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John Hodgson  
*The Nottingham Law School*

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# Rights of the Terminally Ill Patient\*

*John Hodgson\*\**

## INTRODUCTION

This topic can be treated broadly or narrowly. The broad view takes terminally ill patients as merely a subset of patients, with all the rights and expectations involved. The narrow view concentrates on those rights and expectations peculiar to the terminal phase. I propose, for reasons of time, to veer to the narrow view, thus excluding, for instance, any discussion of absolute or relative entitlement to care, in other words, the whole debate on rationing. I do propose, however, to treat all permanently incompetent patients as within the scope of these remarks, notwithstanding that a vegetative, rather than a cerebral, existence may be capable of being sustained for a prolonged period. This probably reflects my personal persuasion that if there is "no one at home," the essence of human life is absent.

Within these parameters, there are four distinct issues: (1) distinguishing between competent and incompetent patients; (2) giving effect to the wishes of the competent patient; (3) making decisions about the incompetent; and (4) defining the boundaries of euthanasia.

## I. COMPETENCE

By no means do all terminally ill patients lack competence. It is important to distinguish four categories: (1) the competent; (2) those, such as children and those with learning difficulties, who have never been competent; (3) those who have become incompetent, but previously expressed an intention in relation to their treatment by means of an advance directive or otherwise; and (4) those who have become incompetent prior to expressing any intention.

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\*\* John Hodgson received his Master of Laws *magna cum laude* from Cambridge University. He served as a solicitor and is now a Principal Lecturer at The Nottingham Law School, The Nottingham-Trent University in Nottingham, England.

It is submitted that, in principle, the first and third group can be equated, as can the second and fourth group. There are two specific problems, namely the extent of the competence of children, and the extent to which either doctors or judges are bound by a prior declaration of intention.

## II. THE EFFECT OF CONSENT

One of the ruling axioms of medical ethics is the autonomy principle. In the case of a competent patient, self-determination is paramount and that patient may validly refuse consent to treatment.<sup>1</sup> This may extend to requiring the discontinuance of life support.<sup>2</sup> Senior judges have repeatedly emphasized this. Lord Scarman, in *Sidaway v. Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital*, stated that this right to accept or refuse treatment "may be seen as a basic human right protected by the common law."<sup>3</sup> Lord Templeman in the same case stated that the refusal may be for reasons that are rational or irrational or for no reason. The absolute and unconditional nature of the right of the competent patient was reiterated by Lord Mustill in *Airedale NHS Trust v. Bland*.<sup>4</sup> There is one first-instance decision that rejects this view, *Re S*.<sup>5</sup> In this case, Sir Stephen Brown, P. (President of the Family Division of the High Court), compelled a woman to undergo a caesarean section, which proved unsuccessful. The woman and her husband both objected on religious and/or moral grounds. The judge used a discredited line of United States authority that gave great weight to the supposed interests of the foetus, and the decision has been trenchantly criticized on principle and also on ethnic grounds (the woman in *Re S* was black). It has been suggested, however, that the judge was also motivated by a desire, in the face of advice that the woman's own life was in danger, not to leave her existing young children motherless. There is some tentative support for this approach from comments of Lord Donaldson, Master of the Rolls, in *Re T (Adult: Refusal of Treatment)*.<sup>6</sup> Although the right of self-determination was normally absolute, allowing it where it would lead to the death of a

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1. *R. v. Blaue*, [1975] 3 All E.R. 446 (C.A.).
  2. *Nancy B. v. Hotel-Dieu de Quebec*, 86 D.L.R.4th 385 (Que. Super. Ct. 1992).
  3. [1985] 1 App. Cas. 871 (H.L.) (LEXIS, UK library, ALLCAS file at \*8).
  4. [1993] 1 All E.R. 821 (H.L.) (LEXIS, UK library, ALLCASE file).
  5. *Re S (Adult: Refusal of Treatment)*, [1992] 4 All E.R. 671 (Fam.).
  6. [1992] 4 All E.R. 649 (C.A.). Sir Stephen Brown, P. notes in *Re S* that this central point was left open in *Re T*.

viable foetus would be a novel problem of considerable legal and ethical complexity, our first issue.<sup>7</sup>

It therefore seems to follow in all other cases that if an adult patient has clearly stated a desire not to be subjected to certain forms of resuscitation, or indeed to any other form of treatment, the doctor must respect those wishes.<sup>8</sup> In *Blaue*, a criminal case, the victim of an assault was a Jehovah's Witness and refused consent to a blood transfusion. There was no suggestion of criticism of the doctor, who respected her wishes. Indeed, it might well have been a wrongful invasion of her interests to treat her.<sup>9</sup>

These cases presuppose that there is a currently competent patient. This can be problematic. Is the patient actually compos mentis and/or sui juris? There is a strong temptation to say that a wish to die expressed by one who, objectively, has the prospect of a reasonable quantum of life of good quality is itself so irrational as to be prima facie evidence of such mental disequilibrium as to amount to incapacity. Doctors have learned to hold back where this view is expressed on defined religious grounds, but the temptation to intervene can be irresistible otherwise. Similar problems also occur in relation to patients who arguably become incompetent after giving a formal or informal advance directive.<sup>10</sup>

The law rebuttably presumes that all adults have the requisite capacity.<sup>11</sup> The crucial question is what test is to be used to assess whether the presumption is rebutted. The current test in the Mental Health Act of 1983 is whether the patient understands the "nature, purpose and likely effects" of the treatment.<sup>12</sup> In *Re F (Mental Patient: Sterilisation)*,<sup>13</sup> Lord Brandon referred to understanding the nature or purpose of the treatment proposed. There is a distinction between long-term mental disablement and short-term factors such as shock and stress. In the latter case, it is a question, as it was in *Re T*,<sup>14</sup> of

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7. See LAW COMMISSION CONSULTATION PAPER NO. 129, MENTALLY INCAPACITATED ADULTS AND DECISION MAKING: MEDICAL TREATMENT AND RESEARCH § 2.1 (HMSO 1993) [hereinafter LAW COMM'N].

8. *Blaue*, [1975] 3 All E.R. 446.

9. *Malette v. Shulman*, 67 D.L.R.4th 321 (Ont. Ct. App. 1990). There is plenty of anecdotal evidence of patients being treated despite objections who subsequently express gratitude to the doctors who overrode their apparent exercise of autonomy.

10. *Re T (Adult: Refusal of Treatment)*, [1992] 4 All E.R. 649 (C.A.).

11. *Id.*

12. Mental Health Act, 1983, c.20, §§ 57(2)(a), 58(3)(b) (Eng.).

13. [1990] 2 App. Cas. 1 (H.L.).

14. [1992] 4 All E.R. 649 (C.A.).

determining whether these factors vitiate an apparent refusal of treatment.<sup>15</sup> The Mental Health Act Code of Practice stresses capacity to understand the risks of treatment, although this is in the context of avoiding claims for unauthorised interventions.<sup>16</sup> In *Re C (Adult: Refusal of Medical Treatment)*,<sup>17</sup> Mr. Justice Thorpe suggested that to be competent, the patient must comprehend the information supplied, believe it, and balance needs and risks. The Law Commission has proposed a revised wording for a “cognitive, or function, test” for the mentally disordered:

A mentally disordered person should be considered unable to make the medical treatment decision in question if he or she is unable to understand an explanation in broad terms and simple language of the basic information relevant to taking it, including information about the reasonably foreseeable consequences of taking or failing to take it, or is unable to retain the information for long enough to make an effective decision.<sup>18</sup>

This avoids the subjective element in *Re C*, where the decision may depend on the nature of the explanation actually given.<sup>19</sup> It has been suggested that even where there is cognitive understanding, an “irrational” decision should still be overridden.<sup>20</sup> This is, however, dangerous. There is far too much scope for the conscious or subconscious interposition of the social, cultural, and moral values of the tribunal.<sup>21</sup>

The second issue deals with children: the general age of majority is eighteen, but this does not apply to consent issues. First, there is a modification of the general law that allows a child to give consent at sixteen.<sup>22</sup> Second, the court in *Gillick v. West Norfolk & Wisbech Area Health Authority*<sup>23</sup> held that it is understanding rather than age that is the key. In *Gillick*, a mother asked for a ruling that a doctor could not give her daughter contraceptive advice or treatment until she reached the age of sex-

15. See LAW COMM'N, *supra* note 7, at §§ 2.5-2.6.

16. *Id.* at § 2.9.

17. [1994] 1 All E.R. 819 (Fam.).

18. LAW COMM'N, *supra* note 7, at § 2.12.

19. See Jean McHale, *Consent and the Adult Patient: The Legal Perspective*, in NURSING LAW AND ETHICS 100 (John Tingle & Alan Cribbs eds., 1995).

20. See Margaret Brazier, *Competence, Consent and Proxy Consent*, in PROTECTING THE VULNERABLE 34 (Margaret Brazier & Mary Lobjoit eds., 1991); Ian Kennedy, *Consent to Treatment*, in DOCTORS, PATIENTS AND THE LAW (Clare Dyer ed., 1992).

21. See McHale, *supra* note 19, at 100; LAW COMM'N, *supra* note 7, at § 2.

22. Family Law Reform Act, 1969, c.46, § 8(1) (Eng.).

23. [1986] 1 App. Cas. 112 (H.L.) (LEXIS, UK library, ALLCAS file).

ual consent (sixteen). The court declined to make this ruling, saying instead that it depended on whether the individual concerned had sufficient understanding to consent to the particular treatment:

[P]rovided the patient, whether a boy or a girl, is capable of understanding what is proposed, and of expressing his or her own wishes, I see no good reason for holding that he or she lacks the capacity to express [his or her wishes] validly and effectively and to authorise the medical man to . . . give the treatment . . . .<sup>24</sup>

It must, however, be stressed that much of the case law following *Gillick* concerns the issue of children wishing to consent to treatment that their parents wish to withhold. The courts are not anxious to allow *Gillick* competence to justify a child's refusal of lifesaving treatment. In *Re S (A Minor) (Consent to Medical Treatment)*,<sup>25</sup> a fifteen-year-old girl was found not competent under *Gillick* to refuse treatment for thalassemia (a blood disease), including blood transfusions. She was influenced by the beliefs of her Jehovah's Witness mother, and it was said that she did not have capacity commensurate with the gravity of the decision.

In the case of a child, it is in the first instance the parents who must make any decision and give any necessary consent. If they will not do so, the correct procedure is to make the child a ward of the court and ask the court to make the decision.<sup>26</sup> The equivalent procedure in the case of an adult who is not competent is to apply to the court for a declaration; the Official Solicitor is then asked to represent the interests of the patient.<sup>27</sup> There is no legal power to take responsibility in this sphere for an incompetent adult.

24. *Id.* at \*9 (Lord Fraser).

25. [1994] 2 F.L.R. 1065 (Fam.). See also *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)*, [1993] 1 F.L.R. 1 (C.A.). A child competent under *Gillick* can override parental objection, but not the objection of the court, whose power transcends both.

26. *Re B (A Minor) (Wardship: Medical Treatment)*, [1990] 3 All E.R. 927 (C.A.). The court also has jurisdiction to make a specific issues order under section 8 of the Children Act, 1989 (Eng.). *Re R (A Minor) (Blood Transfusion)*, [1993] 2 F.L.R. 757 (Fam.).

27. *Bland*, [1993] 1 All E.R. 821 (H.L.). Lord Mustill, in particular, expressed doubts as to the propriety and convenience of this procedure for reasons of a legally complex and technical nature.

### III. GIVING EFFECT TO CONSENT

In principle, giving a consent its due effect is simply a matter of ascertaining the wishes of a competent patient and respecting them. This is easy to state in legal terms. Of course in practice, a decision by a terminally ill patient to reject or discontinue treatment requires very considerable input from medical and nursing personnel. There is an obligation on the Secretary of State<sup>28</sup> to provide an efficient health service. The provision of appropriate levels of advice, counseling, and care to the terminally ill is clearly a part of such a service. It may not always be possible to provide this, but there is no individual legal right to any specific provision.<sup>29</sup> Of more legal concern is when the patient's wishes are not regarded as binding.

This may arise in an acute case, of which *Re T*<sup>30</sup> is a graphic example. It is, however, much more likely to arise where there is a relatively long-standing advance directive. *Re T* was, strictly, an advance directive case, since by the time the action was launched, T was unconscious—but it is far from typical.

Advance directives are still relatively little understood here, but American experience with them, both generally and in the context of resuscitation, has highlighted several dilemmas. These largely centre around the issue of what is in the patient's "best interest." Traditionally,

treatments are offered only when there is some degree by which the expected benefits exceed the expected risks. In short, physicians routinely make judgments based on risk-benefit calculations, judgments that could plausibly be viewed as not purely medical and that therefore could be made by patients based on their personal benefit and risk preferences.<sup>31</sup>

This process applies also to the decision to withhold or discontinue treatment. Orentlicher concludes from an analysis of the extent to which physicians respected advance directives that they did so only when they coincided with the physician's own value judgments about the patient and the prognosis.<sup>32</sup> In other words, while no doubt paying lip service to patient autonomy, these doctors cannot resist the temptation to substitute their

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28. National Health Service Act, 1977, c.49, § 3 (Eng.).

29. See Diana Brahams, *The Critically Ill Patient: The Legal Perspective*, in NURSING LAW AND ETHICS § 9.1, at 199 (John Tingle & Alan Cribb eds., 1995).

30. *Re T (Adult: Refusal of Treatment)*, [1992] 4 All E.R. 649 (C.A.).

31. David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101, 2101 (1992).

32. *Id.*

own judgment for that of the patient. The substantial anecdotal evidence suggests that in the majority of cases, this leads to aggressive intervention, although the converse may also occur.<sup>33</sup> Cohen and Cohen point out the separate problem of context.<sup>34</sup> The prognosis for those who arrest on general wards is very poor because this is usually the culmination of the patient's fatal illness, and a do-not-resuscitate (DNR) order, whether pursuant to an advance directive or not, is justifiable by reference to the ruling opportunity/benefit or best interests criteria. The prognosis for a perioperative arrest is much better. This is often brought on by events in theatre (surgery) and can be relatively readily reversed. Nontreatment is therefore not justified in this context. It could be argued that any advance directive could be construed as not applying to such circumstances.

The most authoritative consideration of these issues in the United Kingdom was undertaken by the House of Lords Select Committee on Medical Ethics.<sup>35</sup> It strongly endorsed the principle of self-determination. It also endorsed the principle that any advance directive should be respected. In ethical terms, this approach can be defended on the basis that it is the only approach that fully respects the value of the patient as a human being and as an autonomous agent (which is much the same thing).<sup>36</sup> It is, however, in Canada that the principle has been most clearly and unequivocally stated, by the Ontario Court of Appeal in *Fleming v. Reid*, as a traditional common law principle:

A patient, in anticipation of circumstances wherein he or she may be unconscious or otherwise incapacitated and thus unable to contemporaneously express his or her wishes about a particular form of medical treatment, may specify in advance his or her refusal to consent to the proposed treatment. A doctor is not free to disregard such advance instructions, even in an emergency. The patient's right to forego treatment, in the absence of some overriding societal interest, is paramount to the doctor's obligation to provide medical care. This right must be honoured, even though the treatment may be beneficial or necessary to preserve the patient's life or health, and

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33. Robert Campbell, *The Critically Ill Patient: Ethical Perspective—Declining and Withdrawing Treatment*, in *NURSING LAW AND ETHICS* 218 (John Tingle & Alan Cribb eds., 1995).

34. Cynthia B. Cohen & Peter J. Cohen, *Required Reconsideration of "Do-Not-Resuscitate" Orders in the Operating Room*, 20 *L. MED. & HEALTH CARE* 354 (1992).

35. HOUSE OF LORDS, PAPER 21 (1994).

36. See Campbell, *supra* note 33.

regardless of how ill-advised the patient's decision may appear to others.<sup>37</sup>

The English authorities do not go so far, stressing that only advance directives that are "clearly established" and "applicable in the circumstances" must be respected.<sup>38</sup> The Law Commission recommended that the current English position should be formalised and adopted: "If a patient is incapacitated, . . . a clearly established anticipatory decision should be as effective as the contemporaneous decision of the patient would be in the circumstances to which it is applicable."<sup>39</sup>

There is on the one hand a danger that slavish adherence to an advance directive, as the Canadian ruling suggests, may lead to treatment being withheld when the patient might have had second thoughts, and on the other hand, a risk that the latitude given by the English approach leads to replacement of the patient's autonomy by the, however benevolent, intrusion of the reasonable man. The Law Commission suggests that if there is evidence of second thoughts, the requirement of applicability in the circumstances will not be met.

#### IV. DECISIONS ABOUT THE INCOMPETENT

An incompetent patient, specifically one who has not given an advance directive, can give no direct guidance as to a decision, which must be *about* rather than *by* him or her. There are, however, several mechanisms available. The three principal ones are: (1) the court appointing a proxy or guardian to make decisions for the patient; (2) the court acting as a surrogate to make the decision that, on the evidence, this patient would have made if free to decide (a quasi subjective test); and (3) the court making a decision based on the best interests of any patient in the position of this patient (a quasi objective test). It is possible to conflate the first two if the decision of the guardian is subject to the jurisdiction of the court.

The seminal case in this area is *In re Quinlan*.<sup>40</sup> In this case, a guardian was appointed and his decision, which was based on a substituted judgment, was subjected to the scrutiny of the court. Later United States decisions have adopted the same approach,

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37. 82 D.L.R.4th 298 (Ont. Ct. App. 1991) (LEXIS, CANADA library, DLR file at \*10).

38. *Re T*, [1992] 4 All E.R. 649 (C.A.); *Bland*, [1993] 1 All E.R. 821 (H.L.).

39. LAW COMM'N, *supra* note 7, at § 3.13.

40. 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

with or without the interposition of a guardian, based either on a notional attitude where there was no evidence of the particular patient's views,<sup>41</sup> or on such informal evidence as there may be of the views of the patient if available.<sup>42</sup> This approach was approved by Lord Donaldson, Master of the Rolls, in *Re J (Wardship: Medical Treatment)*,<sup>43</sup> but has not subsequently been adopted by other courts here. The Law Commission accommodated it in part in suggesting that any evidence of actual wishes or attitudes should be taken into account in assessing best interests.<sup>44</sup>

The English approach, as suggested above, is indeed the outwardly objective best interests test. This was expressly stated in *Bland*, and this approach was also approved by the Law Commission. The Commission also suggested that medical treatment attorneys could be appointed by patients in anticipation of incapacity, and medical treatment proxies appointed by a judicial body for an incapacitated patient. These could make decisions and give or withhold consent to treatment within a new statutory judicial framework, but would be obliged to act in the best interests of the patient.<sup>45</sup>

The court will lean toward preserving life unless the evidence suggests that the future will be demonstrably so intolerable that life will not be worth living. However, it has been recognised that there may be cases where "life" may be sustained indefinitely by artificial means without evident suffering, but with a negligible quality of life (for example, the persistent vegetative state (PVS) cases). Sir Stephen Brown, P., the Court of Appeal, and the House of Lords all ruled in *Bland* that it was not unlawful to withhold treatment in PVS cases, and that artificial nutrition is treatment for this purpose. Sir Stephen relied on the judgment in the United States case of *Cruzan v. Missouri Department of Health*, which reached the same conclusion.

The House of Lords placed the *Bland* decision on somewhat different grounds. A PVS patient has no best interests that are

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41. See, e.g., *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

42. *Cruzan v. Missouri Dep't of Health*, 497 U.S. 261 (1990). Cf. *In re Conroy*, 486 A.2d 1209 (N.J. 1985).

43. [1990] 3 All E.R. 930 (C.A.). In this case, the quality of life was not such as to justify treatment on a balance of evils test. Cf. *Re JHL* (1992) (unreported), a New Zealand case where it was held inappropriate to treat a terminal cancer patient for an unrelated condition. Again, there was a balance to be struck.

44. LAW COMM'N, *supra* note 7, at § 3.49.

45. *Id.* at § 5.16 (attorney), § 4.25 (proxy).

discernible. It cannot, therefore, be said that continuing treatment is in this patient's best interests. It cannot, therefore, be the doctor's duty to continue to treat, and there is, thus, no justification for the continuation of bodily invasion. This is not the same as the United States approach, which is that the surrogate decision maker steps in the shoes of the patient.<sup>46</sup> It is an objective test, without enquiry as to what *this* patient would have wanted.

Each of the five Law Lords used different language, but it is all to the same effect: (1) withholding treatment<sup>47</sup> is an omission; (2) criminal liability exists for omissions only where there is a breach of a duty to act; (3) with an incompetent patient, the doctors must decide on treatment in the patient's best interests and on the basis of sound professional judgment (nonconsensual invasive treatment could be justified on this basis while there is a hope of recovery); (4) in a hopeless case, there is no best interest in being kept alive, so the justification is gone; and (5) since the duty is gone, there can be no criminal liability.

It is the fourth proposition that is crucial since it admits, albeit in a negative sense, an argument about quality of life. This was fully recognised by the judges, who were, as a result, deeply concerned about the implications of the case. They expressly accepted that there was a divergence of views. They also accepted that very different considerations would apply in the more typical case where it could not be shown that the cortex had been physically destroyed and there was some element of sentience present.<sup>48</sup>

Concern has rightly been expressed by a range of commentators that if one allows an argument about quality of life, one has crossed an essential moral dividing line and is on the proverbial slippery slope to "euthanasia" of the unfit on grounds of convenience or even economics. In an attempt to ward off this fear, the judges did make it clear that a ruling was required from the court in every case, that two expert medical opinions would be

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46. *Saikewicz*, 370 N.E.2d 417.

47. Nasogastric nutrition and hydration were held to be treatment, rather than basic care.

48. *Bland*, [1993] 1 All E.R. 821 (H.L.). Lord Goff, Lord Browne-Wilkinson, and Lord Mustill all refer specifically to Guillain-Barré Syndrome as typifying this problem.

required,<sup>49</sup> and that the wishes of relatives must be taken into account.

Lord Mustill articulated certain issues that had been raised in a veiled way. It was being half-suggested that treatment could be withheld or terminated in the “best interests of the community.” This, in part, addressed the stress on the family and caretakers of pursuing treatment, but also acknowledged the question of the allocation of health resources:

The large resources of skill, labour and money now being devoted to Anthony Bland<sup>50</sup> 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 many years to come. . . . In social terms [this argument] has great force, and it will have to be faced in the end. But this is not a task which the courts can possibly undertake. A social cost-benefit analysis of this kind, which would have to embrace “mercy-killing,” to which exactly the same considerations apply, must be for Parliament alone, and the outcome of it is at present quite impossible to foresee.<sup>51</sup>

This is, in part, a matter of resource allocation.<sup>52</sup> It also raises other social, rather than economic, issues of the impact of actions on the family. In *Bland*, the family supported what was being done. The Law Commission stressed that it is the interests of the patient that are paramount, and the impact on the family and others must be subordinated to them, although they should be fully consulted and their views given great weight.<sup>53</sup> The judges were also all too clearly aware that they were creating a narrow legal distinction<sup>54</sup> between permissible killing by omission and impermissible active killing.<sup>55</sup>

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49. BRITISH MEDICAL ASSOCIATION MEDICAL ETHICS COMMITTEE, DISCUSSION PAPER ON TREATMENT OF PATIENTS IN THE PERSISTENT VEGETATIVE STATE (1992).

50. One estimate is direct costs of £40,000 per year.

51. *Bland*, [1993] 1 All E.R. 821 (H.L.) (LEXIS, UK library, ALLCAS file at \*39).

52. The courts have always refused to become involved in such issues of resource allocation. See, e.g., the “Baby Barber” case. Diana Tribe & Gill Korgaonkar, *Withdrawal of Medical Treatment*, 2 J. MED. DEF. UNION 42 (1993) (concluding that for this and other reasons, legislation is necessary).

53. LAW COMM’N, *supra* note 7, at § 3.57.

54. Lord Lowry specifically referred to the possibility that the sceptical layman might see a distinction without a difference, since the intent in each case was the same, namely to curtail life.

55. The distinction between active and passive euthanasia is well known, if illogical, and respected by all legal systems. The Dutch Parliament has passed legislation that alters this position. Active euthanasia has been officially tolerated in Holland for some years.

A doctor who follows the directions of the court in a wardship case is of course acting lawfully, as is a doctor who obtains a declaratory judgment in relation to an adult. In essence, the court is saying that such issues are matters of medical ethics. The court will not seek to define the parameters of proper medical action, but will limit itself to a ruling on the case in point to protect the particular doctor.

The difficulty of the *Bland* case from the point of view of those responsible for emergency and intensive treatment is that they must, in effect, treat as long as there is any hope, since it is impossible to establish initially the extent of some conditions such as hypoxic brain damage. Indeed, no diagnosis of PVS can be made for twelve months. Within that time, some degree of recovery is possible. It is, therefore, not possible to say with certainty that treatment is to no avail, and, therefore, not possible to withhold it lawfully. The best interests argument must result in the presumption to treat at that stage.

It was stressed in *Bland* that these issues are so important that a reference to the court will be necessary, wherever this is practicable. The procedures and tests to be applied were further considered by the Court of Appeal in *Frenchay Healthcare NHS Trust v. S*.<sup>56</sup> In this case, S had been unconscious for over two years following a drug overdose. The medical evidence suggested no quality of life, although not all the doctors specifically referred to it as a PVS case; there was some suggestion of limited cognitive function, and the court accepted that this was a less clear-cut case than *Bland*. The matter came before the court as an urgent application when a gastrotomy tube became dislodged; the doctors did not consider it to be in S's best interests to operate to replace this, but wished to have the benefit of a declaration of lawfulness. There was time for S to be legally represented, but the only medical evidence was that adduced by the Trust.

The court acknowledged that there might be emergency cases when no application at all was feasible, cases like the present where an abbreviated legal process was properly adopted, and cases where the full *Bland* procedure could be adopted.

The main criticism of the judge in the case was that he had allowed the doctors to make the decision by uncritically accepting the medical evidence. This is not a new criticism; there

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56. [1994] 1 W.L.R. 601 (C.A.) (LEXIS, UK library, ALLCAS file).

are many observers who assert that judges abdicate their responsibility to investigate medical standards and practices. Sir Thomas Bingham expressed a view that this approach was wrong:

It is, I think, important that there should not be a belief that what the doctor *says* is the patient's best interest *is* the patient's best interest. For my part I would certainly reserve to the court the ultimate power and duty to review the doctor's decision in the light of all the facts.<sup>57</sup>

However, he goes on to say that in this case, there is a clear and essentially uncontroverted medical opinion, and that to reject it is to compel doctors to act contrary to their beliefs. He stated:

That may sometimes be the right course for the court to adopt, but it seems to me to be a highly unsatisfactory position into which one should be reluctant to lead doctors unless the court has real doubt about the reliability, or bona fides, or correctness of the medical opinion in question.<sup>58</sup>

That gives a prima facie validity to medical opinion evidence that is not accorded to any other type of evidence adduced by a party who bears the burden of proof. One inevitable side effect is to increase the burden of moral responsibility on the doctors in the case, since it will, in practice, be their opinion, not that of the court, that is determinative and, therefore, the effective cause of the withdrawal of treatment.

It is, of course, vitally important in this context to ensure that there is a proper procedure for dealing with resuscitation issues.<sup>59</sup> The nontreatment issues associated with nonresuscitation are the emergency cases where there is not even the fig leaf of a legal declaration to stand between doctors and their consciences. It may be difficult to argue that the treatment meets the standard expected in *R. v. Malcherek*<sup>60</sup> if there is an absence of a coherent policy in this respect. The British Medical Association and Royal College of Nursing have issued proposed guidelines to meet this lack of consistency.<sup>61</sup> The guidelines stress the need to respect the wishes of the patient where known. This is

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57. *Id.* at \*8 (LEXIS, UK library, ALLCAS file) (emphasis added).

58. *Id.* at \*8-9 (LEXIS, UK library, ALLCAS file).

59. The absence of such procedures in English practice was highlighted in a Chief Medical Officer's circular dated December 20, 1991.

60. [1981] 2 All E.R. 422 (C.A.).

61. Chris Mihill, *BMA Urges Right to Die Hospital Code*, GUARDIAN, Mar. 3, 1993, Home Page.

clearly right. In other cases, *Bland* indicates that the best interests approach be followed.

The guidelines appear to give great weight to the wishes of the family. This appears to run counter to the views of the Law Lords, who indicated that the family should be consulted and involved but should not be the final arbiters.<sup>62</sup> This indication is also consistent with the rejection in *Bland* of the American doctrine of "substituted judgment," where the court seeks to put itself in the position of the victim with an assumption of prescience and purports to decide the case on the basis of a putative advance direction: "[T]he court must decide what its ward would choose, if he were in a position to make a sound judgment."<sup>63</sup> It may be simply that the concept of the advance directive is still so alien to the English judges that they do not know how to apply it to the wishes of the typical victim. In *S*, there was some reference to the wishes of the parents, who were apparently divided in their views. There is no reference to any assumed wishes of *S* himself. I am aware of at least one potential PVS case in the East Midlands where the mother has expressed objection to withdrawal of treatment, although the diagnosis is, provisionally, as poor as in *Bland*. No application has been reported in this case.

Against this background, it is reasonable and understandable that English courts have reacted as they have by giving great scope to the doctor's professional judgment. The application of the *Bolam*<sup>64</sup> test, which this entailed, has attracted reservations, as in *Bland* itself. This was exemplified in *Malcherek* and again in a recent case<sup>65</sup> where the court declined to direct doctors to treat in circumstances where, in their judgment, it was not in the best interests of the patient. However, in an American case,<sup>66</sup> the court refused to allow doctors to withdraw ventilation against the opposition of the family. This decision appears to indicate that there may be situations where even a bona fide exercise of medical judgment is open to review. It seems doubt-

62. The majority of complaints are of inappropriate resuscitation. There is up-to-date evidence that cardiopulmonary resuscitation is often applied inappropriately. Annie Chellew, *Outcome, Ethics and Accountability*, 17 NURSING STANDARD 37 (1993).

63. *In re Weberlist*, 360 N.Y.S.2d 783 (N.Y. Sup. Ct. 1974).

64. *Bolam v. Friern Hosp. Management Comm.*, [1957] 2 All E.R. 118 (Q.B.).

65. *Re J (Wardship: Medical Treatment)*, [1990] 3 All E.R. 930 (C.A.).

66. Steven H. Miles, *Informed Demand for "Non-beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512 (1991) (referring to *In re Helga Wanglie*, No. PX-91-283 (Probate Ct., Hennepin County, Minn. June 28, 1991)).

ful that an English court would accept an invitation to carry out such a review.

## V. EUTHANASIA

The law takes a very clear, indeed simplistic, view: deliberate killing is wrong. It will be murder whatever the motive, unless reduced to voluntary manslaughter by the defence of diminished responsibility, which may apply to a relative rendered mentally disordered by grief and stress.

In only one case in recent years has a member of the healing professions been arraigned to face a murder charge as a result of a good faith clinical decision to end another's life.<sup>67</sup> It is, in fact, a case involving a handicapped neonate, but the underlying principles also apply to other cases. The baby in question was born with Down's syndrome and was rejected by his parents, who did not want him to survive. Dr. Arthur concurred with their view.

The child was not fed and was dosed with dihydrocodeine (DF 118), a sedative/painkiller. He died some three days later. Dr. Arthur was initially charged with murder, but this was changed to a charge of attempted murder when it became clear that the child had other serious disabilities, which were only detected postmortem and which might well have proved fatal within the same time span in any event.

The basis of the prosecution case was that, although it was accepted that Dr. Arthur acted from the highest motives, he had overstepped the boundary; it was impermissible for a doctor to take steps to ensure that a patient would not survive, even when that patient faced a life of suffering and, in the context of a neonate, the parents supported the decision.

A number of eminent paediatricians were called by the defence, and they testified that there was a narrow, but crucial, dividing line between taking life and allowing death to occur. The former was unethical and impermissible; the latter was permissible in a limited number of cases where there was massive handicap and the parents concurred. The judge made it clear to the jury that they were the judges of the standard that was to apply; it was not enough to establish what the consensus of medical opinion was:

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67. *R. v. Arthur*, [1981] 12 B.M.L.R. 1 (Crown Court) (LEXIS, UK library, ALL-CASE file). In *R. v. Adams*, [1957] Crim. L.R. 773, there were undertones of unethical practice.

However serious the case may be; however much the disadvantage of a mongol or, indeed, any other handicapped child, no doctor has the right to kill it.

There is no special law in this country that places doctors in a separate category and gives them extra protection over the rest of us. Neither, in law, is there any special power, facility or licence to kill children who are handicapped or seriously disadvantaged in an irreversible way.<sup>68</sup>

On the other hand, the standards of the profession were not to be ignored altogether:

[W]hatever a profession may evolve as a system of standards of ethics, it cannot stand on its own, and cannot survive if it is in conflict with the law. . . . But I imagine that you will think long and hard before deciding that doctors, of the eminence we have heard, representing to you what medical ethics are, and apparently have been over a period of time in that great profession, have evolved standards which amount to committing crime.<sup>69</sup>

In the end, Dr. Arthur was acquitted, and the case was not referred to the Court of Appeal by the Attorney General for further consideration.<sup>70</sup> There is no way of establishing the actual basis of the jury verdict. It has been suggested that the result gave excessive weight to the parents' wishes, whereas the doctor's duty was to the child.<sup>71</sup>

It would seem to follow from *Bland* that if Dr. Arthur was omitting to treat (in other words, if the DF 118 was not itself designed to kill), then the approach was correct, and the jury was rightly directed to consider whether there was a duty to treat, seen in the light of best interests and *Bolam*.

Without in any way diminishing or trivialising the anguish associated with any such decision, it is relatively easy for a doctor to decide either to terminate treatment, or not to intervene, if the patient's condition is demonstrably hopeless. What is much more difficult is the decision where the prognosis is a very bad one in terms of quality of life, as distinct from quantity. Fletcher, writing from an American perspective, talks of the termination of ventilation as "permitting death to occur" rather than causing death, so that a doctor will be liable only if he has

68. *Arthur*, [1981] 12 B.M.L.R. 1 (LEXIS, UK library, ALLCASE file at \*13).

69. *Id.* at \*21.

70. There is in England no appeal against an acquittal, but a case may be referred for a ruling on any point of law of general importance.

71. Malcolm Brahams & Diane Brahams, *R. v. Arthur: Is Legislation Appropriate?*, 78 LAW SOCIETY'S GUARDIAN GAZETTE 1342 (1981).

permitted death to occur in breach of his duty to the patient.<sup>72</sup> Skegg prefers the phrase “letting the patient die,” but appears to favour the same approach.<sup>73</sup>

The earlier case of *R. v. Adams*<sup>74</sup> also concerned a prosecution of a doctor for the murder of a patient. The elderly patient was terminally ill and was given high doses of morphine and heroin. These resulted in a shortening of the quantum of life, although there was evidence that they were therapeutic in the sense of palliating pain. This case recognises that quality of life may be as relevant as quantity, and that the secondary function of medicine, if cure is not possible, is care. There must, however, be a reasonable balance struck.<sup>75</sup>

Until recently, the debate on these issues was conducted essentially as one of medical ethics. Such litigation as there was tended to be civil in nature; doctors sought approval for decisions they had already made in principle, or patients (or those responsible for them) sought ratification of their choices. Even before the *Bland* case, the apparently only tangentially relevant Irish litigation over abortion reminded us that there is also a criminal law aspect to the matter.<sup>76</sup> A similar issue arose in the United Kingdom in 1939 as the result of a highly publicised decision by a leading gynaecologist to carry out an abortion on a teenage rape victim on the grounds of risk to her life due to psychological stress; the response was a prosecution for an offence of unlawfully procuring an abortion.<sup>77</sup> Although the summing up to the jury was fairly sympathetic to the defendant, drawing a sharp distinction between the activities of the sordid commercial back-street abortionist and the actions of a leading surgeon acting purely philanthropically, it was made clear that the jurors were ultimately the arbiters of what was legitimate in this area. They had to decide in the instant case whether what was done was done in good faith for the preservation of the life of the mother. The result was an acquittal.<sup>78</sup>

Prior to *Arthur*, this case was the leading one in the field of medicocriminal law. Both cases show the same judicial attitude:

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72. GEORGE FLETCHER, *RETHINKING CRIMINAL LAW* 610 (1978).

73. PETER D. G. SKEGG, *LAW ETHICS AND MEDICINE* 174 (1984).

74. [1957] *Crim. L.R.* 773.

75. See Brazier, *supra* note 20, at 446; Campbell, *supra* note 33.

76. The apparent issue was the liberty of the teenage rape victim to seek an abortion abroad in the face of Irish legislation prohibiting abortion and counseling.

77. *Offences Against the Person Act, 1861*, 24 & 25 *Vict. c.100*, §§ 58-59 (Eng.).

78. *R. v. Bourne*, [1939] 3 *All E.R.* 615 (K.B.) (Ireland).

respect for the standards of the profession, but a refusal to allow the standards to determine the issue. In each case the jury appears to have endorsed the views of the profession, although it is not possible to say whether this was a positive endorsement or merely a refusal to scapegoat a professional who was clearly acting conscientiously, albeit improperly.

This approach will mean that a jury (or in a civil case the judge) will have to consider the doctors' actions in light of their conception of what is required by public morality, guided, but not constrained, by the evidence of professional practice and ethics. This approach has the advantage of allowing a doctor who abides by the standards of the profession to have this considered by the court, but the opinion of society at large is the overriding factor.

The position in respect of positive treatment is clearly different. It is, as we have seen, legitimate to administer drugs or other treatment for the purpose of relieving pain and suffering, even though life is incidentally shortened.<sup>79</sup>

Several years ago, Dr. Lodwig was tried and acquitted on the basis of the use of a cocktail of drugs including powerful painkillers and potassium chloride (KCl). It was accepted that there was a therapeutic effect overall, even though the KCl was simply a poison.<sup>80</sup>

In September 1992, Dr. Cox was convicted of the attempted murder of a patient to whom he had administered a fatal dose of KCl. The case raised strong emotions. Dr. Cox had been treating the patient for many years. She had been in appalling pain and was terminally ill. She had asked for relief from pain. Her family fully supported the doctor's actions. The jurors were clearly deeply affected at the necessity of returning a guilty verdict, and Mr. Justice Ognall, in imposing a suspended sentence, made it clear that he fully accepted that Dr. Cox was acting out of the highest motives.

Although Dr. Cox had seriously transgressed the law, it was a conscientious error, not opportunism or malice in the ordinary sense of the word. The subsequent decision of the General Medical Council (GMC) to take no further action after finding

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79. R. v. Adams, [1957] Crim. L.R. 773.

80. Diana Brahams, *Criminality and Compassion*, LAW SOCIETY'S GAZETTE (London), Sept. 30, 1992, at 2.

Dr. Cox guilty of professional misconduct also reflects this consensus view.<sup>81</sup>

A straw poll of doctors from a variety of specialties whom I met fortuitously at a college reunion a few days later elicited that, while most sympathised with Dr. Cox, they also felt that he had been ill advised to administer a substance with no known therapeutic effect. They considered that if he had administered a cocktail, partly therapeutic and yet clearly life shortening, no prosecution would have been brought. This is, no doubt, a practical answer, but it leaves the issues of principle unresolved.<sup>82</sup>

The immediate lesson is clear: while inaction is allowable, unless there is a clear duty to act, any positive treatment must be demonstrably therapeutic, in the sense that it is either an attempt to save or prolong life or, at the least, a bona fide attempt to relieve suffering, and that a doctor or health professional who dares to go beyond this limit is at risk of prosecution.

Although the Law Lords in *Bland*<sup>83</sup> were at pains to point out that they were not discussing active euthanasia, which amounts to murder, they indicated that they believed the answer they were able to give was unsatisfactory, being at best a narrow and legalistic one. They were comforted by the thought that the case before them was a very clear one, but they all believed that any consideration of the parameters of euthanasia was a matter for Parliament:

Where a case raises wholly new moral and social issues, in my judgment it is not for the judges to seek to develop new, all embracing, principles of law in a way which reflects the individual judges' moral stance when society as a whole is substantially divided on the relevant moral issues. . . . The judges' function in this area of the law should be to apply the principles which society, through the democratic process, adopts, not to impose their standards on society.<sup>84</sup>

With respect, this seems to be unanswerable.

Even from this limited perspective, it is clear that the law is not clear. There is a reluctance on the part of the prosecuting authorities, judges, and juries to stigmatise as criminal, or even tortious, behaviour that is conscientious and ethical.

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81. *Id.*

82. Subsequent discussion with experts in pain relief (nurses rather than doctors) produced a similar result, but rather less sympathy with the doctor, who ought to have taken advice.

83. *Bland*, [1993] 1 All E.R. 821 (H.L.) (LEXIS, UK library, ALLCAS file).

84. *Id.* at \*24 (Lord Browne-Wilkinson) (LEXIS, UK library, ALLCAS file).

However, there is no special rule for the health care professional. There have been a number of proposals for a statutory offence of failure to treat a patient, but these have come to nothing. There is certainly no official enthusiasm for a witch hunt. The *Arthur* case was only taken because of a complaint from a member of the public with very strong views. The *Cox* case arose from a complaint by a nurse who realised the implications of the entry in the victim's records made by Dr. Cox. It is noteworthy that the initial reaction was that this nurse had destroyed her own career by breaking ranks. There is certainly a growing concern with standards and a belief that the various forms of enquiry available—Coroner's inquest, complaint to the GMC or United Kingdom Central Council (the principal regulatory body for nurses, midwives, and health visitors), internal National Health Services disciplinary systems, and civil actions for damages—are insufficient to identify and remedy inadequate or dangerous practice. Landmark cases such as *Bourne*, *Arthur*, and *Cox* may have a part to play, but at what cost to the unfortunate practitioner involved? The court in *Barber v. Superior Court of Los Angeles County* stated: "[A] murder prosecution is a poor way to design an ethical and moral code for doctors who are faced with decisions concerning the use of costly and extraordinary 'life support' equipment."<sup>85</sup> Or, one might add, in any health care context.

This discussion has inevitably been medicocentric. The law does tend to marginalise the patient. The cases, at least in the United Kingdom, have turned on an evaluation of the doctor's conduct.

Attitudes toward euthanasia embrace a wide spectrum. At one end stand Dr. Jack Kevorkian and certain Dutch practitioners who regard the decision as being one for the patient. If patients wish to die, they are entitled to competent help to achieve this with dignity and without undue pain or distress. It is the ultimate expression of individual autonomy. The most extreme, such as Dr. Henk Prins, will even terminate the lives of those who are not competent to reach their own decision on the basis of best interests.<sup>86</sup> It was the prosecution case of Dr. Arthur that fell into this category. This view is not acceptable officially

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85. 195 Cal. Rptr. 484, 486 (Cal. Ct. App. 1983).

86. There is persistent anecdotal material concerning the attempts of certain, usually Dutch, practitioners to encourage euthanasia. This is equally legally unacceptable.

in any jurisdiction, although Dr. Prins was not subjected to any sanction for murder and Dr. Cox was dealt with very leniently. Euthanasia of competent adults is semiofficially tolerated in the Netherlands, and, no doubt, occurs unofficially to varying degrees elsewhere.

At the other extreme stand the militant supporters of the right to life. In most cases, this view-point arises from religious conviction, although it may arise from a belief in the need for an absolute protection of life to prevent descent on a slippery slope leading to compulsory euthanasia.

Supporters of the hospice movement and experts in palliative care claim that most requests for euthanasia from the terminally ill arise from a failure to provide the best care practicable.<sup>87</sup> There is undoubtedly much in this, but there is clearly a body of patients and potential patients who claim that they actually or prospectively wish to have the option of euthanasia, or at least assisted suicide, which raises similar ethical dilemmas. At present, English law leans firmly against this. As stated above, the judicial House of Lords in *Bland* set themselves against it. The legislative House of Lords came to the same conclusion in endorsing the recommendation of their Select Committee that there be no change to the law, even to the extent of reducing mercy killing from murder to manslaughter.

## VI. ASSISTED SUICIDE

Suicide (*felo de se*) and attempted suicide were decriminalised by the Suicide Act of 1961. It remains an offence to aid, abet, counsel, or procure the suicide of another.<sup>88</sup> There has been little use of the Act, and the only reported case is not a prosecution, but a civil action to determine the scope of the section.<sup>89</sup> A pressure group called EXIT issued a booklet entitled "A Guide to Selfdeliverance," which, as the title implied, gave advice on methods of suicide. The court refused to declare that the mere issue and supply of this booklet necessarily amounted to the offence. There is no doubt that suicide in a euthanasia context occurs, and that it is achieved with the assistance of relatives, friends, and medical advisers. Indeed, in some cases the

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87. See Michael Kearney, *Hospice Medicine*, in *CHANGING IDEAS IN HEALTH CARE* 15 (David Seedhouse & Alan Cribb eds., 1989).

88. Suicide Act, 1961, c.60, § 2(1) (Eng.). The maximum penalty is 14 years of imprisonment.

89. *Attorney General v. Able and Others*, [1984] 1 All E.R. 277 (Q.B.).

dividing line between assisting suicide and actual euthanasia is hard to draw and may not represent any real ethical distinction. This is, however, not an issue that impinges on the public consciousness to any extent.<sup>90</sup> There is certainly no agitation here for any entitlement to physician-assisted suicide, let alone a decision authorising it. There is, indeed, no framework of constitutional guarantees of liberty of action that could be invoked to provide legal warrant for this.<sup>91</sup>

### CONCLUSION

Most of the conclusions that follow are all directly supported by the House of Lords decision in *Bland*. In many cases, this decision confirms what was already known to be the law, rather than breaking new ground. Many of these conclusions also relate to other case law and are supported by the Law Commission and/or the House of Lords Select Committee. While these do not have the force of law, they are highly persuasive.

Some things are clear:

- It is always lawful and ethical to provide (with actual or constructive consent) palliative treatment, such as pain relief, although this may have the side effect of shortening life.
- It is never lawful or ethical to take positive action designed to curtail life.
- Withholding treatment by omission may or may not be lawful, depending on the circumstances. It will be lawful if there is an operative consent, or the "best interests" test is satisfied. Artificial nutrition and hydration are treatment and may, under certain circumstances, be lawfully withheld. Switching off life support is an omission to continue it.
- A competent patient may always refuse treatment or require treatment to be discontinued. This consent may be in the form of an advance directive or the appointment of a medical attorney. There may have to be an enquiry as to competence or the continued effect of the consent.
- Parents or the court in wardship proceedings may consent or withhold consent on behalf of a child. A child who is compe-

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90. Contrast the position in the United States. See Thomas J. Marzen, *Out, Out, Brief Candle: Constitutionally Prescribed Suicide for the Terminally Ill*, 21 HASTINGS CONST. L.Q. 799 (1994).

91. See Brian Bix, *Physician Assisted Suicide and the United States Constitution*, 58 MOD. L. REV. 404 (1995).

tent under *Gillick* may refuse consent, but must appreciate the full consequences of this refusal.

- No one has the power to consent in the case of an adult who is physically or mentally incapable, but the court may make a declaration as to the legality of a proposed course of action.
- The judges are uncomfortable at being given the role of arbiters of social morality.

Some issues are tolerably clear:

- In the case of a patient who is not competent, the doctor must act in the best interests of the patient. These are established objectively. Any indication of actual intentions should be taken into the best interests equation.
- Invasive treatment can be justified only by consent or necessity; it is not necessary to preserve a wholly vegetative existence and is unjustified in this context.
- It is not wrongful to refuse or withhold treatment in a hopeless (vegetative) case.<sup>92</sup> Omission to treat is only wrongful where it arises in breach of a medical or other duty to act.
- The duty is owed to the patient, not to the family.

Some issues are unresolved:

- At what point it is proper to conclude that treatment is not in the interests of a patient who is to some degree sentient? The issue of how best interests are determined is a medical and ethical, not a legal, analysis of benefit and detriment.
- When and under what circumstances is active euthanasia justified? This is a matter for Parliament.<sup>93</sup>
- Can, and if so to what extent, decisions on withholding treatment be influenced by the availability of resources and competing demands on them? This, too, is a matter for Parliament.

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92. The court will not compel doctors to treat contrary to their professional judgment. *Re J (Wardship: Medical Treatment)*, [1990] 3 All E.R. 930 (C.A.). This issue was not discussed in *Bland*.

93. The House of Lords Select Committee Report appears to have concluded the matter for the time being.