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# MOVING ON FROM *BLAND*: THE EVOLUTION OF THE LAW AND MINIMALLY CONSCIOUS PATIENTS

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#### ABSTRACT

The decision in Bland centred on the withdrawal of artificial nutrition and hydration from a patient in a persistent vegetative state (PVS). Since then, a new medical condition has emerged, known as a minimally conscious state (MCS). In W v M, the Court of Protection was asked to authorise the withdrawal of artificial nutrition and hydration from a patient in a MCS. Baker J refused to grant the declaration. More recently, however, the courts were also asked to rule on the lawfulness of withholding treatment in a similar, albeit factually different, case. In the Court of Appeal decision in Aintree University Hospitals NHS Foundation Trust v David James and Others, Sir Alan Ward, with the agreement of Arden LJ and Laws LJ, granted a declaration that it would be lawful to withhold treatment. The Supreme Court then upheld this ruling, Lady Hale stating that the Court of Appeal reached the right result but for the wrong reasons. This article seeks to critically appraise the evolution of the law in regard to withdrawing treatment from MCS patients. The piece begins by explaining the differences between the two conditions of PVS and MCS and defines the law from the starting point of Bland. From here, the discussion progresses to focus on the challenges that the law has had to face in trying to keep pace with the advancing nature of medical understanding of conditions of the brain and explains how it has responded to these. The narrative then critiques the legal mechanism of best interests as it has been employed in the case law concerning MCS patients to date by analysing the various judicial perspectives on the concept. After addressing both the narrow and wide viewpoints, a conclusion is ventured as to how the balancing of best interests should be approached in respect of future MCS cases.

KEYWORDS: Best interests, Bland, Futility, MCS, PVS, Withdrawal

#### I. INTRODUCTION

The House of Lords' decision in *Airedale NHS Trust v Bland* was significant to say the least. For the first time in English law, the then highest domestic appellate

Airedale NHS Trust v Bland [1993] AC 789.

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court countenanced the withdrawal of artificial nutrition and hydration (ANH) from a patient in a persistent vegetative state (PVS). The judgment itself was looked upon favourably by some commentators, whereas others were more critical, if not of the outcome itself, of the reasoning and legal analysis in support of their Lordships' conclusions. Despite this, the law in respect of PVS patients has remained largely unchanged. Medicine, however, is a constantly evolving discipline and this is particularly evident in respect of understanding the brain. A new condition has now emerged. A minimally conscious state (MCS) resembles PVS in many ways in that it shares what appear to be, *prima facie*, similar characteristics. Nevertheless, there are subtle yet crucial differences between the two which mark out MCS as being distinct.

In W v M and Others (W v M), the Court of Protection, for the first time, was asked to authorise the withdrawal of ANH from a patient in a MCS. Baker J refused to grant the declaration. In 2013, however, the Court of Appeal was confronted with having to rule on the lawfulness of withholding treatment in a similar, albeit factually slightly different, case. In Aintree University Hospitals NHS Foundation Trust v David James and Others (Aintree) Sir Alan Ward, with the agreement of Arden LJ and Laws LJ, granted a declaration that it would be lawful to withhold treatment. Recently, the Supreme Court, hearing its first case under the Mental Capacity Act 2005, upheld the ruling of the Court of Appeal. Lady Hale delivered the judgment stating that, although she agreed with the result, the reasoning of Sir Alan Ward and Arden LJ was flawed. On closer inspection, Lady Hale, with respect, may have been too quick to dismiss certain aspects of their reasoning.

This article seeks to critically appraise the evolution of the law in regard to with-drawing treatment from MCS patients. The piece begins by explaining the differences between the two conditions of PVS and MCS and defines the law from the starting point of *Bland*. From here, the discussion progresses to focus on the challenges that the law has had to face in trying to keep pace with the advancing nature of medical understanding of conditions of the brain and explains how it has responded to these. The narrative then critiques the legal mechanism of best interests as it has been employed in the case law concerning MCS patients to date by analysing the various judicial perspectives on the concept. After addressing both the narrow and wide viewpoints, a conclusion is ventured as to how the balancing of best interests should be approached in respect of future MCS cases.

<sup>2</sup> See P Singer, Rethinking Life and Death: The Collapse of our Traditional Ethics (St Martin's Griffin 1995) 1; JM Finnis, 'Bland: Crossing the Rubicon?' (1993) 109 LQR 329; J Keown, 'Restoring Moral and Intellectual Shape to the Law After Bland' in J Keown (ed.) The Law and Ethics of Medicine (Oxford 2012), ch 12.

<sup>3</sup> See JT Giacino and others, "The Minimally Conscious State: Definition and Diagnostic Criteria" (2002) 58 Neurology 349.

<sup>4</sup> W ν M [2011] EWHC 2443; [2012] 1 WLR 110.

<sup>5</sup> Aintree University Hospitals NHS Foundation Trust v David James and Others [2013] EWCA Civ 65; [2013] Med LR 110.

<sup>6</sup> Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67.

<sup>7</sup> Ibid at [48].

## II. BACKGROUND: FROM PVS TO MCS AND THE LEGAL RESPONSE

## A. PVS and the Decision in Bland

It has been reported that certain patients who have been diagnosed as being in a PVS have, on occasion, miraculously recovered.<sup>8</sup> This has led some to suggest that the condition is not completely irreversible and that there remains a chance of improvement, albeit not full recovery. In these rare cases which have been reported, there is research to suggest that this was less to do with the potential reversible nature of the condition and more to do with an inaccurate diagnosis of a PVS being made in the first place. 10 The key features of the condition are now generally agreed by the medical profession and include a complete absence of awareness of self-environment, lack of behavioural responses to stimuli, no evidence of language comprehension or expression, intermittent wakefulness, bowel and bladder incontinence and variable preservation of cranial nerve and spinal reflexes. 11 Patients, however, retain sufficient autonomic functions which allow them to survive with appropriate medical care. The damage to the brain is irreparable; there is no prospect of recovery.

Tony Bland, the 96th and final victim of the Hillsborough disaster, was diagnosed as being in a PVS. When the House of Lords was confronted with the question of whether or not they should grant a declaration that it would be lawful to withdraw his ANH treatment, the legal test of best interests played a central role in the judgment of their Lordships. Making decisions for incapacitated patients on the basis of best interests is easier said than done and at the time of Bland, before the introduction of the Mental Capacity Act 2005, 12 the meaning of best interests was somewhat underdeveloped by the courts. 13 The assessment of best interests requires a court to engage in a careful balancing exercise of a range of factors when forming its opinion as to what is the best course of action for a patient. 14 Where the issue concerns the withdrawal of ANH, this exercise will involve weighing in the balance the advantages and disadvantages of maintaining or withdrawing the treatment. In the eyes of Lord Goff, however, the reality was that in relation to PVS patients, no balancing exercise was needed as in every case the scales would tip in one direction—in favour of withdrawal. 15 This was

See K Higashi and others, 'Clinical Analysis of Patients Recovered from Persistent Vegetative State, with Special Emphasis on the Therapeutic and Prophylactic Effects of L-dopa' (1978) 30 Brain Nerve 27.

See W Matsuda and others, 'Awakenings from Persistent Vegetative State: Report of Three Cases with Parkinsonism and Brain Stem Lesions on MRI' (2003) 74 J Neurol Neurosurg Psychiatr 1573.

<sup>10</sup> See K Andrews and others, 'Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit' (1996) 313 BMJ 13.

<sup>11</sup> See RCP, The Vegetative State: Guidance on Diagnosis and Management (2003), ch 2.

The Mental Capacity Act 2005 came into full force in England on 1 October 2007.

Best interests were traditionally dictated by the medical understanding of the term. See F v West Berkshire Health Authority [1990] 1 AC 1; Bolam v Friern Hospital Management Committee [1957] 1 WLR 582.

Re A (Mental Patient: Sterilisation) [2000] 1 FLR 549, 560; Re J (A Minor) (Wardship: Medical Treatment) [1991] Fam. 33, 55. This approach has been held to be consistent with European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), incorporated into domestic law by the Human Rights Act 1998. In NHS Trust A v M [2000] WL 1544593; [2001] Fam 348 Butler-Sloss P confirmed that Arts 2, 3, and 8 were not infringed by the balancing exercise, at [35]-[50]. A number of best interests arguments have been advanced in relation to PVS and MCS patients. However, these are beyond the scope of this piece. For discussion see J Herring, 'Forging a Relational Approach: Best Interests or Human Rights?' (2013) 13 Med Law Int 32.

Airedale NHS Trust v Bland [1993] AC 789, 869. 15

because the treatment had exhausted its therapeutic benefits. Its only effect was to sustain an unconscious patient and it was therefore effectively futile. The futility of the treatment in *Bland* provided the justification for its withdrawal, as it was not in the best interests of the patient that his life should be prolonged by the continuance of the ANH.<sup>16</sup>

Safeguards were placed on the decision to limit its scope. Their Lordships stressed that their ruling was confined only to those patients who were actually diagnosed as being in a PVS, and said that an accurate diagnosis could only be made by two independent doctors within a minimum twelve-month time frame. They also advised that a declaration of lawfulness should be required from the court before ANH could be withdrawn from PVS patients in future cases. 17 The intention therefore was to remove treatment decisions of this type solely from the remit of doctors' clinical discretion. Nonetheless, there have been some subtle developments in the law since Bland. In a number of cases where the patient did not fall squarely within the agreed medical definition of a PVS and their feeding tube became disconnected, the courts held that there was no need to reinsert it. 18 Thus, as Brazier and Cave state, 'whether judges like it or not, the effect of the long series of judicial decisions relating to withdrawal of treatment is that judges are making life or death decisions'. 19 The decision in Bland has been the subject of academic criticism, most notably from Professor John Keown, whose main concern is that the decision dealt a 'body blow' to the inviolability of life ethic (IOL).<sup>20</sup> One problem in cases that concern the withdrawal or withholding of treatment is that judges prefer to speak in terms of 'preservation of life'. The law regards the preservation of life as a fundamental principle and thus there is a strong presumption in favour of taking the necessary steps to extend life. However, this rule is not absolute and in certain exceptional cases preserving a patient's life may not be deemed to be in that patient's best interests. The problem for Keown is that in using the terminology of preservation of life, judges frequently misunderstand what is meant by the IOL. He thus critiques the decision in Bland on a number of different levels, his principal allegation being that the reasoning of their Lordships demonstrated a misunderstanding of the IOL.<sup>21</sup> Keown asserts that it is always wrong to withhold or withdraw treatment because 'death is thought to be in the "best interests" of the patient'22 and that we have to distinguish what he terms 'quality of life benefits' from 'beneficial Quality of life'. 23 The former is used to judge whether a treatment would be worthwhile, comparing its benefits and burdens, whereas the latter is used to judge whether or not the patient's life itself is or will be worthwhile.<sup>24</sup> He cites passages in the judgment which indicate that their Lordships elided the two questions

<sup>16</sup> Airedale NHS Trust v Bland [1993] AC 789, 869.

<sup>17</sup> Airedale NHS Trust v Bland [1993] AC 789, 870, 874.

<sup>18</sup> See Frenchay Healthcare NHS Trust v S [1994] 1 WLR 601; Re D (Adult: Medical Treatment) [1998] 1 FLR 411; Re H (A Patient) [1998] 2 FLR 36.

<sup>19</sup> See M Brazier and E Cave, Medicine, Patients and the Law (London 2011) 572.

<sup>20</sup> Keown, above, n 2, 328.

<sup>21</sup> Keown, above, n 2, 330-41.

<sup>22</sup> Keown, above, n 2, 12.

<sup>23</sup> Ibid.

<sup>24</sup> Ibid.

and incorrectly based their judgment on the premise that Tony Bland's life was in fact not worthwhile instead of the treatment not being worthwhile.<sup>25</sup> Thus, the correct approach for Keown in withdrawal cases is to ask: 'is tube-feeding "treatment" and, if so, is it worthwhile?'26

The line of reasoning advocated by Keown has not gone unchallenged, with scholars identifying that there is some difficulty in drawing a bright line between notions of the worth of treatment and the worth of life, and also that the there is no cogent reason why the IOL would ever countenance withdrawal of tube feeding as medically futile treatment.<sup>27</sup> On the other side of the debate, then, there exists a school of thought that clearly opposes the IOL ethic whose philosophy is grounded in the quality-of-life (QOL) approach. This is based on the utilitarian view that it is acceptable to consider whether a particular life is worth living.<sup>28</sup> The pros and cons of the IOL compared with the QOL continue to provoke disagreement. Yet, important to this analysis is the tenet of Keown's philosophy that in certain situations withdrawing or withholding treatment from a patient can be justified and would not offend the IOL principle, provided it was done so on the basis of an assessment of the worth or otherwise of the treatment. This is possible because while the IOL holds it is always wrong to intentionally kill, either by act or omission, it is permissible to act with the intent of relieving pain and suffering, provided that is the only intent of the doctor.<sup>29</sup> It does not matter that death is a foreseen consequence as this is merely an incidental side effect of the doctor's morally acceptable conduct. Thus, withdrawing or withholding treatment may be acceptable in some cases, depending on the circumstances and how much pain and suffering that treatment is causing the patient. For this to hold firm, the IOL demands that the law does not recognise oblique intent as actual intent. However, this is problematic because English law at present has held that intent may be inferred if death is a virtually certain consequence of an action. <sup>30</sup> A doctor is consequently left in a precarious position and so there needs to be some other justification as to why he or she would not be guilty of murder. Withdrawal cases have therefore been justified on the basis of lawful omissions, but this again is at odds with the IOL because a lawful omission may be underpinned by a direct intent to shorten life because the life itself is not considered to be worthwhile. The distinction between foresight and intent, and acts and omissions, is beyond the scope of this article. The assessment of the futility of treatment, however, is where the emphasis will lie as it is directly relevant to the question of best interests.

Keown, above n 2, 332-5. Specifically, see Airedale NHS Trust v Bland [1993] AC 789, 863 (per Lord Goff), 879 (per Lord Browne-Wilkinson), 897–8 (per Lord Mustill).

Keown, above, n 2, 340. 26

See D Price, 'Fairly Bland: An Alternative View of a Supposed New "Death Ethic" and the BMA Guidelines' (2001) 21 LS 618; A McGee, 'Finding a Way through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia' (2005) 13 Med L Rev 357.

See P Singer, Practical Ethics (2nd edn Cambridge 1993); J Harris, The Value of Life: An Introduction to Medical Ethics (London 1985); L Doyal, 'Dignity in Dying Should Include the Legalisation of Non-Voluntary Euthanasia' (2006) 1 Clin Ethics 65.

The IOL embraces the principle of double effect; it is permissible to bring about a foreseen bad consequence (in this case death) if the bad effect is not intended (in this case the only intent being to alleviate pain and suffering).

See R v Woollin [1999] 1 AC 82. 30

Approaching withdrawal cases from the perspective of futility alone is dangerous; it is an ambiguous concept and open to a range of different interpretations. 31 Futility can be viewed from the broader perspective of what the patients themselves, or indeed others, would classify as futile. This is problematic because a range of wider factors then have to be considered that are independent of the pure medical assessment of the productiveness or otherwise of treatment.<sup>32</sup> Mason and Laurie, on the other hand, define futility in terms of 'non-productive' treatment. 33 This focus places the concept within the medical field and so avoids the value judgments on the worth of life that are so offensive to the IOL. That being said, placing emphasis on 'nonproductive treatment' is not trouble-free. First, it narrows considerably the scope of the concept of futility. Second, it raises the rather difficult question of what counts as non-productive treatment? It is usually possible to point to at least some positive effect of treatment, no matter how slight. Therefore, very few if indeed any treatments could be categorised as completely non-productive in the strictest sense of the word. The dilemma which naturally flows from this is how productive does a treatment actually have to be before we can rule out a finding of futility? The upshot, then, is that the meaning of non-productive treatment needs to be considered in context. This problem is particularly evident in relation to patients who are on the margins of consciousness. Medical treatment may actually confer some therapeutic benefit to the patient and so in the strict sense of the term cannot be said to be non-productive, but the therapeutic benefits may only be minimal and therefore not a strong enough justification for keeping the patient alive. Thus, assessing futility from the perspective of benefits compared with burdens is perhaps more useful insofar as medical futility alone is concerned.

However, the Mental Capacity Act 2005 does not confine best interests to an assessment of medical futility. It now provides for a more rounded assessment, which applies to PVS patients in the same way it does to others. This has since been recognised in later case law and so it is important that all relevant factors are considered and analysed when determining what is in a PVS patient's best interests. In the first instance case of *Ahsan v University Hospitals Leicester NHS Trust*, for example, it was suggested that PVS patients not only have best interests, but ones that demand particular understandings of 'benefit' that have direct, practical implications not just for whether treatment should be given, but for the nature of its provision.<sup>34</sup> A careful balancing act should therefore take place where PVS patients are concerned, weighing

<sup>31</sup> See RK Mohindra, 'Medical Futility: A Conceptual Model' (2007) 33 J Med Ethics 71; NS Jecker and RA Pearlman, 'Medical Futility: Who Decides?' (1992) 152 Arch Intern Med 1140; See also Sir Alan Ward's analysis in *Aintree University Hospitals NHS Foundation Trust v David James and Others* [2013] EWCA Civ 65 at [35].

<sup>32</sup> See R Cranford and L Gostin, 'Futility: A Concept in Search of a Definition' (1992) 20 Med Law Hlth Care 307.

<sup>33</sup> JK Mason and GT Laurie, Mason and McCall Smith's Law and Medical Ethics (9th edn Oxford 2013) 505.

<sup>34</sup> Ahsan v University Hospitals Leicester NHS Trust [2006] EWHC 2624; [2007] PIQR P19. For discussion see E Wicks, 'When is Life Not in Our Own Best Interests? The Best Interests Test as an Unsatisfactory Exception to the Right to Life in the Context of Permanent Vegetative State Cases' (2013) 13 Med Law Int 75.

the perceived futility of the treatment against the wider social, psychological, and emotional benefits that could be achieved from a continued existence. Some benefit, in the wider sense of the word, could perhaps be gleamed from sustaining a PVS patient in a familiar and loving environment and also, to the extent that it is possible, by allowing them to be cared for by family members. Benefit here has to be construed in the widest possible manner and it is important that this is held in mind during the course of any balancing exercise, even though it is clear that in nearly every case the evidence will still point to withdrawal.<sup>35</sup>

### B. The Evolution of MCS

The central difference between PVS and MCS is that in the former, patients have no sensory awareness. MCS patients remain conscious, have a degree of awareness, and can, in some cases, demonstrate signs of response. The problem is that while medical knowledge of the condition has progressed over time, there is still no exact way of knowing precisely what degree of awareness a particular patient has; there is a sliding scale of consciousness within MCS in which patients at one end of the spectrum will be borderline PVS and those at the other will maintain higher levels of consciousness and sensory awareness.<sup>36</sup> The evolution of MCS has posed considerable difficulties for the law when it comes to the question of authorising the withdrawal of ANH. Where a patient has a level of consciousness and exhibits signs of awareness and response, no matter how slight, the question of futility is much more complex. Awareness and response are difficult to measure and treatments may confer positive benefits on some patients but not others.<sup>37</sup> Add to this the fact that MCS patients may recognise, and respond to, certain stimuli it is evident that there are a number of important factors present which trigger a more sophisticated best interests assessment.<sup>38</sup>

The decision in *Bland* was heard before the introduction of the Mental Capacity Act 2005 and so was dealt with under the common law. The two recent cases concerning MCS patients were dealt with under the Mental Capacity Act 2005. The legislation provides a statutory definition of best interests.<sup>39</sup> When assessing best interests, section 4 (6) of the Mental Capacity Act 2005 instructs the court, as the decision maker, to consider, so far as is reasonably ascertainable, (a) the person's past and present wishes and feelings, (b) the beliefs and values that would be likely to influence the decision if the person had capacity, and (c) the other factors that the person

Brazier and Cave assert 'the incontrovertible physical evidence and irreparable damage to the brain distinguishes Bland from some subsequent cases.' See Brazier and Cave, above, n 19, 568.

<sup>36</sup> See S Laureys and others, 'Cerebral Processing in the Minimally Conscious State' (2008) 63 Neurology

See M Boly and others, 'Perception of Pain in the Minimally Conscious State with PET Activation: An Observational Study' (2008) 7 Lancet Neurol 1013.

See F Perrin and others, 'Brain Response to One's Own Name in Vegetative State, Minimally Conscious State, and Locked-in Syndrome' (2006) 63 Arch Neurol 562; WL Magee, 'Music Therapy with Patients in Low Awareness States: Approaches to Assessment and Treatment in Multidisciplinary Care' (2005) 15 Neuropsychol Rehabil 522.

For a recent discussion see M Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 Med L Rev 1.

would be likely to consider if he were able to do so. 40 Section 4 (7) also states that the views of anyone engaged in caring for the person or interested in his welfare must be taken into account. 41 In principle, the law has now firmly recognised that best interests encompasses 'medical, social, and emotional' considerations. 42 It is an objective assessment, yet the legislation has opened up a range of subjective considerations that have to be considered within that. The subjective terminology of best interests under the Mental Capacity Act 2005 causes problems for scholars such as Keown because it paves the way for judgments to be made about the quality of a life instead of focusing exclusively on the worth of a treatment. 43 For many, however, this is a sensible way to approach the question, from a legal standpoint at least.<sup>44</sup> One clear difficulty, though, resides in the fact that when the question is opened up in this manner, it allows for a range of different interpretations as to where the emphasis should be placed in determining what is in a patient's best interests. Ascertaining any consistent line of reasoning from the courts is therefore a challenge, which is evident in the two recent cases that have concerned patients in a MCS. This article now analyses what can best be described as two contradictory approaches in the emerging MCS case law.

#### III. BEST INTERESTS: A CAUTIONARY TALE

## A. Background

In *W v M and others*, the patient, M, was forty-three years old. After suffering from viral brain stem encephalitis, she regained consciousness and was diagnosed as being in a MCS. <sup>45</sup> There was a consensus of medical opinion which suggested that there was no realistic prospect of improvement and, in view of this, her family applied to the High Court for two declarations: first, that M lacked capacity to make decisions about her future medical treatment; and second that it would be lawful to discontinue and withhold all life-saving treatment, including ANH. <sup>46</sup> On the 23rd January 2007, Sumner J made a declaration that M lacked capacity to conduct her own affairs, to litigate and to make decisions regarding her medical treatment. At a later direction hearing on the 25th February 2010, Holman J ordered the proceedings to be transferred to the Court of Protection. Here, Baker J refused to grant the declaration in respect of the withholding of the AHN treatment. <sup>47</sup>

The interesting aspect of the case is not so much the final outcome, although some would disagree with it, but is more concerned with the balancing exercise

<sup>40</sup> For the weight that should be attached to the patient's past and present feelings, and their beliefs and values see *Re G (TJ)* [2010] EWHC 3005 at [45]–[53]; *ITW v Z and M* [2009] EWHC 2525 at [35]; *X v MM* [2007] EWHC 2003 at [121].

<sup>41</sup> See A London Local Authority v JH and MH [2011] EWHC 2420 for the views of professional and non-professional carers; The London Borough of Hillingdon v Steven Neary and Mark Neary and Others [2011] EWHC 1377 at [24] for significance of views of family and family care.

<sup>42</sup> Re A (Mental Patient: Sterilisation) [2000] 1 FLR 549, 555.

<sup>43</sup> Keown, above, n 2, 16-8.

<sup>44</sup> R Heywood, 'Parents and Medical Professionals: Conflict, Cooperation and Best Interests' (2012) 20 Med L Rev 29; Donnelly, above, n 39.

<sup>45</sup> W v M [2011] EWHC 2443 at [14].

<sup>46</sup> Ibid at [2].

<sup>47</sup> Ibid at [252].

performed by Baker J and where he placed the emphasis in the assessment of best interests. From the outset, it was identified that MCS was not a condition such that in the course of any balancing exercise the scales would always point in favour of withdrawal in every case. <sup>48</sup> The varying nature and severity of the condition from patient to patient effectively means that each case will have to be assessed on its own facts. Consequently a lot will rest on the medical evidence in a given case. The difficulty is that the medical evidence is, in itself, uncertain. <sup>49</sup> The question of medical futility therefore hangs in the balance and so too the range of other factors that must be considered under the terms of the Mental Capacity Act 2005.

## B. The Balancing Exercise

Baker J did recognise the need for a holistic approach to best interests. His analysis encompassed a number of important considerations such as the preservation of life, M's wishes and feelings, her experience of pain, her enjoyment of life, her prospects of recovery, her dignity, and the wishes and feelings of family members and carers.<sup>50</sup> In terms of the balance sheet, the advantages of withdrawing ANH from M were identified as follows: M would be freed from the pain and discomfort that she is currently experiencing, and the prospect of increased pain in the future; she would not have to endure further intrusive treatment with unpleasant side effects; she would be spared from the distress she demonstrates after seeing her partner and after hearing certain pieces of music; she would be freed from the indignities associated with her current circumstances; she would be allowed to die with dignity in accordance with the wishes of her family members, reflecting not only what she would have wanted, but also what was in her best interests based on her family's views; she would be spared further years of surviving in a MCS; and, even though she may experience some pain and discomfort as a result of discontinuing the ANH, those experiences would be limited in time and controlled by medication and experienced end of life care.<sup>51</sup> On the other side, the advantages of continuing the treatment were: M would be kept alive for a further ten years and preservation of life is a fundamental principle; she would be spared the effect of withdrawal of ANH which would cause her pain and distress and ultimately lead to her dying by starvation and dehydration; she would continue to experience life with a degree of awareness of herself and her environment and she would continue to gain pleasure from company, listening to conversation, music, and the sensory experience of the 'snoozeroom' 52; she would be likely to gain extended enjoyment in her life from a planned programme of stimulating experience; her surroundings and environment could be altered to add to her pleasure; and, as she is clinically stable, she would continue to experience life at this level for a number of years.<sup>53</sup> After considering all these factors, Baker J placed his emphasis solely on the preservation of life.<sup>54</sup>

<sup>48</sup> Ibid at [35].

<sup>49</sup> Ibid at [46].

<sup>50</sup> W ν M [2011] EWHC 2443 at [219]–[242].

<sup>51</sup> Ibid at [247].

<sup>52</sup> Ibid at [122]. The 'snoozeroom' is a small room which can accommodate one or two residents in which there is music and special lighting and other things to provide a sensory experience for the residents.

<sup>53</sup> Ibid at [248].

<sup>54</sup> Ibid at [249].

## C. Futility: A Restrictive Interpretation

Keown welcomes the decision in  $W \nu M$ . However, when the judgment is assessed through the prism of his own analysis, it is evident that the question of the 'worth' or 'futility' of the treatment was not given the attention it deserves. 56

Baker I accepted medical evidence supporting the fact that the continuation of the ANH would provide a platform upon which M's positive experiences and QOL may be extended by changes to her care plan.<sup>57</sup> However, he rejected medical evidence to the effect that M's experiences were wholly negative. 58 What he did not do, though, was provide sufficient justification as to why the benefits of continuing the treatment specifically outweighed the burdens. It is true there were therapeutic benefits; the ANH would sustain the patient's life which could, possibly, allow the opportunity for increased pleasurable experiences.<sup>59</sup> Nonetheless, in terms of the IOL, the mere fact that a treatment is providing some therapeutic benefit does not necessarily rule out justified withdrawal. As Keown himself states: 'a treatment may not be worthwhile either because it offers no reasonable hope or benefit or because, even though it does, the expected benefit would be outweighed by burdens which the treatment would impose, such as excessive pain' [emphasis in original].  $^{60}$  In W v M, there were clearly burdens. The ANH was invasive; it caused the patient an unascertainable level of pain and discomfort; it was intrusive and carried with it unpleasant side effects. The treatment would sustain the patient in this state of indeterminable pain and these burdens would continue to get progressively worse over time. 61 The medical evidence at first indicated that M was at the lower end of consciousness, although it was later accepted that she was probably more likely to be closer to a mid-range of consciousness. 62 This was interpreted as a positive factor insofar as the benefits of the treatment being administered were concerned, yet it overlooked the fact that an increased level of consciousness may expose the patient to greater pain and discomfort and so may act as a burden.<sup>63</sup> Thus, it is not clear as to why the mere 'reasonable prospect' of some increased benefit outweighed the much clearer burdens that the treatment was imposing. 64 Moreover, certainly at no point were the questions explicitly posed: 'is this treatment?' and, if so, 'is it futile?'65 This raises the question: does Keown support the reasoning, or simply the outcome? If it is the latter, and preservation of life is favoured without any concrete support as to why it was the decisive factor, or why it garnered

<sup>55</sup> Keown, above, n 2, 354.

<sup>56</sup> Keown, above, n 2, 340.

W v M [2011] EWHC 2443 at [251]. 57

<sup>58</sup> Ibid.

<sup>59</sup> Ibid.

<sup>60</sup> Keown, above, n 2, 343.

<sup>61</sup> W v M [2011] EWHC 2443 at [247].

<sup>62</sup> Ibid at [211]-[212].

Ibid. This was acknowledged by Professor Turner-Stokes in relation to patients at the lower end of MCS spectrum. Her evidence also implied that a patient at a moderate level of MCS would experience an indeterminable amount of pain and discomfort, at [211]-[214]. Baker J, however, seemed to imply that experiencing life at this level of consciousness for a number of years would be an advantage of continuing the ANH, at [248].

W v M [2011] EWHC 2443 at [251]. 64

Keown, above, n 2, 340. 65

elevated status compared with the other considerations, is this not running dangerously close to the vitalist philosophy of preservation life at all costs?66 Thus. if the analysis was approached purely from the perspective of assessing the 'quality of life benefits' conferred by the medical treatment, there is, at the very least, a sustainable argument that on the medical evidence Baker I could have reached the opposite conclusion than he in fact did. If he had done so, it would have been the incorrect legal approach, but provided it was accepted that ANH is in fact 'treatment', the supporters of the IOL would have to concede that justified withdrawal was at least theoretically possible.<sup>67</sup>

## D. Wider Considerations Viewed From a Narrow Perspective

Beyond medical futility, the Mental Capacity Act 2005 invites a much more expansive analysis of best interests, which does enter into the territory of making assessments about QOL. The minute the law moves in this direction, a much stronger argument can be made out that the scales should have tipped in the opposite direction in  $W \nu$ M and that the outcome itself was incorrect.<sup>68</sup>

The troubling question for the law is where to set the bar in terms of the QOL threshold and in relation to whose eyes should it be defined. QOL, at its core, is an inherently subjective question and in an ideal world ought to be judged in reference to the value that a patient places on their own life. <sup>69</sup> This is sometimes difficult to do because in certain cases it is impossible to know how a patient would perceive a particular situation. Similarly, the legal test of best interests remains objective, so a judge is asked to assess objectively questions which are inherently subjective in nature. 70 This can lead to interpretational ambiguity and conclusions that seem at odds with what the patients themselves would have wanted.

In  $W \nu M$ , there was unchallenged evidence as to what the patient's wishes would have been about her continued existence in a MCS. 71 She indicated in previous conversations with family members that she would not want to be kept alive in a similar state to that which Tony Bland had to endure.<sup>72</sup> In the absence of a legally valid advance decision, this fell under a section 4 (6) assessment of the Mental Capacity Act 2005. Baker J did consider the patient's prior wishes, and did factor them into his balancing exercise, but it is clear that very little emphasis was placed on them in relation to the weight attributed to preservation of life. The inherent danger with cases such as this is that a judge can never be absolutely certain about what a patient would

<sup>66</sup> For discussion see R Huxtable, Euthanasia, Ethics and the Law: From Conflict to Compromise (Oxon 2007) 10-3.

<sup>67</sup> Keown, above, n 2, 340. One suspects they would not do though as it is always possible to argue the toss in respect of the burdens compared with benefits of treatment, or from a different and less convincing tack that ANH should not be classified as medical treatment. The latter analysis is beyond the scope of this

See A Mullock, 'Deciding the Fate of a Minimally Conscious Patient: An Unsatisfactory Balancing Act?: W v M and Others [2011] EWHC 2443 (Fam)' (2012) 20 Med L Rev 460.

<sup>69</sup> Singer and Harris, above, n 28.

See the explanatory notes to the Mental Capacity Act 2005 at [28]; see also A London Local Authority v JH and MH [2011] EWHC 2420, 34.

W v M [2011] EWHC 2443 at [225]. 71

<sup>72</sup> Ibid.

think or feel about their current situation; patients can quickly change their minds when placed in a situation that is real instead of hypothetical, and circumstances can also change which may affect a patient's views. That being said, if there is convincing evidence to support what the patient's wishes would have been then this has to play a significant role in the balancing exercise and should not be marginalised in the way that it was. The patient's wishes have to be given significant attention because this represents crucial evidence pertaining to that patient as an individual. It is the law acknowledging that it is important to consider, insofar as possible when making a decision for another, what was important to that person in their life and what they would have wanted to happen based on their beliefs, values, and opinions. Affording appropriate weight to the patient's wishes serves to ensure that the law at least recognises that different individuals may hold different views about what is best for them and in this sense it attempts to pay heed to vital notions of patient autonomy within the wider best interests assessment. In terms of both PVS and MCS patients, then, within best interests careful consideration should be given to how the patients themselves would perceive their existence now, compared with the life that they once enjoyed and the life that they are faced with in the future.

There was another aspect of the balancing exercise that was open to criticism. M's partner and family members were of the opinion that the treatment should be withdrawn.<sup>73</sup> These views received a cursory nod in Baker J's balancing exercise, but it was not explained why, for instance, the views of M's carers took precedence over the wishes of the family.<sup>74</sup> On the one hand, it was acknowledged that the carers have more day-to-day contact with M and, in some cases, carers may develop a closer relationship with the patient than the family members. However, on the facts, this did not appear to be the case as the relatives remained close to the patient. Equally, carers can sometimes become too close to patients and their professional judgment may, with the best of motives, become clouded.<sup>75</sup> The concern for a judge in placing too much emphasis on the views of relatives may reside in fears about the credibility of the evidence. Relatives could easily misrepresent, or indeed misinterpret, what the patient would have wanted, or, without any malice on their part, fall into the trap of supplanting the wishes of the patient with wishes of their own. Regrettably, relatives do also sometimes act with improper motives and so judges are correct to be hesitant in placing too much importance on their views, but this was not the case in W v M and will not be the case in the majority of situations. Therefore it is important for judges to recognise that appropriate, if not decisive, weight should be accorded to this component of the balancing exercise. This evidence is crucial because family members will often (although not always) be the ones who know the patient the best and who will be most familiar with the patient's values and beliefs. They will therefore, not infrequently, be in an ideal position to offer evidence as to what that particular patient would want to happen in a given situation. Amid the dangers identified with evidence of this type, it will, naturally, demand careful scrutiny of the evidence in each individual case, but this should not be beyond the capabilities of any judge.

<sup>73</sup> W v M [2011] EWHC 2443 at [242], [247].

<sup>74</sup> Ibid at [251].

<sup>75</sup> This was acknowledged by Baker J. Ibid at [251].

Whichever position one chooses to adopt in respect of W v M, that of respect for the IOL, or a commitment to the OOL, a case can be made out for a different and arguably more humane outcome. An expansive approach to the question of best interests certainly lends support to that proposition. <sup>76</sup> Baker J purported to approach the question from the correct legal position, but his balancing exercise was little more than a token gesture. For the law to move forward in this field, a more expansive approach is needed.

#### IV. BEST INTERESTS: AN EXPANSIVE APPROACH

# A. Background

Two years on from W v M, the Court of Protection was again confronted with a case concerning a patient in a MCS. In Aintree University Hospitals NHS Foundation Trust v David Iames and Others<sup>77</sup> the patient, after enduring a long battle with cancer, suffered from multi-organ failure and was eventually diagnosed as being in a MCS.<sup>78</sup> The hospital treating the patient sought declarations in support of withholding the following treatments in the event of further clinical deterioration: cardiopulmonary resuscitation; invasive support for circulatory problems; and renal replacement therapy in the event of deterioration in renal function.<sup>79</sup> Jackson I refused to grant the declarations. The main thrust of the judgment was that the treatment could not be said to be futile. 80 The decision was appealed to the Court of Appeal and was heard before Laws LJ, Arden LJ, and Sir Alan Ward.<sup>81</sup> The appeal was allowed principally on the basis that Jackson J erred in law by adopting too narrow a view of futility. 82 The Supreme Court upheld the decision of Court of Appeal, but Lady Hale was only prepared to agree with the end result, and not the underlying reasoning. 83 The facts to this case differ slightly to those in  $W \nu M$ , and it is important to acknowledge this. First, while the appeal was allowed and the declarations granted shortly before the patient died, the actual judgment and reasons for the decision were handed down after the patient had sadly passed away.<sup>84</sup> The reasoning of the Court of Appeal therefore had a retrospective air to it, which may or may not have affected the manner in which the conclusions were justified. This applied equally to the judgment of the Supreme Court. Second, death was more visibly imminent for the patient in Aintree, whereas this was not the case in W v M because the patient was clinically stable. 85 Thus, Aintree concerned the withholding of treatment and not the withdrawal of treatment; there was no suggestion that the baseline ANH treatment should be discontinued.<sup>86</sup> As a

<sup>76</sup> For further discussion see R Heywood, 'Withdrawal of Treatment from Minimally Conscious Patients' (2012) 7 Clin Ethics 10-6.

An NHS Trust v DJ and Others [2012] EWHC 3525. 77

<sup>78</sup> An NHS Trust v DJ and Others [2012] EWHC 3524 at [37].

<sup>79</sup> Ibid at [8].

<sup>80</sup> Ibid at [84].

Aintree University Hospitals NHS Foundation Trust v David James and Others [2013] EWCA Civ 65.

<sup>82</sup> Ibid at [38].

Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 at [48].

Ibid at [2]. 84

W v M [2011] EWHC 2443 at [248]. 85

Aintree [2013] EWCA Civ 65 at [20]. 86

consequence, there is less scope to query the outcome based on the fact that what was being withheld was not in fact medical treatment at all.

## B. The Balancing Exercise

In Aintree in the Court of Protection, there were certainly less factors on both sides which were identified as being relevant to the balancing exercise. Jackson J identified five factors in favour of treatment in the event of deterioration. These included: life itself is of value and treatment may have lengthened the patient's life; the patient had a measurable QOL from which he gained pleasure and although his condition fluctuated, there had been improvements as well as deteriorations; it was likely that the patient would have wanted treatment up to the point where it became hopeless; his family strongly believed that this point had not been reached; and it would not be right for the patient to die against a background of bitterness and grievance.<sup>87</sup> The factors against treatment in the event of a deterioration were identified as: the unchallenged diagnosis that the patient had sustained severe physical and neurological damage and the prognosis was gloomy, to the extent that it was regarded as highly unlikely that he would achieve independence again, and that the treatment was invasive with every setback placing him at a further disadvantage; the treatment may not have worked; the treatment would have been extremely burdensome to endure; it was not in his interests to face a prolonged, excruciating, and undignified death. 88

That there were numerically less factors is unproblematic, as is the case where there are more factors on one side than the other. The balancing exercise is not simply an exercise in adding up the factors on each side and favouring which has the most. Any one factor on a particular side can be sufficiently overpowering to override a range of factors on the other, as ostensibly seemed to be the reasoning in W v M. However, what can be said, and which was not readily apparent in W v M, is that in cases where one single factor is perceived to dominate, clear justifications need to be provided as to how that particular factor relates to, and compares with, the others. Equally there needs to be some support for why, when weighed in the balance, one factor is deemed worthy of taking precedence.

# C. Futility: A Refreshing Perspective

When *Aintree* progressed to the Court of Appeal, Sir Alan Ward recognised the problems inherent in the concept of futility and his analysis of its meaning was significantly broader than Jackson J in the Court of Protection before him. He started from the premise that what is worthwhile can only be assessed relative to its goal. Thus, the correct question to ask is: what is the proper goal of life-saving treatment?<sup>89</sup> Following this, a number of goals were then identified including: preventing the patient's imminent death from a particular ailment which the treatment is designed to overcome; to prolong life if only for a relatively brief time; to delay death even though it will not result in any significant alleviation of the patient's suffering; to provide a minimum

<sup>87</sup> An NHS Trust v DJ and Others [2012] EWHC 3525 at [79].

<sup>88</sup> Ibid.

<sup>89</sup> Aintree [2013] EWCA Civ 65 at [35].

QOL for the remainder of the patient's life; to allow the patient to achieve the goal (or the wish) he has set for himself; or, to secure therapeutic benefit for the patient in the sense that it must have the real prospect of curing or at least palliating the life threatening disease or illness from which the patient is suffering. 90 Jackson J's initial judgment ran too close to assessing this question by reference to the first three goals, but for Sir Alan Ward the correct approach to the question of futility was to consider it in light of the sixth and final goal.<sup>91</sup>

Sir Alan Ward's approach was criticised by Lady Hale in the Supreme Court. In an untypically narrow judgment, her Ladyship criticised Sir Alan Ward for setting the goal 'too high' in saying that a treatment was futile unless it has a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering. 92 Lady Hale seemed to read from this that Sir Alan Ward's assessment of futility was based predominantly on whether or not the treatment would provide a real prospect of cure for the patient; if it did not provide this, it could legitimately be classed as futile. Indeed, the inference seems to be that Sir Alan Ward focused on the curative, rather than palliative and beneficial, nature of the treatment. With respect, his judgment is capable of being interpreted in a different manner and Lady Hale's criticisms are, perhaps, unfair. He did not assess futility solely in respect of whether or not the treatment would have a realistic prospect of curing the patient; he assessed the therapeutic worth of the treatment by offsetting the benefits against the burdens. Lady Hale identified that a treatment may bring 'some benefit to the patient, even though it has no effect upon the underlying disease or disability'. 93 However, identifying some benefit from a treatment is not enough, in isolation, to justify a conclusion that that treatment can never be said to be futile. The evaluation of the worth of the treatment should only be made in light of an assessment of the benefit to burden ratio. Lady Hale's suggestion that Jackson J in the Court of Protection did engage in an effective assessment of the burdens compared with the benefits is to give him too much credit.<sup>94</sup> From the wording of his judgment, he may have given the impression that a careful balancing exercise took place, but in reality it was an illusion as his analysis was too one sided, with inappropriate emphasis being placed on benefits alone. It was only in Sir Alan Ward's judgment that a true balancing exercise actually bore fruit.

Thus, Sir Alan Ward's interpretation of futility is welcomed. He did not focus solely on the benefits of the treatment in the past, nor did he limit his analysis to the mere fact that the treatment would provide some therapeutic benefit to the extent that it would be useful in keeping the patient alive. He was willing to consider the therapeutic benefit, but was also willing to offset this against the potential burdens that the treatment would inflict on the patient if carried out. It is this latter aspect which is frequently overlooked by judges and so an approach that assesses the worth of the treatment against the backdrop of the patient's general well-being and overall

<sup>90</sup> Ibid.

<sup>91</sup> Ibid at [38].

<sup>92</sup> Aintree [2013] UKSC 67 at [43].

<sup>93</sup> 

Ibid at [40]. 94

medical, psychological, and physical health is encouraging. <sup>95</sup> In *Aintree* to restore the patient's blood pressure, the doctors would have had to insert a very large drip and deliver potent drugs to the patient. These would have caused considerable discomfort to the patient, requiring large amounts of local anaesthetic to administer, and would also have placed an increased strain on his heart. <sup>96</sup> Similarly, the renal replacement therapy would have involved the placement of a large bore tube to administer blood thinning drugs, which carried a risk of stroke. There was also a risk of bleeding within the stomach or gullet and the burden of a temperature imbalance which would cause the patient to become cold and shiver for the duration of the 24-h treatment cycle. <sup>97</sup> The burdens here clearly outweighed the therapeutic benefits and so if approached exclusively from the question of futility alone a strong argument can be made out for condoning the withholding of the treatment. Nonetheless, neither Sir Alan Ward nor Arden LJ limited their judgment to this question.

## D. Wider Considerations: Intolerability and the Wishes of the Patient

English judges have, understandably, shied away from basing their reasoning on an assessment of the worth of a patient's life. <sup>98</sup> Judges are right to approach this question cautiously and sometimes problems are created by the fact that they claim that they are not assessing the worth of a life, when the reality is that they are. <sup>99</sup> A further positive element of Sir Alan Ward's judgment in *Aintree* was that he recognised that this was a question fraught with difficulty, but he was explicit about the fact that it was one important factor that needed to be considered and he then went on to consider it. <sup>100</sup>

The notion of intolerability thus featured in his assessment. The danger in placing too much weight on this is that a judge has to assess it objectively, when in actual fact what is intolerable is inherently subjective. Some patients will have a higher pain threshold than others. Likewise, some patients will be more willing to persevere with a debilitating medical condition. Any attempt to view these considerations through the lens of what is reasonable invites conclusions which may end up being at odds with what the patients themselves would think about their situation. Objectively defined intolerability can also become difficult to detach from the medical evidence in a given case and so judges need to remain sensitive to the fact that it is a broad concept and should not be confined only to the intolerability of the medical treatment, but should encompass the intolerability of the medical condition in its entirety, and the surrounding circumstances of the patient. In Aintree, for instance, Sir Alan Ward recognised that if the patient suffered another setback in his condition, 'the risks and burdens of keeping him alive would be disproportionate to the diminishing opportunities for him to take pleasure from his family. 101 Continuing to insist on medical treatment would therefore have made his existence intolerable and this was a

<sup>95</sup> For a discussion of futility in both the qualitative and quantitative sense see R Halliday, 'Medical Futility and the Social Context' (1997) 23 J Med Ethics 148.

<sup>96</sup> Aintree [2013] EWCA Civ 65 at [41].

<sup>97</sup> Ibid at [42].

<sup>98</sup> Airedale NHS Trust v Bland [1993] AC 789, 894 (per Lord Mustill).

<sup>99</sup> This represents Keown's main criticism of the reasoning of their Lordship in Bland.

<sup>100</sup> Aintree [2013] EWCA Civ 65 at [48]-[50].

<sup>101</sup> Ibid at [49].

strong indicator that it was in his best interests to sanction the withholding of it. Intolerability, though, should not be regarded as the tool that provides the authoritative answer in these cases. It has long been recognised that it is a useful guide for best interests, but is by no means a substitute test, something which was reinforced by Lady Hale in the Supreme Court. 102

In Aintree, Arden LJ arrived at the same conclusion as Sir Alan Ward, but via a different route. 103 She was much less comfortable in confronting the QOL question. For her, then, the emphasis in the case ought to be placed on the patient's wishes. It is one thing to acknowledge that 'great weight' 104 has to be given to the wishes of the individual, but it is quite another to approach a judgment exclusively from this viewpoint. In this regard, Arden LJ's judgment verges on the groundbreaking, but her reasoning seems slightly inconsistent. To state on the one hand that the case raises no issues in respect to the QOL, but then on the other to quote directly from the Law Commission whose view was that decisions for those who lack capacity require 'careful, focused consideration on that person as an individual', creates a contradictory tension. 105 It may have been better to be open about the fact, as Sir Alan Ward was, that sections of the Mental Capacity Act 2005 do demand some examination of certain QOL questions, which are especially pertinent when it comes to examining the past and present wishes of patient. In assessing the past wishes of an individual patient, a judge is essentially being asked to take account of opinions, wishes, and desires that the patient may once have expressed as a result of values that they have placed on their own life. Problems are encountered though when there is no indication of what those wishes would have been, or what they are at present. Judges then have to embark on the challenge of ascertaining what they think those wishes would indicate.

Difficulties are further exposed when judges attempt to conceal the subjectivity of the patient's past and present wishes by claiming that they can be accessed from a purely objective perspective. When this happens, it defeats the purpose of the sections of the legislation that are aimed towards the patient as an individual and has the potential to obscure the coherence of a judgment. In Aintree, the evidence pointed to that fact that the wishes of the patient may have indicated a preference for survival and continuing the treatment. 106 Arden LJ admitted this and suggested that his past wishes were some indication of his present wishes but, as there was no direct evidence on this point, then the court must proceed on the basis that the individual would act as a reasonable individual would act. 107 This allowed her to reach the conclusion the treatment involved such risk and potential increased burden to the patient that 'a reasonable individual in light of the current scientific knowledge would reject it $^{108}$  This may well be the case, but, as Lady Hale identified in the Supreme Court, the evidence

<sup>102</sup> Aintree [2013] UKSC 67 at [37]. See also Portsmouth Hospitals NHS Trust v Wyatt [2005] EWCA Civ 1181; [2005] 1 WLR 3995 at [76].

<sup>103</sup> Aintree [2013] EWCA Civ 65 at [51].

<sup>104</sup> Aintree [2013] EWCA Civ 65 at [53].

<sup>105</sup> Aintree [2013] EWCA Civ 65 at [55].

<sup>106</sup> Aintree [2013] EWCA Civ 65 at [46].

<sup>107</sup> Aintree [2013] EWCA Civ 65 at [58].

<sup>108</sup> Aintree [2013] EWCA Civ 65 at [63].

did not point to the fact that the patient in *Aintree* would have reached that conclusion and so the outcome cannot really be justified by reference to a consideration of the wishes and feelings of *that* patient alone. <sup>109</sup> A more appropriate approach would have been to adopt the line of reasoning demonstrated by Sir Alan Ward and to be open about the fact that the patient's wishes and feelings may have intimated a preference for continuing the treatment, but that this was just one factor in a much wider overall objective assessment, which, in this situation, could be justifiably overridden in view of a range of other overwhelming considerations which pointed to where the patient's best interests actually lay. <sup>110</sup>

#### V. WEIGHING THE FACTORS: WHERE THE EMPHASIS SHOULD LIE

## A. Different Cases, Different Outcomes: A Justified Distinction?

What can we discern from the two cases of W v M and Aintree and in which direction should the law travel? It is certainly interesting to view the differences in approach between the judges in the Court of Protection and the judges in the appellate courts. In the former, a much narrower line of reasoning was adopted by Baker J in W v Mand Jackson J in Aintree, and it is perhaps surprising that Lady Hale agreed with Jackson J in Aintree in the Supreme Court. In contrast, Sir Alan Ward and Arden LJ developed their reasoning from a significantly broader perspective in Aintree in the Court of Appeal. Given that it has been argued here that this is the correct approach, what then would have been the situation if W v M had been heard before Sir Alan Ward and Arden LJ? Would the fact that the patient possessed a higher degree of response and awareness in W v M, coupled with the fact that they would have had to authorise the withdrawal of baseline ANH treatment instead of the withholding of more interventionist treatment, have caused them to think differently? If they adopted their reasoning in Aintree, there is no reason why this would have been the case. Baker J in W v M did recognise that if the patient deteriorated in the future, the question of withholding treatment should not be completely ruled out; he also ruled that the DNR underpinning the treatment plan should be continued. 111 Thus, had the patient been in a visibly worse position, there was at least some evidence that his decision may have been different. Nonetheless, there was no need to wait for the patient to suffer further and unnecessary setbacks in order to justify a different conclusion. As they stand, arguably Aintree and W v M are not set so far apart from one another to warrant the differing outcomes, and it is also possible to identify the correct way in which to approach the balancing of best interests, which, if applied consistently in both cases, would have led to the same defensible conclusion.

# B. Futility: Weighing Benefits against Burdens

A considerable amount of emphasis does have to be placed on the medical evidence in cases such as these. The scale and severity of MCS will vary greatly from case to case and it is essential that a judge is made to understand, so far as is reasonably

<sup>109</sup> Aintree [2013] UKSC 67 at [45].

<sup>110</sup> Aintree [2013] EWCA Civ 65 at [49].

<sup>111</sup> W v M [2011] EWHC 2443 at [255].

possible, the extent of the patient's awareness and response. To that end, evidence must also be presented relating to the potential worth of continuing the treatment, when compared with the burdens it will impose. Medical understanding of MCS is slowly evolving, but it is improving all the time and the SMART assessment technique, now accepted as the most reliable diagnostic tool in assessing the levels of consciousness in MCS patients, will invariably have a big role to play in the future. 112 This evidence is intertwined with the question of futility and needs to be interpreted in a wide manner and not just confined to the question of whether or not the treatment will sustain the patient with the reasonable possibility of conferring some potential future benefit. Within the wider overall balancing exercise of best interests, a self-contained balancing exercise must take place which weighs carefully the benefits of treatment against the burdens. It is true that the SMART assessment in some MCS cases may reveal that the treatment being provided is conferring significant benefits on the patient, and in these situations there will have to be compelling evidence to suggest that the burdens outweigh those benefits. Nevertheless, it should be acknowledged that just because a patient is at the mid or even higher end of consciousness, it does not automatically mean that the treatment is providing greater benefit. MCS is a horrific condition in which patients will experience a degree of pain and suffering, but because they are trapped within that condition they cannot express accurately the level or extent of that feeling. Had this been analysed carefully in  $W \nu M$ , there were very clear burdens in insisting on the treatment regime which, arguably, were enough to overshadow the benefits.

## C. The Balancing Exercise beyond Futility

Other factors do need to be contemplated beyond the question of futility. Without trespassing too far into the rights or wrongs of the two philosophies of the IOL and the QOL, for this is beyond the scope of this article, it is appropriate for the law to consider wider non-medical factors, at least in part. Inviting judgements about the quality of a patient's life may be offensive to the IOL, but is it not sensible for the law to recognise that there are many different facets to a person's existence which deserve consideration? The 'life' itself is certainly of value but so are the principles, feelings, wishes, and beliefs of the person living that life. All of these issues are worthy of scrutiny in determining best interests. Similarly, focusing exclusively on futility aligns the law too closely with the medical view of best interests, which has the potential to foster paternalistic traits within both law and medicine. This is so notwithstanding the fact that futility ought to encompass at least some consideration of the views of the patient. This was recognised as being important in Aintree by both Sir Alan Ward in

<sup>112</sup> The SMART assessment consists of both formal and informal components. The formal component requires an assessment by the SMART assessor over ten sessions within a three-week period. There are two aspects to this; the SMART Behavioural Observation Assessment and the SMART Sensory Assessment. The informal component of SMART is completed by carers, family, and friends and consists of a 'Communication Lifestyle History Questionnaire' and a further assessment tool known as SMART Inform. See H Gill-Thwaites and R Munday, 'The Sensory Modality Assessment and Rehabilitation Technique (SMART): A Valid and Reliable Assessment for Vegetative State and Minimally Conscious State Patients' (2004) 18 Brain Injury 1255.

the Court of Appeal and Lady Hale in the Supreme Court. <sup>113</sup> Yet the danger is that it is all too easy to lose track of patient views in an assessment of a concept that has roots firmly embedded in medical discourse, and so therefore it is necessary to look beyond futility in isolation.

In *Aintree*, the concept of intolerability was considered. <sup>114</sup> It was hardly given any attention at all in W v M and, had it been, an argument for withdrawal may have emerged from Baker J's reasoning. Intolerability, however, is such a sweeping concept and pervades so many aspects of the best interests assessment that it is nigh on impossible to view it as a consideration in its own right. Is the burden of continued treatment making the patient's life intolerable? If so the question merges into the analysis of futility. On the other hand, is the question of intolerability dictated, or at least guided, by evidence from the relatives, friends, loved ones, and carers of the patient? Or is it based solely on what a judge thinks about this question? Moreover, how do those individuals make that assessment? Is it through the lens of what they would perceive to be an intolerable life, or should it be based on what they think the patient herself would consider to be an intolerable life?

In WvM, the evidence from M's carers was that M's life was not completely unbearable and did have moments of pleasure, but they answered that question from their own perspective rather than considering what the patient would have thought about it. On the other hand, M's relatives seemed to answer that question based on what M's own perception of her life would have been. In many respects, the latter sits more comfortably, but the former influenced a significant portion of Baker J's reasoning. The correct legal position is that it is for a judge to decide objectively the meaning given to intolerability, based on elements of all of the above. Nonetheless, the number of different permutations is troubling and one may be forgiven for questioning whether it is a useful tool in the balancing process.

Defining the precise amount of emphasis that should be placed on a patient's past and present wishes is also a vexed problem. It is not as straightforward as simply saying that 'appropriate' or 'great' weight should be given to them without expounding further on the meaning of those two phrases. First, the courts should be explicit about the fact that the investigation has traces of subjectivity at its core; it is inappropriate to maintain that this is a wholly objective exercise. Judges should assess from the patient's point of view what that patient would think, wish, or feel about a given situation. Similarly, if evidence exists indicating what the patient's present wishes actually are, this is again subjective. The subjectivity then feeds into the wider objective examination of best interests. In Aintree Arden LJ, and to a lesser extent Sir Alan Ward, both introduced unnecessary confusion into their judgments by attempting to circumvent the fact that the patient, based on evidence pertaining to his past wishes, probably would have wanted the

<sup>113</sup> Aintree, Per Sir Alan Ward in the Court of Appeal at [35]; per Lady Hale in the Supreme Court at [44].

<sup>114</sup> Aintree [2013] EWCA Civ 65 at [49]; [2013] UKSC 67 at [37].

<sup>115</sup> W v M [2011] EWHC 2443 at [251].

<sup>116</sup> W v M [2011] EWHC 2443 at [242], [247].

<sup>117</sup> It has been held that intolerability ought only to be a guide as to where a patient's best interests lie. *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181; [2005] 1 WLR 3995 at [76].

treatment to continue. They avoided the consequences of this conclusion by recasting the analysis of his present wishes, of which there was no direct evidence, through the eyes of objective reasonableness. Indeed, Lady Hale acknowledged this point in the Supreme Court ruling. 118 It is true that past and present wishes can fluctuate, but in the absence of any other evidence the past wishes have to be a solid marker for indicating what the patient would now want and judges need to acknowledge this. It is only if there is no evidence at all that the courts will be justified in a certain amount of speculating to ascertain what the patient's wishes would have been, and what they now are. This exercise, however, needs to be approached with the utmost caution. For this reason, in rare cases such as this, it is submitted that the patient's past and present wishes should, inescapably, play less of a role in the overall balancing exercise.

It is important to note here that the argument is not proposing a wholly subjective approach to the question of best interests. Some jurisdictions employ a substituted judgement approach, whereby the decision maker attempts to put themselves into the shoes of the patient to determine what they would have wanted to happen. 119 This has the potential to cause anomalies. For instance, a substituted judgement approach in Aintree, or indeed the earlier case of Burke v GMC, may well have led to the conclusion that the treatment would have had to be maintained at all costs. 120 Sometimes. patients do believe in courses of action that are patently at odds with everything else that the evidence points to in respect of their best interests. It is important that the wishes and feelings of patients are considered, from their perspective, but that they are carefully factored into a holistic balancing process. There has, of late, been some useful guidance from the courts on this point.

In ITW v ZM, Munby LJ recognised that while the patient's wishes and feelings will always be a significant factor that the courts must have regard to, they will always be case specific and fact specific. In certain cases, they will carry extreme weight; in other cases, they will carry very little weight. Accordingly, it is contextual and impossible 'to attribute any particular a priori weight or importance to P's wishes and feelings; it all depends, it must depend, upon the individual circumstances of the particular case'. 121 He elaborated on this, stressing the importance of considering each case in light of the relevant circumstances, which ought to include, but by no means exclusively, consideration of: the degree of the patient's incapacity, for the nearer to the borderline the more weight must in principle be attached to the patient's wishes and feelings 122; the strength and consistency of the views being expressed by the patient; the possible impact on the patient of knowledge that her wishes and feelings are not being given effect to 123; the extent to which the patient's wishes and feelings are, or are not, rational, sensible, responsible, and pragmatically capable of sensible implementation in the particular circumstances; and, crucially, the extent to which the patient's wishes and feelings, if given

<sup>118</sup> Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 at [45].

<sup>119</sup> See In re Quinlan (1976) 355 A.2d 647; Cruzan v Director Missouri Department of Health (1990) 110 S Ct 2841 (USA Supreme Court).

<sup>120</sup> R (on the application of Burke) v GMC [2005] EWCA Civ 1003.

<sup>121</sup> ITW v Z and M [2009] EWHC 2525 at [35].

<sup>122</sup> Ibid.

<sup>123</sup> Ibid.

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effect to, can properly be accommodated within the court's overall assessment of what is in her best interests. 124

Applying this to Aintree and W v M, we can see how these considerations ought to have been accommodated within the balancing exercise. In Aintree, the patient was at a lower end of consciousness and so attaching less weight to his wishes, on Munby I's analysis, would have been justified. 125 Nonetheless, there was some evidence of his past wishes and this was reasonably strong evidence. 126 There was no direct evidence about his present wishes but, based on what was known from the patient, it is possible that he would not have been happy with the decision to withhold the treatment. Similarly, it is reasonable to suggest that some may view the continued wish to be maintained as irrational and not sensible in the circumstances. However, again, when looked at from the point of view of the patient, he would have been entitled to reach the opposite view. In short, objectively his life may have been viewed as intolerable, but to him it may not have been. The significant question is then how these subjective considerations can be properly accommodated in the overall best interests exercise. The question of futility in Aintree was more easily established due to the clear burden to benefit ratio of the treatment. Thus, while some weight had to be given to the wishes and consideration of the patient and of his family, the objective emphasis on the futility question was clear enough on the facts to override any preference which the patient and his relatives may have indicated for continued treatment. Had the wishes of the patient and his relatives been the opposite, and indicated a preference for the withholding or withdrawal of treatment, then the justification for withholding the treatment would have been even stronger.

In contrast, even though in W v M the patient did not possess legal capacity, she was closer to it than the patient Aintree and so on Munby J's analysis this should have meant that more significance was attached to M's prior wishes. The evidence about what the patient's wishes would have been admittedly did not come directly from the patient herself, but the evidence from her family and partner was still convincing and unchallenged. 127 Equally, everything pointed to the fact that M would have been severely distressed to be maintained in her current state because this contradicted her previously expressed views about the QOL of patients who are kept alive where there is no realistic chance of recovery. 128 Finally, while some may disagree, if she had a preference for death over life in a situation similar to, if not worse than, Tony Bland's, it cannot be said to be wholly irrational, nonsensical, and irresponsible. Thus, once again the question then centres on how to incorporate these views into the overall balancing exercise. In  $W \nu M$ , the question of futility was much less easy to determine as the burden to benefit ratio of the treatment was less one sided. However, be that as it may, the delicately poised nature of the futility argument, which was not as clear cut as was made out, ought to have been coupled with the evidence of the wishes of the patient. Given on one view, there was a plausible argument that the treatment was

<sup>124</sup> Ibid.

<sup>125</sup> Aintree [2013] EWCA Civ 65 at [47].

<sup>126</sup> Aintree [2013] EWCA Civ 65 at [16].

<sup>127</sup> W v M [2011] EWHC 2443 at [225].

<sup>128</sup> Ibid.

futile, and on anther that the patient would have objected to being sustained in a condition in which she was surviving rather than living, this ought to have been enough to swing the overall assessment of best interests in favour of withdrawal. Other evidence from the carers pointed in the opposite direction and would have needed to be considered, but it is submitted that that should not have been enough to justify the outcome that was reached in the end. If this reasoning was applied in  $W \nu M$ , the outcome could have been different, thereby aligning both MCS cases on a solid basis.

This is not to say that withdrawal will be desirable in every case. If the patient is at the higher end of consciousness within MCS, and if there are very clear and discernible benefits to the treatment which clearly outweigh the burdens, then, even if the evidence of the patient's prior wishes and relatives may point elsewhere, the argument for sustaining the treatment will be much stronger and objectively may be sufficiently overpowering. This, however, can only be ascertained on a careful examination of the facts of each case and, on the facts, W v M did not support this conclusion.

#### VI. CONCLUSIONS

It has been argued here that medical recognition of MCS has caused considerable difficulty for the law. Where the patient has increased awareness and response, the balancing exercise inherent in the best interests assessment is complicated, more so than when a patient is in a PVS. Both W v M and Aintree point to the fact that some judges will place significant weight on certain factors, whereas others will chose to place the emphasis elsewhere. In W v M, Baker J adopted a narrow approach to his assessment of best interests, interpreting futility in a restrictive manner and paying only a fleeting glance to the range of wider factors which fell to be considered in the case. On the other hand, Sir Alan Ward in Aintree in the Court of Appeal illustrated a more expansive attitude, focusing on the benefits of the treatment compared with the burdens, and showing appropriate regard to wider non-medical considerations as one component of a more holistic balancing exercise. It is acknowledged that the two cases are not identical, but seldom, if ever, will they be in terms of a MCS patient. Nonetheless, I have argued that the cases are not so different so as to justify opposite outcomes and, if the reasoning adopted by the Court of Appeal in Aintree was applied to W v M, then a defensible case for withdrawing and withholding medical treatment can be made out in both. This argument can be sustained along two different lines.

First, in sticking to the futility issue alone, it could be said that insufficient consideration was given to the burdens of treatment compared with the benefits in W v M. If it had been, then it could be said that the sustaining treatment was in fact worthless, mirroring what is submitted to be the correct approach and conclusion reached by Sir Alan Ward in Aintree in the Court of Appeal. From this standpoint, the argument for withdrawal in both cases would not, in theory, offend the IOL.

The second view, which is the correct legal position, is to open up the analysis beyond futility to encompass a wider consideration of both medical and non-medical factors. This reasoning was correctly employed in Aintree but was only superficially considered in W v M. Had the wider factors been given thorough and appropriate consideration, the argument for permitting the withdrawal of treatment would have been much stronger.

The question which then arises is how best to resolve the competing tensions which will naturally be present as and between the range of factors which fall to be considered in MCS and similar best interests cases. It is a question to which there is no formulaic answer and the courts have quite sensibly been reluctant to lay down principles of general application. The precise circumstances of each case will be different. Nevertheless, something can be said about when it may appropriate to place greater emphasis on certain factors at the expense of others. In cases where it is evident that the treatment is conferring very little if any benefit to the patient, greater emphasis should perhaps be placed on futility. This is so because it is more visibly ascertainable that the treatment is not medically worthwhile when assessed through the lens of burdens compared with benefits. The wider non-medical factors which fall to be considered under sections 4 (6) and (7) of the Mental Capacity Act 2005 should still undoubtedly form part of the balancing exercise, yet in cases where the question of futility is more clear cut, there is a stronger justification for placing greater emphasis on this factor.

Where futility is less certain, the balancing exercise immediately becomes more multifaceted. Here it becomes even more essential to assess carefully the benefits of the treatment compared with the burdens and not to become too distracted by the mere fact that the treatment is having at least some positive effect on the patient. There are cases in which positive effects can be justifiably outweighed by negative effects and in these cases it is still possible to hold that the treatment is futile. Equally, in cases where this particular issue is more open to debate, it may be desirable to then look more closely at the wider non-medical considerations and to place greater emphasis on these factors when reaching a decision as to where the best interests of a MCS patient truly lies.

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