who are aware of themselves and surroundings, but through temporary or permanent incapacity cannot reasonably be
expected to make rational treatment decisions. In such cases it is desirable (but not obligatory) for staff to involve a patient's close friends and family in choosing an appropriate level of care. This helps to ensure that a decision is made which all parties feel is in the patient's best interests. "In this situation, the patient's own reactions to his or her current state can be perceived and the decision (at least to some extent) discussed with the patient."3

3. **The brain dead patient:** This state has been identified as a unique subset of death because of the special similarities that the 'breathing' brain dead patient shares with the iPVS patient. However, two consequences of brain death are often overlooked in the rush to equate it to, or distinguish it from, iPVS. Firstly, the cessation of cardio-respiratory function is inevitable, as the centres for initiation and integration of such functions have been destroyed. Secondly, the characteristics that made the patient a 'person' have been irrevocably lost. Only the latter is also true of iPVS patients.

Because iPVS patients exhibit characteristics of both the living and the dead, it is not surprising that ascribing them an ethical status is one of the most contentious points in the discussion. Nor is it surprising that they are often referred to as "...the living dead..." or said to be suffering "...a fate worse than death". What is it these patients have lost that prompts some to regard them as dead? And what is it they still possess that provokes others to be outraged by such suggestions?

2.1.1 **The Significance of Personhood**

There are two dimensions that together define who an individual is: their personhood – the mental dimension; and the biological shell housing that personhood – the physical dimension. Gillett identifies three features that make up the mental dimension. These traits characterise who and what a person is:

1. **A person has identity:** Not defined purely in physical terms, identity includes aspects of a man's thinking and his character that help to form who he is, both to himself and to others. "Identity is important because we treat a person as a being with continuity over time. Many of our moral attitudes towards a person are based on the fact that he is an individual with a longitudinally coherent mental life and set of relationships."7

2. **A person has the capacity to be conscious:** It is this capacity that mentally distinguishes the human being from a protozoan or a pot plant, and enables him to possess and develop

---

*b* Seeking advice from family makes good clinical and ethical sense. However there is no legal obligation to do so. If a medical team has an appropriate reason (e.g. suspected child/elder abuse) it is justified in excluding family from treatment decisions.

*c* See 1.5.1 Whole Brain Death and Brain Stem Death - All brain dead patients must be artificially ventilated in order for their hearts to continue beating.
the other two features of personhood. This capacity can also equip him with the ability to rationalise and to experience - two features seen as being "...essentially significant to the nature of a man." His consciousness allows him to "...appreciate life and the world around [him], pursue personal projects, and be aware of [his] own development and abilities. Such good features of human life are relevant to one's perceptions, thoughts, character, interests, and purposes and depend upon the proper functioning of the nervous system."9

3. **A person has the ability to interact with the world:** This ability both depends on, and helps to define, the other two features of personhood. "Action is important because by acting a person takes a role in human life and relationships which partly defines [his] standing among us."10

Some commentators do not accept this division:

"This sort of dualism, which thinks of the body as if it were some kind of habitation for and instrument of the real person, is defended by few philosophers indeed (religious or otherwise). ... One’s living body is intrinsic, not merely instrumental, to one’s personal life. Each of us has a human life (not a vegetable life plus an animal life plus a personal life)..."11

However, most agree that personhood is absent in the iPVS patient. "While there are many different views of the nature of personhood, all of them, except for those that simply identify personhood with minimal biologic functioning...would agree that PVS patients are not persons."12 This is the feature that they share with brain dead patients. Further controversy develops when it is claimed that this shared feature makes the two states equal. Proponents of a higher-brain definition of death suggest that iPVS patients be accorded the same status as those who are brain dead, based on the unique role of the cerebral cortex in maintaining consciousness and cognition: once the cortex ceases to function, the individual dies. "[W]hen, and only when, there is the capacity for organic (bodily) and mental function present together in a single human entity is there a living human being."13

Those who challenge this view argue that it fails to take into account the ethical significance that society places on functioning bodily systems.

2.1.2 The Significance of Biological Function
iPVS differs from brain death as iPVS patients retain brain stem integrity. They are not terminally ill: they still possess their airway-protecting reflexes and, if fed, can survive for many years. On the other hand, the hearts of brain dead patients, even with continued ventilation, rarely beat longer than 72
Most importantly iPVS patients do not require ventilatory support: they have a spontaneously beating heart and spontaneously ventilating lungs. These functions have polarised the debate.

Ethicists who would like to see iPVS patients defined as dead claim that such functions are a means to an end and not in themselves ethically significant enough to differentiate them from a corpse. At the other end of the spectrum are those who believe that “...the heartbeat counts for life.” For some, any sign of life is sufficient and patients exhibiting such should be aggressively treated in order to prolong that life. “A small minority – call them ‘vitalists’ - believes that life at any cost is always preferable to death.”

The remainder occupy a position between the two extremes; believing that, with the physical characteristics of the living and the mental characteristics of the dead, iPVS patients have a status all their own. “Regardless of one’s views on human life, death and personhood, permanently unconscious patients are in an entirely separate category from all others.”

“Patients in a PVS may not be persons, in an ethical sense, but that fact does not put an end to our responsibility to the biological remains. ... He...is not any longer a ‘person’ and never again will be, but he is not ‘dead’. ... The body of the former patient is technically alive. ... Indeed it would seem that we are stuck, for the time being at least, with an intermediate moral category. ... [The terribly difficult ethical challenges that such a patient presents us with] cannot be adequately addressed by defining this perplexing intermediate category out of existence.”

“I still do not believe that these patients are dead. But does that necessarily imply that they are alive? I am no longer sure that we ought to say that. ... Perhaps troubling cases, like PVS patients, belong neither to the set of the living, nor to its complement, the set of the dead.”

2.1.3 Ethically Recognising this Unique Group

Failure to formally recognise such an intermediate state has resulted in a stalemate. On the one hand are those who do not wish to see the presence of spontaneous breathing condemn an iPVS patient to a lifetime of futile treatment; on the other, those who do not wish to see the absence of consciousness condemn that patient to cremation. The solution is not to define iPVS patients as dead in order to appease the former group. Nor is it to define them as living persons to appease the latter. “Society must begin to grapple with the substantial implications of this unique class of individuals.”

In any politically correct setting it is considered inappropriate to suggest that some individuals are less valuable than others. And rightly so. It is perhaps the most fundamental principle in a democratic society: That all are of equal moral worth. However, to extrapolate this equality to include the iPVS patient is to stretch the principle. This person is no longer a member of society. This person is no longer a person. “[W]e are now extending to this category of human beings respect that properly
belongs to human ‘persons’ alone.” If iPVS patients continue to be recognised as our equivalents, satisfactory answers to the ethical questions surrounding their treatment will not be found. This intermediate category of ‘decorticate non-persons’ should not be accorded the ethical status, legal protection or right to medical care that are reserved as belonging to conscious (or temporarily unconscious) patients.

However, a sense of protection and intuitive respect for what was once a person prohibits iPVS patients from being defined as dead. Some commentators fear the worst if all the legal and ethical references to life were to be erased.

“[I]f an organism may be declared dead and yet have its vital functions maintained by various devices, it may seem both tempting and permissible to use it as a self-replenishing blood or skin bank [or] a reservoir of transplantable organs kept in the freshest possible condition…” A distasteful and extremely unlikely scenario, given the reverence with which human remains are treated. In fact, the 1993 Bioethics Research Centre Report suggests that the respect society pays its dead will influence its treatment of iPVS patients:

“Firstly we recognise that human remains have a value to the people who knew the deceased, and our respect for the human remains is in part derivative from the respect we accord to the feelings of the living; and secondly we feel that human remains are owed a respect in and of themselves, independent of that owed to the living. Both of these moral dispositions are likely to be more intense when we are considering a PVS patient who is reacting, in some respects, like a living but unconscious person.”

In the same way that a body is of great symbolic significance, so too are the functions of respiration and circulation. It matters not that these functions have ceased to provide benefit for the iPVS patient: to friends, relatives and hospital staff they are of tremendous importance. Spontaneous respiration and circulation have for so long been associated with being alive that most would be angered and repulsed by the suggestion that individuals exhibiting such were dead. To define iPVS patients as dead would be to deny the respect due to one who is still biologically alive. More importantly, it would undermine the significance of living functions in all human beings.

Society has developed the medical technology to interrupt the journey from life to death before it has developed the insight to realise that, in doing so, it has created a state of neither – an existence in a “...twilight zone of suspended animation...” The solution lies in the medical, ethical and legal acknowledgement of iPVS patients as a unique ‘intermediate’ category: individuals who have lost the characteristics used to define persons, but not lost the ability to perform the vegetative functions that have for so long defined biological human life.
2.2 The Ethics of Feeding iPVS Patients

Almost all iPVS patients are artificially fed through a nasogastric or gastrostomy tube. Nasogastric tubes are introduced through a patient's nose and guided down their oesophagus into the stomach. Gastrostomy tubes require a minor operation – they are inserted through the skin of the abdomen and a small opening made in the stomach wall. Various nutrient-rich liquid diets can then be gravity-fed at a rate dependent on the patient's calculated caloric needs. Supplying ongoing nutrition in this way makes it possible for the biological systems of the iPVS patient to survive for many years. Much debate has surrounded whether or not such feeding is medical treatment; whether it is taking ordinary or extraordinary steps; whether or not it is futile and; whether or not it is a fair use of healthcare dollars.

2.2.1 Medical Treatment vs. Necessary of Life

When considering the 'rightness' or 'wrongness' of terminating a regimen of care, ethicists traditionally make a distinction between those that are medical treatments and those that are necessaries of life. It is generally believed that society is under a greater obligation to provide the latter than the former. In other words, while it is acceptable to take other factors into account when making medical treatment decisions, everyone is entitled to the necessaries of life regardless of such factors. Consequently, whether nasogastric feeding is a medical treatment or a necessary of life has been central in discussions on withdrawal of nutrition and hydration from iPVS patients. A majority of health professionals consider it to be medical treatment.

"[I]t is an intervention to prolong life that requires medical skills (imagine leaving to medically unskilled people the nutrition and hydration of long-term unconscious people for whom there was a reasonable prospect of good recovery.)"

This is the position that many courts have also taken.

"Artificial feeding cannot readily be distinguished from other forms of medical treatment."

"In any event, the administration of nourishment by the means adopted involves the application of a medical technique."

Those who argue that nutrition and hydration are necessaries of life believe that such feeding cannot be a medical treatment, as it is not treating any pathological state.

---

\[d\] Hereafter collectively referred to as nasogastric feeding.

\[e\] The ethical issues of nutrition and hydration withdrawal will be discussed in later subsections. The focus here is the status of nasogastric feeding and the benefit, propriety, and economic justice of continuously providing it to iPVS patients.
"At the trial I suggested that treatment, by its very nature, was given to treat an abnormality and said that I could not understand what abnormality the food was supposed to be treating – its purpose being to supply normal nutrition to an otherwise healthy body." 

Others feel that "...food and fluids have a symbolic nature that is not associated with other forms of treatment." But the applicability of these arguments to the case of an iPVS patient is questionable. Firstly, to look at nasogastric feeding in isolation and label it a necessary of life is misleading. It makes up part of a ‘treatment package’ initiated to sustain the vegetative patient while the possibility of recovery exists. Its administration enables other aspects of treatment to be trialled. Once the possibility of a return to consciousness is gone, treatment as a collective has failed. Even one of the opponents quoted above later concedes that, “...the tube is therefore the treatment, the food is not. Neither can be effective without the other, however, and the package, of tube and food, must therefore be the treatment.”

"...I am of the opinion that regard should be had to the whole regime, including the artificial feeding which at present keeps Anthony Bland alive. That regime amounts to medical treatment and care, and it is incorrect to direct attention exclusively to the fact that nourishment is being provided.”

Secondly, it is deceptive to speak of the ‘symbolic nature’ of food and fluid to an iPVS patient. Nasogastric feeding is not in place to combat the human feelings of thirst and hunger; rather to keep the body’s physiological and biochemical processes perpetuating. While food and fluids may be symbolic to those around the patient, it is inaccurate call them so in reference to one who can no longer appreciate symbolism. The emblematic significance of food and fluid has been lost for the iPVS patient.

"The argument that food and water are basic needs that should never be denied rests on their normally assuaging the ravages of hunger and thirst and enabling a life that is enjoyed to continue. Neither applies to vegetative patients, and the symbolic significance of feeding is therefore lost.”

Thirdly, the previous section maintained that iPVS patients belong to a category that fails to exhibit satisfactory characteristics for either life or death. Some may therefore think it contradictory to speak of ‘necessaries of life’ for a patient who no longer fulfils the fundamental criteria for human life.

---

See 2.2.3 Medical Futility and 2.2.4 The Goals of Medicine.

2 Twenty year-old Anthony Bland sustained serious injuries in the disaster at the Hillsborough football ground in 1989. He was in an iPVS for more than three years. His doctors and parents sought permission from the courts to lawfully discontinue all life-sustaining treatment. See 3.1.3 Airedale NHS Trust v Bland.

3 It is for this reason that the more impersonal and less emotionally-charged terms ‘nutrition’ and ‘hydration’ are widely used and the terms ‘thirst’ and ‘starvation’ discouraged.
Notwithstanding the exchange above, to focus on making a distinction is to engage in a largely academic exercise. One commentator believes that using any disparity to justify a decision “…makes a fetish out of the details of the method of feeding, which otherwise would be regarded as relatively inconsequential.”34 “Once one is clear about why the question is being asked, it does not matter whether one calls it medical treatment, nursing care or anything else.”35 Defining nasogastric feeding as a medical treatment or a necessary of life does little to address the relevant ethical issues. It is more important to determine its propriety and benefit for the iPVS patient: “What matters is whether it is care: care requires the intention and prospect of benefit…”36

2.2.2 Ordinary vs. Extraordinary Care

The concept of care has itself received attention. In particular, whether a clinical regimen amounts to ordinary or extraordinary care. Using much the same reasoning as that for ‘medical treatment’ above, it has been widely suggested that, while extraordinary care could be withdrawn in certain situations, ordinary care could not.

“Within the context of Moral Theology, the term ‘ordinary’ means ‘ethically ordinary’, which means ‘ethically obligatory’, or more specifically, ‘obligatory on its own merits’. … By contrast, the term ‘extraordinary’ means ‘not obligatory’ in this sense.”37

Such emphasis on a word that had enjoyed the quality of being unambiguous inevitably led to it being invested with meanings beyond the notion of ‘usual’, ‘normal’ and ‘commonplace’. Its exact connotation was now highly dependent on the medical context in which it was being discussed. It became apparent that some treatments considered ordinary for most patients were actually extraordinary for patients who could not benefit from them. Criticising these changes in its 1983 report, the President’s Commission38 identified three principal meanings of “ordinary” as it was being used: ‘common’ as opposed to ‘uncommon’; ‘simple’ as opposed to ‘complex’, and; ‘beneficial’ as opposed to ‘burdensome’. Following their recommendation that the third meaning be adopted, the concept of ‘benefits vs. burdens’ has been widely recognised as a more definitive criterion on which to gauge the propriety of a treatment.

“Regarding the first, it is difficult to see why an uncommon practice should not be required if it is simple and effective. Regarding the second, it is difficult to see why a complex management schedule should not be required if it were both commonly practised and clearly beneficial to the patient. The third definition effectively reduces the analysis of ‘that which is ordinary’ to ‘that which achieves a net balance of benefits over burdens.’”39
Analysis of a treatment’s benefits and burdens requires a prior understanding of that treatment’s goals. What are the reasons for providing nasogastric feeding to an iPVS patient? Are those objectives being effectively met? The following section focuses on a broad issue that helps to ascertain the worth of a treatment: medical futility.

2.2.3 Medical Futility

A futile action can be described as "...one that cannot achieve the goals of that action, no matter how often repeated." Medical, legal and ethical commentators agree that health professionals are under no obligation to initiate or to continue treatment that is futile. In fact, there is often an obligation to withdraw or withhold such treatment: "The Hippocratic Corpus, for example, encouraged doctors to recognise the limits of medicine, 'to refuse to treat those who are overmastered by their diseases, realising in such cases medicine is powerless.'" The New Zealand Medical Association Code of Ethics requires health professionals to "...[r]ecommend only those diagnostic procedures which seem necessary to assist in the care of the patient and only that therapy which seems necessary for the well being of the patient." The New Zealand High Court has quoted a Federal Court of Appeal judgment that states: "A physician has no duty to continue treatment, once it has proved to be ineffective."

Discussion about medical futility illuminates the complex interaction between patient autonomy and medical paternalism. Commentary in the Proposed Draft Code of Rights for Consumers of Health and Disability Services states: "While services will not always be able to meet consumers’ expectations (since positive outcomes cannot be guaranteed), they must always be consistent with their needs." In most treatment scenarios, both patient and family recognise that health professionals are in a good position to decide the effectiveness of a treatment. If a medical team carefully explains why a regimen is no longer appropriate, few will question that it should be removed. However, there will be times when families demand treatment despite exhaustive explanations. It is important to recognise that enthusiastic insistence on a treatment alone does not make it any less futile.

"If health professionals could never say no to patient or family demands for interventions, they could never have control over the consequences of the procedures they perform. ... [T]he denial of choices is an infringement of the patient’s right to autonomy only if the patient has the right to demand the option in question."

"Patients cannot demand ‘futile’ therapy, and society and doctors are under no obligation to provide such therapy."

See 2.2.5 Benefits and Burdens.
Whilst the theory of withdrawing futile treatment receives widespread support, there is much dispute over what exactly constitutes a futile treatment.

"Serious ethical consequences flow from the doctor’s claim that a particular treatment is futile, and although such claims have far-reaching implications, there is little consensus about how futility should be determined in practice."\(^{47}\)

"[T]he plurality of values in our society makes agreement on the concept of futility difficult if not impossible."\(^{48}\)

"The Council [on Ethical and Judicial Affairs, AMA] finds great difficulty in assigning an absolute definition to the term futility since it is inherently a value-laden determination."\(^{49}\)

Most literature now chooses to distinguish quantitative from qualitative futility.\(^{50}\) While the former is defined in terms of probability, the latter is a concept founded on the acceptability of outcomes. Evidence-based medical practice continues to highlight areas of quantitative futility and there is little disagreement that provision of such care is inappropriate — "It is uncontroversial that clinicians have no obligation to provide a treatment that cannot work... Such treatment falls outside the bounds of 'appropriate care'."\(^{51}\)

However the concept of qualitative futility is far more contentious. It is not suited to a mathematical approach; it cannot be proved or disproved. It requires, by definition, an assessment of quality and human diversity dictates that individual assessments will be similarly diverse — "Disagreements about so-called qualitatively futile treatments are not about probabilities — they are about values."\(^{52}\)

While nasogastric feeding of the iPVS patient is not quantitatively futile — "...since it so often does succeed in prolonging life..."\(^{53}\) it is arguably qualitatively futile — "The clearest of these qualitatively poor results is continued biologic life without conscious autonomy."\(^{54}\) However not all would agree with the latter statement; judging the preservation of vegetative function a worthy result. For this reason some commentators feel that the use of 'medical futility' as a justification to withdraw treatment intentionally blurs the two concepts:

"Futility bundles uncontroversial cases involving treatment that cannot work with cases involving effective treatment that supports controversial ends... In doing so, the concept of futility is an attempt to redefine a debate about conflicting values as a debate about medical probabilities."\(^{55}\)

---

\(^{1}\) The Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996 will be closely examined in 3.2.1 Health and Disability Commissioner Act 1994.
Even without such disagreement, announcing that a particular treatment is futile conveys little without further qualification. The aims and limitations of that treatment must be outlined before futility can be put into perspective.

"In order to address more completely the fundamental issues in the debate about futility, it is necessary to consider the claim of some physicians that providing futile treatment is simply not good medicine. Those who hold this position state that there is no justification for providing treatment that will not achieve any legitimate goal of medicine... Thus, the way persons define the goals of medicine will largely determine their views on futility. The question ‘Futile in relation to what?’ becomes the central issue."\(^{56}\)

2.2.4 The Goals of Medicine

Whether or not one regards a medical treatment as qualitatively futile will ultimately depend on what one sees as the legitimate goals of medicine. One broad account of these goals is given by Jonsen et al: i) the restoration of health; ii) the relief of symptoms; iii) the restoration of function; iv) the saving or prolonging of life; v) the counselling of patients, and; vi) the avoidance of harm.\(^{57}\) In the case of an iPVS patient, it is the fourth of these objectives comes under scrutiny, begging the question: ‘Is the maintenance of an iPVS patient’s biological functions a legitimate goal of medicine?’ Opinion on this matter is once again divided.

"[C]onflict becomes apparent when we attempt to determine the boundaries of legitimacy for defining goals of medicine. For some persons, the mere prolongation of biological existence is an independent good and, thus, a worthy goal of medicine. For others, such prolongation is an anathema and finds no place in the goals of medical practice."\(^{58}\)

On the one hand ‘vitalists’ believe that life at any cost is always preferable to death, and therefore, “...the prolongation of mere biological existence is considered a good and part of the goals of medicine.”\(^{59}\) And on the other hand their opponents state that, “...once it can be determined that a human being is permanently unconscious, the traditional goals of medicine can no longer be served.”\(^{60}\)

Where should the debate turn at this impasse? "How can we reconcile competing views of the value of preserving biological life as a goal of medicine?"\(^{61}\) This report proposes that the prolongation of biological life is only a goal of medicine by association — in that it must be present before others goals can be achieved. Once it is no longer possible for the other goals of medicine to be attained, it ceases to be of itself, a legitimate goal of medicine.

In a later commentary, an author of the six goals above makes a statement suggesting that the vitalists’ application of goal four (‘the saving or prolonging of life’) to the case of an iPVS patient is flawed.
“There are strong arguments against accommodating vitalists at all. Even patients who have expressed a preference for vitalism experience no satisfaction from their choice once they become permanently unconscious.”

This statement also refers indirectly to the fundamental principle in determining legitimate goals of medicine. The mention of an ‘experience’ of ‘no satisfaction’ rightly identifies that without proven, presumed or prospective benefit, the pursuance of an outcome is difficult to defend. Indeed, regardless of what one considers the worthy goals of medicine to be, a prerequisite of all of them should be some evidence or hope that the benefits will outweigh the burdens.

“The qualitative aspect of futility highlights the need to weigh and compare the expected effects and the outcome benefits that might come from medical intervention.... One of the more usual ways of determining whether a medical treatment is obligatory or optional is to consider its expected effects, benefits and burdens.”

2.2.5 Benefits and Burdens

The desire to benefit patients has been the ethos of medicine since its inception. The Hippocratic Oath states: ‘The regimen I adopt shall be for the benefit of the patients according to my ability and judgment, and not for their hurt or for any wrong.’ More recently – along with non-maleficence, autonomy and justice – beneficence has become widely recognised as one of the fundamental principles of bioethics. Indeed, accepting that the other three are benefits as well as principles in their own right, it can be said that the intention to bring benefit lies behind all of the medical profession’s endeavours.

“The central and moral objective of medicine – adhered to by doctors and health care workers since Hippocratic times – is to produce net medical benefit for the patient with as little harm as possible.”

Some commentators have epitomised this principle in the notion of ‘substantial benefit’ – “We could define [substantial benefit] as an outcome that now or in the future would be regarded by the patient as worthwhile.”

The partner in the beneficence dyad has already been mentioned: non-maleficence. The premise remains the same; benefit the patient by first doing no harm – *primum non nocere*. Harms of any nature, along with the other negative impacts of a medical intervention, constitute the *burdens* of that intervention. There is general acceptance that it is inappropriate to initiate or continue treatments when burdens exceed benefits: an evaluation that will now be applied to the nasogastric feeding of iPVS patients.

2.2.5.1 Improvement in Prognosis: Some supporters of such feeding claim that a benefit is the improvement in prognosis that it provides. “To the family, the fact that the [patient] is alive means he or
she has beaten the odds already.” They mistakenly see their loved one’s survival as an indication that prognosis is improving. To them any chance of recovery, however slim, is a benefit and should be clung to in favour of the finality that follows treatment withdrawal. “If life-sustaining treatment for PVS patients keeps them alive, and it surely does, then it improves their prognosis...so why do they judge it to be non-beneficial?”

As was discussed in 1.7 Prospects for Recovery, this belief is incorrect. The longer a patient spends in a PVS, the slimmer the chances of improvement become. When a period has passed, beyond which medical experts believe recovery is exceedingly unlikely, the patient is said to be permanently unconscious. In these situations it is the doctor’s obligation to explain that the patient’s biological tenacity is not a will to survive, nor is the mere prolongation of their unconscious existence offering them any prospect of experiencing benefit.

“The only possible benefit to them of life-sustaining treatment is the possibility that the diagnosis of irreversible unconsciousness is wrong and they will regain consciousness.”

“If one accepts the fundamental medical view that permanent unconsciousness can be diagnosed with a high degree of certainty, that permanently unconscious patients do not have the capacity to experience thoughts or feelings, pain or suffering, and that the goals of medicine can no longer be achieved in the class of patients, then certain major considerations appropriate to the care of these patients and to their moral and legal status need to be addressed.”

Supporters of this ‘benefit’ should also ask themselves what the best outcome of all this striving is. They need to be careful about promoting the ‘benefit’ of continued treatment when the best proven recoveries from iPVS to date have been minimal; resulting in an ‘improved state’ that many would regard as more burdensome than the original.

“The recovery of a limited degree of awareness may indeed be worse than non-sentience for the patient, whatever satisfaction it may bring to the carers.”

---

This report explains in detail why the concepts of benefit, burden and interests cannot be applied to the iPVS patient. However, if a patient retains or regains minimal consciousness, they are not in a vegetative state – see 1.5.5 Minimally Conscious State. It would then be possible to argue for the removal of alimentation on the grounds that burden outweighs benefit: “Already, in one Irish case, we have seen that a person who was described as being nearly in PVS has had nutrition/hydration removed with the authority of the court.” (McLean SAM. Legal and ethical aspects of the vegetative state. Journal of Clinical Pathology 1999;52:490-3) While lengthy commentary on this category of non-vegetative patients lies outside the scope of this report, it is worth noting that courts and ethicists are already recognising that minimal recovery renders a patient worse off than the vegetative state they were oblivious to. (See Coleman D. Correspondence. Neurology 2002;58:506 – in which the wife of Robert Wendland, a severely brain-injured but minimally conscious man, her lawyers, “...as well as 43 bioethicists, argued for the right to kill him by withholding nonburdensome medical treatment...”) See also 2.4.2 Patients in ‘Near PVS’ and footnote.
"[A] remote possibility of recovery must be weighed against the probability that the patient will regain consciousness only to be severely disabled. Many people would consider this possibility to be more of a burden than a benefit."73

2.2.5.2 Preservation of Biological Life: Others believe that, despite the permanence of iPVS, such a state is a benefit to the patient. To them the fact that the iPVS patient has biological life is, of itself, a benefit.

"There are those who believe that preservation of life – any sort of life – is a benefit and worth striving for. For them even maintaining the life of a patient in the persistent vegetative state (when the patient is reliably believed to be in a state of permanent unconsciousness) is a medical benefit..."74

This belief is often held all the more strongly if it is known that the patient’s prior wishes were to be kept alive in such a state: “According to this view, if the goal of the patient or the surrogate decision maker is to sustain the biological life of the patient, treatment is neither futile or non-beneficial.”75

“...I see no basis for their restricted account of benefits. Suppose that someone proposed...to include prolonging life on the list of benefits as a separate form of benefit. Or, even more plausibly, suppose that someone proposed to add to the list the satisfaction of previously expressed preferences.”76

Again, the reasoning behind these views is flawed. In the first instance, an action is not a benefit without conscious experience. That is to say: unless the possibility exists for a positive action, such as a medical treatment, to have its results experienced, it cannot be said to be a benefit.

"[T]he moral obligation of the doctor is to provide care, which entails the intention and prospect of benefit, and the mere prolongation of unconscious life is not a benefit."77

"The basis of good medical care is to benefit the patient. Medical treatment thus aims at preservation of life, relieving pain and suffering, protection against disability, and return to maximally effective functioning. If a patient is permanently unconscious, however, continued treatment cannot confer these benefits."78

Since Nancy Cruzan is incapable of deriving any physical pleasure, emotional enjoyment or intellectual satisfaction from life, the Cruzan Court failed to apply the benefits portion of the analysis when it decided biological life alone was a benefit.”79

Also, the fact that a patient proclaims in advance that prolonged survival in iPVS is going to be a benefit to him, does not make it so. It serves only to illuminate his lack of understanding about the condition; it does not change the medical or ethical reality of permanent unconsciousness.1

1 The reasons why iPVS patients cannot have interests are discussed in 2.3.5 The Best Interests Standard. ...cont. page 48.
"True [irreversible] PVS is a situation in which no medical treatment can be of substantial benefit to the patient in that there is nothing that the patient would currently or in the future regard as worthwhile."  

"Medicine cannot promote the beneficence of the benefit/burden calculus because, again, the patient cannot experience either benefits or burdens of treatment, non-treatment, or of continued existence."  

2.2.5.3 Alleviation of Discomfort: It is the alleviation of discomfort that some hold to be another benefit of ongoing nutrition and hydration. In their view, the positive outcome of nasogastric feeding is that it successfully combats thirst and starvation. Phrased alternatively, they would argue that withdrawal of feeding brings about these afflictions and therefore constitutes a burden.

"We need, however, to be honest about what we are trying to do and find more satisfactory ways of ending lives than by starvation."  

"It might also be argued that the withdrawal of food and fluids would constitute an insult to the patient (in the sense that it would condemn the patient to starvation or death by thirst) and hence be a 'burden.'"  

As was discussed in 1.10.2 Pain, Suffering and Consciousness, iPVS patients do not possess the ability to experience thirst or hunger. They have lost those areas of the brain responsible for the analysis and interpretation of such stimuli. Therefore to mention the ravages of thirst and starvation in the case of an iPVS patient is misleading; and to promote continued feeding as a beneficial protection against them is equally so.

"The…concern – that PVS patients from whom nutrition and hydration is withdrawn will suffer a slow and horrible death – is refuted by the medical facts of PVS. Because PVS patients have suffered neurological destruction in the neocortical area of the brain, they are unable to experience any pain or suffering from the withdrawal of treatment."  

"Medicine cannot minimise or relieve pain and suffering because these patients cannot experience pain and suffering."  

Unfortunately, some opponents of continued nutrition and hydration not only proclaim that such feeding is of no benefit, but that it may in fact be a burden. They argue that the imposition of invasive medical intervention against a patient’s wishes amounts to a harmful action.

"Two possible conclusions from these remarks would be directly relevant to the treatment of PVS patients:

(Footnote ‘I’ cont. from previous page.) While the arguments also explain why such a patient cannot experience benefits or burdens, regardless of his prior wishes, outlining them again in this section would involve much repetition.
(i) there are states in which a human body still shows biological life but in which the living person is no longer amongst us;

(ii) there are states in which a person may still be alive but in which the benefit from treatment is insignificant compared with the burdens imposed by that treatment.

"[Anthony] Bland's continued existence was not merely no benefit but actually a harm to him, a source of indignity, violation of his wish to be remembered well, humiliation."\(^{87}\)

This stance is contradictory. If an iPVS patient is unable to experience benefits, then he is equally unable to experience burdens. Therefore, appeals to withdraw feeding because it constitutes a burden or is an insult to dignity have no place in the case of the permanently unconscious patient: i.e. Insult to dignity requires an awareness by the one insulted that such an event took place (either at the time of or after the event.)\(^{88}\)

"It is simply not possible, based on available evidence, for the permanently unconscious patient to experience the burdens of pain and suffering as these require the integrated functioning of both the brainstem and the cerebral cortex. The provision of artificial nutrition and hydration to these patients can never be perceived by them as a burden because they remain permanently unaware."\(^{88}\)

2.2.5.4 Bringing Comfort to Friends and Family: Finally, some supporters of continued nasogastric feeding believe that the encouragement and comfort that friends and family experience is a benefit. In their view, the fact that a third party takes comfort from the continued biological life of the permanently unconscious patient counts as a justifiable gain.

"Some individuals may find personal meaning in attending to an unconscious patient."\(^{89}\)

"Feeding the PVS patient may be judged to be futile if the medically determined goal is to restore cognition, but it may nonetheless be regarded as worthwhile in terms of the emotional and symbolic benefits accruing to the patient's family or society."\(^{90}\)

Health care workers in any area should be sensitive to the needs of friends and family; those involved in the care of an iPVS patient especially so. Much of what is understood and accepted by relatives depends on effective support and communication by staff.

"Because inadequate or insensitive communication by providers probably accounts for a substantial proportion of unrealistic requests, such discussions will successfully resolve many conflicts. ... Nevertheless, even after providers make sustained attempts to clarify patients' preferences, some patients or surrogates will continue to demand life-sustaining interventions when the care givers feel deeply troubled about providing them."\(^{91}\)

\(^{86}\) See footnote 'I' on page 47.
Treatment in cases where the sole effect is the satisfaction of kin is seldom continued; and never on the temporal and fiscal scale required by iPVS patients. The goal of developing medical technology has not been to treat relatives' emotions and health professionals need not feel obligated to indulge them beyond accepted parameters. There are very few examples of iPVS in which a moral responsibility to consider the impact of benefits or burdens on a third party exists. In most cases, to do so is to lose sight of the real issue: ‘What is the net benefit to the patient?’

“Continued existence and treatment or non-treatment may be of enormous importance to the patient’s loved ones and to society, but not to the patient.”

“If life of any quality is an ultimate value, then appeals based on the physician’s standards, the tremendous cost, the probable futility, or just plain reasonableness will fall on deaf ears as it did in the case of Mr. Wanglie.” At that point an impasse had been reached, but the question remained: how much moral authority did Mr. Wanglie and his family command?

If any other than personal factors should be included in the weighing up of benefits and burdens, it is not the sentiments of family and friends; rather the needs of other patients who have been denied treatment to pay the huge costs of iPVS maintenance. “Is the allocation of resources to preserve a life of absent or probably permanently severely impaired consciousness fair or just given that this will deny those resources to all other possible claimants?”

2.2.6 Justice

Medicine has always been a scarce resource and, as public purse-strings are drawn ever tighter, is becoming more so. The demand for health care dollars is unlimited and will always exceed supply. Health professionals, economists and hospital managers weigh up the actual costs and opportunity costs of competing treatments as they seek to gain maximum net benefit for dollars spent. Consequently, rationing and prioritisation decisions must be made in order for that capital to be consumed in the most effective way possible. Medical ethicists epitomise and analyse this process within the principle of justice.

“Justice [is] the ethics of fair and equitable distributions of burdens and benefits within a community…Classically defined as ‘giving to each his due’, different theories of justice

---

86-year-old Helga Wanglie suffered a cardiac arrest that left her in a PVS and dependent on a ventilator. Her husband, citing her pro-life beliefs, withheld his consent to have treatment withdrawn: a decision the court supported.

The term ‘opportunity cost’ is used in economics to emphasise the impact of spending. The opportunity cost of a dollar spent in one area (e.g. surgery) is a dollar’s worth of whichever area was ‘next in line’ to receive funding (e.g. research.)
debate about what is ‘due’ and to whom it is due. In general, the maxims, ‘to each equally’, ‘to each according to contribution’, ‘to each according to merit’, ‘to each according to need’, compete for priority.95

This section suggests that justice provides the main moral justification for withdrawing nutrition and hydration from iPVS patients. In a public health system such as New Zealand’s, allocation of resources is largely determined according to need. That is to say, the sickest receive treatment first, regardless of their standing within, and contribution to, society.9 Distribution is only equal between groups of individuals with a similar need for treatment – ‘like are treated alike’; those with less need receive less – ‘treat unlike, unlike.’ However, need is not the only factor contributing to a group’s claim for funding. Disease prevention and health education are examples of large areas where the need is not yet evident, but the long-term benefits will be considerable. They highlight the fact that expected outcome following a particular expenditure option is an important factor influencing resource allocation. Therefore the net benefit of a treatment depends on the initial need of the patient, how much improvement in his condition the treatment can provide, and for how long.7

2.2.6.1 Quality Adjusted Life Years (QALYs): As these examples show, comparisons between individuals whose needs differ so vastly are not simple. Health economists have invented the QALY in an attempt to find a rational basis for resource allocation.

“The essence of a QALY is that it takes a year of healthy life expectancy to be worth 1, but regards a year of unhealthy life expectancy to be worth < 1. Its precise value is lower the worse the quality of life of the unhealthy person. If a patient is likely to live for 8 years in perfect health after one form of treatment, he gains 8 QALYs; if another treatment would give him 16 years but at a quality of life that is rated by him at only 25% of the maximum, he would gain only 4 QALYs. The dream of health economists is to buy the most QALYs for a given budget…”96

Cynics may doubt whether the dreams of economists and ethicists coincide very often. Indeed, in the allocation of medical resources there are some major insufficiencies of QALY analysis. Firstly, while they allow individuals to compare their own QALY judgments of various treatment outcomes, they do not solve the difficulty of comparing judgments between individuals. The value that one patient places

---

9 The most obvious example of this is seen in surgical waiting-lists, where priority of operations descend a step-wise gradient - Emergency, Urgent, Semi-urgent, and Elective.

9 While a terminally ill cancer patient may have enormous need, the relief that chemotherapy can achieve may be negligible and transient. Conversely, while a simple operation may provide the patient complaining of bunions with a lifetime cure, the initial condition is minimally debilitating.
on a particular state of ill health will be different to another. Secondly, QALYs can be unfairly discriminatory:

"Those with mental or physical handicaps will have less claim on resources because their handicap means that each year of their life is given < 1. And, in general, the old do badly because palliative intervention is likely to result in fewer QALYs because their life expectancy is less."

Thirdly, the system neither outlines who the decision-makers should be, nor makes their job any easier. Doctors, patients and politicians may all have different views on treatments with similar QALY values.

2.2.6.2 Is it Fair to Distribute Resources to iPVS Patients? Despite its deficiencies, QALY analysis correctly focuses attention on the question: 'What exactly, in terms of calculable benefit, are we trying to achieve when we undertake treatment X for patient Y?' In the case of continued nasogastric feeding for the permanently unconscious patient, it is difficult to defend an answer. The last section 2.2.5 Benefits and Burdens discounted all claims that iPVS patients can be benefited - a consideration that makes it impossible to justify continued feeding at the expense of real benefit to other sentient patients.

"The principle of distributive justice requires that scarce resources be utilised by those who will benefit most from them. ... Once a patient is reliably diagnosed to be permanently unconscious, the principle of distributive justice allows the withdrawal of treatment because the probability for benefit to the patient is very low while the costs of securing the benefit are very high."

"Given that there are limited resources available for medical care, is it right to devote money to sustaining the lives of those who are, and always will be, unaware of their own existence rather than to treating those who, in a real sense, can be benefited..." There are those who feel that limited resources should not lessen society's obligation to feed the permanently unconscious. One commentator states: "It is gruesome to envision a day when feedings are withdrawn based on financial considerations." "It is encouraging that for Tony Bland a decision regarding omission of treatment in the persistent vegetative state was made on the basis of his best interests rather than for financial reasons."

Others believe that, while worthy of consideration, the allocation of resources is an economic issue rather than an ethical one.

"It is difficult to imagine, however, that anyone would think that cost is irrelevant. If the Wanglies had had to pay for her care out of wholly private funds or the hospital had known that it would not be paid, then economic factors would much more likely have been thought to be relevant by the parties. The Wanglie case would then not be seen as a so-called pure ethics
case, as some commentators have called it. In fact, it is not a 'pure ethics' case at all. The economic factors were relevant because the fact that they were not contested may have reinforced the family’s demands.\textsuperscript{102}

To the contrary, justice is not a theory that ‘tarnishes’ a paradigm of pure medical ethics. Rather, it is fast becoming the most important ethical principle to be considered in such cases. By definition, no amount of economic juggling can provide unlimited medical treatment for all. Subsequently, fiscal issues become moral ones. It may be that “...a physician risks legal sanction if she denies available treatment to a patient on the grounds of cost containment.”\textsuperscript{103} If so, all the more reason for health professionals, ethicists, lawyers and economists to busy themselves with the tasks of rationing and prioritisation mentioned earlier. So low is the priority of treatment for an iPVS patient, justice demands that those resources be employed elsewhere. For, as Gillett states, “...when it comes to conflicts of interests, mere biological organisms must lose out to persons every time.”\textsuperscript{104} Society’s failure to accept this will result in failure to exercise its duty of distributive justice.

“Any efficient health care system will require limits on treatments, and if we cannot agree about the nontreatment of permanently unconscious patients, there is little hope of agreeing to any boundaries at all.”\textsuperscript{105}

“The resources that our society allocates to health care must promote the legitimate goals of medicine. Continued treatment of permanently unconscious patients merely sustains biological life, a goal that our overburdened health care system can no longer rationally pursue. Our finite human and financial medical resources would be more wisely directed toward preserving health and treating patients who will benefit from therapy.”\textsuperscript{106}

2.3 Autonomy and Surrogate Decision-Making

The last section proposed that continued nasogastric feeding of iPVS patients fails to promote the legitimate goals of medicine or provide any worthwhile benefit. It also violates the ethical principle of justice. These findings provide sufficient justification for the cessation of treatment, regardless of the past and present preferences of patient or family. However, much published discussion regarding iPVS patients has been devoted to ascertaining how the decision to continue or withdraw feeding can be formulated from such preferences. In ethical and legal commentary alike, great importance has been placed on: the prior wishes of the patient concerned; the treatment decisions that his surrogates feel he would have made, and; the option that serves his best interests. This section concentrates on these issues of autonomy and surrogate decision-making and their applicability in the case of the iPVS patient.
2.3.1 Autonomy

While justice is arguably the most important consideration in ‘community’ ethics, autonomy is undoubtedly the fundamental principle in ‘individual’ ethics. An acceptable definition is, “...the moral right to choose and follow one’s own plan of life and action.” In short, autonomy is the right to self-governance. One is at liberty to make any and all decisions concerning one’s destiny, provided the consequences of those decisions do not adversely affect another. Medical care is no exception and, consequently, the principle is evident in all treatment decisions: “The question of the patient’s wishes must always be given paramount consideration.” The process of informed consent epitomises the patient’s right to make an educated choice regarding the delivery of their care. Beauchamp and Childress identify a number of factors that must be present in order to satisfy grounds for informed consent: Competence; Voluntariness; Disclosure (of material information); Recommendation (of a plan); Understanding; Decision, and; Authorisation (of the chosen plan). Clearly, not all of these can be satisfied all of the time.

“In practice, however, many forces obstruct and limit the expression and appreciation of patient preferences. These forces – such as the compromised competence of the patient, disparity between practitioner’s knowledge and that of the patient, the psychodynamics of the patient-physician relationship, the stress of illness – often make difficult the realisation of respect for the autonomy of the patient.”

2.3.2 Implied Consent in the Case of an Incapacitated Patient finds that an iPVS patient cannot give legally effective consent. Obviously such a patient cannot give ethically effective consent either. Complete nonsentience makes the exercising of autonomy impossible.

“[A]utonomy, self-determination, and the constitutional right to privacy are simply meaningless for a patient in this condition. Important social goals may be served, however, by showing respect and care for the body of a patient who is permanently unconscious, as well as respect for the previously stated wishes of the patient. But the patient cannot in any way experience, enjoy, or effectuate the rights or benefits of autonomy or privacy.”

Ethicists have overcome the obstacle by developing several methods of surrogate decision making that enable appropriate treatment choices to be made on an incompetent patient’s behalf. They involve a chosen surrogate first considering a host of variables: from the prior expressed wishes of the patient, to

---

the severity of their disability, to the prospect of there being any benefit from treatment. Then, on the strength of these, deciding the best course of action for the patient.

“Surrogate decision makers are required to follow certain guidelines and standards when making treatment decisions for an incompetent patient. Depending on the amount of information available, the substantive standards applied to surrogate decision making are the subjective standard, the substituted judgment standard, and the best interests standard. These standards limit the authority of the surrogate and ensure that the appropriate decision is made.”112

2.3.2 The Subjective Standard

The subjective standard focuses on the stated wishes of a patient before they became incompetent. The surrogate’s task is to uncover evidence that a patient has made a prior decision regarding medical care options, and then act accordingly. Thus the subjective standard embodies the principle of prospective autonomy – self-governance in advance.

“The subjective standard requires clear and convincing evidence of the patient’s treatment preferences. ... [United States] Courts generally require evidence of a patient’s advance directive to satisfy the standard, although more lenient courts may allow oral standards to satisfy the requirement. This standard is the ideal approach for surrogate decision-making because it allows the surrogate to do precisely what the patient would have done. However, its application is difficult because it requires foresight that many individuals do not possess or choose not to exercise.”115

The lack of public interest in advanced directives, along with other practical problems, is discussed in 3.4.3 Practical Difficulties Associated with Advanced Directives. In 1993 the American Neurological Association suggested that doctors “...urge their patients to consider their own values and to clarify, as much as possible, their preferred viewpoints in advance directives.”114 Within the Commonwealth also, neither written nor verbal advance directives have been common enough to assist in making iPVS patient decisions.

“Some people make it clear in advance that, if they should fall into a state which seems to them in anticipation to be intolerable, they do not want life-sustaining treatment to be continued. The right of self-determination entails that such wishes should be respected. ... But Anthony Bland expressed none at all. There is nothing to show that in the course of his short life he gave the matter any thought. All that his family can say is that from their knowledge of him and his general attitude to life, the things that interested him and gave him pleasure, he would not have wanted to survive in his present state.”115
This excerpt from the *Bland* Court of Appeal judgment is referring to the use of the *substituted judgment standard*, an approach based on similar reasoning to the subjective standard. It involves the surrogate endeavouring to exercise the patient’s autonomy on his behalf by making the same treatment decision that he would have made. Because of their similarities, the ethical insufficiencies of the two approaches will be discussed together in 2.3.4 *The Problem with Prospective Autonomy*.

2.3.3 The Substituted Judgment Standard

The substituted judgment standard can be described as ‘prospective autonomy by proxy’. The surrogate decision-maker strives to gain an understanding of the patient’s prior wishes based on the comments, attitudes and decisions they exhibited before their state of incompetence commenced. Then, armed with this knowledge, she attempts to choose the treatment option that the patient would have chosen. The difference between it and the subjective standard is that the surrogate must do so without the luxury of a clear statement outlining the patient’s preferences.

“[The substituted judgment standard requires the surrogate to make the decision that the patient would have made under the same circumstances, ideally by relying on subjective expressions make by the patient before becoming incompetent. However, surrogates must often rely on an objective evaluation in making a decision because inadequate evidence exists to determine what the patient would have wanted.]{16}

There are a number of practical problems that accompany such an attempt by the surrogate to ‘fill in the gaps’. As Schrode implies above, the subjectivity is often lost and it can become very difficult to establish how much of a decision was the patient’s and how much was the proxy’s. Furthermore, there is always a danger that the surrogate will be tempted to make decisions based on an ulterior motive.

“Surrogates who are the patient’s next of kin are especially susceptible to conflicts between often contradictory financial or personal motives and the patient’s interests.”{117}

2.3.4 The Problem with Prospective Autonomy

Practical difficulties aside, the concept of prospective autonomy appears an attractive solution to a clinical conundrum. However, there are a number of ethical problems associated with the application of the subjective and substituted judgment standards to the case of the iPVS patient. Firstly, prospective autonomy can exist only if the incompetent person has a chance of later regaining (at least some of) their competence, thereby becoming aware of the outcome of their decision. Any autonomy, prospective or otherwise, is meaningless in the absence of consciousness. {1 The prior wishes of an iPVS patient cannot

---

1 See 2.3.1 Autonomy
be equated to those of a patient under anaesthetic who has a good chance of regaining consciousness (and with it an awareness of the outcome that resulted from their requests being followed).

Secondly, it is not clear that a moral obligation exists to honour the prior wishes of someone whose situation has changed so drastically since those wishes were expressed. Once a patient has entered an iPVS the benefits of ongoing treatment, that no doubt prompted him to issue advanced instructions, no longer exist for him.

"[C]ommentators argue that both the subjective and substituted judgment approaches are flawed because they ignore the welfare of the patient in his current state. According to these critics, the current interests of the permanently unconscious patient are not served by treating the individual in accordance with preferences held at a time when the patient was competent and in possession of previous interests and values. They suggest that the patient’s previous interests and values are invalid because his situation has changed so dramatically."\(^{118}\)

Thirdly, continued treatment of an iPVS patient was found to be illegitimate, non-beneficial and in breach of the principle of justice. That they stated a preference for such treatment in advance does not alter those findings.

2.3.5 The Best Interests Standard

In the absence of any pre-nominated proxy or knowledge of a person’s prior wishes, courts and ethicists have sought to make decisions based on a patient’s best interests. "The primary basis for medical treatment of patients is the prospect that each individual’s interests...will be promoted."\(^{119}\) The application of the best interests standard when decision-making on a patient’s behalf does as its name suggests. Health professionals and/or legal representatives and/or family members take into account all the clinical and social variables and then attempt to make the treatment choice that will best serve that patient’s interests.

"[I]f there is no indication of the actual wishes of the patient, the surrogate must try to make a choice for the patient that seeks to implement what is in her best interests by reference to more objective, societally shared criteria."\(^{120}\)

One of the most common examples in clinical practice is a parent consenting for their child. In paediatric wards around the world guardians are required to make treatment decisions that they (usually after consulting with clinicians) deem to be in the best interests of their charges. Likewise family (with or without legal power-of-attorney) add their consent to that given (or withheld) by the demented or infirm.
2.3.5.1 The Best Interests of an iPVS Patient: Inevitably, best interests doctrine has also been applied to the iPVS patient as surrogates attempt to justify treatment withdrawal. That application has been confusing at best. The following statements from the *Bland* judgment epitomise the contradictory reasoning that must be invoked if ‘best interests’ is to form the basis for cessation of nasogastric feeding.

“In circumstances such as these, it may be difficult to say that it is in his best interests that the treatment should be ended. But if the question is asked, as in my opinion it should be, whether it is in his best interests that treatment which has the effect of artificially prolonging his life should be continued, that question can sensibly be answered to the effect that his best interests no longer require that it should be.”

“So that the decision shall thus not be made by default it is necessary that someone other than Anthony Bland should consider whether in his own best interests his life should now be brought to an end...”

McLean rightly points out the ‘ethical and legal sophistry’ that took place in applying the best interests principle (and others) to the permanently vegetative Anthony Bland. However, in highlighting the irony of attributing ‘best’ interests to the insensate, she implies no less of a riddle: “By the nature of the diagnosis, such a person has no interests whatsoever (or at least no contemporaneous interests), far less any ‘best’ interests.” She seems to be inferring that the person may have interests... but none that apply to him at present.

It is difficult to follow the logic. If the iPVS patient’s interests are not contemporaneous, then either he had them or he is going to have them. If he had them (prior to entering iPVS) then we are to presume that he has them no longer, having held them not to be contemporaneous. Certainly it is difficult to see the relevance of an expired interest. If, on the other hand, he is going to have interests then we are to presume that he will experience some change to bring about this acquisition. Likewise it is difficult to envisage any such change in an iPVS patient’s condition.

2.3.5.2 Can an iPVS Patient Have Interests? This report suggests that to focus on what the interests of an iPVS patient are, and who should decide them, is to miss the point. Instead the question should be asked: ‘Can the permanently unconscious have interests?’ Most commentators in the field believe not – that it is contradictory to identify the cares, thoughts or feelings of one who can never again care, think or feel.

“Medicine cannot promote the best interests of these patients because these patients have no interests in further treatment or discontinuation of treatment, or in continued existence at all.”
"It is argued for the respondents, supported by the amicus curiae, that his best interests favour discontinuance. I feel some doubt about this way of putting the matter. ... It is, however, perhaps permissible to say that to an individual with no cognitive capacity whatever, and no prospect of ever recovering such capacity in this world, it must be a matter of complete indifference whether he lives or dies."125

While support of this view is widespread, its opponents believe that iPVS patients can have interests ascribed to them. In their view the permanent loss of one’s consciousness does not necessarily result in the loss of all one’s interests.

"The fact that Bland could indeed have been subjected to indignities, e.g. by being treated as a sex object or thrown, living, into the hospital rubbish, confirms that he remained a person, with some interests, and could be harmed or benefited."126

It is not self-evident or explained how ‘being treated as a sex object’ confirms that one remains a person; or how, having been thrown into the rubbish, it directly follows that one must have interests. Indeed, neither is it accepted that the iPVS patient can be subjected to indignities: for indignity, by its very nature, requires knowledge and understanding that one is being thus violated." Those close to the iPVS patient may view the ongoing treatment as burdensome and undignified, but such feelings are not possible for the patient himself.

2.3.5.3 A Wider Definition of Interests: Fenwick is among others who believe that a wider definition of interests would take these familial and other social interests into account.

"Medicalisation admits only a narrow conception of ‘interests’. A broader perspective, seeking ‘best interests’ in totality, might view medical best interests as just one segment, others perhaps comprising: ‘personal’ interests, incorporating non-medical aspects such as religious belief; ‘familial’ interests, admitting views of those emotionally closest to the patient; and even ‘societal’ interests, considering a decision’s effect upon society or other, similarly placed patients, potentially including the issue of resource allocation.’"127

Undoubtedly the non-individualistic interests are contentious but, before rejecting them out of hand, it should be borne in mind that they may already play an unofficial role in PVS decisions.128

This report does reject them: not out of hand; rather out of much discussion; recognising that it is important to avoid situations where “...the interests being served are at best speculative and at worst actually the interests of others.”128 However, Fenwick raises a much more contentious point later in her

---

* See also 2.2.5.3 Alleviation of Discomfort.

† Familial interests – see 2.2.5 Benefits and Burdens; Societal interests – see 2.2.6 Justice; Religious belief is considered on the following page.
article when she suggests that "...[i]nterests deriving from [a PVS patient’s] previous personality are surely still attributable to him, and potentially relevant."129

2.3.5.4 Ascribing Mental States to the iPVS Patient: Serafini argues that it is not contradictory to ascribe a mental state to the comatose.130 He takes issue with Gillett’s assertion that iPVS patients have lost the capacity for conscious mental life.131 He gives examples of mental-state descriptions and then applies them to a comatose person – Smith.

A. Smith is thinking about his girlfriend
B. Smith believes in God.

He concedes that the process in A. cannot be ascribed to the comatose Smith as it requires current and on-going thought. However he argues that the generic state in B. can be ascribed to the comatose Smith as it does not require Smith’s current or on-going thought – "He need only have expressed this view once, and never retracted it."132 He proceeds to relay a personal experience whereby an ill family member was admitted to hospital in a deep coma (from which she never recovered consciousness). He regarded the present-tense language used by the attending physicians during her coma as confirmation that she was being ascribed real mental states – e.g. ‘Does she have strong religious beliefs?’

The fact that many of us have participated in ascribing mental states to the comatose does not make doing so any less metaphysically incorrect. In response to Serafini, Gillett points out that we are even in the habit of ascribing interests to the dead:

“We normally ascribe self regarding interests in, say, the disposal of one’s property or the use to be made of one’s private effects, to the dead or brain dead for reasons that are hard to define. I suspect that two elements are in play: (1) we wish to respect their memory in a way incompatible with disregarding their final wishes; and (2) we regard a person’s life as an autobiography which is sometimes not brought to a fitting end until after its effects have been finalised.”133

He continues to consider the case of the ill family member in coma:

“On admission of a young person in deep coma due to cerebral haemorrhage, there is uncertainty about prognosis and this warrants straightforward talk about present abiding ‘mental states’ (such as beliefs, wishes etc.). At this point we are open to the possibility that the life now suspended will be resumed as it would be after sleep... As the situation declares itself and it is clear that we are dealing with either an irreversible coma or brain death our language shifts to take account of the impropriety of present tense mental ascriptions.”134
2.3.5.5 Honouring Prior Wishes: What of an individual’s interest in having a previously expressed wish honoured? Brody comments that whether or not continued treatment is in an iPVS patient’s best interests will depend on what their prior preferences were.

“If a PVS patient had wanted, while still conscious, to be kept alive even if as a PVS patient, then keeping patients alive when they are in that state does satisfy their most recent preferences and is in their best interest according to the subjective preference satisfaction approach.”

He addresses and discounts three possible responses to this statement:

1. Only experienced satisfactions count. “Why should we disregard that preference because they would have no belief about its satisfaction if that fact didn’t stop them from having the preference?”

2. Previously expressed preferences count for very little because the person who expressed them no longer exists even if that person’s body has not died. “…only works if one accepts their view about personal identity…”

3. Preferences to be kept alive as a PVS patient are so unusual and pathological that they do not count. “If one disagrees with their argument, it is because of one’s disagreement with their fundamental metaphysical premises about the inherent goodness of mere biological existence, not because one sees their reasoning as fallacious.”

2.3.5.6 Acknowledging Religious Beliefs: In fact all three of Brody’s objections are founded on the fact that there is a minority whose fundamental metaphysical beliefs differ to those held by others.

“[A] deeply rooted belief in the sanctity of life, a belief in the God-given sacredness of human life…is a view shared by members of a variety of religions, including Orthodox Judaism, fundamentalists: Protestants and conservative Catholics. In the Orthodox Jewish faith, there is a religious obligation to seek out and accept life-prolonging treatment. The principle of respect for persons requires that physicians take such beliefs and choices seriously.”

Certainly it is of the utmost importance that patients and their families feel heard and respected in clinical situations. Any practitioner who believes otherwise will soon find himself at odds with his colleagues and reprimanded by his institution. As one commentator warns, “…physicians must be careful not to project their own culturally biased assessments on patients of different backgrounds…”

However to allow iPVS patient families to demand indefinite treatment in the name of cultural compulsion is surely a case of ‘letting the tail wag the dog’. No matter how overwhelming the medical evidence and ethical arguments and how reasonable the compromise, there will be those who continue to promote this ‘interest’ of the iPVS patient and request unlimited resources. While society should never seek to silence the extreme views of a minority, it should neither feel obliged to fund them.
People are always entitled to an unorthodox belief, but they should not be entitled to demand financial support from the public purse.

“Tolerance for the values of vitalists, however, requires that they be permitted to seek - but not entitled to demand – life at all costs. ... Vitalists should be free to seek life-extension at their own expense. Vitalism should be a purely personal and private matter that is not supported by public funds. ... If private rather than public funds are used, it is easier to respect the preferences of a passionate minority.”

### 2.4 Further Criticism of Treatment Withdrawal

There is additional opposition from those who feel that (whether or not an irreversible unconscious state is to be valued) withdrawal of feeding marks the beginning of a threatening advance in end-of-life decision-making. They believe that such withdrawal from iPVS patients will ultimately have serious consequences for the severely disabled and the infirm. Their objections can be broadly divided into: those who believe that withdrawing nutrition and hydration from an iPVS patient is discriminating against the disabled by making a value judgement based on someone’s quality of life, and; those who instead/also believe that such a withdrawal amounts to euthanasia.

#### 2.4.1 Discrimination Based on Quality of Life

Some commentators feel that the recent rulings and recommendations by courts and medical bodies concerning iPVS patients have sinister overtones with regard to other disabled groups. They feel that justifications based on lack of personhood, futility and justice, are no more than smoke-screens for a decision that this group of individuals represent a low quality of life believed not to measure up to an acceptable level.

“Some defenders of the proposal might employ the term ‘futile’ in the new and sinister sense assigned it by writers who call a treatment futile if it is efficacious in the ordinary sense but sustains a life that falls below some inchoate standard of ‘quality of life’ fancied by these writers. ... The question, ‘Is this patient worth saving?’ is not one known to medicine (except in occasional bizarre episodes of derangement such as German medicine’s shameful performance during the Third Reich.)”

“Millions of disabled people will probably disagree, and the implication of clinical advantage – if based on recovery – must be of concern to those with multiple sclerosis, stroke, Huntington’s disease, cancer, rheumatoid arthritis, and so on.”
Irresponsible statements from experienced clinicians indulging in exaggeration. To compare the considered withdrawal of feeding from an iPVS patient to the atrocities performed by Nazi doctors is repugnant. It is also unnecessarily emotive. The question is not ‘Is this patient worth saving?’ – rather, ‘Is the patient’s condition worth treating?’ Surgeons must often face carcinomas that are too advanced to operate on, just as physicians must decide that lungs are too damaged for assisted ventilation. The result is not a judgement that a life has ceased to be of worth, but in the Vatican’s words, “...a wish to avoid the application of a medical procedure disproportionate to the results that can be expected.”

It is almost as distasteful to suggest that decisions reached about the futility of rehabilitation efforts for the permanently unconscious may have ominous implications for citizens with multiple sclerosis and rheumatoid arthritis. Pain control, limiting deterioration and other palliative cares are all recognised as valuable goals of medical rehabilitation. While they have been recognised as offering no benefit to the insensate, to imply that the next advancement is to withdraw their provision from other groups of conscious patients is misleading and inflammatory. Happily, the same general objection has been voiced by others in a more rational manner: “Critics argue that assessing quality of life is merely a euphemism for judging that certain individuals are of no value to society and should therefore be allowed to die.”

2.4.1.1 Quality of Life: Quality of life is difficult to define.” Subsequently many commentators are uncomfortable with an arrangement in which one group of society defines quality for another, because “...[w]hatever our opinion of someone else’s quality of life, if that person disagrees then we must be wrong.” The controversy is further stirred by there being two ways in which ‘quality of life’ has been conceptualised.

“There are, however, two different uses of the phrase ‘quality of life’. One use of the phrase signifies the individual’s value to society or to others. Generally, courts and ethicists agree that such utilitarian judgments are unethical and should not be used to determine whether or not to continue life-sustaining treatment. A second type of quality of life determination focuses on the worth of the patient’s life to himself as an individual, rather than his worth to society as a whole.”

It is the latter that is being applied to the iPVS patient when it is suggested that his complete and irreversible loss of appreciation denies him any quality of life. However, some believe that even the individual-focused usage does the unconscious a disservice. “Is life-sustaining care ‘futile’ for those patients who might maintain PVS to be a satisfactory quality of life?”

---

*See 2.2.6.1 Quality Adjusted Life Years.*
"An extreme point of view could be that patients in the persistent vegetative state have a good quality of life, since they are fed, watered, warm, safe and without worries."\textsuperscript{146}

Such a statement represents the misunderstanding of a small minority. For indeed, to experience quality, one must first be capable of experience. As the loss of consciousness and cognition precludes experience the permanently insensate can have no quality of life. A judgment is not being made that an iPVS patient’s quality of life is good or bad. Rather that he is completely oblivious to the ‘goodness’ or ‘badness’ of anything and therefore the concept is one that cannot be applied to him. \textbf{We have not decreed that he is worthless to society; instead we have recognised that society is worthless to him.}

\section*{2.4.1.2 Discrimination Against the Disabled:}

It has been suggested that such decisions regarding iPVS patients discriminate against a disabled group and threaten to influence the treatment of others – "...we have found a convenient method of shortening the life of a disabled person."\textsuperscript{147} This is deceptive for two reasons. Firstly, it is somewhat of an understatement to refer to the permanently unconscious patient as disabled. They are not simply blind, paralysed or disorientated. Nor are they ‘gallantly soldiering on’ in the face of handicap. Indeed, to list the extent of their infirmity would be a lengthy exercise for they have lost anything and everything that makes human life unique.

"Medical cannot minimise disability because disability is maximal. Permanently unconscious patients are not weak, disabled, disadvantaged, handicapped, or helpless any more than someone who is dead."\textsuperscript{148}

"Persistent vegetative state is not merely an advanced stage of dementia; it is amentia, an absence of everything for which people value existence."\textsuperscript{149}

Secondly, the iPVS patient is in a unique and distinct category. Precedents pertaining to them cannot be stretched or diluted to apply to others unless the initial premise is ignored – \textit{that the patient has irreversibly lost all capacity for consciousness and cognition}.

"Persistent vegetative state is not a vague concept; indeed, it could be expanded slightly to read ‘permanent cessation of consciousness and feeling’ ... but would not affect the merely unhappy, confused or disoriented."\textsuperscript{150}

"Such patients are distinguishable from the dead, the terminally ill, and from patients with serious neurological impairments, for example those who are seriously demented, but retain some degree of consciousness."\textsuperscript{151}

"Does the decision in the Bland case have adverse implications for disabled people?" No more than for anyone else who is unfortunate enough to become permanently unconscious..."\textsuperscript{152}
2.4.2 Patients in 'Near-PVS'

One of the Lords in the Bland ruling predicted that courts would eventually be faced with cases requesting treatment withdrawal from patients with severe cognitive impairment, but not so as to be in a vegetative state. Indeed this has come to pass, with precedents already in England, Ireland, the United States and here in New Zealand allowing such withdrawal. Although the facts differ somewhat between cases, they are similar in that the patients did not meet criteria for iPVS. The question that the courts have asked is:

"Do the principles of sanctity of life, self-determination and the patient's best interests, which formed the foundation for the Bland decision, apply equally to other cases of withholding treatment?"

Certainly. In fact, those principles apply better to cases of minimally conscious state (MCS) than they do to iPVS. Throughout, this report has maintained that the doctrines of autonomy, benefit vs. burden, best interests, etc. are poorly suited to cases of complete and irreversible unconsciousness. Indeed, the ethical and legal attempts to do so (including Bland) have, at times, been nothing short of imaginative. That same creativity does not have to take place in applying the principles to an MCS.

---

8 Frenchay Healthcare NHS Trust v S [1994] 2 All ER 403 (CA): The Court of Appeal granted the hospital's urgent application that it was not in the best interests of Mr S (with very limited cognitive function) to have his gastrostomy tube surgically reinserted.

In the Matter of a Ward of Court [1995] 2 ILRM 401 (SC): The Irish Supreme Court applied the best interest test to a patient who had been spastic, bed-ridden, incontinent and non-communicative with little purposeful movement for 20 years. The court found that it was not in her best interests for treatment to continue and therefore declared withdrawal lawful.

Re G [1996] NZFLR 362: Fraser J also applied the best interest test, giving six reasons for his decision that withdrawal of treatment was lawful: 1. Even though Mr G was not quite PVS the differences were slight; 2. The four senior clinicians who had examined him were unanimous in their belief that there was no prospect of meaningful improvement and withdrawal of treatment would be good medical practice; 3. The Otago Ethics Committee had no objections; 4. The application was fully supported by Mr G's wife and 3 adult children; 5. Although there was no advance directive, all anecdotal evidence from loved ones suggested that Mr G would choose to discontinue treatment if he had the capacity to do so; 6. There was agreement that such withdrawal would bring about his death without pain or suffering. (Peart N, Gillett G. Re G: A Life Worth Living? Journal of Law and Medicine 1998;5(3):239-51) See also 2.2.5.1 Improvement in Prognosis and footnote.

9 The medical community has recently moved to formally recognise this group of minimally conscious state (MCS) persons. See 1.5.5 Minimally Conscious State.

2 The judiciary would reply that their 'resourcefulness' is necessary to allow treatment withdrawal within the existing legal framework. This is examined in Section 3: The Legal Issues, which finishes with recommendations including the recognition in statute of iPVS patients as a unique category of individuals. Such an enactment would hopefully remove the need to perform sleight-of-hand with the existing legal and ethical principles that still apply to conscious persons (including the Minimally Conscious State).
patient. At least it can be said of him: 'It is possible he is aware of this state that he would never have chosen to stay in.' (Autonomy), or: 'There is a slim chance that he can perceive the indignity of his state or the burden of his treatment...' (Best Interests/Benefit vs. Burden).

The 'near-PVS' rulings have outraged some (especially those who work with the disabled) who see them as the start of a 'slippery slope' and proof that the fears of discrimination outlined above will be realised.

"It does not take a trained physician to see that the criteria for diagnosing MCS are vague and overbroad. 'Intelligible verbalisation' is one of them. ...[A] broader application to people with dementia and labels of mental retardation is already being contemplated. The clearest aspect of these criteria is that it is very easy to be diagnosed with MCS and very difficult to graduate from it. ... It appears that [he] and others... feel that physicians should determine who is a 'person' entitled to basic constitutional rights... MCS is not a diagnosis; it is a value judgement."155

Discussing the medical, ethical and legal issues of the MCS lies outside the scope and aims of this report. Indeed, a detailed discussion would require its own thesis. Suffice to say that it will likely prove even more controversial than iPVS; as predicted by the Bland Lords and the workgroup who advanced the MCS criteria.

"There was agreement that these patients, formerly referred to as 'minimally responsive'... were often misdiagnosed with vegetative state. ... We did not intend or attempt to draw conclusions about treatment discontinuation or the myriad of related ethical issues. ... We agree... that consciousness is 'intrinsically unknowable'; however, even arbitrary boundaries are required to ensure that researchers can consistently identify a particular clinical population. ... Health professionals clearly have no special claim on ethical value judgements that relate to individuals with severe disorders of consciousness. We hope that by clarifying these disorders, clinicians and the public will be better equipped to engage in a more informed debate."156

That debate is welcome and courts and ethical bodies will surely become familiar with MCS. This report believes they will be able to more appropriately apply the fundamental principles of bioethics than they have done to iPVS cases. In doing so, they will likely often come to the same conclusions as Lynch J in In the matter of a Ward of Court:

155 The dissenting Egan J in In the Matter of a Ward of Court felt that, given the presence of some cognition, an arbitrary line was being drawn: "If slightly more cognitive function existed, would a right to withdraw sustenance still be claimed to be permissible?" [1995] 2 ILRM 401 at 437 (in Peart N, Gillett G. Re G: A Life Worth Living? Journal of Law and Medicine 1998;5(3):239-31)
"[I]f such minimal cognition as she has includes an inkling of her catastrophic condition, then I am satisfied that that would be a terrible torment to her and her situation would be worse than if she were fully PVS.\textsuperscript{[137]}

The discussion and recommendations in this report apply only to patients in true PVS. It presumes that careful diagnosis has already taken place and all differentials have been excluded.\textsuperscript{bb}

Once someone regains awareness, to any degree, they cease to be in PVS – they need not meet any functional standard in order to be found non-vegetative.

2.4.3 Is Withdrawing Treatment from iPVS Patients Euthanasia?\textsuperscript{cc}

Another criticism of decisions to withdraw nutrition and hydration from iPVS patients is that it amounts to passive, non-voluntary euthanasia. While literally meaning ‘gentle, painless death’\textsuperscript{[158]} euthanasia has come to mean the putting to death of another person in this way – "%now more commonly used to refer to the killing of the terminally ill or of patients in unbearable pain."\textsuperscript{[159]} When the polarising debate flares up in the media, as it inevitably does every year or so, it is almost always in regard to active, voluntary euthanasia. To some it is inconsistent and unacceptable that society should allow intervention to bring about the death of an unconsenting patient while outlawing any intervention to assist the death of a consenting one.

"Those who view the termination of artificial nutrition and hydration as euthanasia argue that withholding food and fluids from a stable PVS patient constitutes starving the patient to death. They emphasise that if nutrition and hydration were continued, the patient could continue to live for quite some time."\textsuperscript{[160]}

"This is intentional killing by omission, which, as the official solicitor in the [Bland] case argued, is murder."\textsuperscript{[161]}

"When voluntary euthanasia is accepted as a legal method of medical care, starvation is highly unlikely to be an accepted way of assisting the death of the patient. Why then should we choose this method for involuntary euthanasia?"\textsuperscript{[162]}

The following discussion explains why the withdrawal of nasogastric feeding from an iPVS patient is not the same as euthanasia.

\textsuperscript{bb} It also assumes that the requisite period for irreversibility has elapsed before the patient is labelled iPVS and treatment withdrawal initiated - see 1.7.5 Prognostic Guidelines.

\textsuperscript{cc} A full discussion of euthanasia is found in: Gillett G, Bloore S, Ngata P. A New Zealand Medical Association Report on Euthanasia. September 1996. Prepared by The Bioethics Centre, University of Otago; copies are available through NZMA, 26 The Terrace, PO Box 156, Wellington, NZ.
2.4.3.1 Passive Euthanasia: Firstly, the concept of 'passive euthanasia' in a clinical setting is misleading. The authors of *A New Zealand Medical Association Report on Euthanasia* were not comfortable with the phrase because it implies that the same thing is being done in a passive manner, and for the same reasons, as would be done actively.

“It is this unavoidable connotation that allows advocates of active euthanasia to use the argument that one type of euthanasia is already in use, and that to legalise the active kind is to take a relatively small step. Doctors and nurses, however, see a great difference between an intervention to end life now (e.g. giving a lethal injection) and an intervention to withdraw futile (and often expensive) treatment.”

The report went on to encourage the use of phrases such as 'withdrawing futile treatment' or 'informed treatment refusal' as the authors felt that these more accurately reflected the spirit in which such decisions are made. In practice, 'passive euthanasia' is no more than patients exercising their right to refuse treatment, or clinicians exercising their duty to administer only that treatment which is deemed efficacious. In the case of iPVS patients it is the latter that is invoked, as they cannot affect their right to refuse ongoing care.

Notwithstanding these comments on passive euthanasia, there is a danger of inconsistency in attaching too much significance to the distinction between acts and omissions. Indeed, it is possible to invent a set of circumstances in which true euthanasia could be carried out in a passive manner. In holding that withdrawal of nutrition from an iPVS patient was not euthanasia because there was no *actus reas* (guilty act), the Lords in their *Bland* judgments also felt that they were drawing a fine line.

“How can it be lawful to allow a patient to die slowly, though painlessly, over a period of weeks from lack of food but unlawful to produce his immediate death by a lethal injection, thereby saving his family from yet another ordeal to add to the tragedy that has already struck them? I find it difficult: to find a moral answer to that question.”

2.4.3.2 The Mode of Death: Difficulty finding a moral answer is to be expected because in the case of an iPVS patient, there is no moral distinction between such an act and such an omission. In

---

66 Active euthanasia is used to describe an action performed within a clinical setting, the intention of which is to terminate a human life - e.g. lethal injection. Passive euthanasia is taken to be the withdrawing or withholding of a medical treatment necessary for the continuance of human life - e.g. switching off a ventilator.

67 Both are embodied in the Health and Disability Commissioner’s Code of Rights. See Section 3.2.1 Health and Disability Commissioner Act 1994

68 Starving a prisoner would effectively result in his death without active measures on the part of his captors. This would clearly be homicide and no jurisdiction permits it. Note however that in such a case neither of the conditions for morally defensible treatment withdrawal exist - the prisoner has not chosen to exercise his right to refuse food, nor do his captors have a legitimate duty to withhold it.
their case, ‘Exactly what is dying?’ becomes a more important question than ‘How will they die?’ It is not an act or omission alone that determines whether euthanasia has taken place – one must take into account the duties and motives of the care-giver as well as the interests, rights, and state-of-being attributable to the patient. Once a decision has been made that such a patient is to have treatment withdrawn, there is no metaphysically rational justification for choosing the withdrawal of nutrition and hydration over a lethal injection as a means to end what is left of their life. Euthanasia will not have taken place in either case because a person has not been put to death.

For now society is choosing to allow these patients to die by withdrawing feeding, perhaps because it appears more natural. A continuation of this method seems prudent because, once a rapid and invasive alternative is accepted as a means of ending the lives of this unique group, some will find it “…difficult to see any logical basis for excluding it in others.” Indeed, some already see the acceptance of nutrition withdrawal as a mandate to demand active euthanasia.

“We were aware…of the danger of misinterpretation and misuse of the principle, and we were aware that there are forces in our society that would welcome the highly publicised withdrawal of nutrition…as an invitation to active euthanasia.”

Putting forward the arguments for and against the active euthanasia of conscious persons is a substantial essay in itself and lies outside the scope of this document. This section serves to highlight that, as iPVS patients are not persons, much of the emotionally-charged discourse surrounding euthanasia does not belong in discussions of nutrition withdrawal.

2.4.3.3 Death of a Person: Euthanasia is a concept that applies to persons alone. Its advocates use language consistent with patients either exercising certain rights themselves (e.g. ‘a right to die with dignity’) or having rights exercised on their behalf (e.g. ‘a duty to relieve suffering.’)

“The debate over euthanasia centres on the agonising conflict which can arise when…the duty to act with kindness and humanity comes into conflict with the absolute prohibition on the violation of the person.”

The theme of this report is that iPVS patients are a unique category of non-sentient, non-persons – neither satisfying enough criteria to be judged living persons, nor lacking enough to be judged dead. Accepting this finding that iPVS patients are no longer persons, their death cannot come under the ambit of euthanasia. They are not terminally ill. They are not suffering. They are unable to experience the indignity of their treatment or the pain of their condition. They have no interests and no rights – as interests and rights cannot exist in the absence of present or potential consciousness.
If a term must be used to describe the withdrawal of feeding from such patients, 'euthanasia' is not the right one. Just as this category of individuals is new, so too must the term be that defines the demise of what is left of their life. Misplaced use of 'euthanasia' will continue to fuel misunderstanding.

2.5 Summary of Ethical Issues

iPVS patients do not fit any group that clinicians or ethicists have been familiar with. They are not brain dead and the bioethical paradox of a spontaneously breathing cadaver precludes them from being so defined. Respiration and circulation have great symbolic significance. They have defined life for so long that most would be angered and repulsed by the suggestion that individuals exhibiting such were dead. Yet iPVS patients are not alive in anything more than a technical sense. Whether or not commentators agree upon what exactly defines personhood, all acknowledge that iPVS patients fail to meet the requisite criteria to be persons. This unique group should not be accorded the ethical status, legal protection or right to medical care that are reserved as belonging to conscious (or temporarily unconscious) persons. If iPVS patients continue to be recognised as our equivalents, satisfactory answers to the legal and ethical dilemmas surrounding their treatment will not be found. The fundamental theme of this report is that iPVS patients are neither persons nor corpses, but a separate unique group who should be recognised and treated as such.

Almost all iPVS patients are artificially fed nutrient-rich liquid diets through a nasogastric or gastrostomy tube. Although most clinicians and laymen agree that such feeding is both a medical treatment and an ordinary care, neither finding is hugely significant. What matters is 1. whether the feeding is futile or whether it is achieving a legitimate goal of medicine and 2. whether that achievement (or lack of it) justifies ongoing expenditure to the detriment of others in need of healthcare dollars. Whilst the theory of withdrawing futile treatment receives widespread support from medical, legal and ethical commentators alike, there is much dispute over what exactly constitutes a futile treatment. How one regards a medical treatment will ultimately depend on what one sees as the legitimate goals of medicine. The underlying principle in determining legitimate goals of medicine is that without proven, presumed or prospective benefit, the pursuance of an outcome is difficult to defend.

Nasogastric feeding does not improve the prognosis of the iPVS patient, it can only prolong biological life. This report proposes that the prolongation of biological life is only a goal of medicine by association – in that it must be present before others goals can be achieved. Once it is no longer possible for the other goals of medicine to be attained, it ceases to be of itself, a legitimate goal of medicine. The fact that some vitalists see biological life as a benefit does not change the medical or
ethical reality of permanent unconsciousness. This report rejects all claims that iPVS patients can be benefited, as that which is unaware cannot experience benefit. The bioethical principle of justice requires that health resources be distributed fairly, striving where possible to ensure maximum benefit to the greatest number. Quality Adjusted Life Year analysis focuses attention on the question: ‘What exactly, in terms of calculable benefit, are we trying to achieve when we undertake treatment X for patient Y?’ In the case of a permanently unconscious patient, it impossible to justify continued feeding at the expense of real benefit to other sentient patients. So low is the priority of treatment for an iPVS patient, justice demands that those resources be employed elsewhere.

Despite sufficient grounds above for withdrawing treatment from a iPVS patient, most commentators have attempted to justify such actions by implying that it is what the patient himself would have wanted. Because complete nonsentience makes the exercising of autonomy impossible, ethicists have developed several methods of surrogate decision making that enable appropriate treatment choices to be made on an incompetent patient’s behalf – the subjective standard, the substituted judgment standard, and the best interests standard. Aside from the practical difficulties in ascertaining exactly what a patient’s prior wishes were, the main failing of the subjective and substituted judgment standards is that they are founded on prospective autonomy. Prospective autonomy can only exist if the incompetent person has a chance of later regaining (at least some of) their competence, and thus becoming aware of the outcome of their decision. The prior wishes of an iPVS patient cannot be equated to those of a patient under anaesthesia who has a good chance of regaining consciousness (and with it an awareness of the outcome that resulted from their wishes being followed). It is also illogical to suggest that there is a moral obligation to follow a decision made when one possessed interests and values that have since been lost. The best interests standard focuses on what the interests of an iPVS patient are and who should decide them, rather than asking the question: Can a permanently unconscious patient have interests? This report agrees that medicine cannot promote the iPVS patient’s best interests, as he no longer possesses any interests to promote. It is contradictory to identify the cares, thoughts or feelings of one who can never again care, think or feel. However compelling those arguments are, a minority will always disagree. While society should never seek to silence the extreme views of a minority whose fundamental metaphysical beliefs differ to those held by a majority, it should neither feel obliged to fund them.

Many are uncomfortable with treatment decisions being made on a patient’s behalf because a third party perceives his quality of life to be bad. However, nutrition and hydration are not withdrawn from an iPVS patient because society has decided that it does not value that individual’s life any longer. Instead it recognises that his complete and irreversible loss of appreciation removes the worth of that patient’s
life to himself, thereby denying him any quality of life. Thus, as has been highlighted, the iPVS patient is in a unique and distinct category. He is not minimally conscious. **Precedents pertaining to him cannot be stretched or diluted to apply to other disabled persons unless the initial premise is ignored: that the patient has irreversibly lost all capacity for consciousness and cognition.**

Likewise, as iPVS patients are not persons, much of the emotionally-charged discourse surrounding euthanasia does not belong in discussions of nutrition withdrawal. In their case, ‘Exactly *what* is dying?’ becomes a more important question than ‘*How* will they die?’ **Once a decision has been made that such a patient is to have treatment withdrawn, there is no metaphysically rational justification for choosing the withdrawal of nutrition and hydration over a lethal injection as a means to end what is left of their life. Euthanasia will not have taken place in either case because a person has not been put to death.** Nevertheless, a continuation of treatment withdrawal seems prudent because, once a rapid and invasive alternative is accepted as a means of ending the lives of this unique group, some will inevitably demand that it be made available to other societal groups.
SECTION 3: THE LEGAL ISSUES

Due to overwhelming advances in medical technology, legal systems the world over are having to consider situations never imagined even half a century ago. Subsequently, the medico-legal field is still in its adolescence. Within the Commonwealth, it enjoys nothing like the solid foundation that centuries of common law offer to most legal disciplines. Despite this scantiness of case law, and the traditional reluctance of legislators to intervene in areas of a controversial moral nature, admirable progress has been made in the medico-legal arena. Section 3: The Legal Issues focuses on how New Zealand law approaches the legal challenges that irreversible persistent vegetative state (iPVS) patients raise. It looks at a number of cases involving patients from here and abroad and the various statutory provisions which have influenced decisions regarding their treatment. Discussion includes: whether nutrition and hydration constitutes medical treatment; the legal rights to, and to refuse, medical treatment; advanced directives; the law of homicide, and; whether there is a need for further legislation. It begins by considering the status that the legal system has attributed to individuals in iPVS.

3.1 Are iPVS Patients Legally Alive or Dead?

Despite widespread discussion over many years, a statutory definition of death in New Zealand remains conspicuous by its absence. While many believe that a statute would clarify the issue, others have continued to voice their reluctance for death to be defined in this manner. The opposers of legislation have argued that: nothing should be set in statute before the medical profession is unanimous in its own attitudes; it would be impossible for such a definition to cover all future scenarios, and; once in place, it would prove too inflexible. The supporters suggest that – i) "...a lack of unanimity...may be seen as a reason for, rather than against, legislation of this matter"; ii) the emergence of any new scenarios can be addressed through new or amended legislation, and – iii) inflexibility is desirable in the definition of something as fundamentally important as death.

Perhaps because "...the matter can be better dealt with in other ways more conducive to doctor-patient trust [than a statutory definition]..." the last few decades have seen the medical profession left to draw its own conclusions regarding when a diagnosis of death is appropriate. These have usually followed advances made in other countries, the latest of which has been an adoption of the brain dead criteria discussed earlier in this report. These criteria exclude the possibility of an iPVS patient being

---

<sup>6</sup> See Section 1.5.1 Whole Brain Death and Brain Stem Death.
medically diagnosed as dead. And while the NZ legal system has chosen not to formally confirm or dispute these findings by way of legislation, the issues surrounding the status of an iPVS patient have been closely scrutinised in case law.

Why do the courts feel the need to address issues of a technical, medical nature? After all, the diagnosis of PVS is a complex clinical process. The answer is found in Glanville Williams' observation that, although the diagnosis of death is medical, the definition must be legal. It follows that "...[i]n the absence of a statutory definition of death in New Zealand...the courts must apply the common law to determine whether a person is dead." Skegg makes specific reference to iPVS in echoing the same sentiments:

"Whether the patient is in an irreversible non-cognitive condition is undoubtedly a medical question. But whether a patient in this condition is alive or dead...is not a matter on which the courts should feel obliged to follow the views of the doctors who gave evidence, or even the views of the medical profession generally." (Italics added.)

3.1.1 Joe v Joe

The first NZ case to address the status of a permanently unconscious patient was Joe v Joe. What was being questioned was Mrs Joe's state-of-being for the purposes of s32-s35 of the Family Proceeding Act 1980. Mr Joe was applying to the Family Court for an order to dissolve his marriage with Mrs Joe on the alternative grounds: (1) that she may be presumed to be dead; and (2) that they had been living apart for the requisite period. It is the discussion prompted by the first of these reasons that has relevance to iPVS patients. The court recognised that this was the first time that these issues had been addressed in a legal setting in NZ: "These issues take us into largely uncharted territory. There is no statutory definition of death in New Zealand, nor is there any known direct precedent in any common law country." Before discussing the various findings, it may be helpful to set out the following provisions from the Act:

32. Application for declaration of presumption of death - Any married person who is domiciled in New Zealand may apply for an order declaring that the other party to the marriage is presumed to be dead and that the marriage is dissolved.

33. Power of Family Court to make declaration of presumption of death - Every application under section 32 of this Act shall be heard and determined in a Family Court.

34. Grounds for making declaration of presumption of death - In proceedings on an application under section 32 of this Act, a Family Court, on being satisfied that reasonable

Following a stroke which affected the brain stem, Mrs. Joe had been in a ‘coma’ for nearly four years. Her condition had shown no improvement since the stroke, and neither party questioned the neurologists’ prognosis that her unconscious state was irreversible.
grounds exist for presuming that the party to the marriage in respect of whom the application has been made is dead, may make an order declaring that that party is presumed to be dead and that the marriage is dissolved.

35. Evidence of death - In proceedings on an application under section 32 of this Act, the fact that for a period of no less than 7 years the party to the marriage in respect of whom the application has been made has been continuously absent from the applicant, and that nothing has happened within that time to give the applicant reason to believe that the other party was then living, shall be evidence that the other party is dead in absence of proof to the contrary.

Inglis J had first to determine whether such a case (in which the respondent had not disappeared, but where there were different reasons for uncertainty regarding her state of being) could even proceed under the Act. He concludes: "In my opinion nothing is to be found in the intent, meaning or spirit of the Family Proceedings Act contrary to an interpretation of ss 32-35 which would bring the present inquiry within their provisions."\(^{10}\)

As the court began a detailed pursuit of the legal criteria for death and whether those criteria had been met by Mrs Joe, specific reference was made to the United States Quinlan\(^ {11} \) case - "By any accepted criteria she was not dead."\(^ {12} \) Inglis J explained that the case of Mrs Joe differed from that of Karen Quinlan\(^ {6} \) in two important respects:

"In the first place no direct question arises in the present case of depriving Mrs Joe of any so-called life-support mechanisms or care because the question is whether she has already ceased to be alive. ... The second difference...is that Mrs Joe's condition is clearly very much more limited than was that of Karen Quinlan... The question is whether this is a difference only of degree, or whether it marks a difference between life and death."\(^ {13} \)

The court discussed the accepted criteria for brain death, as outlined in the 1968 Harvard Medical School Committee report.\(^ {14} \) It was noted that Mrs Joe had retained her ability to respire spontaneously, and therefore failed to meet these criteria. A broader, alternative definition, that "...conceptually, death should be defined as occurring when the individual attains a state of permanent and irreversible unconsciousness..."\(^ {15} \) was also considered. However, Inglis J stated:\(^ {d} \)

"While it is possible to argue on philosophical, psychological, and sociological grounds that an individual's lapse into permanent and irreversible unconsciousness marks the point at which

---

\(^ {c} \) See footnote at 1.3.1 Diffuse Laminar Cortical Necrosis.

\(^ {d} \) In this statement Inglis J has erroneously concluded that, because there is a lack of unanimity over whether or not permanently unconscious individuals are dead, opinion is equally divided over whether such individuals have ceased to be persons: see 2.1.1 The Significance of Personhood.
that individual ceases to exist as a person,...there is no indication in any of the material I have considered that such an argument would attract general agreement and acceptance."\textsuperscript{16}

He continued that it would be wrong for the common law to fix the threshold of death at different points depending on the individual circumstances.

"Some might find it acceptable to regard a state of permanent and irreversible unconsciousness, on its own, as a sufficient indication of death for the purposes of remarriage or for a grant of probate or administration. But it could be expected that there would be general difficulty in accepting the same criterion for the purpose of tissue or organ transplants, or for burial or cremation." \textsuperscript{17}

He also felt that it was not the place of the Family Court to broaden what has for decades been accepted as the definition for death.

"If a threshold for death is to be fixed for any purpose below a level which attracts general acceptance in situations where there must be a high degree of certainty that death has occurred, that is a function of Parliament, not the Courts." \textsuperscript{18}

However Mr Joe had not appealed to the court to define Mrs Joe as dead, but to presume her to be dead for the purposes of marriage dissolution. There is no need to presume what is known for certain. Inglis J explained that presumption should be on a balance of probabilities, which in this case could lead to only one conclusion.

"This is not a case where she has physically disappeared in circumstances which would give rise to a permissible inference that it is more likely than not that she has died. She is there, in her hospital bed, breathing, and her heart is beating." \textsuperscript{19}

He believed that to make a decision based on sympathy for Mr Joe, or on societal interest in the dissolution of such a marriage would, to quote a cliché, "...be a matter of a hard case making bad law." The application for marriage dissolution, on the grounds that the respondent be presumed dead, was therefore dismissed.\textsuperscript{5}

\textbf{In this case, the patient with a condition "...clearly very much more limited..." than iPVS was found not to fulfil criteria for the accepted definition of death. Nor was the court prepared to expand that definition to include her. Furthermore, it did not accept that, on the balance of probabilities, the patient could even be presumed to be dead. These decisions were made despite the non-threatening consequences to that patient - dissolution of a marriage. Without legislation to the contrary, it seems highly improbable that a later judgment will find a patient with the 'less limited'

\textsuperscript{5} Mr. Joe was subsequently awarded marriage dissolution on alternative grounds: that the parties had been 'living apart' for the requisite period.
condition of iPVS to be legally dead. And how much more unlikely when the reasoning behind the change of definition is to justify the withdrawal of a life-sustaining treatment?

3.1.2 Auckland Area Health Board v Attorney General

This case involved "...an application made by doctors...for a declaration clarifying whether in law they would be guilty of culpable homicide...were they to withdraw the ventilatory-support system which maintained the breathing and heartbeat of a patient [Mr L] with an extreme case of Guillain-Barre syndrome." (The law of homicide, and the issues it raises with respect to withdrawal of life-sustaining treatment, will be examined later in this legal section.) Although the possibilities of brain death and iPVS were considered by the experts who treated Mr L, it became clear that he did not fulfil criteria for either of these conditions.6

"Indeed he was, in one sense, the exact opposite to the PVS patient. The PVS patient has no higher or conscious brain function but his bodily nerves are working normally. Mr L may well have had completely intact conscious function and may also have had visual impressions but he was cut off from all bodily expression and communion; he was a denervated, isolated mind trapped in an immobile and silent human frame."7

Notwithstanding these differences, it is worth examining Thomas J's comments on the passing from life to death.

"The difficulty of defining the demarcation between life and death in absolute terms is plain. It is possibly better, as has been suggested by Professor [Glanville] Williams, to regard a person's passing as a continuous process with no scientifically ascertainable moment of death, and to accept that in seeking to pinpoint the instant of death we are engaged in a 'verbal activity' and not primarily a scientific exercise."8

He believed that these problems have been largely created, and certainly magnified, by the enormous advances in medical technology. Intensive care intervention has blurred the boundaries, so that is now "...unclear whether life is being sustained or death being deferred."9 He closes the discussion on death by stating:

---

1 Hereafter referred to as Re L.

2 Guillian-Barre syndrome is a disease which attacks the nervous system - "The nerves of the body are stripped of their covering over a crucial length such that they no longer function to transmit information to and from the brain." - (Gillett G, Goddard L, Webb M. The Case of Mr. L: A Legal and Ethical Response to the Court-sanctioned Withdrawal of Life-support. Journal of Law and Medicine 1995;3(1):49-59) Mr. L's condition deteriorated to the point where he was totally paralysed, showed no responses, and displayed no awareness of himself or his environment.
"Whether or not ever-advancing technology and the maturity of thought which may be no more than the product of the passage of time will lead to a further revision of the moment when a person can be accounted dead is an open issue. That is as it should be. It will ultimately be for the medical profession, sensitive to the values of the community and alert to the requirements of the law, to decide whether the irretrievable destruction of nervous tissues which are as imperative to breathing and heartbeat as are the 'tissues' which constitute the brain stem, requires the definition of death to be revised.

Certainly I am not required to answer that question. The present application is to be resolved on the basis that Mr L is not 'brain-stem' dead. I can therefore move to a consideration of ss 151 and 164, but I do so in the conviction that Mr L deserves the description of 'living dead' as much as if he were brain-stem dead.""25

In contrast to the views expressed seven years earlier by Inglis J in Joe v Joe, Judge Thomas' comments in this case suggested that society may be ready to discuss a change in the definition of death. He acknowledged the uncertainty that surrounds the threshold between life and death, especially when that life is being suspended 'in limbo' for long periods with the use of life-supporting treatment and mentioned that a better option may be to regard death as a process rather than an instantaneous event. This is not a satisfactory solution. Firstly, recognising death as a process brings us no closer to pinpointing when, once the process has started, one ceases to be alive. Secondly, medicine struggles hard enough to maintain boundaries between precise groups or entities - it seems unreasonably optimistic to expect health professionals to hold their footing during such an indistinct and emotionally charged 'process.'

Thomas J went on to endorse future revision of the current definition of death. However, in declaring that '...it will ultimately be for the medical profession...' to decide whether such revision is necessary, he is himself avoiding the responsibility of helping to catalyse any change. Not only does this burden the medical profession with the task of setting ethical boundaries for the rest of society, in doing so it contradicts comments made earlier in his judgement:

"I do not consider that the doctors should be required to pursue their 'healing vocation inhibited in making their independent medical judgments for the well-being of their dying patients' under the threat of a nightmarish criminal prosecution if they, or their advisers, prove to be in error in their evaluation of the law or the legal process. In such circumstances I consider that it is appropriate for the Court to respond by clarifying the law.""26

---

Taking it to absurdity, some have suggested that dying is a process that commences when we are conceived.
Suggesting that the medical profession find its own definition is not a satisfactory response. His closing comment on the issue can be interpreted as supporting the inclusion of iPVS patients in an amended definition of death. He states that Mr L, who has retained fractionally more of his faculties than a patient in iPVS, “…deserves the description of ‘living dead’ as much as if he were brain-stem dead.” That Judge Thomas chose to use as colloquial a term as ‘living dead’ is a concern and a mystery. ‘Living dead’ suggests any one of a number of states – brain-death, coma, iPVS, locked-in syndrome, etc… – states that this report has gone to some lengths to differentiate. “These categories of patient raise very different ethical and legal questions, and it is unfortunate that the judge chose to treat them as equivalent.”

3.1.3 Airedale NHS Trust v Bland

This British case was decided in the House of Lords and serves as a very influential judgment for courts throughout the Commonwealth. It involved the doctors of 20 year-old Anthony Bland seeking permission to lawfully discontinue all life sustaining treatment and medical support measures.1 While the House was never asked to make a ruling on the matter, Anthony’s life or death status was an important issue in the case. If he had been defined as dead, there would have been no need to continue with proceedings. Rather, all of the judgements employed language consistent with Anthony being a living person. The artificial feeding was said to be ‘...keeping him alive...’ and removal of the same would ‘...allow him to die.’ Some made specific reference to Anthony being alive.

“I do not refer to these factors [ventilated corpse] because Anthony Bland is already dead, either medically or legally. His brain stem is alive and so is he.”29

“I start with the simple fact that, in law, Anthony is still alive. It is true that his condition is such that it can be described as a living death; but he is nevertheless still alive.”30

While the Lords recognised that they had the power to create new law in this area, they also did not believe that the courtroom was the right forum for such a fundamental change to be made.

“Existing law may not provide an acceptable answer to the new legal questions which it raises. Should judges seek to develop new law to meet a wholly new situation? ... I have no doubt that it is for Parliament, not the courts, to decide the broader issues which this case raises. Until recently there was no doubt what was life and what was death.”31

James Munby, QC for the Official Solicitor: “In theory it would be open to the House to redefine death so as to exclude the ‘living dead’... However, such a legally significant alteration

---

1 Anthony Bland sustained serious injuries in the disaster which occurred at the Hillsborough football ground on 15 April 1989; the results of which left him in an iPVS for over three years.
in the law ought properly to be a matter for Parliament, and is not called for in the present case."

The judgment shares similarities with that of Re L. The court, this time considering a true iPVS patient, suggested that the definition of death be amended, but expressed reluctance to do the job itself.

Although the Lords had no difficulty in defining Anthony Bland as alive under the present legal definition, they indicated that there is sufficient change in societal attitude to prompt a parliamentary redress of the issue.

3.1.4 United States Law

Due to the differences in our legal systems, examples from the United States are not routinely given in this part of the report. However, legislators there have enacted that which remains absent in Britain or New Zealand - a statutory definition of death.

"The Uniform Determination of Death Act (UDDA) was developed in collaboration with the American Bar Association, the American Medical Association and the National Conference of Commissioners on Uniform State Laws. It was reported in 1981 and states: 'An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.' The UDDA incorporates brain death criteria, which all fifty states now accept is the legal definition of death."

United States courts have passed judgment on more cases of iPVS than any other judiciary in the world. This may be due to the large numbers of patients in iPVS, or more likely, because litigation is such a common method of problem-solving there. Whatever the reason, none of them have found iPVS patients to satisfy the UDDA criteria for death, nor have they been prepared to extend the definition to include iPVS. While judges have lamented "the constantly increasing power of science to keep the human body alive for longer than any person would want to inhabit it," they have all followed the Quinlan precedent that iPVS patients are alive. However, a statement from Stevens J in Cruzan v Director, Missouri Dept of Health suggests that the accuracy of referring to such patients as 'alive' is being questioned:

"Nancy Cruzan is obviously 'alive' in a physiological sense. But for patients like Nancy Cruzan, who have no consciousness and no chance of recovery, there is a serious question as to whether the mere persistence of their bodies is 'life' as that word is commonly understood, or as it is used in both the Constitution and the Declaration of Independence."
To date in the United States, only commentators outside the judiciary have declared that the definition of death should include iPVS patients.\(^{38}\)

### 3.1.5 Legally Recognising this Unique Group

There should not be a continuation of the status quo - with iPVS patients being legally recognised as living members of society and legally protected as such. An individual in iPVS has lost the characteristics regarded as fundamental to personhood. These characteristics are so elementary that their loss necessitates a change in legal status - those in iPVS have forfeited certain legal rights reserved for conscious persons alone.

"In the absence of will, thought, expression, or consciousness, legal rights and liberties have no reference and thus no meaning... Can any of the rights enumerated in the Bill of Rights... be experienced, effectuated, or exercised by a person who is permanently unconscious? The answer is clearly and unequivocally no. All rights enumerated in... the Bill of Rights are predicated on consciousness, or the capacity for consciousness, except for the right to life itself, which becomes meaningless... when consciousness is forever extinguished, as in a vegetative state patient."\(^{39}\)

Neither should the current legal definition of death be expanded to include iPVS patients. To do so would introduce more problems than it would solve. The medical profession was not simply following tradition when it set the boundary for death at a point excluding those in an iPVS. It was recognising that, while unable to recover the features that characterise a human being, these individuals are not dead "...in any biologically consistent sense of that term."\(^{40}\) More importantly, "...numerous legal mechanisms are triggered automatically at the time of death"\(^{41}\) – mechanisms that would result in some unacceptable scenarios if iPVS patients were thus defined:

- Skegg has noted that "for legal purposes it is necessary to make a sharp distinction between the living and the dead" and, that "death must obviously be a once-and-for-all occurrence."\(^{42}\)

Expanding the definition of death will result in inconsistencies. No sharp distinction exists between PVS and iPVS. Patients in PVS who are 'alive' will 'die' as consultants diagnose their condition as irreversible. Someone who was alive on Wednesday could be dead on Thursday - with no change in condition. Attempted murder trials will see expert medical witnesses called on to argue for or against a diagnosis of death by prosecution and defence teams.
• A 1996 newspaper article\(^4\) reported that a 29 year-old New York woman who had been in a coma for ten years (most likely iPVS) was found to be five months pregnant; apparently the victim of a rapist working at the nursing home where she was being cared for. If as corpses, iPVS patients were only afforded protection under s150 Crimes Act 1961, the perpetrator could only be charged with ‘Misconduct in respect of human remains’—an offence carrying a maximum penalty of two years imprisonment.

• Also, if iPVS patients were included in a definition of death it would be “difficult to see that there could be any legal objection to these spontaneously breathing bodies being cremated or buried.”\(^5\)

Laws exist to protect the rights of the living. While some pertain to the deceased, they are not enforced to safeguard rights, for the deceased have no rights. Rather, these laws are in place to ensure that a corpse is treated with the respect that society feels befits a former member. The age-old ‘right to a decent burial’ is a recognition that anything less falls short of this respect. A former person’s body symbolises who that person was long after they have died. Society is distressed to learn of a corpse indecently treated or a grave desecrated because it so contradicts the love and respect shown towards that person when they were alive. To this end, certain treatment of human remains has been deemed unacceptable. It is not because cremating a breathing body may harm it that such an action should remain unlawful. Put simply, that which is unaware cannot be harmed.\(^k\) Instead it should be unlawful for the harm that the cremation would cause society.

When individuals cannot be satisfactorily described as living or dead, but exhibit characteristics of both, the answer lies in the medical, ethical and legal acknowledgement of a third, ‘intermediate’ state. Such a state would be reserved for iPVS individuals: who have lost the characteristics used to define persons, but have not lost the ability to perform the vegetative functions that have for so long defined biological human life.

### 3.2 The Legal Right To Medical Treatment

Up until The Health and Disciplinary Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations came into force in 1996 there was no direct, statutory right to medical treatment in NZ. However, there were a number of implied rights, in that others had enforceable duties. So while a patient could not walk into a medical centre and demand the treatments of his choice, the medical centre had a duty to provide for that patient an appropriate standard of health service. Many

---

\(^k\) See 2.2.5 Benefits and Burdens and 2.3.5 The Best Interests Standard
aspects of these services have been, and are still, regulated by statutes such as the Consumer Guarantees Act 1993, the Mental Health (Compulsory Assessment and Treatment) Act 1992, or the Hospitals Act 1957\(^1\). In addition, a number of acts regulate the competence, registration, and general discipline of certain health professional groups - for example, the Dental Act 1988, the Medical Practitioners Act 1968, and the Nurses Act 1977.\(^2\) Notwithstanding these statutory controls, evidence of infringement on patients' rights (in particular Judge Cartwright’s Report of the Cervical Cancer Inquiry 1988\(^3\)) highlighted the need for those rights to be clearly outlined.

3.2.1 Health and Disability Commissioner Act 1994

The Health and Disability Commissioner Act 1994 was legislated to:

- “Promote and protect the rights of health consumers and disability service consumers; and
- To that end facilitate the fair, simple, speedy and efficient resolution of complaints relating to the infringement of those rights.”\(^4\)

The rights to be ‘promoted and protected’ have been set out in The Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996. “The Commissioner’s role is to investigate complaints alleging any action of a provider is in breach of the Code.”\(^5\) Clause 1 of

---


the Code’s schedule states that every consumer has the rights contained therein and that every provider is subject to the corresponding duties. Clause 2 then sets out the rights of consumers as follows:

1. Right to be Treated with Respect
2. Right to Freedom from Discrimination, Coercion, Harassment, and Exploitation
3. Right to Dignity and Independence
4. Right to Services of an Appropriate Standard
5. Right to Effective Communication
6. Right to be Fully Informed
7. Right to Make An Informed Choice and Give Informed Consent
8. Right to Support
9. Rights in respect to teaching or research
10. Right to Complain

While some of the other rights will be looked at more closely later in this report, the focus of this section on rights to medical treatment is:

RIGHT 4: Right to Services of An Appropriate Standard

1. Every consumer has the right to have services provided with reasonable care and skill.
2. Every consumer has the right to have services provided that comply with legal, professional, ethical and other relevant standards.
3. Every consumer has the right to have services provided in a manner consistent with his or her needs.
4. Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.
5. Every consumer has the right to co-operation among providers to ensure quality and continuity of service.

3.2.2 Applying the Code to an iPVS Patient

What are the implications of Right 4 for a patient in iPVS? Is a hospital duty-bound to treat that patient and if so, for how long? While the PVS patient is stabilising and being diagnosed, there is benefit in continuing treatment. Even though the patient is unaware, the benefit is the chance that he will recover some degree, any degree, of consciousness. Therefore during this stabilising period the healthcare provider has a duty (under Right 4 (3) of the Code) to continue treatment, as the PVS patient needs it in order for that chance of recovery to exist. However once the diagnosis of iPVS has been made and the chance of recovery lost, there is evidence that withdrawal of nutrition and hydration from such patients is not in breach of the Code. “Consistent with his or her needs” has been employed to prevent consumers demanding a treatment that is of no benefit to them. The iPVS patient no longer has any
needs against which the treatment's 'consistency' can be measured. Nutrition and hydration have lost their benefit.

With respect to Right 4 (4), extensive discussion of both 'harm' and 'quality of life' in Section 2: The Ethical Issues failed to establish a convincing case for continuing to treat an iPVS patient. In addition, the justice of health resource allocation has to be considered when assessing the consistency of needs vs. services provided. Right 4's draft commentary stated: "...it is not the intention of this Act to guarantee access to particular services."\(^{48}\) Therefore in view of the medical, ethical and economic reasons already outlined in this report and the legal reasons to follow, Right 4 not only allows, but requires, the withdrawal of an iPVS patient's nutrition and hydration. It is the only course of action "consistent with his or her needs."

3.2.3 Human Rights Act 1993

Some commentators hold the view that treatment withdrawal from iPVS patients is inherently discriminatory.\(^{49}\) Just as those in the United States have argued that the Americans with Disabilities Act "prohibits withholding treatment from those who are permanently unconscious"\(^{50}\) New Zealand opponents could make the same claim under the Human Rights Act 1993. S21 of the Act reads:

21. Prohibited grounds of discrimination - (1) For the purposes of this Act, the prohibited grounds of discrimination are -

...(h) Disability, which means -

i. Physical disability or impairment:
ii. Physical illness:
iii. Psychiatric illness:
iv. Intellectual or psychological disability or impairment:
v. Any other loss or abnormality of psychological, physiological, or anatomical structure or function: (italics added)
vi. Reliance on a guide dog, wheelchair, or other remedial means:
vii. The presence in the body of organisms capable of causing illness:

Taken literally, the description of disabled given in s 21,(1),(h),(v) appears to include iPVS patients. If so, they are as entitled to ongoing treatment as any other patient and to deny them that right is to discriminate against them on the grounds of disability. Are healthcare teams that withdraw nutrition and hydration from iPVS patients in breach of this Act?

It is not clear whether the legislature had iPVS in mind when it enacted subparagraph (v). All of the other grounds in paragraph (h) are dealing only with impairments - physical illness, intellectual

\(^{48}\) See 2.2.5 Benefits and Burdens and 2.3.5 The Best Interests Standard

\(^{49}\) See 2.4.1.1 Quality of Life
disability, presence of organisms, reliance on a guide dog. There is nothing as catastrophically disabling as iPVS. While (v) specifies “any other loss” there is a strong argument that Parliament would never have envisaged it being stretched to cover total and irreversible loss of consciousness and cognition.\(^5\) The Human Rights Act 1993 has yet to be argued in a case involving the withdrawal of nutrition and hydration from an iPVS patient. However, the Americans with Disabilities Act and the Rehabilitation Act have been employed in a number of cases in the United States involving seriously ill newborns,\(^51\) prompting some explanation as to why anti-discrimination statutes should not apply.

In United States v University Hospital\(^{62}\) the Second Circuit Court of Appeals held that the Rehabilitation Act “only prohibits discrimination against an individual with a disability when that disability is unrelated to the services in question.”\(^{53}\) In other words, ask: ‘if the patient did not have the disability, would the treatment still be necessary?’ If it would not, then to deny that patient treatment may not breach any duty.\(^6\) When this reasoning is applied to the case of the iPVS patient it is not discriminatory to withdraw nutrition and hydration - the patient’s disability has directly invalidated the benefit of that treatment.

“One commentator notes that if the Americans with Disabilities Act prohibits the withdrawal of treatment from permanently unconscious patients, it follows that it is discriminatory to withhold treatment from anyone. From this line of reasoning, one might conclude that Congress must have intended to create a system of unlimited universal access to health care when it enacted the Americans with Disabilities Act. This conclusion is obviously incorrect; interpreting the Americans with Disabilities Act to require the lives of those who are permanently unconscious to be sustained endlessly is not only unfeasible, it is also contrary to the wishes of many people with disabilities who desire beneficial, as opposed to extended, treatment.”\(^{54}\)

The same applies to New Zealand’s Human Rights Act 1993. If it is discriminatory to withdraw nutrition and hydration from a patient once they are diagnosed as being in iPVS, then it must be discriminatory to ever withdraw health services from anyone who satisfies the s 21,(1),(h) criteria, regardless of changes in their medical condition. This suggestion is as medically irresponsible as it is economically impossible and, in terms of resource allocation, ethically repugnant. As will be discussed later in this section, healthcare workers are required, not to provide unlimited health care to everyone,

---

\(^5\) Taking one of the most common scenarios the Act was intended to deal with as an example (discrimination in the workplace), it would be absurd to suggest that an iPVS patient could claim equal rights to a job promotion.

\(^6\) For example, to refuse a blind patient futile eye surgery on the grounds that she is blind, would not be discriminatory because the disability is directly related to the treatment in question. However, to refuse that same patient renal dialysis on the grounds that she is blind would be discriminatory.
rather services to a level consistent with ‘good medical practice’. In doing so the profession should strive, at all times, to use “discriminating judgment, not discriminatory judgment”.

3.3 The Legal Right To Refuse Medical Treatment

The right of a patient to refuse medical treatment has long been recognised by commentators in the ethical arena. It is based on the broader fundamental concept of autonomy - the right to self-determination. The purpose of this section is to provide legal support for what some may believe is only an ethical theory.

3.3.1 Consent

Doctors have a legal duty to obtain consent from a patient before proceeding with any examination or treatment. “In the absence of legally effective consent or some other legal justification, a doctor will normally incur criminal and civil liability if he carries out any medical procedure involving a bodily touching.” One who conducts medical procedures without legally effective consent would be liable under s196 Crimes Act 1961.

1. **Interpretation** - ... “Assault” means the act of intentionally applying or attempting to apply force to the person of another, directly or indirectly.

2. **Common assault** - Everyone is liable to imprisonment for a term not exceeding one year who assaults another person.

Therefore, “if legally effective consent has not been given, and the doctor is aware of that fact, then even the most therapeutic medical touching will amount to the offence of [assault], except where a statutory or common law justification is available to the doctor.” The right to consent is now also acknowledged under The Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996:

**Right 7: Right to Make Informed Choice and Give Informed Consent**

1. Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.

3.3.2 The Incapacitated Patient and Implied Consent

Does this still apply in a case where the patient is unable to give consent? “Capacity to give a legally effective consent depends upon capacity to understand and come to a decision on what is involved, and

---

* See 2.3.1 Autonomy
the capacity to communicate that decision.Obviously, a patient who is rendered unconscious is unable to communicate and so cannot give a doctor the assurance of legally effective consent. What are the statutory and common law justifications that allow that doctor to proceed with treatment? Section 151 (1) of the Crimes Act 1961 states that anyone who has charge of someone (who is unable to withdraw from that charge) is under a legal duty to supply that person with the necessaries of life. Therefore, by law doctors must treat patients who are unconscious and will die unless treated. The duty to obtain consent is waived. Right 7 of The Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 goes on to state:

2. Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent. (Italics added.)

3. Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence. (Italics added.)

The courts have demonstrated their support by acknowledging that “in circumstances of emergency great latitude may be given to a doctor.”

“The common law also recognises that situations will arise where it is impossible through temporary or permanent incapacity for the consumer to give consent, but the consumer’s best interests require that some procedure be carried out. In such cases, consent is not required.”

However, does the doctor’s justification for treating without consent still exist if that patient later regains the capability to consent and chooses not to?

3.3.3 The Right to Refuse Treatment After it has Commenced

Usually the right to refuse medical treatment is exercised by refusing to consent to that treatment in the first place. However, this is no longer an option for someone whose treatment was initiated when they were incapable of consenting, and who is now wishing that treatment to conclude. Section 11 of the NZ Bill of Rights Act 1990 states:

11. Right to refuse to undergo medical treatment - Everyone has the right to refuse to undergo any medical treatment.

The implications of s151 (1) in regard to the subsequent withdrawal of nutrition and hydration from the diagnosed iPVS patient will be discussed later in this section. Here the focus is whether the doctor can initiate treatment without consent.

The NZ Bill of Rights Act 1990 states that it does not implyly repeal or invalidate any other enactments however, wherever an enactment can be given a meaning that is consistent with the rights and freedoms contained in this Bill of Rights, that meaning shall be preferred to any other meaning.
There is now also a right under Right 7 (7) of The Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996.

7. Every consumer has the right to refuse services and to withdraw consent to services. These provide for such people the liberty to refuse permission for continued treatment. It is clear that a formerly incapacitated patient, who is now capable of making decisions, has a right to have treatment stopped.

3.3.4 Have iPVS Patients Forfeited this Right?

The iPVS patient can never recover the abilities needed to be aware of the treatment options, make a decision based on those options, or communicate that decision to care-givers. While the doctor no longer has the justification of an emergency situation, does the iPVS patient (now by way of his permanent incapacity) continue to forfeit the right to have treatment withdrawn? Such questions were addressed by some of the judges during the Bland hearing:

“The House must decide whether patients in the present patient’s condition...should continue involuntarily to be what was described as ‘passive prisoners of medical technology’.”

“In my view, the correct answer to the present case depends on the extent of the right to continue lawfully to invade the bodily integrity of Anthony Bland without his consent.”

The House of Lords was of the opinion that a patient’s incapacity to communicate his wishes should not doom him to a lifetime of involuntary and intrusive treatment.

“It is scarcely consistent with the primacy given to the principle of self-determination...that the law should provide no means of enabling treatment to be withheld in appropriate circumstances where the patient is in no condition to indicate, if that was his wish, that he did not consent to it.”

In the Bland Court of Appeal judgment (whose decision was affirmed by the House of Lords), Hoffmann LJ states:

“Anthony Bland is an individual human being and the principle of self-determination says he should be allowed to choose for himself and that, if he is unable to express his choice, we should try our honest best to do what we think he would have chosen. We cannot disclaim this choice because to go on is as much a choice as to stop. Normally we would unquestioningly assume that anyone would wish to live rather than die. But in the extraordinary case of Anthony Bland, we think it more likely that he would choose to put an end to the humiliation of his being and the distress of his family.”

A commentary on Re L looked at the issues that making a decision on the behalf of Mr L raised:
"If we would consider it reasonable for a competent or conscious patient to make the decision that a course of treatment is too burdensome to continue with, even where that treatment is the only chance of survival, then we should surely not disadvantage a patient who cannot communicate his wishes, but for whom that might also be a legitimate choice. It seems, therefore, perfectly acceptable on a moral basis for someone else to request what Mr L would have requested himself, had he been able to do so."65

Clearly, the NZ Bill of Rights 1990 and The Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996 give every person the right to withdraw consent to treatment at any time. The mistake courts have made is to focus on how to justify exercising that right on the iPVS patients behalf. Instead they should be asking, ‘Does this non-person have rights at all?’

One Lord in *Bland* calls for the law to provide a means by which treatment can be withdrawn from an iPVS patient if that is his wish. Hoffmann LJ believes that we should make the choice that we believe he would have chosen. And in the above commentary it seems clear that the same sentiments were implied in *Re L*. This is known as ‘substituted judgment’ and it applies unsatisfactory reasoning to justify the withdrawal of treatment from iPVS patients.

Firstly substituted judgment places great weight on the patient’s probable choice (were they to be conscious) and fails to provide an ethically defensible outcome in the event the iPVS patient indicates in advance that he wishes ‘to have treatment continued forever’. Surrogate decision-making methods introduce the opportunity for families to make a subjective decision to continue treatment that medicine has objectively shown to be non-beneficial.

Secondly, while it is considered good practise to obtain the agreement of a patient’s relatives before commencing, continuing or withdrawing a life-saving treatment, there is no legal requirement for doctors to do so. Because family can often have separate agendas, the ultimate decision has always been left in the hands of the health professionals. Surrogate decision-making methods reverse this balance of power and potentially authorise next-of-kin to make healthcare decisions for personal gain.

---

65 See 2.1.3 Ethically Recognising this Unique Group and 3.1.5 Legally Recognising this Unique Group

* See 2.3 Autonomy and Surrogate Decision-making
3.4 Advance Directives

Attempting to clarify the confusion surrounding end-of-life decision-making, many legislatures are in the process of introducing advance directives, which provide a more definite insight into a patient’s wishes than the speculation of a substituted judgment.

"Advance directives have emerged as a vehicle for people to control post-competence medical intervention... The object is to permit individuals to prescribe personal preferences in advance and so maintain a measure of autonomy even after incompetency."^66

An advance directive takes one of two forms - a living will or a durable power of attorney (DPOA). While judiciary within the Commonwealth have yet to debate the merits of either, courts in the United States "have come to recognise that prospective autonomy in shaping medical intervention is not only a legitimate concept but an integral part of the self-determination that society respects."^67 Therefore the next three subsections will focus on experiences there. The purpose is to discover whether advance directives offer any real assistance in determining the future of an iPVS patient.

3.4.1 Living Wills

Living wills are written instructions indicating an individual’s treatment preferences, should they lose the capacity to make decisions. At least 47 states in the USA have made "...the use of written substantive instructions aimed at governing future medical intervention..." legally binding. The courts there have clarified that, not only should the living will be recognised as a form of prospective autonomy, but a doctor complying with those prior instructions has not assisted in suicide or committed any other impropriety.

"A written format provides the opportunity for elaboration of a person’s preferences and for deliberation on the complex issues involved. As an evidentiary tool, a writing is clearly preferable to testimony about prior oral declarations."^69

Health care professionals have subsequently found living wills of great assistance when making decisions on behalf of incompetent patients. A number of living wills in the United States now include sections allowing for the nomination of an agent to implement that will. While this may ensure that the will is more faithfully observed, the agent is still bound by the living-will statute of the relevant state. Such statutes may allow living wills to be employed only in the case of terminal illness - a constraint that would exclude iPVS patients. "A more promising mechanism is the use of a durable power of attorney."^70
3.4.2 Durable Power of Attorney

A durable power of attorney (DPOA) is a document in which an individual (principal) pre-authorises an agent (or proxy) to make treatment decisions on his behalf, should he become incompetent. Statutes providing for some form of DPOA exist in every state. Although in most of these "the agent is given authority to make the same range of decisions regarding life-preserving medical intervention that the principal could make if competent," the nominating individual can define, in advance, the extent of the agent's jurisdiction. Even if no such limitations have been put in place, the agent has authority to make decisions in accordance with the principal's expressed preferences. A living will may be referred to for this purpose or, if none exists, the orally expressed desires of the individual. It is as undesirable as it is rare that an individual would nominate a proxy who knew nothing of that individual's attitudes or wishes regarding treatment decisions.

3.4.3 Practical Difficulties with Advanced Directives

There are however, some practical difficulties involved with the implementation of advance directives, which have become evident in the United States. Firstly, there has been a lack of interest shown by the public towards advance directives. This has been largely attributed to "...people's common unwillingness to confront their own mortality." People spend little time even contemplating the possibility of becoming incapacitated, much less planning for it. Popularity is expected to increase with Congress passing an Act "...requiring health-care institutions receiving federal funds to provide to their patients information about advance medical directives."

Secondly, the range of neurological deficits with the potential to leave the patient incompetent is huge. The individual may well have different treatment wishes for different degrees of incapacity.

"To formulate a comprehensive advance directive, a person might have to consider a spectrum of potential mental states (within the range of incompetency), infinite combinations of mental and physical dysfunction, and a variety of possible factors bearing on a decision whether to receive life-sustaining medical intervention."

However, this multiplicity of possible conditions need not prevent advanced directives being made. While it may be impossible to leave instructions for every condition, "...every competent person is capable of addressing a few precepts or guidelines regarding future medical care." In this way, the individual's attitudes can be applied across a wide range of medical conditions.

Finally, there is evidence that, in some situations, advance directives are not closely followed.

"One recent study and some anecdotal reports show that physicians in charge of medical intervention in a dying process may be influenced more by the wishes of surrounding family members than by the incompetent patient's living will."
Not surprisingly, in the United States the risk of legal action also contributes to such non-compliance."

"In the typical terminal care scenario, it is the surrounding family which looms as a litigation threat if their wishes are contravened and not the helpless, moribund patient."

3.4.4 The Current New Zealand Position

Right 7 (5) of The Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996 states:

5. Every consumer may use an advance directive in accordance with the common law.

As no advance directives have been scrutinised in courts here, this can perhaps be seen as an invitation to follow the examples set by other countries until such time as they are accepted or rejected in New Zealand law: common or statutory. Living wills have not been legally recognised in New Zealand legislation. While it is ‘good medical practice’ to consider any prior oral or written instruction of the patient, a doctor is not compelled to follow those wishes.

Certain sections in the Guardianship Act 1968, the Children Young Persons and their Families Act 1989, and the Protection of Personal and Property Rights Act 1988 provide statute whereby next-of-kin are empowered to give consent on another’s behalf. The Protection of Personal and Property Rights Act 1988 is the only one of interest where, in s98 it authorises individuals to appoint a welfare guardian to make decisions on their behalf, should they become incapable. While this is a form of durable power of attorney, the proxy is strictly limited when it comes to treatment withdrawal.

"Those who become attorneys pursuant to that legislation cannot refuse consent for the donor of the power of attorney to receive ‘standard medical treatment or procedures intended to save that person’s life or to prevent serious damage to that person’s health.’"

This limitation prevents the Act being used for the withdrawal of nutrition and hydration from iPVS patients. Specific advance directive legislation will have to be introduced in New Zealand before such patients have the right to request that their prior wishes be acted out.

3.4.5 Advance Directives and the iPVS Patient

This possibility of introducing advance directive legislation in New Zealand has received much attention in recent years. The 1993 Bioethics Centre Report for the NZ Medical Council, on withdrawal of nutrition and hydration from iPVS patients, recommended the preparation of draft advance directive

---

* Given New Zealand’s relative paucity of malpractice action, it is unlikely that the same risk of litigation would accompany advance directives should they be introduced here.

* This form of consideration is undertaken when healthcare workers respect a patient’s Do-Not-Resuscitate (DNR) order.
legislation to assist in managing their predicament. This report suggests that such legislation, as it would pertain to the iPVS patient, is unnecessary and inappropriate.

Implicit in the reliance on advance directives is the presumption that patients are going to make prospective decisions to refuse treatment. Most commentary on the subject focuses on the widely-supported view that autonomy to refuse services should not be forfeited when one loses competence. While the involuntary infliction of treatment is arguably undesirable, little consideration is given to the alternative possibility—that a patient may request all medical measures to be continued beyond the limits deemed appropriate by a majority. The discussion earlier in this section found that even conscious, competent patients have no right to demand futile treatment. What then is the rationale behind granting such a right to those who are incapacitated? Advance directive legislation does just that, when it invites individuals to give future instructions regarding medical treatment. The alternative (offering an individual the choice of ‘any treatment option as long as it’s withdrawal’) contradicts the very essence of autonomy.

Indeed the true fallacy of honouring the advanced directive of an iPVS patient is that it wrongly assumes that such an individual still has autonomy. Advance directive legislation is an attempt to justify the removal of nutrition and hydration by way of making it one’s own decision. Such an approach may neatly tie up the legal problems but it makes little medical, and even less metaphysical sense. Autonomy is a principle that, by definition, requires the existence and awareness of at least two options—e.g. to proceed with a treatment or not to. Those options are rendered meaningless if the person to whom they are given never experiences the outcome of their decision. As it will never be of consequence to the iPVS patient which option is implemented, the principle of autonomy no longer applies to them. It is on the grounds that it accords with ‘good medical practise’ that treatment should be legally withdrawn in all iPVS cases; not the false notion that a formerly conscious patient was given free reign over his treatment options.

3.4.6 Advance Directives in Other Conditions

Finding that advance directives can not satisfactorily justify the withdrawal of nutrition and hydration from iPVS patients does not imply that they have no place in the treatment of severely impaired

---

7 The New Zealand Medical Association published a *Advance Directives: A Policy Paper* in 1995. “We strongly endorse the principle of patient’s autonomy, and therefore recommend the acceptance and promulgation of the idea of the living will ... We would strongly recommend that serious consideration be given to the introduction of specific legislation to allow unquestioned acceptance of a suitably drafted advance directive...” Copies available through NZMA, 26 The Terrace, PO Box 156, Wellington, NZ.

8 Advance directives seem to work very well when patients ‘opt out’ of on-going treatment as we expect them to. However, when one decides to use his advance directive to ‘opt in’ to further care, inconsistencies arise.
patients. There are similar, but not identical, clinical situations where the public might choose to ‘opt out’ of continuing care:

- For the period of PVS before irreversibility has been confirmed: It may be desirable to give patients the opportunity to ‘opt out’ of continued treatment earlier than the time-frames discussed in 1.7.5 Prognostic Guidelines.
- For conditions where the loss of consciousness and cognition is not as profound or as permanent as iPVS.

3.5 The Right Not to be Deprived of Life

“Life, and the concept of life, represents a deep-rooted value immanent in our society. Its preservation is a fundamental humanitarian precept providing an ideal which not only is of inherent merit in commanding respect for the worth and dignity of the individual but also exemplifies all the finer virtues which are the mark of a civilised order. Consequently, the protection of life is, and will remain, a primary function of the criminal law.”

Every individual in New Zealand has the right to life. s8 of the New Zealand Bill of Rights Act 1990 states:

8. Right not to be deprived of life No one shall be deprived of life except on such grounds as are established by law and are consistent with the principles of fundamental justice.

This section is merely reinforcing a right that has existed for centuries, enforced through laws prohibiting individuals from taking another’s life, and severely punishing any transgression of that right.

“A profound respect for the sanctity of human life is embedded in our law and our moral philosophy, as it is in that of most civilised societies in the East and the West. That is why murder (next only to treason) has always been treated here as the most grave and heinous of crimes.”

There are exceptions to the rule. “This is not to say, of course, that the sanctity of life represents an absolute value. Few, if any, values can be stated in absolute terms. The qualification in section 8 itself confirms that to be the case.” What this section of the report will focus on is whether the withdrawal of nutrition and hydration from iPVS patients has been established in law to be grounds for exception.

3.5.1 The Law of Homicide

s158 of the Crimes Act 1961 states:

---

8 See 3.6.4 Advance Directive Legislation
88 See 2.4.2 Patients in ‘Near-PVS’
Homicide defined - Homicide is the killing of a human being by another, directly or indirectly, by any means whatsoever.

Section 160 then makes the distinction between culpable or not culpable:

Culpable homicide - (1) Homicide may be either culpable or not culpable.
(2) Homicide is culpable when it consists in the killing of any person -
   a) By an unlawful act; or
   b) By an omission without lawful excuse to perform or observe any legal duty;...
(4) Homicide that is not culpable is not an offence.

There are a number of sections in the Crimes Act 1961 that could be stretched to make the withdrawal of nutrition and hydration from iPVS patients an offence of culpable homicide. This section will focus only on those which are considered the most applicable, and would therefore be most likely to form the basis of any prosecuting legal action.

3.5.2 Section 151 (1) Crimes Act 1961

Duty to provide the necessaries of life - (1) Everyone who has charge of any other person unable, by reason of detention, age, sickness, insanity, or any other cause, to withdraw himself from such charge, and unable to provide himself with the necessaries of life, is (whether such charge is undertaken by him under any contract or is imposed upon him by law or by reason of his unlawful act or otherwise howsoever) under a legal duty to supply that person with the necessaries of life, and is criminally responsible for omitting without lawful excuse to perform such duty if the death of that person is caused, or if his life is endangered or his health permanently injured, by such omission. (italics added)

It was this section that received most of Thomas J's attention in Re L. Although in that case the question was whether artificial ventilation could be terminated, there are a number of parallels with withdrawing nutrition and hydration from an iPVS patient. These must be discussed before it can be determined whether or not a doctor has failed in this duty when she withdraws nutrition and hydration from an iPVS patient.

3.5.2.1 Cause of Death: In support of withdrawing ventilatory support from Mr L, Gillett states: "In my opinion it would be fair to concede that in this case what caused his [Mr L's] death was the underlying disease process which prevented him from breathing on his own or sustaining his own vital functions." A similar attitude from a legal point of view has been given earlier by Skegg:

"In many circumstances it would undoubtedly be improper to terminate artificial ventilation, and if a doctor did so his conduct would be regarded as a cause of death. But if the doctor
terminated artificial ventilation in circumstances in which the court accepted that it was proper to do so, the doctor's conduct would not be regarded as a cause of death. 484

He goes on to explain that "it is not unusual for the courts to manipulate the concept of causation to achieve a desired result, and a willingness to do so would be preferable to holding a doctor guilty of murder..." While legal causation carries a quite different connotation than simply 'consequence following action', it is unnecessary and dangerous to find a legal distinction here. Indeed, "...it is perhaps somewhat bizarre to suggest...that where a doctor tries his conscientious best to save the life of a patient brought to hospital in extremis, skilfully using sophisticated methods, drugs and machinery to do so, but fails in his attempt and therefore discontinues treatment, he can be said to have caused the death of the patient." 488

However, it is more bizarre to have a situation where an act or omission is the cause of death if it is not legally acceptable but not the cause of death if it is legally acceptable. The question should not be one of causation, but rather, whether the act or omission of the doctor was justified: that is, focusing not on the intricacies of whether such an act amounted to 'legal causation', but on whether that causative action was legally permissible49. If there was 'lawful excuse' then it is unnecessary to attempt further justification by employing that excuse as a reason to disclaim causation. There is already adequate provision within s151 (1) which states that the doctor has committed no offence, and therefore no reason to manipulate the definition of causation. The danger in such a manipulation is that, once the withdrawal of life-sustaining measures has been found not to be grounds for 'causing death', doctors may feel they are no longer obliged to have lawful excuse before taking such measures.44

3.5.2.2 Necessaries of Life: Thomas J in Re L believes there is no doubt that medical treatments are included in the phrase 'necessaries of life'. However, he goes on to explain that, in previous cases, where treatment was found to be a necessary of life, it was "...intervention necessary to prevent, cure or alleviate a disease that threatened life or health." As to whether a ventilator can be included in that phrase, he acknowledges that it has not been dealt with before in a legal setting, and comments that "...there is no absolute answer; the answer in each case must depend on the facts." He draws a

Promoted throughout this report has been the belief that, before the issues of iPVS management can be adequately addressed, it must be recognised that such patients belong in a unique category. As society accepts that an iPVS patient is neither person nor corpse, the focus of s151 (1) will shift from what is meant by 'cause' to what is meant by 'person'. The original insult causes the state of iPVS and the subsequent withdrawal of nutrition and hydration caused biological functions to cease - together they have caused the death of a person. The question will then become, not one of 'Did the doctor cause the death?' but rather, 'What died, if it wasn’t a person?' and, 'Is causing the death of such a being culpable under s151 (1)?'

Resulting in the unacceptable situation whereupon the very reasoning initially applied to disclaim causation (lawful excuse) is no longer present.
distinction between Mr L’s situation (where the ventilator is “serving no other purpose than deferring certain death”\textsuperscript{49}) and a situation where the ventilator enables a patient to continue a conscious and communicating existence (for example, a polio victim). In Thomas J’s view, such a distinction is sufficient to make artificial ventilation a necessary of life in one case but not in the other.

“No question of withdrawing the ventilator-support system would arise in such a case [e.g. the polio victim]... ...If, however, the patient is surviving only by virtue of the mechanical means which induces heartbeat and breathing and is beyond recovery [i.e. Mr. L], I do not consider that the provision of a ventilator can properly be construed as a necessary of life.”\textsuperscript{90}

This statement somewhat contradicts his earlier reasoning for not making a similar distinction regarding causation — “The fact that in one case the application of ventilatory support is futile and has no real therapeutic or medical benefit is not a difference which could, at least on the face of it, go to the question of causation.”\textsuperscript{91} It is difficult to follow Thomas J’s logic when, having applied the doctrine of causation equally to the two groups, he chooses to justify the withdrawal of ventilation by defining it differently for those same two groups. The ventilation machine is successfully keeping Mr. L’s vital functions just as stable as it would in the case of a polio patient. Thomas J is mistakenly applying the concept of futility to a ‘necessary of life’ in order to redefine it. Having found an aspect of care to be futile (in this case inducing a heartbeat and breathing, but not bringing about recovery) it does not directly follow that it ceases to be a necessary of life.\textsuperscript{92} Skegg comments that, for legal purposes, it is unnecessary, and potentially confusing, to adopt a restricted definition of ‘necessaries of life’.

“In the criminal context, there is no need to seek to restrict the ambit of ‘the necessaries of life’, so as to exclude some interventions which are in fact necessary if death is to be prevented. The life-prolonging interventions that might be excluded from the ambit of the term ‘necessaries of life’ will invariably be those which there would be lawful excuse to omit to provide. The possibility of some life-prolonging treatments being excluded from ambit of ‘necessaries of life’, even though the patient will die without them, will leave health professionals uncertain whether it is necessary for them to have a lawful excuse, if they discontinue treatment and let the patient die.”\textsuperscript{92}

Much of this reasoning was applied above to argue against disclaiming causation, as the consequences of either change are similar. This is an area where the law needs to maintain strict boundaries, not lose itself in semantics. If it can be found that a doctor has legal justification to withdraw a necessary of life, then that is sufficient. We should not strive to manipulate the common sense definitions of ‘causation’

\textsuperscript{92} 2.2.1 Medical Treatment vs. Necessary of Life qualifies its findings in the closing line — ‘...to focus on making a distinction is to engage in a largely academic exercise.’ As was highlighted then, and will be discussed next under ‘lawful excuse’, it is the futility of a treatment especially in relation to the life it is being applied to that must come under scrutiny.
and ‘necessaries of life’ in order to create a series of loopholes, when ‘lawful excuse’ is adequate, if indeed it exists.

3.5.2.3 Lawful Excuse: This qualification in s151(1) provides that a doctor only fails in her duty to supply the necessaries of life if that omission is without ‘lawful excuse’. ‘Lawful excuse’ has no concrete definition. The Court of Appeal in R v Burney approved the following dicta from the Privy Council case, Wong Pooh Yin v Public Prosecutor:

“Our Lordships doubt if it is possible to define the expression ‘lawful excuse’ in a comprehensive and satisfactory manner and they do not propose to make the attempt. They agree with the Court of Appeal that it would be undesirable to do so and that each case requires to be examined on its individual facts.”

It is appropriate to remember at this point that “…it is axiomatic that those who drafted the original sections...more than a century ago could not have contemplated the ‘life’ preserving techniques of modern medicine.” Does the underlying ethos of medicine, combined with the realisation that ‘life’ can now be held in limbo, offer a ‘lawful excuse’ to doctors who find themselves in this situation? Thomas J states: “In my view, doctors have lawful excuse to discontinue ventilation when there is no medical justification for continuing that form of medical assistance.” He places great emphasis on the concept of ‘good medical practice’ in his judgment. It is the fact that it accords with ‘good medical practice’ that has seen most courts rule that nutrition and hydration should be allowed to be withdrawn from iPVS patients.

3.5.3 Good Medical Practice

So fundamental has this doctrine been to the establishment of ‘lawful excuse’ in medical cases that it warrants separate and substantial consideration. Put simply, it is practice that would be met with general approval by the medical profession. Thus ‘good medical practice’ should accord with the respected traditions, standards, practices, and procedures of the profession. While such a term may be accused of being imprecise, the enormous range of possible situations that it must cover require it to be so. The Re L judgment lists four criteria that must be met in order for ‘good medical practice’ to exist:

1. That the doctor’s decision to withdraw ventilatory support was bona fide and in the patient’s best interests.
2. That the decision would “command general approval within the medical profession”.
3. That the patient’s immediate family or guardians gave fully informed consent and concurred with the decision.
4. That a recognised ethical body approved the doctors’ decision.
Whether the withdrawal of nutrition and hydration from iPVS patients has been found consistent with 'good medical practice' will be considered shortly.

3.5.3.1 **The Bolam Test:** The 'good medical practice' doctrine is also referred to as the Bolam test as it originates from the landmark ruling in *Bolam v Friern Hospital Management Committee*.

"The jury returned a verdict in favour of the doctor's employer after being directed that a doctor is not negligent if he acts in accord with a practice accepted as proper by a responsible body of medical people skilled in that particular art, even though there may be other members of that profession who take a contrary view."  

Recently, a number of courts have chosen to reject the Bolam test. Here in New Zealand, such rejection has been confined to criminal law. The Court of Appeal held, in *R v Yogasakaran* (a case in which an anaesthetist was found to have acted with negligence and was thereby guilty of manslaughter under s155 *Crimes Act 1961*), that it was for a jury to decide whether or not a doctor had exercised reasonable care in practice.

"The case did not hinge upon technical questions of diagnosis or treatment, but whether the doctor should have checked to make sure he was administering the right drug. The Court of Appeal consequently thought that the issue as to whether or not reasonable care had been exercised could be decided by a jury making its own assessment. It was held not to be a case in which professional standards would be conclusive. That reasoning may produce in New Zealand criminal law a slightly different criterion from that which has hitherto applied in civil cases of medical negligence in England...."  

3.5.3.2 **Rogers v Whitaker:** Two years later, in 1992, the High Court of Australia unanimously rejected the Bolam test in a civil case – *Rogers v Whitaker*. It determined that "what constitutes 'good medical practice' in the context of disclosure of risk is, ultimately, a legal issue in which current medical opinion will be relevant but not decisive." The decision has been welcomed by commentators who feel that the medical profession has no mandate to make decisions, the implications of which will reach far beyond the medical arena.

"...even if that [Bolam] principle has some appropriate sphere, its application or extension to the question who have or have not lives worth sustaining (and protecting against intentional termination) seems radically unsound. ... The issue is not one of disguise or sincerity, but of the true implications of principles and notions being put into practice by a group of citizens whose medical qualifications, experience and ethos confer no standing to settle for the whole community such issues of meaning, consistency, humanity and justice."
The ratio decidendi of *R v Yogasakaran* and *Rogers v Whitaker* applies to the iPVS situation thus: while the diagnosis of iPVS is undoubtedly a task for the medical professionals, deciding whether or not maintaining a patient in that state is futile, should be the task of judge or jury — thus reflecting society’s ideals.

Instead, it is likely to end in circular justification. iPVS is not an area of medicine that lends itself easily to scrutiny by the layman. Unlike the above negligence cases, the question is not simply one of whether a doctor failed to take reasonable care or to say what a reasonable patient wanted to hear. The judges to whom doctors will turn to decide whether withdrawal of nutrition and hydration is appropriate, will in turn rely on evidence from those same doctors about the nature of the state and the best course of action to take. Therefore, the replacement for ‘good medical practice’ will be founded on ‘good medical practice’.

Moreover, there is not widespread agreement that judges are in any better position to make these recommendations than doctors. Is it committing constitutional blasphemy to suggest that senior clinicians are as in tune with society’s attitudes in this area as High Court judges? Not only do they have explicit knowledge of the medical and social implications of nutrition and hydration withdrawal, there is no reason to believe that the value they attribute to a state such as iPVS is any lower than that of society in general - in fact, given their exposure to the condition and to grieving families, there is every probability that it will be higher.

### 3.5.3.3 Futility

In contrast, both *Bland* and *Re. L* reaffirmed the *Bolam* principle. Much of the justification behind allowing nutrition and hydration to be removed was the fact that a large body of

---

**f** Certainly, many doctors and their patients would not agree. In most iPVS cases the courts are reluctantly approached by staff and families to immunise themselves against the unlikely event of litigation arising from an action *they already feel is morally defensible*. They do so because (having come to terms with the devastating injury, treatment withdrawal and death of their loved one) there can be nothing more unwelcome than a lengthy legal battle seeking to defend those unenviable decisions. Deference to the societal in-tune-ness of judges is usually found in legal commentary.

Intellectual (and, at times, mildly cynical) exchange between disciplines is not new, nor is it unwelcome: Proverbs 27:17 “As iron sharpens iron, so one man sharpens another.” Rannon Gillon writes: “The debate between philosophy, ethics and law is one of the ever more flourishing developments in medical ethics. If… lawyers and judges have concluded that where an agent foresees death to be the ‘virtually certain’ consequence of his action the agent may be inferred to possess criminal intention; and if this… means the agent must be inferred to possess criminal intention; and if ‘actions’ include cessation of action (including withdrawals of trials of treatment); then the law is indeed an ass and required the modification that the House of Lords decision in *Bland* produced.” (Gillon R. Editor’s response. *Journal of Medical Ethics* 1999;25:60)

**g** It would take a confident High Court judge to claim a better understanding than a consultant neurologist of the clinical subtleties, treatment options, possible outcomes and social ramifications that an iPVS patient presents.

**hh** See 2.2.3 Medical Futility
medical opinion would agree that continuation was futile. It is widely recognised that doctors are under no duty to persevere with treatment that is futile. The New Zealand Medical Association Code of Ethics requires that a doctor employ “only that therapy which seems necessary for the well-being of the patient.”

This guideline has been supported by the courts. Thomas J in Re. L quotes a United States Federal Court of Appeal: “A physician has no duty to continue treatment, once it has proved to be ineffective.” Lord Goff of Chieveley states in Bland: “It follows that no such duty [to continue with life-prolonging treatment] rests upon the respondents, or upon Dr Howe, in the case of Anthony Bland,...for whom such treatment or care would, in medical terms, be futile.”

Courts have taken this view even in cases where the termination of that futile treatment will result in death: “Although there may be a duty to provide life-sustaining machinery in the immediate aftermath of a cardio-respiratory arrest, there is no duty to continue its use once it become futile in the opinion of qualified medical personnel.” Thomas J quotes Professor Glanville Williams:

“A doctor...is not bound to fight for the patient’s life forever. His duty in this respect is to make reasonable efforts, having regard to customary practice and expectations, and in particular having regard to the benefit to the patient...expected from further exertions. He need not and should not crassly fix his attention upon mere heart-beats.”

3.5.3.4 Justice: A doctor feels duty-bound to expend scarce healthcare resources wisely and fairly. This report regards indefinite treatment for iPVS patients as neither wise or fair, a belief that is supported in both commentary and in case law.

“The resources that our society allocates to health care must promote the legitimate goals of medicine. Continued treatment of permanently unconscious patients merely sustains biological life, a goal that our overburdened health care system can no longer rationally pursue.”

“The large resources of skill, labour and money now being devoted to Anthony Bland might in the opinion of many be more fruitfully employed in improving the condition of other patients, who if treated may have useful, healthy and enjoyable lives for years to come.”

---

\[a\] A change took place in the standard required of doctors when the Rogers v Whitaker ruling superseded the Bolam test. Whereas doctors had been required to apply the ‘reasonable doctor’ test in their practise (i.e. what a reasonable body of their peers would agree was good medical practice), they were now required to apply the ‘reasonable patient’ test (i.e. what a reasonable layman would expect from their doctor). Much of the application of the new principle was in the area of informed consent - what a reasonable patient would want to know about treatment options before consenting to them - and therefore little relevance to the case of an iPVS patient.

\[b\] See 2.2.6 Justice.
3.5.3.5 Best Interests: It has also been strongly argued that ‘good medical practice’ requires the termination of treatments that are not in a patient’s best interests. Indeed, such reasoning featured prominently in the Bland judgments.

“[I]t must follow that the treatment may, and indeed ultimately should, be discontinued where it is no longer in [the patient’s] best interests to continue it.”\textsuperscript{112}

“(T)he critical decision to be made is whether it is in the best interests of Anthony Bland to continue the invasive medical care involved in artificial feeding.”\textsuperscript{113}

This is not the critical decision at all. An attempt to qualify a patient’s interests directly implies that the patient has the capacity to have interests. This is misleading in the case of an iPVS patient, who possesses no such ability.\textsuperscript{kk} The most that could be said is that an iPVS patient has no further interest in being kept alive. This indifference as to whether or not treatment is continued strengthens the case for futility, which is one of the critical issues in determining what constitutes ‘good medical practice’ in the advent of iPVS.

3.5.3.6 Consulting Family and Ethical Bodies: While it is ‘good medical practice’ to be in contact with a patient’s family, and while one always hopes that their wishes will coincide with the doctor’s judgment, Skegg highlights some potential problems with the need to have their consent:

“One is that doctors would be more reluctant to provide artificial ventilation in the first place, for fear that they might thereby become obliged to continue it indefinitely. Another is that sometimes doctors would find themselves obliged to continue with artificial ventilation indefinitely... because a family member would not consent to its being withdrawn. A greater proportion of the available resources would be taken up with maintaining patients whose prospects were very poor.”\textsuperscript{114}

Much of this criticism can also be levelled at the requirement to have the consent of an ethics committee, especially the mismanagement of resources, as meetings of such bodies are rarely more frequent than fortnightly.

“[D]octors need not fear that they will be acting unlawfully if they do not follow the procedure [regarding concurrence of an ethics committee and family] approved in Re L.”\textsuperscript{115}

“Doctors should not lose sight of the fact that other New Zealand and Commonwealth case law does not suggest that life-prolonging treatment must continue until an ethics committee and a family member agree that it may be stopped.”\textsuperscript{116}

\textsuperscript{kk} See 2.3.5 The Best Interests Standard.
3.5.3.7 Good Medical Practice and Lawful Excuse Summarised: Until such time as Parliament responds to calls for legislation, the situation remains open to much criticism and confusion. In the meantime, this report supports the justification of nutrition and hydration withdrawal on the grounds that it constitutes ‘good medical practice’ and thereby ‘lawful excuse’. It is primarily the futility of ongoing nutrition and hydration as it relates to the unique case of the iPVS non-person that defines its withdrawal as good medical practice. Certainly implicit to such practice is that the condition be strictly diagnosed and confirmed by colleagues to safeguard against the possibility of individual error. Once these criteria are satisfied, a doctor would not have committed an offence under s 151 (1) Crimes Act 1961. She would have acted with ‘lawful excuse’.

“For the most part, however, it is Thomas J’s view that whatever constitutes ‘good medical practise’ provides a “lawful excuse”, for the purpose of s151, that points this area of the criminal law in a realistic and desirable direction.”

3.5.4 Section 164 Crimes Act 1961

Hastening the death of another, even if they are already suffering a terminal condition, may result in a charge of culpable homicide.

164. Acceleration of death - Everyone who by any act or omission causes the death of another person kills that person, although the effect of the bodily injury caused to that person was merely to hasten his death while labouring under some disorder or disease arising from some other cause.

This section codified a case law principle. In R v Burdee, the court reaffirmed that “acceleration of death by improper medical treatment may readily constitute the crime of manslaughter.” The burden of proof for causation is lower for charges brought under s164 than for those brought under s151: “For s164 to be invoked, it must be established that the accused’s actions were a contributory cause of the victim’s death. It need not be the only cause of death. Nor need it be the substantial cause of death.”

Thomas J was asked to comment on the applicability of s164 in Re L. He states that, in his view, the section “has little or no application to the present case” and gives the following reasons:

---

8 See 3.6 The Need for Specific iPVS Legislation.
9 This recognition formed the most ethically and metaphysically logical basis for finding ‘lawful excuse’ in both Re L and Bland. The other attempts to justify withdrawal (i.e. under doctrines of autonomy, surrogacy and best interests, etc...) have been rejected throughout this report.
10 According to the accepted regime of tests and observation discussed in Section 1: The Medical Issues.
11 R v Burdee (1916) 86 LJ KB 871 (CA) Burdee was a ‘herbalist’ who had persuaded an elderly woman to fast for three days as a cure for rheumatism. The woman died and, despite post mortem findings that a heart condition had been present for some time, the Court of Criminal Appeal upheld a charge of manslaughter.
1. That the reasons disproving causation that he gave for s151 (see above) hold also for s164. That causation finding was discounted above and commits no less of a semantic insult under s164. In fact, given the lesser burden of proof for causation required here, the indiscretion seems rather more obvious.

2. That ventilation withdrawal cannot amount to an ‘unlawful act’ when the doctors concerned have breached no duty and have ‘lawful excuse’. Therefore there is nothing with which to determine culpable homicide under s160. This is the fundamental reason to discount s164’s applicability in this case. Any section ceases to have significance once the transgression it is enacted to identify has been found lacking.99

3. That the person charged must have inflicted a ‘bodily injury’ to the victim. Thomas J felt that it would “strain the meaning of s164” to include under that the effects of ventilation withdrawal. Not necessarily. One who suffocates another has, without doubt, caused them bodily injury - the withdrawal of a ventilator has done no less. In fact, defined by the section itself, ‘body injury’ is anything that has an effect on a patient, the result of which is ‘to merely hasten his death.’

4. “There is a significant difference between hastening the hastening the death of a living person who may nevertheless be terminally ill and discontinuing a life-support system which is artificially prolonging the manifestations of ‘life’.”121

The weakness in the Re L judgment is the amount of liberal statutory interpretation it contains. Given the lack of assurance in legislation that withdrawal is justified, it is understandable that Thomas J engage in some interpretational sleight of hand in order to achieve it. However, here, as for s151 (1), he seems determined to find two or three justifications, where one would have sufficed. Promoting this degree of distortion does little to aid those who must apply these same sections to future cases. Nonetheless, applying the judgment to the case of an iPVS patient, reasons 2. and 4. above offer reassurance that a doctor withdrawing nutrition and hydration with the support of his peers, is unlikely to be convicted under s164 Crimes Act 1961. In closing, Thomas J states:

“Again, in my view, the question can be reduced to what is good medical practice. If the doctor, acting bona fide, withdraws the ventilatory-support system because, in accordance

---

99 It is worth highlighting that ventilation withdrawal not being an ‘unlawful act’ was rather presumed to directly follow the finding that doctors had ‘lawful excuse’. The two are not so linked. ‘Lawful excuse’ is only a defence for s160 (2) (b) which involves omissions; ‘unlawful act’ is under s160 (2) (a). It may be pedantic to draw such a distinction and, indeed to cover both adequately here would be to indulge in substantial repetition. However, as an example it highlights the tedious and tortuous manipulations that must be made in order to justify the withdrawal of futile treatments from the insensate under current legislation.
with recognised and approved medical opinion, it serves no therapeutic or medical benefit, he does not act unlawfully.\textsuperscript{122}

3.5.5 Section 157 \textit{Crimes Act 1961}

This section could form the grounds for a criminal charge against a doctor who failed to continue providing a life-prolonging treatment.

157. \textbf{Duty to avoid omissions dangerous to life} - Every one who undertakes to do any act the omission to do which is or may be dangerous to life is under a legal duty to do that act and is criminally responsible for the consequences of omitting without lawful excuse to discharge that duty.

This section could be interpreted as requiring a doctor, having initiated a treatment, to continue providing it regardless of a patient’s irreversible condition. Skegg believes that this could be argued and states: “Given the wording of s157, it may sometimes be desirable that those who provide artificial ventilation make it clear that it is being provided on a temporary basis, while the patient’s condition is being assessed, and that there is no undertaking to provide it indefinitely, irrespective of other conditions.”\textsuperscript{123} This is sage advice also, for those initiating nasogastric feeding in the case of any unconscious patient. Again, any charge relating to nutrition and hydration withdrawal from an iPVS patient would almost certainly be dismissed following the establishment of ‘lawful excuse’ vis-à-vis ‘good medical practice’.

3.5.6 Section 155 \textit{Crimes Act 1961}

155. \textbf{Duty of persons doing dangerous acts} - Every one who undertakes (except in case of necessity) to administer surgical or medical treatment, or to do any other lawful act the doing of which is or may be dangerous to life, is under a legal duty to have and use reasonable knowledge, skill, and care in doing such an act, and is criminally responsible for the consequences of omitting without lawful excuse to discharge that duty.

A charge brought under this section would claim that a doctor who withdrew nutrition and hydration from an iPVS patient omitted to “use reasonable knowledge, skill and [most importantly] care” which was her duty. “[T]o say that a doctor has done something negligently is often simply another way of saying that the doctor has omitted to do what a reasonably knowledgeable, skilful and careful doctor would do in the circumstances.”\textsuperscript{124} The defence would successfully argue, on the other hand, that a large majority of ‘knowledgeable, skilful and careful’ experts believe treatment withdrawal in such a situation to be ‘good medical practice’— all that is needed to establish ‘lawful excuse’.
3.5.7 Miscellaneous Sections of the *Crimes Act 1961*

There are other sections which might be applied to the case of a doctor who withdraws nutrition and hydration from an iPVS patient. However, as considerable distortion of the intended meanings would be required for such charges to be brought (and downright miscarriage of justice for convictions to follow) they will be listed here without discussion.

156. Duty of persons in charge of dangerous things
179. Aiding and abetting suicide
188. Wounding with intent
189. Injuring with intent
190. Injuring by unlawful act

3.6 The Need For Specific iPVS Legislation

The enigmatic challenge of the iPVS patient will not disappear. Cases that highlight the uncertainties of managing such patients within the existing legal framework not become any less complex. Nor will they become any less frequent. The ability of medical technology to suspend unconscious life is constantly improving. Unless Parliament moves also and outlines the limits to which such technology should be provided, cases will continue to their slow procession through the courts.

“Thenine judgments in Airedale NHS Trust v Bland, when combined with the judgment of Thomas J in Auckland Area Health Board v Attorney-General [Re. L] span close to 90 pages and exceed 64,000 words. This observation should not be construed as a criticism. If anything, the voluminous amount of judicial reasoning emphasises that Their Honours and Lordships were obliged to go to extraordinary lengths to provide results in those cases that were in accord with medical ethics and common sense. In so doing, the Courts were forced to weave a tortuous thread through common law principles and a criminal code that were forged in an era when medical technology was in its crudest infancy.”

It is a credit to the courts that they have delivered judgments containing as little distortion of ethical and legal doctrine as they have. Future cases of iPVS, whether addressed in the courts or in a medical setting, cannot expect the same calibre of deliberation. Inconsistency will only be avoided if Parliament heeds the numerous requests for legislation.

Lord Mustill: “The whole matter cries out for exploration in depth by Parliament and then for the establishment by legislation not only of a new set of ethically and intellectually consistent rules, distinct from the criminal law, but also of a sound procedural framework within which the rules can be applied to individual cases. The rapid advance of medical
technology makes this an ever more urgent task, and I venture to hope that Parliament will soon take it in hand.”

Lord Brown-Wilkinson: “…it seems to me imperative that the moral, social and legal issues raised by this case should be considered by Parliament. … If Parliament fails to act, the Judge-made law will of necessity through a gradual and uncertain process provide a legal answer to each new question as it arises. But in my judgment that is not the best way to proceed.”

“A similar plea has been made in New Zealand [Sir John Jeffries, Medico-Legal Conference, Auckland, 17 March 1993]. If ever there is a legislative response it is hoped that parliamentarians will recognise that there must be realistic boundaries to the duty to preserve life in a medical setting.”

The Bioethics Research Centre’s 1993 report on PVS recommended that the Law Reform Commission consider the following legislative options:

1. **Living Wills** legislation to sanction directions whereby competent persons give written instructions as to how they are to be managed if they become incompetent.

2. **Enduring Power of Attorney** legislation. This type of statute would enable a competent person to authorise an agent to make decisions for the principal as to how they would be managed if they became incompetent.

3. Legislation which is a combination of options 1 and 2.

4. **Substituted Judgment** legislation which permits decisions to be made by a relative or friend of an iPVS patient who has neither made a ‘living will’ nor designated another person to be the decision-maker. It is to be emphasised that substituted judgment legislation would aim to enhance the autonomy of the patient by applying the patient’s known values to circumstances in which the patient is unable to express his or her desires.

5. **Best Interests** legislation which permits doctors attending upon an iPVS patient who has not made a ‘living will’ or designated another person to make decisions concerning withdrawal or withholding treatment, provided that decision is made in conjunction with an Ethics Committee. (The Best Interests approach is appropriately reserved for those instances in which the patient’s wishes cannot be readily established.)

Much discussion in this report has already been devoted to suggesting that these are not the key ethical or legal issues in cases of iPVS. ‘Living Wills’, ‘Enduring Power of Attorney’ and
'Substituted Judgment' erroneously grant the prior wishes of the patient moral and legal omnipotence. Prospective autonomy has no application in the case of the permanently insensate. The 'Best Interests' approach has also been found to have no place in discussions regarding iPVS patients. Instead, the subsections below outline the legislative areas in which, this report believes, changes are necessary to enable cases of iPVS to be managed without contradiction or constant recourse to the courts.

3.6.1 Legislation Granting iPVS a Unique Legal Status.

If we continue to apply legal and ethical principles to iPVS patients as though they are our equals, the results will be convoluted and contradictory. When individuals cannot be satisfactorily described as living or dead, but exhibit characteristics of both, the answer lies in the medical, ethical and legal acknowledgement of a unique 'intermediate' state. It is misleading to treat iPVS patients as legally equivalent to conscious persons. They have forfeited certain legal rights reserved for persons alone. On the other hand, society's intuitive respect for what was once a person prevents them from being defined as dead. In the same way that a body has great symbolic significance, so too have the functions of respiration and circulation. Only if Parliament recognises iPVS patients as a unique group, qualifying as neither corpses nor citizens, will it be able to successfully legislate specific guidelines for their management.

Will there be adverse effects for other disabled members of society? Is this a slippery slope? Are there other groups that will be next to lose citizenship? Not unless the initial premise is ignored: that the patient has irreversibly lost all capacity for consciousness and cognition. While some argue that it is a syndrome, common to all definitions is the insistence that all evidence of awareness is permanently absent. Diagnosis does not rely on a subjective measurement of the quantity of consciousness and cognition. If thorough assessment reveals any sign that confirms higher brain function is present, the patient ceases to belong to the iPVS group.

---

91 See 2.3.4 The Problem with Prospective Autonomy and 3.4.5 Advance Directives and the iPVS Patient.
92 See 2.3.5 The Best Interests Standard
93 The medical community has recently attempted to formally recognise those in a minimally conscious state (MCS) - see 1.5.5 Minimally Conscious State. The emerging ethical issues of this 'new' group of patients have also been reviewed - see 2.4.2 Patients in 'Near-PVS'. Already cases of MCS have come before the courts (as the Lords in Bland predicted) and these are likewise mentioned in brief. Commenting on the extensive legal implications of this quite different group lies outside the scope of this report. Indeed, detailed discussion of the medical, moral and legal issues of MCS would require its own thesis. Suffice to say that the recommendations herein apply only to iPVS patients.
3.6.2 Legislation Protecting and Guiding Doctors

As it addresses the fact that iPVS patients are a unique category, Parliament must also recognise that the doctors who treat them are in a unique situation. Current courses of action recommended by medical and ethical bodies run dangerously close to criminal offences. Indeed many criminal and common law principles must be distorted in order to avoid culpability when they are applied to iPVS patients. To avoid the continued expenditure and statutory dilution of future court cases, Parliament should also undertake the following:

- **Legislation that repeals the applicability of criminal and common law principles to iPVS patients**, in particular, sections of the *Crimes Act 1961*; including s151, s157, s160, and s164. iPVS patients no longer require the protection that the *Crimes Act 1961* offers and, thus, its sections can do little more than distract attention from the real issues that their management presents.

- **Replace the above with legislation specific to the treatment of iPVS patients.** Such new law should include:
  1. Procedure for correct diagnosis.
  2. Guidelines on medical treatment and rehabilitation.
  3. Time-frames for when treatment withdrawal would be considered appropriate.
  4. Confirmation that the decision to withdraw treatment is ultimately a clinical one and is, in fact, ‘good medical practise’.
  5. Examples of extenuating circumstances that might allow for a deviation from the guidelines or recourse to the courts.

Doctors could then follow specific iPVS guidelines without being “inhibited by considerations pertinent to their own self-interest in avoiding criminal sanctions.” They would know that only failure to comply with these guidelines would result in them facing prosecution.

3.6.3 Legislation Addressing the Effects in Other Legal Areas

Recognising a unique intermediate state between life and death will alter the applicability of other areas of criminal and civil law to the iPVS patient. These will have to be carefully examined and repealed or amended by new legislation if necessary.

---

*either outlined in legislation itself or, more likely, legislation ratifying guidelines set out by an approved medical authority.*
a) Criminal Law:

- Statutes in the Crimes Act 1961 that apply to the punishment of those who render someone in a state of iPVS through unlawful action - e.g. an assault. At present, such an action is culpable under s197.

197. **Disabling** - Every one is liable to imprisonment for a term not exceeding 5 years who, wilfully and without lawful justification or excuse, stupefies or renders unconscious any other person.

Five years does not seem fitting punishment for someone who has caused so grave and so permanent a state as iPVS to befall another. Alternatively, a charge under s166 could be laid:

166. **Causing injury the treatment of which causes death** - Every one who causes to another person any bodily injury, in itself of a dangerous nature, from which death results, kills that person, although the immediate cause of death be treatment, proper or improper, applied in good faith.

Is it fair that the one responsible for causing the state of iPVS be found guilty of culpable homicide if the ‘treatment’ of that particular state is nutrition and hydration withdrawal?

b) Civil law:

- laws of property and ownership
- laws of marriage
- laws of estate.

“Once a human being no longer participates in the world of persons, it would seem that their legal interests are as void as their intentional and ethical engagement and that their affairs should be settled in the prescribed ways.”

3.6.4 Advance Directive Legislation

Notwithstanding the comments made earlier in this section, there is a place for advance directives in this medico-legal area:

1. In the case of a patient who is in PVS but whom has not yet been diagnosed as irreversible. Some members of the public may find it repugnant to even spend even a few months in such a condition. They would benefit from a system whereby individuals ‘opt out’, thereby having nutrition and hydration withdrawn before the time-frame in the guidelines.

2. In cases where patients are disabled with conditions not as serious as iPVS. In Re. L and the recent case of Mr. G, court orders have had to be sought to allow treatments to be
withdrawn. Recourse to the courts might have been avoided had a legal advance directive been able to prove the expressed prior wishes of the patients involved.\textsuperscript{109}

Initiating such a system would be no straightforward task:

- The establishment would be both time consuming and expensive.
- There is no evidence that the incidence of the conditions in which advance directives would apply warrant such attention.
- There is ample evidence from the United States that indicates a poor response rate, even with the system in place.
- The range of conditions that advance directives would have to cover would be extensive. Even more so would be the directives themselves to outline the patient’s wishes for each scenario.

### 3.7 Summary of Legal Issues

While there has been much discourse over whether it is appropriate to legislate a definition of death, such legislation remains conspicuous by its absence. Left to draw its own conclusions about when to ascribe a diagnosis of death, the medical profession here has followed advances made in other countries; the latest of which has been an adoption of brain death criteria. However, although the diagnosis of death is medical, the definition must be legal. Thus, in determining the status of an iPVS patient, courts have had to apply the common law, given the absence of a statutory definition of death. None of the case law to date has allowed iPVS patients, or any persons in permanent states of extreme disability, to be defined as dead. Judges have, however, suggested that there is sufficient change in societal attitude to prompt a revision of the issue. This, they emphasise, is the role of parliament not the courts. Such revision, rather than expanding the definition of death to include iPVS patients, should legally recognise them as a distinct group, as they have already been recognised medically and ethically. Those in iPVS have forfeited certain legal rights reserved for conscious persons alone, but to define them as dead would introduce more problems than it would solve.

The Health and Disability Commissioner Act 1994 and its Code clearly outline the rights of healthcare consumers. Right 4 is a right to services of an appropriate standard and requires that every patient

\textsuperscript{109} In neither case was the patient in iPVS - see 2.4.2 Patients in Near 'PVS'. The Re. L judgment has been extensively referred to because it discusses thoroughly the issues surrounding futility of treatment and 'good medical practice', not because Mr L's condition was considered equivalent to iPVS.
receive healthcare that is consistent with their needs in a manner that minimises harm and optimises quality of life. Applying that right to a PVS patient, there is a duty to provide treatment during the period in which the diagnosis is uncertain, followed by an obligation to withdraw that treatment once the condition is deemed irreversible. Some commentators feel that such an action would be inherently discriminatory under section 21 of the Human Rights Act 1993. However, in the case of the iPVS patient, the patient’s disability has directly invalidated the benefit of that treatment. **If it is discriminatory to withdraw nutrition and hydration from a patient once they are diagnosed as being in iPVS, then it must be discriminatory to ever withdraw health services from anyone, regardless of changes in their medical condition.** This suggestion is as medically irresponsible as it is economically impossible and, in terms of resource allocation, ethically repugnant.

Doctors have a legal duty to obtain consent from a patient before proceeding with any examination or treatment. Failure to do so not only violates the right to make informed choice and give informed consent outlined in the Health and Disability Commissioner’s Code, it can result in a criminal offence of assault under the Crimes Act 1961. However, in the case of an incapacitated patient, courts have recognised that health professionals must be given latitude to minister without such consent. In fact, the Crimes Act 1961 demands that they provide such patients with the necessities of life. Once a formerly incapacitated patient regains the ability to make decisions, they are entitled to have treatment stopped. Herein lies the problem for iPVS patients. Do they, by way of their permanent incapacity, continue to forfeit the right to have treatment withdrawn? The Lords in Bland were of the opinion that a patient’s incapacity to communicate his wishes should not doom him to a lifetime of involuntary and intrusive treatment. **The mistake they and other courts have made is to focus on how to justify exercising that right on the iPVS patient’s behalf. Instead they should be asking, ‘Does this non-person have rights at all?’**

Many legislatures are in the process of introducing advance directives, which provide a more definite insight into a patient’s wishes than the speculation of a substituted judgment. Advance directives take the form of: a Living Will – in which written instructions indicate an individual’s future treatment preferences, or; a Durable Power of Attorney – an agent pre-authorised to make treatment decisions on their behalf. Despite their practical difficulties, advance directives are becoming increasingly popular in the United States, where doctors are keen to immunise themselves in the litigious environment of end-of-life treatment decisions. Here in New Zealand the application of a living will or durable power of attorney to an iPVS patient has not been legally recognised in common law or in statute. While it is ‘good medical practice’ to give consideration to any prior oral or written instruction of the patient, a doctor is not compelled to follow those wishes.
Implicit in the reliance on advance directives is the presumption that patients are going to make prospective decisions to refuse treatment; little consideration is given to the alternative possibility – that a patient may request all medical measures to be continued beyond the limits deemed appropriate by a majority. The alternative (offering an individual the choice of ‘any treatment option as long as it’s withdrawal’) contradicts the very essence of autonomy. In any case, as it will never be of consequence to the iPVS patient which option is implemented, the principle of autonomy no longer applies to them. It is on the grounds that it accords with ‘good medical practice’ that treatment should be withdrawn in all iPVS cases; not under the delusory premise that a formerly conscious patient has been given free reign over his treatment options.

The right to life is woven into the very fabric of society. Indeed, as the most heinous of crimes, murder earns those convicted of it society’s harshest penalties – with few exceptions. Has the withdrawal of nutrition and hydration from iPVS patients been established in law to be grounds for exception? Section 151 Crimes Act 1961 charges doctors with a duty to provide the necessaries of life and holds them criminally responsible for omitting without lawful excuse to perform such a duty, if the death of a person under their care is caused by such an omission. Courts have found that doctors have lawful excuse to withdraw treatment from iPVS patients because it constitutes ‘good medical practice’. Such actions have been decreed so on the principles of futility and justice, and because they meet with general approval from the medical profession.

Section 164 Crimes Act 1961 makes culpable of homicide anyone who, by an unlawful act, hastens the death of another person. Again courts have held the statute to have little or no application in the case of an iPVS patient because of the agreement that such action is good medical practice prevents it from being unlawful. In fact, it is almost certain that any charge of homicide brought against an iPVS patient’s doctor will be unsuccessful once ‘lawful excuse’ vis-à-vis ‘good medical practice’ is established.

The valiant but tortuous attempts by courts to apply 19th century law to this 21st century medical dilemma has highlighted the need for change. Failure of the law to modernise, as medical technology has done, will continue to result in confusion and recourse to the courts. Simple suggestions to canonise ‘Living Wills’, ‘Enduring Power of Attorney’ and ‘Substituted Judgment’ erroneously grant the prior wishes of the patient moral and legal omnipotence. This is not to say that there is no place for advance directive legislation in New Zealand. Such legislation could allow the public to authorise that treatment be withdrawn, either in the period before their PVS has been diagnosed as irreversible, or in situations where they are not in true iPVS. More importantly, parliament needs to legally
recognise iPVS patients as a unique group, qualifying neither as corpses nor citizens. In so doing it must repeal the applicability of criminal and common law principles to iPVS patients, replacing them with legislation endorsing specific guidelines for their management.
SUMMARY AND RECOMMENDATIONS

Irreversible Persistent Vegetative State (iPVS) is a clinical condition of total and permanent unconsciousness with partially preserved brainstem function. The diagnosis must involve careful observation and neurological examination, as other severely debilitating conditions can initially appear identical. PVS patients are not terminally ill. With appropriate feeding and medical care there are reports of patients living for many years: the economic cost of this survival is significant. PVS patients do not fit any group that clinicians, ethicists or judges have been familiar with. They are not brain dead and the bioethical paradox of a spontaneously-breathing cadaver precludes them from being so defined. Yet they are not alive in anything more than a technical sense. Whether or not commentators agree upon what exactly defines personhood, all acknowledge that iPVS patients fail to meet the requisite criteria to be persons. The fundamental theme of this report is that iPVS patients are neither persons nor corpses, but a separate unique group who should be recognised and treated as such.

Almost all iPVS patients are artificially fed nutrient-rich liquid diets through a nasogastric or gastrostomy tube. Although most clinicians and laymen agree that such feeding is both a medical treatment and an ordinary care, neither finding is hugely significant. How one regards a medical treatment will ultimately depend on what one sees as the legitimate goals of medicine. The underlying principle in determining legitimate goals of medicine is that without proven, presumed or prospective benefit, the pursuance of an outcome is difficult to defend. In the case of a permanently unconscious patient, it is impossible to justify continued feeding at the expense of real benefit to other sentient patients. So low is the priority of treatment for an iPVS patient, ‘good medical practise' vis-à-vis distributive justice demands that those resources be employed elsewhere.

Withdrawal of nutrition and hydration has been thoughtfully promoted by clinicians as the most appropriate method of bringing about an iPVS patient’s death - usually through electrolyte imbalance and dehydration. The obvious physical manifestations of acute dehydration can be minimised with continued nursing care. All but a small minority of healthcare professionals are satisfied that, lacking the primary locus for consciousness, PVS patients are unable to experience pain and suffering.

The main failing of the subjective and substituted judgment standards as a justification for treatment withdrawal is that they are founded on prospective autonomy. As it will never be of consequence to the iPVS patient whether or not their wishes are followed, the principle of autonomy no longer applies to them. Similarly, the best interests standard focuses on what the interests of an iPVS patient are and who should decide them, rather than asking the question: Can a permanently unconscious patient have
interests? It is contradictory to identify the cares, thoughts or feelings of one who can never again care, think or feel.

It is also somewhat of an irony to refer to the permanently unconscious patient as disabled. They are not simply blind, paralysed or disorientated: they have lost anything and everything that makes human life unique. Therefore precedents pertaining to them cannot be stretched or diluted to apply to others unless the initial premise is ignored: that the patient has irreversibly lost all capacity for consciousness and cognition. Likewise, as iPVS patients are not persons, much of the emotionally-charged discourse surrounding euthanasia does not belong in discussions of nutrition withdrawal. In their case, ‘Exactly what is dying?’ becomes a more important question than ‘How will they die?’

**iPVS patients are unique and so must be our legal and ethical approach to them.**

---

**A. Guidelines for the Management of PVS Patients**

1. Treatment should be commenced for all patients suspected of being in a vegetative state while the diagnosis is uncertain. This must include provision of nutrition and hydration and routine nursing cares.

2. The diagnosis of PVS must be made as carefully as possible and involve repeated examination, preferably by more than one specialist in neurology.

3. After the following time periods in PVS, the condition is said to be irreversible.
   - PVS should be considered irreversible (i.e. iPVS) after 12 months in the case of traumatic injury.
   - PVS should be considered irreversible after 6 months in the case of nontraumatic injury.
   - PVS should be considered irreversible if caused by a degenerative or metabolic disease.
   - PVS should be considered irreversible if an infant is anencephalic or has shown no signs of consciousness by 6 months of age.

4. When the diagnosis is certain and the appropriate time period has been observed, nutrition and hydration should be withdrawn.

5. When a decision has been made to withdraw nutrition and hydration, the patient should continue to receive routine nursing and medical cares. It would, however, be inappropriate to intervene with any life-saving or life-prolonging treatment during this terminal period. (For example, resuscitative measures or intravenous antibiotics.)
6. Patients in iPVS should not be considered candidates for organ donation.

B. The Decision-Making Process

1. The decision to withdraw nutrition and hydration should be routinely made by the healthcare team once irreversible PVS has been diagnosed; in accordance with ‘good medical practice’. It is a decision based on the unique status of the iPVS patient, the impossibility of any present or future benefit to them, the subsequent futility of ongoing treatment, and the recognition that medical professionals are required to distribute health care in a wise and fair manner.

2. It is desirable to involve family and friends early in the treatment and discussion surrounding a PVS patient. They should be given appropriate counselling and support as they slowly come to understand a condition that may prove to be permanent. While it is always preferable to have family understand and consent to a course of action, lack of unanimity should not affect the team’s decision to discontinue treatment once the requisite criteria have been met.

3. Likewise the prior wishes of the patient do not change the medical realities of iPVS. During the period before a prognosis of irreversibility has been made, there is an opportunity for PVS patients to opt out of treatment early, by way of an advance directive or unanimous agreement by family, friends and staff about their stated wishes and life ethos. However, prior expressed wishes or advanced directives implying that a patient has an option to have treatment continued, beyond such time as their PVS becomes irreversible, have no place in the decision-making process.

4. Any medical staff who are uncomfortable being involved in a decision to withdraw treatment shall be allowed to excuse themselves from the decision-making process and continued involvement with that patient, without fear of recrimination. Occasionally this may require the transfer of the patient’s care to that of another specialist or ward.

5. Under exceptional circumstances, the medical team may wish to seek the advice of another medical specialist, ethical commentator/committee, or legal representative. While the team should not feel obliged to follow all or any of the subsequent recommendations, it should recognise that such advice may well be highlighting the complex or volatile nature of that particular case. In that event, it would be prudent to continue nutrition and hydration until a resolution can be found.
C. Recommended Legislation

1. Legislation recognising iPVS patients as a unique group of living non-persons and repealing or amending the necessary sections of criminal and civil law. (For example, statutes in the *Crimes Act 1961* that apply to the punishment of those who render someone in a state of iPVS through unlawful action; civil laws of property, ownership and marriage.)

2. Legislation outlining appropriate way to manage the treatment of an iPVS patient as above: either statutory directions or, more likely, legislation ratifying guidelines set out by an approved medical authority.

3. Legislation protecting medical staff from being charged under sections in the *Crimes Act 1961*, or from being issued civil proceedings, for following those guidelines.

4. Legislation allowing the development, and recognition, of advance directives in the form of living wills and durable powers of attorney. These will only be used in the period before a patient’s PVS has been diagnosed as irreversible.

There will, of course be some who find these recommendations repugnant – either because they promote the ending of a human life or because they do so after period that is reckoned to be too short. Those concerns have prompted a thought-provoking response from Raanon Gillon:

"Let them and their sympathisers seek sufficient support from like minded members of the public to establish privately funded hospices in which, unlike the current hospice movement, patients in the persistent vegetative state are kept alive. Let them carry out prospective research. If its results and quality are sufficiently impressive they will persuade colleagues, the public, the media, and, if necessary, parliament that such treatment should be provided by the National Health Service. **Meanwhile I suspect that most of us believe that the one year of life support recommended...is more than sufficient to reconcile the moral requirements of (possible) benefit to the patient with justice to all.**" (Gillon R. Patients in the persistent vegetative state: a response to Dr. Andrews. *BMJ* 1993;306:1602-3 Bold added.)
# Appendix: Causes of PVS

## Acute Injuries

### Traumatic
- Motor vehicle accidents
- Gunshot wound or other direct cerebral injury
- Non-accidental injury in children
- Birth injury

### Non-traumatic
- Hypoxic-ischaemic encephalopathy
  - Cardiorespiratory arrest
  - Perinatal asphyxia
  - Pulmonary disease
  - Prolonged hypotensive episode
  - Near-drowning
  - Suffocation or strangulation
- Cerebrovascular injury
  - Cerebral haemorrhage
  - Cerebral infarction
  - Subarachnoid haemorrhage
- Central nervous system (CNS) infection
  - Bacterial meningitis
  - Viral meningoencephalitis
  - Brain abscess
- CNS tumour
- CNS toxins or poisoning
  - (eg. Carbon monoxide)

## Degenerative & Metabolic Disorders

### In Adults
- Alzheimer's disease
- Multi-infarct dementia
- Pick's disease
- Creutzfeldt-Jakob disease
- Parkinson's disease
- Huntington's disease

### In Children
- Ganglioside storage disease
- Adrenoleukodystrophy
- Neuronal ceroid lipofuscinosis
- Organic aciduria
- Mitochondrial encephalopathy
- Gray-matter degenerative disorders

## Developmental Malformations
- Anencephaly
- Hydranencephaly
- Lissencephaly
- Holoprosencephaly
- Encephalocele
- Schizencephaly
- Congenital hydrocephalus
- Severe microencephaly
REFERENCES

SECTION 1: THE MEDICAL ISSUES

3. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
5. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
8. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
9. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
10. Jennett B, Plum F. 1972 (see Ref. 2).
11. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
12. Jennett B, Plum F. 1972 (see Ref. 2).
13. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
16. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
17. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
18. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
19. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
20. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
21. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
22. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
25. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
26. Report for the Medical Council of New Zealand by the Bioethics Research Centre, University of Otago. *Persistent Vegetative State and the Withdrawal of Food and Fluids*. 1993. p5. (Copies available through the Bioethics Research Centre, PO Box 913, Dunedin, NZ.)
27. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
28. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
29. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
31. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
32. Jennett B. 1993 (See Ref. 24)

34. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)


36. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)


40. The Multi-Society Task Force on PVS: Part One. 1994. (see Ref. 1)

41. The Multi-Society Task Force on PVS: Part One. 1994. (see Ref. 1)

42. Levy DE et al. 1987 (see Ref. 37)

43. The Multi-Society Task Force on PVS: Part One. 1994. (see Ref. 1)


47. Bioethics Research Centre Report. 1993 (see Ref. 26) p5.


49. The Multi-Society Task Force on PVS: Part One. 1994. (see Ref. 1)


51. The Multi-Society Task Force on PVS: Part One. 1994. (see Ref. 1)

52. Jennett B, Plum F. 1972 (see Ref. 2)

53. The Multi-Society Task Force on PVS: Part One. 1994. (see Ref. 1)


56. Bernat JL. 2002. (see Ref. 55)


62. The Multi-Society Task Force on PVS: Part One. 1994. (see Ref. 1)


69. Childs NL, Mercer WN. Late improvement in consciousness after post-traumatic vegetative
70. Childs NL, Mercer WN. 1996 (see Ref. 69)
71. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
72. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
73. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
74. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
75. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
76. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
77. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
78. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
79. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
Practise parameters: Assessment and management of patients in the persistent vegetative
81. Review by a Working Group convened by the Royal College of Physicians. The permanent
82. New Zealand Medical Association Public Issues Advisory Committee. Policy Paper:
Persistent Vegetative State. 10 August 1994. Copies available through NZMA, 26 The
Terrace, PO Box 156, Wellington.
83. Bioethics Research Centre Report. 1993 (see Ref. 26)
84. New Zealand Medical Association Public Issues Advisory Committee. 1994. (see Ref. 82)
331(20):1382
Practise parameters: Assessment and management of patients in the persistent vegetative
87. The Multi-Society Task Force on PVS. Part Two: 1994. (see Ref. 66)
88. Andrews K. Recovery of patients after four months or more in the persistent vegetative
89. Andrews K, Murphy L, Munday R, Littlewood C. Misdiagnosis of the vegetative state:
91. Andrews K, Murphy L, Munday R, Littlewood C. 1996. (see Ref. 89)
92. Ashwal S, Cranford R. 1994 (see Ref. 60)
94. Cranford RE. 1988 (see Ref. 60)
1992;May-June:2-3.
96. The Multi-Society Task Force on PVS: Part One. 1994 (see Ref. 1)
97. Cranford RE. 1988. (see Ref. 60)
98. The Multi-Society Task Force on PVS. Part Two: 1994 (see Ref. 66)
99. Bioethics Research Centre Report. 1993 (see Ref. 26)
100. Giacino JT, et al. 2002. (see Ref. 54)
101. The Multi-Society Task Force on PVS: Part Two: 1994 (see Ref. 66)
103. Boyd KM. Withdrawal of life-support from patients in a persistent vegetative state. The
104. Andrews K. Should PVS patients be treated? Neuropsychological Rehabilitation
105. The Multi-Society Task Force on PVS. Part Two: 1994 (see Ref. 61)
107. Andrews K. 1993. (see Ref. 104)
112. Kennard C, Illingworth R. 1995 (see Ref. 6)
113. The Multi-Society Task Force on PVS. Part Two: 1994 (see Ref. 66)
116. The Multi-Society Task Force on PVS. Part Two: 1994 (see Ref. 66)
117. Kinney HC, et al. 1994 (see Ref. 23)
119. Bioethics Research Centre Report. 1993 (see Ref. 26)
121. Jennett B. 1993 (See Ref. 24)
122. The Multi-Society Task Force on PVS. Part Two: 1994 (see Ref. 66)
123. Airedale NHS Trust v Bland: [1993] 2 A.C. 789-899 at 832
SECTION 2: THE ETHICAL ISSUES

2. Report for the Medical Council of New Zealand by the Bioethics Research Centre, University of Otago. Persistent Vegetative State and the Withdrawal of Food and Fluids. 1993. p9. (Copies available through the Bioethics Research Centre, PO Box 913, Dunedin, NZ.)
7. Gillett G. 1994. (see Ref. 6)
9. Gillett G. 1994. (see Ref. 6)
20. Gillett G. 1994. (see Ref. 6)
21. Stanley JM. 1987. (see Ref. 18)
30. Andrews K. 1993. (see Ref. 29)
31. Airedale NHS Trust v Bland (see Ref. 28) at 858.


35. Airedale NHS Trust v Bland (see Ref. 28) at 834.

36. Gillon R. 1993. (see Ref. 26)

37. Bioethics Research Centre Report. 1993. p33. (See Ref. 2)


40. Schrode KE. 1995. (see Ref. 30) p1650.


46. Mitchell KR, Kerridge IH, Lovat TJ. 1993. (see Ref. 41)

47. Mitchell KR, Kerridge IH, Lovat TJ. 1993. (see Ref. 41)


52. Weijer CW, Singer PA, Dickens BM, Workman S. 1998. (See Ref. 51)

53. Brody B. 1992. (see Ref. 12)

54. Schneiderman LJ, Jecker NS, Jonsen AR. 1990. (see Ref. 50)


58. McCrory SV, Swanson JW, Youngner SJ, Perkins HS, Winslade WJ. 1994. (see Ref. 56)

59. Brody B. 1992. (see Ref. 12)

60. Cranford RE, Smith DR. 1987. (see Ref. 17)

61. McCrory SV, Swanson JW, Youngner SJ, Perkins HS, Winslade WJ. 1994. (see Ref. 56)


63. Mitchell KR, Kerridge IH, Lovat TJ. 1993. (see Ref. 41)


66. Gillon R. 1993. (see Ref. 26)


68. Winslade WJ. 1998. p64 - from draft supplied to author in 1995. (see Ref. 62)

69. Brody B. 1992. (see Ref. 12)


71. Cranford RE, Smith DR. 1987. (see Ref. 17)

72. Jennett B. 1992. (see Ref. 33)

73. Schrode KE. 1995. (see Ref. 30) p1642.

74. Gillon R. 1993. (see Ref. 26)

75. Schrode KE. 1995. (see Ref. 30) p1665.

76. Brody B. 1992. (see Ref. 12)

77. Gillon R. 1993. (see Ref. 26)


80. Gillett G. PVS, feeding tubes, and medical futility. *University of Otago Bioethics Research Centre Newsletter* 1993;2(2):6-7 (Copies available through the Bioethics Research Centre, PO Box 913, Dunedin)

81. Cranford RE, Smith DR. 1987. (see Ref. 17)


84. Schrode KE. 1995. (see Ref. 30) p1638.

85. Cranford RE, Smith DR. 1987. (see Ref. 17)

86. Gillett G. 1994. (see Ref. 6)

87. Finnis JM. 1993. (see Ref. 11)

88. Mitchell KR, Kerridge IH, Lovat TJ. 1993. (see Ref. 41)


90. Mitchell KR, Kerridge IH, Lovat TJ. 1993. (see Ref. 41)

91. Troug RD, Brett AS, Frader J. 1994. (see Ref. 48)

92. Cranford RE, Smith DR. 1987. (see Ref. 17)


94. Gillon R. 1993. (see Ref. 26)


98. Schrode KE. 1995. (see Ref. 30) p1649.

99. *Airedale NHS Trust v Bland* (see Ref. 28) at 879.


102. Winslade WJ. (see Ref. 93) p29.


104. Gillett G. 1994. (see Ref. 6)

105. Schrode KE. 1995. (see Ref. 30) p1667.

106. Schrode KE. 1995. (see Ref. 30) p1650.

108. Bontke CF, Dolan JM, Ivanhoe CB. 1994. (see Ref. 100)
109. Beauchamp TL, Childress JF. 1994 (see Ref. 65) p145-6
111. Cranford RE, Smith DR. 1987. (see Ref. 17)
112. Schrode KE. 1995. (see Ref. 30) p1625
113. Schrode KE. 1995. (see Ref. 30) p1625.
115. *Airedale NHS Trust v Bland* (see Ref. 28) at 828.
117. Schrode KE. 1995. (see Ref. 30) p1640.
118. Schrode KE. 1995. (see Ref. 30) p1641.
119. President's Commission for the study of Ethical Problems... 1983. (see Ref. 38)
120. Bioethics Research Centre Report 1993. p14. (See Ref. 2)
121. *Airedale NHS Trust v Bland* (see Ref. 28) at 868.
122. *Airedale NHS Trust v Bland* (see Ref. 28) at 896.
123. McLean SAM. Legal and ethical aspects of the vegetative state. *Journal of Clinical Pathology* 1999;52:490-3
125. *Airedale NHS Trust v Bland* at 858.
126. Finnis JM. 1993. (see Ref. 11)
128. McLean SAM. 1999 (see Ref. 123)
129. Fenwick AJ. (see Ref. 127)
132. Serafini A. 1992. (see Ref. 130)
133. Gillett G. 1992. (see Ref. 131)
134. Gillett G. 1992. (see Ref. 131)
135. Brody B. 1992. (see Ref. 12)
136. Weijer C. 1998. (see Ref. 55)
137. Weijer C. 1988. (see Ref. 55)
138. Winslade WJ. 1993. (see Ref. 16)
139. Bontke CF, Dolan JM, Ivanhoe CB. 1994. (see Ref. 100)
140. Andrews K. 1993. (see Ref. 29)
142. Schrode KE. 1995. (see Ref. 30) p1628
143. Andrews K. 1993. (see Ref. 29)
144. Schrode KE. 1995. (see Ref. 30) p1629.
145. Tomlinson T, Czlonka D. 1995. (see Ref. 45)
146. Andrews K. 1993. (see Ref. 29)
147. Andrews K. 1992. (see Ref. 82)
149. Wikler D. 1888. (see Ref. 34)
150. Wikler D. 1888. (see Ref. 34)
151. Cranford RE, Smith DR. 1987. (see Ref 17)
152. Gillon R. 1993. (see Ref. 26)
153. *Airedale NHS Trust v Bland* (see Ref. 28) at 835
155. Coleman D. Correspondence. *Neurology* 2002;58:506
157. *In the Matter of a Ward of Court* [1995] 2 ILRM 401 (SC) at 417
160. Schrodé KE. 1995. (see Ref. 30) p1637.
162. Andrews K. 1992. (see Ref. 82)
165. *Airedale NHS Trust v Bland* (see Ref. 28) at 885.
166. *Airedale NHS Trust v Bland* (see Ref. 28) at 865.
168. *Airedale NHS Trust v Bland* (see Ref. 28) at 832.
SECTION 3: THE LEGAL ISSUES

9. Joe v Joe (see Ref. 8) at 679.
10. Joe v Joe (see Ref. 8) at 679.
12. Joe v Joe (see Ref. 8) at 680.
13. Joe v Joe (see Ref. 8) at 680.
14. Ad Hoc Committee of Harvard Medical School... 1968. (see Ref. 4)
15. Joe v Joe (see Ref. 8) at 682.
16. Joe v Joe (see Ref. 8) at 682.
17. Joe v Joe (see Ref. 8) at 682.
18. Joe v Joe (see Ref. 8) at 682.
19. Joe v Joe (see Ref. 8) at 684.
21. Re L (see Ref. 20) at 235.
23. Re L (see Ref. 20) at 246
24. Re L (see Ref. 20) at 245
25. Re L (see Ref. 20) at 247
26. Re L (see Ref. 20) at 242
29. Airedale NHS Trust v Bland (see Ref. 28) at 878.
30. Airedale NHS Trust v Bland (see Ref. 28) at 863.
31. Airedale NHS Trust v Bland (see Ref. 28) at 878.
32. Airedale NHS Trust v Bland (see Ref. 28) at 850.
33. Thalblum D. PVS and immortality: if this is technically life, the legal definition of death should change. UMKC Law Review. 1991, (59) 439-67.
35. Cruzan v Missouri Dept. of Health, 110 S. Ct. at 2859.
41. Cranford RE, Smith DR. 1987. (see Ref. 39)
44. Skegg PDG. 1988. (see Ref. 7) p218.
49. Schrode KE. 1995. (see Ref. 34) p1654.
50. Schrode KE. 1995. (see Ref. 34) p1655.
52. United States v University Hospital 729 F.2d at 144
53. Schrode KE. 1995. (see Ref. 34) p1656.
54. Schrode KE. 1995. (see Ref. 34) p1662.
55. Schrode KE. 1995. (see Ref. 34) p1662.
57. Skegg PDG. 1988. (see Ref. 7) p33.
61. Airedale NHS Trust v Bland (see Ref. 28) at 850.
62. Airedale NHS Trust v Bland (see Ref. 28) at 883.
63. Airedale NHS Trust v Bland (see Ref. 28) at 865.
64. Airedale NHS Trust v Bland (see Ref. 28) at 830.
68. Cantor NL. 1993. (see Ref. 66) p33.
69. Cantor NL. 1993. (see Ref. 66) p34.
70. Cantor NL. 1993. (see Ref. 66) p42.
71. Cantor NL. 1993. (see Ref. 66) p43.
72. Cantor NL. 1993. (see Ref. 66) p34.
73. Cantor NL. 1993. (see Ref. 66) p35.
75. Cantor NL. 1993. (see Ref. 66) p25.
76. Cantor NL. 1993. (see Ref. 66) p35.
77. Cantor NL. 1993. (see Ref. 66) p35.
78. Report for the Medical Council of New Zealand by the Bioethics Research Centre,
University of Otago. Persistent Vegetative State and the Withdrawal of Food and Fluids. 1993. Copies available through the Bioethics Research Centre, PO Box 913, Dunedin p23.

79. Bioethics Centre Report. 1993. (see Ref. 78)
80. Re L (see Ref. 20) at 244.
81. Airedale NHS Trust v Bland (see Ref. 28) at 808.
82. Re L (see Ref. 20) at 244.
83. Re L (see Ref. 20) at 248.
84. Skegg PDG. 1988. (see Ref. 7) p166.
85. Skegg PDG. 1988. (see Ref. 7) p167.
86. Skegg PDG. 1988. (see Ref. 7) p167.
87. Re L (see Ref. 20) at 249.
88. Re L (see Ref. 20) at 249.
89. Re L (see Ref. 20) at 248 and 250.
90. Re L (see Ref. 20) at 248.
92. R v Burney [1958] NZLR 745 (CA) at 753.
95. Re L (see Ref. 20) at 250.
97. Bolam v Friern Hospital Management Committee [1957] 2 All ER 118.
101. Rogers v Whitaker High Court of Australia (1992) 175 CLR 479.
105. Barber v Superior Court of the State of California for the County of Los Angeles pp, 195 Cal Rptr 484 (1983) (US:CA) in Re L (see Ref. 20) 252.
106. Airedale NHS Trust v Bland (see Ref. 28) at 869.
107. Barber v Superior Court of the State of California for the County of Los Angeles see Ref. 106): in Re L (see Ref. 20) at 252.
108. Re L (see Ref. 20) at 253.
110. Airedale NHS Trust v Bland (see Ref. 28) at 896.
111. Airedale NHS Trust v Bland (see Ref. 28) at 867.
112. Airedale NHS Trust v Bland (see Ref. 28) at 884.
113. Skegg PDG. 1994. (see Ref. 92) p221.
119. Re L (see Ref. 20) at 254.
120. Re L (see Ref. 20) at 255.
121. Re L (see Ref. 20) at 255.
122. Re L (see Ref. 20) at 255.
126. Airedale NHS Trust v Bland 891.
127. Airedale NHS Trust v Bland 879.
130. Re L (see Ref. 20) at 253.
131. Stanley JM, Gillett G. 1987 (see Ref.40)