

CASE COMMENT

***WHAT PRICE UNCERTAINTY?***  
**THE PERSISTENT VEGETATIVE STATE IN NEW SOUTH WALES**

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INTRODUCTION

The case of *Northridge v Central Sydney Area Health Service*<sup>1</sup> highlighted the need for a definition and protocol for the diagnosis and treatment of the persistent vegetative state.

Coined by neurosurgeons Professor Bryan Jennett from Glasgow and Professor Fred Plum from New York in 1972<sup>2</sup>, the term 'persistent vegetative state' (PVS) was used to describe a state of severe brain damage with three main characteristics:

- The patient has a pattern of wakefulness and sleep;
- All movements and reactions are reflex responses;
- There is no evidence of meaningful response to anything around them.

Although PVS is an issue which British law has been grappling with for almost a decade, Australia has barely addressed the issue, with the result that an already difficult area of law has been further complicated by an almost complete dearth of judicial commentary.

This essay examines the need for clarification in this area of law in the light of *Northridge*. In particular, there is a need for a clear definition of PVS and the method for diagnosis of PVS needs to be made clear.

At the time of writing, the National Health and Medical Research Council (NHMRC) is in the process of drafting guidelines for the diagnosis of PVS. It is understood that these guidelines, when complete, are expected to be merely informative, and not in any way binding upon physicians due to the lack of

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<sup>1</sup> [2000] NSWSC 1241. (*Northridge*).

<sup>2</sup> Brian Jennett and Fred Plum, 'Persistent vegetative state after brain damage' (1972) 1 *Lancet* 734.

Australian research in this area. It will be argued that it would be wise to formulate unambiguous and *binding* guidelines to avoid such situations as that which arose in *Northridge*, and, that we should adopt the ratio of *Airedale NHS Trust v Bland*,<sup>3</sup> to prevent deviation from these guidelines, as has been apparent in Britain in cases following *Bland*. In the interim, such guidelines would serve the good of those patients in or mistakenly diagnosed as being in PVS, their families and carers, and their physicians.

It is proposed that, in lieu of Australian research and considering the position of PVS low down on the research 'triage list', we should rely on the experience of Britain in order to formulate binding guidelines.

#### THE FACTS OF NORTHRIDGE<sup>4</sup>

John Thompson, a 37 year old man was admitted to the Royal Prince Alfred Hospital on 2 March 2000, suffering from a heroin overdose and cardiac arrest which had left him in an unconscious state. On 8 March, six days later, medical staff decided to cease artificial feeding, hydration and antibiotic treatment. This decision was made without consulting Mr Thompson's family, and was against clear hospital policy.<sup>5</sup> There was substantial evidence to suggest that this was against the family's wishes, and that medical staff were aware of these wishes. As a result of the decision to cease medical treatment, Mr Thompson's death - either from infection or from starvation and dehydration - was certain.

Mrs Northridge, the patient's sister, made numerous attempts to have her brother's medical treatment reinstated, particularly the antibiotics, as Mr Thompson was by this time suffering from 'a raging fever'<sup>6</sup> and his excessively noisy breathing suggested a severe chest infection. She appealed to her brother's doctors, other medical staff, the Guardianship Tribunal and finally the Court. The latter provided relief via intervention on 12 March.

Significant pressure continued to be applied to the family by the medical staff of the hospital for the removal of life-prolonging treatment, with arguments concerning the futility of treatment being made on more than one occasion. The family objected, stating that Mr Thompson would follow members with his eyes, would turn his head when called, and would flinch when treated by nurses. On 12 April 2000, a Not For Resuscitation Order was placed on Mr Thompson against the express wishes of Mrs Northridge.

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<sup>3</sup> [1993] 1 All ER 821. (*Bland*) This case involved a 23-year-old man who had been in PVS for three years before the court gave permission for the discontinuance of artificial feeding and hydration.

<sup>4</sup> *Northridge* [2000] NSWSC 1241.

<sup>5</sup> Policy 3 states that the policy of the hospital is 'to involve patients, families and health care personnel in decisions concerning the patient's care and treatment'.

<sup>6</sup> Comment by Mrs Northridge in the evidence recorded in *Northridge* [2000] NSWSC 1241.

It must be noted that the distinguished neurologist, Emeritus Professor James W Lance found significant improvement in John Thompson over a period of several days. On 2 March 2000, his Glasgow coma score (GCS)<sup>7</sup> was 3 out of 15, with many reflexes abnormal or missing. By 9 March 2000, Mr Thompson had improved to the extent that he was able to obey requests, make sounds (a tracheostomy prevented him from speaking) and move his upper limbs on request. His GCS had increased to 12 out of 15.<sup>8</sup>

Upon further examination of Mr Thompson, Dr Freeman of the National Brain Injury Foundation formed the opinion that a premature diagnosis of 'chronic vegetative state' had been made, that the description of 'vegetative state' was itself unfitting given Mr Thompson's level of awareness, and that there was significant potential for even greater recovery of function than was then apparent.

It is interesting to note that at the end of his report on Mr Thompson [Dr Freeman stated] that the events which had occurred with respect to Mr Thompson were not a rare occurrence. He noted that the essence of this story (the discarding of people with severe brain injury by the health care system in Australia) was not unfamiliar and was very frustrating.<sup>9</sup>

#### DECISION AND ISSUES ARISING

The Court held that Mr Thompson was to be provided with all necessary and appropriate medical treatment for the preservation of his life and the promotion of his good health and welfare as long as he remained under Mrs Northridge's control and in a hospital or other institution, pending the further order of a Court. No Not for Resuscitation Order was to be made in respect of him without the Court's prior leave.

In *Northridge* a diagnosis of chronic vegetative state had been made after a period of only six days. Not only was this diagnosis premature, according to any standard found in the world,<sup>10</sup> but the phrase 'chronic vegetative state' was inappropriate and did not fit into any existing classification code.

<sup>7</sup> The GCS is a measure of brain injury and consists of a score of between 3 and 15 (3 is the worst, 15 the best), composed of three parameters: best eye response, best verbal response, and best motor response. For greater detail, refer to G Teasdale and B Jennett, 'Assessment of coma and impaired consciousness: A practical scale' (1974) 2 *Lancet* 872.

<sup>8</sup> A score of 12 indicates mild to moderate brain injury. See above n 7.

<sup>9</sup> Report by Dr Freeman to the court referred to in the case of *Northridge* [2000] NSWSC 1241.

<sup>10</sup> Current world standards regarding the diagnosis of PVS set the period of time which must elapse before such a diagnosis is made at six to twelve months. Refer to Brian Jennett, 'Letting Vegetative Patients Die' in John Keown (ed), *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (1995) 172, 175.

BRITISH PRECEDENT: ANTHONY BLAND<sup>11</sup>

Although in some respects very different from *Northridge*, *Bland* and similar later cases show what the British courts have done with PVS cases, and highlight the gravity with which the definition and diagnosis of PVS ought to be treated.

The case of *Bland* concerned a young man who had been in PVS for three and a half years following an accident resulting in injuries including severe and irreversible damage to higher brain functions. All doctors who examined him testified to the hopelessness of expecting him to improve at all from his current state, let alone to a cognitive sapient state. The plaintiffs sought permission to lawfully terminate Bland's medical treatment (including feeding and hydration, and antibiotics should infection occur) except treatment necessary to allow Bland to end his life with dignity and in a minimum of pain, suffering and distress. Without this treatment, it was predicted that Bland would die peacefully of starvation at the end of one or two weeks.

At first instance and on appeal, the plaintiffs' declarations were granted<sup>12</sup>, such that their subsequent actions in the case were to be performed or omitted in good faith and in accordance with the order of the judge and as such, were not subject to civil or criminal liability.<sup>13</sup> On further appeal, the High Court supported the decisions of the courts below, but based their decision on a 'best interests' argument. Cessation of medical treatment was considered to be lawful where it was in the best interests of the patient. The 'best interests' principle was articulated *In re F (Mental Patient: Sterilisation)* [1990] 2 AC 1, where it was held that no-one could consent to medical treatment on behalf of an incompetent patient, but that a doctor could treat an incompetent patient if it was in their best interests to do so. In determining the patient's best interests, the doctor must act in accordance with a responsible and competent body of relevant professional opinion.<sup>14</sup>

British cases subsequent to *Bland* have followed the ratio and decision of that case. If it can be shown that the patient is in a persistent vegetative state and that removal

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<sup>11</sup> *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

<sup>12</sup> It was held that such cessation of treatment was lawful in that it was in accord with the order of the court; death was to be attributed to the accident which had caused Mr. Bland to be in PVS, rather than to the removal of artificial feeding and hydration. The precedent relied upon was that elaborated in *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 which states that where it has been determined, according to a respectable body of medical opinion, that it is not in a patient's best interests to maintain treatment, the state's positive obligation to maintain and safeguard life has been discharged.

<sup>13</sup> In *Bland*, it was accepted that artificial feeding and hydration constitute medical treatment which may be discontinued. This author disagrees, and argues that these should be classified 'basic care'.

<sup>14</sup> The legality of the 'best interests' rule in this context was supported by Dame Elizabeth Butler-Sloss in her October 2000 revision of the case upon the *Human Rights Act 1998* (UK) coming into force. (C Dyer, 'Human Rights Act does not affect the law on PVS' (2000) 321 *British Medical Journal* 916). It was also supported by the judges in the cases of *NHS Trust A v M*; *NHS Trust B v H* [2001] 1 All ER 801.

of artificial hydration and nutrition is in the best interests of the patient, the Court has allowed the withdrawal of treatment.<sup>15</sup> Even in cases where there has been some doubt about whether the patient fitted exactly into the definition of PVS, the court has tended to presume in favour of withdrawal of treatment.<sup>16</sup> To date, around 20 people in PVS have died following discontinuation of artificial nutrition and hydration since *Bland's* case.<sup>17</sup>

#### RECOMMENDATIONS

##### *A Model for Definition and Diagnosis of PVS in New South Wales*

The following definition and model for diagnosis of PVS in New South Wales is based largely upon the British guidelines for such cases, although with significant alterations having taken into account the results which have taken place in cases following *Bland*. It is proposed that, unlike the forthcoming NHMRC guidelines, these guidelines should be considered binding and strictly policed, in the interests of those patients who are in PVS, those who have been victims of misdiagnosis, and in the interests of the wider community.

It is proposed that the BMA definition of PVS be adopted in New South Wales, that is, that the persistent vegetative state be understood as:

...[a condition which] results from severe brain damage of the cerebral cortex, resulting in irreparable destruction of tissue in the thinking, feeling part of the brain. Patients appear awake but show no psychologically meaningful responses to stimuli... [They] are unconscious and incapable of suffering mental distress or physical pain although many reflex responses remain... The level of metabolic functioning of the cerebral cortex of PVS patients is the level associated with deep surgical anaesthesia.<sup>18</sup>

The British experience of PVS indicates that diagnosis should be made according to a set, uniform criteria, including the following, largely taken from the BMA guidelines but with some amendment. These are the issues to be considered:

<sup>15</sup> *Re M (A Minor)* (1998) (Unreported, Thorpe and Mummery LJ, 24 November 1998) was a straightforward case of PVS. It involved an application to the court for permission to remove artificial feeding and hydration granted.

<sup>16</sup> *NHS Trust v P* (2000) (Unreported, Dame Elizabeth Butler-Sloss P, 19 December 2000) involved removing treatment from a woman (P) who was not strictly in a persistent vegetative state according to the definition of the Royal College of Physicians. *Re H (Adult: Incompetent)* [1998] 2 FLR 36 involved a fact scenario similar to that in *Re P* and a 'best interests' argument was used to justify withdrawal of treatment. See also *Re D* [1998] 1 FLR 411, a case similar to both *Re H (Adult: Incompetent)* and *Re P*.

<sup>17</sup> Dyer, above n 16.

<sup>18</sup> British Medical Association (BMA), 'Defining PVS'. Guidelines on Treatment Decisions Concerning Patients in PVS, Revised June 1996; <www.bma.org.uk>.

### *Cause of Brain Damage*

The cause of brain damage resulting in the PVS is significant as chances of emergence and/or recovery vary dramatically with etiology. PVS resulting from acute insult - either traumatic (severe head injury) or non-traumatic (medical condition resulting in lack of oxygen/glucose flowing to the brain and causing extensive cell death - for example, anoxia from cardiac arrest) in origin - have some possibility of recovery. PVS arising from a chronic, degenerative condition such as Alzheimer's disease typically has a zero recovery rate.

### *Accuracy of Diagnosis*

Recent studies have shown that accuracy of diagnosis of PVS is significantly poor.<sup>19</sup> Mindful of this, the Royal Hospital for Neuro-disability (RHN) developed an assessment program for those in PVS. Known as the Sensory Modality Assessment and Rehabilitation Technique or SMART, the technique relies on a structured sensory program involving assessment of the five senses, communication, movement and wakefulness.<sup>20</sup> SMART has offered further evidence supporting Childs' findings,<sup>21</sup> and offers a much greater chance of correct diagnosis of PVS.<sup>22</sup> On the basis of this research, accurate diagnosis of PVS is possible. In making a decision of such import as the withdrawal of artificial nutrition and hydration, every possible effort, including the use of the most up-to-date methods of diagnosis, ought to be employed.

### *Period of time in Vegetative State*

Once it has been ascertained that an individual is in a vegetative state, a time-period after which the condition may be labelled persistent must be established.<sup>23</sup> It is

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<sup>19</sup> Recent findings by Childs et al found that 37% of 49 patients diagnosed with PVS or coma more than 1 month post injury were inaccurately diagnosed. The incidence of misdiagnosis rose to 48% where the injury was more than three months before admission and the etiology of injury was trauma. N Childs, W Mercer and H Childs, 'Accuracy of diagnosis of persistent vegetative state.' (1993) 43 *Neurology* 1465, 1465-7.

<sup>20</sup> Website for SMART therapy at the Royal Hospital for Neuro-disability, England: <http://www.smart-therapy.org.uk/>.

<sup>21</sup> Keith Andrews and others produced evidence that, of 40 patients admitted to the RHN between 1992 and 1995 with a referring diagnosis of vegetative state, 43% had been misdiagnosed. Keith Andrews, et al, 'Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit' (1996) 313 *British Medical Journal* 13, 13-16.

<sup>22</sup> The study also suggested that the *method* of diagnosing PVS needed examination, concluding that accurate diagnosis of PVS requires assessment over a long period of time, and cannot be made from a bedside assessment, even by an experienced clinician. It was held that accurate diagnosis is possible with the combined skills of a multi-disciplinary team experienced in the management of people with complex disabilities.

<sup>23</sup> This time-period varies from place to place. In 1993, the American Neurological Association (referred to in Jennett, above n 10) and the Multi-Society Task Force on PVS ('Medical aspects of the persistent vegetative state' (1994) 330 *New England Journal of Medicine* 1499-1508, 1572-9) decided that the vegetative state should be classed persistent after one month, but recognised that this *did not mean that it was permanent*. The determination of a *permanent*

proposed that the BMA recommendation of adhering to a 12-month-insentience safety net prior to making a diagnosis of persistent vegetative state be maintained [in all cases].<sup>24</sup>

#### *Unanimity of Medical Opinion*

Three doctors, at least one of whom must be a neurologist, must examine the patient, and they must be unanimous in their finding of PVS. In addition, they must unanimously give a prognosis confirming the unlikelihood or impossibility of recovery from this state before the condition will be considered permanent and any decision to withdraw artificial nutrition and hydration is authorised.

#### *Application of most aggressive care and rehabilitation in early stages to ensure best possible chances of recovery*

In order to ensure that those in the early stages of vegetative state are not ‘written off’, it is essential that aggressive medical treatment, including stimulation and rehabilitation be provided. In addition, all forms of artificial feeding and hydration must be maintained pending the order of a court.

### CONCLUSION

Although *Northridge* showed the problems which can arise where there is a lack of recognised criteria for the diagnosis of ‘vegetative state’, particularly those of premature and misdiagnosis of PVS, it must be understood that it is the only case of its kind to date. Nonetheless, definitive and binding guidelines may well ensure a higher level of treatment for those currently in PVS, while hopefully eliminating any unnecessary confusion should we ever be called to ask, as in *Bland*, whether or not it is right to withdraw treatment from such individuals.

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vegetative state (and thus any decisions about the treatment or management – or cessation thereof) relies on the potential for recovery (Childs, above n 19). In 1990, the American Medical Association stated that a permanent vegetative state could be found after three months where the cause is non-traumatic, 12 months for traumatic causes (or 6 months for those over 50 years of age). The error at the time was estimated at less than 1 in 1000.

<sup>24</sup>

BMA, above n 18.