

INTERNATIONAL WORKING PARTY
REPORT ON
THE VEGETATIVE STATE

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PREFACE

This International Working Party was set up because several clinicians specialising in rehabilitation and chronic care were expressing concern that there was a general misunderstanding about the potential and management needs of patients in what is known as the 'Persistent Vegetative State'. A number of Working Parties had previously been set up but these had mainly been to discuss the ethical and policy issues surrounding the vegetative state. At the time of setting up the Working Party the Multi-Society Task Force in the United States had not reported though their two papers were available by the time the Working Party met in London in March 1995.

The main concept behind the setting up of the Working Party was to bring together some of the clinicians from throughout the world with a special interest and experience in the rehabilitation and disability management of people in the Vegetative State. It was also recognised that there was a need to involve some neurologists and neurosurgeons who were more experienced in the early stage management of the vegetative state in an attempt to provide a broad view of the problems and opportunities.

As chairman of this group I am greatly indebted to my eminent colleagues from throughout the world who gave up so much of their time in coming to London to take part in the Working Party, and also for their continuing support and constructive criticism in the preparation of the several draft documents before this final version of the report was published.

I recognised from the start that cultural, political and philosophical differences would play a part in the discussions and inevitably lead to some of the difficulties in obtaining agreement on some aspects of the discussions. There were, for instance, substantial differences between the medical culture of the United States and those of the European Countries, especially in the emphasis placed on resource allocation and access to rehabilitation programmes. There were also significant differences in attitude between those clinicians primarily involved in the acute stages of management and those who specialised in rehabilitation or chronic care.

One of the greatest disappointments has been not to achieve agreement on terminology of the different stages or presentations of profound brain damage. This is one area where further discussion is urgently required because without an ability to categorise and name clinical pictures it is difficult for clinicians and researchers to communicate in a way, which will improve our understanding of profound brain damage and help, us define optimal management strategies.

I was, however, extremely pleased to find how much agreement there was between the various members of the Working Party from so many different cultures and backgrounds. I am confident that these deliberations will help others to understand more fully this rare condition and help to set standards for future care.

Dr Keith Andrews MD FRCP

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INTRODUCTION

Working Party

The need for a Working Party on the Management of the Vegetative State was identified at the International Association of Studies in Traumatic Brain Injury conference in Tokyo, Japan in 1993 when several specialists in rehabilitation expressed concern that there were no formal guidelines for the treatment of patients in the Vegetative State. There had been several working parties that have discussed the ethical issues but none which had discussed the management of patients which was required before ethical decisions such as withdrawal of tube-feeding or resource allocation could be made.

The Royal Hospital for Neuro-disability in London, UK agreed to seek funding and to provide financial support to set up a Working Party of specialists in the rehabilitation of the Vegetative State. The original concept was for the working party to consist of rehabilitation specialists but it was recognised that this would provide only a limited picture and therefore neurosurgeons and neurologists from a number of countries were included in the Working Party.

The Working Party met over a period of three days in March 1995. Further correspondence in response to draft documents continued until September 1995. Where relevant these additional comments have been included in the report, giving members an opportunity to consider suggestions made and to provide further evidence of their views.

Acknowledgements

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MEMBERS OF THE WORKING PARTY

Dr Keith Andrews (Chairman)	Director of Medical and Research Services, Royal Hospital for Neuro-disability, London, UK
Prof Graham Beaumont	Head of Clinical Psychology, Royal Hospital for Neuro-disability, London, UK
Dr François Danze	Head of the Neurology and Neurological Rehabilitation Department at the Etablissements HELIO-Marins, Berck sur Mer, France.
Dr Mihai D Dimancescu	Associate Chief of Neurosurgery, South Nassau Communities Hospital; Director of Neurotrauma, Winthrop University Hospital; Founder and Director of the International Coma Recovery Institute, New York, USA
Dr E A Freeman	Medical Consultant to the National Brain Injury Foundation (Australia).
Prof. Axel Fugl-Meyer	Professor of Rehabilitation, Uppsala University, Sweden.
Dr Zeev Groswasser	Professor and Chairman of the Department of Brain Injury and Evoked Potentials Laboratory, Lowenstein Hospital Rehabilitation centre, Tel-Aviv University, Israel.
Prof Bryan Jennett CBE	Emeritus Professor of Neurosurgery at The Institute of Neurological Sciences, Glasgow University, Scotland, UK
Dr James Kelly	Director of Brain Injury Program, Rehabilitation Institute of Chicago; Assistant Professor of Rehabilitation Medicine and Neurology, Northwestern University Medical School; Co-director of Midwest Regional Head Injury Center for Rehabilitation and Prevention, Chicago, USA.
Professeur Jean François Mathé	Director of Neuro-Trauma Rehabilitation Unit, University Hospital of Nante, France
Prof Alexander Potapov	Professor of Neurosurgery, Burdenko Neurosurgical Institute, Moscow, Russia
Dr Jay Rosenberg	Medical Director, Kaiser Permanente Group, San Diego, USA.
Prof Dr. Med. Paul- Walter Schönle	Medical Director and Director of the Research Institute for Neurological Rehabilitation and Neuropsychology, Allensbach, Germany

Professor Henry H Stonnington	Medical Director, Memorial Rehabilitation Centre, Savannah, Georgia, USA President of the International Association of Studies in Traumatic Brain Injury. Editor of the international journal <i>Brain Injury</i>
Dr François Tasseau	Head of the trauma programme at Centre Médical de l'Argentière, Sainte-Foy-l'Argentière, France
Prof T Tsubokawa	Professor of Neurosurgery, Department of Neurological Surgery, Nihon University School of Medicine, Tokyo, Japan
Dr Sarah L Wilson	Lecturer in Psychology, University of Surrey, Guildford, UK
Dr Roger LI Wood	Clinical Director of the Brain Injury Rehabilitation Trust, Milton Keynes, UK
Dr Nathan D Zasler	Executive Medical Director, National NeuroRehabilitation Consortium Inc, Richmond, Virginia, USA Medical Director, Concussion Care Centres of America. Co-Editor of international journal <i>NeuroRehabilitation</i>
Dr George A Zitnay	President and Chief Executive Officer, Brain Injury Association, Washington DC, USA President of the International Brain Injury Foundation

We are grateful to Peggy English, from the Upjohn Company, for her assistance and advice on the workshop proceedings.

EXECUTIVE SUMMARY

1. General

- 1.1 There is little research information about the effect and outcome of rehabilitation and disability management programmes in the vegetative state.
- 1.2 Because of the lack of information and guidelines many patients have not been offered the opportunity of a disability management programme whilst in some cases acute and even life threatening medical treatment has been withheld or withdrawn and therefore these patients may have died before their full potential was reached.
- 1.3 One of the difficulties of making management decisions on behalf of profoundly brain damaged people relates to the incomplete understanding or misunderstanding of the term 'vegetative state' and the general lack of experience of working with profoundly brain damaged patients over the long term.
- 1.4 It is recommended that the terms *Persistent* and *Permanent* be dropped from the diagnosis of "Vegetative State" since these confuse prognosis with diagnosis.
- 1.5 It is considered that the term 'vegetative' (though generally disliked by families and many clinicians) is so ingrained in medical and legal terminology that it would be difficult to introduce new terminology at this stage.

2. Patterns of Recovery

- 2.1 There are three main possible patterns of clinical recovery from coma to cognitive awareness: a continuum through a series of levels or phases; a number of discrete syndromes with specific patterns of recovery; or a branching tree along which different sub-categories of patients may pass. No agreement could be reached as to which pattern was usually followed.
- 2.2 Agreement could not be reached as to whether there was one or more than one vegetative state. It was, however, agreed that there were several presentations of the vegetative state.
- 2.3 Three phases of profound brain damage are recognised: Coma; Vegetative State; Post Vegetative State
- 2.4 There is still some uncertainty about the features that characterise the change from the vegetative into the post-vegetative state.

3. Categorisation

- 3.1. There is a need for categorisation to define, based on regular assessment, whether a patient is actually progressing and to identify those who are no longer vegetative.
- 3.2. A protocol, similar to that for brain death, should be developed for defining the stages in, and recovery from, the vegetative state.
- 3.3. There is a stage in the recovery process when it is uncertain as to whether the patient is emerging from the vegetative state. This can be called the 'border-line' or 'transition' stage'.

4. Difficulties of Clinical Decision Making

- 4.1. There are no tests that can confirm whether the patient has any 'inner awareness'.
- 4.2. Assessments are best based on a series of behavioural patterns.
- 4.3. The diagnosis of the cognitive status is time dependent and cannot be made in a short single assessment even by competent and experienced clinicians.
- 4.4. The ability to generate a behavioural response fluctuates from day to day and hour to hour, and even minute to minute.
- 4.5. There is a clear need for further research using neurophysiological tests and behavioural measurements to help identify or predict the possible degree of recovery.

5 Incidence and prevalence

- 5.1. The exact size of the vegetative state population is unknown because of the lack of accepted diagnostic criteria and due to it not being a codeable condition in many countries.
- 5.2. For severe head injuries (more than 6 hours in coma) the one month incidence rate varies from 1-14%. For non-traumatic coma the incidence is higher.
- 5.3. Information from several studies suggests that the incidence of the vegetative state is about 0.7-1.1/100,000 population.

- 5.4 Prevalence figures from throughout the world suggest that there are between 2-10/100,000 of the population are vegetative.

6. **Diagnosis & assessment**

- 6.1 Brain function is too complex to assess by one single assessment tool.
- 6.2 Assessment of patients in the Vegetative State requires a considerable amount of time, measured in weeks rather than hours, if varying levels of function are to be identified.
- 6.3 The family and other carers are often the first to identify changes in cognitive function, especially when there is gross limitation of motor responses, because of their more sensitive interpretation of facial expression and body language associated with the greater amount of time families spend with vegetative patients.
- 6.4 Behavioural assessments of the vegetative state can be subdivided into those which assess specific aspects of behaviour according to predetermined criteria and those which use techniques such as time sampling of spontaneous behaviour, structured intervals with care staff and/or relatives and the ad hoc recording of observations.
- 6.5 Neurodiagnostic tests alone can neither confirm the diagnosis of a vegetative state nor predict the potential for recovery from awareness.
- 6.6 Neurophysiological investigations are of major help in the acute management of the brain-injured patient but are of little help in clinical management in the post-acute and rehabilitation phases of patients in the vegetative state.
- 6.7 The main aim of investigations following the acute phase of brain damage is to exclude surgically treatable conditions.
- 6.8 The main role of repeat Computerised Tomography scan is to identify developing hydrocephalus or to demonstrate progressive cerebral atrophy.
- 6.9 The role of PET Scanning in management of Vegetative State is, as yet, experimental and warrants further research.
- 6.10. Current methods of assessment do not permit long-term prognosis to be made during the acute stage for any one individual.

7. Clinical management

- 7.1. The main functions of the clinical management programme are to: improve and maintain the clinical state of the patient; prevent secondary complications; provide the clinical and physical environment for optimal recovery; provide support for the family; assist reintegration into the community; and, where recovery is unlikely, to provide a disability management programme aimed at preventing unnecessary complications and minimising the long term care needs of the patient.
- 7.2. The main avoidable complications requiring careful monitoring and appropriate preventative and treatment programmes are: increased muscle tone leading to contractures; bladder and renal tract complications; constipation or diarrhoea; undernutrition; respiratory infections; stress ulceration; deep vein thrombophlebitis; decubitus ulceration; heterotopic ossification; complications of medications and disruption of family dynamics.

8. Stimulation techniques

- 8.1. Improvement in cognitive functioning is one of the prime aims of the rehabilitation programme in management of patients in the vegetative state.
- 8.2. Sensory *regulation* is a more relevant concept than sensory *stimulation* in the rehabilitation management of the vegetative patient.
- 8.3. There is, as yet, only limited research evidence as to the long-term benefits of sensory stimulation programmes.
- 8.4. Many of the studies into sensory regulation/stimulation programmes have been criticised because of the broad range of time since onset of the brain damage, the small number of patients included, lack of control subjects, selection bias and other methodological problems.
- 8.5. Everything should be done to provide the optimal environment to increase the potential for emergence from the vegetative state.
- 8.6. Unregulated stimulation is destructive and counterproductive and therefore patients require a structured environment and control of working practice of the area where the patient is being treated. This is rarely possible in general medical or surgical units.
- 8.7. The windows of potential responsiveness in the vegetative state are often short and can easily be missed.
- 8.8. Stimulation provided at any one time should be simple, consistent, repeated after a period of rest and allow for a delayed response.

- 8.9 There is, as yet, no evidence to demonstrate whether enjoyable or familiar sensations are more effective than unfamiliar or unpleasant sensations.
- 8.10 A *consistent* programme of specific stimulation should be used by all staff and relatives to prevent over-stimulation.
- 8.11 A period of rest should be allowed prior to the specific controlled sensory input programme.
- 8.12 Information from the family as to the pre-brain damage likes and dislikes of the patient before the brain damage may be of assistance in selecting the type of sensory input.
- 8.13 It is important to have a baseline of responses without sensory input against which the effect of sensory stimulation can be assessed.
- 8.14 At present there is little evidence from controlled trials for the value of drugs in promoting recovery from the vegetative state. There is a need for good control trials to identify the potential of drug therapy in modifying the outcome of the vegetative state.
- 8.15 There is, as yet, uncertainty as to whether drug therapy can alter recovery patterns in the truly vegetative patients rather the further support the natural recovery of those in the minimal responsive state.
- 8.16 It is recognised that some medications, such as those for epilepsy or control of spasticity, may impair cognitive function. The need for these drugs should be carefully considered and preference should be given to those with least cerebral inhibitory effect.
- 8.17 Further studies of the experimental work on electrical stimulation of the brain and brain stem are required from controlled trials studying long-term outcome.

9. Interpreting Responses to Sensory Stimulation

9.1. Eye Tracking

- 9.1.1. Localising to a visual stimulus is often the first sign that the patient is emerging from the vegetative state.
- 9.1.2. Response to members of the family and some staff may be more consistent than responses to other members of staff. Also some members of staff, particularly those who spend a considerable amount of direct contact with patients, may be more sensitive than others at an earlier stage to change in level of responsiveness.
- 9.1.3. Some patients may not progress beyond the tracking stage and may develop no other evidence of meaningful responses to the environment.

- 9.1.4. Tracking may occur in a social context but not in formal clinical testing.
- 9.1.5. Tracking may not be possible if the patient has neurological or ophthalmological damage causing blindness or ocular muscle dysfunction.
- 9.1.6. Visual tracking cannot be considered in isolation as evidence as to whether the patient is vegetative or not but must be reviewed in the context of other clinical features.

9.2 Emotional Responses.

- 9.2.1 Emotional behaviour should be in response to a specific stimulus before it can be regarded as indicating cognitive activity.
- 9.2.2 Emotional responses, such as crying or grimacing, which are not stimulus-specific can occur in the vegetative patient and may be a reflex response to stimuli from the environment or from internal sensations (e.g. full bladder, colic etc.).

10. Social and family dynamics

10.1 Family Needs

- 10.1.1. The consequences of brain damage affects a family as well as the individual.
- 10.1.2. Members of the family have several needs including: information; involvement; counselling and emotional support (trained counsellors with experience in the problems associated with brain damage, peer group support, specialist groups, relatives organisations); recognition of the family's needs; and social administration/welfare support where there are financial, resource or legal implications.
- 10.1.3. Family members develop a wide range of feelings and anxieties including isolation, abandonment, fear about the future, guilt and inadequacy about the problems they face.
- 10.1.4. Members of the family have an important contribution to make to the management of patients whilst at the same time having considerable needs of their own.
- 10.1.5. Treating a brain-damaged person involves professional support of the whole family.
- 10.1.6. It is good clinical practice to involve the family at the earliest possible stage, including in the Intensive Care Unit, through all stages into the long-term management or death of the patient.

10.2 Communication with Family Members

- 10.2.1. The fundamental communication role of the clinical team is to provide a realistic opinion without removing hope.
- 10.2.2. Information should be conveyed by a clinician with knowledge about the management and prognosis of acute onset brain injury.
- 10.2.3. The information should be reliable, consistent and repeated, and should be presented using terminology that is comprehensible to the family. This process should not be left to inexperienced junior members of staff.
- 10.2.4. It is often helpful to see the family as a group to ensure that they all feel involved and that there is a greater chance of the family as a unit understanding the problems involved.
- 10.2.5. The emotional state of the family should be taken into consideration. Not every family can, or should, accept the responsibility for caring for the low level patient and there should be no coercion on any family member to be involved in the clinical management of the patient.
- 10.2.6. There are special needs for good communication and counselling for parents when the patient is a child.
- 10.2.7. Having a brain-damaged parent can have a devastating effect on a young child though the effects may not be well expressed. In these circumstances the involvement of a children's counsellor should be considered.

10.3 Additional Implications of Meeting Family Needs

- 10.3.1. Funding authorities should be aware that treatment of people with brain injury requires 'treatment' of the entire family and this should be taken into account when costing care packages.
- 10.3.2. It is important to train staff in communication skills.
- 10.3.3. There is a great potential for the use of training aids and tools in helping families understand the processes involved in brain damage.
- 10.3.4. The involvement of ministers of religion may have an important contribution to play in supporting the family.
- 10.3.5. In some countries there is an important role for lawyers in obtaining additional resources following traumatic injury or negligence claims. The training of lawyers is therefore an important role of the clinical team.

10.4 Limitations to Family Involvement

- 10.4.1. In most countries, in law, the family are not legally empowered to make clinical decisions on behalf of the patient.
- 10.4.2. The clinician has the responsibility of acting in the clinical best interests of the patient based on clinical assessment, level of existing knowledge and observation by carers and family.
- 10.4.3. In most countries a balance is achieved by accepting the involvement of the family in the decision-making but the clinician must act within what he or she regards as the best clinical interests of the patient.

11. Criteria for admission to a rehabilitation programme

- 11.1. Early involvement of a specialist experienced in the neuro-rehabilitation of people in the vegetative state can make an important contribution in assisting the acute care clinicians to provide optimal opportunities for recovery.
- 11.2. All categories of patients with profound brain damage, irrespective of the cause of the brain damage, should be offered the opportunity of a specialised assessment for the appropriateness of admission to a rehabilitation programme.
- 11.3. Once the clinical state has stabilised early admission to a neuro-rehabilitation programme is advisable.
- 11.4. There are advantages of the acute care unit having formal links with a neuro-rehabilitation facility to provide an organised continuum of care.
- 11.5. It is important to have an identified organised interdisciplinary continuum of care for severely head injured patients.
- 11.6. It is important to involve the family in all stages of the management programme and decision-making about the appropriateness or otherwise of admission to a rehabilitation programme.
- 11.7. Age in itself should not be a contraindication to the assessment, treatment or access to a rehabilitation programme though some factors concomitant with the ageing process may be associated with poorer levels of recovery in some patients and will need to be taken into account in the decisions as to the benefit of transferring the patient to a rehabilitation unit.
- 11.8. The rehabilitation programme should include a planning stage for the input required in the long term if unnecessary deterioration is to be avoided.

- 11.9. There are three components to the rehabilitation programme: prevention of secondary complications; minimising neurological impairment and optimising functional ability.
- 11.10. Long-term disability management is required both for the benefit of the patient and to avoid the higher long-term costs involved with managing unnecessary complications.

12. Long term implications of vegetative state

- 12.1. A long life expectancy can be compatible with the vegetative state. It was the experience of members of the Working Party that a life expectancy of 15 years was not uncommon and there are several case reports of longer survival including one of a lady still in the vegetative state 48 years after the brain damage
- 12.2. There is a lack of long term follow up studies of vegetative patients beyond 2-3 years.
- 12.3. There are reports of patients making late recovery beyond a year following the brain injury.

GENERAL OBJECTIVES OF THE WORKING PARTY

The remit of the Working Party was to consider the management of patients in the Vegetative State. It was recognised that, as yet, there was little research information on the effect of rehabilitation programmes and the outcome of disability management programmes. There are several reasons for this including:

1. The Condition is rare and patients are dispersed widely in various types of hospital units, residential nursing homes or at home.
2. There is generally little research carried out into the problems and potential of people who are in the chronically disabled, especially after discharge from mainstream hospitals.
3. There have been few units specialising in the rehabilitation of people in the Vegetative State.
4. There has generally been a nihilistic approach to the treatment of people who are in the Vegetative State and therefore the opportunity of a disability management programme has often not been offered or acute and even life threatening medical treatment has sometimes been withheld or withdrawn. Many such patients may therefore have died before their full potential was reached.

The Working Party concentrated on making recommendations about the management of patients whose profound brain damage was due to acute onset conditions and did not discuss the broader issues of service provision and management of people whose brain damage was due to degenerative or congenital causes.

The guidelines and recommendations made in the report are based on the available research evidence and on the consensus view of clinicians experienced in the management, supported from extrapolation from similar areas of clinical practice, of people with vegetative states or those recovering from these states.

The purpose of the guidelines was to assist non-specialist as well as specialist clinicians, health planners and policy makers in planning the care of people with profound forms of acute onset brain damage.

There was a considerable amount of agreement on the principles of management. Where there was disagreement on clinical management it was largely based on what was considered to be appropriate deployment of limited resources that influenced local practice. The areas of disagreement have been included to show where issues still need to be resolved and to show where knowledge about brain damage and the resultant impairment are still limited.

SPECIFIC OBJECTIVES OF THE WORKING PARTY

The objectives of the Working Party were:

1. To describe the clinical features associated with the Vegetative State and to identify any categorisation that would help clinicians in their clinical management of vegetative patients.
2. To provide guidelines on the clinical assessment of the Vegetative State.
3. Provide recommendations on standards for the assessment of outcome.
4. Provide guidelines for admission to rehabilitation programmes.
5. Provide guidelines for what should be included in rehabilitation programmes for people with the Vegetative State.
6. Make recommendations that will enable policy makers and funding authorities to make the best and appropriate use of resources in the best interests of the patient.
7. To highlight the areas of uncertainty or disagreement about profound brain damage and its management which require further consideration.

TERMINOLOGY

One of the difficulties of making management decisions on behalf of profoundly brain damaged people relates to the incomplete understanding or misunderstanding of the term ‘vegetative state’ and the general lack of experience of working with profoundly brain damaged patients over the long term.

Giacino and Zasler¹ have argued that one of the major problems faced by clinicians in neurotrauma care has been the “lack of consistent nomenclature germane to low-level neurological states after severe brain damage”. They go on to point out that there is also a relative lack of understanding of the existing nomenclature.

There has been considerable debate in the world literature concerning the terminology and categorisation of patients with very severe brain damage, especially those with profoundly altered levels of consciousness. Jennett and Plum² recognised the need for an acceptable term for one group of these patients “in order to facilitate communication between doctors or with patients’ relatives or intelligent laymen, about its implication” and coined the term *Persistent Vegetative State* [See below].

Prior to creating a new term for this particular subset of patients with brain damage Jennett and Plum² reviewed the world literature and identified a number of syndromes including: brain death; akinetic mutism; permanent, irreversible, or prolonged coma, stupor or dementia; decerebrate or decorticate states; apallic syndrome; locked-in syndrome or de-efferent state. They felt that these terms had limitations due to the description of specific clinical syndromes (akinetic mutism) or features (decerebrate or decorticate states); were inaccurate (permanent, irreversible or prolonged *coma*); described an unproven anatomical pathology (apallic state); or was an unrelated syndrome (locked-in syndrome).

Some concern has been expressed about the use of the terms *persistent* and *permanent* in the terminology of the Vegetative State. The Multi-Society Task Force on PVS³ point out that confusion has arisen over the exact meaning of the word *persistent*. They expressed the view that *Persistent Vegetative State* was a diagnosis; *Permanent Vegetative State* was a prognosis. The Multi-Society Task Force and others have placed arbitrary time periods on these terms with the term *persistent* usually describing those patients vegetative for more than one, three or twelve months according to aetiology; and the term *permanent* for those vegetative from a traumatic cause for more than one year.

Members of the Working Party were of the opinion that the terms *persistent* and *permanent* did not add anything to the clinical term ‘vegetative’ and that they were often misused in a way that could have an adverse influence on the decision whether and how to treat the patient.

The Working Party strongly recommended that the terms *Persistent* and *Permanent* be dropped from the diagnosis of Vegetative State since these attempted to add a prognosis to a diagnostic terminology. There was also some concern expressed by many members of the Working Party about the term ‘vegetative’. Whilst recognising

the accuracy of the scientific origins of the term 'vegetative' it is often associated by relatives and some less experienced health workers with the word 'vegetable' resulting in a nihilistic attitude to any form of treatment. Never-the-less it was considered that the term is so ingrained in medical and legal terminology that it would be difficult to introduce new terminology at this stage.

Others have also attempted to find suitable names for the Vegetative State. Roberts⁴ used the term '*decerebrate dementia*' to describe the patient who has a pattern of decerebrate rigidity in response to stimulation though "semi-purposive movements of a limb on one side may develop after many months". He went on to state that "there is usually no detectable intellectual function but there may ultimately be some form of emotional response to the spoken word or gesture". He goes on to point out that this is a more inclusive diagnosis than the term 'persistent vegetative state'.

Sazbon & Groswasser⁵ suggested that the term *Post-Comatose Unawareness* had the advantages that it described the clinical picture of the patient who is no longer in coma but is not showing any evidence of awareness. They suggested that it also had the advantage that the term does not use arbitrary and retrospective criterion of time and does not imply one single outcome.

The members of the Working Party agreed with the concern^{1,6} that there is still a lack of consistent nomenclature related to low-level neurological states and therefore emphasised the need to be able to clearly define the patterns of recovery and to provide more exact and meaningful terminology.

In attempting to clarify these issues the Working Party considered a number of principles:

1. The description of the pattern of recovery
2. The defining of characteristics of specific phases or syndromes
3. The terminology to be used.

Patterns of Recovery

The members of the Working Party considered three patterns of clinical states from coma to cognitive awareness:

- a. That there was a continuum through a series of levels or phases, though there may be rapid progression or skipping of points on the continuum. The transfer through the continuum may vary, not only in the speed but also the regularity/irregularity of the pattern and may become arrested at any stage.
- b. That there were a number of discrete syndromes with specific patterns of recovery
- c. That there was a branching tree along which different sub-categories of patients may pass. The branches would depend upon a number of features such

as aetiology, severity of the brain damage, predominant site of the damage and the age of the patient.

The Working Party felt that there were elements of all three patterns but that for simplicity it was easier to conceptualise the state as being a continuum. It was also recognised that brain damage is a dynamic process rather than a static or fixed condition. This is particularly relevant when it comes to assessment of potential for disability management programmes.

Whilst wishing to recognise this progression through the continuum there was also a conflicting recognition that at different points on the recovery line there were specific clinical features that described the level, stage or state the patient had reached in the recovery process. Many members of the Working Party felt strongly that these could be considered as a number of vegetative states. A minority of the Working Party felt equally strongly that there was only one vegetative state, with a variety of modifiers or descriptors within it.

Those Members of the Working Party specialising in rehabilitation generally expressed concern that the concepts of Vegetative State being a single entity or that all patients described as being 'in the vegetative state' had equally poor prognosis, were major factors which had held back clinical developments and disability management of patients with the vegetative state. Those members of the Working Party who were more experienced in the long-term management were more likely than the clinicians primarily involved in the early stages of clinical management to consider that there were a variety of stages or types of vegetative state.

Whichever model of recovery pattern was accepted by individual clinicians it was agreed that there were three phases of profound brain damage:

a. Coma

State of unarousable neurobehavioural unresponsiveness. The patient does not have a sleep-awake pattern (in absence of bilateral third cranial nerve lesion or lid apraxia) but may respond to painful stimulation by subcortical reflex pattern responses. It is generally accepted that coma rarely lasts more than one month before progressing into the vegetative state or to higher levels of awareness.

b. Vegetative State

The principle difference between coma and the vegetative state is the appearance of a sleep-awake cycle and the return of bulbar reflexes.

The term *Vegetative State* was coined by Jennett and Plum² to provide a clinical diagnosis based on behavioural observations of the patient. The term 'vegetative' was specifically chosen to describe "a merely physical life, devoid of sensation and thought".

The characteristics they described were:

- Absence of any psychologically meaningful adaptive response to the external environment
- Absence of any evidence of a functioning mind which is receiving or projecting information
- Patient has prolonged periods of wakefulness.
- Akinesia is relative because postural adjustments and stereotyped primitive withdrawals are usually possible.
- Patients do not speak (verbalise) though make sounds (vocalise).
- Fail to signal appropriately by eye movements, although they sometimes follow moving objects in a slow intermittent pattern.
- Initially the EEG may be isoelectric, but considerable activity and even α rhythms may be found once the state has lasted several months.

Jennett & Plum² describe in detail the type of clinical picture that may be seen in the vegetative state:

- After a variable period of coma patients open their eyes, at first to pain and then to less arousing stimuli. This is then followed by periods with the eyes open.
- May blink to menace but appear not to be attentive.
- There may be roving eye movements and the patient's eyes may seem to briefly follow moving objects.
- Reflex posturing
- Flexor withdrawal after a delay and is slow and dystonic and never takes the form of a brisk response.
- Non-volitional grasp reflex may be present
- Fragments of co-ordinated movement, such as scratching or even moving the hands towards a noxious stimulus
- Reflex postural alterations of the limbs may be provoked by neck movements.
- Chewing and grinding of teeth
- Liquid and food placed in the mouth may be swallowed
- Grunting and groaning may be provoked by noxious stimuli but no speech occurs.
- No meaningful response to the spoken word

More recently the Multi-Society Task Force on PVS³ gave the following criteria for diagnosing the vegetative state:

- No evidence of awareness of self or environment and an inability to interact with others.
- No evidence of sustained, reproducible, purposeful, or voluntary behavioural responses to visual, auditory, tactile, or noxious stimuli
- No evidence of language comprehension or expression
- Intermittent wakefulness manifested by the presence of sleep-awake cycles

- Sufficiently preserved hypothalamic and brain stem autonomic functions to permit survival with medical and nursing care
- Bowel and bladder incontinence
- Variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes.

They go on to point out that in the vegetative state patients 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, utter grunts or, on rare occasions, moan or scream.

c. Post Vegetative State

This is a state where the patient has progressed from the vegetative state and is making definite responses to the internal (e.g. pain and bowel or bladder discomfort) and external environments that could be interpreted as being an expression of awareness.

There was some difficulty in coming to agreement on the terminology used for those who responded at a simple level. The commonly used term '*low awareness state*' was liked by many members of the Working Party but some, especially neuro-psychologists, expressed concern that even fully mentally alert people may, temporarily, not be 'aware' of their surrounding when absorbed in other activities.

Giacino et al⁷ have suggested the term '*minimally responsive state*'. Some members of the Working Party felt that this had limitations in that all vegetative state patients have minimal responses, albeit at a subcortical reflex level.

Considerable discussion took place about the stage between (b) and (c) where there is uncertainty as to whether the patient is emerging from the vegetative state. At this point there are inconsistent signs of awareness and observation from some members of the family or clinical team suggests that responses are beginning to appear. This can be considered as a level of covert awareness (as opposed to overt awareness). Suggestions that this stage be termed 'transitional' or 'border-line' stage had advocates. Others felt that the patient was either vegetative or not and that any purposeful responses which could be identified, no matter how inconsistent, indicated that the patient was no longer vegetative.

Giacino and Zasler¹ have pointed out that there is no method yet available to clinically assess 'internal awareness' in a patient who is otherwise unable to express awareness relative to external environmental stimuli. The concept that we are only able to *infer* the presence or absence of conscious experience has also been pointed out by Bernat⁸ and the Multi-Society Task Force³.

The problem of finding terminology which was acceptable to all clinicians and which was easily interpreted caused considerable difficulty for the Working Party. This is seen in the attempts to define when a response from a patient implied a level of awareness. The use of the term 'meaningful response' was criticised on the grounds that this required a considerable amount of subjective interpretation on the part of the observer and that what was meaningful for the patient may not be considered meaningful by those treating the patient. Similarly the term 'purposeful response' was criticised because of the subjective interpretation and that a withdrawal reflex could be considered as purposeful in that it removes the limb, for instance, from danger. Others, however, felt that a purposeful response could be defined objectively, based on prescribed parameters of what constituted a response for a particular patient related to a behavioural baseline that made it possible to compile a frequency and/or duration profile of spontaneous responses of the patient.

These difficulties with terminology are fundamental to the understanding of profound brain damage. This is one area that warrants further considered debate.

Categorisation

The Working Party members suggested that there were several aspects to categorisation:

1. That there was a need for categorisation to define, based on regular assessment, whether a patient is actually progressing and to identify those who are no longer vegetative. It was recommended that a protocol, similar to that for brain death, be developed.
2. That there is a stage in the recovery process when it is uncertain as to whether the patient is emerging from the vegetative state. This can be called the 'border-line' or 'transition' stage'. The purpose of identifying this stage is to recognise what further levels of assessment and treatment are required to confirm whether the patient will progress into a fuller state of awareness or will remain vegetative.
3. That the relevance of the category is time dependent. Patients who remain in the lower levels of the vegetative state for several months are less likely to recover than those patients who show progression through the stages, although some show increase in reflex responsiveness with time but remain vegetative.

Because of the complexity of brain function and the variability in the types and extent of the brain damage each patient will present with features that are specific to him or her. It is, therefore, difficult to produce categories into which all patients can be placed. This is especially relevant where the clinical features show variation at different times of the day or on different days or with different people.

There are several basic categories that may be of help in evaluating the changing pattern of patients.

Coma:

This is a single entity. The patient does not have a sleep awake pattern (in absence of bilateral third cranial nerve lesion); may respond to painful stimulation by reflex pattern responses but displays no detectable signs of awareness

Vegetative presentations:

There are several presentations of the vegetative state including:

- Patients who have a sleep-awake pattern, may respond on occasions by a reflex activity in a delayed fashion but are generally unresponsive to stimulation from the environment.
- Patients who have sleep awake patterns, generally respond in mass extensor responses or startle responses to stimulation without habituation[†]. This may progress into flexor withdrawal responses. There may be roving eye movements but not tracking; facial expressions may occur to stimulation.
- Patients who have sleep awake patterns; single limb response to stimulation; withdrawal or intermittent localisation may occur to touch, sound or visual stimulation; random eye movements may occur but the patient does not focus on objects or people; though may turn to sound or touch.

[[†] The term *habituate* is defined as a decreasing effectiveness of a stimulus. Thompson and Spencer's definition of habituation is "a response decrement as a function of stimulus repetition which does not result from either receptor adaptation or effector fatigue" Wood¹⁰ on the other hand considered that when presented with sensory stimuli a patient's response capability was blunted because he had already habituated to the presence of frequent continuous background stimulation]

Borderline Presentations:

The patient has a sleep-awake pattern being awake for a major part of the day; generally more definite localising to visual, auditory or tactile stimulation; tracking eye movements following objects or people; may show emotional responses to presence of family; may smile or cry.

Agreement was not reached as to whether this stage was vegetative or non-vegetative.

Non-Vegetative Presentations:

There were two main non-vegetative or early post-vegetative presentations based on the level of consistency of response:

- The patient has a sleep-awake pattern; responds to simple commands inconsistently; remains totally dependent; and has profound cognitive impairments.
- The patient has a sleep-awake pattern; consistently responds to simple commands; remains totally dependent; and has profound cognitive impairments.

The Working Party had great difficulty in agreeing terminology for the various presentations of the vegetative state and those who have progressed from it. Since terminology is important for discussions about clinical states, and we were unable to resolve the differences in opinion, the points raised in discussion are presented in Appendix 1.

The Working Party strongly recommended that a high priority should be given to discussions to resolve this important issue of providing suitable terminology to help clinicians communicate about the complex problems associated with such severe levels of brain damage.

DIFFICULTIES OF CLINICAL DECISION MAKING

It was recognised that deciding the cognitive awareness of the patient, especially when at a very low level, was an educated guess since there are, as yet, no tests which can confirm whether the patient has any ‘inner awareness’.

The assessments in general use are based on a series of behavioural patterns. The clinician is therefore dependent on overt responses that depend on:

- a. the physical ability of the patient to respond.
- b. the desire or willingness (if possible) of the patient to respond
- c. the abilities of the observer to make rapport with the patient
- d. the ability to observe accurately.
- e. the time available for observation and assessment
- f. the lack of available and reliable assessment tools.

At an extreme level this dependency on interpreting overt responses is found in the Locked-in Syndrome where the patient may be fully cognitively aware but has very little ability to communicate with the external world. Although it is generally stated that the Locked-in Syndrome is easily diagnosed by a neurologist, several members of the Working Party who worked with profoundly brain damaged people in long term

care settings had come across patients where the locked-in syndrome had been misdiagnosed as the vegetative state.

The diagnosis of the cognitive status of profoundly brain-damaged patients is time dependent and cannot be made in a short single assessment by even a competent and experienced clinician. The ability to generate a behavioural response fluctuates from day to day and hour-to-hour, and even minute to minute, depending on fatigue factors, general health of the patient and the underlying neurological condition. For this reason the need to involve all members of the clinical and caring teams, especially the family, in the assessment process was emphasised.

There is a clear need for further research using neurophysiological tests and behavioural measurements to help identify or predict the possible degree of recovery. This is important in making decisions about the appropriate use of limited resources and in ethical and clinical management decisions.

INCIDENCE AND PREVALENCE

Incidence

The exact size of the vegetative state population is unknown partly because it is such a rare condition and the figures are difficult to interpret from the few epidemiological studies¹¹⁻¹³ available. The Multi-Society Task Force³ also pointed out that prevalence figures are unknown because of the lack of accepted diagnostic criteria and that in many countries it is not a codeable condition.

The figures on the incidence vary, depending on the cause of the brain damage and the interval since the onset required for a diagnosis of the vegetative state. Thus an international study¹⁴ of severe head injury showed the percentage in vegetative state at 1,3,6 and 12 months to be 10%, 4%, 2% and 1% of admissions. For severe head injuries (more than 6 hours in coma) the one month rate varied from 1-14%¹⁵⁻²⁴. For non-traumatic coma the incidence is higher. In one series²⁵ of 500 patients in non-traumatic coma for 6 hours, 12% of admissions and 31% of survivors at one month remained vegetative.

Sazbon et al¹² record that between 1975-1982 there was a yearly average of 17 patients in vegetative state due to head injury admitted to their unit, which was equivalent to four cases per million of the population.

Other studies^{11, 26-28} have reported an incidence level of 0.7-1.1/100,000 population.

Prevalence

Lehman²⁹ states that the widely accepted estimate of the number of Americans who are currently in the vegetative state is around 10,000 (3.9/100,000 population) but gives no background to how these figures were obtained.

Higashi et al¹¹ carried out a survey of 269 hospitals in 16 prefectures of western Japan in June 1973. Although they were unable to assess the incidence of PVS for all of the districts they did find 37 patients in a population of 1.5 million people giving a prevalence rate of 2.5/100,000 populations. These figures include PVS of all causes.

In France²⁷ the estimated incidence is 0.6/100,000 population with a prevalence of 2/100,000 population.

The Multi-Society Task Force³ estimated that in the USA there were between 10,000-25,000 (i.e. 4-10/100,000 population) in a persistent vegetative state.

DIAGNOSIS & ASSESSMENT

Principles

Because of the dynamic nature of brain function in brain damaged people the assessment requires a considerable amount of time, measured in weeks rather than hours, if varying levels of function are to be identified. This is important when decisions are being made about the potential for recovery, appropriateness of treatment and planning of services for the individual person.

In view of the fluctuation of clinical responsiveness there is an important role for time sampling techniques in evaluating the different aspects of behaviour such as circadian effects, response to specific treatment, environmental effects and changes in behaviour as recovery progresses.³⁰⁻³²

The family and other carers are often the first to identify changes in cognitive function, especially when there is gross limitation of motor responses, by their more sensitive interpretation of facial expression and body language. There can be difficulties, however, where 'wishful thinking' results in interpretation of random or reflex activity as a meaningful response. Considerable skill and experience is required in differentiating the relevance of these responses.

The aim of assessment is to provide objective evaluation of three levels of functioning: reflex; involuntary; and voluntary responses.

Behavioural Assessment

Behavioural assessments of vegetative state can be subdivided into two main types:

1. Those which assess recovery by evaluating specific aspects of behaviour according to predetermined criteria.³³ Such assessments frequently have protocols that include the application of specific stimuli to elicit behaviour.

2. Other methods include the use of techniques such as time sampling of spontaneous behaviour, structured intervals with care staff and/or relatives and the ad hoc recording of observations.^{30,31, 34}

It was recognised that such assessment scales are used for a number of different purposes including:

1. To be able to record change over time in individual patients - improvement, no change or deterioration.
2. To classify patients into the most appropriate treatment programme group.
3. To classify the patient into prognostic groups.
4. To identify clinical features which need treatment or special attention.
5. To provide epidemiological data for audit and service planning.
6. To compare results from various studies or between units.
7. To assist the legal process for claims damages.

Whilst recognising the importance of scientifically correct standardised data collection the Working Party was concerned that a considerable amount of important information was often lost if only the assessment by clinicians made during short examination periods were taken into account.

It was also emphasised that brain function is too complex to assess by one single assessment tool.

There are several behavioural assessment scales available.^{31,33} The Working Party did not wish to recommend any particular assessment but felt that it was more productive to make recommendations for the characteristics of the optimal measurement system.

The basic principles for the optimal measurement tools have been suggested by several authors.^{31,35} The Working Party recommended that a good tool for assessment in profound brain damage should include:

1. Nominal scales were preferable to ordinal scales.
2. The tool should be time sensitive i.e. it should clearly identify the time from the onset of the brain damage when the test was carried out.
3. A record should be made of the time since the last activity (to ensure optimal assessment following rest); the time of day the assessment carried out; and should state the time from stimulus to the response.
4. The optimal response to the optimal stimulation should be identified and recorded, along with the frequency of the response and lag time between stimulation and response.
5. The response achieved by any member of the team, including the family, should be recorded. The person making the observation should be identified in the records and any differing views of other members of the team should be recorded. It is common experience that one member of the team is more sensitive to early changes than others and therefore it is important to identify the possible reasons for differences in opinions between team members, including the family.

6. Clinical factors which may be adversely affecting the responsiveness level should be recorded e.g. severe constipation, infections, post-epileptic attack.
7. A behavioural baseline against which subsequent change could be measured is an important tool in assessing patterns of recovery and responses to specific stimuli or circumstances.
8. Measurements should be as objective as possible. Where subjective scales are used these must be explicitly defined.
9. There should be the opportunity for additional comments, for instance in describing the difference between optimal and consistency of responses.
10. The optimal channel of response (e.g. finger, eye blink, foot movement) for the individual patient should be identified and recorded.
11. Optimal responses should be defined in specific time intervals e.g. over one day, three days or weekly.
12. Differences between elicited responses and spontaneous activities should be clearly identified and recorded.
13. The time to the response should be recorded in relationship to various types of stimuli used.
14. Assessments should be simple and practical to administer for use in general units; more sophisticated scoring systems are more appropriate for specialist centres and for research purposes.

The Role of Investigations in the Management of the Vegetative State

The Multi-Society Task Force³ recognised that neurodiagnostic tests alone can neither confirm the diagnosis of a vegetative state nor predict the potential for recovery from awareness.

The Working Party accepted that neurophysiological investigations were of major help in the acute management of the brain injured patient. However, it was generally felt that investigations were of little help in the diagnosis of the vegetative states or in the management in the post-acute and rehabilitation phases. In general investigations were of little help in determining the cognitive ability or the potential for recovery.

The following opinions were generally accepted by the Working Party:

1. The main aim of investigations following the acute phase of brain damage is to exclude surgically treatable conditions, for instance mass lesions and those with hydrocephalus.
2. A repeat Computerised Tomography scan at, say, four months following the brain damage may be of value to identify developing hydrocephalus or to demonstrate progressive cerebral atrophy.^{36,37} There was also a view expressed that CT scanning was of value when the patient's improvement pattern had plateaued or showed deterioration in order to rule out a treatable cause, such as hydrocephalus. The absence of progressive atrophy indicates greater potential for recovery and has been a feature in some of the reported cases of late recovery.

3. EEG is useful in establishing electroconvulsive status. It is important to note that status epilepticus may be either convulsive or non-convulsive - the latter is more likely to be missed.
4. Evoked potentials have not been shown to change the management of the vegetative state patient.

The presence of a P₂₅₀ amplitude of the Sensory Evoked Potentials may be prognostic of survival depending on the amplitude.³⁸

5. The role of PET Scanning in management of Vegetative State is experimental and warrants further research.

Early Prognostic Indicators

The area of prognosis identification in the acute stage for long-term management outcome needs further study and validation. Current methods of assessment do not permit long-term prognosis to be made during the acute stage for any one individual.

CLINICAL MANAGEMENT

The functions of the clinical management programme are:

- a. To improve and maintain the clinical state of the patient
- b. To prevent secondary complications
- c. To provide the clinical and physical environment for optimal recovery
- d. To provide support for the family
- e. To assist reintegration into the community
- f. Where recovery is unlikely, to provide a disability management programme to prevent unnecessary complications and minimise the long-term care needs of the patient.

Prevention of secondary complications:

The main avoidable complications requiring careful monitoring and appropriate preventative and treatment programmes are:

- a. Increased muscle tone leading to contractures and permanent deformities.
- b. Bladder and renal tract complications (infections, bladder stone and contracted bladder).
- c. Bowel complications - constipation or diarrhoea.
- d. Undernutrition
- e. Respiratory infections
- f. Stress ulceration
- g. Deep vein thrombophlebitis
- h. Decubitus ulceration
- i. Heterotopic ossification

- j. Family dynamics
- k. Complications of medications

Whilst it is recognised that many of the preventative measures are basic good care it was a common experience of the members of the Working Party that preventable complications were common in patients referred to rehabilitation programmes. Since much of the prevention will require expertise in the management of complex conditions expert advice from a specialist in brain damage rehabilitation should be sought in the early phases of the management programme.

Abnormal Muscle tone

Motor tone should be considered in terms of motor control and assessment for the most rostral motor control level. From an adequate assessment a treatment plan can be created that enriches the environment of sensory-motor performance.

Abnormal muscle tone is usually related to increased tone but patients with decreased muscle tone are also seen. Increased muscle tone can lead to muscle contractures and permanent deformity. For this reason every effort should be made from the onset of the brain damage to control the muscle tone. The following preventative options are available to the clinical team:

- a. Negate and/or remove precipitating factors that lead to increased tone (nociceptive environmental stimulating factors)
- b. Correct positioning of the patient in bed using appropriate aids and techniques.
- c. Provision of an appropriate supportive seating systems. Standard chairs rarely provide sufficient support. Emphasis should be placed on providing good support at the trunk, neck and head with specific emphasis being placed on keeping the hips, knees and ankles maintained at right angles.
- d. Passive exercises and range of movement exercise on a regular basis
- e. Passive supported standing on tilt table or prone stander.
- f. Orthotic management.

Drug therapy is of limited value in the prevention of increased muscle tone in brain damage.

Treatment of abnormal muscle tone

1. Spasticity

The principles of treatment are similar to that of prevention and include:

- a. Negate and or remove precipitating factors that lead to increased tone (nociceptive environmental stimulating factors)
- b. Maintenance of good posture and position in lying and sitting is a fundamental part of the programme to prevent and control spasticity.³⁹

- c. Oral medication may have value in the treatment of hypertonicity.⁴⁰⁻⁴¹ Some have found that dantrolene sodium to be less effective in brain damage than spinal cord injury⁴² though others⁴³⁻⁴⁴ have it to be equally effective. However, the side effects, especially sedation and cognitive impairing effects, of these drugs must be taken into consideration in the decision for their use
- d. Intrathecal anti-spastic drugs may be effective but may require twice the dose used for spasticity due to spinal cord damage⁴⁵⁻⁴⁶ and in the presence of structural brain disease can induce epilepsy.⁴⁷ However, intrathecal baclofen produces cerebrospinal fluid levels approximately ten times higher than oral administration, and at 100th of the dose.⁴⁸ There can be serious side effects such as sedation and respiratory depression and this treatment should be reserved for skilled specialist teams
- e. The use of botulinum toxin has a clear place in the management of resistant spasticity.
- f. The use of physical interventions such as ice, heat or vibration, may provide transient reduction in muscle tone.⁴⁹
- g. Splinting of joints by casting has a clear role in the management of resistant spasticity.⁵⁰⁻⁵¹
- h. Other modalities including motor point and nerve blocks⁵³⁻⁵⁴ and botulinum toxin should be considered as options in refractory hypertonicity

2. Hypotonicity:

- a. Good physical management including positioning and careful range of motion activities is required.
- b. Particular care is required to protect joints from over extension.
- c. Posture in a special seating system requires particular attention to full truncal support to avoid deformities.

Contractures

The prime preventive measures are the modulation of abnormal muscle tone and the maintenance of neutral joint position to the extent possible.

Where contractures have developed then surgical interventions with tenotomies may be required. Tendon lengthening is relevant where it is necessary to preserve function; tendon release is more commonly used where preservation of function is not essential. Tenotomies require a prolonged post-operative physiotherapy programme to prevent recurrence of the contracture.

Infections

Patients with severe brain damage are particularly susceptible to infections, especially of the skin or respiratory and urinary tracts. These are due to multiple factors, often in combination, such as undernutrition, inactivity, incontinence and the presence of tracheostomy, nasogastric tubes or bladder catheterisation producing foreign bodies on which bacteria can grow.

Particular attention should be made to identify infections in patients who are unable to communicate.

It is important to differentiate between infection and colonisation in the presence of indwelling tubes if unnecessary antibiotic treatment is to be avoided with its concomitant risk of producing resistant organisms and side effects to the drugs.

Chest Infections

The basic principles of preventing chest infections are:

- a. Maintain a good nutritional hydration state
- b. Maintain good oral hygiene
- c. Prevention of aspiration of food or fluids.
 - Minimize and prevent gastro-oesophageal reflux
 - Consider insertion of percutaneous endoscopic gastrostomy in order to begin swallowing therapy and to decrease the higher risk of inhalation pneumonia associated with naso-gastric tube feeding.
- d. Decannulation of tracheostomy tubes as soon as feasible through a weaning procedure
- e. Oral feeding should not be reinstated until:
 - Swallowing and coughing reflex has returned
 - Adequate nutrition is assured.
 - Adequate spontaneous breathing and patent airway is present
 - Absence of tracheal stenosis
 - No active pneumonia
- f. Positioning addressed to maximize pulmonary drainage and to minimising the risk of aspiration.

Urinary Tract Infections

1. The use of intermittent catheterisation and indwelling or external catheters are associated with increased incidence of urinary tract infections compared to pads and pants/diapers. If the latter are used, frequent changes and monitoring are needed to avoid skin maceration and breakdown. Experience suggests that external penile sheaths are associated with a lower risk of urinary infection than

indwelling urethral catheterisation though there are other risks of penile inflammation and ulceration if these aids are not used correctly.

2. Maintenance of good nutrition
3. Maintenance of appropriate hydration and acidity
4. Monitoring for urine calculi by visually inspecting the urine for sediment and crystals
5. Maintenance of good posture.

Nutrition

1. In the initial phase following traumatic brain damage there is often a hypercatabolic state. It may be difficult to regain the associated lost weight and a chronic state of undernutrition may occur. Even the introduction of gastrostomy feeding may not result in an immediate weight increase after prolonged undernutrition, possibly due to secondary malabsorption.
2. Fine bore percutaneous endoscopically placed gastrostomy (PEG) feeding is preferred to nasogastric tube feeding⁵⁵ because of the higher risk of complications of aspiration or oesophageal and gastric ulceration. Since nasogastric feeding may require up to three hours of attendant time to ensure adequate intake of nutrition there is a risk of undernutrition due to lack of staff resources to meet this need.
3. Periodic monitoring of the patient's weight is important. The use of Body Mass Index (Weight in Kgs/ [Height in metres]²) is a useful monitoring tool.
4. Ensure an adequate protein intake as well as calories to achieve optimum body weight
5. Bolus feeding increases the risk of oesophageal reflux but may be more physiological. This has to be balanced against the increased risk of aspiration and the time out of therapeutic activities. Some units consider overnight continuous feeding, with smaller daytime boluses, a more satisfactory compromise.
6. If aspiration is a problem lower volume continuous feeding is indicated. Attention should be given to the posture of the patient with preference to the natural feeding position. Drugs, such as Cisapride, may be of benefit in controlling gastrointestinal dysmobility problems.

Constipation

1. Vegetative patients are incontinent of faeces but this is often associated with constipation due to inactivity. Many patients develop marked forms of constipation that may require manual removal and enemas.
2. Generally bowel clearance can be controlled by the use of suppositories two or three times a week with continence maintained during these periods.
3. An adequate quantity of fibre and hydration enhances normal bowel function.

Diarrhoea

In the presence of diarrhoea the following measures may be of help:

1. Avoid the use of hyperosmolar feeds.
2. Recognise and treat bacterial infection or overgrowth
3. Live Yoghurt is used in some centres to normalise bacterial growth in the bowel.
4. Investigate the possibility of overflow incontinence from impaction of faeces.

Medications

Whilst drug medication may be necessary the beneficial effects of the drugs have to be balanced against the side effects in the presence of severe brain damage. Many of the drugs used in brain damage, such as anti-epileptic agents and anti-spasticity drugs, have a cerebral inhibitory effect and therefore special care should be taken to ensure that the drug is necessary and that the least cerebral inhibiting but effective drug, and dose, is being prescribed.

General recommended principles of drug medication management include:

1. Avoid sedating medications where possible
2. Evaluate and establish the appropriateness of anticonvulsant therapy
3. Simplify medication regimens
4. Select drugs that have the least cerebral inhibiting effect whilst providing effective management.
5. Avoid drugs that potentially retard neural recovery and function
6. Be aware of additive and potentiating effects of drugs used.

7. Be aware of protein binding effects in the presence of poor nutritional states.

Deep Vein Thrombophlebitis (DVT)

1. The incidence of venous thromboembolism is probably very low following brain damage⁵⁶ though there are no specific figures available for the vegetative state.
2. The standard procedures for the prevention of DVT apply to these patients.
3. There is insufficient evidence to support the use of prophylactic use of anticoagulants in this population.

Seizures

1. It is important to differentiate between early seizures (between 24 hours and one week post-injury) and late seizures (presenting after one week following the injury)⁵⁷.
2. It is unclear whether the presence or absence of a seizure changes the overall outcome of the patient, though status epilepticus is associated with a poorer outcome. Evidence from studies of Veterans in World Wars I and II who had epilepsy following brain injury suggests that they had a higher mortality than non-epilepsy brain-injured patients.⁵⁸⁻⁶⁰, but this was not supported from evidence from the later Vietnam war.⁶¹ It has been suggested⁶² that advances in medical care may have resulted in the changing pattern.
3. There are few comparative studies of neurobehavioural impairment due to drugs such as carbamazepine, phenytoin and valproic acid specifically in traumatic brain injured patients⁶³. In one study⁶⁴ it was found that both phenytoin and carbamazepine seemed to have a negative effect on cognitive performance, particularly on tasks with significant motor performance and speed components, though the effects were small and of little clinical significance. It is uncertain as to the specific implications in the case of the vegetative state where changes can be small. Inference from studies on epilepsy due to other causes suggests all three drugs appear to exert some adverse effects on cognitive function that increases with drug dosage.
4. Due to a lack of placebo-controlled trials there is, as yet, little evidence for the use of prophylactic anti-epileptic drugs to reduce the incidence of early (within one week of injury) seizures.⁶⁵ Evidence that prophylactic drugs may decrease the incidence of late onset seizures is still uncertain. Some studies⁶⁶ suggest that it has a beneficial effect whilst others⁶⁷ suggest that there is no benefit from prophylactic anti-epileptic drugs after the first week.
5. Penetrating brain injuries have a higher incidence of seizures than non penetrating injuries and may justify prophylaxis

6. Two or more late post traumatic seizures warrant treatment with anti-epileptic drugs using the same criteria as for other forms of epilepsy.⁶⁸ It is still uncertain whether the first late post-traumatic seizure requires treatment with anti-epileptic drugs.
7. Regular monitoring of the dosage of anti-epileptic agents is required to ensure that the optimal dosage to control the epilepsy whilst minimising the adverse cognitive and motor effects of the drugs. Particular review of the drug level should be made in the presence of clinical deterioration or recurrent seizures.
8. Increase frequency of the epilepsy after a period on anti-convulsant therapy may be an indication of alteration in the pharmacokinetics of the drug over time rather than a worsening of the epilepsy.⁶⁹
9. The vulnerability of brain injured patients to undernutrition is an important factor when assessing dosage of drugs, such as valproate, which are influenced by hypoalbuminaemia.⁷⁰
10. It is important when changing anti-epileptic drug therapy to do so in a progressive manner.

Periarticular New Bone Formation (Heterotopic Ossification)

1. The members of the Working Party knew of no good data to help in the prevention of heterotopic ossification (HO) or peri-articular new bone formation.
2. When clinical signs of HO are suspected (such as decreased range of movement, swelling of the joint with or without erythema, and local induration to palpation) appropriate radiographic studies are indicated. Since the presence of HO in one joint often indicates the potential for presence in other joints a bone scan may be warranted in addition to plain films of the large joints.
3. The potential methods of treatment include:
 - a. Passive Range of Motion - There is no evidence to show that range of movement exercises exacerbates the condition provided that they do not produce further trauma.
 - b. Medication - There is weak evidence supporting the role of pharmacological intervention (non steroidal and diphosphonates) in the suppression and/ or promotion of regression of the condition, at least when the heterotopic ossification is related to brain damage.
 - c. Surgery - Surgical intervention is indicated where heterotopic ossification interferes with proper management of the patient such as positioning, hygiene, skin care, pain control and general nursing care. There is some risk of the condition recurring and may be exacerbated by the surgical

procedure. Very clear and practical goals should be identified before proceeding to surgical intervention for heterotopic ossification in the vegetative patient.

- d. Perioperative radiotherapy has a part to play in inhibiting the recurrence of Heterotopic Ossification following surgical excision.

Skin Care

Severely brain damaged people are particularly vulnerable to decubitus ulceration (pressure sore) due to their immobility, incontinence of urine and faeces, risk of undernutrition and their general debility. The principles of good nursing care are essential and include:

1. Optimal nutrition
2. Maintenance of skin turgor
3. Treatment of anaemia
4. Posture and position control
5. Appropriate transfer techniques to avoid shearing forces
6. Provision of appropriate support systems, e.g., bed, mattress, seating, wheelchair.

Autonomic Disturbances

Autonomic disturbances are characterised by tachycardia, diaphoresis, hyperthermia and pyrexia, hypertension, postural hypotension, tachypnoea, bowel hypomobility, hypertonicity and skin changes.

The diagnosis is largely one of exclusion.

Treatment:

1. A treatable infectious aetiology must be excluded and treated where appropriate. It was recognised that patients with autonomic dysfunction may also develop infections.
2. Hyperpyrexia of central origin is characterized by lack of diurnal variation, absence of sweating, resistance to antipyretic drugs and a quick response to rapid cooling.
3. There is no clear pharmacological treatment supported by the literature, however drug therapy may include: alpha blockers (parasympathetic action), beta blockers (sympathetic), anti-epileptic drugs, benzodiazepines and dopamine agonists.

STIMULATION TECHNIQUES

Improvement in cognitive functioning is one of the prime aims of the rehabilitation programme in management of patients in the vegetative state. Three approaches have been suggested: structured sensory stimulation; drug therapy; and brain stem stimulation.

Structured Sensory Stimulation

The concept of structured sensory stimulation is based on the recognition that sensory deprivation has an adverse effect on mental functioning.

The Working Party recognised that there is, as yet, only limited research evidence as to the long-term benefits of sensory stimulation programmes. Some evidence is, however, beginning to appear that structured stimulation may have a positive effect on recovery patterns⁷¹⁻⁷⁶ or arousal levels,^{31,77,78} though others⁷⁹⁻⁸¹ have not found significantly better outcomes following sensory stimulation programmes. Others have tried using changes in heart rate⁸², EEG^{81,83} or changes in intracranial pressure during stimulation programmes as assessment tools but the results are difficult to interpret because they do not directly indicate cognitive responses.

Many of the above studies have been criticised⁸⁴ because of the wide variety of time since onset of the brain damage, the small number of patients included, lack of control subjects, selection bias and other methodological problems, many of which are related to the rarity of the condition.

The collection of information is complicated by the fact that the whole of the care of the patient produces some sensory stimulation and it is therefore difficult to separate the effects of the stimulation programme from the general sensory stimulating environment¹⁰. Wood et al³², in a pilot study, found some evidence to suggest that a controlled environment could influence the recovery pattern.

In view of the complexity of sensory input from environmental activity as well as specific sensory stimulation programmes some members of the Working Party were of the opinion that the term *Sensory Regulation*, as originally proposed by Wood¹⁰ was more relevant than *Sensory Stimulation* when discussing the rehabilitation approach to the vegetative patient. It was felt that the treatment should consist of discrete stimuli being applied in an environment as free from extraneous stimuli as possible. It also emphasises the importance of periods of *no* stimulation and the need for rest-periods.

The Working Party expressed the following opinions:

1. Everything should be done to provide the optimal environment to increase the potential for emergence from the vegetative state.
2. As it is highly likely that these patients will have disruption of the systems that control selective attention they are in danger of easily being overloaded with sensory input. Unregulated stimulation is destructive and counterproductive.

In view of this a structured sensory stimulation programme should include periods of rest in a quiet area. This requires control of the working practice of the area where the patient is being treated and is difficult, if not impossible, to achieve in a busy general medical or surgical unit.

3. The windows of potential responsiveness in the vegetative state are often short, though this will vary not only between patients but also for the same patient at different times. In view of this it seems logical that stimulation programmes should be for short periods but at the optimal time of responsiveness. This can be difficult to achieve in general units and requires great sensitivity on the part of the clinical team even in specialist units.
4. Assimilation of even basic information can be expected to be slow in the patient emerging from the vegetative patient and therefore information provided at any one time should be simple, consistent, repeated after a period of rest and allow for a delayed response.
5. Stimulation can be differentiated into positive (i.e. something which would be enjoyable for the patient) or negative (i.e. a stimulation which the patient would not have enjoyed). There is, as yet, no evidence to demonstrate whether enjoyable or familiar sensations are more effective than unfamiliar or unpleasant sensations.
6. A *consistent* programme of specific stimulation should be used by all staff and relatives to prevent overstimulation.
7. General activities are part of the stimulation programme and should be taken into account in timing the specific sensory input programme.
8. A period of rest should be allowed prior to the specific controlled sensory input programme.
9. Information from the family as to the pre-brain damage likes and dislikes of the patient before the brain damage may be of assistance in selecting the type of sensory input though the members of the Working Party differed in their views as to whether familiar sounds and pictures were more effective than non-specific sensory modalities.
10. The sensory input needs to be tailored to the progress of the patient. Initially very basic inputs may be required but as the patient gains more function the sophistication of the stimuli needs to be increased.
11. It is important to have a baseline of responses without the sensory input against which the effect of sensory stimulation can be assessed.
12. Some patients who are non-vegetative may be unresponsive due to sensory impairment such as deafness or blindness. Attempts to assess the possibility of these impairments is important in the interpretation of the sensory stimulation programme.

13. One concept presented was that the patient who was beginning to recover would find themselves in a strange environment. Emotional deprivation and the inability to control the environment produces anxiety that the patient is unable to express. During this phase they have receptive ability without the ability to communicate. The role of the family in helping to bridge this gap of emotional deprivation was emphasised.

Sensory Regulation

In considering the role of Sensory Regulation the Working Party recommended that the following points should be recognised:

- a. Sensory regulation, in itself, does not result in mental recovery.
- b. Sensory regulation attempts to optimise the sensory conditions present in the patient's external environment, within the limits of any information processing capability retained by the severely damaged brain, to enable accessing (and possibly interpreting) the sensory input. This means regulating not only ambient noise levels, but also the nature of the interaction between staff and patients, as well as the imposition of rest intervals between treatment and nursing care activities.
- c. In using specific sensory stimulation within the framework of sensory regulation, it is essential to record progress, as measured by the patient's improved response capability to specific stimuli, according to the criteria outlined for the assessment scale.

Drugs in the treatment of vegetative state

There is, as yet, too little research information available to confirm that drug therapy can *per se* effectuate a change in the ultimate degree of neurological recovery associated with profound brain damage.

Recent publications have begun to focus attention on pharmacologic treatment in the post-acute stage of recovery following brain injury particularly with regard to the potential for having an effect on the rate of recovery, a phenomena previously not felt to be under any external control.

In the late period following significant brain injury the drug classes which have been theoretical beneficial effect on the rate of recovery are cholinergic agonists⁸⁵⁻⁸⁷ and catecholaminergic agonist.⁸⁸

Drug classes that are presently theorised to be inhibitory to facilitation of recovery rate include catecholaminergic antagonists⁸⁸, anticholinergics, GABA agonists⁸⁹ and serotonergic agonists⁹⁰

There has been some evidence for the use of dopaminergic agents in patients with akinetic mutism^{91,92} or brain damage^{93,94} with avolitional states and it has therefore been this group of drugs that have been tried in the vegetative state, with some promising results. Higashi et al¹¹ reported at least two patients out of their study of 110 PVS patients who recovered after treatment with laevodopa. They report that those who responded were young adults who had good cortical function as demonstrated by the initial EEG.

The benefit of laevodopa has also been described in the treatment of patients in hepatic coma.⁹⁵

Dramatic improvement after 28 weeks in the vegetative state has been described by Haig and Ruess.⁹⁶ The patient, a 24 year old man, had been vegetative following a road traffic accident and had been accepted for maintenance therapy. At 28 weeks following his injury he was started on carbidopa (10mg)/levodopa(100mg) combination. Within two days there was a subjective improvement in his mental state so the dosage was increased to 25mg carbidopa/250mg levodopa combination and within the next two days he began to say his mother's name. Within the next few days he began saying short sentences, recalling previously known names and able to recall a newly introduced name after five minutes.

There is some animal research⁹⁷ to suggest that amphetamines can improve motor recovery, probably by improvement in the consciousness level. There have also been some case reports^{98,99} describing a beneficial effect of the central norepinephrine precursor L-DOPS on prolonged impaired consciousness.

Drug therapy may have an adverse effect on the rate of recovery as well as provide optimal opportunities for recovery. Drugs with sedative effects are often prescribed to treat epilepsy or spasticity and great care must be taken to ensure that the least sedative, but effective, drug is being used and the necessity for the medication assessed regularly.

There is, as yet, uncertainty as to whether drug therapy can alter recovery patterns in the truly vegetative patients rather the further support the natural recovery of those in the minimal responsive state. However, at present there is little evidence from controlled trials for the value of drugs in promoting recovery from the vegetative state. There is, therefore, a need for good control trials to identify the potential of drug therapy in modifying the outcome of the vegetative state.

Brain and Brain Stem Stimulation.

Some experimental work on electrical stimulation of the brain and brain stem is being developed in Japan^{100,101} and France¹⁰² that may be of some value in the management of vegetative patients in the future. Further studies of these approaches are required from controlled trials studying long-term outcome.

INTERPRETATION OF COGNITIVE RESPONSES

Interpreting Responses to Sensory Stimulation

There can be some difficulty in interpreting the clinical behavioural responses to stimulation. There was general agreement amongst members of the Working party about the following responses:

1. Eye Tracking

Tracking is when a patient follows a moving object by moving the eyes. There has been considerable debate as to the implications of eye tracking in the decision as to whether the patient is still vegetative. Some have held the view that eye tracking does not occur in the vegetative state.^{1,2,103,104} The Multi-Society Task Force³ in their review of the vegetative state stated “Sustained visual pursuit is lacking in most patients in a vegetative state. They do not fixate on a visual target, track moving objects with their eyes or withdraw from threatening gestures. When patients undergo a transition from the vegetative state to a state of awareness, one of the first and most observable signs of this transition is the appearance of sustained visual pursuit”. They go on to state “In rare cases, patients who have no other evidence of consciousness over a period of months to years have some degree of briefly sustained visual pursuit or fixation, which is believed to be mediated through brain-stem structures. Nevertheless, one should be extremely cautious in making a diagnosis of the vegetative state when there is any degree of visual pursuit...”. The Task Force, therefore, seems to differentiate between sustained and non-sustained pursuit, though it can be difficult to define ‘sustained’ in this context.

The opinions of the Working Party based on clinical experience were:

- a. Localising to a visual stimulus is often the first sign that the patient is emerging from the vegetative state. This may then be followed by tracking or visual pursuit.
- b. Roving or random non-specific eye movements may be mistaken for eye tracking but the patient appears to ‘look through’ the object i.e. does not focus on the object. Roving eye movements appear to be non-specific; tracking is specific.
- c. There are two components to tracking: eyes following the object; and fixation on the object.
- d. Eyes may follow the moving object but not focus on it. This may occur in the vegetative state and be a subcortical fixation reflex.
- e. Patients whose eyes follow moving objects and focus on them may be in a transitional stage of becoming aware and warrant further detailed observation.

- f. Some patients may track and follow some objects or pictures but not others. For instance, experience of one unit represented suggested that patients were more likely to follow a mirror than a picture. Others expressed the view that pictures more meaningful to the patient were more likely to produce a positive response than unfamiliar objects.
- g. Response to members of the family may be more consistent than responses to members of staff. Also some members of staff may be able to obtain the tracking responses whereas others obtain no response.
- h. Sustained tracking and focusing on objects is evidence that the patient is emerging or has emerged from the vegetative state.
- i. Some patients may not progress beyond the tracking stage and may develop no other evidence of meaningful responses to the environment.
- j. Tracking may occur in a social context but not in formal clinical testing. This response should be recorded.
- k. Tracking may not be possible if the patient has neurological or ophthalmological damage causing blindness or ocular muscle dysfunction. This should be considered in patients who do not track.
- l. Visual tracking cannot be considered in isolation as evidence as to whether the patient is vegetative or not but must be reviewed in the context of other clinical features.

Emotional Responses.

A number of patients show emotional type responses, such as smiling or crying, to certain situations. Patients may respond to family arriving, as demonstrated by change in facial expression or changes in body language, becoming relaxed or showing increased agitation without there being any other evidence of cognitive response. One member of the Working Party described a patient who was otherwise vegetative behaviour but laughed at TV cartoons. Even after seven years of observation he shows no other evidence of cognitive functioning.

The Multi-Society Task Force felt that facial expressions in response to various stimuli do occur in stereotyped patterns potentially indicated reflexive responses integrated at the deep subcortical levels and these types of patterns were theorised to be consistent with complete unawareness.

The general opinion expressed by the members of the Working Party was that emotional behaviour required some degree of cognitive awareness that indicated that the patient was no longer vegetative. However most were of the opinion that emotional responses, such as crying or laughing, which were not stimulus specific can

occur in the vegetative patient and may be a reflex response to stimuli from the environment or from internal sensations (e.g. full bladder, colic etc.).

The emotional behaviour should be in response to a specific stimulus before it can be regarded as indicating cognitive activity. For instance consistent smiling at the appearance of specific members of the family when they arrive or crying when they leave. Patients who laugh consistently at relevant points in a story can also be considered as being out of the vegetative state. It has to be recognised that even non-brain damaged people are not necessarily consistent in their response to the same stimulus.

As for other responses, emotional expression has to be taken in the context of whether it is random and whether it is in response to a specific stimulus.

Concept of being 'In' or 'Out of' Vegetative State

A considerable amount of attention has been given, both in medicine and the law courts, concerning whether a patient is 'in' or 'out of' the vegetative state. This was also seen in the discussions in the Working Party as to whether certain features, such as tracking or emotional responses, could occur 'in' the vegetative state. Some members of the Working Party were of the view that this was an artificial separation and that there was more to be gained by considering the process from coma to full recovery as a continuum. This is relevant at a practical level in that the patient with low level responses to the environment will be equally physically dependent, and will have the same high level of care needs as the patient in the vegetative state. The distinction is, however, important in those countries where decisions are made about withholding and withdrawing certain medical treatments.

SOCIAL AND FAMILY DYNAMICS

The effects of brain damage affects a family as well as the individual. Family members develop a wide range of feelings and anxieties including isolation, abandonment, fear about the future, guilt and inadequacy about the problems they face¹⁰⁵. They may oscillate between acceptance and denial and present with a wide range of emotions including sadness, exhaustion, weariness, denial, excessive protection, aggression, anger, demands and appearing not to hear the information which is given to them.

The main points accepted by the Working Part were:

- a. Many relatives become particularly distressed by the term 'vegetative state' and confused by much of the terminology used in attempting to describe and define brain damage and its clinical features. These reactions have been described in detail by Tzidkiahu et al¹⁰⁶.
- b. The family have an important contribution to make to the management of patients whilst at the same time having considerable needs of their own.

- c. Treating a brain-damaged person involves professional support of the whole family.
- d. In the long term, in many cases, the family will have the responsibility of care when the clinical teams have withdrawn or decreased their input. They will become the main authority on behalf of the patient and will develop expertise based on experience in the management of that person.
- e. In making recommendations about family involvement and needs the Working Party recognised that there were considerable cultural differences between, and indeed within, the various countries throughout the world that should be taken into account.
- f. The members of the Working Party considered it to be good clinical practice to involve the family at the earliest possible stage, including in the Intensive Care Unit, as well as through all stages into the long-term management or death of the patient.

Communication with Family Members

In communicating with the family the following guidelines are recommended:

- a. The fundamental communication role of the clinical team is to provide a realistic opinion without removing hope.
- b. The information should be conveyed by a clinician with knowledge about the management and prognosis of the patient who has sustained acute brain injury. The information should be reliable, consistent and repeated. This process should not be left to inexperienced junior members of staff.
- c. The information should be conveyed as early as possible.
- d. In the early stages following brain damage the main concern of the family is life or death prognosis. In the rehabilitation phase the concern is more related to the quality of the recovery and whether everything is being done to achieve the optimal outcome.
- e. It is often helpful to see the family as a group to ensure that they all feel involved and that there is a greater chance of the family as a unit understanding the problems involved.
- f. The terminology used should be comprehensible to the family.
- g. Given that families are not always ready to accept the information, time should be allowed for assimilation of the information and some form of follow up and

repeated opportunities to discuss clinical and social issues should be offered. These opportunities should be offered at all stages of the recovery programme.

- h. The emotional state of the family should be taken into consideration. Not every family can, or should, accept the responsibility for caring for the low level patient and there should be no coercion on any family member to be involved in the clinical management of the patient.
- i. It is generally accepted that the involvement of the family in clinical management decisions can contribute to the care of the patient and also helps the family understand the implications of the brain damage. The type of involvement will depend on the confidence and experience of the team and the personality of the member of the family.

In some cases more may be achieved by the family members meeting with the senior clinician or case manager. This may, for some families, prove to be less intimidating and allow them to make statements and express their own worries that they would not make in a more formal and open case conference.

It was also recognised that in some instances family attendance at case conference can inhibit some team members from expressing their own concerns or to inform other members of the team of their observations and assessments, especially when these might be negative. It is important that members of the team give a consistent opinion otherwise unnecessary stress is caused for the family when conflicting information is provided. In view of this some members of the Working Party accepted that on some occasions it is appropriate to hold case conferences in the absence of the family. Where this occurred it was agreed that a formal method of discussing the management with the family was still required.

- j. The effect of a brain-damaged parent can have a devastating effect on a young child though the effects may not be well expressed. In these circumstances the involvement of a children's counsellor should be considered.
- k. There are special needs for good communication and counselling for parents when the patient is a child.

Additional Implications of Meeting Family Needs

1. Funding authorities should be aware that treatment of people with brain injury is treatment of the entire family. The cost and time involved in education and support for the family should be recognised as a valid chargeable part of the treatment programme.
2. The essential component of good communication in the management of the family of people with brain damage emphasises the importance of training staff in communication skills.

3. There is a great potential for the use of training aids and tools in helping families understand the processes involved in brain damage.
4. The involvement of ministers of religion may have an important contribution to play in supporting the family. This has implications for supporting the ministers with relevant information without breaking confidentiality and in the need to train clergy in working with people who have brain damage.
5. In some countries there is an important role for lawyers in obtaining additional resources following traumatic injury or negligence claims. The education of lawyers about the consequences of brain damage is therefore an important part of the role of the clinical team.

Limitations to Family Involvement

Whilst recognising the importance of the family, in most countries in law the family are not legally empowered to make clinical decisions on behalf of the patient. The clinician has the responsibility of acting in the clinical best interests of the patient based on clinical assessment, level of existing knowledge and observation by carers and family. This can have implications where there is conflict between the family and professional staff about the clinical management and the level of input that is required.

In most countries a balance is achieved by accepting the involvement of the family in the decision-making but the clinician must act within what he or she regards as the best clinical interests of the patient. It is traditional that best interests are considered in terms of the views held by a 'responsible body of medical opinion'. Since the number of people with profound brain damage is so small it can be difficult to find an experienced body of knowledgeable opinion to be able to provide an informed view as to appropriate approaches.

It is not uncommon to have differing views within a family and this can lead to further complications in the communications between the clinical team and members of the family.

Methods of Supporting Families

Families have several needs:

a. Information:

The family often have a need to understand the clinical situation thus requiring information and education. The usual requirement is for factual information about the brain damage and its consequences.

Many of the questions asked by families are difficult to answer satisfactorily. Questions are often self-accusatory - "Why did this happen?", "Is it my fault?", "What could I have done to stop it happening?", "If I hadn't let him go out that

evening it would not have happened”. Other questions are related to the present “why is he not recovering?” or quite often “Why can you not see that he is recovering?”, “Why can I not feed him?”, “Why are you not working harder to make him recover?”. Other questions are often about the future - “What is going to happen?”.

There are several options for supporting families of people with profound brain damage. These include:

- i. Regular explanations by an experienced senior member of the clinical team.
 - ii. Attendance and involvement at therapy sessions.
 - iii. Tape-slide presentations.
 - iv. Booklets and other publications about brain damage.
 - v. Attendance at Case Conferences.
 - vi. Attendance at special training/teaching sessions or seminars.
- b. Involvement

Involvement of families can include being part of the observation of clinical patterns since they are more aware of the pre-brain damage person and often spend more time in direct patient contact than professional staff do. As such they will have much to inform the professional staff about the individual patient.

The family can be asked to write in a notebook the observations they make of any activity the patient carries out or abnormal clinical features that occur. The staff can also write their own observations for the family to read. This gives the opportunity of identifying areas where there is a difference in the observations for further consideration, whilst at the same time improving the communication between family and the clinical team.

Families quite rightly feel that the need to be involved in the management and decision-making. Whilst this can be difficult for staff it is easier to cope with these needs on a specialist unit rather than in a general unit where the more physical needs of other recovering patients create a different environment for family involvement.

- c. Counselling and Emotional Support

The counselling needs of individual families vary. Some need considerable individual support whilst others receive considerable support from their own inner strength, family, friends and local community.

Families often have difficulty in coming to terms with a person who is no longer the person they were used to. They, therefore, often have a need to develop a new relationship with the person with severe brain damage.

The disruption to the whole family following the brain damage often results in the need for counselling to preserve the family dynamics. This is especially relevant where there have been difficulties within the family pre-morbidly and where there are children involved.

There are several ways of providing counselling and emotional support for families:

- i. Trained counsellors with experience in the problems associated with brain damage.
- ii. Peer group support.

The ability of families to discuss progress, gain knowledge and obtain support from other families is of great benefit. Some units have a formal approach of bringing families of several patients and staff together for a social occasion away from the ward. In these meetings a member of staff may give a short talk about brain damage as a basis for general discussion about any topics that the family want to raise. These sessions provide good opportunities for family support and cement the relationships between the families and members of staff.

- iii. Specialist Groups.

Tasseau et al¹⁰⁷ describe the setting up of a programme to support families focusing on a) helping the family through the observation period; b) providing the family with socio-administrative support; and c) providing the family with psychological support. The family was encouraged to take part in the assessment process by writing down any observations and any remarks and are trained to differentiate between automatic and reflex actions and those that are cognitive responses.

- iv. Relatives organisations

In many countries there are support organisations that provide support at a local and national level for relatives of patients with brain damage. These include Brain Injury Association (USA), Headway (UK), National Brain Injury Foundation (Australia), Head injury Council (Australia), Headway (Australia), Hjärnkraft (Sweden), Union Nationale des Familles de Traumatismes Crâniens (France).

- d. Emotional support and recognition of the family's needs.
- e. Social administration/welfare support where there are financial, resource or legal implications.

CRITERIA FOR ADMISSION TO A REHABILITATION PROGRAMME

The criteria for admission to the various rehabilitation programmes depends on the resources available and the medico-political organisation of individual countries.

Where resources are adequate most patients in the vegetative phase are accepted into rehabilitation programmes. Where resources are scarce priority is generally given to those with traumatic over those with anoxic brain damage.

The overall opinions of the members of the Working Party included:

- a. Early involvement of a specialist experienced in the neuro-rehabilitation of people in the vegetative state is important to assist the acute care clinicians in providing optimal opportunities for recovery.
- b. All categories of patients with profound brain damage, irrespective of the cause of the brain damage, should be offered the opportunity of a specialised assessment for the appropriateness of admission to a rehabilitation programme.
- c. Once the clinical state has stabilised early admission to a neuro-rehabilitation programme is advisable.
- d. There are advantages of the acute care unit having formal links with a neuro-rehabilitation facility to provide an organised continuum of care.
- e. It is important to have an identified organised interdisciplinary continuum of care for severely head injured patients.
- f. It is important to involve the family in all stages of the management programme and decision-making about the appropriateness or otherwise of admission to a rehabilitation programme.
- g. Age in itself should not be a contraindication to the assessment, treatment or access to a rehabilitation programme though some factors associated with the ageing process may be associated with poorer levels of recovery in some patients and will need to be taken into account in the decisions as to the benefit of transferring the patient to a rehabilitation unit.
- h. The rehabilitation programme should include the planning stage for input required in the long term if unnecessary deterioration is to be avoided.
- i. There are three components to the rehabilitation programme: prevention of secondary complications; minimising neurological impairment and optimising functional ability.

- j. Long term disability management is required both for the benefit of the patient and to avoid the higher long-term costs involved with managing unnecessary complications.

LONG TERM IMPLICATIONS OF VEGETATIVE STATE

There is very little information in the world literature about the outcome of very severely disabled people.

Life Expectancy

A long life expectancy can be compatible with the vegetative state. Although a high proportion of patients in the vegetative state die during the first six months it was the experience of members of the Working Party that a life expectancy of at least 15 years was common.

There are reports of people in the vegetative state still being alive between 10-15 years after the brain damage.^{108,110} Jennett and Teasdale¹¹¹ describe the case of a man who remained vegetative for 18 years. The longest surviving PVS patient in the study by Tresch et al¹¹² was 16.8 years in a 35 year old lady following a road traffic accident and she was still alive at the time of reporting. The longest patient in 'coma' on record according to the Guinness Book of Records (admittedly not the most scientific of sources) is that of over 37 years and there is a case reported of a lady in the vegetative state who is still alive 48 years after the brain damage.

Late Recovery

Although it has been stated that patients who are still vegetative at three months following the brain damage do not make significant levels of recovery there are several reports in the world literature of patients who have made a late recovery. Andrews¹¹³ described a number of patients who recovered from the vegetative state between 4-8 months after the brain injury, though many of these remained severely disabled. Rosenberg et al¹¹⁴ describe the case of a 43-year-old man who was in a vegetative state for 17 months following anoxic brain damage before showing the first signs of awareness. He progressed to being able to tell stories and jokes though was unable to recognise complex collections of objects in pictures and was unable to read. In another case¹¹⁵ a 44-year-old man in a vegetative state showed signs of recovery only one year following a subarachnoid haemorrhage to regain nearly normal physical and mental capabilities

Information from the Traumatic Data Bank²³ of 84 PVS patients who were followed up long term (by phone rather than by clinical examination) found that 6% made some recovery between one and 2.5 years.

In a five year follow up¹¹⁶ of 30 patients in PVS, five recovered from PVS between one and five years though only two recovered to a level where they could communicate. One was a 61-year-old lady who was vegetative for three years following a subarachnoid haemorrhage. The other was a 26-year-old man who was vegetative for 8 months before beginning to respond. Both reached levels where they could read, watch television, write, calculate simple mathematical addition and subtraction, tell the time, feed himself or herself, were wheelchair independent and could speak well.

Other reports of recovery after a considerable length of time include that of an 18-year-old lady in a vegetative state for two and a half years following a road traffic accident. She progressed to a state within the following three years of being able to comprehend and communicate, take a considerable interest in her environment and able to establish interpersonal relationships¹¹⁴. An even longer period of six years in a vegetative state is described concerning a 25-year-old woman who was involved in a road traffic accident. After 14 months of rehabilitation she was able to feed and groom herself and could dress and transfer with some assistance whilst her speech and cognitive function improved considerably¹¹⁸.

It is recognised that there is a lack of long term follow up studies of those patients still vegetative beyond 2-3 years. This is understandable since the number of patients is small and the patients are usually widely dispersed in hospitals, nursing homes or at home away from academic centres. The information on patients who have survived, say 20 years, has to be considered in terms of the health and social care available at the time of onset and may therefore not be applicable to those entering the vegetative state at the present time.

CONCLUSION

The Vegetative State is an uncommon disorder that, especially for the long-term care, has not been widely studied. This has created problems in carrying out research and therefore there is a lack of good quality information to help in policy decision-making.

There are still difficulties, even for those clinicians with a special interest in vegetative state, to agree on the terminology to be used. It was one of the more disappointing aspects of the Working Party that we were unable to reach agreement on categorisation and terminology. It is a high priority that such agreement is reached in the near future since without such agreement on terminology it is difficult for clinicians and researchers to communicate. This in turn is limiting further development of clinical management and meaningful policy decision-making.

There has been a negative attitude to the potential for recovery and it seems possible that the full potential of many vegetative patients has not been reached.

Whilst there was general agreement on most forms of management there is still uncertainty about the specific role of sensory regulation and stimulation techniques within the total management programme

There is still much to learn and there is a need for further good quality research before definitive statements can be made about the management potential (or lack of) of vegetative patients.

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APPENDIX 1

Terminology

Terminology was one area where there was no clear agreement amongst the members of the Working Party and therefore recommendations are not made in the main body of the report. However, since terminology is so fundamental to the communication about the condition this Appendix explains some of the discussions in an attempt to provide a basis for other groups to reach a more satisfactory conclusion.

There was considerable discussion and marked differences in opinion among the Working Party as to whether there was one or several forms of Vegetative State. What was agreed was that there were at least several presentations within the diagnosis of Vegetative State.

Attempts were made to define and name these presentations. There was general agreement on the presentations but no agreement was achieved on the terminology to be used. There were members of the Working Party who wanted the term 'vegetative state' to be included, whilst others wished to avoid the term altogether. There were some members who felt that there were distinct types of vegetative state whilst others felt that there were only variations within a single state.

- A. The approaches attempted for those who were vegetative were as follows:
1. To describe the level of responsiveness: hyporesponsive or nil-reactive state; reflex responsive state; and localising responsive state. For those who wanted to include the term 'vegetative' then this could become hyporesponsive vegetative state; reflex responsive vegetative state and localising responsive vegetative state. One of the major arguments against this is that all reflex activities can be regarded as being a response and therefore the term may add to confusion.
 2. To describe in terms of the reflex presentation: hyporeflexic state; primary reflexic state; localising reflexic state. For those wishing to include the word 'vegetative' this could be added before the word 'state'.
 3. To simply term the presentations as Type I, Type II, Type III vegetative state and avoid descriptive terms. There was concern from some members that this implied that vegetative state was more than one diagnosis, a concept that they did not accept.
 4. To name the terms in Stages (I,II,III) of the Vegetative state and avoid descriptive terms. Some felt that these were not necessarily 'stages' but specific entities.

5. To avoid the term ‘Vegetative State’ and describe in terms of ‘Types’ or ‘Stages’ of ‘Profound Brain Damage’. there were strong arguments placed that this would not be helpful because it would include too broad a range of disorders and presentations.
 6. There were some who preferred the term ‘Non-Relational’ to replace the term ‘Vegetative’ i.e. Hyporesponsive Non-Relational State, Reflex Non-Relational State etc. This would then fit in with the use of the terms ‘Inconsistent Relational State’ and ‘Consistent Relational State’ for the non-vegetative conditions (see below).
- B. Several approaches were also discussed for those who had progressed from the vegetative state but were still at a very low cognitive level. It was agreed that there were two basic levels - inconsistent and consistent responses. Within each of these categories terminology could be used as follows:
1. To continue the theme of ‘responsive state’ as inconsistent and consistent responsive states. The term ‘vegetative’ could obviously not now be added to this group.
 2. To introduce the term ‘relational state’ to take over from the ‘reflex states’ described above.
 3. To accept the commonly used term ‘low (or minimal) awareness states’ (subdividing into inconsistent and consistent). The main reservation was that even cognitively unimpaired people might become temporally unaware of their surroundings. This terminology, however, did have strong supporters.
 4. To accept another commonly used term of ‘minimal responsive state’. The concern by some members was that reflex reactions can be regarded as minimal responses and that the term was not as definitive as was required.

The following tables put these terms together with the description of the clinical presentation:

Coma	Patient does not have a sleep-awake pattern (in absence of bilateral third cranial nerve lesion); may respond to painful stimulation by reflex pattern responses; displays no detectable signs of awareness.
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Vegetative Presentations	
Hyporesponsive State/ Hyporeflexic State/ Nil Reactive State/ Type I Vegetative State/ Type I Profound Brain Damage Stage I Vegetative State Type I Profound Brain Damage Stage I Profound Brain Damage	These patients have a sleep-awake pattern. They may respond on occasions by a reflex activity in a delayed fashion but are generally unresponsive to stimulation from the environment ; displays no detectable signs of awareness.
Reflexic Responsive State/ Primary Reflexic State/ Type II Vegetative State/ Type II Profound Brain Damage Stage II Vegetative State Type II Profound Brain Damage Stage II Profound Brain Damage	Patient has sleep awake patterns. The patient generally responds in mass extensor responses or startle responses to stimulation without habituation [†] . This may progress into flexor withdrawal responses. There may be roving eye movements but not tracking ; displays no detectable signs of awareness; facial expressions may occur to stimulation.
Localising Responsive State/ Localising Reflexic State/ Type III Vegetative State/ Type III Profound Brain Damage Stage III Vegetative State Type III Profound Brain Damage Stage III Profound Brain Damage	Patient has sleep awake patterns; single limb response to stimulation; withdrawal or intermittent localisation to touch, sound or visual stimulation may occur; tracking eye movements may occur but the patient does not focus on objects or people; may turn to sound or touch.

[[†] The term habituate is scientifically defined as a decreasing effectiveness of a stimulus. Thompson and Spencer’s definition of habituation is “a response decrement as a function of stimulus repetition which does not result from either receptor adaptation or effector fatigue”¹.]

Undecided*	
Transitional State/ Borderline State/ Type IV Vegetative State/ Type IV Profound Brain Damage Stage IV Vegetative State Stage IV Profound Brain Damage	The patient has a sleep-awake pattern being awake for a major part of the day; generally more definite localising to visual, auditory or tactile stimulation; tracking eye movements following objects or people; may show emotional responses to presence of family; may smile or cry.

* Agreement was not reached as to whether this stage was vegetative or non-vegetative.

Non-vegetative states	
Inconsistent Responsive State/ Inconsistent Relational State/ Inconsistent Low Awareness State/ Inconsistent Minimal Awareness State/ Inconsistent Minimal Responsive State Type V Profound Brain Damage Stage V Profound Brain Damage	Patients has sleep awake pattern; responds to simple commands inconsistently; remains totally dependent; profound cognitive impairments.
Relational Responsive State/ Consistent Low Awareness State/ Consistent Minimal Awareness State/ Consistent Minimal Responsive State Type VI Profound Brain Damage Stage VI Profound Brain Damage	Patient has sleep-awake pattern; consistently responds to simple commands.

Overall Opinion

Although no overall agreement could be achieved the preferences with the largest amount of support were:

Hyporesponsive Vegetative State
Reflex responsive Vegetative State
Localising Responsive Vegetative State
Borderline or Transitional Vegetative State had equal number of supporters.
Inconsistent Low Awareness State
Consistent Low Awareness State.

Conclusion

It has not been possible to obtain unanimous agreement from the Working Party on terminology. There seems to be a general acceptance that it will not be possible to remove the term vegetative state. The terms with the greatest number of supporters were descriptive of the type of response (hypo-, reflex or localising) for the vegetative

state and the use of the term Low Awareness State subdivided into those responses, which were consistent, and those that are inconsistent.

There is a clear need to have common agreement on terminology if the subject of the Vegetative state can be more fully examined and clinicians can communicate with each other.

1 Thompson R F, Spencer W W. Habituation: A model phenomenon for the study of neuronal substrates of behavior. *Psychol Rev* 1966; **73**: 16-43.