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## NEUROIMAGING AND THE WITHDRAWAL OF LIFE-SUSTAINING TREATMENT FROM PATIENTS IN VEGETATIVE STATE

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### I. INTRODUCTION

In a recent English case before the Family Division of the English High Court, the Official Solicitor objected to the withdrawal of treatment from a patient diagnosed as being in vegetative state (VS) despite agreement between the NHS Trust and the patient's family that treatment should be withdrawn: *An NHS Trust v. J.*<sup>1</sup> One objection arose from the possibility, based on a recent medical article,<sup>2</sup> that a functional magnetic resonance imaging test (fMRI, commonly called a brain scan) might indicate that the patient retained a degree of consciousness.<sup>3</sup> This seems to be the first objection of this kind and in this case, after a short time,<sup>4</sup> the Official Solicitor agreed with the family and the Trust that treatment should be withdrawn without performing fMRI. However, all cases involving the withdrawal of life-sustaining treatment from patients in VS must come before a court (now the Court of Protection) and the issue is likely to be raised again. Indeed, given the significant advances in neuroimaging studies of VS since 2006, and probable further scientific progress in the near future, questions about the legal significance of fMRI are likely to become increasingly important.

This paper assesses the possible effects on decision making about the withdrawal of life-sustaining treatment if fMRI suggests that a patient in VS has some level of consciousness. It focuses on the principles set out in the Mental Capacity Act 2005 (UK) (which has come into force since the case mentioned above),<sup>5</sup> the Mental Capacity Act Code of Practice (CoP)<sup>6</sup> and the common law. Relevant legal factors include the patient's wishes expressed in an 'advance decision to refuse medical treatment' under the Act, decisions by a donee of a lasting power of attorney appointed under the Act, both of which are binding under the Act if they apply in the circumstances; and, if there is no such provision, the patient's best interests, taking account of the patient's wishes inferred from general evidence and the futility of continuing treatment. Current research suggests that neuroimaging will at most establish that some patients diagnosed as being in VS are in fact in a condition that clinicians describe as a 'minimally conscious state' (MCS). The patients reported to date have not recovered beyond that state and, indeed, may revert to VS. However, applications for fMRI when judicial approval is sought from the Court of Protection to withdraw treatment from patients in VS may delay the process and raise issues for the Court in assessing the relevance of fMRI to the patient's interests. This paper outlines legal principles relevant to judicial review and discusses underlying philosophical issues, including the limited availability of resources for health care.

### II. VEGETATIVE STATE

A common ground for withdrawal of life-sustaining treatment from patients is that they are in a vegetative state (VS). Usually the VS is required to have continued for long enough to be regarded as 'persistent' or 'permanent'.<sup>7</sup> VS may be described as 'wakefulness without awareness'.<sup>8</sup> Patients have wake-sleep cycles, opening their eyes periodically, and may utter incomprehensible sounds. They may turn their eyes fleetingly towards a visitor entering the room but without engaging with that person (visual fixation).<sup>9</sup> Patients appear awake but

there is no evidence that they are, in fact, aware of themselves or their environment and they are unable to communicate or respond to commands.

It is possible for patients in VS to recover and there is a higher chance of recovery if the patient has had a traumatic injury, like a blow to the head, than a non-traumatic injury, like a stroke. The chances of recovery are also better for a child than an adult.<sup>10</sup> However, if VS has been present for a prolonged period, it is a good predictor that the patient will not recover, even if life can be sustained for some time with artificial nutrition and hydration (ANH).<sup>11</sup>

Some patients who recover from VS enter a minimally conscious state (MCS).<sup>12</sup> This is a state of severe impairment following brain injury in which there is some evidence of voluntary movement but without the ability for functional communication. Unlike VS patients, MCS patients do manifest some intermittent or minor responses to stimuli such as tracking an object with their eyes, or responding to questions with a gesture or word. The distinction between VS and MCS is prognostically important. Patients who are in VS for more than 6 months after sustaining brain injury have only a very small chance of significant recovery. Prognosis for patients in MCS is more variable.<sup>13</sup>

### III. NEUROIMAGING AND RECENT RESEARCH

With brain activity, the flow of blood in the brain changes and this change can be observed with some forms of neuroimaging, for example with fMRI. Over the last few years, patients in VS have been observed on fMRI to have brain activity in response to the spoken word,<sup>14</sup> but this activity may be an automatic, non-conscious response, akin to an involuntary reflex, and of uncertain significance. More recent research by Professor Adrian Owen, however, suggests that some patients in VS may be able to follow instructions leading to a pattern of brain activity that can be observed by fMRI.<sup>15</sup>

Professor Owen asked seventeen patients diagnosed as being in VS or MCS to imagine they were playing tennis, moving their arms (motor imagery); or that they were moving from one room to another, or driving home from work (spatial navigation). These two types of cognitive processes are associated with activity in different parts of the brain, as indicated by differences in the fMRI readings of the brains of normal subjects who engage in such mental tasks. Observations can be checked with 30 seconds of imagining the activity followed by 30 seconds of rest over five minutes, to check that the effect is not due to chance.<sup>16</sup>

Two of the patients observed by Professor Owen manifested characteristic changes on brain scanning after being instructed to imagine playing tennis. Both of these patients had been diagnosed as being in VS at the time, but both subsequently improved clinically to the point where they inconsistently manifested behavioural responses to stimuli and thereby met the criteria for MCS.

The results are significant because they imply that the two patients may be able to act of their own volition; their responses were sophisticated enough to suggest they were not merely due to automatic, non-conscious information processing.<sup>17</sup> Volition in turn suggests some level of awareness, indicating the preservation of at least a measure of consciousness that goes significantly beyond what is suggested by these patients' observable behavioural responses. These findings raise the possibility that a patient who is capable of making such a voluntary response may be able to communicate at an even more sophisticated level, such as responding to questions: 'Is your husband Charlie? If yes, imagine playing tennis'. 'Are you feeling pain? If yes, imagine walking from room to room in your house'. If such brain-damaged patients can be shown to succeed in such complex tasks, this will indicate that their awareness and cognitive function is higher than we have believed possible with patients in

VS of MCS . However, we must await findings from further research to determine the degree to which consciousness and cognitive function might be preserved in some patients who were until now diagnosed as being in VS.

These findings may have legal implications when courts are asked to decide whether it would be lawful to withdraw life-sustaining treatment from a patient who is believed to have no chance of recovery. However, one may question what the results of fMRI of patients in VS actually mean. Are they legally or philosophically significant in themselves; could they be a predictor for a substantial and sustained improvement in the patient's condition or could they provide other information that may assist in evaluating the patient's condition and prognosis?

#### IV. LEGAL SIGNIFICANCE OF POSSIBLE MINIMAL CONSCIOUSNESS IN PATIENTS IN VS IN ENGLAND AND WALES

In England and Wales, it is lawful to withdraw artificial feeding and hydration (ANH) and other life-sustaining treatment from an incompetent patient under the Mental Capacity Act 2005 (UK) and the Mental Capacity Act Code of Practice (CoP) if the patient has made a valid advance decision to refuse such measures; or a properly appointed donee of a lasting power of attorney has done so; or it is in the patient's best interests not to have treatment continued. In such circumstances, health care providers cannot be compelled by a patient's earlier direction or the family's wishes to continue treatment. There have been many highly publicised cases in the United Kingdom,<sup>18</sup> North America,<sup>19</sup> Australia<sup>20</sup> and New Zealand,<sup>21</sup> in which courts have ruled that life-sustaining treatment may be lawfully withdrawn, despite objections from the family. This extends to the withdrawal of ANH, though food and water were once considered the necessities of life.<sup>22</sup>

##### A. Refusal of treatment in advance by the patient

The Mental Capacity Act 2005 (UK)<sup>23</sup> enables patients to make an 'advance decision to refuse treatment' (which includes ANH): s 4(10); CoP, para 9.28). To be binding under the Act, the advance decision must be in writing and witnessed and it must stipulate that it is to apply even when the person's life is at risk: ss 25(5),(6); CoP, para 9.24. To refuse ANH, it might also be required to refuse ANH specifically (though that would be open to interpretation) as an advance decision may not apply if 'the treatment in question ... is not the treatment specified in the advance decision': s 25(4). Patients may also refuse treatment in advance by an advance directive or similar means under the common law.<sup>24</sup>

Before acting on a patient's advance decision, health professionals must consider whether the patient had the capacity to accept or refuse treatment (s. 25(3)) or has 'done anything that clearly goes against their advance decision', 'has withdrawn their decision' or 'would have changed their decision if they had known more about the current circumstances'.<sup>25</sup> For patients in MCS, the last factor might raise a doubt about the applicability of the advance decision for reasons similar to those discussed in the paragraphs below and the matter may go no further. However, if the health care providers decide that it is appropriate to withdraw ANH from a patient in VS, authority must be sought from the Court of Protection.<sup>26</sup> Also, if 'there is no one appropriate to consult about whether the decision [to withdraw treatment] is in the patient's best interests, other than paid care staff', the NHS body must instruct an Independent Medical Capacity Advocate: s. 37; CoP, para 10.42,<sup>27</sup> because this is 'a serious medical treatment decision'.<sup>28</sup>

Where the Court is required to consider an advance decision, it clearly has scope under the provisions in section 25 to interpret it and to determine whether it applies in the particular

circumstances.<sup>29</sup> Evidence of the presence of even a low level of consciousness or cognitive capacity could be relevant. Applying section 25(4), a court might consider whether ‘any circumstances specified in the advance decision are absent, or ... there are reasonable grounds for believing that circumstances exist which [the patient] did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them’. The CoP gives examples of changed circumstances that might influence a patient’s decision whether to refuse the treatment, such as changes in the patient’s personal life or developments in medical treatment.<sup>30</sup>

Thus, if the patient had refused ANH if he or she should be ‘in VS’, a diagnosis of MCS on the basis of a brain scan might make the advance decision inapplicable,<sup>31</sup> on a literal interpretation, or more generally, on the ground that a person who had previously not wished to be kept alive ‘in VS’ might have had a different wish if actually in a state different from the one initially anticipated – a state of partial/intermittent awareness. In such cases, a court might interpret what the patient meant by ‘in VS’ – was this a shorthand way of saying ‘if life is meaningless’ or ‘if I am unconscious’? Or the court might take a more conservative view. Studies show that people who have disabilities value their own quality of life more highly than those who observe them, even their carers who know them well;<sup>32</sup> and some patients who have previously expressed a wish not to go on living later change their minds as they become accustomed to their new condition.<sup>33</sup> However, arguing by analogy with other patients with ‘a disability’ seems far fetched with patients in MCS. The cognitive capacities of patients in that condition may be preserved only at a rudimentary level which is not sufficient for genuine comprehension of the patient’s state and the formation of an alternative wish.

If the Court decides that an advance decision does not apply, or if the patient has not made any advance decision under the Act, the Court will make a determination based on what is in the patient’s best interests. This will require consideration of similar issues to those that have arisen at common law and this aspect is discussed under heading C below.

## **B. Refusal of treatment by a donee of a lasting power of attorney**

Under the Act, a person may appoint a donee of a lasting power of attorney to make decisions for the person if he or she is later incompetent to decide.<sup>34</sup> The Code of Practice states that, when an advance decision is being followed, the ‘best interests’ principle does not apply: CoP, para 9.36. The overriding principle is that a competent individual’s express desires about treatment should be respected where possible. However, under s. 4(5), a surrogate decision maker who has to make a ‘determination [relating] to life-sustaining treatment’ must consider, ‘so far as is reasonably ascertainable’ the same factors ‘in determining ... what is in a person’s best interests’ as in making any other medical decision for the patient. These factors are set out in s. 4(6) (quoted in the next paragraph). Matters similar to those discussed earlier may be relevant also in this context.

## **C. The patient’s best interests**

Where a patient has not made an advance decision, or appointed a donee of a lasting power of attorney, or the Court of Protection is not satisfied that an advance decision applies in the circumstances, it may be lawful for ‘life-sustaining treatment’<sup>35</sup> to be withdrawn if the Court decides that continuing treatment is not in the patient’s best interests.<sup>36</sup> The following matters are to be considered ‘so far as is reasonably ascertainable’ under s. 4(6) of the Act in relation to ‘best interests’:

- a. the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

- b. the beliefs and values that would be likely to influence his decision if he had capacity, and
- c. the other factors that he would be likely to consider if he were able to do so.

To the extent that these matters refer to the patient's known or presumed wishes, beliefs and values, they raise the same issues as those discussed earlier. What would the person have wanted?<sup>37</sup> This must be determined on a subjective basis. That is, there must be some evidence for the Court to consider. If a person valued independence, and refused treatment in coma, this value might be important in determining whether life in MCS was in the person's best interests. Another, who deeply valued any chance of decent survival, however small, might be kept alive in a MCS. However, in the absence of some evidence of the patient's wishes and values, there is no scope for an objective assessment of the patient's wishes (what an ordinary person might be presumed to have wanted in such a case).<sup>38</sup> This is significant with patients in MCS where there may be a tendency to believe that it would be worse to continue life in MCS than in VS.<sup>39</sup>

The presumed response of patients with conditions like Guillain-Barre syndrome who are competent and able to communicate often differs from what we might expect. We can empathise with Lord Mustill's reference in *Bland* to the 'mental torture' of a severe form of Guillain-Barre syndrome, where a patient has a level of preserved consciousness and cognitive capacity well above MCS but is immobile and unable to communicate except by eye movements; the patient is 'rational but trapped and mute in an unresponsive body'.<sup>40</sup> On the other hand, one hears of 'locked-in' patients who want to stay alive even with that condition<sup>41</sup> and we recall the inspiring story of Jean-Dominique Bauby in *The Diving Bell and the Butterfly: A Memoir of Life in Death*.<sup>42</sup> We simply do not know what a patient in such a state would have wanted if asked in advance (and able to form such 'wishes' in that state) and, as with any medical condition, the patient's response may vary from patient to patient.

It is at least conceivable that future research will show that some patients who respond to fMRI may be able to use this or a similar technique to communicate and make their wishes known, though it seems unlikely on the basis of what we know about the nature of the global brain injury in patients in VS. If such a form of communication were established with some brain-damaged patients, it would certainly be relevant, especially if the patient wanted treatment to be stopped.<sup>43</sup> However, it would probably not be determinative, even concerning the withdrawal of treatment, as the meaning of a response to fMRI and its significance in assessing the competence of the patient are so uncertain. However, even if the patient's wishes can be determined from general evidence, they are not binding in the same way as a formal advance decision. Also, in many cases, there will not be even general evidence of the patient's wishes in such circumstances, as with Anthony Bland, for whom there were no 'materials upon which a surrogate could act'.<sup>44</sup> As Lord Mustill said, a surrogate could not '[build] up a picture of the patient's former character, feelings, convictions and so on from which the putative choice is deduced'.<sup>45</sup> The Court therefore had to consider other factors in determining whether it was in the patient's best interests to continue the treatment.

Courts have held in a number of cases that it is lawful not to provide life-sustaining treatment if it is 'futile',<sup>46</sup> justifying this on the ground of the patient's best interests. As Lord Goff said in *Bland*, 'if the treatment is futile ... it is no longer in the best interests of the patient to continue it'.<sup>47</sup> This principle is reflected in the Mental Capacity CoP, para 5.31, which states that it is not in a patient's best interests to continue treatment that is 'futile, overly burdensome to the patient; or where there is no prospect of recovery'.



Evidence from fMRI may be relevant in several ways in deciding whether it is 'futile' in this sense to continue treatment.

First, it may help to establish, confirm or question a diagnosis, either in general terms or for a particular patient. Evidence from fMRI may cast doubt on the criteria for deciding whether a patient is in VS, or the medical evidence concerning a particular patient. A patient who otherwise meets the criteria for VS but responds to fMRI may be diagnosed instead with MCS,<sup>48</sup> or the patient may be regarded as accurately diagnosed as being in VS but recognised to have covert awareness on the basis of fMRI evidence of consciousness. Even those low levels of consciousness or awareness could be legally significant as the patient would not then meet the test posed by Lord Goff in *Bland* for withdrawal of treatment on the ground of futility: 'where the patient is *totally unconscious* and where there is no hope whatsoever of any *amelioration* of his condition'.<sup>49</sup> While there is reasonable consensus among health professionals and in the case law about the permissibility of withdrawing life-sustaining treatment from patients in VS, there is much less agreement about MCS, and the possibility of some awareness in MCS has only recently been described.<sup>50</sup>

The patient's level of consciousness and the application of the criteria for diagnosing permanent (the term that has replaced 'persistent') vegetative state issued by the Royal College of Physicians (R.C.P. Guidance)<sup>51</sup> are routinely considered by English courts when deciding whether it would be lawful to withdraw ANH from a patient in VS.<sup>52</sup> But evidence from fMRI may provide another means for distinguishing between types of impairment of consciousness and arguing that the legal precedents and the RCP Guidance should not be applied to patients in MCS. For example, in Terri Schiavo's case,<sup>53</sup> a medical witness called by her parents testified as to her ability to respond to commands; the evidence was considered and rejected by the court but it might have been significant if it had been accepted.<sup>54</sup> Although responding to commands may seem little different from other signs of awareness, like eye-tracking, evidence from fMRI may be persuasive due to its perceived scientific basis and objectivity. It may also indicate more accurately than present techniques the prognosis for particular patients. To date, a patient's prognosis in VS has been indicated by the length of time during which the patient has been in the existing condition and experience of improvement in other patients at that point. Evidence from fMRI might provide grounds for medical opinion that a patient has an increased chance of recovery.<sup>55</sup> That would depend on the results of future research. To date, Professor Owen's research has indicated that only two patients out of 17 showed characteristic responses on brain scans in response to instructions and, although those two patients were the only ones in the group whose level of consciousness had risen to that of MCS, they had not progressed further and one of the two later returned to VS.<sup>56</sup> If fMRI evidence suggested that a particular patient had a prospect of improvement to such a degree that it would not be lawful to withdraw treatment for that patient and that the improvement would be sustained, then that evidence might refute medical opinion that continuing treatment is futile because the patient cannot benefit from it. The patient would have a chance of what Lord Goff called 'amelioration of his condition' (above).

Information of a positive response to fMRI could possibly provide the basis for new treatment. Patients in VS with some awareness may be amenable to experimental treatments that could lead to more meaningful recovery (e.g. deep brain stimulation in one patient) although we do not know at present what the likely outcome of that treatment would be.<sup>57</sup> Or the information may be relevant in assessing the patient's likely quality of life (see below).

## V. UNDERLYING PHILOSOPHICAL ISSUES

There are underlying philosophical issues in determining a person's best interests when the person's own wishes are not known. Some decisions concerning the withdrawal of life sustaining treatment from patients in VS have relied upon an assessment that such patients do not have interests at all, and that consequently continuing treatment cannot be in their interests. That view suggests that consciousness is a necessary condition for a patient having interests,<sup>58</sup> and it is contentious.<sup>59</sup> But the loss of consciousness with no possibility of retrieving it suggests that a patient no longer sustains a personality or significant psychological activity, capacities that seem necessary for a meaningful life.<sup>60</sup>

Some commentators take a different view. John Keown and Luke Gormally, for example, say that 'human rights are enjoyed in virtue of our common humanity, not the possession of some arbitrarily stipulated human ability at some arbitrarily stipulated level', i.e. autonomy, or the mental capacity to make certain types of decisions.<sup>61</sup> This view, commonly based on the 'inestimable value of life itself' and 'a set of religious beliefs' is not absolute, as M.R.Gillick says, noting that the 'Roman Catholic position' presumes that ANH should be provided at the end of life only so long as it 'is of sufficient benefit to outweigh the burdens involved to the patient'.<sup>62</sup>

This raises the issue of the intrusiveness of life-sustaining treatment. ANH has been said to impose possible burdens and discomfort on patients, when tubes are kept in place or need to be regularly replaced.<sup>63</sup> If patients are unable to feel pain and cannot suffer when tubes are inserted and replaced, they are presumably not aware of what is being done to them and so have no interest from their own perspective. Similarly, because they have no consciousness, they have no interest in ending distress to others, their families and carers. As Lord Mustill said of Anthony Bland, '*Unlike the conscious patient* he does not know what is happening to his body, and cannot be affronted by it; he does not know of his family's continuing sorrow. By ending his life the doctors will not relieve him of a burden become intolerable, for others carry the burden and he has none' (emphasis added).<sup>64</sup> However, patients in MCS, or VS with some awareness, can suffer and continuing tube feeding for such patients is therefore different from continuing it for other patients in VS, who are, so far as we know, unable to feel pain or discomfort.

Those patients are closer to the patients in *Re L*<sup>65</sup> and *Nancy B*<sup>66</sup> and ANH might not only cause pain and discomfort,<sup>67</sup> but also compromise their dignity and personal privacy, as Thomas J. noted in *Re L*.<sup>68</sup> That case concerned the withdrawal of artificial ventilation from a patient with Guillain-Barre syndrome who was '[l]ifeless and motionless, unable to communicate by even elementary means' (at 238). Thomas J. referred to:

another set of values [in addition to sanctity of life] which are central to our concept of life; values of human dignity and personal privacy ... constantly keeping the patient on the respirator without her consent constituted an intrusion and interference which violated her person.<sup>69</sup>

Finally, whether a patient's diagnosis is VS, MCS or VS with some awareness, the issue of limited health resources (distributive justice) is not relevant to the legal determination as the matter to be determined is the patient's best interests, not those of other patients or the community. Thus, there is no scope for judges to follow the two Law Lords in *Bland* who mentioned resource issues without making them a basis for their decision. Lord Browne-Wilkinson said:

Given that there are limited resources available for medical care, is it right to devote money to sustaining the lives of those who are, and always will be, unaware

of their own existence rather than to treating those who, in a real sense, can be benefited, e.g. those deprived of dialysis for want of resources.<sup>70</sup>

Lord Mustill said:

The large resources of skill, labour and money now being devoted to Anthony Bland might in the opinion of many be more fruitfully employed in improving the condition of other patients, who if treated may have useful, healthy and enjoyable lives for years to come. ... In social terms [this argument] has great force, and it will have to be faced in the end.<sup>71</sup>

This means that if health professionals and courts adopt the conservative view towards patients who respond positively to fMRI that seems to follow from the Mental Capacity Act, patients who have little hope of recovery on the basis of current experience may nevertheless be kept alive for considerable periods. Health resources will be used for those patients when they might be better spent on other patients who could benefit more from the expenditure. One may compare this situation with the judgment in *R v. Cambridge Heath Authority, ex parte B*<sup>72</sup> in which the court refused to interfere with the local health authority's decision not to provide leukaemia treatment that it considered 'neither standard nor formally evaluated' because of its need 'to ensure it had sufficient funds for the treatment of other patients'.<sup>73</sup>

One might question whether the possibility of a very small change in the patient's condition (from diagnosis of VS to one of MCS) is sufficient to warrant the continuation of treatment that would otherwise be withdrawn, given the remote chance that the patient will ever make a reasonable recovery.<sup>74</sup> Also, as argued above, it should not be assumed that minimal consciousness would give us more reason to keep such patients alive; the reverse may be true.<sup>75</sup> In such a life, unlike in VS, a patient clearly has interests, including an interest not to suffer, that might be compromised by continued existence, something not true of other patients in VS.

## VI. CONCLUSION

It can be seen from this discussion that evidence from fMRI that a patient who has been diagnosed as being in VS has even a low level of consciousness or awareness may be legally significant in several ways in deciding whether to withdraw life-sustaining treatment. If the patient has executed a formal 'advance decision to refuse treatment' under the Mental Capacity Act 2005 (UK), stating that it is to apply even if the patient is in VS or similar circumstances, health professionals or the Court of Protection may find that it is inapplicable if there is a doubt whether the patient is in VS. If the patient's wishes are not known, there is some scope for presuming them from general evidence but not for an entirely objective approach. The Court must decide on the basis of the patient's best interests, as set out in the Act, and in determining best interests, decisions may be conservative, though courts have endorsed withdrawal of treatment from patients with some level of awareness.<sup>76</sup> Evidence of a positive response to fMRI may be considered relevant to the patient's diagnosis or prognosis, which in turn may be relevant in determining whether the continuation of treatment is 'futile'. If there is a chance that continued treatment might improve the patient's condition, albeit marginally, then it will only be lawful to withdraw treatment if there is a broad assessment that continuing treatment is not in the patient's best interests, in view of the patient's likely quality of life and such determinations are problematic. There is no scope within existing law to consider the distribution of health resources and the impact on other patients of keeping alive patients with minimal consciousness who have almost no chance of making a reasonable recovery.



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16. Owen. *supra* n. 15
17. The absence of such a response by the other patients examined does not in itself establish that they do not also possess some level of awareness; they might be deaf or have no memory of playing tennis, for example.

18. *Bland*, *supra* n. 7; *NHS Trust 'A' and 'B' and NHS Trust 'B' and 'H'* [2001] 2 F.L.R. 367; *Re AK* (2000) 58 B.M.L.R. 151 (High Ct, Fam. Div., Hughes J.); *R (Burke) v. General Medical Council (Official Solicitor and others intervening)* [2005] E.W.C.A. Civ. 1003, [2006] Q.B. 273; *Re B (Adult: Refusal of Treatment)* [2002] 2 All E.R. 449.
19. *In the matter of Karen Anne Quinlan* 355 A 2d 647 (1976) (S.C.(N.J.)); *Cruzan v. Director, Missouri Department of Health* 497 US 261 (1990); *Schiavo ex rel. Schindler v. Schiavo ex rel. Schiavo*, 403 F.3d 1223, 2005 WL 648897 (11th Cir. Mar. 23, 2005); *Nancy B v. Hotel-Dieu de Quebec* (1992) 86 D.L.R. (4th) 385 (Que. Sup. C.).
20. *Northridge v. Central Sydney Area Health Service* [2000] N.S.W.S.C. 1241 (O'Keefe J.); *BWV; Ex parte Gardner* [2003] V.C.A.T. 121; [2003] V.S.C. 173 (Morris J.); *In the Application of Herrington; Re MC* [2003] Q.G.A.A.T. 13; *RWG* [2000] Q.G.A.A.T. 2; *Messiha (by his tutor) v South East Health* [2004] N.S.W.S.C. 1061; *Krommydas v Sydney West Area Health Service* [2006] N.S.W.S.C. 901; *Re King* [2007] V.S.C. 151 (unreported, Williams J., 24 April 2007, BC200703616).
21. *Auckland Area Health Board v Attorney General* [1993] 1 N.Z.L.R. 235 (HC(NZ)) (*Re L*)
22. See also, CoP, para 9.5.
23. See also CoP, Ch 9.
24. Advance refusals of medical treatment were binding under the common law before the Mental Capacity Act came into force: See, e.g., *Re T (Adult Refusal of Treatment)* [1993] Fam. 95; *Bland*, *supra* n. 7, at 864 (Lord Goff); 891-894 (Lord Mustill); *Re C (Adult: Refusal of treatment)* [1994] 1 W.L.R. 290. The new formal requirements in the Act mean that some prior advance directives will no longer be binding if they do not meet the criteria in the Act, but not all. An advance directive that is inapplicable because it does not meet the statutory requirements to refuse life-sustaining treatment (see text) could be evidence of the patient's wishes even if it is not binding.
25. CoP, ch. 9, Quick Summary.
26. CoP, para 8.18.
27. This is the case even for decisions that are so serious they need to be made by a court: CoP ch. 8 and para 10.48.
28. A 'serious medical treatment decision' includes 'stopping life-sustaining treatment': CoP, paras 10.40, 10.43, 10.44; and 'withholding or stopping artificial nutrition and hydration': CoP, paras 10.45, 10.48.
29. See Maclean AR. Advance Directives and the Rocky Waters of Anticipatory Decision-Making. *Med. Law Rev.* 2008; 17:1. [PubMed: 19088093]
30. CoP, 'Scenario: assessing if advance decision is applicable' following para 9.44.
31. At present, there is little indication of whether some brain-damaged patients diagnosed as being in VS might in fact be in MCS and what their wishes might have been if they had been asked when they were competent to consider themselves in a state of MCS rather than VS. MCS is a neurological condition that has been clinically defined only recently and very few patients are likely to have expressed explicit wishes concerning the provision of life-sustaining treatment in MCS rather than VS.
32. Fuhrer MJ, Rintala DH, Hart KA, Clearman R, Young ME. Relationship of Life Satisfaction to Impairment, Disability, and Handicap among Persons with Spinal Cord Injury Living in the Community. *Archives of Physical Medicine and Rehabilitation.* 1992; 73:552. [PubMed: 1622304]; Albrecht, G.; Devlieger, P. The Disability Paradox: High Quality of Life Against All Odds; *Social Science and Medicine.* 1999. p. 977
33. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and Desires Related to Euthanasia and Physician-Assisted Suicide among Terminally Ill Patients and Their Caregivers. *J.A.M.A.* 2000; 284:2460.; Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' Experiences with the Oregon Death with Dignity Act. *New Engl J. Med.* 2000; 342:557. [PubMed: 10684915]
34. Mental Capacity Act 2006 (U.K.) ss 9; 11(7) (c); Sch. 1, Pt 1. Note s 11(8): may refuse consent to life-sustaining treatment only if the instrument confers power to do that. To become operative, lasting powers of attorney must be registered with the Public Guardian: s. 9(2)(b), s 58(1)(a), Sch 1, Pt 2. See also, CoP ch. 7.

35. Defined in s 4(10).
36. Mental Capacity Act 2005 (UK) ss 1(5), 4 (Factors relevant to best interests defined), 9(4), 16(3).
37. CoP, para 5.32
38. Compare *Public Advocate v RCS (Guardianship)* [2004] V.C.A.T. 1880 (27 Sept. 2004), in which a state-appointed guardian was able to refuse treatment under the Medical Treatment Act 1988 (Vic.) on the basis of an objective assessment of the patient's wishes. The decision may be open to question but the President of the Tribunal, Morris J., presided.
39. Dr Fine 'fear[s] it represents a state of greater suffering [than VS]': *id*, *supra* n. 12 at 305. See also, Wilkinson D, Kahane G, Savulescu J. Letting Vegetative Patients Die, the Implications of Functional Neuroimaging. (under review)
40. *Bland*, *supra* n. 7, at [1993] 1 All E.R. 821 at 894; [1993] A.C. 789, 897.
41. Dr Fine notes that none of the four or five patients he encountered in 25 years of medical practice who were in 'locked-in state' wanted to stay alive in that condition but some physicians have reported patients who do want to stay alive: *id*, *supra* n. 12, at 305.
42. Vintage Books; New York: 1998.
43. A positive response would not *require* treatment to be continued, as patients are not legally entitled to require treatment to be provided: See text to notes 18-21 *supra*.
44. *Bland* *supra* n. 7, All E.R. at 892; A.C. at 894 (Lord Mustill).
45. *Bland*, *supra* n. 7, All E.R. at 892; A.C. at 895.
46. *Bland*, *supra* n. 7; *Schiavo ex rel. Schindler v. Schiavo ex rel. Schiavo*, *supra*, n. 19; *Ex parte Gardner*, *supra* n. 20.
47. *Bland*, *supra* n. 7 at All E.R. at 871; A.C. at 870.
48. However, the converse is not true. If a patient is found not to respond to fMRI (such as not responding to the 'tennis' or other such exercise), that should not be taken in itself as supporting a diagnosis of VS. As Owen *et al.* observe (*supra* n. 2), positive evidence is far stronger than negative evidence, since the patient might not be conscious or attentive at the time of the scanning. However, evidence from failed repeated attempts might have more significant weight.
49. *Bland*, *supra* n. 7, at All E.R. at 869; A.C. at 868; compare *BWV*; *Ex parte Gardner*, *supra* n. 20 at 490: treatment is futile if 'it [has] no prospect whatever of *improving* [the patient's] condition' (emphasis added).
50. Owen *et al.*, *supra* n 2, 15.
51. R.C.P. Guidance, *supra* n. 7.
52. The application of the R.C.P. Guidance was considered in *An NHS Trust v. D and others* [2005] E.W.H.C. 2439 (Fam.) at [39]; *NHS Trust A v. M*; *NHS Trust B v. H* [2001] 2 W.L.R. 942 at [11]-[13] (H.C.); *NHS Trust v. P*, 19 Dec 2000 (H.C.); *Re D (Medical Treatment)* [1998] F.L.R. 411 (H.C.) (the latter three approving the earlier 1996 edition of the RCP Guidance). Other cases involving diagnosis of PVS include *Re H* [1998] 2 F.L.R. 36; *NHS Trust v P*, 19 Dec 2000; *NHS Trust A v. H* [2001] 2 F.L.R. 501.
53. *Schiavo ex rel. Schindler v. Schiavo ex rel. Schiavo*, *supra* n. 19.
54. J. Greer stated that 'The court saw few actions [from 12 hours of videotape of the [patient] that could be considered responsive': quoted by Fine, *supra* n. 12, at 307.
55. Though a negative response is less significant unless repeated on later occasions.
56. Owen A, et al. Functional Neuroimaging of the Vegetative State. *Nat Rev. Neurosci.* 2008; 9(3): 235-43. [PubMed: 18285801] ; Owen, A. March. 2008 personal communication
57. Schiff ND, et al. Behavioural Improvements with Thalamic Stimulation after Severe Traumatic Brain Injury. *Nature.* 2007; 448(7153):600-3. [PubMed: 17671503] See also Glannon W. Neurostimulation and the Minimally Conscious State. *Bioethics.* 2008; 22(6):337-45. [PubMed: 18522593]
58. As suggested by Lord Mustill in *Bland*, *supra* n. 7 at 897.
59. For example, J. Keown disagrees with this proposition: Restoring Moral and Intellectual Shape to the Law after Bland. *Law Quarterly Rev.* 1997; 113:481.
60. For further discussion, see Kahane G, Savulescu J. Brain-damaged Patients and the Moral Significance of Consciousness. *Journal of Medicine and Philosophy.* Jan..2009 (forthcoming).

61. Keown, J.; Gormally, L. Human Dignity, Autonomy and Mentally Incapacitated Patients: A Critique of Who Decides?. <http://webjcli.ncl.ac.uk/1999/issue4/keown4.html>
62. *Supra* n. 62, citing National Conference of Catholic Bishops. Ethical and Religious Directives for Catholic Health Care Services. U.S. Catholic Conference; Washington D.C.: 1995.
63. New South Wales Department of Health. Guidelines for End-of-life Care and Decision Making. 2005. p. 7. [http://www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005\\_057.pdf](http://www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_057.pdf)
64. *Bland, supra* n. 7, at All E.R. at 894; AC at 897.
65. *Supra* n. 21.
66. *Supra* n.19.
67. Gillick states that ‘Recent information supports the conclusion that tube feeding ... can cause [suffering]’. The incision in the abdominal wall to insert the tube has ‘a long-term rate of complications ... rang[ing] from 32 per cent to 70 per cent’. Medical problems include ‘superficial skin infections and dislodgment or clogging of the tube’, diarrhoea, and ‘aspiration [that] appears to result from reflux of gastric contents and aspiration of saliva’: Gillick, *supra* n. 62.
68. *Supra* n. 21.
69. *Supra* n. 21, at 245, referring to *Nancy B v. Hotel-Dieu de Quebec*, *supra* n. 19, another case concerning a patient with respirator-dependent patient with Guillain-Barre syndrome.
70. *Bland, supra* n. 7 at All E.R. 879; AC at 879.
71. He said that this was a matter for Parliament to decide: All E.R. at 893; A.C. at 896.
72. [1995] 1 WLR 898, [1995] 2 All ER 129, [1995] 1 FLR 1056 (CA).
73. [1995] 2 All E.R. 129 at 129.
74. However, others have said that, from a person’s point of view, even a tiny chance of recovery from VS makes continued treatment worthwhile and that patients should consider this seriously in order to make an informed decision about advance directives: Stone J. Pascal’s Wager and the Persistent Vegetative State. *Bioethics*. 2007; 21(2):84. [PubMed: 17845492] ; see also, Fenwick, A. Applying Best Interests to Persistent Vegetative State - A Principled Distortion?; *Journal of Medical Ethics*. 1998. p. 86
75. *Wilkinson et al., supra* n. 39.
76. And in *An NHS Trust v. J*, *supra* n. 1, the parties accepted that fMRI was not in the patient’s best interests; unfortunately there was no explanation for this conclusion, as Penney observes: *supra* n. 1 at 393.