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Disorders of Consciousness: Is a Dichotomous Legal Approach Justified?

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Abstract

Advances made in medical care mean that many critically ill patients with an acquired brain injury may survive with a disorder of consciousness. This may be in the form of a vegetative state (VS) or a minimally conscious state (MCS). Medically, there is a growing tendency to view these conditions as occupying the same clinical spectrum rather than be considered as discrete entities. In other words, their difference is now understood as one of degree rather than kind. However, is English law keeping pace with this development in medical knowledge? This article seeks to highlight the duality that exists in the legal decision-making process in England and Wales, and question the justifiability and sustainability of this dichotomous approach in the light of medicine's current understanding on disorders of consciousness.

Keywords

disorders of consciousness; vegetative state; minimally conscious state, best interests; life-sustaining treatment; clinically assisted nutrition and hydration; Mental Capacity Act 2005; English law

1 Introduction

Technological advances in medical care have enhanced the capacity and capability to prolong the lives of critically ill patients. This development has not, however, courted continual celebration. Cases are frequently brought to English courts to determine whether such existence is in the best interests of those patients. Prominent among these relate to disorders of consciousness particularly those diagnosed as being in a vegetative state (VS) and a minimally conscious state (MCS). In just two decades after the first VS case was heard in 1993 by the House of Lords, the same court¹ ruled on its first MCS case in 2013. *Airedale NHS Trust v. Bland*² and *Aintree University Hospitals NHS Foundation Trust v. James*³ are today the seminal authorities for how the determination of best interests should be managed for patients in a VS and MCS respectively. Two separate approaches are therefore espoused under English Law depending on the diagnosis. At the same time, recent medical research increasingly describes these two conditions as part of a continuous spectrum rather than distinct disorders. On this view, the difference between them is therefore one of degree rather than kind. In light of this

¹ Although now under its new name - The Supreme Court.

² [1993] 1 All ER 821.

³ [2013] UKSC 67.

important development, this article questions whether the dichotomous legal approach is justified.

The discussion will proceed as follows. Part 2 will take a close look at disorders of consciousness from a medical perspective. It aims to illustrate that VS and MCS are today understood as two states of consciousness that are essentially on the same spectrum. It will also highlight the prevalence of diagnostic errors in practice, including in the cases that have come before the courts. Part 3 will examine how the law responds to the question of whether the provision and continuance of life-sustaining medical intervention including clinically assisted nutrition and hydration (CANH) are in the patient's best interests. It will compare and contrast the pathways that have thus far been carved for VS and MCS patients. Part 4 summarises our earlier discussion and challenges the sustainability of the dichotomous approach in view of the current medical understanding of such disorders and the prevalence of mistakes in diagnosis. The work concludes by making a number of recommendations.

2 Disorders of Consciousness

The term vegetative state (VS)⁴ has been in the medical lexicon since 1972.⁵ It was joined by the term MCS three decades later in 2002.⁶ Both now are part of an umbrella term⁷ known as disorders of consciousness.⁸ Whether a patient has a disorder of consciousness is dependent on two factors: the level of consciousness (wakefulness) and the content of consciousness (awareness).⁹ Patients in a disordered level of consciousness are usually characterised by their disordered sleep-wake cycle and this is demonstrated by their somewhat erratic and alternating phases of eye opening.¹⁰ In contrast, patients in a coma lack a sleep-wake cycle, cannot demonstrate signs of wakefulness, and exhibit no features suggestive of awareness.¹¹ Disorders of consciousness are almost always secondary to an acquired brain injury, and causes of such an injury can be considered either traumatic or non-traumatic.

2.1 *Difference of Degree or Kind?*

The main difference between VS and MCS is the level of awareness in wakefulness, i.e. differences in the content of consciousness rather than the level.¹² Patients in VS are awake and may respond to stimulation with spontaneous behaviours, for example gasping or grimacing. The characteristic feature of VS patients is the presence of arousal, i.e. being awake,

⁴ The term is now commonly known simply as vegetative state (VS) in the medical literature, though PVS may be used interchangeably with VS in case law. Direct quotes of judgments in this work will use the terms adopted by the relevant judges.

⁵ B. Jennett and F. Plum, 'Persistent vegetative state after brain damage: A syndrome in search of a name', *Lancet* 299(7753) (1972) 734-737.

⁶ For a discussion of the clinical criteria defining MCS, see J. T. Giacino, *et. al.*, 'The minimally conscious state: definition and diagnostic criteria', *Neurology* 58 (2002) 349-353.

⁷ O. Gosseries, *et. al.*, 'Disorders of consciousness: What's in a name?', *NeuroRehabilitation* 28 (2011) 3-14.

⁸ S. Laureys, *et. al.*, 'Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome', *BMC Medicine* 8 (2010) 68-71, DOI: 10.1186/1741-7015-8-68.

⁹ S. Laureys, *et. al.*, 'Residual cognitive function in comatose, vegetative and minimally conscious states', *Current Opinion in Neurology* (2005) 18 (6) 726-733.

¹⁰ The Multi-Society Task Force on PVS, 'Medical aspects of the persistent vegetative state', *New England Journal of Medicine* 330(21) (1994) 1499-1508.

¹¹ O. Gosseries, *et. al.*, 'Disorders of Consciousness: Coma, Vegetative and Minimally Conscious States' in: D. Cvetkovic and I. Cosic (eds.), *States of Consciousness* (Berlin: Springer-Verlag 2011) pp. 32-33

¹² C. Shnakers, *et. al.*, 'Diagnostic accuracy of the vegetative and minimally conscious state: Clinical consensus versus standardised neurobehavioral assessment', *BMC Neurology* 9 (2009) 35-39, DOI: 10.1186/1471-2377-9-35.

but without signs of awareness. Such patients are unable to make intelligible verbal communication and lack the ability to make any voluntary response to demonstrate self-awareness or changes to the environment.¹³ In contrast, the term MCS describes a broad array of responsiveness - this may range from patients who are awake making several non-reflex movements to seemingly facial or emotional responses in a consistently meaningful manner. Therefore, MCS is defined by the presence of variable *but* reproducible responsive behaviours that suggest an underlying, albeit a minimal level of consciousness.¹⁴

There have been various terms used in the past to ascribe the notion of chronicity to patients in VS. For patients with an acquired brain injury (regardless of cause) remaining in VS for over *one month* following the injury, such patients are termed to be in a *persistent vegetative state*.¹⁵ In contrast, patients with an acquired non-traumatic brain injury in VS lasting over 3 months *or* traumatic brain injury in VS lasting over 1 year are believed to be in a *permanent vegetative state*.¹⁶ '*Persistent VS*' and '*permanent VS*' have the same abbreviations and can often be mistakenly used interchangeably.

VS and MCS are considered to be prolonged if lasting for longer than one month¹⁷, though it is possible for patients to remain in these states for many months and years. Some patients in VS may remain irreversibly in this clinical condition for many years,¹⁸ yet some may evolve and transition into a minimally conscious state.¹⁹ Interestingly, a very recent French study had demonstrated the possibility of alleviating the consciousness of a patient who have been in VS for 15 years by experimental vagus nerve stimulation.²⁰ Though the study was limited and only involved *one* test patient, this experimental treatment was effective and a transition from a diagnosis of VS to MCS was observed. Thus, this single-patient study appears to support the notion that the entities of VS and MCS are much intertwined, rather than discrete, as originally believed.

The diagnosis of disordered consciousness is heavily reliant on clinical judgement and this in turn is based on observations covering several variables. Accurate diagnosis has historically been difficult for the following reasons: patients may have an accompanying mental or physical disability that may limit their ability to respond to stimulation;²¹ patients are frequently assessed for their consciousness during a time when they are medically unstable;

¹³ M. Willems, *et. al.*, 'Longitudinal changes in functioning and disability in patients with disorders of consciousness: The importance of environmental factors', *International Journal of Environmental Research and Public Health* 12(4) (2015) 3707-3730, DOI: 10.3390/ijerph120403707.

¹⁴ D. Wade, 'Back to the bedside? Making clinical decisions in patients with prolonged unconsciousness', *Journal of Medical Ethics* 43(7) (2017) 457-458, DOI:10.1136/medethics-2015-103140.

¹⁵ The Multi-Society Task Force on PVS, 'Medical aspects of the persistent vegetative state (Part 1)', *New England Journal of Medicine* 330(21) (1994) 1499-1508.

¹⁶ American Congress of Rehabilitation Medicine, 'Recommendations for use of uniform nomenclature pertinent to patients with severe alterations of consciousness', *Archives of Physical Medicine and Rehabilitation* 76 (1995) 205-209.

¹⁷ This is the same timing clinicians use to reach a diagnosis of *persistent VS* for patients in a vegetative state and considered to be a particularly worrying prognostic milestone.

¹⁸ D. J. Strauss, R. M. Shavelle and S. Ashwal, 'Life expectancy and median survival time in the permanent vegetative state', *Pediatric Neurology* 21 (1999) 626-631.

¹⁹ *Ibid.*, at pp. 629-630.

²⁰ M. Corazzol, *et. al.*, 'Correspondence: Restoring consciousness with vagus nerve stimulation', *Current Biology* 27 (2017) 994-996.

²¹ S. Majerus, *et. al.*, 'The problem of aphasia in the assessment of consciousness in brain-damaged patients', *Progress in Brain Research* 177 (2009) 49-61.

patients' responses to stimulation are often delayed and inconsistent with poor reproducibility of clinical findings;²² and there is a degree of subjectivity in clinical observations.²³

Ever since the concept MCS was characterised, several authors have questioned the use of differentiating between it and VS.²⁴ Several prospective studies have shown that the prevailing prognoses of patients in MCS are comparatively better than that of VS. Nevertheless, both of these prognoses remain poor with many in MCS may continue to remain severely disabled.²⁵ The European Task Force on Disorders of Consciousness has recently proposed that the nosology of VS and MCS be part of a clinical and diagnostic spectrum rather than distinct clinical entities. This is in recognition that a spectrum may exist where some patients in MCS may only demonstrate non-reflex movements akin to that of VS, through to patients retaining the ability to make reproducible behavioural interactions like command following and communication.²⁶ Depending on where on this VS/MCS spectrum patients lie, it is believed that those on the spectrum resembling closest to VS are likely to suffer severe disability. On the whole, the scientific and medical view on disorders of consciousness is that the dichotomy between VS and MCS is likely to be false,²⁷ and that significant overlap has been demonstrated to occur between the two clinical entities.

2.2 Prevalence of Diagnostic Errors

Given that patients may evolve, transition²⁸, or recover from a state of disordered consciousness, making a clinical determination on the nature of the disorder is often challenging.²⁹ Neurophysiological and neuro-radiological studies comparing VS and MCS patients have indeed demonstrated clear but subtle differences³⁰. Although the scientific discussion of these differences is beyond the scope of this paper, such neurophysiological findings can aid in the formulation of disorder of consciousness – though such diagnoses are primarily made by clinical judgement. Moreover, the practical difficulties involved in

²² N. L. Childs, W. N. Mercer and H. W. Childs, 'Accuracy of diagnosis of persistent vegetative state', *Neurology* 43(8) (1993) 1465-1467.

²³ A. C. Byram, *et. al.*, 'Ethical and clinical considerations at the intersection of functional neuroimaging and disorders of consciousness – The experts weigh in', *Cambridge Quarterly of Healthcare Ethics* 25 (2016) 613-622.

²⁴ M.A. Bruno, *et. al.*, 'Assessment of consciousness with electrophysiological and neurological imaging techniques', *Current Opinion in Critical Care* 17 (2011) 146-151.

²⁵ For a fuller discussion on the long term outcomes of patients in VS versus MCS, see J. Luaute, *et. al.*, 'Long-term outcome of chronic minimally conscious and vegetative states', *Neurology* 75 (2010) 246-252; and G. Dolce, *et. al.*, 'Clinical signs and early prognosis in vegetative state: a decisional tree, data-mining study', *Brain Injury* 22 (2008) 617-623.

²⁶ Gosseries, *supra* note 7.

²⁷ Strauss, *et. al.*, *supra* note 18; J. Luaute, *et. al.*, 'Long-term outcome of chronic minimally conscious and vegetative states', *Neurology* 75 (2010) 246-252; O. Gosseries, *et. al.*, *supra* note 7.

²⁸ I.e., initially diagnosed with MCS but subsequently deteriorate into VS or *vice versa* where the VS condition improves into MCS.

²⁹ A. Demertzi, *et. al.*, 'Is there anybody in there? Detecting awareness in disorders of consciousness', *Expert Review of Neurotherapeutics* 8 (2008) 1719-1730.

³⁰ For discussions on the neurophysiological differences between VS and MCS see: E. Landsness, *et. al.*, 'Electrophysiological correlates of behavioural changes in vigilance in vegetative state and minimally conscious state' *Brain* 134 (2011) 2222-2232; E. Formaggio, *et. al.*, 'Assessment of event-related EEG power after single-pulse TMS in unresponsive wakefulness syndrome and minimally conscious state patients', *Brain Topography* 29 (2016) 322-333; A. A. Fingelkurts, *et. al.*, 'The value of spontaneous EEG oscillations in distinguishing patients in vegetative and minimally conscious states', *Clinical Neurophysiology* 62 Suppl (2013) 81-99; G. Varotto, *et. al.*, 'Altered resting state effective connectivity in long-standing vegetative state patients: an EEG study', *Clinical Neurophysiology* 125 (2014) 63-68.

translating neuroscientific discoveries of residual cognitive function in both VS and MCS patients continue to contribute to misdiagnosis at the clinical level.³¹

Previous studies have demonstrated that up to 37-43 per cent of patients diagnosed to be in VS had some clinically demonstrable signs of awareness suggestive that MCS was a more appropriate diagnosis.³² A prospective study in 2006 had found that 29 patients diagnosed with VS were subsequently identified to have MCS.³³ Although the criteria for the diagnosis for both VS and MCS are well defined in the literature, misdiagnoses between the two entities continue to persist.³⁴ This may be due to a lack of standardisation on how patients in either VS or MCS are identified and assessed.³⁵

Various factors that are thought to be contributory to the rate of misdiagnosis: (1) patients in a state of disordered consciousness often have very limited physical function, which is the mainstay of how patients demonstrate awareness; (2) there are difficulties in differentiating between what is voluntary and reflexive behaviours which in turn are compounded by inconsistencies between clinical assessors in their observations for signs of consciousness;³⁶ and (3) there is a lack of tailored quantitative assessment procedures that document temporal trends and reproducibility of particular behaviours that are patient-specific.³⁷ Furthermore, a comprehensive diagnostic workup combining clinical behavioural, neurophysiological, and brain imaging modalities would mitigate the degree of misdiagnosis.³⁸

This prevalence of diagnostic errors is certainly discernible in the existing case law. In *W v. M*,³⁹ for instance, the patient was initially thought to be in VS before further investigation transpired in a revised diagnosis of MCS. Similarly, in *St George's Healthcare NHS Trust v. P (by his litigation friend, the Official Solicitor) and Q*,⁴⁰ the patient was presented as being in a VS at the start of the hearing, only for the diagnosis to be altered to MCS at the end of the case. Likewise in *M v. Mrs N (by her litigation friend, the Official Solicitor), Bury Clinical Commissioning Group, A Care Provider*,⁴¹ the expert witnesses could not agree throughout the hearing on whether the patient was in a VS or MCS. This led the judge, Mr Justice Hayden, to remark that: 'any "bright line" delineation between PVS and MCS is largely, perhaps even, entirely, artificial'.⁴² This observation corresponds with the informed clinical suggestion that VS and MCS share significant overlaps in regards to the content of consciousness. As discussed, it is clear that these entities only differ in degree rather than kind. Since any dichotomous separation between them is likely to be false, is the current legal approach justified?

³¹ B. Kotchoubey, 'Apallic syndrome is not apallic: is vegetative state vegetative?', *Neuropsychological Rehabilitation* 15 (2005) 333-356.

³² K. Andrews, *et. al.*, 'Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit', *British Medical Journal* 313 (1996) 13-16; Childs, Mercer and Childs, *supra* note 22.

³³ C. Schnakers, *et. al.*, 'Does the FOUR score correctly diagnose the vegetative state and minimally conscious states?', *Annals of Neurology* 60 (2006) 744-745.

³⁴ N. D. Zasler, 'Terminology in evolution: caveats, conundrums and controversies' *Neurorehabilitation* 19 (2004) 285-292; M. Graham, *et. al.*, 'Acknowledging awareness: informing families of individual research results for patients in the vegetative state', *Journal of Medical Ethics* 41 (2015) 534-538.

³⁵ Kotchoubey, *supra* note 31.

³⁶ S. Majerus, *et. al.*, 'Behavioural evaluation of consciousness in severe brain damage', *Progress in Brain Research* 150 (2005) 397-413.

³⁷ J. Whyte, M. C. DiPasquale and M. Vaccaro, 'Assessment of command-following in minimally conscious brain injured patients', *Archives of Physical Medicine and Rehabilitation* 80 (1999) 653-660.

³⁸ J. T. Giacino and C. M. Smart, 'Recent advances in behavioural assessment of individuals with disorders of consciousness', *Current Opinion in Neurology* 20 (2007) 614-619.

³⁹ [2011] EWHC 2443 (Fam).

⁴⁰ [2015] EWCOP 15.

⁴¹ [2015] EWCOP 76.

⁴² Para. 73.

3 VS and MCS: The Legal Frameworks

English courts have had the daunting task of adjudicating on prolonged disorders of consciousness cases for the last quarter of a century. This began when Airedale NHS Trust sought a declaration that it would be lawful for all LST to be withdrawn and subsequently withheld from a patient who have been in a VS for over 3 years after his lungs were punctured and ribs crushed in the Hillsborough Disaster of April 1989. Given the uniqueness and novelty of the situation at the time, as well as the grave repercussions of the declaration sought, the case made it all the way to the House of Lords. By contrast, the first few MCS cases⁴³ did not reach the highest court in the land, now the Supreme Court. This only took place in 2013 in *Aintree University Hospitals NHS Foundation Trust v. James*.⁴⁴ These two landmark cases set out the legal framework for determining the best interests of VS and MCS patients respectively. This section will take a close look at what they prescribe for these two conditions, and analyse their similarities and differences. It will also examine the relevant sections of the Mental Capacity Act 2005, a statute passed by Parliament midway between these two landmark cases.

3.1 *Determination of Best Interests*

3.1.1 *Airedale NHS Trust v. Bland*

This case, as is well-known, concerned a football fan, Anthony Bland, who suffered from hypoxic brain damage after being seriously injured in the Hillsborough Disaster. When the prospect of improvement or retention of consciousness seemed no longer in sight, a court declaration was sought by his doctors, with the support of his parents. This was for a pronouncement that it would be lawful to have all LST and medical support including CANH withdrawn, and thereafter for medical treatment to be withheld. As these were with a view to letting him die, the declaration was opposed by the Official Solicitor who argued that such a move would amount to manslaughter if not murder.

In a judgement that engaged no small amount of creativity, the House of Lords granted the declaration by putting forward a number of controversial propositions.⁴⁵ One, that CANH was considered as medical treatment rather than basic care, as they involve the application of medical technique.⁴⁶ Two, that the removal of LST and medical support, though clearly requiring a physical act, constituted a permissible omission from a legal perspective. Three, both on the issue of removal and of the subsequent withholding of medical treatment including CANH, doctors were given assurance that they would not be breaching their legal duty of care as it would no longer be in Bland's best interests to receive those interventions.

In determining best interests, it was first acknowledged that Bland was indeed still alive as his brainstem was functioning. However, it was ruled that the duty of doctors towards a patient in VS does not extend to prolonging his life at all costs.⁴⁷ Where 'the patient is totally unconscious and where there is no hope whatsoever of any amelioration of his condition',⁴⁸ the principle of sanctity of life must yield to the doctor's duty to act in the best interests of the patient. According to Lord Goff, the question to be asked 'is not whether it is in the best interests of the patient that he should die. [Rather], [t]he question is *whether it is in the best*

⁴³ E.g. *W v. M* [2011] EWHC 2443; [2012] 1 WLR 110; *An NHS Trust v. L* [2012] EWHC 4313 (Fam).

⁴⁴ *Supra* note 3.

⁴⁵ For discussion, see J. Laing, 'Food and fluids: human law, human rights and human interests', in: C. Tollefsen (ed.), *Artificial Nutrition and Hydration: The New Catholic Debate* (Dordrecht: Springer, 2008) pp. 80-85.

⁴⁶ *Per* Lord Keith.

⁴⁷ *Airedale NHS Trust v. Bland* [1993] AC 789 *per* Butler-Sloss LJ. at p. 823.

⁴⁸ *Per* Lord Goff.

interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care'.⁴⁹ The latter, according to His Lordship, 'can sensibly be answered to the effect that it is not in his best interests to do so'.⁵⁰

Hence since LST is considered futile (in the sense of not carrying any therapeutic value) for VS patients, it follows that it is not in their best interests to continue receiving it. As to the question of futility, this was to be determined by doctors in accordance with the *Bolam* test, thus restricting both the notions of futility and best interests to be viewed only from a medical perspective.⁵¹ The House of Lords nevertheless stated that court declarations must be sought in future whenever doctors contemplate withdrawing CANH from VS patients.⁵²

3.1.2 The Mental Capacity Act 2005

Before the legal framework for MCS is explored, it is necessary to highlight that the Mental Capacity Act 2005 was passed midway between the House of Lords' judgment in *Airedale* and the Supreme Court's ruling in *Aintree*. This Act placed decision-making process for all incapacitated patients (including VS and MCS patients) with the Court of Protection. Importantly, it gives legislative recognition to the key issues averred by the House of Lords in *Airedale*.

The most notable is the endorsement that LST can be withdrawn and withheld from patients who are not legally dead. This is through a number of routes. According to the Act, all adults can, when competent, make an advance decision for LST to be withdrawn and withheld when they are incapable of making the decision in the future.⁵³ They can also appoint donees by conferring upon them a lasting power of attorney to make such a decision for them when they are not competent to do so.⁵⁴ For incompetent patients without advance decisions or appointed donees, the court is empowered to make a declaration on the lawfulness of any act done or about to be done.⁵⁵ Like *Airedale*, an act in this context includes omission.⁵⁶ Further confirming the House of Lords' standpoint, paragraph 5.31 of the Act's Code of Practice provides that, 'where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery... it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death'.

In addition, section 1(5) of the Act makes clear that any acts done or decision made under the Act for or on behalf of one who lacks capacity must be done or made in their best interests. In determining what is in their best interests, the court must apply the provisions outlined in section 4 of the Act. Thus any assessment of whether LST is in the best interests of the patient must not be motivated by a desire to bring about the patient's death.⁵⁷ It is crucial to consider the patient's past and present wishes and feelings; his beliefs and values that are likely to influence his decision if he had capacity and other factors that he would be likely to consider if he were able to do so.⁵⁸ Views must be taken of anyone named by the patient as someone to be consulted on such matters; anyone caring for the patient or who takes an interest

⁴⁹ *Ibid.*

⁵⁰ *Ibid.*

⁵¹ *Ibid.*

⁵² At pp. 870 and 874.

⁵³ S. 24(1).

⁵⁴ Section 9.

⁵⁵ Section 15(1)

⁵⁶ Section 15(2)

⁵⁷ S4(5)

⁵⁸ S4(6)

in his welfare; anyone whom the patient has granted a lasting power of attorney and any deputy appointed by the court.⁵⁹

Another fundamental endorsement of *Airedale* can be found in paragraph 5(a) of the Act's Practice Direction E. This specifically states that decisions about proposed withholding or withdrawal of CANH must be brought to court not only for VS patients, but also for MCS patients.⁶⁰ However, as the discussion below will demonstrate, best interests and how far the factors outlined in section 4 of the Act are engaged, are determined differently in court depending on whether a patient was diagnosed as VS or MCS.

3.1.3 *Aintree University Hospitals NHS Foundation Trust v. James*

Compared to VS, the first few MCS cases were only heard by the Court of Protection. *Aintree*, apart from being the first MCS case heard by the Supreme Court, was also the first case under the 2005 Act to come before this court. It is also unique in that the case was heard posthumously. It was initially brought to the Court of Protection by the doctors of David James who was gravely ill at the Aintree University Hospital NHS Foundation Trust. He had a host of medical problems including a diagnosis of MCS. The hospital sought a declaration that it would be in his best interests and thereby lawful to withhold the following LST in the event of a clinical deterioration: invasive support for circulatory problems; renal replacement therapy; and cardiopulmonary resuscitation (CPR). This decision was objected to by his family. The Court of Protection refused to grant the declaration⁶¹ but this was overturned by the Court of Appeal.⁶² Although James passed away after the Court of Appeal hearing, his wife was given permission to appeal to the Supreme Court.

At this juncture, it is worth noting that prior to *Aintree*, the courts have taken a position that stands in polar opposite to VS cases. It was held that it was never in the best interests of MCS patients for LST to be withdrawn.⁶³ In so proceeding, determination of best interests failed to apportion proper weighting to precedent autonomy, wishes and beliefs of both the patients and their families.⁶⁴ Although the views of the patient and their family and other carers were taken into consideration, preservation of life carried 'very great weight'⁶⁵ in that balancing exercise. This was such that the principle of sanctity of life trumped very strong evidence as to the patient's wishes.⁶⁶ In *Aintree*, although the Supreme Court's starting point was a similarly strong presumption that it is in a person's best interests to remain alive, it was acknowledged that there are cases where it will not be in a patient's best interests to receive LST. With James' situation sadly considered as one, the court upheld the Court of Appeal's decision. It nevertheless helpfully provided clarification on a number of issues.

One, that in the case of MCS patients, the proper question to ask is whether it is in the patient's best interests *to be given* a particular serious medical treatment.⁶⁷ And almost for the purpose of drawing a distinction with PVS, Lady Hale emphasised that it is this that should be the focus 'rather than on whether it is in his best interests to withhold or withdraw it.'⁶⁸ Two,

⁵⁹ S4(7)

⁶⁰ Practice Direction 9e (which supplements Part 9 of the Court of Protection 2007).

⁶¹ *An NHS Trust v. DJ* [2012] EWHC 3524 (COP)

⁶² *Aintree University Hospitals NHS Foundation Trust v. James* [2013] EWCA Civ 65

⁶³ *W v. M* [2011] EWHC 2443; *An NHS Trust v. L* [2012] EWHC 4313 (Fam).

⁶⁴ W. Glannon, 'Burdens of ANH outweigh benefits in the minimally conscious state', *Journal of Medical Ethics* 39 (2013) 551-552; A.L. Hebron and S. McGee, 'Precedent autonomy should be respected in life-sustaining decisions', *Journal of Medical Ethics* 40(10) (2014) 714-716.

⁶⁵ *W v. M*, *supra* note 64, *per* Baker J. at 222.

⁶⁶ J. Lombard, 'Navigating the decision-making framework for patients in a minimally conscious state', *Medico-Legal Journal of Ireland* (2016) 78 at 83.

⁶⁷ *Supra* note 3, para. 21 (our emphasis).

⁶⁸ *Ibid.*, para. 22.

echoing the ethos of the Mental Capacity Act, the Supreme Court affirmed that medical factors form only part of a wider panorama of best interests for the individual. As remarked by Her Ladyship:

decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try to put themselves in the place of the individual patient and ask what his attitude is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.⁶⁹

Three, it was confirmed that the purpose of the Mental Capacity Act is to enable the courts to do for an individual what one could do for himself if he had full mental capacity but nothing more.⁷⁰ A ‘balance sheet’ of the advantages and disadvantages of a proposed course of action is prescribed.⁷¹ In other words, what are the benefits and challenges associated with the continuation of LST? This evaluation needs to be made in tandem with a consideration and weighing of all factors in the Act’s best interests checklist as well as all available information about the patient’s views as regards LST i.e. his likely precedent wishes and feelings, in consultation with his family members and carers. Unlike pre-*Aintree* MCS cases, all these relevant factors are assessed in detail, rather than for the preservation or sanctity of life to carry inordinate weight.⁷² This balance sheet is to facilitate an assessment of whether a particular serious medical treatment is worth giving or continuing.

Fourthly, when exploring the wordings of paragraph 5.31 of the Mental Capacity Act’s Code of Practice,⁷³ a number of clarifications were provided. Medical interventions, it was stated, could not be said to be futile in the sense that they could only return the patient to a quality of life that was not worth living.⁷⁴ Further, whether there was any prospect of recovery, this did not mean a return to full health as ‘will avert the looming prospect of death’.⁷⁵ Rather, it is sufficient if the continuation of the medical treatment enables the resumption of a quality of life which the patient would consider worthwhile. However, it was added that reasonable steps should be taken to ensure that the giving or continuation of a particular treatment would not have the resulting effect of causing intolerable suffering. If it does, the matter transforms into the analysis of futility.⁷⁶ This ‘touchstone of intolerability’ is therefore used to decide whether the presumption in favour of the continuation of life has been rebutted.⁷⁷ Since ‘if the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it

⁶⁹ *Ibid.*, para. 39.

⁷⁰ *Ibid.*, para. 18.

⁷¹ This was not, however, the first time that the approach was adopted by the courts. Almost a decade before, it had been recommended in *Re L (Medical Treatment: Benefit)* [2004] EWHC 2713 (Fam) that ‘[t]he task ... is ... to weigh up that which is sometimes called the “benefits and disbenefits” but which I would prefer to call the advantages of giving or not giving potential treatments, and to balance them in order to decide the best interests [of the patient] with regard to his future treatment’, *per* Butler-Sloss LJ.

⁷² Lombard, *supra* note 67, p.83.

⁷³ Which as referred to above, states that ‘there will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery’.

⁷⁴ *Supra* note 3, para. 30.

⁷⁵ *Ibid.*, para. 21.

⁷⁶ R. Heywood, ‘Moving on from Bland: The evolution of the law and minimally conscious patients’, *Medical Law Review* 22(4) (2014) 548-571.

⁷⁷ C. Foster, ‘Taking an interest in best interests’, *New Law Journal*, 13 December 2013.

will not be lawful to give it'.⁷⁸ These, which include CANH, would be tantamount to an omission.

By virtue of the balance sheet exercise, patients are not automatically resigned to just one fate as in the case of VS. Instead, MCS cases post-*Aintree* have generated mixed outcomes. It was ruled in at least one case that treatment should continue to be given,⁷⁹ while it was held that it should not be so in a number of other cases.⁸⁰ Further, consistent with the Mental Capacity Act, the Supreme Court expects hospitals and doctors to seek declaration from the courts concerning the lawfulness of providing CANH to MCS patients.

3.2 A Comparative Analysis

It seems clear from the discussion above that there are key differences in the trends that have developed for VS and MCS cases. One of these relates to how the issue of further medical treatment is framed for judicial consideration. For VS patients, the approach is to ask whether it is in the best interests of the patient for LST to be *withdrawn and withheld*. The purpose of a court declaration therefore pertains to the *lawfulness of withdrawing and withholding treatment*. For MCS patients, the approach is to ask whether it is in their best interests to be *given* treatment. The purpose of a court declaration therefore concerns the *lawfulness of continuing and providing treatment*. This imports an initial presumption to preserve life in favour of treatment and pay more heed to the principle of sanctity of life than for VS patients, but must ultimately yield to the tolerability of the interventions.

The second difference flows from, and is connected to the first. As mentioned previously, it is now clear that the treatment does not necessarily have to imply cure or to return the patient to full or reasonable health. It is acceptable that if treatment is capable of allowing the resumption of a quality of life which the patient would regard as worthwhile, then it is reasonable to continue receiving the treatment. However, in the case of VS, it is usually held that there is no advantage to be gained in any attempts to prolong the patient's survival through the continual use of artificial and invasive procedures.⁸¹ The patient, it is observed, will neither improve nor recover awareness.⁸² As noted by Mr Justice Baker in *Gloucestershire Clinical Commissioning Group v. AB (by his litigation friend, the Official Solicitor)*, CD⁸³, 'this state (PVS) is permanent and that there is no prospect of any recovery'.⁸⁴ This echoes Lord Goff's observation in *Airedale* that this condition is one where 'there is no prospect of any improvement'⁸⁵ so much so that 'life-prolonging treatment is properly to be regarded as being in medical terms useless'.⁸⁶ And where the treatment is futile and no longer in the patient's best interests, the courts have made it clear that they should not be subjected to anything further than those which are necessary to allow them to pass peacefully and with dignity.⁸⁷ Thus where

⁷⁸ *Supra* note 3, para. 22.

⁷⁹ *St George's Healthcare NHS Trust v. P* [2015] EWCOP 42.

⁸⁰ E.g. *United Lincolnshire Hospitals NHS Trust v. N* [2014] EWCOP16; *An NHS Trust v. VT* [2013] EWHC B26(Fam); *Re S* [2016] EWCOP 32; *Re N* [2015] EWCOP 76; *Re D (Withdrawal of Medical Treatment)* [2016] EWCOP 24; *Cwm Taf University v. F* [2015] EWHC 2533 (Fam); *Briggs v. Briggs* [2016] EWCOP 53.

⁸¹ *A NHS Trust v. D* [2006] 1 FLR 638.

⁸² *Cwm Taf University*, *supra* note 80, para. 22.

⁸³ [2014] EWCOP 49.

⁸⁴ *Ibid.*, para. 16.

⁸⁵ *Supra* note 2, para. 17.

⁸⁶ *Ibid.*

⁸⁷ *A NHS Trust v. D*; *Portsmouth NHS Trust v. Wyatt* [2004] EWHC 2247; *Re L (A Child)(Medical Treatment: Benefit)* [2004] EWHC 2713.

a diagnosis of VS is confirmed, the courts have consistently countenanced the withdrawal of LST.⁸⁸

This takes us to the third distinction which is that the best interests criteria outlined in section 4 of the Mental Capacity Act are almost bypassed, with an automatic assumption made that it is in the best interests of VS patients to no longer be in receipt of LST and be allowed to die. This approach seems to contradict or compromise paragraph 5.32 of the Act's Code of Practice which states that:

before deciding to withdraw or withhold life-sustaining treatment, the decision maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests' checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.

Indeed, these factors are only considered in MCS cases where a balance sheet exercise is prescribed. Thus for judges, where the patient is in a PVS, 'identifying best interests is a clearer exercise'.⁸⁹ According to Mr Justice Baker, for instance, 'the balance sheet approach is not normally appropriate because all the factors that are relevant normally fall on one side of the scale'.⁹⁰ Once it is established that the patient is in VS, 'it is axiomatic that treatment is futile'⁹¹ and 'the decision whether to continue life-prolonging treatment does not involve a weighing operation of competing factors'.⁹² To put it simply, it is no longer in the patient's interest to continue receiving LST, and that it is lawful and in their best interests for CANH to be withdrawn.

Contrasted to this, where the patient to whom further LST was to be given is in MCS, an assessment must be made of their best interests. Mr Justice Baker pointed out in the early case of *W v. M* that MCS is 'not condition that in the course of any balancing exercise the scales would always point in favour of withdrawal in every case'.⁹³ Rather, it was acknowledged that '[w]ithin MCS, there is a spectrum of consciousness extending from patients who are only just above the VS to those who are bordering on full consciousness'.⁹⁴ This gives rise to a need to engage in an assessment of the advantages and disadvantages of the continuation of LST. Where it is not in the patients' best interests for LST to be continued, it is unlawful for it to be given. In the case of *United Lincolnshire Hospitals NHS Trust v. N*, for example, LST was removed from the MCS patient as it was regarded as not being in her best interests for 'invasive, risk laden, medical care as would be involved in a further attempt at artificial feeding'⁹⁵ to be continued. This is irrespective of protestations from family even on grounds of religious beliefs.⁹⁶ The court stressed that although the wishes, views and feelings of the patient must be accorded utmost respect, they are not determinative of the patient's best interests. They would have to be weighed against other considerations like the nature of the

⁸⁸ See e.g. *Gloucestershire Clinical Commissioning Group v. AB (by his litigation friend, the Official Solicitor)*, CD [2014] EWCOP 49. This is so, irrespective of protestations from family members – see e.g. *A NHS Trust v. D* [2006] 1 FLR 638.

⁸⁹ Per Hayden J. in *Cumbria NHS Clinical Commissioning Group v. Miss S, Mrs D, Miss T* [2016] EWCOP 32, at para.16.

⁹⁰ Per Baker J. in *Gloucestershire Clinical Commissioning Group*, *supra* note 88, para. 17.

⁹¹ Per Hayden J. in *Cumbria NHS Clinical Commissioning Group*, *supra* note 89, para. 20.

⁹² Per Charles J. in *Briggs*, *supra* note 80, paragraph 1.

⁹³ *Supra* note 39, at 35.

⁹⁴ Baker J. in the Oxford Shrieval Lecture p. 5. See *infra* note 122.

⁹⁵ *Supra* note 80, para. 66.

⁹⁶ *Abertawe Bro Morgannwg University Local Health Board v. RY* [2017] EWCOP 2.

contemplated treatment, how intrusive it might be and the likely outcome.⁹⁷ As for the views and feelings of family members, these must always be subordinate to the patient's best interests, objectively assessed.⁹⁸

Indeed, the differing and contrasting approaches were made very clear by Mr Justice Newton in *Cwm Taf University v. F.*⁹⁹ According to His Lordship, '[t]he important distinction of diagnosis (between minimally conscious state and vegetative states) so far as the court is concerned self-evidently dictates a different path, with different considerations and vastly different outcomes. In relation to a permanent vegetative state it may mean that the LST is futile, whereas in a MCS the court takes a holistic balance sheet approach'¹⁰⁰. The decision for VS patients is therefore made on the basis of an objective assessment of their best interests which is a one size fits all best interest test. Whereas for MCS patients, the courts observe the Mental Capacity Act's instruction to ensure that the patients' previously expressed views, wishes, values, beliefs and other factors they are likely to consider if they are able to do so, are taken into account. With these serving as essential components of the decision,¹⁰¹ the best interests assessment is interpreted from the patient's viewpoint.¹⁰²

The two diagnoses nevertheless share a number of characteristics from a legal perspective. The concern of both is as to whether it is in the best interests of the patients that their lives should be prolonged by the continuance of the relevant treatment and care.¹⁰³ Where the provision of LST is considered futile or intolerable, this can be legally withdrawn to allow the VS or MCS patient to die. Its removal or withholding is recognised as an omission rather than an act which causes the patient's death. Alongside this, CANH can also be removed and further withheld as it is considered as medical treatment rather than basic care. Although this could lead to agitation and distress that may persist for a period of days and weeks due to the protracted dying process from starvation and hydration,¹⁰⁴ courts have refrained from allowing the death to be expedited through the administration of a lethal injection.¹⁰⁵ An artificial line is therefore maintained between killing and allowing to die (i.e. act versus omission)¹⁰⁶ to allow the court to assure doctors that they are no longer under a duty to treat the patient, and that the withdrawal and withholding do not generate criminal liability for the consequent death.¹⁰⁷ Rather, the death is said to have been caused by the patient's natural condition.

Another shared feature is that there is a requirement to seek a declaratory relief from the court whenever the removal of CANH is contemplated from patients diagnosed as VS or MCS. As we finalised the last draft of the present paper, the Court of Protection ruled in *M v.*

⁹⁷ *Ibid*, per Hayden J. at para.10.

⁹⁸ *Ibid*, para. 20.

⁹⁹ *Supra* note 80.

¹⁰⁰ *Ibid.*, para. 13.

¹⁰¹ B. Clough, '“People like that”: Realising the social model in mental capacity jurisprudence', *Medical Law Review* 23(1) (2014) 53-80 at 63.

¹⁰² S.D. Pattinson, 'Contemporaneous and advance requests: The fight for rights at the end of life' in: J. Herring and J. Wall (eds.), *Landmark Cases in Medical Law* (Oxford: Hart Publishing, 2015) pp. 255-270 at 269.

¹⁰³ *Per* Lord Goff and Lord Browne-Wilkinson in *Airedale NHS Trust supra* note 2, at pp. 868 & 884 and *per* Charles J. in *Briggs supra* note 80, para. 17.

¹⁰⁴ M.Y. Rady and J.L. Verheijde, 'Nonconsensual withdrawal of nutrition and hydration in prolonged disorders of consciousness: authoritarianism and trustworthiness in medicine', *Philosophy, Ethics and Humanities in Medicine* 9 (2014) 16 at 18.

¹⁰⁵ Removal of CANH, it has been claimed, is ethically inferior to actively ending that life in this manner – see Z. Fritz, 'Can “best interests” derail the trolley? Examining withdrawal of clinically assisted nutrition and hydration in patients in the permanent vegetative state', *Journal of Medical Ethics* (2015), DOI:10.1136/medethics-2015-103045.

¹⁰⁶ A.M. Capron, 'Borrowed lessons: The role of ethical distinctions in framing law on life-sustaining treatment' (1984) *Arizona State Law Journal* 647 at 650.

¹⁰⁷ S. Halliday, *et. al.*, 'An assessment of the court's role in the withdrawal of clinically assisted nutrition and hydration from patients in the permanent vegetative state', *Medical Law Review* 23(4) (2015) 556-587 at 566.

*A Hospital*¹⁰⁸ that court oversight is no longer required where the family are in agreement with the treating team that it is in the best interests of the patient that LST be stopped. To withdraw CANH, the treating team would need to act in accordance with the Mental Capacity Act and the prevailing professional guidance.¹⁰⁹ This absence of a need for court ruling, it was reasoned, would avoid putting additional pressure on the overstretched public health resources, and prevent prolonged suffering for the patient and his family.¹¹⁰ The impact of this judgment is still uncertain, not least because it had come from a lower court, and that the Official Solicitor is said to likely launch an appeal.¹¹¹ What is clear, is that court declaration is still required where families and the treating teams are not in agreement as to whether the removal of CANH is in the patients' best interests; and is still available in any case in which the parties deem right to involve the courts.¹¹²

4 Conclusion and Recommendations

Patients with disorders of consciousness are not terminally ill¹¹³ or as Keown puts it, 'neither dead nor dying'.¹¹⁴ They can continue to live with the assistance of LST and CANH for an indeterminate period.¹¹⁵ Given the severe compromise in their apparent quality of life, the issue of whether it is in their best interests to persist in this state of existence comes up with alarming regularity. However, as discussed, the approaches taken are divergent.

In VS, withdrawal of LST including CANH would always be allowed as they are automatically considered futile. Thus a blanket approach is taken in regards to this condition. In other words, it is the diagnosis which decides the outcome. For MCS by contrast, it is the patient who is the central focus of the decision-making process. His or her wishes, views and attitudes as well as the advantages and disadvantages of providing him or her with LST receive a fuller analysis. Withdrawal could only be allowed when LST is deemed to cause intolerable suffering. In MCS, a decision is therefore made only after a host of factors are considered, none of which holds or are accorded greater gravity than the other. The diagnosis itself does not wholly determine the outcome. Whereas, it is still considered to be in the best interest of VS patients for LST to be withdrawn on grounds of futility and for the determination of best interests only to be viewed from a medical perspective. Hence despite the passage of a quarter of a century and the deepening of medical understanding of disorders of consciousness during this time period, *Airedale* remains the leading authority for the determination of the best interests of VS patients.

However, as discussed previously, VS and MCS are now perceived as conditions that lie on the same spectrum. In fact, the distinction between VS and MCS from a medical perspective is often very difficult to define and wrought with many individualised patient factors and variables. The Court of Protection makes its demand that an accurate diagnosis of

¹⁰⁸ [2017] EWCOP 19.

¹⁰⁹ *Ibid*, para. 37(3).

¹¹⁰ At para. 37(2)(iii), thereby approving the Court of Appeal's ruling in *Director of Legal Aid Casework v. Briggs* [2017] EWCA Civ 1168, para. 26.

¹¹¹ BBC News, 2017, 'Court Ruling Not Needed to Withdraw Care, Judge Says' 21 September 2017. Retrieved 16 October 2017, www.bbc.co.uk/news/uk-41341482.

¹¹² *M v. A Hospital*, *supra* note 107, para. 38.

¹¹³ L.S.M. Johnson, 'The right to die in the minimally conscious state' (2011) 37 *Journal of Medical Ethics* 175-178 at 177.

¹¹⁴ J. Keown, *The Law and Ethics of Medicine: Essays on the Inviolability of Human Life* (Oxford: Oxford University Press, 2012), p. 328.

¹¹⁵ R.J. Jox and K. Kuehlmeier, 'Reconsidering disorders of consciousness in light of neuroscientific evidence' *Neuroethics* 6 (2013) 1-3.

disorder of consciousness be made and clinical guidance followed in order for it to make a decision.¹¹⁶ In the context of misdiagnosis, the surrogate decision-making processes from a legal perspective may lead to separate medical and legal outcomes. Within the current case law, the accuracy and the nature of the underlying diagnosis in a patient with a disorder of consciousness is of paramount importance given that the judicial approach on VS patients is to consider whether it is in their best interests to withdraw LST, whilst with MCS it is whether it is in their best interests to provide LST.

With the introduction of the Mental Capacity Act 2005, the use of best interests testing adds some degree of transparency in judicial surrogate decision-making. It is therefore not wholly unreasonable to advance the argument that all patients in any disorder of consciousness should be subjected to the same best interests test in accordance with the Act. This measure would allow the advantages and disadvantage of LST and CANH to be carefully considered and weighed, and antecedent views from the individual and relatives heard. Thus, the Supreme Court's approach in its ruling on *Aintree*, which applied the relevant provisions from the 2005 Act should be advocated as the reference point when considering the best interests of an individual in a disorder of consciousness, unable to make informed choices, and whose best interests are uncertain. A balance sheet of advantages and disadvantages should therefore be a major determinant on whether a mental incapacitated patient with a disorder of consciousness be lawfully given LST.

If all patients with a disorder of consciousness (irrespective of whether VS or MCS) are reviewed by the courts in a similar and standardised fashion, then it would follow that the impact of misdiagnosis (or rather confusion between the two clinical entities) on a court's surrogate decision-making would be mitigated. Errors and mistakes in such a circumstance propagated by a misdiagnosis will have serious legal consequences.¹¹⁷ In view of this, it is fair to propose that the legal logic used in understanding the best interests of a patient in VS advanced in the *Bland* judgement to be antiquated. With current medical advances made on the research in disorders of consciousness, adopting a uniform judicial approach irrespective of VS or MCS would represent a paradigm shift on how surrogate decisions for patients with disorders of consciousness are made. This shift will also be reflective of the increasingly accepted medical viewpoint that VS and MCS fall on the same spectrum of disorder of consciousness and that the difference between the two is one of degree rather than in kind.

This article will conclude by maintaining that a dichotomous judicial approach for patients in a disorder of consciousness (i.e. one set of case law for VS patients and another for MCS patients), is not justified. It is recommended that VS patients should now be brought under the same legal framework used for MCS patients. This move would represent a more convergent and transparent approach to surrogate decision making involving the retention or removal of LST and CANH. To clarify, what we are advocating is for all patients with a disorder of consciousness to undergo the same legal process. Our concern is therefore not with the outcomes. Be it the continuation or withdrawal of LST and CANH, the outcome would in our view be defensible as long as the process is satisfactory. It goes without saying, however, that inasmuch as this step is necessitated by the current state of medical knowledge, it does not represent the conclusive legal framework for disorders of consciousness. This is, after all, a fast-moving area of medicine.¹¹⁸ As it evolves, so must the law. The existence of two distinct

¹¹⁶ *Cwm Taf University*, *supra* note 80, para. 15.

¹¹⁷ Our position is that the misdiagnosis of VS patients (as MCS) is not as important and detrimental as the misdiagnosis of MCS patients (as VS) since the law offers patients diagnosed with MCS more protection in terms of the processes involved.

¹¹⁸ O. Bodart, S. Laureys and O. Gosseries, 'Coma and disorders of consciousness: scientific advances and practical considerations for clinicians', *Seminars in Neurology* 33 (2013) 83-90.

decision-making frameworks does not align well with the current state of medical knowledge. Their preservation only serves to widen the gap between the two disciplines.

Lastly, although some commentators, as now supported by the Court of Protection, have advocated for decision-making power to vest in doctors, thereby doing away with court involvement particularly where all interested parties agree on withdrawal,¹¹⁹ this is not a position we support. Indeed, as observed by Mr Justice Baker in the Oxford Shrieval Lecture, ‘until such time that as we have greater clarity and understanding about the disorders of consciousness, and about the legal and ethical principles to be applied, there remains a need for independent oversight’.¹²⁰ Considering the gravity of the decisions, it is only natural that these should be open to public scrutiny as how these decisions are made at the court level concerns everyone in the wider society.¹²¹ With proper court oversight, this would ensure public safety and offer protection to the vulnerable.¹²² This is undeniably costly, but as aptly noted by Mr Justice Hayden in *Cumbria NHS Clinical Commissioning Group v. Miss S, Mrs D, Miss T*, ‘[t]hose who are [believed to be] beyond pain, understanding or without any true consciousness require vigilant protection of their rights and interests, all the more so because of their unique level of vulnerability’.¹²³

¹¹⁹ C. Kitinger and J. Kitinger, ‘Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: family experiences’, *Journal of Medical Ethics* 42 (2016) 11-17; A.R. Keene, ‘Procedure, practice and legal requirements: a commentary on “Why I wrote my advance decision”’, *Journal of Medical Ethics* (2016), DOI: 10.1136/medethics-2016-103969; L. Turner-Stokes, ‘A matter of life and death: Controversy at the interface between clinical and legal decision-making in prolonged disorders of consciousness’, *Journal of Medical Ethics* (2016), DOI: 10.1136/medethics-2016-104057.

¹²⁰ Baker J., 2016, ‘A matter of life and death’, Oxford Shrieval Lecture on 11 October. Retrieved 16 October 2017, www.judiciary.gov.uk/announcements/speech-by-mr-justice-baker-a-matter-of-life-or-death/.

¹²¹ Hayden J. in *Cumbria NHS Clinical Commissioning Group*, *supra* note 89, para. 23.

¹²² M. Varney, , ‘Is the Court of Protection still as protective?’ 22 September 2017, online at 2017, www.leighday.co.uk/Blog/September-2017/Is-the-Court-of-Protection-still-as-protective, accessed 16 October 2017; M.Y. Rady and J.L. Verheijde, ‘Judicial oversight of life-ending withdrawal of assisted nutrition and hydration in disorders of consciousness in the United Kingdom: A matter of life and death’, *Medico-Legal Journal* (2017), DOI: 10.1177/0025817217702289.

¹²³ *Cumbria NHS Clinical Commissioning Group*, *supra* note 89, para. 13.